ANGLIA RUSKIN UNIVERSITY

THE RELEVANCE OF RECOVERY TO CARERS OF PEOPLE WHO HAVE SCHIZOPHRENIA

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Submitted: October 2013

A thesis in partial fulfilment of the requirements of Anglia Ruskin University for the degree of Doctor of Philosophy

ANGLIA RUSKIN UNIVERISTY

ABSTRACT

FACULTY OF HEALTH, SOCIAL CARE AND EDUCATION

DOCTOR OF PHILSOPHY

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Recovery is a new concept positing that people with schizophrenia can lead fulfilling, satisfying, and productive lives. Family carers often play a helpful but largely unacknowledged role in the support of service users with schizophrenia, and the nature of their contribution to and their role in recovery has hitherto not been investigated. This original PhD explores whether learning about the recovery approach through participation in a training intervention changes the way carers view recovery, whether they find the concept helpful, whether it modifies their behaviour, and their evaluation of the intervention.

A participatory action research methodology was applied in this study, actively supported by a steering group consisting of different stakeholders. Training on the recovery approach was delivered to a group of eleven carers to explore their response to the recovery concept. The training programme was delivered by me and a carer, utilising my personal experience as a service user with the diagnosis of schizophrenia. Focus groups and individual, semi-structured follow-up interviews were applied to assess self-reported changes in attitudes and behaviours. Mainly qualitative data were collected with supplementary socio-demographic data.

The analysis of the qualitative data suggests that being more 'recovery-aware' gives carers increased hope and optimism for their own and the service user's future. Greater awareness of the impact of caring upon the service user's life helps them to begin to care in such a way as to promote recovery in the service user, and gain more confidence in their own expertise-by-caring. Professionals have a key role to play in recovery, a three-cornered partnership between the carer, professionals and the service user is desirable. The carers evaluated the training programme as helpful, and particularly valued its authenticity as it was led by a service user and carer trainers.

Conclusions suggest that recovery is a helpful concept for carers. It shows that learning about recovery helps them to care more effectively for the service user and for themselves. It suggests the usefulness of developing a recovery concept for carers based on reconciliation of their caring identity, their caring role and their relationships with the service user and professionals. Recovery for the service user and for the carer requires support from professionals, based on a partnership service model, a contribution to the development of recovery practice. The training programme is a useful way of conveying the hope in recovery and is strengthened by the service user perspective of recovery.

Keywords: Mental health; recovery; carers; schizophrenia; user-led research; participatory action research.

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Chapter 1. Introduction

1.0 Introduction

This original study addresses the relevance of the recovery concept to carers of people with schizophrenia. The recovery concept in mental health originated from the service-user movement in the 1990s as service users sought to counter negative perceptions of mental ill-health and present the possibility of recovery from mental illness (Deegan, 1996; Coleman, 1999), reinforced by clinical studies in the 1980s and 1990s that found that service users can and do recover (Huber, Gross,and Schuttler, 1975; Tsuang, Woolson, and Fleming,1979; Ciompi, 1980; Harding et al, 1987; Ogawa et al 1987; McGorry et al 1996; Harrison et al 2001; Warner 2004). The model of personal recovery emphasises that a service user can lead a good quality of life, despite and beyond the limitations caused by mental illness symptoms (Anthony, 1993; Coleman, 1999; Davidson, 2003). Recovery is slowly developing in the UK as professionals groups, policies and services commit to the recovery approach.

Carers have hitherto had little influence on defining recovery, developing an understanding of their role in a recovery context or contributing to the development of recovery service models (SRN, 2009; Kilyon and Smith, 2009). Carers have an often unacknowledged role in supporting the service user (Jones, 2002), yet both carers and service users note the potential of carers to support the service user in recovery (Brown and Kandirikirira, 2006). The relevance of the recovery concept to carers of people with schizophrenia has not hitherto been investigated.   The research questions which aim to fill this gap in knowledge are:

- How do carers define recovery?

- Do carers believe recovery is possible?

- How do carers describe their role in recovery?

- Do their views on recovery change as a result of a training programme?

- Does their behaviour change as a result of a training programme?

- What do carers see as the major obstacles and opportunities in recovery?

- Do they evaluate the training package as helpful in enabling them to explore these issues?

This study describes how learning about recovery impacted on a group of carers' lives, their attitudes, their caring roles, the service user they support, and their self-care.

An interpretative paradigm underpinned the research, with participatory action research (PAR) supporting the implementation. A steering group of experts from different backgrounds, including experts-by-experience,[1] experts-by-caring and professionals at different levels of seniority, contributed to the development of a training programme on recovery, the research design and methods and data collection tools used.

The training programme was delivered to a small group of eleven carers of people with schizophrenia and the long-term impact of their learning about recovery was evaluated one month and six months later. Mainly qualitative data were collected to explore the meaning of recovery to the carers and their evaluation of the programme's delivery. Data collection methods included written questionnaires with open questions, focus groups, and semi-structured individual phone interviews.

The carers responded to the recovery concept and found it a valuable and helpful approach that supported their caring role. They contributed to definitions of its meaning, how it could influence their caring roles and how professionals could best support both the service user and the carer in their journeys of recovery. The research suggested the development of a *model of carer recovery* alongside the service user's model. While the personal model for service user recovery is a relatively well-known and accepted concept in mental health policy, the carer recovery model is relatively unknown. The model of carers' recovery in this study embraces the carer's journey and relates to the different points in the caring journey as they care for the service user from the emergence of symptoms to the point where they are self-managing their illness.

The training programme developed in this study was unique in building on a strengths approach to caring underpinned by an optimistic outlook. It emphasises how they learn to care effectively by *caring for recovery* (caring in a way that promotes the service user's recovery). The nature of the training programme links with the carers' recovery

1 Expertise-by-experience and expertise-by-caring are terms used to describe the knowledge and expertise derived from personal experience of mental health issues and personal knowledge of caring. They highlight that service users and carers are often best placed to know the support that they need.

concept as the carers become reconciled to their own caring identity, relearn to live beyond their caring role and take up their lives again as the service user in recovery lives beyond their diagnosis (Davidson, 2003).

The data contributed to the development of a service model of recovery. Carers' viewpoints have hitherto been unconsidered in the development of recovery oriented services and their views are often unaddressed in research (MHRN, 2012a; 2012b). The PAR methodology emphasises the importance of the participants' learning and development in the research process which underlines the need for their active involvement in care planning processes and service planning. This empowerment of carers is a key aspect of this research.

The contributions of the methodology and the research design along with the strengths and limitations are discussed, and recommendations highlighted for future research.

1.1 Chapter outline

The content and format of the chapters are described in this section.

Chapter 2 sets out the context of the study. Mental health policy in the UK from the mid 1980s to the present is introduced with a focus on the shift from institutionalised care to provision of care in the community, and later models of personalisation with increased service user involvement. The politicisation of mental health carers is described which began with the emergence in 1972 of the National Schizophrenia Fellowship (later named Rethink) in response to the poor care experienced by patients in the community. Policies which were developed to acknowledge, support and protect the needs and interests of carers are highlighted. The suitability of the geographical context of the study is described with detailed information about mental health service provision from the Cambridge and Peterborough Foundation Trust. My personal experiences as a service user, which underpin my desire to learn more about recovery (Fox, 2007; 2013), are described and my professional experience of working with carers is highlighted (Fox, 2009).

Chapter 3 introduces and discusses the recovery concept in mental health. The experience of schizophrenia and the element of the diagnosis are described alongside a critique of its origin and development. Different models of mental illness are

highlighted with a discussion of the dominant medical model and the development of alternative models such as recovery. The context that led to the emergence of recovery is explored with a focus on the personal model of recovery. This chapter addresses the implementation of recovery-oriented services across the USA, Australia, and New Zealand and their current impact on the British context.

Chapter 4 highlights the existing literature on carers and sets out the role they may play in the recovery of people with schizophrenia. It defines the terminology used to describe the carer, noting the complexity of the term. Explanatory frameworks used to describe the relationship between carers and service users are considered, followed by a discussion of the role of psycho-education in teaching carers problem-solving skills to care more effectively for their loved one. Their role in the recovery process is described first as perceived from the viewpoint of service users and then from the viewpoint of the carers themselves. The carers' needs as they support the person with schizophrenia are identified, followed by a description of the vision that they hold for effective service provision. The need for carers to become more involved in research is highlighted and the impact that this has on their active involvement in other settings such as the development of mental health services or in care planning is considered. This discussion reveals the gap in knowledge that the research seeks to address, which leads to the development of the research questions.

Chapter 5 sets out the methodology and methods that support this research.   The suitability of the interpretive paradigm for this study, underpinned by PAR is affirmed. The involvement of the steering group of stakeholders who contributed to planning, development and implementation of a training programme on recovery and its subsequent evaluation is described. I focus on the research design, which comprises the delivery of a training programme on the recovery approach to a group of eleven carers. The impact of learning about recovery on the carers' attitudes to the caring role and their behaviour was evaluated at follow-up points after the training intervention. The data collection methods are discussed, with more detail provided about the content of the training package. Sampling aims and recruitment processes are considered, followed by a discussion of how the data from the study is and supported by quality assurance procedures. Finally, ethical issues in the study are addressed.

Chapter 6 sets out the research findings, interweaving them with consideration of the research questions. The first section describes the steering group's contribution to the development of theory about the nature of caring and recovery. The second section discusses the key findings about the carers' understanding of recovery. The study found that the carers understood recovery in different ways and saw it as a rich and valuable concept. I describe how their understanding of recovery changed over the course of the research and influenced their caring role, and posit a model that suggests that carers traverse their own journey of recovery (Cool (Carers-one-to-one-Link) Recovery, 2003) as they live beyond their caring role. The third section describes the formal evaluation of the training programme and its effectiveness in teaching carers about recovery.

Chapter 7 contextualises the findings and highlights this study's original contribution to knowledge. The relationship between the carers' journey of recovery and the service user journey are described, developing a conceptual framework based on models developed by Spaniol et al (2002) and Cool Recovery (2003). This provides a new contribution to theory: the development of a recovery concept for carers. A service model of recovery is proposed, based on both carers' and service users' needs and their requirements of their relationships with professionals. The chapter concludes by addressing the uniqueness of the training programme and its suitability for teaching carers about the recovery approach.

Chapter 8 considers the methodological assumptions and research design. It discusses stakeholder involvement in the research programme, and examines its positive influence on the study. It considers the importance of PAR in supporting the active involvement of experts-by-experience in the research, and highlights the different means and levels of involvement across the study. I reflect on the sampling procedures used, highlighting their strengths and weakness and implications for the successful research implementation and the wider significance and applicability of the findings. The strengths and weaknesses of the data collection strategies and their implications for the findings of the research are explored. The analytical procedures are examined alongside a discussion of quality management issues and the impact of validity and reliability for this study.

Chapter 9 concludes the thesis with a summary of the research and discusses the significance of the findings. The research limitations and recommendations for future

research are considered. I conclude by reflecting on how the research has impacted on my personal and professional development.

Chapter 2 introduces the context, describing pertinent mental health policy and the politicisation of carers and resulting policy. It sets the scene for the development of the research in this geographical locality describing the mental health provision for service users and carers.

Chapter 2. The research context

<u>2.0 Introduction</u>

This chapter provides an overview of the mental health policy that forms the backdrop to this study and locates it in the geographical, social and cultural systems that underpin its implementation. The first section describes key issues in UK mental health policy, legislation and practice from the mid-1980s to the present. Mental health policy is influenced by interacting macro, meso and micro factors that respond to societal, community, cultural and political contexts (Thornicroft and Tansella, 1999; Thompson, 2003; 2006). Understanding the political assumptions underpinning the development of this research explains the relevance of the study.

The second section introduces the political struggle that carers in the UK have faced to get their role recognised. It gives an overview of the policies developed to formally recognise carers and specify the support they can expect from mental health services. This focuses the thesis on its central concern.

Next, the geographical area and the socio-economic context in which the research was undertaken are described. Mental health service provision in this locality is discussed with a particular focus on services for carers. There is a brief introduction to the local Carers' Strategy followed by a description of the plans by the NHS Trust to improve processes of consultation with carers and provide them with better services.   This shows the mismatch between national rhetoric about the needs of carers and the current state of local service delivery; highlighting the problems that carers continue to face.   The relevance of conducting this study in England is explored, and its wider importance in the international context is identified.

Finally I focus on my personal and professional reasons for undertaking the research and on how my own journey of recovery makes this a labour of love to bring about change for individuals and carers.

<u>2.1 Mental health policy in the UK from the mid-1980s to the present</u>

This section covers changes in mental health policy from the mid-1980s to the present, a period that spanned a number of government administrations: the Conservative Thatcher /Major governments, New Labour and the early years of the Coalition. This period was chosen as the mid-1980s mark a watershed with legislation that formally

enshrines the rights of people to receive care in the community (H.M. Govt, 1990) and to be involved more than previous eras with planning their own care and more widely developing and monitoring mental health service provision. Rogers and Pilgrim (2001) note that the term 'mental health policy' incorporates legal arrangements, policy directives and service investment. Mental health policy is 'partly about the control of behaviour, partly about promoting wellbeing, partly about ameliorating distress and partly about responding to dysfunction' (ibid, p. 226).

Factors that have influenced the development of mental health policy during this period include:

- risk management processes to promote the wellbeing and protection of those with mental ill-health (Rogers and Pilgrim, 2001; Bogg, 2010)
- the shift of resources from institutionalised care to care in the community (Lester and Glasby, 2006)
- the management of effective laws to protect public safety (Rogers and Pilgrim, 2001)
- the professionalisation of psychiatric occupations (Rogers and Pilgrim, 2001; Bogg, 2010) and the diversification of professional roles (Pilgrim and Ramon, 2009; Golightley, 2011)
- mental health promotion and anti-stigma campaigns (Time-to-Change, 2012)
- the new relationship that service users have with mental health professionals in response to changing practice (Pilgrim and Ramon, 2009)
- changes in legislation (e.g. the Mental Health Act (2007) as well as Carers Assessments in 1995)
- the potential impact of Payments by Results on the development and reconfiguration of mental health services.

The interplay of these factors has led to changes in the experience of the people who use services, those who care for them, and professionals and managers who deliver mental health services.

Deinstitutionalisation brought major changes in the philosophy, context, experience and delivery of mental health services in the 1960s-1980s. Care in institutions was replaced by care in the community with the redistribution of resources to support community mental health staff and relocate long-term users of care to community living. Ramon

(1998) refers to this as a process of 'dehospitalisation' rather than 'deinstitutionalisation', describing a process that allowed patients to move out of hospitals without necessarily reconnecting with their wider communities. Care in the community significantly changed the experience and delivery of services. Despite this sea change, experiences of social exclusion marked and continue to affect many service users' lives as they struggle with living in poverty, poor housing, and discrimination caused by the stigma of mental ill health (Royal College of Psychiatrists, 2009; Secker, 2011).

The implementation of community care was modelled in two white papers: Caring for People (DH, 1989) and the National Health Service and Community Care Act (1990). These acts represent some of the biggest changes in the welfare state since the inception of the National Health Service (NHS) (Lester and Glasby, 2006). New responsibilities were given to local authorities to lead the development of community care, and for the first time, market principles were introduced into the provision of publicly-funded health and welfare services, leading to an internal market with a mixed economy of care. This allowed local authorities to purchase social care services from private and voluntary agency providers. Health authorities were established with responsibility for purchasing health care from NHS trust providers.

Patient care was reorganised: the long-stay population was resettled in supported accommodation, becoming more visibly part of society, while those who were newly diagnosed were more likely to be treated in the community with support from a multidisciplinary team.

The move to care in the community was accompanied by fears for public and patient safety after Christopher Clunis, a mental health patient, killed Jonathan Zito, a musician. The Ritchie Report (*Ritchie, Dick, and Lingham,* 1994) on Zito's murder concluded that mental health systems had failed to protect patient and public safety because professionals had not collaborated on his care, shared information, monitored his movements adequately or assessed his risk appropriately. Campaigning organisations such as SANE (Schizophrenia: A National Emergency) deliberately exploited the public's fears and campaigned for increased defensive practice. SANE is a pro-carers group that highlights poor practice but arguably ignites discrimination against those with a diagnosis of schizophrenia.

The emphasis on care in the community led to a drop in the number of inpatient beds for those in acute crisis, increasing pressure on bed occupancy, and resulting in a higher threshold of mental illness for hospital admission, a concentration of people with more acute symptoms and increased disturbance on acute wards (Quirk and Lelliot, 2001). This problem persists today. Services that focus on recovery emphasise the importance of hospital as a 'springy safety net' (Roberts and Wolfson, 2004) with voluntary access an 'asylum' for those who need support. However, too often this is not the case, with many service users reporting poor experiences of inpatient wards that impede rather than promote recovery (Mind, 2004) with little nurse-patient contact, and staff often experiencing low morale and high sickness rates (SCMH, 2004).

Community Mental Health Teams (CMHTs) were established to deliver the new model of care in the community. They promoted multidisciplinary working, allowing professionals from different backgrounds and models of practice to influence the delivery of care. This new way of working was alien to many professionals as mental health care was no longer concentrated in larger 'total institutions' (Goffman, 1961), most being delivered at primary care level as service users resided in the community; however, even today service users and carers report that GPs lack mental health awareness and are slow to react to deterioration in mental wellbeing (Repper et al, 2008a). The Care Programme Approach (CPA), a care management model to support multi-professional collaboration in the treatment of services users in the community and to provide a framework to support new ways of working, was introduced in 1995. It was intended to provide a coordination system to ensure comprehensive holistic assessment, a care planning and reviewing framework, and exists to this day as the major process for supporting and planning mental health service users' care, but is criticised as becoming too administratively oriented, and insufficiently recovery oriented (Pilgrim and Ramon, 2009).

During this period of system change, the move towards internalised markets allowed a more consumerist service use model to emerge (Barnes and Cotterell, 2012) as the Griffiths Report (Griffiths, 1988) had earlier focused on the introduction of customer satisfaction surveys and market research in NHS services. Local Authorities and the NHS set up initiatives to involve service users in consultation and planning. The Standing Advisory Group on Consumer Involvement in the NHS Research and

Development Programme was initiated in 1996, later named INVOLVE. This model of consumerism became a major tenet of New Labour reforms in later years, as discussed below.

Change in the culture and delivery of services from total institutions (Goffman, 1961) to care in the community was accompanied by the development of empowerment philosophies (Ramon 1991) such as social role valorisation and normalisation (Wolfensberger 1972; 1983) and O'Brien's (1988) five accomplishments. This reflected the rich flow of notions of user empowerment that accompanied the philosophy of the reintegration of service users into communities, even if reintegration was more rhetoric than reality (Ramon, 1991). Brandon (1991) reflects on how the principles of normalisation influenced professional practice, for the first time allowing practitioners to understand the importance to service users of living ordinary lives in the community. The strengths approach in social work (Rapp, 1992; 1998; Rapp and Goscha, 2012) promoted a new way of working focusing on consumers' strengths rather than their deficits.

Accompanying the change in philosophy, the implementation of direct payments, emerging from research into service brokerage (Brandon and Towe, 1989), offered a new model of practice. Direct payments were initially made available to service users in 1996 under the Community Care (Direct Payments) Act 1996. This allowed social services to provide cash payments in lieu of services to people assessed as eligible for community care. Direct payments were taken up very slowly by people with mental health needs; there was often little information available about the processes and advantages involved, and people who became mentally unwell were assessed as incapable of managing their own funds to purchase support (Glasby and Littlechild, 2009). The model was further expanded with the development of personalisation in health and social care services from 2006.

In 1997, New Labour came into power with a commitment to rebuilding the NHS. The wider health agenda during this period emphasised:
-   choice in the location of hospital treatment (DH, 2008a)
-   the necessity of partnership between patients and staff (DH, 2008a)
-   the need to tackle stigmatisation through mental health promotion and public campaigns such as Time to change (DH, 1999a; Time-to-change, 2012)

- choice in treatment regimes and the provision of talking therapies (DH, 2009)
- the development of functionalised teams to support people at different stages in their recovery (DH, 1999a; DH, 2000a).

Shortly after the election, the Secretary of State for Health, Frank Dobson, declared that care in the community had failed. He was particularly concerned about patients who were a nuisance or a danger to themselves or others (Dobson, 1998). Two key policy documents were developed in response to his concerns: *Modernising Mental Health Services: Safe, Sound and Supportive* (DH, 1998) and the *National Service Framework for Mental Health* (DH, 1999a). The former promised to 'modernise' mental health services, increase access to services and involve service users and carers in the planning of services, while the latter specified seven standards focusing on mental health promotion, improved quality of care, increased access to services, services for carers and suicide prevention.[2] This was accompanied by an injection of money to develop and improve mental health services. Pilgrim and Ramon (2009) believe that the focus was firmly on the institution of 'safe' and risk-averse services rather than the introduction of more supportive services. This focus was despite the successful resettlement of many former long-stay institution patients (Leff et al, 2000).

To ensure the delivery of safe, supportive and effective services, mental health provision was reorganised. Functionalised mental health teams were developed to provide specialist services to particular kinds of clients who needed additional support, assertive outreach or support at times of crisis (DH, 1999a; DH, 2000a). The CMHTs were seen as the central delivery arm of care in the community, with duties to liaise with primary care and refer patients to more specialised teams.[3] Health and social care teams were brought together in partnership trusts with the aim of ensuring that service users received a more seamless service and benefited from practitioners' interdisciplinary approach. This process of wholesale reorganisation responded to the need for collaboration identified in a number of acts (the Health Act 1999, the Children's Act 2004, the Local Government and Public Involvement in Health Act, 2007), but was particularly a response to Lord Laming's report on the death of Victoria Climbie (Laming, 2003) .

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2 See Appendix 1 and 2.

3 See Appendix 3.

As they were subsumed into community mental health teams dominated by the medical model, social care staff were concerned at the loss of their identity (Carpenter et al, 2003). Tew (2011) reminds us of the importance of the social perspective on mental health that is delivered by social workers trained in the social model. It ensures that the psychosocial model is at the centre of assessment and allows service users to access services that reflect their needs holistically rather than focusing on the medical model of care. The Ten Essential Shared Capabilities (NIMHE and SCMH, 2004) were accordingly designed to provide interdisciplinary standards for health and social care professionals, focusing on the recovery model.

The social inclusion agenda was advocated by New Labour as it sought to tackle social exclusion for people from disadvantaged backgrounds including service users with mental ill-health. (ODPM, 2004a; 2004b). Secker (2011) identifies two elements of social exclusion: the first relating to the deprivation of rights as a member or a citizen of a particular group, community, society or country; and the second relating to the lack of opportunity to participate in key functions or activities of society. The former relates to the politics of mental health whilst the latter relates to experiences of stigmatisation by society – notions of social inclusion are central to this research as a feeling of belonging is fundamental to recovery (Royal College of Psychiatrist, 2009; Tew et al, 2012,).

Following the increase in multidisciplinary and interdisciplinary working, New Ways of Working (NWW) (DH, 2007a) reconfigured the way that staff roles and duties are defined. Professional groups received extended powers and responsibilities which, for example, allowed community mental health nurses to take on prescribing roles with further training; although very few of those who completed the training in Cambridgeshire were given responsibility for prescription. Many professionals found NWW difficult because it incorporated a dilution of professional standards and roles. Although there was an emphasis on working to a recovery model in the development of the new standards, Pilgrim and Ramon (2009) believe that the wider process focused on the medical model rather than recovery. New roles were created with the development of Support Time and Recovery Workers, people with experience of mental ill-health who used their knowledge of recovery to support their peers (DH, 2007b). The development of peer support workers is increasingly acknowledged as being of real value in supporting the recovery of people with mental ill-health (Repper and Carter, 2010;

Cheeseman, 2012). Peer support workers use their own knowledge of personal recovery as experts by experience to mentor other service users in the recovery process, helping them to self manage and learn to cope with their mental illness.

Major changes accompanied the reconfiguration of services as NHS organisations were constantly evolving and being reorganised. CPA, the major care management process, was redefined in October 2008 to support only those who, before this, were eligible for enhanced CPA[4] (DH, 2008a). Many service users saw this as a denial of their right to receive services, as only those with the severest mental health needs were now able to access specialist mental health services (Rethink, 2013). In the UK there is no right to receive services apart from the right to aftercare following compulsory detainment in hospital under Section 117 (MHA, 2007). Service users and carers felt let down when the amendments to the Mental Health Act (MHA) (2007) failed to secure the right to receive services, known as the 'principle of reciprocity' (Pilgrim and Ramon, 2009). Recovery-oriented services advocate that service users should not necessarily be in contact with services all their life, but should have access to professionals 'on tap' when they need them (Roberts and Wolfson, 2004; Stickley and Wright, 2011a); some users believe that the withdrawal of services from those 'in recovery' is a by-product of current mental health policy connected to the 2008 reorganisation of the CPA (Rethink, 2013).

The rhetoric underpinning many of the major changes in the NHS was of increased public involvement in health and social care decision-making processes, with flexibility and choice in service delivery. The NHS Plan (DH, 2000a, p. 88) promised greater partnership with all patients with services 'shaped around the convenience and concern of patients' with patients having 'more say in their own treatment and more influence over the way the NHS works'.

The Primary Care Trusts (PCTs) were seen as the flagship of the reconnection of local service provision with the needs of local people. PCTs were responsible for

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4 The CPA originally had two levels: standard and enhanced. The former governed the care of those with less complex needs, while the latter governed the care of people with complex and severe mental health needs requiring multi-disciplinary input.

commissioning services that matched the needs of the local population (DH, 2005) to ensure connection between local public health policy and the delivery of appropriate services.[5] NHS organisations now had to consult with patients and the public at an early stage of planning or changing services and when undertaking new research (Health and Social Care Act, 2001). Further reorganisation followed, as organisations providing mental health services became Foundation Trusts. These had greater fiscal freedom from government to develop their own specialities and deliver locally accountable services. They had a duty to elect service users, carers or members of the public to sit on their boards to strengthen their accountability to the public (DH, 2002).

Alongside this, the Expert Patients Programme (EPP) (DH, 2001a) was initiated to enable people with long-term chronic health conditions to learn techniques to manage their symptoms more effectively and become experts on their own illness. This had the potential for redefining the individual relationship between professional and service user. Pilgrim and Ramon (2009) remark that the EPP failed somewhat as it was an American programme taken off the shelf and transported into the English context without adaptation to suits the needs of UK users with only medical information about mental illnesses given to experts patients. This is particularly problematic in mental health as different models of mental illness are emphasised by different professional groups who argue diverse causes for its origins.

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5 In the late 1980s under the Conservative government, GP practitioners assumed fund-holder status and began to purchase services directly to support their patients and families. Labour abolished the internal market within the NHS and GP fund-holding (DH, 1997) and reformed GP practices into Primary Care Groups which could commission local services. Primary Care Groups were later amalgamated to become Primary Care Trusts (DH, 2001c), which had a duty to commission services to meet the needs of the local population. In 2005 smaller PCTs were amalgamated into bigger ones to achieve economies of scale, and many believe that PCTs lost their connection with the local population then. The coalition government plans to abolish PCTs and replace them with GP-led commissioning. It appears that policy has gone full circle with a return to a situation resembling to GP fund holding.

It is questionable whether the user involvement policy has been proactive in generating increased participation in decision-making or reactive in responding to the user movement that has grown in the UK and across the more developed world (Beresford and Branfield, 2012). Effective user involvement in mental health has grown more organically than the political context would suggest; it has developed more along the lines of a democratic than a consumerist model of involvement (Beresford and Branfield, 2012). The democratic model of user involvement emphasises the importance of citizenship, equal opportunities and the development of a rights- and responsibility-based society. Some writers argue that the user involvement tradition developing in spite of rather than because of mental health service developments (Beresford and Branfield, 2012).

The **personalisation agenda** is a model of practice that seeks to optimise individual users' choice and control of social care resources, building on the notion of user involvement in care. It is now the model for the delivery of services and is preferred by the current government. It was given greater prominence with Our Health, Our Care, Our Say (DH, 2006a), building on the work of Brandon and others (Brandon and Towe, 1989) who campaigned for the rights of service users to receive direct cash payments in lieu of social services in the mid 1990s. The emphasis on personal budgets is intended to give service users greater control over the cash available for their care, ranging from complete control of it to knowing how much is available, what services they can buy, and how. This has been further extended with the suggestion of individualised budgets, which can include payments in lieu of health and social care services. Its take-up by people with mental health issues has been limited. Recent research, however, highlights the need to provide clear and accessible information to help people to make the right decisions about their needs (Newbronner et al, 2011). The report concludes that service users need support to access individual budgets from an empowering professional who consults with the carer (when they are involved in the direct care of the client) on their potential role in helping to manage it.

Secker (2011) has argued that personalisation models address *experiences of social exclusion* but fail to support the *social inclusion* agenda. Spandler (2007), cited in Secker (2011) notes that the personalisation agenda seeks to remedy the experiences of social exclusion for *individual* service users rather than addressing the *collective responsibility* of society to address the structural barriers which impede social inclusion.

Spandler (2007) cited in Secker argues that the experience of social exclusion is derived from a deficits model of mental health, whereby assumptions are made that the service user's 'low aspirations and fatalism' prevent them from participating in society rather than believing that 'structural barriers in society work to exclude people' (Secker, 2011, p. 506). This places the responsibility for social exclusion on the service user, rather than acknowledging society's responsibility in impeding their opportunities to engage in wider mainstream activities.

Culham and Nind (2003) similarly note that social role valorisation (SRV) (Wolfensberger, 1972; 1983) that underpins person centred planning in learning disability theory (O'Brien, 1988; O'Brien and O'Brien, 1998) lacks reference to the social inclusion agenda. They argue for the importance of the social model of disability in social role valorisation theories which places responsibility on society for impeding disabled people's inclusion as full citizens in their communities, e.g. a person who uses a wheelchair is denied physical access to a building because there is no ramp; their impairment does not impede access rather the physical structural barrier. Indeed Beresford (2010) notes the importance of the social inclusion agenda to mental health models and argues for their greater reference to the social model of disability; and in Fox (2011a) I argue for a greater alignment between the social model of disability and the recovery model.

The introduction of these policies and the reorganisation of the NHS claimed to place service users at the centre of care and promote choice in treatment, seemingly moving towards a more liberal form of health care. An emphasis on greater choice in health care has been counterbalanced by developments in coercive mental health treatment. The Mental Health Act 1983 (amended by the MHA 2007) sets out the legal criteria for detention in hospital for assessment and treatment, and the rights of patients detained under the Act.[6] The 2007 MHA amendments introduced Community Treatment Orders to allow some patients subject to this order to be recalled to hospital if they were not compliant with specified arrangements agreed with mental health practitioners for their care, including medication compliance or living at a particular address). It extended the role of Approved Social Worker to professions other than social workers, reducing the importance of the social perspective when undertaking mental health assessments. The

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6 See Appendix 4.

MHA (2007) extended patients' right to make decisions through Advanced Directives, such as a decision to refuse ECT[7] and introduced the right to advocacy for people detained in hospital.

Up to today, carers have had a significant role to play in the mental health assessment process in the Mental Health Act (1983).[8] Identification as the nearest relative (NR) in the UK is determined on a hierarchy of nearest relationships and age. The Approved Mental Health Practitioner (trained to undertake and co-ordinate mental health assessments for admission into hospital) must involve the nearest relative in the process and seek their agreement where possible. The role of the nearest relative was drafted in the mental health legislation to protect the service user from arbitrary processes of 'sectioning' against their will and to ensure the use of the least restrictive option.

While other legislation has strengthened the role of the carer, the MHA (2007) has weakened the role of the nearest relative in the assessment process by allowing professionals to apply to the County Court for their displacement when their actions are considered inappropriate or counterproductive. This has placed more powers in the hands of clinicians and removed power from the nearest relative. According to Rapaport (2005), the role of the nearest relative (NR) in mental health legislation can potentially be very empowering for the service user, although it depends on the relationships between a specific NR and a specific service user. Rapaport describes this relationship during the mental health assessment process as an example of reciprocal role valorisation (RRV) seeing this relationship as akin to that of the advocate in the mental health assessment process.

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7 The MHA (2007) was supported by implementation of the Mental Capacity Act (2005). The 'Bournewood' problem, which plays out when patient are detained under MHA (2007) but lack the capacity to consent or refuse treatment, has been resolved by the Deprivation of Liberty Safeguards. Five principles were introduced to ensure that people without capacity who are detained have some right to refuse or consent to treatment (see Appendix 39).

8 The legislative powers of the nearest relative are found in Appendix 5.

The UK mental health acts are very different from other health acts because of their focus on instances of high risk and compulsory action: the commitment to service users with other chronic health conditions focuses on choice, support and decision-making based on a partnership between the clinician and the patient. Implicit in the arguments about user involvement in mental health is the experience of mental health services as coercive, punitive and discriminatory. Many service users feel that they are more often survivors than consumers of mental health services (Beresford and Branfield, 2012). Beresford and Branfield (2012, p. 37) state that the history of disabled people's movements is characterised by the 'segregation, isolation and degradation – unintentional or otherwise – of disabled people and service users'. The Labour government's rhetoric emphasised choice yet focused on the development of more risk-averse services in response to concern about public safety (Pilgrim and Ramon, 2009).

In the final years of the Brown government, a review of the NHS undertaken in 2008 by Lord Darzi (DH, 2008b) focused on helping people to stay healthy through working in partnership with staff. New Horizons (2009) aimed to build on the foundations of the National Service Framework for Mental Health (DH, 1999a) by setting out the next stage in Labour's strategy for improving mental health in England by 2020.[9] Another flagship enterprise, the Improving Access to Psychological Therapies (IAPT) programme, greatly increased resources for the delivery of psychological therapies to around 900,000 patients suffering from mild to moderate mental health difficulties such as anxiety and mild depression.

This marked the end of the Labour government's 13-year struggle with mental health policy, a period of great NHS reorganisation and renewal, changing the delivery of mental health services. Labour promised greater investment in mental health services, although many think that this claim was over-inflated (Pilgrim and Ramon, 2009). It promised greater opportunities for user involvement, although this has been questioned (Beresford and Branfield, 2012), and it extended new methods of delivering and receiving services through personalisation, although difficulties have been raised with these processes (Newbronner et al, 2011). It was a time of great promise tinged with disappointments, and made many changes to how services are experienced by service users and carers.

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9 See Appendix 6.

A few months after the election of the Coalition in 2010, No Health without Mental Health (DH, 2011a) was published, promising:

- extensive funding to improve the Access to Psychological Therapies programme (IAPT)
- funding for the Time to Change anti-stigma campaign (£18 million)
- a focus on a cross-government approach to public health, early intervention and recovery, and reducing stigma.

Funding for the IAPT programme marked recognition of the importance of the provision of talking therapies in enabling recovery.

The Coalition emphasised the importance of service users returning to work, lamenting the 'welfare scroungers' who claim disability benefits unfairly as a drain on society. Many service users with long-term mental ill-health felt tainted by these pronouncements, which elicited protest from service user groups. Fox and Ramon (2011) raised concern about the unfairness of processes used to assess people's capacity to work, as returning to work too early can undermine and disrupt the recovery process.

The liberalisation of financial arrangements in the NHS is reflected in the implementation of Payment by Results (PbR) in 2005 which now extends across all forms of NHS delivery, including mental health (DH, 2011b). The three building blocks of PbR are classification, currency and costing[10] (DH, 2011b) which underpin the arrangements that allow commissioners to pay for actual services that are provided by NHS organisations. Draft guidance (DH, 2011b; 2011c) suggests that clustering processes will dominate the administrative systems that support financial arrangements (DH, 2011c) necessary to the practical operation of PbR from 2012/13. A mental health care cluster identifies the needs of the service user, takes into account their diagnosis and suggests the kind of care they will require.

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10 A person is classified into a healthcare resource group (HRG) that reflects their diagnosis and needs. Each intervention or treatment cannot be priced separately they are therefore grouped into currencies, the unit of healthcare for which payment is made. The currency is then analysed and attached a cost and assigned a price. The price is evaluated and paid at a national rate for agreed care.

PbR seems an antithesis to current mental health policy which promotes the importance of user-centred, user led care (DH, 2011a); it suggests rather a reconfirmation of the dominance of the medical model of mental health that emphasises the primacy of the clinician in diagnosing and treating mental illness. It remains to be seen if this is little more than an accounting procedure, or whether it reflects a change of direction in care services as administrative procedures to support financial processes may replace recovery models (DH, 2011b; 2011c).

Despite this, much research currently underpins the development of organisational change in mental health to transformative recovery services. Shepherd, Boardman and Burns (2010) identify 10 key organisational challenges that support the implementation of recovery services.[11] The process is based on a methodology of co-production between stakeholders and 'depends on changing the ways in which things are done, rather than on an injection of new resources' (ibid, p. 4). The methodology is two staged: the first stage is a benchmarking assessment using the 10 key organisational challenges; the second stage requires the development of a SMART[12] action plan to refocus the organisation towards a recovery orientation. The action plan proceeds via an internal audit loop (or 'Plan-Do-Study-Act' cycle) to produce sustained organisational change (Iles & Sutherland, 2001) that is monitored and evaluated via service indicators and data sets which evidence progress against each challenge.

The Refocus for Recovery programme (http://researchintorecovery.com) which began in July 2009 seeks to develop a manualised recovery intervention for use in adult community mental health teams to transform traditional mental health services into recovery oriented mental health services. The REFOCUS study is taking place in South London and Maudsley NHS Foundation Trust and 2gether NHS Foundation Trust in Gloucestershire. The programme will develop
- recovery-focussed fidelity measures and outcome measures
- manualised recovery interventions
- randomised controlled trial evidence

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11 See Appendix 7).

12 SMART goals are Specific, Measureable, Agreed-upon, Realistic, Time-based

This approach is intended to contribute to organisational change across both teams and the mental health systems.

The Implementing Recovery Oriented Change (ImROC) programme began in April 2011, supporting twenty-nine NHS mental health provider organisations in the UK, to pilot the organisational change of recovery oriented services in mental health (MHN NHS Confederation, 2012). Intensive individualised support was provided to six pilot sites which received expert advice on employing and establishing the role of paid peer support workers in clinical teams, on the establishment of a local recovery college,[13] and through the provision of training co-produced and delivered by experts by experience and professionals to all stakeholders and key staff within mental health services. The project team (MHN NHS Confederation, 2012) found that these key foci could encourage change in practice and culture of organisations.

Action learning sets in the pilot areas were established to develop learning and best practice in delivery of mental health services through bottom up change rather than top down implementation underpinned by partnership-working between service users and carers key. The project team (MHN NHS Confederation, 2012) find the 10 key organisational challenges helpful in implementing recovery however note their limitations with regards to the needs of carers and people from BME Groups. They believe that a sound and well-defined outcome framework for recovery needs to include improved quality of experience, enhanced subjective perceptions of hope and control, and the achievement of personally relevant life goals. They note that lack of resources and the format of traditional practice are seen as barriers to effective organisational change. They believe that recovery change will require a 'big bang' (ibid, p.6) as services are reconfigured and practices are changed with the development of a local recovery college and the employment of peer support workers.

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13 Study and training facilities that provide a range of courses and resources for service users, families, friends, carers and staff with the aim of supporting people to become experts in their own self care and for families, friends, carers and staff to better understand mental health conditions and support people in their recovery.

As the country emerges from a period of fiscal austerity, it remains to be seen how the government will further develop mental health services and change the direction set by New Labour although the government remains committed to the recovery model in its latest mental health policy (DH, 2011a). Although Shepherd, Boardman and Burns (2010) note the planned agenda for change proposed by payment by results arrangements they emphasise the importance of using these proposed changes 'as levers' to 'drive the performance of providers towards more recovery-oriented delivery' (p.4). They see the *opportunity for recovery* whilst acknowledging that limited resources and rapid policy changes place increasing demands on the ability and capacity of individuals and organisations to implement recovery in mental health.

Summary

Section 2.1 has provided a historical review of mental health care since the 1980s. It has shown how deinstitutionalisation led to care in the community and the inherent difficulties faced during these changes. The section has explored Labour's promises of investment in the NHS which led to changes in the constitution of services and the extension of traditional professional roles, and highlighted political efforts to increase service user and carer representation in the development and planning of mental health services and choices about care. The contradictions inherent in the assumed liberalisation of mental health care with the implementation of the MHA (2007) have been explored. This section has provided the policy context to this study, highlighting the socio-political background and the assumptions inherent in this thesis.

2.2 The carers' movement and the politicisation process

This section introduces the formation of the National Schizophrenia Fellowship (NSF) in the 1970s, which gave a voice to the carers' movement, and provides an overview of the raft of policies that followed from 1995 onwards, partly in response to intense and persistent lobbying by carers' representation groups.

The development of the NSF in 1972 was a pivotal point in the politicisation of carers (NSF, 2002). Pringle published 'A Case of Schizophrenia, by a Correspondent', in *The Times* of May 9th 1970, describing the difficulties experienced by a family supporting a relative with schizophrenia at home. He dismisses the notion that schizophrenia may be caused by parents, and notes the increased burden on carers following the closure of mental health institutions. This article was a rallying point for many carers as they came

together into a carer group to campaign for better services for both themselves and their relatives: the NSF was formed. NSF (2002, p. 5), which describes its development, states:

> 'A strong motivation for the eventual foundation of NSF was the recognition that a specific voluntary organisation focussed on schizophrenia was needed to promote the welfare and build the confidence of carers and users of services. It was considered very important to seek and reinforce the views of sensible and well-informed experts and, with their help, to present a reasoned account of the problems posed by schizophrenia to government.'

NSF was a strong force for change, adopting a highly medicalised perspective of schizophrenia emphasising the importance of professional knowledge and expertise rather than expertise-by-experience. Membership grew slowly from around 300 in 1973 and 800 in 1975, reaching 3000 by 1981. By 1975 there were 60 local groups which doubled to 120 by 1978 (NSF, 2002).

In 2002 NSF changed its name and became 'Rethink: Severe Mental Illness', an organisation that began to embrace change for service users as well as carers, possibly diluting the influence that carers had from having an organisation representing their own interests. National Rethink is active in research and has a stake in key projects such as Time to Change, a national anti-stigma campaign. Local regions organise varying facilities to support carers and service users, and local relatives' groups often provide mutual support groups, helplines and advice services for carers. The Princess Royal Trust for Carers (PRTC) has latterly also begun to focus on the needs of carers for people with mental health problems, holding their first national Mental Health Conference in 2001. This area was traditionally covered by mental health organisations such as Rethink and Mind, but demand for the development of increased support was recognised with the NSF MH (1999).

About half of those with serious mental health needs in the UK live with and are supported by family and friends (DH 1999b). In the UK that there are 5.2 million carers, of which over 1 million care for somebody for more than 50 hours a week (DH, 2008c, p.33) and about 1.5 million may be caring for someone with mental health problems or dementia (Arksey et al 2002, p. 13). Their support saves public services an estimated £87 billion per year (House of Commons Work and Pensions Committee, 2008, p. 5), with carers in South Cambridgeshire alone saving the economy £144 million per annum

(CPFT power point, 2012c). Carers are an economic force in this country, and as such are politically important as voters.

Caring for People provided the first official acknowledgement of the carer's role (DH, 1989). The Carers (Recognition and Services) Act (H.M. Govt, 1995) formally recognised the carer's role, giving them a right to an assessment of their own needs independently of the person they cared for, on request from their local authority. The Carers National Strategy (DH 1999b) further identified three strategic elements of caring: information, support and care for carers, and conferred the right to support in their choice to care and involvement in the planning and monitoring of services for the care of the person they support.[14] The NSF for Mental Health (DH 1999a) Standard 6 focused on the needs of mental health carers, stipulating that carers for CPA service users have a statutory right to an assessment of their needs. The executive summary acknowledges their vital role in caring and emphasises that providing information, advice and support to carers can optimise service user outcomes (DH 1999a).

The Carers and Disabled Children's Act (H.M. Govt, 2000) gives carers over 16 years old who care for someone over the age of 18 the right to an assessment of their needs, even if the person they are caring for is not assessed, and the right to receive direct payments for their own care services.[15] The NHS Plan (DH 2000a) committed to providing 700 additional support workers by 2004 to increase the breaks available for carers and strengthen support networks. The Carers Equal Opportunities Act (H.M. Govt, 2004a) states that local authorities have a duty to inform carers of their right to an assessment and that the carer's work, leisure and lifelong learning needs must be taken into account in the assessment process.

Recognition of their political status led to carers demanding participation at local and national levels in the planning, monitoring and review of services. The opportunities for this have increased over the last 10-15 years (H.M. Govt, 1995; DH, 1999a; 1999b; H.M. Govt, 2004a; DH, 2008c; 2010; H.M. Govt, 2010). DH (1999a) recognises the

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14 Information to make them real partners in the provision of care to the person they care for. Support for Carers from the communities in which they live, and in the planning and provision of services. Care for carers so that they can make real choices about the way they run their lives.

15 For young carers under 16, The Carers (Recognition and Services) Act (1995) gives children the right to an assessment, while the Children's Act (1989) gives children in need the right to service provision.

importance of involving carers in the planning and monitoring of services. It states (ibid p. 5) that people should be able to expect that services '...involve services users and their carers in the planning and delivery of care'.

The *Scottish Nursing Review* (The Scottish Executive, 2006) underlines the importance of a culture of recovery and working with carers as well as service users. The Carers Strategy (DH, 2008 p 38) recognises the role of the carer as expert in their caring role, which means:

> '... ensuring that professionals … should recognise that while the person being looked after is usually the expert in their own care, the carer too is a real expert. That being the case, carers should be consulted as partners in care and their unique knowledge and expertise recognised.'

The Carers Strategy (2008, p. 9) goes on to state that support should be offered to carers 'tailored to their individual needs' enabling them 'to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen'.

The latest Carers Strategy (DH, 2010 p. 10), introduced by the current government, recognises how carers 'have developed an expert knowledge of the condition of the person they are supporting and have a close understanding of that person's own aspirations and needs'. It focuses on carers' right to a life outside caring and need for personalised support to enable them to have a family and community life, as the previous government promised. It commits to enabling carers to work or be involved in education and believes that adults of working age caring for someone should not have to give up work in order to be a carer (DH, 2010). It has therefore strengthened the protection of carers in the workplace and from discrimination in seeking work in The Equality Act (H.M. Govt, 2010) by recognising their need for flexible working conditions. DH (2010) promises to involve carers from the outset in both designing local care provision and planning individual care packages, building on the vision of the Big Society which seeks to create stronger links between the community and its members.

Recognition of the role of the carer in the support they give to the service user is now well documented. The politicisation of carers' role and their need to be involved in the development, planning and monitoring of services is now evident in mental health

policy. Carers are acknowledged as service consumers with an interest in the provision and development of services. Despite this rhetoric, the current government does not offer carers any more support than the previous government did. This underlines the importance of continuing to highlight the needs of carers and to acknowledge their role in the recovery of the service user.

2.3 The research context

This section sets out the socio-economic context and local geographical environment that influenced the development of the research. It provides demographic data about the local population and how ethnic status influences the use of mental health services and details of the local authority's provision for carers, with an introduction to the Carers' Strategy. Local mental health service provision is described with a particular focus on the experiences of carers, followed by a discussion of the Mental Health Trust's proposal to develop services for carers alongside the current provision for this group. The suitability of the locality for the study and its place in the international context is discussed.

The socioeconomic and geographical contexts of the study

This study was conducted in Cambridge, in the Eastern Region of England. Cambridge is situated about 1 hour from London and 40 minutes by car or train from London's third airport, Stansted (Cambridge County Council, (CCC) 2012a). An estimated 605,000 people lived in Cambridgeshire in 2010, of which 111,000 were aged 0-15 years, 405,000 15-64 years and 99,000 were over 64. Cambridge itself had a population of 120,000 (CCC 2012b, 23.08.12).

Cambridge is home to two universities: the leading international University of Cambridge and Anglia Ruskin University, on the site of the former Ruskin School of Art founded by John Ruskin. The university status of the town influences the population of Cambridge: it has a high student population and attracts a large number of international summer-school students. Cambridge is an affluent, well-connected and prosperous place to live, which defines the type of person that it attracts: 46% of its residents are educated to degree level compared to the national average of 26% (CCC, 2012a). The city hosts many high-tech companies and attracts well-educated and affluent workers (CCC 2012a). Greater Cambridge is predominantly rural, with many outlying villages, many of which are poorly served by public transport, isolating non-drivers (CCC, 2012a). Due

to the wealth of the population in Cambridge it is difficult for people in the lower socio-economic brackets to access social housing, and stock is very limited (CCC, 2012a).

The Eastern Region has the fifth largest population of non White-British residents in the UK, with 7% of the non White-British population. It has slightly smaller proportions of all Black and Minority Ethnic (BME) groups than are present in the overall population, with White-Irish and White-Other groups most prevalent (Dunn, 2005). Residents of mixed ethnicities live most commonly in Hertfordshire and Essex, and the Asian populations are highly concentrated in Luton and Hertfordshire. Large proportions of Black residents live in both Luton and Hertfordshire but also in Suffolk, possibly due to the presence of armed forces there. Cambridgeshire boasts the largest number of people from the Chinese community, probably due to the number of students in this ethnic group. Their presence is also concentrated in Essex and Hertfordshire (Dunn, 2005). Peterborough has a broad ethnic mix and became home to many East London evacuees following resettlement after the Second World War.

The Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC) survey suggests that common mental disorders such as depression and anxiety are most frequent among Irish men and Pakistani and Indian women in the Eastern Region (Dunn 2005) and least frequent among Bangladeshi women. Psychotic disorders, such as schizophrenia were found to be double the average rate in Black-Caribbeans. More men than women were patients in the psychiatric care population in the Eastern Region, and an increased number of Other-Black men used these services. Male and female members of the Black-Caribbean community were also present in disproportionate numbers among those who used mental health services.

This latter statistic is replicated across many mental health services. The Care Quality Commission and National Mental Health Development Unit (2010), in a national census of mental health inpatients, found that people from BME backgrounds were disproportionately represented in mental health services, received more coercive treatments while in hospital and were more likely to be detained under the MHA (2007). BME service users experience institutionalised racism. A mother with schizophrenia who is Black and from a poor background may experience multiple oppressions: the stigma of being a mother with a mental health problem who has a child (Fox, 2012); discrimination against being Black; and has limited access to resources (Kalathil, 2010).

These experiences impact on service users' recovery rates and their relationship with services.

The low number of people from BME backgrounds in the local population influenced the sample of the study; only one White-Irish female carer attended the programme. I was initially interested in investigating the experiences of BME carers but it was difficult to recruit this population to the study despite extensive efforts (see Chapter 8).

Carers in Cambridgeshire

Cambridgeshire County Council (Carers Strategy, 2008-2011, CCC, 2008) identified 50,673 family carers from a population of 552,658 living in Cambridgeshire at the time of the 2001 census. There are 8,620 family carers caring for over 50 hours per week and over 886 young carers aged 5-15.[16] The Mental Health Trust has no accurate record of the number of carers in its locality because the limited database only contains the number of carers' assessments completed. As relatively few assessments have been completed, the number is not representative of the carer population. The Carer's Grant allocated to Cambridgeshire in 2011 totalled £1,663,000: £129,483 of this was spent on those supporting people with mental ill-health (CCC, 2008, p. 12) compared to £332,600 spent on those caring for children and £84,600 on those caring for people with learning disabilities.[17]

The local authority, Cambridgeshire County Council (CCC, 2008), has the lead role in undertaking carers' assessments under NSF MH (DH, 1999a) Standard 6. The Carers Strategy (2008-2011) (CCC, 2008) builds on the national Carers Strategy (H.M. Govt, 2008c). It acknowledges that current services are not up to the required standard. It notes that all health and social care agencies need to collaborate to provide better care for carers. The Cambridgeshire Carers Strategy is committed to ensuring that carers are supported to stay mentally and physically well, are able to have a life and identity outside caring and have adequate access to services that support them as expert partners.

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16 See further breakdown in the Appendix 8.

17 See Appendix 9 for a further breakdown of funding allocation.

They should have opportunities to pursue their own leisure and work roles and not suffer financial hardship due to caring.[18]

The geographical area in which the study took place is covered by the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT). Its vision is founded:

> '... on ensuring that we put service users and their families at the heart of all of our services and service development activity. We are committed to involving service users and carers in their personal care, in service evaluation and development and in helping to set CPFT's strategic direction.' (CPFT website 2012a)

During the active phases of the research and the delivery of the training programme, service provision was organised along recovery lines reflecting a stepped model of care. Recently services have been reconfigured at the time of write up (May, 2013) to reflect new models of care: organised around the delivery of acute care, community support and specialist treatment. Despite this reorganisation, CPFT continues to be committed to the recovery approach as it is one of the six demonstration sites in the ImROC project described in section 2.1.

In 2008, the Trust launched its Experts by Experience programme to support the involvement of service users in a variety of activities. It has appointed service user and carer ambassadors to represent their peers at all levels of management in the trust. It is committed to developing the role of peer support workers across its workforce. Service user and carers are involved in research: a designated manager has a budget to support this work across the Trust area.[19] During the delivery of the programme the trust organised a conference on recovery in summer 2009 which was attended by five carers who participated in the study. Both the carer trainer (AM) and I were invited to present the initial research findings there.[20]

Carer consultations were undertaken across the catchment area in early 2012 to develop a CPFT Carers Strategy (CPFT, 2012c), to be approved and launched by March 2012.

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18 See Appendix 10.

19 The manager for developing service user and carers involvement in research, JS, was, a member of the steering group supporting the implementation of the project, as described in more detail in Chapter 5.

20 See Appendix 11 for a summary of the presentation.

The final Strategy, however, had not been delivered even as late as April 2013 due to staff changes, although the vision to drive services forward from the consultation process had been developed. CPFT's proposed strategy from 2012-2014 (CPFT, 2012c)[21] commits to recruiting and appointing more Carer Ambassadors to represent the views of carers across the Trust; develop new training for staff involving carers to make them carer aware; ensure that services develop a 'carer aware' self-assessment process; and ensure that young carers are identified and supported appropriately.

Carer involvement in planning care is, however, not as well developed as the national strategy standards propose (DH, 1999a; 1999b; 2008c; 2010) In 2012, CPFT undertook an audit of adult in-patients across the region to evaluate their perceptions of their carers' contribution of to their recovery, both during their admission to hospital and following their discharge from care (CPFT, 2012b). This audit sought to evaluate whether carers were involved in the CPA process and if their contribution was effective. The questions were designed with contributions from users and carers.[22] The findings reported that patients felt carer involvement was positive when the carer supported their recovery (CPFT, 2012b), but that carers were only sporadically involved in decision-making about patients' care and patient had low expectations of them being involved in planning their discharge. Anecdotally, the need for confidentiality was used by staff as a barrier to engaging with carers. These experiences are not uncommon; similar findings are reported in other national studies (Repper et al, 2008a; Worthington and Rooney, 2009).

Mental health carers are supported throughout Cambridgeshire by the Making Space carer support service. Carer support workers offer support, information about mental health needs, carer assessments and information about their rights, and they signpost to local services (Making Space website, 2012). Carers can directly refer themselves to the service or be referred by health and social care professionals.

The service supported carers participating in this research who needed help beyond what I could provide. The manager of Making Space participated in the steering group that

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21 See Appendix 12.

22 See Appendix 13.

supported the implementation of this project (described in chapter 5). A Rethink Advocacy service offers similar support to mental health carers in Peterborough. In addition, local Rethink groups are organised by volunteers and meet regularly across Cambridgeshire and East Anglia. They helped us to recruit carers to the research programme.

The suitability of the context

The research was undertaken in this locality for a number of reasons. The area was initially considered for expediency as it is close to my home and place of work and study, therefore little travelling was involved. CPFT also has a history of collaboration with Anglia Ruskin University on research and development.

At the start of the project, I held several meetings with high-level and middle management in the Trust to ascertain whether they were keen to participate in the research programme. There was positive managerial support and enthusiasm for developing the research; one senior manager (KE, responsible for managing the CPNs in the Trust) and another middle manager (JS, responsible for developing and supporting user and carer involvement in research in the Trust) were also involved in implementing the research (described later in Chapter 5) The Trust gave permission for the research to be undertaken within their boundaries following the university's ethical approval.

The political context in the UK is appropriate for this study involving carers in its development and delivery. Carers in the UK are a definitive force, whereas those in Europe are less organised. During a four-week stay in Germany interviewing carers and service users, it became clear to me that they were less knowledgeable about their rights, had fewer rights and were less politicised than their counterparts in England, except in projects such as the Trialogue in Austria and Germany (Bock and Priebe, 2005). More widely across Europe, the, European Federation of Families of People with Mental Illness (EUFAMI), founded in 1992, advocates on behalf of carers by lobbying European Union bodies.[23]

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23 EUFAMI is an international not-for-profit charity consisting of family organisations in 26 European and one non-European country. It is a federation of 41 family associations, and 5 other mental health associations (EUFAMI, accessed online 30.10.2012).

Carers in the UK, however, are less influential than those in the USA, who overtake service users in leading policy (Pilgrim and Ramon, 2009). It is doubtful whether the primacy of carers over service users in leading policy is desirable in the UK. Although the NSF (2002) expressed the importance of carers' views and the historical problems of excluding them from care, and DH (2010) underlines their significance in planning care, carers' views are more often secondary to those of service users in determining policy. Carers and service users may have different opinions about the delivery of services and experiences of receiving services: carers may be more medication-focused and may have a stronger commitment to coercive treatment regimes for their relatives, who may not be compliant with the recommendations of medical experts.

The chosen methodology for this research is appropriate for the UK context. User involvement in research is more developed in the UK than in other European countries (Videmsek and Fox, 2009). The utilisation of a Participatory Action Research (PAR) research methodology, which allowed me to identify myself as a service user involved in research as an acceptable part of the research process in PAR tradition in the UK, is less acceptable in other countries and is a key determinant of this research (Fox, 2007, 2008). Research that involves carers is developing in the UK (MHRN, 2012a, 2012b) building on the existing expertise of involving service users in research.

This section has identified the unique geographical, social and cultural context of this study. It provides background information to the services delivered in this area and the gaps in service provision for carers. It provides insights into the factors that influence the research development, implementation and findings and details the appropriateness of the context.

2.4 Personal and professional reasons for choosing the research topic
I have both personal and professional commitments to undertaking this research. My life as a service user going through a recovery journey makes the concept of recovery immediately attractive. Recovery was a relatively new concept as I was beginning my PhD study in 2006. I was attracted to the recovery approach and its potential for changing services and developing practice. Experiencing the recovery journey made this an area that I was passionate about, had expertise in and was excited about studying. I also had a commitment to supporting carers: I myself had been supported by my family,

and I wanted to pass on to other carers some of the hope and determination that they had held for me.

This personal commitment was underpinned by professional expertise from working with carers in research and supporting them in their caring role. From 2000-2003, I worked with carers at a Carers' Centre in Barnet, North London, UK. This was a new area of specialism being developed. I was first appointed in 2000 to develop a Carers' Strategy for the NSF MH Standard 6. This was initially a nine-month short-term contract; in 2001, further funding enabled me to continue to work in this area, providing support for carers and developing services. It was a role that personally felt a little safer than working with service users, as it was removed from my own experience of mental health symptoms.

I found carers confused, self-blaming, under-informed and with little knowledge about the experiences of mental ill-health and how to work with services. Talking to a service user who was positive, enjoyed her job and was knowledgeable about the experiences of mental ill-health helped them to care more effectively. I was also a qualified social worker with insider knowledge of the mental health system and helped them to find their ways around the services. This helped them to improve their lives and increased their sense of self-empowerment, which is fundamental for carers.

Alongside my work I was completing the final stages of a Master of Arts in Mental Health Professional Practice based at Anglia Ruskin University (then Anglia Polytechnic University (APU). My final major project focused on a PAR study to enable carers to have their voice heard (Fox, 2009). We wanted to develop a group that would enable carers to influence mental health services and develop their sense of self-empowerment. The group named itself Carers Against Stigma (CAS) in Barnet. It sought representation on a number of committees across the Trust's area and began the process of involving carers in planning and developing services in this locality. In 2003, on completion of my MA, I left this role to work in Patient and Public Involvement (PPI) in the NHS as a Forum Development Officer in a third sector agency supporting the development of patient and public involvement forums.

I began to work at Anglia Ruskin University for two days a week in 2005, developing user and carer involvement in the training of social work students. This increased my

knowledge and expertise in involving service users and carers at the heart of developing initiatives and led to my wish to begin my PhD.

2.5 Conclusion

This chapter has explained the assumptions inherent in this study by detailing mental health policy, carer legislation, the local context of the study and my personal and professional reasons for choosing this topic. The political timeliness and relevance of this work can be seen in the raft of documentation supporting the carers' role. The ambiguities in policies and attitudes of professionals towards carers, and the inherent ambiguity in the relationship between service users and carers continue to re-surface. This is taking place, alongside the persisting gaps in services, carers' experience of barriers to their involvement in care and the ineffectiveness of local services in supporting carers indicate the need to involve them in research and service design. This chapter has presented the current context for this research.

The next chapter details the gap in knowledge that this research seeks to address. It introduces the recovery concept in mental health focusing on the personal model of recovery and considering the implementation of recovery in different countries, including the UK.

Chapter 3. The recovery concept in mental health

3.0 Introduction

In the last twenty years, the negative status of the 'schizophrenic patient' has been confronted and the traditional psychiatric model challenged. A model of recovery has been posited by a number of studies since the late 1960s (Huber, Gross,and Schuttler, 1975; Tsuang, Woolson, and Fleming,1979; Ciompi 1980; Harding et al, 1987; Ogawa et al 1987; McGorry et al 1996; Harrison et al 2001; Warner 2004). The service user movement has grasped this model enthusiastically, and a new meaning of recovery has emerged in which living well with mental health problems and not necessarily a complete cure from the symptoms dominates the agenda (Anthony 1993; Repper and Perkins, 2003). This involves a life lived beyond the label of schizophrenia (Spaniol et al, 2002; Davidson, 2003), where the experiences and symptoms of mental ill-health are synthesised through a process of living well and successfully with this diagnosis beyond merely managing its symptoms.

This chapter discusses the background to mental health recovery, focusing particularly on the experiences of people with schizophrenia. It begins by setting out the literature search strategy. Different models of mental health are then introduced, and alternatives to the traditional biomedical model are explored which prepare the ground for the concept of recovery to emerge. The development of the concept of recovery in the USA and New Zealand (NZ), is outlined, including how it has grown from its political roots in the mental health service user movement. The concepts of personal recovery and clinical recovery (Slade, 2009a), or *recovery in mental health* and *recovery from mental health* (Davidson and Roe, 2007) are introduced, and their different origins are explored. Finally the components of a recovery-oriented service, differentiating between traditional models of psychiatric care and a model that focuses on recovery are illustrated, with a focus on the implementation of recovery in the UK. I close by reflecting on the importance of the recovery approach to me as a service user, and the potential of this concept for service-user empowerment.

3.1 Literature review strategy

This section sets out the literature search strategy, highlighting my selection and inclusion criteria, discussing the advantages and disadvantages of the approach used and assessing whether there are any gaps in the literature review.

A search of academic databases at the start of the study revealed little evidence of literature in the personal recovery tradition. The literature focused mainly on research relating to the clinical recovery model from positivist paradigms. A wide-ranging literature review was therefore conducted via an extensive trawl of Google Scholar and Amazon plus manual sorting of bibliographic sources from relevant papers to identify further sources from the personal recovery model. I was not completely new to the research field, and this process was therefore informed by my personal and professional interest in participatory forms of inquiry and caring issues which had been the focus of previous work undertaken as a MA study (Fox, 2009) and of work in my role as a professional developing carers' support services in North London (Payne, 2001). This enabled me to focus on relevant research in this field. The process familiarised me with seminal works on recovery, emancipatory research and other paradigms which were integral to my research development and design. I continued to use this strategy throughout my research as I searched for literature to inform my study, and developed the conceptual framework.

The *Cochrane Collaboration Handbook* (Higgins and Green, 2011) establishes the quality of the validity and reliability of studies that contribute to evidence-based health research, as shown in Figure 1 below.

Figure 1. The Evidence Hierarchy, (SUNY Downstate Medical Centre, 2013)

A more systematic search of academic databases would have identified more studies conforming to the higher levels of this triangle. Research which informs and develops the evidence base about the clinical recovery model occupies a different paradigmatic position from that adopted in this study and is a very different concept to that of personal recovery (Slade, 2009a). On reflection, the strategy utilised in this study may have privileged personal narrative and qualitative research over positivistic studies of the recovery concept as I used this approach in preference to trawling academic databases. This may have lacked the systematic approach that would have been entailed if I had preferred to use academic databases such as Medline and Pub Med.

Trafford and Leshem (2008) note that the purpose of engaging with the literature in a PhD study is to demonstrate that the researcher has a clear and comprehensive understanding of the field and a breadth of contextual understanding of the discipline, proving that they can successfully critique the different established traditions within the

field by engaging with other significant works. The authors further note that a literature review process delimits the research by positioning it in the appropriate paradigm that informs the research design and designates the conceptual framework. May (1993, p. 20) adds: 'Theory informs our thinking, which in turn assists us in making research decisions and sense of the world around us'. This legitimises my approach, although my approach may have led to limitations in the literature review strategy and a lack of positivist research in the literature review.

In summary, as I engaged with the literature I was drawn to the user-led personal model of recovery and research that describes processes of emancipatory research, both of which are positioned within a interpretative paradigm. The focus on this paradigm throughout the literature search allowed me to demarcate the boundaries of the research and develop my research design (Hart, 1998). Although this process was effective, its limitations and disadvantages might have been mediated by a more systematic approach to utilising academic databases throughout the research process.

3.2 What is schizophrenia?

This section explores the nature of schizophrenia and examines its classifications. It discusses the work of a number of authors who argue that schizophrenia is a socially constructed concept and challenge the biomedical model of schizophrenia. A brief discussion of the political implications of the schizophrenia diagnosis follows.

The biomedical model of mental health has dominated mental health care for over 100 years. Early writers such as Kraepelin (1905; 1919), and Bleuler (1950) developed the concept of schizophrenia. In the early 1900s, Kraepelin observed the behaviour of patients in a psychiatric hospital, noting symptoms common to a particular group. Based upon this observation of symptoms, he developed a 'diagnosis' for a condition that he called dementia praecox, (young dementia), emphasising the chronicity of the condition.

Within the biomedical approach, schizophrenia is described as a family of symptoms that persist for a specified length of time. Gelder et al (1996 p. 246) describe the acute stages of schizophrenia as characterised by the 'positive' symptoms of 'delusions, hallucinations, and interference with thinking'; patients may either recover directly from the acute phase or further deteriorate into chronic schizophrenia. The chronic symptoms of schizophrenia are 'characterised by thought disorder and the 'negative' symptoms of

under-activity, lack of drive, social withdrawal, and emotional apathy' (ibid p. 246). Gelder et al (ibid) argue that patients with chronic schizophrenia do not recover. Diagnostic Statistical Manual IV (DSM IV) and the International Classification of Diseases 10 (ICD 10) carry the most accepted up-to-date description of the schizophrenia diagnosis, although DSM V is currently under development.

A number of authors claim that this diagnosis was not developed using rigorous scientific methodologies (Boyle 2002, Bentall, 2003, Slade, 2009a) and so the ICD and DSM classifications of schizophrenia are built on unsound foundations. Boyle (2002 p 212) rejects the diagnostic criteria for schizophrenia, claiming that:

- schizophrenia has no biological markers
- the genetic basis for schizophrenia is doubtful
- abnormalities in the brains of people diagnosed with schizophrenia may be caused by alcohol or drug misuse
- clinicians cannot decide on the distinction between bizarre and non-bizarre behaviour for people diagnosed with schizophrenia.

Boyle describes how the historical framework of the early 1900s required the development of a scientific approach to the diagnosis of mental illness to reflect the professionalisation of psychiatry as a medical discipline. Bentall (2003) adds that the commercial interests of the drug companies influenced its wide acceptance as a discreet disease.

According to Slade (2009a), drawing on Karl Popper's work, mental illness differs from physical illness. A diagnosis can *explain* the symptoms of a physical disease, whereas, he argues, the diagnosis of a mental illness can only provide an *understanding* of its symptoms and causation. It cannot be said, for instance, that bereavement causes depression; it may be one of many contributing factors. A person may have symptoms of depression that are related to lifestyle and environmental, social, biomedical and psychological factors, therefore it is difficult to say that the diagnosis of depression infers a way of *explaining* a service user's reaction to these factors. Schizophrenia has a number of causes that are not yet understood or definitively identified (Bentall, 2003; Slade, 2009a), and so it is hard to accept the biomedical model, or any other model of schizophrenia. It is better to comprehend diagnosis as an understanding of symptoms of mental distress than as a discreet illness explained by a set of symptoms.

Schizophrenia as a disease, or a set of symptoms, negatively affects the lives of many people with this diagnosis. Whether it is possible to reject this as a discreet disease is in some ways hypothetical: it is a disease that often involves suffering and disability.

Many clinicians argue that when a patient accepts a diagnosis of 'schizophrenia', this is a step to getting better – they are accepting and taking responsibility for the illness. Yanos et al (2008) argue, however, that accepting a diagnosis of schizophrenia can lead to internalising society's negative stigmatisation and stereotyping. This process adds further disability to the mental health symptoms as it subscribes to society's low expectations and belief in their non-achievement. Indeed, the stigma of schizophrenia restricts and halts many patients' recovery. Much of the public has no understanding of the term 'schizophrenia' and discriminates against this group in housing opportunities, employment, relationships and in their daily life because of their fears of the 'mentally ill' and the demonisation of the condition of schizophrenia.

Boyle (2002) argues that the conferment of a biological diagnosis on schizophrenia is political: it places the social control of the patient with schizophrenia in the hands of professionals. As a political diagnosis, it confers authority and power upon medical practitioners rather than assisting service users to improve their health experience. This political dimension, posited by Boyle (2002), is echoed in the history of care of people with schizophrenia. Bentall (2003) reflects on how a diagnosis of schizophrenia and subsequent treatment was imposed on dissident citizens in the former USSR in the 1980s as a method of political control and containment.

For a long time in western society, people with schizophrenia were contained in asylums to protect the general public and power was placed in the hands of professionals to hold or release them. The process of deinstitutionalisation is complex and too broad to cover, but it has been challenged in a number of ways by models and principles developed by the service user movement and associated philosophies. In the 1960s, writing by service users (Kesey 1962) began to challenge the politics of mental health care. The development of normalisation, the principles of social role valorisation[24] (Wolfensberger

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24 Social role valorisation and normalisation are concepts that emphasise the importance for service users of occupying valued and useful roles in society. This allows their identity to be expressed and valued in terms of their

1972) and concomitant moves towards care in the community were associated with the shifting power balance in care and treatment.

The development of the strengths model (Rapp, 1992; 1998; Rapp and Goscha, 2012) for the case management of those with mental ill-health challenged practitioners' persistent focus on their clients' deficits. It reminded them of the need to encourage practice based on empowerment and enablement, with an emphasis on the management of risk-taking to enable the service user to build on his/her strengths rather than focusing on risk avoidance based on a culture of paternalism. This slow but perceptible shift of power in the care and treatment of people experiencing mental ill-health was further driven by the conception of the social model of disability and the growing rejection of the medical model of mental health care (Oliver 1996). The recovery model builds on these different traditions and recognises the service user as the author of their own recovery.

Reflecting this emerging user-led tradition, other theories of voice hearing – a symptom typical of schizophrenia – have been developed. Romme and Escher (1993) and Romme et al (2009) explored the many ways in which different people perceive voice hearing and the source of those experiences, from extra-sensory perception to spiritual sources, 'guides from above' and religious experiences. They have investigated how different voice-hearers who have not been identified as psychiatric patients experience and work with their voices. People identified as coping with their voices describe them as an often positive, intuitive force that adds value and often another dimension to their lives. However, service users often find such experiences negative and frightening. Romme and Escher show how the experience of hearing voices can be normalised by people who cope with them, not as a psychiatric experience but as something that can be explained and experienced in different ways.

Romme (2006) echoes the previous authors and believes that a diagnosis of mental illness is about labeling the personality rather than improving the patient's experience of illness. He argues that the use of the medical model gives the mental health professional power over the client. He sees the schizophrenia concept hiding or blanking the

contribution to society, rather than devalued by their service user or disabled identity.

patient's emotional problems by placing them under that label, and advocates a process of accepting and dialoguing with the voices to try to understand the source of the patient's traumatic experiences. For him voice-hearers experience trauma-induced psychosis and the voices are manifestations of that experience of trauma; by dialoguing with the voices it is possible to find the source of the trauma and enable the patient to overcome the experience. The schizophrenia concept does not enable the patient's problems to be solved; he focuses rather on finding strategies that give voices a meaning in the person's life, and strategies for controlling the voices instead of being controlled by them.

Only by engaging with the *experience of schizophrenia* is it possible to begin to understand the conceptualisation of the disease. Whether it is socially constructed, a political diagnosis or an accurate diagnosis of disease, the suffering of many service users is only too real. Indeed, for me personally the diagnosis of schizophrenia was a diagnosis of exclusion carrying with it many negative stereotypes of the 'mentally ill' based on the stigmatisation of people with such a label. I found this negativity in the attitudes of those around me as they struggled to comprehend who I was and who I became with this diagnosis. For me, the possibilities offered in the recovery approach provide the opportunity to challenge the negativity of the diagnosis and the stigma of mental illness.

3.3 Models of mental health and the emergence of recovery models

This section reviews the traditional biomedical model of mental health that has long dominated psychiatric care and addresses the emergence of the clinical model of recovery. Following this alternative models of mental health are introduced and service users' perceptions of the different frameworks are highlighted.

The biomedical model that has dominated psychiatry implied a life of social disability, mental illness and inability to work or function in society. Kraepelin's dementia praecox was characterised by continued deterioration and illness. Coleman (1999 p. 19) comments that as a result of the prevailing negative perception of the outcome of schizophrenia, psychiatry was based on 'a concept of maintenance and social control', and further negative prognoses of mental illness affected the course of the illness.

The expectation that people with mental illness, and more particularly, with schizophrenia, would lead a life of failure devoid of quality was first challenged in the late 1960s by Bleuler (1968). His research has since been strengthened by several studies that show that recovery from schizophrenia can and does happen (Huber, Gross, and Schuttler, 1975; Tsuang, Woolson, and Fleming,1979; Ciompi 1980; Harding et al, 1987; Ogawa et al 1987; McGorry et al 1996; Harrison et al 2001; Warner 2004). Of Harding et al's (1987) study of 262 individuals, 46%-68% of patients met the criteria for recovery. Calabrese and Corrigan (2005, p. 71) conclude:

> 'Each of these studies found that, rather than having a progressively deteriorating course, schizophrenia has a heterogeneous range of courses from severe cases requiring repeated or continuous hospitalization to cases in which a single illness episode is followed by complete remission of symptoms.'

They found that 'roughly half of the participants recovered or significantly improved over the long-term, suggesting that remission or recovery is much more common than originally thought' (ibid, p. 71).

Although Harrison et al (2001, p. 14), presented data supporting the premise of recovery for service users at 15 and 25 year intervals after first diagnosis, they expressed some concerns about the recovery concept:

> Working concepts of recovery require qualification as well. Our study relied heavily upon absence of symptoms, social disability, and resource utilization. This should not be equated with level of function achieved before the onset of illness, and even less with the recovery of lost potential.

Harrison et al's (2001) working concept of recovery is based on a biomedical model which perceives mental illness as a neurological disease. This concept, as presented above, differs from the model of recovery espoused by the service user movement in which recovery is about living well with mental health symptoms, beyond the illness label (Davidson, 2003), and developing a life unrelated to the illness.

Harrison et al (2001) and Liberman and Kopelowicz (2002; 2005) argue that any kind of recovery model or improvement in illness outcome should be based on an empirical, evidence-based and operational model. Successful recovery must include the ability to:
- function independently
- take responsibility for one's own personal care

- and manage one's own medication, health and money without regular supervision (Liberman and Kopelowicz, 2005, p. 739).

This form of recovery derived from the medical model has been referred to as *clinical recovery* (CSIP, RCPsych, and SCIE, 2007; Slade 2009a) and is defined by Slade (2009a, p. 29) as:

- an outcome or a state
- observable by the clinician; objective not subjective
- rated by the expert clinician, not the service user
- a definition of recovery that does not vary across individuals.

This is differentiated from the service user movement's *personal recovery* (see section 2.3). Clinical recovery reflects the well-known idea of remission and focus on a reduction of symptoms that allow the person to function well in society, while the latter focuses on enabling the person to achieve a more stable and enduring state of wellness characterised by participation in the mainstream community (Davidson et al, 2008). Davidson and Roe (2007) note the importance of differentiating between *recovery from mental illness* (clinical recovery) and *recovery in mental illness* (personal recovery)*, stating that their convergence:

> '...has now contributed to a situation in which recovery has come to mean different things to different people, resulting in a remarkable degree of inconsistency in how the notion is used to inform practice.' (ibid, p. 462)

The model of clinical recovery is supported by many institutions, based on the dominant biomedical model. Examples of this include both the DSM and the American Psychiatric Association's (APA's) Practice Guidelines for the Treatment of Schizophrenia (Lehman et al, 2004). The DSM describes complete recovery as a return to pre-morbid levels of functioning (APA, 1980) or a complete return to full functioning (APA, 1994). The APA's Practice Guidelines (cited in Liberman and Kopelowicz, 2005) identifies a two-year period of stability without relapse as an empirically convincing period that demonstrates recovery.

Beresford (2005a, p.110) argues that the medical model is derived from a deficits model 'based on assumptions of the inherent deficiency and pathology of 'the mentally ill''. Dell Acqua and Mezzina (1998) note that once a diagnosis of schizophrenia is given *a posteriori*, the definition of a person's character is tied up in the illness rather than in

her/his life experience. In a survey of responses to the different models of mental health, service users reported an ambiguous relationship with the medical model (Beresford, Nettle and Perrin 2010). It was useful when they needed to access benefits or justify sick leave from work, because mental health needs can be validated as 'illness'; in general, however, they found the medical model unhelpful because it locates the pathology in the person and assures the primacy of medication as a treatment method, preventing holistic treatment (Beresford, Nettle and Perrin 2010).

The influential stress vulnerability models of schizophrenia (Zubin and Spring 1977) posit that the prognosis of schizophrenia is responsive to social and environmental factors in the person's life. Service users in Beresford, Nettle and Perrin's (2010) survey endorsed this model and understood their own mental health condition in terms of the social perspective influenced by their environment and upbringing.

On reflection, for me coming to terms with the diagnosis of schizophrenia involved a personal journey that required synthesis of the different models of illness. It entailed a difficult process of separating out what I considered to be my 'mind', which represented my personality, and differentiating this from the thoughts that belonged to my 'illness'. For me this involved reconciliation to the different models of illness that were presented and developing a model that I felt comfortable with. This personal model combined elements of the medical and social models with a consideration of spiritual experiences.

In summary the biomedical model emphasises neurological deficiencies of the brain and arguably pathologises and medicalises an illness that may be more social (Tew, 2005; 2011), economic (Duggan, Cooper and Foster, 2002) or spiritual in origin (Clarke, 2010). Davidson et al (2005) describe a different approach to the diagnosis-led medical model. They focus on the idea of *wellness* in the daily lives of people living with serious mental illness. It is not necessarily the absence of symptoms that defines a person's wellness, but what they do with their lives. A mental health service user bowling with his friends in a bowling alley is not judged by the status of his mental health but by how good s/he is at bowling (p. 178).

This conceptualisation of mental health is reflected in the World Health Organisation website (2012):

'Mental health is not just the absence of mental disorder. It is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.'

More often the lack of good mental health is defined in Western society as the presence of mental disorder or mental illness.

Rejecting the medical model, the service user movement does not perceive recovery from mental illness as a return to pre-morbidity functioning but as the journey that a person with mental health issues needs to take to absorb and respond to their experience of mental ill-health, and how this experience is incorporated into their personality. This is understood as a journey defined by the service user with life outcomes chosen by themselves. This model is discussed later in the chapter. This section has discussed the medical model of mental health and some alternatives to show how the debate leaves room for the emergence of the concept of recovery.

3.4 The context of recovery

This section describes the political scene that made the development of the personal recovery model in mental health possible, focusing on the political development of the service user movement. Recovery has been strongly advocated by the consumer/service user movement, first in the USA and NZ and now in British psychiatry, as discussed later in this thesis. Its importance as an emerging concept and ideology in Australia and the UK is documented by Ramon, Healy and Renouf (2007).

The consumer/service user movement began in the USA in the 1960s and is represented well by Chamberlin (1988). The radical anti-psychiatry movement of the 1960s drew on the popular writings of Kesey (1962) and Szasz (1961), which propose the notion of psychiatric survivors, emphasising the damage caused by psychiatric care rather than its benefits. In Italy in the 1980s there was a move from asylums to care based in the community (Dell'Acqua and Mezzina, 1998) with the increasing recognition that patients were becoming institutionalised and negatively stigmatised by long stays in psychiatric wards. In the UK, a number of factors linked to fiscal austerity, the greater availability of effective drug treatments in the 1950s and a change in the philosophy of mental health care led to the beginning of deinstitutionalisation (Rogers and Pilgrim, 2001).

In Britain, the consumer/service user movement began with the physical disability movement's rejection of the medical model of care and the development of the social model of disability. (Oliver 1996). The mental health service user movement draws upon the democratic model of user involvement and builds on the physically disabled user movement's strong voice advocating disability awareness, the philosophy of independent living, and normalisation (Wolfensberger 1972). The physically disabled movement was supported by the prolific work of Oliver (Oliver 1996; Oliver and Barnes, 1998; Oliver and Sapey, 1999). The following statement from the Union of Physically Impaired against Segregation (1976, p. 14) draws out the themes: 'Disability is something imposed on top of our impairments by the ways we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society'.

The physical disability movement's rejection of the medical model began a new era with the development of the social model of disability, which, coupled with social role valorisation, began to acknowledge the role of service users not just as service recipients but as citizens in society living beyond their disease label. According to Beresford (2002), the social model of disability has been less well developed in the mental health service user movement than its potential suggests. He argues that mental health lacks a 'big philosophy', unlike the disability movement that propounded the social model.

Davidson et al (2012) advocate that mental health care should be underpinned by a community inclusion paradigm rather than one of community integration. The former demands the equal inclusion of people *in recovery* in society, making reasonable accommodation for their mental health needs in all aspects of society including work, leisure and housing, while the latter expects their adaptation to community as 'fully cured' people. In Fox (2011a) I argued for a concurrence between the social model of disability and the recovery model. I reflected on my own experiences as a disabled person in the workplace and emphasised that the non-disabled environment disables and excludes people from the workplace, and an understanding of recovery requires an acceptance that people with mental distress may have to manage the limitations of their ill-health at work. Indeed, personal recovery, which embraces the paradigms of equality, collective advocacy and community inclusion, has the potential to be the big idea in mental health policy, service implementation and philosophy.

Below I address the concept of recovery and the definitions that underpin its development.

3.5 The model of personal recovery

The definition of recovery reflects the politicisation of the service user/consumer movement. In this section I describe how consumers have begun to develop and define their own sense of wellbeing and recovery from mental illness.

Experiencing mental health problems can be very distressing because of:
- suffering the impact of mental health symptoms
- the stigma experienced on being labelled a mental health patient
- lost potential in life
- lost lived experiences and opportunities that other people may have
- lost income and resulting poverty
- discrimination at work

The recovery concept does not negate this suffering but tries to define a place beyond the initial experience of mental illness. Many consumers define recovery as a process, a movement or a journey (Deegan 1996; Coleman, 1999), in contrast to psychiatric outcome measurements of schizophrenia. Recovery is no longer about maintenance: it is about living well with mental health problems, and living beyond the label. Recovery is a process, a concept, an ideology that means many different things to different people.

As already discussed, professionals have long argued that treatment for schizophrenia should be based on a cure model, not a recovery model (Repper and Perkins 2003; Warren 2003). Service users argue that to them, the reduction of symptoms is not necessarily a cure or even necessarily what they are seeking (Repper and Perkins, 2003). The model of recovery is defined as: '...a continuing process of growth of and adaptation to disability as opposed to time-limited interventions directed at symptom removal'. (ibid, p. 18).

Anthony's (1993, p 13) description of the process of personal recovery is perhaps the best known:

> '... a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and

contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness'.

Anthony focuses on the personal attributes of recovery as an individual journey of development. According to Deegan (1997), recovery from mental illness is not necessarily defined by one group or another; it is a personal and individual journey. Recovery should embrace all people's experiences and needs. It is not necessarily a continuing positive development; it may be a spasmodic process of recovery, accepting failures along the way (Deegan, 1996). Recovery is defined in a number of papers as a journey or a process (Spaniol et al, 2002; Andresen et al, 2003; 2006).

Brown and Kandirikirira (2006) identify the personal constructs that were necessary in Scottish service users' experience of recovery, using narrative story-telling techniques. The service users reported what helped and hindered their journeys of recovery (ibid p. 3):

- hope, confidence and optimism
- diagnosis
- self-acceptance, self-responsibility, self-belief and self-esteem
- self-efficacy
- self-awareness
- negative identity and low expectations
- stigma – spoiled identity
- thriving – growth beyond the label
- powerlessness – removal of identity
- reclaiming power and self-determination
- physical image
- sexual identity
- creative identity
- cultural, social and community identity
- group identity – activism
- spiritual identity

The experience of stigmatisation and discrimination was reported to hinder the journey towards recovery. The narrators told of how negative attitudes to their mental ill-health lowered their sense of self-esteem while, unsurprisingly, positive messages helped them

to foster a positive self-image. They reported the need to take risks in their lives. Others reported the need for self determination, or agency' to increase their sense of wellbeing and good mental health. Brown and Kandirikirira (2006 p. 20) conclude:

> 'For many, identity focussed upon being valued as an individual irrespective of, or indeed, in spite of their mental health problems, whilst for others the experience of ill health and recovery had been embraced and had been a focus of value to them. From the narratives gathered in this project, it was evident that much of the subject of identity appeared to be about the issue of personal growth and development and change internally. This challenge can make a belief in the possibility of recovery difficult for some. Given the complex interaction between identity and recovery which we have described, it is clearly not possible to impose recovery on people. People must be willing, ready, able and, in some circumstances, allowed to action change'.

Recovery must come from the individual who is ready to move to the position where it is possible to experience recovery for themself. It is about moving on from the suffering of the mental illness to a place of greater optimism and hope – about living as well as possible with or without mental health symptoms, and living beyond the diagnosis in a fulfilling and satisfying role (Davidson, 2003). Deegan (1988, p. 11) notes that recovery is an active and unique process:

> 'Persons are not passive recipients of rehabilitation services.... Rehabilitation refers to the services and technologies that are made available to disabled persons so that they may learn to adapt to their world. Recovery refers to the lived or real life experience of persons as they accept and overcome the challenge of the disability'.

Leamy et al (2011) have developed an empirically-based conceptual framework of recovery through a systematic review and narrative synthesis. The overarching framework of the recovery concept consists of the characteristics of the recovery journey, recovery processes and recovery stages. The characteristics of the recovery journey represent the nature of recovery as a unique journey with stages that require active struggle involving moments of spasmodic change achieved through trial and error. The recovery process requires connectedness, hope and optimism about the future, the creation of identity, meaning in life and the need for empowerment (given the acronym CHIME). The final categorisation of recovery identifies its phases and stages. The results, synthesised from 13 studies, are shown below in Table 1. This category incorporates the notion of progression in the recovery journey. The results presented in this paper are consistent with how recovery is represented in my PhD study.

Table 1: The characteristics of the recovery journey (Leamy et al, 2011)

Precontemplation	Contemplation	Preparation	Action	Maintenance and growth
	Novitiate recovery-struggling with disability		Semi-recovery – living with disability	Full recovery – living beyond disability
Stuck	Accepting help	Believing	Learning	Self reliant
Descent into hell	Igniting a spark of hope	Developing insight / activating instinct to fight back	Discovering keys to recovery	Maintaining equilibrium between internal and external forces
Demoralisation		Developing and establishing independence		Efforts towards community integration
Occupational dependence		Supported to occupational performance	Active engagement in meaningful occupations	Successful occupational performance
Dependent / unaware	Dependent / aware		Independent / aware	Interdependent / aware
Moratorium	Awareness	Preparation	Rebuilding	Growth
	Glimpses of recovery	Turning points	Road to recovery	
	Re-awakening of hope after despair	No longer viewing self as primarily person with psychiatric disability	Moving from withdrawal to engagement	Active coping rather than passive adjustment
Overwhelmed by the disability		Struggling with the disability	Living with the disability	Living beyond the disability
Initiating recovery			Regaining what was lost / moving forward	Improving quality of life
Crisis (recuperation)		Decision (rebuilding independence)	Awakening (building healthy interdependence)	
	Turning point	Determination		Self esteem

Source: Leamy et al (2011 p. 449) Table 3

Service users themselves sometimes hesitate to use the word 'recovery'. For some, the experience of mental illness is one of disability or impairment that they feel they cannot overcome. In reflection on recovery, some service users of the Scottish Highland User Group felt uncomfortable with the concept of recovery altogether (HUG, 2006):

> 'Many of us … made the point that there is no cure for many of the major mental illnesses and that it was misguided to talk of recovery. We felt that a word had been adopted and given values that it didn't previously hold. ... We felt that people were asking us to reach for perfection and resented this. Some of us also felt that the whole idea was wrong – we have very hard lives and to expect these to change for the better is silly and misguided'. (ibid p. 8)

This suggests that recovery is frightening for some service users and they see their mental ill-health as insurmountable. Some perceive that recovery denies the real distress of their mental health needs; moreover they are reluctant to use the recovery concept to move from the position of suffering as a victim to taking control of their own life. For some, recovery can only be about freedom from symptoms and impairment. However, as developed by the service user movement, recovery is not necessarily about freedom from symptoms; it is about living as good a life as possible, with or without a diagnosis of mental ill-health (Deegan, 1988; Anthony 1993; Coleman, 1999). Whitwell (1999, p. 622) concurs: 'It may be an empirical truth that surviving mental illness is a better description than recovery. Surviving the damage and coping with disability and disadvantage are alternative models to the illness model'.

Some service users may be limited by their social circumstances. They may be living in poverty in poor housing, or isolated without transport to optimise their access to services to support their recovery. Recovery may be about not only what is within but also what is without. Some service users draw upon the medical model, which defines recovery as optimal life functioning, seeing it in Liberman and Kopelowicz's (2002) terms, where clinical recovery is central to personal recovery.

Onken et al (2007, p. 19) argue that recovery involves both a 'personal disposition toward positive recovery' and a 'facilitating environment'. The first-order changes in a person's attitude and strength to recover must be supported by second-order change – an environment that provides opportunities and potential for recovery. Changes in the individual alone cannot drive recovery but the economic and social environment must help facilitate this change.

The service user movement defines mental health recovery as leading a valued and valuable life, accepting the self and the limitations – when present – of the illness. Anthony (1993: 15) states:

> 'Successful recovery from a catastrophe does not change the fact that the experience has occurred, that the effects are still present and that one's life has changed forever. Successful recovery does mean that the person has changed, and the meaning of these facts to the person has therefore changed. They are no longer the primary focus of one's life'.

A UK study (Mind 2002) reports that the concept of recovery means many different things to different people, concluding: 'These respondents highlight the very different ways people define recovery and how difficult it is to find one way of describing it'. (p. 4).

This section of the literature review has presented service users' experiences of their own recovery journeys, drawing on their narratives. It reflects many of my own struggles and tribulations in coping with a diagnosis of schizophrenia, showing elements that both supported and hindered my recovery. This literature both excited and inspired me as I identified with the experiences of other service users in recovery. I also identified with the feelings of failure and disbelief about the possibility of recovery. I found that the only way to lead the life I wanted was to hold on to hope and opportunity, and to forge ahead with the constant need to keep going.

3.6 Recovery-oriented services

This section examines the components of a recovery-oriented service. Such a service supports the service user to live the best possible lifestyle with their mental health problems and its effects on their life. Concerns have been raised that recovery will become the latest buzzword, but that it will simply be a new name for the same old practice (Ridgway, 2001; O' Hagan, 2002; Slade and Hayward, 2007). However, as an emergent concept, it is being grasped enthusiastically by many service users (Coleman 1999; Rethink 2005a); it is also argued that this is a new model for mental health services (NIMHE 2005). It is important to establish what is meant by a recovery-oriented service, as it has implications for the way service users and carers experience the support they receive from professionals.

The objectives of a recovery-oriented service focus less on *effective role function* in society and more on *occupying a socially valuable role* in society. It is about not abandoning the service user to a lonely road to recovery but supporting and enabling that recovery process. Professionals can both impede and facilitate recovery. Jacobson and Greenley (2001, p. 482) emphasise that besides the individual's internal resources, it is external events – 'the circumstances, events, policies and practices' of a recovery-oriented service – that help to facilitate, or impede, recovery. As far back as 1999, Birchwood (1999) noted that the delivery of regular treatment of people with schizophrenia is inadequate and focuses on the management of crisis, rather than prevention of disability. Coleman (1999) echoes this, pointing out that traditional services focus on maintenance and relapse-management rather than recovery.

In the USA, and in particular over the last 10–15 years, the recovery model has been advocated across mental health services. In July 2003, the President's New Freedom Commission on Mental Health declared that the mental health system was a shambles, and a commitment to the recovery model of mental health followed. Jacobson (2004) tells the story of the fight to implement a recovery model in service provision in Wisconsin, Ohio, where, the history of the recovery movement began in 1996. The Blue Ribbon Commission Implementation Advocacy Group (BRI-IAC), made up of service users (consumers), service providers, carers, advocates, and bureaucrats, was set up to develop services focused on a recovery model.

Crowley (2000, cited in Jacobson, 2004) describes a Wisconsin service that used a recovery model with the following principles:

- recovery is possible

- mental health consumers must be welcome as partners in their care

- a 'just start anywhere' mode of consumer action must be fostered

- a broad range of consumer-run services is promoted

- meaningful work/educational activities are valued and worked towards

- service providers must encourage and facilitate an increase in consumer' abilities to self-manage disorders

- use of community resources should be encouraged

- staff must be empowered and encouraged to be flexible in the delivery of services.

Recovery has gone on to be developed as the 'big idea' in NZ's mental health services as well as in the US. As far back as 1998, mental health services development in NZ was underpinned by a recovery approach (Mental Health Commission, NZ, 1998). Its Blueprint states that the provision of services must: 'empower consumers, assure their rights, get the best possible outcome for them, increase their control over their mental health and well-being, and enable them to fully participate in society'. (p.16)

O'Hagan (2004, p. 2) notes, however, that the recovery approach needed adaptation to ensure that it conformed to the social, economic and political culture of NZ rather than focusing exclusively on the liberal values of individualism from the USA. The NZ context required recovery to reflect traditions of collective advocacy and social responsibility before it could be adopted by mental health services. I return to NZ recovery literature later in the chapter.

Anthony (2000) believes that a recovery-based service rejects the schizophrenia diagnosis' notion of chronic deterioration and builds upon the ideal of recovery. He defines the basic assumptions of a recovery-focused mental health system believe that recovery can occur without professional intervention; that recovery can occur when symptoms reoccur but it changes the frequency and duration of symptoms, and is often not a linear process. Being in recovery does not mean that a person was never ill and sometimes the effects of stigma and discrimination are more difficult than recovery from the illness itself.[25]

Anthony (2000) defines what a recovery-oriented system might look like. It places service users and carers at the centre of the service, builds on their strengths and needs and has a mission statement supporting these developments. He argues that the recovery concept must be placed at the level of systems standard dimensions rather than merely apparent in the service's practice or development – the very systems that define the quality of services must incorporate recovery-based models. For example, a standard for the quality of service design must incorporate the language of recovery, and the mission

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25 See Appendix 14 for more detail.

statement must include the recovery concept in all aspects of its development, incorporating the views of consumers and families in its design. The standard for the evaluation of each programme must identify the particular outcomes that will be achieved for each service user, and these outcomes must achieve improvement in the consumer's role functions. Under the establishment of standards for the quality of consumer involvement in each service, Anthony specifies that:

- Consumers should be sought for employment at all levels in the organisation.
- User-controlled, self-help services should be available in all geographic areas
- Consumers and families should be integrally involved in system design and evaluation.

Anthony's system standards are specific, measurable and consumer/family focused. He argues that the standards for recovery-oriented systems must reflect this focus to ensure the best delivery of quality services for consumers and their families.

Pitt et al's (2007) user-led evaluation of recovery-oriented services emphasises the importance of mental health services *facilitating the process of recovery* rather than emphasising service targets or standards for recovery-oriented services. They relate to the need to rebuild the self, to rebuild one's life, and for hope for a better future. Their emphasis is on services supporting consumers in their journey through the experience of recovery. These standards seem to lack a level of clarity identified by the other writers, but they do relate to service users' own experiences of the journey.

NZ led the way in the development of services that support recovery. Recovery-oriented services enable service users to lead valued lives and optimise choice and autonomy (Lapsley et al 2002). The NZ Mental Health Commission developed standards for what a recovery-oriented system might promote (2004, Our Lives in 2014).[26]

Davidson (2005a) noted that the shift in practice must be strengths-based, individually focused, and support the person to manage their condition while regaining a meaningful and constructive membership of the wider community. Lester and Gask (2006) concur that recovery-oriented care needs 'to offer systematically organised and personally tailored collaborative help, treatment and care in an atmosphere of hope and optimism'

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26 These are found in Appendix 15.

However, while focusing on hope and optimism, Roberts and Hollins (2007, p. 397) caution that for those whose experiences of mental ill-health have been experiences of suffering and disability, the promise of recovery 'can seem a bit empty and denying the reality of severe mental disorder'. Glover (2012), however, provides a reminder that it is service users who 'do recovery', not professionals; the internal resources of the service user must lead recovery, and services can only provide a facilitating environment and opportunity – a statement I concur with as a service user, whilst acknowledging the importance of the support of family members and professionals in the recovery process.

Tew et al (2012) recognise the importance of the social inclusion agenda in recovery which (ibid, 453) 'involves both an active form of citizenship and a subjective sense of belonging' (echoing the work of Secker (2011) described in section 2.1). Secker (2011) however notes that a person may occupy both a position of being socially included in that they have a job and an acknowledged role of social value in society, yet experience social exclusion as they are isolated from their communities and social networks through stigma. She argues for a separation between the two concepts:

> 'It is arguably more helpful, however, to separate out the two and to think of exclusion as operating on a structural level through barriers that work to exclude individuals and groups from full participation in society. By contrast, inclusion operates on an individual or group level and relates to the extent to which people are accepted and feel they belong within different social contexts'. (ibid, p. 495)

Tew et al (2012) and Secker (2011) note the importance for mental health services to promote recovery by working both with individuals to overcome their social exclusion and within communities to promote the social inclusion agenda.

One example of particularly successful service provision, where services have been developed to ensure the best mental health outcome for people experiencing psychosis for the first time, is the Early Intervention in Psychosis Service (EIP). EIP seek to promote mental wellbeing, prevent the development of secondary disability through prolonged mental ill-health and to prevent the problems of stigmatisation that so often accompany serious mental illness. I focus specifically on this service because it can be seen as a service that seeks to optimise the improvement of mental health needs and have been implemented widely across the UK.

The EIP was developed as a treatment model to tackle the onset of first-episode psychosis. Edwards and McGorry (2002, p. 145) note that care and treatment is often

geared to the needs of people with chronic conditions, while early intervention services focus on minimising the negative experiences of disability and stigmatisation that follow the first onset of mental illness (Edwards and McGorry, 2002).

The EIP philosophy is in some ways closely related to the recovery model of schizophrenia in which where living well with mental illness and the prevention of further health deterioration dominate the agenda. This time period targeted for early intervention is described as the 'critical time period' by Birchwood et al (2000). If the problems of unemployment, impoverished social networks and loss of self-esteem are not addressed in the critical period of illness they become entrenched. (Iris, 2006). Advocates of early intervention argue that if treatment is offered during this time, the longer-term social disability and stigma of illness can be ameliorated (Iris, 2006). Early intervention services focus on bringing effective treatment to young people who are most vulnerable to first-episode psychosis and treat the disease before it becomes chronic. This promotes a model of good mental health and wellbeing.

Birchwood et al (2000) has developed further work building on EIP with service users to enable them to build relapse signatures that recognise the early warning signs of relapse. The service user uses the relapse signature to put together a relapse drill to ensure s/he knows where to turn and what to do if s/he should start to relapse. Relapse drills focus on building coping strategies and identifying the resources the patient has to support him/her in a time of relapse, and if possible protect him/herself from relapse. Patients, carers and professionals each have their own role to play in the relapse drill. Early intervention is not the same as recovery; while it is a component of learning to be an expert in one's own mental health and understanding one's own management of distressing symptoms, these are only a part of the recovery journey. Recovery involves a process of focusing on issues beyond the illness label.

3.7 Recovery in the UK

Recovery is now a growing movement defining mental health prognosis and service models in the UK. It is important to understand how it is uniquely placed in this country to understand its influence and development. Processes of organisational change in mental health services were addressed in Chapter 2, section 2.1, and its significance in the research is addressed in Chapter 7, section 7.2. This section highlights the importance of recovery as an emerging concept and developing service model in the UK.

Turner-Crowson and Wallcraft (2002) expressed some concerns about the suitability of the recovery concept when it began to emerge in the context of mental health care in the UK in the late 19990s early 2000s. Its influence became more apparent as service users themselves began to reflect on its potential meaning for their own lives (Coleman, 1999; Coleman, Baker and Taylor, 2000). Turner-Crowson and Wallcraft had concerns about the importation of recovery language to the UK, which at the time used terms such as 'self-management' and 'strategies for living' which were already well-developed concepts and, they believed, more appropriate to the UK. They questioned whether the term 'recovery' implied acceptance of the medical model. If people needed to 'recover', they must be 'sick' or 'diseased'; indeed the service user movement in the UK has preferred the concept of 'survivors' of mental ill-health, seeing society and the mental health services as disabling rather than the disease itself. Recovery' implies something different.

Three articles reviewing the literature from 2001-2009 provide a comprehensive and current review of the place of recovery in the UK (Bonney and Stickley, 2008; Stickley and Wright, 2011a; 2011b). There is no universally accepted definition of recovery (Stickley and Wright, 2011a). It connects with concepts such as agency, control and identity as a personal construct of the experience of recovery. Hope and optimism are key to a positive recovery (Bonney and Stickley, 2008; Stickley and Wright, 2011a; 2011b), while negativity, stigmatisation and discrimination can have a lasting negative impact on the service user's life (2011b). Individual narrative is key to the recovery paradigm and can help people to draw meaning from their mental distress (2011a; 2011b); and taking part in a meaningful occupation is central to individuals' recovery.

Recovery services focus on encouraging responsibility and self-management techniques (Bonney and Stickley, 2008). Effective services are respectful, hopeful and informed by humanistic philosophy (Stickley and Wright 2011a); more importantly, services cannot be both recovery-orientated and risk-averse (2011a; 2011b). Indeed, the grey literature (Stickley and Wright, 2011b) promotes many models of recovery practice which are better described as a collection of approaches that promote a particular way of working; more of a 'how' than a 'which'. Stickley and Wright (2011b) note that services are influenced by social, historical and political contexts: in the UK, personalisation has

become the preferred model of practice, and therefore recovery and personalisation are often seen as moving hand in hand (2011b).

The recovery concept began to be implemented in the UK in policy and service models from the early 2000s. *The Journey to Recovery* (DH, 2001b) discusses improved service delivery as an opening to recovery in England. It focuses on including service users and carers in the planning, development and monitoring of services, and seeks to refocus mental health services on the service user: 'The mental health system must support people in settings of their own choosing, enable access to community resources including housing, education, work, friendship – or whatever they think is critical to their own recovery'. (DH, 2001b p 22)

The recovery model is found in the National Institute for Mental Health in England's (NIMHE's) commitment to recovery (2005), *Emerging Practices in Mental Health Recovery.* In its *Guiding Statement on Recovery* (DH, 2005 p 48), recovery is defined as follows:

> Recovery is not just about what services do to or for people. Rather recovery is about what people experience themselves as they become empowered to manage their lives in a manner that allows them to achieve a fulfilling meaningful life and a contributing positive sense of belonging in their communities.
> We define recovery to include the following meanings:
> 1. A return to a sense of wellness
> 2. Achievement of a personally acceptable quality of life
> 3. A process or period of recovering
> 4. A process of gaining or restoring something
> 5. An act of obtaining usable resources from apparently unusable sources
> 6. To recover optimum quality of life and have satisfaction with life in disconnected circumstances.

For services to be recovery-focused they must focus on changes to the services user's environment as much as on the management of their mental health. The government's National Director of Mental Health stated: 'Increasingly, services aim to go beyond traditional clinical care and help patients back into mainstream society, re-defining recovery to incorporate quality of life – a job, a decent place to live, friends and a social life' (Appleby, 2007).

DH (2011, p. 6), the Conservative-Liberal Democratic Coalition's first policy on mental health, declares in the second of its six objectives:

'More people will recover: More people who develop mental health problems will have a good quality of life – greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live'.

This declaration focuses on the model of personal recovery with its demand for full inclusion in society for people in recovery. Indeed, the principles of recovery have recently been adopted by occupational groups who support people with mental ill-health in clinical psychology (British Psychological Society Division of Clinical Psychology, 2000), mental health nursing (DH, 2006b), occupational therapy (College of Occupational Therapists, 2006) and psychiatry (Care Services Improvement Partnership, Royal College of Psychiatrists, & Social Care Institute for Excellence, 2007).

A number of authors have written guides for professionals on working in a recovery-focused way (Roberts and Wolfson, 2004; Shepherd, Boardman and Slade, 2008; Slade 2009a; 2009b). Roberts and Wolfson (2004), in the British context, argue that recovery practice should be the mainstay of mental health services and set out the central tenets of recovery practice.[27] Perhaps the best-known operationalisation of recovery has been found in the Wellness Recovery Action Planning (WRAP). Copeland's (1997) work on WRAP promotes five key principles of recovery and has spread internationally.[28] Evans and Sault (2012) tell of the introduction of WRAP in Hampshire, UK and how it has influenced care management processes and implementation of the Care Programme Approach to develop elements of recovery-oriented practice. This was fundamental in changing service users' and carers' experience of services.

Despite the commitment to recovery in the UK detailed above, Slade and Hayward (2007, p. 81) express concern: 'Services have appropriated the term without meaningfully changing their function, e.g. re-labelling rehabilitation services as 'Recovery and Rehabilitation Services'. Slade and Hayward (2007) argue that because there is so little evidence of what constitutes effective recovery services it is difficult to know how to develop such services further. Schrank and Slade (2007, p. 324) add that recovery services must be operationalised with a firm evidence base developed to ensure

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27 See Appendix 16.

28 See Appendix 17.

that 'the recovery concept will outlive its current fashion and acquire lasting importance for service delivery'. Both papers emphasise the need for more research to investigate how recovery can be operationalised into practice. Dickerson (2006, p. 647), however, questions the possibility of operationalising recovery into evidence-based practice, stating that it is 'a process – part spiritual, part political' (although it must be reiterated that some researchers have already proposed the introduction of recovery-oriented service standards (Anthony, 2000; Pitt et al, 2007).

The institution of personal budgets in the UK emphasises a neo-liberal individualist agenda of care and treatment and is becoming the dominant service model. However, in 2.1 I identified issues raised by Spandler (2007) cited in Secker (2011) about the dissonance between the personalisation agenda and social inclusion theories as personalised services allow service users to combat individual experience of social exclusion by enabling their participation in mainstream society, but the process does not address societal structures which impede inclusion. Tew et al (2012) focus on the tradition of peer support in the recovery process, which has allowed many service users to gain a sense of collective empowerment from engagement with their peers; they fear that individuation may impede this process which many identify as key to their recovery (Lapsley et al, 2002; SRN, 2006). Tew et al (2012) suggest that social work practice in the UK, with its commitment to social justice as well as individual empowerment (International Association of Schools of Social Work, 2012), needs to both engage in individual practice with service users to overcome experiences of social exclusion and work collectively with communities and wider society to promote social inclusion.

Service change requires deep-rooted and committed change from all members of the mental health community. Connor (2008) undertook a study to evaluate the introduction of recovery practice into a mental health service in Scotland. He noted that change in the culture of practice within a psychiatric hospital ward required continued access to staff training; the development of action learning sets in hospital wards to improve learning; time and space for wards to be creative in their practice; support from an external mentor to advise on changes in practice; and recognition that continued effort was needed by all managers and stakeholders to change practice. He recognised the need for continued effort sustained over time and for all members of the organisation to own the change. Valinejad et al (2007) echo this, noting that recovery training must be

offered to a whole team rather than individual members in order to sustain change in practice and embed it in the organisational culture of the service.

Slade, Luke, and Knowles (2009) evaluate the best ways to deliver recovery training programmes to UK mental health service staff. Of the methodologies they evaluate they find that professionals learn how to support recovery through concrete and simple tools that identify the *what* and *how* of recovery practice rather than more complicated methods. Practitioners were asked to identify whether responsibility to complete actions in the care plan was given to the professional to carry out by themselves, the service user to carry out by themselves, or the service user to carry out with support from the professional. Giving service users the responsibility for completing identified actions allows them more power and responsibility in their care helping them to manage their life themselves or with support from the professional when needed. The evaluation reveals that a care plan audit was the most effective way of the methodologies they evaluate to help professionals implement recovery in their daily practice.

When carers and service users were asked about the best services for their relatives, both groups shared many similar visions. Rankin (2005a, 2005b, 2005c) sets out a service consisting of a community health centre with an access worker available to provide information and support. A service model of the future will contain the following components:
- renewed focus on primary care and community health
- a role for access workers
- the development of community health centres
- improved access and provision of non-pharmacological treatment for service users with mental ill-health
- pilots of personal recovery budgets
- refocusing of inpatient care

The access worker will no longer be the GP, but will provide information and advice to health service users and their carers. Community health centres will reflect the needs of each community, and thus the model will differ across localities. Access workers and community health centres serve members of the community, people with mental health issues and their carers. Rankin (ibid) suggests piloting personal recovery budgets akin to direct payments, but promotes the idea that budgets from different people can be pooled

to increase choice. Inpatient care should continue to be refocused to provide effective support within the community, in which people with mental health issues included in society, work and social life. The importance of access to crisis houses with 24-hour information and support is identified, with greater use of advance directives and crisis plans.

It seems strange that developments in mental health policy do not follow the development of policy in physical health, which emphasises choice and involvement. The previous government made a policy commitment to the recovery model in National Institute for Mental Health in England's (NIMHE) *Guiding Statement on Recovery* (DH 2005 p 48). There is a potential conflict between these ideologies: mental health policy now reflects a concern with crime and disorder and focuses on care, control and risk management (Prior, 2005) rather than providing a service focused on choice and empowerment.

The studies identified show the current place of recovery in mental health services in the UK, and present its significance as an emerging concept and service model. Chapter 7, section 7.2 returns to the significance of a recovery service model to this research.

3.8 Personal reflections

Writing this chapter has allowed me to reflect on my own experiences of recovery and the processes that have allowed me to live beyond my disability. Brown and Kandirikirira (2006) identify the elements that support and hinder recovery; Coleman (1999) describes the challenges he faced on his journey in vivid detail; Deegan (1997) describes the pain of this process; while in contrast HUG (2006) denies the possibilities of recovery and of a good life lived with a diagnosis of schizophrenia. This highlights the difficulties, pain, and tribulations that are experienced in the journey of recovery – a difficult process that cannot be underestimated. However, for me recovery offers more opportunities than obstacles: it acknowledges the difficulties of mental illness but provides a focus on hope and optimism that no other model provides.

This chapter has explored the elements of a recovery-oriented service and what it means in practice: elements that I can draw on as central to my journey but which are so often missing in the delivery of mental health services. My own journey of recovery began as a social work student under the mentorship of Professor David Brandon (Brandon and

Payne, 2002). It was this process that enabled my own journey back to participation in the work force, contributing positively to society and taking responsibility for my own life. Many people describe such mentorship as having enabled their journey of recovery (Coleman, 1999). The strengths of recovery lie in its possibilities, rather than its challenges.

3.9 Conclusion

I started this chapter by setting out the arguments concerning the diagnosis of schizophrenia, describing the traditional positions derived from the medical model to understand this diagnosis. Alternative conceptualisations of schizophrenia and mental ill-health were described, introducing viewpoints that reject the biomedical model of mental health. The emergence of the recovery model from within the service user movement was explored with its potential to become a service model. Next I set out what recovery means to individual service users and how they define it, discussing the opportunities and obstacles they identified from this approach. In the closing section, discussion showed how a recovery-oriented service differs from a traditional service model, underlining how it may improve the outcomes of service users' lives in the UK. The section concluded by describing the developments of recovery oriented organisational change in the UK. I closed by a short reflection on the meaning of recovery and its centrality to my own life.

In this chapter I have differentiated the model of *personal recovery* from that of *clinical recovery*. These two perspectives originate from different traditions: the biomedical model of mental health and the service user movement. While acknowledging that *clinical recovery* may, for some service users, be the beginning of the process of their *personal recovery,* I argue that that clinical recovery is different to personal recovery. Personal recovery focuses on the service user living the best life possible, while acknowledging the limitations that her/his mental distress may bring; this requires a life lived beyond and above the diagnosis to a life that is 'ordinary' and fulfilling in each individual's circumstances (Davidson, 2003). It is believed that a service user can begin a journey of recovery including his/her experiences of mental ill-health, just as a wheelchair user can lead a positive and fulfilling life within the limitations of impairment. This is key to understanding the conceptualisation of recovery in this thesis. In this next chapter I introduce the role of the carer in the recovery of people with schizophrenia.

Chapter 4. The carer's role in supporting the service user with schizophrenia

<u>4.0 Introduction</u>

The role of the carer is still often viewed negatively by health service clinicians (Hogman and Pearson 1995; Jones 2002), who may brand them as 'interfering' and 'awkward' (Hogman and Pearson 1995) at best, or at worst as playing a part in the development of their family member's schizophrenia (Fromm-Reichmann, 1948; Hatfield and Lefley, 1987). The family carer shares the stigmatisation of the service user with schizophrenia (Struening et al, 2001), an experience that Goffman (1963) calls 'courtesy stigma'

The role of the carer supporting a loved one with schizophrenia can be difficult and complicated:

- they often do not receive information about their loved one (Repper et al, 2008a)
- they may not know or understand the mental health diagnosis or the needs of the service user (Hogman and Pearson, 1987)
- they are not involved in the care team (Worthington and Rooney, 2009)
- they are socially excluded from their own community, friends and family circle by the stigma of mental ill-health (Struening et al, 2001).

Much of their understanding and experience of mental ill-health can be negative and the outlook for the future for the family may seem difficult.   Many carers focus on this negativity, which is reinforced by service providers and others.   However, carers are central to recovery and their contribution to the recovery process can be both positive and negative (Lapsley et al. 2002; Rethink 2005a).

Neither carers' perspective of their role in the recovery of their relative nor their view of the recovery approach have been widely researched (SRN, 2009). In this chapter the gap in research is identified that this thesis begins to address, focusing on how the carer can play a role in the recovery of people with schizophrenia and how they can understand their own role. This chapter shows how this research is politically timely, relevant and appropriate in today's health and social care field.

In section 4.1, the meaning of the term 'carer' is clarified.   In 4.2, explanatory frameworks traditionally used to describe the relationship between the carer and the service user are identified, followed in 4.3 by a description of the development of carers'

psychoeducation, which seeks to provide information and support to enable them to care more effectively. These developments are all pre-recovery frameworks that focus on symptom and illness management. In 4.4 the role of carers in the recovery process is considered from the point of view of service users, followed in 4.5 by carers' perspectives on caring for and supporting service users with schizophrenia. 4.6 identifies good and bad practice that helps or hinders carers in their role, continuing in 4.7 with a discussion carers' involvement in research, and in 4.8 the originality of this research is clarified and the research questions are set out.

4.1 Terminology

The role the carer plays in supporting and looking after a person with mental health issues has been identified by many authors (examined later in the chapter). In this research the term 'carer' is used rather than 'care-giver' or 'informal carer'- because some carers feel uncomfortable with the term 'informal carer' because they feel that it downplays the significance of their role (Repper et al, 2008a).

The label 'carer' has become shorthand for family members who provide regular and substantial care to the service user (DH, 1999a). Yet this label is rejected by some people, who believe that it is imposed on them to enable them to access services for themselves and their family member and it makes them feel pigeon-holed by practitioners (Repper et al, 2008a). Some carers prefer to continue to see themselves as parent, spouse or sibling (Repper et al, 2008a), viewing this as more positive than the carer label, although others begin to recognise the value of the role in the recovery context and see themselves as experts-in-caring (see Chapter 6). Indeed my own parents saw themselves as parents first and carers second; as a service user, the former was a role that I could accept whilst the latter felt belittling and embarrassing as I identified myself as a university student rather than a mental health service user. Sometimes a carer may be a neighbour or a partner rather than a family member: the label of carer incorporates a broad range of relationships and roles.

Having noted the difficulties with these terms, the term 'carer' is used predominantly in this study to denote this role.[29] A carer is defined in the following way for the purposes of this study:

> An adult carer is someone aged 18 or over who looks after a relative, partner, or friend who may be experiencing mental distress. The carer may offer regular or irregular care which may be emotional or practical, such as help with filling in benefit forms, support with mental health needs or helping to manage medication. The person may not necessarily use or accept services but may be found eligible for them if assessed.

Although the needs of young carers are important (Grant, Repper and Nolan, 2008), this study focuses specifically on adult carers as opposed to young carers under 18-years-old, because of the immediate gap in research knowledge (as will be demonstrated in this chapter) and my own research expertise. The term 'service user' or 'family member' is used to refer to the person with schizophrenia. Although difficulties are noted with the term 'service user' (see Pilgrim, 2009), this is currently the preferred terminology in British literature (ibid) as opposed to 'consumer', as used in the USA (Deegan, 1998) or Australia (Glover, 2012) and NZ (O'Hagan, 2004).

4.2 The traditional perception of the relationships between carers and service users

A number of broad approaches have been developed in the last 50 years as explanatory frameworks to describe the relationship between the carer and the service user. These are family systems research and therapy, expressed emotion research and studies of family burden.

Proponents of family systems research and therapy state that schizophrenia and its set of symptoms are created within the family environment, in particular in relationship with the parents. Fromm-Reichman (1948) coined the concept of the 'schizophrenogenic

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29 Sometimes the term family member is also used to denote the role of carer. Although the term family member may be an inaccurate description of the relationship between some service users and carers who are friends, I use it in this study because the caring relationship is more often underpinned by kinship or partnership relationships; and moreover all the caring partnerships in this study are underpinned by partnership relationships.

mother' who causes schizophrenia in her son/daughter by withholding emotional warmth from the child when a young baby.

Brown, Birley and Wing (1972) identify the problematic concept of Expressed Emotion (EE) with over-involvement in the relationship between family members. High levels of EE within families (ibid) are identified as a trigger that increases the frequency of relapse in people with schizophrenia, while over-involvement is the carer's over-protectiveness of the service user, causing higher levels of dependency (Leff and Vaugh, 1980, 1985). Family interventions based on EE research have been formulated to support carers in their interactions with the service user and help them to build agency and confidence (Kuipers, Leff and Lamm, 1992).

'Burden research' is a further body of work that tries to measure the mainly negative effects of mental illness on the carer and family (Grad and Sainsbury, 1963). It focuses on the family to examine the effect of the relative with schizophrenia on the different family members.

In response to the theories presented above, family interventions have been designed to support the development of effective relationships between carers and service users. The best-known interventions are:
- cognitive behaviour intervention (Barrowclough and Tarrier, 1992): working with both users and carers to assess their needs and provide carers with psychoeducation on how to work best with their relative
- family work for schizophrenia (Kuipers, Leff and Lamm, 1992): psychotherapeutic principles with problem-solving approaches
- behavioural family therapy (Falloon and Graham-Hole, 1994): assesses all family members and develops behavioural-type learning and problem solving.

The World Schizophrenia Fellowship (WSF, 1998), which identifies key ingredients for delivering effective family interventions, underlines the importance of working with the service user and their family both separately and together as a unit. It emphasises the need to include carers in decisions about care and addresses issues of information sharing between all parties. Many professionals can feel bound by the principle of confidentiality and feel unable to share information; however, open and honest debate between all members of the team, including the service user and the carer, can often

overcome this.   WSF (ibid) recommends that professionals ensure that carers too have access to information and support for their own emotional, practical and support needs.[30]

In the next section I focus more closely on research on family interventions to highlight the social and psychosocial needs of carers, and identify the barriers that carers experience to participating in family interventions and, more widely, their relative's care.

4.3 The role of carers' education

Carers' psychoeducation programmes focus on providing information to carers to help them to develop their own strategies to care.   Psychoeducation is an evidence-based practice (Addington et al, 2005) found to be internationally effective.   Dixon et al (2004) report the success of the Family to Family Education Support Programme in the USA, a peer family-member-to-family-member training programme delivered, organised and implemented by the National Alliance on Mental Illness (NAMI).   Its effectiveness has been reported in Asia (Chakrabarti, 2011), China (Chien et al, 2010) Hong Kong (Chien et al, 2007) and Australia (Stephens et al, 2011).

Next, I examine studies of psychoeducation interventions for family carers by Ramon and Morris (2000) and Santa Maria et al (1999), chosen because they reflect the UK context.   After that I highlight a study that uses a change model to reflect barriers to carers' participation in family interventions and, more widely, in the service user's care.   This study shows the process that carers experience as they choose to become more involved.   Finally I discuss family support in an early intervention psychosis team that adheres to the recovery model.

Ramon and Morris's (2000) evaluation of an educational programme highlights the benefits of teaching carers how to look after themselves and the person they support more effectively.   The authors used a variety of techniques to evaluate the programme: focus groups, in-depth telephone interviews, observation of group dynamics and processes and questionnaires presented to participants at the beginning and after the end of the course.   Group members felt they had benefited from participating in the group in several ways as they:
-   had greater awareness of mental illness

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30 See Appendix 18 for further recommendations.

- had increased knowledge of how to deal with difficult situations
- had increased ability to communicate among themselves and with the speakers and professionals
- were better informed
- had more strength to carry out their caring role.

Ramon and Morris (2000) also identified a number of benefits from participation in the meetings:
- carers' confidence increased and they felt more able to continue in the caring role through receiving information, gaining knowledge, and identifying avenues for support
- carers made connections with other group members, leading to greater insight into the experiences of other carers and how they interacted with their relatives
- carers understood the complexities of supporting someone with a mental illness better and how services could respond
- carers' own needs were recognised in requiring their own support systems

Often carers did not tell the person they cared for about their participation in the group. The service user might not like being talked about or their relative seeking support with this relationship. This potential conflict between the interests of the service user and the carer is recognised in Santa Maria et al's (1999) study, where the Community Psychiatric Nurse (CPN) running the educational programme provided the service user with direct support. They had to ensure that the service user did not feel anger or resentment at being excluded from the group.

Carers identified transport to meetings and someone to take their place while they were away at them as desirable. The time and venue of the meetings were also important accessibility factors for the group.

Santa Maria et al (1999) describe a partnership between a local university and local mental health services that set up an education project for mental health carers to provide support, advice and information to carers of clients with severe and enduring mental illness; it aimed to:
- identify carers' needs and break down family/agency barriers

- to educate family carers about the realities and practical difficulties of supporting someone with mental ill health.

They identify a number of difficulties carers encountered:
- confidentiality of information between the user and the carers
- the need for respite
- a need to be acknowledged and understood
- the family's emotional state
- different personal perspectives on coping with 'difficult' behaviours.

The carers in these two studies identified practical and emotional difficulties in participating in family interventions and highlighted the benefits of increased confidence and knowledge in caring.

Sherman et al (2005) contribute usefully to highlighting the barriers to participation in and organisation and delivery of family therapy for four stakeholders: service users, families, clinicians and administrators. They provide an explanatory framework based on change processes to understand each stakeholder's response to the introduction and delivery of family therapy; however the study's reference to carers is particularly useful in this context.[31] The researchers applied the Trans-theoretical Model (TTM)[32] in order to elucidate how carers could be motivated to participate in supporting the service user's care. The TTM identifies five stages of readiness to change: pre-contemplation, contemplation, preparation, action and maintenance. This change process highlights the carer's movement from reluctance to willingness to become involved in supporting the service user, illustrating how not all carers choose to become involved in their family member's care. This paper shows that carers need support and encouragement appropriate to each stage to help them to find the confidence and motivation to choose to provide care.

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31 This model is part of the theoretical framework underpinning Leamy et al's (2011) conceptualisation of recovery.

32 The TTM was originally developed by Prochaska and Di Clemente (1983) to understand how people change addictive behaviours

Addington et al (2005) describe a model of family intervention delivered by an early intervention psychosis service in Canada. The intervention is tailored to provide the family member with optimal support at each stage in the service user's recovery. This programme is underpinned by an acknowledgement that the service user's recovery follows a progressive trajectory, yet the intervention's goals focus on illness management and optimal functioning. It does not focus, as my study does, on teaching carers about recovery and helping them to find their own solutions.

Psychoeducation is reported to have many benefits but it relies on the professional as expert. Addington et al (2001, p272) comment:

> Intervention programmes respect the importance of the context of the family as *crucial to recovery* and incorporate assessment processes which seek to document the strengths and resilience of the family – but overall an emphasis on 'psychoeducation' – does not equally value expertise by experience – even in early intervention services.

This suggests the importance of the experiential expertise of carers in their caring role and of recognising their positive contribution and natural resilience. Peer-to-peer training was found to be effective in studies in the USA (Dixon et al, 2004) and Australia (Stephens et al, 2011) as carers responded to the authenticity of their carer peers in delivering the training.

The research presented in this chapter is only indirectly related to recovery. These frameworks come from a pre-recovery perspective: they are concerned with 'symptom management' and illness management rather than with living with or beyond the experience of mental ill-health. Little has been produced about the role of carers in the recovery process; and my research seeks to address part of this gap in the literature.

4.4 Relationships between service users and carers in the recovery process: the service user's perspective

In this section the carer role in the recovery process is addressed. Few research projects focus on what carers think (see section 4.5); first I consider how service users can recognise and value the role that carers can play in the recovery process.

Rethink's self-management project (Martyn, 2006) asked service users how carers, friends, family and other people contribute to their recovery. Their responses included: (p. 9/10)

- encouragement

- exploration

- faith in me

- positive expectations

- understanding

- practical help

- inspiration

- acceptance

- guidance

- support

Some service users commented that they went to stay with their parents at times of crisis; others that their partners' practical help with affairs such as budgeting and financial support and their emotional support were very important in their self-management. However, it must be noted that in such a survey service users and their relatives focus on the positive mutuality of their relationship rather than any conflict that may exist.

Carers play a big role in the recovery of relatives with mental health needs. Lapsley et al (2002, p. 61/62), looking at recovery processes in NZ, identify specific ways in which carers, family, friends and other people offer support:
- presence: being there to listen, understand and support
- faith: families could powerfully convey hope (or despair), and being believed in was important to recovery
- active support: helping to look after the children, making a home available, paying debts and many other forms of help
- challenge in the context of support: sometimes supporting them in dramatic ways such as taking the family member to a Maori faith healer or removing them from a difficult situation.

In a relationship of caring and receiving care there can be conflict and antagonism. Sometimes the service user does not improve at the rate that the carer expects, or does not improve at all. The carer may expect his/her relative to return to pre-morbid functioning, and this may not be the outcome of the illness. This can also work in

reverse, with carers having too low expectations of the service user and not enabling them to take control of their life. In my experience, as carers my parents found it hard to understand that there were times in my recovery when I needed to rest as I stabilised. They wanted to see constant forward progress and found it hard to be patient. They felt that they could expedite my recovery and do it for me – thus forgetting that it could only progress at my own speed.

Carers' expectations, however, do not reflect the emerging concept of recovery in which service users define their own recovery and make their own journey. Recovery is not about return to pre-morbid functioning; it is about absorbing and working within the limits of the mental health experience as an individual making a journey to live well with mental ill-health. This research draws on carers' reflections upon this journey and asks whether the recovery concept can have any influence on their lives.

4.5 Relationships between service users and carers in the recovery process: the carer's perspective

Caring is stressful and confusing, particularly at the point of first occurrence of the positive illness symptoms of schizophrenia and dramatic change in personality (Repper et al, 2008a; Worthington and Rooney, 2009), although even before this there may have been changes in behaviour and social withdrawal that were ambiguous and difficult to interpret. At this point carers do not know the extent of their caring role and often have very little idea of what is happening and how the illness will affect their loved one. Their experience of being seen as exacerbating the mental ill-health of the service user by some professionals (e.g. the High EE studies, or the conceptualisation of the schizophregenic mother) underlines their feeling of exclusion and courtesy stigma (Goffman, 1963).

Carers have long argued that they should partner their relative in the recovery process and need information and support to assist in this (Hogman and Pearson, 1995; Jones, 2002). Few research studies look at the role of the carer from their perspective. This section introduces the carers' perspective of supporting the recovery process of the service user with schizophrenia.

Jones (2002) undertook a series of interviews about carers' experiences of looking after relatives with schizophrenia. He identifies experiences of love, hate, shame and anger in

coming to terms with the illness in their relative. A carer might experience the following emotions in the process of accepting that their relative has the diagnosis of schizophrenia:

1. Acceptance that an illness is operating as an agent of change
2. Acceptance of the long-term nature of the changes perceived to have taken place
3. Acceptance of the person who has emerged from that process of change. This involves the renegotiation of the relationship.

This narrative clearly describes the bereavement process that carers experience following a diagnosis of schizophrenia and the all-too-frequent accompanying decline in health and well-being. Although this is a useful description of the journey a carer might make in accepting the diagnosis of schizophrenia in a relative, it is pre-recovery-oriented. It presents a process of *negative acceptance* rather than the *positive rebuilding of identity* as found in the concept of recovery discussed in the previous chapter.

A number of studies reinforce the notion that mental health carers commonly experience caring as a temporal staged process expressing similar needs at different times in the journey (Repper et al, 2008a; Karp and Tanarugsachock, 2000; Rose, Mallinson, and Walton-Moss, 2002). Karp and Tanarugsachock (2000) interviewed 50 respondents and identified four stages to caring from the point of first illness to ongoing rehabilitation; Rose, Mallinson, and Walton-Moss (2002) interviewed 29 family members and identified a three-stage temporal journey.[33] Karp and Tanarugsachock (2000) highlight the confusion, frustration and sense of being overwhelmed at the beginning of the caring process before a firm diagnosis is established; Rose, Mallinson, and Walton-Moss (2002) identify similar emotions but begin with describing the point from the establishment of the diagnosis. The second stage in both papers is characterised as seeking control over the illness (Rose, Mallinson, and Walton-Moss, 2002) as the carer attempts to seek out information, navigate the mental health systems, and to inform themselves of the nature of the condition (Karp and Tanarugsachock, 2000). This point is characterised by positive emotions of love and support as the carer seeks to 'save' the service user from their illness (Karp and Tanarugsachock, 2000). Karp and Tanarugsachock (2000) mark

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[33] See Appendix 19 for Karp and Tanarugsachock's (2000) four stages model of caring and see Appendix 20 for Rose, Mallinson, and Walton-Moss's (2002) three-stage temporal journey of caring.

the next point when initial optimism gives way to a sense of the likely permanence of the mental health need as the carer begins to doubt the possibility of recovery. This point is characterised by negative feelings of anger, resentment and frustration. Finally Karp and Tanarugsachock (2000) define a sense of acceptance as the carer recognises their lack of control over the user's situation and acknowledges that they are responsible for their own life. In contrast the final point identified by Rose, Mallinson and Walton-Moss is when the family adopts a stance of possibilities and realities by rejecting the overwhelming negativity of the mental illness prognosis. They emphasise the possibility of recovery which re-affirms hope for the future and redefines their relationship with the cared for person they seek to help them both maintain their stability but strive for development.

These studies are significant as they emphasise the temporal nature of caring but show how respondents have both common and diverse experiences of their caring journey – the carers in Karp and Tanarugsachock's (2000) study focused on the negative implications of the diagnosis; while the carers in Rose, Mallinson and Walton-Moss's (2002) study managed to hold on to a belief in recovery. This research also shows that carers identify similar needs at different stages in their caring which highlights the importance of providing tailored services for different points in their journey (discussed in 4.6).

Stern et al (1999) explore seven carers' experiences caring for an adult son, a daughter or a spouse with mental ill-health using a narrative technique - although a small scale study it highlights interesting findings. The moment of onset of illness is described as a moment of 'ontological insecurity' when all the carer's beliefs and assumptions about life became uncertain and unreliable. As they cared for longer periods, they narrated two differing responses to their situation: they either told a chaotic and frozen narrative or related stories of reparation and restitution.

When carers were stuck in a frozen or chaotic narrative characterised by negativity and self blame it was difficult for them to reconstruct their sense of self and identity and they were unable to focus on solutions or positive processes. They had little belief in recovery, so the open-ended nature of the illness made it impossible for them to find an end point to the suffering. In contrast, carers who reflected on the idea of reparation or restitution and had hope for the future developed more positive coping mechanisms.

The results of this study suggest that teaching carers to focus on recovery, emphasising hope and optimism, has the potential to change their experience of caring – a premise that my own experience supports.

Gender differences were also identified in the caring of mothers and fathers or spouses. Mothers were more protective and more often over-involved with their children, intuitively seeming to understand them emotionally while fathers often remained on the periphery of the caring relationship.

Caring in the learning disability field lends helpful evidence to development of the conceptual nature of caring in mental health. Grant, Nolan and Keady (2003) present a temporal staged process of caring for carers of people with intellectual disabilities.[34] Grant, Ramcharan and Flynn (2007) and Grant (2010) develop a psycho-social model of resilience in families supporting children or adults with intellectual disability;[35] this incorporates:

- the ability to search for meaning in challenging circumstances
- the need for a survival instinct and capacity for development
- the capacity of the individual to change and develop in the face of adversity
- the individual's relationship with familial, social and cultural environment which allows them to construct their sense of self esteem and confidence.

This reflects the work presented above that underlines that carer need to achieve ontological security and resilience as they meet the demands of the caring role and begin their recovery.

Struening et al (2001) interviewed carers about their experience of stigmatisation and role devaluation following the diagnosis of schizophrenia in the cared-for person. The carers felt that the community was prejudiced against both the family and the service user in a number of ways: they saw service users' status reduced by their mental ill-health, restricting their role in life, with the view that they are not being marriageable or

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34 See Appendix 21.

35 Grant, Ramcharan and Flynn (2007) and Grant (2010) draw on the work of Antonovsky (1987). Antonovsky is important because of his focus on the sense of coherence.

able to work, and bringing rejection from others when seeking friendship. The family was also stigmatised and seen as not caring for the family member with mental ill-health. Often their community believed that they had caused the illness and they were rejected because of the mental ill-health of the cared-for person. This shows the negativity associated with this stigmatising diagnosis and carers' growing feelings of social exclusion and rejection.

Carers-One-to-One Link (Cool) Recovery for Carers (2003)[36] developed by a group of carers in Devon, was an early attempt to encapsulate the carer's journey of recovery in the following stages:

- recognition of grief
- when services become involved
- detaching with love
- setting a vision/goal of recovery for relationships
- setting a vision/goal of recovery for the carer.

The first stage requires recognition of the bereavement process with grief at the lost opportunities of the cared for person. This is often characterised by the realisation that things are going to be different. Then the services become involved; professionals may not involve or share information with the carer, who may have to detach a little and let go of some of the control in their relationship with the service user. In the next stage, the carer begins to rebuild relationships with professionals carers begin to look at their own needs and requirements and to rebuild their life. This stage enables them to reach a place where they recognise the need/wish to live a life that is both *mutual* with the service user but also *separate* and *independent*, through the process of detaching with love.

Cool Recovery notes the possibilities of positively rebuilding the identity and opportunities for recovery. It recognises the separateness of the carer in her/his life and the importance of having a life beyond caring. It is a true recovery model that recognises possibilities rather than being stuck, giving the carer permission and space to detach from the caring identity and look to their own needs, seeing themselves as a whole person rather than merely a carer supporting the service user.

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36 See Appendix 22.

Kilyon and Smith (2009) present a groundbreaking collection of personal narratives of mental health carers, in which a number of themes recur that help and hinder the carers' role in their relatives' recovery. The editors draw out these themes:

- difficulties in identifying early signs of mental health problems
- the expectation that services will help to solve the problems
- lack of informed choice about treatment options
- staff attitudes
- confidentiality
- guilt and blame
- lack of belief in or understanding about recovery. (p. 8)

Many carers face an initial becalming at the first signs of mental health needs. They do not know how to address them or what to do. The general practitioner (GP), normally the first point of access to health care, may be less than ideally aware of mental health needs. The carer does not know where to turn. Once mental health professionals are involved, carers expect the health professionals to help to resolve the problems, but sometimes their intervention can be more harmful than beneficial; there is often a lack of choice of treatment options, including effective talking therapies, for the service user. The carer is not involved in these choices.

Carers' narratives included problems of staff with confrontational attitudes towards them as carers, often coupled with particular issues related to confidentiality. Carers acknowledged a sense of guilt and blame when the person they are supporting does not seem to be recovering. Many carers already believed in the possibility of recovery and identified other mechanisms preventing their relative's recovery.

Finally a brief scoping exercise undertaken by the Scottish Recovery Network (SRN) (2009) further highlights the importance of this debate. A small postal survey and four focus groups provided data on carers' views about recovery. The carers defined the recovery of the service user as 'a sense of having to rework life expectations in the context of renewed and renewable hope and enjoyment in the lives affected by mental health problems' (ibid p. 15). A number of themes related to the importance of recovery arise from the research:

- the recognition that small things and successes lead to greater successes in life

- time and space are needed for recovery
- stigmatisation is a barrier to recovery
- the importance of social contact for the service user in the recovery process
- the carer's important role providing intensive support for recovery
- the carer's own behaviour in practical matters is key to the recovery process
- the important role of services co-working with carers and service users
- carers must learn to manage risk and let go of their control in the service user's life
- the carer experiences co-recovery with the service user.

The study concludes: 'This very preliminary study can only raise emergent issues and more systematic work needs to be done'. (ibid p. 35)

These themes, identified in the narratives of carers and research undertaken with them, reverberate throughout in a number of different ways throughout this chapter. This section underlines the dearth of literature on caring and recovery, making space for this original PhD research.

4.6 The provision of support for carers

This research explores carers' role in the recovery of their relative with schizophrenia. Much of the debate relates to many carers' belief that they have been left to do the caring alone without support. Part of the political debate in the 1990s about the role of the carer focused on the lack of support for them in their caring role. They were expected to support and look after their relatives without any service provision to support them. Ramon (1985) remarks how carers were not consulted when policy was developed to move service users from hospital and inpatient care to community care. Provision was made for long-term users of care, but no long-stay equivalent to asylums were developed for new long-stay service users (Rapaport, 2005). Families were left to fill the gaps for this client group. Hogman and Pearson (1995) comment that service users living away from their families have issues with their accommodation, financial, and practical problems (Shepherd, Murray and Muijen, 1994), but receive more support from services than service users who live at home. This suggests that families provide ongoing support to fill the gaps where a service user continues to live at home.

Hogman and Pearson (1995) describe how carers experience stress and depression associated with their caring tasks. The Office for National Statistics (2002) shows that increased caring hours are reflected in adversely-affected health (Rapaport, 2005). Caring can have negative effects on the carer's leisure time, financial situation, working patterns, health and well-being.

The government recognises the role of the carer in legislation, giving them the right to an assessment of their needs, which are taken into account when planning services (DH 1999a; 1999b; H.M. Govt, 2004). Part of this recognition has sparked growing research on appropriate services to support carers, and in this section I highlight this research.

In 2002, the UK government commissioned a research project to look at what support was needed by mental health carers to help them to look after the service user in their family. According to Newbronner and Hare (2002) carers felt that care and support was most effectively delivered when it was given to the family as a holistic unit and not just to the carer and the person supported. They thought that care should be integrated into local mental health services rather than an add-on. Effective mental health services offer five types of benefit:
- for the carer
- for the person with mental health needs
- for the family as a unit
- for mental health services
- for society as a whole. (ibid p. 9)

This shows the intrinsic connection between caring for the carer and providing adequate services to support the service user, as reflected in further surveys of carers' needs. Faulkner and Williams (2005 p. 11), in another study, report: 'Some carers expressed the common view that as long as the person they care for is supported then their own personal needs are being met. In other words, 'If they're ok, I'm ok''.

Simultaneously with the passing of legislation described in the context chapter, the Carers Impact Study (Kings Fund 1998) developed a service model for providing appropriate services to carers. The Carers Compass, developed by Banks and Cheeseman (1999) indicates the constituents of appropriate care for carers.[37]

37This can be found in Appendix 23.

According to Newbronner and Hare (2002), carers especially identified the importance of 'effective communication between professionals and carers to achieve a two-way flow of information' (ibid, p. 7); However, the service user may find the carer interfering, negative or overwhelming and may not give consent for information to be shared, leaving the carer ignorant of the diagnosis, care provision or treatment offered to the service user, which can be difficult for both the service user and the carer. Repper et al (2008b, p. 421) note how this is particularly difficult for carers of people with mental health issues because of 'the fluctuating nature of problems, the potential for conflict between service users and carers' views and the widespread fear and ignorance about mental health problems adding to the isolation and sense of guilt among carers'.

Szmukler and Bloch (1997) look at confidentiality and ethical considerations. They propose reasons for involving the family in the care of the service user:

- the family is a unit, not just made up of individuals
- the best care for the patient often requires the family's support
- the family experiences carer burden
- often the treatment team has information that will assist the family in caring for the patient.

The decision to share information should also be influenced by whether the service user resides with the carer and their family, or independently.

Carers believe that their needs are tied up with the service user's needs. However, they also stress their desire for one-to-one access to a professional to support them in their carer role, recognising their individual and personal needs (Faulkner and Williams, 2005). Carer support groups are also recognised as a valuable source of peer support, enabling carers to share their mutual experiences and feel understood; although Karp and Tanarugsachock (2000) identify the negative impact of peer support groups on new carers as longer-term carers report the 'horror stories' of caring accompanied by their conflict with mental health services, destroying a belief in the possibility of recovery for new carers.

When carers were asked what would support a better quality of life for them, they reported that they wanted to be respected and listened to as equal partners in the care team, to have the opportunity of respite and to be fully informed about the person they cared for (Faulkner and Williams 2005). This, they believed, would enable them to care more effectively and help the service user to recover more quickly.

Repper et al (2008a; 2008b) undertook interviews with carers about their experience of receiving carer assessments under DH (1999a) and caring for their family member. They note that 'caring needs to be seen as a temporal experience with different stages in the journey of caring' (2008a, p. 48) (see 4.5) recognising that carers have different needs at different times in their caring experiences. They (2008a; 2008b) identified that some carers felt despair at the start of caring when they found themselves left alone to care until there was a crisis. They quickly realised that they were a source of support to the cared for person, although this was not always recognised by services. Although carers wanted support for themselves, first and foremost they wanted adequate and appropriate support for their family member. They felt inequitably treated by professionals; they were expected to give information about the service user but received little information to help them in their caring in return.

Carers felt pathologised as 'fussers', interfering and troublemakers, when all they wanted was to do the best for their loved one. They feared the tension between positive risk-taking and being risk-averse. Although positive risk-taking has a role in recovery practice, Chandler (2010) notes that it is the carer who must ultimately live with the consequences of mismanaged risk if things go wrong. Carers sometimes feel they do not have enough support or information to ensure that the service user experiences effective and safe services, yet DH (2011a) clearly states the importance of *working with carers to manage risk;* moreover the guidance recommends a whole-family approach to care planning and risk management to ensure that the responsibilities of all stakeholders are made clear and that assumptions are not made about who will provide what care and when.

Carers wanted to be able to look forward to the future with hope and expectation and to receive enough support from services to enable them to have a life outside caring. They wanted services that valued and recognised their expertise in a partnership of care and that were proactive, dependable and responsive to their family, community and cultural

beliefs. They wanted professionals to recognise their right to a life outside caring, with opportunities for leisure, work and other pursuits. DH (2010) states that support should be personalised, taking cultural and religious needs into account, and that the assessment should include a whole-family approach so that no carer is *compelled* to care.

Carers want to be included in a triangle of care between professionals, carers and service users (Worthington and Rooney, 2009) developing a working relationship of trust, transparency and support. Professionals have focused on the needs of the service user for so long that they have forgotten the need to engage with and support the carer for the benefit of all members of the triangle. It is important for staff to receive adequate training so that they can understand and 'walk in the shoes' of a carer (Worthington and Rooney 2009). Carer support services offer emotional support and give carers an opportunity to receive peer support from other carers, to learn, provide reciprocal support and get information and advice. Guidelines and policies are needed that support operational practice rather than merely pockets of good practice by individual teams or individual staff members.

Grant (2010, p. 179) in a related field provides a useful summary of the services that carers of people with learning disabilities need at different times in their journey:
- Family systems thinking to support individual case work
- An awareness of mutualities and reciprocity in family relationships
- Tailoring of services to support the different needs of families at different times in the caring life course
- Viewing families as expert partners in care
- Utilising the family as a gateway to wider community resources
- Recognising the need for families to have a life beyond caring
- Involving families in decision-making about care of the service user
- Supporting families to empower themselves
- Respecting and working with families as equal partners.

This reflects a systems approach to caring that embraces both the needs of the family, the needs of the service user, and the wider life course of the caring journey. Such an

approach is reported as helpful by many carers in the delivery of mental health services (as detailed above) but seems to be missing from their experiences.

Carers' poor experience of services highlights the need for more research to change current policy and practice to ensure that services match the rhetoric of policy on carer support (DH, 2008; 2010). This is the gap in which my PhD begins to connect the experience of recovery with the support of carers.

4.7 Personal reflections

These themes reflect my own parents' experiences as they battled for my recovery. Sometimes my mother became classically over-involved, drawing on her instinct to fight for her daughter's recovery, to never let me lose heart or hope, to constantly feed me with messages of hope and optimism, and sometimes to 'do recovery' for me. I remember the conflict that sometimes existed between us but also her constant battle to never lose hope and never let me despair.

I think of my first experiences of meeting a Community Psychiatric Nurse (CPN), which was the only contact I had with community mental health services apart from the psychiatrist. About six months after my voluntary hospitalisation when home from university for the long summer vacation a CPN came to visit at our house, spoke to me alone in a room for approximately ten minutes and then left. She failed to introduce herself to my parents or to engage in any contact with them. I was unsure whether she would visit again (she never did!) and had little recall of what she had said to me. My parents were confused and angry as they had hoped that this practitioner would support me in my recovery, and afterwards felt even more alone and more certain that they would have to forge their own path to caring and supporting my recovery. They themselves sought support from a local voluntary Rethink carers' support group, and found this an important source of information and advice as we all began our journey of recovery together.

In summary, my own experiences of being cared for and my parents' experiences of being carers reflect the literature that I have presented so far in this chapter. It reflects the need:
- for carers to offer hope

- for professionals to provide carers with information and see them as partners in care
- to offer carers their own sources of support
- to acknowledge the possible conflict between carers and service users
- to work effectively with the family both as a unit and separately as people working together to institute a recovery journey.

4.8 Involving carers in research

This section introduces the principle of involving carers in research, although the processes of involvement are discussed in more detail in Chapter 5. Only a limited number of studies have involved carers as partners in the research process (Pinfold and Hammond, 2006; MHRN, 2012a; 2012b), although the commitment to involving service users in research is well established (Rose, 2001; Glasby and Beresford, 2006). Pinfold and Hammond (2006) investigated the involvement of mental health carers in research and conclude that while a number of projects and forums have developed to address the carer perspective there is no coordinated move to involve carers as partners in research.

Repper et al's (2008a; 2008b) Partners in Carers' Assessments Project (PICAP) involved carers playing an active role in research not only as research participants sharing experiences of assessment but also as co-researchers, working as part of the research team and influencing the questions asked, the selection of participants, analysis of the data and the presentation of the findings.

In Fox (2009) I present a project in which I facilitated a group of carers setting up a representation group called Carers against Stigma in a North London borough. The establishment of the group and the first year of its life were evaluated by the carers themselves, using participatory action research.

Lammers and Happell (2004) describe policy developments in Victoria, Australia, that enabled and facilitated the increased involvement of carers and service users in service planning and evaluation. They conclude that 'the carers unanimously stated that their level of participation and involvement with mental health services was minimal' (ibid, p. 269), and that they were more concerned about the needs of service users than their own as carers. However, this does not explain the sustained lack of carer involvement in research.

MHRN (2012a; 2012b) reviews the involvement of mental health carers in research and reports that they should be given support similar to that provided to service users. They have a unique perspective to offer that differs from the service user perspective: they reflect a perspective grounded in the daily experience of supporting and caring about people with mental ill-health (MHRN 2012b). MHRN concludes that involving carers in research is 'of real value' because it represents democratic ideals and has the potential to develop a culture in mental health services that ensures that 'carers are respected, included and valued as a key stakeholder within the mental health system' (ibid, p. 24). Involving service users in research has led to their increasing influence in developing and monitoring mental health services, and such a process could be replicated with carers.

The lack of a carer involvement evidence base in research is surprising, considering the government's commitment to involving carers as partners in the care of the service user with mental health needs, and indeed in service development and evaluation (DH, 2008; 2010; 2011a); my research addresses this gap.

4.9 The research questions

In this chapter the definition of the term 'carer' has been set out and contextualised within its political and systemic framework. I have described the traditional explanatory frameworks developed to understand the relationship between the carer and the service user and surveyed some of the therapeutic interventions designed to improve this relationship. I have introduced the role of carers in the recovery process from the perspectives of service users and carers. The limited research on how carers see recovery and understand their role in it has been highlighted, with practices that help or hinder them in this process identified, and best practice in mental health care for carers presented. I have reflected on my own experiences of how a practitioner engaged with both myself and a service user and my parents as carers. I have introduced the involvement of carers in research and the lack of an evidence base in this area.

This existing literature base on carers' views could be described as addressing 'pre-recovery'; it is only concerned with living with illness rather than living well with it, and not at all with living beyond the illness (Davidson, 2003). The current literature focuses on the supportive contribution they can make to the service user's life (Hogman and

Pearson, 1995; Jones, 2002) their experience of the care burden (Grad and Sainsbury, 1963) and expressed emotion (Brown, Birley and Wing, 1972).

The contributions that carers can make to the recovery journey include their ability to:
- offer hope to the service user
- encourage the service user to build strategies to prevent relapse
- support the service user in his/her struggle to take control over his/her life

The recent literature on the role of carers in recovery that I have identified is brief and makes the case for greater research in this area (SRN, 2009; Kilyon and Smith, 2009). Service users and providers (NIMHE 2004, Rethink 2005a, CSIP, RCPsych, SCIE 2007) views of what recovery is and how it may be achieved have been researched but carers have so far been neglected in this process and have had less opportunity to be involved in research than their service-user colleagues (Pinfold and Hammond, 2006). In this literature review I have illustrated the importance of carers as partners in the care process and posit that they are under-involved in research and evaluation.

The lack of research on recovery from the perspective of carers makes my research original, and indeed the lack of carers' involvement in research positions this thesis uniquely to explore this subject.

This research delivered a training programme on the recovery approach developed by a team of service users, carers and professionals, to a small group of carers. It enabled us to explore together their views on recovery and how they perceive their role in the recovery of people with schizophrenia. I collected mainly qualitative data, supported by supplementary quantitative data.

My research questions are:
- What does recovery mean to carers?
- How do carers define recovery?
- Do carers believe recovery is possible?
- How do carers describe their role in recovery?
- Do carers' views on recovery change over time?
- How do carers evaluate their own road towards recovery?

- o (Recovery is a concept that some carers are now applying to themselves. I look into this in more detail later).
- What do they see as the major obstacles to and opportunities in recovery?

These research questions focus on the central tenets of recovery, and the answers enable the development of a rich understanding of carers' views of recovery and how it impacts on their lives and the lives of the people for whom they care. Through the development and delivery of the intervention with the carer participants:

- I explore whether learning about recovery, with its commitment to hope and optimism, changes the way carers care for the service user
- I evaluate whether any changed approach to care improves the long-term well-being of the service user (as reported by the carers) and changes the way carers care for themselves.
- I evaluate whether there are any improvements in carers long term well-being

I develop an overview of what carers understand by 'recovery', whether their views on recovery are sustained or change over time, and whether learning about recovery provides lasting benefits for the carer/service user relationship. I asked the group to identify obstacles and opportunities in recovery in order to gain greater understanding of what the concept of recovery means to this client group.

This research adds to the growing evidence base on recovery and contributes to the debate from a hitherto underexplored area. Using a participatory methodology, it contributes to the growing evidence base of carers involved in research and, through this process, contributes to their empowerment.

Chapter 5. The Methodology

5.0 Introduction

Thus far, relatively little work has been undertaken in the UK or elsewhere to ensure that carers are well-informed about the recovery approach. This study explored whether and how a small group of carers' attitudes to their caring situation changed when they learned about the recovery approach from participation in a training programme, and whether knowing about it altered their views about the prospective future of the service user. Mainly qualitative data were collected at different points before, during and after the training programme to capture carers' views of their caring and personal situations, with supplementary quantitative socio-demographic data collected.

The following research questions were addressed:

- How do carers define recovery?
- Do carers believe recovery is possible?
- How do carers describe their role in recovery?
- Do their views on recovery change as a result of the training programme?
- Does their behaviour change as a result of the training programme?
- What do carers see as the major obstacles to and opportunities in recovery?
- Do they evaluate the training package as helpful in enabling them to explore these issues?

Section 5.1 describes why the interpretative paradigm was appropriate for this research. Section 5.2 sets out the choice of constructivism as the research framework; 5.3 discusses the choice of participatory action research as the methodology; 5.4 sets out the tradition of PAR in user led participatory inquiry; in 5.5, I discuss why acknowledgment of the role and identity of the user researcher is important in this study. Sections 5.6 – 5.11 focus on the research design (5.6), data collection methods (5.7), the training package (5.8), sampling (5.9) data analysis (5.10) and ethical issues (5.11) with a conclusion in 5.12.

5.1 The research paradigm

This section introduces the philosophical underpinnings to the choice of research paradigm. Research is always conducted within some broader understanding of what constitutes legitimate inquiry and warrantable knowledge, therefore the methods used, the way the data are presented, the assumptions behind the criteria for judging quality

and accuracy are all related to the epistemological, ontological and methodological assumptions of the research design (Henwood and Pidgeon, 1992; Guba and Lincoln, 2005). Bryman (1988) asserts that the distinction between qualitative and quantitative research is a technical matter with the choice between them to do with their suitability for answering particular research questions. This chapter shows that the choice of research methodology is both a technical and a philosophical matter, and demonstrates how careful consideration of the philosophical concerns underpinned the research.

The questions below set out the philosophical assumptions which are fundamental to defining how knowledge is understood in research and how it is developed and conducted:

- What is the form and nature of reality? (ontology)
- What is the relationship between the knower, and what can be known? (epistemology)
- How can the inquirer find out about what s/he believes? (methodology)
- What is extrinsically worthwhile about the study? (axiology)

(Taken from Heron and Reason, 1997)

The next sections explore the implications of these questions for the development of this study's research design.

The choice of paradigm

This subsection describes the paradigms of positivism and interpretivism and how they relate to the research design and the philosophical assumptions endemic in the study, highlighting the importance of social constructivism and participatory research. This draws on a discussion of the ontology, epistemology, methodology, and the axiology of the study.

Positivism

Positivism, based on Cartesian dualism, assumes that there is a direct reality in the world that can be understood by a human's mind through rational technical means. This paradigm grew out of the Enlightenment, which celebrated man's reason and ability to understand and comprehend nature. Knowledge is understood as an 'accurate representation of what is outside of ourselves' (Smith and Hodkinson, 2005, p. 216). It is believed that data from social science research can be obtained via reliable and valid

methods of inquiry similar to how they are obtained in the study of physical sciences such as chemistry and physics.

Researchers from the positivist framework tend to present quantitative data. Quantitative research is used to analyse large samples. It is not as useful in capturing the experiences of people and their complex social processes in context, or for revealing the understanding that they construct about their experiences (Esterberg, 2002). Quantitative researchers employ methods such as structured questionnaires, surveys, and large-scale data collection methods in which data can be codified, often presented in the form of statistics. Such research tends to provide much generalised information from a large sample. Researchers from this tradition hold that social science knowledge gained in this way is objective, valid knowledge. Quantitative researchers generally generate theories through deductive reasoning based on the body of the research and then test them using the data generated from the research; *a priori* theory 'directs the processes of collection, analysis and interpretation of data' (Henwood and Pidgeon, 1992, p. 101).

The positivist paradigm was rejected for this research project for a number of reasons. The research is exploratory in nature therefore a deductive process was unsuitable. The research process required me and my co-researchers to collect in-depth data from carers about their views about recovery, therefore qualitative data collection tools were primarily employed (as discussed in 5.7). Some quantitative demographic data were collected to support and strengthen the qualitative analysis, but inductive processes were used to analyse the data and generate theories. The positivist tradition makes assumptions about the nature of knowledge and how it is transferred which are not compatible for the underlying philosophical approach of the research design.

Further reasons for this consideration are explored in the next subsection, which discusses interpretivism and its implications for the research design.

Interpretivism

Researchers from the interpretative tradition argue that it is not possible to gain direct understanding of people in the world, as positivist researchers believe. In this tradition, researchers emphasise understanding people's experiences in context and reject the notion that all knowledge can be understood by rational, technical means. When researchers from this tradition try to understand the experiences of other people, they not

only recognise that the knowledge of the research participants is contextualised to the research setting, but also acknowledge that their analysis of the results is informed by their own beliefs and context. Researchers from this tradition often employ inductive processes of reasoning as there is 'a move from data towards theory' (Henwood and Pidgeon, 1992, p. 101), although the pre-existing evidence base also informs theory development alongside my own status as a service user which informs the development of the study.

The interpretative paradigm is very suitable for this inquiry, which was conducted with a small group of carers and captured rich, complex and in-depth data that contributed to and informed debate in this under-researched area. It was not, in my opinion, appropriate in this case to sample a large group of carers or undertake survey based research, because this would have generated more general data rather than explored individual experiences in detail.

I am a service user myself and have been through my own journey of recovery (Fox, 2007; 2013); this influenced the way in which I collected and interpreted the data. It enriched the study and the findings it generated. The interpretivist paradigm allowed me to both recognise and value the multiple identities of the co-researchers throughout all stages of the study and the presentation of the findings (Nicholls, 2001).

This differs from the positivist tradition, which does not acknowledge the subjectivities of the researcher and where the aim is to produce an accurate and generalisable depiction of reality through the use of reliable research methods 'untainted' by subjectivities. This consideration was essential in the choice of the interpretative paradigm for this research design, as my own identity fed into the choice of research topic and research design (see further discussion in section 5.5).

Qualitative researchers reject the existence of objective knowledge and cannot claim, as positivists do, that the discovery of knowledge accurately represents reality, as the data are often influenced by the identities of the research participants and are context-specific (Denzin and Lincoln, 1998; Lincoln and Denzin, 2000). If research is to be believable it must include some kind of recognisable truth or commonality. For example, when many service users read about the recovery journey, they identify with the collective experience of other service users – they have a common experience. Qualitative

researchers within a constructivist framework argue that reality is shared and mutually co-constructed through the research process. In this study, carers had their own experience of supporting a service user's recovery and their own caring situation, but were able to identify experiences held in common with their peers. Understanding the constructivist framework in the interpretative paradigm helped me to rationalise my position. This is discussed in greater detail in section 5.3.

Ledwith and Springett, (2010) argue for a participatory paradigm: they believe that ontology and epistemology directly influence each other and the implementation of the research. They state (2010, p. 212): 'Our epistemology of participation – our world view based upon participation – influences our ontology – our action based on participation'. They believe that there is an intimate connection between the development of knowledge and the research process: arguing that a research epistemology based on social justice and transformative action necessarily influences research practice.

I found that interpretativism was the appropriate paradigm for this research inquiry, as it is an exploratory research design that captures in-depth complex data with a small sample. It:
- acknowledges the contextualisation of knowledge
- utilises qualitative data collection
- enabled me to acknowledge my own identity/bias in the research process
- and supports inductive processes of reasoning.

5.2 Research framework

Guba and Lincoln's (2005) seminal work identifies and compares a number of frameworks within the postmodernist paradigm. These include critical theory, social constructivism, naturalism, and the participatory framework. This section considers a number of elements related to my choice of an appropriate framework for the research design.

Guba and Lincoln, (2005) suggest that three questions be addressed in the choice of research framework in the interpretative tradition:
- Whose voices are heard in the research process? How are those voices heard and interpreted to build meanings from the inquiry?

- Who controls the research processes or participates in decision-making processes?
- To what extent are action/change featured as part of the different research frameworks?

Many elements of social constructivism fit well with the research framework. In social science research using a constructivist framework, the researcher's emphasis is on understanding how individuals construct and interpret the meanings of social reality (Gubrium and Holstein, 1997; Esterberg, 2002). Social constructivism is based on a theoretical tradition called symbolic interactionism.[38] Social constructivist researchers acknowledge that meanings change in different cultures and even across different research projects; therefore the main research task is to interpret how meanings are constructed. The research process itself can be seen as 'social production'.

Proponents of social constructivism acknowledge that the meanings of the participants' views expressed during a study are *constructed by the research processes*, and therefore may not be sustainable, objective knowledge outside the research situation (as introduced above). This contrasts with positivist researchers who claim to capture the 'social facts' and 'objective knowledge' that are believed to exist in the world. Social constructivism, however, is a more appropriate framework for this study as it is exploratory, and researchers in this tradition believe that meaning is constructed through social interaction in the research process.

In the framework of naturalism, the goal is to present the lives of those studied as faithfully as possible and to understand their social world (Esterberg, 2002, Lincoln and Guba, 2005). The researcher has to preserve their story so that their voices are heard in the research findings. They do not influence it with their own views, so their voice is not heard. The researcher has the final say on what goes into the report, and controls the research processes. This is not suitable for this research which acknowledges the place of the identity of the researcher in research processes and that the meaning of the views the participants express are constructed within the research process.

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38 This rests on three premises identified in Appendix 25.

Critical social research, including feminist research, is a 'moral and political activity' (Esterberg, 2002 p. 18). Critical social researchers seek insights into the social world in order to help people to change oppressive conditions. Hodageneu-Sotelo (1996) studied immigrant women who cleaned in private households, and then produced novellas in comic strip format that informed women of their rights with regard to the minimum wage, reducing the possibility of their being exploited. Critical social researchers are concerned with the nature of inequality and work towards the empowerment of those who are oppressed. They seek to understand people's subjective feelings and experiences as well as the material world and power relationships within it, and hope to use their research to change oppression.

Critical social research is a framework that might have had some influence on the research design, because this project seeks to influence and change people's perceptions in a moral and political sense. However, it appears to be topdown rather than bottomup. Control lies in the hands of the researcher, in the research design and in how the voices are presented. When critical social research is contrasted with participatory forms of inquiry, both are found to share many common facets, but for the reasons discussed below the former is less appropriate than participatory inquiry approaches.

Researchers championing participatory approaches (Heron and Reason, 1997; Reason and Torbert, 2001) have a value base promoting democratic decision-making processes in which control in research is shared; although Participatory Action Research embraces a variety of approaches with different levels of involvement within this tradition (Minkler and Wallerstein, 2008a; Ledwith and Springett, 2010). Participatory research is often more bottomup than topdown compared to critical social research, which does not have the democratic basis for power and decision-making. This study seeks the active involvement of stakeholders from different backgrounds in the research process, although acknowledges that different levels of involvement are appropriate to different research projects (Staley et al, 2009; Faulkner, 2010). Like critical social research, research from the participatory framework should be practical and useful (Reason, 1994), with an underlying ethical and political imperative to utilise research to bring about change. This is demonstrated in this study. Philosophically, participatory researchers believe that knowledge grounded in experiential collective meaning-making can lead to greater validity in research processes. This research is underpinned by a

commitment to expertise-by-experience and expertise-by-caring which influences the study's theory development (described later in this chapter).

The postmodern constructivist and participatory framework were considered the most appropriate to underpin the research design because the research sought:

- to present the voices of participants and develop a co-constructed reality through their involvement in the research process
- to acknowledge the researcher's voice and identity
- to build upon a democratic process where decision-making power is shared
- to gain validity from participatory forms of mutual meaning-making
- to enable desired change in the research participants.

5.3 The methodology

The methodology selected was Participatory Action Research (PAR). PAR has emanated from different traditions: the *northern tradition* and the *southern tradition* (Wallerstein and Duran, 2008, Minkler and Wallerstein, 2008a). The former, from the British and North American practice of action research, based on the work of Kurt Lewin (1946), emphasises the managerial processes of action research in organisational change. The latter, developed since the 1970s, has its roots in the political PAR that originated in liberation theology and community development with oppressed and undereducated populations in Africa, Asia and Latin America (Hall, Gillette and Tandon, 1982). It is represented in the work of Paolo Freire in Brazil (Freire, 1970), who writes (p. 38): 'One objective of PAR, then, is to create knowledge rooted in the lives and perspectives and experiences of ordinary people and directed towards social change. Thus, PAR emphasises investigation, education, and political action'.

Freire emphasises the political nature of research and the importance of education as a political process. The use of PAR in user-led health and social care research in the UK embraces elements of both the northern and southern traditions, as discussed in the next section.

PAR utilises the action research cycle, which is '...a process which alternates continuously between inquiry and action, between practice and innovative thinking – a developmental spiral of practical decision-making and evaluation reflection'. (Winter and Munn-Giddings (2001, p. 5). It is both 'reflective practice and practice-based

research' (ibid, p. 5), and is often employed by health and social care researchers to conduct effective work-based inquiry. This process of close reflection on and revision of one's own place in the research or practice situation is known as reflexivity, which consists of continually and critically evaluating one's own professional and personal values to generate improvement in the practice situation through reflection (see section 5.5.). It contributes to the generation of theory through the action research cycle, as shown in Figure 1, below. The formative research model means that any improvements detected through the action research cycle can be implemented immediately and subsequently evaluated.

Figure 2: The Action Research Cycle (Kemmis and Mc Taggart, 1988)

Ledwith and Springett (2010) emphasise the transformative nature of PAR as a political tool for change that uses education to challenge structures of oppression. It melds education, emancipation and change in a single process. The authors (ibid, p. 209) present a transformative model for participatory practice that contains five equals and opposites that work together to bring about change: ontology and epistemology; action and reflection; collective and self; local and global; inner and outer consciousness. This model shows how individual action, reflection and learning can generate collective consciousness which may lead to transformative change in social and political systems. This relates closely to the connection that Ledwith and Springett (ibid) posit between participatory epistemology and participatory ontology.

Although PAR is presented as a model to promote transformative action (ibid), McIntyre (2008) reminds us that its strengths are in its ability to change and respond to situations:

> 'As with other forms of research, there are ambiguities, complications and unexpected challenges. Yet those challenges do not derail the PAR process. Rather they can be used to reconstitute how we 'do research'. As a result of the reconstitution, practitioners of PAR can provide opportunities for participants to strengthen their awareness about their individual and collective skills, resources and abilities to build communities of inquiry and change'. (ibid, p. xvii)

Its nature as a research methodology that embraces formative process as well as summative outcomes is central to its effective implementation.

5.4 The tradition of PAR in user-led participatory inquiry

PAR has been adopted to support participatory forms of inquiry in health and social care research. This reflects its roots in empowerment work, developed by feminist researchers and those of colour (bell hooks, 1989; Collins, 2000; Maguire, 2006). It began to be utilised in this tradition when service users and carers became more involved in service evaluation and service development in the 1990s (DH, 1990), reflecting the philosophical shift enabling them to participate in planning their own care.

Early examples of participatory inquiry that included the voices of users in research and evaluation include Beeforth, Conlan, and Graley (1994) and Carpenter and Sbraini (1997). The former involved service users in its design and execution, and part of its focus was to '[redefine] users as thinking and reflecting people who are partners in the process of care'. (ibid, p. 3). The latter research involved users and carers acting as collaborators, research interviewers and members of the project advisory group. Increasingly service users and carers want their voices to be heard in research that evaluates and monitored the services that they use (Rose, 2001; Ramon, 2003).

Service users and carers have a strong emotional investment in the process of participatory research (Slade et al, 2010; Faulkner 2010) and often have a real commitment to making change happen (Faulkner 2010). While the involvement of service users in research is increasing (Staley, 2009; Faulkner, 2010), carers have long been under-involved as full members of the research team (Repper et al, 2008a; MHRN, 2012a; 2012b; SRN, 2009). MHRN (2012a, p. 24) advocates:

> 'The involvement of carers in research is not only necessary in terms of democracy and current mental health policy; it is also of real value. It has the potential to contribute to a culture in mental health where carers are respected, included and valued as a key stakeholder within the mental health system. Through research the profile of carers can be raised by having more research focussed on carers, prioritised by carers, informed by carers, as well as some being led by carers'.

Carers are often closely involved with the service user's life and can understand their needs therefore they can make an important contribution to mental health research by providing perspectives on its acceptability and accessibility, analysing and interpreting data, and advising on processes of dissemination to ensure that the results reach the widest audience (MHRN, 2012b). Carers often also bring to the table other expertise

beyond caring, (MHRN, 2012b; Uhm et al, 2012), but it is important to ensure that their views do not replace those of service users and are incorporated alongside them.

Participatory inquiry seeks its validation from expertise-by-experience. Indeed, in participatory inquiry the methods used and the presentation of the data may be subordinate to a process that seeks to empower and enable the research participants through the development of new skills (Ramon, 2003). This reflects the political and moral imperative within the participatory framework to bring about change and learning. In my thesis the nature of this topic and the use of PAR are complimentary aspects that contribute to the development of the research, and the service users and carers felt comfortable with the paradigm and contributed happily to its development.

However, user participation in research is still in its infancy (Hulatt and Lowes, 2005) and many practical, ethical, moral, methodological and philosophical questions remain unanswered (Nolan et al, 2007); there is still debate about what constitutes good user-led/user-controlled research (Beresford 2009). Glasby and Beresford (2006) focus on the validity of user knowledge. They look at the current demand for evidence-based practice in health and social care research and argue that evidence-based research needs to include, but should not be placed above, the learned knowledge of practitioners and the knowledge of service users. They believe that service user and professional knowledge can be just as valid as academic research dominated by belief in the physical sciences and the medical approach, as discussed in the literature review. This presents a tradition where a political and moral imperative to change conditions supersedes ontological and methodological concerns, challenging assumptions in traditional research designs about the hierarchy of evidence and knowledge.

5.5 The role of reflection and identity in PAR

PAR has a political ideology which values collaborative democratic processes of learning that are empowering and developmental for all research participants, and is facilitated in an environment of partnership and mutual respect (Winter and Munn-Giddings, 2001; Minkler and Wallerstein, 2008a). Similarly the PAR tradition in user-led research values the service user identity in research (Nicholls, 2001; Fox, 2007; Fox and Ockwell, 2010; Fox, 2012) and explores the impact of identity on reflection and learning. This section addresses the role of reflection and identity in this study.

My dual identity as service user and researcher added layers of reflection and experience to this research (Fox, 2007; Fox and Ockwell, 2010). Nicholls (2001), who acknowledges her own involvement as a user researcher in researching the Strategies for Living project with other service users, relates how her own identity and values changed and responded to the research process. My identity authenticated, validated and enhanced the research process and informed all stages of the research.

I captured my thoughts throughout the research period by reflecting on the research projects in which I was engaged. This reflection informed and developed my thinking about recovery and influenced the development of research presented at conferences and in articles (Fox, 2007; 2008; 2009; Videmsek and Fox, 2009; Slade et al, 2010; Fox and Ramon, 2011; Fox, 2011a; 2011b; 2012). This documented my thought processes throughout the PhD journey.

Reflection can enhance, develop and clarify understanding, but it needs to be grounded in rigour, in research data and in collective understanding or it runs the risk of being one person's crusade based on unsubstantiated and loose associations. The views of the different participants fed into the development of findings generated from the research.

In this and the previous section I have described the choice of PAR as the methodology, drawing out the key elements that define its suitability for this study. In summary, PAR was suitable for the research design as it has a value base that acknowledges:
- the centrality of those with direct experience participating in the process from a desire to improve service provision (Winter and Munn-Giddings, 2001; Minkler and Wallerstein, 2008a)
- the need to engage all stakeholders in the process (Winter and Munn-Giddings, 2001; Minkler and Wallerstein, 2008a; MHRN, 2012)
- the inequality of the power relationships between researcher and participants (Ramon, 2003)
- the need to include and recognise the identities, values, and experiences which both the researcher and the co-participants bring to the process (Nicholls, 2001; Rhodes et al, 2002; Uhm et al, 2012)
- the need to value the research process itself (Nicholls, 2001)
- the status and sense of achievement that a research process confers on is co-researchers (Ramon, 2003; Rhodes et al, 2002; Uhm et al, 2012).

5.6 The research design

The research design comprised a preliminary data collection process to evaluate carers'
attitudes to recovery, followed by a training programme to teach carers about recovery
and explore their reactions to it. Both the research process and the outcomes were
evaluated. Follow-up contact at intervals following the training programme assessed
whether changes were sustained. The research design involved the elements presented
below. The research designed in depicted in Figure 3 below.

Figure 3: Graphical representation of project milestones and data collection

A steering group of experts made up of carers, service users and professionals was asked to contribute to the planned design and implementation of the research project.[39] I reviewed the initial outline of the training programme in the group. They participated in the design of the training, the design of the pre- and post-training evaluations and analysis of the data. This process enabled their input into the development of the research without placing too many demands on their limited time.

Initial individual written responses were collected and a focus group discussion was held with carer participants before the training programme, to explore what they already knew about recovery and what they hoped to gain from participating in the study. A vignette of a hypothetical person with schizophrenia and their carer was used as a prompt to generate individual written responses from each participant about the nature of caring and recovery. The responses were then discussed in the focus group. This data was compared with data collected during and following the training programme.

The training programme was delivered to the group of carers at Anglia Ruskin University, Cambridge in five sessions from 6:30 to 9:00 pm held over a three-month period from April 2009 – July 2009. Sessions focused on personal, practical and policy aspects of recovery. The training utilised paired work, teaching sessions and group and individual discussion sessions. There was time in the sessions to discuss reactions to the new knowledge and how it affected participants' attitudes to caring (see section 5.8).

Follow-up individual written responses and a focus group meeting were held with all participants. The same vignette used at the first data collection point was again used as a prompt to generate written responses and focus group discussion. The follow-up focus group was facilitated by two members of the steering group who had been involved in designing and developing the training programme, but not in delivering the training.

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39 At points in the methodology and beyond, the pronoun 'we' replaces 'I'. This change in terminology reflects moments when the steering group contributed to developing the thought processes of the research and the programme. 'We' is also used to refer to both R2 (the carer trainer) and me when we delivered the training programme. The constituents of 'we' in either case above are clear when read in context.

This session evaluated the content and usefulness of the training, how the participants' awareness of recovery changed and whether it had affected their caring relationships.

Follow-up contacts were made at one and six months by me via telephone using a semi-structured interview to evaluate whether previously-identified changes in carers' attitudes had been sustained.

The PAR model ensured that the research design built on the expertise of stakeholders yet used a framework that empowered all participants in the process. It encouraged the participants to increase their learning through the action research cycle and sought an important part of its validation in the expertise of carers as collaborators in the research process

The steering group

Steering group members were recruited via purposive and snowball sampling, as specific participants were needed to fill particular roles in the research programme. Practitioners, managers, researchers and stakeholders were recruited[40] to collaborate in a group that included people with either commitment to recovery practice or expertise by experience, caring or research. A mixture of expertise available from different perspectives can facilitate discussion and inform decision-making, while the involvement of service users and carers can help to elucidate patients' ideas, facilitate patients' discussion and aid decision-making (Uhm et al, 2012). (See Chapter 8 section 8.2 for further discussion).

Terms of reference were agreed at the first meeting[41] and notes of each meeting produced to record decisions and agreed changes to the training programme and research tools. (See 265). Meetings were recorded with permission and transcribed verbatim. Transcripts were circulated, but no changes were ever made, although amendments were made to the minutes on several occasions.

The steering group members were involved in the presentation of the initial findings of the research. I co-presented a poster with R2 at the Involve conference in 2008 (Fox and

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40 See Appendix 25

41 See Appendix 26

Smith, 2008) which had been reviewed by the steering group. Initial findings were presented at the local mental health conference in June 2009 with R2.[42] The service user KI and the carer R2 were paid for their participation in the steering group and their travelling expenses from Cambridge and Peterborough NHS Foundation Trust.

5.7 Data collection methods

The following data collection methods were used:

- Preliminary quantitative data about carers' demography and caring situation collected through an initial questionnaire with closed and open questions to support and supplement the qualitative data collection

- Individuals' written responses to open questions about their perceptions of their caring situation, and their responses to a vignette

- Carer focus group held to establish an initial assessment of their understanding of recovery, based on the use of a vignette

- Data collected from discussions and responses during the training sessions

- Written responses to open follow-up questions about the participants perception of their caring situation and their reactions to a vignette

- Follow-up focus group with carers to evaluate the training programme and ascertain whether their views on recovery had changed after the training

- Follow-up semi-structured telephone interviews with carers one and six months after the end of the training programme to evaluate any sustained changes in their attitudes or behaviour following the training programme

- Secondary data from policy documents, service-user and carer narratives and articles to support the research findings.

The evaluation of the training programme was a focal point of the research therefore data were collected through conversations and reflections at the end of each session and at each data collection point following the delivery.

I collected mainly qualitative data, with supplementary quantitative demographic data. Qualitative data allow information to be gathered about the *nature of the experience of recovery* rather than *survey-based data*, which provide trends in the general population. The data type offered an in-depth exploration of carers' experiences of recovery, which

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42 See Appendix 11

was the focus of our topic. The type of data collected was appropriate to the size of the sample and aims of the study, whereas using quantitative processes would have provided more general data that would not have captured the individual experiences of carers.

Data were collected on two levels: first on an *individual* level, and second at a *collective group* level. Data were collected on the individual level using a number of methods. To establish a point of comparison, at the first meeting carers were asked to respond in writing to open questions about their knowledge of recovery and how it related to their caring situation (Q1),[43] to fill in a questionnaire with open and closed questions to capture socio-demographic data and data about their caring situation (Q2),[44] and to respond in writing to three questions about a vignette (Q3),[45] Q1 and Q3 were presented to carers both before and after the training programme to identify changes in their knowledge, attitudes and caring behaviour following the training programme.

Hughes (1998, p. 381) has described vignettes as 'stories about individuals and situations, which make reference to important points in the study of perceptions, beliefs and attitudes.' They allow participants 'to respond to these studies with what they would do in a particular situation or how they think a third person would respond' (ibid, p.381), providing participants with the opportunity to highlight issues 'from a non-personal and therefore less threatening perspective' (ibid, p.383). The open questions accompanying the vignette served to enable respondents to both explore their own reality and to consider how they thought the characters in the vignette ought to act – which is a strength of vignette techniques (Schoenberg and Ravdal, 2000; Hughes and Huby, 2004). The vignettes and accompanying questions were designed with feedback from the steering group to improve their credibility (Schoenberg and Ravdal, 2000).[46] Schoenberg and Ravdal (2000) note that the story-telling aspect of the technique may make respondents more relaxed thus reducing the burden and pressure of the interview –

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43 See Appendix 28

44 See Appendix 29

45 See Appendix 30

46 The development of the vignettes by the steering group is described in section 8.2.1.

an important aspect as this programme had a high burden of data collection on participants.

Focus group discussion was used to explore change at a group level. The discussions centred on the same questions and the vignette to which they had responded earlier in Q3.[47] Focus groups were particularly useful for eliciting the views of carers before and after the training programme as they create 'concentrated conversations' that might never occur in the real world (Morgan 1998 p. 31) through 'a process of *sharing and comparing* among the participants' (p. 12). The beauty of this process is that the participants explored and discovered issues for me as the researcher, and in doing so also generated their own interpretations of the topics under consideration (Morgan 1998). This is particularly appropriate to the constructivist framework of the research design.

Another focus group was held at the final meeting[48] facilitated by two members of the steering group who had not been involved in delivering the training programme. This enabled the carers to reflect on the training programme honestly and openly but ensured that the facilitators were familiar with its content.

Telephone interviews were used for the follow-ups at one and six months to enable carers to report any sustained changes following the training period. The telephone interviews were semi-structured, with mainly open questions. The research interview is particularly appropriate as an interpersonal situation in which two partners share a dialogue about a theme of mutual interest to generate knowledge (Kvale, 1996). The themes that emerged were further triangulated with data from the focus groups and written responses. [49]

Telephone interviews were appropriate because visiting all the carer participants at their homes at the two follow-up contact points would have placed too many demands on me

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47 See focus group agenda in Appendix 31

48 See Appendix 32 for follow up focus group schedule.

49 See Appendix 33 for the follow-up semi-structured interview schedules at one month and Appendix 34 for the schedule for the six months follow-up.

as a sole researcher because the participants were spread across East Anglia; it would also have placed too many demands on busy carers, who worked and had family and caring responsibilities, to come to Anglia Ruskin University. We agreed on this approach used because it was my PhD study and I knew the participants, it was also expedient because of my limited funding, although a study with more funding might have utilised a different team to evaluate the research to increase the independence of the evaluation.

5.8 The training programme

Before the carers attended the programme we gave detailed consideration to group guidelines [50] and how we would encourage and support people participating in the group without letting them dominate proceedings or take over discussions. The training package was initially reviewed within the steering group and then evaluated and amended following discussion among the group.[51] The five sessions were delivered over a three-month period to give the group time to respond to material between sessions. Time was allowed for carers to discuss material from the previous session and how it had influenced their thinking. Sessions were supplemented by information on handouts.

The training sessions

The training sessions were held in the evenings at Anglia Ruskin University. The rooms used were comfortable, had access and parking for people with disabilities and good transport links. With hindsight, we (the steering group) questioned whether the venue might only attract carers who were educated and used to a university environment. Would holding it in a community hall attract another kind of participant? We concluded that the most essential elements of an inviting environment are warmth, the availability of refreshments, comfort, accessibility and a well-kept appearance.

CPFT agreed to fund travelling expenses for carers' living in the trust area to attend the programme. The local East Anglia Mental Health Research Network (MHRN) hub was approached to fund expenses for carers travelling out of county, and agreed to meet this

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50 See Appendix 35

51 The content of the training sessions is set out in Appendix 36.

cost. East Anglia MHRN also funded the production and printing of the books for the training programme, with additional books printed for members of the steering group.

<u>5.9 Sampling aims and recruitment strategies</u>

Purposive sampling using maximal variation (Flick, 2006) was intended to recruit an optimum number of 13-15 carers to the research project following consideration of other strategies. Purposive sampling proceeds 'according to the relevance of cases instead of their representativeness' (Flick, 2009, p 121) and emphasises the need to incorporate both typical and extreme or deviant cases. This sampling method requires extensive variation among a small number of participants. Morse (1998, p. 73) suggests the use of 'good informants', who are knowledgeable, articulate and able to fulfil the criteria essential for participating effectively, as key to effective sampling techniques. The recruitment strategies were linked to the sampling aims as I aimed to recruit carers from a range of backgrounds and in a range of ways to achieve diversity because family members (including partners, parents, siblings, neighbours, and friends) respond in a different way to the person that s/he cares for and cultural backgrounds impact on experiences of caring.

The steering group was instrumental in recruiting carers to the training programme. They contributed to development of the leaflet advertising the training [52] and spent a lot of time and energy helping me to link up with appropriate networks and people who would recruit the participants. Professionals were asked to circulate information and approach carers who might be suitable participants. This is a well-used strategy (Rhodes et al, 2002); however, professionals may only refer people with a positive experience of services because they only approach cooperative and positive clients.

My contacts with voluntary agencies and CPFT were utilised (including carer support groups in the voluntary sector: the county's Rethink Support Groups and Crossroads for Carers, the voluntary organisation supporting mental health carers in the area). I sought to increase the diversity of the group by targeting carers from specific groups such as CPFT's Early Intervention Service, services with long-term service users, targeting BME groups and visiting carer support groups based in the lower socio-economic are in the north of the City. However the difficulties with recruitment meant that I didn't achieve

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52 See Appendix 37

the ideal sample that I set out to obtain. (The implications of this process are discussed in Chapter 8.5).

Information about the training programme and research project was circulated across the Eastern Region via the local MHRN hub as it was difficult to recruit carers in the initial sampling area within 15 miles of Cambridge city. This proved very fruitful.

Eleven carers from a number of different areas within and outside the immediate target zone were identified. Two carers came together from the same support group in Cambridge, recruited through information posted in the local city Rethink newsletter (F01, F02); five carers were referred by Rethink carer support workers in East Anglia (three through the Norfolk branch (F03 and M02, F04) and two through the Suffolk branch (F07 and M04); one carer in Essex (F06) received information about the programme from her son's mental health worker, one (F05) came through professionals in Cambridge, and two more (M03, M01), via the network of professionals contacted by JS and KE two members of the steering group. Six participants (M02 and F03 (married couple); M04 and F07 (married couple); F06, F04) travelled over a hundred miles to attend the group each week. Travelling expenses were offered.

The sample of eleven carers was composed of seven females (referred to as F0) and four men (referred to as M0). This sample size was large enough to enable in-depth qualitative exploration, and was a good size for effective delivery of the training programme. All participants were White-British apart from F04 who was White-Irish. The female carers' ages ranged from 51-years-old to 77-years-old (mean age of 63 ½ - years-old), and the male carers' ages ranged from 64-years-old to 78-years-old (mean age of 70 ¾ - years-old). Two sets of married couples (M04 and F07; M02 and F03) attended who were both supporting either a son or daughter with schizophrenia. All parents were married to a long term partner apart from M01 who was divorced; F04 lived in a civil partnership. Five of the seven female carers were educated to tertiary level; all male carers were educated to tertiary level.

Four of the eleven carers were now fully-retired (F01, F03, M02, M03) and of these, three had previously undertaken professional jobs (F01, M02, M03). Three carers were semi-retired: one older married couple ran their own business (M04 and F07) and one did consultancy work to supplement his income (M01). At the start of the programme,

of the rest of the carers one worked as a support and language teacher (F02); one worked as a private tutor (F05); one worked in administration (F06); one did voluntary work (F04).

All the carers were quite affluent and lived in owner-occupied houses; apart from F04 who rented accommodation with her partner. All except for one carer supported a son/daughter with schizophrenia; F04 was the only non-parent and supported her brother who lived in another UK province.

Most service users cared for by the participants in this study had been diagnosed with schizophrenia more than 5 years ago, F02's son had been diagnosed 3-5 years ago, and M04 and F07's daughter had been diagnosed 1-3 or 3-5 years ago (different period provided by both parents). The carers supported seven male service users aged 27-years-old to 44-years-old (mean age of 33 ½ - years-old) and two female service users aged 30-years-old and 46-years-old. All of the service users were White-British, except for F04's brother who was White-Irish. At the first data collection point, two of the male service users lived alone in social care housing (M03's son, M01's son) and one in accommodation provided by their parents (F03 and M02's son), three lived with their parents (F01's son, F02's son, F06's son), one lived in an inherited farm in another UK province (F04's brother). One of the female service users lived alone in accommodation provided by her parents (M04's and F07's daughter), and one lived in mental health service rehabilitation accommodation (F05's daughter). All the service users who were cared for were single.[53]

Most carers attended most sessions, but not all participated in all the sessions so some data are missing across the set.[54] In such a study it would be hard to ensure that each carer attended each session due to the nature of caring and people's difficult lives. I therefore decided to include the data from each carer who participated from the start of the programme to the end, for two reasons. First, this study explores the nature of

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53 Further details about the carers who participated in the programme are found in Appendix 38.

54 See Appendix 39 for a breakdown of the carers' attendance patterns.

recovery to carers as a whole not necessarily seeking to track change in each individual's life, so the inclusion of incomplete sets did not invalidate the data. Secondly, the formative nature of PAR, which emphasises participative learning and development, acknowledges the realities of human lives and situations; indeed, McIntyre's (2008) study using PAR notes that participation fluctuates and people participate in different ways to the best of their ability.

5.10 Data analysis

Thematic data analysis (Miles and Huberman, 1994; Braun and Clarke, 2006) was applied to the entire data corpus. It is a process that is widely used but there is little consensus as to what the method comprises or how it is done (Braun and Clarke, 2006). Braun and Clarke (2006, p. 79) describe thematic data analysis as 'a method for identifying, analysing and reporting patterns (themes) within data'.

Aronson (1994 p. 1) emphasises the importance of examining the whole data set and describes how the themes generated using this process 'form a comprehensive picture of the collective experience'. Braun and Clarke (2006, p. 82) note: 'A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set'. (ibid, p. 82)

Themes do not merely emerge from the data corpus during the process of analysis but are rather *discovered* by a researcher engaging in an active process of analysis.   The processes I used in this study were based on best practice examples (Miles and Huberman, 1994; Braun and Clarke, 2006) but also grew organically as I tried to manage the mass of data, as described below.

The training sessions, focus groups and semi-structured interviews were audio-taped and transcribed, with consent. The data were transcribed by me and anonymised immediately with all identifying information removed. I initially used NVivo to manage the whole dataset and break down the mass of information and Word to allow me to work with and transform the data by writing down my ideas as they emerged from the quotations.   I moved constantly between the two to ensure that the analysis was grounded in the data using inductive techniques to generate the general themes of the project. I then took each data set associated with each contact point (e.g. all data from written evaluations) and, using NVivo, sorted the data more carefully into categories and sub-categories. I

constantly interrogated the data in an iterative process, moving between the codes and the data to ensure that the categories were commensurate with the whole. As I generated the themes, 'sensitizing concepts'[55] (Blumer, 1954) that had emerged during the literature review and research process informed the development of categories and confirmed the relevance of emerging theories. Descriptive documents containing direct quotations were prepared in Word to help manage the analytic process and sort the categories. Finally a draft was prepared, which allowed me to move from identifying ideographic (focusing on describing individual situations) to nomographic analysis (focusing on the overall experiences of the group as a whole).

Coffey and Atkinson (1996) describe two differing approaches to data analysis: first as a 'coding and retrieving procedure' based on strict analytical procedures (ibid, p. 29); and secondly as a looser process of expanding, transforming and reconceptualising data to allow themes to emerge in the 'imaginative reconstruction of social worlds' (ibid, p. 7). Miles and Huberman (1994) and Dey (1998) advocate that the former is more effective than the latter particularly when supported by computer processes that manage data organisation; whereas advocates of more participatory research emphasise the latter as they embrace the importance of personal reflection in the research process (McIntyre, 2008). I used elements from both approaches by using Nvivo and Word to ensure the effectiveness of the analytic process; indeed (Braun and Clarke, 2006, p. 86) note:

> 'Analysis involves a constant moving back and forward between the entire data set, the coded extracts of data that you are analysing, and the analysis of the data that you are producing. Writing is an integral part of analysis, not something that takes place at the end, as it does with statistical analyses'.

In the PhD research and beyond, I occupy multiple identities pertinent to both the data collection and the data analysis processes which influence the ways I facilitated the training programme, collected the data and interacted with the carers during the training programme and follow-up interviews. My own experience as a service user influenced my understanding and presentation of the recovery concept (Fox, 2007; 2013), therefore reflexivity was important in helping me to consider the influences that led to the development of themes. These identities contributed both benefits and barriers to the

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55 This is a process of extensive reading to ascertain from the evidence base what are the important themes that emerge from the literature that relate to the study.

effectiveness of the data collection and analysis but the ability to be open about my own identity and experience is one of the features which attracted me to the PAR methodology.

5.10.1 Strategies to enhance validity

Underpinning processes were employed to enhance the rigour of the data analysis (Silverman, 2005):

- Refutability principle: I tried to disconfirm themes in the data until it became clear that the assumed relationships between phenomena could not be refuted.

- The constant comparative method required me to compare newly collected data with all the fragments of data in this study to ensure the stability of the theories, and to confirm the validity of the theories generated in this study by comparison with data from previous studies.

- The comprehensive data treatment required me to analyse the data as a whole and develop themes that related to the whole study and not just selected examples.

- Deviant case analysis ensured that I compared the provisional themes generated through small batches of the data with the rest of the data, looking for negative or discrepant cases until I derived a set of themes that incorporated the whole dataset

Triangulation increased the validity of the data. Denzin (1970) identifies different forms of triangulation:

- Data triangulation – involves the triangulation of different data from the different methods

- Investigator triangulation – different observers or interviewers are included, to triangulate the different views

- Theory triangulation – approaching the data with multiple perspectives and hypotheses in mind.

The processes outlined above were utilised in the following ways: the different forms of data (from focus groups, steering group meetings, questionnaires, semi-structured interviews, recordings from the training group sessions) that were collected were triangulated. The carer participants, steering group and supervisory team contributed to this process of investigator triangulation.   The data were approached from many different perspectives before final conclusions were drawn (theory triangulation).

Both the themes and the full transcripts were made available for the participants to check. This technique, communicative validation, is used to validate data and enhance the quality of data analysis. Often full transcripts (as used in Onken et al, 2002) given to research participants can afford further insight by enabling them to put statements they made into context or clarify issues. (This is discussed in more detail in Chapter 8). In action research with service users, it is anecdotally reported that most service users find reading the scripts daunting and can be distressed to read what they had said or even concerned at how they had talked. As decided by the carers themselves, we provided full access to the transcript and provided brief summary notes.

Using PAR, the research participants and steering group members were encouraged to participate in the data analysis through feedback. The carers' feedback was sought during a training session after the initial analysis of the research data that formed part of the content of a presentation to the local mental health trust recovery conference to which the carer trainer and I were invited.[56] The carers reminded me that caring can be positive and rewarding when the cared for person shows improvement, whereas the content of my presentation only reflected the negativity of carer burden. MHRN (2012b p. 2) underlines the importance of involving carers in the data analysis process with their unique perspective:

> 'Involving carers in interpreting and making sense of research findings can provide novel insights that help researchers develop their understanding and provide recommendations for practice that move beyond the academic and routine'.

The carer trainer (R2) was asked to provide feedback on the content of the findings chapter along with JS, a steering group member.

5.11 Ethical issues

I obtained permission from the Anglia Ruskin University Ethics Committee to undertake the research (01.11.2008) and from Cambridge and Peterborough Mental Health Foundation Trust Research Services to undertake a service evaluation (20.03.2009). The process of seeking ethical approval required me to assess potential risks to the

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56 See Appendix 11.

participants and researchers and identify methods to mitigate any such harm. I address the participants' issues first and then those of the researchers.

5.11.1 Ethical issues for participants

There was a potential risk for some carers that participation in the research could lead to their reliving bad memories or other potentially negative emotions. Moreover, learning about the recovery approach, with its emphasis on hope and optimism, could be distressing and disturbing as they explored their own sense of loss as a result of the mental ill-health in the life of their relative (Jones, 2002). In order to mitigate this risk I offered support:

- After each meeting I remained behind for 30 minutes with the carer co-trainer and we were both available for individual debriefing.

- I made my work phone number available to the carers for the duration of the research process.

From the start of the research I contacted a voluntary-sector organisation that supports carers in the locality of the Foundation Trust. The manager of the service participated in the research steering group (QN) and agreed that the organisation would provide additional support from a named worker should the carers require independent advice. The carers were also provided with national independent advice and support phone lines from which they could seek assistance. The carers did not to my knowledge make use of these additional forms of support.

The training programme was designed to provide sufficient time for the carers to share their thoughts and feelings and explore the meaning of recovery in their lives. This however entailed their sharing personal and potentially upsetting experiences with their peers. To ensure their safety in the training sessions, the steering group developed initial group guidelines to ensure that the carers understood the need for mutual respect and for keeping personal information confidential.[57] The guidelines were shared with the carers at an initial individual face-to-face meeting (described below) and reinforced on different occasions during the group training sessions. Finally the evaluation process that followed the training package provided additional opportunities for them to debrief.

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57 See Appendix 35.

I had individual face-to-face meetings at Anglia Ruskin University with half of the carers before they joined the programme and telephone interviews with the six who lived far from the university or joined the programme late. This ensured that the applicants were informed about the project, able to give their informed consent to participate, and their questions were answered before being accepted on the training programme. They were given an information sheet detailing their involvement in the project including details of the requested consent,[58] and were asked to sign the consent form stating that they had received the information sheet and consented to be involved in the training programme and research. Both I and the research participants retained a signed copy of the consent form. They were informed that they could withdraw from the training programme or research process at any time without affecting any service they might expect to receive from the mental health trust, and assured that all information would be kept confidential and would be anonymised immediately on writing it up. All members were reminded of the need to maintain confidentiality on issues discussed within the group. I ensured that the process was governed by ethical procedures and that my research complied with the Mental Capacity Act (H.M. Govt, 2005) and the Data Protection Act (H.M. Govt, 1998).

The Mental Capacity Act

I ensured that this study research only involved carers who had mental capacity[59] and were able to give informed consent:

- by interviewing each participant prior to asking for their consent
- by giving each participant full information about the programme before they agreed to participate.

No-one under the age of 18 participated, as this research focused on understanding the experiences of adult carers.

The Data Protection Act

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58 See Appendix 40

59 See Appendix 41

The research complied with the Data Protection Act (DPA, 1998), which gives individuals the right to know what information is held about them and provides a framework to ensure that personal information is handled properly.[60]

The Data Protection Act also clarifies individuals' important rights including the right to know what personal information about them is held on computer and most paper records. In line with the Act (ibid), I got permission from each participant to hold the information that they provided. All electronic and paper documents were held securely in compliance with the Ethics Committee regulation and anonymised immediately at the point of transcription. Audio-taped information, computer records and paper documentation will be destroyed five years from research completion.

5.11.2 Ethics for the researchers

The steering group contributed to the research design and the development of the training programme. We had to ensure that we respected each other's opinions by listening to what each member had to say without interruption. At the first steering group meeting we agreed on ground rules that set out the expectations of our behaviour.

PAR promotes the involvement of service users and carers in research processes and legitimises the validity of user knowledge (Glasby and Beresford, 2006). However, participation in research by people with lived experience of disability and caring can come at a high personal cost as it may cause them to relive bad memories or experience negative stress (Fox, 2011). Within the steering group there were people who were experts-by-experience and/or experts-by-caring, including myself. There was a potential risk that both mine and others people's lived / caring experiences (R2 and KI) would be negatively affected by sharing our experiences or being reminded of painful memories. For example, at one steering group meeting the co-trainer, R2, an expert-by-caring, reported that that many carers become hopeless about their relative's future because they have been exposed to constant negativity from practitioners. She agonised about whether she had conveyed enough hope to her son when he had first become unwell. She admitted how much this discussion was affecting her equilibrium and undermining her confidence:

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60 See Appendix 42

> And you see some of it does touch me, because I'm a carer… And I'm trying to be objective, but also trying to tell you it's gone right through to me, because some of your things, do you know… right through, really quickly. If that's happening to me, it'll happen really quickly to the other carers. (SG7R2)

This served to remind us again how emotionally-charged the programme could be for the carer participants and also that it was essential for the steering group members to support each other.

As the research progressed and R2 and I facilitated the training, we developed a bond of mutual support that sustained us when carers challenged us during the sessions. I often became anxious after we had delivered a session, overanalysing and re-experiencing their success or failure, and R2's positive encouragement helped me to recover my equilibrium. We also both had access to additional support mechanisms: as a PhD student I had access to the university counselling services or could talk directly to my supervisors, and R2 had access to support from the voluntary sector organisation that was also available to provide assistance to programme participants.

The meetings took place at Anglia Ruskin University from 6:30 pm to 9:00 pm. Although this was after the university closed for the evening, security staff were present on site and the carer co-trainer, R2, and I travelled back home together. This ensured that our physical safety was not compromised.

5.12 Conclusion

This chapter has described the philosophical assumptions underpinning the research which led to the choice of methodology and influenced the development of the research design. It has described the role of the steering group in reviewing the training programme and developing the research tools and the implementation of the research from sampling and recruitment processes, to data collection methods, data analysis processes, highlighting the ethical issues underpinning this research. It has highlighted the role of reflection and the importance of participation in the research process. Throughout the discussion the link has been maintained between the philosophical underpinnings of the study and the practical implementation of the research, as is key to a PhD study; both aspects inform the effective development, operation, and implementation of the research process and the analysis of the data, the development of the findings, discussion of their wider significance and the dissemination of the research.

The next chapter, highlighting the central research findings, uses rich thick description in the carers' own words to report the results of the training programme and evaluation as the research questions are addressed.

Chapter 6. The research findings

6.0 Introduction

This chapter presents the findings by addressing the research questions set out at the start of the study:

- How do carers define recovery?
- Do carers believe recovery is possible?
- How do carers describe their role in recovery?
- Do their views on recovery change as a result of the training programme?
- Does their behaviour change as a result of the training programme?
- What do carers see as the major obstacles and opportunities in recovery?
- Do they evaluate the training package as helpful in enabling them to explore these issues?

The chapter explores these issues by focusing on three aspects of the study:
- the steering group's contribution to the development of theory about the nature of caring and recovery (6.1)
- the key findings about the carers' understanding of recovery and its impact on their attitudes and behaviour (6.2)
- the evaluation of the training programme and its effectiveness in teaching carers about recovery (6.3).

The research process and the findings are described throughout, because in PAR both the formative process and the summative outcome are important (Winter and Munn-Giddings, 2001). The research questions are addressed throughout and interweaved in the presentation of the findings.[61]

6.1 The contribution of the steering group to initial theory generation

The steering group consisted of seven experts from different backgrounds, experts in: managing caring support (QN), developing and delivering recovery services (KE), expertise-by-experience (KI) and expertise-by-caring (R2), research (JS) and mental health practice (QH)[62] including me (R1) as principle investigator and facilitator. The

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61 The reference list that provides the key to the source of the quotation is found in Appendix 43

62 The membership of the group is described in more detail in Appendix 25.

steering group participated in the development of the training programme and the design and implementation of the research, in accordance with PAR. We held eight steering group meetings at six-weekly intervals from February 2008 to February 2009 and a review meeting in November 2009 to allow me to feed back the initial results of the data analysis to the steering group.[63] Data were collected from the transcripts and meeting notes.

In this chapter the steering group's contribution to the development of initial theory about the nature of the caring identity, the content of the caring role, and the connections between caring and recovery is considered alongside their influence on the development of the training programme; later in Chapter 8, 8.1 - 8.3, the steering group's development of the methodology and evaluation tools is discussed in more detail.

The definition what a 'carer' is was revisited many times during the lifetime of the steering group. Discussion was wide-ranging drawing on the group's prior experiences of considering these issues in their research and practice as they helped to develop initial theory in this study. Members identified how service providers use the term 'carer' to give people different labels so they can be assessed for their eligibility for services (SG1JS),[64] legitimatising the terminology and giving it a technical and quantifiable meaning. They noted that many people are confused about the difference between the 'informal carer' and the 'paid care worker' (SG1JS). The term 'carer' is often used to describe the care worker who is employed and paid to assist people at home or in other settings rather than the informal carer who voluntarily supports a relative or friend

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63 See Appendix 44 for meeting dates and attendance patterns.

64 This identification as a carer is particularly important when seeking to qualify as providers of regular and substantial care, as designated under the NSF for Mental Health Standard 6 which makes them eligible for services. Some services require carers to offer unpaid support to their family member for a specific amount of time in order to qualify as a carer with the right to access services, and some authorities have decided, for example, that a person must care for a service user for more than 25 hours per week to be acknowledged as a 'carer'.

without pay. QH reflected on how individual 'family carers' were reluctant to identify themselves as such:

> ... I think that is where the debate starts. I am not a carer. I am a partner, relative, mum and dad. I don't know again how it is resolved because there are so many views that people have… (SG1QH)

At the second meeting of the steering group the members piloted an exercise that was intended to explore the nature of the caring role and identity;[65] furthermore this helped us to consider how to approach this topic with sensitivity in the training programme. The members were asked to write down and then read out three words that they associated with the word 'carer':

> KE
> Off the top of my head, someone who has concern for another which may or may not involve practical or emotional support.
>
> QH
> Oh no, I don't know if this will work. But illness, time, help.
>
> JS
> The definition of the carer: I thought about emotional needs and dependency.[66]
>
> QH
> I put helper, supporter and friend. (SG2)

Three different ideas associated with the word 'carer' were identified from this exercise:
-   the tasks and role that a carer undertakes that contribute to their caring identity (helper, supporter, friend)
-   the carer's relationship with and emotional tie to the person they care for (emotional needs and dependency)
-   the carer's perception that the cared-for person needs regular and on-going support (practical or emotional support, illness, help, dependency).

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65 Most of the exercises intended for the training programme were piloted within the steering group to assess their suitability for generating discussion in the training sessions.

66 JS went on to explain that carers support the service user's emotional needs but can sometimes over-care, leading to their dependency.

These elements fit into three categories: an exploration of the nature of caring, an identification of the content of caring tasks, and a definition of the boundaries of different types of care. A consideration of these elements underpins much existing research about the nature of caring (Brown, Birley and Wing, 1972; Pernice-Duca, 2010); and moreover this discussion was central to the development of the training programme. For example this research highlighted the importance of discussion about what tasks carers undertook to support recovery, how care could be *protective by over-caring* based on perceptions of the service user's dependency, and how care could be *supportive through enabling* based on fostering agency and self determination in the service user.

After undertaking the first written exercise described above, the group members were asked to write down their definition of 'recovery' and read it out – this was another exercise I proposed to use with the carers in the training programme.[67]

The group held a common view of recovery based on a personal recovery model. QH drew on her own life experience as well as her professional involvement in mental health services. This response was very unusual, because the tensions between maintaining professional and personal boundaries often prevent the practitioner from empathising with the service user, yet QH, a team manager of a community mental health team, acknowledged how she herself identified with the journey of recovery. Similarly anecdotally it is reported that carers find it hard to relate the concept of recovery to their own lives - perhaps because they believe it identifies them more closely with mental ill health in their family member which is the object of stigmatisation.

I was concerned about presenting the recovery concept to carers on the training programme: how could I avoid undervaluing the suffering of service users and carers while conveying the value of hope and optimism? This discussion illuminated issues inherent in the research questions about the tensions endemic in the nature of recovery and the process of caring. QH suggested the most important elements in which we could convey the value of recovery to carers at the second meeting:

> It's about support and discussion. You can't just teach somebody... Again this is a process the carer has to go through. So it's not just about being unwell, but

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67 See Appendix 45.

adapting to that grief process, their loss process, their sense of loss. And go through all the stages of that before they are able to get into recovery. (SG2QH)

The carers would only be able to process and synthesise this understanding by themselves.

There were many barriers that made learning about recovery difficult. JS recognised that it is very hard for carers to understand or believe in recovery if they feel they cannot 'contribute' to the service user's recovery (SG2JS). They feel helpless if they are excluded from their family member's life or not given information that might help them to provide support. QN recognised how difficult it is for carers to let go of the adult child who has suffered from schizophrenia, whereas recovery requires the parent to let go and foster greater independence (SG2QN). This element of recovery required us to teach parents about a different way of caring: to offer care in a way that promoted agency, independence and facilitated recovery, referred to hereafter as 'caring for recovery'. We needed to focus on *the nature of caring, the caring tasks* and an *identification of the boundaries of caring*, elements identified earlier in the section. We focused on developing a central message to deliver to the carers: recovery cannot be 'done to' or 'done for' somebody. The carers had to learn how to care for recovery, as R2 summed up in session 7 of the steering group meetings:

It's about educating them that there is a better way of thinking and supporting and being a safety net. Rather than being the full support that pushes all the time… (SG7R2)

The steering group made a significant contribution to initial understanding about the nature of caring and the caring identity in the context of recovery, sensitising me to issues that would arise later. The group's contributions helped us to understand the key elements central to this research:
- the nature of the caring identity
- the exploration of the tasks of caring
- the difficulties of learning about recovery, with its belief in hope and optimism
- the importance of learning about the boundaries and caring with the tendency of carers to over-care and over-protect
- the change in behaviour that learning about recovery would require.

This laid the foundations for later analysis and understanding in the research. In later steering group meetings the members contributed to the development of the research design and evaluation tools which is discussed in Chapter 8.

6. 2 Learning about recovery: the carers' reflections

This section presents the beliefs and attitudes that the carers formed about recovery as a result of their participation in the training programme.[68] The carers' understanding of recovery on an individual and a group level at different points in the research is described in section 6.2.1. The positive and negative implications of believing in recovery are explored and its impact on both carers' and service users' lives considered. This is followed by findings in section 6.2.2 which explore the carers' own views of their caring situation and how they revised their identity in the light of learning about recovery. This section forms a new synthesis by exploring the relevance of the recovery concept to the carer identity and role. Third, the notion of living beyond the caring identity is introduced in section 6.2.3, discussing how carers make their own journey of recovery.

The following elements led to a focus on these themes:
- applying the initial research questions to the process of data analysis
- the design and focus of the training programme, influenced by the perspectives of the steering group
- immersion in the data using inductive reasoning processes supported by a knowledge of recovery.

Data were collected from across the training programme, focus groups and interviews and synthesised to show how the carers' thoughts, opinions and behaviour changed as a result of the training. The stakeholders fed into the analytic process through the methods described in 5.6, and my identity as a service user influenced the generation of themes as described in 5.5.

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68 An outline of the training programme is found in Appendix 36.

6.2.1 The meaning of recovery and changes over time

This section provides an introduction to what recovery meant to the carers individually and collectively before, during, and after the training programme. Participation in the training programme gave carers the opportunity to explore their own experiences of hope and acceptance, growth and renewal, fear of failure and tentative optimism as they learnt about recovery – capturing this process of learning was fundamental to developing an understanding of the carers' definition of recovery. This section highlights how their views of recovery changed over the course of the research and influenced their attitudes towards both their and the service user's future, and considers the implications of this learning for their caring role.

Many members of the group described recovery in simple terms at the pre-training point, defining a state of 'being recovered' as an end state achieving clinical recovery. F01 emphasised the notion of 'functioning':

> Being able to function again in the outside world, albeit not in exactly the same way as before his illness. (WE1F01)[69]

F06 defined recovery in terms of clinical recovery and occupational standards of self care:

> Hopefully return to normal social interactions and ability to function on a day to day basis; i.e. cooking, personal care and ability to relate to others again without being totally wrapped in self. (WE1F06)

F03, who was involved in mental health service development, had a more complex understanding of personal recovery with its emphasis on leading a fulfilling life:

> Being able to cope with day to day events and have a positive purposeful life. Not being socially isolated and enjoying life. Recovery is being able to get through life on track. (WE1F03).

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69 The carers were asked to write responses to four open questions at the pre-training and post training data collection points. The open questions are found in Appendix 28.

The male members of the group saw recovery as living a socially-valued life by being productive in society. Two men first defined recovery as:

> When the subject can take a meaningful part in society and be happy. (WE1M02)

> Achieve clinical and personal recovery (QoL). Lead a useful, meaningful and enjoyable life. (WE1M01)

One can surmise that this reflected the men's expectations of their family members achieving this valued role in society.

For many carers at the pre-training point recovery was a notion that resembled 'cure'; it assumed greater complexity as the group participated in the training programme.

From the first time the carers met, many expressed a sense of grief at the missed opportunities in the lives of their family members, and had little belief in the possibility of recovery. F01 believed that her son could never have a worthwhile identity with a diagnosis of schizophrenia:

> And looking at the past as well, because it takes you time to realise that even if they do come through, that they may never be the person that they were before, and I think this is one of the sad things about it that you find it difficult to accept …. (FG1F01)

She despaired of her son's situation, and it appeared that even he seemed overcome by learned hopelessness and intransigence as she mourned the loss of friendships, hobbies and purpose in his life.

The notion of social recovery with friendships and a life of value seemed very alien to the carers as many service users experienced isolation. This distress was clearly expressed by F05:

> ...that's not the bereavement, the grief about losing someone, that is the pain you felt when your child was little and wasn't invited to a birthday party... but when they're adults and they still have no friends, you feel it so, so... painfully. (TP5F05)

Moreover ostracism affected service users and carers alike and was influenced by hidden and overt stigma. Stigmatisation reduces the choices and friendships of people with

schizophrenia and their carers, as carers are associated with the stigma which Goffman (1963) calls 'courtesy stigma'. Their distress at this experience was reflected in the written evaluation at the start of the programme when carers reported they found the courtesy stigma of mental ill health difficult when old friends dropped away and they experienced isolation (WE1F06, WE1M03). Peer support groups and meeting with other carers who know the difficulties of caring (WE1F02, WE1F03, WE1F04, WE1F07, WE1M01) were therefore fundamental sources of support.

The self-stigmatisation experienced by service users and their carers was equally negative and a barrier to recovery. M01 reported in the fourth session of the training programme about his son's response to his diagnosis:

> We had the same experience that our caree had the label schizophrenia, and that was it for the rest of his life and he would never recover from it which has happened. My son was told that absolutely clearly and that immediately demoralised him and he gave up hope, and I am sure setting him on the downward path... I am still fighting to get that back. (TP4M01)

Self-stigmatisation is experienced by many service users and reduces the life chances of people with schizophrenia as they absorb the negative messages of those around them. Both stigmatisation and self-stigmatisation are real obstacles to recovery for both the service user and the carer.

The carers found the word 'recovery' was confusing as it means 'cure' in everyday parlance and something different as a mental health concept (see chapter 2). As they participated in the training programme their understanding of recovery changed. The new meaning of recovery departs from the traditional medical model and sees growth and development possible as F02 reported at the third training session:

> ... when you think of recovery the term recovery, you see, in medical terms when they been in hospital, they've often recovered from something … it often means that now they are better, but in some ways... perhaps it is more of a pathway to recovery and maybe that perhaps is worth thinking about it more as a pathway, and as sometimes on journeys and pathways, it is like a car journey, sometimes it is smooth and rough ... but I think rather than being recovery which seems it is a final thing, which it isn't, it is a pathway to recovery… (TP3F02)

In the final session of the training programme F04 suggested using the word 'discovery' to replace recovery, a term used by Julie Repper in the local conference that the carers

had attended during the training programme. A journey of discovery implies a process of being, growing and developing, replacing the confusion inherent in the term 'recovery' (Liebrich, 1999).

The carers' understanding of recovery grew more complex as they participated in the training programme. The notion of hope was central: at the follow-up focus group immediately after the training programme, F02 wrote down the best things about recovery:

> It gives you hope. Knowledge of recovery and the illness with all its ups and downs gives you confidence to tackle the difficult as well as the easier decisions. (WE2F02)

Although the concept of recovery was seen as positive it opened fresh wounds for the carers. Learning to hope was frightening, and made them realise what both they and the service user had lost. Even when things were going well it was frightening to look too far into the future, because failure and relapse could be just around the corner. This exchange between F02 and F05 at the follow up focus group shows the tensions endemic in recovery and caring as F05 talks about her daughter's wish to apply for a job as a chamber maid:

> F05
> And we're on that whole rollercoaster again, and I'm trying to protect her from it, but equally I'm feeling awful because I'm stamping her down and it makes you feel awful, it's discussion, it's not just the course, talking to all of you, and now I say why don't you do that, let's see, see what will happen and talk to [worker] and see what will happen. She hasn't done it yet but I think she might, I think she... we don't immediately have that negative discussion where I am reinforcing the fact that it's going to be disastrous.
>
> F02
> Yes I think that we need to look at forward steps and try and think more positively and it's been quite hard in the middle of the course when the situation changed with our son and we had to make him homeless, and very very difficult time, but I think the course helped me to see him move on and move forward to his independence. (FG2).

Many carers felt that recovery was very fragile and temporary. They had to protect themselves from the distress of a hope that could be dashed. This was a real obstacle to believing that recovery was possible. They had to learn to balance a sense of acceptance and hope, of possibility for the future and realism with its life limitations.

Some carers spoke of fearing a false dawn in the life of their family member as they became a 'revolving door patient'[70] – this made hope for the future very difficult to accept. This was reflected in the experiences of F01. When she was interviewed at the six-month follow-up (SSI2), she knew that her son was on the road to recovery but was aware that 'he has relapsed in the past after seemingly being on the road to recovery'. This was very difficult for her, but she just tried to 'to think about what he is now and how things are improving' (SSI2F01).

The carers feared that fluctuation in a service user's well-being would halt their recovery and take them back to the beginning of their journey. Renewed hope is central to the recovery concept; however the carers found it hard to be optimistic as their family members had experienced repeated relapse – this made the carers fear failure. Moreover when there was no sign of recovery, the carers found it very hard to feel any optimism. They found it hard to fully believe in the concept of recovery – as such a belief was painful as it could leave them open to despair and disappointment. Indeed many carers mourned the lost potential of their family member, who experienced life-limiting mental illness symptoms, yet learning about recovery challenged them to be more optimistic about the service user's future.

The carers oscillated between accepting that the service user's life opportunities might be limited due to their mental illness and believing the recovery approach that encouraged them to have an optimistic outlook for the service user's future. This impacted on their belief in the possibility of recovery for their family member, and how they defined recovery. They had to be both hopeful for the future, yet accepting of limitations of mental illness, realistic yet optimistic – this was a difficult balance to

70 They were referring to the feeling of hope and relief when the service user appears to be improving, and then the feeling of despair and loss when the service user might slip back again. This was distressing for the carers and knocked all their confidence and the feelings of positivity they might hold. A revolving-door patient is one who is admitted to hospital, stabilises and is then discharged. They may stop taking medication or become overwhelmed by life, and their mental health starts to deteriorate. The patient then returns to hospital, often under Sections of the Mental Health Act, and is detained. The cycle thus starts again.

achieve. F05 had learnt to manage both disappointment and optimism alongside acceptance and had realised that recovery was possible and that her daughter could lead a fulfilling life despite the diagnosis of schizophrenia:

> Well, I do think I'm more optimistic than I was, partly because of me being more accepting of some limitations, but they are not limitations really … I just feel ...that she can have a fulfilling life now in a way that I didn't feel that before, I felt that it would always be a second best kind of thing, but it's not, it can be just as good a life for her... (SSI1F05)

The tension between hope and acceptance was expressed in different ways throughout the programme: the participants hung on to hope but had to come to terms with their situations. Acceptance was both the best and worst thing about recovery, as F05 reported at the six-month follow-up:

> ...Somebody as seriously ill as [service user] and with her difficulties will always be set apart, but it makes it possible for her to lead a full life, and also makes it clear to us as carers or family that she'll always have schizophrenia, she'll always have those symptoms, but in a way knowing that is a help. She's never going to recover; actually you could say she will never recover in the traditional sense of the word, she's going to be living a life a useful productive life with schizophrenia, so it puts it more on par with diabetes, or something like that... (SSI2F05)

Recovery empowered the carers to accept the boundaries and limitations of the illness yet at the same time released them to hope. M02 described recovery in the 1 month follow-up interview as:

> I think it is being able to cope with the problems better really. I think that is probably it. You understand that there are going to be problems and it's understanding that it's like that cycle of up and down, and hopefully the ups… get longer. (SSI1M02)

This journey was liberating for many, as it marked the beginning of their own recovery journeys with an acceptance that schizophrenia does not condemn a person to be segregated from society.

The carers had changed their views about recovery at the one- and six-month follow-up interviews. The meanings presented by all of the carers focused less on acceptance and more on living a successful and meaningful life. F01 began to have faith and belief in her son's recovery. The shift was subtle but tangible between 1 month and 6 months.

Recovery was understood as meaning: 'improving but not necessarily being cured' at 1 month (SSI1F01), whilst at 6 months F01 stated:

> Well a process by which somebody with particularly a mental illness can get better than they were before without being cured and by which they can begin to live a reasonably normal life. (SSI2F01.)

Likewise, when asked if they believed her son's recovery was possible at the six-month follow-up interviews, she reported:

> ... And whether total cure is possible I don't know, but whether he would ever be able to focus without medication, obviously I don't know, but hopefully on the medication he is on at the moment, and with support, I hope that he can function. (SSI2F01)

A similar situation could be seen in the change between F02 at 1 month and 6 months as recovery was no longer about acceptance in the negative sense, but constituted optimism and progression.

> ... it's an approach and view of moving on from psychotic episodes really... And gradually changing because of it, and hopefully getting a life back again, even if it isn't like the same as it was before the psychotic episode. (SSI2F02)

Similarly the importance of the diagnosis in F05's daughter's life was diminishing, and she understood recovery to mean 'living with a severe mental illness ... in such a way that you can still have a fulfilling life without it dominating your life'. (SSI2F05). F06 balanced hope and acceptance, as when asked about the possibility of recovery at 6 months, she said:

> Only in the sense of the acceptance of his life and hopefully having a better life than he does now. Not full recovery in the sense that I once thought recovery was. (SSI2F06)

By the end of the programme, many understood the fundamental nature of the recovery concept yet continued to define it in very individual ways relating to their particular circumstances. The carers had a conventional vision of what recovery would constitute. The vision of the service user's recovery included a job, friendships, a social life, a partner – all the elements of a fulfilling quality of life, and all valued social identities. F03 hoped 'that he will have quality of life, you know and he will enjoy life'. She listed the elements of her son's recovery:

> 'He might find a partner and you know if he gets a job he will be more self sufficient and not always struggling for money, just I mean a more fulfilling life than he's got at the moment'. (SSI2F03)

The carers tended to believe that recovery was possible. Each carer expressed different sides of the recovery concept, from acceptance to optimism, hope, and realism, although the definitions posited by the carers' group are readily understood within the recovery-minded community as elements of the recovery journey. A major obstacle to believing about recovery is fear of its fragility and fear of the distress that dashed hope might bring. Recovery encouraged them to hope for a better future for their relative yet forced them to accept the limitations of the mental illness as they paradoxically feared its attainment might only be temporary. They believe it might be possible but are forever balancing fear for the future and acceptance of the limitations of the illness against a belief in the hope of recovery. Indeed this is a new finding as the negative implications of accepting the diagnosis have not yet been explored.

6.2.2 The carer: caring for recovery

This section explores the different ways in which the carers supported their family member and learnt how to care in a way that supported their recovery, to 'care for recovery'. It discusses how they came to understand the symptoms of mental illness more clearly and how this impacted on their relationship with their relative, and highlights the personal tasks that carers could and should undertake in caring for recovery. The elements of an effective working relationship between professionals, carers, and service users are addressed, as well as how a model of shared responsibility can make recovery a reality. The implications of learning about recovery and the difference its makes to caring attitudes and behaviour are explored alongside carers' changing role in recovery.

Caring: an environment to support recovery

This section describes how the carers saw their role in supporting the recovery of their family member both before and after learning about recovery. It considers their difficult and contradictory role as both parents/siblings and carers and explores the tasks they undertook to support their family member. The discussion highlights the double role of the carer, helping and supporting the service user in their everyday life as well as promoting the family member's independence and agency by caring for recovery. It addresses the impact of learning about recovery on the carers' attitudes and behaviour.

The changing caring role

The carers were asked through a number of ways to identify the content of their caring and to explore their role in recovery. The carers responded with free flowing text to open questions about what helped and hindered them in their caring role at the pre-meeting (WE1) and the meeting immediately following the training programme (WE2).[71] They identified personal qualities such as patience (WE1F01) as being very helpful. M02 saw his role as supporting his spouse (M03) who is taking leading role in care (WE1M02) but felt guilty when times were difficult that he should be more supportive (WE1M02). Both at the first point and when the exercise was repeated, peer support and sharing things with family and friends (WE2F01, WE2F02, WE2F03, WE2F05, WE2F07, WE2M01) predominated the answers carers gave as helpful to caring. F01 reported finding strength from a faith in God (WE2 F01). M04 believed his caring role was frustrated and limited when the service user stopped taking medication and became unwell again (WE2M04). Appropriate relationships of partnership working and respect with the mental health services were highlighted as helpful to carers at both contact points; this is discussed in more detail in the next subsection.

Following their written responses, a hypothetical vignette of John[72] was presented at the same points before and immediately after the training to the carers. This was used to identify their practical views on caring and to prompt discussion in the focus groups about what the carers considered would help John to recover and what advice they

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71 WE1 refers to the written responses given by the carers before the programme at the pre-meeting data collection point when the first focus group was held and WE2 refers to the answers they gave to the same questions conducted after the programme when the second focus group was held. See Appendix 28 for the questions.

72 Two vignettes were presented to the carers in the course of the training programme. The vignette of John (Appendix 30) was presented to the carers both before and after the training programme to prompt discussion about the meaning of recovery and how they saw their caring roles. The vignette of Peter (Appendix 49) was presented to the carers in training session four to allow them to discuss the importance of direct payments and to think about the role of mental health services in supporting recovery.

would give his parents about caring for him.[73] The data collected before the training showed that the carers recognised the fluctuating nature of the course of John's illness and prioritised a clinician's diagnosis of mental ill-health. They believed that the service user could only reach recovery when insight was restored and that only medication or talking therapies could help.[74] They advised the parents to undertake many of the tasks that they themselves had found effective: increasing their contact, finding out about mental ill-health and attending a peer-support group for mutual help. They suggested short contact visits or visits to a neutral venue if they found meeting John uncomfortable. Their view at this point reflected the traditional caring role of 'being there and doing for': the group was not aware of the need to promote independence. They focused on fire-fighting and living from one day to the next rather than on planning for future recovery.

The discussion continued in the first focus group with an expressed commitment to the primacy of the medical model of care which continued to dominate during first few sessions of the training programme. The carers believed that when a service user lacked insight they lacked mental capacity to make meaningful decisions or even to live independently; they believed that recovery was impossible without capacity. M04 continued to believe this as expressed at the start of training session 3:

> I think the problem here is that the patient won't accept that they are ill and that they don't have insight, that the people out there are out to get them but they are out to get them and there is these abnormal people who are trying to do them harm. And I think if they are in that lack of insight, they are in a very difficult position, but if that patient has insight and can accept that they need to take their medication, that they need to take it for the rest of their lives then they have relapses, then if they are on that path you can have a lot of hope. (TP3M04)

Only F04, who had her own experience of mental distress, expressed some concerns with a mental health service dominated by the medical model during the first session:

> 'If they sit inside the medical model, like they do in the hospital, you've got a problem like a broken arm, so they are going like you've got the broken head, so take the tablets, and here's how we're going to mend it up, and they don't really

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73 See Appendix 30.

74 The carers defined 'insight' as the service user accepting the diagnosis of schizophrenia as valid and understanding the nature of their symptoms.

want to engage with their own failure so that's why they get so stuck in this is how we do it. (FG1F04).

The group in general was concerned that their family member often lived in the 'unreal world' when overcome by the symptoms of schizophrenia (TP3) and reported that they found it difficult to support their family member in disengaging from the voices and delusions they experienced (TP4F05). M03 had however recognised the need to acknowledge his son's voice as a real experience in early care he provided to him:

> To have denied his voices for a long time, and that would undermine his sense of judgement, which he's always been like, he's always lacked confidence over his own judgment … (TP4M03)

Many did not recognise the ambivalence that many service users feel towards using medication because of the side effects, although F02 noted how the medication enabled her son to live in the real world but dampened his personality:

> … He's not affected by the things he was affected by, but he's kind of damped down, and so when you are saying have another world to go into, the real world and use that more, while the other one has gone, I don't think he is participating in an awful lot in the real world without a kind of push. (TP4F02)

F02's son found little of value from participating in the real world – making a belief in recovery difficult. The carers had little insight into the nature of mental illness: indeed F07 reported at the follow-up focus group that for many years her daughter had had ME because of her listlessness and apathy and not schizophrenia.

> Because for years I thought our daughter had ME and ... I didn't know anything about voices and I think probably she hid a lot of things and we ... wondered what she was doing or why she never finished a sculpture... (FG2F07)

The work of the Hearing Voices Network (see Chapter 2), which emphasises the importance of working with symptoms and voices in the context of the service user's life, was introduced. It stresses the normalcy of this experience in contrast to the medical model, which emphasises mental illness as a psychiatric experience. This began to reframe their understanding of mental illness and they started to think that recovery was possible even when mental illness symptoms were present.

Understanding the complexity of the experience of mental ill-health enabled the carers to let go of some of the negativity and confusion that had dogged their relationship with

their family member. M02 reported that he had come to realise that mental illness is real and that his son's delusions are not manufactured to gain attention:

> ...because he is so intelligent, I definitely couldn't accept that he couldn't understand that he couldn't hear electricity running round the walls, you know, that he couldn't see that that was right, so I needed as much help as he did. (FG2M02).

This taught him to respect his son's integrity regarding his mental health experiences.

F05 reported in the follow-up focus group that as a result of the programme she had learnt to understand more about the nature of paranoia and mental illness symptoms and begun to talk with her daughter about the content of her delusions and auditory hallucinations:

> I think one of the things you have just reminded me, one of the key things that I changed my approach to my daughter as well, is the insight that R1 was able to help me with in relation to what I was talking about coping with the real and the unreal world.... How R1 explained she could be in the unreal world and kind of know that it was unreal, but it was still more real than unreal, and you know I have really explained it again but it did give me that insight into [it], I am more tolerant of, it was sort of like I said before about being kind of frightened, so if [daughter] is talking about voices I am better [at engaging] her with it ... (FG2F05)

The carers began to understand recovery as the service user leading a good life, even with the limitations caused by mental distress – and that alongside their mental health symptoms service users could still retain their capacity. Understanding recovery as a constant, ongoing process required a change in the carers' attitudes and caring behaviour as we challenged their mindsets about the nature of decision-making, agency, independence and choice alongside the experience of schizophrenia.

At the start of the programme F02 was washing her son's clothes, cleaning his flat and involving him in her family unit more than a typical adult son or daughter would be involved. This approach was common to the female carers in the group, who treated their adult 'children' as teenagers. At the first of the training programme sessions, F02 reported that she found it difficult to ask her son to do things for her:

> F02: He has to follow a recipe absolutely exactly and after he had ... been cooking that it had actually been very stressful for him because he had he was just crashing out in the evenings he was just so shattered in the evenings...

> F04: It was good that it stretched him a wee bit.

F02: Yes it was. And he is going to continue doing some of it. He doesn't need to cook all the time… (TP1)

This represented the dichotomy that the carers felt: wanting to make sure the family member was supported but knowing that they had to find their own way. This was a difficult balance to achieve as they sought to care by being there as well as promoting independence. She had to learn how to care for recovery and to reframe her caring.

During the third session of the training programme, the carers were asked to discuss, in small groups, what helped and hindered the recovery journey *from the service user's point of view* and to consider how their family member had already equipped themselves with their own tools to support their recovery.[75] It was important to encourage them to explore the service user's strengths and abilities rather than their failings, and to put them at the centre of their illness as the expert in managing their own mental health. The carers found this exercise particularly difficult as they thought about the situation from their own point of view rather than the service user's as they tried to pinpoint the service user's own strategies for managing their illness. F01 reported:

What are the strategies? Difficult one… I don't know really? I am not too sure if he really has strategies, he will often disappear when he will go off and take himself off to his room and watch the television upstairs... (TP3 F01)

As the service user followed their own aspirations and made their recovery, this surprised the carers and renewed their belief in recovery. At the follow-up focus group, F01 realised that her son was acquiring a new identity with value and purpose: he was attending university and succeeding, even though he still experienced mental ill-health.

And like his two brothers, and his sister, and us of course, we always think it's not the old [service user], whereas other people, it doesn't matter... they accept

75 In TP3 the carers were introduced to the WRAP flower, a recovery-oriented tool used to facilitate thinking about these issues. The WRAP flower shows the good and bad things in my life and what helped and hindered my recovery journey. We also began to think about how the service user's WRAP flower, drawn up by the service user her/himself, would differ from the WRAP flower drawn up by the carer *for* the service user. It was important to get the carers to think about moving the locus of control to the service user, rather than trying to get the service user to adopt the carer's values, life choices and life responsibilities. See Appendix 46 for the WRAP flower.

him for what he is... I think he's realising he's getting an identity back and it's helping such a lot, and I think that it's helped me, coming and realising that this is [service user]; maybe it's not [service user] as he was 15 years ago, but this is [service user]. FG2F01

This helped her to value her son's achievements and reframe the nature of her care-giving by not focusing on past losses but looking forward with optimism to future gains, which is fundamental to care-giving that promotes recovery. Participation in the programme helped her to believe that her son's recovery was possible and that he could live a valued life, even if its trajectory was different to what it had been before the onset of schizophrenia.

Learning that recovery was possible, even when the service user's life is limited by symptoms, opened up a new relationship focusing on seeing the service user as responsible for their own life and recovery, changing the carers' attitudes and behaviour and reframing their role as a carer. We sought to enable them to release their control over the service user's life, laying the foundations for the carers to become recovery mentors. This was a different kind of care in contrast to her earlier approach, as F02 reported at the 1 month follow-up.

So it is really trying to support him by seeing him and talking things over with him, and trying to give some advice where I think he needs it and where he's asked me for it. So not interfering too much. (SSI1F02)

F05 similarly recognised that she needed to keep faith with the possibility of her daughter's recovery and described her caring role as 'keeping [my daughter] going and giving her hope that things will get better, even if we can't see it ourselves' (SSI2F05). She had also learnt to look at her daughter differently, and acknowledged the strength of character she needed to manage her illness: 'You know she's very brave, on the face of it she is very courageous' (SSI2F05). M02 also felt that celebrating the 'little tiny inconsequential things' (SSI2M02) supported his son by reassuring him that he was making progress in his recovery. By reinforcing positive hope and optimism, F05 and M02 felt that they were supporting the recovery of their family members. They realised the importance of hope and optimism through participation in the training programme.

Letting go of a child can be frightening for any parent, but it is even harder for a carer whose 'child' has met with the distress of schizophrenia. The group felt helpless at not being able to put things right, and this brought feelings of guilt and distress. They found

themselves trying to make up for the service user's lack of life chances, friendships and opportunities by filling the gaps and 'over-caring'. After the training, F02 looked back and stated that she 'was learning to stand back a little bit and help [her son] to get his independence' (TP5F02), acknowledging his place as an adult with responsibility for his own life. Similarly, F01 realised that her support could be more like 'smothering' than 'mothering' although she believed that she had to continue to help her son to cook and clean when he moved out to live independently after the training programme:

> There are two ways of looking at it. There's you might look at it and say that I am smothering him, rather than mothering him, you know it depends how you look at it.... I try not to smother him, but I am aware that some of the things that I do that I like to think of as support, could be looked upon as smothering. (SSI1F01).

The carers reflected on the different elements of caring in the recovery journey, understanding the importance of their roles in relation to the service user. They began to see the primacy of the service user's right to autonomy in their lives and the need to respect their capacity, even when mental health symptoms were present. Discussion about the nature of caring was particularly relevant in this research because at the beginning of the programme many of the cared-for people were dependent on their parents' and financial, emotional and practical support as carers. The carers had to become enablers rather than 'doers for' and learn to let the service user lead on the recovery journey.

Working in partnership with professionals to support recovery

Carers often complain that they are under-informed, under-consulted and not involved in the care of their relative. This section discusses the group's reports on their involvement in the user's care, highlighting their experiences of exchanging information with professionals and the carers' assessment, which they were offered as providers of regular and substantial informal care. I conclude by considering how learning about recovery influenced the carers' expectations of mental health practitioners, reframing their relationships by redressing the balance of power. This discussion highlights the aspects of recovery practice that promote wellbeing and the obstacles which can impede this process.

The carers were asked to respond to some written questions recording what they found helpful or unhelpful in their caring role both before and after the programme (as described in the subsection above). The carers could respond with free flow text

addressing any issue – however managing professional contact was a key area of concern. Having sufficient and appropriate information (e.g. understanding of side effects) and how to support service user in managing symptoms (WE1F05) was important with appropriate access to mental health practitioners (WE1F06). This contact should be characterised by 'co-operation as part of a team which includes my son, wife, CPN, psychiatrist and any relevant key workers (WE1M03)' with the possibility of carers being able to negotiate access to appropriate care such as talking therapies (WE1F07). This issue was reflected at the follow up contact point after the training programme (WE2F03, WE2M01, WE2M02). It was important for F03 that she could share things with carer support worker (WE2F03), and for F04:

> Being asked my opinion and respected by the health authority and having a circle of support professional and personal who acknowledge me and listen to my concerns (WE2F04),

F05 felt guilty that she never did enough. This sense of guilt immediately made her wary of professionals and very defensive. To some practitioners she could appear a 'nuisance carer', but she needed them to see her as mother and acknowledge her feeling of helplessness.

> 'Going over the same thing with professionals. Feeling judged by professionals. Feeling helpless in the face of [service user's] distress (WE2 F05)'.

People with negative attitudes (WE2F06) towards service user damaged the confidence and hindered the caring role in the recovery process. F07, states: 'Being told my daughter has no insight and seems to be written off (WE2F07)'. For M03, negative attitudes based on indifference from health service provider (WE2M03) hindered his caring role. F04's response focused on the feeling of being excluded, neglected, and overwhelmed by the negative views of 'experts':

> CPNs who don't want to talk to me or see me as part of the recovery process and who say they are the experts and that my brother will never be 'well' again or be in recovery. (WE2F04).

Many carers want to be involved as part of a three-cornered equal partnership between the service user, carer and practitioner. They see this three cornered partnership as fundamental as they seek to contribute to the recovery process, although some carers in this and other studies complain that they are the first point of call when things go wrong and find that the chaos resulting from a mental health crisis can lead to anxiety and exhaustion (Fox, 2009). F03 underlined the importance of sharing information

effectively: her son draws on his parents' support but does not permit any information about his care to be shared, due to her role in a sectioning procedure many years earlier (TP4F03). However she described experiences of best practice when her son had been supported by an assertive outreach team which managed communication effectively:

> So they seemed to have a different approach, the team seemed to have their act together better, and I could tell his key worker, I could ring her up and tell her something and I was quite happy that it wouldn't be divulged to [service user] ... I trusted them as well. They were very professional but I could communicate to them without it getting back to [service user] and upsetting the situation. (SSI2F03).

F02 highlighted the necessity of knowing the boundaries that govern the content of information that can be shared (see Chapter 4), and described how she, the practitioner and her son had sat down and 'discussed guidelines for confidentiality and guidelines on my part as well as [my son's], and I knew what we could say to each other' (FG2F02).

The carers were introduced to best practice models of recovery throughout the training programme as they considered their own role in recovery and that of the professional. They began to realise the reality of recovery practice when they listened to the Early Intervention in Psychosis (EIP) team, who summed up their philosophy as encompassing ''some positive-risk thinking' to ensure they did not all get stuck'. This team 'sells it as the norm' (TP4manager) that they communicate with the service user and their family/carer. The carers felt that sharing effective information in such a team would help the service user to access support faster and expedite the recovery process, stopping the long-term entrenchment of disability, and reported their frustration that their own family member could not access such a service.[76]

Individual teams and professionals with a commitment to communicating with the carer and the service user can overcome barriers to confidentiality by facilitating open and honest debate about what information can be shared. The data shows that when this process works well, it can support recovery by ensuring that all the stakeholders are reinforcing a positive message; however, it also shows that failed communication can seriously impede the recovery journey.

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76 The carers all supported people who had been in the mental health system for over five years and so they were not eligible for the EIP team, which has a remit to support people who are undiagnosed or have been in the system for under five years.

Mental health services seek to communicate with carers who offer regular and substantial informal care in a systematic way via carer assessments. Information about the carer assessment was introduced to the carers in the training programme and discussed throughout the research, although many of the group had already had or knew about these assessments. F02 explained that she had found the carers' assessment process a relatively positive experience that enabled her to communicate directly with the team about her son's care from her point of view, reporting:

> I found it a very useful experience as you can actually say what you find is difficult and the parts that you find are difficult to cope with. And that particular set up that they have, I know that was going back to the actual team who see [service user]. (TP4F02)

Other carers would have preferred guidance and information about how to care effectively to an assessment of needs that could not be met (SSI1F05). F06 reported:

> 'I enjoyed the chat, I had a bit of a cry, and she didn't know much about schizophrenia but she was a good listener. And I haven't heard from her since. But you know she tried'. (TP4F06)

F03 reported how information from her carer assessment had been inadvertently shared with her son, the service user – this had caused enormous suspicion on his part, as he did not want information about his care shared with his parents. She felt that the information she shared at a carer assessment should be confidential.

A carer assessment can be a key tool for facilitating conversation and allowing communication; however, the data shows it must be completed by knowledgeable and skilful staff who are informed and aware of the support available. A carer's assessment is less important when there is an effective working relationship with the professional, because information crosses between the three parties as and when required in this 'three-cornered partnership' (TP5M03); however, without trust, a carer assessment takes on a more important role.

Only F02 reported any outcomes from the carer assessment: she was funded to attend an art evening class. A carer's assessment could not take the place of effective communication in the recovery process but it could facilitate discussion about the carers' expectations of services and open up dialogue about how to communicate more effectively between the service user, carer and professional.

Learning about recovery influenced the carers' relationships with individual practitioners and their expectations of professional practice. They believed that recovery requires a proactive professional to arrange activities for the service user, as F02 reported at the six-month follow-up:

> So I think actually to persist with him and to persist in suggesting things to him... And yes I think they need to be a bit more proactive with [service user], and I've said this to them already. (SSI2F02)

This reflects the carers' belief that recovery is action and doing rather than being. F03 found that occupational therapists were the most successful because they 'actually tackle the person behind the illness and focus on the interest and get them motivated to do things' (TP3F03). The carers felt that professional support was fundamental to the success of the service user's recovery. M02 emphasised the importance of a professional working as a mentor with the service user:

> It's no use doing it as a parent, because we have been in there for years telling them what to do… Advising them or something. But somebody else who can get that spark going. (TP4M02)

They assumed that the recovery mentor should be a paid professional rather than a peer with experience of mental ill-health,[77] whereas many service users report having recovered with support from peers *despite* professional intervention (Coleman, 1999, Rethink, 2010).

As they learned more about recovery, the carers expected to be treated with more respect and acknowledged and valued as an informed member of the team. It changed their attitude to themselves, to professional knowledge, and to expertise-by-experience and expertise-by-caring, changing how they interacted with professionals and allowing them to see themselves as experts-by-caring. It gave them greater knowledge, power and confidence, and moreover it gave them the language of recovery, as F04 stated at the one-month follow-up interview:

> I think the most important aspect is that it says we each individually have the responsibility for ourselves and for how we interact with each other. We don't have to go to health service professionals to ask if we're doing the right thing, or help us to do the right thing, because basically it just gives the power back to us. (SSI1F04)

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77 This mental health trust was expanding its training and employment of peer support workers, experts-by-experience who offered support and recovery guidance to other service users.

She began to have faith in her own knowledge and ability as a carer rather than relying completely on mental health services.

Their sense of increased responsibility and empowerment left some carers feeling surprisingly confused and disempowered, feeling that many professionals were less informed than they were themselves and unable to respond to the responsibility that this knowledge gave them. M03 questioned at the close of the training programme how professionals could support his son appropriately and promote his recovery if he as the carer was the only one who believed in it? This left him with a sense of helplessness rather than empowerment. However at the one-month follow-up he reported:

> and to hear the early intervention team talk seriously about the recovery model and the idea of recovery is something that is genuine and possible, it's terrific, it's a terrific antidote to the more despairing negative feeling and with that antidote it brings with it optimism, energy to stay with that things can be done, things can change for the better, and with that energy one can do things. (SSI1M03).

Equally F07 and M04 gained more confidence because they realised that mental health staff do not have all the answers (SSI1F07), and now they themselves could talk 'in a more knowledgeable way about the illness' (SSI1M04).

Recovery practice encourages the service user to actively engage in meaningful mainstream community activities of their own choosing. Social inclusion is central, the carers believe, to making recovery possible for the service user, and for many it was part of the way they defined recovery. F01 reported at the six-month follow-up that a CPN had suggested that her son go to a sports day with other mental health service users, and he had replied: 'I like to spend my time with normal people'. The mental health service had missed the fundamental meaning of recovery, which the service user himself clearly expressed. This service encouraged service users to be active in a segregated community of people with a diagnosis of mental ill-health.

When money is controlled by mental health services, activities may be organised in a segregated community restricted to service users with a diagnosis, but when money follows the service user and they have control of their own individual budget and direct payments, services and service priorities can change. Individual budgets and direct

payments have the potential to support the refocusing of mental health services with a recovery agenda.

The group was introduced to the policy of direct payments and individual budgets. Some service users had already received these and their carers reported both positive and negative experiences. Many thought that individual budgets provided a real opportunity to promote a recovery agenda. At the one-month follow-up, F03 reported that her son had received a direct payment and had bought himself a car:

> He's not reliant on us, and I hadn't realised just ... how important it was for him to be independent. And that independence has had spinoffs in other ways, he is desperate to try and get a job, umm he keeps applying, I am a bit concerned that constantly getting rebuffed and no success is going to make things worse for him... (SSI1F03)

F02, however, had been let down by the procedures governing direct payments. She had given her son money in advance for a course that was to be paid for through a direct payment and he had gambled it away. The group had questions, many unanswered, about what safeguards would be put in place to support the implementation of direct payments, but saw them as having real potential to support the recovery of their family members by overcoming the isolation and social exclusion which impeded their achieving a good quality of life.

The carers believed that the recovery approach was both positive and negative for mental health practice and in making the service user's recovery possible. F01 believed that recovery was sometimes seen as an excuse to withdraw services from those in recovery, while other carers recognised that real recovery practice demands much more of professionals than traditional practice. F05 reported that recovery practice is:

> ...very much more difficult for them than being a psychiatric social worker who monitors and talks to someone, but a recovery worker works properly; they're doing things like finding work and stuff. (FG2F05)

She was concerned, however, that recovery did not become a 'soft option' and that there was a strong danger that it would become 'just another term and just becomes another mantra ... on the recovery approach, but it's much harder, it's much harder work' (FG2F05). She saw the potential of recovery to bring about service change '... as a lever to get the kind of services you've always wanted for our people'. (TP5F05). M03 echoed this, replying:

> If it has to be a lever then or a stick to beat them with, then it has to be our stick. I mean I hope that [the professionals] will want to engage with it, or it will be very hard… (TP5M03)

This section shows the carers' complex relationship with caring and working with professionals. It reveals the new relationship with professionals that not only carers but also service users need in a recovery model. Although the issues of effective caring and partnership working have been raised many times by this group and others, this exploration of the carers' contribution to the recovery process lends new insight to the debate. This study clearly underlines that the process and limits of the carers' assessment need to be explained clearly to both carers and service users to prevent confusion and suspicion arising. It shows how effective partnership is fundamental to effective caring in the recovery process.

The carers began to believe that the recovery approach was real and tangible, rather than just an academic concept, by hearing how it could work in practice. They emphasised the importance of professional support and mentorship and of making recovery practice a reality, but were concerned about how to promote recovery when professionals were ignorant of this approach. Staff had an important role to play in making recovery possible for their family member which could only be achieved by effective partnership between all stakeholders.

6.2.3 The carer's own journey: life beyond the caring role

Carers follow their own journey of recovery as they care for their relative from the onset of mental ill-health to recovery. This journey requires that they come to terms with their relative's illness, find a way to 'care for recovery', manage the impact on their relationship with the family member and with others, and find a place for their caring role while also living their own life. This section introduces how the training programme changed how the carers cared practically and then reports how they progressed on their own journey of recovery to live a life beyond the illness of their relative and subsequently beyond their caring identity.

The course: growth and change

It was important to evaluate the impact of the training programme, so we asked the carers if their caring had changed following their participation in the course. Some felt

that they had changed, or had become more aware of the need to change. This section highlights a selection of carers' responses to illustrate the impact of the training on the group.

Some carers felt that they had begun to change how they encouraged their family member to take risks or do things outside their comfort zone. F05 had begun to appreciate that her daughter had her own aspirations for the future and had supported her application for voluntary work at a zoo where she had volunteered before but had left due to mental health problems that interfered with her work. F05 stated:

> In the past I would have been pleased that she was having these aspirations but trying to protect her from disappointment that she wouldn't achieve them, and so would perhaps not help her to go for them, but now I am much more likely to help her to go for them. (SSI1F05)

F05 recognised the tension between protecting her daughter from disappointment and encouraging her to take some risks. This difficulty reflects the tension between hope for the future and fear of failure as discussed in section 6.2.1. They very much wanted their family member to achieve but feared the disappointment if they failed. This dilemma is faced by many professionals as they balance risk aversion with the complex issue of positive risk-taking, and is even more difficult for a mother. F05 walked a tightrope as she supported her daughter.

F06 recognised the need to change her approach to the care she provided to her son:

> I've just realised I think that I have treated him really like a little boy and he is 31, and maybe I have just started treating him like a man really. (FG2F06)

She began to realise that her son had to care for himself more. She was empowered by the training programme and felt less frightened of using the word 'schizophrenia', feeling that it was the responsibility of those touched by schizophrenia to fight the stigma (SSI1F06). She began to recognise the need to support her son's independence and encourage his agency.

The carers began to understand that their role had to be more than 'doing for' – it had to be enabling. They realised that the service user had to enable their own recovery at their own pace, as was reflected in discussion during the training programme:

> F03
> And you can't see that small steps are important, and you think you can organise it and move it more quickly, but you can't, you have to let the person take their

own time, find their own route. I've found that the most difficult thing, trying to stand back and be patient…

F01
Be patient…

F03
And let them take their time. I've learnt it over the years, but….

F01
One learns it over the years, but then one unlearns it for the next occasion.
(TP3)

The training programme influenced two male carers in the group. At the follow-up evaluation, M03 wrote that for him the meaning of recovery was:

> Recovering a sense of purpose and motivation and belief that progress is possible. (WE2M03)

By the six-month follow-up meeting, M03 had moved to a place where he became his son's recovery mentor. He felt that the motivation and aspiration needed to come from his son, not himself. He wanted his son:

> ... to exercise some control over his own life. To set his own goals and to take steps to achieve them. (SSI2M03)

His role was to enable his son to take control and set his own objectives.

M02 occupied a qualitatively different father and carer figure in relation to his son than M03, yet his carer role had changed dramatically and he understood a lot more about the symptoms of mental ill-health. He reported that F03, his wife, was the intermediary between his son and himself. She had formerly communicated with him about the symptoms of his son's mental illness. He had learnt to be much more aware of his son's symptoms and was much closer to him as a result.

> If you took 6 years ago when he was accusing me of trying to murder him, doing his wheel on some car because he had had a crash, wouldn't speak to me, I wasn't allowed to see him in hospital, and we sort of, I mean we went to [village] last Sunday, no the Sunday before and completely different, the difference in the quality of our life has got enhanced as his has enhanced… (FG2M02)

He said 'I think the process had started before, but I think this emphasis on exercises and this sort of process [had accelerated the change]' (FG2M02).

F01 did not think her support for her son had changed. She felt that she and her family had found out about the illness over the years and supported him effectively. At the six-month follow-up, her son had moved into a flat in Cambridge. F01 did practical things to help him, like cleaning and laundry. However she noted at the training programme session 5:

> Because we all say oh gosh wouldn't it be nice not to have this responsibility and I could do this and that thing, and then when it's not there you've got to learn to cope in a way… (TP5F01)

F02's son also moved into an independent flat during the course of the project. She saw him regularly and similarly advised him on housekeeping. Effective housekeeping was important to these two carers, and they felt their sons would not keep their flats clean without help. Perhaps this reflects the way both wanted to ensure that their sons lived in comfortable and supported environments. F02 hoped that her son would continue to take his medication and have appropriate support so that he would

> ...have friends and be able to cope with day-to-day living, and maybe get a job or something or do some work where he can be in contact with people and not have the isolation. (SSI2F02)

She found it difficult to believe that recovery could be sustained and constant. Both carers saw their role as continuing to protect and support their grown-up sons, but like F06, they were aware of the need to ensure that they began to control their own lives.

Following the training programme, the carers changed the way they cared for their family members, some quite dramatically. There was a general change in how they now saw them as adults rather than children, and changed their care appropriately.

The carers' journeys of recovery: living beyond the caring identity

The carers' journey of recovery involved the realisation that they needed to recover from their experience of suffering and learn to live a life beyond their caring role. 'Carer' is a complex identity with both positive and negative impacts: it can overwhelm all other identities and can be valued or devalued, rejected or accepted. The process of recovery[78] required them to detach themselves from their caring identity and look to their own needs, seeing themselves as a person rather than solely a carer. In this section I describe

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78 This is presented in Cool Recovery for Carers in Appendix 22.

how the carers perceived the identity of caring, how this changed and how they described their individual journeys, reflecting on the mutuality and the separateness of the service user and the carer's journeys.

At the first focus group, before the training programme began, one carer, F05, rejected the caring identity as neither valuable nor positive, using it only to access services or enable other people to understand this dual role of mother and carer (FG1F05). Both the carers and their family members had an ambiguous relationship with the term 'carer'. This underpinned how they related to their role in recovery and to the possibility of recovery to themselves as carers. At the first training session they considered the carer's identity:

> I find that our son is very averse to us being called his carers; we are not his carers… It used to alienate him if somebody mentions we are his carers. I am not sure if being an adult, you know, it's putting him down… (TP1F03)

> ... Would you think they would think of themselves as having a mental illness if you called them a carer? That is why my brother wouldn't let me be called a carer. I do, because I like the kind of identity thing, I can connect with support for myself. But if he knew I was sitting here, and when a carers' group leaflet comes to the house, he says, why are you getting that? I'm not mentally ill. So it's a bit like that. It is a name for us in a way, and not for them. (TP1F04)

As the carers reflected on their roles during the training programme, they thought about the guilt and the grief they had experienced. F04 reflected on the practicalities of caring; her life had no order or structure because she was overwhelmed by the chaos of supporting her brother and driven by the unpredictability of this illness:

> There could be an emergency call, you know, or whatever. And so you feel your life is just full of chaos, and you can never really let go of the feeling that you have to be a carer and having to be responsible, and life's really busy anyway. (TP5F04)

She had a real fear about being labelled a carer with all her other identities subsumed into that one chaotic role:

> But there was an overriding fear and worry that if you do become such a carer, you're the carer: that's your role! Then what happens when you're not there anymore, the stress and what to do, because you can't let go now, and what to do if you know your life makes you let go and you can't physically do it? (TP5F04)

The carers' views of their caring role began to change towards the end of the programme. At the one-month follow-up interview, M03 described the value of selflessness in caring:

> This is a kind of a continual commitment, and unlike all other kinds of support we're not changing. We're there for him as long as we're capable. And during that time we're not changeable – other people come and go, and quite naturally, so they should – a kind of anchor of stability in his life, which I think is very important for somebody when a person is sort of buffeted here and there by circumstances. (SSI1M03)

He felt that their role was unchanging, providing constant and effective support as a positive influence on the life of the service user. He began to look with greater positivity on his caring role, on his identity as a carer, and on the recovery of the service user.

Guilt was a theme connected with the carer identity. A number of the carers questioned whether they had done enough to support the recovery of their family member or if they had failed in their caring role? This theme reoccurred throughout the research project as they reiterated their insecurities and sense of guilt. However, the peer support enabled them to let go of their grief. F05 realised that schizophrenia in her daughter was not her fault:

> ... it has taken away the guilt I felt, maybe having contributed to her illness in a major way, and... learning about the process of recovery because it has involved being with the group as well because it was such a support group element of the group, was such a crucial part of my understanding of recovery, and also coming to terms with just being better at caring for [service user] and seeing how other people were doing it... (SSI1F05)

The feeling of self-blame impeded their recovery, burdening their sense of positivity and optimism. The journey that F05 undertook in this training programme was the beginning of their recovery to expiate this sense of guilt and grief. When asked views of the future of the service user at the six-month follow-up interview, she said:

> I feel optimistic in that all her lovely qualities are on show, are there, I feel I can enjoy those, her good qualities as a person, rather than being constantly anxious about the fact that that she is too ill to lead the kind of life that I imagine she would like to lead. You know, you know, it's partly time, but also the course helped me to appreciate her better as herself. (SSI2F05)

As they considered the caring role, the group realised that they needed a separate identity as a person and not solely a carer. They began to value this identity and to see it as making a strong contribution to the life of their family member. Being a carer is an

all-consuming role, yet the hope of recovery endowed it with value and worthiness that neither the carers nor other people afforded it. Even though it can be a stressful, lonely and relentless role, the carers could see that it was possible to reach a point of living with and beyond the caring identity, embracing its hardships and its joys and appreciating its value.

Following participation on the training course, F04 moved to the farm[79] where her brother lived and established Growing Connections, a project open to all community members to grow vegetables in an eco-friendly way. She reported that she would put in two years of intensive care to support her brother to recovery. She had fully embraced her caring role and but had put some boundaries around it. Learning about recovery helped F04 to realise at the six-month follow-up interview that she had a place as an expert-by-caring:

> All the way through the best portion of the recovery approach, the best aspect of it, is the fact that it empowers the person who is the service user and the person who is the carer, and it brings it all back to you: you are the expert. I am the expert in being the carer; [the service user] is the expert in how best he can get well, and what he wants for his health and his recovery... It is kind of up to him... (SSI2F04)

This realisation was liberating. Conversely, she still acknowledged at the same interview that 'my whole personal identity is linked into how well I achieve as a carer and as a person doing the project' (SSI2F04). She had no identity other than that of a carer because of the practical demands of the role. Being an expert placed a lot of responsibility and stress on her shoulders, yet it gave her a sense of empowerment and strength. She had to learn to balance the caring identity with her needs as a person leading her own life. She was learning to apply a possible recovery model to her own life, as she defined her own sense of recovery.

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79 The farm was owned by her brother in another country in the UK. This was a huge move for F04, who was giving up her rented accommodation and travelling with her partner to settle on her brother's farm to support him for a maximum of two years, after which time they would return to England. Her brother was interested in environmental issues and sustainability.

At their individual follow-up interviews at one and six months, the carers were asked if they would describe themselves as being on a journey of recovery. M02 described the emotional journey he had traversed over the past ten years:

> ... so that decade has been, after the initial trauma as it were, and the first hospitalisation, that has been an incredible journey actually, and of course looking at it from this perspective it's not all been negative; there's been a terrific amount that has been positive in it. We learnt so much about ourselves, didn't we? (SSI2M02)

The carers' journeys were intimately tied in with the journey of the service user: if the service user began to recover, this reflected immediately on the carers' sense of well-being. M02 now felt he had space and time to reflect, an opportunity made possible by attending the training programme.

Many, however, also came to recognise that they had a separate journey to take from that of the service user, which related to their own life and identity and how they planned their own future. At the six-month follow-up F02 looked back on the time when her son had lived with her and she had feared the 'ranting and raving' that would greet her when she came through the door:

> I think that I just used to escape from the house, so I am trying now to consciously think you don't have to escape, you can be happy in the house and do things in the house. (SSI2F02).

Her home was now a place where she felt safe and happy again. It is very important to have a place of refuge to recuperate; F02's home had previously been a place of stress and tension.

M03 was also asked about his journey of recovery: he recognised that his own recovery had to be separate from that of his son – although their lives were connected, his could not completely revolve around that of his son.

> There has to be a level of detachment there. I have to look after my own recovery. (TP5M03)

M03 had understood the need to disengage his own recovery from that of his son – a very difficult process.

The carers had been on a long journey of reflection over the course of the training programme, exploring different elements of the concept of recovery as it applied to their

own and the service users' life. Some had re-evaluated their caring role and reassessed their life trajectory, sometimes reflective of and sometimes apart from the service user's recovery journey.

After the training course the carers all seemed more aware of the care they provided and how they provided it. Some did not feel they had changed their approach, but seemed more aware of how they should not be 'doers for' but enablers. This appeared to help their general understanding of how they could support their children as adults to achieve their dreams and visions for their own future. The carers interpreted recovery in different ways. Some saw it as a helpful concept describing their own journey, whilst others located the pathology in their family member and believed that this would be where the recovery began. The recovery journey was for both the service user and the carer, built on the mutuality and separateness of their journeys. Some could only build on the positive recovery of their family member and could not see their journeys as separate; others were able to detach themselves from this intimate relationship to look to their own journey living beyond the illness label of their family member and their own identity as carers.

6.2.4 Summary

In section 6.2 I have described the overall meaning of recovery to the carers, their understanding of their role in the recovery process, and how learning about recovery influenced and changed the trajectories of their own lives. The programme enabled the carers to reflect on the different ways in which they understood recovery. They understood that recovery is a complex and multi-faceted concept. Their conclusions reflect the findings of the research community on the new meaning of recovery, but reflect a perspective that is uniquely the viewpoint of carers rather than of service users or professionals.

The findings show how understanding recovery provided the carers with a new perspective on how to care and how to think about the caring role. Learning about recovery dramatically changes the traditional notions of how care is provided from 'doing for' to enabling – a move from dependency to agency. They also valued the importance of developing a tripartite relationship with the professional, emphasising how sharing responsibility and knowledge are fundamental to greater success. Their

reports remind us of the tension they experience in looking towards the future, balancing hope with an anticipated fear of failure.

The group of carers moved from a point of rejecting the caring identity, accompanied by a sense of grief, to a place of transition where they were holding on to hope and optimism. The recovery of the service user and the carer are intricately linked: the carer feels unable to be hopeful and optimistic without the forward movement of the service user. When the service user's recovery appears slow or stunted the carer must begin a difficult process of detachment towards the independence of each party. These carers emphasised the interdependence and mutuality of the two journeys of recovery, shared between the service user and the carer.

6.3 Formal evaluation of the training programme

This final section evaluates the training programme and addresses whether it was an effective, useful and interesting way of introducing the carers to the recovery approach. The training programme was evaluated comprehensively both through continuous feedback during its delivery and at the follow-up contact points (see Chapter 5). The categories derived from the analysis of the carers' responses focused on evaluating the *content* and *format*, *authenticity*, and *process* of the training programme, and inform the structure of this section. The first subsection reveals the carers' evaluation of the content and format of the course material and its delivery and organisation; the second discusses the programme's authenticity, focusing on its grounding in expertise-by-experience; and the third subsection presents a discussion about the nature of the course and how the *process* impacted on attitudes and behaviour.

The content and format of the training programme

The carers were asked to evaluate the content of the training programme by reflecting on the information and knowledge imparted to them. Some remembered particular sessions as useful and others reflected that it was the overall impact of the training programme that enabled change in their attitudes and behaviour. The carers' reports are presented from different data-collection points; some feedback was 'real-time' and other feedback drew on their memories. The evaluation of the *content* is inextricably linked with a presentation of the *impact* of the programme as the carers reflected on how participation in the programme changed their behaviour.

The group members were asked to describe what sessions they had found helpful on looking back to the training programme one and six months later. On reflection at six months, M03 reported that the exercises most useful in the long-term were the practical sessions on WRAP (wellness recovery action planning)[80] and direct payments, which had reminded him that his son's aspirations for his own recovery were paramount and that his son needed to set his own life objectives. This learning reinforced the feeling that the carer should take on the role of recovery mentor rather than being a 'doer for'.

At six months, F02 reflected that it had been useful when:

> ...we talked about little steps and helping them move on, and also focusing on the person who was ill as an individual with their own thoughts, rather than as your son or daughter who has an illness. (SSI2F02)

This encouraged F02 to see her son as a whole person and not just a person with the illness. She had learnt to be more hopeful that when her son took a couple of steps backwards he would go on to resume his progress forwards.

At the follow-up focus group immediately after the training programme, the carers reported that they had found the visiting speakers useful because they had reinforced their learning about the recovery approach by providing different perspectives (FG2M01). Additionally during the training programme, M01 reflected that it was helpful that the local NHS Trust conference focusing on recovery, which was attended by six of the carers in the group, had happened at the same time as the course because it increased the credibility of what we were teaching by reinforcing the material. F04, who had also attended the conference, noted how a session revealed the importance of how language was used:

> … the fact that it's OK not to talk about somebody as a patient, and it's alright not to say the person is ill, mentally ill; it's OK to talk about somebody who is experiencing being a certain way at that time and not see it as, 'This person's got schizophrenia' or 'is a schizophrenic person', and that to be allowed not to talk in those ways, is I think really really good, (SSI1F04)

This refers to labelling theory, which stereotypes different client groups by using thoughtless language. Language, F04 believed, could be liberating for her brother as it could enable him to redefine his relationship with his diagnosis and thereby with her as his carer.

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80 See Appendix 46

The programme utilised a mixture of different activities to help the carers to learn: small group activities, direct teaching, whole group discussion, and reporting back to the main group. Two carers reported independently that they found the small group exercises particularly helpful as this format allowed everyone to discuss the topic and then feed back to the main group (SSI1F01, SSI2F02).

At the follow-up focus group immediately following the training programme the carers were asked how they would improve the content of the programme. F01 suggested that there could be more information sessions like the direct payments session, although she noted that it was important that it did not become just a support group with information sessions. F06 reported that she had found some of the language and concepts used were complicated and that greater clarity and simplicity would have helped her to understand better. She felt that sometimes too much jargon was used.

The provision of travel expenses enabled the carers to participate in the group regularly. For F03 it was a 100-mile round trip to attend the training programme, and she particularly appreciated being able to come 'out of area', describing the travel expenses as 'a real bonus' (SSI1 F03).

The carers responded positively to the content of the sessions and remembered different aspects of it that had informed their learning. The practical sessions seemed to be the most effective at conveying information. The content of material was reinforced when other people, either those invited to make a presentation to the group or from the conference, spoke about recovery in similar ways. The format of the programme gave the carers space to reflect on their learning in different ways. At the six-month follow-up interview, F03 summarised her response:

> Just that you ought to bottle it and market it. (SSI2F03)

The authenticity of the training programme

The programme was unique because it was led by a service user and a carer trainer. This contributed to the carers' understanding of the nature of recovery and how they could care for recovery. A number of carers found that listening to my story clarified the

understanding of the journey of recovery (SSI2F03, SSI2M04, SSI2F01, SSI2F06 and SSI2M01). M02 stated at the six-month interview:

> ...actually meeting somebody who had firsthand experience of what the client had been going through, I think, is absolutely invaluable. There are so many people who talk about it from outside until as a carer, until you come across somebody whom you know has got positive improvements, you feel as if you are in the whirlpool going down. There's nothing like it, and I think that is the biggest improvement in the relationship for me, and also helping the client. (SSI2M02)

M02 found that my story pulled him out of the quagmire of confusion and stress. To hear about success gave him a real sense of hope and optimism. The carers acknowledged that the input of a service user was very different from that of a professional (SSI1M02); however, one felt that the programme could be delivered by a professional as long as there was some dedicated service user input into sessions (SSI2F05).

F03 appreciated seeing the perspectives of both sides, as she reported at the six-month follow-up:

> Yes, because you had the two perspectives and you saw it from both sides. The most valuable was your side, because it was the one side of the situation that had never been exposed to us before. But we had met carers, other carers, and talked to other carers, but to actually have it laid in front of us so vividly was the most impressionable thing that I had ever had. (SSI2F03)

F06 suggested that the carer facilitator, R2, could have been used more effectively to head some of the smaller groups in to which the carers were sometimes split up (SSI2F06). F01 summed up the carers' overall response to this aspect of the programme:

> I mean it was so inspiring! Certainly your side of it, R1, and to realise the recovery process is possible and that there is life beyond the onset of the illness. That you can still function with a brain, and thinking about other people and things; and then of course it was interesting to hear it from R2's point of view, because that was us. You were our son or daughter, shall we say, and R2 was us, so yes, it was definitely very useful to have the two points of view there. (SSI2F01)

These responses reveal the strength of this aspect of the programme, but also illustrate its potential weakness: does the involvement of service users and carers in delivering the programme encourage over-identification in the research, leading to bias? F01's statement suggests that this carer projected her and her son's identities onto the trainers, giving her possibly unrealistic expectations of recovery. Does it mean that she will

always be disappointed in her son's recovery and have unrealistic expectations? Or did it rather give her hope and enable recovery?

In mental health practice, peer support workers increasingly use their own stories of recovery to inspire their peers. Indeed, role modelling gives hope to those without hope. Similarly the authenticity represented in this programme has the potential to impact positively on the carers' lives and indirectly on the service users' lives. The carers agreed unanimously that this dual approach was fundamental to the success of the programme.

Process of the programme

This section identifies how the *process* of the training programme as a whole experience impacted on the carers' attitudes, behaviour, and beliefs. It concludes by reviewing the carers' suggestions about improving different aspects of the programme.

The carers found that the programme as a whole contributed to their learning over time, although not necessarily immediately following each session. F04 reported at the one-month interview that the cumulative effect of the training programme had influenced her in a very subtle way.

> It was a weird thing; it helps you without you realising it, in different ways. I like the way it was every two weeks or three weeks. It wasn't too intense, it allowed you time to process things or for things to change in your life, and to experience different things, and there was the continuity of having the same people there when you go... (SSI1F04)

Delivering the training course sessions every two or three weeks meant that the learning was processed slowly with emotional space to absorb and think about the content of the programme. Others reflected how initially they had thought that the gaps between the sessions would be too long, but on reflection this stopped it being too intense and overwhelming.

The feeling of mutual support enabled the carers to grow and change in a safe environment and allowing them freedom to discuss their negative feelings of grief and concern, as expressed by F05 at the six-month interview:

> You built up an element of trust with everyone, so when it was a bit tedious or I felt that it wasn't that useful, or I might have felt that I wasn't in the mood for it, there is all those components ... I knew it would be alright in the end, but the

> trainer who delivers the course is crucial really. ... Because I just looked forward to going to it, and trusted that it would be a safe place to talk that I'd learn, my understanding and ability to help would develop... (SSI2F05)

The facilitators had to build up trust and safety in the group to allow frank and open discussion.

At the beginning of session 3 some carers (M03 and F01) fed back their negativity after hearing messages of hope about recovery. They vented their fears and explored their frustration with recovery practice. The Early Intervention in Psychosis (EIP) team took up the rest of the session, allowing the carers to explore the nature of best practice in recovery care. When they came together again at the next session they felt much more positive.

> Well, to know that people are thinking about it, that there are models like this and it influences a service like [the EIP] team, umm, it's really sort of encouraging… And makes me start thinking about something that I was thinking about last time, blow me, I'm thinking about recovery for my son, and I will apply this wrap flower to myself. [81]. (TP4M03)

The peer mutuality in the course and the feeling of safety and trust allowed them to experience the programme as a cathartic process enabling them to let go of their negativity and begin to move forward with hope.

However F04 identified at the six-month follow-up that the training imbued her with a sense of optimism that may not necessarily result in her brother's recovery:

> ... so I think that the unhelpful thing is in a way when you do the training that you do expect people to recover in your way of thinking and I know part of the training is the other person's way of being, but I think it gave me an idea that he can pull out of this, you've got to think to think that, because the good thing about the recovery approach is you don't keep thinking [service user] has had a diagnosis, the professionals keep saying he will never get better they are right, you disregard all of that and you go again... that is the good thing about recovery, but the bad thing is ... you want the recovery to happen and you want it to happen soon ... (SSI2F02)

The training programme left her with a hole that was difficult to fill.

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81 For details of the WRAP (wellness recovery action plan) flower see Appendix 46).

At different points in the research the carers were asked how they would improve the course. At the follow-up focus group they reported that they had found the balance between keeping them on track with the teaching material and allowing them space to express their feelings had not always been maintained.[82]   F01 reported that she found digression helpful, but at times it got distracting. Some felt that the reflective element of the course was very important, as they recognised that they needed space to express their frustration, grief, hopes and dreams.

The independent facilitators of the follow up focus group asked for suggestions about how to resolve some of these issues. M03 emphasised that it was important to chair the sessions quite firmly. F02 suggested restructuring the course to enable participants to share in the first session, but M02 felt it would not be good to have a sharing session too early in the course as it was difficult to confide in strangers. In contrast, F04 emphasised that the course enabled the participants to work through their anger, and in her case it had given her the chance to express her grief. There was consensus that strong chairing was needed but that there should be an element of flexibility to enable discussion and exploration.

Digression seems to have been frustrating for a few of the carers, as they returned to it at both follow-up interviews M03 reported that he had found it frustrating when people digressed from the point of the conversation. He noted that sometimes:

> ...one or two people in the group seemed to dominate ... conversation and wander a bit off what seemed to be the point of the discussion. It became a bit tedious. But looking back, if you get a group of people together, that's going to be inevitable; it's part of a process of developing the group through the course, isn't it. (SSI1M03).

F02 noted this problem as well, but found that 'by not staying on the point, [we] actually discuss[ed] some things that were valuable and useful' (SSI2). F04 recognised that many of the carers lacked a forum where they could discuss their caring situation and their own lives outside the group, with other carers (SSI1F04). These discussions showed that the cumulative effect of the programme required flexibility to allow the

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82 With hindsight, I was a relatively inexperienced facilitator and researcher and chairing the programme more strongly would have been more effective. However, I was very aware of the need to enable the group members to work through their anger and frustration. A number of members found it difficult to participate effectively in a group environment, despite reminders of the group guidelines. The group went through a process of Tuckman's group dynamics (1968) and learnt to be more cohesive and work together. The trust endemic in the group encouraged them to stick together and learn together.

carers space to grieve and explore their emotions, but the training also needed to stay on track with the content of the programme.

Akin to this, some carers had found the purpose of the course unclear at the beginning. At the follow-up focus group immediately after the training programme F05 pointed out that it was not always clear what the course was about or where it was going. She felt that clearer course objectives would have been helpful. F02 echoed this and reported, with hindsight at the six-month follow-up interview, that she had not always been sure of the focus of the particular day, and 'sometimes we seemed to stray away a little, but sometimes it was good things we strayed onto' (SSI2F02). M03 reflected with some insight that it was difficult to have clear course objectives because the course sought to change attitudes and values through participating in the process of learning, and he did not feel that course objectives could do justice to the process in which the carers were involved. Indeed, by participating in this very process of learning, the carers were challenged by the knowledge and concepts they met and needed the opportunity to share their feelings – this alone made it hard to remain on track, although a more experienced facilitator might have achieved this balance more effectively.

The carers were asked if they had any other suggestions for improvements to the package. At the follow-up focus group immediately after the training programme F05 raised concern about the lack of diversity in the group, whose members had all been white, middle class and well-educated. She asked if the format and content of the course would be transferable to a more diverse group whose members were not so well educated and less accustomed to learning. This reflected some comments about the need for greater clarity and simplicity regarding the terminology and content of the programme.

At the six-month interview, F05 suggested that the handouts could be more professionally printed for future delivery of the course. She suggested that the course could be developed online supported by a facility that allowed participants to keep a diary (SSI2F05). She felt that this would have informed her learning better and enabled her to track her journey.

M03 raised some concerns for the future at the follow-up focus group: he was very positive about his participation in the course but wanted to know how he could

implement the learning he had acquired. He felt that changing the culture of the mental health services was the key to changing the circumstances of each individual, and wanted to know how his learning could contribute to this change – he did not want to have learnt about recovery for nothing and wanted it to influence his son's care and treatment. He wanted recovery to be embedded as part of the culture of mental health services, and professionals to promote recovery in their practice.[83]

Summary

The carers found the content and format, the authenticity and the process of the training programme useful in teaching them about recovery. They found it particularly effective when it was evaluated as a whole experience that built up change over time. They found elements of the digression and discussion important, but frustrating when one member dominated the discussion. The opportunity to work in small groups helped to overcome some of this. The strength of the programme lay in its freedom to give the group space to explore their feelings and emotions, and although digression was sometimes frustrating it was also important and necessary. Strong chairing of future deliveries of the course would be helpful.

6.4 Conclusion

The final section concludes by summarising the research findings presented in this Chapter. Figure 4 shows the major issues that the findings identified and how the carers' views of the possibilities of their family member's recovery, of caring, and of the role of professional support changed from before participation in the training programme to immediately afterwards and during the follow-up period. Figure 5 shows the changes in their conceptual understanding of the elements that make up the recovery   approach before, during and after the training period.

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83 His son had recently been assigned a practitioner who did not practise recovery in her work, although at the six-month follow-up interview he reported that his son had achieved a change in personnel.

The carers defined recovery in ways that are well-recognised within the research community. As Figure 5 indicates, at the start of the programme they defined recovery from within the medical model as being cured from symptoms. They perceived recovery as fragile as they oscillated between hope for the future and fear that the service user might relapse. They believed that recovery could only take place when the service user accepted their mental illness as real and had an insight into their illness. They had no notion of a personal model of recovery. The carers believed that their role in supporting recovery was 'being there and doing for'. They often over-cared and over-protected the service user, creating a relationship of dependency as the service user lost confidence in their own ability to live their life independently. (See Figures 4 and 5).

During and following participation in the training programme, the carers' views on recovery changed. As Figure 5 indicates, they began to see recovery as a much more complex notion, with the possibility of a good life lived within the limitations of mental illness. They began to acknowledge that the service user may retain capacity to make their own decisions, even while experiencing mental health problems, and alongside this realised that the service user must be the author of their own recovery. As they responded to the new definition of recovery they began to see the need to care in a different way: as promoting recovery by encouraging self determination and agency. The carers acknowledged that the service user might have hopes, dreams and aspirations for their own recovery which might be different than those they held. They realised the need to renegotiate their caring relationship with the service user to promote their autonomy and independence. (See Figure 4).

The carers noted the importance of the professional in supporting recovery as one of the biggest opportunities or impediments to recovery. (See Figure 4). When the professional does not know, or does not want to know about recovery, it becomes very difficult for the service user to move towards it. The carers felt that when professionals refused to recognise and acknowledge their value and role in recovery this created a real impediment to recovery. They saw the importance of service models such as individual budgets and direct payments in supporting recovery processes and recognised the essential role of services in recovery.

As the carers experienced the recovery of the service user, they began to acknowledge their own need to recover. They progressed on a journey towards life beyond the caring role. Fundamental to this is their own relationship to their caring identity and their

burgeoning belief in their own expertise-by-caring, as by occupying valued and esteemed roles both the carer and the service user can move on to recovery. The training programme facilitated the journey of recovery for many of the carers as they began to let go of their guilt at the emergence of mental illness in their relative. This was, for many, the beginning of letting the service user own their own recovery and, for themselves, living a life beyond their caring identity.

The carers evaluated the training programme as useful in that it enabled them to explore these issues. Their formal evaluation of the programme examined its content and format, its nature as user- and carer-led training and the process of the course, summarising their recommendations for future development of the training.

The next section examines the findings as a whole and contextualises them in the existing evidence base on recovery. It tracks the carers' own journey of caring, with its changing tasks and identity, onto the journey of the service user and presents a carers' recovery model. It explores the contribution that professionals can make to the recovery journey by proposing a recovery service model. It concludes by considering the uniqueness of the training programme and its potential to change caring behaviour.

Chapter 7. Discussion of the key research findings and wider implications of the study

7.0 Introduction

This chapter discusses the main findings and considers the responses to the research questions in describing its unique contribution to knowledge and theory. Section 7.1 develops theory about the nature of recovery and its relationship with caring, presenting a carers' recovery concept.   It describes the original contribution to knowledge generated by this research. Section 7.2 draws on the research findings and the wider literature to present a recovery service model for carers and the service users they care for. It addresses issues of service change and development. Section 7.3 describes the unique nature of the recovery training and how it contributed to change in the carers' attitudes, beliefs and behaviour. Section 7.4 provides a conclusion to the chapter.

This chapter draws on the literature review of the existing evidence presented in Chapters 3 and 4, which described the gap in knowledge that this research sought to address, and considers the focus of the research questions that I explored in Chapter 6.

7.1 The service users' and carers' journeys of recovery

As already highlighted in the literature review, recovery is described by many researchers, service users and professionals as a journey, a process, and a pathway (Anthony, 1993; Brown and Kandirikirira, 2006). There is a consensus about the common experiences of service users on this journey (Spaniol et al, 2002; Andresen, Oades and Caputi, 2003; Andresen, Caputi and Oades, 2006). This research captures the individual experiences of a group of carers exploring the meaning of recovery in their life and that of their family member with schizophrenia.

The findings indicate that the carers identified changing needs at different points in their caring journey, reflecting research that describes caring as a temporal process (Karp and Tanarugsachock, 2000; Repper et al 2008). This research adds new insight by indicating that the carer's journey of recovery is contiguous with that experienced by the service user and shows how each impacts on the other in the process of recovery.

This study has found that the following elements are central to the carer's journey, from the first signs of illness in the service user to the beginning of the service user's recovery:

- the experience of chaos at the emergence of mental illness symptoms
- the point at which mental health services become involved and the carer is no longer alone
- the process as the carer relinquishes control of the service user's life
- recognition that the service user is beginning to make their own journey of recovery
- the carer begins to find meaning in their life and a life beyond caring

The literature on carers and recovery is very limited (SRN, 2009), and I found only one framework that maps carers' journeys as they support their family members through mental health recovery. Cool Recovery (2003) is a model developed by and grounded in the experience of a group of carers in Devon describing their own journeys of recovery. My conceptual development, as depicted in Figure 6, combines Spaniol et al's (2002) model of service users' recovery with the Cool Recovery (2003) model of carers' recovery.[84]

Although each carer and service user's recovery journey is unique (Mind, 2002), I chose the Spaniol et al (2002) and Cool Recovery (2003) models as the foundations of my conceptual framework because they provide an overarching structure that offers flexibility at each stage, although I acknowledge that there is a tension between arguing that recovery is unique and representing it in a staged model. The carers in this study recognised the uniqueness of each journey and felt it more helpful to think about recovery as a process of 'discovery', a word suggested by Julie Repper at the local conference that many of the carers attended.[85] The development of the model is furthermore grounded in my own expertise-by-experience and informed by the broader evidence base on recovery, and addresses the focus of the study as identified in the initial research questions.

Figure 6 (overleaf) maps the carer's recovery journey alongside that of the service user. It shows how the carers related to the different stages in the service users' recovery

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84 See Chapter 4 and Appendix 22.

85 The notion of discovery in recovery originated in early work on recovery by Liebrich, (1999).

pathway and explores how their caring role required tuning to each part of the process. The service user's experiences are presented through the eyes of their carers, as this study focuses on the latters' perspective.

Figure 7, above, shows a snapshot of how the Triangle of Care between carers, practitioners and service users should be configured within a recovery approach. It draws on the research findings and relates them to the research presented in Chapters 2-4 about the nature of recovery-oriented services. Figure 7 presents the carers' beliefs about the tasks that determine an effective relationship between carer, service user and professionals when they work in partnership to enable the service user's recovery. These tasks are then linked with the conceptual theory that underpins the task and how it is best undertaken.

This section presents the carer's temporal experiences of caring, outlining a unique contribution to knowledge about the nature of caring in the recovery context; furthermore, it describes how this differs from and adds to existing work by locating it in the current policy, research and practice contexts.

7.1.1 The stages of the recovery journeys

Stage 1: The service user becomes unwell

Service users note that when they first become unwell they feel confused, frightened and anxious. They may hear voices and understand little of what is happening. The carers in this study and beyond report that they, their families and those around them may not realise that mental distress is present and there is confusion and chaos as the family and service user begin either to seek help or to avoid contact with medical services. This reflects the work of Taskenen et al (2011), who emphasise how stigma, fear, lack of knowledge and lack of awareness of what is happening act as obstacles to seeking help at the first episode.

Kalathil (2010) reports that people in black and minority ethnic (BME) communities may be more reluctant to seek help than those in the white majority community, as their communities often fear the stereotypes of 'the mentally ill' and the shame that mental illness brings on the family. Moreover the perception that institutionalised racism exists in the mental health services may increase their reluctance to engage with such services (Care Quality Commission and National Mental Health Development Unit, 2010).

At this point, as identified in the findings, the carers did not know the extent of their caring role or the impact of mental ill-health on their loved one. They noted the

complexity of the carer label, with many reluctant to self-identify as carers when the service user was first diagnosed with schizophrenia. Some found it helpful to talk to their peers; however, some acknowledged that participating in support groups could be detrimental as longer-term carers presented negative stories involving bad outcomes for the service user (Karp and Tanarugsachock, 2000).

As identified in the literature, carers need adequate and appropriate information in order to be able to understand the service user and their illness and symptoms, and to support them better (Szmukler and Bloch, 1997; Newbronner and Hare, 2002; Faulkner and Williams, 2005). Research has identified that caring affects the carer's ability to work, look after other family members, pursue everyday leisure pursuits and carry on with their normal routines (Repper et al, 2008; DH, 2010). The present study found that the carers were overwhelmed by their caring role and identity to the detriment of their other roles and identities.

However, UK policy (DH, 2010) identifies that carers should be supported on their first contact with mental health services, because if they do not seek help early on they often do not have enough information to make informed and proactive choices about their life regarding such questions as returning to work. They may feel overcome by the effects of the caring role that they may give up work and their social life, leisure pursuits and hobbies to become 'just a carer'.[86] The carers' experience in this study reflects this state of being, as they struggled with the carer label of and tried to reconcile it with their other roles and responsibilities.

The carers in this study noted that they received a negative prognosis for their family member from professionals at this time, although Ramsey and Till (2009) emphasise how important it is for messages of hope to be reinforced. The major obstacles to recovery that the carers identified are a lack of professional awareness of the possibility

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86 The coalition government is committed to enabling carers to either work or be involved in education, and believes that adults of working age who are caring for someone should not have to give up their work to care (DH, 2010). The government has sought to strengthen the protection of carers in the workplace and to protect them from discrimination when seeking work through the Equality Act (2010) and by recognising their need for flexible working conditions.

of recovery, lack of best-practice team-level protocols for working with carers and lack of information about the symptoms mental ill-health in their relative, as reflected in other carer accounts (Repper et al, 2008; Worthington and Rooney, 2009).

The carers in this study had been caring for at least five years, so the data about the relevance of the recovery concept at this point in the journey was limited to their recall of events.

Stage 2: Overwhelmed by the disability

This next point in the service user's recovery journey is feeling <u>overwhelmed by the disability</u>. This is a state of confusion after the first occurrence of mental ill-health in the family, when there is often little time for reflection; it is dominated by fear of the future and the stigma of mental ill-health. This is when the carer becomes a 'carer', although they are unsure what is happening or what the future might hold.

The carers in the group said that this point holds confusion, chaos and trauma, with the recognition of grief following the establishment of the presence of mental illness, even if it is not yet diagnosed. It coincides with the <u>involvement of services</u>, as detailed by Cool Recovery (COOL, 2001). When services become involved, carers may receive little information about what is happening to the service user and find that they have less responsibility for determining what happens to them. They may have a sense of relief that things will get better now that professionals are involved, as reflected in the experiences of the carers' in this research.

Following the recovery training, the carers believed that it was important at this stage in the recovery journey that:
- professionals offer a positive prognosis for the service user
- the carer encourages the services user's agency and prevents their dependence
- the service user is encouraged to participate in meaningful activities in mainstream society.

Many of the carers in the group spoke of the trauma of this time as they struggled with chaos unsupported by professionals, family or others.

The early intervention in psychosis service - a local model of best practice - described their approach to the group of working with service users and carers in a recovery oriented way. As the carers reflected on this example they said that they believed professionals should become coaches in the recovery process (Roberts and Wolfson, 2004), enabling positive risk-taking, with responsibilities agreed by all in a Triangle of Care. Figure 7 illustrates the ideal elements that the carers identified in the relationship between the professional and the service user. They felt that professionals should be recovery mentors who encourage community engagement, believing that recovery was about doing.

This study also explored with the carers theories of social role valorisation (SRV) and labelling theory as underpinning the recovery concept and fundamental to its implementation;[87] drawing on Anthony (2000), who notes that the objectives of a recovery-oriented service should focus less on enabling the service user to function in society and more on enabling them to have a socially-valuable role. They believed that this would prevent the entrenchment of long-term disability by ensuring that the service user does not become over-dependent on the carer and mental health service providers. This best-practice model was not always reported by carers in this study, who sometimes felt very alone, as reflected in other research recounting carers' experiences (Kilyon and Smith, 2009).

As Figure 7 illustrates, this research found that in an ideal relationship between the carer and the professional, that the carer should understand the limits of professional responsibility and barriers to sharing information, and acknowledge that the opinions expressed by both them and the professional can differ. This should be underpinned by recognition that the carer's expertise is different to that of professionals. Similarly, professionals have a responsibility to agree on information protocols, work in partnership with the carer and agree their constituent responsibilities. This research emphasises the importance of team-level protocols in governing information-sharing

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[87]The former stresses the service user's need for a socially-valued role (Wolfensberger,1972; 1983), and the latter acknowledges the negative effect of a mental health diagnosis, generating discrimination against both service users and carers.

processes so that good practice is replicated by all practitioners in a mental health service.

This adds to existing work highlighting the importance of a three-cornered triangle of care between professionals, carers and service users (Hogman and Pearson, 1995; Worthington and Rooney, 2009), with careful sharing of information by all parties in an agreed and sensitive manner.

Stage 3: Struggling with the disability

The next stage for the service user is struggling with the disability (Spaniol et al 2002). They may struggle with chaotic thought patterns, negative symptoms, anxiety, stress and the debilitating side effects of medication. They may have to come to terms with the life-changing knowledge that they have a mental health diagnosis necessitating a long journey of recovery to health.

Cool Recovery describes this point in the carers' journey as recognition of grief, a time of acceptance and readjustment as the carer comes to terms with the situation and their new relationship with the cared-for person.   With an emphasis on recovery, the carers recognised that at this point they require:

- a positive prognosis and vision of recovery from professionals
- the family to maintain hope that the service user can recover
- the carer to support the service user by promoting their agency and independence.

Many of the carers had a family member who was at the point of 'struggling with the disability' in their recovery journey (Spaniol et al, 2002) , and recognised the need to work alongside professionals to promote the latter's independence. This study reinforces the perception that when the service user is struggling with the disability services should be hope-inspiring and positive in their outlook (Ramon, Healy and Renouf, 2007; Ramsey and Till, 2009; Shiers, Rosen and Shiers, 2009).

It was important at this stage for the carer's approach to change so that they became enablers rather than doers for their family member. Sometimes families believed that asking the service user to do small things added to the service user's stress, confirming the existing evidence base: Pernice-Duca (2010) reports that service users who felt

themselves in a relationship that involved giving as well as receiving made more progress towards recovery. It increased the sense of equity in the relationship and enhanced the service user's confidence and self-esteem. Pernice-Duca (ibid) found that a relationship of reciprocity also increased the service user's sense of optimism about the future. Lévi-Strauss (1969) refers to univocal reciprocity, which involves at least three people who indirectly benefit from each other (e.g. A gives to B who in turn gives to C). Family support that is not returned directly may be reciprocated to peers or the community, thus building up feelings of positivity. Family members' efforts may not be directly reciprocated but they need to be aware of how their actions may influence those of the service user. By building up expectations of reciprocity they can instil a sense of self-respect and personhood, and by requiring a level of respect both towards and from the service user they can help them to progress and support their recovery. Pernice-Duca (2010) emphasises that it may be important to modify family expectations of reciprocity and develop ways of constructing it by helping the family to reframe ways of giving that do not create stress in the service user.

Through a combination of creating opportunities for reciprocity and recognising the importance of giving the service user responsibility, carers can assist in their recovery, promoting agency, self-esteem and a sense of empowerment. This is a form of caring that begins during the later stages of recovery. It requires the carer to modify their own behaviour to enable the service user to feel more valued and able to participate in their own journey of recovery. Figure 7 reflects this notion of caring, which is underpinned by recognition of the expertise of both the service user in leading their own recovery and the carer's role as an expert in caring.

The carers in this research realised that the service user's self-esteem increased when they were able to reciprocate by helping out. This rebalanced the relationship and increased the service user's feelings of self-worth. However, the carers felt it more important to support the service user and did not like to stretch them beyond what they felt they were prepared to give. At the beginning of the training they had little recognition of the service user's responsibilities towards them except in terms of controlling aggression. As they discussed this throughout the research period they began to recognise that the service user's relationship to them should be underpinned by a recognition of the limits of caring and respect for the carer's person and belongings, as identified in Figure 7. Up to this point the carers believed that reciprocity should always

be on the service user's terms rather than on their terms. This finding adds to the existing knowledge base about the nature of giving and receiving care and provides a new synthesis about the effectiveness of caring roles in mental health recovery.

Stage 4: Living with the disability

The next point for the service user is a place of <u>living with the disability</u> (Spaniol et al 2002). This is characterised by the service user working actively towards a positive identity, setting meaningful goals and taking control of their own life. This can be very difficult to attain as they may feel stuck in a struggle with symptoms, and when they do reach this point the illness may limit what the service user can do. However, they feel that life has some worth and they have an identity of value. For most carers in this research, the pinnacle of recovery for their family member was learning to live with the disability.

The carers felt that acceptance was a key component of the journey of recovery: accepting that mental ill-health was present and that the diagnosis was real, and that long-term medication and treatment from the mental health services might be necessary to manage the condition. This echoes research that underlines carers' belief in the dominance of the biomedical model which identifies the professional as the expert in diagnosing and treating mental illness (Golightley, 2011), in contrast with more radical notions that identify the service user as an expert in managing their own condition (Coleman, 1999). However, as the training progressed the carers in this study developed a belief in their expertise-by-caring – a fundamental element in teaching carers about recovery and helping them to develop a sense of mastery in their caring role. Recovery care posits the importance of other methods of treatment beyond medication, emphasising that recovery means living with and managing the limitations of illness (Roberts and Wolfson, 2004), although after their initial diagnosis some service users may experience few symptoms throughout their lifetime.

Yanos et al (2008, p, 1437) discuss how a sense of acceptance of the mental distress diagnosis, when the service user aligns with that identity, can hinder rather than promote recovery because the service user 'loses previously held or hoped for identities (self as student, self as worker, self as parent, and so on) and adopts stigmatising views (self as dangerous, self as incompetent, and so on)'. This sense of a worthless and pathological self is referred to as 'internalised stigma'. It can seriously hinder the service user's

journey of recovery because even if they have opportunities to succeed, they no longer have the will or capacity to do so due to their feeling of inherent self-worthlessness. Internalised stigma can therefore affect the rebuilding of identity in recovery.

The research findings present the complexity of the notion of acceptance. Acceptance can positively influence recovery, enabling the service user and the carer to recognise the limitations that mental ill-health might place on the service user's life, accepting that the life course may be different – but still good – with mental ill-health; or it can hinder recovery, damaging all the service user's dreams and visions of the future, causing them to lose all hope. The carers struggled with the complexity of recovery as the acceptance of an illness and as hope for a good life beyond the illness label. This understanding adds to the existing evidence base on the carers' relationship with the recovery concept.

Cool Recovery identifies this point in the carer's journey as a process of <u>detaching with love</u>. It involves detaching and letting go, but doing this in hope and love – sometimes referred to as 'tough love' by carers of people who misuse substances. The carer begins to recognise that the service user must own their own recovery and begins to set a vision for both their own recovery journey and the new relationship that will emerge as the service user takes more control of their life.

The carers in the research all agreed that they had a central role to play in recovery, but learnt from participation in the programme that caring for recovery requires a redefinition of their tasks, role and identity as carers. They recognised the need to let the service user take recovery at their own pace, and how as carers they needed to let go of feeling responsible for their family member's life. The need to 'detach with love' is similarly described in traditional research on EE that recognises the over-involvement of carers (Brown, Birley and Wing, 1972), often females (Stern et al, 1999), in their support of a person with schizophrenia. However, redefining this process as detaching with love builds upon the positive aspects of recovery, allowing the carer to see themselves as an expert partner in care (Repper et al, 2008) rather than a malfunctioning family member.

The carers thought that service models such as an individual budget provided to service users can promote agency and prevent prolonged dependency. Yet although they noted that positive risk-taking is considered part of the recovery process, sometimes 'doing recovery' is used as an excuse to reduce services due to a lack of resources, as identified

by Stickley and Wright (2011a; 2011b). Many carers felt that they had to care for their relative to prevent the deterioration of the service user's health, and even filled the gaps between safe service provision and the lack of resources; as identified from carers' accounts in other studies (Repper et al, 2008). Sometimes they felt criticised for being overprotective, yet as Chandler (2010) notes, ultimately the carer must live with the consequences of mismanaged risk. Living with the disability requires carers and services to release control, ensuring that adequate risk management processes are in place. Yet this research emphasises the importance of a triangle of care with responsibilities agreed by all parties so that the care is seamless and safe but not risk-averse, as defined in current mental health policy (DH, 2010; DH, 2011a).

Stage 5: Living beyond the disability

The next step for the service user is living beyond the disability (Spaniol et al, 2002), when they live a full and meaningful life characterised by self-management of the illness, resilience and a positive sense of self. The illness dwindles in importance and stops dominating their life and interactions with the world. They are 'in recovery'.

As the carers learnt about recovery they were excited at the sense of hope that recovery conveys, but found it hard to believe that it could be anything but fragile and temporary. Sometimes, because of the fluctuating nature of recovery, the carers found it safer and less painful to believe in disappointment. In summary, believing in recovery can also entail a frightening and painful journey for the carers. When recovery was progressing it was a fragile belief, and when it was stationary it was a painful hope. They continued to believe that the mental health need would dominate the person's life and did not seem to recognise a place of living beyond the disability. Living beyond the illness encompasses not only independent living but also elements of enhanced self-esteem and self-worth.

This point in the recovery journey of the service user is represented in Cool Recovery as the carer setting a vision/goal of recovery. At this point the carer has the space and time to move on and get on with their life rather than being solely engaged in the caring role. They can look again at their own needs, see who they are and begin the journey of becoming themselves again rather than 'just a carer'. This point in the journey demonstrates the extent to which caring dominates both the life and the identity of the person supporting a family member with schizophrenia.

When service users with a diagnosis of schizophrenia can live successfully with their disability, some forms of acceptance of mental ill-health can lead to a positive sense of self. The person may accept the label of schizophrenia but see it as part of their expertise-by-experience, which they may use to become involved in research, improving mental health services or training other service users (Fox, 2011; 2012). Carers, too, need to be able to live beyond the caring label in their own journey of recovery.

The carers identified few responsibilities on the part of the service user towards either the carer or professionals. They did not acknowledge the service user's need for reciprocity, believing that this was a one-way relationship. As Figure 7 illustrates, using a strengths approach (Rapp, 1998), the research identified how professionals want service users to agree to levels of support and identify their own recovery needs; such an approach is at the heart of recovery. Underpinning these concepts is the acknowledgement that recovery is service-user-owned, requiring the service user to recognise their own autonomy and agency. Throughout the research period the carers grew increasingly aware of the need to acknowledge the service user's capacity, agency and responsibility for their own recovery.

At this stage of caring the carer can become a 'recovery mentor' by enabling the service user to take more control of their destiny and increase their agency, reflecting the role that Roberts and Wolfson (2004) identify for professionals as a 'coach'. The carer must move to a place where they can detach with love and support the service user in taking responsibility for their own life and destiny.

In the final stage, the carer begins to rebuild their own life, reclaiming their identity as a person beyond being a carer. They recognise that they need and want to live a life that is both intertwined with the service user's but also separate and independent.

This builds on existing research about the nature of caring in the related field of learning disability research, as identified by Grant (2010) (see Chapter 5). This research reiterates the importance of the professional recognising the mutualities in the relationship between the person with learning disabilities and their carer, and moreover recognising the family member as an expert and supporting them in their journey as a partner in care; a point must be reached at which all parties can reflect on the situation and plan for a future. Few service users in this study reached the point of living beyond

the disability, and consequently the carers did not reach a position of being able to detach with love. So much depends on the service user's own journey of recovery; although the principle of reciprocity identified by Pernice-Duca (2010) shows that the carer can promote the service user's recovery by encouraging them to be their own agent.

A new meaning of the recovery concept for carers

This chapter opened by discussing a journey of recovery for both service users and carers, based on the research findings reported in Chapter 6. The literature review in section 4.5 described the journey that carers' face in their caring role (Stern et al, 1999; Struening et al, 2001; Jones, 2002). The carers' journey described by these authors focuses on experiences of bereavement (Jones, 2002), stigma and role devaluation (Struening et al, 2001), with only one stressing the carers' ability to focus on positivity (Stern et al, 1999). Chapter 4 introduced two studies (Cool Recovery, 2003; SRN, 2009) focusing on the importance of carers' recovery, the former presenting a framework for understanding the carers' journey of recovery and the latter emphasising the need for more research in this area. In this chapter I focus on contextualising the findings and showing their relevance to developing an original contribution to knowledge.

The carers in this study experienced a journey of recovery that was contiguous and mutual yet was still separate from that of the service user. I have described how the carers understood the concept of recovery and responded to the different theories that underpin its development. Their response to their caring role was complex, reflecting the pain and disappointment that mental health issues can bring, but also the sense of positivity in recovery. Caring in a recovery-oriented way provided new opportunities for living their own lives beyond the caring role and beginning to let go of some of their fears, releasing the service user to lead a more independent life.

This chapter adds new meaning to the recovery concept for carers which draws on the findings and contextualises them to develop this original contribution to knowledge, which includes:
- how the carers related to what recovery meant for themselves and their family member
- their need to care differently at different stages in the recovery journey
- the impact that learning about recovery had on their caring role

- the elements that made up the carers' journey of recovery
- a vision of partnership with professionals in support of the recovery of both the service user and the carer.

This new meaning reflects the questions that the research sought to explore, as set out at the beginning of the study. It encompasses carers' relationship with recovery and their vision of recovery in their caring role. It emphasises the need for carers to 'care for recovery', embracing a process that fosters the user's independence, agency and autonomy. It embraces the impact of learning about recovery on their caring role, allowing them to further their own recovery and live beyond their caring identity.

A new meaning of the recovery concept for carers reflects and complements the notion of personal recovery in the service user movement. It embraces the notion of living well within the limitations of the illness, yet acknowledges both the carer's and the service user's desire and need to live beyond the diagnosis. It embraces the importance of hope and optimism combined with acceptance and realism, but always holds onto the possibility of recovery for both parties. It indicates ways in which recovery can be achieved through practical ways of caring and being cared for. It is a useful, original and important contribution to the debate about the relevance of recovery to carers of people with schizophrenia.

The next section explores the implications of these research findings for practical service implementation and connects the carers' journey of recovery with a recovery service model.

7.2 A service model of recovery

Recovery has become a service model of increasing interest over the past ten years (DH, 2005; 2009; 2011a) as is described in Chapters 3 and 4. Carers have had little influence in the development of mental health services (Lammers and Happell, 2004; Fox, 2009) or in the development of the recovery concept (SRN, 2009; Kilyon and Smith, 2009). Carer involvement in care planning processes and service planning is less than their service user counterparts (Arksey et al, 2002) despite the formation of specific

organisations such the National Schizophrenia Fellowship[88] (NSF) (described in Chapter 2) and other carer organisations such as the Princess Royal Trust for Carers and Carers UK. Cambridge and Peterborough Foundation Trust (CPFT, 2012b) reports that local carers are under-involved in care planning procedures (see Chapter 2), despite policy which acknowledges their expertise in the person they support (DH, 2010; 2011a); although it is committed to developing more Carer Ambassador roles[89] and encouraging carers to become Governors on its Board as a Foundation Trust.

Despite rhetoric and policy to the contrary, carers are an under-involved and under-used resource in mental health. Learning about recovery allowed the carers in this research to see the potential for mental health services to work in new ways and to allow them to influence service change.

Although service design and delivery was not a principal focus of my work, nevertheless implicit in the carers' discussion throughout the research were their views about good and bad practice, how they dreamed their family member would be supported by professionals, and how they themselves wanted to be treated by mental health services. These ideas extend beyond the empirical focus of my study, but are relevant in a broader perspective as there has been relatively little research that explores carers' views on recovery or processes that actively seek their contribution to this process (SRN, 2009; Kilyon and Smith, 2009).

Figure 8 builds on the carers' vision for services and their belief in partnership working between the service user and the carer. It presents a possible developmental service model of recovery, building on the snapshot of recovery oriented Triangle of Care in

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88 As described in Chapter 2, the power of carers in the National Schizophrenia Fellowship has been diluted as it focuses more on the needs of service users. Its name change to Rethink also reflects the change of direction.

89 CPFT offers selected carers the opportunity to represent the views of other carers in the Trust area and be involved in research, patient and public involvement processes, and in providing their views on policy and practice developments.

Figure 7, and promotes both the carer's and the service user's recovery, but it based on the views expressed by the carers in this study.

Building on the literature review and the findings from this study, Diagram 6 depicts a service model developed from the carers' perspective that reflects both their needs and those of service users. It builds on the findings presented in Chapter 6 and the existing evidence base described in Chapters 3 and 4 which depict the key determinants for effective service delivery.

Figure 8 draws on Thompson's (2003; 2006) systems map and Thornicroft and Tansella's (1999) mental health matrix. The former presents a circular systems map that shows the interacting levels of a system around an individual patient and denotes cultural and structural elements that impact on their life.[90] The latter consists of two parts: a temporal and spatial framework. (The temporal framework is not applied). The geographical levels demonstrate a hierarchy of geographical location starting from the widest framework to the narrowest experience of service delivery. These levels are identified as: country / regional level, the local level, and patient level.[91] Thompson's model shows the dynamic interaction of each part of the system, while that of Thornicroft and Tansella is more static and less responsive to change and learning as a recovery service needs to be (Ramon, 2011). Figure 8 seeks to describe and understand the carers' vision of each different element in the system that is needed to develop and deliver recovery for service users and carers.

Based on the perspective of the carers in this study the inner circle of Figure 8 reflects issues identified in more general terms in Figure 7. It envisions that support at the patient level should focus on a three-cornered partnership between the service user, carer and professional based on transparent and agreed processes of information exchange. The professional should emulate a role as a coach rather than an authority, promoting self management of mental ill health.

The second circle shows how a mental health team could develop a recovery focus and engage in training processes to up-skill staff focusing on:
- Training staff to work as mentors and coaches

90See Appendix 47.

91 See Appendix 48.

- Providing activities which re-build identity through encouraging roles of social value
- Developing effective care planning procedures which encourage self management of mental health through personalised support
- Developing effective risk management processes
- Developing partnership protocols with families.

The final outer circle shows the how the country / regional level interacts and governs the action of the two inner rings. The government administration is responsible for setting the mental health agenda, the development and implementation of policies that protect service users' and carers' rights, processes that support mental health promotion at a societal level and for developing protective mental health laws. Figure 8 uses systems theory, presupposing that a change in one element of the system influences and subsequently changes another element and the system as a whole. Systems change can only happen when all levels of the circle are working together towards a new model.

The carers were concerned at how recovery services could be developed when professionals were less aware of recovery than they or did not want to work to recovery values which demanded so much more of them than traditional models of practice. The political commitment to recovery was stated but the carers found it hard to believe that recovery practice was real or different; however following the presentation from the Early Intervention in Psychosis Service in the training programme they could understand the composition of such a model although they questioned the effectiveness of implementation processes.

Recent research describes the successful introduction of recovery practice into diverse mental health settings in the UK (Valinejad et al, 2007; Connor, 2008; Slade, Luke, and Knowles, 2009, Shepherd, Boardman and Burns 2010; Ramon, 2011; MHN NHS Confederation, 2012). Chapter 2 describes processes for introducing the 10 key organisational challenges in reconfiguring mental health services (Shepherd, Boardman and Burns, 2010), highlights the progress of the ImROC programme (MHN NHS Confederation, 2012) and considers the REFOCUS study developed at the Institute of Psychiatry. Chapter 3 describes the implementation of recovery in mental health services focusing on the need for a team approach to transform the delivery of services (Valinejad et al, 2007; Connor, 2008; Slade, Luke, and Knowles, 2009), the need for

concrete exercises to help practitioners understand the *how* rather than the *what* of recovery (Slade, Luke, and Knowles, 2009) and a system approach to transform organisational culture (Connor, 2008). Recent research on recovery oriented change is described below which builds on the existing evidence base.

Ramon (2011) emphasises the importance of each organisation becoming a 'learning organisation' (Argyris and Schon, 1978; Senge, 1990; Gould and Baldwin, 2004) with a participatory approach to learning in order for transformative change to occur. The learning organisation must encompass three layers of leadership, working together to support the diffusion of recovery-oriented practice:
- local line leaders, who undertake meaningful organisational experiments to test the effectiveness of new learning capabilities
- executive leaders who support the line leaders, develop learning infrastructures and lead by example
- internal networkers or community builders, whose role is to spot those more ready for change, help in organisational experiments and aid the diffusion of new learning (Senge, 1990).

Service reconfiguration needs to include the views and opinions of all stakeholders from practitioners to carers to service users to managers and policy makers at all levels of the system (Ramon, 2011; Boardman and Shepherd, 2012). This emphasises the need for all stakeholders in a system to work together to effect change.

Boardman and Shepherd (2012) believe that services need to change on three levels to make recovery a reality in the UK: practice with staff and professional training; service organisation and delivery; and the culture of services. Change must happen systematically, accompanied by service user and carer collaboration in the redesign of services. At the level of the relationship between the practitioner and service users there needs to be a shift of emphasis to partnership between experts-by-experience, with professionals facilitating recovery, offering hope and encouraging full inclusion in the community. At the cultural level, service users need to be involved at all levels of decision-making in the organisation regarding staff development, management processes and physically at all levels in the organisation.

These programmes present the current status of the implementation of recovery services in the UK and the current evidence base that underpins transformational organisational change in mental health. Learning from the ImROC project (MHN NHS Confederation, 2012) however confirms that there is 'no one size fits all' to implementing recovery oriented services but note that it is easier and quicker to progress change when the organisation is already founded on recovery principles. None of these studies however address the needs of carers and family members who support their friend, spouse or relative with mental ill-health on their recovery journey which gives greater credence to the model set out in Figure 8.

Although these studies reinforce the importance of systems level changes to ensure that recovery is implemented at all levels of a mental health service, Stickley and Wright (2011a; 2011b) note that recovery needs to remain true to its roots in the service user movement and not be appropriated by professionals, remaining a way of working that is person-centred rather than service or model-led. Indeed Boardman and Shepherd (2012) suggest that services can maintain connections with the grass roots by ensuring that service users lead recovery training and by employing peer support workers in mental health services. This reinforces the need for professionals to learn about recovery as a service user-owned experience rather than a new practice model.[92]

Carers' potential to be involved in service planning and development is important, and their involvement in research is a key to facilitating this; MHRN (2012a; 2012b) notes that the active involvement of carers in research has the potential to increase their involvement in planning care at an individual level and in service development and monitoring. This research was founded on an emancipatory methodology that emphasises action, learning and transformative change (Ledwith and Springett, 2010) therefore its application to practical service delivery and implementation is important. Indeed, although some carers (F03, M03, F05) were actively involved in influencing the development of services before participation in the training programme, two carers (F01 and F02), who had formerly not been involved in developing services in any way, later

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92 The possible diminishing role of recovery as a service model is acknowledged as new models of Payments by Results and clustering are introduced into mental health systems; although it is too early to yet predict either the same or a new direction of travel in mental health policy.

became involved as advisors to a research project on shared decision-making process in mental health medication. By teaching carers about recovery, they can begin to participate in the growing debate about the future of mental health services, and as a much neglected stakeholder group (MHRN, 2012a; 2012b) need an opportunity to participate in shaping its development.

7.3 The training intervention

The carers evaluated the training programme as useful in enabling them to explore issues associated with recovery and helpful in enabling them to understand the practical impact of caring on their role in the recovery process. The study explored the meaning of recovery for carers, and using extensive follow-up processes, evaluated whether learning about recovery led to lasting change in their attitudes, behaviour and caring roles. It enabled the carers to reflect on the progressive nature of recovery, consider their own process of recovery (Spaniol et al, 2002) and live beyond their caring role (Davidson, 2003).

A training intervention programme which focuses on recovery has to reflect and understand the journey of recovery faced by both carers and service users. The first part of this chapter described the journeys that were traversed by both the carer and the service user and how caring had to respond to different stages in the service user's recovery journey. It also showed how the carers themselves experienced a staged model of recovery.

As the literature review showed, few interventions have been developed which focus on a recovery foundation, many focus on pre-recovery frameworks such as family systems research and therapy (Fromm-Reichman, 1948), expressed emotion research (Brown, Birley and Wing, 1972) and studies of family burden (Grad and Sainsbury, 1963). This section discusses the uniqueness of this training programme as a recovery intervention in the wider context of family interventions.

I could not find any previous studies that focused on delivering recovery-oriented interventions to carers or evaluated the change in carers as a result of learning about recovery. As discussed in the literature review, most training for carers originates from a pre-recovery model and focuses on the carer burden or carers' psycho-education, rather than on the carer as the expert in caring for the service user. This training programme is

unique focusing on the meaning of recovery to carers. This topic is addressed by Glynn et al (2006) who identify the potential impact of the recovery movement on family interventions for schizophrenia. They argue that many family interventions already draw implicitly on the recovery approach with their commitment to information about the illness, the importance of problem-solving through skills training and commitment to working towards long-term consumer-driven goal setting; however, they note (ibid, p. 452):

> 'Nevertheless, most of the validated family interventions would benefit from further refinement to be totally consistent with recovery values. Modifications in language, content, and outcomes of concern are necessary to reflect fully a recovery orientation'.

The success of traditional family interventions has been evaluated by the reduction in service user relapse rates by addressing high Expressed Emotion (EE) and over-involvement in carers (Brown, Birley, and Wing, 1972); however, family interventions need to refocus on recovery values by emphasising the quality of life in the 'journey of recovering, rather than focusing solely on relapse management (Glynn et al, 2006). They need to focus on longer-term service users who are experiencing recovery rather than solely on the new population of service users diagnosed with mental ill-health. Moreover, they need to emphasise the service user's opportunities to lead a successful life in recovery, rather than focusing on their achieving long-term management of a chronic condition that may need life-long treatment. Many family support programmes lack emphasis on the importance of peer support in enabling recovery, yet this is central to the recovery movement (Glynn et al, 2006). It is often the relative or family who leads the goal-setting in family therapy, rather than goals that are consumer-owned and -driven (ibid).

Family interventions were originally aimed at parents caring for young to middle-aged dependent adults with content and format targeted at caring for this population. They should now address the needs of carers for service users of different ages, at different stages of recovery, and with different needs (ibid). For example, family interventions rarely focus on or address the needs of the partners or spouses of people with schizophrenia in recovery, such as sexual dysfunction due to medication, emotional withdrawal as a result of illness, or indeed issues of parenting. Similarly there has been a failure to incorporate life span development theories into family interventions as older people and siblings become the primary carers of older people with schizophrenia in

recovery as their parents die. And finally, Glynn et al (2006) note that family interventions need to be tailored to the cultural requirements of each family, as service users from different backgrounds have different expectations of their family's involvement in their care (Kalathil, 2010).

The training programme developed in this PhD research has addressed some of the issues identified by Glynn et al (2006). It targeted carers who provided long-term care for at least five years, specifically meeting the needs of carers who had had time to reflect on the illness course and could reflect upon their caring behaviour, rather than carers who were in shock at the initial chaos of mental ill-health. We noted during its development that a training programme for carers who had supported their loved one for a shorter period of time would have to be different in nature and content. Our training met the needs of carers for people in recovery, rather than focusing solely on relapse reduction and management. The carers revealed how learning about recovery changed their attitudes and behaviour and gave them hope, despite having cared for the service user for more than five years. The cathartic process of the training programme helped them to experience their own recovery through participation in the project.

Expertise-by-caring and expertise-by-experience underpinned the development and delivery of this programme and were fundamental in its success. The carers noted how seeing the authenticity of recovery in both trainers, particularly in me in my identity as a service user, made recovery credible. This training programme emphasised the centrality of service-user-owned recovery and the need to recognise the service user's aspirations for their life. Spending time on the training programme and building on positive caring helped the carers to see the difference between mothering and smothering, enabling them to realise that the service user must own their own recovery.

This recovery training used the language of personal recovery, which is positive and active couched in a comprehensive and logical framework, building on a strengths approach to caring. By talking about recovery that focuses on building hope rather than changing behaviour, the carers automatically moved on to thinking about how they could change their own behaviour. The training emphasised the carers' expertise-by-caring, allowing them confidence in what they were doing and changing their behaviour constructively. The evaluation showed that changes in behaviour were sustained six months after the end of the programme.

This study was important in changing the carers' individual approach to caring, and has the potential to be rolled out and delivered more widely to carers in the Mental Health Trust and beyond. However Dixon et al (2001) note that family interventions of all types have not been implemented successfully. Obstacles that prevent clinicians and practitioners from supporting the wider implementation of psycho-education include their lack of awareness of the contribution that carers can make to recovery and their doubts about the effectiveness of family psycho-education compared to the more immediate relief of medication at less cost. Experience shows that effective implementation of family interventions at a wider level relies on the provider organisation working in partnership with family and consumer organisations to repeat the programme over a number of years to build on successes (Dixon et al, 2001).

This section has described the uniqueness of this training programme in the wider context of family interventions, highlighting the influence of the recovery approach in its development and delivery.

7.4 Conclusion

I have shown how the carers related to the recovery concept and began to see it as a real possibility for their family member and for themselves, how they defined their own role in the recovery process, responding to the learning in the training programme which influenced their attitudes, behaviour and beliefs about caring. Most carers in the group felt undervalued by practitioners and often excluded from their relative's care, despite policy recognition that carers have 'an expert knowledge of the condition of the person they are supporting and have a close understanding of that person's own aspirations and needs' (DH, 2010 p. 10). The carers believed that the importance of learning about recovery was in its practical implementation. They identified how different actions by mental health services and mental health professionals can support both their and the service user's recovery. Positive risk-taking has a role to play in the new way of caring for recovery, and personalisation and direct payments are ways of supporting recovery-oriented care. A service model based on the carers' optimal contribution to the service user' recovery was highlighted in the second section with an exploration of the conditions necessary to implement service change. The third section described the uniqueness of this training programme in focusing on recovery and its potential to lead

to sustained change in carers' behaviour and attitudes with its focus on recovery rather than pre-recovery models and its emphasis on expertise-by-caring.

Although the findings only represent the viewpoints of a small number of carers, the data clarify and enrich this under-researched topic and contribute to the development of a recovery concept for carers. This original contribution to knowledge is both theoretical, presenting new knowledge about carers' relationship with recovery, and practical, in its potential impact on services. I have identified the major obstacles and opportunities in recovery, and the potential for connection between research theory and the practical implementation of recovery.

The carers' definition of recovery and how it is used is important for the research community, because it throws fresh light on how carers perceive and relate to recovery, and indeed how we can support carers and, indirectly, the service user in the future. For the carers to begin to live their recovery, they had to stop seeing their identity as only that of a carer and begin to value themselves and their knowledge, seeing themselves as experts-by-caring as at the follow-up focus group F04 said:

> I really learnt a lot from doing this course and thinking about what recovery is. And for me, it's just freed me up so much, it's stopped me thinking that there are experts out there who diagnose my brother, who tell me what will happen, and I'm desperate for them to help me. I'm not looking there anymore; it's me and my brother, and we can work through it. (FG2F04)

Empowering carers can promote recovery as a reality for carers and the service user.

Chapter 8 considers the methodological assumptions of the research and discusses the strengths and weaknesses of the research design.

Chapter 8. Consideration of the methodological assumptions and research design

8.0 Introduction

Participatory Action Research (PAR) is a process of simultaneous collaborative learning, action and reflection (Winter and Munn-Giddings, 2001), with an emphasis on the power of research to bring about transformative change in practice and society (Ledwith and Springett, 2010).   As set out in Chapter 5 the following criteria underpin the methodological perspectives and the choice of research design, which are fundamental to the discussion of the research process in this chapter:

- the need for inter-subjective validity (Steinke, 2004)
- belief in the experiential content of knowledge (Heron and Reason, 1997)
- belief in the moral and political imperative of PAR, and all research, to change and develop situations (Reason and Torbert, 2001)
- the belief that no researcher can be objective (Guba and Lincoln, 2005)
- the belief that the researcher's identity is part of the research process, and it is better to bracket and present that identity than attempt to exclude it (Guba and Lincoln, 2005)
- belief in the valued knowledge of service users, carers and practice wisdom (Glasby and Beresford, 2006)
- the importance of presenting the collaborators' dialectical discussion for rigorous and valid data (Winter, 2002)

McIntyre (2008) underlines the importance of undertaking PAR ethically and justly and notes that the formative process is as important as the summative outcomes in the quest for social justice.   This chapter reflects on the formative processes in the research and describes the strengths and limitations of the research design and the difference between my intentions and the actual actions in the research process.

8.1 Stakeholder involvement

PAR seeks to promote meaningful rather than tokenistic stakeholder involvement throughout the lifetime of the study concerned (Freire, 1972; Winter and Munn-Giddings, 2001; Staley, 2009; Faulkner 2010). This section discusses the stakeholders' contribution to the study as both members of the steering group and participants in the programme, highlighting the methodological implications.

The involvement of the public is increasingly politically mandated in the development of publicly-funded health service research in the UK (NIHR, 2012), due to:

- a commitment to the human rights of people who use services (Uhm et al, 2012)
- its effectiveness in supporting effective methodologies (Faulkner, 2010) and
- reasons of political expediency (DH, 2011a).

Stakeholders were not involved in writing the PhD research proposal or setting the agenda of the research as best practice might suggest (Staley, 2009). The steering group was formed once the proposal had been accepted, Ethics Committee permission had been granted and the training programme had been developed to the point of an initial draft. As a new researcher, it was too difficult to build an effective team around me as I formulated the research proposal, although now, with increased experience and confidence in my ability to conduct PAR, I would incorporate steering group viewpoints earlier. Despite this, the group members felt that their involvement was brought in at the right time and their expertise was used correctly.

It is important to pay stakeholders involved in research and reimburse their expenses (Staley, 2009; Faulkner, 2010), as this provides recognition of their expertise and rewards them for their time.[93] Initially there was no budget to support the involvement of the service user and carer in the steering group. This was sourced from the CPFT while developing the research proposal. Realistic costs should be built into the research right from the beginning of the project (Staley, 2009) although in this study I was unable to involve and pay service users at the development stage, as I had not sourced the funding at that point. This limitation is reported by many researchers who are unable to involve service users in the initial research design stage (Staley, 2009). Some service users believe that offering a financial reward can provide the wrong motivation for participation (Staley 2009), as people may then participate for the reward rather than through a commitment to change. Faulkner (2010) finds that user researchers often have a strong emotional investment in seeing the research succeed, and commit more hours to undertaking research than the funds they are allocated can support. The experts-by-

93 The complexities of the welfare benefits system can often impede service users who are in receipt of benefits from accepting payment (Staley, 2009) for their involvement. It is important to allow them the choice to accept or refuse payment.

experience/caring in this research found the payment for their time a valuable acknowledgement of their skills and abilities.

The members of the steering group were recruited via purposive sampling for their individual expertise and skills. The professionals all had expertise or commitment to recovery in research or practice or expertise in working with carers, and the service user and carer were selected for their expertise in delivering service-user and carer training and their commitment to recovery, ensuring that they were familiar with the topic as well as being informed by lived experience (Uhm et al, 2012). Selecting the members carefully from a cross-section of experts kept the research grounded in the concerns of carers with a strong ethical base and the potential to change practice in the Foundation Trust and beyond.

Some researchers express concerns that people who regularly use their knowledge of their disability to inform research and practice have become 'professional' service users and are disconnected from the reality of experience (Harrison, 2002). It could be argued that I limited the service user/carer representation on the steering group to seasoned committee members who did not represent the wider service user/carer population (Rhodes et al, 2002) and that the service user and carer on my steering group could not meaningfully represent their wider peer group as they were selected for their skills and expertise (Harrison, 2002). This debate raises wider concerns about the validity of user knowledge (Fox, 2007; 2008) and prompts questions such as, 'Who is an authentic service user?' and, 'Can expertise by experience be informed by knowledge and refined by reflection and still remain grounded in real experience?'

In Fox (2011; 2012) I describe my experiences of discrimination in my workplace and when receiving maternity services as a mother-to-be as a service user with a diagnosis of schizophrenia. Both articles are grounded in lived experience, but the process of reflection and writing enhanced and refined my struggle with both work colleagues and maternity services to create a narrative that critiqued their response to my mental health needs. This process of reflecting and writing the articles did not minimise the struggle: I was no less a service user because of my knowledge and expertise, and no more a professional service user having recorded my experience. Similarly, in this study the knowledge of the service user and carer steering group members was authentic: it was grounded in their identities as user of services and carer.

<u>8.2 The action research cycles</u>

This project involved research collaborators at the top end of Arnstein's (1969) ladder of involvement. Arnstein's ladder was the first presentation of community involvement in research, and shows the different levels of involvement that organisations can achieve (See Figure 9).

Figure 9: Arnstein's (1969) Ladder of Participation

It has been argued that to be pure PAR or pure user-led research, power and control must be shared through a structured and rolling process that incorporates the action research cycle with distinct and identifiable collective decision-making (Staley, 2009; Faulkner, 2010). The participation and control of the decision making in this research were more pronounced in the steering group, which contributed to the design and development of the training programme; the action research component was more pronounced in the training programme as the carers contributed to its evaluation and subsequent development.

Figure 10 depicts the utilisation of PAR in this research. Each cycle of PAR (Kemmis and Mc Taggart, 1988; Ledwith and Springett, 2010) contributed to the development of theory about recovery, the development, implementation and subsequent evaluation of the training programme, and the development of the findings. Figure 10 indicates how individual phases in the research were inter-related; each individual phase of the PAR process was underpinned by an interlocking PAR process governing the whole project.

Each cycle was underpinned by the Action Research Cycle of: Plan, Act, Review, Revised Plan (Kemmis and Mc Taggart, 1988) described in the methodology and illustrated in Figure 2. This cycle underpins the research process and the action and reflection that resulted from each cycle. The planning phase of each cycle included setting up ethical procedures to govern each interaction (e.g. Terms of Reference for the Steering group and individual meetings with each individual carer to ensure they understood the research and could participate in meetings having given their informed consent). Each phase of the research undertook an action to achieve its identified outcomes (e.g., contributing to the development of the training programme for the steering group). Each phase produced its own reflections to improve later action and inform the generation of research theory. This process led to improvements in the overall research process which in turn fed into a revised plan.

Figure 10 illustrates how the first PAR cycle is utilised by the steering group to develop the initial theoretical underpinning of the research, and research design, data collection methods and training programme delivery. This cycle was characterised by participatory decision-making processes that are central to PAR. The supervisory team contributed most intensively to this phase of the research, supporting the development of the research design and methodology.

A second PAR cycle took place with the carers as they participated in the training programme and contributed to its evaluation. The carers shared their experiences with their peers, reflecting on the meaning of recovery. They contributed to the iterative cycle of PAR that allowed me to develop the research findings and were subsequently encouraged to contribute to the formative evaluation of the training programme.

A third PAR cycle took place in the final stages of the research. This phase was underpinned by a process of reflection – for indeed as Winter and Munn-Giddings (2001) note, reflection can be part of action in the Action Research cycle. This phase involved a personal process of reflection that led to the development of the findings. I sought methods to involve both the carers in an iterative cycle of reflection at the follow-up contacts at one month and six months, and the steering group throughout the project life course. This process contributed to the preparation of the training programme for further roll-out through Recovery College East.

The whole process was governed by a cycle of planning, action, reflection and revision that underpinned each phase of the research. As the sole researcher, I ensured that:

- each different constituent of the research was coordinated to ensure it contributed effectively to the overall development of the research
- reflections and ideas generated from each different stakeholder group were recorded to give equal parity to different expertise
- each phase was underpinned by the ethical processes of PAR
- both the formative development of theories and processes in each phase were valued and the summative outcomes that each research phase needed to accomplish were achieved.

I now discuss each individual phase of the three action research cycles and consider how as a whole they contributed to the development, implementation and findings of the research.

8.2.1 The steering group involvement
In this section, I give a flavour of the way that PAR was used in this study and then provide reflection on the way the steering group contributed to the research design, the development of the data collection tools, and how they held power in this process. I discuss their concerns about the relationship with the supervisory group and conclude this subsection with a summary of the members' reflections on their involvement.

Figure 11 shows how each cog represented below fed into the first PAR phase of the overarching research process shown in Figure 10. The steering group contributed more intensively than in other cycles to the first cycle of PAR, while the supervisory team had an overview of the whole process of this first phase. The different expertise in the group from different perspectives (as researchers, service users, carers, practitioners and managers) underpinned the interacting cycles and influenced the process. As a sole researcher, I had to manage the different expertise from the steering group and the supervisory team and manage any conflicting issues. The operation of this first phase in the research is now discussed.

Figure 11: The interacting influences in the first PAR cycle

The strengths of the steering group were in their practical expertise as practitioners who worked closely with carers and service users, in research, and with their personal expertise as a carer and a service user. The group process of reviewing a vignette, which was intended as a prompt to support discussion with carers about caring for someone and support from direct payments is described. The discussion shows how each type of knowledge was valued and how each member was able to bring their knowledge to the study.

The vignette[94] described the relapse of a hypothetical service user with schizophrenia, Peter, and his difficult and conflicting relationship with his parents. The steering group had approved the vignette at a meeting when KE was absent. KE, a trained CPN, challenged me about its suitability when it was discussed at a later meeting (SG7). KE noted that the vignette seemed to originate from a medical rather than a recovery model. It focused on stopping medication as the only reason for Peter's relapse, and on a relationship of dependency with professionals and carers. To become recovery-led it needed to focus on Peter leading a life as a person who was 'more than a patient', and to include positive factors that gave him a life worth recovering to. Indeed Hughes (1998) states that the vignette must be authentic enough to allow the respondent to relate to it, but 'vague' enough to force participants to describe what precipitating factors influenced their decisions about what actions to take in the vignette.

I was the principle investigator, convener and facilitator of this group, and knew what I wanted them to achieve at each meeting. As a new researcher I was very nervous about the facilitation process and concerned about how to allow enough time for group discussion without risking us becoming too side-tracked. My first reaction to KE's challenge was to close the discussion because I felt insecure and confronted. My second response was positive, accepting the criticism and being open to where it took us.

The steering group members introduced a recovery focus to the vignette: Peter was given a life that was interesting and rewarding with opportunities for development. A

94 See footnote 72 for clarification.

relationship breakup had contributed to his breakdown, but he had a good life which offered independence and volunteering opportunities, to which he could return on his recovery. The vignette was finally approved by all steering group members after being circulated for further discussion and amendment.[95]

When I reflected on this incident I realised that PAR requires the facilitator to have the personal confidence to allow discussion to take place and to trust the collaborators and their skills. This situation taught me that PAR is underpinned by a creative process which demands that the researcher shares power and allows the collaborators the freedom and flexibility to influence the research, while requiring the group to achieve the research deadlines; as such the group facilitator needs high standards of facilitation and negotiation skills, underpinned by respectful communication (Staley, 2009).

When the steering group first began to meet, the members expressed concerns about their relationship with the supervisory team, which they feared might overrule their decisions. KE believed that the strength of the group was in how it '[brought] a sort of realism and practicality to the thing' (SG1KE) and felt that this important contribution should not be undermined. The group members acknowledged that it was important to have a working relationship with the supervisory team, which had a different responsibility in the research process: the overall responsibility to the University to advise on quality aspects of the PhD study and ensure its ethical conduct. The supervisors were sensitive to these concerns and offered helpful and constructive advice by providing an overview of practical methodological concerns. Slade et al (2010, a paper that I co-authored) suggest that in a project with multiple steering groups it is helpful to ensure:

- that each group has effective terms of reference
- effective cross-fertilisation between groups
- awareness of how the different types of expertise and of knowledge (user, practitioner, researcher, carer) interact, contradict and inform the research processes.

By being open and transparent about decision-making processes, no difficulties were encountered.

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95 See Appendix 49 for the final version of the vignette.

Throughout the lifetime of the steering group meetings, members spoke about their involvement in the group and its impact on their personal and professional learning. Their reflections on their participation in the group are now described which contributed to the generation of theory as they participated in the research process.

KI was a service-user trainer who was accustomed to thinking about the primacy of the service user in the training she delivered. She felt that the training programme had enabled her to think more about the interconnection between service users, professionals and carers:

> I know that my head is so firmly service-user focused that this has made me actually look through a carer's eyes, and I find it enormously difficult, because my focus has always been so service-user. (SG5KI)

The steering group members reflected on involvement in the research at the follow-up meeting after the delivery of the training programme, set up to review initial results.[96] This meeting was only attended by JS, R2 and I, with the others asking for written feedback. R2 felt that her involvement as a carer trainer reassured the carers as they participated in the training and increased the authenticity of the research:

> And I felt that early on I had to talk to them about why I believed in recovery, and I had to lay my cards on the table, and then after that they didn't really challenge me very much, they challenged R1... But they would talk to me about little things that had gone wrong in a sort of 'this had happened', 'that had happened' and in between and what not. So I think it's quite important to have a carer presence there... (SG9R2)

JS and KE facilitated the follow-up focus group with the carers. JS's professional role was to increase the involvement of service users and carers in research undertaken in the mental health trust area. She also had strong personal commitments to this process. She noted how my identity as a service user trainer was central to the research allowing the carers to identify with the possibility of recovery – as they could see it really happening in me.

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96 The initial research findings were presented at the Cambridgeshire and Peterborough Foundation Trust recovery conference in June 2009. This was presented to the steering group at the follow up meeting and also to the carers in the last training programme session. The latter part of the presentation is found in Appendix 11.

> I think that's one of the main things that came out of the focus group as well, the power of the trainer that has direct experience of mental health issues. (SG9JS)

She found the service user identity a key to the success of the programme.

The research process taught me valuable skills of negotiation whilst facilitating a meeting or a discussion. It taught me some of the essential the skills that are inherent in facilitating research which uses PAR and how process can be as important as outcome for research. Steering group members found that their involvement challenged their learning and practice and was a useful and helpful part of their development. The personal experience of being a service user or carer sometimes made involvement difficult and emotional, but the close-knit feeling of the group, with its openness to learning, ensured that contributors were supported.

8.2.2 The carers' involvement

The carers fed into the second phase of the PAR cycle as depicted in Figure 10. They contributed to the process of data collection and analysis through different mechanisms including participant validation, formative development of the training programme, recognition of their power in the training process and feedback on the development of the data analysis. These mechanisms meant that while their views were actively sought, they did not have equal power with me in the project. The levels of their involvement are highlighted alongside a discussion of the theory and practice supporting service user and carer involvement.

INVOLVE, the UK body charged with responsibility for developing public and patient involvement in health and social-care research (Hanley et al, 2000; 2004; 2012), proposes three levels of service user and carers' involvement in research: consultation, collaboration and control. Staley et al, (2009, p. 13) define the meaning of public involvement as 'doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public'. Nolan et al (2007 p. 10) further develops these ideas connecting involvement in research with levels of power disseminated to service users. Nolan et al (2007, p. 10) surveyed the literature and present a number of criteria developed by different authors to propose the levels of involvement that should govern truly participatory research.[97] This also relates to the levels of power disseminated to service

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97 See Appendix 50.

users and carers involved in the research processes. It moves from the levels defined by Minkler and Wallerstein (2003) which focus on the elements of co-operation and partnership working, to that embodied by Turner and Beresford (2005b) that research must be emancipatory and controlled by service users themselves.

Sweeney and Morgan (2009) acknowledge the different stages of research that involve different levels of involvement or decision making. They propose an extra level of involvement between consultation and collaboration on the INVOLVE level which they call 'contribution' and define as: '...research where service users/survivors make a significant and meaningful contribution to research but with power and decision-making still residing with traditional researchers' (ibid p. 9).

The carers' participation in the training programme was situated at this level of 'contribution' as described by Sweeney and Morgan (2009) allowing them to influence the research and make a significant contribution. It can however be difficult for service users and carers to believe they have power in a research process because their contact with services can lead them to feel under-skilled, under-prepared and often disempowered (Fox, 2009). Their contribution however influenced the second action research cycle developing the content, format and process of the training programme and the development of theory about carers and recovery. Their empowerment is seen in their reflections on their new found confidence in their expertise-by-caring and a belief in their own knowledge and skills as described in Chapter 6.

8.2.3 The reflective process

Reflection took place throughout the research, as the opportunity to engage in the research topic helped me to develop ideas and concepts that reached further than my PhD study and contributed to other research projects. This formed a third action research cycle as shown in Figure 10. My personal reflective processes were influenced by different elements that made up my identity and my different roles in the research, as:

- the facilitator of the training programme who has got to know the carers and built up a good relationship and rapport with them
- a researcher undertaking the evaluation and exploring the data collected both during the training programme and the follow up interviews
- a service user who understands and relates to the recovery journey and has been supported through the recovery process by parent carers.

- a trained and registered social worker
- a lecturer who has taught students about the recovery approach and
- a committed facilitator of the involvement of service users and carer in health and social care training.

Winter, Buck, and Sobeichowska (1999) highlight the importance of personal narrative in research and practice through writing patchwork texts which promote reflection and storying. Their book informed a MA research module led by Professor Richard Winter at Anglia Ruskin University which I attended. This allowed me to reflect for the first time upon the significance of my lived experience of mental ill-health (Payne, 2003)[98] and its potential positive impact on my life rather than its stigmatisation of my future.

The study taught me how the process of reflexivity, honest personal reflection of the impact of identity on research and findings, can enhance user led research. Reflexivity can be achieved through keeping a reflective diary to record personal reflections – indeed although my diary keeping was sporadic, I kept a limited record which later contributed to the development of other research projects and articles.

Resulting work, enhanced by learning and reflection in the PhD process, was presented at different conferences (Fox and Smith, 2008; Anghel and Fox, 2009; Fox and Ockwell, 2009; Ramon et al, 2010; Fox, 2011, Larsen et al, 2012); in peer-reviewed journals (Fox 2008; 2009; 2011; 2012; Slade et al, 2010; Fox and Ramon, 2011); books (Fox and Brandon, 2009; Videmsek and Fox, 2009; 2013), and monographs (Anghel, Fox, and Warnes, 2010; Fox and Ockwell, 2010). This enabled me to reflect on the topic of recovery, the methodology used and the importance of service-user reflexivity.

My experience as a service user informed my thinking in a variety of ways but needed to be grounded in effective and rigorous research processes. This was ensured by the quality control of supervision and training and by the inbuilt mechanisms in the research methodology: collective reflection by the steering group and the carer group. Their professional and personal identities informed the development of the training programme, research project, evaluation processes and analysis of data to explore the

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98 At this time my surname was Payne. Following my marriage in 2005 I changed my name to Joanna Fox.

research questions. This collective process of reflection was captured in steering group meetings and carer training group sessions, which were recorded and transcribed.

The action research cycle facilitated a process of learning for both me and my co-researchers that was personal and collective, and changed ourselves. The process moved the group from being merely researchers and research collaborators on a particular topic to being experts in that area. PAR promotes personal empowerment through both personal and collaborative learning via the process of reflection. Indeed the action research cycle itself can bring about change through reflection – i.e. action can be reflection –because it changes both the situation and the actors. The steering group members noted how involvement in the research had impacted on their personal and professional development (described in section 8.2.1). The carers noted in the report of the findings in Chapter 6 how they had become experts-by-caring with increased confidence in their own knowledge and abilities to support their family member – the process of reflection and learning enabled their sense of empowerment.

8.3 Summary

In sections 8.1-8.2 I have highlighted how PAR supported the implementation of the study by recognising the importance of individuals' identities in the research process and the need for all to contribute to the decision-making. The steering group's active contribution to the programme influenced many aspects of the training programme and research design. We developed an open forum to discuss different issues as the members brought their perspectives to the research and participated in a process of collaborative learning with the potential to change practice. This initial iterative cycle in the research demonstrated PAR's effectiveness in developing, learning and supporting change. The groups' different types of expertise, supported by a positive working relationship, ensured that no real difficulties were encountered.

The carers contributed effectively to the development of the research and although holding little decision-making power supported PAR processes in the research as their views were actively sought and responded to. Different levels and processes of involvement took place in the research which led to the successful implementation of the project maintaining the commitment in PAR to stakeholder involvement.

The process of reflection helped us to evaluate the significance of the research and improve process and contribute to outcomes. This formed a third PAR cycle in this research phase. Both individual and collective reflection was important to the development and implementation of the research.

The three cycles were interlocking and were managed by me as a sole researcher. Each phase was coordinated throughout the research. There was recognition of the importance of

- acknowledgement of different expertise that contributed to the research (Nicholls, 2001) with equal value for each perspective in the research (Staley, 2009)
- both the formative and summative processes of PAR (Ledwith and Springett, 2010) that involved reflection and action in research (Winter and Munn-Giddings, 2001)
- the need to coordinate and manage the different stakeholder groups (Slade et al, 2010) with processes underpinned by respect and support for each different member (Staley, 2009).

8.4 The research design: Sampling aims and recruitment strategies

Choices about sampling reflect the paradigms and frameworks used in the study (Creswell, 1998, Gray, 2009) and influence the quality of the data and theory generation (Miles and Huberman, 1994; Huberman and Miles, 2003; Flick, 2009). This section discusses the sampling aims and the recruitment strategies that were utilised in the research and the implications.

I intended to recruit the carer sample using purposive sampling with maximal variation as described in Chapter 5.9. Theoretical sampling is appropriate for this methodology as methods of qualitative data analysis seek to provide rich and thick description of the topic under inquiry rather than provide statistically-representative information about the population in general (Flick, 2009).[99]

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99 Classical sampling procedures that draw on statistical traditions to form a representative sample may be more appropriate to the logic of quantitative research which seeks to survey representative data about a general subject in the population.

The sample contained a good mix of male and female carers, which is quite unusual in carer groups. Gender differences are commonly identified between the caring of mothers and that of fathers and spouses (Stern et al, 1999), and women are more likely to attend carer support groups or information sessions than men. The sample group was however mainly middle class, from a white background and educated to tertiary level.[100] It included a specific type of motivated carer who was willing to make the effort to attend the programme, some being prepared to travel a significant distance. Carers who are not motivated to change are less likely to respond to flyers or to make the significant commitment to being involved in a programme.

The support of key people in the steering group was central to the recruitment process. They gave me access to personal support from senior and middle managers in the locality who helped me to disseminate the information about the training programme and research in the form of leaflet and presentations at mental health services and carers' groups. I made personal contact with a number of organisations with follow-up visits and presentations (as described in Chapter 5.9). Utilising local contacts and support and making persistent and sustained contact with key people is essential to effective recruitment.

It was difficult to recruit either the ideal sample of carers or to recruit to numbers, as reflected in many other studies (Ramon and Morris, 2000; Rhodes et al, 2002; Fox, 2009; Taskenen et al, 2011). Carers can often be overburdened by caring, and the demands of their task can fluctuate, making their lives complicated and busy. Committing to training can be practically and emotionally difficult. Three carers made contact with me but decided not to participate in the programme: two were unable to travel the distance and one found learning about recovery too difficult as she oscillated between optimism and pessimism about her son's recovery. I gave them information about support that they could access in their locality.

People from BME (Black and Minority Ethnic) communities are underrepresented in Cambridge (Dunn, 2005), which made it difficult to recruit anybody from such backgrounds to the study. I recruited only one white Irish female and nobody from the

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100 See Appendix 38 for a description of the carers.

Black or Asian communities. I contacted a variety of BME support services to recruit this population to my sample: a number of meetings were held with the Chinese Community Centre, the Cambridge Ethnic Community Forum and BME religious groups. This is a well-tried strategy, but often community groups are not aware of the special needs of their users (Rhodes et al, 2002) so it can fail. Barriers to recruitment include: English as a second language and the stigma of mental ill-health (Kalathil, 2010) which lead to reluctance to access programmes outside the community. It might have been more appropriate to visit mosques or temples directly to recruit the sample, a process that is time-consuming and resource-costly (Rhodes et al, 2002).

I originally hoped to recruit purposively to produce a diverse sample, however in practice the sample was self-selected as we took everybody who applied. This may be a limitation of the study. The carers in this study were from similar socio-economic, cultural and ethnic backgrounds whereas carers from different backgrounds may have a different experience of caring, therefore learning about recovery may affect them and their propensity to change in a different way. This homogeneity of the sample impacts on the applicability of the study and presents as a limitation in this research. This issue reveals a need for future research to be undertaken with a different sample of carers from different backgrounds to that of this sample in this study. Recommendations for future research are discussed in more detail in Chapter 9.

8.5 Data collection strategies

I chose data-collection strategies that reflected the assumptions inherent in the research design and underpinned the way the data were analysed and the theories generated (Flick, 2009; Gray, 2009). This section highlights the strengths, limitations and implications of the data-collection strategies.

The topics covered in the data collection were strongly influenced by the knowledge and experience of the steering group members, who were expert in their fields. My colleagues wanted me to include questions in the focus group and interviews about carers' perceptions of the carer assessment process and its effectiveness in assessing the carer's needs. Although I knew that such data is relevant in many carers' studies (Repper et al, 2008) because carers' assessments are the most prominent system-wide approach used to communicate with carers and identify needs, I questioned its relevance in this study focusing on carers' relationship to the recovery concept. I included these

questions, and with hindsight found that this information was pivotal to understanding both the carers' relationships with services and the role they play in the recovery process, and that it contributed to the theory generated from this study.

The evaluation of the training programme was undertaken mainly by me, both the researcher and facilitator of the training programme. This may be perceived as a significant weakness of the study for those working within other paradigms as it may indicate a lack of independence in the conclusions that I draw. However PAR emanating from a user led tradition:

- builds on learning and development (Winter and Munn-Giddings, 2001) and action and change (Minkler and Wallerstein, 2008a; Ledwith and Springett, 2010) through the action research cycle (Kemmis and Mc Taggart, 1988)

- values research processes which build capacity and develop the personal and professional skills of the researcher (Staley, 2009; Faulkner, 2010)

- embraces the contribution of identity to processes of collaborative learning (Hodgson and Canvin, 2005) and

- builds on the value of expertise-by-experience (Nicholls, 2001; Staley, 2009; Faulkner, 2010).

These elements can only be achieved if the identity and contribution of the researcher is valued and acknowledged in the research process. A research process that drew so heavily on my own commitment to recovery (Fox, 2007; 2008), my love of learning, and a commitment to carer empowerment (Fox, 2009) required me to bracket off my own experiences as I collected data (described in this section) and to reflect on the carers' overt and latent meanings as I conducted the analytic procedures (described in section 8.7).

With the support of the steering group and my supervisors data-collection strategies were developed to provide thick rich data about the nature of carers' recovery and the effectiveness of the training programme.[101] The data reflected two perspectives: how the carers experienced the group as a collective; and how they individually experienced learning about recovery and its impact on their lives at home. I had originally intended to collect data via a focus group administered at points before and immediately after

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101 'We' refers to the members of the steering group and me.

participation in the training programme and then via semi-structured individual telephone interviews at the one month and six months follow-up points. The steering group members advised that this strategy would mean that data was collected about the carers' collective experiences via the focus group and about their individual experiences via the phone interviews, i.e. that data would be collected via different methods with different perspectives. We therefore introduced written questionnaires and vignettes with open questions into the data collection process which were administered alongside the focus groups. This allowed me to collect individual data before and immediately after the training programme to match the individual data collected at the one month and six month follow-up points, in addition to the collective data captured in the focus groups.

Vignettes were found to be an effective technique as I invited the respondents to provide written responses to the questions accompanying them and used them as prompts for discussion in the training and evaluation. Schoenberg and Ravdal (2000) however caution the use of vignette methods in research, advising that:

- respondents may not want to offer advice or make judgmental statements about the conduct of the parties in the vignette

- the respondents may interpret the vignettes in multiple ways leading to disparity in the researcher's data

- the response to the vignettes may not accurately reflect or predict what the respondent would do in the future.

Barter and Renold (2000)) echo the final point above and argue that vignettes do not reflect the dynamic and paradoxical nature of interaction with a changing environment, because a vignette is a static and simplistic representation of reality, adding that 'that the undefined association between belief and action' is problematic in using this technique (p. 310). Hughes (1998) similarly questioned the use of vignettes in evaluating risky behaviour in the use of illicit drug-taking, asking whether participants responded in specific ways either because they wanted to receive approbation from the researcher and reflect social norms; or because they felt unbounded by social pressure and rejected normative behaviour. Hughes (1998) recommends the importance of probing the response and exploring the implications of participants' reactions to overcome this problem. In this study, the questions accompanying the vignette aimed to overcome these issues by

- inviting the carers to predict the reactions of the characters in the vignette
- asking them to provide constructive advice to the characters
- encouraging them to further explore both their responses to the situation for the characters in the vignette and to relate it to their own situation in follow up discussion with other carers.

On reflection, despite the introduction of improvements to data collection strategies, this process still had methodological limitations: different methods were used to track changes from the first data-collection point (written responses and a focus group) to the final point (semi-structured interviews), which may impact on theory generation.

The three methods were conducted in different ways: questionnaires were completed with initial instructions from the researcher followed by minimal input; the semi-structured interview relies on the skills of the researcher to engage with the participant despite following a semi-structured schedule; and the focus group captures information on a collective level. There is more potential for researcher bias to influence a semi-structured interview or focus group than there is in a questionnaire: a researcher conducting a semi-structured interview has the potential to lead the participant to 'construct' an experience in different ways in response to the researcher's inadvertent reactions and behaviour. Likewise, a focus group allows participants to construct a different social reality together: if one carer is positive about the training and expresses a growing belief in hope and optimism this may impact on how other carers present their feelings about recovery. Participants responding to a written questionnaire are less influenced by the reactions of the researcher and their group and focus more on their individual responses, although some may find it hard to write full responses or put their views onto paper. With hindsight, it might have been methodologically sounder to compare data collected in the same way both before and after the training programme.

As described above I was the sole researcher undertaking the evaluation therefore there was potential for researcher bias to impede the data collection and imprint my viewpoints on the evaluation as described above. For example, an interview conducted from a deficit model may elicit different responses to one conducted from a strengths model. Parton and O'Byrne (2000) illustrate this by noting that a social worker can use 'change talk' in social work practice to encourage clients to change their stories and their views of themselves. By conducting an interview that focused on the positivity of

recovery I could influence the carers' responses. I tried to be neutral in the way I carried out the interviews and to bracket off my own beliefs to allow the carers to express their true feelings. The independent facilitation of the focus group by two steering group members not involved in the delivery of the training programme also helped to overcome some of the methodological issues that my influence may have raised.

The recommendations implemented by the steering group meant that the first session required the carers to provide a lot of written data and participate in an explorative focus group discussion (see Chapter 5, 5.6 and 5.7). I felt uncomfortable with this process, fearing that so much form-filling and explorative discussion would discourage them from attending future training sessions. Some were a little taken aback at the first session, but reported that they had made a commitment to the programme and were willing to see how it developed. They all returned to the next session.

F06, M04 and F07 were unable to attend the first session and completed the questionnaire at home. This may have affected their answers; however, I included their data in the study as it was an important contribution because of the small size of the sample. (See chapter 6 for more details).

In summary, the complexity of the different data collection strategies could have resulted in carers not returning after the first session, and the mixing of methodological perspectives may have impeded the generation of theories. However, the overall strategy worked effectively, providing exciting and surprising information about the carers' relationship with recovery and their experience of participating in the programme. This enabled me to develop rich thick descriptions from the data and to generate new original theories from this study.

8.6 The analytic process

This section discusses the strengths and weaknesses of the data analysis process highlighting quality assurance procedures in my approach with a consideration of the nature of validity and reliability and their applicability to the interpretive research paradigm.

8.6.1 The strengths and weaknesses of the analytic process

Thematic data analysis was used as Chapter 5 describes. The process of research was both data-driven (inductive) as the themes emerged from the data through my active engagement with the analytic process and also theoretically driven (deductive) seeking to reveal themes that were identified in the research questions (Braun and Clarke, 2006). I sought to provide a description of the data corpus as a whole and also detailed insight into some of the carer's individual experiences (Braun and Clarke, 2006) presenting both nomographic and ideographic themes (described in Chapter 5, section 5.10). This first subsection considers the strengths and weakness of the analytic process highlighting the suitability of the approach to the study's philosophical and methodological assumptions.

As the sole researcher, I categorised the data myself. This process, although rigorous, might have given certain themes precedence. Indeed multiple stories could be told from the same data and the narrator needs to show why the particular perspective s/he chooses is appropriate based on appropriate coding of the data. The researcher has an active role in generating and developing themes (Braun and Clarke, 2006) - they do not just emerge from the data - therefore the process of reflexivity (as described in 5.5) is very important. It helped me to acknowledge my own identity in the research and its influences on the analytic process by allowing me to bracket off my own experiences as a service user enabling me to present the views of the research participants.

To ensure that the analysis remained true to the meanings of the carers in the spirit of the programme and the research project, the carers fed back their comments throughout the process as they had access to the full transcripts and made comments on the themes that I was developing from the analytic process.[102] It has however been noted that the participants do not have 'privileged status as commentators on their actions' (Fielding and Fielding, 1986 p. 43) and may not like the themes that emerge or may not agree with them; therefore this process only serves to provide yet another source of data and insight. I focused on reporting the words of the participants rather than identifying the latent meanings in their expressions, whilst still making sense of their meanings within the wider data corpus. This is commensurate with the social constructivist framework

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102 Their feedback was evidenced particularly in the comments they made on the presentation that was developed for the local mental health trust and were gathered at all times throughout the data collection process.

that emphasises that meaning is 'constructed not discovered' (Gray, 2009, p. 18) within social interaction.

Dey (1998) emphasises that it is important to clarify the context in which the study is undertaken, to explore the intentions of the participants and how their actions are interpreted and to explore the processes that drive their actions over time. This can help to ensure that the voices of participants are communicated in the research and the meanings of the participants are conveyed.[103] This approach is however perhaps more commensurate with naturalism and does not represent the participatory approach to this study.

Braun and Clarke, (2006, p. 78) believe that thematic data analysis can be applied to most research designs because of its 'theoretical independence' from philosophical and methodological assumptions, although it is important for the researcher to clarify the way data is understood and presented in a study. Indeed, Hodgson and Canvin (2005) comment on the importance of a partnership approach to create mutually-informed and co-constructed knowledge by all members of the research process in a PAR study. For example, a larger study (see Castillo, 2011; a PhD study but supported by more resources than my research) using PAR might have used more participatory forms of analysis by inviting the carers to take part in the analytic process; however, this was not possible, given the nature of this study and the resources available. The carers had already committed a large amount of time to the project; their lives and commitments had moved on in the year since their involvement in the training programme. It would therefore not have been practicable to place greater demands on their time or to ask them to contribute further to the research process. I believe that referring themes to the two steering group members after the completion of the data analysis added further insight and valuable data, ensuring the validation of themes by other participants as appropriate to the participatory and constructivist frameworks.

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103 This is exemplified by Dey (1995) in the words of Derek Bentley, who was hanged for inciting the death of a policeman. What exactly did the words 'Let him have it' mean? Did he mean his accomplice to give the gun to the policeman, or to shoot him?

In summary, in presenting the data I have remained close to the words and meanings of the carers, reflecting the context of the discussion. I use rich thick description and give credence to participants' different voices in the study. The process of reflexivity allowed me to recognise the influence of my identity in the research and bracket them off from the analytic process. The implications of the theoretical and philosophical assumptions that underpinned the research have been discussed in the analytic process.

8.6.2 Managing the quality of analytic process
This subsection addresses the quality management of analytic processes in this study considering notions of validity and reliability.

Researchers from different traditions approach the question of validating data and establishing the robustness of findings in contrasting ways. Researchers from the positivist tradition, using quantitative data, claim to produce objective results that are transferable and generalisable across different situations (Madill, Jordan and Shirley, 2000) by depending on the reliability of methods, the validity of the data and the exclusion of the researcher's identity.[104] Researchers from the interpretivist tradition, however, see reliability and external validity or objectivity as less useful in establishing the robustness of qualitative research (Miller and Kirk, 1986; Tobin and Begley, 2004).[105]

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104 Reliability is often assumed in the positivist tradition when data can be replicated by different observers or by the same observer on different occasions (Silverman, 2005). External validity or objectivity are assumed if the context in which the data are collected is controlled (i.e. the variables in the experiment can be controlled and managed) and reliable methods are used to collect the data.

105 Reliability is unsuitable in research which utilises methods to collect qualitative data; it is not possible to repeat the same narrative in a qualitative interview or to get identical results from another, similar interview. Validity problems are similar: it is not possible to have comprehensive control over the context conditions as the situations of data collection and analysis cannot be standardised, and therefore validity and reliability – as defined in the positivist paradigm - cannot be predeterminants of good qualitative research.

Researchers in the interpretivist tradition begin with a different assumption to that of positivist researchers. They value the individuality and complexity of the research situation. Qualitative researchers have traditionally tried to build different criteria for establishing the robustness of qualitative research (Lincoln and Guba, 1985; Stiles, 1993; Elliot, Fischer and Rennie,1999) by producing strategies to support its development and implementation. Lincoln and Guba's (1985) seminal work argues that **it is important to establish trustworthiness in qualitative research by evaluating whether the interpretations are credible, transferable, dependable and confirmable**.[106]

- **credibility** is improved by showing that the researcher has empathised with the participants and related their experiences accurately
- transferability is achieved by providing a thick description of the research process. This allows another researcher to evaluate whether the results can be transferred to a different setting
- dependability can be achieved by examining the audit trail
- confirmability allows the accuracy of the categories to be checked by looking at the audit trail.

Guba and Lincoln (2005) consider the different criteria for establishing processes of quality assurance in emancipatory rather than in positivist research. For example, emancipatory research is governed by ideas of control, voice and reflexivity, and the researcher becomes a political actor supporting transformative change. The authors propose criteria that evaluate the effectiveness of methods to ensure that analysis processes are fair and effective.

In summary, I acknowledge that validity and reliability – as defined within the positivist paradigm - are not very useful in qualitative data. However, Lincoln and Guba (1985) have perhaps developed the best-known strategy for assuring quality in qualitative research; their useful and well-accepted definition of quality helps to govern this research. Using their criteria I enhanced the trustworthiness of the data by including examples of raw data in the text; describing the data analysis and reduction processes;

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106 See Appendix 51.

showing how categories and their themes were developed through the different stages of analysis; and including information on how instruments were developed.

8.7 Conclusion

This chapter has discussed the stakeholders' involvement in the research process, describing their contribution to this PAR study, focusing on both the steering group's and the carers' contribution to the research process.

The chapter has explored the strengths and weakness of the research design, focusing on the sampling procedures, data collection methods and quality management of the data analysis procedures. The difficulties of recruiting were discussed which led to difficulties in achieving the ideal sample.   The data collection strategies were discussed highlighting the successes but revealing how the use of different methods may have compromised the data collection procedures.   The strengths and weaknesses of the study's analytic process were described with a consideration of how the participants' views were presented in the research findings.   Quality assurance procedures for managing the analysis of data were discussed with concepts such as reliability and validity considered.

In conclusion this chapter has considered the methodological and philosophical assumptions underpinning the research process discussed in Chapter 5 and shown how they contributed to the implementation of the study. It has shown how different elements of the research design set out in Chapter 5 worked successfully, and others less well. It has drawn these elements together establishing their contribution to the practical research process and their implications for the study.

The next chapter concludes the thesis, providing an overview of the research and considering the original contributions to knowledge that this research has made.   It addresses the limitations of the study and recommends future research.

Chapter 9. Conclusion

9.0 Introduction

This chapter concludes the study, linking the earlier chapters, which set the scene for the research and describe its design, with the later chapters that present and discuss the findings and consider the strengths and weaknesses of the research methodology. It begins by summarising the initial reasons for undertaking the study and the gap in knowledge that I sought to address. The research questions are described, with a justification of the methodology. The main findings are presented, and the original conceptual and methodological contributions are considered alongside the potential application to policy and practice.   Personal reflections about the research and the impact of involvement on my professional development follow. The chapter concludes with a discussion of the limitations of this study and suggestions for future research.

9.1 The reasons for undertaking the study

Recovery is a new concept in mental health (Stickley and Wright, 2011a; 2011b), an emerging model for service users to grasp (Fox, 2013) and a service model to drive hopeful and progressive mental health provision (Roberts and Wolfson, 2004; Slade, 2009a). The model of personal recovery emphasises that a service user can lead a good quality of life beyond their illness label (Davidson, 2003), despite the limitations caused by mental illness symptoms (Anthony, 1993; Coleman, 1999).

Carers play a significant and unique role in supporting their relative with mental ill-health (SRN, 2006; Rethink, 2010), yet there is insufficient evidence on the role that they can play in recovery (Kilyon and Smith, 2009, SRN, 2009). The development of recovery policy and practice needs to reflect carers' perspectives as key stakeholders in mental health care.

Carers' involvement is often missing in all aspects of research (Pinfold and Hammond, 2006), yet their perspective is key to the development of effective mental health policy, practice and service provision (MHRN, 2012a; 2012b).   Exploratory research about carers (SRN, 2009; Kilyon and Smith, 2009) presents the need for an investigation of the relevance of recovery to carers. This thesis is therefore timely and significant, as it presents an in-depth exploration of an under-researched area of mental health and promotes the active contribution of carers (MHRN, 2012a; 2012b).

This study connects my personal commitment to recovery as a service user, my experience of being supported throughout my recovery by family, friends and professionals (Fox, 2007), my knowledge and expertise in working with carers (Fox, 2009), and working in an under-researched area (Kilyon and Smith, 2009; SRN, 2009). It seeks to make original conceptual and methodological contributions to research that have useful application to policy and practice. It allows me to explore both the personal and the professional impact on my learning, as PAR demands (Winter and Munn-Giddings, 2001).

9.2 The research questions

This research seeks to fill the gap that emerged from a wide and extensive literature review, by developing original research on the carer's relationship with recovery and their role in supporting their relative with schizophrenia. The process led to the formation of the research questions:

- How do carers define recovery?
- Do carers believe recovery is possible?
- How do carers describe their role in recovery?
- Do their views on recovery change as a result of the training programme?
- Does their behaviour change as a result of the training programme?
- What do carers see as the major obstacles and opportunities in recovery?
- Do they evaluate the training package as helpful in enabling them to explore these issues?

This research area was investigated by developing and delivering a training programme on recovery to carers and evaluating the impact of learning about this concept on their lives.

The questions are focused on recovery evidence rather than pre-recovery evidence and originate from an optimistic paradigm of recovery that is very different to existing research on carers and caring focusing on the carer's 'burden' (Grad and Sainsbury, 1963), negative aspects of caring (Kuipers et al, 1992), family therapy (Brown, Birley and Wing, 1972), and carers' need for effective services (Hogman and Pearson, 1995).

9.3 Methodology and methods used in the study

The recovery concept originated in the service-user movement (Deegan, 1996; Coleman, 1999) and fits the choice of methodology well. More traditional paradigms of research are less suited to the recovery concept (Slade et al, 2010) and may also be less acceptable to the service user and carer communities; PAR, with its emphasis on liberation and empowerment through learning (Freire, 1970), is more appropriate.

PAR underpinned the planning, development and operation of the study, with two consultation cycles happening sequentially. First the steering group with different expertise contributed to the design and development of the training programme and evaluation tools, and participated in the evaluation itself. Next, the carers shared their views of recovery in the delivery of the programme and its evaluation. These two cycles were connected, with my role as researcher balancing the information and learning emanating from each group, and my role as a facilitator of the training programme supported by the carer co-trainer.

Data were gathered on the carers' knowledge of recovery, their caring role, approach to self-care and supplementary socio-demographic data before their participation in the programme. The methods used throughout the research included closed questionnaires, semi-structured written questionnaires with open and closed questions, vignettes with open questions, semi-structured focus groups and follow-up semi-structured individual telephone interviews.

The carers participated in a training programme on the recovery approach which comprised five sessions delivered over three months. It offered information about recovery and facilitated discussion of its impact on their caring behaviour and the implications for professional practice. Qualitative data methods captured a detailed picture of their responses.

The data were analysed using thematic data analysis (Braun and Clarke, 2006) to provide rich, thick description from the mass of data accumulated. The computer programme NVivo helped me to manage the data and organise it into comprehensive chunks in word documents. The process was both theory-driven – drawing on the research questions and existing evidence base to categorise the data – and data-driven, as

I actively engaged with the data corpus to discover themes and generate theory (Braun and Clarke, 2006).

9.4 Key research findings

At the beginning of the research the carers believed that recovery equated to a state of being 'cured', emphasising it as a functional clinical outcome. They believed that the service user could only recover if they had insight into their mental illness and accepted their symptoms as real. They saw their role in recovery as preventing the service user from becoming isolated, supporting them in taking their medication and helping them to manage and clean their house; seeing their own role as 'doing for'. They had little belief in the possibility of recovery and little hope for the future.

During and after participation in the training programme they began to realise the complexity of the recovery concept, seeing the relevance of the personal recovery model in their own lives – a concept which is very different from the clinical model. Their views on recovery changed as a result of the training programme, which in turn influenced their behaviour and attitudes towards caring. They learnt to foster agency rather than increased dependency in the service user – to 'care for recovery'.

The carers' belief in the possibility of recovery relied on their seeing progression in the service user's functional outcomes and quality of life. They balanced this optimism about recovery with fear of imminent relapse, and wanted to protect themselves from having their hopes dashed. Repeated relapses in their family member's life led them to an assumption that the recovery process is fragile and to fear that recovery is only a temporary moment between relapses, whereas the recovery journey presented a life journey of continuous learning and striving. Believing in the recovery of the service user led to a process of recovery for the carers themselves as they recognised the need to move beyond their own caring role (Davidson 2003).

The carers saw recovery practice as key to enabling recovery in the service user.   They hoped that professionals could become recovery mentors, focusing on carrying hope, encouraging the service user to engage in mainstream activities and to develop an identity of social value.

The carers evaluated the training programme as helpful in enabling them to learn about recovery and explore its relevance to their lives. They particularly identified the need

for skilled facilitation to stop over-digression from the topic but to allow participants adequate space to explore the implications of recovery to their lives. They believed that the identities of the trainers as an expert-by-experience and expert-by-caring were fundamental to the effective delivery of the programme.

9.5 The originality of the research

The research made a significant and original conceptual contribution to the model of recovery. It builds on previous frameworks describing service users' and carers' recovery journeys to provide a rich narrative account of the carer's journey and to show how their journey is interwoven with that of the person they care for.

SRN (2009) and Kilyon and Smith (2009) begin to look at the carers' relationship with the recovery concept and their role in promoting it but do not provide a comprehensive evaluation of its meaning to them and impact on their lives; and Cool Recovery (2003) proposes a model for a carer's journey of recovery. The methodology adopted in this exploratory study enabled very detailed qualitative data about how a group of carers understood the nature of recovery, with illuminating discussion about the significance of its impact on their attitudes and caring roles at different times during the research process. It gives credence to a carer's recovery concept as the carers identified their own journey of recovery alongside the service user's recovery journey (See Diagram 2 in Chapter 7, 7.2).   While this research is only exploratory, as it involved a small number of carers, it significantly develops the existing evidence base and offers an original contribution to our knowledge about carers' perception of the relevance of recovery to their lives.

The training programme developed in this study is unique. Systemic family therapy notions of high expressed emotion and over-involvement, described in Chapter 3, focus on changing the carer's negative behaviour in their caring relationship with their family member. Family therapy begins from a deficit philosophy, whereas recovery focuses on building hope. This difference is significant, as it enables the carer to change their own behaviour by reflecting on a strengths model rather than a deficits model (Addington et al, 2001). The recovery approach uses a positive message that emphasises how inter-dependence, rather than dependency, can build confidence, and how professionals and carers can support increasing levels of agency in the service user. The training highlighted the role of carers as experts-by-caring, which gives them the confidence to

reflect on their caring in a non-judgemental environment. This is a particular strength of this training programme and offers a different focus to that of evidence-based systemic family therapy.

This is the only study known to me that focuses on user experience as fundamental to the delivery of a recovery training programme for carers, as well as on the importance of carers' experiences. Many training programme for carers include the perspectives of carers, or are delivered by carers (Rethink – Carers Education and Support Package; the American family-to-family programme (Dixon et al, 2004) with reflections from the user perspective, but none focus so strongly on it. A key tenet of the recovery experience for carers was in seeing its authenticity in my life as a service user. Moreover my own experience of recovery, of being supported by family members, and the impact of over-caring and over-protective parents, informed the training programme's development and delivery, along with representations from the steering group. Getting to know the service user perspective and learning from it emerged as   fundamental to enabling carers to understand recovery and respond to its possibility in their lives.

The carer co-trainer, who had also experienced her own journey of recovery and had learnt to 'care for recovery', reflected the carer's perspective. Seeing recovery enacted in both trainers modelled its possibility for both carers and the cared for alike, turning it into a credible and real process. This underlines the need for both service users and carers to be involved in planning and delivering recovery programmes or research on recovery for carers.

The original contribution to methodology is now highlighted. Carers' involvement is often missing in the development of research and its decision making processes, yet their perspective is valuable and is different to that of service users (MHRN, 2012a; 2012b). There are few examples of carers being involved in research (Lammers and Happell, 2004; Repper et al, 2008; Fox, 2009; Atkin et al, 2012), despite the emphasis of new-paradigm emancipatory research, which increasingly encourages the active involvement of service users in all aspects of research (Staley, 2009; Uhm et al, 2012).

In this study the two cycles of PAR represent two distinct phases in the research. Conventional PAR supported the first steering group cycle, enabling the participants' active involvement in decision-making processes, while the second cycle simultaneously

allowed me to gather data about the carers' response to recovery and, through feedback loops, allowed them to influence the research processes. Members of the steering group both participated in the research and influenced the research processes. The carers' involvement in the research was defined as a 'contribution' (Sweeney and Morgan, 2009), as their opinions were sought and valued even though they had less formal power in the decision-making processes than the steering group. This double cycle of PAR is a useful contribution to the development of this methodology building on studies which use a steering group to support PAR (Brandon, Helme and Sendall, 2012) and those which already promote simultaneous participant involvement and influence in the research process (McInyre, 2008).

Although supported by the steering group in one cycle, and the carers in the other, I was in essence the sole researcher undertaking PAR due to limited resources and the nature of a PhD study. Indeed success on such a small scale study relies heavily on the researcher's open facilitation style and commitment to PAR (Staley, 2009; Faulkner, 2010) as s/he embraces opportunities for the participants to share in the research process. My approach in this research draws on previous studies that I have undertaken using action research (Payne, 2002 [107]) and PAR (Fox, 2009) which adapt procedures to support a sole researcher. In these two studies I as the sole researcher undertook the main research activity: the first study (Payne, 2002) was an action research study in a homeless hostel called Jimmy's undertaken by me the sole researcher with support from two insiders in the homeless hostel; in the second study (Fox, 2009) I used PAR to facilitate carers to organise and evaluate their involvement in a carers' representation group. The previous research experience has influenced the development of PAR in this study as I balanced the tension of being a sole researcher facilitating the research, with the power and influence of the steering group who support it, and with the carers who both contribute to and participate in it. This adaptation to the conventional PAR methodology remains firmly committed to its value base but reflects its utilisation in a small scale PhD study.

9.6 Significance of the key findings to policy and practice
The significance of the key findings of the research to policy and practice are reflected in two areas: the effectiveness of the training programme as a unique intervention; and

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107 My maiden name.

the implications of the research for carers' engagement in policy and practice development.

This training programme is unique and focuses on the recovery approach. The success of the programme relies heavily on the experience of the facilitators, who must be confident in their expertise-by-experience and expertise-by-caring. This issue highlights difficulties with scaling up the training programme and rolling it out to other areas as this programme demands highly skilled facilitators who can:

- manage discussion and digression through strong chairing
- support carers' possible distress as they relive painful memories
- support challenging moments as carers battle with their grief and frustration
- manage their own distress as the carers describe their experiences.

In order to make the training more widely available, the selection of trainers with expertise-by-caring and –by-experience and with adequate skills will be important and the process of developing effective train-the-trainer programmes will be fundamental to its success.

Although the effectiveness of family interventions for carers of people with schizophrenia has a strong evidence base (see Chapter 3), training for carers has not been widely implemented due to resource costs (Dixon et al, 2001) and the lack of skilled practitioners (Watkins, 2007). Glynn et al (2006) recognise the need for family therapy to focus on long-term carers of people with schizophrenia – a group often forgotten with the focus on early intervention in psychosis programmes – in the light of the recovery concept (Addington et al, 2005). This suggests that there is a gap in the market for cost-effective training programmes to support carers to learn about caring techniques, which this course has the potential to fill.

At the time of writing (May 2013), discussion is ongoing with the Recovery College East to offer this training programme to more carers in the local area. This training programme, unique for a number of reasons, with its focus on conveying recovery, its focus on the user experience, its co-production and delivery by professionals, a carer, and service users, its focus on a strengths approach to embrace expertise-by-caring, fits well into the courses deemed suitable for recovery college curricula.

Carers are a valuable resource, but they often feel that professionals do not provide them with enough support, acknowledge their contribution or understand their needs (Hogman and Pearson, 1995; Watkins, 2007). There is little evidence of carers being involved in developing, planning or monitoring mental health services, or in presenting their views about the nature of recovery oriented practice (Lammers and Happell, 2004; Fox, 2009). Despite this, the Cambridge and Peterborough Foundation Trust is establishing local processes to increase accountability to this group.

The carers in this study had strong opinions about what constituted best practice and proposed a service model for recovery (see Diagram 3 in Chapter 7, 7.2). It draws on enabling processes such as direct cash payments in lieu of services, and addresses how mental health professionals can deliver best-practice services that engage with carers as well as service users, drawing on policy directives from government. It reflects their demands for empowering services that carry hope for service users and their families when they have little hope (Ramsey and Till, 2009), that focus on professionals being on tap but not on top (Roberts and Wolfson, 2004), that prevent isolation by focusing on community engagement (Anthony, 2000), and develop safe but not coercive mental health services which manage risk appropriately (Chandler, 2010).

This study builds on the limited earlier data about carers' lack of influence in research and service development (Lammers and Happell, 2004; Repper et al, 2008; Fox, 2009) and suggests how their active involvement in research can increase their participation in developing policy and practice (MHRN, 2012a; 2012b). Moreover the PAR model reinforces the need for research to be emancipatory, empowering and able to promote both local and transformative change (Ledwith and Springett, 2010). Involvement in the research empowered a number of the carers as afterwards some became involved in further research programmes (F01, F02), in advocating for better services for their relative (M03, F04, F07, M04), and in continuing to influence mental health (F03) and drug services (M01).

9.7 Personal reflections about this study

Participating in this research made me return to my own experiences and reflect on them. I have kept a limited personal diary of reflections that turned into academic articles as I considered the importance of the recovery concept in my life and how it has influenced my thinking, practice, knowledge and skills as a researcher, academic,

lecturer, service user, wife and mother. Learning about the recovery approach enabled me to extend my learning and begin to live the meaning of recovery from the mental health symptoms with which I have struggled intermittently for all of my adult life.

In Fox (2008) I reflect on my perspectives as a service user, a researcher and an academic which influenced the models of recovery that I brought to this study. I question whether this bias would enhance or detract from the relationship I built with the carers, whether it would present recovery in a false light and whether it would strengthen the carers' relationship with the recovery model. Now, at the end of the study, I can reflect on how my own experiences of recovery were fundamental to the success of the programme, enabling the carers to relate to the reality of recovery and giving them hope that things could get better.

In Videmsek and Fox (2009) we reflect on the role of concept-mapping as a method to support learning. I discuss how it has the potential to capture change and learning in the present study and map changes in the lives of the carers. It helped me to organise my learning, but I chose not to use this method extensively in this study.

In Fox and Brandon (2009), published after the untimely death of Professor David Brandon, we describe the evaluation of an advocacy project undertaken from 1999-2002 in Scope (an organisation that supports people with cerebral palsy) homes across East Anglia. This helped me to realise the importance of organisations that promote an open environment with opportunities for service users to fully involve themselves in the running of the organisation and in helping to develop future policies and procedures in their residential setting. They clarified the importance of recovery-oriented practice and the need for service users to be involved in all aspects of the management and development of organisations, as underlined in Farkas et al's (2005) discussion of the importance of involving service users in developing, planning and monitoring a recovery-oriented service.

My involvement in this study and beyond has shown me the importance of the recovery concept. It has reminded me of how mental illness is viewed as a tragedy in many people's lives accompanied by loss of identity and potential for success. In Fox (2011), I reflect on the difficulties of the 'hiddenness' of mental health symptoms: how people found it difficult to recognise and to believe me when I said that I was unwell, as I

presented a calm face to a world that was actually confusing and anxiety-provoking due to my experience of mental health symptoms. My research has reminded me of the symmetry between the social model of disability and the recovery model, of how much I have fought as well as of how fortunate I am to be well most of the time, and of how people who do not understand cannot relate to the experience of mental ill-health. It is a hidden disability. I have been reminded of the stigma of mental illness, which can be as disabling as the symptoms themselves.

In Fox and Ramon (2011), we reflect on the positive contribution that work can and does make to the recovery process. I reflect on the importance of appropriate work for recovery, the Government's moves towards the Work Capabilities Test, and the almost unquestioning association between work and recovery. In this article we question the assumptions in DH (2011a) that all service users should and can work. This again made me reflect on the importance of recovery and its implications for the service user's life.

In Fox (2012) I reflect on the experience of becoming a mother with a diagnosis of schizophrenia, the stigmatisation that this diagnosis incurs from other professionals, their immediate assumption of my incapacity and weakness and their unshakeable belief in my potential to harm my baby. This reminded me of the continuing stigmatisation and demonisation of those with a mental health diagnosis and the need for my own self-advocacy to challenge negative stereotypes of mental illness.

This study has opened up a new world of academia and returned me to the love of learning I once had. It has had a positive impact on me as I have learnt about the importance of recovery in my life, discovered its meaning and lived its essence, and a positive professional impact as I teach Social Work students about the importance of recovery and the need to recognise expertise-by-experience. It has also had an academic impact as I have written and responded to recovery in my life. At times it has reminded me of the hard task of caring, and of how my parents grieved, fought and supported me as I watch their health deteriorate. It has driven home the tensions in recovery: the tragedy of mental illness, need for belief in recovery by those who have lost faith, and the continued importance of reinforcing hope and optimism for those who no longer believe that recovering a meaningful life is possible once they have been given a diagnosis of schizophrenia. This study has meant more to my life than merely a research

degree or a thesis to be written: it has been a journey of understanding mental ill-health and the reality of recovery in my own life.

9.8 The limitations of the study and how they could be overcome in future research

This section considers the limitations of the study and suggests how they could be overcome in future research. The applicability of the research is influenced by a number of factors, particularly relating to the size and homogeneity of the sample.

The sample of carers was limited to parents and one sibling of service users; they were all White British except for one White Irish, and middle class, which may limit the applicability of the findings. Ten of the eleven carers were educated to tertiary level[108] in keeping with the location of the study in Cambridgeshire, which has a high-majority White British population with a higher level of educational attainment than other areas.

The expertise and characteristics of the carers in the programme shaped the research as much as their caring identity. Many of the carers changed in their caring roles after participating in the training programme – was this due to the nature of the sample, who were motivated and hungry for change? The sample was an optimum size to support an exploratory study of the meaning of recovery to carers and highlighted issues that need to be verified in studies with more representative samples. This limitation reflects on the recommendations for future research in Chapter 10.

The research lacked reference to carers from BME backgrounds. Carers from a non-Westernised background may see the service user's place as within the family rather than believing that they should live separately and independently, and may understand the caring as a collective process that relies on mutuality and support among all family members. This impacts on the content of the training programme that currently emphasises the importance of carers promoting autonomy and independence rather than other ways of caring. Training interventions for future delivery should be modified to reflect the cultural needs of different communities (Glyn et al, 2006).

The impact of courtesy stigma (Goffman, 1963) may be greater for BME carers, with service users more stigmatised and isolated from their communities by their mental ill-

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108 See appendix 38 for vignettes of the carer sample.

health diagnoses (Kalathil 2010), leading to their greater reluctance to engage with services, and perceptions of institutionalised racism.[109] This combination often means that their voice is unheard and is less represented in research and service development than that of the majority population. This suggests the need for further research actively involving the perspectives of BME carers and supporting their involvement in service planning.

It would be useful to replicate this study with carers from a different socio-economic background. The carers had to understand difficult concepts, be willing to analyse their current caring responses and plan and respond to change. The training should take place in a non-university setting that would emphasise the accessibility of the programme to people with lower educational qualifications, who might find a university setting a barrier to participation.

The size of the sample and its homogeneity limit the applicability of the research. Future research should be undertaken with a more representative and diverse sample of people from different socio-economic strata and different cultural and ethnic backgrounds. Furthermore a larger pilot should be considered to evaluate the effectiveness of the training programme and build on the work of this study.

Methodologically, it would have been helpful to engage the carers in analysis of the data, or failing that, to have involved the steering group in collective data analysis (Atkin et al, 2012). The former approach would have allowed the generation of themes closer to the ideas that the carers themselves were expressing; the latter would have been more in keeping with the PAR cycle. Processes of collective data analysis have only recently been reported in research (Castillo, 2011; Atkin et al, 2012), and were not built into research design when the study began in 2007. It would have been difficult for the carers to come together again at the end of the programme after their agreed participation in the

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109 Relatively large numbers of African-Caribbean men receive a diagnosis of schizophrenia compared to white or other minority ethnic groups. They are more likely than their white counterparts to be coerced into services against their wishes, for example through compulsory admission to hospital, and once in hospital they are more likely to be physically restrained by staff and to receive particularly high doses of powerful medication (DH, 2002).

group processes had finished, because they were dispersed across the Eastern Region. The steering group members' time commitments made this difficult and therefore it was not feasible to ask them to contribute further to the research.

9.9 Conclusion

This original research builds on previous evidence which describes service users' and carers' recovery journeys to provide a rich narrative description of the carer's journey and to show how their experiences of recovery are connected with and reflect that of their family member with schizophrenia. The research has developed a unique training programme that fits the needs of this often neglected group and has further potential for roll-out to other carers. Carers' participation in the programme has the potential to increase their confidence in their expertise-by-caring, providing new opportunities for them to become involved in developing improved services for both themselves and their family member.

This original and significant research seeks to fill the gap in the current evidence base identified in the early chapters of this thesis. This research shows that recovery is a concept that belongs to carers as well as service users. It allows carers to begin to recognise and validate their own journey of caring, leading to the possibility of living beyond the caring role.

The training programme builds on the existing evidence base and offers an intervention that focuses on carers' strengths, offering a message of hope based on the recovery concept, teaching them to care for recovery. It shows that the user's perspective of recovery, as well as the carer's, is fundamental to the success of any recovery research or training for carers. The potential of this course to be rolled out more widely and possible difficulties have been highlighted.

Building on the literature about carers' lack of involvement in care planning and service development, the study has developed a recovery service model based on enabling services which promote partnership working between stakeholders. It has highlighted how carers' active involvement in research can lead to their increased participation in care planning and mental health service development.   The suitability of the methodology in supporting this aim was considered.

PAR melded well with the values and roots of recovery, with its focus on promoting learning to bring about action and change (Ledwith and Springett, 2010) fitting well with the aims of the research to train and empower carers. The methodological originality was highlighted through its adaptation in supporting a sole researcher to use PAR, helped by a steering group who developed the research, and carers who both participated in and influenced its progress.

The limitations of this exploratory study were identified relating to the size and homogeneity of the sample. Strategies to overcome this were highlighted for future research such as replication with a different type of sample, and a larger study to evaluate the effectiveness of the training intervention. Methodological limitations related to the paucity of resources were considered.

Finally, hearing the carers' stories of caring, which oscillated between hopelessness and hope, reminded me of my own journey and that of my family. It has shown me how important recovery is to carers, and how this training programme has the potential to model recovery for them. Using my own expertise-by-experience to build hope for carers and the people they support fills me with a sense of purpose and validates my own experience of mental ill-health and its potential to bring about change. This was reflected in the carers' words as they saw recovery modelled by both me and the carer trainer:

> It was so inspiring – certainly your side of it, R1 [me] and to realise the recovery process is possible and that there's life beyond the onset of the illness. That you can still function with a brain, and thinking about other people and things –and then of course it was interesting to hear it from R2's [carer trainer] point of view, because that was us. You were our son or daughter, shall we say, and R2 was us, so yes, it was definitely very useful to have the two points of view there. (SSI2F01)

10. Recommendations for practitioners, services and researchers

1. Carers and service users alike need to receive positive messages at the first diagnosis of mental ill health and throughout the service user's recovery. Although it is important to discuss the severity of distress and its implications for the service user and their carer, a negative prognosis can only impede recovery. It is important for the clinician to indicate that there is potential for recovery and to offer hope by confirming that a service user can lead a good quality of life even with a diagnosis of schizophrenia.

2. Information-sharing still remains an issue for many carers. The practitioner should not use the confidentiality clause as an excuse to exclude the carer. Practitioners need to discuss confidentiality issues and information-sharing processes with both the carer and the service user, revisiting this discussion at regular intervals. When the service user does not want to share information, the limits of the information that can be shared should be clarified with the carer. Services should develop a common approach to sharing information by developing protocols for addressing issues between carers and service users when there is conflict.

3. Carers are partners in care, but should not be left to pick up the pieces in times of crisis on their own. Practitioners should ensure that plans are put in place to manage risk appropriately so that the carer is not left to manage a crisis alone.

4. Practitioners need to recognise the complexity of the carer identity, understanding that not all carers want to be identified as only carers. Carers are on a journey of learning about the illness and only become experts with time.

5. Practitioners need to recognise the potential for carers to work in a Triangle of Care together with the service user and practitioner, playing a role in the recovery journey.

6. Carers need more information about caring, the recovery process and its relevance to their lives as carers. They need information about what to expect at each point in the recovery journey and about the appropriate service provision. Services should develop more leaflets and information about recovery for service users and carers. Professionals need to signpost carers to where they can receive help.

7. Services need to ensure that carer involvement is embedded at all levels of decision-making in the organisation, and that practitioners receive carer-led training to make them more aware of the needs of carers and the positive contribution they can make to recovery.

8. Organisations need to become learning organisations to embrace the development of recovery-oriented services. They need to ensure that service users and carers are involved in this process and that their participation underpins the development of all ideas.

Further research

9. Carers need access to good quality training programmes on recovery. This can improve outcomes for both the service user and the carer. The usefulness of this programme needs further evaluation.

10. It would be useful to replicate this study with carers from a different socio-economic background. The carers had to understand difficult concepts, be willing to analyse their current caring responses and plan and respond to change. The training should take place in a non-university setting that would emphasise the accessibility of the programme to people with lower educational qualifications, who might find a university setting a barrier to participation.

11. Research should be undertaken with a more representative and diverse sample of people from different socio-economic strata and different cultural and ethnic backgrounds. Furthermore a larger pilot should be considered to evaluate the effectiveness of the training programme and build on the work of this study.

12. Training interventions for future delivery should be modified to reflect the cultural needs of different communities (Glyn et al, 2006).

13. The carers valued the centrality of expertise-by-experience in this training programme. This is a unique feature of this research: the contribution of different kinds of expertise to the development of co-produced training on the recovery approach should be further investigated.

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Appendices

Appendix 1 The aims of Modernising Mental Health Services: Safe, Sound and
      Supportive (DH, 1998)

DH (1998) promised to

- To modernise mental health services by providing 'safe, sound and supportive services'.
- To manage risk effectively by enabling 24 hour access to services
- To involve all stakeholders: carers, service users, and patients in the planning of services
- To develop mental health services and move them into primary care
- To work in partnership with education, employment and housing

The National Service Framework for Mental Health (DH, Executive Summary, 1999a, p.6) had seven standards focusing on mental health promotion, delivery of services, services for carers and suicide prevention. These are:

- Standard one addresses mental health promotion and the discrimination and social exclusion associated with mental health problems.

- Standards two and three cover primary care and access to services for anyone who may have a mental health problem.

- Standards four and five cover effective services for people with severe mental illness.

- Standard six relates to individuals who care for people with mental health problems.

- Standard seven draws together the action necessary to achieve the target to reduce suicides as set out in Saving lives: Our Healthier Nation

Appendix 3 Provision by specialist mental health teams

Assertive outreach teams were designed to support those people with serious mental health problems who were resistant to engaging with mental health services. Teams would have smaller case loads and would engage more intensively with people who were not treatment compliant, avoided services, and were reluctant to continue to engage with mental health services with increased support for family and carers with an emphasis on relapse prevention.

Crisis intervention and home treatment teams were developed to support people with acute mental health symptoms in their own home to avoid hospitalisation. Services would visit a person at home, monitoring them and providing adequate support to prevent admission into hospital if home treatment could support the patient adequately. The team would engage actively with the service user both during and after the crisis point, enabling them to cope more effectively with their life following a discharge if needed. It was part of the AMHP's armoury in delivering care to those who were assessed under the Mental Health Act in the provision of the least restrictive option. Other options to avoid hospitalisation include user led crisis houses and day hospitals.

Early intervention in psychosis teams were developed on the evidence base emerging from Australia which emerged to show that if the duration of untreated psychosis was reduced then service users would be less disabled in the longer team. If services could reduce the length that psychosis went untreated, and provide early intervention, then there was less chance that service users would become entrenched in experiencing strange behaviour, become less isolated, and less likely to become chronically disabled by the experience of mental ill health.

Forensic services also form a major component of the mental health system. They provide services to patients who are assessed as mentally ill but who are in contact with the criminal justice system. Many prisoners with mental ill health also reside in prisons where it can be difficult to meet their mental health needs.

Appendix 4 Summary of the Amendments in the MHA (2007)

Definition of mental disorder: There is now a single definition of mental ill health that is described as 'any disorder or disability of the mind'. It now includes people with personality disorder and autism

Criteria for detention: A patient may be detained if 'appropriate medical treatment' can be given on their detention in hospital. The 'treatability test' has been abolished.

Professional Roles: The role of the Approved Social Worker has been extended to other professional groups and changed to an Approved Mental Health Practitioner (AMHP). This role can be occupied by: nurses, chartered psychologists, and OTs.

Nearest Relative (NR): The new Act gives patients under the MHA the right to apply to the County Courts to have their NR displaced, if they are found to be no longer appropriate. The NR can also be someone who is in a civil partnership with the patient.

Supervised Community Treatment (SCT): SCTs have been introduced for patients following a period of detention in hospital. It allows patients to be recalled to hospital if they refuse to comply with medical treatment.

Mental Health Review Tribunal: This reduces the time before a case has to be referred to the MHRT by hospital managers.

Age Appropriate Services: This requires hospital managers to ensure that patients under 18 are accommodated in age-appropriate facilities.

Advocacy: Help must be provided where needed by Independent Mental Health Advocates.

Electro-convulsive Treatment: New safeguards have been introduced to allow patients to refuse ECT, for example using an Advanced Directive. All decisions can however be overridden if treatment is necessary in an emergency to save a life or prevent severe deterioration in mental health.

Taken from Rethink website and Mind website.

Appendix 5 The powers of the Nearest Relative (NR)

The powers of the nearest relative (civil sections of the Mental Health Act 1983) are:

- To require the local social services authority to direct an ASW to carry out an assessment of a patient to decide whether he or she needs compulsory admission (Section 13 (4))
- To make an application to detain the patient in hospital (section 11(1)) for assessment (section 2) or treatment (section 3)
- To make an application for the patient's reception by the local authority in guardianship (section 11(1); section 7)
- To notify the ASW that he or she objects to an application fro admission for treatment or reception in guardianship (section 11(4)
- To seek to discharge the patient from 1. an assessment or treatment or 2. from guardianship by a written application in the first instance to the hospital managers and in the second, to the local social services authority (section 23)

(Taken from Rapaport 2005, p 158)

<u>Appendix 6 The focus of New Horizons (DH, 2009)</u>

New Horizons focused on:
- Prevention and public mental health
- Stigma
- Early intervention
- Personalised care
- Multi-agency commissioning/collaboration
- Innovation
- Value for money
- Strengthening transition

Appendix 7 Ten key organisational challenges for implementing recovery

1) Changing the nature of day-to-day interactions and the quality of experience

2) Delivering comprehensive, user-led education and training programmes

3) Establishing a 'Recovery Education Unit' to drive the programmes forward

4) Ensuring organisational commitment, creating the 'culture'. The importance of leadership

5) Increasing 'personalisation' and choice

6) Changing the way we approach risk assessment and management

7) Redefining user involvement

8) Transforming the workforce

9) Supporting staff in their recovery journey

10) Increasing opportunities for building a life 'beyond illness'

Taken from Shepherd, Boardman & Burns (2010 p. 2).

Appendix 8 Breakdown of carers in Cambridgeshire by region and designation

(Cambridgeshire County Council, Carers Strategy, 2008 – 2011, p. 10)

	City	South Cambs	East Cambs	Fenland	Hunts	Total	%
Population	108863	130108	73214	83519	156954	552658	
Unpaid carers	8901	12837	7026	8159	13750	50673	9.2
Carers caring for more than 50 hours per week	1249	1657	1202	1994	2518	8620	1.6
Young carers 5-15	150	199	105	167	265	886	

(CCC, 2008)

Appendix 9 The allocation of spending of the Cambridgeshire carers grant by carer designation

Carers Grant 2007-08 revised to reflect Children's Service 20% allocation

Departments 2007/08	Total Grant £
Children	332,600
Learning Disability Partnership	284,587
Mental Health	129,483
Older People	227,314
Physical Disability	84,600
Voluntary Organisations	137,916
OP Respite within Base Budget	150,931
Carer Project	315,569
Carers Grant Total	1,663,000

(Taken from Cambridgeshire County Council, Carers Strategy 2008 – 2011, p. 12).

<u>Appendix 10 The vision for the Cambridgeshire Carers Strategy</u>

The Cambridgeshire Carers Strategy has a vision that:

Carers will be supported to stay mentally and physically well and be treated with dignity.

Carers of all ages will be able to have a life of their own alongside their caring role

Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.

Carers should have the opportunities and space they need to participate in activities outside their caring role. They should be free to have an identity that is separate from that of the people they support.

We are committed to providing the services that carers need to carry out their caring duties. Services across the board, whether they are provided from central, local government or the third sector, must be fit for purpose in supporting carers. For this to happen, services must be sensitive to the needs of people from all sectors and groups within society, and must reflect local diversity within communities.

Carers will be supported so that they are not forced into financial hardship by their caring role.

Our vision will be characterised by carers feeling that not only are services working together but also they are 'on their side'. (CCC, 2008)

What the research reported:

How would the service user's life be if they were going to get better?

Financial security

Ability to find work

To be in a loving relationship

Social interaction

To be able to experience pleasure

Be motivated

Structure their own day with a purpose

Association with the word carer

Support / helping

Pressure

Frustration

Responsibility

Regain parenthood (rather than have the identity of a 'carer')

Worry

Anxiety

Relentless

Themes

It takes patience on the recovery journey

- The carers wants to support and encourage that journey but can't do it for the service user

It is about finding that chink of light at the end of the tunnel.

- You always have to hope

Bereavement

- The person that there might have been had the illness not struck

The stigmatising label of schizophrenia

Discoveries

The difference in the journey when straddling the real world and the unreal world

- What is the nature of 'insight' and 'capacity'?

- How does it affect the recovery journey?

Difficulty for some people to differentiate the development of the service user's own strategies from their perspective as a carer

- It is difficult to let go of your dreams as a carer and think what the service user might want from life

Emotional reactions

Feeling inspired

Feeling hope

Negativity from hearing my journey:

- Anger

- A process of bereavement / Disappointment

- a process of 'lost identity' of the son / worker / student and a new identity as a service user

Role of the services in playing a greater role in the support process

In summary

Too early to draw any conclusions…

Carers have a lot to say about their own story – often not heard or listened to

Does learning about recovery create hope?

Do carers feel guilt when they think about the recovery process?

– do they feel they are being blamed for getting it wrong?

Appendix 12 Commitment by the Cambridge and Peterborough Foundation Trust to fulfil in the Carers' Strategy by 2013 (Taken from CPFT, 2012c)

- A training module to raise the importance of the role of carers and the specific needs of Young Carers, will be established & mandatory for all staff by September 2012
- 85% of all staff will have completed this training by Nov 2013
- Survey results will demonstrate Carers satisfaction rates of >80% by 2013
- Each Team will have conducted a self assessment on being 'Carer Aware' and will have evidenced improvements in practice by March 2013
- Patient assessments will have clearly identified Carers & Young Carers
- CPFT will have developed action plans in conjunction with Centre 33 to continually improve awareness & services for Young Carers http://www.centre33.org.uk/what-we-do/young-carers.html
- CPFT will have access to a minimum of 20 Ambassadors for Carers to assist them in developing good practice for Carers by September 2012

Appendix 13 Cambridge and Peterborough Foundation Trust: Patient experience of involvement of the carers during the CPA process

Questions asked of the inpatient participants:

1.) Has the most significant person/carer/Next of Kin been identified within your care?

2.) Has your SP/C/NOK been involved in decisions about your care?

3.) Has this person been accessible to you during your stay?

 EMAIL PHONE IN PERSON

4) Was this person's involvement beneficial to you as a Service User?

5) Do you anticipate that this person is going to be involved in your discharge planning?

6) Do you believe this person's involvement will be useful in your recovery?

Appendix 14 Standards for a recovery oriented service

1. Recovery can occur without professional intervention. Professionals do not hold the key to recovery; consumers do.
2. A common denominator of recovery is the presence of people who believe in and stand by the person in need of recovery.
3. A recovery vision is not a function of one's theory about the causes of mental illness.
4. Recovery can occur even when symptoms re-occur.
5. Recovery changes the frequency and duration of symptoms.
6. Recovery does not feel like a linear process. Recovery involves periods of growth and setbacks, periods of rapid change and little change.
7. Recovery from the consequences of the illness is sometimes more difficult than recovering from the illness itself.
8. Recovery from mental illness does not mean that one was not 'really mentally ill'. (Anthony 2000 p. 18-19)

Appendix 15 Service standards for a recovery oriented system developed by the Mental Health Commission, NZ

The Mental Health Commission, NZ (2004 Our LIVES IN 2014) developed standards for what a recovery oriented system might promote. These include:

- a sense of personal power
- a valued place in our communities including education work and money,
- access to housing and transport,
- access to community activities, and services which promote a recovery model by flexible service models,
- a fundamental shift to recovery philosophy,
- easy access and optimal choices,
- service user control and leadership,
- no discrimination,
- no poorly served populations,
- a broader range of services available to all,
- a focus on wellness,
- service user control in treatment and medication,
- less use of mental health act,
- better services for poorly served communities,
- diverse positive workforce,
- supportive families,
- health promotion and prevention.

Appendix 16 Recovery practice in the British context

Roberts and Wolfson (2004), in the British context, argue that recovery practice should be the mainstay of mental health services. They set out the central tenets of recovery practice.

- focusing on the core significance of hope and optimism
- there must be a shift in the professional role from authority to coach
- medication management must involve more than compliance
- mental health practice must move from risk avoidance to risk-sharing
- practice must promote self-management
- hospital must have the potential to become a springy safety-net rather than an experience of incarceration
- recovery must be possible, and life must be worth recovering to and
- and professionals and service users must use a common language that does not contain unnecessary jargon.

Appendix 17 Five principles of recovery developed by Copeland (1997)

Copeland's (1997) five key principles of recovery

1. Hope: people who experience mental health difficulties can get as well as they can, stay well, and go on to meet their life dreams and goals.

2. Personal responsibility: it is up to you, with the assistance of others, to take action and do what needs to be done to keep yourself well.

3. Education: learning all you can about what you are experience so you can make good decisions about all aspects of your life.

4. Self advocacy: effectively reaching out to others so that you can get what it is that you need, want and deserve to support your wellness and recovery.

5. Support: while working towards your wellness is up to you, receiving support from others, and giving support to others, will help you feel better and enhance the quality of your life.

Taken from Copeland, M.E., 1997. Wellness recovery action plan. Dummerton, VT: Peach Press

Appendix 18 World Schizophrenia Fellowship (2012) guidelines for effective family
    interventions

World Schizophrenia Fellowship (2012) identified the following the key ingredients in effective family interventions. According to this international panel of experts, successful programs accomplish the following tasks:

-   Coordinate all elements of treatment and rehabilitation to ensure that everyone is working towards the same goals in a collaborative, supportive partnership.
-   Pay attention to both the social and clinical needs of the consumer.
-   Provide optimum medication management.
-   Listen to families' concerns and involve them as equal partners in the planning and delivery of treatment.
-   Explore family members' expectations of the treatment program and expectations for the consumer.
-   Assess the strengths and limitations of the family's ability to support the consumer.
-   Help resolve family conflict by responding sensitively to emotional distress.
-   Address feelings of loss.
-   Provide relevant information for the consumer and his or her family at appropriate times.
-   Provide an explicit crisis plan and professional response.
-   Help improve communication among family members.
-   Provide training for the family in structured problem-solving techniques.
-   Encourage family members to expand their social support networks (eg, to participate in family support organisations, such as the National Alliance for the Mentally Ill [NAMI]).
-   Be flexible in meeting the needs of the family.

Appendix 19 A carers' four-stage journey of caring

Karp and Tanarugsachock (2000) identify four stages to the caring journey:

- Emotional anomie: this occurs before a firm medical diagnosis is established. It marks a place of confusion and frustration with experiences of chaos and a life marked by unpredictability with little understanding of what is happening.
- A diagnosis is given and this allows the carer greater understanding of the illness as they put a label on it and begin to subscribe to the medical model. This period is often accompanied by a process of learning as the carer seeks to inform themselves about the illness and is characterised by positive emotions of love and support as the carer seeks to save the service user from their illness.
- The initial optimism gives way to a sense of it likely impermanence as the carer begins to doubt the possibility of recovery. This point is characterised by negative feelings of anger, resentment and frustration.
- This final point gives way to a sense of acceptance as the carer recognises their lack of control over the user's situation and acknowledges that they are responsible for their own life.

Appendix 20 A three-stage temporal journey of caring

Rose, Mallinson, and Walton-Moss (2002) describe a three-stage temporal journey. The
components of the process were threefold:

- confronting ambiguity of illness: the diagnosis led to feelings of unreality and a
  loss of the normal and predictable routines of life. Their responses included
    o keeping watch / losing trust in life's routines
    o becoming overwhelmed by the illness
    o a process of making sense of the illness
- seeking control over the illness: as the illness progressed they began to seek
  explanations, seek out information, and regain control over the illness. Their
  response included:
    o managing the experiences of grief
    o navigating the mental health system
    o and questioning the responsibility of the mental illness
- adopting a stance of possibilities and realities: for families who regained some
  hope they began to reject the overwhelming negativity of the mental illness
  prognosis by
    o re-affirming hope for the future
    o redefining relationships
    o maintaining stability whilst striving for development
    o and reaching conclusions as they contemplated the future.

Appendix 21 A temporal stage of caring for carers of people with intellectual disabilities

Grant, Nolan and Keady (2003) draw connections with the experiences of carers of people with intellectual disabilities as they make sense of their caring role. Their journey embraces a temporal process of caring:

- Building on the past: this is the time before the baby is born and underlines their experiences of anticipatory care as they contemplate how they will care with a baby with learning difficulties and as they transition through their life

- Recognizing the need: this is when a diagnosis of disability is made when the child is born or after their needs have become recognised. This is when the carer begins to recognise that they will need to care for their child both now and in the future.

- Taking it on: this is when the carer realises the difference that caring will make in their life as they take on the caring role. It underlines the difference between their experiences and those of their peers, the needs they will have to support them, and the requirements for support from other professionals. They may struggle with other tasks of parenting other children, maintaining their career, and maintaining a life apart from caring.

- Working through it: the carer begins to become an expert in their care-giving role and knowledgeable about the needs of the service user. They often build skills as advocates for their family members and need professionals to recognise their capabilities.

- Reaching the end: this is when the carer is able to launch their family member into more independent living or support by other professional care workers. Sometimes this can leave them with a gap in their life as the object of their expertise and care has moved on. This can leave a gap in the lives of many carers.

- A new beginning: many carers may take on the role of being an advocate for their disabled young adult or monitoring care standards to ensure that the quality of life for the young person is adequate to ensure their comfort and happiness.

Appendix 22 Cool Recovery for carers

Cool (Carers' One-to-One Link) started discussing recovery for carers in 2000, when a carer realised she needed and wanted to recover her own life though the person she cared for and about was not able or willing to recover his own life at the time. She realised she too was stuck in his illness which was the main focus of family life. All revolved around being mentally ill.

Carers' experiences

'The chaos that ensues is emotional, physical, practical, and social.

It threatens the ability to love and cherish.

It prompts a desire to get away. It engenders denial and a need to be absolved of guilt.

Sometimes it gives rise to the real fear of personal safety of anyone involved.

Jobs are threatened and friendships are seriously disrupted.

This is a personal disaster which often with little warning, rips apart the fabric of life, challenging values and distressingly altering expectations for the future'.

- **Recognition of grief**

Recognition that grief plays a large part here.

What is needed is consolation, comfort, kindness, and hope.

Achieving tranquillity, by whatever means, is a major objective along the recovery highway.

Carers' Experiences

You have done all that you can or more than you should. Nothing seems to make a difference.

You are the main carer and the closest.

You bear the brunt of the person's' illness' and share the isolation, helplessness, and fear.

You have tried everything, you are exhausted, depressed, feel guilty – 'what have I done wrong'.

You feel bereaved – you have lost someone you were close to.

You do not know this new person.

And then everything seems OK, for a while, until the next time.

This leaves you on tender-hooks, alert for any sign of change.

Often this is happening well before someone becomes a client of mental health services and before you realise your additional role as carer (as well as being partner, parent, child, sibling etc.)

- Relatives may have been caring on their own for years, months, weeks.
- People generally know very little about mental health issues or illness
- Families often don't know what help is available or where to find it.
- People want to cope and find ways of coping until a crisis develops beyond their scope.
- Often the carer knows the person cared for intimately.
- Carers can get stuck at the point where their relative becomes ill, caught up in the strangeness of it all.
- It's different for everyone.

- **<u>When services become involved</u>**

- Services must listen and respond to carers
- Carers must be involved and included in planning and treatment. You often know the client best – having lived, loved, worked, and had fun with them, maybe all their life.
- Carers must be helped to consider their own needs – regarding what you want and are able to do, and changes you want or need to make for your own well being and for the person you care for.
- Be real and honest.

- **<u>Detaching with love</u>**

- **Setting boundaries** – not tolerating abuse from anyone. Mental illness is not an excuse.
- **Consider your own needs** – for sleep, family, friends, socialising, work, leisure activities, spirituality, and ensuring these needs are met.
- **Risk** – allowing the person to face the consequences of their actions. i.e. no longer rescuing. If we keep rescuing we may inadvertently create a dependency and be helping people to keep on with their self destructive behaviour and not find the help they need to embark on their own journey of self discovery. This idea comes from Alcoholics Anonymous, where people have to hit rock bottom before they themselves decide to get well.
- **Developing faith** – the person is on his / her own personal journey.
- **Developing trust** – they can handle their life and its challenges – with support. They are not helpless.
- **Letting go** of total responsibility for 'caring' by developing good relationships with professional staff and trust them to do their bit. Engaging other family members or friends and trusting them also.

- **<u>Setting a vision or goal for recovery of relationships</u>**

What could this look like? ***Professionals share their goals.***
We have a good relationship, see each other regularly, enjoy each others company, and lead our own lives.

- **<u>Vision for carers' personal recovery</u>**

- **Carers leading a full life**, able to maintain equilibrium in face of the ups and downs of the person you care for and about.
- **Ability to detach with love**; 'I am not abandoning you. I am trusting you to find your own recovery path when you are ready. I am here to help you when I can'.
- **Acceptance of what is.** Life isn't going the way you thought it might and all your feelings: anger, guilt, depression, sadness, bargaining and acceptance are part of the grieving process and have been acknowledged and integrated.

- **Joy can return.**

- **Ideas about how to get there**

1. Taking responsibility.
2. Develop a healthy self-regard.
3. Keep the focus on your own recovery.
4. Professionals develop a healthy regard for carers, and carers for professionals.
5. Get the support you need. For example: see friends, join a support group, see a nutritionist or other complementary therapist, counsellor, or Carer Support Worker, or find other ways to get the emotional support you need, ie. Talking through with friends, reading self-help books, attend courses on unrecognised grieving, co-dependency, etc.
6. Be willing to invest in yourself; spend time, money, and most of all care for care for yourself. Do whatever it takes.
7. Be gentle with yourself; allow yourself to make mistakes. Be forgiving. You have been through a lot.
8. Know that it will take time. The grieving process can take two years and more, and personal growth is a life-long process.
9. Introduce things you love to do at times, when you would have made a sacrifice to meet the needs of the person you care for.
10. Consult yourself as to how much you actually want to give.
11. Let go of obligations and responsibilities which are not your and over which you have no power or control.
12. Have fun and enjoy yourself sometimes.

Appendix 23 The Carers Compass

The Carers Compass includes:
- Providing information
- Recognising and assessing carers' needs
- Listening to the voice of carers in service planning
- Having quality services
- Opportunities for a break
- Emotional support
- Training and advice to care
- Financial security (and support to remain in employment)

Appendix 24 Social constructivism and symbolic interactionism

Social constructivism is based on a theoretical tradition called symbolic interactionism. It rests on three premises identified below.

1. Humans act towards things based on the meaning those things have for them. If people are presented with a pile of sticks, members from different cultures will immediately identify them as different things: to a Chinese person they may be chop sticks; to an English person they may be a bunch of stick for burning; to a child from a USA culture a group of dolls to play with.

2. The meanings of objects arise out of social interaction. The meaning of chopsticks to a Chinese person arises from the culture where people use sticks to eat food. In this culture the child would think of these sticks as chopsticks because they learn to eat with chopsticks from an early age.

3. The meanings are created and changed through a process of interpretation. We understand the use of things through a process of interpretation. We create their meanings. If the sticks are laid next to our dinner table in a western culture situation, we have learned to use them as chopsticks. The little girl waiting for her dinner might still play with them as if they were dolls – and then when dinner started change to use them as chopsticks. The meaning is created through a process of interpretation. (Taken from Esterberg 2002 p15 – 16)

<u>Appendix 25 The members of the steering group</u>

JS worked for the mental health trust and was involved in managing user and carer involvement in research.

KE was a senior member of the mental health trust, a CPN by training, responsible for managing the CPNs in her sector.

QH was a CPN who managed a mental health team within the mental health trust.

QN was the manager of a local charity supporting mental health service users and their carers in the mental health trust area.

R2 was a carer and governor in an adjacent mental health trust area.

KI was a service user who worked as a mental health trainer in the mental health trust area and beyond.

Confidentiality of information

Due to the nature of this group, sensitive information may be shared, therefore all information shared within the group will be kept confidential unless there is risk of harm to participants or people they care for or support when information will be divulged to the relevant body.

Role of steering group

The Steering group is meeting as an advisory group to the research project 'Carers and Recovery' for the purposes of Jo Fox's PhD project. The group will meet 6 – 8 times for 2 hours meetings across 2008 to fulfil this requirement. A follow up steering group meeting will be held in 2009 following the delivery of the training programme to the carer participants to report back on progress to the steering group and evaluate the perceived effectiveness of this group.

Role of supervisory team

The supervisory team consists of Professor Shulamit Ramon and Dr. Nicola Morant. They may advise and make changes to the project without reference to the steering group. Although these changes will be reported back to the steering group to inform them of the reasons for changes in the project.

What we want to achieve

The group will meet to advise on a number of topics including:
- The training programme
- Evaluation tools
- Recruitment of carers
- Meetings with carers
- Carers' expenses to attend meetings
- Methods of delivery of training programme – involvement of carers?

Information Copyright

As the information is for the purposes of Joanna Fox's PhD study, Jo Fox will retain copyright of all information produced within the steering group and resulting from the steering group. Participants will be acknowledged for their involvement in the development of the project, training programme, and evaluation tools.

Dissemination of information

Members of the steering group will be invited to participate in the dissemination of results of the project following its completion. This includes dissemination at local and national conferences, journal articles, and other publications.

Recording of information

Information from the steering groups will be recorded with the permission of participants. The meetings will be transcribed and copies can be viewed at the request of steering group members.

Analysis of information

The steering group meetings will form part of the information collected for the PhD project. Members will be invited to validate information from transcripts and be involved in the analysis of information.

Minutes
Recovery and carer exercise steering group Minutes
16.07.08, Mellish Clark 116, Anglia Ruskin University

1. Who is here?

R1, JS, R2, QN

2. Who is not here?

KI, QH, KE

3. Items from last meeting

Because the meeting was late to start, we decided not to look at issues from the last meeting.

4. Recruitment of carers

We discussed how and where we might recruit carers.

The carers would need to live fairly close to Cambridge because of my and their travelling time (mine in interviewing carers and theirs in travelling to meetings).

We need a good mix of carers: including partners, parents, siblings, daughters, and sons. It would be good to have couples attending as well. They both take away different things from the training and re-inforce them in difference ways.

How can carers be more representative of the population?
There is no accurate data on the demographics of the population of mental health carers. The database has been created from the Carers Assessments – but so few have been undertaken, that the data is not very meaningful of the whole population.

Ways to recruit carers include:
- going to Carers Support Groups
- making contact with professionals and asking them to refer interested carers
- R1 has some contacts with the X Community and will seek to get representation on the group from BME community.
- Turning Point can assist with this.

- Via Trust staff who undertake Carer's Assessments.

> **ACTION**: QN will send R2 an updated list of Carers Support Groups

- R1 will produce flyers and these can be distributed.

> **ACTION**: R1 will produce flyers for approval at next steering group meeting.

- Turning Point hosts the Carers Conference on October 10th. (R2 is unfortunately not able to attend due to holiday already booked!). These leaflets can be left on tables.
- R2 can try to visit carers support groups of EIP and other diverse services to get a good mix of carers. This may be a possible way of getting a diverse mix representing different stages and periods of the cared for person's care pathway.

- A local Carers' Strategy has been updated in Cambridgeshire. Manager and Managerare leading on this.
> **ACTION**: QN will send this to R1.

- The MH Trust is re-organising the way it delivers services.
- R1 will spend some time informing herself more about what is happening in the Trust.
> **ACTION**: R1 to find out more about Trust.

- The training programme may take place from Mid-March – June. R1 goes to Berlin for four weeks in January, and it would be good to ensure there is time to recruit more carers if some drop out from the recruitment phase in September – December.

CARERS EXPENESES

- JS agreed that the mental health trust will probably be able to pay carers expenses to attend the meetings.

<u>**ACTION**</u>: R1 and JS will liaise.

5. Training session 3

The session will take 2.5 hours in total. With ½ hour for break depending on how quickly the sessions start on time.

It is essential that the aim of the session is made clear.

Purpose: The session is about encouraging, you, the carer to think about how the service user can develop his/her own strategies to support and help him/herself and how this may affect how you care for the service user.

It must be clear that the wrap flower is about the carer putting themselves in the place of the service user and thinking about the way the service user develops their strategies, not the way the carer might develop strategies.

The slides have been re-arranged to help the carer think to reflect on how the service user has developed his / her own strategies. Self help and development of own strategies moved to before wrap flower.

It must be clear that 'Build a support package for the service user' refers to the service user and not to the carer. (This has been amended). This slide and a recovery oriented service will be given to the professional to talk to.

We will ask QN if she will be prepared to come in and speak to this part of the session. She, or another professional, will be invited to the whole session and will also participate in the wrap flower.

It must be clear that this session is to make them reflect on how the service user might be able to develop their own strategies; and if they do think about this how this reflects the way the carer may care for the service user.

Appendix 28 The evaluation questions Q1

As part of the evaluation, carers were asked to fill in these questions before and immediately after participation in the training programme. They filled in it at a preliminary meeting before the training programme and at a follow up meeting after the training programme. They were all given the same instructions on how to complete it. I was present to answer any questions if they had any queries whilst filling in the questionnaire.

Write a sentence on each of the following:

1. What do you find helpful in your caring role?

2. What do you find less helpful in your caring role?

3. What is recovery?

4. Does the idea of recovery affect your caring role?

Yes / No

If yes, please give further details:

<u>Appendix 29 The socio-demographic questionnaire (Q2)</u>

The carers were asked to fill this questionnaire in immediately before participation in the training programme. They filled in it at a preliminary meeting before the training programme and were all given the same instructions on how to complete it. I was present to answer any questions if they had any queries whilst filling in the questionnaire.

Q2. ABOUT YOU AND YOUR CARING SITUATION

1. QUESTIONS ABOUT YOU

1.1   Date of birth   Date   //

                                 d   d   m   m   y   y

1.2   Sex   1 Female

                                     2 Male

1.3   Marital status   1 Single

                                     2 Married

                                     3 Separated

                                     4 Divorced

                                     5 Widow/widower

1.4   Country of your birth   Country

      _____

1.5   What is your ethnic group?

1.Asian / Asian British – Indian   9. Chinese or Other – Other

2.Asian / Asian British – Pakistani   10. Mixed – White and Asian

3.Asian/ Asian British – Bangladeshi   11. Mixed – White and Black African

4.Asian/ Asian British – Other   12. Mixed – White and Black Caribbean

5.Black and Black British – Caribbean   13. Mixed – Other

6. Black and Black British – African   14 White – British

7. Black and Black British – Other   15 White – Irish

8. Chinese or Other – Chinese   16.White – Other

17. Not disclosed

                                     Ethnic group

1.6   Highest completed level of education

                                     1 Secondary education

                                     2 Tertiary / further education

2. *YOUR USUAL LIVING SITUATION*

2.1   What is your usual   1 Living alone (+/- children)

      living situation now?   2 Living with husband/wife (+/- children)

                                        3 Living together as a couple (+/- children)

                                        4 Living with parents

                                        5 Living with other relatives

                                        6 Living with others

                                        7Other(specify) _____

2.2   What kind of accommodation do you usually live in?

      <u>Domestic / family</u>   1 Owner occupied flat or house

                                        2 Privately rented flat or house

                                        3 Rented from local authority/

                            or housing association/co-operative

2.3   How many adults live there?   Number of adultsincluding the participant

      (aged 18 or over)

      And how many children?   Number of children

      (under the age of 18)

2.4   Who do you care for with mental health needs?

1 Son   6. Wife

2. Daughter   7. Friend

3 Mother   8. Neighbour

4 Father   9. Partner

5 Husband   10. Other _____

2.4.1   Do you care for anybody else **other** than the person with mental health needs?

1. Yes

2. No

2.4.2   If yes, please give further details_____

_____

2.4.3   Does the person(s) you care for (**other than the person with mental health needs**) live with you?

1. Yes

2. No

3. *YOUR EMPLOYMENT AND INCOME*

3.1   What is your main employment status?

     1 Paid or self employment
     2 Voluntary employment
     3. Unemployed
     4 Student
     5 Housewife/husband
     6 Age-related retirement
     7 Other _____

3.2   *If employed*: state occupation:

     1 Manager/administrator
     2 Professional *(eg health, teaching, legal)*
     3 Associate professional *(eg technical, nursing)*
     4 Clerical worker /secretary
     5 Skilled labourer *(eg building, electrical etc.)*
     6 Services/sales *(eg retail)*
     7 Factory worker
     8 Other_____

     Please state your job title: _____

3.3   If employed, do you work:

     1. Full time
     2 Part time

3.3.1   How many hours per week do you work?

3.4

How many days have you been absent from work owing to illness within the last 12 months?

     Days absent from work

3.5   What is your <u>main</u> income source?   1 Salary/Wage

2 State benefits

3 Retirement pension

4 Family support *(e.g. from spouse)*

5 Other

4. *THE CARE YOU PROVIDE FOR THE MENTAL HEALTH SERVICE USER*

4.1 Do you give help round the house for the service user with mental health needs with any of the following?

Type of help	*Circle*		*Average number of hours help per week*
Child Care (circle 'No' if interviewee has no children)	No	Yes	
Personal care (e.g. washing, dressing etc.)	No	Yes	
Help in/ around the house (e.g., cooking, cleaning etc.)	No	Yes	
Help outside the home (e.g., shopping, transport etc.)	No	Yes	
Other Please give details _____ _____	No	Yes Yes	

4.2   Have you had a Carer's Assessment?

            1. Yes

            2. No

If no, go to question 5.1

4.2.1 **If yes**, is this connected to the care you provide for the service user with mental health needs?

            1. Yes

            2. No

             3. Not applicable

4.3.1 **If yes**, what was the most helpful thing about it?

_____

_____

4.3.2 What was the least helpful thing about it?

_____

_____

4.3.3   Have you received any services for yourself as a result of the Carer's Assessment?

            1. Yes

            2. No

If yes, please give more details:

_____

5. DETAILS OF THE SERVICE USER WITH MENTAL HEALTH NEEDS

5.1   How old is the service user?   years old

5.2   Sex   1 Female

                                              2 Male

5.3   Marital status   1 Single

                                              2 Married

                                              3 Separated

                                              4 Divorced

                                              5 Widow/widower

5.4   Country of service user's birth   Country _____

5.5   What is his / her ethnic group?

1.Asian / Asian British – Indian   9. Chinese or Other – Other

2.Asian / Asian British – Pakistani   10. Mixed – White and Asian

3.Asian/ Asian British – Bangladeshi   11. Mixed – White and Black African

4.Asian/ Asian British – Other   12. Mixed – White and Black Caribbean

5.Black and Black British – Caribbean   13. Mixed – Other

6. Black and Black British – African   14 White – British

7. Black and Black British – Other   15 White – Irish

8. Chinese or Other – Chinese   16.White – Other

                                              17. Not disclosed

                                              Ethnic group

5.6   When was the service user diagnosed with schizophrenia?

                                              1. 0 – 6 months ago

                                              2. 7 months – 1 year ago

                                              3. 1 year – 3 years ago

                                              4.   3 years – 5 years ago

                                              5. More than 5 years ago

                                              6. Awaiting diagnosis

5.7	What is the service user's living situation now?	1 Living alone (+/- children)
		2 Living with husband/wife (+/- children)
		3 Living together as a couple (+/- children)
		4 Living with parents
		5 Living with other relatives
		6 Living with others
		7..Other (specify)
		_____

5. 8 Where does the service user usually live?

Domestic / family	1 Owner occupied flat or house
	2 Privately rented flat or house
	3 Rented from local authority/housing association
Community (non-hospital)	4 Overnight facility, 24-hour staffed
	5 Overnight facility, staffed (not 24-hour)
	6 Overnight facility, unstaffed at all times
Hospital	7 Acute psychiatric ward
	8 Rehabilitation psychiatric ward
	9 General medical ward
	10 Homeless / roofless
	11 Other _____

5.9   Please give details of the service user's employment or educational activities undertaken currently or over the last 12 months.

_____

_____

_____

_____

5.10 Please give details of the services s/he has used currently or over the last 12 months? (e.g. inpatient services, outpatient services, particular professional contacts)

_____

_____

_____

_____

_____

_____

A vignette was presented to the carers immediately before and immediately after participation in the training programme. They were asked to read the vignetteand respond individually in writing to the three questions. They filled in it at a preliminary meeting before the training programme and at a follow up meeting after the training programme. They were all given the same instructions on how to complete it. I was present to answer any questions if they had any queries whilst filling in the questionnaire. The three questions then served as a prompt for discussion in the focus groups.

Q3. **Vignette**

John came out of a psychiatric ward 6 months ago. He was diagnosed with schizophrenia 2 years ago. He is 22 years old. He used to work and enjoyed his job as a trainee electrician, but hasn't worked since he was diagnosed. He doesn't really like taking his medication because of the side effects. Before he went into hospital again, he had split up with his girlfriend, which made him feel very unhappy. He had also taken a new medication for about 3 months, started to feel better, and then decided he didn't really need the medication. When he becomes unwell, he hears voices and becomes paranoid. He describes his paranoia as 'thinking everyone is talking about him when he wanders down the street'. The medication helps to keep him well, but it makes him quite sedated and tired. It also makes him put on weight. He lives alone in a flat. He recently joined the gym and has lost weight. He saw a couple of friends there from his old circle, who share his liking of 60s music. One friend has invited him to go to a 'Beetles Night' at a local pub. He is really looking forward to it. He has a Support Worker who visits twice a week. His mother and father live about 10 miles away. John wonders why they don't visit more often. They find it difficult because it makes them feel uncomfortable when they come to see him. They had been quite close to John before his diagnosis. John has said he would like to start thinking about going back to work. John has asked the Support Worker to help him explore the possibilities of returning to his apprenticeship.

Individually write down your answers to these three statements.

We will then discuss your ideas as a group.

1. Could you state what you think is likely to happen to John in the next two years?

2. What would you like to happen to John?

3. If his parents were to ask for your advice, what would you suggest?

A focus group was held with carers before participation in the training group sessions to find out what they knew about recovery, and how hopeful they were about their caring situation. The questions served as a prompt for discussion. Initial questions related to the vignette presented in Appendix 29.

FG-1

Introductory focus group 02.04.08

1   Could you state what you think is likely to happen to John in the next two years? Can you explain your reasons for this?

2. What would you like to happen to John?
Can you explain your reasons for this?

3. If his parents were to ask for your advice, what would you suggest?
Can you explain your reasons for this?

4. What does recovery mean to the group?
What are the positive things about recovery?
What are the negative things about recovery?

5. How do you describe your role as a carer supporting the service user in his / her recovery?

Appendix 32 Follow up focus group schedule FG-2

A focus group was held with carers at the end of the training group sessions to find out if what they knew about recovery, and how hopeful they were about their caring situation had changed as a result of learning about recovery. The questions served as a prompt for discussion. Initial questions related to the vignette presented in Appendix 29. This focus group was facilitated by two members of the steering group who had not participated in the delivery of the programme: JS and KE.

FG-2
Follow up focus group schedule

Looking at this vignette again:
1. Could you state what you think is likely to happen to John in the next two years?
Can you explain your reasons for this?

2. What would you like to happen to John?
Can you explain your reasons for this?

3. If his parents were to ask for your advice, what would you suggest?
Can you explain your reasons for this?

4. How does the group understand recovery?
What are the positive things about recovery?
What are the negative things about recovery?

5. Has the training programme facilitated an understanding of the recovery approach?
If so, in which way?
Which sessions were helpful? Why?
Which sessions were least helpful? Why?
Was it helpful for the sessions to be delivered by a service user and carer trainer?
Did it make any difference for the sessions to be delivered by a service user and a carer trainer, rather than professionals?
What were the most helpful aspects?

What were the least helpful aspects?

6. Has learning about the recovery approach changed the way you care for the service user?

7. Has participating in the training programme changed the way you care for yourself?

At one month following participation in the training programme the carers were asked to participate in an individual semi-structured telephone interview to evaluate their understanding of recovery and see if they perceived if they had changed their attitudes or behaviour about their caring role. The follow up semi-structured interview schedule at 1months (SSI-1) is found below.

Semi structured interview follow up contact at 1 month SSI – 1

1. An understanding of recovery:
What do you mean by recovery?

2. Your views about the future of the person you care for:
What makes you feel optimistic about the future of the service user?
What makes you feel pessimistic about the future of the service user?
Do you believe his/her recovery is possible?
What do you mean by his/her recovery?

3. Your support for the service user:
If you believe recovery is possible, what are the tasks you undertake to support him / her in his / her recovery?
What are the particular times that your support in the recovery process is needed? E.g. relapses;
What is the most helpful aspect of the recovery approach to your caring role?
What is the least helpful aspect of the recovery approach to your caring role?
Has learning about the recovery approach changed the way you care for the service user? If so, how?

4. Working with mental health professionals:
Has the training programme enabled you to work with professionals in a different way?
How could professionals support you and the service user in applying the recovery approach?
5. About your experience of Carer's Assessments

Have you had a Carer's Assessment?

If yes, did you have it before or after the training programme?

What was most helpful aspect of it?

What was the least helpful aspect of it?

Have you received any services as a result of the Carer's Assessment?

If no, do you intend to have one?

Do you need any further information on this?

6. Effects of participation in the training programme on how you care for yourself:

Has participating in the training programme changed the way you care for yourself?

Have you tried any new activities?

If so, what are they?

What impact have they had?

Would you describe yourself on a journey of recovery?

If so, how would you evaluate your own journey of recovery?

7. Evaluation of the training programme:

Was the training programme helpful in enabling you to explore these issues?

If so, in which ways?

Which exercises / sessions did you find particularly helpful?

Why?

Have you applied any of them to the way you care for the service user?

Which exercises / sessions did you find the least helpful?

Why?

Was it helpful for the training programme to be delivered by a carer and service user trainer?

What was most helpful about this aspect?

What was least helpful about this aspect?

At six months following participation in the training programme the carers were asked to participate in an individual semi-structured telephone interview to evaluate their understanding of recovery and see if they perceived if they had changed their attitudes or behaviour about their caring role. The follow up semi-structured interview schedule at 6 months (SSI-2) is found below.

The follow up semi-structured interview schedule at 6 months (SSI-2)

1. An understanding of recovery:

What do you mean by recovery?

2. Your views about the future of the person you care for:

What makes you feel optimistic about the future of the service user?

What makes you feel pessimistic about the future of the service user?

Do you believe his / her recovery is possible?

What do you mean by his / her recovery?

3. Your support for the service user:

If you believe recovery is possible, what are the tasks you undertake to support him / her in his / her recovery?

What are the particular times that your support in the recovery process is needed? E.g. relapses;

What is the most helpful aspect of the recovery approach to your caring role?

What is the least helpful aspect of the recovery approach to your caring role?

Has learning about the recovery approach changed the way you care for the service user? If so, how?

4. Working with mental health professionals:

Has the training programme enabled you to work with professionals in a different way?

How could professionals support you and the service user in applying the recovery approach?

5. About your experience of Carer's Assessments – question to be asked if the person had not reported having a Carer's Assessment at earlier meetings

Have you had a Carer's Assessment?

What was most helpful aspect of it?

What was the least helpful aspect of it?

Have you received any services as a result of the Carer's Assessment?

If no, do you intend to have one?

Do you need any further information on this?

6. Effects of participation in the training programme on how you care for yourself:

Thinking back: has participating in the training programme changed the way you care for yourself?

Have you tried any new activities?

If so, what are they?

What impact have they had?

Would you describe yourself on a journey of recovery?

How would you evaluate your own journey of recovery?

7. Evaluation of the training programme:

Thinking back: which exercises / sessions do you remember as particularly helpful?

Have you applied them to the way you care for the service user?

If so, how?

Were they successful?

Thinking back: which exercises / sessions did you find the least helpful?

Why?

Was it helpful for the training programme to be delivered by a carer and service user trainer?

What was most helpful about this aspect?

What was least helpful about this aspect?

Appendix 35 Group Guidelines for carers training group sessions.

The steering group developed guidelines which could be used to support the carers as they participated in the training programme. This was then circulated and agreed with the carers as they participated in the preliminary meeting before the training programme.

These guidelines will help us to ensure that all group members feel comfortable and safe to share and learn together

- What we say inside this room may be sensitive, so please don't share the content of our conversations outside this room.
- Please respect confidentiality and don't share whatever is said inside this room with anyone else.
- .All our sessions will be tape recorded. This is to ensure that all that is said is captured and that nothing important is missed. Content will be anonymised immediately on writing up and will be used to help evaluate the sessions. The transcripts will not be shared with people outside the project. However,you can ask for the recorder to be switched off at times in the discussion
- It is your choice what you would like to share in the group
- Be respectful and listen carefully to what others are saying without interrupting
- It is important that everyone has an opportunity to talk

There may be times when the facilitator needs to bring individuals or the group back to the topic under discussion

All sessions were delivered from 18:30 – 21:00

A pre-session group discussion to find out what the group knows about recovery

5 sessions of training

A follow up evaluation comprising a group discussion

1. Base line evaluation – group discussion Thursday 2nd April 2009

2. Session 1: Thursday 23rd April, 2009

    In the first session, all participants introduce themselves and describe their situations. As a group, we agree group guidelines for the way we interact in the sessions: including respecting each other and respecting confidentiality of what is discussed within the sessions. As part of this session we want to encourage carers to consider their own needs as people and not just as carers. We then introduce the recovery concept and what it might mean in a service user's life.

3. Session 2: Thursday 7th May 2009

    We introduce the service user journey of recovery and ask how this might relate to the carer's journey: how the service user may change before and after the onset of schizophrenia and how this might impact on the carers and his / her journey. We then look at how we might be able to understand the recovery journey and relate it to some of our own life experiences.

4. Session 3: Thursday 21st May 2009

    We introduce what recovery might mean in practice. How service users might develop their own strategies to look after their own health and be more aware of their own needs and resources in monitoring their mental health. We look at how we might be able to promote this by using a practical example of wellness recovery action planning – that enables service users to look at their own resources for recovery. We invite a front line professional to discuss how they might promote the recovery approach in their practice.

5. Session 4: Thursday 4th June 2009

We introduce the notion of the carers' right to be involved in care planning and service evaluation. We introduce the practice of direct payments and how they may be able to facilitate the recovery process. We invite a senior Cambridgeshire and Peterborough NHS Foundation Trust representative to talk about carers' rights to an assessment of their needs and the development of the recovery approach in this area.

6. Session 5: Thursday 25th June 2009
    We explore the differences between service user's expectation and carer's expectations of the journey of recovery. We consider our own journey of living with and beyond the mental health problems of the service user. We also leave space to answer any questions and explore any issues that carers
    might have left over from other sessions.

7. Follow up evaluation: Thursday 9th July 2009

Appendix 37 Leaflet for carers

F01, female, 68 years of age, married, White British, educated to tertiary level, retired, lives in owner occupied house with husband, cares for son, 39 years of age, who was diagnosed with schizophrenia more than 5 years ago. [Service user] is single, White British, lived with parents at start of the training programme, but has now moved out to live in social care housing. [Service user] is studying for a BA at a local university, sees a psychiatrist regularly, and seems willing to take medication. F01 drives [service user] to places if he needs to get anywhere. F01 has had a Carer's Assessment. She found the experience wasn't very useful, but at least it put the mental health services in contact with [service user].

F02, female, 65 years of age, married, White British, educated to tertiary level, employed as language support teacher, lives in owner occupied house with husband, cares for son, 27 years of age, who was diagnosed with schizophrenia 3 – 5 years ago. [Service user] is single, White British, lived with parents at start of training programme, had to be made intentionally homeless by parents due to his gambling addiction, and now lives independently in social care housing. [Service user] has a team of support to enable him to live more independently. He enjoys cooking. [Service user] has received direct payments in the past to enable him to access a cookery course. When he lived with her, F02 said she provided general support - every day all day according to needs. F02 has had a Carer's Assessment. F02 found it helpful in that she was able to say how her son's illness affected them and find out information. The least helpful thing about it was that it's a tick list so not as flexible as it could be.

F03, female, 70 years of age, married to M02, White British, educated to tertiary level, retired, lives in owner occupied house with husband, cares for son, 34 years of age who was diagnosed with schizophrenia more than 5 years ago. [Service user] is single, White British, lives in owner occupied house. [Service user] has not had a good experience with services and resents his parents' involvement in the sectioning process on one occasion, he, therefore, will not allow them access to information from practitioners and professionals. F03 provides variable hours of support and general support. F03 has had a Carer's Assessment. The most helpful thing about it was it enabled her to talk to one of the mental health team, and the least helpful thing about it was she did not receive any paperwork so there were no outcomes.

F04, female, 51 years of age, living in a civil partnership with a female partner, White Irish, educated to tertiary level, voluntary employed in project co-ordination, lives in owner occupied house with partner, cares for brother, 44 years of age, who was diagnosed with schizophrenia more than 5 years ago. [Service user] is single, White Irish, lives in Northern Ireland. F04 goes out to Ireland every 6 weeks at the start of the programme. [Service user] has a very ambivalent relationship with services and receives a depot injection as the only mental health contact. F04 supports her brother in social events, befriending, house maintenance; financial controller. I spend 5 hours per week organising things when I am away and doing befriending calls on phone and internet. F04 has not had a Carer's Assessment as these are not available in Northern Ireland.

F05, female, 57 years of age, married, White British, educated to tertiary level, employed as freelance tutor, lives in owner occupied house with husband, cares for daughter, 30 years of age, who was diagnosed with schizophrenia more than 5 years ago. [Service user] is single, White British, lives in a residential community ward for people with schizophrenia. She has been passed between learning disability team and mental health team in the past, and has worked as a cleaner in the past. F05 provides support in employment, friends. F05 has had a Carer's Assessment.

F06, female, 56 years of age, married, White British, educated to secondary level, employed as a sales manager, lives in owner occupied house with husband, cares for son, 31 years of age, who was diagnosed with schizophrenia more than 5 years ago. [Service user] is single, White British, lives with parents but has a flat of his own which he doesn't live in. [Service user] takes medication and sees a psychiatrist and CPN regularly. F06 has had a Carer's Assessment. The most helpful thing about it was being able to talk to somebody who appeared to understand the difficulties of being a carer. The least helpful thing about it was the fact that it couldn't take place at home.

F07, female, 77 years of age, married to M04, White British, educated to tertiary level, retired but also managing a property portfolio, lives in owner occupied house with husband, cares for daughter 46 years of age who was diagnosed with schizophrenia 1 – 3 years ago. [Service user] is single, White British, lived in owner occupied flat at the start of the training programme, and spent some periods in hospital and is now living with her parents. F07 provides support by being on call 24 hours. F07 has not had a

Carers' Assessment. Due to her confusion and misunderstanding, even after the training programme she still did not seem to understand the reasons for a Carer's Assessment or what it was about.

M01, male, 70 years of age, White British, educated to tertiary level, divorced, self employed as proprietor of own company, lives in owner occupied house by himself, cares for son, 27 years of age, who substance misused and was diagnosed with schizophrenia more than 5 years ago. [Service user] is single, White British, lived alone in flat at start of training programme. During the programme, he has ceased taking heroin and is now receiving services in a drug rehab centre is now hoping to move to an inpatient community residential ward for people with mental health problems. M01 provides general help with all aspects of life. [Service user] visits his home. M01 has had a Carers' Assessment. He commented nothing came out of it - maybe it informed the mental health team about drug abuse problems. The least helpful thing about it was it took up a lot of his time.

M02, male, 71 years of age, married to F03, White British, educated to tertiary level, retired, lives in owner occupied house with wife F03, cares for son, 34 years of age, who was diagnosed with schizophrenia more than 5 years ago. [Service user] is single, White British, lives in owner occupied house. [Service user] has not had a good experience with services and resents his parents' involvement in the sectioning process on one occasion, he, therefore, will not allow them access to information from practitioners and professionals. M02 helps with DIY. M02 has not had a Carers' Assessment.

M03, male, 64 years of age, married, White British, educated to tertiary level, retired, lives in owner occupied house with wife, cares for son, 32 years of age, who was diagnosed with schizophrenia more than 5 years ago. [Service user] is single, White British, lives independently in social care housing. In SS1 and SS2 interviews, the family had a lot of concern about an ineffective CPN and have worked to have her replaced. This was a source of great concern to the family. M03 provides assistance with finance. M03 has had a Carer's Assessment. The most helpful thing about it was just that someone considered his needs. The least helpful thing about it was that nothing materialised out of it.

M04, male, 78 years of age, hard of hearing, married to F07, White British, educated to tertiary level, retired but also managing a property portfolio, lives in owner occupied flat with wife, cares for daughter, 46 years of age who was diagnosed with schizophrenia 3 -5 years ago. [Service user] is single, White British, lived in owner occupied flat at the start of the training programme, and spent some periods in hospital and is now living with her parents. At the start of the programme, M04 cared by keeping a general view of the situation because his daughter lived in her own accommodation. M04 has not had a Carer's Assessment. Due to his confusion and misunderstanding, even after the training programme he still did not seem to understand the reasons for a Carer's Assessment or what it was about.

Appendix 39 Attendance patterns of carers and response rates to research instruments

The table below shows the attendance patterns of the carers during the whole research process. An 'X' denotes that a particular carer attended a particular session or participated in a particular element of the research process.

	Face inter	Tel Inter	WE1	WE1a	FG1	TP1	TP2	TP3	TP4	TP5	WE2	FG2	SSI1	SSI2
F01	X		X		X	X	X	X	X	X	X	X	X	X
F02	X		X		X	X		X	X	X	X	X	X	X
F03		X	X		X	X	X	X	X	X	X	X	X	X
F04		X	X		X	X	X	X	X	X	X	X	X	X
F05	X		X		X	X	X	X	X	X	X	X	X	X
F06		X		X		X	X	X	X	X	X	X	X	X
F07		X		X			X	X	X	X	X	X	X	X
M01	X		X		X	X	X	X	X	X	X	X	X	X
M02		X	X		X	X	X	X	X	X	X	X	X	X
M03	X		X		X	X	X	X	X	X	X	X	X	X
M04		X		X			X	X	X	X	X	X	X	X

Session key:

Face interview: Initial face-to-face interview with carers who participated in the programme to ensure their full information and their questions were answered

Tel interviews: Initial telephone interviews with carers who participated in the programme to ensure their full information and their questions were answered

WE1: Written evaluations (including open questions, responses to vignette, socio-demographic questionnaire) completed at first pre-meeting and focus group 1 session.

WE1a: Written evaluations (including open questions, responses to vignette, socio-demographic questionnaire) completed after first pre-meeting and focus group 1 session as participant unable to attend first pre-meeting.

FG1: Focus Group 1

TP: Training Programme sessions 1 – 5

FG2: Focus Group 2

WE2: Written evaluations (including open questions, responses to vignette) completed at final evaluation and focus group session.

WE2b: Written evaluations (including open questions, responses to vignette) completed after final evaluation and focus group session as participant unable to attend final evaluation session and focus group

.

SSI1: Follow up telephone interview 1 month

SSI2: Follow up telephone interview 6 months

Appendix 40 Participant information sheet and consent form

Participants were provided with an information sheet and asked to sign a participant consent form showing that they had received information about the research and had given their agreement to participate.

<u>**PARTICIPANT INFORMATION SHEET**</u>

An exploration of the role of carers in the recovery of service users with schizophrenia

- <u>**WHY HAVE I BEEN INVITED TO TAKE PART IN THE RESEARCH PROJECT?**</u>

Family members, neighbours, and friends play an important role in supporting people with mental health problems. We would like to invite carers (people who support people with schizophrenia) to come to a brief meeting to discuss whether you would like to participate in a group engaged in a research project on recovery. As part of the research process, you will participate in a group exploring your views on recovery and receive a training package. The training package will aim to raise your level of knowledge of recovery, and you then contribute to evaluating its effectiveness. This will help us explore what carers think about recovery and if it can help them care for someone with schizophrenia better.

Different carers may have different experiences of and attitudes to caring, therefore a mixed group of carers will be recruited. This will enable the research to explore these attitudes to recovery, and how relevant recovery is to carers in general. I will have an individual informal discussion with all carers who express an interest in taking part in the training programme and research to ensure that all participants understand the research and are comfortable with it.

- <u>**WHAT IS THE RESEARCH PROJECT ABOUT?**</u>

The aims of the project are to explore the role of carers in the recovery process of service users experiencing schizophrenia. 'Mental health recovery' is a new term which has been used to describe the journey back to well-being that the service user follows after an experience of mental illness. It is the new principle underpinning English mental health policy and practice.

We will use Participatory Action Research. This is a research model that values the experiences of all the different participants in the research, and enables their voice to influence and shape the direction of the project. It is *formative research*. This means

that any lessons we learn can be acted on immediately and incorporated into the research processes.

Who is organising the research?

The research is being undertaken by Joanna Fox, a qualified social worker and a researcher, and service user, for her PhD study based at Anglia Ruskin University in collaboration with Cambridgeshire Mental Health Partnership Trust. Joanna worked as a carer development officer in Barnet for three years developing the Barnet Mental Health Carers Strategy, then went on to support and further develop services for mental health carers. The research is supervised by Professor Shulamit Ramon and Dr. Nicola Morant, both from Anglia Ruskin University.

What will happen to the results of the research?

The research results will be published in my PhD, in articles, and discussed both locally and nationally at conferences and workshops. If you have participated in the project, you will also be invited to participate in the dissemination of the results if you wish to do so.

Who is funding the research?

The research receives limited funding from Cambridgeshire Mental Health Partnership Trust for carer and service user participants in the Steering Group.

WHAT FURTHER INFORMATION DO I NEED TO CHOOSE TO PARTICIPATE?

1. How will you participate in the research project?

The project consists of the following components, each of which will involve the participation of carers:

- **A steering group** will develop the research methods, evaluation procedures, and training package with the researcher, Joanna Fox. This group will consist of service users, carers, voluntary and statutory sector representatives from the local area.

- **An initial focus group** will be held with you as a group before the delivery of the training programme. You will be asked to fill in a questionnaire to tell us what you

know about recovery and a little about your caring situation. This will enable us to compare the information collected during and following the training programme. The group will be divided into two for focus group discussions (between 4 and 6 people). It will be combined for participation in the main training programme.

- **The training programme** will be run with a group of between 13 and 15 people. It will take place in the evenings at Anglia Ruskin University, Cambridge. There will be five sessions of 2½ hours each, spread over a 10 week period. Sessions will focus on personal experiences of recovery for the service users and the carers, practical aspects of recovery, and policy issues. The style will be informal, using pairs working, teaching sessions, and group discussion times. There will be space within the sessions for you to discuss reactions to new knowledge and how it affects attitudes to caring in a supportive environment with other carers. I will ask you to help us evaluate the training package both during and at intervals after you have received it.

- **A follow up focus group meeting** will then be held to evaluate the content and usefulness of the training, explore how your awareness of recovery has changed, and discuss the impact on your caring relationships. (The group will be divided into two with the same participants as for the initial focus group discussion).

- **Follow up contacts** (at 1-2 and 6 months) will use a written questionnaire and follow up telephone conversation to evaluate whether any changes you identified following the training package have been sustained.

Discussion time in the training programme and focus groups will be audio-taped and transcribed (written down) for the purposes of further analysis. All transcripts will be immediately made anonymous. You will receive a copy of the transcribed discussion for you to check. If there is anything you do not want included on the document, you may ask for it to be removed. All material will be destroyed 5 years after the completion of the project.

2. Can I refuse to take part or withdraw from the research?
You can refuse to take part in the research without affecting any services or support you or your relative receive from Cambridge Mental Health Trust or any other organisation

collaborating in the research. You may withdraw from the research process at any time without any negative implications. You may do this either by informing the researcher verbally, in writing, or via email at any of the contact details provided below.

3. What are the benefits and risks of being involved in the research project?

You will participate in a group of carers expressing their views about recovery and participating in a recovery training package. Hopefully you will learn about the recovery concept in mental health in a mutually supportive group, and how to care more effectively for your relative with schizophrenia and swap ideas and experiences with other carers. In a wider context, if evaluation shows the training package to be effective in helping carers to care both for themselves and their relative with schizophrenia, it may result in improved training packages or better services for carers.

Research shows that the caring role can be difficult and stressful. Participation in groups where people talk about their experiences may occasionally raise difficult feelings or bring back difficult memories; therefore, we will ensure you have all the support that you may need in case you feel upset or distressed.

4. Is there any additional support for me if I feel upset or distressed?

I will be responsive to different ways in which you need support. You will be able to contact me by telephone during the research process. I work with Turning Point for Carers, who can offer additional support in case you need to talk through any experiences. Turning Point offers confidential support and a listening ear to carers of those who experience mental ill health aged 18 – 65. We will encourage you to 'buddy up' for mutual support. I will also enable you all to meet together in the group for a limited period following the training package if you need to.

For independent support or advice, you may also contact the **Carers Line** on **0808 808 7777** (Wednesday and Thursday 10 am – 12 pm, 2 – 4 pm). It offers independent advice and support to carers. Or **Saneline** on **08457 678000** (available every day of the week 1pm – 11 pm). It offers independent advice and support to carers and users.

5. Ethical issues

The project has approval from Anglia Ruskin University Ethics Committee.

6. Confidentiality of information

I will ensure that information is kept confidential. We will agree group rules for participation in the group so that everyone can discuss their experiences in a safe and comfortable environment. Nobody will be able to identify you when the research findings are presented at conferences, in papers and in reports. Confidentiality will be maintained unless this presents a danger to the health or safety of research participants or other vulnerable people.

7. Your consent

This information sheet detailing your involvement in the research project will be given to you. I will ask you to sign a consent form stating you have received the information sheet and consent to be involved in the research. Both you and the researcher will receive a signed copy of the consent form with the information sheet.

TIMESCALE OF PROJECT

June 2007 – January 2008	Ethics Committee Approval
	Development of training
	Put together steering group
	Liaison with Mental Health Trust and local voluntary sector groups to develop training, and support recruitment of carers for pilot, and steering group members. (Liaison with these groups continues throughout the project to support process)
January 2008 – December 2008	Steering group inputs into development of training
	Pilot completed
	Evaluation tools developed and piloted
	Analysis of pilot and its evaluation
January 2009 – April 2009	Training and evaluation tools amended following pilot
	Sample of carers for training sessions put together
	Steering group feeds into process continuously
May 2009 – December 2009	Training delivered
	Evaluation undertaken by carers
	Data collected
	Support received from steering group to feed into process
January 2010 – April 2011	Analysis of data
	Initial dissemination of findings
	Support from steering group to feed into processes
	Write up of full dissertation

For further information, contact:

X information

PARTICIPANT CONSENT FORM

Project Title: An exploration of the role of carers in the recovery of service users with schizophrenia

NAME OF PARTICIPANT:_____

Main researcher: X and contact details

Members of the supervisory team: Professor Shula Ramon, Dr. Nicola Morant

1.I agree to take part in the above research. I have read the Participant Information Sheet which is attached to this form. I understand what my role will be in this research, and all my questions have been answered to my satisfaction.

2.I understand that I am free to withdraw from the research at any time, for any reason and without prejudice.

3.I have been informed that the confidentiality of the information I provide will be safeguarded.

4.I am free to ask any questions at any time before and during the study.

5.I have been provided with a copy of this form and the Participant Information Sheet.

Data Protection: I agree to the University[110] processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me.

Name of participant (print)……………………….Signed………………..
….Date………………

Name of witness (print)…………………………..Signed………………..
….Date………………

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP

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110 "The University" includes Anglia Ruskin University and its partner colleges

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If you wish to withdraw from the research, please complete the form below and return to the main investigator named above.

Title of Project: <u>An exploration of the role of carers in the recovery of service users with schizophrenia</u>

I WISH TO WITHDRAW FROM THIS STUDY

Signed: _____ Date: _____

Appendix 41 Mental Capacity Act (2005)

To comply with the Mental Capacity Act the research must fulfil a number of functions. The Act applies to England and Wales only. It came into force on 1st October 2007 and generally relates to people aged 16 years and over. The Act empowers and protects people unable to make decisions for themselves e.g. relating to property and financial affairs or healthcare treatments. It also covers 'intrusive research' (e.g. that which would have normally required consent). There are a range of factors which can cause incapacity, including learning disabilities, dementia and mental health problems. Loss of capacity can also be temporary, for example due to shock or the effects of drugs or alcohol. The Act introduces two new criminal offences against people who lack capacity

1) ill treatment
2) wilful neglect

The five key principles that underpin the Act are:
- A presumption of capacity (the starting point is that people have the right to make their own decisions);
- People have the right to be supported to make their own decisions;
- People should be allowed to make what may be viewed as unwise decisions;
- Anything carried out for or on behalf of people who do not have capacity must be in their best interests;
- The least restrictive option must be taken.

The two-stage test of capacity is:

→ Is there an impairment or disturbance in the functioning of the person's mind or brain?
→ If yes, is this sufficient to cause the person to be unable to make that particular decision at the relevant time?

If the answer is yes, the research will need to meet all the requirements of the Mental Capacity Act. The ability of a person to make a decision should be assessed in each different situation. It is important to acknowledge that people may have the capacity to make some decisions but not others, or their ability to do this may fluctuate over time.

Any research that falls under the Act will need to be reviewed by an ethics committee recognised by the Secretary of State (an NHS Research Ethics Committee), even if it does not involve the NHS. The University Research Ethics Committee is not authorised to review research that falls under the Act. Researchers who carry out research that is within the remit of the Act are also legally required to have regard to the Code of Practice[111].

Taken from **Important information for researchers** issued by Anglia Ruskin University Research Ethics Department 2008

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111 http://www.publicguardian.gov.uk/mca/code-of-practice.htm

Appendix 42 The Data Protection Act (DPA, 1998)

The Data Protection Act came into force in March 2008 and it is essential that you ensure that your research complies with it. The Eight Principles of the Act are:

• First Principle – fair and lawful processing;

• Second Principle – purposes for holding data;

• Third Principle – status of data;

• Fourth Principle – accuracy of data;

• Fifth Principle – retention and disposal of data;

• Sixth Principle – rights of data subjects;

• Seventh Principle – disclosure of data;

• Eight Principle – transfer of data.

There are some exemptions for some of the Principles regarding research. You do, however, need to ensure that you meet any requirements of the funder (if applicable) and of your ethics approval. The Policy advises that it is customary for research data to be kept for five years and 15 years for some clinical data.

The Act defines personal data and sensitive data. Personal data is that which a living individual can be identified from and includes photographs and email messages.

Sensitive data is information regarding a person's:

• Racial or ethnic origin;

• Political opinions;

• Religious beliefs;

• Trade Union membership;

• Physical or mental health;

• Sexual Life;

• Commission or alleged commission by him/her of any offence;

• Proceedings for any offence committed or alleged to have been committed.

Greater care must be taking in storing this data and deciding who has access to it.

For further information regarding the Eight Principles and other requirements of the Act, please see the Information Commissioner's website:

http://www.ico.gov.uk/what_we_cover/data_protection.aspx

Taken from **Important information for researchers** issued by Anglia Ruskin University Research Ethics Department

<u>Appendix 43 The reference list to the quotation sources</u>

SG1 – SG9: This refers to the steering group meetings. There were 9 steering group sessions, the number refers to which steering group session the quotation was sourced from. (e.g. SG 1 refers to the first steering group meeting and SG2 to the second steering group meeting).

WE1: Written evaluations (including open questions, responses to vignette, socio-demographic questionnaire) completed at first pre-meeting and focus group 1 session.

FG1: Focus Group 1

TP: Training Programme sessions 1 – 5. This refers to the training programme eering group meetings. There were five training programme sessions, the number refers to which training session the quotation was sourced from. (e.g. TP1 refers to the first training session and TP2 to the training session).

FG2: Focus Group 2

WE2: Written evaluations (including open questions, responses to vignette) completed at final evaluation and focus group session.

SSI1: Follow up telephone interview 1 month

SSI2: Follow up telephone interview 6 months

The source of the quotation is followed:
- by a professional who supported the development of the training. Anonymised initials are provided.

or a carer – referred to as F0 (female + number) or M0 (male + number).

Appendix 44 List of Steering group meeting dates and attendance patterns of members

Meeting	Date	Attendance	Apologies
SG1	20.02.08	R1, R2, QN, QH, KE, JS, KI	None
SG2	16.04.08	R1, JS, QN, QH, KE	JS, R2
SG3	04.06.08	R1, JS, R2	QN, QH, KE, KI
SG4	16.07.08	R1, R2, QN, JS	QH, KE, KI
SG5	24.09.08	Cancelled due to people not able to attend	
SG6	05.11.08	R1, R2, KI, KE, JS	QN, QH
SG7	07.01.09	R1, R2, KE, KI, JS	QN, QH
SG8	25.02.09	R1, R2, KE, QN, KI,	QH, JS
SG9	20.10.09	R1, R2, JS	QN, QH, KE, KI

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Appendix 45 The steering group's definitions of recovery

SG2JS.
Social Recovery, relationships, work / education, leisure, satisfactions. Be able to deal with 'symptoms', challenges, problems derived from mental health condition and live a fulfilling life. Gain, rather than lose / opposite of being isolated.

SG2KE.
Recovery is an individual journey whereby a person lives their life feeling under control of the factors influencing their personal well being. It is about the pursuit of a person's own goals, dreams and ambitions despite any illness or disability. It is about moving forward and backwards with hope and optimism.

SG2QH.
...This isn't just about me and my profession. It's not just about mental health. So I will start, Having been unwell, incapacitated, not able to function to full potential for whatever reason – recovery is the process of 'getting better'. Achieving what one wants to achieve, balanced lifestyle, sense of well being. Recovery is an on-going process.

<u>Appendix 46 The WRAP Flower – Care planning for people with mental health needs</u>

<u>Draw a stem of the flower then:</u>

<u>Overall aim</u> – **Centre of the flower:**

What is the key overall focus that the service user wants to achieve?

<u>Wellness</u> – **Petals**:

Breaking down the Overall aim to show what the service user might be doing to achieve this goal.

<u>Wellness tools</u> – **leaves:**

What do we need to support us to achieve this goal

<u>External and internal triggers</u> – **Greenfly:**

What could happen both internally or externally that would undermine what we are doing and turn positive to negative?

<u>Supporters</u> – **Watering cans:**

Who can we get support from to be effective and stay well?

<u>Crisis</u> – **Thunder cloud:**

What would be our worst case scenario if things really broke down

Appendix 47 Thompson's (2003, 2006) systems map

- Psychological / Patient: a level of thoughts, feelings, attitudes, actions and prejudices
- Cultural: shared ways of seeing, thinking and doing
- Structural: social divisions are sewn into the fabric of society and oppression and discrimination are based in structural systems
(Thompson, 2003, 2006).

Appendix 48 The Mental Health Matrix

Temporal Dimension

	A Input Phase	**B Process Phase**	**C Outcome phase**
1 Country / Regional level	**1A** Expenditure on mental health services and budget allocation Mental health laws Government directives and policies Planning for training of mental health staff Treatment protocols and guidelines	**1B** Performance / activity indicators (e.g. admission rates, bed occupancy rates, compulsory treatment rates Clinical guidelines and treatment protocols Minimum standards of care	**1C** Suicide rates Homelessness rates Imprisonment rates Special inquiries
2. Local level	**2A** Local service budget and balance of hospital and community services Assessment of local population needs Staff numbers and mix Clinical and non-clinical services Working relationships between services	**2B** Monitoring, service contacts and patterns of service use Audit procedures Pathways to care and continuity Targeting of special groups	**2C** Suicide rates Outcomes aggregated at local level Physical morbidity
3 Patient level	**3A** Assessment of individual needs Demands made by patients Demands made by families Skills and knowledge of staff Content of clinical treatments Information for patients / carers	**3B** Subjective quality of treatments Continuity of clinicians Frequency of appointments Pattern for care process for individual patients	**3C** Symptom reduction Impact on care-givers Satisfaction with services Quality of life Disability Needs

Geographical Dimension

Taken from Thornicroft and Tansella (1999) (Amalgamated from three different figures on different pages)

The vignette of Peter was presented to the carers in training session four to allow them to discuss the importance of direct payments and to think about the role of mental health services in supporting recovery.

Peter has schizophrenia and has had several acute episodes requiring compulsory hospital treatment in the past 15 years. In the last two years he has been building on his successes. Recently, he had gained in confidence, was going out more, and had made some friends at the local gym. He had met a partner several months ago and was feeling much more positive, happy, and outward going. He was thinking about trying out a computer course at the local college. This could be an opportunity to try out some volunteer work at the local volunteer centre. He was living in a housing corporation house by himself. He had a Support Time and Recovery (STR) worker who visited fortnightly and his Community Psychiatric Nurse (CPN) regularly visited. He got on well with the STR worker, who encouraged him to try new things. It was her idea to join the gym. His CPN never seemed to listen to him about his medication problems. This frustrated him a lot.

Recently things had broken down with his partner. He was putting on weight because of the medication and had problems with sexual dysfuntion. He stopped taking his medication, although it seemed to help him to manage his symptoms. He stopped looking after himself, going out, and his symptoms seemed to have worsened. Although he managed to remain out of hospital, his life seems to have come falling down around his ears. He is feeling very low.

He is now living at home again with his retired parents. He has some mild psychotic symptoms and generally appears apathetic and sluggish. He finds it very difficult to do things. He spends long periods in bed alone in his room, and finds it difficult to get up in the morning. Peter seems reluctant to go out and face the world.

His father is a proud man who finds it difficult to accept that there is anything wrong at all with Peter. He believes that Peter is lazy, should do more to help himself and his mother, and should go out and find himself a job.

The longer Peter stays in bed in the morning, the higher the household tension rises. Every so often there is an explosive confrontation between Peter and his father that threatens to eventually break down into physical violence.

A social worker visits, she talks about direct payments and the advantages of using this to arrange care to support Peter; to get support when he wants, how he wants and what he wants.

Questions

1. How is everyone feeling about the set back?

2. If Peter had a wish list of things that could help him get back on his feet, what would they be?

3. How could these things help his parents?

4. What will Peter and the family have to consider before setting up a direct payment?

Appendix 50 Typical values informing user participation in research

Taken from Nolan et al (2007, p. 10)

Minkler and Wallerstein 2003	Beresford 2005b	Turner and Beresford 2005	Dewar 2005
Participation	Support to get people together	Empowerment	Equality
Co-operation	Equal opportunity to get people together regardless of age, gender, race etc.	Emancipation	Fairness
Co-learning	Ensuring good access and support	Participation	Clear sense of purpose and roles
	Addressing ethical issues	Equality	Commitment to learning
		Anti-discriminatory	Shared values and beliefs