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Wendy Brown & Niki Kandirikirira

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# Recovering Mental Health in Scotland

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**Report on Narrative Investigation  
of Mental Health Recovery**



Scottish Recovery Network

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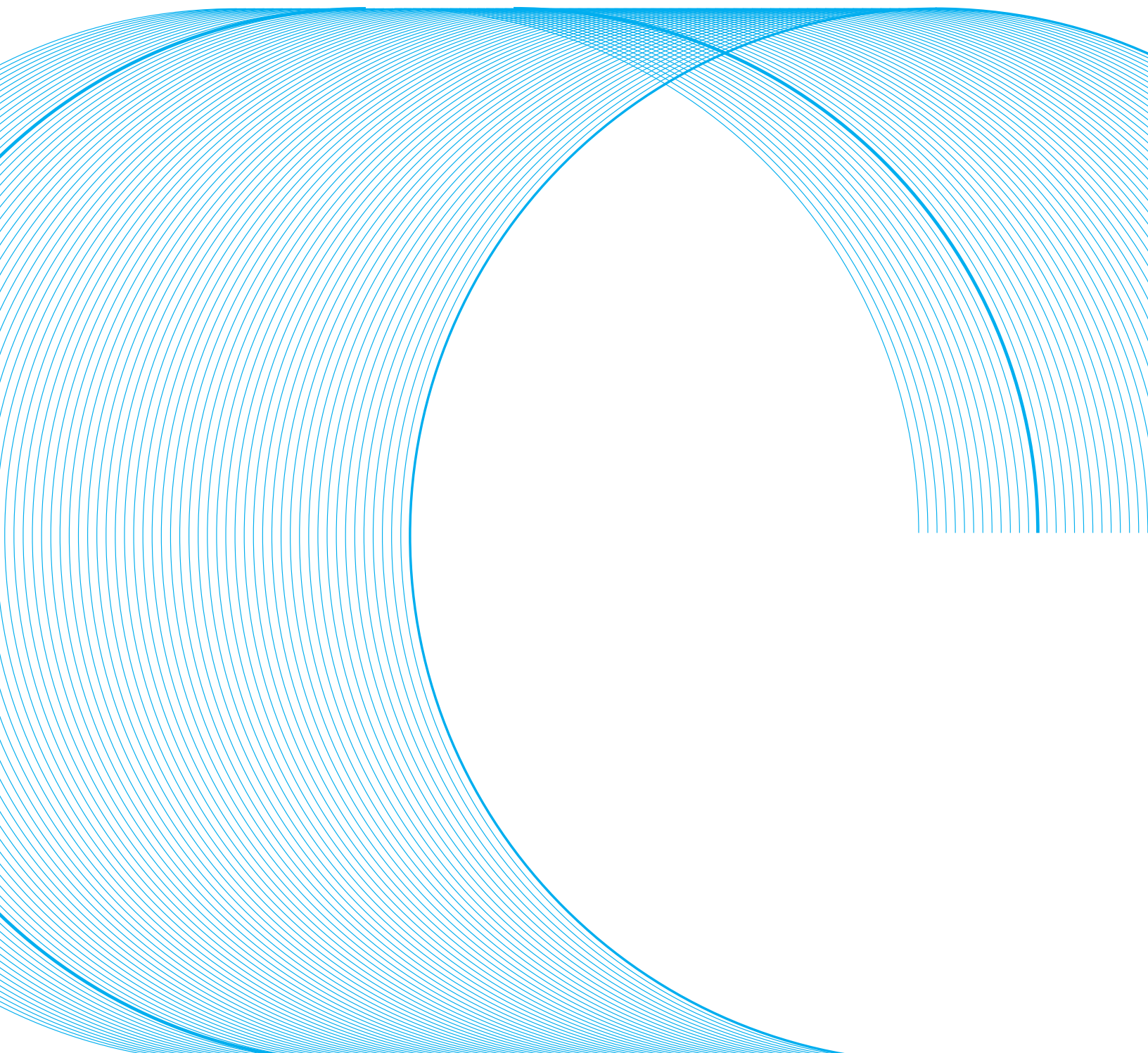
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# Foreword

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**Our Programme for Government includes core commitments to build a Healthier and a Fairer Scotland, and health improvement and social inclusion are key parts of these commitments. We want to help people in Scotland to help themselves in sustaining and improving their health; to help support healthier homes, communities and environments; and to enhance individuals' quality of life, including the mental wellbeing and health and social connectedness of those living with mental ill-health.**

One of the four key aims of the Scottish Government's National Programme for Improving Mental Health and Wellbeing is promoting and supporting recovery from mental health problems, including severe mental illness. This key aim recognises that the majority of people can and do recover from periods of mental illness; and that many others learn to live with their symptoms and lead full lives.

Every experience of recovery is unique. But for everyone who has experienced mental ill-health, it is about having the tools to sustain their own good mental health and wellbeing even where they may continue to live with ongoing symptoms.

This report is the result of an innovative approach to research. By using a narrative method it clearly states that people in recovery from long-term mental health problems are experts by experience and it reminds us that people can and do recover.

This report helps us to learn from the uniqueness of each individual's experience of recovery but also identifies common factors; offer tools and techniques for recovery for service users, carers, friends and families, service providers and the wider community; and establishes a Scottish evidence base of factors that help or hinder an individual's recovery from long-term mental health problems. This evidence base will feed into our commitments on improving mental health services which are currently being implemented and which aim to deliver better outcomes in terms of social inclusion, educational opportunities, housing, training and employment and family and social life. Given that a key aspect of the report's findings is the diversity of factors which help and hinder recovery, this means that in our efforts to provide better services we must continue to emphasise the need for person-centred, recovery-oriented approaches.

What strikes me most about this publication is the drive and commitment of research participants to live well and recover. It reminds us all that even in the most trying circumstances it is possible to develop and harness our inner strengths and this resource should help share these collective strengths and wisdom.

This report provides a message of hope. It does not suggest that recovery is straightforward but it does show that it is possible. For many people a key factor was the belief in that possibility of recovery.

For friends, family members and the wider community alike there is a responsibility to share and support this message of hope – and to raise expectations.

We are committed to maintaining and developing the advances in thinking around recovery which are being encouraged by the Scottish Recovery Network, as part of our wider work for a Healthier and Fairer Scotland.



**Shona Robison MSP**  
**Minister for Public Health**

# Preface

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**Part of the human experience is that we seek to find ways to make sense of our lives. The experiences and challenges that we encounter on our journey through life are often unexpected, sometimes exhilarating, sometimes painful, occasionally overwhelming. Often we realise looking back that the toughest times were in fact those which enriched us most as individuals.**

This piece of research, undertaken by the Scottish Recovery Network, is an inspiring and courageous account of how a very diverse range of people faced mental ill-health and the consequences that followed in its wake. Although the narrators' stories are very different and highly individual, what they have in common is an aspiration to live life to the full, an enduring hopefulness and a resilience of spirit. It is a great privilege to have access to such compelling first hand accounts of mental health recovery.

The narrative research was undertaken with a purpose. It was intended from the beginning to be a means to better understand recovery in contemporary Scotland from a range of different perspectives. That understanding should now encourage each of us to reflect on our values and attitudes and on our expectations and assumptions. It should also help us to consider what we can do to support our own mental health and the mental health of the people close to us.

The narrators in the research have had the courage to share their life experiences with a very wide readership. As the readers of this report, we now have a reciprocal responsibility to make good use of what has been entrusted to us. The Scottish Recovery Network looks forward to the opportunity to discuss the themes and issues raised in this report and to debate the implications that arise from the stories recounted here.

**Allyson McCollam**  
**Chair**

Scottish Recovery Network Strategy Group

**Chief Executive**

Scottish Development Centre for Mental Health

# Acknowledgements

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The Scottish Recovery Network would like to thank the academics, service users and professionals on our project steering group for their ethical guidance and invaluable support throughout this research. We are indebted to them and to the numerous reviewers who provided feedback on a draft of this report. We would also like to thank the interviewers who supported the authors by providing consistency in conducting and transcribing the narrative interviews, and would like to thank Craig Hutcheson for providing additional guidance in conducting ethical research.

We extend our deepest gratitude to Allyson McCollam for her time and advice, and for her enduring support to the authors of this research. Finally, we extend a special thank you to the individuals who generously agreed to share their experiences and thoughts in the research interviews. Although they remain anonymous, without their courage, participation and support, this research could not have been written.

We hope we have done them justice.

**Simon Bradstreet**  
**Network Director**  
Scottish Recovery Network

# The Scottish Recovery Network

The Scottish Recovery Network is part of the Scottish Government's National Programme for Improving Mental Health and Wellbeing. It is working to help achieve one of the four key aims of the programme: *To promote and support recovery*. The Network comprises a loose affiliation of individuals and organisations with an interest in researching, promoting and raising awareness of recovery from long term mental health problems and mental illness.

The National Programme's vision is to:

***Improve the mental health and wellbeing for everyone living in Scotland and improve the quality of life and social inclusion of people experiencing mental health problems.***

For more information on the National Programme see **[www.wellscotland.info](http://www.wellscotland.info)**

The Scottish Recovery Network (SRN) aims to:

- 1** Raise awareness of recovery from long term mental health problems and mental illness and the things that help and hinder that process.
- 2** Develop a better understanding of recovery by gathering and sharing information about the factors which people identify as having an impact upon their recovery.
- 3** Highlight approaches which we believe to be particularly effective in the way they promote recovery and to support and encourage local action towards recovery.

It has a number of key tasks including organising and developing local and national events, gathering and sharing recovery stories, organising education and training initiatives and supporting the development of local recovery networks around Scotland. The SRN is also working to develop and maintain international links and to support and encourage the development of more recovery oriented mental health services.

This report, compiled from the recovery narratives of 64 individuals in Scotland who identified themselves as being in recovery or recovered from a long-term mental health problems, has been produced to help us achieve our aims and to support our continuing efforts to promote hope and raise expectations. Additional learning materials taken from the narrative research project which compliment this report include a booklet and podcast of individually summarised narratives called 'Journeys of Recovery' (2006), and a booklet of tips and strategies informed by the research called 'Routes to Recovery' (2007).



# Purpose and Rationale

The recovery paradigm has emerged as a positive approach to mental wellbeing suggesting that people previously diagnosed with long term or enduring mental health problems are able to establish independent and healthy lives even in the presence of symptoms (William A Anthony, 1993; P E Deegan, 1988; Harding *et al.*, 1987). Over recent years, stories on recovery, particularly from the US and New Zealand, have been increasingly reported in professional, academic press and 'grey literature' (Baker & Strong, 2001; DIPEX.org, 2003; Jacobson, 2001; Lapsley *et al.*, 2002; Leibrich, 1999; Ridgway, 2001; Thornhill *et al.*, 2004) The SRN narrative research adds to this evidence base with research that represents and reflects the experience of recovery from mental health problems in Scotland.

Most commentators including Allott & Loganathan (2002), and Hatfield & Lefley (1993), agree that the definition and meaning of recovery will vary for individuals as it will be based on an individual's own system of personal values developed through life experiences. There is an emerging understanding around the basic factors and principles which promote it, suggesting that recovery is a unique process, vision, attitude or life journey (W A Anthony, 2000; Copeland *et al.*, 1996; P E Deegan, 1988). It is about regaining self-esteem and hope for a productive present and future, and recognising that you can lead a fulfilling life (Leete, 1988, p. 52). It is about embracing the identity and self-determination of a healthy and hopeful person, rather than living the life of an ill person. DeMasi (1996) found recovery to encompass economic and interpersonal wellbeing as well as good physical and mental health. Whilst all these factors could apply to recovery in Scotland, this research provides a distinctly Scottish perspective to mental health recovery, allowing comparison with recovery experiences worldwide.

The purpose of collecting recovery narratives across Scotland is to:

- Learn from the uniqueness of each individual's experience and identify common factors.
- Share stories to inspire hope and offer tools and techniques for recovery among service users, carers, friends and families, service providers and the wider community.
- Establish a Scottish evidence base of factors that help or hinder an individual's recovery from long-term mental health problems.
- Use the evidence to contribute to the development of policy and practice across all sectors, promoting a better understanding of what supports recovery and wellbeing.
- Guide and inform the work of the SRN.

This report intends to generate discussion about recovery in Scotland and as such has provided limited direction or recommendations for policy makers and services. We hope that by limiting recommendations within the report, researchers, service providers and policy makers will have more opportunity to deliberate and determine the best means to promote recovery at an institutional and policy level.

We start from the premise that recovery is about much more than an absence of symptoms – it is about having the opportunity to live a satisfying and fulfilling life in the presence or absence of symptoms.



# Executive Summary

**In Scotland the opportunities provided by policies that promote mental health recovery and social justice have coincided and supported this research and have created the space for learning from the research to be more widely adopted in services and communities. (For further policy information, see, Mental Health (Care and Treatment) (Scotland) Act, 2003; Rights, relationships and recovery, 2006; National Programme for Promoting Mental Health and Wellbeing, 2003b; Delivering for Mental Health, 2006)**

Although the data set for this study encompassed a diverse range of views, clear themes emerged which reflected the findings of similar international studies (See: Barnett & Lapsley, 2006; Jacobson, 2001; Jacobson & Greenley, 2001; Lapsley *et al.*, 2002; M. A. Mancini *et al.*, 2005; S. Onken *et al.*, 2002).

Across the stories consistent internal and external elements could be found. For a recovery journey to begin and continue to prosper, narrators accounts of their experiences suggest that six basic **internal** (individual and self controlled) elements were required (though not necessarily in this order and not necessarily seen in every case):

- Belief in self and developing a positive identity.
- Knowing that recovery is possible.
- Having meaningful activities in life.
- Developing positive relationships with others and your environment.
- Understanding your illness, mental health and general wellbeing.
- Actively engaging in strategies to stay well and manage setbacks.

Six **external** (social or environmental) elements that helped promote recovery journeys encompassed:

- Having friends and family who are supportive, but do not undermine narrator's self-determination.
- Being told recovery is possible.
- Having contributions recognised and valued.
- Having formal support that is responsive and reflective of changing needs.
- Living and working in a community where other people could see beyond your illness.
- Having life choices accepted and validated.

The answers and drivers to recovery were often found internally. Finding comfort 'in your own skin' and developing self-confidence, **self-belief** and self-determination were key factors in facilitating and maintaining many recovery journeys. This often involved a reframing of one's self-perception and a shedding of factors that promoted negative identity. It also involved recognising and appreciating the more positive aspects of self, for example one's creative, spiritual, or social nature. **Re-finding and re-defining one's sense of self was as important to recovery as symptom alleviation.**

Acknowledging the small achievements that one makes in everyday life, recognising strengths and being **given optimistic messages of recovery potential** (from friends and family, professionals, carers, peers) whilst **witnessing the recovery journeys of others** made a positive impact on individuals and gave them the emotional strength to fuel their own recovery journeys. Relating with others who have mental health problems in a positive and safe environment is beneficial to recovery.

Many narrators found that the knowledge they held about their ill health could in fact help their recovery. They found that **taking note of triggers**, events and symptoms could help them if they used these as indicators of wellbeing and what keeps them well. Knowledge of these factors could also better prepare individuals for dips in recovery and provided them with the reassurance that **problems are not insurmountable**. Learning to value the unique episodes of ill health that have made individuals more fully formed as people was often an empowering step forward.

Having a diagnosis was found to be empowering for some and catastrophic for others.

The positive or negative impact of a diagnosis often stemmed from how it was given.

**The power of an optimistic or positive message often cushioned the impact of diagnosis and additional information about symptoms and coping strategies empowered individuals.**

Having some **close friends and supporters who develop a good understanding of your health** and an understanding of how to react (with action or inaction) to patterns of behaviours was valued as a great support to recovery. Whilst help from friends was often appreciated during dips in wellness, knowing when to let individuals 'work it out for themselves' was a skill that was equally valued.

Although narrators were mostly positive about mental health services, they argued that **services need to be more responsive to the changing and diverse needs of people**. Many believed that a greater range of **person centred services would help recovery** and that current services should focus more on recovery in their design and practices.

Narrators had striven to develop a new positive identity, but at times this was at odds with the way that society perceives mental health, wellbeing and illness. People recovering from mental health problems develop ways of engaging and contributing that may challenge the norm of 'nine-to-five' working. Creativity, working, and volunteering all provided meaning and purpose to individuals. These forms of **meaningful activity also provided structure and responsibility** which was found to be helpful to individuals. It helped them take control of their life by moving from being internally focussed to viewing themselves in relation to others and the environment in a way that facilitated control of illness, health and life. These **alternative forms of engagement** and any contributions made by individuals in voluntary, paid or creative employment provided the opportunity to **socialise and gain a sense of achievement** and allowed individuals to **feel valued** in their internal and external communities as a social or economic contributor.

**Belonging** to a group with which individuals can identify, either within or outside of the mental health arena, gave individuals a positive identity. The groups existed in workplaces, voluntary organisations, within social networks and within mental health networks. Where for some individuals the experience of being part of a group was positive, the experience was found to be exclusionary or difficult for others.

Many individuals began their recovery journey with an identity transformation. Whether this transformation occurred through **finding value in self**, or **recognising that others value you**, or through embracing a **collective and socially supported 'recovery identity'** was irrelevant. The important measure was that the **identity gained through recovery was a positive one**.

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External factors such as the availability of necessary or desired treatments and services, financial pressures, the availability of support from non-mental health services such as housing, fear of fluctuating benefit income, the perceived stigma and isolation of mental health problems, and the fluctuating nature of these **external problems often had to be addressed and managed in order to further individuals recovery journeys.**

Other social influences on recovery included the **flexibility and responsiveness of services to individual needs**, the willingness of friends, family and community to encourage, enable and **empower individuals to take risks**; and the willingness and cooperation of others not to undermine individuals by allowing them the **right to self-determination.**

Recovery usually followed an **acceptance of illness, rejection of the stigma** associated with mental illness, and a determination that the illness will not rule one's life.

All these factors combined in various measures to provide a rich tapestry of recovery experiences that were diverse in nature and inspirational in content.

# Methodology

The aim of this research is to better understand what factors help and hinder recovery from long-term mental health problems. This aim helped determine the decision to collect narrative accounts of recovery from mental health problems from 64 people across Scotland.

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# Methodology

**Increasingly, studies have used narrative or qualitative methodologies as a route to uncovering factors that help individuals towards recovery from mental health problems and as a means to explore in some depth the nature and meaning of individual recovery (Barnett & Lapsley, 2006; Larry Davidson, 2003; L Davidson & Strauss, 1992; Jacobson, 2001; Lapsley *et al.*, 2002; M. A. Mancini *et al.*, 2005; Ridgway, 2001; Thornhill *et al.*, 2004). Using narrative or story collection as a research method allowed us to acknowledge that each person's experience of recovery is unique, that definitions of recovery vary and that the criteria people use to measure their progress are difficult to quantify or compare.**

The use of narrative is compatible with the ideas of recovery. Narrative often emphasises things happening over time or a chronological sequence of events and recovery is often visualised as a journey over time and experience. Ageing and growing is emphasised in narrative literature as are the same processes and constructs in recovery literature. Of more importance, the use of narrative places the narrator, not the researcher or clinician, at the centre of the journey. Although the social context is critical, the emphasis within this report is on collective, individual journeys, personal experience and meaning. (Individual narratives from this research have been summarised and reproduced in a booklet; 'Journeys of Recovery' (2006), and podcasts and are available to hear online at the Scottish Recovery Network website: [www.scottishrecovery.net](http://www.scottishrecovery.net)).

It has been shown in other narrative studies (Kelley, 1995; Ridgway, 2001) that the process of narrating, re-framing, re-telling, re-storying, re-authoring, questioning and reformulating one's life story can provide a sense of meaning and possibility to individuals, and can have a positive and empowering impact on a recovery journey, allowing narrators to demystify and re-focus on the positives of their experience. Indeed, many participants within this research reported that giving their story was both a powerful and positive experience, offering them the opportunity to frame their experience in a more positive light.

To facilitate and help unfold the recovery narratives it was decided to use a semi-structured interview schedule because it would:

- Provide interviewer support to the 'narrator'.
- Provide a common framework for analysis whilst not prohibiting the narrator's self expression and thus deepen reflection.
- Allow the narrator to lead the pace and direction of the research.
- Reduce questions that lead to preconceived research outcomes.
- Generate data that could be used to illustrate personal experiences of recovery (e.g. Journeys of Recovery booklet).

## Ethics and Data Protection

Initial ethical guidance and approval was drawn from the project's steering group. The dignity, rights and welfare of participants and interviewers were core criteria when establishing ethical guidelines for research. External training on ethical approaches to researching was provided to interviewers to ensure research was conducted within strict ethical guidelines.

Research purpose and the ways in which transcribed interviews were to be used was explained to all participants at each contact point in the research and participants were

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asked to give informed consent for their involvement in the research. Anonymity and confidentiality was assured at all stages of participation and researchers have done their utmost to ensure confidentiality was upheld in story sharing and data handling. All personal contact details linking individual participants to this research have been erased from SRN databases to comply with data protection laws.

As researchers we have a moral responsibility to ensure that participants were not exposed to harm as a consequence of participation. A counsellor was made available to narrators and interviewers at each 'research event', and signposts to further sources of help were made available. In a bid to empower individuals and to ensure they were comfortable with their participation, individuals were given the opportunity to review and amend the transcription of their interview. This allowed them to clarify data and remove information that in retrospect they may wish they had not shared. A 'follow up call' post interview also served to ensure that narrators were not harmed as a consequence of their participation in this research.

## Research process

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The interview guide and questionnaire were piloted with two key informants prior to research commencement.

## Language

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Key informants – the individuals on whom this research is based will be referred to throughout this report as narrators, participants, individuals, people, activists and service users. All terms are used to refer to the individuals who have contributed their recovery story to this research. Similarly, in recognition of the various means by which our narrators and other authors have described the experience of having mental health issues, a variety of terms will be used throughout including; mental health, mental ill-health, mental illness, and mental health problems.

## Recruiting narrators

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The focus of the research was upon adults (over eighteen years of age) living in Scotland who defined themselves as recovering from or having recovered from long-term mental health problems. Notions of health and recovery are subjective, therefore allowing individuals to self define as 'in recovery from a long term mental health problem' was considered a reasonable approach to recruiting participants. To facilitate recruitment of a diverse range of individuals, an advert was placed in national and local press requesting individuals in recovery to contact SRN for information on participation. Individuals were also recruited through SRN mailings, existing contacts, other press and word of mouth.

Participants were purposively selected to achieve diversity in terms of geography, recovery stage, medical condition and demographics.

## Preliminary telephone interview

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All participants were informally interviewed by a trained counsellor (Niki Kandirikira) to assess their suitability to take part in the project. Where the applicant was felt not ready to participate, the decision to withdraw was taken by that person. In such instances applicants were provided with information on how to access external sources of help if necessary.

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Whilst we attempted to value all offers of participation, sample quotas were met quickly and research was over subscribed. The individuals who missed out on participating were asked to submit their recovery story to the SRN in writing allowing the SRN to recognise and use their contribution in other aspects of its work. Every individual's contribution was therefore valued.

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## Structured questionnaire

Individuals chosen for interview were asked to complete a structured questionnaire several weeks prior to interview. The questionnaire provided background and demographic information for interviewers and principal researchers. Interviewees were also given a preview of general interview topics at this time. It is hoped that prior disclosure of questions would help to minimise unease and eliminate fear of unexpected questions. It would also provide individuals with a chance to think about what they had experienced in relation to recovery.

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## Interview topic guide

The interview guide was adopted to initiate and generate discussions with narrators and to provide minimum consistency of research. Techniques were developed within this guide to move narrators' stories towards their recovery journey.

Narrators were asked to:

- Reflect upon factors that had helped or empowered them on their recovery journey.
- Comment upon factors that had been detrimental to their wellbeing and recovery journey.
- Discuss what factors have helped them sustain their wellbeing.
- Discuss any learning they had experienced from their journey.
- Describe what recovery felt like for them.

The results from these interviews provided a view of people's recovery journeys as they perceived them at the time of interviewing.

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## Interviewing

Each interview was prefaced by a brief discussion with the principal researcher (Wendy Brown) to ensure participants could give informed consent for their participation in this research.

The semi-structured narrative interviews were conducted face to face to increase rapport, confidence and sharing. Two interviewers and one participant attended each interview. One interviewer conducted the interview while the second observed, paying attention to the process and recording. Interviews were held in seven venues (hotels and business suites) throughout Scotland including locations in Aberdeen, Dumfries, Dundee, Edinburgh, Glasgow, Inverness and Kirriemuir. Interviews were conducted by a pool of seven interviewers who were supervised by two principal researchers (Brown & Kandirikirira).

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## Data handling and analysis

Interviews lasted between 40 and 90 minutes and were tape recorded digitally and transcribed verbatim. Additional field notes (observations and reflections) were added by



observers. Initial themes were checked with narrators after which interviewers and principal researchers collaboratively constructed broad interview themes across the interview population. Using NVivo data management software, whole transcripts were double coded by the two principal researchers using the broad themes. Themes were further refined through inductive thematic analysis of the data which identified anomalous, recurrent and contrasting features in the transcripts. Finally, themes were imported into Excel software for ease of data manipulation before final analysis and write-up.

## Inclusive research

Scottish Recovery Network sought to involve people with experience of mental health problems in this research in several different ways. Participatory approaches within this research included:

- Encouraging participant involvement. All transcripts were returned to participants for final editing and approval prior to analysis and dissemination.
- Designing research processes that reflected inclusive practice. We held in-depth discussions with a range of active groups on the strategic direction and ethical implications of the research.
- SRN positively promoted the employment of individuals who have experienced mental health problems and recovery as interviewers.
- Research practice and methodological choice were inclusive and favoured empowerment of participants through allowing them to narrate the shape and flow of each interview.

Narrators, not the authors, the SRN or the mental health system, are the ‘champions’ of these stories and this research.

## Limitations of the methods and research

According to Lucius-Hoene (2000, June) the narrative interview not only provides a method for constructing the life experience of the narrator, it can also be seen as an ongoing process of construction, motivated by the focus and interest in self-exploration at the time of the interview. The authors of this report share this belief. Narrators who participated in this study provided important insights and a fresh interpretation of the recovery journey, but the stories they told represent only a snapshot of their journey determined by the narrator and their interviewer’s attitudes at time of interview and analysis.

In a desire to better understand the recovery process the authors argue that qualitatively investigated experiences would best distinguish between positive and negative aspects of recovery. They would unveil the effects of the recovery process allowing researchers to appreciate the personal experience as well as the more commonly held experiences of recovery.

Narrators were self selecting; that is, they actively volunteered to participate in this research. They were also purposively selected for diversity of experience. Therefore the views and opinions captured within these findings represent only a small number of unique experiences that can not be statistically projected or generalised across a population as diverse as those in recovery from mental health problems. Throughout this research we have striven to value the contribution each individual narrator made and as such have reported upon unique as well

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as common experiences. We have attempted to draw greater attention to more commonly experienced factors and have referenced other literature where they are found to be similar to other studies.

With every qualitative research project comes an element of subjectivity in analysis and interpretation. We are analysts using techniques to shape and retell stories translated with chance into research and as such face the possibility of being too reductionist. Storytellers may modify or withhold certain information either deliberately or subconsciously.

How to evaluate and validate a narrative analysis can present a problem. Traditional notions of reliability do not apply to narrative studies so validation is difficult and may need to be strengthened or supported by other research methods. Perceptions of validity need to be radically re-conceptualised to include persuasiveness of the accounts, correspondence (cross checking with the story teller), coherence of findings and their pragmatic use. Despite their limitations, narratives are emerging as a primary unit of analysis in social psychology, education and cultural anthropology (Bruner, 1987).

Many factors have helped and hindered narrators' recovery journeys. To add a more dynamic element to this research it might have been helpful (prior to deletion of contact details) to have arranged to revisit participating narrators in up to three years time to engage them in a further dialogue about what factors have affected their recovery journeys in the intervening period. Also, it may be pertinent to purposively investigate the individual topics presented in this report in order to identify their significance to recovery.

## Report structure

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The narrative research conducted by Brown and Kandirikirira for the SRN has produced very complex, rich data. In order to ensure that this data can be easily accessed and assimilated by readers, the authors have produced several chapters of evidence that will highlight the things that have helped individuals along their recovery journey. The chapters include: re-finding your self and your identity, re-engaging socially and finding meaning and purpose in life, building meaningful relationships, finding the right treatment and supports for you, recovering at your own pace, recognising opportunities for recovery and reframing your attitudes to be more recovery oriented.

Each chapter will contain a brief summary of contents, a review of relevant literature, findings and a brief discussion of the policy implications of findings. In order to fully engage our network in the dissemination of this research it is the intention of the authors to invite wider comment upon the policy implications of our findings. It is hoped that in doing so we can generate wider discussion and thought about what helps people recover from long term mental health problems.

# Demographics

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A synopsis of demographic figures relating to the narrators is presented here. Narrators derived from rural, urban and island environments throughout Scotland. Sixty seven individuals completed a telephone interview and demographic questionnaire and 64 completed an intensive narrative interview. Of the 67 initial participants, 84% described themselves as Scottish, the remaining individuals as English (5%, n:3), Irish (3%, n:2), Welsh (1%, n:1) and of other nationalities (7%, n:5). Only two individuals (3%) were of non-white ethnic origin. There was an even gender balance with 52% (n:35) female and 48% male (n:32). Individuals ranged in age from 28 years to 70 with a median age of 46 years at time of questionnaire completion. Eighty one per cent (n:54) of individuals were heterosexual, 9% (n:6) homosexual and 5% (n:3) bisexual (four individuals preferred not to indicate sexuality).

# Demographics

Most individuals (n:52) voluntarily described some form of diagnosis ranging from various types of depression, anxiety, mania, and personality disorder, to various forms of psychosis (diagnostic terms were provided by narrators). Twelve per cent of narrators (n:8) had no 'official' diagnosis and 11% (n:7) were unsure of their 'official' diagnosis. Some individuals had previously contemplated suicide or self-harm. A number of individuals stated that their diagnosis (and subsequent treatments) had changed over the course of their ill-health and many narrators had been hospitalised. Seventy-nine per cent (n:53) of individuals were being prescribed medication for mental health problems and 25% (n:17) were receiving therapeutic non-drug treatments for mental health problems at the time of questionnaire completion. Twenty one per cent (n:14) of narrators had an additional physical disability.

Narrators held various types of housing tenancies. Thirty six per cent (n:24) lived alone without support, 27% (n:18) lived with a partner and 12% (n:8) lived with family members or dependents for whom they held responsibility. Twenty one per cent (n:14) of participants lived alone with support, and 6% (n:4) lived in supported accommodation.

Thirty-three per cent of participants (n:22) were in full or part-time work, including 6% (n:4) who were full or part-time self-employed. Another 34% (n:23) of individuals were in voluntary unpaid employment with the remainder of participants being retired, in education, on sickness benefits or employed in unpaid domestic capacities. Of those not in paid work, many aspired to be in paid employment (n:12), others wished to pursue voluntary work or further education whilst 14 individuals (21%) felt incapable of working full time in any capacity.

Eighty four per cent (n:56) of narrators received some form of state benefit with many receiving multiple sources of benefit income. Health related benefits ranged from various types of Disability Living Allowance (n:33) and Severe Disablement Allowance (n:4) to Short and Long Term Incapacity Benefits (n:25). Other benefits received included work, housing and family related benefits and tax credits. Sixteen per cent of participants (n:11) received no form of state benefits.

Educational attainment of participants varied widely with some individuals obtaining a basic high school education and others obtaining further and higher education qualifications. Several participants held university masters qualifications or a PhD. Others were vocationally well qualified having completed apprenticeships and having gained work experience.

The authors recognise that the high level of educational attainment found within this group could be considered atypical of individuals with long term mental health problems. Overall, a relatively heterogeneous population was represented. They were however, held together by their common experience of being in recovery or having recovered from long term mental health problems.

# Identity Summary

In this chapter issues of identity and re-finding self are explored through an examination of narratives offered by individuals who are in recovery from mental health problems.

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# Identity Summary

**The recovery experiences of these narrators capture the richness and complexity of the self in every human identity and recovery journey. There are a number of findings discussed in this chapter that can positively or negatively influence an individual's identity and recovery, including:**

- Having hope, confidence and optimism that recovery can happen.
- Accepting and having belief in self.
- Taking responsibility for your own wellbeing.
- Increasing your own self-esteem and self-efficacy.
- Being more self-aware.
- Rejecting the negative identity of ill health and its associated stigma.
- Growing beyond your label or diagnosis (and helping others to see beyond it).
- Reclaiming power and self-determination.
- Improving your physical image or your perception of your physical image.
- Accepting and expressing your sexual identity.
- Developing a creative, cultural, social and community identity.
- Being empowered by your mental health identity.
- Embracing spirituality.

It is clear there is a complex relationship between identity and recovery. 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 internal change. Narrators showed numerous facets to their own identities, some unique and several embodying common characteristics, experiences and expectations. Re-finding and re-defining a sense of identity and self-confidence that has potentially been eroded by institutionalisation or ill health was often the first step on a recovery journey.

Drawing from the narratives, we highlight the importance of developing a positive identity to furthering recovery, and to promoting mental health issues more generally. Together and individually, the narratives form a hopeful picture of recovery. The data we present in this report will have implications for understanding and promoting recovery experiences in Scotland, as well as for developing mental health recovery theory and practice in general.

# Recovering Identity

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Recovery can be seen as a complex process of adjusting personal attitudes and beliefs in self, recognising a more hopeful or optimistic view of life. Kirk (2002) recognised recovery as “a process of restoring or developing a positive and meaningful sense of identity apart from one’s condition and then rebuilding one’s life despite or within the limitations imposed by that condition.”



# Recovering Identity

**Erik Erikson (1980) used the term identity to designate a sense of self that develops in the course of a person's life and that both relates them to and sets them apart from their environment. Ricoeur (1985) also accepted that identity is not fixed or persistent arguing that conceptions of self and identity vary throughout one's life.**

Within recovery literature, identity has been considered by other authors to be about more than an individual's self-knowledge about their personal characteristics, personality or self-affiliation. It combines this knowledge with the individual's sense of importance in a social context, one's self-confidence, and how self is reflected in other people's perceptions according to Onken *et al* (2002). It often reflects an individual's micro and macro culture (who they identify with at a local and social/media level), and holds their aspirations and objectives. Davidson and Straus (1992) argued that re-finding and re-defining one's sense of self were as important to recovery as symptom alleviation.

How identity affects recovery journeys has been discussed by many researchers who identified different aspects to identity as being either destructive or essential to recovery. Numerous commentators have indicated that having an optimistic and hopeful outlook can have a positive impact on recovery. Indeed, Scheier & Carver (1992) found that at the physiological and psychological level, optimism and positivity can provide the motivation to start exploring how to begin the recovery journey. Pearson (2001) describes a "prescribed identity" for service users and recognised the difficulty in removing this identity once attributed as "*over time our identity becomes synonymous with how services choose to define us. This identity is such a powerful one that it is hard to shake.*" Other authors identified the concept of 'identity politics' as being used by the recovery movement to alter the self conceptions and societal conceptions of the self.

In the United States Dornan (2003) found that identity and recovery was enhanced through community engagement. Lapsley *et al* (2002) suggested that community and cultural issues heavily influenced recovery journeys for individuals in New Zealand. This view was also shared by the US President's New Freedom Commission on Mental Health for whom "*aspiring to build an acceptable identity for self and in the community at large is an essential component of recovery from mental illness.*" (Fisher, 2003a).

Art has often been cited as a means of self-expression, emancipation, discovery and therapy (NNAH, 2006). Bluebird (2000) showed that creativity was used as a conduit for expression of those parts of the self which may be difficult to express or may not have been expressed in any other way. Griffiths (2005) and Parr (2005) have also added to a growing body of evidence that suggests that developing a creative identity and engaging in creative activity can have positive benefits for mental wellbeing providing individuals with a sense of purpose or meaning to their life. This proposition was shared by Faulkner & Layzell (2000) in their Strategies for Living report for the Mental Health Foundation which identified creative expression as one of the most helpful strategies and supports.

In addition to creativity, Faulkner and Layzell (2000) also found that religion and spirituality offered a fundamental belief system that provided meaning in people's lives and a reason to carry on through distress. Similarly, Leibrich (2002) argues for considering both spirituality and mental health in terms of the experience of the self. She also argues that mental illness can lead to spiritual progress, and ultimately to mental health.

All of these factors identified in studies internationally emphasise the creation of a positive identity as a major component of recovery journeys for individuals.

# Identity Findings

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**In this chapter we explore issues of identity through an examination of narratives offered by participants who are in recovery from mental health problems. We focus on how confidence, self-perception, creativity and social contribution can positively affect identity and recovery as well as looking at how negative identity, stigma or a spoiled identity, powerlessness and sexuality can affect recovery.**

Drawing from the narratives, we investigate collective as well as individual identity and the impact that this shared consciousness has on society's attitudes to recovery and mental health issues more generally.

Together and individually these narratives form a hopeful picture of recovery.

Mancini *et al* (2005) reported that the transformation from an illness-dominated identity to one marked by meaning and wellbeing is at the heart of recovery. The recovery experiences within this report capture the richness and complexity of the self in every human identity and recovery journey. Providing a narrative is in itself a confident, self-determined act that defines identity as narrators construct and present a preconceived concept of self within their stories for their interviewer.

## Confidence

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The narratives considered here emphasise the agency of the self in the healing process. Regaining a sense of identity and self-confidence that has potentially been eroded by hospitalisation or ill health was often the first step on a recovery journey.

**"I think for me, being able to manage my recovery in the way that I have done... I suppose working with people who believe that we have an innate capacity for self healing. I had that belief when I came to my own recovery process and so for me the largest part of my own learning has been learning to listen more clearly to myself."**

**"I feel I have been able to maintain my sense of identity and that's been really, really important. And I have achieved a lot of new learning in terms of insight into my own experience."**

**"I think it's hard to praise yourself but that was one thing that I was learning all the time during my recovery, that you have to praise yourself for overcoming the challenges that you're facing. I'm just so much more self-assured. I feel that the whole process was about learning about me."**

Crucial to an individual's identity was their self-confidence. This confidence was a multi-faceted trait that encompassed the individual's self-worth, self-esteem, self-belief, self-efficacy, optimism, hope and sense of wellbeing. These factors were found across participants on their recovery journey, as illustrated more fully below.

## Hope and optimism

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A recurrent theme in almost all stories is that of having hope. Almost all narrators implicitly or explicitly expressed themselves as 'having hope' that they would live a meaningful life and continue to be well. This optimistic attitude is at the heart of recovery.

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**“Have a vision of where you want to be and try and find ways of getting there.”**

**“I think that parts that have made me stronger were a willingness to get well in the first place and you have to have that willingness to get well and a hope that you’re going to get well.”**

Individuals reported that the confidence gained from this reframing or having an optimistic and hopeful outlook had a positive impact on them physiologically (as they became more active and energetic) and psychologically, providing them with the motivation to explore how to begin their recovery journey. For some individuals this involved a redefinition or rebuilding of self apart from their condition.

**“(Reflecting on a pre-recovery state) I think sometimes, certainly myself, the thing that prevented recovery was that I didn’t know anything else. I’d got a mental illness. There’s some safety in being ill, although I hated every minute of it, there was still some security in that.”**

Parallel to the hopeful attitude of our narrators came an optimistic sense of ambition. Narrators were overwhelmingly responsive when asked if they had any future plans or aspirations. Some plans were ambitious, others less so, but the point of importance was that individuals now looked to the future. They planned for it with hope, purpose and anticipation instead of trepidation or inertia. Individuals recognised that they were better equipped to deal with adversity when they adopted a more positive optimistic outlook seeing problems as solvable as opposed to insurmountable.

**“One of the things I’ve realised is that if something doesn’t work out initially, it doesn’t mean it’s not going to work out. It’s a case of you’ve got to persevere.”**

Having a dream to hold on to and something to believe in and work towards was helpful for some.

**“Don’t let people tell you who you are, what you are, what you can be. You can be whatever the hell you want... if you want to be a kite maker, if you want to be a teacher, if you want to be a singer. Nothing should ever stop you from being what you want to be... don’t ever let anyone tell you. It’s not their life, it’s your life.”**

For some narrators part of their recovery consisted of moving away from the identity of an individual dependent on medicines or being a benefit recipient, whilst others identified themselves as being in recovery and independent thanks to the support they received from benefit income and medicines. For some, ambitions lay elsewhere in terms of building stable relationships, being more creative or working to suit themselves. Overall, ambitions varied but had little to do with ill health or staying well. Once the possibility of wellness was recognised by individuals staying well was positively (and hopefully) assumed by many narrators.

## Diagnosis

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Diagnosis provided hope for some and fear for others.

**“I had never even been told my diagnosis... I found them out from when I got a medical certificate from my GP. So it was a bit of a shock when I came out of a GP (surgery) one day and read my... ‘Paranoid Schizophrenia’ – What? (laughs) I was just having a formal diagnosis of what I thought at the time was a life sentence.”**

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Frequently, the way in which diagnosis was delivered determined its effect on the individual. The provision of diagnosis accompanied by information and the emphasis of a positive message of hope gave some narrators the label they required to make sense of their 'self.'

**"It (diagnosis) gave me a possible identity, it gave me something I could relate to, yes you hear voices, I could meet other people that have also had this label put on them, oh yes you hear voices."**

**"It took seven years to get the right diagnosis... It helped, at least then, that was just the start. That gave me at least the chance to say: 'Well I agree with this diagnosis' – perhaps then that gave me something to look into further."**

Some narrators felt let down by the professional services delivering their diagnoses. They felt that diagnoses were sometimes suppressed by professionals only to be given at a later date without information or support leaving them to feel disempowered about their own health. Overall, it was felt that if a message of hope is delivered at the time of diagnosis and treatment, this hope is carried by the individual and can be a catalyst to getting better.

**"What's made me more confident... for the future, is that I know I've got an illness and I can do something about it."**

## Self-acceptance, responsibility, belief and esteem

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Narrators explained that recovery is a process of self-discovery and acceptance. Learning to accept and be responsible for your mental health and to value yourself was a step every narrator took when beginning their recovery journey. Acknowledging and learning about their illness and recognising and addressing their own limitations (irrespective of others' expectations) or being receptive to the opportunities it can create was considered important by several narrators.

**"Don't try to meet other people's expectations of what you 'should' be doing; just do things for yourself and that you know are going to make you feel better."**

When unwell, narrators felt they were more accustomed to deferring responsibility for self and actions to others, but with recovery came a growth of confidence and a desire to take responsibility for their own actions and the right to take risks. With each achievement and with each step taken, came the reassurance that they were recovering something positive to learn from. A number of individuals found it difficult to judge how hard to push themselves, finding it necessary to pace their own expectations and choices. However, some managed to turn self-doubt into a positive by thinking **"maybe I am worthless so it's not going to hurt me to try something."** Although this premise was initially negative, it promoted a challenging perspective and where success from efforts was found, it encouraged the individuals' belief in their abilities to do something well.

Self-acceptance, learning about self and having belief in self-worth was often accompanied by a recognition that many other individuals are in the same situation. It was often reflected through external influences, that is, if peers gave positive messages of belief to narrators, this in turn promoted the narrators' belief in themselves.

**"The belief that I've got in myself, belief that other people have shown towards me. I think their belief helped me to believe I could get better."**

A number of narrators valued the help they received (and often provided) through services involving people who had their own experience of mental health problems. Participating

in user involved services helped nurture self-belief and create self-worth. Voluntary work and involvement in service user and self help groups gave meaning and purpose to many often helping to ***“fill a void...or...fill a lot of negative feelings and guilt, about being unemployed.”*** It also helped build confidence, self-belief and efficacy in the activities that individuals undertook. To be told you are worthwhile and of value was essential to many narrators to help them foster self-belief and esteem. However, being perceived as a ‘service user’ wasn’t always considered a favourable identity.

**“I don’t know if I want to be endlessly frustrated by going along to meetings or being seen as a service user all the time.”**

Recovery was often initiated in situations beyond the scope of the mental health system. Indeed, narrators often described the importance of developing an inner strength or having self-determination and a positive mental attitude by controlling their own destiny and making their own initial decision to get well.

**“I have taken ownership of my illness and I take responsibility for what I do and do not do. I don’t let it control me. And it is an ‘it.’ It’s not the whole of my life it’s just part of my life now.”**

Intrinsically linked to narrators’ optimistic views and self-acceptance came a greater level of self-esteem or a global feeling of favorability towards self. This was very important to narrators’ recovery journeys. Whilst individuals who were active within the recovery movement generally belonged to groups that promoted self-esteem through participation and meaningful activity, others built upon their self-esteem through finding value in the roles they occupied in life and being valued by others.

Often individuals had to muster their internal reserves to continue to function in the role they occupied, but this determination had a positive role to play in developing self-esteem and a ‘can do’ attitude. Having positive identities and responsibilities such as a carer, a responsible pet owner, guardian, friend or employee forced several narrators to determine coping mechanisms to maintain their adopted identity and promote their self-belief.

**“I seemed to be able to sort of raise my game and overcome anxieties... God help me. Come hell or high water, I was going to do it for the kids... it’s an interesting quirk that I could manage to make that effort. I do suppose that it’s that family bond or whatever. Wanting to see your kids and everything.”**

To foster feelings of self-belief it was often best to measure recovery in terms of how far one had travelled as opposed to where one wanted to get to, as one insightful narrator pointed out.

**“I find it helpful not to measure my recovery by where I’m trying to get to because I always feel I fall short. But if I look at that in terms of where I’ve come from, then that’s a more helpful frame to measure things.”**

Sometimes preparing a list of achievements to review, just to remind themselves of how far they had come on the recovery journey was helpful.

## Self-efficacy

Related to self-esteem but slightly different was the issue of self-efficacy. Self-efficacy facilitated goal setting and drove ambition through building narrators’ confidence. This was evidenced through individuals’ confident belief in their ability to perform novel or difficult tasks and cope with adversity. To nurture this self-efficacy individuals felt that

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it was necessary to be allowed the opportunity to ‘try and succeed’ or ‘fail without fear.’

**“Being able to take a calculated risk with something and go for it. Funnily enough I’ve actually got something like that at the moment, a gardening thing that requires a three day commitment and I’ve been thinking about it for ages and I feel it’s really time I should make a commitment to it and at least give it a try.”**

Narrators were found to be efficacious in different things, but the strongest source of self-efficacy was found when individuals successfully engaged in tasks through work or volunteering. Experiencing success in these areas gave confidence to people.

**“It’s gave me back my own self-esteem, the ability for me to stand up, work and provide for my wife and I and in our generation I think that’s quite an important thing.”**

Engaging in groups that allowed them the opportunity to participate and contribute to activities promoted efficacy, confidence and recovery. Some individuals highlighted the positive role others such as family, friends and peers had on developing this positive self-belief and self-determination, however, conflicting experiences were noted by individuals who found themselves to be disempowered by well meaning individuals.

**“When I was very ill... people were saying to me ‘you have to, you have to respect yourself,’ but in the way that they were actually behaving towards me by taking the power and decisions away, they weren’t actually encouraging me to respect myself, and to have confidence in myself. So I think that that’s a key aspect of my recovery that I actually now realise that I have to respect myself, I am a valuable human being.”**

Issues of engagement will be covered in more detail in subsequent chapters.

## Self-awareness

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Following from self-determination and belief came another element of confidence in self that was found to be crucial to many narrators’ recovery journeys; self-awareness. Many participants felt empowered by their own self-awareness and insights into their own health. Being self-aware appeared to promote determination and responsibility which in turn opened up opportunities for individuals and provided them with more self-confidence and a stronger sense of identity and self-worth.

**“I don’t know if I do see it as recovery I see it more as personal acceptance.”**

**“You can’t recover if you’re not actually aware of what’s going on and how you feel. So that awareness then enables me to have a choice and to take responsibility.”**

This awareness also appeared to provide individuals with a broader perspective beyond what some described as a self-centred world of ill health.

**“I think that recovery has just taught me that there are actually more people in the world than just me.”**

It also empowered people to have greater belief in themselves and their knowledge about their own health states.

**“...Go with the feelings that you have, and believe in yourself. Listen to other people obviously, but the decisions have to come from you. Then hopefully your life is going to be long, so what’s a couple of years in getting yourself sorted out?”**

Self-awareness and awareness of others allowed individuals to compartmentalise their health and wellbeing into one aspect of their newly burgeoning life, and ill health no longer defined who they were. Awareness of their illness allowed individuals to make use of the time they were well and to accommodate the time when they were less well with a sense of optimism that the ill period would pass and recovery would continue thereafter.

**“I try to utilise and enjoy the times when I’m well and try and avoid and minimise the times of being low through some self management – self management in terms of being aware, being aware of my illness, being aware of my trends, to being aware of triggers.”**

Self-awareness allowed individuals to plan for a future that could be better controlled and managed.

**“I’m more self-aware, I know what I want from life and where I want to be and I am happy and content within myself. My lifestyle’s the way that I choose it to be. And I if come up against any barriers I know how to break through them, to work through them. And life is now what I wanted it to be many years ago when my life was taken away from me, the control of my life was dominated by somebody else.”**

## Negative identity and low expectations

Having pride and belief in your own self-worth was shown to be important to regaining confidence and recovery potential whilst having too much self-doubt was found to be paralysing. A consistently poor view of self was found to be a barrier to recovery.

Mental ill health was described as being corrosive to some individuals’ confidence and initiative. This left these individuals with a sense of negative identity or lack of self-worth. These negative attitudes, whether they were held internally or held by others around them, limited choices and decision making abilities.

**“The social affliction around your mental health and that, how it has affected you in the negative side, everything that’s been socially acceptable, maybe for a lot of other people that makes you more feel negative in yourself or that you’re taken away from everything that seems to be expected of anybody else, you don’t have anything, really, any property.”**

**“Most of the time I’m not uncomfortable with being by myself.”**

The perceived opinions of others has had various and conflicting impacts on individuals’ attitudes and recovery journeys. Various narrators required the positive belief and support of others to facilitate their growth and subjective wellbeing and considered negative attitudes to have had a profound and damaging effect on their self-worth.

**“Other people believing me was quite vital, cos I didn’t believe in myself.”**

**“I told them that I’d like to work in mental health and I was speaking to the (person) who was in charge of mental health and she felt that I’d be a risk to other clients if I was on medication, which was really quite upsetting – because I’ve never been a risk to myself or others, and I felt she was being quite judgmental really.”**

However, others were driven to overcome the negative perceptions they considered others to have of them. They used the negative expectations of others as a motivator.



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**“(Talking of other people’s attitudes towards narrators’ ability to fulfill a task) It’s hindered me more to a certain extent because it depresses you that people don’t really understand it. At the same time... when things are being negative towards me, I’ve said ‘right’ to myself ‘I’m going to show them that I can... get over this and get on’.”**

It was often reported that negative attitudes lowered self-esteem while an optimistic attitude and positive messages from associates overwhelmingly resulted in a more positive self-image, lessening the negative identity associated with ill health. This led some narrators to indicate that professionals and the public need to be more positive in their approach to service users.

**“Other people with negative thoughts, making the situation sort of worse than what it is, you know. That includes staff or other people that are in there.”**

**“I think people have to really think about being worthwhile. That has to be given to people. That you still have a place in society.”**

## Stigma – Spoiled identity

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People identified stigma as a factor that hindered recovery. The loss of ego, confidence and sense of control derived from this stigma often led to a sense of ‘spoiled identity’.

**“People judge you, you know normal public etc, make assumptions, and those assumptions hinder your recovery, assumptions that, you know, there’s something really wrong with you and that you’re a weirdo and things like that, and it’s unfortunate, but fortunately it’s not true! But those assumptions can really seriously hinder things.”**

**“It’s not until you have experienced stigma that you realise how important and how discriminated against and how bad and how guilty you can feel about having a mental health problem. Being seen as different is not good for you.”**

The ways in which mental health problems are understood in the media and in society at large heavily impacted the construction of identity for some narrators. Indeed, even mental health services potentially hindered recovery through negative projection of identity or through treating the illnesses not the individual.

**“I’d been on anti-depressants from the age of seventeen, and then for the mental health team to turn round to me and say you’re just a drunk basically, it puts you back. You think if they don’t understand, or they don’t even want to get to ken you, what hope is there?”**

Some individuals found difficulty in engaging in community activities, such as work, due to this stigma. Many narrators suggested that others’ preconceived ideas about what individuals with a mental health problem can or cannot do must be addressed to be more reflective of the diverse population of individuals who experience mental health problems.

**“I don’t need someone to take me shopping or help me pay my bills; I can do that if I get emotional support which was what was originally asked for.”**

Many individuals counted the need to see themselves as a whole person beyond their labelled identity as being integral to their positive recovery.

**“I’m not stupid, you know. I may be depressed, I may be withdrawn, I may be psychotic, but I’m not like that all the time... I do still want to relate to people on a level that I’m happy to relate to them.”**

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Abandoning their service user identity, several individuals sought to distance themselves from the mental health community to further their recovery.

**“There’s also something about having other things in my life away from mental health issues, away from support workers, away from, and actually finding a different channel.”**

The right not to be judged was sometimes not afforded to individuals in recovery. Many individuals reported a fear of the consequences of others finding out about their mental health problems, fearing rejection and stigma and feeling vulnerable to being found out. Individuals’ internalised stigma often provided a barrier to socialisation. This fear of being found out, fear of a relapse, fear of never getting well was corrosive to the positive mental attitude that often accompanied an individuals’ recovery.

## Thriving – Growth Beyond the Label

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Some participants, although aware of society’s negative representations of mental health problems and the effects this had on their lives, were happy to be identified as someone who had experienced mental health problems. They had, in essence, reclaimed their identity as part of a significant community or ideological grouping with values and experiences in common, fostering a sense of belonging.

**“We need to come out (those that will and can) we need to stand up and say, yes I am manic and proud.”**

Some in this group described the positive aspects of being someone in recovery, highlighting the resilience and self knowledge developed as a result of experiencing, surviving and recovering from mental health problems. It had made them a more complete person.

**“It was all, every problem and every hiccup was all necessary for me to arrive at where I am today.”**

**“I do feel I’m a stronger person for having the experiences that I’ve had.**

**I do think I’ve benefited as an individual, from the entire, what would you call it? Experience?”**

Viewing the individual beyond their ill health label was seen by many individuals to be central to recovery. A number of narrators recognised that after they had been labelled with ‘mental illness’ their recovery became a dual process as they had to recover not only from the illness, but also from the role and identity of a person with mental illness.

Recovery usually followed an acceptance of illness, rejection of the stigma label or rejection of the perception that the label has stigma, and a determination that illness will not rule one’s life.

## Powerlessness – Removal of identity

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Positive Identity was frequently overshadowed by the unequal power imbalance between service providers and service users. Narrators sometime complained of being ignored, having their wishes disrespected or not being believed when in discussion or negotiation with some more powerful professional or service provider.

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**“They know best and it doesn’t matter what you think because you’ve got to fit into a particular service or whatever.”**

This resulted in feelings of powerlessness. Other peoples’ judgemental or stigmatising attitudes were cited as hindering the recovery process. Equally, non judgmental attitudes were appreciated by individuals as they provided them with a ‘normalising’ sense of positivity.

**“Just by being there, and just how non-judgemental they are, and everyone that works there, no-one has got a mental health, a professional mental health background, no-one, and that’s you know, that’s, they make a point of that.”**

Although positive messages of self-help and self-determination were espoused by service providers, the way in which messages were implied and delivered encouraged helplessness. The ‘helpless individual’ or the ‘dependent’ identity was a self-image that many individuals found difficult to overcome and erase during their recovery journey.

**“If you don’t actually have that awareness about where you’re at and what you’re trying to achieve, you then don’t have the power or the control to actually make changes in your life, and therefore other people take that power in many different ways. I don’t think it’s intentional, but a lot of the time it’s quite an abusive use of power as well, because it de-motivates you and makes you more dependent.”**

## Reclaiming power and self-determination

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The regaining of self-determination or ‘agency’ and the removal of unnecessary constraints on individuals’ activities was a feature of several people’s recovery stories. Being given the right to take risks, to take responsibility for self, to build identity and to have a sense of being in control was commonly cited as crucial to developing the skills that would eventually lead to recovery.

**“To be able to have choice, to be able to be self-determining – that has been very, very important.”**

**“If you’re not actually actively taking choices, you’re not taking responsibility, and then you create into a sort of, you walk into the victim’s role.”**

Paradoxically, although choice was necessary for self-determination, belief and satisfaction, too much choice was found to be corrosive for some narrators as the more choice available, the more doubt some individuals had about the choices to be made. Individuals sometimes relied on others’ guidance to initiate their own self-determination.

**“I felt that she (my support worker) knew instinctively what was the right way to get me to recover and because she believed in me, I started to believe in myself.”**

The use of language to convey optimism and hope when dealing with people was considered crucial by many narrators to help them learn to think positively. Messages of hope have been instrumental in many narrators’ recovery journeys. However, not all narrators found medical or other professionals to be optimistic in their approach. From questionnaire data retrieved prior to the narrative interview, only 43% (n:27) of respondents agreed or strongly agreed that they *“had been given a positive message on their potential for recovery from medical professionals”* and 55% (n:32) agreed or strongly agreed that they *“had been given a positive message on their potential for recovery from other professionals.”* Positive messages of hope that help initiate recovery journeys came mostly from close friends. Only two respondents disagreed that they *“had been given positive messages on potential recovery from friends.”*

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## Physical image

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Visual self-perception (one's self-perceived physical attractiveness) was found to have an impact on mental health, giving or taking away self-confidence. Following a healthy diet can be good for physical as well as mental health and several narrators found that following an exercise regime improved wellbeing and self-esteem and boosted confidence in relationships.

Fresh air and exercise produced feelings of wellness in individuals. The feelings of heightened confidence and wellbeing that improved physicality produced was amplified by changes in some peoples physical self-perception. In a society where physical appearance is as important as skills and knowledge, a positive physical self-image was very important to some individuals' recovery.

**"I just felt physically and mentally healthier than I have in my whole life. My nails were nice and my hair and I just felt healthy, I started to take up yoga as well and swimming, my relationship with my partner vastly improved because I was more open."**

**"I did put on a lot of weight, you know? I was a skinny-looking thing. But eh... that helped, you know, and it made me feel better too because I think if you think your image is a wee bit better, you... become more sort of, eh, easy to talk to and I become... my confidence started to come back, 'cos it had diminished quite considerably, you know, confidence in all aspects, speaking to people, visiting shops, you know, blah, blah, blah."**

Some individuals' self-image was positively influenced by encouraging comments on appearance. However, negative comments had the opposite effect, especially when narrators were unwell. Whilst other people's perceptions did not necessarily match their own, the influence others' attitudes had upon narrators could not be discounted.

Whilst the physical representation of wellbeing (believing you look good) was found to promote self-esteem, confidence and recovery, it could also give a false representation of wellness when ill. In some instances narrators reported that if they looked good all was assumed to be well with their mental wellbeing.

**"(My nurse said) in the past as I come across as quite well presented, people haven't realised that I need help which I do. 'Cos I am presenting... I am well dressed and clean shaven and things like that... it makes me feel good that I am well groomed and all that but people haven't been aware that I perhaps need more help than I would do."**

One participant noted that appearing to be well and looking well presented could impact upon one's ability to access state benefits. Income was also found to impact on physical appearance as individuals needed adequate income to maintain a balanced diet and fresh clothing.

**"Financially, it's very difficult to do, especially if you've got to buy clothes, and things like that, have your hair cut or buy shoes. You can't do it."**

Having something nice to wear and having the opportunity to look good boosted confidence especially when feeling low according to one narrator.

**"Another thing that em, got me down was, I was very fat from the, the drugs, and eh, my clothes weren't nice and my hair was awful and, all that dragged down my,**

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**my mood. I think it's important for people who are very down to try, to have some, something nice to wear and, it adds to confidence a wee bit."**

Often medication side-effects would have a detrimental effect on physical appearance, for example through weight gain, causing narrators to feel more vulnerable and less self-assured in their appearance and overall demeanour. This sometimes adversely impacted other areas of life such as relationships, due to a lack of confidence. Indeed, this was cited by one narrator as a reason for not being able to find a partner.

Since finding a partner or developing a long-term relationship was commonly referred to as an aspiration for single individuals on their recovery journeys, the issue of confidence with one's physical self as well as one's mental self should not be underestimated.

## Belonging

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Belonging, finding stability and a place you can call home in a community that is safe and welcoming was described as being important to many narrators' pride, social identity and recovery.

Having the confidence to stay out of the 'risk neutral' environment of a hospital and accepting challenges and thriving on the responsibility of running your own life and home was important to some narrators' identity.

**"Definitely moving house has helped the recovery just being like, you know, just going about doing my own thing, minding my own business, you know, doing that kind of thing has helped."**

**"When I got the flat that I am in now... for the first time it was my house and it was my space and I could fill it with my memories... there wasn't any baggage there... it was a place where nobody knew me, nobody knew that I had mental health problems, nobody knew who I was."**

Other issues around housing and recovery will be more fully investigated in subsequent chapters.

## Sexual identity

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In the majority of cases sexual identity was not discussed as a factor which impacted on recovery. However, where it was discussed, embracing this identity was considered to be an important issue. In one case this was expressed as confidence in feeling sexually attractive when self-image improved.

Gay and lesbian narrators described the complexity of relationships between their mental health and the difficulty, for themselves and others, in coming to terms with their sexual identity.

**"Until I was able to be honest about that, that was a problem."**

Some individuals had difficulty openly communicating their sexual preference and desires for various reasons including a strict upbringing and fear of criminal reprisal (at the time when being gay was still illegal). One narrator found that letting others know about their sexual preferences boosted their self-acceptance and recovery. However, some individuals experienced stigma that forced them to conceal their sexuality from others, and this suppression of their sexual identity was both frustrating and damaging to their sense

of security, confidence and esteem.

**“I’ve had a lot of confusion over my sexuality and trying to deal with that... I was brought up in a kind of situation where anything to do with sexuality was like (draws in breath) as in ‘something you didn’t talk about,’ you know.”**

One narrator referred to experiencing sexual violence, describing it as a contributory factor to ill health. Coming to terms with this as part of their identity was an integral part of their recovery journey.

There was recognition that sex and feeling sexually attractive could improve one’s sense of wellbeing. However, some individuals felt that they had missed the opportunity to be a ‘sexual being’ through being unwell for long periods of their life. Some narrators expressed feeling sexually repressed by their mental health, and felt that this had a detrimental effect on their self-confidence.

One narrator reported finding acceptance and refuge amongst gay friends in times of illness. They were however clear that they lived outside of the gay ‘scene’ and considered the experience of acceptance within the gay ‘scene’ was less likely to occur.

**“I was amongst gay friends of mine, it’s much more accepted and I feel I’ve always felt like less stigmatised.... it’s been, it’s been easier... I don’t have to go in deep and explain this and that and the next thing, it’s just, quite accepted actually, yeah. Sounds a bit of a cliché, really, but it’s true!”**

## Creative identity

Through creativity, individuals developed a new means by which to express their identity. Diverse forms of creativity from sculpture to gardening were identified as a means of pleasure and self-expression. Using creative means to express things that were otherwise difficult to communicate was also found to be a positive step on some recovery journeys.

**“Because you can’t communicate when you’re ill, you haven’t got a voice, you don’t know what to say, you can’t say what you’re feeling, I found that writing it down got it all out.”**

Creative activity had positive benefits for mental wellbeing. These benefits ranged from gaining socialisation skills through participation, and developing different forms of self-expression, to developing self-esteem through recognising creative achievements. This provided numerous individuals with an improved sense of purpose or meaning.

**“I wrote some poems when I was recovering as well and I’d never ever been able to do anything like that before so it was like a different part of my brain was working and I’ve had some poems published.”**

Creativity, like spirituality, effected change and growth on a personal level. Narrators from this study who practiced creative recovery routes were passionate about its potential to facilitate recovery. It has been used as therapy, as a means to self-express, as a pastime, as a means of developing skills, as a social leveller, and as a means to integrate self into communities.

**“I’m actually doing glass cutting just now. It’s learning different skills as well. So I’ve actually learned something I wasn’t aware I could do. That’s been a big boost to my recovery.”**

Artistic or creative expression used to create an ambiance for health was found at many levels and in a variety of formats from fine art, poetry, music and sculpture to photography and gardening. The beauty of art was found to be that whether you are a skilled artist or an amateur, you could access art and create something of value. Narrators reported that the new identity which this created: that of an artist, could be another string to their bow, as could the skills developed through creative expression. Given that several narrators told us that developing this new creative self often gave them the strength to derive and communicate meaning from the difficult experiences of their illness, it is evident that through creative means, the ill-health experience can again have positive value.

**“I get a lot out of creating and actually being able to give, to give to people something that I’ve actually spent time on, and that’s something that I can do when I’m well.”**

Narrators also highlighted that the group camaraderie and interaction that exists as part of a creative class could be beneficial to redeveloping social skills and developing friendships. Through the development of their creative talents, individuals also developed greater self-esteem and confidence. Some narrators used creative engagement as a means of sharing and hearing others recovery stories.

**“Being involved (in art group) and meeting, meeting people, ehm, new people that have been in similar circumstances and just the, the camaraderie you know, it’s, it’s amazing. It’s like an understanding, and it’s a care, it’s a really caring environment. And I, I’d say that makes me feel better to be able to be involved in that.”**

In addition to the social and therapeutic benefits that narrators detailed, being a ‘creative individual’ helped individuals express themselves into their art (gardening, poetry, painting and other creative outlets) without feeling exposed. Many found that it offered an escape from negative thoughts.

**“My interest in art helps me. It alleviates the symptoms, and it helps you to push the thoughts to the back of the mind.”**

Some narrators expressed a strong desire to be given the opportunity to earn a living through their art and clearly there is a reservoir of creative knowledge, skills and abilities in the recovery community.

## Cultural, social and community identity

Cultural identity was never explicitly drawn upon within our interviews. Of more importance to our narrators was being able to be a part of humanity rather than belonging to or being reflective of a particular culture. However, attributes common to a sense of ‘Scottishness’ can be drawn from many stories. Factors or characteristics described by narrators such as inner strength, determination, passion, benevolence, idealism, pride and having aspirations can be interpreted as being as important to Scottish identity, as to individual identity, as can the more negative characteristics popularly associated with being Scottish. These more negative characteristics include fear of making a mistake, obsession with what others think, pessimism or a failure to see problems as limited or solvable, and that being worthwhile is dependent upon what you do.

**“You find yourself. You avoid social gatherings because people always ask what you do for a living or where you have been on your holidays. A lot of people just**



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**don't go because they know that this is going to happen and they will be made to feel uncomfortable."**

Whilst a national identity was not explicit in stories, a strong community identity could be found in individuals' passions for their immediate environment and mutual peer support. All of our narrators aspired towards being valued for their community contributions (of which there were many).

**"...that's the hardest thing about having mental illness, feeling that you're constantly taking, that people are always giving to you, that people are supporting you, whereas partly recovery has been actually looking at ways that I can actually give back to the people that I care about and to the people that I want to help. And actually just to give back rather than to constantly take. That, you know, gives me self respect."**

Having the opportunity to relate to others and share similar experiences is crucial. For some individuals, rural isolation resulted in a lack of accessible services to bring people with mental health problems together to share their experiences. Many participants in this study indicated that recovery is enhanced through community engagement. Questionnaire data revealed that 58% (n:38) of narrators were active members of a social group. Of this 58%, just under a third belonged to groups restricted to individuals with (or in recovery from) mental health problems. Thirty six per cent (n:24) of narrators felt fully integrated into their local community and 56% (n:37) felt accepted by their local community.

## Group identity – Activism

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Several user groups with which narrators were affiliated appeared to be engaging in identity politics, that is, they sought to alter the societal perceptions of their group.

Whilst many narrators volunteered in the mental health field, offered peer support, or used services, several took a more active role in service user involvement and activism. A few were instrumental in the setting up and establishment of regional service user groups and found fulfilment in being involved.

**"I've had nearly fifteen years experience of helping setting up projects for other people with mental health problems. I served on things like committees. I was on the steering group that set up (ORGANISATION) and that's nearly fifteen years ago. I served as a user representative, I was then a vice convener of the charity so I helped set that up."**

Indeed, many narrators' recovery journeys have been helped by being active in such movements as they gained a sense of positive identity, self-respect, group respect and self-acceptance from their participation.

**"I suppose we fight collectively."**

**"The big thing in my recovery has been being a member of Highland Users Group. I found that the people that are members of the users group are more enthusiastic about recovery than your average person who uses a drop in centre. We are all very motivated. We take part in anti-stigma campaigns..."**

Those within the user movement participated and campaigned to foster a more positive sense of identity and acceptance for issues of mental health. They also sought to raise the aspirations and expectations of people who use services, deliver services, and wider society. Some saw

merit in challenging the way in which services are run, and believed that service users were the unrecognised experts in the field of mental health whose opinions need to be more valued. Holding these values encouraged some narrators to become actively engaged in providing services.

Narrators have shown that recovery has become an exponential phenomenon due to informal peer support and word of mouth. Sharing positive messages on recovery has allowed people the chance to contribute and give back providing a sense of worth and achievement. These positive messages have a multiplying effect as more and more people see the possibility of recovery.

**“I’ve got into various groups, as an advocate and a representative for service users, and I found that extremely beneficial, made you feel less isolated and that you can help others. And hearing their experiences as well means that you could pick up wee tips that you think might actually work for you as well.”**

Many began their recovery journey with an identity transformation whether this was through finding value in them self or becoming part of a wider community of people in recovery was irrelevant. The important thing was the positive identity gained through recovery.

## Spirituality

Recovery was sometimes seen as a spiritual journey rather than a health issue.

**“What I was experiencing was a spiritual emergency and not a mental illness.”**

Whilst there was a consensus view that a vision of hope was essential to beginning and maintaining a recovery journey, some individuals combined this optimism within a structured or unstructured belief system. Narratives from some individuals implicitly represented *“a discovery of self”*, or *“a spiritual ongoing journey.”* Some narrators felt that many medical explanations of recovery failed to recognise the extent to which belief in self and the role of faith can have in furthering wellbeing.

**“I felt was I was having a spiritual awakening.”**

Whilst some individuals’ recovery journey centred on the notion that they had learned to become the master of their own destiny, others believed that an external spiritual entity facilitated their fate. Buddhist, Christian and other philosophy and teachings helped individuals focus on their journeys. These belief systems helped provide control and focus for a few narrators, and helped them be more aware of their surroundings and of others. Whilst it is apparent that faith in something provided contentment in life, it was also apparent that it need not be in an external entity – faith in self was most important.

**“I see my life and my work to serve my fellow man... but I’m also in a way serving God. So God is very much part of my outlook and picture of life.”**

Some narrators expressed the view that mental illness can lead to spiritual progress, and ultimately to mental health. Indeed, spirituality played a key role in recovery for a few individuals and a spiritual approach to life helped them manage symptoms better. Spiritual identity covered not only belief systems but was recognised where individuals felt a clearer sense of self within the world and where recognition of the many elements of the world external to their control existed.

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**“I feel that I’ve grown up and reached a spiritual maturity, personal responsibility and independence, an understanding of other people.”**

Belief in something bigger, another entity, provided a focus for individual’s lives outside of their self. A few narrators gave religious and spiritual perspectives as a fundamental belief system that provided meaning in their lives and a reason to carry on through distress.

**“If I’m in a calm, collected, centred space and believe in God, believe that there is something greater than myself and everything’s okay.”**

Whilst a few narrators believe this spirituality provided guidance in their life and provided a focus and motivation to do well and prosper, individuals with non-religious belief systems spoke of viewing symptoms as cues that ***“something internally was out of balance (and) that the nature of the symptoms held information and if (I) paid attention to that (I) could find a way to work through and get better.”***

Religious beliefs were a catalyst to recovery journeys for some narrators, believing that the whole recovery process is a spiritual journey. In addition to providing the focus for a re-framing, spirituality provided company for individuals who were sometimes debilitated by an illness that created loneliness and alienation.

**“When I have difficulties I haven’t got somebody to turn to, I have God to turn to, and I think that’s very helpful.”**

When hope appeared weak, spirituality or belief in a greater entity provided focus and optimism. However, religious belief also played a negative role in some individuals’ recovery journeys. The idea that ***“illness is a punishment”*** played on one narrator’s conscience.

Though spirituality was prevalent in some journeys it wasn’t usually a religious based sense of spirituality. Religious philosophies and teachings were apparent in individual life paths chosen, but the key elements that appeared to promote recovery were a sense of hope, optimism, meaning and purpose.

# Identity Discussion

**Narrators showed numerous facets to their own identities, some unique and several embodying common characteristics, experiences and expectations. 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.

Re-finding and redefining a sense of identity and self-confidence that has potentially been eroded by institutionalisation or ill health was often the first step on a recovery journey. Indeed, strengthening identity was viewed as an important component of recovery by narrators. These findings are similar to those from the New Zealand Mental Health Commission (2001a, p. 3), Davidson and Strauss (1992), Sacher (1999), and Noordsy (2002).

From the Scottish context, programmes and services that facilitate the development of a sense of self and identity have been appreciated and advocated by narrators. The underpinning elements of service development should therefore highlight identity, engendering hope, personal responsibility, and self-determination. The central role of identity in recovery has strong implications for the way we provide mental health services. More person-centred and individualised approaches that allow maximum self direction and participation should be most helpful. It is important to consider the extent to which services and care planning are focussed around fostering and encouraging discussion of identity issues.

Narratives from this study in part corroborate the findings of Kirk (2002), Marin *et al* (2005) and Onken *et al* (2002), with many individuals counting the need to see themselves as a whole person beyond their labelled identity as being integral to their positive recovery. According to Leete “*none of us would strive if we believed it a futile effort*” (1988, p. 52). This appeared to be the working mantra of many of our research participants. Similarly the agency of the self in the healing process was emphasised by many narrators, this is echoed in Deegan’s (2001) findings.

In our treatment and supports chapter we will highlight the important role of talking therapies in promoting recovery. It is within this tradition that perhaps the greatest emphasis is placed upon identity, making it all the more important that access to such services is improved.

Identity amounted to much more than a single issue for narrators. It is evident that although commonalities exist (such as dealing with stigmatised identities, overcoming negative identities, having a hopeful and positive approach to recovery and taking responsibility and self-determination), it is still evident that individuals in recovery hold varied identities on a temporal and interpersonal basis. Some participants, although aware of society’s negative representations of mental health problems and the effects this had on their lives, did not accept these representations as valid and therefore rejected them as applicable to self. This view reflects findings from Camp *et al*’s (2002) qualitative study of women with stigmatised health problems. Many stigmatised groups have successfully engaged in identity politics to positively influence the societal perception of their membership. It can therefore be argued that embracing the experience of ill health could positively impact recovery at an individual and societal level. Efforts to challenge stigma and raise awareness should learn from and appreciate the positive experience of ill health (For example, *Mad pride: A celebration*

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*of mad culture*, 2000).

Recovery was often initiated in situations beyond the scope of the mental health system. Indeed, narrators have described the importance of developing an inner strength or having self-determination and a positive mental attitude by controlling their own destiny and making their own initial decision to get well. These findings were shared with Marin *et al* (2005).

Many individuals used art or creative expression as therapy and support, or as a way to more abstractly express their feelings and recovery journey. Through these creative activities, people re-script both themselves *and* their mental illness. The positive role of creativity has been explored by other researchers such as Parr (2005), Bluebird (2000), the Mental Health Association (2003), and Morris (2002) as well as a myriad of arts and mental health projects both here and abroad. Narratives suggest that we give greater recognition to the role of creativity in promoting mental health and wellbeing. Through projects like ArtFull the authors see great potential in exploiting the powerful links between creativity and recovery, something which tends to be under emphasised and under funded.

Extrapolating from Craig's (2003) theories on Scottish identity, it can be argued that the more negative characteristics associated with being Scottish could have influenced individuals recovery journeys, such as fear of making a mistake, obsession with what others think, pessimism or a failure to see problems as limited or solvable, and that being worthwhile is dependent upon what you do. The characteristics of a strong Scottish work ethic were evident when individuals spoke of their guilt of being '*indolent*' and of their desire to 'give back' and contribute towards their community. However, narrators did not comment upon, blame or praise any other particular cultural characteristics that could have helped or hindered their recovery journeys. Being valued for contributions within communities was recognised as being beneficial to recovery. Community 'exposures' to people with mental illness often contradict expected outcomes and so funding more innovative and creative means whereby communities and people with mental health problems can be 'exposed', interact and understand each other is important to furthering and sustaining recovery journeys and positive identities.

Relating with others who have mental health problems was beneficial to the creation of a positive identity for individuals. For some individuals being socially connected and active in the development of a service user or recovery 'movement' formed part of their identity whilst for others disconnection from mental health issues was desired. For some, work was a large part of their identity whilst for others it didn't feature. For all, a hopeful vision of the future encouraged them to look forward with optimism, finding meaning and purpose in what they did with their lives and valuing themselves as individuals with something to contribute to society.

It is the opinion of the authors that the findings within this report reflect the day to day struggles for acceptance fought by most people, not just people who have experienced mental health problems. The question could therefore be asked just how different are our life journeys towards self acceptance and self actualisation?

Overall, the identity of narrators was marked by heterogeneity indicating the deeply personal process of recovery. On all recovery journeys diversity should be embraced and valued. An optimistic, confident, creative outlook and identity is not a panacea for recovery. This progressive, ambitious outlook must be fostered in collaboration with other factors like building positive relationships, engaging socially and finding suitable supports to aid one's recovery journey. We must remember that this is a journey and that it is not necessarily a smooth one. The destination is uncertain but the goal is clear – to live well.

# Engagement Summary

The topic of engagement was central to many narrators' recovery journeys. Engagement or participation occurs where an individual in a social or economic setting actively endeavours towards deriving or producing some predefined activity, goal or purpose. It occurs when the individual is ready and interested in taking part in an activity and the opportunity to do so presents itself. Whilst the participatory 'goal' varied widely for our narrators, 'actively engaging' and 'deriving purpose' from the activity were key elements in fuelling many recovery journeys.

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# Engagement Summary

**This chapter details the different elements and dimensions of engagement discussed by our recovery narrators. These elements comprise volunteering, employment (economic engagement), education, community and social participation, and civic and political engagement. Within these dimensions, activity, meaning, purpose and belonging are found to be central to recovery.**

There were diverse perspectives across the narratives on this topic. It is possible that these views might reflect individual stages of recovery. Some individuals longed for the income, status, sense of achievement, routine and structure, security and social elements of paid employment. Others believed that their recovery would be jeopardised by a return to the stresses and responsibilities of earning a wage, lack of confidence in work, loss of benefit entitlement and the potential stigma found in working environments. Some individuals felt empowered by their voluntary work and the identity it provided them with, others felt embittered by society's perceived undervaluing of such work.

Many narrators recognised that actively engaging in social and community activities, education and informal networks was of benefit to their recovery journeys, while others sought to engage less actively. The overarching feeling was that recovery could be furthered by any kind of engagement where:

- Meaning and purpose could be found.
- Your contribution could be appreciated and valued by others.
- You could reconnect to a social life (actively within networks or passively – just sensing people around you).
- Structure and routine could be developed.
- A new identity or external focus (related to the activity, not ill health) could be developed and defined.
- You felt part of the community – belonging, being an active citizen.
- You could develop new skills, experiences and challenges.
- Responsibility, choice and self determination could be exercised.

External or structural barriers to engagement included:

- Stigma.
- Negative messages or pessimistic attitudes of others.
- Undervaluing the contribution individuals make.
- Rural challenges.
- Unclear (or misperceived) welfare rights and income maintenance legislation.

Internal or personal barriers to engagement included:

- Pessimistic attitude towards self.
- Fear of failure.
- Undervaluing your own contribution.
- Perceived benefit traps.
- Confidence issues.

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External factors that were useful in promoting engagement and facilitating recovery included:

- Having a conducive and flexible approach to employing or engaging individuals.
- Allowing individuals to pace their introduction or return to economic/social activity.
- Recognising and valuing the contributions individuals make.

Personal factors that were useful in promoting engagement and facilitating recovery included:

- A conducive and flexible approach to economic or social participation.
- Having your contributions acknowledged and valued.
- Knowing when to slow down.
- Knowing the right type and level of participation for you (meaningful and purposeful).
- Enjoying the activity.
- Having a good work life balance.

Engagement was found to provide an enhanced sense of agency and belonging allowing individuals to find a role in society outside being the 'person with ill health'. There was also recognition of the need for the rights of those who did not want to pursue traditional participatory activities in society to be supported and not challenged or stigmatised.



# Becoming Engaged

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Engagement occurs when an individual is ready and interested in taking part in an activity and the opportunity to do so presents itself. It can be defined as occurring where an individual in a social or economic setting actively endeavours towards deriving or producing some predefined activity, goal or purpose. Whilst the participatory 'goal' of engagement may vary widely, 'actively engaging' and 'deriving purpose' from the activity are key elements in fuelling many recovery journeys.

# Becoming Engaged

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This chapter begins by drawing reference to literature which explores different aspects of mental health recovery and social participation, engagement and inclusion. The main findings highlight the different dimensions of engagement discussed by our narrators which comprised volunteering, employment (economic engagement), education, community and social participation, and civic and political engagement. We then attempt to unfold the ways in which participating in society through these different means has furthered recovery by providing opportunities for socialisation and by providing purpose, structure, and meaning to lives. Proceeding to draw upon multi-layered experiences of engagement, we will show how individuals engage at different operational and social levels in supported and unsupported positions, fulfilling valued roles in the mental health and wider community thus fuelling their recovery journeys.

## Engagement

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Enabling service users to find and maintain employment is a significant strand of UK mental health policy, according to Secker and Gelling (2006). The National Programme for Improving Mental Health and Wellbeing in Scotland (2003b) aims to support improvements in the quality of life and social inclusion for those experiencing mental health problems or mental illness. A key component of this is working to reduce stigma and discrimination, and increase employment prospects, education and training opportunities. Parallel to this, sections 25 to 31 of the Mental Health (Care and Treatment) (Scotland) Act, (2003) have placed new duties on Local Authorities. Section 25 asks Local Authorities to provide care and support services that minimise the effect of mental disorder on individuals, helping to give people the opportunity to lead lives that are as normal as possible. Section 26 places a statutory duty on Local Authorities to promote wellbeing and social development for those who have, or have had, a mental disorder. This includes services which provide social, cultural and recreational activities, and services that provide training and assistance with obtaining and maintaining employment.

Having a meaningful career, volunteering or advancing one's education (NIHME, 2005; Secker & Gelling, 2006), having hobbies (Mind, 2001), physical exercise and engaging in meaningful activities that connect one to the community (Connor, 2004; Dornan, 2003; Onken *et al.*, 2001) are all factors that have been identified by service user groups and researchers as being conducive to wellbeing and recovery. This shows that recovery is about more than the restoration of social aspects of identity and includes attaining meaningful roles in society (Sacher, 1999). Indeed, NIHME (2005) have proposed that recovery is about what people experience as they become empowered to achieve a fulfilling, meaningful and purposeful life whilst contributing positively and developing a sense of belonging in their communities.

## External and internal perceptions

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What you do for a living is a significant component to individual identity. We often come to be defined by our occupation or lack thereof, so having some sort of creative, social or economic activity to be defined by is central to affirming a positive identity. It can also help to influence an individual's confidence, self-worth and self-esteem (Social Exclusion Unit, 2004).

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## Dignity, socialisation, meaning and structure

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Many people with mental health problems have aspirations to work. Parallel to other means of social engagement, work has been found to provide structure and purpose (Faulkner & Layzell, 2000), to increase self-esteem, to give opportunities for learning and provide the opportunity to meet new people and develop new relationships, as well as provide a sense of dignity, worth and meaning in life. All of these benefits assume particular significance for individuals with mental health problems. Mezzina *et al* (2006a) and Provencher *et al* (2002) found that one dimension of the role of work (or social activities) in recovery was that it had the potential to empower people and build upon their self-efficacy and self-development.

Occupation was found by Mezzina *et al* (2006a) to be an important issue in recovery as it allows individuals to become more financially independent and allows them to have a higher standard of living. It also provides individuals with the opportunity to acquire a positive identity that has nothing to do with being a 'person who has a mental health problem'.

From the community perspective work also provides the opportunity for individuals to develop skills, and give something back to society, all of which boost individuals' confidence and self-esteem (Social Exclusion Unit, 2004). Mee *et al* (2004) reiterated this point adding that productive activity provides a *"means for building competence through the acquisition of skills, coping with challenges and achieving success."*

The ability to participate in productive activity has been found to contribute significantly to both physical and psychological wellbeing. NIHME emphasise that individuals are able to recover more quickly when life roles with respect to work and meaningful activities are defined and individuals are supported to achieve their goals (NIHME, 2005).

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## The 'expert patient' and peer support

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The Kerr Report (2006) on the future of the NHS in Scotland recommended that *"citizens of Scotland need to take a greater responsibility for their own health."* It argues that greater involvement in the health care system can ensure individuals lead a more self-determined life in the community rather than remaining dependent on the health system for a lifetime. It also recommended a greater emphasis on using the skills of the 'expert patient' suggesting that individuals take more responsibility for their own health with less reliance on professional health experts.

Partly in response to the Kerr Report and in response to other developments in mental health, Delivering for Mental Health (2006), has made a commitment to harnessing people's lived experience to support others in their recovery through a new type of 'peer specialist worker' role. The peer support role is premised on the assumption that experience is an empowering asset that can be harnessed for the good of others as well as the person themselves. Commentators such as Mead *et al* (2001), Campbell and Leaver (2003), Woodhouse and Vincent (2006), and Bradstreet (2006) through reviews of peer support literature have provided a rationale for engaging service users as peer specialists suggesting that having a shared experience is a crucial element to support for recovery that often cannot be provided by other professionals.

Felton *et al* (1995), found that individuals served by peer specialists demonstrated greater gains in several areas of quality of life and an overall reduction in the number of major life

problems experienced. They have argued that this shared experience serves as a source of empowerment for both parties and provides positive role modelling and an increase in the self-esteem of the employee through participation in (remunerated) valuable and meaningful work.

Jacobson and Curtis (2000) have argued that, because of their ideological heritage, peer support or peer-run services are the only truly recovery-oriented services available.

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## Social citizenship – belonging and being valued

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Mezzina *et al* (2006b), argue that recovery is an interactive journey which requires a meaningful social context. That is, people need to feel part of the community within which they live and need to experience the same rights, opportunities and responsibilities of other citizens to complete their recovery journey. They argue that individuals in recovery need a supportive environment which is often developed within the context of “clubs that allow people to be who they are beyond their symptoms” in order to overcome interpersonal barriers. However, he warns of “a ghettoizing effect” if the clubs being engaged with operate solely within the confines of the mental health system.

Although no-one can be forced to recover, ultimately, recovery requires that others are complicit in the journey towards wellbeing. Social recovery cannot occur within a mental health vacuum, but requires the cooperation of communities. Indeed, many commentators have contended that recovery is enhanced through engaging in meaningful activities that connect one to the wider community (Onken *et al.*, 2001). Participation in communities through working, volunteering and socialising can help integrate people into society.

There appears to be a dichotomy between desire for mainstream inclusion described in policy and the often expressed desire service users have to seek mutual support and understanding from peers and specialised services (Highland Users Group, 2007). Mutual support has been found to contribute widely to recovery (Highland Users Group, 2006c), but there is also a recognition that community integration is important.

Argyle and Bolton (2005) maintain that participation and inclusion in the wider community, particularly participation that is *outside* the mental health arena, allows individuals the chance to form a new identity beyond that of a patient or service user. Connor (2004) identified several types of connections or engagement within communities that were considered to be helpful as part of recovery including engaging in informal networks, such as hobby and interest groups, and joining informal groups at work which can often offer support to individuals (even if that is not their primary purpose). Connor also reasoned that more structured networks based around a shared experience or characteristic can help expose individuals to a more diverse range of people within a community and can contribute to social recovery in many ways.

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## Educational opportunities

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In a learning environment, Feinstein *et al* (2003) argues that simply mixing or engaging with others in a supportive context where objectives are shared and discussion and co-operation encouraged, contributes to the wellbeing of individuals who are otherwise relatively isolated. Additional research from the Centre for Research on the Wider Benefits of Learning, suggests that learning can improve health through improving human capital (knowledge and skills),

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social capital (trust and interdependency), and identity (Health Scotland, 2006).

NIACE (2003) has argued that participation in learning can be used as a springboard to other forms of engagement. As well as potentially increasing qualification learning or re-training, it influences access to employment, can provide a re-introduction to a structured day and potentially increases challenges without the more pressing demands of the workplace. They also argue that achievement in education can challenge and change negative self-belief.

## Getting back into the swing of things

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Various strategies to help people re-engage or return to work, who might otherwise have difficulty in doing so, have been researched by commentators. Ruth Crowther *et al* (2001) in a study of the employment outcomes of a range of work initiatives for people with mental health problems, concluded that supported employment is more effective than pre-vocational training at helping people with severe mental illness to obtain competitive employment.

## Barriers to engagement and participation

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It has been established that being engaged in meaningful productive activity is both rewarding and empowering for individuals with mental health problems (Dornan, 2003; Faulkner & Layzell, 2000; D. Fisher, 2003a; Mezzina *et al.*, 2006a; Provencher *et al.*, 2002; Sacher, 1999). Evidence of the range of negative costs that derive from being out of work extends well beyond the loss of financial rewards, and people who have mental health problems may be particularly sensitive to these consequences (Anthony, 1994; Howarth *et al.*, 1998). Several corresponding factors that potentially inhibit individuals in recovery from participating in social, economic and community activity have been identified. Symptoms, medication, discrimination and potential damage to health were identified by Marwaha and Johnson (2005) as the problems that people believe affect their ability to work. Secker and Gelling (2006) found that lack of available support inhibited high numbers of mental health service users from pursuing employment and education or training goals, and Boevink (2006) has argued that some people just needed all their energy to keep going and didn't have the energies to divert towards things such as work or volunteering.

Parr and Philo (2003), whilst studying the social geographies of rural mental health, identified social exclusion as a particular problem experienced by individuals with mental health problems in rural communities. A strong theme within their research was the reported "culture of silence" around mental health issues, cultural stoicism and the difficulties of avoiding "rural gossip networks" in areas with high degrees of social proximity and gemeinschaft-like characteristics. Drawing data from the same study Parr *et al* (2004), found that social and physical isolation often occurred due to attempts to hide health problems, and that a culture of resilience in rural areas (particularly Highland Scotland) forced high expectations upon individuals to "soldier on" in spite of health problems or sparse services. Converse to this, they revealed that on some occasions, social proximity was perceived to contribute towards community care where community members provided informal caring practices in rural communities.

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## Personal and social consequences

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The costs of unemployment to the individual are reported to include a loss of routine, social contacts, self-esteem and loss of the feeling of belonging, self-worth and purpose that has been found to accompany a 'worker' identity (Department for Work and Pensions, 2002, p. 1; Social Exclusion Unit, 2004). When no other form of participation or engagement such as voluntary, community or social activity takes the place of work, individuals can become extremely isolated or disfranchised and there is a strong relationship between unemployment and the development of mental health problems, including an increased risk of suicide (Choose Life, 2002). This under-engagement or unemployment that Claussen (1999) and Flatau *et al* (2000) have associated with poor mental health is often referred to as both a consequence and a cause of mental health problems. People with long-term mental health problems have the lowest employment rate of any of the main groups of disabled people with official recordings of only 24 per cent in work (Social Exclusion Unit, 2004, p. 51).

Studies show that the longer a person is absent from work the less likely it is they will return. The Scottish anti stigma campaign 'see me' (2005) has found that over two fifths (43%) of people with mental health problems who have experienced mental illness when in work felt encouraged to leave and not return because of their ill health. They also found that stigma could preclude individuals from retaining tenure and from accessing the workplace, and revealed that one third (34%) of Scottish employees who have taken time off work due to mental health problems have felt forced to conceal their reason for absence, fearing the negative reactions from colleagues.

Marmot and Wilkinson (Eds, In: Bartley *et al.*, 2003, p. 18), strongly suggest that *"people who have more control over their work have better health."* They report on a body of research (Social Determinants of Health) that looks at job characteristics, employment, job security and unemployment and how these relate to employee mental health. Ferrie *et al* (1999) link job insecurity to ill health and Sverke *et al* (2002) in their meta analysis of literature on job insecurity and its personal and economic consequences, concur that mental (and physical) health appears to decrease with the increase in experiences of job insecurity.

Health Scotland in reviewing literature on indicators of mental wellbeing found that job satisfaction or dissatisfaction has also been strongly associated with mental health problems (Health Scotland, 2006).

Failure to maintain a job due to stigma at work merely compounds employment problems for individuals in an already prejudiced market where employers are not keen to employ individuals who have mental health problems. A Department of Work and Pensions survey which sought to examine how to secure employers' commitment to employing disabled individuals, found only 37 per cent of employers would recruit people with mental health problems compared to 62 per cent being willing to take on people with physical disabilities (Bunt *et al.*, 2001b). The repercussions of this type of prejudice are reflected in another study by the Mental Health Foundation (Ponte *et al.*, 2000), which reports that 37 per cent of people with mental health problems report facing discrimination when seeking employment.

From these statistics it is obvious that access to paid employment and the ability to retain paid employment is an issue of concern for those in recovery from mental health problems.

# Engagement Findings

**Finding your identity could be described as an internal process of change and acceptance. Engagement can be seen as an extension of this process where you seek to secure external acceptance, belonging and a sense of purpose. What you do for a living is important to how you are perceived and valued in society. It often determines your social status and the social circles within which you engage, giving you a sense of inclusion, purpose, and a role in life. Being engaged in productive activities in a paid, unpaid or recreational capacity was found to be beneficial for most narrators. They implied that the value derived from being engaged and attributed to being economically active (contributing) made them feel more accepted in their communities. It also provided individuals with socialisation, friendships, status, an identity beyond service user or mentally ill person, income (not benefits), and it was found to influence confidence and esteem.**

Most narrators in this study identified themselves to some extent through their relationship with work, be it that they are in employment, voluntary or paid, or that they aspire to be able to hold down a job or to be a worker. For some, ambitions in this field are high with a desire to hold down a full time job or become self employed, whilst for others, recognition that symptoms would make paid employment difficult led to a desire to work on a voluntary basis. Whilst many embraced the opportunity or desire to work, some took the opportunity to engage in other means of creative activity unrelated to work or employment. With these activities often came a desire for less responsibility but more creativity. Indeed, the desire for creative expression and a creative identity was evident in many individuals' stories.

Within this chapter, narrators describe several main areas of engagement: through voluntary work, paid employment, education and through social and community participation. They describe the ways in which active participation in society has been meaningful to them and identify the structures through which they felt they have been able to gain greater access to participatory activities. A few narrators provide an insight into their own perception of society's expectations and how this effects their motivations and confidence, providing a reason why they allied a return to work with recovering a normal life.

## Volunteering Being valued – giving back

Numerous narrators were involved in a variety of voluntary occupations from animal welfare to supporting peers, and generally found the experience of volunteering to be worthwhile and conducive to recovery, reporting a desire to give back to society as a reason for seeking this type of participation.

**"I feel now I'm contributing to, okay I'm not paying taxes or nothing, but I'm still contributing... I feel valued and it's given me a bit of self-worth."**

Becoming engaged in voluntary work filled the need for belonging that most individuals craved. It solved the isolation that could be found in being unemployed, disengaged or disfranchised. It also provided individuals with an external focus outside of their own recovery journey.

**"I suppose doing the voluntary work three times a week gives me a sense of belonging and all that mixing with the public, having interaction with your colleagues and I suppose it makes you feel good about yourself doing voluntary work."**



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**“I think volunteering for something that you believe in. You know, having something else to believe in, apart from the fact that you’re sick.”**

**“It was a way for me helping other people and listen to their problems, again it was this escapism, you know, but it has allowed me to deal with my own issues.”**

## Lessening guilt

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Several narrators were unaccustomed to being economically inactive and found that the commitment and responsibility required by some voluntary work lessened their sense of guilt over not being in paid employment. It also provided the social and some of the economic rewards of paid work, like learning new skills and providing structure to a day. It encouraged socialisation, rewarding achievements, having your contribution valued and, to a lesser extent, being partly remunerated (usually expenses) for contributions made.

**“(Factors that keep me well are) probably my voluntary work because I feel like I am achieving something... the work that I am actually doing is full of complications... which are very frustrating sometimes... if I can function at that level then the achievement in doing that is huge for me.”**

Although volunteering was an overwhelmingly positive way for individuals to further their recovery, there was a general feeling from a few narrators that the unpaid nature of this work somehow lessened the recognition or value attached to it and the feeling that the experience of ill health and recovery should be valued more (financially, experientially and academically), particularly in the mental health sector.

## Path to paid work, providing structure

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Participants on benefits were permitted to work voluntarily for a number of hours per week. Many of those who were aware of this working entitlement embraced the opportunity to pursue a variety of voluntary occupations finding the experience of volunteering worthwhile and conducive to recovery.

**“Been volunteering at (ORGANISATION) for a year and then I did permitted work... you know, therapeutic work, you’ve heard of that yeah?”**

A few individuals used their voluntary contributions as a paced driver towards paid employment. Volunteering allowed them the opportunity to work at their own pace and to determine their own level of responsibility in work. It also allowed them the time to work out any work-related anxieties before returning to paid employment. Although individuals didn’t always plan to enter the realm of paid work, the experiences they nurtured and developed through their volunteering, in some cases, helped them to gradually acquire paid work.

**“It started me out into work. It made me get out in the morning more; structured my day, that kind of thing. I’ve done many voluntary jobs before I took my extra hours on... so the whole thing has just helped gradually.”**

**“It was a relatively smooth road through to voluntary work, through to employment being a director and having quite a full and active life.”**

**“I started off a couple of hours a week voluntary, and then sessional and then part-time and now full-time.”**



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Volunteering provided individuals with greater confidence, self-esteem and satisfaction, giving them purpose and meaning through helping causes. It allowed individuals the opportunity to channel their energy into projects without adopting the responsibility of paid work and as such aided their recovery.

**“I’m doing a job, just an unpaid job, you know? Where there’s no responsibility, where there’s no boss... everything you do is voluntary so there’s nobody there telling you ‘you do this, you do that’. It depends on how you feel on the day, what you want to do, and if you’re having a bad day you don’t particularly have to do anything.”**

## Activism

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A few narrators were prominent mental health activists in a voluntary capacity.

**“I am (POSITION) with (ORGANISATION)... The work I do with (ORGANISATION) is a bit like having a part time occupation. I represent them at conferences... (I have) years experience of helping setting up projects for other people with mental health problems.”**

Becoming involved in the delivery of mental health services (and the development of mental health policy) was found to be therapeutic for many narrators. In addition to the skills development, meaning and purpose, sense of value, routine and structure that other volunteering activities provided, volunteering in this sector was found to further an individual’s recovery journey. It was described as giving meaning and value to his or her recovery experience through being able to empathise with others by sharing a common understanding. The individual’s experience of ill health and recovery gave a unique insight into the life and expectations of other service users and prepared him or her to help others in the field.

**“I’ve got into various groups, as an advocate and a representative for service users, and I found that extremely beneficial, made you feel less isolated and that you can help others.”**

Although user involvement has been central in significant numbers of narrators’ recovery journeys, for a few individuals, work in the mental health field was not conducive to recovery.

**“I did get involved with (ORGANISATION) on a voluntary basis... I’m supposed to work with other people who have been in the mental health system, but I have given that up because I don’t really have very much in common with these other people. I realised the thought of going back to get involved with it was making me feel depressed.”**

Overall, participating in voluntary work across a whole range of fields was a positive factor in several people’s recovery journeys. The ability to self-determine level of responsibility allowed individuals to develop their confidence in work and to be less involved in times of ill health. It allowed them to contribute to society and feel valued and provided activities within which people could observe structure and derive motivation, meaning and purpose.

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## Employment Self-employment

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Several of our narrators recognised self-employment as a positive alternative to paid employment or voluntary engagement. They identified the ability to work at your own pace, with the freedom to pursue an activity you want to work at, as being positive characteristics of this type of work. Some were cautious of the perceived financial insecurity associated with working for yourself while others used state benefits to top up their earnings.

**“I’m self-employed. That means I work when I can, I have total freedom not to work when I can’t, and no one can challenge because I don’t get paid a salary.”**

A couple of individuals had been self-employed prior to their illness and allied a return to this as helpful to getting back to a meaningful or ‘normal’ life. This self-employed engagement also provided individuals with status, respect and a meaningful activity with which to employ their time, resources and energy.

**“I think I just want to build the business up again for my own ego basically to get back to where I was, where I felt I was a really good business man and respected in my community.”**

One narrator who was particularly challenged by the responsibilities of paid employment found determination through adversity. This person approached the challenge of work with a creative mind and deduced that entrepreneurship or self-employment was a viable option because of the advantage of determining work hours and commitment. This drive to work and commitment to provide for oneself was widespread in recovery stories, but was often overshadowed by a fear that illness would return and jeopardise employment. The fear of failing in work and being returned to the beginning of the benefit application process acted as a major barrier to self-employment and paid employment for several narrators.

**“It’s the barrier about paid employment that’s... having kind of got trapped in it, not being able to get out of it going down into an awful pit.”**

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## Transition – paced return to work

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Some narrators engaged in voluntary, part-time work or supported employment as a means to pace their re-entry to the workforce. People had varying experience of supported employment schemes. Some were appreciative of the support while others felt patronised by the excessive nannying and lack of commonality between their experience and the role of their supported position. Some individuals complained that the roles offered for support were unchallenging and menial. Supported employment was found to be least effective when it appeared to the narrator (employee) that support is working for the employer as opposed to the employee.

**“I was supported by the (ORGANISATION) when I left work, but I felt – I had a job for three months, but I felt they were supporting the employer more than myself so I felt it was a bit of a hindrance.”**

Return to work programmes were found to have the potential to be valuable in maintaining individuals in employment, where offered, so long as they were properly adhered to by employers. Narrators’ experience of these programmes was mixed, with some individuals complaining of a lack of paced return or transition period which resulted in excessive stress and potential relapse.

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**“They assumed I could handle a great deal more than I was capable of doing. They put me under extreme pressure.”**

**“I was off for nearly a year... I went back to the same kind of job... They’d really left everything in abeyance, for about a year. They’d really sort of just done the basics and nothing more!”**

The element of risk or choice had often been removed from positions that sought not to ‘stress’ individuals too much, but often this lack of challenge, responsibility or control demotivated narrators who felt unappreciated, depreciated in status, undervalued and powerless. The removal of choice and risk effectively removed their right to self-determine their level of participation.

**“I had a ‘return to work’ programme after I’d had been ill, – they gave me a receptionist job which I felt was totally uncalled for because I’m an (OCCUPATION) really; it was a completely different job and they would assess me on that rather than (OCCUPATION).”**

Narrators were sometimes given the impression that they were a nuisance because they had to take time off work for doctors’ appointments during this recovery period. This and other negative feelings associated with returning to paid work were obviously detrimental to individuals’ self-worth and often left them with feelings of powerlessness.

For those contemplating returning to work the consistent conditions for safe return were that individuals were allowed to return to a suitable and meaningful position at their own pace. For those who wanted to enter (as opposed to return to) the work force, part-time work was sometimes sought as a graduated entry to full-time employment, as was voluntary work.

**“I would like to start working again. I don’t think I could do a nine till five. I think that would be good but it will happen at my own pace, in my own time.”**

## Retaining a job: understanding employers

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One narrator stressed that when employers value their staff enough to afford them time off without guilt and help them return to work safely, they build an invaluable sense of worth and confidence into individuals. Those who were in employment were often able to stay in employment because their employers were particularly supportive through the highs and lows of their recovery journey. For these individuals, having an understanding employer played a role, not only in providing consistency of employment, but in the maintenance of self-belief and self-worth.

The narrators who experienced full emotional and financial support from employers were clearly of the opinion that this was not the norm.

**“My boss has been incredibly supportive, been fantastic, absolutely fantastic all the way through... (She allowed me to) go back on a plan staged return to work programme. I’m very, very lucky. I have an understanding employer, which a lot of people don’t have.”**

**“I’ve been in and out of hospital quite regularly and had supportive employers and held down a full time job. And instead of being demoted every time I went back to work they would promote me until I was stock controller or whatever.”**

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Narrators underlined that flexible working needed to be embraced by company and staff if it is to operate successfully.

**“It’s all very well this part time business, but it’s not good enough for the (ORGANISATION). It depends on what attitudes are to flexibility....”**

**“When I came back to work they said...I would be part time and the deal was I could choose my own hours so long as it was half a week. But I found increasingly my boss got fed up with it!”**

Some individuals felt that they had to go to great lengths to satisfy their employers of their ill health, the implication being that mental ill health was not real and that narrators were ‘at it’ when absent. Narrators reported that employers placed a heavy reliance on medical evidence of ill health, requiring a doctor’s note to justify absence. Although narrators recognised the statutory requirement to produce a doctor’s line after a seven day period of self-certificated absence, a few individuals have argued that this approach doesn’t adequately recognise the unique knowledge and experience that people have developed of their own illness that helps them identify periods of illness better or more quickly than their doctor.

**“My experience with my employer was... they sent you for medicals which I found quite terrifying, going for the tests, you know... there was like no element of confidentiality whatsoever... it was almost as if, ‘we think you’re at it.’ You know? There’s nothing wrong with you... they automatically disbelieve rather than believe you.”**

## Meaningful role

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A steady income from work provided for a better standard of living and quality of life for numerous narrators. However, individuals also recognised that work offered them external benefits, amongst other things, it served to give individuals meaning and purpose, it also gave them confidence and personal responsibility and a structure to their daily lives. It occupied people’s minds and created an external focus for individuals, introduced them to new social circles, provided them with a financial means to pursue other activities and restored a sense of normality or expectation for many. It provided a means by which to gain social status and develop confidence, providing a new working identity.

Respondents reported that working gave them a pleasure, pride and self-respect from being able to contribute to society and be responsible for providing for self and others – fulfilling traditional breadwinner roles. The fact that individuals’ contributions were needed, appreciated, and valued, merely added to the economic and social benefits work provided. This led to a greater sense of self-worth which led in turn to more confident individuals which helped promote recovery.

**“That made me feel good, that I wasn’t, you know, totally living off benefits, and I was, you know, I was going out to work, and I was, you know, contributing something.”**

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## Socialisation

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The socialisation aspects of work have been found to be beneficial for numerous narrators. They felt that they have been exposed to more social relations and situations through their work than they would have had they been unemployed. One narrator expressed the view that many of their friendships had been developed through working relations and networks and, for this reason, they felt that working was indeed a major factor in lubricating the social aspects of their recovery.

**“People that I meet through work I tend to make links with and connections and then sometimes they become, like, friends rather than just being associates or colleagues or whatever. That is really the way that I operate, and have operated in the past. It made gaining employment really important for me... And it's also one of the main ways that I develop a social and a support network and whatever so I had lots of reasons for really wanting to get back into a job.”**

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## Want to work

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Narrators indicated that information about employment support rights and employee rights need to be more freely available to help enable individuals to return to work if they want to. For some individuals a sort of epiphany occurred when they realised that atypical work is okay and that not everyone wants to or is capable of working nine to five.

**“Recovery has shown me now that perhaps I just have to look at the bigger picture a wee bit, about ‘right, ok, traditionally work in the sense of nine to five will never be me because I just can’t fit within those guidelines.’”**

**“I think if I had been more aware of some of the kinds of support that are out there, like just being able to access... I think in relation to work, being able to have a conversation with somebody who was neutral about my rights and being able to put things into perspective.”**

Many narrators who were unemployed, underemployed or working voluntarily expressed a desire to engage in paid work. Indeed, getting ‘back to me’ for many narrators was only possible when they found contentment in their contribution and identity as a worker.

**“I definitely want to work, you know, I want to, and I want to work in something that I feel I’m contributing to something.”**

**“I feel like I have a lot of untapped potential and if I can stay well I can make something of my life I don’t want to not achieve anything with my life.”**

**“I have thought to myself quite often that if I had a full week I’d feel more entitled to a relaxing weekend type thing.”**

**“I used to beat myself up that I could not work and I was on benefits.”**

Some people found a social pressure to be in work. They recognised that a considerable emphasis is placed on being employed and having the right job in society. Some described guilt at not working in paid employment.

**“I miss the ability to work. I miss having the ability to work hard. I couldn’t do it now. I’m ashamed of how indolent I’ve become.”**

Most people wanted to work if given the right safe opportunity as they needed a regular income and sought to have a more social and ‘normal’ life. Some individuals wanted to work, but feared repercussions on their benefits if they failed to maintain their employment. In this instance, willing and able individuals were trapped into not working. There was an acceptance that some people can contribute in ways other than working and that there was a need to lose the guilt and stigma of not working.

## Barriers to work

### Negative messages

The issue of negative messages was recurrent for some narrators in relation to their ability to work.

***“You will never take responsibility... you should be considered for sheltered employment...”*** was the message given to one narrator who went on to become actively involved in volunteering. Whilst this message of negativity gave this particular respondent the determination to ***“prove them wrong,”*** negative messages more often served to lower individual self-esteem and often served no constructive purpose.

Organisations and professionals have a role to play in giving a positive message of hope in work related circumstances. Some narrators were disappointed to find people who work in fields aligned to health who were not understanding and who didn’t support their own staff in their recovery journey.

## Stress of work

Findings suggest that when ill health removes the ability to work illness can be exacerbated by not working due to the loss of social networks, self-esteem and confidence. Whilst work can give identity and confidence, inappropriate work or unemployment can remove it.

***“I’m actually working so hard and I’m not getting what I want out of it, but you know, I’m not really happy, I’m sort of miserable. Look, this isn’t making me happy.”***

***“I found my jobs difficult generally. I am still scared of doing a paid job.”***

***“I worked professionally for a number of years and I had a lot of autonomy myself, you know, just the way things were, and when I was made redundant five years ago... I lost all my confidence and all my... it just went through the window, that’s when I became terribly unwell, you know?”***

Meaningful engagement, whether it be work, leisure, volunteering or learning, gave some individuals a sense of self-worth and fulfilment and a positive and valued identity. Other people believed that their sustained recovery depended on avoiding work. Working or engaging as an end in itself was not necessarily productive or good for mental health if no fulfilment or meaning was found in the activity – even if it was financially remunerated.

Some individuals felt stressed trying to fulfil the norms and expectations of working life and for these individuals paid employment did not form a part of their recovery. Fear of the working environment, stigma at work, bad reactions to stresses of work, feelings of not coping, especially when plagued with demands from employers to return to work or produce a doctor’s note during periods of ill health were all given as reasons for not being able to engage

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in paid employment. Not having to work was one less worry for several participants.

**“It was definitely part of my recovery, staying at home and being away from work.”**

**“I found my jobs difficult generally and I am worried about the fact that I am associating recovering with not working.”**

**“My biggest worry at the moment is work, you know, paid work... I feel very much I don't want to work.”**

Some employers appeared to be uninterested in the individual's ability to work but were merely determined that they attend work. For these reasons, individuals implied that negative attitudes from employers caused a major hindrance to their recovery. Narrators did believe that employers can do a lot to ease stress at work. However, being given the wrong type of support was argued to be equally as bad as not being supported. Employers need to ask individuals what type of support they seek to help them provide more structured, relevant and accountable help.

## Isolation

Loss of employment was found to carry with it a loss of prior social networks, leaving individuals to feel quite isolated when they were on long term sick leave or unemployed. The amount of effort afforded to communicating with disgruntled employers for some narrators was immense and extended periods of zero contact for other individuals left them feeling **“astonishingly isolated.”** Feeling forced out of work due to harassment was not uncommon amongst respondents whilst receiving no communication and being ignored was found to be equally as harrowing for others. Neither of these situations was conducive to a positive working environment or recovery.

**“...anything connected with the work (hindered recovery)... it can be receiving a piece of mail from work... They tell me if I don't come back to work I'll get sacked, but they don't say it that way... I'm not keeping in touch with people from work... you feel astonishingly isolated.”**

## Discrimination and stigma

Stigma was found to hinder recovery and served to exclude people or force them out of participation or employment. Some narrators who wanted to re-enter the workforce felt pressure to conceal their ill-health past in a bid to get a job, arguing that if you have a history of mental illness you're not taken seriously or not valued.

**“I didn't mention anything about mental illness so I could get the job.”**

Disclosure of illness or being 'found out' had a detrimental effect on confidence and efficacy, which in turn fulfilled employers' expectations of those with mental health problems being lesser quality workers.

**“It's kind of hard to get employment because you have got the stigma, you've got the label, plus you're not reliable.”**

**“If they know you have a problem, I think you're not taken as seriously... if they know that you have depression, you're just treated that bit differently.”**

Some individuals found that there is a difficult balance between playing down ill health and gauging how accepting an employer will be to accommodating any future illness. Those who experienced stigma generally felt undermined, upset and angry at being made to feel less worthy as a direct result of prejudice. However, employers' negative assumptions and stigma sometimes provided a catalyst or challenge to individuals making them all the more determined to do well and succeed.

**"They have just made me fight all the more, made me frustrated too like! I've come up against stigma at work and all that, it's made me more determined!"**

## Work life balance

There was a feeling that the incidence of ill health had given people a chance to sit back and reassess their lives and to focus upon what was important to them to keep them in a state of wellness. Intrepid steps into employment were sometimes too ambitious. Trying to meet other people's expectations, or having high expectations for self sometimes encouraged individuals to take on too much, too soon. Knowing your limitations and having a good work life balance was found to be really important.

Taking on less responsibility, making sure their job was satisfying, working less and making more time for social participation were all factors that were explored whilst individuals pursued a better work life balance.

**"Having a bit of a work life balance as well is really important. I am really passionate about my work... But the danger in putting yourself above that parapet and saying 'yeah, I'll get involved in that and I'll do that and I'll be on this committee..' is that (it's too much) aye... in the past I've taken on too much stuff and then just felt it being overwhelming."**

People described the importance of learning when to push things and when to take it easy.

**"In terms of pace, just being able to do a bit at a time and then draw back a bit and have some space and some time to kind of assimilate things and not feel pushed has been very important."**

## Education

Education that helped facilitate recovery primarily fell into two categories for narrators, the first being about their condition and the second being more about self expression and a quest for other knowledge.

Some narrators were pulled into education through interest, a thirst for knowledge and a desire to do something academically rewarding and challenging with their lives. Some were directed towards training by employers, and others engaged with training for work programmes.

Individual experiences of education were overwhelmingly positive.



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## Learn about self and condition

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The emergence or onset of ill health sparked an interest in learning about mental health and wellbeing for numerous individuals. This interest in their own health often helped promote their recovery. Although the interest generally started as an investigation to find out more about their illness, being equipped and empowered with more knowledge about their health often aided coping mechanisms and self-awareness and was found to be beneficial.

Knowing about the illness at the same time as experiencing the mental health problems made individuals more able to empathise and communicate with others in a similar position.

**“I’ve started to learn a wee bit about mental health... I’ve started to sort of gain knowledge about it and I think that’s helped my recovery because I really didn’t know anything about it until I became ill.”**

**“Awareness and information is really key...”**

**“I’d been on the week’s counselling course... I wanted to follow through with self awareness and what not, because the person centred counselling is very much about self awareness.”**

Some respondents were given negative messages about learning too much about their condition by professionals who believed that non-expert knowledge could lead to incorrect self diagnosis. They felt these negative messages hindered their recovery.

**“Some of my doctors have blamed me for reading too much about it and knowing too much about it. I think it makes them feel insecure – some of them say it’s not beneficial to know lots about your condition.”**

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## External focus

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Study was found to occupy a lot of time for some individuals and was used by some as a coping mechanism and a means of intellectual challenge. It provided a different perspective on the world and a means of interest, self-development and contemplation away from mental health issues. It was found to provide a source of achievement and pride for individuals who had a wide range of interests and participated in various courses from architecture, computing and gardening to animal welfare and catering.

**“I think there’s also something about having other things in my life away from mental health issues, away from support workers, away from, and actually finding a different channel. Be it the Open University, be it craftwork, be it whatever it is, I think sometimes, certainly myself, the thing that prevented recovery was that I didn’t know anything else.”**

**“You graduate in your gown and I stood and I was about to go up on the stage I felt as though I had really recovered and I never singled out a moment of my life, but I did feel particularly proud of myself that day... I was proud and pleased and happy and triumphant.”**

Engaging in study outside mental health was particularly helpful in developing a new positive identity. It provided the opportunity to mix in different circles, make new friends and develop new skills. People often left behind or forgot their ill health identity whilst in their student guise. Additionally, a mental health problem was often not as stigmatised in an educational environment as it perhaps was when engaging in the workplace. Indeed, individuals who

participated in creative and artistic classes often drew upon their mental health experiences to further their ambitions and skills in creative expression.

## Access to education

Several individuals made use of Individual Learning Accounts and other free study opportunities. Being offered professional development courses through voluntary or paid work gave individuals a sense of achievement and value as it proved that they are worth investing in. This type of education and personal development was a big boost to recovery and morale.

Information about study opportunities is not clear according to a few narrators. These narrators expressed a degree of difficulty in accessing education and training resources and described missing opportunities for personal development as a result. Knowing what opportunities are available for training and study was key to helping one narrator better direct their recovery journey.

**“I got a two day and then a five day training (course)... It took me nearly three years to get to this stage, to think ‘oh I’ve got a brain and somebody believes in me’ you know? That really makes a difference. I’m very good at finding out about what there is, and that’s a skill that I’ve always had..., but (I) also want to make sure that you don’t have a struggle to find out this information because although a lot of it is out there... it’s amazing how ignorant people can be of what there is to help them.”**

## Community and social engagement

Adjacent to having a core group of family and friends to socialise with, having membership of a variety of social networks was regarded as an important source of socialisation and support for individuals. These networks included social action groups, hobby, social or interest groups and self help groups. The groups provided a source of socialisation, bonding and support, even though this might not have been their primary function, and they allowed people to connect with a more diverse population inside and outside the mental health arena.

## Social action groups

Through their experience of mental health services, individuals were acutely aware of the social and economic consequences of being mentally unwell. This knowledge provided a number of narrators with the motivation to become mental health activists. A few held prominent and influential positions in organisations, whilst others organised at grassroots level. Most people appeared to be driven by a desire to help others who had been through similar experiences (evidenced by their support of and participation in this research). This activism and engagement has given a new sense of empowerment and confidence to individuals. Their expertise through experience means they have a valued and valid contribution to make to the understanding of recovery.

**“I want to see recovery as the underpinning principle of all mental health care, and I can’t see it happening in my lifetime, if I’m honest. I’d like to see a national voice as well, that’d be fantastic!”**

Some narrators were quite militant and proud of their recovery experiences and have been involved in campaigns to raise awareness about mental health issues. Many were dissatisfied

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with a perceived lack of user involvement in service and policy development. They felt that often people were consulted only to be ignored on more important matters of concern.

**“People weren’t listening to what we were saying. They were putting their own spin on it and then delivering that as the user voice. So I was very kind of dissatisfied with what was going on.”**

This engagement, whilst primarily political, was also beneficial to individuals’ own recovery as they became more informed about themselves and their conditions and became more confident in their chosen arena.

**“I’ve got into various groups as an advocate and a representative for service users, and I found that extremely beneficial. It made you feel less isolated and that you can help others. And hearing their experiences as well means that you could pick up wee tips that you think might actually work for you as well...”**

Social action groups provided a focus for the greater good – outside of the individual’s own wellbeing concerns. People became activists not only to forward their own agendas, but to help other people who might not have the courage to speak up for themselves. This often resulted in a multiplier effect of building capacity and confidence in an individual who could then proceed to motivate and build capacity and confidence in others who could in turn take up the same fight.

**“...getting involved, wanting to have my say, because I knew that things were wrong and somebody needed to say something, and for every person that there is like me there’s a hundred at home that are frightened, you know, and won’t complain because whatever support is there for them might get taken away.”**

Activism also provided an opportunity for developing social networks with peers that gave people confidence in recognising that they were not alone and were not being adversely judged for their experiences, removing the isolation that is often associated with mental illness and allowing individuals to share coping mechanisms.

## Participating socially

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Engaging socially was a natural thing for many people as they developed their self-confidence and became more externally focussed and aware of their environments. While some people made significant efforts to become engaged in numerous types of social networks and activities, it should be recognised that social engagement didn’t always require active participation. Sometimes being in company, even at the periphery of a group, just listening or watching, was enough socialisation to maintain a positive outlook and a recovery focus.

## Communities and housing

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A source of support and enjoyment was often derived from social groups in the community (drop-in centres, arts classes, gardening groups, computing classes). These groups had a role in providing individuals with support and a sense of belonging. They also allowed individuals to reciprocate the same support they derived.

A few narrators who resided in a ‘community living or supported housing’ arrangement were impressed by its approach to engaging individuals in everyday activities, teaching them new ways of appreciating experiences, being responsible for others, exercising choices and self-determination. Although this type of living and engagement was not typical amongst

narrators, those who had experienced it agreed that it had positively affected their recovery.

**“Sometimes it’s hard to know who is a resident and who is a co-worker because everybody mingles... because you are in a community you also have certain responsibilities, so that actually helps you to become well... you’re picking up responsibilities, maybe letting other people down if you don’t do these things... So it’s light responsibilities I guess, certainly choices. You choose what you do and it’s quite interesting to watch how it works, you sort of fall into doing things.”**

In addition to an appreciation of supported housing, some narrators complimented the inclusive ways in which clubhouses and other drop-in or day services supported their recovery journeys. The ‘family’ environment which was often nurtured within these services was found to be supportive without being overly intrusive in individuals’ lives.

**“Yeah, just a big family all together, but a family that’s like supporting one another, the support is there, it’s not only with the staff but each of the members supports one another.”**

Although the opportunity to engage in hobby, social or interest groups appeared to abound in and out of the mental health field, information about what opportunities are available was argued to be less plentiful. There was a consensus view amongst narrators that it is good to keep busy although there was no agreement over what type of activity was best at promoting recovery.

## Social engagement, exercise and creativity

Social engagement was often the response to an inquisitive mind, where people felt better about themselves and their environment and looked for outlets to channel their new recovery focussed energies.

There was an interaction between confidence and engagement. Although it is hard to identify cause and consequence (whether engaging with external society inspired the confidence to further individuals’ recovery journeys, or whether developing an inward confidence in some way enabled individuals to face engaging in external society), it is clear that this social engagement often had a multiplier effect on developing confidence, extending friendship and other networks, and making people less isolated and more optimistic about their recovery potential.

Generally, social engagement of various sorts: joining clubs, participating in creative activity, being involved in political activity, visiting with friends, gardening, attending groups, shopping, learning new skills, was felt to be beneficial and helped integrate individuals into communities.

Engaging in physical activity was found to be rewarding to individuals on social, physical and mental health levels with the increased social activity (dancing, football, cycling) adding to the pleasure of feeling better and more confident about oneself after exercise.

**“In terms of exercise I used to go running quite a lot, particularly as a way of managing anger, if I felt really irritated I could discharge that kind of energy.”**

**“Well when you are well there’s a big difference. You’re more confident, you have more self-esteem. I think to stay well you have to go back to the basics, you have to get a good night’s sleep, eat properly; I think nutrition is important. Exercise, hobbies and friends... Yes, exercise definitely helps.”**

Creative engagement was reported to be rewarding for numerous individuals. Some used their experience of ill health and recovery as a source of inspiration for their creativity. Others used creativity as a coping mechanism whilst some simply enjoyed exploring their creative side and engaging with others in an informal setting.

**"I wrote poems about self harm, poems about what it felt like, the whole lot of it. And writing was a good thing because what I learnt was (even now I still write) if there's something I can't say to somebody who has really upset me or done something to me, I write it down. I look at it, I put it away, I go and get it the next day, I read it and I think, that's that over."**

**"I took up an art class, my friend and I saw a beginner's art class in the library, and I get a lot of enjoyment from that... It's very therapeutic. The class is two hours and it's the quickest two hours of the week, it just flies by and you wish you could get the time to do more."**

One narrator advised that individuals should re-evaluate their expectations every so often to fully appreciate what they have learned through their experiences and what they can now hope to accomplish.

## Barriers to participation and socialisation

Rural isolation proved to be a problem for some individuals who needed to interact with people who have an understanding of their situation. In addition to a lack of transport and mental health services people were further isolated by not wanting their mental health status to be public knowledge in small communities. The importance of social engagement, even if only within the mental health field, was apparent for this group. These individuals appeared to value time with others more as they were afforded it less.

**"(I stay in) a more rural place. (The drop in centre) is only available one day a week... but you can spend your whole week feeling really, really dreadful and the one thing that keeps you going is that you are going to meet people and have a chance to talk about things that you can't offload on friends and relatives."**

For those who experienced isolation in settings other than rural communities, support workers tended to assume considerable significance to provide social contact to individuals.

**"I can't be lonely, I like my space but it can't be for too long. If I have a day on my own then that is really, really hard. I actually noticed that the vocational worker has called me on the Monday and I thought 'Why is she phoning me?' (She said) 'Because I know on the Tuesday... I know you struggle with a long weekend if (name of partner) is not there.'"**

Perceived barriers to engaging within your community included inadequate income, fluctuating levels of wellbeing, and problems associated with being engaged in too many activities. Similar to being engaged in paid employment, narrators were keen to point out that a work life balance of activities and activity free time should be struck.

**"I've gone from almost inertia to being slightly too busy. And it's getting that balance."**

Engaging was not always an easy task for individuals. Some people expressed reservations about initial encounters with groups and activities. Although they may have found these encounters difficult, they were thought to be ultimately socially rewarding. After first

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encounters, maintaining relationships and developing consistency was thought to be beneficial.

**“I’ve learned to cope with talking to other people with a... and I actually met somebody there that I’m quite close to – my girlfriend, she’s helped me a lot too... and talking to somebody about things so you don’t feel so isolated, you ken?”**

Many narrators are being supported to engage in meaningful activity, access and participate in the delivery of voluntary services, and actively engage in the workplace helping them to recover or live better with their illness. Findings from this study and others have shown that individuals require different levels and types of engagement at different stages of their recovery, and that the purpose or outcome of this engagement needs to be meaningful.

# Engagement Discussion

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The description of recovery detailed within this research does not require an absence or remission of symptoms, nor does it constitute a return to 'normal' functioning. Rather, narrators have drawn a picture of a whole person for whom mental health problems are just one aspect of their life.

# Engagement Discussion

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Similar to the view of recovery detailed by Davidson *et al* (2005), our narrators referred to overcoming the effects of being an individual with mental health problems including isolation, unemployment, loss of valued social roles and identity, loss of sense of self and purpose in life, and the desire to have the full rights of anyone in society – to include belonging, and the right to engage with choice and self determination.

The qualitative findings from this study, along with others such as Marwaha and Johnson (2004), have strongly suggested that engaging in social activity appears to correlate positively with increased self-esteem, finding meaning and purpose in life, and being more satisfied.

## The importance of engagement

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For our narrators, engagement was about feeling empowered by their own actions. It was about finding meaning and purpose in life through everyday social or work activities, but it was also about being valued, fitting in and feeling ‘normal.’ These feelings reflect expectations in wider society.

Supporting the findings of Secker and Gelling (2006) and NIHME (2005), reducing stigma and discrimination, increasing employment prospects, education and training opportunities and access to leisure, culture, recreation were all factors that our narrators found to be important to their recovery.

Ensuring that individuals are enabled to participate and engage in society with all the same rights, responsibilities and expectations of any citizen remain key challenges. Henderson and McCollam (2000) suggested that employment for people with mental health problems has been largely overlooked in public policy because of the complexities involved in addressing an arena of policy which crosses a number of policy areas. These issues are currently being tackled in UK and Scottish policy (Scottish Executive, 2003b). The current UK government’s strategy, Welfare to Work, has been described as “*work for those who can, security for those who cannot*” (Department of Social Security, 1998). Through promoting these welfare programmes, the Government is promoting employment as an effective way to reduce poverty and promote inclusion, both in the short and the long term.

However, it is telling that people with mental health problems continue to report difficulties in finding or retaining work or other forms of meaningful activity despite the recognition in policy that such opportunities are important.

## Meaningful activity

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The merits of being meaningfully engaged cannot be understated as our findings have shown. However these findings are not new for Scotland. The Highland User Group (2006c) found that having meaningful things to do can be a great help to an individual’s recovery. They proposed that activity not only gave individuals an occupation and distraction, but if it is also valued by other people, it can make a big difference to social integration and personal confidence.

Whilst much should be done to ensure there is equal opportunity to access work without stigma or discrimination, some organisations such as the Highland User Group (2006a,



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2006b) have emphasised and reminded us that the current welfare system remains a vital way to provide for people who cannot participate in paid economic activity.

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## Diversity of opportunities to engage

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Most of our major findings regarding engagement are not new. Social psychiatry, rehabilitation and occupational therapy have long explored the value of meaningful activity and have found it to be a positive coping strategy or therapy for individuals, especially where meaning and purpose could be found. What is particularly interesting from our narratives is the diversity of ways in which individuals manage to meet apparently innate human needs for social connectedness and meaning, and the need to reciprocate and contribute and being valued.

Whether people with mental health problems want to maintain their employment and relationship with the workplace, take time out and then re-engage in stages, move to a less structured working pattern or choose not to work at all, it is important that they are supported. Findings have shown that people have very different needs and aspirations and, as such, need flexible, responsive employers, employment rights, support services and benefit systems that do not undermine their efforts or confidence.

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## Flexibility and doing things differently

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Several narrators described the importance of non-conventional patterns of working. Part time and flexible working, volunteering, learning, creative and leisure activities and taking time out from work were described as helpful approaches. Whilst some people invest in their identity as a worker others found their recovery embraced freedom from the constraints of paid employment.

Highland User Group have iterated that *“if only the demands of the workplace could reflect an awareness of the differing needs of people with a mental illness then employment would become more likely and the benefits system used less”* (2006a).

These factors are clearly echoed in our narrators' desire for flexible working patterns to be introduced by employers and adhered to without fear of shame from colleagues. The tensions prevalent in a working environment where other employees disapprove of flexible working (or time off due to ill health) could be addressed through better training for managers around the issues and implications of having a mental health problem. The supports that people with mental health problems state they value in the work place are closely aligned with a workplace culture which promotes the mental health and wellbeing of the whole workforce.

The Scottish Development Centre for Mental Health, in their findings from a large-scale research project which aimed to understand mental health at work from the perspective of employees, proposed that *“actions to improve mental health and wellbeing at work are inextricably linked to actions to support and retain people with mental health problems in work”* (Scottish Development Centre for Mental Health, 2003).

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## Volunteering

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Voluntary work like other forms of engagement can form a role in social and vocational functioning and the integration of the individual into the community according to Ruggeri *et al* (2005) and Young (2004). Evidence from the current study suggests that it does much more

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than this, allowing individuals to regain a valued role or identity for self and creating a sense of self worth and fulfilment.

Volunteering was found to encourage the ‘social self’ to engage and allowed society to value the contribution individuals made of their time and experience. It offered the opportunity for people to contribute, to give back and, in particular, give meaning to their mental health experience (particularly in the case of mental health service voluntary work). Whether people use it to pace their journey back into employment, or as an alternative means of worthwhile engagement, the impact volunteering has on identity as a contributor, not a ‘user’, and the positive perceptions society has of volunteers cannot be underestimated. The aspects that make volunteering a viable option for people should be explored with consideration to making work places more mental health friendly.

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## Challenges for Service Users

Data from the 2001 UK Labour Force Survey show that 628,000 adults of working age in Great Britain regard mental illness as their main disability (Social Exclusion Unit, 2003, March, 2004). Sourcing information from the same labour force survey, Smith and Twomey (2002, p. 421) found that people with mental illness, learning difficulties or psychological impairments are less likely to be found in employment than people with physical impairments, having an employment rate of 18.4 per cent overall – the lowest rate for any group with disabilities.

Corroborating findings from Secker *et al* (2001), these narratives have shown that, although employment is not appropriate for everyone and indeed not everyone wants to work, many people who are in recovery from mental health problems have very real ambitions to become engaged in meaningful economic activity. Aspirations to do well at work were mentioned often.

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## Challenges for employers

There is a tension for people with mental health problems in the workplace. On the one hand they may need their employers and colleagues to be aware of and to accommodate their health needs, on the other, the level of stigma and ignorance in the work place was sometimes found to make it difficult for individuals to disclose issues.

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## Awareness raising

A lack of awareness and confusion amongst employers about the nature of mental health problems has exacerbated discriminatory recruitment and employment practice in the workplace (Bunt *et al.*, 2001a). Education and awareness programmes (e.g.: ‘see.me’ workplace anti-stigma campaign Scotland) for employers and employees about how mental health problems can manifest and be managed in the work place would increase the likelihood of suitable support and would facilitate sustained employment, reduced stigma, and promote better prevention and identification of problems. These efforts should go hand-in-hand with work to promote recovery.

Further effort needs to be invested in ensuring access to information about employment rights, benefit rights and support services. Findings seem to indicate that return to work and supported employment and other less structured approaches should be designed around

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individual needs taking into account their:

- Purpose.
- Objective.
- Contribution (to family, others, community).
- Structure and routine.
- Pace and need for flexibility.
- Support needs.
- Benefit situation.
- Employer's awareness and capacity.
- Colleague's awareness and capacity.

Where individuals no longer see regular employment as an option, but want to find another form of purposeful activity, services, benefits agencies and employers (where possible) should consider how best to support this creatively. For example, where people want to utilise the opportunity of therapeutic earnings to make a transition from benefits to self-employment they will require creative strategies that enable them to establish a business whilst keeping a 'quick response' benefits safety net in place in case of a period of illness.

Narrators described the importance of peer support and our findings support SRN's efforts to promote the development of a new type of peer specialist worker to complement the existing range of mental health services.

## The welfare system

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As people with mental health problems have the highest rate of unemployment among disabled people in the UK (Social Exclusion Unit, 2004), it is important not to overlook the issue of benefit entitlement, and fear of poverty traps that potentially act as barriers to seeking paid employment.

As a result of continued lobbying by mental health and other pressure groups, several developments in UK welfare policy have sought to improve the financial incentive for individuals to engage in paid employment (such as the rolling out of 'return to work credit' payable for twelve months to individuals returning to work and earning less than £15,000 a year (Scottish Association for Mental Health, 2006). From October 2006 people who return to work from incapacity benefits will be able to return to their previous benefits if they become ill again within two years).

As benefit rules are currently changing the authors of this report would advise people to always seek up-to-date comprehensive advice from a welfare rights specialist to help make the informed choice over whether it is financially viable to work. For a fuller discussion and for more information on applied welfare and income maintenance legislation, we suggest that you contact 'www.rightsnet.org.uk' or 'www.samh.org.uk'.

## The right balance

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Jobs with low control and high demand and with an imbalance between effort and reward tend to be damaging to mental health. This has been evidenced by our findings and by other workplace studies (Bartley *et al.*, 2003; Health Scotland, 2006). Finding the right work life balance and ensuring that you are in the right type of work/activity with the right level of responsibility was important to maintaining narrators' wellbeing. Evidence already exists to

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suggest that being in a poor quality or unsatisfying job may be worse for your mental health than being unemployed (Health Scotland, 2006) and this appears to be in line with what the narrative accounts are telling us.

## Educational opportunities

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In a learning environment, Feinstein *et al.*, (2003) argues that simply mixing or engaging with others in a supportive context where objectives are shared and discussion and co-operation encouraged, contributes to the wellbeing of individuals who are otherwise relatively isolated. Additional research from the Centre for Research on the Wider Benefits of Learning suggests that learning can improve health through improving human capital (knowledge and skills), social capital (trust and interdependency), and identity (according to Health Scotland, 2006).

Overall, engaging in educational opportunities was found to be an exhilarating and challenging experience to those who undertook it. It provided a focus for external energies and helped individuals participate in social exchange in much the same way as working, volunteering and other forms of engagement. These positive social exchanges were appreciated by many on their recovery journeys. Although our narrators' experiences of educational engagement were overwhelmingly positive, Wilson *et al* (2006) has identified key areas for improving the ways in which tertiary education can be more sympathetic to student mental health needs. The Scottish Further Education Unit is also seeking to enhance awareness and understanding of mental health in the education sector.

## Socialisation

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Social re-engagement or the maintenance of social engagement is an important aspect of recovery. Narrators, similar to others, have found a variety of ways to do this depending on their sense of purpose. Being able to link experience of mental ill health and recovery with creativity has been fruitful.

For some, it was crucial that they had a sense of self beyond the confines of their mental health and sought to re-engage in mainstream activities that gave them a sense of purpose and achievement. Others only felt safe and able to really engage with people who had similar experiences. It is important that consideration should be given to this need in work on social inclusion.

## Community

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The Social Exclusion Unit is in the process of investigating how to reduce social exclusion among adults with mental health needs. It is considering how to improve rates of employment through support in retraining and taking up work. It will also consider how to promote social participation and access to a broad spectrum of services in the community.

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## Conclusion

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Narratives have shown that individuals are keen to be fully involved members of society and that they have a strong motivation and drive to find structure, purpose and meaning in their lives. Although this is a common human need, it is one which perhaps assumes particular importance for recovery. Institutions and services can assist or impede this drive. Individuals want to be supported in their attempts to access and retain paid and voluntary employment, education and training, and membership of social and community groups or networks. They want barriers to these objectives to be removed and for stigma, discrimination and inequality to be challenged. They also want the right to choose not to engage if they so wish as it may negatively affect their recovery. They want to be defined by what they do (volunteer) not by what they don't do (unemployed) or by their health status. Some people want to use their mental health experiences positively, to let it inform their work and their life, others want to be able to put it in a box and to leave it there without fear of others dredging it up in a professional or personal setting. Individuals want mental health in a working environment to be their own business (if they so desire), and for it to be supported by employers, not discriminated against (should they choose to disclose it). It is an experience like any other from which you can learn... you should value it.

For our narrators, engagement was about feeling empowered by your own actions. It was about finding meaning and purpose in life through everyday social or work activities, but it was also about being valued, being accepted and feeling 'normal.' These things reflect the expectations that are held by many. Being valued for our contributions requires that others are complicit in our recovery. To that end employers, co-workers and those with whom we engage formally or informally can help further recovery journeys.

# Relationships Summary

Interpersonal relationships are important factors for mental and physical health. We know that the quality and meaning of relationships is closely correlated with our mental health. Also, our mental health can affect how we view and experience relationships with other people. Patterns of relationships and their meaning to us are likely to change over our life course. When young, relationships with peers tend to be of primary importance whilst at other stages in life work colleagues and family feature more prominently as sources of emotional and practical support. Throughout our lifetime the individuals we develop relationships with can have an immense impact on our character and wellbeing.

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# Relationships Summary

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**This chapter will attempt to explore different aspects of relationships to reveal how they can impact on mental health recovery. We begin by drawing reference to issues raised in other literature which explore different aspects of mental health recovery, quality of life and relationships. Proceeding to the main findings we highlight the impact of supportive and negative relationships as discussed by our narrators who identified relationships with family, friends, peers, community, pets and service professionals as factors that could potentially influence recovery prognosis.**

Overarching elements of positive relationships seemed to be that they were based on trust and willingness (as opposed to obligation) and were supportive, understanding, consistent, reciprocal and mutually beneficial. Social interactions entailed costs as well as benefits. Negatively perceived relationships occurred in situations where individuals felt that they were not being listened to or were experiencing stigma, excess criticism or emotional detachment.

To close we will look at policy implications and different ways of nurturing and promoting positive relationships to support recovery journeys. Working relationships and spiritual relationships are discussed in previous chapters on engagement and identity.

# Developing Relationships

**When we address the topic of social networks and social relationships we are talking about the interpersonal relationships and informal (and formal) support and company that people can call upon on any given day.**

Much has been written in therapy literature (Clarkson, 1995; Paley & Lawton, 2001) about the importance of developing positive therapeutic relationships with clients. Also, within the field of community development, relationships of mutual support have been viewed as an important source of social capital that can be empowering, both in supporting individuals and in facilitating change. The work of Brown, Bhroichain and Harris in the 1970s drew attention to the importance of close confiding relationships as a protective factor for women at risk of depression. Other researchers (Graham & King, 2005) have recognised that the foundations for good mental health are laid in early childhood where young infants and children have the opportunity to develop strong attachment relationships.

During periods of ill health people with mental health problems can become very isolated. Indeed, ill health often interrelates in complex ways with relationships. This report aims to identify the types of relationships that promote recovery and the ways in which these relationships are supportive of recovery.

Relationships for individuals in recovery from mental health problems span the diverse range of social contacts that anyone may encounter over a lifetime, but particular relationships can be crucial to developing positive images of self and for feeling loved, needed, valued and supported. These positive and meaningful relationships with significant others most helped individuals on their recovery journeys.

## Types of relationships

The Centre for Mental Health Services (2004) recognised that “*peers, families, friends, providers, and others*” can help to foster hope to provide a catalyst for recovery. Calsyn *et al* (1998) differentiated between different types of relationships and support networks to categorise them by those who provided emotional support; who gave advice; who provided materials; and people with whom one socialised. Others have divided relationships into dependent or reciprocal relationships or by size of social networks. What is important is that the positive elements of each type of relationship are highlighted and acknowledged for their part in fuelling and supporting recovery journeys.

## Isolation

The topic of social inclusion has been investigated by researchers who have overwhelmingly concluded that mental health service users are more likely to feel isolated and are less likely to live with or be in a loving relationship with a significant other than the general population. Singleton *et al* (2000) in a survey for the Office for National Statistics found that people who were suffering from any type of psychotic disorder were over three times more likely to be separated or divorced than those without a disorder (29% compared to 8%) and were over twice as likely to live alone (43% compared with 16%).

Similarly, Berzins (2007) in her study of relationships and social inclusion for mental health service users found that service users were four times more likely to live alone and were more than twice as likely to be single than the general population. In addition to this more than half of service user respondents were classed as having poor social support compared to less than



10% of the general population sample. This corroborates findings from Dunn (1999), who, in a report for Mind, suggested that service users were four times less likely to have someone to talk over their problems with than the general population.

In a qualitative study of social relationships of service users, Green *et al* (2002) found that loneliness was reported to be a problem, reasoning that mental health problems had led to changes in network composition and lack of balance in relationships for their respondents. They also found that social contacts were reported to be both protective and potentially damaging to mental health.

Impairments in social functioning have often been seen as a characteristic of severe mental illness (Goldberg *et al.*, 2003). Indeed, the loss of social relationships and friendships in particular have permeated the narrative accounts of people with mental health problems (Boydell *et al.*, 2002), and the resulting isolation has been at least as difficult to cope with as the disability itself.

Quality of social networks in terms of size and intimacy of relationships can be important. Several studies have paralleled the findings of Hintikka *et al* (2000), who, in a population study into mental wellbeing found that the number of close friends was inversely associated with the risk of mental distress in men (suggesting that small social networks are associated with poor mental health in men). For women insufficient family support was associated with mental distress.

## Reciprocal relationships

Engaging in reciprocally supportive relationships was the single most important predictor of recovery in Pernice-Duca's analysis of social network profiles (2006). Similarly, Boydell *et al* (2002) highlighted the benefits of reciprocal relationships in fuelling wellbeing, but they also found that relationships consist of the need for separateness as well as connection. Whilst a degree of isolation can be good, individuals often need to find a balance between engagement with other people and having personal space in their lives.

Findings from our previous chapter on engagement highlight the positive influence work and meaningful activity can have in developing supportive relationships and as a route for people to find the opportunity to contribute and to have a valued role.

## 'Be there', consistent and hopeful

The most valuable support friends can provide is often emotional support, being available to talk and listen and keeping in touch (Mental Health Foundation, 2007b; Topor *et al.*, 2006). Topor *et al* (2006) identified that relationships have a tremendous impact on how people recover from schizophrenia. They highlight that it is important for people in recovery to feel as if they are supported and cared for and identify 'being there' and available as a factor within friendships that seemed to help people in recovery. For professionals or caregivers, to go the extra step, to take a risk, to reach out and make a connection and 'be there' was important.

Torpor *et al* (2006) also reported that where ill health occurs, an individual's social network gets smaller with old friends being replaced by new friends and professionals met within the mental health sector. They argued that it was important for family and friends where possible to provide continuity for the person, and to actively promote recovery by offering messages of hope.

## Quality, size and composition

Yanos *et al* (2001) found that supportive social interactions can play an important role in people's recovery (quality of life) from an episode of mental ill-health. Larger social networks were also found to improve quality of life (Corrigan & Buican, 1995; Corrigan & Phelan, 2004). However, where social interaction was felt to be negative or stigmatising adverse impacts on quality of life or recovery were found to occur (Yanos *et al.*, 2001).

Perhaps the most consistent finding of research on the social networks, social capital or relationships of individuals with mental health problems is that those with more severe forms of mental illness have smaller social networks than others (Corrigan & Phelan, 2004; Furukawa *et al.*, 1999; Goldberg *et al.*, 2003). Various authors have linked social network size and composition to quality of life, decreased symptoms and ability to cope (Cannuscio *et al.*, 2004).

Some have argued that larger networks increase subjective perceptions of satisfaction with quality of life and having hope for recovery (Corrigan & Buican, 1995; Corrigan & Phelan, 2004; Goldberg *et al.*, 2003), however other researchers such as Becker *et al* (1998) have argued that network saturation can occur and that once networks become too big (ten to twelve people) positive quality of life ratings begin to diminish. In the main, however, literature suggests high levels of supportive relationships result in lower levels of depression and are also closely related to good mental health and the capacity to get through life and deal with adversity when it arises.

Another consistent finding around social networks and relationships of people with mental health problems or in recovery from such problems is that more seriously ill individuals have more professionals in their social networks than do individuals with less serious illness (Calsyn *et al.*, 1998) and they more often have a high concentration of mental health peers in their social networks. There have been positive and negative elements to this network composition. Recently, peer support literature has gained favour in professional texts suggesting the benefits of a peer saturated social network (empathy, understanding, support, experiential learning) outweigh the costs (illness-bound relationships).

## Friendships

According to Taylor *et al* (1984) *"Friends can be good medicine for those who are anxious or depressed."*

The importance of friendships for people with, or recovering from mental health problems was highlighted by a special edition of The Journal of the National Alliance for the Mentally Ill, California (v.5, iss.2, 1994) and by the UK Mental Health Foundation in 2007, who used their mental health action week (8–14 April 2007) to focus on the importance of friendships in promoting wellbeing (Mental Health Foundation, 2007a).

Whilst friendship may be important for good mental health, the reverse, good mental health,

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has also been found to be a mitigating factor in developing and maintaining friendships (Boydell *et al.*, 2002).

It can often be difficult for people with mental health problems to maintain their friendships according to new research revealed by the Mental Health Foundation (2007b). Having no friends in a culture that values friendship is a cause for concern. Indeed, it could be interpreted by others as a symptom of personal inadequacy according to Solano (1986).

Other literature identifies the positive effect that having friends can have, but also recognises that having a deficit of positive relationships and social networks can have a detrimental effect on health and can detract considerably from quality of life (Boydell *et al.*, 2002; Goldberg *et al.*, 2003), a factor that many people in recovery may have to address.

## Family

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Lefley (1998) found that in the US, approximately 40 to 70 per cent of people with severe mental illness live with relatives. Individuals with mental health problems or in recovery from such problems have often been found to have relatively more family members than friends in their social circle, and in the main have relationships with other people in the same position (Mental Health Foundation, 2007b; Noordsy *et al.*, 2002).

These findings could be interpreted positively as several other studies have demonstrated that supportive family relationships can help wellbeing and recovery. However, caution should be observed when assessing or comparing this mainly US based literature as family patterns are culturally specific. Also housing issues will be heavily influenced by availability of alternative living options for people who need some level of support.

Nasser & Overholser (2005) speculated that supportive relationships with friends could be more effective at promoting wellbeing and reducing depression than could relations with family because depressed individuals may believe that family feel obliged to maintain relationships and support for them. Friends, however, remain and support individuals out of love. Furthermore, they suggest that family conflict may have been associated with the onset of symptoms therefore dense family centred networks may not be good for wellbeing.

## Intimacy

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The economics of wellbeing draws upon robust evidence that the structure and quality of social relations are fundamental to wellbeing (Friedli, 2005).

Some studies have identified the presence of a confiding relationship to be highly correlated to maintaining wellbeing and reducing depression (Brown *et al.*, 1975; Miller & Ingham, 1976). Roy (1978) found evidence for a protecting effect of confiding marital relationships in his study on depressed women, and Miller and Ingham (1976) drew similar findings to Brown *et al.* (1975) in showing that women reporting the lack of an intimate confidant had psychological symptoms of significantly greater severity than those reported by their more adequately supported counterparts.

Individuals often reported a desire to have more intimate relationships. Indeed, intimate relationships have been frequently identified by individuals as a benchmark of recovery that they hoped to attain.

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## Enduring Partnerships

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Throughout various studies individuals consistently say how important other people can be in helping them to deal with mental health problems. Yet many service users are socially isolated and lack informal relationships, let alone more intimate confiding relationships – a lack of which can adversely impact wellbeing (Brown *et al.*, 1975; Miller & Ingham, 1976). Having positive confiding relationships and friendships has been identified as being beneficial to our mental health and wellbeing and often play a crucial part in maintaining mental wellbeing and helping manage emotional or mental distress. They include sexual partnerships as well as wider relationships with family and friends.

Similar to Roy (1978), Beach *et al* (1986) argued that the quality of intimate relationships could impact on recovery and the frequency of positive social contact with adults other than the spouse were significantly related to depressive symptomology for both men and women.

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## Parenting

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A much overlooked area of relationship research in the field of mental health and recovery is that of parenting. Although parenting can be considered a normal life role for many individuals with mental health problems, scant research that focuses on the positive elements of parenting exist.

Tunnard (2004) explored the impact a parent with mental health problems could have on children and others within the family and argued that for relationships to be successful family members – parents as well as children – need to have their fears allayed (usually in regard to forcible removal of children). They need to have access to information, specialist services, consistent and continuous support, and the same life chances and opportunities as other parents and children. Blanch *et al* (1994) found that parents with mental health problems believe that not being able to parent their children compromises their wellbeing. Interestingly, several studies have indicated that increasing contacts with children and close friends were associated with a decline in symptoms (Zunzunegui *et al.*, 2001).

Olsen and Clarke (2003) describe how parents with physical and mental health problems encounter disability in terms of physical and attitudinal barriers. They also highlight that changes over the course of parenting can interplay between disability and other social factors, requiring flexible support.

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## Peers as friends

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A sense of secure relatedness has often been found amongst peers in the mental health field where people describe having a core of active, connected, mutually supportive relationships. Boydell *et al* (2002) spoke of an enhanced level of understanding, support and acceptance that peers brought to each other and that this alleviated alienation and loneliness.

Many individuals have made peer friends through services (K. Berzins, 2007). However, a strong desire to develop relationships with individuals unaffiliated with the mental health system is frequently identified in studies (Boydell *et al.*, 2002). Occasionally, it has been reported that association with peers with psychiatric illness has been found to be stigmatising and caused individuals to feel ghettoized as part of this group.

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## Community

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Relationships of mutual support within communities have been viewed as an important source of social capital that can be empowering, both in supporting individuals and in facilitating change (Connor, 2004). Parr *et al* (2004) in a study that looked at the social geographies of mental health, questioned whether relationships within rural communities can simultaneously provide support, reducing vulnerability to depression whilst increasing susceptibility to anxiety due to the close social proximity of rural or close-knit communities.

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## Social connectedness and professionals

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According to Noordsy *et al* (2002) individuals with severe mental illness commonly find that their primary relationships are restricted to those with whom they have a professional relationship or other consumers of mental health services. Berzins (2007) found that mental health professionals were fulfilling the role of confidant for over a third of the 88 per cent of her service user respondents who indicated that they had a confidant.

Although having good supportive relationships with professionals is thought to be beneficial, several researchers argued that these relationships should be balanced by other relationships outside the mental health field. Indeed, Corrigan & Phelan (2004) have suggested that people with more professionals in their support system were more likely to be depressed.

Indicating the importance of the therapeutic relationship Norcross (2002) in a review of 1000 control studies recognised that the relationship between therapist and client is an element that can account for the largest variance of outcome that is not attributable to pre-existing client characteristics.

Helpful relationships with health care professionals comprise a re-orientation of what being a professional means according to Borg & Kristiansen (2004), that is, to develop a dedicated and mutual relationship with individuals and to work collaboratively on treatment plans, to have a genuine interest in, understanding of, and empathy for people's situations and listen to individuals offering them hope as well as support.

The desire for professionals to relate to people on a human basis rather than a professional one is echoed in numerous studies (Borg & Kristiansen, 2004; Alain Topor *et al.*, 2006). Professionals who project messages of hope have been found to help clients (S. M. Adams & Partee, 1998; Kirkpatrick *et al.*, 2001). Most have found that for professional relationships to work both service user and provider must actively participate in the relationship and have something to give that is valued. Within clinical relationships "understanding is the intervention" according to Kirkpatrick *et al* (1995).

In a person-centred environment relationships with service providers should be collaborative, empathic, respectful, trusting, understanding, hopeful, encouraging, and empowering according to Adams and Grieder (2005), and Grieder (2006).

It is evident that relationships are normatively experienced and are shaped by living in a particular time, culture and place. Although literature would suggest that having some form of socialisation in your life is beneficial, and cultural expectations about family, friendships and intimate relationships often support this view, there are no prescribed types or numbers of relationships we need to be mentally healthy.

# Relationships Findings

**The purpose of this chapter is to explore how relationships, friendships and social networks impact on recovery through an examination of narratives offered by individuals who are in recovery from mental health problems. There are a number of findings discussed in this chapter that can positively or negatively influence an individual's recovery.**

During periods of ill health people with mental health problems can become very isolated. Indeed, ill health had interacted in complex ways with narrators' relationships. Narrators indicated that maintaining relationships and staying connected socially was an important part of recovery. The loss of connectedness mentally, emotionally and socially during periods of mental ill health and the parallel desire to re-engage with humanity was a strong theme throughout the narratives.

In this chapter individuals describe the role friends, families, partners, peers, the community, religious communities and work colleagues have on their recovery journey and several others describe the role of pets in establishing a reason to 'be' and to recover. The role service providers have in developing positive relationships with service users will be touched upon but will be further explored in subsequent chapters which look in more depth at supports and treatments and their role and impact on recovery.

Together, findings emphasise the importance of service user informed studies in mental health recovery research and provide a starting point for a dialogue regarding the issue of relationships and social networks and their importance to recovery and wellbeing.

## Special friendships

Many narrators mentioned having one or two special friends that they could talk to regularly, freely, intimately and emotionally. They often identified these friends as the people who pick up on the nuances of their behaviour and who know when they are not well or feeling low. These friends were people who could reassure them when things get out of proportion, who didn't judge them, and who believed in them.

These types of friendships were often based on long term relationships, shared histories and similar value systems, and the maintenance of these relationships (where available) has proven invaluable to individuals' recovery journeys.

**"... It was difficult, the social aspects of life had just gone. I had to build up to being comfortable around people, comfortable in a pub and my friend totally understood. She would keep an eye on me and be there for me when I was panicky, and just having somebody with me there reassuring me."**

**"My partner and other friend... she now knows the days where I am not well, she doesn't say anything to me, now she can see it in my eyes but she'll not say anything. So I'll find she will ring me an extra time at night or something. It's not always something we will talk about, it might not be something you and I would talk about, but you would know, I would know you would know."**

**"(The most valuable thing in recovery is)... other people, other people, and... being more open... People come in and seeking you out and making sure you are all right, people recognising the symptoms in you before you are recognising them yourself (and) not going away, sometimes when you've had enough... Not running away."**

Developing and maintaining these positive relationships often necessitated that individuals take the risk of opening up to others about their situation, asking them to see past the illness and to engage with them as a person, whilst still understanding the challenges they face as a consequence of their mental health problems. This self-exposure provided many narrators with a greater sense of self-awareness and when positively received, provided them with more confidence about their own self-worth and worthiness as a friend.

## Losing old friends and making new friends

Over extended periods being unwell had disrupted the lives of many narrators causing some friendships to break down and making it difficult to maintain other friendships. Several narrators shared concerns about having lost or having limited friends, and felt quite isolated and lonely.

**“I literally haven’t seen anybody since I went off work.”**

**“I didn’t mix in at all very well... I didn’t seem to be able to build relationships at all and it was like my worst fears had been realised.”**

Friendships and relationships for some individuals became narrower as friends lost contact and moved on with their lives. Some people articulated their anxiety about having lost the skills and confidence to make and maintain friendships and feared that they wouldn’t live up to the perceived expectations of others.

**“A lot of people my age are already married and have kids... and I’m sort of... struggling with things they have probably already dealt with and moved on from.”**

The making and maintaining of friendships was a priority for many narrators who often identified it as an indicator of their recovery. Individuals set out proactively to re-engage socially, constructing new networks and building stronger personal reciprocal relationships, pacing themselves, but being proactive in phoning and keeping in touch with remaining and new friends.

**“(Of things that assisted recovery)... seeing friends more. Trying to build up friendships again. Make new friendships. Uhm... yeah I mean, yeah, and I am still doing that, I am still working at... making closer relationships with people. Cause I got very, very shut off for, you know, for a long time I didn’t really kind of engage fully I suppose with, with other people, or with a lot of what I was doing.”**

Whilst close personal relationships and social networks appear to be important sources of positive support, some individuals recognised that they can also have a negative impact, particularly where their old friendships or networks linked them to bad habits or exploited them. In contrast to this desire to maintain and nurture old relationships, some narrators associated recovery with having the strength to walk away from less supportive relationships. Knowing when to disengage with negative relationships and social networks was very important.

**“I am on my own. When I look back now I really don’t know how I managed... Uhm, they say they can cope with you and then over time they can’t. They don’t understand or they are not as tolerant as they used to be and they get sick of it... and then you are even further back than square one... and my husband was drinking and lifting his hands and I was trying to be all smiley at work and just be normal, you know.”**



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**“I don’t want to go back (I have to go home there’s no other place to go) and fall into what was so familiar. That is the danger and that’s where I would be needing support workers.”**

## Supportive and accepting friends

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Friends who are consistent and constant, who are not judgemental, who are accepting, embracing and actively try to be inclusive have been instrumental in giving people an anchor, especially during more trying times. Of utmost value were friends that did not impose any expectations upon narrators, but equally did not underestimate their capacity to give (as well as take). Friends that did not expect narrators to conform or participate, but still included them assisted in maintaining narrators’ sense of self worth and identity.

**“I was always outgoing so I never had any problems making friends but, ehh, I’m just choosing my friends carefully now... I’m learning to open up to them more often and not feel like stigma with my illness and they seem to be accepting me as they see myself as what I am, you know, they see inside me, you know...”**

**“My friends still invite me to some things that I would go to... I was, what I would refer to as, ‘the wallpaper,’ but... I wasn’t put down because I was didn’t make the effort to socialise... I may not have contributed (to the chatting) but I was getting a level of stimulation that was still working inside my head... It was a bit of social interaction that I was grateful for, and allowed me to maintain friendships over some very difficult times. But they’re the ones who sustained me - I mean they didn’t drop me because my life got so difficult or I was an embarrassment to have around.”**

**“I think that recovery also has meant that I’ve actually met people who, em, who I regard as being true people... who respect me for who I am, not because I’m (a) service user, or I’m a mentally ill patient, they actually respect me for being (NAME), warts and all!”**

The role of friends in maintaining wellbeing cannot be underestimated. They have offered emotional and instrumental support to individuals, providing practical support and reassurance, listening, offering information and suggesting alternatives, helping with practical tasks like shopping and encouraging people to stay socially engaged. In this respect, the role of friends in maintaining the wellbeing of those in recovery appears to be no different from the role of friends in maintaining the wellbeing of the general population. On multiple occasions friends offered a safety net and advice when people didn’t get the support they needed from services or found themselves in trouble.

**“(I) left hospital because I insisted I was better, you know, and I spent that night sitting in that flat in the dark terrified to put the light on in case anyone knew I was there, terrified to make a noise just sitting in this chair, staring out the window on the other side of the room, and then I phoned my friend the next day and said ‘can you come and get me because I can’t stay here’, so then I stayed with a friend in (TOWN) for about five or six weeks.”**

**“Valuing your friendships and things like that... I don’t know if I’d have recovered had my friend not taken me to the Social Work Department because nothing was happening, nothing was changing.”**



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## Supportive family relationships

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The stigma of having a mental health problem often left narrators self-conscious and wary of developing new relationships or getting to know others in their community. The negative identity that people developed as a consequence of stigma (or anticipated stigma) often left them with a feeling of unworthiness and a fear of being rejected by others. Whilst some people had friends and family to confide in and talk to about their mental health, others found that friends and family avoided the issue. Indeed, some narrators felt that they avoided *them* altogether.

A majority of narrators described supportive families that stuck by them during adversity. Family life and interaction were recognised to be stabilising factors giving individuals a sense of purpose and belonging - a reason to keep going. Family offered sustenance, retreat, protection, care, sympathy, understanding and help during difficulties. They would often notice when individuals became withdrawn and would encourage them to speak up offering a safe and familiar space to allow individuals to stay engaged with the world.

**“My own family nursed me through hell... And the help of my mother through the years. When I’m cutting my throat, she’s there bathing the wounds.”**

Yet again, this support was generously given and warmly appreciated, especially where individuals felt that the support was mutual and that they were not treated as dependents within this relationship.

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## Family, awareness, and understanding

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Having family members who displayed an active interest in their mental health was appreciated by many narrators. Such information, support and interest usually involved the family member being informed and aware about narrators’ mental health and treatment and being prepared to intervene on their behalf if requested by the individual. Their awareness meant that they were not judgemental. They had often researched issues and provided a sounding board. They were open to discussion and offered a different perspective as well as emotional support and a sympathetic ear. Regular contact, awareness of early warning signs and their practical role in intervening on a person’s behalf through contacting services, engaging with support teams and acting as an advisor meant that positive family relationships provided reassurance to individuals.

**“My sister, (NAME), was particularly helpful because she contacted the advocacy service because at the time the doctor had been keen, because I was depressed – he felt I should get ECT, and my ex-partner knew I was against having ECT and things, so he’d said ‘Oh, (NAME) wrote this essay saying how much she hated ECT and she (wouldn’t) have it.’ And then advocacy got hold of that and talked to the nursing staff about it.”**

**“(Advice to other people would be) Also to involve family and friends as much as they can really, because they know you more than anybody and can see when you’re getting better - and can tell staff.”**

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## Having family with mental health problems

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In the main having other family members with mental health problems was described as problematic and often made recovery more difficult. However, for a few people having family with mental health problems meant that they had someone who they could relate to because they understood their situation.

Some individuals recognised that family relations may have been one of the factors that contributed to their mental health problems, and as such, dealing with problematic family histories was part of some recovery journeys.

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## Living up to expectations

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Whilst appreciating that their families had stood by them and that family was significant in their recovery, some people felt the expectations and pressure from their family to conform to *their* standards was not always helpful and devalued them. Consequently, many individuals described their relationship with family as problematic.

**“I was brought up in a family whereby, em, work was regarded as being very important... So it's taken a huge adjustment to not having a successful career... having to give up (occupation) just prior to qualifying, and having to be medically retired... just couldn't sustain the job.”**

**“My partner and I've got my dogs, I've got my friends, my friends are my family. I can choose my friends you see, I wouldn't choose my family.”**

**“My step-sister, when I was in hospital, wouldn't come to hospital to visit me, she says 'no disrespect but I cannot come into that hospital,' she wouldn't come into the ward.”**

Narrators implied that support services could perform better and listen more carefully when dealing with family issues and situations as there can be tensions from expectation, stigma, lack of understanding and problematic histories. They felt that this would better enable services to work with them to develop effective strategies that consider their family situation and better address their expectations.

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## Intimate relationships: partners

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Having meaningful, enduring and loving relationships with significant others were identified as key to helping sustain optimism and drive many recovery journeys. Over half of our narrators spoke about the role of their partners in their recovery while several others were explicit in their desire to have a partner to share their lives.

Supportive, understanding partners provided not only the love, care and attention that most people sought. Many narrators felt that their partners were instrumental in keeping them out of the psychiatric system and helping them to develop strategies to manage their mental state.

Both heterosexual and same sex partners provided much practical instrumental support in maintaining the home as a safe space, putting things into perspective. They also provided appraisal and support, ensuring their partner gets the services and support they need. They provided emotional support, being a confidant, reaffirming narrators' sense of self through

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believing in their abilities, not defining them by their illness and just being there, being loyal, and staying committed.

Where people have managed to sustain or develop intimate relationships they have provided an environment of trust and stability that affirmed the persons sense of worth.

**“Couldn’t do it without her. Not that I’d ever tell her that. She believes in me, it doesn’t matter what I say, what I do, she believes in me. Nobody (has) ever done that for me before. They always wanted to change me or change something... she just likes me the way I am, which is nice.”**

**“My wife gets fed up with me. Because I sometimes go out in the town and say I’ll be home at six o’clock. And then I’ll meet a friend and get into conversation and we go and play pool and I get home after midnight, you know, so... I think she’s a saint.”**

Partners were also identified as having a significant role in assisting people to ‘reframe’ their experiences and situation. Some partners played an active role as advocate, ensuring that their partner gets access to the services and support they need. Partners often understood the nuances of their loved ones’ mental state and could respond appropriately. Indeed, several narrators who discussed partners as part of their recovery implied that the stability of the relationship itself was an indicator of as well as a contributor to recovery. However, others found that their partners could hinder their recovery. For those narrators, ending these negative relationships formed part of their path to self-acceptance and wellbeing.

## Sex and Sexuality

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The few narrators that discussed sex noted that although sex could help mood, it was required to be in a relationship to have any impact on recovery per se.

**“I used to find I could put my mood up through sex (but it’s not a good recovery strategy)... because it’s all about relating isn’t it? It’s about being close to somebody.”**

Adjacent to this, coming out as a lesbian or gay person was noted as being instrumental in the recovery process for a few individuals.

**“(Talking about sexuality) ...Well I was never able to be honest about it. Because when I was young, remember, you went to jail, yeah... so I had that freedom in my later years which I didn’t have as a youth... Until I was able to be honest about that, that was a problem.”**

Other lesbian and gay people discussed finding difficulties in sharing their sexuality or personal relationships in group therapy sessions with their mental health peer group, with colleagues, with service professionals or with their families. This was due to numerous factors, including overt homophobia, their own undisclosed sexual preference, or a lack of support and understanding among their family and friends. In these instances, narrators found that not being able to be open about their sexual orientation put barriers in the way of developing truthful, meaningful relationships and furthering their recovery.

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## Desire for a meaningful personal relationship

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A sense of longing to find a partner and a desire to share life experiences left some individuals with feelings of loss or sadness at not having this experience. Several narrators confided a deep desire to engage in a loving relationship with someone. They hoped that this would provide them with fulfilment and to allow them to share the love they felt they had to give.

**“It’d be nice to meet someone, yeah... But I’m just getting myself together and that eh, it’s a bit hard and that. I’ve done 20 years but yeah, when I get it together... I think that I’d feel more relaxed or happier... Yeah, it’s not difficult to get a girlfriend sometimes, but really to meet someone, that you could be happy with... have something good.”**

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## Parenting: children as motivation

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Children’s acceptance and support was another area from which individuals drew strength. Indeed, where individuals looked after children for whom they had parental or guardian type responsibilities, they proved to be a considerable motivation for recovery. Narrators reported that just seeing them and being involved with them provided a sense of purpose and **“a clear role.”**

Individuals also described their fear about the potential impact of their mental health problems on these children. They describe the responsibility and desire to recover and **“do it for the children”** as driving factors in finding strategies to manage their states.

**“There are times most definitely and I know that to be a fact, most definitely, is that if it hadn’t of been for my son, I think I would have topped myself.”**

**“We were left with our grandchildren to bring up, but I think they kind of helped, they might have helped in a way although they maybe delayed the process because I had to sort of control myself, you know. I had to sort of say ‘well, you can’t be like this because you’ve got the girls to look after.’”**

This nurturing instinct and the need to function for others also came into play when individuals had relationships with sick relatives or other dependents such as pets that needed care or protection.

Several narrators were parents to young children and others were involved with their grandchildren regularly which meant that they have to function and be there for them to keep the relationship open and maintain a sense of worth.

**“I’ve got two children... so it is hard to shut down altogether, but I can work round it and sort of give myself a day off.”**

Having to be able to function because they are needed provided people with a purposeful framework for recovery.

The downside of having these responsibilities was that some narrators indicated that they suffered from enormous guilt about not being there at particular times for their children or being an embarrassment to them. Additionally, several people confided that they had avoided seeking help because they thought they would lose their children to Social Work Services if they were thought to be out of control.

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## Peers

It was often within peer relationships that individuals glimpsed recovery potential for the first time. Inspired by the experiences of other people that had recovered from mental ill health, people began to believe in the possibility of recovery for others and themselves.

**‘Actually it was one of the girls I know.... She went up ...and was telling her story and I realised that I wasn’t an isolated case that recovered, other people do.’**

Learning from other people’s experience allowed people to develop better coping and recovery strategies and helped them to realise they were not isolated in their experience. Such experiences were accessed through stories, therapeutic communities, peer support groups and victim support groups.

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## Security in like?

Some narrators discussed the loving relationships they shared with individuals who had mental health problems themselves. In most cases this was recognised as having advantages for recovery in that narrators had a better understanding of their partners’ experiences and of the challenges they face as a consequence of their shared experience. In some instances it meant that partners had a similar life pattern so could be with each other more and support each other through their recovery.

Shared friendships with individuals who had mental health problems were considered a positive experience for most narrators. People finding themselves isolated by their experience of mental health problems often sought friendships through, for example, clubhouses and through volunteering in the mental health sector. These friendships offered the opportunity of shared experience and understanding and provided many with the inspiration for recovery.

**“Most valuable (thing in recovery) has been... eh, company. Definitely, eh, meeting other people, sharing experiences with other people with mental health problems, listening to their side of the story and passing on your own side... so it really has been meeting people.”**

**“I would say been involved and meeting, meeting people, em, new people that have been in similar circumstances and just the, the camaraderie you know, it’s, it’s amazing. It’s like an understanding, and it’s a care, it’s a really caring environment. And I, I’d say that makes me feel better to be able to be involved in that.”**

People who were on a recovery journey drew a sense of worth from being involved in service user networks and projects, both as an inspiration to others (role models) and in helping people to start out on their own recovery journeys.

However, negative connotations associated with being a service user, being defined by their illness, having limited social networks outside of the mental health area were experienced and expressed by some individuals. Individuals who felt constricted by this narrow network often felt that it was holding them back and made them depressed. They did not want to be defined by their illness and needed a wider network of friends and social capital.

**“My GP sent me to (DAY CENTRE) to sit with a lot of people I couldn’t connect with. I had nothing in common with their problems. Didn’t even come close to the things I needed to talk about and needed to share.”**

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**“I’ve got a new social network which is mainly people with the same problems. I get a lot of support from them... they keep you away from the more chronic services because in a way, if you are going to get better then it is not a good idea to get sucked into mental health and spend all your time with unwell people... It would be better for me if I could branch out on my own and not rely so heavily on the user group.”**

Some narrators felt torn between their interest in engaging in the service user movement and being defined by their illness.

**“I don’t know if I want to be endlessly frustrated by going along to meetings or being seen as a service user all the time... There’s more to me than my mental health. And I’ve hated the fact that my mental health has meant I’ve lost my intelligence.”**

Whilst initially appearing negative, some narrators found that maintaining relative social isolation was a positive step in their recovery. This allowed them to set boundaries around the relationships they chose to develop, and it assisted them in feeling secure and controlling their environment. This deliberate isolation most often occurred where individuals tried to avoid or step outside of mental health networks within which they felt they had become ghettoized. This suggests that relationship ‘needs’ change over time and according to circumstances.

## Colleagues

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Working in a flexible environment with supportive colleagues was noted by several narrators as being helpful to their recovery. Having this support enabled some individuals to plan and implement staged returns to work after periods of ill health. In several cases, awareness and willingness to create a flexible, supportive environment came down to individual manager’s attitudes. Some individuals found supportive employment relationships by moving to work in the mental health sector where it was claimed that individuals (and organisations) have a better understanding of the needs and challenges of those in recovery.

**“In my own workplace I have at this point in time been able to negotiate some flexibility in my working week so that I can continue to attend counselling, and that’s like a sort of reasonable adjustment under the Disability Discrimination Act, it wasn’t that formal, but that was the basis of negotiation.”**

Another important issue with working relationships for narrators was that supportive colleagues kept in touch when narrators were off work, and provided humour and friendship when they returned. Keeping in touch let people feel valued as a colleague and friend. Where a paced return to work was accommodated by managers, it was sometimes less well accepted by other colleagues.

**“Some colleagues were really pleased to help and they would take my phone calls and deal with some issues with me because I didn’t have the confidence to deal with lots of complaints from members of the public and I found that very stressful. I said I’d be ready to do this soon. They were quite happy to help, but other colleagues resented it and couldn’t understand why I couldn’t do certain tasks.”**

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## Community and neighbours

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Sometimes recovery journeys were enhanced by the goodwill of others. Often simple friendly gestures like neighbours looking after an individual's home or garden while they were on holiday or in hospital were enough to help narrators feel secure in their environment and in their community relationships.

**“My neighbours are very good when I moved to my house I thought I'd better get out in the garden... once you get out in the garden the neighbours spoke and they're helpful. They'll watch out for your house and they're very friendly.”**

Other times stigma and assumptions about people with mental ill health left narrators feeling that their private lives were too exposed. Relationships with local community could be severely disrupted by the stigma and lack of understanding around mental health problems and hospitalisation. Uncomfortable community relations, especially in socially proximate communities sometimes led people to relocate to new areas – where people did not know their history – to expedite their recovery journeys. Bad neighbours as well as bad neighbourhoods which were perceived to be judgmental about hospitalisation and unemployment or were openly stigmatising mental illness hindered people's recovery progress.

**“When I lived there (in the bed-sit) I felt people in the other houses were all watching me. They knew I was in and out of hospital, unemployed and on my own, and I couldn't get out the place without them seeing me and where I was going.”**

One person, having moved because of abusive neighbours, described being accepted in their new community with a sense of wonder:

**“... It's actually been a complete change, it's, you know, I feel a part of the new community that I am in. It's like, I go to the local shops and people say 'Oh hello how are you?... how are you doing?... is this you in for your paper?' ...They just know me as a person. They don't know me as a person with a mental health problem!”**

The sense of loss found in not belonging in the community was felt particularly strongly by one narrator causing them to directly associate developing a positive relationship with the community with positive developments in their recovery.

**“(Of negative community relations) What you are and that seems to all be destroyed in a sense you know. It's like the end of the world in a sense. The negative side you know, sometimes your positives can just be as bad. That's what affects you, you know.”**

**“(Of re-engaging with community)... it's a bit of a relief when things start to come together and that again, but it takes a bit of time socially and that.”**

It is clear that people recognise being part of the community as an important aspect of their recovery and recognise that the stigma of mental ill health and community ignorance have hindered their recovery in the past. Feeling safe and building new relationships in a new environment meant having the opportunity to live life more fully and more confidently. Finding suitable housing away from victimisation gave people peace of mind so that they could steer more clearly towards their recovery journey. Moving on physically has helped some individuals move on philosophically in their journey.

Those narrators that have established their place in the community have mostly done so through communities of interest; being very open about their mental health and the recovery journey; and proactively engaging in activities that demonstrate and reaffirm their worth - 'giving back.'

Examples shared included relationships built upon a shared interest in sports or creative activities, sexual orientation, religion, disability and animal rescue.

**"We had some friends... through Animal Welfare and we went to each others' houses. I had a very good friend down the road... she was a marvellous counsellor. I used to be able to tell her anything. Saw her every week for a coffee and we'd talk for a few hours and it really, em, was therapeutic."**

Several narrators discussed deliberately engaging in activities to broaden their social networks and horizons.

**"Well, the self-belief and the friends just seems to grow stronger and stronger and hobbies lead to different hobbies and more hobbies and let's hope that one success leads to another, or it seems to anyways."**

The reciprocal nature of these relationships built upon mutual interest and passion allowed people to thrive outside the world of mental health and often to contribute, support and feel supported in other areas of life.

Many individuals built relationships around mental health focused activities such as peer support or self-help groups and therapeutic communities where they found support and a safe space to build self-esteem. This was often a first step in preparation for re-engagement with the wider community and a first step on the recovery ladder in terms of building up successful supportive relationships and making sense of their mental health experience.

## Pets

Several narrators discussed the positive impact that having a pet had on their recovery. They provided company, unconditional love, a sense of purpose, and a reason to get well and stay engaged. Their effect was similar to that of having a human dependent in that their care provided a reason for 'being' and their love fulfilled a need for love, acceptance, and company.

**"My cat was a major factor in me getting well because I fed him twice a day, so I had to go to my flat, for a time I really, I couldn't go to my flat on my own to begin with, and it was a real barrier. Uhm...but I soon started taking care of my cat again and that meant I had to go there twice a day morning and evening whether I liked it or not and that was really important."**

Their presence was said to be reassuring and provided a means of getting out of negative head spaces.

**"I can sit at home at night and my dog will look at me as if to say, come on dad let me up on the couch, and I'll let him up on the couch and I'll think, I'm here and I'm safe and I'm still alive."**



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Pets gave people unconditional love and a reason to stay engaged with the world. People felt they provided an “ear to listen” non-judgementally and a focus for friendship for some people who had previously felt relatively isolated.

**“(DOG) was somebody to love, and I don’t regret it... He’s a mommie’s boy you know, when I’m feeling down – which I do, not as often as I used to obviously because I have other coping mechanisms – but it’s just lovely to have someone there who doesn’t criticise, doesn’t judge, just loves walks on the beach. I love to walk, that’s something I find very therapeutic.”**

## Service Professionals – A Critical Friend

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Narrators described individuals who acted as a ‘critical friend’ (often nursing staff) as being an important instigator in their recovery journey. The role of a critical friend has been described as someone who believes in you and champions you, who lets you talk and listens to you, who creates a space for you to reflect, and helps you to get things under control, helping you make informed independent decisions at your own pace. They provided narrators with positive feedback as well as encouragement.

**“I think a lot of it was about my worker realising when I was ready. She was very observant and she could sometimes see things without me seeing it and would point out to me and then I would agree with her or disagree. And we did it at my level and pace all the time... and it was all about her saying please think about how well you’ve done.”**

Making independent decisions and reclaiming control over their lives was a primary indicator of recovery for narrators. It is clear that professionals who enabled people to do this had a strong role to play in promoting recovery.

**“My doctor didn’t seem to listen to me... I couldn’t speak so I asked (social worker) to come with me to my GP. And he did... He made the appointment, took me in and my doctor was quite annoyed that ‘Oh, why are you bringing your social worker in?’ And I said... ‘I really can’t speak to you very well, I don’t really feel you are listening... I am sorry I can’t speak anymore I am too distressed’. And, uhm, (social worker) took over explaining everything... From that day on my GP, there has been a whole change of attitude, he now looks at me and he listens.”**

Most narrators who addressed the topic identified that this ‘critical friend’ role required trust, honesty and constructive dialogue between the person on the recovery journey and the service staff. Whilst they were aware that they were developing professional relationships, narrators felt that it was particularly important to be able to trust and communicate with professionals, and feel comfortable with them and that professionals appeared to understand or empathise with what they were going through.

**“(Discussing what has helped recovery)... I didn’t have a game plan but generally recognise and be able to trust in support has been important. And learning where I have been offered skilled support, or I feel met or recognised and valued.”**

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Being treated as an individual and not an illness was extremely important to individuals. Also, being given the opportunity to function on a more equal basis with professionals was important. One narrator explained that taking his support worker out to lunch and not just being seen to ‘take’ all the time meant a great deal to them.

## Support to recover

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Narrators’ capacity to cope often related to the social capital available to them. The support they had from support services and community, work or social networks and the extent to which other aspects of their life such as friend and family relationships were supportive often interacted with the recovery process.

Professional relationships providing instrumental and informative support came in the main from community psychiatric nurses (CPNs), social workers and voluntary agency support workers who supported them in practical tasks like making appointments, organising their homes, linking to support groups, finding work and accessing benefits. These relationships were important as they also provided support to individuals who needed to know that someone believes in them and in their capacity to make choices. However, within these relationships it was important not to overpower individuals and to allow them to maintain their own right to self-determine.

**“...when the CPN visited, perhaps one of the biggest things that the CPN did was get me to, encourage me to apply for or help me to apply for Disability Living Allowance and Severe Disablement Allowance and that played a major part. So the CPN was instrumental in encouraging me to apply for benefits which made a big difference to my life.”**

Having a relationship with someone who would go the extra mile to help narrators organise and re-engage with the world on their own terms appeared to be a very important support to recovery. It increased the choices available to them and allowed them take risks that they would not otherwise.

## Mutual trust and recognition

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Relationships with different service professionals that have been built upon mutual trust have given confidence to individuals. Recognising that others have belief in them helped individuals to believe in themselves and share their hopes, fears, aspirations and frustrations. This has helped people to ask for help when needed without fear. Having a relationship where there is mutual trust has meant that individuals could listen and be encouraged as well as be heard and understood. In cases where narrators felt a service professional blocked, frustrated or hindered their recovery journey the words **“they didn’t listen”** were often used.

**“I didn’t have a game plan, but generally recognise (being) able to trust in support has been important... where I feel met or recognised and valued.”**

**“You’re not listening!’ They weren’t, it was like people weren’t listening to what we were saying. They were putting their own spin on it and then delivering that as the user voice.”**

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**“(COUNSELLER) had this kind of thing of, ‘You tell me what you want to tell me,’ and I went through a lot with her. She went through it with me. And it made a hell of a difference... This sort of distance thing that I had with the psychiatrist before... it’s very, very hard to explain to somebody how bad it feels when (they) don’t actually respond.”**

In an environment where people believe that they could lose their freedom and their right to be heard if a service professional decides they are too ill, the building of mutual relationships based on trust, shared values and recognition was considered crucial. It was also considered important that professionals enable individuals to develop self awareness and self confidence.

## Continuity and responding to need

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Just as sustaining meaningful relationships with friends and family were important in promoting recovery for many, nurturing long-term relationships with those who provided support was equally conducive to recovery. Regardless of the nature of the relationship or whether narrators were addressing psychiatrists, psychologist, CPNs, social workers or voluntary sector support workers, the continuity of relationships played a major role in individual recovery journeys.

**“I’ve actually been able to build on it gradually to be where I am now, I think it’s also something to do with the consultant that I’m with at the moment is actually very, very aware of my history, how the system hasn’t exactly been perfect for me in many ways, and is aware of the pitfalls about using the Mental Health Act, because say for in respect of professionally, I suppose, she’s been prepared to take chances.”**

**“I was put under the wing of (NAME) who was the charge nurse who knows me like a book now. Erm, I know when that stops, I will find it really difficult because she is a really big part of my life, erm, because I go to her if I have a problem once a week twice if its really bad or twice a month. It varies. She was the first person I learnt to lean on and allowed (myself) to lean on.”**

Knowing that someone knows their history and circumstances gave individuals confidence and trust in the relationship, and provided a basis for working through issues and processes in a constructive non-dependent way. Where continuity in psychiatric or support staff was not available, people lost trust in the system and described feelings of isolation.

**“There was absolutely no support network... I saw a CPN who left, after a few weeks I got another who left, after a few weeks and then I got another one. I tried to think that it wasn’t me, they really were moving for professional reasons... It seemed whenever I got close to trusting a CPN or whom ever, they would leave and I would have to start all over again it would be like reliving it every day you know, no moving on.”**

**“I think a major factor (in my recovery) has been somebody who has taken a long-term view of me. And who has been willing to work with me and keep me on the case.”**

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The continuity of worker appears to contribute to a sense of security and trust that allows individuals to talk honestly and manage challenges on their recovery journey.

**“I think my interactions with them... have over a long period of time made me able to have a bit more confidence within myself.”**

Although continuity of relationship was considered important, these relationships were also required to be responsive and supportive without dictating pace. Pace and direction was best led by the person on the recovery journey and would ebb and flow with their mental health, wellbeing and life circumstances.

**“For me to phone out takes a wee bit of pushing sometimes... One of the marvellous things the chap (SOCIAL WORKER) said to me was, ‘Look I will sit here with you, we will have a wee chat and then... you phone the benefits office and if you get distressed enough then I take over.’ And see when he said that it took the frightening bit off... But I couldn’t have done it without him sitting there knowing that he could take over.”**

**“Well I’ve got my occupational health people and I’ve got my CPN. And it’s really just talking with my CPN and eventually the occupational health listens closely to my CPN and we’ll work out a scheme through them. I mean, at the moment it’s all very flexible.”**

The relationships some narrators developed with professionals who were willing to ‘go the extra mile’ were valued and recognised as key components of an individual’s ‘pathway’ to recovery. For other individuals, knowing that there was a familiar voice on the end of the phone or someone who could come at short notice who knew them and their situation was identified as being crucial to helping them engage with an unpredictable world with an element of security.

**“She’s (my consultant) been prepared to trust me as I’m beginning to trust her, so it’s that partnership whereby she’s actually trusting me and I’m trusting her, and that again just creates respect as well.”**

As people progressed on their recovery journey it was clear that having relationships with someone who had the time to listen and talk to them about their mental health and how they were managing without judging them reduced their sense of isolation.

**“I mean I became so close to my CPNs, like you can talk to them like you can talk to your sister, but even closer because you can tell them things about your close family or whatever has been upsetting you, you can speak to them about.”**

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## Hopeful relationships

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When professionals were reassuring and offered positive support and encouragement, narrators were more likely to believe that recovery was possible for them. However, when professionals communicated their prejudices and negative assumptions about narrators' ability to cope, narrators found that their confidence and self-esteem became undermined, and feelings of resentment and frustration against this negativity were expressed.

Professional relationships that were too short, too distant, irregular, and were discontinuous did not foster the trusting and lasting relationships that nurture recovery.

**"It's very difficult to get appointments (for psychiatrist)... six months waiting list. There is only one, we have one small unit which is the acute psychiatric unit, there isn't much else. It's ourselves, (ASSOCIATION) with our drop-in, em, the CPN's are very, very hard to get hold of, it's always an answering machine. There isn't enough you know, the GPs nod sympathetically and write prescriptions."**

# Relationships Discussion

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Findings on the recovery-promoting effects of having supportive relationships have been substantiated by this research. For friends and family, being there and available to listen and talk, being informed and supportive of recovery, being consistent, respectful and empowering individuals was all important and promoted narrators' recovery. For partners, being aware of triggers and understanding the nuances of illness, trying to empathise and support even in the absence of knowledge, helping individuals to develop strategies to manage their mental state, and providing an environment of trust and stability that affirmed the person's sense of worth was important. For peers, sharing, learning, offering hope and supporting each other was helpful. For some respondents, having another being (animal) as company – just being there – could be as supportive as having a friend or significant other. The drive to care for another being – whether animal or human – should not be underestimated. For professionals, letting clients' direct pace and direction of recovery, listening, empathising and allowing a relationship based on mutual respect and trust was important.

# Relationships Discussion

Much of what the mental health literature tells us about developing and experiencing positive relationships does not appear to vary from what we know in general about relationships. Individuals in recovery hold the same hopes and concerns about their relationships and experience the same variety of relationships as the general population. However, the normative nature of relationships and of how one experiences them holds particular significance for those with mental health problems. What we know about the social distance, stigma and fear that surround mental health problems adds weight to the importance of acceptance, closeness, trust, mutuality and respect in relationships. For those in recovery, more effort appears to be invested in securing close, meaningful relationships. Overall, having flexible, responsive, long term relationships that offered mutual respect and reciprocity, consistency and availability were the overarching factors in relationships that were helpful to recovery.

Findings from the current research are consistent with the view (Mental Health Foundation, 2007b; Yanos *et al.*, 2001) that supportive relationships can play an important part in promoting recovery. In allowing for the involvement of a Named Person to advocate formally on behalf of an individual, the Mental Health Act (Scottish Executive, 2003a), recognises the role of supportive and caring relationships in mental health.

As people's sense of control over their state and their immediate environment increases and is acknowledged and validated by others they develop self-worth. Narrators described this as a realisation that not everything was about them, an awareness of their responsibilities in mutual relationships with others and their environment which led to a desire to engage in activities that gave purpose and meaning beyond their mental ill health.

## Isolation

Our findings, similar to Topor *et al* (2006), have challenged the conventional view that people with psychosis prefer to be alone and isolated. For those who did feel isolated at points in their journey, our findings were similar to Boydell *et al's* (2002) in that we found that isolation was usually a consequence of their desire to hide their illness and was possibly as devastating as the illness itself.

For our narrators relationships that were rewarding tended to be sustainable, meaningful relationships that provided social connectedness and emotional support and lead to a mutual acceptance, respect and empowerment. Such relationships were fuelled by the belief that recovery and wellness is possible and were supportive of that objective. They were also in the main fuelled by willingness, mutuality and positivity rather than obligation. Indeed, a consistent finding amongst narrators was that there was an ameliorating effect of positive relationships on illness.

Since overwhelming narrative evidence suggests that maintaining relationships and staying connected socially is an important part of recovery. Issues of social capital and social networks should be more greatly emphasised in mental health services.

In many areas of life people achieve more when they cooperate than when they work alone and to be socially isolated is often a contributory effect of, as well as contributor to, mental ill health. A social capital approach to recovery would place a high value on developing positive relationships, drawing attention to them as an asset requiring investment. In helping

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individuals to invest in their social capital, intermediaries such as friends, relations, peers or professionals could encourage new connections to invigorate network development and maintenance.

## Friends

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Positive social relationships that are stable and enduring, meaningful and supportive positively impact on recovery. Those who experienced positive relationships with friends, family, pets and with other colleagues or community acquaintances appeared more content and hopeful about their continued recovery due to the support they were currently experiencing. However, social interactions can entail costs as well as rewards and social relationships are not always beneficial. It should be noted that several narrators found relative isolation a positive aspect in their lives.

To maximise recovery potential the maintenance of friendship networks should be attended throughout the person's journey, but particularly when their life gets disrupted e.g. hospitalisation. Proactive strategies for maintaining relationships should be developed, especially around transitions.

The key factors in these networks should be that they:

- Are flexible and responsive, (people should be available to listen when required and help should be provided in narrators' own space and arranged round their own time needs).
- Can react quickly and effectively, thus reducing people's sense of vulnerability and encouraging the risk taking required to re-engage.
- Encourage the development of long term relationships and offer long term continuity in support that gives individuals a better understanding of their recovery journey.

## Family

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Service providers should do their utmost to support people in maintaining existing supportive relationships with spouses, family and friends. They should additionally support and promote the development of new friendships within their services at peer and user-professional levels.

Recommendation 2.2 from the US President's New Freedom Commission (Fisher, 2003a) advised that consumers and families should be involved fully in orienting the mental health system towards recovery, building positive relationships that are built upon shared knowledge and respect to positively affect relationships. Findings from this study suggest that individuals should be supported to increase family members' understanding of their mental health problem and the implications for attitudes and behaviours.

## Intimate partners

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Since findings suggests that many individuals' desire to have or maintain loving relationships with significant others (heterosexual and same sex relationships), devising ways to help support and maintain these relationships should be considered carefully when developing services and treatment plans with individuals.

Partners often fulfilled unpaid advocate, lay therapist, and confidant roles and provided a central role in recognising triggers and helping individuals reframe their experiences.



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Since many narrators felt that their partners were instrumental in keeping them out of the psychiatric system, it is obvious that their significant role in helping individuals to develop strategies to manage their mental state should be considered and utilised by services with service users' consent.

## Parenting

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Policy exists to accommodate the needs of children dependent on care from mentally ill parents (local authority 'blue book's', The Children Act, 1989 (c.41), The Children Act, 2004 (c.31), Community Care legislation), and research around children's exposure to parental emotional discord (Rutter & Quinton, 1984), parenting skills (Appleby & Dickens, 1993), young carers, and the mental health of new parents exists in abundance (Condon, 2006; Murray, 1988). However, less examination has been made of the motivational, supportive, challenging and positive elements of having dependents to look after whilst in recovery from mental health problems. Indeed, parents in recovery from mental health problems have been relatively invisible in social research and policy creation.

Research into parenting usually focuses on the problems associated with parents with disabilities (Riordan *et al.*, 1999). Olsen and Clarke (2003) recognised that attitudinal barriers against those with mental health problems parenting exist. Nonetheless, findings from this study suggest that actively parenting and caring for children has been extremely conducive to recovery. The rewarding emotional and motivational aspects of parenting were, however, conflicted with fear of losing those for whom we care due to ill health or compulsion. To remove this fear, services should be developed to provide more flexible support and safety nets to help parents successfully care for their family, and to reassure them that children will not be automatically or forcibly removed when individuals seek help.

Appropriate provision of services to assist parents with mental health problems will require an improved understanding of how parenting effects recovery and how mental health problems effect parenting. The role of schools in providing support to families with mental health problems is less well developed in the UK than in mainland Europe according to Tunnard (2004). Schools, social services, children's services and mental health services must work together to provide seamless and timeous parenting support for individuals in recovery. Taking a positive step to support people function in these roles is likely to be effective at encouraging wellbeing and recovery.

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## Peers

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Much has already been done in Scotland to promote peer support. Clubhouses, self-help groups, support networks, day centres, advocacy and befriending projects all exist to encourage individuals to engage, bond and share their experiences. As previously stated, the Scottish Government have shown support for formalising peer support by training and employing peer support workers as a new specialist addition to the mental health workforce (Scottish Executive, 2006). Lived experience of mental health problems is increasingly being recognised as a qualification for helping others address and explore their own mental health.

Findings demonstrate that the variables that contribute to recovery most definitely include having positive relationships and supportive social networks in one's life. Others exposed to individuals in recovery can have a positive impact if they provide reason, hope, love, comfort, a listening ear. Spending time with other people who are in recovery or recovered from mental health problems also promotes 'modelling' of the recovery experience. Further studies on the importance of personal relationships to the wellbeing of individuals should be conducted.

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## Colleagues

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Whilst the Disability Discrimination Act 1995 allows for accommodations to be made to help people with mental health problems function in the workplace, it does little to address the attitudes of colleagues and managers. Information and materials on mental health and mental health recovery targeted at the general population through campaigns such as "see me" can lead to a greater interest in mental health which will hopefully result in a better understanding of the flexibility and support needed by people in recovery to help them develop positive working relationships and careers.

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## Community

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Findings from this study concur with Parr *et al* (2004), showing that geographical communities can produce contradictory elements of support and victimisation or stigma where communities are socially proximate. Narratives also support the typical view that many people with poor health (albeit in recovery from this poor health) live in poor neighbourhoods. This can cause problems of multiple deprivation.

Living within safe, informed and tolerant communities helped expedite recovery. Communities within which people could become engaged, 'give back' and have their contribution acknowledged were valued. Developing more community integration programmes within and outside of the mental health community would allow individuals the opportunity to increase and diversify their community relationships and could also serve to inform the external community on issues of importance to mental health and wellbeing.

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## Pets

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There is evidence that the presence of pets (Allen *et al.*, 2002) and other dependents have had a positive impact on other areas of health. Although findings from these narratives are more suggestive than definitive, they support the view that having responsibility for others can act as a catalyst to cope. It appears to provide individuals with secure love and attention and a focus outside of their illness as well as a reason for being and for getting on with life.

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## Professionals

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Long-term continuity in support personnel has often been questioned in reference to creating dependency. However, most of our narrators when talking of this issue have asserted that such continuity actually works to facilitate interdependence. The continuity of personality appeared to contribute to a sense of security and trust that allowed narrators to talk honestly and manage challenges on their recovery journey.

Similar to Borg & Kristiansen (2004), we found that narrators valued relationships with professionals who went the extra mile to accommodate their needs by helping to empower and collaborate, empathise, listen to and respect individuals. Treating individuals as a ‘human being’ and conveying a hopeful message of recovery also helped.

There is a clear role for professionals in the role of critical friend. This does not require extra services but a commitment to a way of working that creates space for people to discuss, reflect and decide for themselves what the most appropriate course of action is. This requires trust, honesty and constructive dialogue between the person on the recovery journey and the service staff. This reiterates the findings of Schinkel and Dorrer (2006).

Encouragingly, this research has demonstrated that there are currently many CPNs, social workers, support workers, counsellors and other professionals and service providers that are progressing the recovery paradigm through their work. They are actively developing and promoting recovery based practice and are a valuable resource to increasing understanding of what is good practice in supporting and promoting mental health recovery.

The attitudes of those with whom you have a professional relationship can have a significant impact on people’s sense of self and their confidence about their capacity to recover. Exposing professionals to recovery-oriented ways of thinking and to current recovery-oriented practices could encourage professionals to develop more meaningfully supportive relationships and to explore their role in others recovery process. Research on employment outcomes have already shown that the single most important influence on people’s chances of getting a job is the outlook and expectations of services. We need to develop a better understanding of support deficits in order to improve targeting of interventions to improve relationships for individuals in recovery.

Promoting the premise that mental health recovery is possible and structuring services and support so that it can be reflective and responsive, enabling individuals to develop their capacity to self-determine, would potentially help equalise relationships between service users and professionals and would help people’s recovery.

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## Further Research

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Recovery assumes that people gain better understanding of their own mental health and therefore have a higher level of mental health literacy than the general population. This self-awareness has the potential to add much to human interactions and to the study of human interactions. Investigating the personal and societal benefits of mutually supportive relationships with individuals who have mental health problems could be interesting.

Veiel (1985) argues that a conceptual frame of reference that looks at social support in order to better understand its nature and consequences and how it promotes mental and physical health must be multi-faceted. There is a need for more systematic investigations of individual

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elements of relationships and the circumstances upon which they promote or negate recovery. An undue focus on negatives rather than strengths is often an obstacle to recovery. More focussed research that identifies the positive aspects of relationships and investigates particular types of relationships including parenting, relationships with work colleagues, couples (intimate relationships) and pets would provide a better understanding of how people develop relationships that support recovery and how services and policy can potentially assist in the building and maintaining of these relationships.

Since some studies have shown age (Horowitz & Uttaro, 1998; MacDonald *et al.*, 2005) and gender (Hintikka *et al.*, 2000; Kawachi & Berkman, 2001) to be points of difference in relationship and social network building, it may be interesting to disaggregate these data by these variables, to assess whether they present significantly different experiences of recovery. It may also be interesting to provide more focus on how social network size, composition (friendships, intimate partners, relations, colleagues, peers, professionals, communities etc.), or function (mutual and reciprocal, emotionally supportive, economically beneficial, practically helpful, etc.) effects recovery.

# Treatment and Supports Summary

Narrators' experience of diagnosis, treatments and services varied widely. Diagnosis provided liberation and explanation for the way people felt or behaved, but it also served to stigmatise and categorise people into a set of expected symptoms. It gave some hope and made others despondent, it provided access to treatments and services, and income maintenance entitlement, but some people felt that it excluded them from work and mainstream society due to stigma and low expectation for recovery. The way in which diagnosis was initially shared was important. If delivered with information and an optimistic message for recovery, reactions were more positive.

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# Treatment and Supports Summary

**There was a perceived lack of control over access to supports and services. Service gaps were noted by narrators but also noted was a rationing of services by diagnosis and illness severity. Continuity of supports (personnel and service) and flexible support systems expedited recovery.**

Different responses to medication were provided by narrators. Some felt that their recovery was enhanced by finding the right medication. Others felt that their recovery could be measured by the fact that they no longer considered medication necessary. Side effects, available alternatives, trial and error in finding a suitable effective drug and a desire to be medication free affected decision to take to prescribed medications.

Supports and services provoked both positive and negative responses from individuals. It is obvious that individuals received different levels and types of support often depending upon the knowledge of the person making the referral and the types of supports available in their area. Treatments that were favoured by narrators included Cognitive Behavioural Therapy (CBT) and other talking therapies.

Professionals noted as having a large impact upon recovery included psychiatrists, psychologists, counsellors, community psychiatric nurses (CPNs), social workers, support workers and occupational therapists. Indeed, finding the right professional to work with could provide a significant turning point, helping individuals navigate their own recovery journey.

Housing support, often serving transition periods from hospitalisation to community resettlement, was discussed by narrators who found it to be beneficial, easing the difficult process of reintegration with their community. Additionally, the security to be found in having a 'home' where one 'belonged' was found to be a great source of contentment.

Financial supports in the form of various income maintenance benefits provided much needed financial security and a safety net to those who were not independently financially secure. However, difficulty in accessing benefits, eligibility and entitlement issues, stigma of benefit receipt, fear of withdrawal of financial supports and limited knowledge about 'rights' as a recipient made the support from these income benefits less consistent.

Good supports were described by narrators as:

- Taking a long term view of recovery and support needs.
- Mapping out recovery plans and monitoring progress collaboratively with the person concerned.
- Helping people move forward and reflect on their every achievement, building confidence and motivation.
- Not withdrawing support too early and offering long term support to maintain recovery.
- Incorporating self referral processes.
- Not keeping unnecessary notes on people and having clear practices about information sharing.
- Asking what support people would like and recognising that requirements are not fixed but change over time and with circumstances.

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- Listening and responding to what people want, non-judgementally and respectfully.
  - Treating people as individuals, offering support at a pace that suits them and offering choice in who people work with, providing choice in therapies and treatments.
  - Being proactive and sensitive to changes.
  - Being observant – notice when medication is not working.
  - Allowing individuals to determine when they no longer need support.
  - Providing ongoing links to external support organisations.

Current support services were described as needing to be more:

- Consistent.
- Organised, and on time.
- Open, listening and supportive.
- Flexible in service provision and availability.
- Trained in counselling, confidence building and mental health.
- Non judgemental.
- Observant – noticing when someone is in trouble.
- Prepared to engage with the bigger picture of someone's life and history.
- Supportive and knowledgeable in dealing with practical issues like benefits (finances) and housing.
- Focussed on recovery – not the illness.
- Empathetic and motivating.
- Proactive – not requiring the person to assert himself or herself to get support or attention.

# Treatment and Supports

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Previous chapters of this report detailed areas of internal and external change that could affect recovery. We explored how developing a positive confident identity and having meaningful relationships and activities in life were all factors that individuals could focus on to support their own recovery journeys. Whilst we primarily focussed on the individual in previous chapters, we must recognise that recovery is a journey that often requires support from formal services as well as from friends, families and colleagues.



# Treatment and Supports

**This chapter is focused upon individuals' experiences of accessing treatment and supports and on the issues narrators feel are important to ensure these services are oriented around recovery.**

In this chapter we investigate diagnosis and medications, and cover traditional and non-traditional therapies, and we look at hospitalisation, transition from hospital, perceived service gaps and professionals' attitudes. We also look at community services, finance and housing.

We begin by briefly acknowledging the current relevant literature before providing findings from narrators' interviews about their experiences of and perspectives on these supports and their impact on recovery. We will reflect on what factors narrators feel are important in ensuring that treatments, practice and services are recovery-orientated and conclude by considering briefly the implications of these findings for mental health policy and practice in Scotland, with some observation about the potential for recent policy developments to advance the realisation of a recovery-oriented mental health system.

## Diagnosis

The criterion for categorisation of mental illness has varied according to political and economic trends and has been reflective of shifting community attitudes and values. Even the criteria of symptoms for assessing the 'right to confine individuals' expand and contract depending on political climates (Bassman, 2005; Foucault, 1988). Whilst it has been argued that diagnosis provides clinicians and clients with a useful means for describing different manifestations of mental illness giving an indication of symptoms, expected course, treatment and prognosis, some who have explored the diversity of experience and the human context of mental illness, have increasingly called for an end to 'classificational diagnosis' (Marsh, 2000).

Crepaz-Keay has argued that diagnosis is at best unnecessary and at worst potentially damaging as it can lead directly to discrimination and a negative re-focus for personal identity, ignoring environmental factors that can affect illness. He and others (Bassman, 2005; Crepaz-Keay, 2003) have argued that diagnosis can facilitate discrimination and – controversially – its only real value is to those looking to profit from treatments for conditions. Crepaz-Keay argues that people would be better served by a 'comprehensive assessment of need' than an 'off the peg' diagnosis.

It has been argued that because psychiatric diagnoses (particularly psychosis and schizophrenia) are associated with negative societal reactions, they only exacerbate the course of a person's disorder (Link *et al.*, 1999; Phelan *et al.*, 2000). Diagnostic classification can potentially act to intensify stigma by enhancing perceptions of 'groupness' and 'differentness' when perceiving people with mental health problems (Corrigan, 2007). Also, having a diagnosis may encourage the public to perceive individuals in terms of their diagnostic label thus exacerbating the notion that people with mental illness do not recover. The idea of inevitable inexorable decline after diagnosis has, according to Lester and Gask (2006) become increasingly challenged by an emerging evidence base from long-term follow-up studies suggesting that approximately half the people diagnosed with a psychotic illness have a favourable outcome (Dorrer, 2006; Harrison *et al.*, 2001).

Contrary to these arguments, receiving a diagnosis has been suggested to give hope to some people by providing an explanation for feelings, thoughts and behaviour that have otherwise been difficult to comprehend. In addition, diagnosis can, for some, provide opportunity

to seek out similarly experienced individuals and share coping strategies, and to provide information about an expected course of illness.

The debate over significance of diagnosis and its consequences remains unresolved and it is obvious that researchers, professionals and service users remain fractured in their opinions of whether receiving a diagnosis is positive, negative or unnecessary.

## Service gaps

The treatment of mental health problems has been found to be complicated by gaps in service, including restrictions on the ability of primary care to refer to mental health specialists. This often causes service users to experience the mental health system as compartmentalised, uncaring and fragmented.

Prior to the introduction of the Mental Health (Care & Treatment) (Scotland) Act (2003), Dr Sandra Grant consulted with service users, carers, NHS bodies, local authorities and the voluntary sector in order to undertake a comprehensive assessment of existing mental health service provision in Scotland. Reviewing available evidence about the organisation, management, efficiency and effectiveness of these services, she identified gaps or duplication in the provision of services in order to consider how the range of facilities could meet the objectives of the new Mental Health Act. She found that although the new Act was welcomed, there would be difficulties in implementing it and significant changes and developments would be needed, including arrangements for:

- 24-hour crisis and support services.
- Joint community mental health services.
- Access to appropriate hospital facilities for all.
- A range of daytime activities, talking therapies, help with employment and support people recovering from mental illness.
- Providing more information about rights and treatment, and being treated for without consent.
- Agreement on the way forward for staff planning and training.
- Independent advocacy (Grant, 2004).

Foreign studies investigating access problems and service gaps have been numerous. Although the services investigated in these studies have different structures, cultures and accessibility criteria to Scottish services, it is interesting to note the problems they demonstrated. Communication and follow-up between referring agencies and treatment providers and continuity of caregiver was found to be lacking in Onken *et al* (2002) and Raingruber (2003). Similarly, Tondora and Davidson (2006) found disconnected care offered by different providers to be damaging to recovery.

## Medication

The most recent survey of public attitudes to mental health in Scotland (Braunholtz *et al.*, 2007) reported that 35 per cent of respondents (for whom the question was relevant and who expressed an opinion) felt that medication had been one of the most important factors in supporting their recovery. A survey by SAMH (2004) found that over half of their respondents found their prescribed medications to be helpful in spite of the fact that many people experienced unwanted effects. However, in this study people's experience of individual drugs

was found to vary considerably and finding the right drug was largely considered a question of trial and error.

Issues in medication that researchers have found to be contentious have historically concerned prescribed medication management, adherence to prescription, the right to self-medicate and side effects of medications. Some writers are challenging the negative language of 'compliance' and now talk of 'concordance' with medication which suggests more a process of negotiation than instruction and obedience.

Despite documented studies pertaining to the effectiveness of psychiatric medication, many studies reveal that consistently high numbers of individuals (between 29% and 50%) do not take their medications as prescribed (Roe & Swarbrick, 2007; Sirey *et al.*, 2001; Zygmunt *et al.*, 2002). Consistently poor follow through with care, patient attitude (asserting control or preference (Munich, 1997)), paternalistic treatment systems, side effects of medications, psychiatric symptoms (Mancini *et al.*, 2005), stigma, and denial of illness (Sirey *et al.*, 2001; Weiden *et al.*, 1997) have been advanced as reasons for non concordance to medications. Additionally, those who perceived taking medication as a threat to their freedom of choice are less likely to have taken it as prescribed.

Hamilton Wilson *et al* (2005) argue that honestly discussing the limitations of medication is important when asking people to adhere to prescribed treatments.

Various programmes have been developed in an attempt to increase concordance to pharmacological treatments (like psychoeducation/family therapy, and cognitive behavioural treatments), and have shown mixed results in meeting their aims. Roe and Swarbrick (2007) suggest that if non-adherence is to be perceived as a problem, exploring the meaning of and reasons for it within the context of the service user's life may facilitate understanding.

Deegan and Drake (2006) have argued that compliance with medication management is an inadequate construct that fails to reflect the conflicts individuals must face in managing their wellbeing. Seeing compliance to be at odds with the principles of person-centred care, they and others (Mueser *et al.*, 2002) argue that 'shared decision making' between professionals and clients to collaboratively determine the optimal treatment is a better means to negotiate treatment and medication plans.

According to Fisher (2003b) helping relationships, including psychotherapy, play a much more important role than medications in recovery and this is routinely suppressed by the pharmaceutical industry.

## Hospitalisation & transition

Hospitalisation can often result in feelings of powerlessness, especially where in certain circumstances, doctors have a mandate to treat against the will of patients and where individuals lose the right to make decisions. Indeed, the loss of self-determination was construed by some Highland User Group members to be a 'punishment' for individuals when compelled to receive treatment under the Mental Health Act (HUG, 2005). Also, research on the living conditions on acute wards has suggested that they are 'non-therapeutic' and not necessarily conducive to recovery or getting people well.

Although various studies have shown the benefits and negative impacts of hospitalisation (involuntary or voluntary) on recovery, studies dealing with transition from hospital have more often found services lacking in coordination and accessibility (e.g. resettlement, housing,

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personal care, socialisation services).

From a Scottish perspective, Highland User Group members expressed both elation at the prospect of returning home and anxiety and trauma about being discharged from hospital (HUG, 2003). Some individuals consulted felt disempowered with no involvement in their discharge, some indicated that there was a lack of preparation and found the abruptness of the discharge process to be very disconcerting. Income maintenance (finances), housing and tenancy issues, difficulty reintegrating into the community were amongst the numerous challenges individuals faced during transition from hospital (HUG, 2003). Similarly in the US, Beal *et al* (2005) and Liberman and Silbert (2005) identified that important dimensions of community adaptation for persons with serious mental health problems are usually missed by mental health professionals.

Coordinated inpatient and community treatment, long considered a necessity is far more the exception than the rule. For individuals with serious mental health problems, leaving the predictable, safe, secure, and supervised setting of a psychiatric hospital is a challenging transition.

## Recovery-oriented service systems

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Several studies have identified or developed frameworks for recovery-oriented services. Anthony (2000) assessed that a recovery-oriented service is constructed upon and grounded in the idea that people can recover from mental health problems. This revised service orientation demands a new response from services and professionals, a response which is positive, respectful, facilitating and empowering.

As an alternative to traditional professional-based services (where professionals are assigned responsibility for clients), some people have advocated for recovery-oriented self-help and peer-based services which offer a non-hierarchical system of service delivery (Mueser *et al.*, 2002).

Mosher (2004) identified several factors that are predictive of a positive outcome in recovery-oriented psychosocial programmes, including the presence of a healing context (hospital unit, peer resource centre, community based recovery-oriented team), a therapeutic culture, an expectancy of recovery, opportunities for experiencing success, and the reassurance of confiding relationships with helpers.

Alternatives to traditional mainstream psychiatric practices that embrace values as evidence alongside purely empirical evidence are increasingly being adopted in services and by a range of professions (Allott & Loganathan, 2002). Recovery focussed frameworks such as the Tidal Model (Barker, 2003) promote the intrinsic value of personal experience in the development of personally appropriate mental health nursing care.

## Professional's recovery orientation

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It is extremely encouraging that a range of professional bodies are now making explicit their commitment to recovery and to values based practice.

With the publication of Rehabilitation and Recovery Now (Cope *et al.*, 2003), the Royal College of Psychiatrists describe the opportunities for psychiatrists to develop new recovery-oriented skills throughout their careers, suggesting that recovery may begin to play a larger

role in the philosophy and approach of psychiatrists in the future. More recently the college published a joint position paper with Care Services Improvement Partnership (CSIP) and the Social Care Institute for Excellence (SCIE) confirming a solid commitment to a recovery approach (CSIP, 2007).

Whilst work to orientate stand-alone mental health services in recovery have progressed in Scotland, some allied services appear to be in their nature recovery oriented. Gruhl (2005) suggested that occupational therapy (OT) should take a keen interest in the construct of recovery because core occupational therapy beliefs and assumptions are strikingly similar to those purported to be important to fostering recovery. Occupational therapy is often identified as a profession that focuses upon client strengths and abilities, and in the past OT research has focussed upon self-esteem, self-efficacy, empowerment, self-determination and quality of life (College of Occupational Therapists, 2007a). Despite these similarities between the recovery paradigm and occupational therapy research, little research has been published about the role of occupational therapy in promoting recovery. However, the College of Occupational Therapists in a recent document (2007b) placed recovery and hope along with crisis and compulsion as the two alternative approaches to service delivery and practice.

Occupational therapy is seen by the College of Occupational Therapists in the UK (2007a) as essential to the delivery of social and psychological recovery in people's lives.

Parallel to the increase in recognition of OT as a potentially recovery-oriented service, several researchers (K. M. Berzins, 2005; Carpenter, 2002; Stromwall & Hurdle, 2003) have articulated consistent similarities between empowerment based social work practice and psychiatric rehabilitation or recovery as they both focus on and emphasise skills building, self-determination, empowerment, successful adaptive community functioning, social support, and active self management.

## Psychosocial interventions

The most recent survey of public attitudes to mental health in Scotland reported that twenty per cent of individuals (for whom the question was relevant and who expressed an opinion) indicated that non medical forms of treatment or therapy (talking therapies, counselling, alternative therapies, support groups) had been one of the most important factors in supporting their recovery (Braunholtz *et al.*, 2007).

The basic goal of psychosocial treatments (like family therapy, CBT, vocational rehabilitation, psychoeducation) is to improve individuals' resilience, coping resources and system supports to protect individuals against environmental stressors, thus facilitating recovery (Beebe, 2007).

There is evidence that supports the effectiveness of psychosocial interventions. Mueser *et al* (2002) in their literature review of illness management strategies found that coping skills training using cognitive behavioural techniques reduces the severity and distress of persistent symptoms. Cognitive behavioural strategies have also been used to help people learn how to manage their mental illnesses more effectively.

A consistent finding across studies (Mueser *et al.*, 2002) has been that cognitive behavioural treatment is more effective than supportive counselling or standard care in reducing the severity of psychotic symptoms. Furthermore, studies that assess negative symptoms, such as social withdrawal also report beneficial effects from cognitive behavioural therapy on these symptoms. Zygmunt (2002) in a systematic literature review (of texts between 1980 and 2000) examined psychosocial interventions for improving medication adherence and found that

although psychoeducational approaches were common in clinical practice, they were typically ineffective. Interventions targeted specifically to problems of non-adherence were more likely to be effective (55%) than were more broadly based treatment interventions (26%).

## Recovery competencies and relationships

Research on psychological interventions attest to the singular importance of the therapeutic relationship irrespective of the type of therapy offered. The importance of relationships in all aspects of care and treatment and in maximising the effectiveness of interventions and treatments is widely recognised.

Schinkel and Dorrer (2006) in their recovery competencies research found that despite positive examples of helpful relationships, service users and carers consistently pinpointed unhelpful relationships with mental health workers (especially more powerful professionals such as psychiatrists) as one of the main obstacles to recovery in Scotland. Watkins (2007) argued that *“there is a need to remove a prevailing sense of hierarchy from the helping relationship in favour of collaboration and client autonomy.”* This has added voice to the growing call for professionals to be able to engage with individuals in a way that values and seeks to understand their perspective in a person-centred way, putting hope, optimism and social inclusion at the centre of any treatment plan (Berzins, 2005; Deegan & Drake, 2006; Hamilton-Wilson *et al.*, 2005; Sells *et al.*, 2004).

In their study of service user perspectives of recovery-oriented professional relationships, common helpful factors were identified by Borg and Kristiansen (2004). Service users valued professionals who conveyed hope, shared power, were available when needed, were open regarding the diversity in what helps, and were willing to stretch the boundaries of what is considered the professional role, supporting individuals in their own ways of dealing with problems and struggles. Brauholtz *et al* (2007) found that mental wellbeing was related to the extent to which professionals (and friends and family) provided a positive or negative message of recovery potential. Indifferent professionals could adversely impact recovery whilst the existence of supportive relationships were identified as influential in facilitating recovery in Mancini *et al's* (2005) study of how individuals recover from serious mental health problems.

(For a list of recovery competencies see: O'Hagan (2001) and Schinkel and Dorrer (2006).

Recovery from severe mental illness has become an increasingly relevant concept in the mental health field (Schrang & Amering, 2007; Schrang & Slade, 2007). Recovery-oriented practice builds upon the strengths and resources of individuals enabling them to deal actively with mental health experiences rather than being given 'supports' by mental health services in a passive model of rehabilitation. It allows professionals to use their skills and expertise in a collaborative partnership with service users (Borg & Kristiansen, 2004).

## Other Supports Housing and transition

Appropriate, affordable and safe housing is arguably an essential component of any citizen's life. The need to have somewhere suitable to live is crucial for individuals to gain or retain any sense of community and independence, but having your own accommodation can be daunting as well as liberating for individuals in recovery from long term mental health problems.

Leaving the nurturing and supportive environment of the hospital can be difficult for many, however, Cleary (2003) in his ethnographic study of the way mental health nurses interpret their practice in acute inpatient facilities (in New South Wales, Australia) found that it is disheartening for individuals to be in acute inpatient settings on a long term basis when waiting for suitable accommodation for discharge.

A major goal of a recovery-oriented housing system according to the Canadian South West Mental Health Implementation Task Force (2002, p.17) is to ensure that housing options respect and support individual need and preference. Support in retaining housing is often missing from mental health programmes. The New Zealand Mental Health Commission (2001b, p. 2) found that persons with mental health problems can lose their homes for various financial, social and cultural reasons during extended periods of illness. They also found that having a safe and secure housing environment, a 'home' can *"contribute significantly to identity and self-esteem as well as providing a base in the community."* This emphasises the need not only to ensure people are supported to attain suitable housing, but also where applicable, that they are supported to retain the tenure of the home they reside in.

## Financial supports

A major practical support to recovery is the support found in financial security. Some individuals with severe mental health problems who are in receipt of income maintenance benefits (e.g. Disability Living Allowance, Incapacity Benefit, tax credits) expect to remain on these benefits for the remainder of their lives and view them as a security blanket (Highland Users Group, 2006a, 2006b). It is known that many people who have severe mental health problems are economically inactive and are on incapacity related benefits (Government, 2005; Social Exclusion Unit, 2004). Also, the longer a person is away from their job, the more difficult and stressful a return to work can become as people often suffer a great loss of confidence. So it is obvious that having adequate financial support to ease the loss of wage (where applicable) is essential to supporting many individuals.

Research conducted by the Chartered Institute of Personnel and Development, published by Poverty Alliance emphasised these difficulties, finding that 55% of employers would not, under any circumstances, recruit those claiming incapacity benefit, with 60% admitting to disregarding applications from people who claimed it (Big Issue, 2006; Chartered Institute of Personnel and Development, 2005, 2006). Therefore, although there is a clear link between financial security and wellbeing, the reality is that people with experience of severe mental health problems can and do face enormous barriers in accessing work as a means of securing an income (See Engagement chapter).



# Treatment and Supports Findings

In this chapter we investigate numerous external supports and treatments that can affect recovery. We look at diagnosis and medications, traditional and non-traditional therapies, hospitalisation and transition from hospital, perceived service gaps and professionals' attitudes. We also look at community services, and how finance and housing issues can influence states of wellness. Findings from this chapter reflect numerous experiences of hospitalisation and service use. However, we did not always know how recent people's experiences of these services were and recognise that practice may have improved over time.

## Primary care

Primary care and general practitioners (GPs) were generally the first point of call for our narrators when experiencing mental health problems. They were called upon for practical issues such as getting a 'sick line' and accessing medication to manage their symptoms. GPs were said to support people to manage prescribed drugs and help them to understand and navigate around the mental health system. Several were said to be very aware of mental health issues and where to refer people on to.

**"I know the stories about GPs who have got no time for people with mental illness and eh... you know, I've heard stories about that, but I must say I'm terribly fortunate in so far as my own GP is exceptionally, eh, sympathetic and eh... to people with mental health problems, you know? Lucky!"**

**"I feel that my GP was a great help, she really listened and understood, monitored my medication very well I feel. She referred me to the right people, the psychiatrist and psychologist."**

Where GPs were perceived to offer good support they were said to:

- Be very supportive about all aspects of life not just illness.
- Give the time to listen, allowing people to open up.
- Give opinions on the situation.
- Take time to explain things properly.
- Push people in their recovery.
- Have had a consistent relationship with people over many years.
- Refer people on to appropriate services.
- Provide counselling within their practice.
- Be available.

Some individuals had experienced GPs as unhelpful, but due to the procedural nature of the NHS they still had to be seen in order to access other services, benefits and support. They were said to know too little about mental health to be useful in diagnosis, counselling or recommending appropriate treatments and to have too little time to deal meaningfully with mental health issues. Most often narrators complained that they tended to rely too heavily on medication.

**"Well my doctors... I've been on eight different anti-depressants in the past five years, and, as I said before, some of the side-effects are horrendous... That's what I feel with doctors... I go out the door and four months later or four weeks later, I'm (through) their door again and I'm sitting in front going through it all. It's just like a record. And you begin to doubt the confidence in yourself, because you say 'what kind of human being am I?' I'm trying to justify myself being ill to**



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a point, to being well, but this final step to total recovery disnae seem to be there – you're always grasping for it. So doctors are kind of helpless as well."

"GPs, when you have been mentally ill and they've got it all in front of them they think that your physical symptoms are probably imaginary."

Some people felt that GPs should have at least the same knowledge as a CPN to be useful in dealing with mental health problems.

## Diagnosis

Diagnosis had been a double-edged sword for many. It has provided affirmation in the minds of some individuals, confirming that there *was* something wrong, opening doors for services and treatments restricted to the 'mentally ill', helping to identify signs and symptoms could be managed or controlled with suitable treatments. However, it had also frightened individuals who perceived diagnosis as something that potentially branded them with a categorical label that led to stigma and a lifelong sentence of ill health.

"Two to three years ago I realised that you really could recover... 'Cause I thought once you had it that was it – it was stuck, but you can recover. I find that quite an amazing fact, cause over the years psychiatrists and things, no one actually says 'you can recover' it's never mentioned."

## Feeling informed and in control

A large number of narrators found that getting a diagnosis made them feel more in control of their situation. Once they had a named illness they could embark upon learning more about their illness, researching symptoms, treatments, medication and side effects, and could relate this to their own experience. Describing the diagnosis as *"a big step forward"* as they accessed treatment and support, narrators felt more secure and better equipped to engage and deal with both illness and recovery. They describe being given a diagnosis as leading to a *"thirst for knowledge,"* especially where diagnosis had been delayed, sometimes even from childhood. Without a diagnosis some narrators felt ill-informed and unable to research and understand what was happening to them.

Individuals described a sense of relief on receiving a diagnosis. The confirmation it provided was often needed in social, work and finance-related (social security and welfare benefits) settings to convince other people of the reality of their situation. A named illness, a diagnosis, provided the necessary proof.

Receiving their diagnosis also enabled individuals to learn from others who had coped with receiving and living with a similar diagnosis. They could access self help groups for people with similar issues which enabled them to learn from a range of experiences across a spectrum of different people.

"Well the main thing, initially... especially on diagnosis, was learning about the illness... I tended to attend self help groups... and I suppose I just found it helpful that, surprise surprise, I'm not the only one with manic depression... I'm hearing their stories, their experiences and relating really, really well to them... So I found it a very refreshing way to learn about my illness... I think it was just my thirst for knowledge for what was up with me."

One narrator stated that their diagnosis showed them that they were a special person, not like 99% of people in the world.

**“Psychotic episodes... only one in a hundred have these experiences, it’s a rare condition. And this is a point I want to get across because you turn that statistic round and 99% of the world’s population do not have psychotic episodes. What does that tell you as a researcher? It is a rare phenomena.”**

## Diagnosis withheld

Several individuals considered that not knowing their diagnosis had delayed in their preparation for developing management strategies. Whilst few questioned why their diagnosis had been withheld, one narrator reported finding out their ‘serious diagnosis’ by chance when their medical certificate was *accidentally* left out by their doctor.

**“I had never even been told my diagnosis. I found them out from when I got a medical certificate from my GP. So it was a bit of a shock when I came out of a GP one day and read my... ‘paranoid schizophrenia’ – what?”**

**“I got a late diagnosis and it caused quite a lot of concern, well a lot of upset and chaos... hearing about people... or learning about what triggers... learning about early warning signs, what some of the traits of the illness were. That armed me to form a sort of self management style for myself.”**

Concerned individuals implied that if psychiatrists had been more open-minded about openly diagnosing their illness, it would have helped them access the right treatment sooner. These individuals expressed concerns that they had dealt with the symptoms of their illness from childhood and had never understood that they were ill until they received their diagnosis. Accordingly, some narrators expressed bitterness towards GPs who had been treating them since childhood and had not recognised the symptoms or had not acknowledged that they were ill.

**“I went to see a lot of GPs with depression... since I was at school, and nobody picked it up. I would have liked to be looked into a bit harder that’s what I think. If I got the treatment earlier and the understanding earlier I could have felt like this earlier (i.e.: better) and I wouldn’t have kind of lost 20 years.”**

For some narrators, it took years in and out of hospital before they were given what they considered to be the correct diagnosis, support and treatment.

**“I didn’t get any psychiatric diagnosis until at least fifteen years later when... I was sectioned...”**

Using diagnosis as means of controlling access to services was found to be unhelpful, but not uncommon.

**“The indication was... you know, kind of implying that if you ever get diagnosed as having had psychotic episodes then you’ll get help, and there’s things and that there for you, and if you don’t, if that doesn’t happen, em, you know there’s nothing there for you, but we’re here for you.”**

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## Diagnosis and alcohol use

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A few individuals who were dealing with alcohol problems found the diagnostic system and assumptions made by service staff particularly unhelpful. Met with unsupportive attitudes, lack of understanding and judgement, they were often told that their alcohol habit was at the root of *all* their problems. All narrators concerned were finally acknowledged as having mental health problems that they exacerbated by alcohol abuse rather than mental health problems caused by alcohol abuse. Once it was recognised that the narrators used alcohol as a coping mechanism for ongoing mental health problems, negative attitudes subsided and they accessed the help they needed to deal with their mental health problem and to develop less destructive coping mechanisms.

**“I used to get terrible discrimination... staff looked down their nose at me and treated me like I was a piece of shit, but see now... they’ve accepted that it wasn’t just drink.”**

**“I’d spent years arguing with professionals that I drank because of my mental health, I don’t have mental health problems because I drink.”**

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## Negative impact of a diagnosis on recovery

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Individuals narrated their struggle to get a diagnosis and their problems with changing diagnosis depending on who and where they were being treated. Many described being given an unfair diagnosis or having been given a vague or complicated diagnosis that has hindered their ability to comprehend their situation and recover. This led to a level of cynicism regarding the diagnostic process.

**“You’re re-diagnosed on average every seven years, um, so I’m due for another diagnosis.”**

**“Wrong diagnosis is just a, it’s something you have to accept. Misdiagnosis. Um, the way services are geared, services are geared towards care and containment. You know, and to make you not a danger to the public.”**

Wrong (as well as correct) diagnosis has sometimes resulted in being prescribed medication that has made individuals ill. Even where people knew their diagnosis was wrong they often felt powerless or too ill to challenge it. Negative attitudes, misdiagnosis and delays in diagnosis have hindered people’s recovery and in some cases led to a lack of faith in the entire psychiatric system. Hence, a large number of narrators (equal to those that felt it assisted their recovery) felt that having a diagnosis actually hindered their recovery.

**“It’s the word, it’s the diagnosis: manic depression. As soon as you hear ‘manic’ you think, oh boy... it says ‘insane’. Basically it says that you’re insane or whatever.”**

Several narrators described feelings of rejection and a lack of support at the time of receiving their diagnosis and that this had a negative impact upon them.

**“It was that psychiatrist... over the phone he said it was an informal chat... to begin with, and then he started telling me that he thought I was on the spectrum to manic depression. And I’m like ‘nobody’s ever mentioned this before’. So then he’s sort of going... like it could be your personality... To be told that you were on**

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**the spectrum to manic depression, and not to get a whole explanation; to be told over the phone!”**

Many felt that they needed help in order to come to terms with and be more informed about their illness, to allow them to take more ownership of it. This need for reassurance from professionals that their condition was treatable and that they had not been given a life sentence was evident, but it was often lacking. For some the negative feelings generated by getting a diagnosis persisted for years and made them feel as if they would never recover.

**“I was just having a formal diagnosis of what I thought at the time was a life sentence.”**

**“Uhm, it’s depression, anxiety, uhm, panic attacks, but the depression part, there is so many different kinds, nobody has actually said what kind of depression it is, ‘cause I swing up and down so fast... And I did ask one psychiatrist and she says ‘well really it all depends on who you see and their opinion...’ And I was reading books and things and I was getting myself more muddled... this is making me worse... trying to find an answer.”**

Several people describe not agreeing with or trusting the diagnosis they were given, they also describe feeling disempowered by it. Often in these cases, narrators expressed that having a diagnosis meant that the focus shifted to drug therapies and symptom management and away from seeking the cause of the illness and recovery strategies.

**“It goes back to people making decisions about me because I initially didn’t fit any clear category, so they assumed things that they shouldn’t have assumed, so assumptions have been a huge thing that’s counted against me.”**

## Access to and continuity of supports

Narrators reported a lack of control over which professionals they work with and lack of control over the services they access. It was felt that GPs do not take the time to consult properly, some services send individuals away (even individuals at risk of suicide), and people who felt they needed hospitalisation were often denied it. Those that could afford went private, others had to wait or miss out.

**“I would have liked to have gone to a psychiatrist, but the GP was not at all for it.”**

Individuals felt that it is important to get access to services as soon as possible in order to recover but found themselves hindered by gatekeepers. Long waiting lists, bureaucracy and judgemental or unapproachable staff sometimes added to the barriers between individuals and necessary appointments.

**“I mean they’re not nasty people down at our local health centre, but they’re very able to tell you that all the appointments are booked, regardless of what kind of a state you’ll be in... they’ve been driven to quite a point of despair by being told that there’s no way they can get to see anybody for a long time.”**

**“...it’s really quite a barrier sometimes, getting past the dragon at the reception.”**

**“I was told when I was discharged that all I had to do was phone them up again if I ever felt I needed help from them. Of course when my husband tried to do that, um, it didn’t work!”**

Some individuals also felt that their recovery had been hindered as a direct consequence of not being considered ill enough to access support.

**“A big gap that I found was when I came from the unit and was home, there was a big gap, I don’t know, I’d all this support that had helped and then I was at home and I hadn’t got anybody. And I apparently wasn’t ill enough to have a... well that’s not actually true, I had had some psychiatric help from the doctor, like once a month, but then that finished and then I didn’t have anything and I felt, ‘Oh gosh, how I’m going to cope now?’”**

People who were told they should be seen by a psychiatrist were sometimes not seen for years. One individual lost access to a psychiatrist for over a year because he/she was not a *“continuing patient”*, another was referred to a service where the psychiatrist offered to help but failed to make secondary contact.

Another aspect that was said to hinder the recovery process was that *“you have to be really darn lucky to get the same doctor twice,”* so *“there is no chance to build any sort of relationship with anybody.”* This lack of continuity made it difficult for people to address complex issues with them since they had to try and establish trust and relationship at each session. It also resulted in the need to revisit difficult issues over and over – retelling the story of illness. In regions where resources were low, when a psychiatrist left a service, narrators found themselves stranded without a psychiatrist service for years. Six month waiting lists for first meetings with a psychiatrist often at a time of extreme illness was not uncommon.

**“One of my biggest bugbears with the whole system... not too far into the illness my doctor thought, I’ll get you to see a psychiatrist... and I ended up getting a letter saying that was about a six month waiting list and that was as much good to anybody as a chocolate fireguard. And they thought about counselling and that was a six month waiting list so really at the time when you needed the help, it wasnae there.”**

A few narrators reported having difficulty accessing talking therapies when they needed them. Time limited and restricted courses were often prescribed and were generally inflexible requiring individuals to fight for continuation when something was working for them. Some individuals reported that they were working with psychiatrists for many years before therapies that initiated their recovery journeys were offered. Finding counsellors who were not commercially driven and taking on the cost (financial and emotional) of searching for and trying out new counsellors was reported as problematic.

**“If there were, uhm, structures in place for people to access, uhm, counselling and access psychotherapy and cognitive behavioural therapy and psychosocial interventions and things of that nature, uhm... I think that would be really beneficial. And the only way you can do that is if you’ve got money, cause then you go to The Priory or something, if you are a celeb.”**

There was a clearly articulated need for more flexibility in support services, so that they are accessible day, night and weekends and can provide home support when people are ill.

**“You are not meant to take ill between five o’clock on a Friday and nine o’clock on Monday morning because there is nothing, absolutely nothing. Trying to get a doctor, trying to get a psychiatrist, or a doctor, or a nurse, there is nothing there, and I mean sometimes at the weekend that’s when people are more vulnerable.”**

The non responsive nature of most services hindered recovery for individuals.

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## Flexible support to recover

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An inability to cope with fluctuating illness was apparent in some services and a distinct lack of continuity of care was evident in many circumstances, especially where individuals approached new doctors or changed doctors. To enhance the recovery process, narrators suggested that services need to be more accessible and responsive to people's changing needs. Individuals do not always need continuing services but may need short timely interventions to keep them on track.

When people described support services that worked for them in their recovery they did not describe huge complex support packages but lighter touch, flexible, joined up or coordinated responses that offered choices.

**“Their approach was just amazingly different. They were actually offering it (CBT) to you, they weren't saying ‘Well what do you think you need,’ because you don't know... (They were) putting things in front of you and saying, ‘We think this could be beneficial, what do you think,’ and that made a big difference. They gave you a bit of choice.”**

In addition to this flexible response, individuals needed to know there was a concrete safety net, someone there if needed. This could be access to a key worker, or having the knowledge that there is a mental health team on the end of the phone who knows and understands their personal history, medications and circumstances.

**“Well I've got my occupational health people and I've got my CPN. And it's really just talking with my CPN and eventually the occupational health listen closely to my CPN and we'll work out a scheme through them. I mean, at the moment it's all very flexible.”**

**“I've got a place to go which is supportive, you know, and I know that if there is any trouble, you know, that I am feeling a bit down or whatever, then there are people there that I can talk to...”**

Community psychiatric nurses were cited as particularly good support workers by some, not only in dealing with mental health issues, but also in addressing more practical issues regarding finances, debts, benefits, housing, employment and living alone. Most narrators acknowledge that they could not have managed their recovery without professional help. However, having control over the who, what and when was an important aspect of an effective relationship with a professional. The role of CPNs in supporting the person to negotiate and manage relationships with a range of professionals was noted as pivotal.

**“I found having a CPN doing home visits was really helpful. Just knowing that you have got this connection. They can be a go-between between you and your doctors and if you are really unwell they can access help for you.”**

**“If you are lucky to have services like a CPN then use them and learn from them because what they say and do for you is very important. They can stop you getting unwell through support and encouragement, and for recognising when you aren't coping and need additional help.”**

The challenges highlighted in accessing flexible, responsive services in the community were key and were often related to periods of transition. When people moved from hospital to living at home, some individuals felt the drop off in support was too rapid. In hospital they had often been working with nurses to develop social skills and confidence and in planning their move

home. The drop in support was particularly hard felt if the person was part of group therapy in hospital.

Where individuals transitioned back to employment, there was a similar rapid loss of support reported when individuals were too quickly assumed to be coping.

For some, services were too fragmented and too quickly relinquished. It was felt that this did not reflect the recovery process.

**“Recovery comes and is a slow journey, and that’s where the services let you down very badly because they cannae support you through the whole journey and it’s a pity.”**

## Medication

Nearly a third of narrators indicated that medication was key to their recovery, some also described finding the right medication as the turning point from illness to recovery. Getting the right medication helped to alleviate symptoms and distress, and allowed individuals to focus on rebuilding their lives. It stabilised these individuals, allowing them to have the confidence that they could live symptom free and well and thus sustain their recovery.

**“There had been a slight change in my medicine and the tension episodes stopped and it was like sort of being reborn, it really was.”**

**“Most of the direct help has come from being put on the medication which just helps to deal with the symptoms and not coping with life afterwards.”**

Several people reported having been on medication since their first episode of illness and that they would not risk coming off it. Others have tried to reduce dosages and come off them but found that they become unwell again.

**“The medication became unfortunately a medication that I had problems coming off of and I had side effects coming off it and that was a nightmare.”**

Some people felt that an over reliance on long term drug interventions was not considered to be supportive of a recovery process. Psychiatric medication and care was described by some as being too intrusive and fostered dependency when recovery requires **“taking responsibility for my own wellbeing,”** which **“reduces dependency and increases the odds of remaining well.”**

## Part of the solution, but not the only answer

The role of medication, whilst important, was only part of what most people needed to recover. It was required to be accompanied by other processes, which included working through issues, communicating with people, finding support in community environments, self help and self determination, and other non pharmaceutical treatments.

Several people shared their discomfort with taking medication, not only because of the side effects or dependency, but because they *think* they should not be on them. Negative attitudes towards medication resulted in people recognising their worth, but feeling bad or guilty about taking them.

**“I don’t like being on medication at all but, erm, if I have to be on it... a level of medication is better than no medication at all.”**



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**“I resisted for a long time but I’ve got to the point that I just take what I’m given and don’t let it worry me. If it does some good and is helpful then that’s okay?”**

## Trial and error

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Finding the right medication and dosage was said to be a matter of **“trial and error”** with prescribing clinicians over a long period of time. Narrators reported on their struggle through increasing symptoms, a range of side effects, and a lot of lost time to find the right balance of medication.

**“I reduced my medication about a month ago thinking that I’ve got rid of them (voices)... but within about five or six days I’d begin to get symptoms again... So I took 15mgs instead of 10mg when I got home and I was ok the next day. So I’ve learnt that I can’t go without my medication. It’s just finding the right dose. You can only do that by trial and error which I did.”**

For some, who have not yet found the right medication or dosage, the benefits of taking current medications were still thought to outweigh the side effects. Dealing with sleepiness, physical symptoms, reduced communication abilities, and even the loss of a driving licence was found to be preferable to living with the symptoms of the illness.

**“The neurologist wanted to muck about with my medication because the tremors could most probably be coming from (drug name) and lithium because they can both cause slight hand tremors, and if they’re together it can be worse. Some days it’s alright and some days it’s really bad, and I really dinnae want my medications mucked about with.”**

## Medication problems

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Over a third of narrators felt that the medications and their side effects had actually hindered their recovery. Years of changing medications and coping with the consequences often made people feel worse and potentially set back recovery journeys. For some, the side effects experienced were considered to be worse than the illness, affecting their physical health, and making them tired, de-motivated, and confused about what was happening to them (particularly if not warned about the side effects in advance).

**“I got all the literature and I had a list of all the anti-depressants and anti-psychotics and so I took one (drug name) and looked it up on the form and I thought ‘God almighty! The side effects are worse than the cure!’ and I threw them down the toilet.”**

People were also concerned about the longer term impacts of such medications, addictions and the difficulty associated with coming off them.

**“It scares me that somebody might want me to try coming off my medication, I’m no sure what’s going to happen to me when that happens... But I’ve been on and off anti-depressants since the age of (AGE) and now and then you’d start to feel better and a doctor would come along and say ‘well you’re doing fine now’ and take you off your tablets and within three or four months you’re right back to where you started... I don’t think it’s a case of if it happens, I think it’s when in my experience.”**



Most individuals felt that they did not have enough information about the medication they were asked to take. Some people refused to take them if they did not agree with the diagnosis, had a bad reaction to them, or had heard something bad about them. For one narrator, this resulted in being sectioned and being forced to take medication.

**“So I decided then that I didn’t want to take their medication anymore, because that wasn’t working. I’d tried that for a while, and it wasn’t working, so then they just sectioned me instead, and forcefully gave me the medication... You need to fight for your rights... to make people realise that you’re a human being, you’re not just a set of symptoms... It was that combination of things that gave me the confidence to be able to say ‘No, I don’t agree with what you’re saying to me.’”**

A lot of individuals felt that they were at the whim of their psychiatrist whom they felt often knew little about them as people, with each new psychiatrist prescribing a different drug or removing drug treatments and setting people back when the new drug was not effective or relapse occurred. This sometimes caused a loss of faith in prescribing clinicians.

There was a shared feeling that most doctors focused too much upon medication. Narrators also questioned the advice they were given; that they would have to be on drugs for life. Doctors were said to keep increasing dosage, adding to and changing medications when the first prescription didn’t work which resulted in people being resentful about being over medicated.

**“You know, clinicians tell you ‘oh yes, you need medication forever, you need to do this forever, you need to do that forever’, but that’s not true. And if you don’t take a chance you’ll never know.”**

It was felt that medication is often the easy answer when someone is psychotic, but given time and resources, skilled people can talk you down, medication alone is not enough to help individuals recover. Despite recognising advances in drug therapies over the last 20 years, several narrators stated that talking therapies, establishing support systems and stability were a more effective way forward.

**“Well it’s been a very long process and I think it will always be there so initially it was the talking that helped me, with the psychiatrist, that definitely helped... that helped me feel that I wasn’t so isolated and there were lots of other people from all walks of life that had had problems and that helped me think I wasn’t so alone.”**

**“So really medication doesn’t actually help. In some cases it’s actually talking therapies that we need, it’s psychotherapy and that’s one way to recovery.”**

Medication was not only difficult to get right, it was also considered to be creating a false sense of recovery. It was seen as a response which **“focus(ed) on symptom control and symptom suppression”** rather than a tool for recovery. Individuals describe it as addressing symptoms not causes, and as something that stops you reaching your potential as a person.

**(Medication)... “It’s not about making you a fully functioning member of society, it’s about making you compliant, and you won’t do the bizarre things in the street, you won’t be threatening, you won’t appear anything apart from normal. The fact that your feet are stuck to the floor and you’re bright yellow because you’re jaundiced because of the medication is beside the point... You may be thirty odd years old, but you look like you’re ninety... You can’t walk, you can’t talk, you can’t do anything, but the symptoms of your mental health problem aren’t there to**

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**bother anyone... You know this is my life! It's all right for you to come into my life and tell me 'oh, you need to get a grip, just take your tablets you'll be fine'. You know that's not recovery! That's about keeping, maintaining me in the community."**

There were those people for whom medication just did not work, or worked for short periods and then became redundant. Some felt better without them so disregarded them, others decided ***"I don't want to compound my difficulty by becoming reliant on medication."*** In each of these cases individuals developed alternative strategies to manage their illness and their recovery.

**"I don't feel as if the medication was the big thing that helped. I feel that it was all the hard work that I did, but the medication must have been doing something, it must have done its job as well. And I always took it until I was told not to."**

Some people had not taken medication for more than ten years without significant relapses into mental ill health. For these individuals and for others, recovery is most associated with the reduction or cessation of medication over time. However, they acknowledge that medication has a role to play en route and can be quite difficult to stop.

Most narrators indicated that they would ideally like to live with minimal (or no) medication.

## Hospitalisation

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Findings from this chapter reflect numerous experiences of hospitalisation and service use. However, we did not always know how recent people's experiences of these services were and recognise that practice may have improved over time.

Hospital was the right place to be when *very* ill. With hindsight many of those sharing their stories recognised that when they were very unwell hospital was probably a good place for them.

**"What does it say about society that somebody actually feels more secure and comfortable in a hospital that is far from perfect, but they actually feel more comfortable there."**

A sense of relief at being cared for, getting a diagnosis and accessing the services they needed was described, although the experience was described as being awful but necessary. Several narrators acknowledged their determination to 'get out' and not return as the catalyst or turning point in their recovery.

A range of problems with admission to hospital were identified. These included being forcibly detained, over medicated and under stimulated. People also identified a lack of one on one support and counselling on wards.

**"I felt the staff on the ward were just there to assess me and give me medication when I didn't want it really; I just wanted somebody to talk to about something – and I didn't find them at all supportive."**

**"People would rather be in their own homes because they go into hospital and they deteriorate in hospital because there's not care in hospitals except for medication."**

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## A sense of security

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Hospital was also described as a refuge, a place where individuals could escape from their problems, marriage breakdowns, homelessness and generally not being able to cope, a place where they could be left alone. However, narrators also noted the hospitals' focus on treatment rather than recovery strategies meant that they could end up in a cycle of re-admissions. This severely disrupted their relationship with their friends, family and support networks, disorientated them and created dependency, making it harder for them to recover.

**"That when I first went in... I felt safe, and I didn't want to go anywhere else, I just wanted to be there. I kind of felt cocooned. Not that people understood me I don't think, but I didn't feel that I was in any sort of danger."**

**"So often, actually being admitted to hospital and hospitalisation and dependency actually add to the issues rather than actually solve them."**

For some narrators, hospitalisation was more than a refuge, it was a place where they found that they did not need to put on a front and could access activities, relaxation and visualisation techniques that could help launch, or re-engage with, their recovery journey. It was felt that this could be improved by establishing effective links between hospital services and support services in the community.

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## Peer support in hospital

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Some people found strength in the communal nature of hospital wards making hospital more of a part of their recovery experience. The value of empathetic and informed peer support provided between patients was also recognised.

**"The experience of being in hospital in the ward environment, a communal environment about being together – you're almost there for no reason except to get well. It's a fantastic environment. You hate going in there at first but when you get used to it, it's idyllic in some ways. There's lots of support."**

**"The most help I got was from the other people in the ward who had gone through similar experiences. And this does generally go on when you are sectioned. The nurses, they're great but you find, or I find – you asked for my personal experience – the best people that helped me were other people that had been through psychosis, had some little pointers, were grounded, that's the thing."**

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## Problems with hospitalisation

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Hospitalisation potentially hindered recovery through arousing fears, promoting power relationships between professionals and service users and through enforcing control and a maintenance paradigm. Narrators reported being frightened and shocked by the process of admission, the environment and the way they were treated.

Several people related their shock at the time of being sectioned under the Mental Health Act. In the main, this shock related to feeling uninformed, not knowing what was happening and feeling that 'nobody had the right to do that to me.'

**"I hated it. The first night there I was not even introduced to the night staff, I was made to queue up with everybody else in the hallway for my medication and to have a staff nurse turn to his nursing assistant and say 'Who's this?' Not even introduce themselves."**

The reputation and physical appearance of some hospitals did little to comfort or reassure individuals. Indeed, one individual described their local hospital as *“Dracula’s castle,”* a prison, a building where *“there’s razor wire all round.”*

The mix of people in wards was highlighted as a problem. Women felt uncomfortable about being in mixed wards with men when they felt vulnerable. Concerns were expressed about being on wards with seriously ill and potentially violent people. However the main concern was that being locked up with *very ill* people was impeding people’s recovery.

**“I says, ‘I pray and hope that I have never ever to go back to hospital again’... there are mixed wards, men and women mingling together, and when you are ill and vulnerable you don’t want to wake up and see a man brazing up and down the same place as you are, and it’s horrible, and I have had this argument a lot of times, I don’t like this mixed wards in a hospital.”**

Narrators describe being infantilised, disempowered, treated as if they were dangerous, left uninformed about what was happening and being labelled as an illness not a person. This dehumanisation and lack of understanding of their needs added to people’s poor mental state. This compounded by a lack of freedom, being in locked wards and not going out for weeks was deemed unhelpful and made people *“irritable and aggressive.”*

The reduction or removal of control and choice over space, movement, privacy, money, food, medications, treatment and duration of stay left people feeling disempowered and undermined.

**“Ok, you’re a voluntary patient, technically you can sign yourself out, but you really don’t want to... I was told nicely that I could do that but then I would be getting a visit and I would just be sectioned and straight back up.”**

**“I says ‘I am not a little school-girl to be told you will’. And this is something in (HOSPITAL), you have to line up for your dinner, you have to line up for your medication, which I don’t think is right.”**

Several respondents found convincing professionals of their readiness to leave the hospital environment was difficult. A small number of narrators felt that professionals needed to be less risk averse and to allow individuals to care for themselves when they are indicating that they want to be independent. On the other hand, when individuals were on their way to independence, professionals needed to be more supportive and to offer reassurance that problems faced are not insurmountable.

**“At that level where you really wanted to get out and you knew there was a way somehow but you couldn’t quite find it. Or you seemed to find it and then your specialist would say, ‘no you haven’t found it, you know. We think you should be in for a bit longer. No, no, we’ll extend your weekend pass but that’s all’... and I don’t want to be in here.”**

Whilst narrators recognised that hospitalisation can offer opportunities for recovery, what they have shown is that in practice, much needs to be challenged for recovery to be better realised. During hospitalisation attention to the individual, their sense of self and worth was considered very important. It was felt that a focus on maintaining the rights and dignity of the individual throughout their stay would build on the sense of security and care people experienced and add an element of empowerment as a resource for recovery.

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## Talking Therapies, Counselling and Psychotherapy

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Talking therapies were experienced as particularly helpful and were said to be a primary route to recovery. Already identified as an important recovery strategy by our narrators, they used them to deal with long term issues and to reframe the way they see and feel about things. This type of therapeutic interaction was often expressed as being enjoyable, and resulted in an increased sense of wellbeing that enabled people to re-engage with work and other life situations.

Talking therapies were experienced most favourably when they were supported with other medications.

**“Talking therapies are no good without my medication, I need both. Helping people understand that what might suit one person might not suit another, and, uhm, a bit of everything.”**

**“I got a psychologist for the first time, and started cognitive behavioural therapy; CBT. And the combination of that and the day support and the individual support I got from a voluntary sector organisation. I think that’s what did it.”**

Some articulated the need to extend psychological services to ensure a more holistic approach within the mental health system.

**“There isn’t enough consideration of the person holistically, there isn’t enough consideration of alternative therapies, there isn’t enough consideration that, if people had quicker access to talking and psychological therapies perhaps their reliance on pharmaceuticals could be diminished.”**

The impact of the different types of talking therapies depended most strongly on the extent to which the approach was person-driven (focus of therapeutic process, timing, duration and location) and the rapport with the therapist.

Psychologists who provided people with the opportunity to talk things through, think differently, break through bad feelings and cycles, understand their strengths, see things rationally again and develop the confidence they needed to address issues were found to be instrumental in a number of narrators’ journeys towards wellbeing. Narrators regarded this way of working, where they got feedback on progress as very supportive and also appreciated that, once accessed, psychological services tended to be more available than other services when you were going through *“a low patch.”*

**(Relationship with Psychologist) “It’s been a very important relationship for me. It’s changed my life.”**

Psychotherapy provided people with techniques to move forward, to manage other problems (such as alcoholism) and get back on track quickly and effectively following minor relapses. It was noted that entering the process in a good frame of mind and developing a good relationship with the therapist facilitated its effectiveness. Success was almost without exception dependent on the narrator expressing that they had a good relationship with the therapist.

Having experienced psychotherapy people often wished professionals had suggested psychotherapy sooner and reported that it was the only thing that helped.

**“I think psychotherapy is the only thing that could help me.”**

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**“I think the things that helped this last while, was getting psychotherapy you know it really helped things out.”**

One narrator who paid for a year of psychotherapy reported that it *“didn’t help me at all. I felt worse at the end.”* However, it was recognised that the value base of therapists is more important than their particular methods.

Several narrators found regular counselling over time with the same counsellor to be a useful support to their recovery. It has linked them to internal and external resources that have helped them face issues and better understand why things have happened in their lives. Counselling also helped people to deal with daily anxieties and to make changes for the better. In situations where counselling had been successful, narrators often reported a reduced need for it over time, until it was used rarely – on demand. However, person-centred counselling was found to be particularly useful to some individuals *because* they had developed a longer term client relationship and saw no need to reduce or eliminate counselling from their treatment schedules.

**“I suppose it’s the talking therapy, the counselling and the talking therapy that have been the most useful.”**

**“They started me with counselling. And that was a great place to start because I started realising why things had happened in my life and what way I coped with them, what way I didn’t cope with them and what I was prepared to put up with, what I was not prepared to put up with and how I was going to sort of fit in with my family, things like that. We sort of explored issues from the past and the present and that’s where I started to think.”**

Narrators most often accessed counsellors and therapists through their GPs.

## Group Therapy

Opinions were split on the efficacy of group therapy. Those that were in favour of it often found one to one counselling too intense and appreciated the peer support offered by groups. They felt there was value in working through issues with people in similar positions – it was easier to have their behaviour commented on by their peers than by professionals. Listening to the advice given to others helped them make more sense of their own situations. They also found that other people could offer insight into their lives through reflecting upon their own experiences.

Whilst several narrators found group counselling *“intense”* but unhelpful, a non-heterosexual narrator reported such environments to be difficult due to the assumed heterosexuality of the group and the homophobia of some group members. Where prejudice was apparent in these groups the experience of it appeared to be intensified as individuals could be made to feel like ‘an outsider’ very easily.

Some people had been involved with group therapy as an alternative to one-on-one counselling. Some established group therapy support groups explored alternative therapies such as massage therapy and aromatherapy. Engaging with these types of services was found to be very positive, encouraging socialisation and sharing of coping strategies for recovery in a setting where clear contracts about self-exploration, professional and personal boundaries exist.

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## Cognitive Behavioural Therapy

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We often heard that CBT helped individuals deal with anxiety and managing voices, and helped them to recognise when they were becoming ill. It taught them how to think and react differently and move away from behaviour patterns that could maintain them in illness.

**“I went through a lot of therapy, cognitive therapy, behavioural therapy... While I was being taught it I wasn't actually able to put it into practise because I was at too low a level, and it's only in the last couple of years when I have been thinking about where I was going and what I'm doing, that I can actually use those skills, now, to help me to be where I am. So... in hindsight it has been very, very useful.”**

**“I have found personally that cognitive behavioural therapy is what's worked for me. It doesn't work for everyone... it's hard work and it takes a long time! Um, but it gives you that sense of ownership over yourself again, I think that's what you need, because I agree that the principles of recovery are that you live well, and you live with your symptoms.”**

Whilst many people found CBT useful, others were wary of it. As with other treatments and supports people noted that finding the right person *for them* was central to success or failure. For one person finding a therapist that would acknowledge and talk to their voices was instrumental in making CBT successful.

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## Other therapeutic interventions

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Occupational Therapists were recognised as helpful. They encouraged individuals to focus on wellness and facilitated them to get out and about. They encouraged people to use hobbies such as gardening, carpentry and photography as part of their recovery strategy after leaving hospital, recognising that such activities also help to alleviate symptoms to a certain extent.

A range of alternative approaches to managing their mental state, reducing anxiety, anger and stress and increasing resourceful states were explored by narrators. These range from hypnotherapy, anxiety management, motivation and anger management techniques, anger management courses, relaxation techniques, music therapy, art as therapy, life mapping, re-birthing, bereavement counselling and CBT. Individuals found such approaches useful in providing strategies and techniques to limit stressful states, however some of these processes were quite demanding emotionally.

**“When I did my music therapy I can remember saying my life was a whole jigsaw and it was all broke into thousands of pieces and that I wanted to make a picture on the other side with all the pieces but a different picture and it's putting those pieces together that is very difficult so for the future, just keep putting the pieces in the jigsaw... and being accepted for what I am.”**

A very small number of narrators shared their experiences of therapeutic communities in Scotland and found the opportunity of seeing peers modelling recovery in these communities very useful.

**“(talking of group therapy in therapeutic community) Everybody's in it together, erm, that it's your peers that are commenting on you instead of someone qualified who is almost sitting in judgement – it is people who are going through the same things that you have gone through.”**



Individuals describe a strong sense of belonging when living in such communities and that it feels like being in a family where you have the opportunity to learn from each other. The social aspect of community living provided people with a ready social life that was felt to enhance the recovery process. However, narrators also acknowledged that the intimacy of the community experience made it difficult to leave. Individuals describe leaving on a high that sustained them initially but then having to develop strategies to deal with the short term lows experienced as they re-engaged with their lives outside.

**“It has been a difficult journey since I came out. When you leave a therapeutic community like that I think most people come out on a real high which lasts for a long time... and that tremendous feeling that you have achieved something, and then gradually that very high has faded away to a level probably a more realistic level.”**

## Alternative/complementary medications and treatments

Relatively few people discussed having explored other non-prescribed medications. One person had used Saint John's Wort which reportedly interfered with other medication. More individuals were happy to try complementary therapies. These included aromatherapy, magnetic re-alignment, crystal healing (and others). A few narrators firmly believed that alternative therapies worked more effectively than mainstream ones.

**“In terms of the traditional statutory services, it's like anything else, uhm, it's very much dominated by the medical model. There isn't enough consideration of the person holistically, there isn't enough consideration of alternative therapies, there isn't enough consideration that, if people had quicker access to talking and psychological therapies perhaps their reliance on pharmaceuticals could be diminished.”**

Others were happy to combine the positive elements of mainstream and alternative therapies.

Complementary and alternative therapies and approaches have been an element of people's recovery but the cost of participation in these therapies where they are not provided by the NHS was found to be prohibitive.

## Psychiatrists

Psychiatrists were a significant feature in many narrators' recovery journeys. Once trust was established, they helped people to sort out issues and were seen as a resource to the recovery process whether seen regularly for years or on occasion as required.

**“My psychiatrist said the that fact that people don't get better it means that something is maintaining their illness. He thinks you know to some extent and again he believed in the healing process if something is not healing then there must be something else at play there.”**

## Relationships, attitudes and power

Many people described how they wanted psychiatrists, to take a more holistic view of them. Although they did want them to explore their symptoms, they required to be seen as more



than a set of symptoms. People perceived a lack of empathy and understanding of their history and the circumstances related to their ill health and life situation.

**“Psychiatrists most of the time came across as being cold and unapproachable.”**

**“If psychiatrists were a little more understanding... If they were just taking maybe a little more time to understand what people’s feelings are, there wouldn’t be so many patients.”**

Problems were seen to be, in part, due to the limited time spent with professionals. Consultations were said to be too short, not as often as required and inconsistent. The power differential between service users and psychiatrists, who were described by some as distant, intimidating and authoritarian, was also discussed as a problem.

**“From that first psychiatrist that I saw... I found (them) quite distant.. and that was quite intimidating,.. because they’re keeping me at a distance.”**

**“They got me to see a psychiatrist. I think I was, I was quite intimidated... you know..., authority figures... So I was quite... afraid of this person... and she started asking all these kind of questions... which was very, very difficult because it makes you feel quite exposed... especially if you’re trying to hide. So I had a lot of kind of inner conflict and... to trust somebody that you’re afraid of, you don’t know anything about, and when you’re sitting there – you’ve had a nervous breakdown – and you’re thinking ‘God, I’m absolutely barking, I’ve lost the plot, you know, like you sort of feel... what am I capable of doing? If I come out with such and such – if I actually tell this person what’s going through my head, are they going to lock me up and throw away the key?’”**

People expressed that negative assumptions and judgements being made about them, based on limited information, had prevented them getting the right diagnosis and support, and therefore hindered their recovery. Fear of psychiatrists’ power to incarcerate, make judgements, disbelieve and dismiss people’s experience made them feel particularly vulnerable. The very professionals they needed to turn to for help were the same people that could have them forcibly admitted to hospital.

**“I was scared, I had enough if you like insight to realise that if this psychiatrist sees me and I tell him that I think I’m Jesus I could be locked away for life.”**

Having a good relationship with your psychiatrist was a turning point for several narrators. Where psychiatrists had good rapport, openly communicated in non-complex language and informed service users about their illness in a hopeful way, it gave individuals a chance to be optimistic about their recovery potential. Letting people talk things through, being committed to them and showing empathy for their concerns helped several narrators find their recovery feet.

**“(What’s helped) A good psychiatrist for a start. When I left hospital for the first time I didn’t want to get him because I thought he was some kind of authority figure, but I came round after a couple of years and I have had him for eight years or something he kind of keeps me straight. I see him every two months.”**

**“Well it’s been a very long process and I think it will always be there so initially it was the talking that helped me, with the psychiatrist, that definitely helped.”**

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## Housing and community supports

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Having a supportive environment, somewhere to call ‘home’ was reported as important for stability and safety and provides a base for contact and support from friends and family. Housing problems or the lack of a supportive ‘home’ environment, was found to adversely affect recovery potential if not addressed.

Narrators passed through various types of accommodation on their journeys to wellness, indeed the numerous types of accommodation experienced by narrators adds emphasis to the highly individualised and dynamic nature of recovery journeys. Throughout the various types of accommodation they inhabited narrators were united in their view that affordable and comfortable accommodation that provides security, stability and shelter within a supportive community is necessary to facilitate their recovery journey.

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## Housing Finances

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Housing benefit and other forms of income maintenance has enabled narrators to keep their mortgages and maintain rented tenancies, however, confusion over entitlement and fear of losing benefit often forced individuals to stay in unsuitable accommodation. The rules governing these benefits also proved too stringent for some narrators who feared losing their benefits and associated accommodation after lengthy stays in hospital.

**“I can’t change my mortgage while I am on benefits and be assured of getting the same support. So I am stuck where I am at the moment until I can get back to work.”**

**“The minute you tell them of any changes, like that with the housing and somebody had reported me and they stopped the housing benefit without actually checking it out, they stop it and then they check it out.”**

**“The housing fraud people came to visit. I was thinking that I was going to lose my house because I am not living in it. So my house, if I stay away from more than two years, I lose my house, so it doesnae do anything to help your recovery.”**

Some narrators found that being on benefits limited their ability to choose accommodation whether it be rented or privately owned as they were unsure if current benefits would transfer to cover the costs of new property.

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## Own Home

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Having your own home was found to increase subjective wellbeing. Some narrators indicated that having something to own and look after, a private space in which to develop and recover, gave them a sense of self-respect and pride. This helped them to move from being ‘that person with mental health problems’ to being just another respected member of the community.

**“When I got the flat that I am in now, for the first time it was my house and it was my space and I could fill it with my memories and, you know, there wasn’t any baggage there... and it was a place where nobody knew me, nobody knew that I had mental health problems, nobody knew who I was. I was just a person who had moved into this flat, and it’s still the same to some extent, you know. I’ve got the kind of privacy that, you know, that people, well people know, obviously when coming out of the house, they see me in the lift, but it’s not like ‘here is this person with mental health problems living in this house.’”**

Having physical space was important for individuals. Some people liked to share the space with others whilst others valued solitude and their own space. Narrators emphasised that this choice should be down to the individual. For some of the people that had been hospitalised the idea of living on their own was daunting, whilst some became accustomed to it over time before growing to like it, others felt a sense of isolation and lack of support.

Feeling rooted and stable in their homes increased people's confidence. One narrator believed having your own home puts you on a more equal footing with professionals that visit. Indeed, for some, even contemplating owning property and taking responsibility for it was in itself evidence of recovery.

**“So now as long as I keep working and pay my rent I have my house and it's all mine. I need the security.”**

**“Having my own flat removed most of the power-balance along with a few professionals who rose above their professional barriers and treated me as an equal and supported me through my choices and testing of myself.”**

**“I'd love to have a little house somewhere very modest that is mine you know just to be allowed to live my life in peace.”**

## From hospital to community

Most issues that concerned housing in narrators' stories related to the transition from hospital to community. This transition was regularly smoothed by housing support agencies with varying degrees of success. Having the right and responsibility to look after yourself after a period of institutionalisation helped individuals grow in many ways. Indeed, some narrators fulfilled lifetime ambitions upon gaining their own home after hospitalisation, and many individuals equated moving into their own accommodation with improving their sense of self-esteem. However, many individuals faced numerous accommodations and tenancies before finding settlement and security in their home.

Some individuals in more rural or island settings reported problems in transition from hospital back into the community indicating that resettlement accommodation was often located in isolated areas that were not well serviced by support networks. A small number of other narrators also indicated that the housing offered in the community was often in less preferred locations, forcing 'first offer' houses to be rejected.

**“Some of our members have had major problems when they've come out of, of the acute psychiatric unit and maybe lost their homes because of their illness. They are getting housed, out, way out in the country, the other side of (PLACE).”**

Moving back into the community from the safe, social and nurturing environment of a hospital was a big step and required delicate help. Transition from hospital to the community needed to include time to recover from being *in* the mental health system.

**“You are put back into the community you know, and it takes you a bit of time to get together and that, and how you feel... I think a bit of understanding sometimes with people and that, you know you can't just get through on fresh air, but I think it's a bit hard for people to change, to change from what I was like in a sense, to fit back into the community, from being ill. It's hard like.”**

Phased transition to living at home posed some very practical challenges. Some hospitals

provided link services to patients, trying to help them regain their independence at home. These services were appreciated by narrators who were learning to cope for themselves again.

**“Some of the nursing staff would come over with me in the car and look at things, which again were every helpful and great, and that was good... they did link you back to home, I couldn’t criticise them for that, if I wanted to go then someone would come with me in the car.”**

Services such as link services, supported accommodation or housing support helped ease the initial loneliness and difficulties of moving back into or being isolated in a community.

**“...’Cos for a lot of people it is incredibly lonely when you come off the ward, surrounded by people, to your house, where the only person who lives there is yourself... like a half way house, it’s making that transition, because being in hospital is one thing and being at home is completely different.”**

Some narrators found it difficult to reintegrate into their community after being given their own accommodation. They felt the reduction in support to be challenging and in some instances felt incapable of leaving their house; overwhelmed by the numerous things that householders have to deal with like paying bills, maintaining a house, keeping appointments and socialising on top of looking after themselves. An apparent service gap was evident in these circumstances.

**“They are closing all the hospitals but they are not actually putting trained workers in place to deal with the people coming out of hospital.”**

Overall, this transition process needed to be done at your own pace. Taking on too much too soon was not conducive to good health.

**“I would definitely like to see more support in the time from when you’ve been going all the time and getting it everyday to when you come back and then you’ve got somebody once a month.”**

## Maintaining a link with home

Where narrators were supported to maintain links to their homes whilst in hospital, transition back into the community was much easier. Being encouraged and supported by staff to go back and check their homes, feed their animals and meet their friends at home, and to gradually increase the frequency of this over time eased the return to community. However this gradual reintroduction often created its own domestic problems, especially where people lived part time in both environments.

**“The problem was having to get just enough stuff in the house, just last those three days. Instead of doing a weekly shop, you couldn’t, could only plan it for three days because if you had any more than that, heck if you didn’t come back again it would go off in your fridge and smell.”**

Regardless of phased reintroduction programmes, some individuals still felt that their reintroduction to the community was very fast, and appreciated being able to keep up their links with hospital led activities. The practical help and emotional support provided by CPNs to people returning to the community from hospitals and therapeutic communities was well received.

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## Supported Accommodation

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Many narrators had lived in supported accommodation at one point. Some compared it very favourably to being in hospital.

**“In a way it’s like having the best of both worlds because you’ve got all the home comforts and everything and at the same time if you don’t feel well there’s always someone on the end of the phone to talk to, so yeah it’s the best of both worlds I think.”**

The freedom that supported accommodation affords combined with support allowed individuals to share responsibility for self and others and allowed them to gradually make choices and become more self-determined. It allowed individuals to develop their individual identity offering more freedom than hospital and support as people re-engaged socially finding their place in the local community.

Shared domestic responsibilities and communal living with people who had similar issues allowed for the development of people and life skills in a safe space and built confidence, self-sufficiency and caring skills.

**“It was such a large house, you were sharing with about eighteen people including the staff and the house would tend to get quite dirty and people would leave cups and things all over the place. So in the morning you had a cleaning sort of two hours where you would clean the house and then some people would go out and get shopping for the day as you were going to feed people... In the evenings you’d get involved in cooking, so you would end up cooking for about eighteen people which was quite fun.”**

It was noted that as ‘people living in the community’, individuals were better informed of the range of supports available to them than they were in hospital. Supported housing provided more stability for people in transition from hospital than did the temporary accommodation that a few narrators found themselves in. The stresses associated with temporary accommodation reduced the energy and focus on keeping well, although for one narrator this served to hasten their recovery as they made the effort to move on.

The negative aspects of supported accommodation related to feelings of loss of power and not being at home, and to feeling like a guest in someone else’s home.

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## Housing Support

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Housing support services offered to find accommodation suitable to individuals’ needs – usually via housing associations or local authorities, they also aided individuals’ resettlement in their own home. They assisted individuals with benefit advice, managing finances and documentation, and finding out about local community facilities and services.

**“I think that the support I’ve had from the housing support organisation has been a key factor (in recovery). I was introduced to them a good number of years ago, and I’ve only ever been shown respect, and treated as an equal. I think that recovery has allowed me to take on that responsibility and live independently in a flat, with support from (AGENCY), and that in itself has given has given quality of life that I’ve never experienced before.”**

A few narrators felt that their recovery journeys had been set back by having inadequate support in their homes after release from hospital.

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**“I didn’t get the help that I needed and the type of help I needed at that time, whereas if the support had been there, in the way of housing support and things like that, I could have then gone on, I believe, to recover far sooner.”**

People expressed the need to be in control of the support they were given. The security of knowing that someone could come to your house to provide help should it be required was a very important safety net for individuals as they increased their level of independent living. Even if they seldom needed the support, just knowing it was available was often enough. It was felt that it was important that such support was not forced upon individuals and that they should have a say in the whom, when and how it is delivered.

## Homelessness

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Insecurity of housing tenure and homelessness intermittently hindered recovery for several narrators. To be faced with the prospect of homelessness was considered to be damaging to individuals’ sense of self-confidence and recovery potential.

**“Well, I was in one hostel; it was just a homeless hostel. It wasn’t beneficial, it was good to be around people, but it didn’t help me address myself or my symptoms.”**

**“I was homeless they wanted me to move into a hostel and immediately, and I always owned my own house. I couldn’t, it was the fear factor again, all these men they could be drug addicts or worse or God knows what so that’s sent me over the edge.”**

Homelessness was the result of a variety of factors including an inability to cope with bills, financial difficulties, voluntary or coerced removal from housing due to stigma, housing lost during institutional care or as a result of family breakdown. Whilst many of these reasons for homelessness can affect anybody, of particular concern to individuals with mental health problems is the prospect of losing a family home during extended periods of institutionalisation or being forced to leave a home due to perceived stigma in the community.

The financial implications of hostel living and homelessness are very challenging. Due to the temporary nature of many of these accommodations and the transient situation of the residents, time there was often accompanied by a lack of income. This further hindered recovery.

**“I think it’s quite difficult if you’re staying in a hostel environment, you only have a food allowance and a personal allowance to live a fulfilling life. How do you have a social life on top of that? Financially, it’s very difficult to do.”**

Narrators have shown that recovery is a dynamic and highly individualised process throughout which people develop self-determination and responsibility by developing coping mechanisms that allow the maturation of a sense of identity outside the illness. This recovery is aided by the sense of security and community one can feel when settled into a safe ‘homely’ environment and as such, support to obtain this environment should precipitate recovery.

## Financial security

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Having the knowledge that finances were relatively secure was one less thing to worry about for individuals. Financial security came from income benefits, wages from work, and from partnership incomes in a traditional domestic setting (housewife/househusband type roles) and from inheritance. It was felt by many that to be ill had costly repercussions in terms of lost

income and lost potential for earning greater income. For some erratic spending patterns at times of ill-health could contribute to the financial cost of ill health.

Although income maintenance benefits such as Disability Living Allowance, Severe Disablement Allowance, and Short and Long Term Incapacity Benefit and Tax Credits were found to be essential supports for those who couldn't work (or were on low income) questions of eligibility, entitlement, fear of withdrawal, difficulty in initially accessing the benefit and the low level at which several benefits are paid were factors that recipients found to be challenging and unsupportive to recovery.

## Independent income

Some of our narrators were financially independent and used income sources from paid employment, savings or inheritance to finance their everyday activities. For those individuals who were financially secure it gave peace of mind and was definitely appreciated as 'one less thing to worry about.' Whilst some participants were discretely guarded when discussing issues of a financial nature others were more forthright in their discussion.

**"I don't work at the moment but I had enough money that I didn't have to worry, which was fine. I mean I do know that I was spendy, really spendy but that's fine, I haven't left myself in debt or anything which is good."**

**"I don't have immediate financial problems. That's something that I am very grateful for. Though although I am kind of concerned about (finances) –, and I might say if I had absolutely no worry about finance that might be a help."**

Whilst some individuals had independent means, most received some form of income assistance from the state and in the main narrators' discussions around income focused on issues of benefits and supports and their role in recovery.

**"Well I get benefits obviously but the social security know how much I've got in my building society now and I'm sort of over the limit so that means they have to reduce the benefits... But no, money's not really been a problem over the past few years. I think as long as I've had money to buy fags!"**

## Income from work

Obtaining financial security through employment was an important aspect of a number of individuals' recovery journeys. Earning a living gave several narrators a high degree of pride and a sense of accomplishment especially where individuals had previously been benefit recipients.

**"Actually becoming a member of community and contributing to society instead of living off the state."**

**"At least I had done it and that made me feel good, that at least for three or four month I had actually held down a job and I had actually got paid. And that made me feel good that I wasn't, you know, totally living off benefits and I was, you know, I was going out to work and I was, you know, contributing something"**

**"Yea, and so from that point of view I am not willing to sit back and just be on benefits, I hate being answerable to somebody giving me money, you know, but, other than working for it."**



There was a distinct financial imperative to work and access earnings in spite of ill health. Indeed, getting your life together equated to moving off benefits and into paid employment for several narrators. However, poor finances sometimes forced individuals back to work too early, also, some narrators complained of being forced to accept lesser rank positions in work after a period of absence due to ill health.

**“I know that when I went back to work the last time I was depressed, I had a job to go back to, that I didn’t feel I was ready to go back to work and one of the reasons that was quite nagging at the time was that my pay was going down to half pay and I couldn’t afford to pay the mortgage.”**

**“Aye. I was on £15,000 a year five years ago and I’m on £9,000 a year now. It’s still... there is people power... I’m not sitting here pleading poverty but what I’m trying to say is it’s trying to manage a different amount of money.”**

The pride that is found in the ability to financially provide for yourself and your family was often removed by ill health and welfare dependency. There was a general feeling that narrators didn’t want to be in a financially dependent position but that ill health and an inability to work had forced many into this situation.

**“It was difficult at the start because I didn’t have any way of communicating to authority and money was short so I just struggled on... I didn’t have the worry of a mortgage and Council Tax. That all was taken care of by the DSS. I felt guilty at first taking money, a lot of money, that I hadn’t earned but then it got through to me that I had to do this. But I didn’t like it; I didn’t like taking money from the government for not working.”**

For some individuals, having the burden of coping with family budgets removed or shared with partners aided their recovery journeys.

## Low income

For some, a frugal and diligent attitude towards finances helped them maintain order in their money dealings and helped them evade the stress of financial worry.

**“I try and be more frugal with my money like, try to walk a lot... I don’t need to waste money... So I don’t have to worry too much about financial problems and I’ve got savings in the bank, and the fact that my partner’s not working can be a hindrance but he’s determined to look for a job and I think he’s smart enough and we don’t do dead expensive stuffs, activities I mean.”**

**“(Of being on benefit income) you learn to live on what you need rather than what you want, that’s for sure. And feel quite satisfied with what you need as opposed, I mean, I’ve never really been materialistic anyway but I actually feel guilty spending money on something that I don’t actually need nowadays.”**

For some who had a low income, financial insecurity became an enduring stress. Almost all individuals were of the view that consistent financial security is needed to promote recovery.

**“Finance is very important to me. If I’m in debt I get ill and don’t feel well but when I’ve got money in the bank I feel fine. It’s as simple as that. I don’t know why but there is some kind of correlation.”**



Having a fixed or low income removed the opportunity for some individuals to plan their future with any degree of financial certainty and was therefore a hindrance to maintaining their recovery. Most of the narrators who were not in paid employment received several sources of benefit income to cover living and social expenses. The combination of these benefits plus in kind services was acknowledged as helping them pursue more fulfilling lives. For some it meant that they did not have to consider going back to full-time employment and could establish a more manageable lifestyle that included limited work, volunteering, education and creative activities.

## Income maintenance and dependence

There is a fine line between empowering individuals with benefit income and creating dependence according to several of our narrators. Numerous individuals recognised that dependency on benefits is not conducive to their idea of recovery. They indicated that to become 'used to' being on benefits can be detrimental to self-esteem and the desire to contribute can be eroded by lack of motivation. For individuals accustomed to working, going onto income maintenance benefits were initially found to erode confidence.

**"I think a lot of people have got used to being on incapacity benefit and they don't have so much motivation to pull themselves out of it. And some people are difficult and manipulative and it's not good for me really, and there are others who do a tremendous amount of work for people and a lot of them are as badly off as the people who they are helping. So I found myself getting a bit pessimistic about that really."**

For some, being granted benefit income helped their recovery as it legitimised or confirmed their illness and acted as a focal point from which to recover. Benefit receipt provided many with financial autonomy which improved self-confidence and self-determination as well as easing more pressing money worries.

The overall feeling from narrators was that income maintenance supports take the pressure off financial worries and allow individuals to concentrate on trying to get well, pace their re-entry into work or other purposeful activity, lead a healthy creative life and maintain their social life.

**"Finances are something that can hinder and help recovery. The safety net of having comprehensive benefits... it does help your recovery, it keeps you stable while you're ill. You know but for a lot of people they get too comfortable whilst being on benefit and that can maintain their illness. Certainly I would recommend that people who are ill you know they don't have to have financial hardship while they are recovering you know."**

## Benefit problems

Some individuals were caused undue stress when their means of financial support was removed by social security officers. The removal of time limited benefits often came at a period when individuals were too unwell to challenge this. Indeed, benefit removal served to temporarily impede several narrators' recovery journeys.

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**“I had just had, during a long period of affliction, I had only had Disability Living Allowance for twelve months, and then it was withdrawn. And I was just so hacked off, and I really couldn’t cope with the appealing against that decision, although I should’ve done at the time.”**

**“For two and a half years I had to appeal (for DLA) and obviously during that period of time I was on a very low income...”**

**“So I’m going through an appeal tribunal but the stress of that has made me unwell. I’ve had no support from my health care professionals because some of them have said they won’t provide evidence because they don’t have time to write letters - GPs and things. Others have said the best thing for my mental health would be would be having a job, employment and I agree if I was well enough to work it would maintain my mental health. And they think my motivations are financial and I want to sit on my butt at home and collect benefits and not go to work.”**

For one individual, the trauma of benefit removal proved to be instrumental in beginning their recovery journey. Their ambition had always been to support their family through work and the removal of benefit income forced this situation to a head. This triumph over adversity is further evidence of the diverse and contradictory nature of many recovery journeys.

## Navigating the benefits system

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Often when it came to applying for income maintenance, benefits agency staff and GPs were ill equipped to help individuals fill out complex forms. When people are ill they are not in a position to cope with the complex systems of assessment, information sharing or interaction required of them. Welfare rights officers, CPNs and support workers were often approached to aid form completion and to provide advice on the procedures, rights and implications for working and volunteering.

**“In 2004 I was quite unwell for the whole of the year, and I was so unwell that I couldn’t go through the stress of filling out a 16-page form to try and get the benefit.”**

**“The other week I went to find out what would be the implications if I worked more or less in my job – what would happen to the tax credits and that sort of thing.”**

One narrator commented that there are perverse incentives inherent within the benefit system to encourage folk to ‘stay ill’. The transient and often fluctuating nature of some mental health problems meant that individuals feared losing benefits when feeling slightly better. In return it was felt that this chronic fear didn’t help individuals get any better but merely added to anxiety causing some narrators to imply that the structure of the benefit system hinders recovery.

Trying to prove ill health in order to qualify for benefits was reported to be a rather undignified and often stressful experience. Proving you are ill has consequences on confidence and health as it exposes individuals to the more negative aspects of their mental health experience. Employers and social security officers often tested individuals to prove their eligibility for sick pay or additional disablement allowances. It was felt that this degrading and often undignified and stressful experience doesn’t encourage those in need to claim for the assistance they are entitled to.

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**“To be asked the same questions again and again; and the problem with part of this is the questions tend to be more of a kind of negative, incapable... it’s like... it’s almost like ‘prove to us how ill you are’. And that has an impact on your mental health.”**

It was speculated that the current income maintenance system in the UK is more geared towards helping people with physical illnesses and disabilities. Perceived problems with the current benefit system were that it is overly complex, difficult to negotiate, and depended on strangers (not your general practitioner) ‘believing you are ill’ at time of benefit application and interview.

**“Everyone with mental health problems always gets refused the first time they apply, and it’s all geared around physical problems – the questions they ask on the form doesn’t take into account mental health at all.”**

**“I think the benefits system should be changed to be more geared towards mental health people. And maybe through somebody who really knows you like your health visitor or nurse or the psychiatrist or somebody rather than a stranger who sees you for ten minutes and says, ‘Well you’ve driven yourself there, you know, therefore you’re alright.’”**

Overall benefit receipt was considered a positive experience, but application and a potential development of dependency on that benefit were considered negative experiences. Narrators implied that there is a fine line to balance between empowering individuals with benefit income or creating dependents.

For people with mental health problems the need to re-establish meaningful fulfilling lives is important. The personal, social and economic losses associated with mental ill health are often profound and require resources to recover a sense of positive future. The economic insecurity and stresses related to mental ill health can limit people’s sense of security and aspirations for the future. Although people can and do learn to live with, and take advantage of less money and more time, many narrators needed more clarity and continuity around their benefits and income support entitlements.

# Treatment and Supports Discussion

The recovery stories provided by our narrators describe a journey that is punctuated by occasional setbacks from negative experiences, stigma, loss of faith in self and others and a poor experience of support services. They are also punctuated by positive turning points like witnessing a peer's recovery, receiving a diagnosis or the right treatment, finding the right therapist, becoming financially secure, settling within a community and feeling a sense of belonging or finding love and acceptance in mutually respectful relationships. What is common in these stories is that individuals spring back in spite of adversity and learn from their experiences. Recovery is most definitely a non-linear and unique journey for individuals.

# Treatment and Supports Discussion

**The National Programme for Improving Mental Health and Wellbeing sets recovery within a public health context. The programme is working to improve the mental health and wellbeing of all people in Scotland regardless of their experience of mental health problems. One of the four key aims of the programme is to 'Promote and Support Recovery' (Scottish Executive, 2003b).**

As we have outlined in previous chapters, factors which may be described as internal to people in recovery, like identity and self direction, and the extent to which people are able to engage in meaningful activity are central to recovery. In addition, the way in which people who experience mental health problems are supported within their communities is vital. This reminds us that, in the main, people recover in communities and that we must be wary of assuming that the extent to which people recover is solely determined by treatments and supports offered. However, there are things we can do to consider the extent to which our treatments and supports are oriented around recovery. In doing so we must be prepared to look beyond traditional approaches and to be informed by the lived experience of people in recovery.

Scottish policy is conducive to promoting a recovery approach in treatments and supports. Many overarching policies and reports have explicitly or implicitly acknowledged or highlighted elements which we have been shown in this report to be important to recovery. The Kerr Report (2006) and Delivering for Health (Scottish Executive, 2006) recognise the need for people with long-term conditions to better manage their own health and wellbeing. The Social Work Review (Scotland. 21st Century Social Work Review, 2006) outlined the need to personalise social care services to ensure they meet individual need. The principles of Scotland's Mental Health Act (2003) link closely with many of the principles of recovery offering a supportive and rights-oriented basis for care and treatment at times of most severe illness, while importantly acknowledging the key role of meaningful activity. It puts duties upon Local Authorities and Health Boards to enable access to community supports, like employment and recreation. More explicit references to recovery as a framework for policy development in Scotland are to be found in Rights, Relationships and Recovery (NHS Scotland, 2006) and Delivering for Mental Health (Scottish Executive, 2006).

Rights, Relationships and Recovery articulates a new values base for mental health nursing and suggest that practitioners should adopt recovery '*as the model for mental health nursing care and intervention, particularly in supporting people with long-standing mental health problems.*' It outlines a number of supporting actions including the development of new recovery training for all mental health nurses which is being jointly progressed by NHS Education for Scotland and the Scottish Recovery Network.

The first two commitments of Delivering for Mental Health (Scottish Executive, 2006) relate explicitly to the orientation of practice and values and attitudes in mental health services in Scotland. Commitment one is to develop a tool '*to assess the degree to which organisations and programmes meet our expectations in respect of equality, social inclusion, recovery and rights.*' SRN have been working with partners to realise this commitment, adapting an existing tool 'ROPI' (Mancini & Finnerty, 2005) for use in Scotland. The Scottish Recovery Index (SRI) is being tested in a number of sites across Scotland and should be in general use by 2010.

The second commitment relates to the development of formalised peer support services, where people in recovery are trained and employed as a new type of worker to complement and add value to the existing workforce. Peer workers will be trained to use their own recovery

experience to support recovery planning with service users offering the key elements of hope and self direction. This commitment to recovery-oriented peer support clearly recognises the unique strengths and attributes which can be gained through living with mental health problems and signals a willingness on the part of the Scottish Executive and stakeholder groups to be innovative.

## Diagnosis

Receiving a diagnosis can have both pros and cons. For many narrators getting a diagnosis was reassuring and enabled them to affirm their own understanding of what was happening to them, confirm to themselves and others that they were not ‘making it up’ and allowed them to embark on their recovery journey. This journey included researching symptoms, treatments, medication and their side effects, learning from others and generally taking control of the situation. However, an equal number of people felt that getting a diagnosis disempowered them and opened them up to assumption and stigma, limiting their options in treatment, care, work, benefits and support in the development of recovery strategies. Diagnosis for most narrators continuously changed anyway.

The management of the process of arriving at and communicating a diagnosis and its implications for recovery need to be considered carefully and explored sensitively with people. People need to feel there is hope and need to be empowered not only to manage their symptoms but to take control of their situation. Systemic problems with assumptions around whether people can still work, access disability income benefits, need hospitalisation, care and support need to be addressed at time of diagnosis to ease fears.

The assumption that mental illness is a lifelong condition is reflected in the continuing hesitance of many mental health professionals to provide a positive prognosis for social recovery (if not full recovery) for individuals. Hamilton-Wilson *et al* (2005) argue that experienced clinicians often believe that diagnosis of a psychotic disorder means the end of a fruitful and meaningful life. Given narrators’ responses to diagnosis it is evident that this belief is still being transferred to service users with potentially damaging long term consequences.

## Continuity, access and flexibility

Shifting the balance of care from hospital to the community is a key challenge within Delivering for Health (Scottish Executive, 2006). This continued drive for community based services should hopefully encourage better and more connected services within the community and provide better collaboration between services. The Scottish Recovery Indicator work which is in development at present will help generate best practice examples of care.

Additional attention to the provision of activities, techniques and therapies that create opportunities for people to access and maintain resourceful states would enhance their range of coping and recovery strategies, especially if there was a coherence and consistency between the services, treatments and supports received in hospital and those they are supported with on discharge.

Quicker, more consistent and flexible access to services with fewer gatekeepers and more commitment to providing agreed continuity of support and continuity in personnel is needed

in many services, but most particularly in psychiatric services. Support needs to be more flexible and responsive to people re-establishing themselves. Where such support is offered in a timely and effective manner, it can promote recovery and reduce longer term need for support. We hope this report leads service planners to consider how they can provide services which ensure the flexibility and continuity that people in recovery told us they need to maintain their wellbeing.

## Medication

It is clear that a shared decision making approach to treatment and medication – a therapeutic alliance – should be promoted in situations where professionals can mandate treatments that conflict with the desires of clients. This alliance is clearly preferred by narrators and person-centred clinicians.

Overall, our narrators belonged to four schools of thought regarding medication, although they were not mutually exclusive. The first believed that there was no way they could have recovered without medication. The second believed that the process of getting the right medication was complex and had many problems and should therefore involve the service user in the management and evaluation of medication. The third felt that the side effects were so debilitating that they were not worth enduring and in addition, the only reason medications were used was to make individuals 'fit in' to society. The final group equated recovery with living medication free.

The key issue arising from the narrators, regardless of which of the four schools they subscribe to, is that they should have a prime role in the decision making, management and evaluation of their own medication whenever possible. This not only allows them to better manage the side effects and establish responsive regimes but also addresses the issues of power and disempowerment, rights and self-determination, and self-esteem.

## Treatment and supports

This research adds to the growing body of research, good practice examples and guidance around what types of services support people with long term mental health problems to recover. Promoting access to these services and treatments requires recovery focussed staff and the willingness to support people through their individual recovery journeys to meet their hopes and aspirations. Since a recovery indicator tool is being developed in Scotland to monitor the service level recovery orientation of different agencies and organisations, dissemination of best practice potentially has an important role to play in the implementation of recovery-oriented practice throughout Scottish services.

Although alternative and specialist therapies have proven to be popular and successful with our narrators, access to these therapies through the NHS is currently not consistent. Narrators have shown that they are keen to try out different non-pharmaceutical methods of managing their states of wellbeing and this should be supported and reflected in regional health services through increased consumer choice. Several narrators recounted that the right combination of therapies enabled them to reduce their reliance on pharmaceutical combinations.

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## Professional helping relationships

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Much of what is discussed by our narrators is quite common in ordinary human relationships – the need to feel respected, to be able to trust and share hope and communicate reciprocally with others in a non-threatened way.

The development of a helping and supportive relationship with professionals was often a pivotal turning point in narrators' journeys. Our narrators regarded demonstrations of empathy, trust, collaboration, shared power, respect, personal investment and kind gestures as most helpful in their treatment relationship with mental health professionals. These findings replicate findings from Borg and Kristiansen (2004) and Schinkel and Dorrer (2006).

Narratives do, however, show great variation in the quality of professional relationships experienced. In many ways this reflects the variation one would expect to find in human interactions, particularly where the relationship is founded on an unequal 'service provider/service user' basis. However, we believe that the helping and hindering role of supportive relationships in recovery warrants increased emphasis in the recruitment and training of mental health professionals. In addition, it suggests that service users should be enabled to identify where they do not feel that a relationship with a professional is helpful to their recovery.

A central determinant of whether a relationship with a professional would be helpful to recovery was the attitudes and values of the professional. Narrators clearly identified the importance of working with people who believed in their potential for recovery and who relayed a positive message of hope, perhaps most importantly at initial diagnosis. We believe this provides a clear message to planners, policy makers and practitioners alike around the need to emphasise the key role of attitudes and values in mental health service provision.

The Royal College of Psychiatrists has begun to incorporate a recovery ethos into its work (K. M. Berzins, 2005). Consultant Psychiatrists are now being encouraged to deliver effective person centred care in mental health (Royal College of Psychiatrists, 2005). This will undoubtedly support recovery for clients.

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## Housing

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Agreeing with the Canadian South West Mental Health Implementation Task Force (2002), it is the view of the authors that a continuum of community-based housing with supports, additional community support and private accommodation must be safe and affordable and must provide flexible interventions that respond to individuals changing needs to support recovery.

Housing support organisations' contributions have been valuable to individual recovery journeys in various ways from providing shelter to encouraging responsibility for self and others.

Although Local Authorities have strategic responsibility for assessing and meeting housing needs of citizens recovering in the community (Blackman & Harvey, 2001) homelessness was still an issue that confronted several narrators at intermittent periods throughout their lives. Findings from the New Zealand Mental Health Commission that indicated the importance of housing to self-esteem and community integration were shared with this study. Similarly, several of our narrators experienced losing their homes due to ill health and as a consequence



financial insecurity or extended hospital stays. Increased attention to ‘exit needs’ for individuals whilst in hospital should be addressed to help ease their community transition and to ensure individuals do not lose their homes or other resources (jobs, friends etc.) through ill health, loss of income, community stigma or lack of support to maintain their residency.

Services and benefit systems should not discriminate against those who own or rent their homes but should provide flexibility in support to reflect the diverse population of individuals in recovery from mental health problems. It is also crucial that those people that do not have homes be assisted to establish them and those medical decisions, benefits and support services do not undermine people’s ability to decide on where and how they want to live.

It is important that support in the acquisition, establishment and maintenance of a home is designed around the needs of the individual, taking into account their preference for supported, communal or independent living and acknowledging that this preference may change over time. Support services that provide a responsive, on demand service allow individuals to embark on a recovery journey with an element of security.

## Financial supports

It is more difficult for people to develop and navigate a recovery path when resources are low and income is insufficient. Financial security or insecurity impacts on individuals’ lives in fundamental ways. It can determine diet, health, levels of social participation, where and how they live, and the maintenance of social and family networks, working patterns and aspirations and planning for the future.

The transient and invisible nature of many mental health problems means people are often open to scrutiny and having to prove their mental ill health when least able to cope with such scrutiny. Clearer concise claims processes with definitive criteria for applicability would solve some application related stresses.

Fear of benefit removal hinders people’s recovery. Since risk aversion is a primary problem for many people with mental health problems the risks involved in transition from benefits to work need to be further reduced. As discussed in our previous chapter on engagement, income support policy is slowly beginning to recognise the intricate nature of recovery and mental health problems. As such, legislation now allows for individuals on incapacity benefits to return to their former benefit level if they become ill again within two years of returning to work. This generic rule should in principle encourage and support individuals back into employment without risking loss of benefit upon recurrence of ill health problems.

## Conclusion

Although narrators were mostly positive about treatment and supports they argued that supports need to be more responsive to the changing and diverse needs of individuals. Many believed that more heterogeneous services would help recovery and that current services should be more recovery focussed in their availability, design and practices.

External factors such as the availability of necessary or desired treatments and services, financial pressures, the availability of support from outside services such as housing, fear of fluctuating benefit income, the perceived stigma and isolation of mental health problems, and the fluctuating nature of these problems often had to be addressed and managed in order to further individuals recovery journeys.

It is difficult to construct common descriptions of individuals' unique recovery experiences. However, with a growing body of evidence, it is now widely recognized that people who have serious mental health problems can participate actively in their own treatment and recovery and can become the most important agent of change for themselves (Mueser *et al.*, 2002). Allies and accomplices who are recovery focused have been found to help individuals move towards recovery with astounding resolve. Professionals who show a deep commitment to individuals (over time), using their knowledge, but also learning from and respecting individuals facilitated recovery. Access to the right resources and services at the right time can also facilitate this process.

In some ways our findings around treatments and supports reiterate what many people have been saying for some time, i.e. that person-centred services help people lead fuller lives and better promote recovery. It is perhaps the fact that this message is not new which suggests that we have some way to go before we have a service system which works to the satisfaction of all stakeholder groups, as acknowledged in Delivering for Mental Health. What the narrative research offers is fresh evidence to support the development of recovery-oriented treatments and supports in Scotland and a powerful endorsement of many recent developments in policy and strategy.

Beyond mental health services there is work to be done to enhance capacity and opportunity for people to help themselves and their peers. Throughout this research narrators have identified the broad range of skills and strengths which people in recovery gain. Better harnessing and formalising these strengths, through, for example, self-management and awareness programmes, could help us reduce the demands on formal services, promote self-direction and responsibility and achieve better outcomes.

# Pacing and Turning Points Summary

When recovery journeys are detailed in their entirety as they have been in this research, what becomes apparent is that there are several points at which the opportunity to begin a recovery journey can present itself. These turning points emerge from situations, conversations, realisations or epiphanies, they are often serendipitous in nature, a chance conversation with someone about their recovery; meeting the right support worker with whom you click; trying out a new coping mechanism; or just realizing that *“there’s more to me than my mental health.”* With each turning point came a shift of perspective, from seeing someone as a victim of circumstance to seeing them as an individual with choices and with responsibility, a shift that helped people to make the changes they needed to recover.

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# Pacing and Turning Points

## Pacing and process

Recovery has been described as an outcome or a desirable end state. It has been described as *“a process, a way of life, an attitude, and a way of approaching the day’s challenges. It is not a perfectly linear process... (it is) the aspiration is to live, work, and love in a community in which one makes a significant contribution”* (Deegan, 1988). Recovery literature describes the ongoing process of being ‘in recovery’ (Ralph *et al.*, 2002) as a process or journey that involves regaining various aspects of life that may have been lost or severely compromised by mental illness.

The narrative research illustrates that this journey towards wellness can be lengthy and has to be travelled at an individual’s own pace.

## Starting point

Several researchers have described the process of recovery as having derived or originated from a significant event, defining moment or turning-point (Allott & Loganathan, 2002). Often, these turning points have been positive, but sometimes they have been reported as low points from which to rise (Rakfeldt & Strauss, 1989; A Topor *et al.*, 1997). Allott *et al* (2002) argued that the most significant element of a ‘turning point’, is a change in how individuals perceive themselves in relation to their symptoms and condition and their own lives.

Whilst authors (such as Roberts & Wolfson, 2004) acknowledge that the experience of turning towards recovery may come out of the blue, a number of factors have been identified as having potential to cause a turning point, the most poignant of which is a ‘catalyst of change’ (Allott & Loganathan, 2002), that is: a person who positively affects or changes your perception; a significant event; or change of circumstances that forced decisions to be made. The genesis of recovery is most often described as originating from talking to others, particularly to other service users rather than professionals (Roberts & Wolfson, 2004; Snelling, 2005).

Kirkpatrick *et al* (2001) recall that many first person accounts of schizophrenia describe regaining hope as a turning point in a person’s recovery. Anich (1997) found diagnosis to be a turning point of decline into ill health for some, and Deegan (2001) found diagnosis (or rejection of it) to be a major positive turning point in her recovery. So yet again, different experiences clearly illustrate diverse perspectives on what helps or hinders recovery. Mieke Kotake Smith (2000) found acceptance of one’s disability as the first of many major turning points towards recovery.

Snelling recognised that the narrative interview in itself could provide a turning point for reintegrating valued aspects of self into the recovery journey (Snelling, 2005).

# Pacing and Turning Points Findings

## Shape & pacing

The shape of these recovery stories indicates progression. They hint at life before illness, during illness and then reveal recovery and hope for a better future, showing how reframing for recovery has transformed people's lives in spite of setbacks. People identified glimpses of recovery that occurred throughout their ill health and the critical incidents that eventually led to a change in perception and a realisation that recovery is possible. The stories also show that recovery is not a predictable linear process, that the journey has its downs as well as ups.

Pacing of the recovery journey has been discussed in the engagement chapter where narrators identified that a phased introduction to activities of different types was often necessary to help develop confidence. This pacing principle applies to the whole recovery concept. Narrators were determined that recovery should occur at your own pace, when it is right for you and you are ready and willing to commit to taking control of your own wellbeing.

Learning to recognise signs and triggers of illness helped people to pace their recovery and plan for periods of ill health. Narrators described the importance of learning when to push things and when to take it easy.

**"In terms of pace, just being able to do a bit at a time and then draw back a bit and have some space and some time to kind of assimilate things and not feel pushed has been very important."**

**"In terms of being able to manage my own recovery experience, I feel very fortunate at being able to do things at my own pace."**

For both longer term recovery and managing specific situations, several people found breaking down bigger tasks into smaller achievable goals gave them a sense that they were progressing and managing the situation. This increased confidence and gave them impetus to progress further.

Some people recognised the challenges pacing and timing can create for people who work in services in terms of knowing when people need to be pushed and when they may need to be held. However, when relationships of trust and consistency have been built, it is more likely that support staff will be able to gauge pace in collaboration with service users.

## Process

For recovery to begin, it often took a gradual realisation that things were not as bad as they had been and that the future was starting to look brighter. This gradual process occurred for many people we spoke to.

**"I'd always had good family support from my wife, kids, friends... then I had counselling, psychiatrist over a period of time and I think it was a combined thing rather than an individual thing that helped me."**

For a few narrators, an epiphany or a single event or person were singled out (in retrospect) to mark the beginning of their recovery journeys. To maintain this journey re-engaging in purposeful activities was often found to work. Because it was often described as hard to keep going, people found that establishing and attending to their internal dialogue was useful; listening to themselves so they are clear on what they want, and taking action.

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## Turning Points

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Recovery is hugely complicated and must be driven by the desires and pace of the individual. It is no-one's fault if they feel stuck or unwell, but focussing on the positives can often provide a driver towards recovery. Even recognising the small gains, the small progress one makes on a daily, weekly, monthly basis can form the initial steps, providing the motivation to take control of your own future.

The events, people or set of circumstances that marked turning points in recovery journeys have been documented throughout this report. These events included: recognising how far you have travelled from your lowest point; witnessing others (role models) in recovery; getting a diagnosis; finding medication that worked; befriending someone who believed in you; acting to rectify turbulent financial situations; having responsibilities that require you to cope; settling into a community, job or social setting in which you felt a sense of belonging.

Diverse experiences of recovery catalysts or turning points were shared, these were perhaps reflective of the different stages of recovery presented in the narratives or were reflective of the different life experiences of each individual.

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## Having to cope

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For some people recovery was precipitated by the need to 'pull' or 'hold' themselves together to care for others. Having to get up every day to look after children or grandchildren meant people had to cope. Although hard, and often relentless, these relationships of responsibility strengthened individuals resilience and their resolve to cope and to recover. Individuals were often forced to look outside themselves and their own problems, allowing them to be more aware of those around them.

For one narrator, their income maintenance benefits had been cut and they needed to take action to survive.

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## Other people's experiences

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Hearing about other people's experience of recovery was a catalyst and an inspiration for many people's own recovery. For some this came about through joining support groups and therapeutic communities where they gained inspiration and practical advice and support to start their recovery.

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## Deciding to take control

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Whilst some describe a catalyst, other narrators described a process of realisation that they could move on. Many were determined that they did not want to spend any more time in hospital, that the impact of some of their actions whilst ill was affecting the lives of their loved ones and dependents and that they were letting symptoms control their lives.

**"Me... that's what's changed. Me!.. Um, it was a control thing... There was an unconscious release of control on my part. (For twenty years) I let other people control what I was doing and what I wasn't doing. I let the symptoms of my illness become the centre of my universe, and the symptoms of my illness aren't the centre of my universe."**

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Other realisations of emerging capacity, potential, self-awareness and self-respect fuelled recovery, where individuals realised that they had managed their illness without hospitalisation, that they could manage down periods alone, that ultimately only they could make themselves better and that they had a choice.

## Changes in thinking and being

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As people embarked on their recovery journeys they realised that they were making choices and that they did not have to be victims of circumstance or relationships. This manifested in decisions about belonging, taking risks, not being defined by expectation or relationships. This shift of perspective from a victim of circumstance to individuals with choices and responsibility for their own lives empowered narrators to make the changes they needed to recover.

Feeling more in control encouraged people to try new things out *“to do things even if though they may go wrong”*, They also acknowledged that everyone makes mistakes and bad choices and that this is okay. People felt it was important to be allowed to *“take a calculated risk with something and go for it.”*

## Narrating your story

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The therapeutic effect of narrating or recalling your recovery journey has been well documented and has been evident in this study. Several individuals have identified the narrative interview as a turning point in their perception of their illness and recovery to date and indicated that the process of ‘restorying’ their experiences in such a positive manner has been cathartic and has been beneficial to their self-esteem, and recovery journey.

Recovery can happen suddenly, as a consequence of a turning point, or gradually as the realisation that you are in recovery can happen over time. With time, coping skills develop incrementally, until they are common process. Periods of wellness can still be interspersed with periods of ill health. What is evident from the many stories gathered and reported upon within this research, is that there can be numerous turning points towards a recovery journey – each point significant in itself and contributory to the path to wellness.

# Pacing and Turning Points Discussion

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According to Roberts and Wolfson (2004) most authors consider that the pivot of the recovery process is the individual's active and responsible engagement with his or her distress and difficulties. This may involve many steps and stages, and inevitable uncertainty so that recovery becomes 'an uncharted, unpredictable, and personal journey.' So it is obvious that it is a journey that must run its course at its own pace.



# Pacing and Turning Points Discussion

**Regardless of the catalyst, deciding to get well and developing the optimism and belief that you will recover is critical to establishing the ambition, purpose and determination needed to take the responsibility and risks required to get well.**

Whilst successive turning points can pull people towards recovery critical factors to maintain individuals on course must persist like: developing your own positive identity and maintaining a positive outlook for the future (see chapter 1), having meaningful activities and purpose in life (see chapter 2), developing positive supportive relationships (see chapter 3) and accessing the right treatments and supports (see chapter 4).

It is it the individual's choice to get better, to reclaim control over their lives – where they live, who they relate to, how they relate to them, what they do, what they don't, when they do things – that defines recovery. It can be argued that individuals are not recovering from the illness per se, rather they are recovering from the impacts of the illness, the disempowerment experienced through the course of illness, the loss of a sense of identity and purpose, the loss of meaningful relationships, and the loss of control of your own destiny.

# Reframing for Recovery

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According to Anthony (1993) “(Recovery) is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.”

# Reframing for Recovery

People who have experienced mental health problems have often faced existential challenges, about the meaning and purpose of their lives and their place in the world because their lives and ambitions have been overturned by their illness. But recognising that recovery is possible, having hope for a positive and meaningful future and challenging oneself to meet that future with a sense of optimism has changed the lives of many people. These narratives challenge the commonly held assumptions that severe mental health problems are chronic and enduring leading to a loss of potential for a satisfying life. They have shown that recovery is possible. Recovery *“is neither about an unrealistic hope of magical transformation, nor about the impossible prospect of returning to whatever preceded illness. Instead, it is an open-ended and cautiously optimistic process of sketching out a path forward and developing hope for a more satisfactory life alongside whatever remains of the illness”* (Roberts & Wolfson, 2004). In sum, the narratives have shown that recovery is the active and ongoing journey of personal growth after (and in spite of) the experience of mental health problems.

It would be difficult to realise recovery without hope in its possibility. Allowing individuals to find their own definitions of recovery and wellbeing, and allowing them to work towards this by supporting, promoting and valuing what is important to them can assist the recovery process.

What we have learned from this research is not necessarily new, but it provides a unique Scottish perspective to add to the growing body of evidence (William A Anthony, 1993; Baker & Strong, 2001; Barnett & Lapsley, 2006; Jacobson, 2001; Lapsley *et al.*, 2002; Ridgway, 2001 amongst others) that indicates that recovery from even the severest forms of mental health problems is a realistic possibility.

The reality of recovery is very complex especially as its meaning is focused around subjective experience. It has often been described as a non-linear journey unique to each individual because our physical and economic environment as well as our subjective experiences will impact upon our recovery as will our own hopes, ambitions, attitudes, aptitudes and personalities. This research concurs with that analogy but also draws attention to a pattern that emerged and was repeated through each narrator’s testimony. It is clear from this research that the primary catalyst in recovery is a shift in the beliefs and thinking of the individual with the mental health problem; they need to believe that recovery is possible and that it is possible for them; that they are worthy of recovery and can effect and sustain change, with support when needed.

Findings have shown that recovery is about acquiring the skills and knowledge about your own states of wellness to help ensure that you can focus on what keeps you well. It is both a process and an outcome (in recovery), it can be incremental and paced, building upon the recovery experience in little steps over time, or transformational – in the event of a sudden turning point or change of life experience. When discussing the journey of individuals in recovery, resilience is often a term that springs to mind. We should not underestimate the hard work involved in recovery. The transformation from being a passive recipient of care and support to an active partner in health and social care is very challenging as is the move from being defined as someone with a mental health problem to being someone who has rights and responsibilities in their social world.

What is striking about these findings is that the experiences documented are strikingly similar to the experiences, dreams and hopes that most humans have as they navigate their own paths

in life. What we have learned is that recovery emphasises social inclusion and belonging. It highlights the importance of developing a renewed and valued identity that has moved beyond the constraints of the mental health system, that it provides and is often driven by hope and the recognition of strengths, it provides the opportunity to re-engage with meaningful social and occupational roles and can be helped by having positive, trusting, caring, reciprocal relationships with friends, family, professionals and others in your community. It is the pursuit of a life that has meaning and is full of flavour and purpose. These findings are shared by numerous other studies (P E Deegan, 1988; Mezzina *et al.*, 2006a; Secker *et al.*, 2002).

## Implications for Scotland

In order to believe in the potential for recovery, people need to believe it is possible. Professionals, service staff, friends and relations can all contribute in sharing this message of possibility. Witnessing other people's recovery, and learning from other people's experiences can help. Infusing messages of hope into publications, policies, functions and services that operate in mental health and working on the supposition that recovery from severe and enduring mental health problems is possible is a good starting point.

The data presented in this report will have implications for understanding and promoting recovery experiences in Scotland, as well as for developing mental health recovery theory and practice in general. In agreement with Friedli (2005) we would argue that *“greater public awareness and understanding of mental health as a resource to be protected and promoted could contribute significantly to reducing structural barriers”* to recovery.

To promote recovery, professionals need to reframe their roles in health care. The role of a facilitator of person-centred approaches to wellness rather than an authority in mental health problems appears to be more conducive to a recovery oriented approach. Focussing on developing people's strengths and giving them optimistic messages of hope for recovery throughout their treatment and supports is of central significance in many narrators' accounts of recovery.

A great many opportunities exist that support mental health recovery in Scotland; a rights based Mental Health Act (2003); National Health Service reform that puts people first (Rights, relationships and recovery, 2006; Delivering for mental health, 2006); a focus on community oriented mental health systems (report of the 21st century social work review, 2006: Community Care Legislation); NHS support for talking therapies; an increase in social prescribing and a growing mental health recovery movement that includes people in recovery and their family and friends, policy makers, professionals, service providers, voluntary organisations, researchers and activists.

This research has demonstrated that not only do these opportunities exist but that there are already many staff working within a recovery paradigm; Community psychiatric nurses, support workers, counsellors, psychiatrists, psychologists and other professionals and service providers. They are actively developing and promoting recovery-based practice and are a valuable resource to increasing understanding of what constitutes good practice in supporting and promoting mental health recovery.

In essence, good practice requires that the service professionals and staff believe that mental health recovery is possible, and that they structure their services and support so that it can be reflective and responsive, and that it enables and allows individuals to develop their capacity to self-determine. It also requires support services that help individuals who are in recovery to

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develop their own positive identity and engage in relationships with others, their environment and purposeful activity in a way that has meaning for them. Narrators have detailed a diverse range of skills and strengths which people in recovery gain through their life. Concerted efforts to develop self-management and awareness programmes to harness and promote these skills and strengths, could help promote self-direction and responsibility and promote better outcomes, allowing people the opportunity to move beyond services and to take control of their own recovery.

There are lessons for all of us in the findings from this research. Narrators describe a positive process of seeking meaning and purpose, of self-direction and of action. Regardless of our experience of mental health problems we all have hopes and dreams, strengths and deficits. The narrators show that to a great extent we all set the route for our own journey.

# Glossary, Index and References

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# Glossary

**Catharsis:** the purging of the emotions or relieving of emotional tensions, especially through certain kinds of art, as tragedy or music

**Efficacious:** the quality of being effective at a particular task or producing a desired effect

**Emotional support:** refers to the close relationships most often provided by a confidant or intimate other, although less intimate ties can provide such support under circumscribed conditions (Berkman *et al.*, 2000)

**Gemeinschaft/community:** a social group/society primarily characterised by a strong sense of common identity, close relationships and harmony. (Three types of Gemeinschaft relationships: Kinship, Friendship, and Neighbourhood. Opp: Gesellschaft/association)

**Grey literature:** is the term often used to describe semi or not formally published material, for example internal reports

**Health assets or salutogenesis:** is an approach to public health that focuses on assets and resilience, rather than solely on deficit and vulnerability (Friedli, 2005)

**Identity:** the composite behavioural or personal characteristics by which an individual (or group) is recognisable. Erik Erikson (1980) used the term to designate a sense of self that develops in the course of a person's life and that both relates them to and sets them apart from their social milieu

**Identity politics:** Anspach (1979) identified the concept of identity politics as being 'used to refer to social movements which seek to alter the self conceptions and societal conceptions of their participants'

**Informative relationships:** refers to relationships where the basis of the interaction relates to help in decision-making, giving appropriate advice or information in the service of particular needs. (Berkman *et al.*, 2000)

**Instrumental support:** refers to relationships where the basis for the interaction centres around provision of help, aid or assistance with tangible needs such as shopping (Berkman *et al.*, 2000)

**Paradox of choice:** the more choice available, the more doubt one can have about the choice made. (Schwartz, 2004)

**Self-efficacy:** an individual's belief in their ability to perform a task or effect a situation – a sense of personal competence.

**Social capital:** refers to social networks that may provide access to resources and social support (Bouchard *et al.*, 2006). It refers to features of social organisation such as networks, norms and social trust that facilitate co-ordination and co-operation for mutual and civic benefit (R. Putnam, 2001, 1995). A network of individuals or organisations on which to consult or count on. World Bank states that social capital refers to the norms and networks that enable collective action

**Social recovery:** implies that service users can regain their social roles and full social functioning but may still have some of the symptoms of illness like hearing voices (Warner, 1994).

**Socialisation:** the process by which a person acquires or learns to adopt the norms, habits, beliefs, knowledge and behaviour patterns of the community and society in which they live.

**Spoiled identity:** when people are discriminated against or socially ostracised for being identified with a particular group the identity of that group is often considered a 'spoiled identity'. Being identified within this group sometimes results in a loss of ego, stigma, and to a lessened sense of control resulting from being labeled or cast as a deviant (term originated, (Goffman, 1963)

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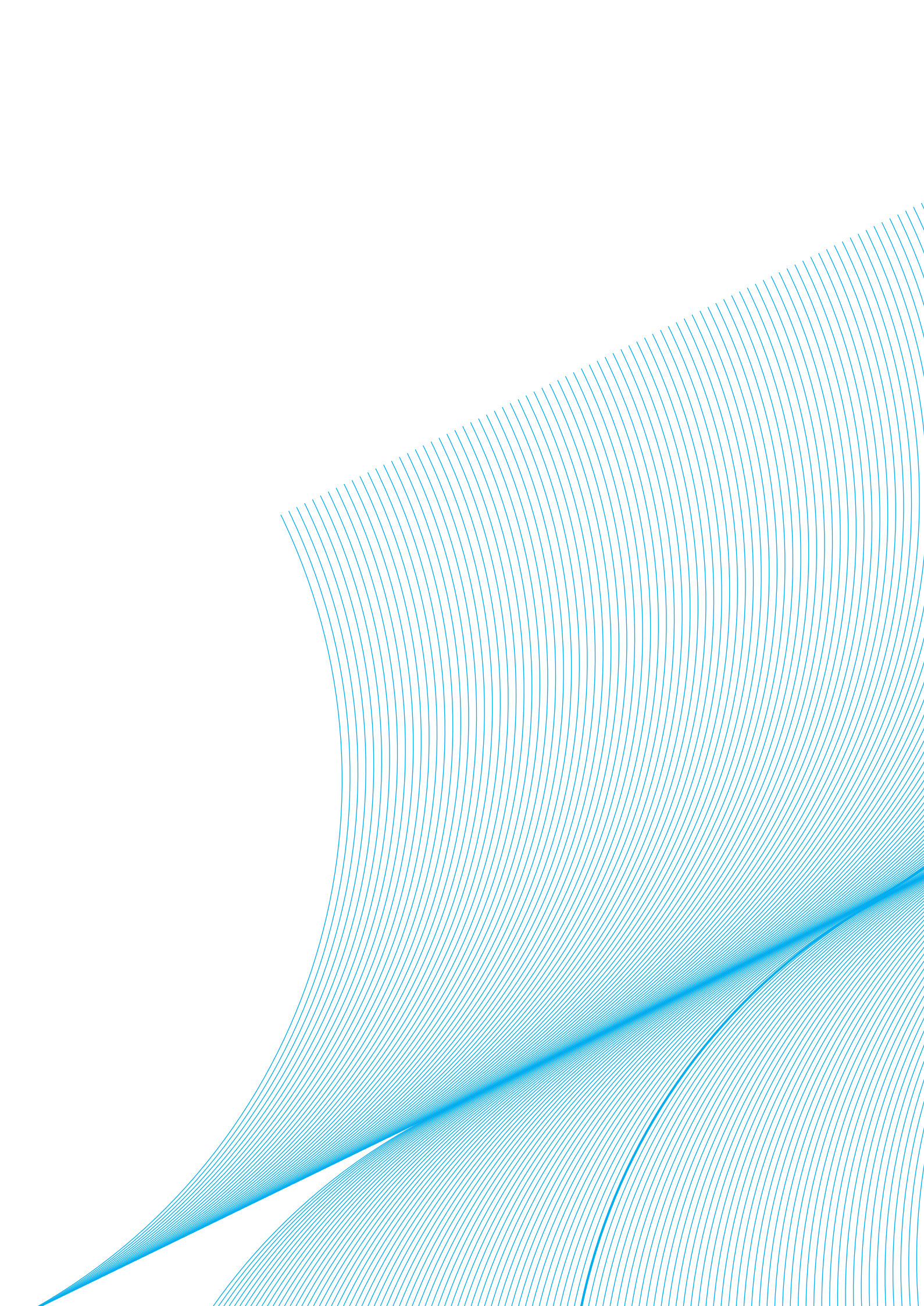
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