Introduction

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In this book people with experience of living with mental health problems talk about how they cope, survive, manage, recover, discover, struggle, combat discrimination, thrive, become liberated and grow – in essence, how they live their lives.

Their stories are about finding meaning and explanations. They are about their beliefs and their strategies for life – strategies that are rooted in deep personal experience. This experience is their expertise and offers a guide to others who may be struggling with living and surviving in the twenty-first century. If anybody can teach us about how to live in our modern, or postmodern, world, it is people who have struggled with the complexities of existence and found their own unique ways of surviving, learning and moving on.

Stories and Narratives

This book can be read on different levels. Certainly, it contains stories that may inspire hope and encouragement. Also, the book may be read as a textbook and the contents may be treated as research that can stimulate inquiry. Either way, what is central is the importance of true stories of people’s lives. In textbook language, stories are often referred to as narratives. Some say that narratives have been fundamental to the development of human history, culture and individual identity (Brockmeier, 2001; Benwell & Stokoe, 2006). Thus storytelling provides meaning to events and enables people to make sense of their world:
People dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticize, construct, learn, hate and love in narrative. (Shkedi, 2005: 12)

The study of narrative is the study of the ways in which human beings experience the world, that is, through the recounting and retelling of experience. Narratives are present in every society. All communities have their local stories, mainly focusing on events that have occurred involving local people. Each civilisation has its own history of mankind. Wherever there are people, there are narratives. People from all walks of life, all human groups, have their narratives. Such is our unquenchable thirst for other people’s stories that we become addicted to fiction and soap operas on television. In recent times, the study and practice of narrative inquiry has gained momentum in qualitative research and is illustrated with numerous journals, books and conferences focusing on the method.

In the psychological arena, psychoanalysis has championed the centrality of the person’s story. The expertise, however, remained firmly with the analyst and the patient remained a case to study. It was much later, with the development of narrative research, that the storyteller became the narrator in terms of research processes. What is fundamental to narrative approaches in research is the notion that it is through the act of storytelling that people make sense of their lives.

It has been said that narrative has become essential for people to have an identity and that identity can be understood in two ways. Identity can be understood as something that is fixed (from the Latin root word for identical: ‘idem’) or something that is permanent but changing. It is this latter meaning from which we create our narrative identity (Ricoeur, 1988). Thus, the River Thames may have an historical identity, but is in a constant state of change. Narrative is therefore a way of balancing both the self that is constant and the self that is changing as we are able to make sense of ourselves through the stories that we tell ourselves (and others) about ourselves. The narrative, therefore, is a product of our constructing, deconstructing and reconstructing ourselves and our identities. It is fine that our stories change over time, and so they should, as we change and grow as people.

**Narrative Research**

Narrative research came to the fore with the work of sociolinguists in the early 1960s (particularly Labov & Waletsky, 1967; Labov, 1972). By the end of the 1970s narrative approaches in various disciplines had become established. Notably, Fisher (1984) observed the central role of narrative in politics and of narrative analysis in political sciences. Polkinghorne (1987) did something similar for psychology; Richardson (1990) for sociology and, by the 1990s, narrative inquiry had had also become common in various science studies (Silvers, 1995) and provided
the foundation for research from a variety of other disciplines (Bertaux, 1981; Ricoeur, 1981; Mishler, 1986; Riessman, 1993; Elliot, 2005).

Whilst we do not locate this book in an illness narrative context, there is much to be drawn from the illness narrative literature. As narrative approaches gained momentum in the social sciences, some working in healthcare recognised the limitations of rationalist frameworks and sought to introduce similar approaches in healthcare. For example, Frank (1995) identifies three fundamental illness narratives: restitution, chaos and quest. Restitution narratives are those of the person anticipating recovery; chaos narratives are enduring with no respite; quest narratives are those where people discover that they may be transformed by their illness. What is common to all types of illness narratives is the focus on the centrality of the telling of the patient’s experience. By gaining knowledge of a disease from firsthand experience and how people make sense of their illness, or how people extract meaning from their experiences, the reader may become hopeful in relation to their own experiences. These principles, based primarily on physical illnesses, are directly paralleled by experiences of mental distress. Narratives have become central to the recovery paradigm in mental health. Stories abound of people’s recovery from mental distress. Naturally, these stories inspire hope in the reader. Belief in recovery is contagious.

In the UK, there is a medical research project that utilises narrative approaches: Health Talk (www.healthtalk.org). Researchers from the University of Oxford have built a massive database of personal and patient experiences through indepth qualitative research into more than 40 illnesses and health conditions. People’s stories are communicated through text and mini-interviews. The idea is that patients, their carers, family and friends, doctors, nurses and other health professionals can access the site, listen to people’s stories and learn from others’ experiences. Historically, in health research, people’s stories are considered to be the weakest kind of evidence. In Health Talk, however, people’s stories are offered as expert evidence:

These methods provide a high quality evidence-based approach to patient experience and ensure that a full range of patients’ perspectives are analysed in terms of what someone might expect to experience when diagnosed with a particular condition or illness.

(www.healthtalk.org)

The Department of Health has provided strong support to the Health Talk research. As far as we can tell, this is the biggest example of narrative health research being put into practice. Recent NHS guidance has endorsed evidence-based methodology and its importance to informed patient choice.

In their examination of the narratives of people who are deaf, Jones and Bunton (2004) have identified two camps: the ‘wounded’ and the ‘warrior’. These distinct categories may also be interpreted as the deficit model or social model, respectively. The wounded are generally those who experience illness as a loss; the warriors are generally those who see themselves as a marginalised and oppressed
minority group who need to assert their human rights. The wounded or warrior concept can illustrate people’s responses to different forms of adversity, including mental health problems. There are those with serious mental health problems who seek cures (e.g. SANE: www.sane.org.uk) and those who are proud to be mad (e.g. Mad Pride: madpride.org.uk).

Illness narratives, however, tell us as much about society as they do about the people themselves. People are social beings and are constantly influencing and being influenced by the society in which they live. Often, sick people may relate to a sick society. Maybe readers need the capacity to look beyond the illness and examine the broader sociocultural contexts, which are inseparable from the experiences of mental health problems.

Experts by Experience

Narrative research focuses on the story of the individual and therefore provides opportunities for individual voices to be heard. As the previous example of the Health Talk research illustrates, people become experts simply on account of their lived experiences. Gabriel (2004) argues for the expert authority of the narrator on the basis of experience. Whilst, for example, the doctor may be considered the expert in terms of education and the experience of implementing that education in practice, doctors can never be fully expert until they have experienced the disease themselves. Thus, there are two experts – one by education and training, the other by experience. In this book, we deliberately give voice to the expert by experience in order to help inform those who may experience similar issues and those who have a caring role. The notion of the patient as expert is enshrined in recent DoH discourse (Department of Health, 2001).

If we are to acknowledge the expertise of patients, we must also accept the importance of the service user/patient knowledge that underpins this expertise. Very little work has been done to establish what service user knowledge is and how it might be incorporated as a key element in the overall mental health practitioner knowledge base (Basset, 2008). We need to build on the work of people like Branfield and Beresford (2006) in their support of service user networking and knowledge.

According to Gabriel (2004), the expert by experience is more vulnerable in terms of potential exploitation from the expert by education, for it is they that are more likely to understand research, publish and receive the plaudits and benefits of a research profile. Neither of us, as editors of this book, has experienced inpatient mental health care. We are therefore more in the experts by education camp. However, we feel that our relationship with the various chapter writers is that of colleagues with a strong desire to tell it how it is and publicise important narratives so that they can reach a wider readership. As regards the potential royalties
from sales of this book, we have arranged to share these equally with two service user-led mental health organisations: Making Waves in Nottingham and CAPITAL in Sussex.

It has been our intention to create a platform for people’s voices to be heard. When people have a voice, they have power. Reality and daytime television have created a platform for a confessional discourse that empowers victims to become survivors through acknowledgement of their suffering (Goldie, 2004). This is also illustrated by the growth of web logs (blogs) where people can tell their story to a global audience. It is estimated that blogs now exceed 60 million. In turn, it is now not unusual for authors of blog confessionals to secure book contracts. Thus a combination of narrative and twenty-first-century technology has the power to emancipate and liberate as well as provide a vast audience. Narrative research should empower participants and is one method that gives voice to the researched; this is especially powerful for those who have been oppressed.

A Platform for Stories

We would argue, therefore, that stories of people’s experiences of mental health problems, survival, discovery and recovery are imperative to mental health research and practice. We hope that people from all walks of life will read this book and may understand more about what it is like to experience mental health problems. Many mental health problems are rooted within the society in which we live. A book such as this may do very little to bring about positive change in society, but if we can bring about some positive change in even a few readers, we will have achieved something important.

We thank all the contributors to this book. We shall refrain from commenting directly on their stories, as we believe that we should allow their stories to speak for themselves. We shall, however, attempt to draw out some themes that emerge from the narratives in the final chapter. There are only a few narratives within this book and we do not suggest that they are representative of the many. In this respect, it is important to state that everybody’s story is uniquely different. We acknowledge that, throughout history, people have paid a great price for being considered ‘mad’, ‘insane’ or simply an outsider to mainstream society. The price may have been incarceration, loss of relationships, role and personhood, indignity and in some situations even death. By providing a platform for people’s stories, we believe we are performing one small act of restoration. This book may shock, challenge or inspire; whatever it does for you, the reader, we hope it imparts greater understanding and harmony for the future.
The Policy Context

It is not our intention here to write a long piece about policy changes in mental health. Suffice it to say that the Conservative government in the 1980s and 1990s oversaw the running down and closure of the majority of the large Victorian hospitals with the subsequent media frenzy (often front-page news) about the perceived failures of community care. In their final days they came up with ‘The Spectrum of Care’ (Department of Health 1997), which, at 12 pages in length, was perhaps a little brief given the size of the task!

The ‘New Labour’ government, elected in mid-1997, could not be accused of producing mental health policy documents that were on the laconic side – quite the reverse. Placing mental health at the top of their agenda, in particular by publishing, and subsequently following up, ‘A National Service Framework for Mental Health (NSF)’ (Department of Health, 1999), a steady stream of policy documents poured forth in subsequent years.

The NSF was a 10-year programme running from November 1999 to November 2009. It would be churlish to be too critical of a government that has made an enormous effort to improve mental health services. Their focus on mental health was unprecedented in the UK. However, they always ran the risk of not knowing quite how much should be changed. They wanted to modernise services, but they also wanted to use existing structures on which to build this more modern approach. Hence the decade 1999–2009 can be seen as one which sent very mixed messages – with messages of social inclusion in the policy and messages of exclusion inherent in additional compulsory measures in the Mental Health Act 2007. These mixed messages, perhaps a product of applying modernisation in a distinctly postmodern age, were at times confusing, particularly to service users and grassroots mental health workers.

A hopeful atmosphere was nevertheless created, based on an overall policy direction that championed social inclusion, fighting discrimination, mental health promotion, self-management and self-help, holistic approaches and recovery. These approaches see service users and their families working alongside mental health workers in partnership. The role of the worker is to enable and facilitate in assisting service users to live their lives to their potential, using their strengths and abilities. Finding ways of living with mental distress is a part of the picture. Fighting discrimination is everyone’s task.

However, it is not always easy to graft new approaches onto old systems. These new philosophies of support and enablement could not be easily placed within an existing care, treatment and illness model. The idea that service users are experts in their own right does not always sit well with professional mental health workers, who have their own expertise. Nowhere is the difference more pronounced than when mental health professionals talk of their patients not having insight, when what they are really saying is that the patient has a different understanding of their
experience and situation. Clearly, one of the aims of this book is to deliver insight from the service user’s perspective.

The mental health service system has recent knowledge of the complexity of these attempts to change ways of working as a similar situation occurred when, in closing the large hospitals, the institutional practices in these establishments sometimes followed patients into the community.

Another reason for producing this book is to cast some light on the term ‘recovery’. A close inspection of the NSF for Mental Health (Department of Health, 1999) reveals no mention of recovery. However, it does emerge briefly (albeit quite upfront in the title) in ‘The Journey to Recovery’ (Department of Health, 2001a) – this policy document was subtitled ‘the government’s vision for mental health care’. There are four short paragraphs on recovery, stating that a more optimistic approach is needed with ‘the vast majority of those using mental health services having real prospects of recovery’ (p. 22).

Eventually, after some key people involved at the National Institute for Mental Health in England (NIMHE) had pushed through a recovery agenda, NIMHE produced their Guiding Statement on Recovery (NIMHE, 2005). It was not long after that that many mental health services declared that they were moving towards recovery-oriented services.

We feel that despite the central position that recovery attained from 2005 onwards, it came in slightly by the backdoor, and so had even less chance than other approaches of being implemented properly. The NSF for Mental Health (Department of Health, 1999) has an underpinning message that services will be much improved with greater resources and a real effort to bring in evidence-based practices: assertive outreach, early intervention and crisis resolution across the whole service. As such, it is pretty much accepting that a properly resourced and modern medical model of service provision is what is needed. Of course, there is some emphasis on involving service users and their families as part of this. Nevertheless, it is just about possible to do all that is necessary within the remits of the NSF and for the power and expertise to still remain firmly with the professions.

This is not the case with recovery, which is much more of a challenge to the medical model and the status quo, with service users both taking the lead and having their expertise acknowledged alongside that of the professionals. As a result, we think recovery has struggled when put into practice because of the culture of most of the services, which could handle the NSF as not too great a challenge to the expertise of the professionals, but see recovery as a step too far. Sometimes they do take the step and end up thinking they are following a recovery approach when they are clearly not.

In essence this book contains accounts of recovery in that some contributors use the word to describe their experience. Others, however, find the word unhelpful and still others prefer to use the words discovery or survival, often aided by self-management and peer support. The word ‘recovery’ itself can mean many
things and hence it is open to different interpretations. However, at root, recovery
starts with and belongs to the service user so one cannot escape the conclusion
that bolting it onto a mental health service which does not really celebrate and
value the expertise of its service users, as has happened in various NHS Trusts, is
simply not going to work. We shall revisit this discussion in chapter 16.

This book was written in the latter part of 2009 as the NSF for mental health
programme reached its final days. As such it is both partly a celebration of
what has been achieved during the era of the NSF and also partly a challenge
for the future.

The Chapters

In chapter 2, Peter Chadwick explores his journey as one of ‘total psychology’
from cognitive neurochemistry to the sociopolitical and spiritual. He recounts
the alienation he felt from within the culture in which he grew up. He sees his
recovery as a product of science, art and spirituality.

In chapter 3, Peter Campbell explains how his experience of mental distress has
been much more about ‘living with’ than ‘recovering from’. He has found that
coping with mental distress is partly about learning practical strategies to mitigate
the worst aspects and partly about making sense of it through frameworks of
understanding that can confer meaning and value. He explores how his involve-
ment in survivor action has helped him progress in his life and combat the dis-
crimination that is deep-rooted in society. He makes some important observations
about in-patient services.

In chapter 4, Alison Faulkner writes about her work as a researcher and her
belief in empowering service users and survivors through doing their own research.
This includes her work as the leader of the ‘Strategies for Living’ project at the
Mental Health Foundation. She also outlines her own strategies for living.

In chapter 5, Joy Pope explains and explores her own and other people’s coping
strategies, drawing on her experience of working as a general practitioner and
journeying with and through depression. She elaborates on a number of ideas,
but also stresses the importance of an individual approach, with each person
having different strategies and things that work for them. She writes about facing
stigma and staying well.

In chapter 6, a Canadian contributor, Peter Amsel, describes how he has coped
living with bipolar affective disorder for 25 years. Peter is a composer of classical
music and also a writer. He compares the impact of his mental health problems
on his work with Beethoven’s deafness and the impact this had on the composer.
Peter describes a faith (not ‘merely spiritual’) that enabled him to continue his
work. It has been important to him to understand his illness, his symptoms and
diagnosis in order to protect him from the dragon that might snap off his head.
Understanding brings liberation. For Peter, mental illness has been an enemy. Ultimately, the enemy can be defeated by working in partnership with healthcare professionals and taking responsibility for oneself. Recovery is possibly if we really want to recover.

In chapter 7, Ruth Dee talks about how she has coped with the effects of childhood trauma for nearly all of her life. Having experienced horrendous childhood abuse she began to dissociate when she was aged three. In this chapter, Ruth describes in detail how dissociation was first a form of coping and then how she learnt to cope with experiences of dissociation. Ruth was not diagnosed with dissociative identity disorder until later in life, when she experienced health problems while working as a senior manager. Although Ruth’s experiences might be considered extraordinary, she learnt very practical ways to cope. She describes the specific help she has received from healthcare professionals and explains the significance of each.

In chapter 8, Laura Lea gives a detailed account of how she gradually rebuilt her life after breakdown. She also gives some insight into how relatives/carers can feel when someone they love has a mental health issue. She describes some of the strategies and building blocks that have helped in her recovery and survival.

In chapter 9, Peter Gilbert recalls his personal pilgrimage and how his life’s journey led him into and out of depression. He speaks of discovery rather than recovery and broadly explores the role of spirituality in its many forms and in relation to the human condition.

In chapter 10, Richard Lilly explains how the Holy Spirit and his Christian faith has sustained, nourished and helped him to make sense of his life, with nearly 40 years’ experience of the mental health system.

In chapter 11, various members of CAPITAL (Clients and Professionals in Training and Learning) relate their narratives of coping, survival, discovery and recovery. The importance of CAPITAL as an organisation that supports and encourages is often central to their stories.

In chapter 12, Sarah Collis, Caroline Bell and Joan Cook discuss the ways in which people can help each other through self-help groups and peer support. Whilst there is clearly merit in professionally-led groups, self-help groups are defined, run and controlled by their members. The core activity of self-help groups is mutual support. Deep connections are made when members identify with the experiences, emotions and reactions of fellow members. Participants benefit from helping each other and by pooling coping strategies, sharing information and drawing on the collective wisdom of the group. The authors invited people from various groups to write letters to them describing the significance of the groups to their lives. People who have experienced the benefit of such groups have therefore contributed to this chapter. People have experienced respect, healing and found hope for their lives.

In chapter 13, Premila Trivedi delivers a critique of mental health services and illustrates how they can take service user/survivor concepts like recovery and
mould them to fit their structures and frameworks, thus robbing them of their original ethos. She gives examples of how this has happened in her own experience. She raises questions about the current recovery model and questions whether it is relevant for black and ethnic minority (BME) service users. At least, it needs to address social and political as well as personal issues for it to be relevant to BME service users, who face discrimination through racism in addition to the stigma and discrimination that is linked to mental ill health.

In chapter 14, Jonathan Naess writes about his experience in taking a sabbatical from his corporate job in the City of London to set up Stand to Reason. Stand to Reason is a ‘Stonewall’ for mental health, being a service user-led organisation committed to fighting discrimination and stigma, challenging stereotypes and changing attitude. He explains how his experience of mental health problems led him to do this. He reviews the successes of Stand to Reason and talks about the organisation’s plans for the future.

In chapter 15, John Stuart Clark (also known as the cartoonist ‘Brick’) employs a conversational style as he describes his mental breakdown. Escaping to China was not the answer, and back in England John encountered ‘Atro’, a giant lizard, white and cynical. Atro was to become an unshakeable nuisance in the coming years. John sensitively reflects on the impact his experiences have had on his relationships. He is on a journey: ‘To travel hopefully is better than to arrive, and the true success is to labour.’

In chapter 16, Joan Cook joins the editors to revisit the concept of recovery and discuss the role of explanations, beliefs and strategies as part of people’s journeys. The importance of self-help and peer support is again highlighted. The chapter ends with an exploration of the role of the mental health worker, and this is summarised in the form of a diagram, which illustrates key elements in relation to how mental health workers and service users can work together in partnership.

The poems that illustrate the text are broadly on the theme of living with and surviving mental distress. Mariyam Maule’s poems are reproduced by permission of the Maule family.

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Minute by minute
we cope
And hope we can cope
One day at a time
Gradually we recover
And see the sky
And the clouds move
And the sea change colour
And the snowdrops
And the daffodils
Appear through the snow
And remember the snowman
And the Halloween parties
And the birthday parties
And the happy times

Libby Jackson, ‘Recovery’