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Mike Slade
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Section 1 Chapter 1

Mental illness and recovery

Overview of the book

This book is about mental health services – what they currently do, and how they would need to change if their goal is to promote 'personal recovery'. What does this term mean? Different understandings of recovery are considered in Chapter 3, but personal recovery is defined in this book as meaning[1]:

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

Focussing on personal recovery will require fundamental changes in the values, beliefs and working practices of mental health professionals. Why is this necessary?

What's the problem?

People using mental health services lie on a spectrum.

At one end of the spectrum are people who benefit from mental health services as currently structured. Typically, this group contains people who are progressing well in life, and are then struck down by mental illness. The application of effective treatments helps the person to get back to normal – to come to view the mental illness experience as a bump in the road of their life, which they get over and move on from. For this group, mental health services as currently configured promote recovery (because clinical recovery, which we define in Chapter 3, is the same as personal recovery).

In the middle of the spectrum are a group of people for whom mental health services promise much but do not fully deliver. This group find that the impact of the mental illness does lessen over time, but it is not clear how much this is because of the treatment and how much because of other influences – the passing of time, learning to reduce and manage stress better, developing social roles such as worker and friend and partner, making sense of their experiences in a way that offers a hopeful or better future, etc. For this group, mental health services as currently configured are insufficient – they provide effective treatments but personal recovery involves more than treatment.

At the other end of the spectrum are a group of people for whom the mental health system, with its current preoccupations, imperatives and values, is harmful. This group find that the impact of the mental illness increases over time, to the point where their whole identity is enmeshed with the mental patient role. The more treatments and interventions are provided, the further away a normal life becomes. The horizons of their life increasingly narrow to a mental health (i.e. illness) ghetto. In previous generations, these people would have lived in a visible institution. Nowadays they are increasingly likely to reside in a virtual institution[2] – a life lived exclusively in dedicated buildings and social networks containing mental health patients and staff. For this group, mental health services as currently configured are toxic – they provide treatments with the promise of cure, but in reality they hinder personal recovery.

This book will identify how this situation has come about, identify the elements of mental health services which can be either insufficient or toxic, and chart a way forward. The central thesis is that if the primary aim of mental health services is to promote personal recovery, then the values, structure, workforce skills and activities of the service should all be oriented towards this end.

Aims of the book

This book is written primarily for mental health professionals, and has three aims in relation to personal recovery: convincing, crystallising and catalysing.

The first aim is to **convince** that a focus on personal recovery is a desirable direction of travel for mental health services. Five broad reasons are proposed. The epistemological rationale is that the experience of mental illness is most helpfully understood from a constructivist perspective, which necessarily involves giving primacy to the values and preferences of the individual. The ethical rationale is that an emphasis on professionally judged best interests has inadvertently done harm, and a better approach would involve support oriented around the individual's goals rather than around clinical imperatives. The effectiveness rationale is that the benefits of the most common treatment (medication) have been systematically exaggerated, and a broader approach is needed. The empowerment rationale is that a focus on clinical recovery has consistently involved the interests of the individual person with a mental illness being subordinated to the interests of other dominant groups in society – 'their' life has not been safe in our hands. Finally, the policy rationale is quite simply that, in many countries, public sector mental health professionals have been told to develop a focus on personal recovery. Chapters 24 and 25 also contribute to this aim, by providing potential responses to some concerns expressed by clinicians and consumers about personal recovery.

The second aim is to **crystallise** exactly what personal recovery means. This is addressed in two ways. First, in Chapter 9 a Personal Recovery Framework is proposed. I was hesitant about developing a theoretical framework, since one impetus for writing this book was a belief that the recovery world needs a little less theory and ideology, and a bit more of a focus on concrete implications and working practices. However, the recovery support tasks identified for mental health professionals are implicitly based on an underpinning theory of personal recovery, so it seemed better to make this explicit and hence more amenable to debate and improvement. Second, the book is written from the perspective that there are different types of knowledge. Evidence which comes from group-level scientific designs is currently valued in the scientific literature more than evidence that comes from individuals. It will be argued in Chapter 4 that the pendulum has swung too far, and what is needed is a blending of group-level and individual-level evidence. The optimal balance involves attaching importance to both the individual perspective of the expert-by-experience and the training, knowledge and (occasionally) personal views of the professional expert-by-training. The style of writing is intended to model what this means in practice: arguments are made using both empirical study data (e.g. clinical trials and systematic reviews) and insightful quotes from individuals, sprinkled with a few personal observations. More authoritative statements can be made where there is concordance between different types of knowledge, e.g. in the content of consumer accounts of recovery and the scientific focus of positive psychology (explored in Chapter 14).

The third aim is to **catalyse** – to provide a response to the mental health professional who is convinced about the values, has crystallised beliefs and knowledge about personal recovery, and wants to know where in practice to start. Case studies of best practice from around the world are included. These provide a resource of innovative, established strategies which increase the organisational and clinical focus on personal recovery. They also serve as a bridge between the worlds of theory and practice. The coherence of a good theory is seductive – it makes the world simpler by ignoring its complexity. In reality, no theory is universally applicable, and the case studies serve to illustrate the challenge of turning theory into practice. Web resources listed in the Appendix give further pointers to some recovery resources.

New goals, values, knowledge and working practices

We will argue that the primary goal of mental health services needs to change, from its current focus on treating illness in order to produce clinical recovery, to a new focus on supporting personal recovery by promoting well-being.

Supporting personal recovery requires a change in values. The new values involve services being driven by the priorities and aspirations of the individual, rather than giving primacy to clinical preoccupations and imperatives. This will involve mental health professionals **listening to and acting on what the individuals themselves say**. Although, as Henry Mencken cautioned, 'There is always an easy solution to every human problem – neat, plausible, and wrong'[3] (p. 443), this simple suggestion is in fact both necessary and revolutionary, with deep implications for how mental health services are provided.

Why is a values shift needed? Because many constructs held by clinicians as incontestable revealed truths are in fact highly contested, although those contesting them – service users – have until recently not had a voice. Repper and Perkins[4] note that there has been a systematic denial of this voice. For example, media reporting on mental health issues disseminates the views of clinical experts, family members, politicians, indeed anyone other than the people actually experiencing the difficulties[5]. The evidence-based response to this diversity of views is to show modesty in the claims made for the scope and applicability of any individual clinical model. A term used in this book is being tentative – applying professional knowledge competently but humbly to support people in their recovery journey. Professionals who recognise that their world-view is built on sand work very differently to those who believe that their own world-view is true. This is why values and relationships are central – it's not just what you do, it's how you do it.

New knowledge will be needed, because the treatment of illness and the promotion of well-being require different, though overlapping, actions. The science of illness provides only limited levers of change. For the clinician, treating illness in order to promote well-being is like fighting with one hand tied behind their back. Furthermore, mental health services can be toxic in relation to personal recovery where the trade-off between short-term and long-term effects is not recognised. Avoidance of illness is a clinical preoccupation, and has a short-term horizon. Development of well-being is a long-term process, and involves different tasks. For example, being relieved of employment demands has short-term benefits for treating illness, but chronic unemployment hinders wellness. Having responsibility for your life taken by others can allow stabilisation in the short term, but long-term leads to dependence and disengagement from your own life. Being given a mental illness diagnosis brings the short-term relief of understanding, but if it becomes a dominant identity then it creates an engulfing role which can destroy hope for a normal life.

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Some of the new knowledge comes from the lived experience of people with mental illness. Their authentic and clear voice is becoming heard throughout the system, and has deep consequences for mental health services. Their voice is given prominence in Chapters 3 and 9. Some of the new knowledge comes from positive psychology: the science of well-being. This emerging science involves empirical investigation of what is needed for a good life, and is applied to mental health services in Chapter 14. It is a central assumption in this book that people with mental illness are fundamentally similar to people without mental illness in their need for life to be pleasant, engaged, meaningful and achieving. A sophisticated and balanced perspective on the trade-off between actions to treat illness and actions to promote well-being places the clinician in a better position to contribute beneficially to people's lives.

What does this mean in practice? We propose in Chapter 9 a theory-based Personal Recovery Framework, which is based on four key processes involved in the journey to recovery: hope, identity, meaning and personal responsibility. On the basis of this Personal Recovery Framework, recovery support tasks for mental health services are identified and elaborated in Chapters 10 to 23.

So this book is arguing for fundamental shifts in clinical practice:

- A change of goal, from promoting clinical recovery to promoting personal recovery
- A values-based shift to give the patient perspective primacy
- The incorporation of scientific knowledge from the academic discipline of positive psychology into routine clinical practice
- A focus by mental health professionals on tasks which support personal recovery.

The profound ethical, behavioural and professional implications of these shifts are considered.

Structure of the book

The book has four sections. Section 1 provides an overview of where mental health services are now, and different understandings of recovery. The aim is to show that clinical recovery and personal recovery are not the same thing, and to raise the question of which should be the primary goal for mental health services.

Section 2 outlines five rationales for giving primacy to personal recovery. This section contains the more detailed discussions of, sometimes, esoteric theory. The goal is to provide a range of arguments in favour of personal recovery.

Section 3 puts meat on the bones of the idea of a mental health service focussed on personal recovery, both in terms of what personal recovery means, and envisaging what recovery-focussed services look like. Some of it is speculative, involving comment on current practice with un-evaluated suggestions about how this could be different. Some of it is already implemented, and reported as case studies from innovative recovery-focussed sites internationally.

Section 4 looks to the future, in two ways. First, by addressing the potential concerns of clinicians and consumers. Second, by suggesting concrete actions for the mental health system, with illustrative case studies.

Many references are cited, partly to provide a response to the 'What's the evidence for recovery?' question, and partly to acknowledge where the ideas presented here have come from others. The book is therefore intended to signpost some of the many resources in the large and growing world of recovery.

The book is written to be dipped into. Readers new to the field of recovery might start with Section 1, and then read Chapter 22 for indicators of a recovery-focussed service.

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Knowledgeable but unconvinced readers might start with Chapters 24 and 25, and then pick from Section 2 as per their personal tastes for different types of argument. Readers wanting to crystallise their understanding of what personal recovery means might read Section 1 followed by Chapter 9. Finally, readers looking to change their own practice might read Section 3 and Chapter 26, and to influence the practice of others will find Section 2 and Chapters 24 and 25 relevant.

Collective nouns

This book is about the group of people whose lives are lived in actual or potential contact with mental health services. What to call these people, and their defining characteristic? Existing suggestions range along a spectrum, and each contains implicit assumptions.

At one end of the spectrum, the problem (and therefore the label) is seen as internal to the person. This finds expression in calls to use the term brain illness instead of mental illness[6], and for schizophrenia to be re-named as dopamine dysregulation disorder[7].

In the middle lie perspectives which are sensitive to the implications of locating the problem either entirely internally or entirely externally. For example, clinical psychology literature is often somewhat antagonistic towards the underlying assumptions of discontinuity embedded in descriptive taxonomies, yet diagnostic categories are nevertheless routinely adopted as the best available organising framework[8]. At this point on the spectrum, the validity issues with diagnosis are recognised[9;10], and addressed by seeking to develop more valid categories, such as a disaggregation of schizophrenia into Sensitivity-, Post Traumatic Stress-, Anxiety- and Drug-related psychosis[11].

At the other end of the spectrum, the problem is seen as external, and so described by the person's relationship to or history in mental health services. Labelling suggestions from this perspective include[12]:

- Mental health consumer
- Psychiatric survivor
- Person labelled with a psychiatric disability
- Person diagnosed with a psychiatric disorder
- Person with a mental health history
- Person with mental health issues
- Consumer/Survivor/eX-inmate (CSX)
- Person who has experienced the mental health system
- Person experiencing severe and overwhelming mental and emotional problems, such as 'despair'
- Person our society considers to have very different and unusual behaviour, such as 'not sleeping'.

From this end of the spectrum, there is a call for the term schizophrenia to be abandoned altogether[13].

In this book, the term **mental illness** will be used to describe the experience itself. This term places the experience in the domain of medicine, despite arguing for the limitations of this frame of reference. However, any euphemism for a person with a mental illness cannot easily escape this implication. For example, in relation to the phrase 'person with mental health problems', Repper and Perkins ask, 'What is a "health problem" if not an "illness"?'[4] (p. viii). Their solution is to adopt alternative and less value-laden terminology, such as unshared perceptions and unusual experiences, which are intended to avoid the assumptions

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embedded in psychiatric terms such as delusions and hallucinations. However, these terms are too specific for the trans-diagnostic focus of this book.

What about the person with the mental illness? The international shift from talking about psychiatric services to mental health services has highlighted the need to find a more neutral term than patient. Certainly, language is important – how you say it is how you see it. But a preoccupation with language can be all too easily dismissed as political correctness, and provides a convenient excuse to ignore the real epistemological, ethical and clinical challenges. Therefore, the standard terms **consumer, peer, patient, client** and **service user** are used to describe the person. They are used interchangeably, with the most appropriate term chosen for the particular context.

This book is written for people working in mental health services who are employed on the basis of their professional training and skills. Most multidisciplinary mental health teams routinely include occupational therapists, mental health / psychiatric nurses, social workers, psychiatrists and clinical or counselling psychologists, and can also include art therapists, benefits advisors, dance therapists, dieticians, drama therapists, employment advisors, housing advisors, music therapists, physiotherapists and psychotherapists, among others. All these professional groups will be referred to collectively as **professionals, mental health professionals** or **clinicians**. Much inter-professional jostling for position takes place (normally) behind the scenes in multidisciplinary teams, and this book tries to side-step these issues by using these generic terms for all varieties of professional. This is not of course meant to imply that all professional groups are the same, or that the nomenclature is accepted by all groups (e.g. in the UK many social workers do not see themselves as clinicians), but rather that this book is focussed on the emergent properties of the mental health system as a whole.

Author perspective

I write as a clinical academic, working in both the scientific world which values particular types of knowledge and the clinical world which involves individuals struggling to find a way forward in their life, and creating complex ethical and practice dilemmas for professionals.

Personally, I think mental illness is real in the sense of being a meaningful phenomenon. That said, strong statements such as ‘schizophrenia is a brain disease’ seem to me to go beyond the available evidence[9;10;14], and are as unhelpfully simplistic in understanding human experience as ‘love is a brain condition’. In this I am influenced by my professional identity as a clinical psychologist, which socialises into a multiple-model view of the world. This is a good antidote to rigidity of thinking, but creates the vulnerability of being unable to say anything with clarity and certainty. I have tried to overcome this disability by communicating as clearly as possible what a mental health service which is focussed on personal recovery might look like. No doubt this makes visible my own beliefs, including tribal loyalties to my profession, a therapeutic orientation towards cognitive behavioural therapy and away from long-term psychological therapies, and my perspective on the diverse views of people using mental health services.

This book aims to highlight discrepancies between some aspects of current practice and what is needed to support personal recovery. It is not intended to be a comprehensive text-book on mental health care – excellent text-books already exist[15;16], and omission of a topic does not imply unimportance. Furthermore, presenting alternatives necessarily involves depicting current mental health services somewhat negatively. The danger is that some

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individual professionals may feel criticised, which is far from the intention. The clinical reader who thinks ‘But I don’t do that’ may well be right. There is much to value in mental health services, and this book has emerged from seeing skilled, caring and recovery-promoting mental health professionals in action. Current mental health values and working practices which hinder recovery, insofar as they exist, are emergent system properties rather than resulting from the practice of individuals.

I do not write from the perspective of a consumer. However, many of the ideas on which this book is based have emerged from consumer rather than professional thinking about mental illness. My goal is to be a messenger: translating the consumer notion of recovery into the language and mindset of professionals. Inevitably, my own opinions (e.g. that recovery is at its heart an issue of social justice) may lead to translation errors. My hope is that the reader, whether consumer or professional, will choose to look past these biases and errors, and be challenged instead to create mental health services which focus on well-being more than illness, and are based on the priorities of the consumer rather than of the professional.

We turn now to the nuts-and-bolts of what mental illness is, and is not.

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Chapter 2 The nature of mental illness

What is mental illness?

The centre of gravity of mental illness is subjective experience. All branches of medicine require a combination of signs (observable indicators) and symptoms (subjective report of the patients) to reach a clinical explanation, but psychiatry is the only branch in which illnesses are primarily diagnosed and treated on the basis of the patient's self-report. There is no test which demonstrates that mental illness exists where neither the affected person nor the people in their life were aware of any problems. A central proposition then is that the start point for understanding mental illness is as an experience.

In this regard, mental illness differs from physical illness. Indeed, examples such as syphilis and epilepsy suggest that once a physical marker or cause is found, it moves to another branch of medicine and ceases to be viewed as a mental illness. The debate about the dividing line is of course ongoing, with calls for depression to be viewed as a neurological condition[17]. Overall, the pragmatic meaning of mental illness is a disorder with no established physical cause: a functional illness. The *emphasis* in understanding mental illness should be on the subjective experience.

What approaches have been developed to make sense of these experiences? Three broad ways of understanding mental illness have developed, which we call Clinical, Disability and Diversity models. We start with Clinical models, which are the dominant explanatory framework used in mental health services[18].

Clinical models

Clinical models are ways of seeing the world which have been developed by the various mental health professions, and which inform day-to-day clinical practice. The dominant professional group in mental health care has been psychiatry, and so inevitably many of the issues that will be raised relate to the ideas of psychiatry. However, the intention is not to criticise medical approaches specifically. Other groups have their models too, and if they were more dominant then the limitations of their models would become all too apparent. Indeed, at a personal level, one driver for writing this book was a recognition that psychological models do not always help individuals to make sense of their experiences. Rather, the intent is to raise cross-cutting issues with all clinical models used by mental health professionals, such as their emphasis on the role of the expert, privileged knowledge, best interests, and the central role expectation of intervening and treating.

One term we deliberately avoid is medical model, which is usually used pejoratively by non-medical people[19;20] to imply either a reductionist focus on biology to the exclusion of human experience or a general critique of the dominance of psychiatry[21;22]. Most mental health professionals are extremely aware of the suffering and the social challenges experienced by people with mental illness. However, since professionals often feel they can do little to directly influence the environment, they tend to focus on the individual. We will later argue that the social and environmental context of the person is too influential to be simply ignored.

Clinical models of mental disorder use evidence from clinical science, with a focus on accurate assessment of the individual followed by application of the evidence base to identify the most effective treatment. We will consider the three most commonly used models of mental disorder: biomedical, biopsychosocial and cognitive.

Clinical model 1: biomedical

The biomedical model of illness involves two key assumptions: an illness has a single underlying biological cause (a disease), and removal of this disease will result in a return to health[23]. Neither assumption is universally true in relation to mental illness. For example[23]:

> many patients present with symptoms that are not attributable to any underlying pathology or disease. Nevertheless, such patients are often given a medical diagnosis, implying an underlying structural cause and reflecting cultural expectations . . . Most healthcare systems also assume that treatment after diagnosis is brief and acts quickly. Indeed, the medical model might more accurately be termed the surgical model, given the pre-eminence of surgery in popular culture and health organisation.
>
> (p. 1399)

The biomedical model has been incorporated into medical understanding of mental illness, especially through the influence of the German philosopher and psychiatrist Karl Jaspers[24]. He emphasised the importance of understanding (*verstehen* in German) over causal explanation (*erklaren*). This leads in his phenomenological approach to the use of empathy and intuitive understanding by the clinician to establish meaningful connection with the inner world of the patient, through careful listening[24]: 'the phenomenological approach involves painstaking, detailed and laborious study of facts observed in the individual patient at the conscious level' (p. vi). This listening allows the clinician to see what the patient really means, and indeed to amplify or elaborate aspects which connect with or fit for the patient. However, this listening is not neutral – it is done to fit the patient's report into a predefined theoretical framework.

A key feature of Jasperian phenomenology is a belief in a universal *form* over a context-specific *content*: a third-person auditory hallucination is viewed as the same form for anyone who hears a voice talking about them, whether the voice is of an ancestor, a father, a childhood abuser, or an alien. Jaspers's phenomenology gives primacy to psychopathology in the individual (expressed in the form of diagnosis or symptoms) over the epiphenomenon of its socioculturally influenced expression in the environment. The purpose of the phenomenological approach is therefore to obtain a 'precise description of psychopathology'[25].

The biomedical model of mental illness is then a model of psychopathology, in which listening is used to elicit phenomena of psychopathology. Pat Bracken and Phil Thomas note that this focus on systematic examination of conscious mental phenomena is held up as a clear advance[26]:

> Most contemporary psychiatrists would argue that their assessments involve a detached, factual listing of the patient's symptoms accompanied by a clear analysis of the person's mental state . . . In this process, the experiences that trouble the patient . . . are taken out of the patient's own language and reformulated in psychiatric

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> terminology . . . This process is carried out in an attempt to render psychiatric practice more scientific, the idea being that if we are to have a science of psychopathology, we need a clearly defined language through which a scientific discourse can proceed. Without this, we are 'limited' to a level of interpretation that is based only on personal narrative and locally defined meanings. A science of psychopathology demands concepts that are universally valid and reliable. In other words, it demands a concern with the 'forms' of psychopathology.
>
> (p. 108)

They go on to highlight the implicit assumption: 'Psychiatry has never really doubted the idea that a science of psychopathology is needed or even possible . . . It has never been in doubt that there *are* forms, diagnostic entities 'out there' awaiting identification and clarification' (p. 108). An assumption they challenge:

> Meaning involves relationships and interconnections; a background context against which things show up in different ways . . . The world of psychiatry, involving emotions, thoughts, beliefs and behaviours, is a world of meaning and thus context. Indeed, it is the centrality of these twin issues of meaning and context that separates the world of the 'mental' from the rest of medicine . . . psychiatry is precisely delineated by the fact that its *central* focus is the 'mental world' of its patients. Meaning and context are thus essential elements of the world of mental health and simply cannot be regarded as 'inconvenient limitations', issues that can be ignored or wished away.
>
> (pp. 109–110)

The interested reader is referred to their detailed discussion of the evolution of thinking about phenomenology. (Summarising, they argue that Jaspers's distinction between form and content reflects a Cartesian duality, and leads to a view that investigating phenomenology of form and hermeneutics – interpretation – of content are different activities. Heidegger's critique of this duality is that human reality is always embodied and encultured.) However, the point here is a pragmatic rather than philosophical one. The approach of eliciting features of psychopathology through mental state examination is a core feature of the biomedical model of mental illness. The problem with this is expressed by Lucy Johnstone[27]: '*Personal meaning is the first and biggest casualty of the biomedical model*' (p. 81). She elaborates:

> Psychiatry not only fails to address emotional and relationship problems, but actually reinforces them, for lack of a whole-person, whole-system way of understanding them. By using a medical label to 'Rescue' people, it takes responsibility away from them, encouraging them to rely on an external solution which is rarely forthcoming, and then blaming them for their continuing difficulties and powerlessness. The personal meaning of people's distressing experiences and the psychological and social origins of their difficulties are obscured by turning them into 'symptoms' of an 'illness' located within one individual.
>
> (p. 201)

The result of filtering human experience through the psychopathological sieve is an impoverished and decontextualised version of meaning. This ignores other approaches to understanding the experience of mental illness. For example, Simon Heyes has written an articulate guide for other consumers to recovery[28], and the resulting media coverage reported[29]:

> In Heyes view, people with mental health problems provide a sort of 'early warning system' for society. 'If dolphins start getting washed up on the beach, people start to