Personal Recovery and
Mental Illness

A Guide for Mental Health Professionals

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for Charlotte

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Acknowledgements

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.

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.

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

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

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.

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

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

think there might be something wrong with the environment, they don't blame the dolphins for their lifestyle. Living in a constant state of flux places huge pressure on individuals. There is a perception of almost limitless choice combined with a sense of personal responsibility, while at the same time things that might have once given grounding have broken down.'

(p. 5)

How can the loss of meaning arising from Jasperian phenomenology be addressed? The approach used in the biopsychosocial model of mental illness is to more explicitly include consideration of psychological and social factors.

Clinical model 2: biopsychosocial

Most mental health professionals now align, at least in rhetoric, with a biopsychosocial model[30]. This model proposes that mental illness does not exist in a biological vacuum, and recognises that interpersonal, contextual and societal factors impact on the interpretation, onset, course and outcome of mental illness[31]. The model is based on a stress-vulnerability diathesis – that an internal vulnerability interacts with an aversive environment to produce psychotic experiences[32].

However, biopsychosocial models have been criticised for being disguised reincarnations of a biomedical model. As Repper and Perkins put it[4]:

It is a perspective which suggests that a person's thoughts and behaviour can be explained by physical malfunctioning, usually of neurotransmitters within the brain. Since it is clear that social and environmental factors have an impact on physical processes, an organic approach does not discount these influences, but views physical malfunctioning as the underlying cause of problems.

(p. 23)

This critique has an empirical basis. The anthropologist Robert Barrett found that the biopsychosocial model in reality gives primacy to the bio-[33]. His analysis of Australian psychiatric hospital casenotes indicated that schizophrenia is constructed as a disease process located externally to the person, which fragments the individual as an entity. The casenote structure divides the account of the person into segments, which are 'ambiguously connected elements including "history," "presenting complaint," "appearance," "insight," etc., based upon ideas such as . . . [the] "biopsychosocial" model of mental illness'[34]. In other words, and not surprisingly, the structure of the mental state examination influences the results obtained. If the questions implicitly locate the problem as an illness in the person, then the responses probably will as well.

In reality the biopsychosocial model is far more closely aligned with a biologically focussed biomedical model than with either psychological or social models. We illustrate this in relation to schizophrenia (Box 2.1).

This call for modesty in not over-extending what we know is a central value in this book.

The bio- in biopsychosocial

Lucy Johnstone points out that the biopsychosocial model has two meanings[35]. In a weak sense, it is of course true that biology and psychology and social all interact, but by explaining everything the model explains nothing. In a strong sense, the model gives primacy to the bio-part as the primary causal factor, hence preserving the assumption that psychological and social factors are merely triggers of an underlying illness, and do not have any inherent meaning. The key indicator of a biomedical model of illness – diagnosis – remains central to

the biopsychosocial model, rather than one of three equally valued components. This has led even its adherents to reduce their ambitions for the model[36]: 'the value of the biopsychosocial model has not been in the discovery of new scientific laws, as the term 'new paradigm' would suggest, but rather in guiding parsimonious application of medical knowledge to the needs of each patient' (p. 576). Why does the biopsychosocial model give primacy to the bio-? One reason is that research is complex, needing to integrate biological (e.g. symptoms, genetic influence), psychological (e.g. interpersonal coping skills, resilience, cognitive stages of change), environmental (e.g. access to effective psychosocial rehabilitation programmes and supportive social networks) and sociopolitical (e.g. impact of stigma from the community, attributes of the treatment system, impact of consumer advocacy) levels[37]. Faced with this complexity, it is easy to understand why clinicians and researchers focus their efforts on the 'low-hanging fruit' of specific intrapsychic deficits.

Box 2.1 The causes of schizophrenia

The example of schizophrenia: what do we know about its causes?
Psychiatric epidemiology has identified many risk factors for schizophrenia[a]:
  Odds ratio 8.0–10.0
    Family history
  Odds ratio 6.0–7.9
    Obstetric central nervous system damage. Prenatal bereavement
  Odds ratio 4.0–5.9
    Rubella. Central nervous system infection
  Odds ratio 1.1–3.9
    Obstetric (hypoxia, Rh incompatibility, pre-eclampsia, low birth weight). Birth (winter, urban). Infection (influenza, respiratory, poliovirus). Prenatal (famine, flood, unwantedness, maternal deprivation)
Non-genetic sources of vulnerability have also been identified:
- Higher rates of childhood trauma in people who subsequently experience symptoms of psychosis than those who do not, with the possibility of a causal relationship shown by a dose–effect relationship[b,c].
- Reasonable[d] (though not undisputed[e]) evidence that cannabis is causal for schizophrenia, e.g. a study of 50 000 Swedish conscripts showing a dose–effect relationship, with the odds ratio for incident schizophrenia rising from 1.2 in those who had used cannabis at all before conscription to more than 6 in frequent cannabis users[f].

Current evidence indicates that the strongest effect is genetic. This is certainly a dominant element of psychoeducational programmes and information leaflets[g]. However, a comprehensive review of genetic evidence in schizophrenia concluded[h]:

> At present, the data for schizophrenia are confusing, and there are two broad possibilities. The first possibility is that the current findings for some of the best current genes are true. This implies that the genetics of schizophrenia are different from other complex traits in the existence of very high degrees of etiological heterogeneity: schizophrenia is hyper-complex, and we need to invoke more complicated genetic models than other biomedical disorders. The alternative possibility is that the current findings are clouded by Type 1 and Type 2 error. Schizophrenia is similar to other complex traits: it is possible that there are kernels of wheat, but it is highly likely that there is a lot of chaff . . . At present, we cannot resolve these possibilities.

(p. 617)

Box 2.1 (*cont.*)

Indeed, the largest study to date found no significant association between the strongest 14 candidate genes and schizophrenia[i]. What we know for sure is limited, even in highly researched conditions such as schizophrenia. Yet the presentation of schizophrenia research systematically over-emphasises the evidence that mental illness is a brain disease[j], and ignores alternative explanations[k,l,m,n]. Especially given the huge disparity in funding for biological versus other ways of understanding schizophrenia, current evidence does not support giving absolute primacy to biology in understanding schizophrenia. The mechanism of interaction between identified risk factors remains unclear, with credible proposals covering biology (e.g. phenotypic expression[o], dopaminergic dysregulation[p]), psychology (e.g. bias against disconfirmatory evidence[q], jumping to conclusions[r]) and social (e.g. economic systems[m]). Since biological, psychological and social factors are all potentially implicated, a truly biopsychosocial model of schizophrenia – rather than one giving primacy to biological explanations – is indicated.

Notes:

[a]Murray RM, Jones PB, Susser E, van Os J, Cannon M. *The Epidemiology of Schizophrenia*. Cambridge: Cambridge University Press; 2003.

[b]Read J. Childhood trauma, psychosis and schizophrenia: a literature review with theoretical and clinical implications. *Acta Psychiatrica Scandinavica* 2005; 112:330–350.

[c]Raine A, Mellingen K, Liu J, Venables P, Mednick S. Effects of environmental enrichment at ages 3–5 years on schizotypal personality and antisocial behavior at ages 17 and 23 years. *American Journal of Psychiatry* 2003; 160:1627–1635.

[d]Henquet C, Murray R, Linszen D, van Os J. The environment and schizophrenia: the role of cannabis use. *Schizophrenia Bulletin* 2005; 31:608–612.

[e]Hall W, Degenhardt L, Teesson M. Cannabis use and psychotic disorders: an update. *Drug and Alcohol Review* 2004; 23:433–443.

[f]Zammit S, Lewis G. Exploring the relationship between cannabis use and psychosis. *Addiction* 2004; 99: 1353–1355.

[g]Read J. Schizophrenia, drug companies and the internet. *Social Science and Medicine* 2008; 66:99–109.

[h]Sullivan PF. The genetics of schizophrenia. *PLoS Medicine* 2005; 2(7):e212 0614–0618.

[i]Sanders AR, Duan J, Levinson DF, et al. No significant association of 14 candidate genes with schizophrenia in a large European ancestry sample: implications for psychiatric genetics. *American Journal of Psychiatry* 2008; 165:497–506.

[j]Boyle M. It's all done with smoke and mirrors. Or, how to create the illusion of a schizophrenic brain disease. *Clinical Psychology* 2002; 12:9–16.

[k]Read J, Mosher L, Bentall RP (eds). *Models of Madness: Psychological, Social and Biological Approaches to Schizophrenia*. Hove: Brunner-Routledge; 2004.

[l]Boyle M. *Schizophrenia, a Scientific Delusion? 2nd edn*. London: Routledge; 2002.

[m]Warner R. *Recovery from Schizophrenia: Psychiatry and Political Economy*, 3rd edn. New York: Brunner-Routledge; 2004.

[n]Ross CA, Pam A (eds). *Pseudoscience in Biological Psychiatry: Blaming the body*. New York: John Wiley; 1995.

[o]Tsuang MT. Schizophrenia: genes and environment. *Biological Psychiatry* 2000; 3(1):210–220.

[p]Murray R. Phenomenology and life course approach to psychosis: symptoms, outcome, and cultural variation. *Psychiatric Research Report* 2006; 22(3):13.

[q]Woodward T, Moritz S, Cuttler C, Whitman J. The contribution of a cognitive bias against disconfirmatory evidence (BADE) to delusions in schizophrenia. *Journal of Clinical and Experimental Neuropsychology* 2006; 28(4):605–617.

[r]Colbert SM, Peters E. Need for closure and jumping-to-conclusions in delusion-prone individuals. *Journal of Nervous and Mental Disease* 2002; 190(1):27–31.

A second reason may be professional. If what is currently understood to be a mental illness moves to being understood as primarily a psychological or social phenomenon, then this has potential implications for the status and power of existing professional groups. For example, it is unclear how this will fit with the struggle of psychiatry to position itself as a legitimate branch of medicine, with equal status and credibility. This struggle finds

expression in the neo-Kraepelinian (i.e. following Emil Kraepelin) movement towards an emphasis on reliable diagnosis and application of evidence-based medicine in psychiatry. Nancy Andreasen predicted in her influential book '*The Broken Brain*' that future psychiatric consultations would last for no more than 15 minutes, to allow the optimal medication to be chosen[38]. Clearly, such a consultation has no room for the messiness of meaning.

Whatever the reason, the emphasis on biology in biomedical and biopsychosocial models has not been without its critics. Concern has been expressed by many psychiatrists, including Duncan Double[39], Ronnie Laing[40], Joanna Moncrieff[41], Marius Romme[42], Thomas Szasz[43] and Pat Bracken and Phil Thomas[26]. Nonetheless, these models remain dominant[44]: 'At present, almost all of health care spending is directed at biomedically oriented care. As George Engel[30] stated 30 years ago ". . . nothing will change unless or until those who control resources have the wisdom to venture off the beaten path of exclusive reliance on biomedicine as the only approach to health care"' (p. 2). Biomedical and biopsychosocial models have many strengths. They are systematised bodies of knowledge, amenable to testing and amendment in the light of new knowledge. They are transferable across time and space – an intervention developed in one country can at least in theory be transferred to another, and new generations of health professionals can be trained into the models of the previous. Clinical models lead to action – they provide guidance for expert practitioners about what to do. Finally, and most importantly, the testimonies of individuals show that many patients have benefited from the treatments based on these clinical models.

However, the goal of this book is to argue for a transformation *within* mental health services, so it is helpful to map out problems as a precursor to arguing for this change. Therefore we now review some of the negative implications of these models. A central argument is that the imposition or use without reservation of any clinical model is unjustified in almost all circumstances.

What's the problem?

To understand why there is a problem, it is helpful to illuminate the core assumptions and evolved working practices of the biomedical and the biopsychosocial clinical models. These are shown in Table 2.1.

Any characterisation is necessarily limited by outliers. Clinicians working with mentally disordered offenders might view their primary role as protection of the public. Clinicians working with people experiencing early psychosis or long-term mental illness may have a more nuanced rhetoric about recovery than 'getting back to normal'. However, these assumptions and working practices are found in most mental health services. The problem is that they do not fit reality, in four ways:

Mismatch 1: mental illness is not (only) *caused* by disturbed homeostasis
Mismatch 2: diagnosis does not 'cut nature at its joints'
Mismatch 3: assessment processes create stigma
Mismatch 4: treatment does not cure

We now consider each mismatch.

Mismatch 1: mental illness is not (only) caused by disturbed homeostasis

The Jasperian distinction between understanding and explaining is crucial. Understanding is an *interpretation* or a partial view of a phenomenon. Since there are always many possible interpretations, no single understanding is intrinsically superior – they cannot be ranked a priori. We can certainly construct methods of ranking different understandings. The degree

Table 2.1 Working practices in the biomedical and biopsychosocial models

Domain	Dominant concept/approach
Responsibilities and relationships	
Ethical imperatives on clinicians	Acting in best interests, responsibility for the patient
Clinician's primary responsibility	To diagnose and treat the mental illness
Patient's primary responsibility	To take treatment as prescribed
Clinician's relationship with patient	Expert and authoritative
Assessment	
Basic understanding of mental illness	Psychopathology resulting from disturbed homeostasis
Assessment focus	Intrapsychic deficits and problems
Meaning attributed by the patient	Peripheral
Assessment goal	To identify the mental illness and hence make a diagnosis
Action	
Driver for clinical and patient action	Avoidance motivation – the avoidance of symptoms or suffering
Focus of action	Clinicians treating the patient
Proximal aim of treatment	Symptom reduction, functional improvement
Distal aim of treatment	Cure the illness
Evaluation of treatment success	By the clinician, through objective outcome assessment
Meaning of recovery	Restoration of disturbed homeostasis – getting back to normal

of consensus and the implications for specific stakeholder groups are common approaches. But these are post hoc constructions – there is nothing intrinsically better about one interpretation over another. Therefore the usefulness of a particular understanding should be judged in relation to whether it is helpful, not whether it is true (i.e. measurably more accurate than other understandings).

By contrast, an explanation reveals something of the *essence* of a phenomenon. Explanations can be ranked – the best explanations most closely fit current observable data and are a better predictor of the future. At any point in time, it is reasonable to treat an explanation as the closest available approximation to a true picture of what is going on. This revelatory aspect justifies primacy over descriptive accounts.

The centre of gravity of the biomedical and biopsychosocial models is diagnosis. But there is a key difference between diagnoses of physical and mental illness. A diagnosis of a physical illness provides an explanation. The statement '*Inflammation of the meninges causes meningitis*' is an explanation, and more true than the descriptive lists of the signs and symptoms of meningitis (each of which may be present in a specific patient to a differing amount). It tells us something of what is going on (aetiology) and how things will unfold (prognosis), irrespective of what the patient believes or the social context of the patient.

A diagnosis of a mental illness, on the other hand, is an understanding. The statement '*Bereavement causes depression*' is an understanding, which may or may not apply or be helpful for different patients with depression. Its utility depends crucially on the beliefs and context of the patient and whether they find it a useful way of making sense of the experience. It is descriptive, not explanatory. Hence the axiom that *diagnosis is prognosis*[45]

is true in physical illness (because explanations predict) but does not apply within mental illness. As the creators of DSM-IV-TR (www.dsmivtr.org) put it:'Patients sharing the same diagnostic label do not necessarily have disturbances that share the same etiology nor would they necessarily respond to the same treatment.' A conceptual framework for identifying the implications of this distinction is provided by Ray Pawson and Nick Tilley, in their seminal book 'Realistic Evaluation'[46]. They identify two theories of causation: generative and successionist[47]. **Successionist theory** holds that causation is unobservable, and observational data are the only mechanism for inferring causality. This theory leads to the methods of experimental manipulation and pre-post-comparison of experimental and control groups. **Generative theory**, by contrast, holds that there is an observable connection between causally connected events, and that internal features of the thing being changed are central to understanding causality.

Within this framework, a successionist notion of causality underpins the statement *Gravity causes an apple to fall to Earth*. The word 'causes' could be prefaced with 'always'. A statement underpinned by a generative notion of causality would be *Rising house prices cause consumer confidence to fall*. The word 'cause' cannot here be prefaced by 'always'. In a health context, the statement '*Inflammation of the meninges causes meningitis*' is successionist, whereas '*Bereavement causes depression*' is generative.

Pawson and Tilley apply this distinction to social programmes, which they define as 'the interplays of individual and institution, of agency and structure, and of micro and macro social processes' (p. 63). They argue for a move from a successionist to a generative model of causation, in which 'causal outcomes follow from mechanisms acting in contexts' (p. 58). Prediction can then be made through an understanding of the causal mechanisms linking input with outcome and of the contextual factors influencing these processes.

This distinction allows an unpicking of two meanings of the term 'mental illness is caused by disturbed homeostasis'. One meaning is that mental illness is observable in the biological substrate. This is true but uninteresting. All human feelings and behaviours can be observed at the level of biology – consider the experiences of savouring, being in love, sexual arousal, aggression, etc. These experiences can clearly also be understood as psychological or social phenomena. It may of course be helpful to understand the biological correlates of mental illness, since these may provide points of remedial intervention, but they do not explain mental illness.

The second meaning is that mental illness occurs as a result of disturbed homeostasis – all would be well if it were not for the imbalance in these internal processes, and mental illness exists and can be explained in isolation from psychological and social context. It is this explanatory meaning which is explicitly rejected by taxonomists. Identification of invariant final common pathways which are biological (e.g. dopamine dysregulation) or effective treatments targeting restoration of homeostasis (e.g. pharmacotherapy) only impacts on how useful the understanding is – it does not provide an explanation. Mental illness is not *essentially* biological. This is concordant with the emphasis on context in *Postpsychiatry*[26]:

> A key element of what we call postpsychiatry is the view that modernist psychiatry has been built on what some commentators have called 'methodological individualism', the assumption that different psychological states can be examined in isolation from the world around them. Postpsychiatry seeks to overcome this orientation by bringing contextual issues centre stage. By contextual issues, we are referring to the fact that human psychology is always embodied (wrapped up in the complex biology of a

human body), encultured (involved in the linguistic, cultural and political reality of the society in which it exists) and temporal (never fixed, but constantly in flux and always involved in a journey from past to future).

(p. 170)

The experience and interpretation of mental illness occurs within this complex social vortex of biology, culture and time. This is depicted in the model of the person shown in Figure 2.1.

Figure 2.1 is not of course meant to be a grand theory of the person, so it is deliberately left unelaborated. (I would include existential and spiritual as other important dimensions – others would have different preferences.) Rather, the diagram is intended to make the simple point that increasing understanding at any modality (e.g. biological, psychological, etc.) is a welcome scientific advance, but does not – and cannot – provide *the* explanation of experience. This interconnectedness of levels of explanation is beginning to be discussed in mainstream psychiatric literature[48].

A generative model of causation is more helpful to understand why bereavement causes depression in some people but not in others. This would involve moving away from the decontextualised invariant understanding exemplified by diagnosis, and instead seeking to understand the meaning and context of mental illness. For some people, their experience is most helpfully understood in terms of a mental illness diagnosis. For others, it is not. This is why the invariant use of a biomedical or biopsychosocial model is sometimes helpful, sometimes insufficient, and sometimes toxic. This issue is often apparent in clinical practice. For example, I was asked to provide psychological therapy for a woman with 'treatment-resistant depression'. The referral letter detailed her depressive symptomatology and the various pharmacological approaches which had been tried with the patient, none of which had successfully treated her depression. When I met the lady, she disclosed that she was being regularly beaten by her husband. Although she clearly was depressed as a consequence, the use of depression as an explanation for her experiences was toxic.

A mental illness diagnosis should therefore not be treated *as if* it is an explanation. If diagnosis is one of many ways of understanding, what does this mean for clinicians? A truly evidence-based clinician (i.e. one who recognises the limitations of their world-view) would offer their expertise as a resource, which may or may not be helpful to or utilised by the patient. This clearly will involve a role transition. It may be reasonable to state to a patient '*You have meningitis*', if this is the best available explanation. The statement '*You have depression*' is a different animal – it should more precisely be stated as '*Your experience can be understood as depression*'. This then becomes an informed suggestion about how it might
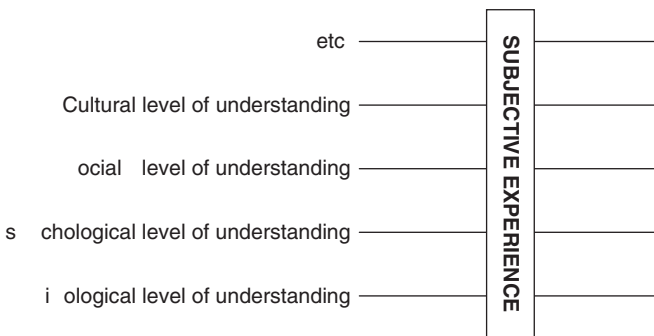
Figure 2.1 A model of subjective experience.

etc

Cultural level of understanding

ocial   level of understanding

s chological level of understanding

i ological level of understanding

SUBJECTIVE EXPERIENCE

be helpful to understand the experience, rather than an authoritative pronouncement about what is really going on.

This will be challenging for professionals trained to believe they are being taught how things really are. Diagnosis does not reveal truth – it has a different purpose[49]: 'The primary purpose of the DSM is to facilitate communication among mental health professionals.' Viewing diagnosis as primarily an inter-professional communication aid rather than a revealed truth would lead to a tentative attitude towards diagnostic categories. This tentativeness would occur not because of a desire to withhold the awful truth from the patient, but because of a recognition that diagnosis no more captures what is really going on than a book can be described by listing all the words it contains. Beyond a certain point, head-counts (of words or symptoms) have no information content. Knowing the number of times that depression-related words occur in a book may say something about what the book is about, but knowing the number of times the letter 'e' occurs adds virtually nothing. Similarly, each taxonomic iteration has diminishing returns. At the time of writing, great effort and debate is going into the development of DSM-V. What is striking is that this edifice of descriptive psychopathology will probably have no impact whatsoever on clinical practice. Beyond a certain level of granularity, all people with symptoms of psychosis are (literally and clinically) treated the same. Again, this is recognised by the leaders of DSM-V (www.dsm5.org/planning.cfm): 'limitations in the current diagnostic paradigm embodied in the current DSM-IV suggest that future research efforts that are exclusively focused on refining the DSM-defined syndromes may never be successful in uncovering their underlying etiologies.' In this regard a certain humility is called for. The semantic groupings which were used to make sense of difference 200 years ago are unrecognisable from the diagnostic categories in use today. Without doubt, in another 200 years the way we conceptualise subjective experiences will be similarly different. To make categorical pronouncements that a disorder exists and that the patient has it does not reflect this changing reality. We now explore this point further.

Mismatch 2: diagnosis does not 'cut nature at its joints'

A consequence of viewing diagnosis as a partial understanding rather than as a revelatory explanation is that there cannot be stable, invariant (over time and culture) psychopathological diagnostic categories. Therefore we would expect debate about diagnostic categories to be based on non-empirical considerations. This is exactly what we find.

The history of how diagnostic categories have come and gone from DSM is salutary reading for anyone who views diagnosis as objective descriptions of discrete disorders. The battle between neo-Kraepelinians and psychoanalysts over 'neurosis', successive gay rights demonstrations eventually leading to the removal of 'homosexuality' as late as 1974, and debates about paraphilia as a mental illness[50] are simply some of the more interesting tips of the diagnostic iceberg. The issue can again be illustrated in relation to schizophrenia.

Box 2.2 captures some of the debate about the diagnosis, but the point to note is that this is not a scientific debate – the absence of a disease marker for schizophrenia means that arguments for and against it relate to its clinical and social consequences, rather than its empirical basis as a discrete disorder.

The diagnostic endeavour is out of control. The Diagnostic and Statistical Manual (DSM) I contained 112 mental disorders when published in 1952. This has risen incrementally: 182 in DSM-II (1968); 265 in DSM-III (1980); and 374 in DSM-IV (1994). The only obvious hindrances to introducing new diagnostic categories are the views of existing stakeholders (e.g. psychoanalysts) or 'patient' groups (e.g. gay and lesbian people). These

> **Box 2.2** The diagnosis of schizophrenia
>
> **The example of schizophrenia: should the diagnosis be retained?**
> The validity of the diagnostic category of 'schizophrenia' has been repeatedly challenged[a,b,c]. This has led to the suggestion from some consumer groups, such as the Campaign for the Abolition of the Schizophrenia Label (www.asylumonline.net), to abolish the label 'schizo-phrenia'. Even from within psychiatry there are calls to discontinue the term as stigmatising, not scientifically valid and unhelpfully focussing on a biological explanation of what is a heterogeneous and context-influenced disorder[d].
>
> One response has been to argue that we should keep the status quo, because changing the name may foster a belief that the person rather than the illness is to blame for their symptoms[e].
>
> Another approach has been used in Japan, where the previous term for schizophrenia (*Seishin Bunretsu Byo* – a disease of a split and disorganised mind) has been replaced with *Togo-Shicchou-Sho* (a transient state of loosened association)[f]. However, this approach has been criticised on the grounds that stigmatising associations are not reduced simply by changing the name[g].
>
> A third response is to propose 'better' categories. For example, David Kingdon proposes to replace Schizophrenia with Sensitivity Psychosis, Post Traumatic Stress Psychosis, Anxiety Psychosis, Drug-related Psychosis. He showed that whereas 63% of service users were negative about the term schizophrenia, this proportion dropped to 16% with these new terms[h], and in a study of 241 medical students there was a much greater likelihood of generating positive views about the potential of recovery with these new categories[i].
>
> *Notes:*
> [a]Read J, Mosher L, Bentall RP (eds). *Models of Madness: Psychological, Social and Biological Approaches to Schizophrenia*. Hove: Brunner-Routledge; 2004.
> [b]Maddux JE. Stopping the "madness". Positive psychology and the deconstruction of the illness ideology and the DSM. In: Snyder CR, Lopez JS, eds. *Handbook of Positive Psychology*. New York: Oxford; 2002. 13–24.
> [c]Boyle M. *Schizophrenia, a Scientific Delusion?* 2nd edn. London: Routledge; 2002.
> [d]Kingdon D. Down with schizophrenia. *New Scientist* 2007; **2625**:22.
> [e]Penn DL. Politically correct labels and schizophrenia. A rose by any other name? *Schizophrenia Bulletin* 2001; **27**:197–203.
> [f]Kim Y, Berrios GE. Impact of the term schizophrenia on the culture of ideograph: the Japanese experience. *Schizophrenia Bulletin* 2001; **27**(2):181–185.
> [g]Lieberman J, First MB. Renaming schizophrenia. *BMJ* 2007; **334**:108.
> [h]Kingdon D. Down with schizophrenia. *New Scientist* 2007; **2625**:22.
> [i]Kingdon D, Kinoshita K, Naeem F, Swelam M, Hansen L, Vincent S et al. Schizophrenia can and should be renamed. *BMJ* 2007; **334**:221–222.

are an insufficient buttress against the two powerful forces which have led to this avalanche of diagnostic categories – 'a kaleidoscope of putative disorders'[51]. The first force is a consequence of Enlightenment values. As Bracken and Thomas put it[26]:

> One important promise of the Enlightenment was that human pain and suffering would be overcome by the advance of rationality and science. To this end, psychiatry has attempted to replace spirituality, moral, political and folk understandings of madness with the framework of psychopathology. The culmination of this was the 'decade of the brain' when it was firmly asserted that the causes of madness are to be found in neurotransmitter abnormalities.
>
> (p. 9)

The second spur to this 'development' has been a confluence of commercial and profes-sional interests. The greater the spread of diagnostic categories, the more money is to be

made in treating these conditions, and the more influence can be obtained by mental health professions. One in eight adults in the USA are now prescribed anti-depressants each year[52]. The opening up of new markets by pharmaceutical companies through disease marketing[53] is discussed in Chapter 6.

This increase in diagnostic categories is not science – it is colonisation of the human condition. It is also not a neutral activity – it directly impacts on social understandings of human experience[54]: 'DSM is a guidebook that tells us how we should think about manifestations of sadness and anxiety, sexual activities, alcohol and substance abuse, and many other behaviours. Consequently, the categories created for DSM reorient our thinking about important social matters and affect our social institutions' (p. 11). This issue is particularly germane to psychiatry, given the centrality of diagnosis to professional practice. David Whitwell, a psychiatrist, notes and apparently agrees with the concerns about diagnosis expressed by clinical psychologist Richard Bentall[14], but then concludes:

> Bentall is able to do this because he is a psychologist. For a psychiatrist the fact remains that having a diagnosis is still central to medical ways of understanding people with mental health problems. If I, as a psychiatrist, were to say to a court or a tribunal that after assessing someone's condition . . . that they had serious problems, but I did not choose to make a diagnosis, it would call into question whether I was acting as a psychiatrist at all . . . It is a bit like asking the church to consider the claims of atheism. There is a whole world of psychiatric literature, and much of it only makes sense on the assumption that there are separate mental illnesses.[22]
>
> (p. 30)

If clinical practice is to match reality, then it needs to be recognised that diagnosis is one of many ways of making sense of experience. This is important, because giving a diagnosis is a powerful act. Some people find a diagnosis to be positively helpful in making sense of their experiences[55]:'Getting a diagnosis helped. It at least gave me the chance to say "I agree with this diagnosis", and it gave me a starting point to work forward from' (p. 54). Whereas for others, it is a hindrance to recovery[56]: 'Certainly to my self-esteem, to the people I go to church with, the people that I've worked with, to my family, to former friends, [being given a diagnosis of schizophrenia has] been a big disadvantage' (p. 29). It is this aspect of diagnosis to which we now turn.

Mismatch 3: assessment processes create stigma

As we will discuss more in Chapter 16, clinical assessment should cover four dimensions[57]:

Dimension 1:   deficiencies and undermining characteristics of the person
Dimension 2:   strengths and assets of the person
Dimension 3:   lacks and destructive factors in the environment
Dimension 4:   resource and opportunities in the environment

However, to make a diagnosis only Dimension 1 need be considered. Since assessment in biomedical and biopsychosocial models is oriented towards making a diagnosis, clinical interactions tend to focus on Dimension 1. This focus leads to three problems[57]:

Problem 1. Deindividuation

The process of labelling leads to perceptions of diminished within-group differences and exaggerated between-group differences[58]. This creates a toxic cocktail with the *optimal distinctiveness theory*[59], which suggests that identification with a group simultaneously meets the need for similarity (through within-group comparisons) and difference (through between-group comparisons). People who are made to believe that they are very different

from others will assert their similarity by identifying with large, inclusive and indistinctive groups. The resulting genuine lack of distinctiveness then provides confirmatory evidence for the belief that people with mental illness are fundamentally similar. Social psychology experiments show that within-group deindividuation (attenuation of differences) has consequences for how the person is seen. For example, more 'librarian-like' behaviour is remembered about a person when they are presented as a librarian than as a waitress[60]. The issue is recognised in caveats attached to DSM-IV[61]:

> Individuals sharing a diagnosis are likely to be heterogeneous even in regard to the defining features of the diagnosis
>> There is a need to . . . capture additional information that goes far beyond diagnosis
>> A common misconception is that a classification of mental disorders classifies
> people, when actually what are being classified are disorders that people have.

This subtlety is not, however, evident in research[62], public perception[63] or clinical practice[33]. For example, a review of how diagnosis is used in research studies showed a decline in the proportion of people-categorising instances (e.g. 'schizophrenic', 'borderline patients') from 94%–100% (across diagnoses) in 1975–9 to approximately 50% in 2000–4. The authors conclude[62]: 'Terminology categorizing patients continues to be used and is still used equally as often as terminology categorizing disorders among people who are supposed to be the most educated about this important human rights issue' (p. 103). Labelling with a diagnosis emphasises similarity with others from the same group. The huge amount of financial and human resource put into establishing the reliability of categorising increasingly fine-grained slices of human experience cannot disguise the essentially impoverished (i.e. lacking ecological validity) picture that results. People with the same mental illness are fundamentally different from each other. A key problem with diagnosis is that it ignores these differences.

Problem 2. Neglect of environment

The neglect of environment in diagnostic taxonomies is *almost* total. The exception is Axis IV 'Psychosocial and environmental problems'. However, the influence of this axis on current clinical practice is virtually nil, and in any event the Axis focus is on problems (i.e. Dimension 3), not resources (Dimension 4). Indeed, the advice is to avoid listing 'so-called positive stressors, such as a job promotion' unless they 'constitute or lead to a problem'[61] (p.29). This focus on individual over environment is discordant with the experiences of people with mental illness, with the result that 'many of them find biomedical interpretations limited – at best unhelpful, and at worst harmful'[64].

Problem 3. Negative bias

The concepts of saliency, value and context combine in toxic ways in mental illness to lead to a negative bias. If something about the person stands out sufficiently (i.e. with sufficient **saliency**, such as a diagnostic label presented as an explanatory fact) and is regarded as having a negative **value** (i.e. has stigmatising associations), and if the **context** is vague or sparse (i.e. nothing else is known about the person), then this will adversely influence views about the person[65]. Use of diagnosis as an explanation accompanied by neglect of the environment leads directly to a negative perception about the person.

This negative bias is then maintained through a learned clinical discourse which systematically elicits risk factors, problems and deficits, and substantially ignores protective factors, strengths and abilities. For example, protective developmental factors associated with good psychosocial resilience are shown in Table 2.2[66].

Table 2.2 Protective developmental factors associated with psychosocial resilience

Level	Type	Protective factor
Child	Cognitive	Intelligence; problem-solving skills; attentional skills; easy temperament (infant) and adaptability (later)
	Personality	Positive self-perceptions; self-efficacy; faith/sense of meaning in life; positive outlook; good sense of humour; sociability/attractiveness to others
	Emotional	Ability to self-regulate emotions; self-esteem; values own talents
Family	Caregiver	Close relationship with adult caregivers; authoritative parenting (high warmth, structure, monitoring and expectations); parental involvement in child's education; parents with protective factors listed for child (above)
	Environmental	Positive family climate; low parental discord; organised home environment; close relationships with other prosocial, competent, supportive adults; connections to prosocial and rule-abiding peers
	Social	Post-secondary education of parents; socioeconomic advantages
Community	Educational	Effective schools; ties to prosocial organisations (e.g. clubs, scouts)
	Environmental	High 'collective efficacy' in neighbourhood; high public safety; good emergency services; good public health care availability

These factors are not elicited during clinical assessment. Indeed, they are not taught in most professional training. By contrast, the risk factors for schizophrenia (shown earlier in Box 2.1) will all be assessed during a 'good' history-taking. Current assessment procedures are guaranteed to show up some deviation or other, such as a breakdown experienced by your great-aunt ('family history of mental illness'), a forceps delivery ('perinatal complications'), taking longer than typical to learn to walk ('delayed developmental milestones'), finding it hard to make friends ('schizoid personality'), and being naughty ('conduct disorder') – all of which become evidence for the validity of a diagnosis. The confirmation bias that results further reinforces the belief that patients have deficits and problems, but few intrinsic strengths. As Peter Chadwick puts it[67]:

> Deficit-obsessed research can only produce theories and attitudes which are
> disrespectful of clients and are also likely to induce behaviour in clinicians such that
> service users are not properly listened to, not believed, not fairly assessed, are likely
> treated as inadequate and are also not expected to be able to become independent
> and competent individuals in managing life's tasks.

Sometimes the absurdity of the resulting assessment discourse is highlighted, as by the woman with a diagnosis of schizophrenia who exasperatedly exclaimed during an interview[68]: 'Why don't you ever ask me what I do to help myself?' (p. 182). It is also parodied, as in Chadwick's call to add Pathologically Middle-of-the-Road Personality Disorder (MORPID) and Totally Colourless Personality Syndrome (TOCOLOPS) to DSM-V[69]. Chadwick was one of the first writers to write from the perspective of a consumer academic[67]:

> Rather than concentrating on those aspects of the psychology and physiology of
> schizophrenic people that reveal *deficits*, this [book] attempts to turn the coin over and
> seek what has become known as the 'schizophrenic credit'. In the context of
> this endeavour it is legitimate to ask, for example, whether . . . schizophrenia-prone
> people . . . have areas of enhanced functioning compared to 'standard-minded' people.
> (p. xii, references omitted)

This focus on deficits has several implications. It creates an assessment mentality in which the patient is a holder of a mental illness, and the illness can be identified through a mental state examination. By emphasising difference, it maintains stigmatising views within mental health professionals[70]. It supports the belief that the clinician's job is to treat the illness, not the person's job to recover their life. It fosters dependency – the good patient is compliant with treatment. Finally, since the treatment doesn't actually cure the person, a role as a person with mental illness can become an engulfing role[71]. Rapp and Goscha identify the implications of this last process[72]:

- These engulfing roles – bag lady, junkie, schizophrenic – are viewed in a highly negative way by others
- People in these roles increasingly associate only with others in the same group, leading to impoverished social networks
- The person is defined by others exclusively in terms of their engulfing role
- There are no established routes of gaining status in, or exiting from, the role
- There are therefore few incentives to set or work towards realistic longer-term goals, leading to impoverished expectations of a good future
- There is an absence of natural processes that lead people to recognise and amend their unrealistic perceptions or attributions
- Poverty is common and opportunities to become economically productive are limited, which creates further stress and, in some, the desire to seek reinstitutionalisation.

A deficit-focussed assessment process aimed at establishing diagnosis creates stigma. Lucy Johnstone illustrates the impact on people following diagnosis[35]:

> I walked into (the psychiatrist's office) as Don and walked out a schizophrenic . . . I remember feeling afraid, demoralised, evil.
>
> The diagnosis becomes a burden . . . you are an outcast in society. It took me years to feel OK about myself again.
>
> The killing of hope . . . it almost feels like, well, your hands are tied, your cards laid and your fate set.
>
> I think schizophrenia will always make me a second class citizen . . . I am labelled for the rest of my life.
>
> Once it was known that I had spent time in the 'nutters' hospital, my neighbours gave me hell.

This diagnostic frame of reference is in marked contrast to how most individuals make sense of their problems[73]: 'Being treated in a medicalised way, as if they had physical illnesses, formed the basis of negative evaluations and complaints on the part of most users in every aspect of their management . . . In summary, the professional discourse and the lay discourse about personal distress are incompatible.' This discordance persists in public explanations[63]: 'The public, internationally, continues to prefer psychosocial to biogenetic explanations and treatments for schizophrenia.' This tension is not present to the same degree in physical illness. Even in chronic conditions, people do not self-label as a diabetes service avoider, or an asthma clinic survivor, or a renal unit ex-inmate. I have heard DSM-IV described by consumers as *The Book Of Insults*. Peter Chadwick notes that[67]: 'even the briefest perusal of the current literature on schizophrenia will immediately reveal to the uninitiated that this collection of problems is viewed by practitioners almost exclusively in terms of dysfunction and disorder. A positive or charitable phrase or sentence rarely meets the eye' (p. xii). The acceptance of a deficit-saturated reality has profound consequences for

role expectations. Since patients are not seen as having any self-righting capacity, and since few environmental strengths and supports are identified, the person needs to be 'righted' through treatment by others. We therefore turn now to treatment.

Mismatch 4: treatment does not cure

The need to treat has been described by David Whitwell as 'the curse of psychiatry'[22]:

> The professionals know that they can be judged to be negligent if they fail to use the powers [of compulsion] available to them. The psychological effects of this are profound on both sides. The effects have become more intense in recent years due to high profile cases where professionals have been blamed for failing to prevent disasters. The message that has come from such cases is that members of staff are responsible for the outcome; – that if only they did their jobs properly, tragedies would not happen.
>
> (p. 171)

He identifies naïve psychiatric practice as based on a belief that treatment makes people recover, and so the job of medical professionals is to deliver treatment. This is true not only of psychiatry. In the UK, care plans set out the planned intervention elements, and are written by the care manager (generally nurses, occupational therapists or social workers). An audit of 1732 care plan entries for 244 patients found that 74% of actions involved staff doing something *to* the patient, with only 14% involving doing something *with* the patient and 11% the person doing something for themselves[74]. Treatment involving the clinician doing something to the patient is the norm.

The problem with this approach is that the promise of treatment leading to cure is not delivered. Each new round of treatment (e.g. insulin coma therapy, psychosurgery, electro-convulsive therapy) has heralded a 'revived cult of curability'[75]. Invariably, some patients benefit (reinforcing clinician's beliefs about the effectiveness of the treatment). But some partially or temporarily benefit, and some seem to decline despite (or, perhaps, because of) aggressive treatment. The initial optimism soon fades, and the limitations of the treatment for both staff and patients become apparent. Creating an expectation that the expert clinician will treat and cure the patient is actively unhelpful. As Whitwell puts it[22]: 'It is unfair to give treatment saying that it will bring about recovery – yet knowing it will not; saying that the treatment is enough to make an average person better – so if it doesn't work for you, then it must be your fault. Giving directions, yet knowing that nobody reaches the destination' (p. 15). The biopsychosocial model contains a double bind[35]: the message about responsibility is both 'you have a medical illness with primarily biological causes' and 'your problems are a meaningful and understandable response to your life circumstances'. This creates unresolvable contradictions: you have an illness which is not your fault BUT you retain responsibility for it and must make an effort to get better BUT you must do it our way because we are the experts in your illness. This leads to some of the 'problem behaviours' which are evident in mental health services: not taking medication (non-compliance) versus keeping asking for medication (too dependent); not accepting they're ill (lacks insight) versus sitting around on the ward not getting better (sick role behaviour); being too demanding of services (leading to a borderline personality disorder diagnosis) versus not engaging with services (leading to assertive outreach team involvement). Within this parody is a serious reality: services often inadvertently end up replicating the very problem that brought the person into contact with services.

A focus on treatment as something done to the patient has two specifically damaging effects. First, it locates the primary responsibility for change in the wrong place – with the clinician rather than with the patient. This assumption is imported from health contexts

where patient passivity is an advantage (e.g. surgery), although even in physical health settings the debate about the role of lifestyle (e.g. patient behaviours such as smoking or over-eating) is unresolved.

Second, the assumption that treatment involves the clinician doing something to the patient constrains possible solutions. For example, protective factors for resilience were described in Table 2.2, and it was noted that these are not in general assessed when taking a history. Their absence means that interventions to promote resilience are unlikely to be considered, which (drawing from Table 2.2) might include community programmes to reduce teenage substance misuse, easy access to emergency housing, community policing to reduce crime levels, individual tuition to improve academic attainment, building skateboard parks, funding and supporting attendance at youth clubs, teaching effective coping strategies, developing mentoring relationships with prosocial older children, providing extra-curricular activities to foster relations with prosocial peers, and supporting cultural traditions that provide opportunities for bonds with prosocial adults[66]. It is no coincidence that the majority of these interventions are environmental rather than individual.

Pragmatism versus consistency

Do these mismatches between biomedical/biopsychosocial models and reality really matter? Clinical work is pragmatic: patients, often in desperate situations, ask for support and treatment. Surely it's our job as clinicians to help? Perhaps these inconsistencies are clever academic points to make, but simply irrelevant to day-to-day practice?

Four pragmatic arguments might justify the unreserved and invariant use of a clinical model to make sense of a person's experience:

Justification 1: the model is the only way of understanding the experience

OR

Justification 2: the benefits always outweigh the costs

OR

Justification 3: the model predicts prognosis

OR

Justification 4: the resulting actions cure the patient.

It can be argued that all four justifications are present for many physical illnesses. The biomedical model has generated important advances for physical illness, from abdominal aneurysm to zyomycosis. In these cases, authoritative and unreserved use of a biomedical model may be justified.

However, none of the conditions is satisfied for mental illness. For Justification 1, we have already noted the existence of multiple credible (and incompatible) models of understanding mental illness. More generally, the meaning attributed to mental illness has varied over time, as we discuss in Chapter 7. For example, in relation to psychosis, Rachel Perkins argues that[76]: 'Different models of madness derive from different constructions of the world and events within it, but none is "true" in any absolute sense. There is nothing "truer" about assorted neurotransmitters than there is about intrapsychic processes, inner children or various deities.' The apparently dispassionate statement in Justification 2 is actually a statement of values, since comparing costs and benefits involves putting value on each. Placing more value on the experiences, aspirations and preferences of patients would significantly change the cost–benefit analysis away from the imposition of a clinical model.

We have specifically considered Justifications 3 and 4, and concluded that neither accurate prognosis nor consistent cure follows from the use of biomedical/biopsychosocial models.

Biomedical and biopsychosocial models have been evaluated. These are of course not the only clinical models. At present, there are two putative cure-alls: pharmacotherapy and cognitive behaviour therapy (CBT). Evidence for pharmacotherapy is reviewed in Chapter 6. For now, we turn to the third clinical model, which underpins CBT.

Clinical model 3: cognitive

Early psychological efforts to explain mental worlds and developmental changes through clinical observation underpinned Freudian, Kleinian and Jungian theories. These core insights were then stretched into general theories, applicable across time and culture. By the 1950s the limitations in the ability of these theories to be applied to, and fix, problems of mental distress became apparent.

Psychology as an academic discipline (equally as keen as psychiatry to demonstrate scientific credibility) retrenched into experimental and information-processing approaches – the former involving rats in mazes, the latter esoteric cognitive processing tasks. These provided some clinically important insights. You can make a rat (and so, perhaps, a person) depressed by inducing learned helplessness – a sense that there is no order to the chaos of life, and no pattern of behaviour which consistently leads to a desired reward or avoidance of punishment. People with a diagnosis of schizophrenia (and so, perhaps, the patient sitting in front of you) tend to jump to conclusions in the absence of the typical amount of evidence, and to hold those conclusions with unusually high levels of conviction.

These approaches culminated in the cognitive revolution in the 1960s. Cognitive therapy developments were led by the American psychiatrist Aaron Beck. The central insight of the cognitive model of mental disorder is that cognitions (beliefs) matter. The way we see the world, the interpretations we put on events, the expectations we have about how things will turn out, and our self-image all influence what experiences we have. Expecting the day to go badly, staying in bed because there is no reason to get up, having no sense of agency to change one's situation, coping with feeling low in ways that bring short-term relief but cause long-term damage – these all both create and maintain depression. This is not a new insight – Epictetus stated 'We are disturbed not by events, but by the views which we take of them'. More recently, the Personal Construct Theory of George Kelly proposed that people do not experience reality directly, but interpret or construe their experiences in the world[77]. The importance of behavioural as well as cognitive change has become evident over time, and since the 1990s the dominant cognitive model has been CBT. CBT has been embraced by the profession of clinical psychology, which has developed considerable empirical evidence of effectiveness for many conditions, and with many modes of therapy delivery (e.g. group, individual, computerised).

The key distinction from the biomedical model is the emphasis on interpretation mediating experiences. However, although this approach has the potential to work outwards from the individual's meaning, in practice the CBT movement has gone in a different direction. For example, the practice of clinical psychology in the USA has been characterised as based on four traditional assumptions[78]:

1. Clinical psychology is concerned with psychopathology – deviant, abnormal and maladaptive behavioural and emotional conditions
2. Psychopathology, clinical problems and clinical populations differ in kind, not just degree, from normal problems in non-clinical populations
3. Psychological disorders are analogous to biological or medical diseases and reside somewhere *inside* the individual

4. The clinician's task is to identify (diagnose) the disorder (disease) inside the person (patient) and to prescribe an intervention (treatment) that will eliminate (cure) the internal disorder (disease).

Not much has changed for clinical psychology since its inception as a profession[79]:

> the language of clinical psychology remains the language of medicine and pathology – what may be called the language of the illness ideology. Terms such as *symptom*, *disorder*, *pathology*, *illness*, *diagnosis*, *treatment*, *doctor*, *patient*, *clinical* and *clinician* are [used]. These terms emphasize abnormality over normality, maladjustment over adjustment, and sickness over health. They promote the dichotomy between normal and abnormal behaviors, clinical and nonclinical problems, and clinical and nonclinical populations. They situate the locus of human adjustment and maladjustment inside the person rather than in the person's interactions with the environment, or in sociocultural values and sociocultural forces such as prejudice and opposition. Finally, these terms portray the person who is seeking help as passive victims of intrapsychic and biological forces beyond their direct control who therefore should be passive recipients of an expert's 'care and cure'.
>
> (p. 14)

CBT is individualised in the sense that it is based on a person-specific formulation rather than a diagnosis, and has the potential to restore meaning and personal responsibility[80]. Formulation is not of course a new idea: its origins include Freud's case studies and the use within therapy of a co-constructed formulation in Cognitive Analytic Therapy[81]. Formulation moves assessment in the right direction – away from the reductionism of diagnostic categories and towards the richness of personal meaning. However, psychological therapies are not free from meaning-diminishing assumptions, such as their focus on the individual[82]: 'Psychoanalysis and humanistic psychology are prone to particular forms of reductionism in their conception of the human condition. This leads to their being conservative-by-default in that they frame socially derived forms of oppression as individual problems.' CBT can certainly be added to the list, with its emphasis on interpretation of phenomenological experience rather than a focus on poverty, abuse, homelessness or other socially and interpersonally toxic life events. CBT remains embedded in a psychopathology framework. It focuses on meaning in the post-Enlightenment sense of rationality, evidenced by its use of techniques such as collaborative empiricism and reality testing, with their embedded philosophical assumptions which we explicate in Chapter 4. For now, the point being made is that CBT as currently practised is congruent with many of the same assumptions about underpinning psychopathology as biomedical and biopsychosocial models.

All three clinical models impose a theoretically based framework which de-emphasises context and gives primacy to professional interpretation. Genuine understanding, by contrast, is contextualised and meaning-rich[83]:

> A young man hears a voice threatening 'I'm going to desecrate your daughter's grave'. Prior to a recurrence of his psychotic illness he heard indirectly that his daughter, living far away with his estranged wife, had died some months earlier and he has missed the funeral. He did not even know where she was buried. There seemed a meaningful connection between his life experience and his current symptoms. We could understand that he felt guilt and bereaved, that this news of loss has rekindled a deep sense of failure and loneliness, that his self-critical and self-punishing feelings had some relationship with the threatening voice – but how could this ever be proven? What kind of experimental method comparing people who had experienced either bereavement or psychosis would give sound evidence of a causal connection?

> Understanding these meaningful connections was very helpful in his care and
> treatment and unlocked many other meanings besides, but clearly did not explain
> why he was presenting with a psychotic illness.

We started this chapter by positioning mental illness as, before all else, a type of experience. This has two deep implications, both of which we have identified as key problems with clinical models. First, mental illness exists alongside the rest of phenomenological experience – the inner, subjective world. Therefore to overly focus on the illness part is misplaced. Second, great caution should be exercised in imposing a model of understanding the experience, rather than supporting the person to find their own interpretation.

So what other options are available? We consider two classes of model: disability and diversity.

Disability models

A social disability model for mental illness is a different approach to mental illness[4]. It has been defined by Liz Sayce[84]:

> The social model of disability holds that a person is disabled if he or she is, for
> example, blind, and experiences barriers and exclusion as a result. The term is not
> limited to those who 'use' blindness services nor to people who are 'surviving'. It
> covers everyone affected by discrimination on the grounds of the supposed
> imperfection of disability. It allows for transforming negative associations into
> positive ones, through disability pride.

This approach has several advantages. First, it does not presume a particular construction of understanding – medical, psychological, familial, societal, cultural and spiritual constructions can all be accommodated. A social disability model thus side-steps some of the issues of clinical models.

Second, the alignment is increased between mental illness and other, more established, disability groups. This has potential benefits in terms of more benevolent societal attitudes. For example, the success criteria for treatments then become much more focussed on ecologically valid measures of important social roles, rather than myopically fixated on symptom reduction. The effectiveness of a wheelchair is not judged in terms of whether it helps the person to walk, but how much it enables the person to do the things they want to do[4]. A social disability model encourages the use of treatments and support which keep the individual in their life.

Finally, this alignment de-emphasises illness, and the issue moves from 'What's the matter with you?' to 'What do you need to do your job or live your life?'. The focus on adaptation includes both the need for the individual to adapt to the new and changed reality of their life, and (because of the adverse social consequences) the contribution of a socially inclusive and accessible environment. This leads to a more holistic view of the person-in-context. As Rachel Perkins put it[85]: 'Mental health problems are not a full time job – we have lives to lead. Any services, or treatments, or interventions, or supports must be judged in these terms – how much they allow us to lead the lives we wish to lead.' It also leads to a wider role for mental health professionals. Instead of a focus primarily on the direct consequences of the illness itself, at least three levels of impact need to be considered:

1. **The illness**

    The direct impact of the symptoms – people in contact with mental health services often present with high levels of distress caused by their experiences.

2. **The treatment**

A social disability model highlights that treatment is not only about making an 'ill' person 'well'. This brings into view a wider set of questions about the impact of treatment.

Autonomy and responsibility – if I get benefit after an intervention, did I get better because of the pill, the therapist, or the therapy? All locate the source of control externally, rather than enhancing autonomy by generating an internal locus of control.

The centrality of social roles – work and relationships are a cause, not a consequence, of mental well-being. Encouraging a sick role can be toxic, if the cessation of social roles and responsibilities becomes long-term.

The harmful aspects of treatment – the side-effects (note the minimising language) of medication and other treatments can be more important than the intended therapeutic effects. Treatment which marks someone out as different (e.g. by causing them to look odd, or be overly sedated, or be constantly thirsty) reduces the opportunities for the person to be accepted in society.

Hopefulness and hopelessness – the degree to which clinical actions keep people in their lives is vital. Interventions which create dependency or passivity or promote hopelessness are damaging.

3. **The social consequences**

People who are in contact with mental health services experience stigma, defined by Graham Thornicroft as having three elements: problems of knowledge (ignorance), problems of negative attitudes (prejudice) and problems of behaviour (discrimination)[86]. These problems arise from mainstream beliefs about madness. Personal experience of mental health problems remains a taboo among mental health professionals[70], indicating a negative them-and-us view which supports and informs negative public attitudes.

These multiple levels can leave 'many people with mental illness feeling devalued and ignored and [have] resulted in mistrust and alienation from the mental health system'[87]. Repper and Perkins suggest that[4]:

> It is these multiple and interlocking traumas that have such a devastating impact on people's lives, often leaving them disconnected from themselves, from friends and family, from the communities in which they live, and from meaning and purpose in life. Unless mental health workers understand and address this complex range of barriers, we may inadvertently impede recovery by alienating people from the services that are supposed to assist them.
>
> (p. 49)

A particularly important domain of social exclusion is in relation to work and employment. This is an area in which biomedical and biopsychosocial models of mental illness can be harmful, since the focus on treating the illness before returning to work can lead to a loss of established work skills, a reduction in confidence, and internalised low expectations. Jed Boardman identifies several advantages of a social disability model in this domain[88]:

- It offers a more helpful conceptual basis for understanding and promoting employment opportunities for people who use mental health services and offers more hope of recovery of social roles
- It better captures the experience of discrimination and exclusion central to the lives of many mental health service users and addresses the barriers to employment
- It is consistent with current government policy . . .

- It is consistent with the views of users and people with disabilities
- It assists in achieving dialogue with employers

(p. 330)

We all need accommodations at work. For example, office-based workers need light and a chair. The social disability model points to the importance of accommodations at work for people with mental illness, not as an act of charity but because there is a legal right for people with mental illness to be able to work. It also addresses disclosure issues. Expecting job candidates to disclose about their experiences of mental illness is unrealistic when they believe they will be actively discriminated against during the recruitment process[89]. Similarly, expecting employers to provide active accommodations for people with mental illness is unrealistic, where their view of mental illness is informed by highly negative media portrayals and social beliefs, and where they are unaware of their legal responsibilities. The social disability model positions responsibility as shared.

Diversity models

A third type of model is more explicitly challenging about embedded psychopathological assumptions contained in clinical and disability models. Diversity models align with other liberation movements, and focus on emancipatory changes needed in society rather than either treatment of, or adaptation by, the individual. This follows in the tradition of established forms of identity politics, such as civil rights movements, gender politics and disability rights/independent living movements. Diversity models challenge three embedded assumptions: that mental illness is psychopathology, dichotomous and negative.

Assumption 1: mental illness experiences are psychopathological

We saw earlier how anthropological research shows that mental health practice constructs mental illness as an external entity[33]. Diversity models challenge this construction, and instead focus on the need to integrate all aspects of human experience (including those labelled by others as 'mental illness') into a proud and coherent self-identity. Part of this involves challenging the illness-based, and consequently negative, values by re-appropriating language. The term 'madness' is increasingly being used by service users[90] and non-medical mental health professionals[9] over the legal term 'insanity' or the (literally) clinical term 'psychosis'. For example, Mad Pride (www.mindfreedom.org) seeks to directly challenge the value attached to mental illness terminology[91]:

> When people enter mental health services, they assume a role in relation to that service. People become 'consumers', 'clients' and 'service users' . . . The effect of this, though it may be well-meaning, is to disenfranchise and create a stigmatised identity, both internally for the 'consumer', and in the larger culture . . . A key idea behind Mad Pride . . . is to counter stigma and discrimination through celebrating mad culture . . . [This involves] reclaiming of words like 'mad', 'lunatic' and 'psychotic and proud', just as African-Americans reclaimed the word 'black' and lesbian and gay culture reclaimed the word 'gay'.

(p. 138)

One initiative to challenge perceptions was the 'First National Nutters Conference' held in Napier, New Zealand in 2006, which was open to both 'nutters' and 'the chronically normal' (www.lighthousetrust.co.nz). Consumer-led and carer-led groups are forming coalitions to fight stigma (see Appendix). More politically active coalitions, such as Mad Pride and Mad Chicks (www.mad-chicks.org.uk), challenge basic understandings of 'mental illness' experiences.

Assumption 2: mental illness is dichotomous – people are either normal or mentally ill

A related assumption is that mental illness can be constructed as a discontinuous phenomenon. This is embedded in the concept of a psychopathological 'form', yet not empirically validated. Surveys of non-psychiatric populations find that the annual period prevalence of any mental disorder in the adult US population is 22%[92], in Germany is 31%[93], and lifetime prevalence in New Zealand is 40%[94]. Up to what prevalence level is it helpful to view an experience as deviant?

Perhaps only 'severe' mental illness is discontinuous? Not so. The lifetime prevalence of self-reported psychosis symptoms in the National Comorbidity Survey was 28%, compared with a clinician-rated prevalence of psychosis diagnosis of 0.7%[95]. At 15-year follow-up, 25% of the Dunedin birth cohort reported at least one delusional or hallucinatory experience that was unrelated to drug use or physical illness, but only 3.7% fulfilled criteria for schizophreniform disorder[96]. A population-based survey in Australia found that 11.7% of respondents endorsed one or more items designed to identify delusion-like experiences[97]. As Johns and van Os put it[98]:

> disease at the level of the general population generally exists as a continuum of severity rather than as an all-or-none phenomenon. Thus, blood pressure and glucose tolerance are continuously distributed characteristics in the general population, but because the clinical decision to treat is dichotomous, terms such as hypertension and diabetes are used in medicine. This clinical perspective, however, cannot be taken as evidence that these conditions exist as such in nature; they are the extremes of a continuous characteristic.
>
> (p. 1126)

Moving from population-level epidemiological data towards more focussed investigation is revealing. For example, there is no difference in range of, or conviction in, delusional items endorsed from a psychosis check-list between in-patients with psychosis and either Hare Krishna or druidic practitioners[99]. The patients were distinguishable only by their higher levels of distress and preoccupation, which suggests that the distinction between mental illness and other forms of deviation from normality may be subjective rather than objective. This finding has been replicated in other populations[100,101]. Indeed, when 84% of mental health nurses report having experienced an auditory hallucination[102], it is easy to see why service users who feel they are being positioned as fundamentally different from the rest of society may challenge this assumption. Mad Pride has developed an alternative Universal Declaration of Mental Rights and Freedoms:

> **We hold this truth**
> That all human beings are created different. That every human being has the right to be mentally free and independent.
> That every human being has the right to feel, see, hear, sense, imagine, believe or experience anything at all, in any way, at any time.
> That every human being has the right to behave in any way that does not harm others or break fair and just laws.
> That no human being shall be subjected without consent to incarceration, restraint, punishment, or psychological or medical intervention in an attempt to control, repress or alter the individual's thoughts, feelings or experiences.

Assumption 3: mental illness is wholly negative

Many people achieve eminence in their field whilst simultaneously exhibiting symptoms of mental disorder. For example, Felix Post[103] investigated the lives of 291 eminent

scientists, writers, politicians, artists, thinkers and writers. He found that 15% had shown no evidence of mental disorder, 25% had shown evidence of mild mental disorder, 30% of marked mental disorder, and 30% of severe mental disorder. He also showed a similar result with mental disorder among 93 of 100 poets, prose fiction writers and playwrights[104]. Lawrence went further, describing the lives of 75 luminaries who achieved greatness not despite but because of their manic depression[105]. Therefore high achievement and mental illness can co-exist, so a severe mental illness label should not, from an empirical perspective, lead to impoverished expectations.

At least as important, and possibly more inspiring, are the first-person accounts of life being deeper, stronger or richer after mental illness has struck. Compilations of these accounts[106–108] make salutary reading for professionals, both in highlighting the disjunction between clinical and self-reported accounts, and in the diversity of what helps people recover. For example, Repper and Perkins[4] include the following quotes:

> I have often asked myself whether, given the choice, I would choose to have manic depressive illness . . . Strangely enough I think I would choose to have it. It's complicated. Depression is awful beyond words or sounds or images . . . So why would I want anything to do with this illness? Because I honestly believe that as a result of it I have felt more things, more deeply; had more experiences, more intensely, loved more, and been loved; laughed more often for having cried more often; appreciated more the springs, for all the winters; worn death 'as close as dungarees', appreciated it – and life – more; seen the finest and the most terrible in people, and slowly learned the values of caring, loyalty and seeing things through.[109]
>
> As I found myself, psychosis – particularly in the early euphoric phase, if it obtains – can be at least the beginning of spiritual enlightenment. It may open doors to such experiences that the person can make productive use of later when they are well.[67]
>
> Because I have faced this pain, I am able to feel more deeply, reach out to others more authentically. To this day, the experience's bewildering array of symbolism involves me in its interpretation. Much of it involved the modern day anxiety towards death: from the stranger who I first met who I thought was death, to the attempt to write the last page of history in black. But the experience also showed me that there is a world on the other side of death.[110]

This has profound implications for how we view the mental illness experience. For example, Peter Chadwick has suggested that whilst madness is a discontinuity, it is still meaningful and not all negative, since over-active pattern recognition enhanced his creativity[67]. He concludes that 'it's a poor show if we can only aim to be sane'. This is succinctly expressed by Susie Crooks[91]: 'There's probably a bit of madness in all of us. I see my condition as actually contributing to who I am as a person. I don't see it as a disability. I just work hard to put a human face on madness' (p. 139).

Implications of a diversity model

Diversity models are overtly challenging to clinical and disability models. For example, rationalism is not given automatic primacy as a superior state. This post-modern rejection of a core Enlightenment value leads consumers to ask why, if it is unacceptable in a liberal democracy to forcibly change the religious beliefs of people, is it acceptable to forcibly change the 'delusional' views of people with mental illness?

The balance of power also changes. For example, the expertise of professionals is subverted by the suggestion from consumer-activist Arana Pearson (www.keepwell.com.au) to encourage consumers to use the letters QBE after their name – Qualified By Experience.

A diversity model also has some need for separatism. If oppression shapes the consciousness of the oppressed such that they internalise their oppression, then only when members of the oppressor group are not present to enforce unjust notions of equality, justice and right can the oppressed begin consciousness-raising. For the oppressed, this separation is a means to the end: liberation defined in their own terms. This is one reason why some user groups are actively opposed to involvement from clinicians, and why even the most liberal clinicians can avoid attempting to involve consumer-activists. Being thought of as an oppressor (from the clinician's perspective) or willingly working with oppressors (from the alienated consumer's perspective) are uncomfortable positions.

Clinical work within a diversity framework is also different, with much greater attention paid to empowerment of the individual, and awareness of sociocultural pressures and assumptions. If someone wants helps on their own terms with their 'mental illness', all well and good – a civilised society will respond to this, in the same way as it will respond to support someone coming to terms with their own sexuality, ethnicity or spirituality. If someone does not want help, then the implications of a diversity approach are that any discomfort arising from this choice is not the individual's problem, but should be located where it belongs – in the microcosm of the mental health system and the macrocosm of society.

Adjudicating between models

We have identified three broad ways of understanding mental illness, summarised in Table 2.3.

Each model has its merits and, in the absence of comparative data, it is not possible to adjudicate between them. What can be said with certainty is that the proponents of each approach should realise that their model is simply a hypothesis – the current reasonable

Table 2.3 Clinical, disability and diversity models

	Clinical model	Disability model	Diversity model
Source of problem	Illness in the person	The combination of mental illness and societal response	Society
Treatment	Necessary and appropriate	Necessary but insufficient	Only if wanted, never if not wanted
Expertise	In the professional	Shared	In the consumer
Central role of the mental health professional	Providing evidence-based treatments	Advocacy	Supporting consumer activism
Role of the mental health service user	Taking treatment	Developing inter-dependence – taking appropriate support and developing self-management skills	Accepting and valuing oneself, losing self-stigmatising beliefs
Strengths	Provides a clear explanatory model, and leads to well-developed treatments	De-emphasises illness Encourages social inclusion Consistent with existing disability discrimination legislation	Doesn't pathologise Places power in the hands of the individual consumer
Weaknesses	Doesn't fit for everyone Promises cure but doesn't deliver	Retains paternalistic approach	How to gate-keep support resources if everyone is 'normal'?

explanation of the facts. Therefore an authentic (rather than simply expressed) tentativeness is needed in applying the model to an individual.

Tentativeness has costs and benefits. Whitwell notes the calming effect of even a novice psychiatrist who applies the clinical model with confidence, and can contain the anxiety of an otherwise chaotic situation[22]. However, as Repper and Perkins note[4], this can lead to over-involvement and blaming:

> It is not uncommon for mental health workers to become 'over-helpful', to make decisions for the person and to do things for him/her rather than supporting him/her to do things unassisted . . . If our sense of worth is dependent on continued improvement, then we all too easily become disappointed and angry when, despite our best efforts, the client does not make the progress we expected. We feel let down and may blame that person for 'lack of motivation', 'non-compliance', 'self-defeating behaviour', and 'failure to follow advice'.
>
> (p. 72)

In mental health crises there is often a need for certainty, but in life there is often a need for uncertainty. The tension between these two needs is a difficult balance, especially given the almost total absence of empirical evidence comparing different approaches.

Having identified that there is more than one reasonable explanatory model of understanding 'mental illness' experiences, we turn now to a cross-cutting theme: recovery. Talking about recovery involves addressing some disputed issues: what does recovery mean and involve, how do we recognise and measure it, and how can it be supported? Addressing these issues is the focus of the remainder of this book.

We start by considering different approaches to understanding recovery.

What is recovery?

One word, two meanings

The term 'recovery' is at the heart of a debate about the *raison d'être* of mental health services. In Chapter 2 we argued that treatment of mental illness does not always cure the mental illness. We now present empirical research into schizophrenia demonstrating that recovery in the sense of cure – what we will call **clinical recovery** – is indeed lower than 100%, but also higher than consistent with a degenerative course of the disorder. However, some consumers self-report as being recovered, even when they experience ongoing symptoms. This new understanding of recovery – which we call **personal recovery** – would represent a fundamental shift in the values of mental health services if (as we argue it should be) it is embraced as the primary goal of mental health services.

We begin with clinical approaches to operationalising recovery.

Meaning 1: clinical recovery

The first meaning of recovery has emerged from professional-led research. Clinical recovery has four key features:

1. It is an outcome or a state, generally dichotomous
2. It is observable – in clinical parlance, it is objective, not subjective
3. It is rated by the expert clinician, not the patient
4. The definition of recovery is invariant across individuals.

Various definitions of recovery have been proposed by mental health professionals. For example, Torgalsbøen proposes that recovery in schizophrenia be defined as[111]:

- A reliable previous diagnosis of schizophrenia
- Criteria for diagnosis not fulfilled at present
- Out of hospital for at least 5 years
- Present psychosocial functioning within a 'normal' range (e.g. scores > 65 on GAF)
- Not on antipsychotic medication or only on low dosage (less than half 'defined daily doses').

The intention with this definition is that it be operationalisable – suitable for use in empirical research. It contains diagnostic, service use, functioning and treatment elements. Each of these can vary for reasons not related to the individual and whether they are recovered. Diagnostic criteria can (and do – see Chapter 2) change. Hospitals close and home treatment teams operate in the deinstitutionalisation era, so admission thresholds alter. Functioning is dependent on the opportunities in the environment. Medication regimes are influenced by prescriber beliefs.

A more socially focussed definition is proposed by Libermann and Kopelowicz[112]:

- Full symptom remission
- Full or part-time work or education

Table 3.1 Recovery rates in long-term follow-up studies of psychosis

Lead researcher	Location	Year	n	Mean length of follow-up (years)	% Recovered or significantly improved
Huber[a]	Bonn	1975	502	22	57
Ciompi[b]	Lausanne	1976	289	37	53
Bleuler[c]	Zurich	1978	208	23	53–68
Tsuang[d]	Iowa	1979	186	35	46
Harding[e]	Vermont	1987	269	32	62–68
Ogawa[f]	Japan	1987	140	23	57
Marneros[g]	Cologne	1989	249	25	58
DeSisto[h]	Maine	1995	269	35	49
Harrison[i]	18-site	2001	776	25	56

Notes:
[a]Huber G, Gross G, Schuttler R. A long-term follow-up study of schizophrenia: psychiatric course and prognosis. *Acta Psychiatrica Scandinavica* 1975; **52**:49–57.
[b]Ciompi L, Muller C. *The Life-course and Aging of Schizophrenics: A long-term follow-up study into old age*. Berlin: Springer; 1976.
[c]Bleuler M. *The Schizophrenic Disorders*. New Haven, CT: Yale University Press; 1978.
[d]Tsuang MT, Woolson RF, Fleming J. Long-term outcome of major psychosis. *Archives of General Psychiatry* 1979; **36**:1295–1301.
[e]Harding CM, Brooks G, Ashikage T, Strauss JS, Brier A. The Vermont longitudinal study of persons with severe mental illness II: long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *American Journal of Psychiatry* 1987; **144**:727–735.
[f]Ogawa K, Miya M, Watarai A, Nakazawa M, Yuasa S, Utena H. A long-term follow-up study of schizophrenia in Japan, with special reference to the course of social adjustment. *British Journal of Psychiatry* 1987; **151**:758–765.
[g]Marneros A, Deister A, Rohde A, Steinmeyer EM, Junemann H. Long-term outcome of schizoaffective and schizophrenic disorders, a comparative study, I: Definitions, methods, psychopathological and social outcome. *European Archives of Psychiatry and Clinical Neuroscience* 1989; **238**:118–125.
[h]DeSisto MJ, Harding CM, McCormick RV, Ashikage T, Brooks G. The Maine and Vermont three-decades studies of serious mental illness: II. Longitudinal course. *British Journal of Psychiatry* 1995; **167**:338–342.
[i]Harrison G, Hopper K, Craig T, Laska E, Siegel C, Wanderling J et al. Recovery from psychotic illness: a 15- and 25-year international follow-up study. *British Journal of Psychiatry* 2001; **178**:506–517.

- Independent living without supervision by informal carers
- Having friends with whom activities can be shared
- All sustained for a period of two years.

Their conclusion is that 'it is now realistic to set as a goal the feasibility of recovery from schizophrenia for half or more individuals with first episode'. Does this fit with findings from naturalistic longitudinal studies? Results are difficult to interpret due to differences in participant selection, definition of recovery, use of retrospective versus prospective tracking, frequency of repeated measurement, length of follow-up, location and time period[37]. Perhaps the most meaningful data comes from studies with long follow-up periods. In Table 3.1 we show all 20-year or longer follow-up studies published until 2008.

For example, Courtenay Harding's study in Vermont involved 32-year follow-up of the most difficult-to-place third of people resident in a psychiatric institution[113]. At follow-up she found markedly higher rates of recovery indicators than would be expected from this institutionalised group, with 81% able to look after themselves, and 68% having moderately close to close friendships. Just over half (54%) were still in touch with mental health services. Overall, 25% were fully recovered and 41% showed significant improvement,