i.e. 68% of the most dependent third had at least partially recovered, implying that only 11% of people with severe and enduring mental health problems remain unrecovered and deep in the system. This is of course much less than the clinical rule of thirds (i.e. a third recover, a third have fluctuating course and a third will never get better) would suggest.

These empirical data challenge the applicability of a chronic disease model to mental illness, with its embedded assumption that conditions like schizophrenia are necessarily life-long and have a deteriorating course. The most recent collation of all long-term follow-up studies included over 1000 patients between 12 and 26 years after initial assessment[114]. Commenting on the results, Richard Warner concludes[115]:

> What do we learn of the lives of people with schizophrenia from this fascinating study . . .? Most importantly, Kraepelin's view that a deteriorating course is a hallmark of the illness just isn't true. Heterogeneity of outcome, both in terms of symptoms and functioning, is the signature feature . . . bad outcome is not a necessary component of the natural history of schizophrenia; it is a consequence of the interaction between the individual and his or her social and economic world.

Consistent with the issues discussed in Chapter 2, we need to acknowledge that sometimes this recovery has been in spite of, rather than because of, mental health services[116]: 'The psychiatric system far from being a sanctuary and a system of healing was . . . a system of fear and continuation of illness for me. Like so many others recovery was a process that I did not encounter within the system, indeed . . . it was not until I left the system that the recovery process really got underway in my life.' Perhaps this problem arises from treating recovery as an outcome. Although this allows prevalence questions to be addressed, it also implicitly involves deep assumptions about normality. As Ruth Ralph and Patrick Corrigan put it[117]: 'This kind of definition begs several questions that need to be addressed to come up with an understanding of recovery as outcome: How many goals must be achieved to be considered recovered? For that matter, how much life success is considered 'normal'?' (p. 5). The people who use mental health services have called for a new approach[118]: 'The field of psychiatric disabilities requires an enriched knowledge base and literature to guide innovation in policy and practice under a recovery paradigm. We must reach beyond our storehouse of writings that describe psychiatric disorder as a catastrophic life event.' The second meaning of 'recovery' provides this enriched knowledge base.

Meaning 2: personal recovery

People personally affected by mental illness have become increasingly vocal in communicating both what their life is like with the mental illness and what helps in moving beyond the role of a patient with mental illness. Early accounts were written by individual pioneers[116;118–122]. These brave, and sometimes oppositional and challenging, voices provide ecologically valid pointers to what recovery looks and feels like from the inside.

Once individual stories were more visible, compilations and syntheses of these accounts began to emerge from around the (especially Anglophone) world, e.g. from Australia[123], New Zealand[107;124–126], Scotland[55;127], the USA[118;128;129] and England[106;108]. The understanding of recovery which has emerged from these accounts has a different focus from clinical recovery, for example in emphasising the centrality of hope, identity, meaning and personal responsibility[123;130;131]. The translation of these ideas into an action plan for mental health services is the primary goal of this book.

We will refer to the consumer-based understanding of recovery as **personal recovery**, to reflect its individually defined and experienced nature. To note, other distinguishing terms

have also been used, including recovery 'from' versus recovery 'in'[132], clinical recovery versus social recovery[133], scientific versus consumer models of recovery[134], and service-based recovery versus user-based recovery[135].

Opinions in the consumer literature about recovery are wide-ranging, and cannot be uniformly characterised. This multiplicity of perspectives in itself has a lesson for mental health services – no one approach works for, or 'fits', everyone. There is no right way for a person to recover.

Nonetheless, some themes emerge. A first clear point of divergence from the clinical perspective is that recovery is seen as a journey into life, not an outcome to be arrived at. As Repper and Perkins put it[4]: 'Recovery is not about "getting rid" of problems. It is about seeing people beyond their problems – their abilities, possibilities, interests and dreams – and recovering the social roles and relationships that give life value and meaning' (p. ix). Many definitions of recovery have been proposed by those who are experiencing it:

> Recovery refers to the lived or real life experience of people as they accept and overcome the challenge of the disability . . . they experience themselves as recovering a new sense of self and of purpose within and beyond the limits of disability[119].
>
> For me, recovery means that I'm not in hospital and I'm not sitting in supported accommodation somewhere with someone looking after me. Since I've recovered, I've found that in spite of my illness I can still contribute and have an input into what goes on in my life, input that is not necessarily tied up with medication, my mental illness or other illnesses [55].
>
> (p. 61)

This book will use the most widely cited definition, by Bill Anthony[1]:

> Recovery is 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.

It is consistent with the less widely cited but more succinct definition proposed by Retta Andresen and colleagues, that recovery involves[123]: 'The establishment of a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self determination' (p. 588). For those who value succinctness, the definition we use in our local service is[136]: 'Recovery involves living as well as possible'.

One implication of these definitions is that personal recovery is an individual process. Just as there is no one right way to do or experience recovery, so also what helps an individual at one time in their life may not help them at another. If mental health services are to be focussed on promoting personal recovery, then this means there cannot be a single recovery model for services. This is a profound point, and challenging to the concepts of clinical guidelines, evidence-based practice and care pathways. The issue will be explored further in relation to the Apollonian versus Dionysian spectrum, in Chapter 4. For now, we note that a recovery-focussed service is an approach, a way of thinking, a set of attitudes and values put into practice by skilled mental health practitioners. Caution should therefore be exercised about being highly prescriptive about the nature of recovery, and what a recovery-focussed service should look like and how it should work.

Key elements of a recovery approach have been identified by Rachel Perkins and Julie Repper[4] in the UK and Ruth Ralph[137] in the USA, and are summarised in Table 3.2.

Table 3.2 Descriptions of personal recovery

Summary description	Aspect identified by Perkins and Repper	Aspect identified by Ralph
Recovery involves a journey	*Recovery is a continuing journey, not an end-product or a result*	*Recovery is a journey from alienation to a sense of meaning and purpose*
from disengagement to engagement,		*Recovery is moving from withdrawal to engagement and active participation in life*
from surviving to living and growing.	*Recovery is about growth*	*Recovery is active coping rather than passive adjustment*
Although awareness of the journey often starts in adversity, such as mental illness,		*Recovery is breaking through denial and achieving understanding and acceptance*
	A recovery vision is not limited to a particular theory about the nature and causes of mental health problems	
the journey is not about the adversity.	*Recovery is not the same as cure*	
Although the journey of recovery has many routes,	*Recovery can, and does, occur without professional intervention*	
and each person's journey is unique,	*Everyone's recovery journey is different and deeply personal. There are no rules of recovery, no formula for 'success'*	
it often involves finding the courage to hope for a good future and to relate to yourself		*Recovery is the reawakening of hope after despair*
	Recovery is about taking back control over one's own life	*Recovery means no longer viewing oneself as primarily a person with a psychiatric disorder and reclaiming a positive sense of self*
and others in beneficial ways.		*Recovery is not accomplished alone; the journey involves support and partnership*
Setbacks are inevitable, but the challenge is universal	*Recovery is not a linear process*	*Recovery is a complex and nonlinear journey*
	Recovery is not specific to people with mental health problems	

Personal recovery has high ecological validity – it emerges from the narratives of people with mental illness who describe themselves as recovered or in recovery. It also removes the unhelpful evaluative element of whether, according to some externally defined criteria, someone has achieved recovery.

A disadvantage of personal recovery is that it makes operationalisation of the concept and empirical investigation problematic. If recovery is an ongoing, idiosyncratic and sometimes cyclical process, how can we get a reliable snapshot or show positive change? This does not mean that empirical quantitative research is impossible. For example, Sandra Resnick and colleagues used principal components analysis and confirmatory factor analysis to identify four domains of a recovery orientation in patients: empowerment, hope and optimism, knowledge, and life satisfaction[138]. This allows the prevalence of a recovery

orientation among service users, and the impact of interventions on this orientation, to be investigated empirically.

We have presented clinical recovery and personal recovery as having fundamentally different meanings. Is this distinction valid?

Are clinical recovery and personal recovery incompatible?

Two overlapping but nonetheless different understandings of recovery have been proposed. Not all authors identify two meanings of recovery. For example, Ruth Ralph and Patrick Corrigan propose three definitions of recovery[117]:

1. Recovery is a naturally occurring phenomenon.

   Some people who meet diagnostic criteria for a serious mental illness are able to overcome their disabilities and fully enjoy a life in which their life goals are accomplished without any kind of treatment.

2. As with other medical illnesses, people can recover from mental illness with proper treatment.

   Others who do not enjoy spontaneous recovery from mental illness are able to achieve a similar state of goal attainment and life satisfaction as a result of participating in a variety of services.

3. Recovery reintroduces the idea of hope in understanding serious mental illness

   . . . It means that even though a person is diagnosed with schizophrenia or other serious psychiatric disorder, his or her life need not be limited to institutions.

(pp. 4–5)

They note that mental health professionals gravitate towards the second definition (clinical recovery), whereas consumers typically find more value in the first (spontaneous recovery) and third (personal recovery).

These three definitions are also used in the joint statement on recovery issued by the Care Service Improvement Partnership, the Royal College of Psychiatrists and the Social Care Institute for Excellence in the UK[139]. Each definition is valued: 'Many concerns about engaging with a recovery approach arise from thinking that these different conceptions are in competition with one another, whereas they are complementary and synergistic . . . Adopting a recovery approach harnesses the value of current treatments but is directed at living with and beyond these continuing limitations' (p. 2). This book takes a different position. It envisages a future in which the goal of mental health services is more explicitly the promotion and support of personal recovery. Clinical recovery has value, as one approach to supporting personal recovery. However, a primary focus on personal recovery would fundamentally change the values, goals and working practices of mental health services. Clinical recovery is subordinate to personal recovery.

Personal recovery encompasses the three types of recovery listed above. Spontaneous recovery occurs for some people, when the individual's biological, psychological, social and spiritual self-righting skills and supports combine to manage the mental illness. Personal recovery occurs for some people through receiving evidence-based treatments, so treatment is an important element of mental health services. But, crucially, personal recovery is underpinned for all people by hope, meaning, identity and personal responsibility.

A primary focus on clinical recovery is incompatible with a primary focus on personal recovery. This is a strong statement, so we will illustrate with examples of how the current focus on clinical recovery can hinder personal recovery in three domains: hope, meaning and symptoms.

Clinical recovery and hope

Hope is central to personal recovery. It leads to action based on approach rather than avoidance motivation[140] – having positive goals, rather than trying to avoid negative outcomes. It also sustains through the inevitable (but otherwise unbearable) setbacks and suffering: 'Having some hope is crucial to recovery; none of us would strive if we believed it a futile effort'[141] (p. 32); 'The thing that keeps me going is the knowledge that I'm going to get better. The one thing I do know about my illness, if history tells me anything, is that I bounce back. And when I bounce back the trick is to bounce back and stay well'[55] (p. 60).

Hope is a problem in mental health services. The rhetoric is clear: services should work in ways which foster hope and optimism[142]. However, the reality for many people who use mental health services is quite the opposite[143]: 'The belief held by hospital staff was that I would be powerless to influence the return of psychotic symptoms that could at any moment strike again. For me to escape this prophecy, it felt like wading through miles and miles of swamp. This was an incredibly lonely journey. I had no guides, no specialist support, no stories of success' (p. 307). This is not a new problem. In 1959, Menninger commented on mental health professional training that: 'I perceived vividly how hopelessness breeds hopelessness, how the non-expectant, hope-lacking or "unimaginative" teacher can bequeath to his students a sense of impotence and futility, utterly out of keeping with facts known to both of them'[144]. This leads to a situation where the possibility of a good future is rarely communicated by mental health professionals. It is therefore all too easy for people using services to develop the belief that they will never recover, and the self-fulfilling nature of such a belief is obvious. This is why people exposed to the idea of recovery often express surprise and disbelief[55]: 'About two years ago I realised that I really could recover. I find that quite an amazing fact, because over the years no one has actually said, "You can recover". I thought once you had mental health problems you were just going to be stuck with it' (p. 38).

Some consumers find that interactions with mental health professionals engender feelings of being disrespected, discouraged and hopeless. This phenomenon is labelled as 'spirit breaking' by Patricia Deegan[145]:

> The experience of spirit breaking occurs as a result of those cumulative experiences in which we are humiliated and made to feel less than human, in which our will to live is deeply shaken or broken, in which our hopes are shattered and in which 'giving up', apathy and indifference become a way of surviving and protecting the last vestiges of the wounded self.
>
> (p. 306)

This lack of hope has toxic consequences. The self-fulfilling nature of being told by an expert that you'll never be able to work, or live independently, or have children or be treatment-free is profoundly damaging. The reason that clinicians should never make these statements (either explicitly or – more commonly – implicitly) is not some vague notion of withholding damaging information. It is because these statements are often wrong. The evidence about recovery rates was reviewed earlier in this chapter. Work is a specifically important contributor to recovery, yet one study found that 44% of people with mental illness who had obtained employment had been previously told by a clinician that they would never work again[146]. A focus on clinical recovery, with its emphasis on engendering realistic (i.e. low) expectations, can destroy hope.

Clinical recovery and meaning

Finding meaning in life is a central challenge for anyone, with or without mental illness. It involves making sense of experience, and generating a story which fits for the person.

This gives a narrative of how they come to be where they are in life. Often there is a liberating aspect to the narrative, such as a discovery that we don't need to be a prisoner of our auto-biography or a slave to our genes. It also provides a context and purpose for the future – it is the spring-board for hope.

The importance attached to meaning has been downgraded in contemporary mental health services[83]. In Chapter 2 we identified how imposing a biomedical or biopsychosocial model on the person's experience can remove its meaning. For example, depicting delusions as 'empty speech acts, whose informational content refers to neither world nor self'[147] does not support individuals to meet the universal life challenge of finding how to understand and grow from experience.

How do people develop meaning? Alain Topor interviewed 16 people with severe mental illness who both self-defined and met professional criteria for recovery[148]. They identified experimenting with four types of explanatory model:

1. Life history (e.g. a difficult childhood)
2. Medical, often expressed with ambivalence, such as a view of medication as a 'necessary evil' (with recovery as present when medication had ceased to be an 'issue')
3. Spiritual, in line with other studies[107]
4. Social, especially constructing a self-narrative through telling one's story, and negotiating or compromising on the basis of the listener's response.

The implication of this diversity is that imposing any single explanatory model can be damaging. It is more productive to support the person in their quest for meaning through a stance of offering an understanding rather than imposing an explanation.

One response by mental health professionals to a call to emphasise the development of meaning is to invoke issues of insight: people with mental illness *by definition* cannot make sense of their experiences, because it is exactly that capacity for self-awareness which is impaired by the illness. The professional knows what is going on whereas the patient may or may not.

The embedded assumptions, that there is an absolute reality to know and that one party has privileged access to it, are challenged in Chapter 4. However, even within a clinical frame of reference, empirical studies do not support an automatic focus on promoting insight. Pat McGorry cautions against adding 'insight to injury', by ignoring the individual's readiness to accept an illness explanation[149]. Indeed, a shift in the first 6 months from integration to sealing over is associated with symptomatic improvement[150] and increased self-esteem[151]. Or, to put it in the language of lived experience, isolation and withdrawal from life and reality is 'a perpetual suspended animation that is better than never-ending pain' (p. 71). This is not to argue that what clinicians perceive as a lack of insight is desirable, but it may be necessary.

In a service focussed on personal recovery, disagreement with a clinical model simply does not matter – what is important is that the person finds their own meaning, which makes some sense of their experience and provides hope for the future. Why? Because suffering with meaning is bearable – meaningless suffering is what drives you mad. Finding meaning *is* moving on. By contrast, in a mental health service focussed on clinical recovery, lack of insight is always to be avoided, because it is a symptom of illness and symptoms are by definition undesirable. We turn now to symptoms.

Clinical recovery and symptoms

For clinical recovery, symptom abatement is necessary. For personal recovery, there is no universal stance about symptoms. This issue plays out in the realm of medication. Even

if pharmacotherapy consistently reduced symptoms (which it does not – see Chapter 6), compliance with prescribed medication limits its effectiveness. If symptom reduction is a predefined goal of mental health services, then increasingly coercive approaches to ensuring medication compliance are justified. If, by contrast, empowerment, autonomy and self-determination are primary goals, then judgements about compulsion are more individual-ised. The issue does not reduce to a simplistic clinician versus patient power battle. For example, some consumers argue for a tiered approach to decision-making, with transfer of control gradually happening as the individual re-obtains capacity[152], whereas others argue that it is precisely at times of acute crisis when empowerment is most important[153].

There are at least two pragmatic reasons not to view symptom reduction as the primary goal of mental health services. First, it leads to this escalating cycle of increasing compul-sion. Second, a view of symptoms as always undesirable ignores the potential benefits. This is not intended in any way to romanticise the suffering commonly occurring in mental illness, but rather to note the reality that symptoms of mental illness are not always all bad. In Chapter 2 we described how mental illness can co-exist with high achievement, or contribute to a richness in life. Even more challengingly, some people report that the experience of symptoms can itself be therapeutic or cathartic[55]:

> I think sometimes there can be confusion between getting better and being symptom free. It is often during the times when I have had the most PTSD (Post Traumatic Stress Disorder) symptoms that I have achieved greater gains in recovery. For example, when new memories are surfacing my speech may be affected, but once I get through the difficult patches I am better than before.
>
> (p. 30)

Personal recovery is not always about symptoms, although it is almost always about the relationship with the symptoms[127]: 'I have taken ownership of my illness and I take responsibility for what I do and do not do. I don't let it control me. And it is an "it". It's not the whole of my life; It's part of my life now.'

Personal recovery and mental health services

We have argued that clinical recovery and personal recovery are different, and in some respects incompatible as primary goals for a mental health system. Specifically, the values, goals and working practices associated with clinical recovery are one of several approaches to promoting personal recovery. Clinical recovery is a sub-set of personal recovery. There-fore, prioritising clinical recovery is helpful for many people in supporting their personal recovery, but inadequate for others, and toxic for some.

Having made this distinction, we will now argue that mental health services should be focussed on the promotion of personal recovery, and not of clinical recovery. Five justifications for giving primacy to personal recovery over clinical recovery are presented in Section 2.

1. Epistemological – personal recovery places more value than clinical recovery on the knowledge of the individual
2. Ethical – acting in the professionally defined best interests of the patient should not be a primary value of mental health services
3. Effectiveness – the most common treatment (medication) does not cure, so the central promise of a clinical recovery approach is simply not fulfilled.
4. Empowerment – 'their' life has not been safe in our hands
5. Policy-based – national policy requires a focus on personal recovery.

4

The primacy of personal recovery
Epistemological rationale

Summary of the epistemological rationale

Evidence-based medicine is based on Enlightenment principles, and downgrades the importance of subjective experience. Since mental illness is fundamentally subjective, constructivism would provide a better basis for mental health services, as it values both expertise-by-training and expertise-by-experience.

The epistemological basis of clinical research was developed during the Enlightenment. Shortcomings of this approach to knowledge will be outlined, and alternatives identified.

What is knowledge?

Epistemology is the branch of philosophy which deals with knowledge and belief, including the nature of knowledge itself, how it is obtained, what people know, and how knowledge relates to concepts such as truth and belief. A central assumption in the field of epistemology shifted during the Enlightenment.

Classical understanding of knowledge was influenced by the Greek philosophical world-view. Aristotle defined truth and falsehood: 'To say of something which is that it is not, or to say of something which is not that it is, is false. However, to say of something which is that it is, or of something which is not that it is not, is true'. Drawing on this assumption of objective truth, Plato identified knowledge as a subset of that which is both true and believed.

The existence of absolutes and the centrality of belief dominated thinking until the Age of Enlightenment in the seventeenth and eighteenth centuries. The period is sometimes called the Age of Reason, as it involved a move from belief to reason as the primary basis of authority. The transition is sometimes called *the mechanisation of the world-picture*[154], and followed from wider cultural assumptions, such as empiricism (basing cognition in experience common to all) and the democratisation of knowledge. The idea of an experiment – '*a question we put to nature*' through intervention and observation – was developed by Francis Bacon[155] and others during this period. Crucially, the central goal of science was to establish causal relationships and processes which allow predictions to be made about what will happen in the future. The goal is not understanding meaning or reasons.

Scientific principles emerging from the Enlightenment emphasise a particular type of knowledge, called nomothetic knowledge. The distinction between nomothetic and idiographic knowledge was introduced by Wilhelm Windelband. **Nomothetic knowledge** is based on what Kant described as a tendency to generalise, and involves the effort to derive laws that explain objective phenomena. It is derived from the study of groups which represent populations, normally using quantitative methodologies. **Idiographic knowledge**, by contrast, is based on the tendency to specify, and involves efforts to understand the meaning of contingent, accidental and often subjective phenomena. It is derived from the

study of individuals and the properties which set them apart from other individuals, normally using qualitative methodologies.

Research focussed on the development of nomothetic knowledge seeks to develop generalisable explanations of the world derived from group-level experimentation. This involves **reductionism**: squeezing all the subjectivity or meaning or perspective out of a situation, so that truth can be revealed. Reductionism in the natural sciences is an asset – it indicates a robust theory, and allows reproducibility of a theory to be established through experimentation.

This world-view is the cultural and scientific context in which clinical research has developed, and accounts for why evidence from the randomised controlled trial has become dominant. The evidence-based medicine movement has developed the hierarchy of knowledge (which is in fact a hierarchy of method):

Highest (i.e. strongest) type of knowledge:

Systematic review and meta-analysis of randomised controlled trials

Followed in order by

Randomised controlled trials with definitive results

Randomised controlled trials with non-definitive results

Cohort studies

Case-control studies

Cross-sectional surveys

Lowest (i.e. least compelling) type of knowledge

Case reports

It goes without saying (because it has been said many times[156–158]) that this hierarchy brings benefits. The focus on randomised controlled trials (RCTs) as the gold standard of research methodology means that uncontrolled or poorly controlled studies are given less weight, more importance is attached to methodological issues, and more caution is exercised in evaluating outcome. As Derek Bolton puts it[159]: 'RCTs are here to stay. They are based on deep philosophical and cultural assumptions about nature and knowledge, assumptions that have well proved their effectiveness elsewhere.' How applicable to mental illness are scientific methods based on Enlightenment principles?

The development of a science of mental illness

We argued in Chapter 2 that mental illness is, before all else, a subjective experience. Therefore the object of mental illness research is the inner subjective world of experience. This gives rise to a basic problem: it is not possible to directly access subjective experience. It is only possible to investigate the observable world, either inside the body (e.g. biochemistry, neuroanatomy, self-reported cognitions) or outside (e.g. life events, social context, familial history). Clearly these inside and outside phenomena influence experience, and so research into the relationship between observable phenomena and subjective experience may be informative. But if the essence of mental illness is the inner subjective world, then only the person themselves can access this stratum.

The central challenge for any science of mental illness is to accommodate knowledge from both observation and subjective experience. This integration has been problematic. Two broad (and opposing) philosophies have dominated thinking.

On the one hand, **subjectivism** holds that the existence of every object depends on someone's subjective awareness of it – that perception is reality and that there is no

underlying, true reality independent of perception. For example, Wittgenstein argued that 'the subject doesn't belong to the world, but it is a limit of the world'[160]. The problem with subjectivism is that this reduces clinical insight to intuition – if there is no objective reality, then clinical feel is as good a guide as any.

On the other hand, the end-point of an emphasis on observable reality is Ayn Rand's **objectivism**, which holds that there is a mind-independent reality, that contact with this reality is through sensory perception, and that objective knowledge is obtained from this perception by measurement[161].

A transition from subjectivism to objectivism in mental health services occurred with the development of descriptive taxonomies. Perhaps the most celebrated development in psychiatry is Emil Kraepelin's description of dementia præcox[162], the underpinning for what was re-christened by Eugen Bleuler as a 'group of schizophrenias'[163]. In Chapter 3 we noted the unhelpful assumptions of chronicity and deteriorating course which are embedded in these descriptions of dementia at a precocious age and of a splitting in the mind through loss of integration between mental functions. Nonetheless, this framework forms the basis for modern psychiatric practice. Arieti describes post-Kraepelin developments[164]:

> Once he defined this syndrome, Kraepelin tried his best to give an accurate description of it . . . one cannot help admiring the accurateness of his description; however, his description is remarkable for its extension and completeness, not for its depth. The patient appears as a collection of symptoms, not as a person; or if he appears as a person, he looks as if he belongs to a special species and thus should be differentiated from the rest of humanity and put into the insane asylum. The psychiatric hospital is a zoological garden with many different species.
>
> (pp. 11–12)

Figure 4.1 Charcot's presentation of a case of hysteria.

The problem with pure objectivism is that the patient becomes an object of enquiry. This is illustrated by Charcot's presentation of a case of hysteria at the Salpêtriére in 1887 (Figure 4.1).

Evidence-based medicine is vulnerable to this process of objectifying the person with mental illness. This may sound like an exaggeration, so we will explore it further.

Problems with evidence-based medicine

In the natural sciences there is a great emphasis on reproducibility – the ability to repeat an experiment and produce the same result. This does not translate directly into effectiveness research in the human sciences, because (as we noted in Chapter 2) causation is generative, not successionist. Unlike humans, a chemical cannot refuse consent, or be thinking of something else, or have a preference for treatment modality. The human sciences analogue of reproducibility is the use of inferential statistics – evaluating the likelihood of intervention X producing outcome Y. This likelihood is expressed as the Number Needed to Treat (NNT) statistic, meaning the number of persons who must be treated to either achieve a positive outcome or prevent a negative outcome for one extra person. The aim of effectiveness research is to identify optimal (i.e. lowest NNT) treatment strategies, which at least in theory (and sometimes in practice[165]) can be expressed as a deterministic flowchart.

The problem with using this model of reproducibility is twofold[166]. First, clinicians in general treat individuals not groups. Therefore the scientific question of interest is not what would a group of people benefit from, but rather what would this individual benefit from? This particular person may be in the group who don't benefit from the intervention with the lowest NNT. Second, the relationship between an intervention and its effect is mediated by a host of complex internal and external factors. Exploration of groups cannot directly illuminate individual processes. Idiographic knowledge is needed to predict the impact of an intervention on an individual. A generative notion of causality[46] involves a context (in this case, the patient in their environment) mediating the association between a mechanism (a treatment) and outcome. Asking group-level questions, trying to ignore the contextual issues by random allocation of confounders, and then applying the results to individuals is the wrong method. It is missing the necessary idiographic knowledge about the person receiving the treatment.

Evidence-based medicine defenders might counter that these are technical problems, simply pointing to the need to better understand the mediators of treatment effectiveness, through techniques such as process evaluation[167]. For example, pharmacogenomics investigates the influence of genetic variation in individuals on drug response, by correlating gene expression or DNA-sequence variations with a drug's efficacy. The aim is to optimise pharmacological treatments on the basis of the individual's unique genetic profile. Similarly, psychological therapies are more effective for some individuals than others. Psychological mindedness is the umbrella term for predictors of response to psychodynamic therapy, and includes belief in the benefit of discussing problems, ability to access feelings, interest in meaning, and openness to change[168]. Predictors of effectiveness can be empirically identified. For example, response to hypothetical contradiction – the ability to entertain the possibility of beliefs being wrong – is associated with a better response to cognitive behavioural therapy for psychosis[169].

Each of these developments is desirable. Any effort to identify for the individual patient whether a treatment will be helpful is to be welcomed. However, the reliance on nomothetic

data means that these are necessarily broad-brush efforts. A swab test cannot capture expectancy based on past experiences, or personal preferences for treatment modality, or cultural beliefs, or a host of other predictors of treatment response. Similarly, nobody would suggest that people who don't exhibit adequate psychological mindedness or demonstrate the ability to respond to hypothetical contradiction be denied access to psychological therapies.

The current science of mental illness remains slanted towards the objectivist position. Clinical guidelines and research are focussed on diagnostic groups. Evidence-based practice uses nomothetic knowledge developed using randomised controlled trial methodology. Interventions are evaluated in order to identify generalisable rules expressed as NNT statistics.

The central problem is that nomothetic knowledge only provides half the story, because mental illness research is a human science, not a natural science. Humans differ in important ways from the objects of study of the natural sciences: we have attitudes, we are active agents in our world, we have consciousness, we can make decisions and change our minds. These attributes mean that Enlightenment principles which work so well in the natural sciences do not work as well in clinical settings.

In the human sciences, reductionism is a problem, not an asset. It objectifies the person by squeezing all the meaning out of their experiences. $2C_2H_5OH+CO_2$ may always be champagne. Is labelling a person as 295.3 (DSM-IV code for paranoid schizophrenia) really the same type of activity? By ignoring all that makes the person human, what is left is an undifferentiated shadow of humanity. It may be possible to describe this shadow in detail, and the shadow is related to the human, but it remains a shadow. The loss of meaning arising from biomedical and biopsychosocial models was explored in Chapter 2. Why then have these models been so embraced in mental health services? We suggest there is a higher-level, societal explanation.

The distinction between nomothetic and idiographic knowledge parallels a deeper dichotomy. In Greek mythology, Apollo and Dionysius were the sons of Zeus. Apollo was the god of the sun, lightness, music and poetry. Dionysius was the god of wine, ecstasy and intoxication. These two gods have come to be associated with two world-views.

The Apollonian view of the world is characterised by a focus on truth, logic and order. For the Apollonian, the best society is one which emphasises order and predictability. The guiding ethical principle is utilitarianism, expressed in Jeremy Bentham's rule of utility: the good is whatever brings the greatest happiness to the greatest number of people[170]. An Apollonian society emphasises uniformity and group norms, and meeting obligations such as work and relationships. Dissent is actively discouraged.

By contrast, the Dionysian view emphasises spontaneity, intuition and rebellion. The ethical framework is focussed on personal fulfilment and hedonism. A Dionysian society emphasises freedom, liberation from previous constraints, and the central importance of creativity and subversion of existing power structures.

To flesh out this distinction, Table 4.1 shows other words identified by Michael Thro as associated with each perspective[171].

Societies oscillate between the two ends of this spectrum over time. For example, in England the most prominent recent Dionysian eras were the 1920s (the Roaring Twenties) and the 1960s (the Swinging Sixties). The last swing toward the Apollonian end was in the 1940s and 1950s (World War II and the austerity years). At present, society is also leaning towards an Apollonian phase, shown by the development of league tables in education and health services, restrictions on human rights in the context of the 'War on Terror', an escalating series of policy and legislative initiatives in every area of government, and so forth.

Table 4.1 Poles of the Apollonian–Dionysian continuum

Apollo	Dionysus
Sun	Earth
Ego	Id
Psyche	Eros
Stoic	Epicurean
Mind	Heart
Reason	Emotion
Thinking	Feeling
Order	Chaos
Restraint	Excess
Male	Female
Hierarchy	Equality
Science	Art
System	Spontaneity
Compulsiveness	Impulsiveness
City	Country
Classicism	Romanticism
Civilisation	Nature

What is the relevance of this dichotomy to mental health services? An Apollonian society provides a context in which the values of traditional evidence-based medicine are more likely to dominate. An emphasis on the needs of the group over the perspective of the individual means that nomothetic knowledge fits the zeitgeist better than idiographic knowledge. The desire for order and uniformity leads to an increasing emphasis on evidence-based treatments, i.e. with the lowest Number Needed to Treat score and hence the most likelihood of benefiting the group, irrespective of their impact on individual patients. Clinical judgement is seen as a potential source of bias to be reduced through increasingly prescriptive clinical guidelines, rather than a creative resource in the mental health workforce.

This Apollonian–Dionysian spectrum underpins the changing definition of recovery. The 'get back to normal' everyday meaning is Apollonian – concerned with re-establishing social order, valuing being normal (i.e. lacking in any individuality) and conforming to social norms. Personal recovery is Dionysian – concerned with individual well-being, valuing idiosyncrasy, and liberating from stigma and discrimination.

The dominance of nomothetic knowledge

The mental health system values nomothetic knowledge more than idiographic knowledge, for at least three reasons.

First, the evidence-based medicine movement has successfully equated 'evidence' with nomothetic knowledge. Since it is prima facie undesirable to work other than on the basis of evidence (e.g. on the basis of clinical anecdote, historical precedent or personal whim) then the acquisition and application of nomothetic knowledge becomes an ethical imperative for clinicians.

Second, clinical guidelines are based on the hierarchy of evidence shown earlier, which gives primacy to nomothetic knowledge. Clinical guidelines are becoming increasingly influential in informing resource allocation decisions, such as mental health team composition. Since personal concerns such as being employed and having a reasonable degree of status loom large for most professionals, this development is likely to shape research and clinical discourse. Psychoanalytic psychotherapists, for example, have traditionally been negatively disposed towards randomised controlled trials, but are now issuing urgent calls to develop a credible (i.e. nomothetic, clinical trial-based) evidence base[172].

Third, it fits the perceived role requirement. If the clinician's job is to make authoritative pronouncements in highly emotional situations, then the ability to make decisions quickly

and with confidence is needed. Using nomothetic knowledge meets this need. Assessment primarily involves allocating the individual to the right group, and since action is based on predefined priorities and behavioural templates it leads to more apparent certainty than idiographic knowledge.

However, downgrading the importance of idiographic knowledge creates blind spots for clinicians, including an over-emphasis on current treatment vogues (e.g. medication – see Chapter 6), difficulty in using multiple models of understanding experience to offer genuine choice, and a belief that a diagnosis is true rather than a hypothesis.

The epistemological tension

There is a fundamental epistemological tension between nomothetic and idiographic know-ledge. We will illustrate this tension in relation to professions, science and service users.

Emphasising nomothetic knowledge leads to the job of a professional being understood in terms of 'technical rationality'[173]:

> Technical rationality holds that practitioners are instrumental problem solvers.
> Who select technical means best suited to particular purposes. Rigorous professional
> practitioners solve well-formed instrumental problems by applying theory and
> technique derived from systematic preferably scientific knowledge.
>
> (pp. 3–4)

But technical rationality is an inadequate approach for addressing human problems[174]:

> If the model of Technical Rationality is incomplete, in that it fails to account for
> practical competence in 'divergent' situations, so much the worse for the model. Let us
> search instead for an epistemology of practice implicit in the artistic, intuitive
> processes which some practitioners do bring to situations of uncertainty, instability,
> uniqueness, and value conflict.
>
> (p. 49)

Eraut notes the 'ideological exclusivity of a paradigm in which only knowledge supported by rigorous empirical research is accorded any validity'[175] (p. 10). In relation to education, Grimmett refers to[176]: 'the unmindful aping of natural science paradigms in the social sciences (sometimes referred to as scientism) that seems so pervasive in the professional schools of universities' (p. 25).

Giving primacy to nomothetic knowledge also impoverishes scientific discourse. For example, sociological research is almost totally absent from mental health literature[177], due to the 'troubled relationship between sociology and psychiatry'[178]. This makes some contentious issues – such as compliance[179], patient aggression[180], schizophrenia[181] and being a patient[182] – less visible.

To illustrate, Galbraith's work on countervailing powers involves the proposal that powers are dynamically related to each other, so increasing power in one group is linked with the possibility of resistance and reassertion of power by another[183]. Bridget Hamilton argues that the construct of insight requires a notion of identity in the patient (who expresses a view as to whether they have a mental illness or not) which is stable and located in the mind, whereas the post-modern notion of subjectivity highlights the socially con-structed and constantly changing subjective experience of self[177]. The assumption of insight as an objective reality therefore ignores the power relationships which it supports[184]. A discourse in which the position of the professional expert is given primacy over the 'lay' patient is an exercise of power. Therefore disagreement about the explanatory model of

illness and the consequent need for treatment is an act of resistance by the patient to this dominant discourse. Framing this resistance as a lack of insight can then be seen as a means of reversing this power exchange. It is noteworthy that guidance for DSM-IV-TR recognises the importance of listening to the patient in the psychiatric assessment because this gives the opportunity to 'correct any distortions'[185] (p. 29).

Sociological research challenges the belief that scientific development involves the dispassionate and disinterested aggregation of knowledge over time, with each new level of understanding building on the strong foundations of established fact. Only by stepping outside the clinical frame of reference do the contradictions caused by this tension become evident. For example, assumptions about what matters become apparent when service users lead research. User-focussed monitoring is a consumer-led research method which has been used to find out from service users what they want from mental health services[186]:

- acceptance
- shared experience and shared identity (i.e. meeting others who have had the same experiences)
- emotional support
- a reason for living
- finding meaning and purpose in their lives
- peace of mind, relaxation
- taking control and having choices
- security and safety
- pleasure

Two points emerge from this list. First, they are very different to clinical preoccupations around symptom reduction, risk management and crisis containment. Second, they are all positive and forward-looking – not at all about getting rid of things like symptoms or social disability. In psychological terminology, they relate to approach motivation rather than avoidance motivation. They point to a completely different way of constructing the job of a mental health professional.

Individual service users give primacy to idiographic knowledge. There are several reasons for this. Individuals hold detailed self-knowledge about what makes them the person they are. Emphasising group membership (e.g. a diagnostic category) over individual difference does not value this self-knowledge. There is also a fear that nomothetic knowledge will be used to justify actions which lead to damage for the individual. For example, if the clinician believes that evidence shows that medication works, and this person refuses their medication, so they need to be compulsorily medicated, then the end-point is the individual experiencing coercion. The evidence-based medicine movement does not give primacy to individual choice. Finally, there is a close association between nomothetic knowledge and clinical practice. Some consumers experience services as aversive and unhelpful, and so by extension reject the evidence base underpinning the service.

On the other side of the epistemological tension, no one would argue for the abandonment of nomothetic knowledge in favour of *vulgar situatedness*[187]. An exclusive focus on idiographic knowledge leads to a number of blind spots, including a difficulty in separating what is helpful for the individual from what is helpful for others, instinctive mistrust of professionals who operate on the basis of nomothetic evidence – 'they don't listen to us', 'they don't give us genuine choices' – and an oppositional discourse, highlighting shortcomings in the mental health system and implicitly or explicitly blaming mental health professionals for problems.

We can and must do better than simply relying on clinical anecdote (in which care depends on the intuition of the clinician), historical precedent (since, as we will discuss in Chapter 7, this has not been an auspicious success), or even consumer demand – the person is seeking help precisely because they are stuck and don't know the way forward. So how can this tension be resolved?

Epistemology and personal recovery

And so we come (at last!) to the central implication. A focus on personal recovery addresses the epistemological challenges outlined above. It places value on observable and nomothetic data – nobody wants treatment provided on the whim of the clinician who happens to see them. It also places value on idiographic knowledge – which is solely accessible by the patient. The practical implication for mental health services is that the application of evidence-based treatments is an important, but not exclusive, element of mental health services. As Rob Whitley put it in relation to the idiographic endeavour of cultural competence[188]: 'Cultural competence can ensure that evidence-based practices do not transmogrify into one-size-fits-all mindless technical application. Similarly, evidence-based medicine can ensure that cultural competence does not dissolve into anarchic reinvention of treatment for every individual' (p. 1589).

A good life involves a balance of the Apollonian and Dionysian – doing what you must and doing what you want. The absence of either element leads to an impoverished existence. This is a perennial truth – in 2400 BC the Egyptian Ptahhoptep wrote 'One that reckoneth accounts all the day passeth not a happy moment. One that gladdeneth his heart all the day provideth not for his house. The bowman hitteth the mark, as the steersman reacheth land, by diversity of aim'[189]. Or, as Maria Edgeworth put it in more modern parlance, 'All work and no play makes Jack a dull boy – All play and no work makes Jack a mere toy'[190].

A central proposition of this book is that both nomothetic and idiographic knowledge are necessary types of evidence. Both are authentic: they each tell us something meaningful and valid about the world. Both types are also necessary to provide a full and balanced picture of the world. This integrative stance mirrors modern resolutions of other dualisms. Donald Hebb responded to a journalist's question about whether nature or nurture contributed more to personality by asking whether the length or width of a rectangle contributes more to its area[191]. Similarly, Peter Chadwick commented on the mind–body dualism that *psychology without brain is like biology without mind*[67].

As noted in Chapter 1, this book is written to illustrate the blending of both types of knowledge. It combines insights from many individuals with arguments based on nomothetic studies. My interest in personal recovery in part emerged from noticing discordance between, on the one hand, the dissatisfaction I heard in conversations with patients and when reading first-hand accounts of recovered individuals (idiographic knowledge), and on the other hand the much more positive picture of increasingly effective psychological and pharmacological interventions emerging as nomothetic knowledge in the last 20 years in the academic literature.

Neither nomothetic nor idiographic knowledge in isolation are a sufficient underpinning for clinical practice. Some commentators draw nihilistic conclusions[22]: 'My solution – to the problem of mental illness – is that there is and can be no general solution. There is no general theory that can inform our decisions . . . [Unlike general medicine] In psychiatry there are no such basic principles . . . The ultimate criteria in deciding what to do in a psychiatric emergency are ethical, not scientific' (p. 73).

I agree that foundational or universal theories are suspect, but disagree with the pessimistic implications. A suspicion about the universality of theory simply places in the foreground the importance of values – as Bracken and Thomas put it, ethics before technology[26]. Theories differ in their implicit values, and the choice of theory is not value-free. Therefore, debate about theory *is* debate about values. We propose key values relating to personal recovery in Chapter 15. For now, we identify an alternative epistemological basis.

Constructivism – a more helpful epistemological basis

A balance point between subjectivism and objectivism can be found in the epistemology of constructivism. This holds that all knowledge is constructed, and does not necessarily reflect external reality, but rather depends on convention, individual perception and social experience. It specifically criticises the notion of ontological reality (i.e. reality as it is in itself) as incoherent, since one must already know what reality consists of in order to confirm it.

This perspective is not new. Gautama Buddha (560–477 BC) wrote 'We are what we think. All that we are arises with our thoughts. With our thoughts we make the world'. Heraclitus (540–475 BC) said that 'one cannot step into the same river twice . . . all is flux; all is becoming' (i.e. neither the person nor the river is ever the same). More recently, Immanuel Kant (1724–1804) described the mind as an active organ 'which transforms the chaotic multiplicity of experience into the orderly unit of thought'. The Swiss philosopher and psychologist Jean Piaget is credited with the development of formal constructivist epistemology[192].

Mahoney identifies five basic themes in constructivism: activity; order; identity; social-symbolic processes; and dynamic, dialectical development[193]:

> Constructivism views the living system as a proactive agent that participates in its own life dynamics. This portrayal is in contrast to traditional physical science renditions, in which the living system is a passive conduit of energies, forces and masses that are moved or modified only by being impacted by other external entities. In constructivism, complex systems – and certainly those we call 'living systems' – are organic processes expressing self-movement and ongoing self-organization.
>
> (p. 747)

A key theme in constructivism is the role of disorder, as a trigger for dialectical development (i.e. change generated by contrasts). Disorder, the opposite of order, is necessary for the development of complex systems, so processes of disorder are not pathologised as opponents of health. This observation underpins the discussion of risk in Chapter 20. New life patterns emerge from the chaos and dysfunction that occur when previous patterns are no longer viable[194]. The accounts of people with a diagnosis of schizophrenia contain many examples of this type of personal growth[195]:

> Before when I was a kid and not having any really bad symptoms, if I saw somebody who really looked [odd], stood out, I might giggle like the rest of the kids. Now, I would have compassion for the person.
>
> It [having schizophrenia] made me more human . . . it made me really have compassion and empathy.
>
> I still had to struggle with was I ever going to get a Bachelor's degree and . . . ever have kids and I've come to terms with those two things – no and no . . . Strangely

enough, it doesn't bother me. I just felt a release of negative energy when I gave up those aspirations.

Well, it, my illness, actually got me writing poetry. For which I've been published. I got some recognition.

This does not of course mean the experience of mental illness should be romanticised, or that the personal growth opportunities are readily apparent or proximal. It does, however, suggest caution in viewing mental illness as a wholly negative experience. This is consistent with consumer narratives reviewed in Chapter 3, which indicated that the experience of mental illness can bring both burden and benefit.

From a constructivist perspective, identity is not a single stable entity, or a collection of enduring personality traits. Rather, it is an embodied and emerging process, combining both consistency and diversity. Furthermore, this process is embedded in a social and symbolic context, in which the development of personal identity occurs within human and other relationships. A prime focus in supporting recovery is therefore on relationships, covered in Chapters 10 to 13.

In common with other knowledge bodies (e.g. cultural studies, ecological ethics, linguistics, human rights movements), a key assumption in constructivism is that everything and everyone is connected. This emphasis on intrapsychic and interpersonal process and the dynamic, changing nature of development provides a more helpful model of self when applied in mental illness. It opens up the possibility of adaptation, re-orientation, integration, and other responses to the experience by the individual. It also recognises the dynamic nature of social role negotiation – if everyone treats the person as being mentally ill, then this inexorably influences the self-image of the person, just as the behaviour of the person influences how others respond to them. In particular, the *way* that mental health staff work with people in the 'patient' role may be as important as *what* they do. The role of identity and social roles underpins the Personal Recovery Framework developed in Chapter 9.

A key advantage of constructivism is that it encourages a scientific and professional self-awareness and tentativeness. A constructivist perspective is mindful of being an ideology rather than 'how things are' – unlike the evidence-based health care (EBHC) lack of awareness[196]:

> EBHC is an ideology . . . but one that violates its own ideology. Indeed, one of the basic tenets is that only what has been scientifically proven in RCTs is credible, and it is a matter of faith that only what has been proven in such research is safe to be used in health care to improve health . . . Evidence-based medicine is for believers . . . EBHC adepts will be in the belief state forever.
>
> (p. 1374)

Constructivism is also pro-scientific in the wider sense of the term, whilst recognising the limitations of any universal or foundational theory. As Foucault put it[197]:

> The intellectual's role is no longer to place himself 'somewhat ahead and to the side' in order to express the stifled truth of the collectivity; rather, it is to struggle against the forms of power that transform him into its object and instrument in the sphere of 'knowledge', 'truth', 'consciousness' and 'discourse'.
>
> (pp. 207–208)

Constructivism offers the opportunity to integrate the knowledge underpinning clinical models with the uniqueness of the individual.

Box 4.1 Principles for a mental health service based on a constructivist epistemology	
Principle 1:	Clinicians are not dispassionate scientists – our values, beliefs and actions influence the sense we make of the patient
Principle 2:	A clinical model produces a hypothesis – it is not reality, and so may need amending or discounting
Principle 3:	A clinical model is valuable when the hypothesis it generates is useful to the patient
Principle 4:	Clinical work is inherently a collaborative endeavour, involving the patient and the clinician working to re-construct new and more helpful understandings about the person and their world

Mental health services need to work in ways which value both professional (nomothetic) and personal (idiographic) knowledge. We have proposed constructivism as a more helpful epistemological basis, which integrates these two approaches. A constructivist perspective would lead to four principles for mental health services, shown in Box 4.1.

These principles are highly supportive of personal recovery. They emphasise the importance of both professional knowledge and the self-knowledge of the consumer. The clinician's job is more than a technical role implementing treatments defined in clinical guidelines. It is to be an active and influential person working in partnership with the consumer, bringing nomothetic expertise-by-training to complement the person's idio-graphic expertise-by-experience. A key tool in the clinician's armoury is the ability to apply well-developed clinical models as one means of making sense of the person's experience. The crucial advantage offered by a constructivist perspective is that the focus is on utility – does the clinical model help the person? If not, change the model, rather than trying to change the person.

Epistemology is, as we have noted, intimately entangled with values. We therefore turn now to the issue of ethics – the values prioritised by mental health services and systems.

Ethical rationale

Summary of the ethical rationale

The consumer is in general better placed than the mental health professional to identify what is in their best interests. Therefore care should normally be provided on the basis of the consumer's goals and preferences. The two ethical justifications for compulsion are the interests of society and the best interests of the patient. Best interests are better defined by the patient or their nominated proxy decision-maker than by mental health professionals.

The aim of this chapter is not to provide an overarching ethical framework or describe the legal justification for compulsion, since that is a task better left to experts[198;199]. Rather it is to make the point that an orientation towards doing things to a person on the basis of professional views about their best interests does not promote personal recovery. A better guiding principle is to orient action by clinicians as far as possible around the consumer's goals, rather than professional goals. We then consider the exceptions to this principle.

Working with the consumer

We start with a guiding ethical principle: that mental health services should as far as possible be oriented towards supporting the individual to achieve personally valued goals, rather than towards the goals professionals might have for them. This sounds like an orientation to which every mental health professional would sign up, and yet the emergent properties of the system are not always consistent with this principle. For example, care plans typically focussed on amelioration of deficits, resolution of symptoms, avoidance of hospitalisation and relapse, and restoration of social functioning are based on clinical goals rather than life goals. These aspects may be necessary stepping stones, but these are not in themselves life goals. Practical approaches to identifying the individual's life goals will be described in Chapter 17.

An orientation towards giving primacy to consumer-defined goals means the primary job of mental health services is to support the person to progress towards their own life goals, not to provide treatment to meet clinical goals. Treatment is one important resource available from mental health professionals, but it should be a means to an end of the individual's life goals, not an end in itself. Clinical skills remain central. For example the clinician may observe consistent links between a particular behaviour of a patient (e.g. self-neglecting, becoming euphoric, reporting an increase in preoccupation with voices, stopping medication, having arguments with neighbours) and an undesirable outcome. This is important information, which the professional should actively highlight in their work with the patient, and support the person to engage in processing. But the difference is that this professional expertise is a resource to be offered to the consumer, as we discuss in Chapter 18.

This principle is the ethical justification for a focus on personal recovery. However, there are obligations conferred on mental health professionals which require some things to be done which are not based on the individual's life goals, and with which the individual may not agree[200]. Until there is a change in political stance about concepts such as responsibility, mental health professionals need to meet this obligation. The remainder of this chapter explores when compulsion is acceptable. This underpins the approach described in Section 3, where recovery-focussed approaches to medication (Chapter 19), risk (Chapter 20) and crisis (Chapter 21) are outlined.

We suggest that there are two justifications for doing things to people against their will.

Compulsion justification 1: benefit to society

Societies have values. The extent to which deviance is valued or tolerated, the balance between individual and community good, the role of the state in the protection of minors, the importance of public safety and the acceptability of suicide are all examples of societal values. They reflect the relative importance attached at a given point in time to individual freedom and group freedom: the Apollonian–Dionysian spectrum described in Chapter 4. Societal values change over time, but at any one time they are invariant. Societal values are expressed as mandated behavioural constraints. Most commonly in relation to mental health these constraints are that no one will be left to die (whether wilfully through suicide or unintentionally through self-neglect) or allowed to harm others. These behavioural constraints are non-negotiable.

One obligation placed on mental health professionals is to constrain behaviour in order to uphold these societal values. This obligation is conferred either directly through mental health legislation or indirectly through codes of conduct and mental health policy. It is an obligation which cannot and should not be ignored in a recovery-focussed mental health system. These societally imposed, non-negotiable constraints on behaviour provide one ethical justification for compulsion.

Distinguishing between intervening to benefit society and intervening to benefit the patient is helpful. It is honest, and places responsibility for this decision where it belongs – with society, rather than the individual professional. Professional judgement about whether the person has crossed over the societally mandated line remains central, but the line itself is not a professional judgement. It also makes clear that compulsion is not necessarily in the patient's best interests. For example, the responses of people who have experienced compulsory detention are highly variable, ranging from extremely positive ('It saved my life') to extremely negative ('It traumatised me')[201]. As another example, for people showing a pattern of disengagement, relapse and compulsory admissions, the professional response of taking responsibility may well ultimately be damaging for some patients, if it gets in the way of the individual taking personal responsibility for their own well-being. Since we cannot predict with certainty whether a specific patient will benefit from a compulsory intervention, we cannot know if it is in the patient's best interest. The justification for intervening is to uphold societal rules (which we can know), rather than for the benefit of the patient (which we cannot know).

Compulsion justification 2: best interests

Over and above societally mandated boundaries of behaviour, there is an ethical justification to intervene in situations where there is a risk of damage to the person's life, health and well-being. There is no law that says someone cannot give away all their money or ruin their

marriage through promiscuous behaviour when manic, or isolate themselves when depressed, or blot out voices with alcohol, or any of the other dilemmas with which mental health professionals routinely become involved. Yet the right to autonomy is reasonably over-ridden for some people at some points in their life by considerations of best interests. This is recognised in mental health legislation. For example, in England the legal justification for compulsion is risk to self or others (i.e. the societal rules justification) or risk to health (i.e. the best interests justification). A recovery orientation does not mean standing back, on the grounds that the person refuses help, whilst their life thins out and slips away.

This ethical justification for compulsion is paternalism: a clinician is acting paternalistically towards a patient when: his action benefits the patient; his action involves violating a moral rule with regard to the patient; his action does not have the patient's past, present or immediately forthcoming consent; and the clinician believes they can make their own decision[202]. Some clinicians might reject the label of paternalism, viewing their work as client-centred and not involving compulsion. The argument which we will present is as applicable to the more acceptable ethical principle of beneficence: doing things to a person on the basis of professional beliefs about what is in their best interests.

The idea of doing things to the patient in their best interest has been a consistent theme in the evolution of the mental health system, as we discuss in Chapter 7. The marker of a service in which ethical imperatives such as paternalism or beneficence are given primacy is a discourse in which actions are justified on the basis of duty (e.g. 'I'm a Doctor, so I treat people'), with professional (rather than the individual's) perceptions about their best interests driving care. This approach arises from a world-view that treatments are effective, and the privileged access of health professionals to these effective interventions places an ethical requirement on those practitioners to provide treatment. This has led to an often unchallenged assumption that best interests are necessarily defined by professionals. There are four challenges to this assumption.

First, this ethical imperative is increasingly out of step with wider societal values, which instead emphasise personal responsibility, informed choice and the right to self-determination. In other areas of life there is a recognition that the goals, aspirations and values of the individual should (in a moral sense) take primacy over those of the professional. This is eloquently expressed by consumer-activist Judi Chamberlin[203]:

> The ethical system . . . that drives the involuntary treatment system is paternalism, the idea that one group (the one in power, not oddly) knows what is best for another group (which lacks power). The history of civilisation is, in part, the struggle against paternalism and for self-determination. People in power are always saying that they know what is best for those they rule over, even if those poor unfortunate individuals think they know best what they want . . . The struggle for freedom has always been seen by the powerful as a denial of the obvious truth of the superiority of the rulers.
> (p. 406)

It is also recognised by professionals[26]:

> Until now, most psychiatrists wanted to hold on to an identity centred on the idea that they were delivering science-based technologies to patients suffering from certain identified illnesses . . . As such, psychiatry is very much a modernist venture. Its primary discourse is scientific, mainly around biology and positivistic versions of psychology. Issues such as meaning, values and assumptions are not dismissed but they are relatively unimportant, secondary concerns.
> (p. 5)

Second, health professionals no longer have sole access to information about treatments. Many patients have easy access through the internet to diverse sources of information about their mental illness. More deeply, in the previous chapter we identified changes in the world-view occurring during the Enlightenment. An implicit dichotomy that developed was between knowledge which is held by professionals and belief which is held by lay (i.e. non-professional) people. The implication of this dichotomy is that professional knowledge is more highly valued than lay beliefs. This distinction is challenged in a constructivist epistemology (outlined in the previous chapter), in which all forms of knowing are positioned as belief, and there is no true, unchanging knowledge.

The third challenge to the professional judging what is in the best interests of the individual arises from an awareness that the interests of people with mental illness have not been well served when responsibility for their well-being is assumed by others. This aspect will be elaborated in Chapter 7. Clinicians recognise the issue[198]:

> Ethical concerns about the psychiatrist's role and functions have dogged the profession for at least three centuries . . . Moral harms have emerged from the misuse of the asylum as a custodial 'warehouse', misunderstanding of the transference relationship, the gruesome effects of physical treatments such as leucotomy and insulin coma (to name but two), the misuse of psychiatry for political purposes (as occurred in the former Soviet Union) and systems of healthcare that jeopardise the needs of the individual, purportedly to benefit the many.
>
> (p. 7)

The final challenge to giving primacy to a professional perspective on best interests is that it is inconsistent with modern capacity-based legislation. For example, in England and Wales the Mental Capacity Act[204] defines best interests as what the patient would have chosen for themselves in the situation if they had capacity. This necessarily requires attention to the person's goals, values and preferences.

So we argue that: (a) best interests are a justification for compulsion; AND (b) in a recovery-focussed system, the closer to the individual's view of their own best interests the compulsion is, the more it can be ethically justified. How can the person's views of what is in their best interest be identified? The best approach is for the person themselves to state in advance what they wish to happen when in crisis. Where this is not possible, a proxy decision-maker is the next best alternative. Since family or friends will often know the person better than the clinician, professional judgement is not in general the best approach to identifying what the person themselves would have chosen. If neither the individual's preference nor a nominated proxy decision-maker is available, then a clinical perspective on best interests may be the best remaining approach. In Chapter 21 we explore what this means in practice.

We have argued that the two justifications for compulsion are non-negotiable behavioural constraints mandated by society and the best interests of the patient, and that best interests are better defined by the patient or their nominated proxy decision-maker than the clinician. This points to a need for professional certainty and tentativeness: certainty about the non-negotiable behavioural constraints, and tentativeness about what is in the best interests of the patient.

Balancing ethical imperatives

Acting to uphold societal rules or in the person's best interests can conflict with other values[198]. For example, the post-Enlightenment focus on 'self' as a primary unit of analysis leads to a view that distress is internal, individual, unhealthy and unnatural. This

understanding of rationality emerges from, and has the embedded assumptions of, a White, male, Western perspective. The existence of other perspectives raises important questions[26]:

> If psychiatry is the product of a culture which was preoccupied with rationality and the individual self, what sort of mental health care is appropriate in the postmodern, multicultural world in which many of these preoccupations are losing their dominance? . . . Should we not attempt to develop a discourse about distress that incorporates insights from more than 30 years of feminist and postcolonial thinking and writing in this realm? Is Western psychiatry appropriate to cultural groups which do not share Enlightenment preoccupations, but instead value a spiritual ordering of the world and an ethical emphasis on the importance of family and community?
>
> (p. 12)

Clinical judgement is a central approach to balancing conflicting values. In a recovery-focussed service this is even more true, because developing decision-making approaches in which the consumer is more empowered will create new ethical dilemmas, especially in relation to professional accountability where what the person wants is incompatible with the clinical perspective[205].

If values need to be balanced, how is this done? One approach is values-based practice, which we discuss in Chapter 15. Another approach is to draw from biomedical ethics. Beauchamp and Childress propose four guiding principles[206]:

1. Respect for autonomy: the importance of personal choice and self-determination is emphasised
2. Non-maleficence: there is an active focus on avoiding hopelessness and dependency
3. Beneficence: there is an equally active focus on providing effective treatments and interventions
4. Justice: there is support to exercise citizenship rights.

In their framework, actions justified on the basis of beneficence are balanced by the need to promote autonomy and support citizenship.

A third approach is to use different values. We explore this in Chapter 15. For example, a modern version of the Hippocratic Oath, written by Louis Lasagna in 1964, puts this well:

> I will respect the hard-won scientific gains of those physicians in whose steps I walk . . . I will apply, for the benefit of the sick, all measures [that] are required, avoiding those twin traps of overtreatment and therapeutic nihilism . . . I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug . . . I will not be ashamed to say 'I know not,' nor will I fail to call in my colleagues when the skills of another are needed for a patient's recovery . . . I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.

Incorporating these values into mental health services would change basic assumptions. At present it is difficult to identify any use of the concept of 'overtreatment'. The result is that many patients receive unnecessary and (for some) harmful treatments. Similarly, few clinicians admit 'I know not', even when patients present with the most intractable of life difficulties. The rationale is the importance of maintaining therapeutic optimism, but the stance is underpinned by Enlightenment principles: the triumph of rationality and the dominance of evidence-based medicine. Admitting ignorance would destroy the illusion

that the clinician will be responsible for the patient, but would also give back responsibility to the patient for finding their own way forward. We explore the implications for clinician–consumer relationships in Chapter 13.

Many of the case studies in this book illustrate what a greater emphasis on values looks like in practice. As a precursor, the Soteria Project[207] focussed on the values expected of workers[26]:

- *Do no harm*
- *Do unto others as you would have done unto yourself*
- *Be flexible and responsive*
- *In general the user knows best*
- *Valuing choice, self-determination, the right to refuse and informed consent*
- *Anger, dependency, sexuality and personal growth are acceptable and expected*
- *Where possible, legitimate needs should be met*
- *Take risks*
- *Make power relationships explicit* (pp. 265–266)

An emphasis on values positions the application of scientific knowledge as a means, not an end. Debates about method become recognised as debates about values and ethics. This change is happening in other areas of society, such as a questioning by the organic food movement of the primacy given to efficiency. In mental health services, a focus on values challenges the predefined goal of transforming the abnormal human into a normal human. Rather, the goals (and resulting methods) of mental health services become truly patient-centred: based on what individuals themselves aspire to in their life.

Effectiveness rationale

Summary of the effectiveness rationale

The effectiveness of medication for mental illness has been exaggerated, the indications widened, and the potential disadvantages under-stated. Having a balanced and evidence-based approach to medication, rather than predefining it as a necessity, will focus services on personal rather than clinical recovery priorities.

Medication is the dominant treatment offered for mental illness. Across all users of specialist mental health services, 92% have taken medication for their mental illness in the previous year[208], rising to 98–100% for people admitted to in-patient units[209]. More widely, there has been a huge increase in prescription of medication for common mental disorders in primary care. For example, primary care prescriptions for antidepressants in England have tripled, from 9.9 million in 1992 to 27.7 million in 2003[210]. Primary care physicians are well aware of clinical guidelines that medication should not be a first-line treatment for mild to moderate depression[211], but prescribe antidepressants because of the lack of available alternatives. In the past three years, 78% of primary care physicians prescribed where they thought an alternative approach would have been more appropriate, including 66% because the alternative was not available and 62% because of the waiting list for the suitable alternative[212]. Similarly, for severe mental illnesses such as psychosis, treatment almost always involves medication, with a much lower level of provision of psychological and social interventions[213].

The intention in this book is not to be anti-medication but pro-choice, and in Chapter 19 we discuss the contribution of medication to recovery. However, in this chapter we argue that the dominance of medication as a treatment strategy is empirically unjustified. We make this case by critically outlining the stages by which medication comes to be seen as a necessity.

Creating markets

Before a drug can be tested, it needs a condition (or, from the perspective of pharmaceutical companies, a market). One means of opening up a new market is to identify a new condition. However, if done overtly the profit motive would be transparent and invoke suspicion. Pharmaceutical companies therefore use covert strategies to develop new markets. One method is to get the sufferers to raise awareness – a particularly powerful approach, since who can criticise the patient voice? Many user or consumer or patient groups receive funding from drug companies. For example, Andrew Herxheimer[214] notes that the Global Alliance of Mental Illness Advocacy (GAMIAN Europe) was founded by Bristol-Myers-Squibb, and in the USA the National Alliance for the Mentally Ill 'between 1996 and 1998 received almost $12m from 18 drug companies, led by Eli Lilly. The organisation promotes the nationwide expansion of PACT (Program of Assertive Community

Treatment), which includes home deliveries of psychiatric drugs backed by court order' (p. 1209).

Eloquent explorations of disease mongering – widening the boundaries of medicine to grow markets for those who sell and deliver treatments[215] – are becoming available, and should be required reading for professionals who view a diagnosis (such as bipolar disorder[216], attention deficit hyperactivity disorder[217], social phobia[218] or post-traumatic stress disorder[219]) as revealed truth rather than social construction.

Once the existence of the condition is established, whether through lobbying by sufferers or other forms of disease awareness campaigns[53], it is then more acceptable for pharmaceutical companies to propose their product as the solution. This is done under the guise of providing information – again, who could deny that people have a right to information?

The problem is that the information is biased. This is shown by experiences from the USA and New Zealand, the only countries so far to allow direct to consumer advertising (DTCA) by pharmaceutical companies. For example, after legalising DTCA in 1997 with regulation by the Food and Drug Administration (FDA), spending on advertisements in USA went from $266m in 1994 to $2.5bn in 2000[220]. A review concluded[221]: 'DTCA is also often inaccurate . . . From 1997 to 2001, the FDA issued 94 notices of violations, mostly because benefits of the drug were hyped up and risk minimised' (p. 1709).

The 'science' of commercially funded drug trials

What about the science? Drug research is not independent. Pharmaceutical companies directly fund between 70%[222] and 90%[223] of all drug trials. Even where the funding is from non-industry sources, between one quarter[224] and one third[225] of investigators have industry affiliations. Increasingly in the USA, drug trials are performed by commercial organisations called contract research organizations who compete with each other for business. This means that there is a financial incentive to design and perform trials in ways which produce advantage for the customer – the drug company[26].

Research funded by a pharmaceutical company is more likely to show benefit for their product, due to selection of an inappropriate comparator or publication bias[226]. Biased scientific designs include exposing the control group to a washout period (i.e. creating a withdrawal effect)[26] or using older drugs with worse side-effect profiles as the comparator[227], or even dropping 'under-performing' sites altogether[228].

This bias in scientific quality is then amplified by bias in reporting of results. Publication bias is strongly present in reporting of drug-company funded research. One strategy is multiple publication of results favouring their product[229], disguised through author rotation and substitution[230]. For example, the 1999 Cochrane review of the effectiveness of one popular atypical antipsychotic (olanzapine) found the same study cited in 83 separate publications[230]. The 2005 update concluded[231]:

> A great deal of global effect / mental state data are missing from the studies supplied by Eli Lilly . . . We find it surprising that a compound worth $3.69bn per year is so successful even though there is a lack of important data for people with schizophrenia, their families and professional carers . . . We have found no evidence of an attempt to conceal the fact that the hundreds of presentations relate to a limited number of studies but inclusion of the unique company trial codes in each presentation would have helped piece together the few sausages from the very thinly sliced salami.

This is in no way a company-specific issue. Publication bias has also been shown for another popular anti-psychotic – clozapine[232].

A second strategy is selective reporting and publishing of mixed results[233]. For example, a review investigated the association between FDA-registered antidepressant studies (with FDA ratings of efficacy) and resulting publications[234]. They considered 74 studies, involving 12 antidepressants and 12 564 patients. Of 38 studies rated by the FDA as positive for the sponsoring drug company, 37 were published. Of the 36 studies rated either negative ($n=24$) or questionable ($n=12$), 22 were not published, 11 were published as positive, and 3 were published as not positive. This publishing bias inflates the apparent effect size of each individual drug (ranging from 11% to 69% inflation), and the FDA-rated overall mean weighted effect size of 0.31 was inflated to an apparent effect size of 0.41. A similar picture emerges in Sweden[229]. (Disconcertingly, immediately after writing this paragraph I looked at the online BBC news to find the lead article titled 'Anti-depressants "of little use"', about a new study indicating drug–placebo differences only occurring in very severe depression[235] – media interest may change practice more than scientific findings.)

Presumably mindful of potential litigation, surprisingly few commentators label these practices as fraud for profit. If industry-funded studies are to be viewed as research (which they apparently are, given their publication in academic journals), then these practices are unethical. If (as they perhaps should be) they are treated as marketing material, then their status is a matter of commercial ethics, but they should not be accorded the status of academic research.

There are numerous other areas of concern, including:
- Pharmaceutical industry links with political leaders[236]
- Industry funding of regulatory bodies in Europe[237] and the USA[238]
- Citing 'data on file' and 'educational information' (i.e. not peer-reviewed) in marketing material given to professionals[228]
- Use of popular internet sites to propagate a financially advantageous biomedical model of schizophrenia[239]
- Industry influence on clinical guideline development[240].

The depth of the problem is becoming apparent in increasingly common reviews in medical journals[234;235;241;242]. A former editor of the New England Journal of Medicine, Marcia Angell, commented on the pharmaceutical companies that[243]: 'This is an industry that in some ways is like the Wizard of Oz – still full of bluster but now being exposed as something far different from its image. Instead of being an engine of innovation, it is a vast marketing machine' (p. 20). It is not clear why this particular journal seems to so galvanise its editors about the issue, but another former editor, Arnold Relman, goes further (cited by Moynihan [244]): 'The medical profession is being bought by the pharmaceutical industry, not only in terms of the practice of medicine, but also in terms of teaching and research' (p. 1190).

The actual effectiveness of pharmacotherapy

Can we get an unbiased view about the effectiveness of psychotropic medication? Two approaches have been used.

First, analysis of results from studies registered in the Food and Drug Administration (FDA) database: this addresses several sources of bias – it includes full disclosure of all data from world-wide testing of a drug (so selective or multiple reporting and dropping of sites is minimised), and has robust quality standards (so poor comparators and methodology are minimised). For antipsychotics ($n=10\,118$), annual rates of suicide and attempted suicide were 1.8% and 3.3% for placebo, 0.9% and 5.7% for typical antipsychotic, and 0.7% and

5.0% for atypical antipsychotic[245]. Symptom reduction was experienced by 1.1% of participants for placebo ($n=462$), 17.3% for typical antipsychotic ($n=261$) and 16.6% for atypical antipsychotic ($n=1203$). For antidepressants ($n=19\,639$), annual rates of suicide and attempted suicide were 0.4% and 2.7% with placebo, 0.7% and 3.4% with active comparators (i.e. control group antidepressants), and 0.8% and 2.8% with investigational antidepressants[246]. Symptom reduction was experienced by 30.9% with placebo ($n=2805$), 41.7% with active comparators ($n=1416$), and 40.7% with investigational antidepressants ($n=4510$). These data suggest nil or marginal benefit from psychotropic medication – certainly not the uniform substantial benefit that would justify current prescription levels.

A second approach has been used in the UK and USA, where non-industry funded pragmatic trials of first-generation (typical) versus second-generation (atypical) antipsychotics have been completed. The US Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) Study ($n=1493$) and the UK Cost Utility of the Latest Antipsychotic Drugs in Schizophrenia Studies (CUtLASS) ($n=363$) had consistent findings[247]: 'Our conclusion must be that first-generation drugs, if carefully prescribed, are as good as most second-generation drugs in many if not most patients with established schizophrenia' (p. 163).

The conclusion drawn by the principal investigators of the two studies is interesting[247]:

> It is worth reflecting on how crudely we often use antipsychotic drugs. Polypharmacy, the prescribing of two or more antipsychotics in parallel, is widespread despite the lack of evidence to support it and the knowledge that it doubles cost and multiplies safety risk. Off-label prescribing is common. It is perhaps not surprising that, in the context of a severe, chronic illness, clinicians are tempted to resort to untested measures. It is the same sense of frustration that allowed us to be 'beguiled' . . . by the promise of a new class of drugs. These trials emphasise again the urgent need for discovering new, safe, effective medications, as well as knowing how to best use our effective treatments.
>
> (p. 163)

My conclusion is different. CUtLASS, CATIE and studies reviewed earlier in the chapter all indicate that the benefits of each generation of medication have been systematically exaggerated, both in absolute terms and relative to previous generations. The winners from this arrangement are pharmaceutical companies, who make more money, and those who prescribe, whose status is enhanced. The losers are patients.

The close ties with pharmaceutical companies and the support for a model locating mental illness as a biochemical disturbance may come to be seen as the central failure of the profession of psychiatry in the late twentieth century. In the words of the President of the American Psychiatric Association[248]: 'as a profession, we have allowed the biopsychosocial model to become the bio-bio-bio model . . . Drug company representatives bearing gifts are frequent visitors to psychiatrists' offices and consulting rooms. We should have the wisdom and distance to call these gifts what they are – kickbacks and bribes' (p. 3).

An empirically supported view of medication

Clinical guidelines[142] emphasise the value of maintenance medication, with the results that psychotropic medication prescription is near universal in mental health services[213]. This needs to change.

Overall, a balanced appraisal of the effectiveness of medication would be that medication has some benefits, generally modest, for some people some of the time. The development of better medications is of course welcome, and pharmacological treatment should be

available to all. But prescription of medication should be a genuine choice for patients. This has important implications.

Because medication will have a neutral or harmful impact on some patients, the professional orientation towards prescribing when in doubt is damaging. For example, polypharmacy becomes the norm, and difficult to address through quality improvement approaches[249]. I have yet to meet a prescriber who states that they prescribe when in doubt, and yet the level of prescribing especially in specialist mental health services suggests that this belief exists and influences practice. David Whitwell – a practising psychiatrist – asks an important question[22]: 'If only 50% derive benefit from the drugs, why are 100% still being encouraged to take them? The 50% who do not benefit may be positively disadvantaged by the unwanted effects of the drug. Efforts to raise the amount that patients actually take of the prescribed drugs fail to address well-founded patient scepticism' (p. 21).

Almost all clinical trial evidence in favour of antipsychotic medication involves short-term (i.e. less than two years) follow-up[250]. Even accounting for the bias in presentation of medication trials reviewed earlier, consistent benefits at the group level are shown for symptom reduction during acute relapse. What is less clear is the need for long-term maintenance medication as a prophylactic against relapse. The Vermont longitudinal study[113] found different approaches to medication among the recovered patients:

- 20% were prescribed no psychotropic medication
- 30% were prescribed but did not take any medication (i.e. non-compliance)
- 25% were prescribed and made targeted use (i.e. partial compliance)
- 25% were prescribed and 'religiously' took their medication (i.e. full compliance).

The view that prophylactic medication should in all cases be prescribed long-term (the euphemism meaning for life, unless the patient complains) is neither empirically supported nor promoting of personal recovery. Literature on this subject inadvertently highlights the values embedded in prescribing[250]: 'Although we should understand and respect our patients' decision to opt for a trial off medication, in the majority of cases it would be most responsible to recommend maintenance of antipsychotic medication on an indefinite basis' (pp. 286 and 290). A recovery-promoting approach would involve the availability of medication long-term, for the individual patient to use (in an active sense) if *in their judgement* the benefits outweigh the costs.

The view that there is something irrational (linked to lack of capacity) in not taking psychotropic medication as prescribed is common, but also not empirically supported. Rates of compliance in physical and mental illness are broadly similar. One review found 58% of prescribed antipsychotic medication was taken, 65% of antidepressant medication and 76% of medication for physical illness[251]. Other studies find no difference between compliance rates[252].

Reasons for not taking prescribed psychotropic medication are varied. For example, a study investigating the predictors of medication compliance in 228 people admitted to acute units in England and Wales found that coercion during admission, an unhelpful relationship with the prescribing clinician, low involvement in treatment decisions, prominent side-effects, poor 'insight' and negative attitude to treatment all predicted poorer compliance[253]. More generally, a key emerging determinant is the match between the explanatory model of the patient and the prescriber[254]. Unsurprisingly, therefore, collaborative decision-making is associated with improved adherence[255]. Finally, there is now preliminary evidence that use of neuroleptic medication on first presentation may not be necessary[256], and that discontinuation can in itself be harmful[257]. Non-compliance may be a highly rational response for some patients.

If decision-making is based on realistic concerns, why does medication seem to be the focus for so much of mental health services? Again, Whitwell's analysis is clear[22]: 'There is an expectation in psychiatric hospitals that people will be given medication . . . If none is prescribed it will lead to the question being asked of whether the person is really ill and really needs to be in hospital . . . there are no serious psychiatric illnesses for which no drugs are indicated' (p. 32).

We need to move away from professional imperatives to prescribe, and towards genuinely patient-led approaches which place the individual at the heart of decision-making. Some patients will take medication as suggested by the prescriber. Some will negotiate the dose, type or duration of prescription. Some will choose non-pharmacological approaches to self-management. All choices are valid, because making choices promotes self-determination and personal responsibility. Can we estimate the proportions in each group? The Soteria Project is an approach developed by the late Loren Mosher to provide care for people experiencing acute psychosis, which emphasised the role of the environment and relationships ('interpersonal phenomenology') rather than medication[207]. The approach was not anti-medication but pro-choice. At two-year follow-up, 58% of people had received neuroleptic medication at any time and 19% continuously during the two-year period[258]. The overall approach was associated with improved outcomes[258] and reduced costs[259] compared with admission to standard acute units. In Chapter 19 we will explore what a recovery-supporting approach to medication looks like in practice.

This will not be a simple shift. What is the compassionate clinician to do when confronted with someone experiencing severe and disabling symptoms? How can the experienced professional respond when the person seems intent on following a path of action which looks certain to repeat previous damaging cycles? These real-life clinical dilemmas will be addressed in Section 3. We now turn to the fourth rationale for focussing on personal recovery.

Empowerment rationale

Summary of the empowerment rationale

The interests of people with mental illness have consistently been subordinated to the interests of other dominant groups in society. 'Their' life has not been safe in our hands. Consumers should have primacy in decision-making about their own lives.

In this chapter we provide some illustrations of the ways in which the emergent properties of the mental health system have subordinated the interests of people with mental illness to the interests of other dominant groups in society.

For convenience the presentation is chronological, but the chapter is not intended to be a history of the mental health system. Nor is it intended to be balanced. The point of this chapter is to note some of the many examples when the lives of people with mental illness have not been safe in the hands of the mental health system. It is about emergent system properties, not about individual practitioners or specific professional groups. It is a description not a criticism – although there are lessons to be learned, which are suggested at the end of the chapter.

The changing treatment of mental illness

The idea that mental illness was a legitimate focus of medicine emerged after the European Enlightenment[26]. The historian Roy Porter summarises this development[260]:

> The enterprise of the age of reason, gaining authority from the mid-seventeenth century onward, was to criticise, condemn and crush whatever its protagonists considered to be foolish or unreasonable . . . And all that was so labelled could be deemed inimical to society or the state – indeed could be regarded as a menace to the proper workings of an orderly, efficient, progressive, rational society.
>
> (p. 14)

The primary purpose in creating asylums was to socially exclude these unreasonable people. There were of course other purposes: asylums were (initially) humane places, often with uplifting architecture, open spaces and compassionate attention to human needs. As with much to come in this chapter, the intention is not to judge past actions through current values. The aim is to highlight examples of things being done to people with mental illness.

1750–1900: madness as illness

Medical involvement was initially to treat physical illness and offer moral guidance[26], but changed into a process of systematically ordering and classifying the inmates after a battle between the medical profession and the legal profession for control of the asylum[261]. Madness came to be seen as illness, with a consequent focus on treatment and charity.

Since madness was an illness, the pre-Enlightenment focus on expunging the evil from the individual was replaced by a twin focus on protecting the vulnerable and segregating the ill – further contributing to the rise of asylums. A range of treatment regimes were employed, included bleeding patients, spinning them, dunking in cold water, holding underwater until unconscious, and tranquiliser chairs. How were these treatments justified? In line with Enlightenment values, the emphasis on rationality underpinned a view that those who had lost their ability to reason were de facto not fully human, and therefore any approach to restore rationality was defensible.

Alongside these developments, England and France saw the growth of moral treatment. For example, the Retreat in York was opened by William Tuke in 1796, and later run by Samuel Tuke[262]. Aversive medical treatments for insanity were de-emphasised in favour of creating a relaxed and therapeutic environment focussed on nursing care. Simultaneously Philippe Pinel was appointed by the revolutionary government in France to run the Parisian institutes of the Salpêtrière for women and the Bicêtre for men. Pinel focussed on management of the mind, involving talking and listening to the patient rather than medically treating them. Both these early clinical models emphasised the twin virtues of kindness and empathy: kindness towards the individual with their illness, and empathy implying for the first time there may be meaning in the experiences. These two values were associated with a challenge to treatments that worked by breaking the patient. The first shoots of an expansion in this approach, such as the opening of an asylum in Philadelphia modelled on York[26], soon dwindled as the focus of mental health care shifted back to technological responses to madness.

1900–1950: madness as 'other'

The early twentieth century saw the rise of the eugenics movement, a *soi-disant* science which viewed madness as a spreading genetic disorder. The short step to viewing people with mental illness themselves as a threat to civilised society was soon made, leading to forcible incarceration in asylums to protect the vulnerable (it was never entirely clear if this meant people with mental illness or the public). Compulsory sterilisation was introduced as a progressive health measure. Asylum budgets, and the results on inmates, were bare-bones – consistent with a socially devalued role for people with mental illness.

Changes to the public view of insanity were accompanied by new clinical developments. Novel treatments included gastrointestinal surgery, water therapies (keeping patients in water for several days), induction of fever, and refrigeration therapy (cooling patients until they lost consciousness). The most widely used physical treatments were insulin coma therapy, metrazole convulsive therapy and electro-convulsive therapy – all intended to work by changing the brain[227]. For example, insulin coma therapy was proposed as a scientific treatment, after its discovery in 1927 by Manfred Sakel, a neuropsychiatrist from Berlin. After publication in 1933, it became a widely used treatment for schizophrenia in Europe and the USA. Scientific text-books on the treatment highlight the embedded Enlightenment assumptions about what matters and, consequently, what doesn't. For example[263]:

> Careful investigations have shown that in patients with a prolonged series of deep comas there is sometimes a mild degree of intellectual impairment . . . The degree of impairment has been of practical importance in only a handful of patients reported in the literature, and is in any case not comparable with the disability caused by the disease itself.

Insulin coma therapy was abandoned in the 1960s, partly because controlled trials showed it to be ineffective[264], and partly due to the advent of neuroleptics.

The ultimate expression of the cure-at-all-costs approach was brain surgery, which was publicised as a miracle therapy for madness[227]. Prefrontal lobotomies were widespread in the 1930s and 1940s, and were seen as a safe treatment – indeed, the Portugese neurosurgeon Egas Moniz received the Nobel Prize for Medicine in 1949. Over 40 000 lobotomies were performed in the USA, about 17 000 in the UK, and 9300 across Norway, Sweden and Denmark. Now widely (though not totally) abandoned, the reason for their enthusiastic introduction is clear[265]:

> Lobotomy . . . exemplified a common characteristic of medical practice, in which doctors and patients have often felt the need to 'do something' in the face of seemingly hopeless situations . . . Sometimes, the interventions are the first step toward a successful remedy; in other instances, they prove worthless.
>
> (p. 120)

It is reasonable to want to do something to alleviate suffering. It is reasonable to try new approaches, although the non-use of randomised controlled trial approaches when developing these treatments was indefensible given that these were established methods – the first randomised controlled trial was published in 1753[266]. But any treatment should be both scientifically justified and ethically defensible. The evidence-based medicine movement has created a framework for a scientific justification for new treatments. This is to be welcomed. The remaining challenge is ethical – to both listen to and act on what people receiving treatments and interventions say is of importance to them: which brings us to the present day.

1950 onwards: madness as neurotransmitter disturbance

The 1950s saw the chemical revolution. The first antipsychotic medication – chlorpromazine – became available, rapidly followed by several others. The early marketing as a chemical lobotomy or as a means of producing symptoms of encephalitis lethargic virus changed by the 1960s to describing chlorpromazine and other neuroleptics as a safe, antischizophrenic medication[227]. The message communicated to the public was that antipsychotics: (i) are effective; (ii) normalise the overactive dopamine systems in the brains of people with schizophrenia; and (iii) are safe. However, none of these assertions is true. We addressed the effectiveness question in Chapter 6. We now consider the second and third claims.

Neuroleptics do not restore disturbed homeostasis. They work by antagonising (blocking) dopamine D2 binding. In other words, they have affinity but no efficacy (biological response) for dopamine receptors. This difference from homeostasis is important, because it produces several problems on discontinuation: cholinergic rebound, supersensitivity psychosis (also known as rebound psychosis), withdrawal dyskinesias and activation syndrome[267]. Furthermore, the dopamine hypothesis of supersensitive dopamine receptors is an argument equivalent to observing that aspirin relieves pain, and concluding that pain is caused by an absence of aspirin[268]. Of course, it is now possible to contextualise neurotransmitter changes with greater clarity: as a final common pathway, as related to D2, also involving serotonin (5-HT1, 5-HT2, 5-HT3), as a component of a neurodevelopmental hypothesis, etc. However, these are descriptions rather than explanations of overactivity. The question of *why* is not asked. Writing about schizophrenia 30 years ago, Anthony Clare suggested that[269]: 'For all the advances, in understanding and treatment, the condition

remains a baffling and enigmatic one, a harrowing experience for the individual sufferer, and a challenge to the ingenuity and skill of those intent on unlocking its secrets' (pp. 214–215). Major investment has not brought major advances in genetic[270;271] or psychopharmacological[245;247] research. There is much description, but not much explanation, for schizophrenia. This suggests the need for modesty rather than certainty in working with people with mental illness, especially when considering doing things to them.

Antipsychotics are also not safe. Neuroleptics have many side-effects (i.e. directly cause many health problems), including dystonia, akathisia, parkinsonism, tardive dyskinesia, tachycardia, hypotension, impotence, lethargy, seizures, hyperprolactinaemia, weight gain, diabetes mellitus, agranulocytosis and neuroleptic malignant syndrome. Alongside these direct health effects, they are also stigmatising. The characteristic shuffling gait associated with the parkinsonian symptoms marked out people as from the local asylum. When I entered mental health work, patients with these features were colloquially referred to as doing the modecate shuffle or the haloperidol hop. In the 1990s a new form of atypical antipsychotic medications was brought to market. These were hailed as safer and more effective than the previous generation of typical antipsychotics. The exaggerated claims about their effectiveness were discussed in Chapter 6. In relation to safety, these atypicals have a different side-effect profile (i.e. cause a different set of health problems), such as diabetes and agranulocytosis. Whether this is safer than health problems caused by typical antipsychotics is clearly an individual judgement which can only be made by the person taking the medication.

The empowerment rationale for personal recovery

Of course, there have been many desirable developments in mental health services: the closure of the total institution[71] in which patients with a mental illness lived, died and were buried in graves identified by numbers, not names[272]; an awareness of the importance of environment, such as Dutch social psychiatrist Arie Querido's development of community-based mental health services for people in acute distress[273]; the application of anti-discrimination legislation to people with mental illness, creating a legal framework to challenge social exclusion; the development and evaluation of specific health care structures, which foster specialisation for different patient groups; availability of a broader range of interventions (e.g. vocational rehabilitation, cognitive behaviour therapy), which creates the possibility of choice; and so forth.

However, the selective presentation in this chapter emphasises the negative to make three points.

First, to raise the issue of whether an apology is justified. This question arises in any situation where the dominant group has inflicted harm on the subordinate group over a sustained period. It is not an issue of mental health or even health services, but a general socio-political concern about how best to respond to past wrongs. Recent examples include the Truth and Reconciliation Commission in the post-apartheid era in South Africa, and the apologies for Nazi atrocities by German Chancellor Konrad Adenhauer and for the associated role of the Roman Catholic church by Pope Benedict. Politicians face calls for this. In the UK, Tony Blair expressed deep sorrow in 2006 for the role of England in the slave trade. In Australia, John Howard refused to apologise for the treatment of indigenous Australian people, but this was the first act by Kevin Rudd following a change of Government in 2008. In the same year, Stephen Harper apologised for Canada having forced 150 000 aboriginal children to attend state-funded Christian boarding schools aimed at assimilating

them. Real reconciliation and partnership may only be possible once a line has been drawn through the symbolism of an apology, which explicitly recognises the need for a new trajectory in the future[274]. Public acknowledgements of harm from the mental health system have been made, such as to the 185 former psychiatric patients of the Lake Alice Hospital child and adolescent unit in New Zealand for 'sexual abuse, being locked up with adult service users, and being punished using unmodified electro-convulsive therapy and paraldehyde'[91] (p. 35). A few other examples of local apologies exist[272], but no general apology for maltreatment (however well-intentioned) of people with mental illnesses has ever been made by a government or a mental health professional body. The Confidential Forum for Psychiatric In-Patients of Psychiatric Hospitals sought to understand the experiences of former in-patients in New Zealand. It was held between 2005 and 2007, and after hearing the accounts of many former in-patients concluded[275]: 'Many expressed a hope for a public acknowledgement by the Government that their experiences in psychiatric institutions had been humiliating and demeaning and had often taken a lifelong toll' (p. 3). There has been no formal response.

Second, to underscore the message of Chapter 5 about caution in pronouncing on what is in the person's best interests. Mental health professionals are with very few exceptions good people, wanting to help and make life better for the people they are working with. However, doing things to patients on the basis of professional perspectives about their best interests or because something needs to be done has inadvertently inflicted harm on many people. It would surely be arrogant to assume things are different now.

Finally, to raise awareness for people entering the mental health professions, who do not understand why there is such an oppositional discourse from some consumer perspectives. There is a clear pattern of the citizenship rights of individuals being consistently subjugated to the needs of other, more powerful groups in society. Whether the subjugation was of women through moral insanity justifying incarceration for adultery[276], or of homosexual people whose deviance was treated with aversion therapy (i.e. electrocution)[277], or of political dissidents previously in the Soviet Union[278] and currently in relation to the Falun Gong sect in China[279;280], or simply of the everyday people who experienced the systematic stripping away of their identity[71], the implication is the same. The mental health system internationally has, at times, been a means of oppression.

How can oppression be addressed? The only sustainable approach is to not have the power to oppress. The primary agenda of the mental health system in the nineteenth century was protection, and in the twentieth century was treatment. In the next chapter we suggest that the policy direction indicates the primary agenda for the twenty-first century will be about recovery. Without engagement in discussions of power, there is a real danger that this agenda simply becomes the next thing to do to people with mental illness.

If personal recovery is about anything, it is about empowerment. A focus on personal recovery will involve giving primacy to the preferences, wishes and values of the individual. This will require social and political debate about responsibility, difference and risk, but it may be the only effective way to ensure people with mental illness are not harmed by the mental health system.

Policy rationale

Summary of the policy rationale

Public sector mental health professionals have been told to develop a focus on personal recovery in mental health services.

The final rationale is that there is an emerging policy consensus that the primary goal of mental health services is to promote personal recovery. Quite simply, mental health services should be focussed on supporting personal recovery because that is what, at a policy level, has been identified as the goal of mental health services[281].

This will be illustrated by reviewing mental health policy from five countries.

Policy in the United States of America

In 2003, the President's New Freedom Commission on Mental Health concluded that[282]:

> the system is not oriented to the single most important goal of the people it serves – the hope of recovery . . . Most individuals could recover from even the most serious mental illnesses if they had access in their communities to treatment and supports that are tailored to their needs.
>
> (p. 3)

The Commission explicitly identified recovery as the goal of a transformed system. It defined recovery:

> *Recovery* refers to the process in which people are able to live, work, learn and participate fully in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms. Science has shown that having hope plays an integral role in an individual's recovery.
>
> (p. 5)

Two principles for system transformation were identified:

> **First, services and treatments must be consumer and family centered**, geared to give consumers real and meaningful choices about treatment options and providers – not oriented to the requirements of bureaucracies
>
>   **Second, care must focus on increasing consumers' ability to successfully cope with life's challenges, on facilitating recovery, and on building resilience**, not just on managing symptoms.
>
> (p. 5)

The profession of psychiatry in the USA has signed up to this orientation[283]. Individual States differ in their progress. Those with more advanced implementation of a recovery orientation include California (www.dmh.ca.gov), Connecticut (www.ct.gov/dmhas),

Georgia (mhddad.dhr.georgia.gov), Massachusetts (www.mass.gov/dmh), New York (www.omh.state.ny.us) and Philadelphia (www.phila.gov/dbhmrs).

Policy in Australia

The approach to developing mental health policy in Australia has since 1992 involved a consecutive series of five-year National Mental Health Plans. The latest plan states[284]:

> These [mental health] services should provide continuity of care, adopt a recovery orientation and promote wellness.
>
> (p. 4)

The plan defines what a recovery orientation involves:

> A recovery orientation emphasises the development of new meaning and purpose for consumers and the ability to pursue personal goals.
>
> (p. 11)

This federal plan is then interpreted at State level. For example, the plan for Queensland identifies five common elements necessary to support individuals during their recovery journey: Hope, Active sense of self, Personal responsibility, Discovery and Connectedness[285]. In South Australia, the emergent emphasis from local consultation was that 'the prevailing organisational culture of the mental health system should be an orientation to recovery'[286]. Pro-recovery State-level guidance has also been issued by Australian Capital Territories[287], Tasmania[288], Victoria[289] and Western Australia[290].

Policy in New Zealand

In New Zealand, the development of mental health services is led by the Mental Health Commission, a body established by the government in 1996. The vision statement of the Commission is[91]:

> To ensure that people with mental illness live in an environment which respects their rights, provides fair and equal opportunities, and have access to a fully developed range of mental health services which is provided by the right combination of people responding appropriately to people's needs in order to achieve the best possible outcomes and recovery.

In 1998 the Mental Health Commission published the Blueprint[291], setting out the guiding principles for mental health services. The Mental Health Commission (www.mhc.govt.nz) has been highly active in producing recovery-oriented research and practice guidance[107;124–126;292–297], which are described in Case Study 22.

Policy in Scotland

In Scotland, a national mental health plan was launched in 2006, called *Delivering for mental health*[298]. The vision stated:

> We must ensure that we deliver on our commitments in respect of equality, social inclusion, recovery and rights. Doing this is central to our vision and to the success of the plan.
>
> (p. vi)

A number of initiatives have been supported by the Scottish Executive in order to deliver on this plan, including an anti-stigma programme (www.seemescotland.org), making information

about recovery more visible (www.scottishrecovery.net), training for staff working with children and young people (www.headsupscotland.com), and a telephone listening service for people experiencing low mood, targeted at men (www.breathingspacescotland.co.uk).

The vision was underpinned by a number of commitments. For example, Commitment 1 states 'We will develop a tool to assess the degree to which organisations and programmes meet our expectations in respect of equality, social inclusion, recovery and rights'. The Scottish Recovery Indicator has been developed and is now being piloted[299]. Commitment 2 states 'We will have in place a training programme for peer support workers by 2008 with peer support workers being employed in three board areas later that year'. This work was informed by a briefing paper from the Scottish Recovery Network in 2005[300], and the development process is described in Case Study 4.

Policy in England and Wales

In 2001 the Department of Health issued a policy statement in relation to recovery[301]:

> We need to create an optimistic, positive approach to all people who use mental health services. The vast majority have real prospects of recovery – if they are supported by appropriate services, driven by the right values and attitudes.
> The mental health system must support people in settings of their own choosing, enable access to community resources including housing, education, work, friendships – or whatever they think is critical to their own recovery.

This direction of travel has been reinforced by a series of policy initiatives in relation to the Expert Patient[302], self-management[303], social inclusion[304] and choice[305]. The recovery approach has been signed up to by all main mental health professions, including psychiatry[139], clinical psychology[268] and occupational therapy[306]. For example, a new strategic direction for mental health nursing was set following a national review by the Chief Nursing Officer[307]: 'The key principles and values of the Recovery Approach will inform mental health nursing practice in all areas'.

Implementation toolkits have been developed[308], including a values-based workbook[309]. Skills in Promoting Recovery are identified as one of the ten Essential Shared Capabilities needed across the mental health workforce[310], and a training programme has been developed[311]. An innovative policy development has been a consultation around guidance for how people's mental health problems should be understood[312]. Another specific focus has been on modernising day services[313], which identified 'opportunities for people with mental health problems to run their own services' as one of the four key functions because 'Many people particularly value help from others who are, or have been, in similar situations'.

Summary of the policy rationale

This brief review has outlined the policy support for a focus on personal recovery in the USA, Australia, New Zealand, Scotland and England. In other countries including Ireland[314;315], Canada[316] and the German-speaking world[317], there is an emerging focus on recovery reflected in policy and practice.

This is not of course to ignore two challenging realities. First, policy is often inconsistent. An emphasis on recovery can and does simultaneously co-occur with policy encouraging a focus on risk, deficit and segregation. Second, policy is not practice. This chapter is not about implementation, but rather is focussed on the policy context in which practice occurs.

There is a consensus at a policy level, especially in the Anglophone world, about the centrality of personal recovery. Section 3 addresses the translation of this rhetoric into reality.

Recovery-focussed mental health services
The Personal Recovery Framework

In this chapter we develop an overarching Personal Recovery Framework, describing the processes involved in personal recovery.

The framework is intended to be theoretically based, empirically informed and widely applicable. It is underpinned by a constructivist epistemology (described in Chapter 4), which points to the changing and negotiated nature of experience. Therefore this framework is not intended to be prescriptive about what recovery is, since there can be no invariant generalisable theory or model. Rather, the aim is to provide a trans-theoretical framework to guide mental health professionals in supporting personal recovery. One aim is to identify how clinical models can help, and hinder, recovery. Another aim, consistent with the issues identified in Chapter 2, is to focus attention on the person rather than the illness, and on the person in their social context rather than decontextualising the individual.

Empirical foundations

The framework will be based on empirical research into the domains and stages of personal recovery.

The domains of personal recovery

Several writers identify key domains relevant to personal recovery. Leroy Spaniol and colleagues identify four negative impacts following from being diagnosed with a mental illness[87]:

- Loss of a sense of self, as it is replaced by an identity as a mental patient
- Loss of power, including agency, choice and personal values
- Loss of meaning, such as through loss of valued social roles
- Loss of hope, leading to giving up and withdrawal.

Ruth Ralph extracted four processes from a review of personal accounts[131]:

- Internal factors, such as awakening, insight and determination
- Self-managed care, including coping with difficulties
- External factors, especially connection with others who express hope for the person
- Empowerment, combining internal strength and interconnectedness with others.

Larry Davidson and colleagues reviewed published qualitative accounts of recovery, and identified common themes of redefining self, being supported by others, renewing a sense of hope and commitment, accepting illness, being involved in meaningful activities and expanded social roles, managing symptoms, resuming control over and responsibility for one's life, overcoming stigma, and exercising one's citizenship[128].

Lapsley and colleagues organised the findings from their narrative research with 40 New Zealand people in recovery into the HEART acronym[107]:

- Hope
- Esteem (self-esteem)
- Agency
- Relationship
- Transitions in identity, comprising
  - Personal Identity
  - Māori identity
  - Cultural identity (other than Māori)
  - Achieving lesbian or gay identities
  - Leaving behind illness identities

A particularly relevant framework was developed by Retta Andresen and colleagues on the basis of a review of consumer accounts of recovery. They extracted four emergent themes[123]:

- Hope as a frequent self-reported component of recovery
- Self-identity, including current and future self-image
- Meaning in life, including life purpose and goals
- Responsibility – the ability to take personal responsibility for one's own recovery.

Synthesising these and other accounts[318], four key domains involved in personal recovery are proposed in Table 9.1.

Table 9.1 The four key domains of personal recovery

Domain	Definition	The central question	Importance in mental illness
1. Hope	A primarily future-oriented expectation of attaining personally valued goals, relationships or spirituality which lead to meaning and are subjectively considered possible[135]	*What will happen to me?*	Mental illness and its devaluing consequences can take away hope for a good future
2. Identity	Those persistent characteristics which make us unique and by which we are connected to the rest of the world	*Who am I?*	Mental illness undermines personal and social identity
3. Meaning			
Direct meaning	An understanding which makes adequate personal sense of the 'mental illness' experience	*What has happened?*	Mental illness is a profound experience, which requires a personally satisfactory explanation
Indirect meaning	An integration of the direct meaning into personal and social identity	*What does this mean for me?*	Mental illness leads to re-evaluation of values and personally meaningful life goals
4. Personal responsibility	A constellation of values, cognitions, emotions and behaviours which lead to full engagement in life	*What can I do?*	The mental illness itself and responses from the person, mental health services and wider society can all undermine the ability to be responsible for one's own life

The stages of personal recovery

Several studies have mapped the stages through which people recovering from mental illness typically pass. Davidson and Strauss interviewed 66 people with mental illness over a 3-year period, to investigate the processes involved in reconstructing a sense of self in recovery[121]. They identified four stages:

1. Discovering the possibility of experiencing agency
2. Taking stock of one's strengths and limitations
3. Putting aspects of the self into action
4. Using this enhanced sense of self as a resource in recovery.

Baxter and Diehl interviewed 40 people about their recovery experiences, and identified three psychological events[319]:

1. Crisis, followed by a stage of recuperation, accompanied by denial, confusion and despair
2. Decision to get going, followed by rebuilding the ability to resume normal life roles, suffering setbacks and developing a more integrated sense of self
3. Awakening to restructured personhood, followed by the stage of recovery and rebuilding healthy interdependence – a stage characterised by future goals, meaningful work, advocacy and fun.

Young and Ensing synthesised the views of 18 people with mental illness who were living independently, to identify three phases[320]:

1. Initiating recovery, involving accepting the illness, finding hope, and the desire to change
2. Regaining what was lost and moving forward, including taking responsibility, self-redefinition, and a return to basic functioning
3. Improving quality of life, involving an overall sense of well-being and striving for new potentials.

Pettie and Triolo developed a detailed understanding of recovery in two people, leading them to suggest two phases[321]:

1. 'Why me?' followed by the search for the meaning to the illness
2. 'What now?' followed by the task of developing a new identity and positive sense of self.

Spaniol and colleagues undertook a longitudinal qualitative investigation of the recovery experiences of 12 people, and identified four phases[130]:

1. Overwhelmed by the disability, feeling confused, out of control of life, lacking self-confidence and connection with others
2. Struggling with the disability, involving finding an explanation for the illness, learning to cope, fear of failure and building strengths
3. Living with the disability – managing it, developing a stronger sense of self, more meaningful roles and a satisfying life within the limits of the disability
4. Living beyond the disability – living a contributing life, unlimited by the disability, with a sense of meaning and purpose to life.

In an effort to synthesise these studies, Retta Andresen and colleagues proposed five stages[123], shown in Box 9.1.

An alternative formulation is provided by the National Institute of Mental Health for England (NIMHE)[318], derived from earlier work in Ohio[322]. They identify four levels, shown in Box 9.2.

Box 9.1 Andresen's five-stage model of recovery

1. **Moratorium** – characterised by denial, confusion, hopelessness, identity confusion and self-protective withdrawal.
2. **Awareness** – the first glimmer of hope for a better life, and that recovery is possible. This can emerge from within or be triggered by a significant other, a role model or a clinician. It involves a developing awareness of a possible self other than that of mental patient.
3. **Preparation** – the person resolves to start working on recovery, e.g. by taking stock of personal resources, values and limitations, by learning about mental illness and available services, becoming involved in groups and connecting with others who are in recovery.
4. **Rebuilding** – the hard work stage, involving forging a more positive identity, setting and striving towards personally valued goals, reassessing old values, taking responsibility for managing illness and for control of life, and showing tenacity by takings risks and suffering setbacks.
5. **Growth** – [may also be considered the outcome of the previous recovery processes] whether or not symptom-free, the person knows how to manage their illness and stay well. Associated characteristics are resilience, self-confidence and optimism about the future. The sense of self is positive, and there is a belief that the experience has made them a better person.

Box 9.2 NIMHE four-stage model of recovery

Stage 1: Dependent / Unaware
Stage 2: Dependent / Aware
Stage 3: Independent / Aware
Stage 4: Interdependent / Aware

A stage model was also developed by a group of consumers across the USA[137]. The Recovery Advisory Group Recovery Model proposed non-linear development through six stages:

1. Anguish – described as *bottoming out*
2. Awakening – a *turning point*
3. Insight – the *beginning of hope*
4. Action plan – *finding a way*
5. Determined commitment – *to be well*
6. Well-being, empowerment, recovery.

Any stage model necessarily suffers from at least two shortcomings. First, it imposes an order on human growth and development which may not fit some people's experiences. In other words, its external validity is limited. An image of a spiral rather than linear stages may be a more helpful metaphor. Second, it can easily become seen as a model for what *should* happen, with consequent feelings of failure incurred for people who do not seem to be recovering. The response to these concerns is to distinguish between a map and a route. Providing a map of the terrain does not prescribe the best way through it. Similarly, providing a synthesis of the kinds of domains and processes involved in the recovery journey of others has value in a general way, but does not provide an individualised list of instructions to follow. Each person needs to find their own way forward.

Stage models of recovery have several important clinical advantages:

1. They contribute to therapeutic optimism. The very fact of established pathways to recovery becoming more visible combats the clinician's illusion that no-one recovers (supported by the evidence that clinicians only see people when in crisis and not when well[323]), and has the potential to impact on the (often implicit) prognostic communications embedded in clinical discourse.

2. They provide a way of making sense both of progress and of lack of discernible progress in a non-stigmatising and non-pathologising way.

3. They help clinicians to become more sophisticated in providing support matched to the person's stage of recovery, with different sorts of action needed to support people at different stages of recovery. For example, encouraging someone who lacks hope to take personal responsibility may simply accentuate the feelings of failure and despair.

So on the basis of the lived experience of people with mental illness, it has been possible to identify common domains and stages involved in a journey of personal recovery. Building on this theoretical basis, we now develop a framework for personal recovery.

The ultimate goal of personal recovery is healing – a taboo word in mental health services. This involves reclaiming or regaining or restoring or discovering oneself and one's world. It is a much deeper process than treating mental illness. The starting point is to consider who or what is in need of healing, which involves the concept of identity.

Identity

What does identity mean? A comprehensive analysis of the concept has been provided elsewhere[324]. Broadly, the term is used differently by psychologists and sociologists.

Psychologists use identity as a term to describe *personal identity* – the things that make a person unique. Being unique is the different, idiosyncratic, interesting, damaged, impassioned part of us. Components of a personal identity include a mental model (or self-image) of oneself, self-esteem (a valued personal identity) and individuation (the process of differentiated components becoming a more indivisible whole), along with a capacity for self-reflection and awareness of self. Personal identity involves that which sets us apart – having our own aspirations, dreams and preferences which make us a person. This individuality is the reason why there cannot be one model of recovery which fits all people, why professionals should be cautious about saying (or thinking) 'we do recovery', and why the individual's views on what matters to them have to be given primacy.

Sociologists more commonly use the term as meaning *social identity* – the collection of group memberships that define the individual. Components of this understanding include role-behaviour, discrimination towards outsiders by members of the in-group, and identity negotiation in which the person negotiates with society about the meaning and value of their identity. Social identity encompasses that which joins us. It involves the development of a contextual richness to identity, which gives a sense of being like others and provides a buffer against identity challenges. This contextual richness comes through having layers of identity. The most intimate or proximal layers are those that define our views of who we most deeply are, and whose loss would fracture our self-image. More distally, there are the range of other identities and social roles which prop up and reinforce our overall sense of self.

Both these definitions are underpinned by the philosophical definition of identity. Philosophers use the term as meaning persistence – the existence of a persisting entity particular to a given person. Components of this understanding include change, time and

sameness. Identity is that which is preserved from the previous version in time when it was modified, or it is the recognisable individual characteristics by which a person is known.

Combining these schools of thought allows a definition of identity to be proposed:

> **Identity comprises those persistent characteristics which make us unique and by which we are connected to the rest of the world.**

This definition encompasses those things which differentiate and those which integrate us. It does not capture all forms of identity. For example, the identity of indigenous Australian people is interwoven with the physical world[325]. Spiritual identity is shared with the land, a description of reality which clearly incorporates a concept of identity quite different from the psychological, sociological and philosophical definitions presented above. Similarly, Native American conceptions of health involve a relational or cyclical world-view, balancing context, mind, body and spirit[326]. Māori and Pacific Islanders in New Zealand also have a cultural identity influenced by Whānau Ora – the diverse families embedded in the culture.

Having noted its limitations, the above definition of identity will be used. Emergent identity in this definition can be weighted more towards either personal identity or social identity. It therefore encompasses both a Western view of the world in which the person is the unit of identity, and a more familial or cultural definition of personhood in which the person-in-context is the unit of identity. Indeed, it recognises that personal and social identity will often overlap. I am a clinical psychologist, partly because my own professional training encourages that self-definition (personal identity), and partly because this role shapes the interactions I have with others (social identity).

This approach to identity is deliberately trans-theoretical. It can be described in cognitive models as core schema, in psychoanalytic models as object-relations, in behavioural models as learned behaviours, in genetic terms as phenotypic expression, in personal construct counselling as self-constructs, and so on. The intention is to construct a framework for personal recovery which is not specific to one therapeutic orientation or professional group, since no single clinical model or profession has a monopoly on knowledge.

To illustrate the richness of the concept, Box 9.3 lists some types of identity.

Box 9.3 illustrates a few of the many dimensions in which people create and maintain their sense of self. It is noteworthy that few of these identities are rooted in biological or biochemical or anatomical modalities. This is one reason why physical means of understanding (and consequently treating) are not concordant with the dimensions used by most people to form and shape their identity[63]. Given this discordance, it is easy to see how mental health professionals and consumers can sometimes be speaking different languages.

Applying the definition of identity to mental illness, there are three component elements of an identity as someone with a mental illness:

(a) I see myself as a person with mental illness (personal identity)

(b) Others relate to me, and I relate to others, as a person with mental illness (social identity)

(c) Both (a) and (b) are ongoing (permanence).

In general, people with mental illness do not struggle to feel different – the associated social and clinical messages reinforce this personal identity. Indeed, the engulfing role of mental patient leads to what Erving Goffman called a spoiled identity[327], or what Glynis Breakwell calls a threatened identity[328]. After an ethnographic study involving living for 9 months as a client of an assertive community treatment team, Sue Estroff came to a view of schizophrenia as a disease of the self[329]: 'Schizophrenia is an "I am" illness, one which may take over and redefine the identity of the person'. This fits with the accounts of people experiencing

Box 9.3 Some of the many dimensions and types of identity		
Individual dimension	*Social dimension*	*Cultural dimension*
I am an optimist/realist/pessimist	I am a citizen	I am an Eritrean
I am important/unimportant	I am a campaigner	I am a European
I can/cannot cope	I am a volunteer worker	I come/do not come from one culture
I am fat/thin	I am a neighbour	I live/do not live within my culture
I am tall/short	I am employed/unemployed	I am defined by my culture
I am a moral/immoral person	I am popular	I am proud of/shamed by my culture
Interpersonal dimension	*Spiritual dimension*	*Sexual dimension*
I am a wife/husband	I am a Muslim	I am a lover
I am a carer	I am a Christian	I am straight/gay/bisexual
I am a good/bad friend	I am a humanist	I am attractive/repulsive
I am a loner	I am an agnostic/atheist	I am faithful
I am a father/mother	I am in touch with God	I am asexual

psychosis, who use terms such as phantom, demon, machine, robot, a 'nobody nowhere' and a 'nothing' to describe this feeling of being something other than, or less than, fully human[330]. The challenge is most often feeling connected to and like others. This can involve connecting in a new way with yourself (personal identity) or with the world (social identity).

Engaging with this complexity, rather than fixating on an impoverished deficit-focussed view of the self, is a vital step on the road to recovery. Recovery begins when you find somewhere to connect to. Or as Elizabeth Baxter, a psychiatrist who experienced a severe psychosis, notes[331]: 'One crucial reason people with serious mental illnesses recover is because they find someone who believes in them and their recovery'.

If promotion of personal recovery is the goal, then it is important to establish the tasks involved in personal recovery.

The four tasks of recovery

Four recovery tasks can be identified: developing a positive identity, framing the mental illness, self-managing the mental illness, and developing socially valued roles. Each will now be considered.

Recovery task 1: developing a positive identity

The first task of recovery is developing a positive identity outside of being a person with a mental illness. This process involves establishing the conditions in which it is possible to experience life as a person not an illness. This can be described as the *me–it* difference. Over-developing the *it* – the identity as one who has a chronic illness – is one iatrogenic

impact of current mental health services. Developing a positive identity involves finding the *me* who has the *it* – the mental illness. This ability to differentiate self (me) from the diagnosis and illness experience (it) is associated with a positive long-term outcome in schizophrenia[121].

A positive identity gives the possibility of a personally valued future. This is why the recovery literature emphasises so strongly the importance of hope. Identity elements which are vitally important to one person may be far less significant to another, which underlines that only the person can decide what constitutes a personally valued future *for them*.

Overall, the goal for people with mental illness is to move from an either-or stance to a both-and stance – I am a person in my own right *and* I have a mental illness (or whatever other frame of meaning is helpful). This involves two elements: amplifying the sense of self, and diminishing the identity as a person with mental illness. This push-pull strategy may involve approaches for both promoting well-being and treating illness.

This is not making a case for denial. The argument being made is not that mental illness and its impact should be ignored and then all will be well. Even if the mental illness were removed (or cured) totally, an imprint on identity would remain. Rather, the point is that the direction of the spot-light dictates what you see – if the sole focus of the person, other significant people in their life and mental health professionals is on the mental illness part, then this is all that will be seen, which sets the context for the mental illness to become an engulfing role. To extend the metaphor, the brighter the spotlight the deeper the shadow – an exclusive focus on illness both enhances its apparent importance and also makes it harder to develop or maintain a sense of self separate from the illness.

However, forming a new or altered identity is a slow and potentially painful process, involving changes to core beliefs and giving up previously cherished self-images. Although it is necessary to operationalise recovery as an outcome to allow scientific study, it is in essence an ongoing process, a journey, an attitude, a readiness to embrace the challenges of life. It is not an end-point, a result (e.g. of treatment), or a state. It takes a long time.

How does recovery happen? Relationships lie at the heart of identity. A positive identity is developed by establishing or re-establishing identity-enhancing relationships. Each relationship may be a relationship with aspects of the self (a positive personal identity), or a relationship with things outside the person (a positive social identity), including but not limited to other people, social role, higher beings, and social or cultural or political identities.

The process of developing a positive identity can involve establishing new or different relationships, or re-establishing previous relationships. This is because people start from different places. The NIMHE framework described in Box 9.2 differentiates six meanings of recovery[318]:

1. A return to a state of wellness
2. Achievement of a personally acceptable quality of life
3. A process or period of recovering
4. A process of gaining or restoring something
5. An act of obtaining usable resources from apparently unusable sources
6. Recovering an optimum quality of life in disconnected circumstances.

For some people, developing a positive identity will mean re-connecting with their previous sense of self. This is the closest meaning to the everyday sense of the term recovery as synonymous with cure. For others, it will involve replacing their previous sense of self with a new and more constructive identity achieved through personal growth[121]. For others, it involves finding a sense of who they are now[332]: 'We can never go back to our "premorbid" selves. The experience of disability and stigma attached to it, changes us

forever' (p. 87). In all cases, the essence of this recovery task is moving from an identity focussed on illness and difference to one which contains the possibility of a better future. This, of course, requires hope.

Recovery task 2: framing the 'mental illness'

The second recovery task involves developing a personally satisfactory meaning to frame the experience which professionals would understand as mental illness. This involves making sense of the experience so that it can be put in a box: framed as a part of the person but not as the whole person. This meaning might be expressed as a diagnosis, or as a formulation, or it may have nothing to do with clinical models – a spiritual or cultural or existential crisis (hence the quotes in the task title). The actual meaning does not matter, since (consistent with a constructivist perspective) there is no one way to interpret reality. What matters is that the meaning both provides a constraining frame for the experience, and can serve as a springboard to a better future.

This task is important because it is difficult, perhaps impossible, to recover when mental illness is the wallpaper of your world. Unframed mental illness experience creates an enveloping role which diminishes agency:

I can't do that because . . .

> *. . . I have an illness*

> *. . . I need to go to a day centre*

> *. . . I might have a relapse*

> *. . . I am an illness – no-one expects anything else of me*

> *. . . Others know more about me than I do*

> *. . . I'll have to ask the doctor first*

Which over time leads to:

I can't do that because . . . I am different

Framing involves making sense of the experience. To re-iterate, this may or may not be as a mental illness. What matters is finding a way of framing the experience which makes the experience comprehensible and allows for a positive future. People get stuck at the '*Why me?*' point, and need to find a personal meaning before they can move on. This might involve understanding the cause, but this is only helpful if it provides a springboard to meaning. The understood cause might simply be fate – '*It just happened to me . . . there's no reason . . . I was just unlucky*'. The aim of this process is to move from the '*Why me?*' point to the '*Yes . . . but*' point:

> Yes, I have a mental illness, but at least I can now get treatment
>
> Yes, I will always be a schizophrenic, but at least I now understand what is happening to me
>
> Yes, I have had these devastating bouts of depression, but now I know that the bouts don't last forever
>
> Yes, I have been the battleground for satanic forces, but now I know what's going on is nothing to do with me
>
> Yes, I have offended my ancestors, but now I realise that I can make amends

Framing also requires a level of acceptance or integration of the mental illness experience into broader identity – what we called in Table 9.1 the indirect meaning of the mental illness. It avoids either extreme – total denial of any problem leading to maladaptive strategies focussed on maintaining this denial, and total loss of self in the engulfing role

as a person with a mental illness. This does not mean accepting any one particular conceptual or clinical model of illness. Rather, framing one's illness involves redefining how a person understands this particular life challenge in the context of a broader sense of self[128]. As Onken and colleagues put it[333]: 'Recovery involves replacing a view of the self as centered on psychiatric disability to that of one who is a whole person facing challenges, thus broadening the telling of one's life story through transformation of suffering into a significant life experience' (p. 13).

Recovery task 3: self-managing the mental illness

Framing the mental illness experience provides a context in which it becomes one of life's challenges, allowing the ability to self-manage to develop. The goal of self-management might involve (for different people):

- Cure – getting rid of it
- Adaptation – learning ways of living with it
- Positive re-framing – finding value in it
- Minimising – downgrading its impact on identity
- Displacing – getting on with more important things

Self-managing mental illness is not easy, but then who said life would be easy? Finding a way of living with or journeying beyond the experience of mental illness is a challenge requiring strength, resilience, hope, support, etc. In other words, just the same qualities as everyone else needs to meet their challenges. But the emerging stories of successful individuals show that personal recovery is possible.

The key transition is from being clinically managed to taking personal responsibility through self-management. The term self-management does not mean doing everything on your own. It means being responsible for your own well-being, including seeking help and support from others when necessary –the Aware / Interdependent phase in Box 9.2. An eloquent description is provided by Patricia Deegan[334]:

> To me, recovery means I try to stay in the driver's seat of my life. I don't let my illness run me. Over the years I have worked hard to become an expert in my own self-care. For me, being in recovery means I don't just take medications. Just taking medications is a passive stance. Rather I use medications as part of my recovery process. In the same way, I don't just go into hospital. Just 'going into hospital' is a passive stance. Rather, I use hospital when I need to.

Why are framing and self-managing not the first tasks? Because a person who is focussed on personal recovery gives primacy to well-being over illness. Passively receiving treatment with the intention of subsequently re-establishing a positive identity once better runs the very real risk of becoming stuck in the mental illness role. This pattern is commonly observed in mental health services. People using mental health services receive an increasingly aggressive (in both the medical and lay senses) programme of interventions and treatments, as they journey from acute care through rehabilitation to continuing care, with the initial therapeutic optimism gradually being replaced by labels such as treatment-resistant, non-compliant and, ultimately, heart-sink patient.

Developing a positive identity is closely connected with framing and self-managing the mental illness. The positive identity creates a push on the mental illness part, and framing and self-managing create a pull. The positive identity is then supported by the final recovery task, of creating and maintaining an embedding network of valued social roles.