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## SOCIETY, MENTAL HEALTH AND ILLNESS

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## UNDERSTANDING MENTAL DISORDER

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### INTRODUCTION

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The purpose of this chapter is to review some ways in which mental illness has been (and is being) thought about. Our current perspectives build on and incorporate earlier ways of thinking and acting in relation to people who have been defined as mentally ill. This means that our review of ways of thinking must be, in part, historical. We begin with consideration as to how we might view this history, including noting some of the contemporary influences on mental health practice in the twenty-first century. Then we will attempt some account of that history, lingering longest on developments throughout the last century. The viewpoint of these sections is a combination of medical and social history. Throughout this book, the input of consumers of mental health services is voiced in a number of places. Here in the opening chapter we introduce the notion of empowerment and, more generally, the operation of power from a consumer perspective, noting in particular the theoretical developments from within the consumer movement influencing contemporary thinking. The concept of Recovery is introduced, highlighting the importance of understanding and appreciating consumers' everyday experiences of relationships, activities and environments, where material and social circumstances are recognised as central to power and as significant to the processes of recovery.

### CONCEPTUALISING THE HISTORY OF MENTAL DISORDER

There are numerous choices about how to convey this history, each of which would provide us with different, perhaps rival, interpretations of the past

and the present. We believe it is helpful to examine this history in terms of continuing and unresolved debates about:

- how to make sense of mental illness, its causes and effects
- how to respond to mental illness
- who it is who should do something about or for or with people with mental illness.

These questions arise from a sociological perspective, which views history as evolving and emerging from the debates and events that make up social life and are expressed in social practices. In the following sections of this chapter we discuss each of them.

### MAKING SENSE OF MENTAL DISORDER

In struggling to make sense of the phenomenon of mental disorder, various attempts have been made to conceptualise it. These include philosophical considerations of the nature of mind, the interconnections between mind and body, the characteristics distinguishing human beings, the impact of social structure on individual life and making sense of the experience of mental disorder from within one's own mind. Recent developments in neuroscience have made observable events in the brain accompanying conscious experiences that hitherto were objects only of introspective analysis. For at least the last 15 years, the field of consciousness studies has been in active ferment (Blackmore 2003; Dennett 1991; McCrone 1997; McCrone 1999), and there is increasing recognition of the physicality of emotion, with arguments arising against separating mind from body (see, for instance, Damasio 2000).

#### Beginnings

We can cite streams of thought in ancient Greece that held that mental disturbance could be seen as an outcome of brain disease and hence to be treated by physicians. However, these beliefs subsequently lost influence through much of Western Europe, where the legacy of thinking from the Middle Ages

was that bizarre thoughts and behaviour were likely to be construed as evidence of demonic possession or witchcraft. Although relatives might care for individuals or local communities might tolerate the mentally ill, in many settings they were at risk of being subject to harsh treatment.

With increased population and urbanisation came a trend towards institutional confinement of the mentally ill, along with others seen as deviant, with little or no notion of rights to humane treatment. Large institutions, variously labelled as hospitals, jails, madhouses or asylums, contained many people who would now be seen as suffering from mental illness.

## The Enlightenment to the twentieth century

### The age of reason

The intellectual movement of the seventeenth and eighteenth centuries, referred to as the Enlightenment, gave privilege to reason as a way of approaching understanding the world, and in time this change of view affected the way in which those seen as mad were treated.

During the Enlightenment, when rationality was privileged, the position of the mad and the irrational provided a particular challenge (Jones 1996). There was considerable debate over whether or not, with the right kind of 'moral treatment', the mad could become rational once more. Moral treatment here consisted in placing the patient in an environment that encouraged behaviour in line with accepted social standards, and was pervaded by religious teachings. The Enlightenment belief that progress would proceed on the basis of scientific study gave increasing influence to medicine as a scientific practice, and held hope that psychiatry, as a branch of medicine, could devise specialist medical treatment for the insane. Scull (1989) argues that the outcome of these debates over the virtues and benefits of moral versus medical treatment of the insane was a finding in favour of science: mental illness was thereby 'captured' in the late eighteenth century by the medical profession. Mental disorder achieved the status of an illness, to be conceptualised, diagnosed

and treated as other somatic ailments. The asylums were thought of not only as places for confinement but also as places with programs aimed at treating and rehabilitating sufferers.

As we have noted, a key aspect of Enlightenment thinking had been the attainment of rationality, a desire to gather and order knowledge. This ordering of knowledge took the form of sorting, grouping, dividing and classifying phenomena, to generate categories and make distinctions on the basis of those characteristics identified as descriptive of a group. In medicine, this expressed itself in work from Linnaeus and Sydenham on medical classification systems (nosologies). In the nineteenth century, in the mental health field the nosological work of the German psychiatrist Kraepelin is particularly significant; many of the conceptual structures established by Kraepelin and other psychiatrists and philosophers of this time persist, largely unchanged, to the present.

### Positivism and its challengers

The positivist tradition, arising in the twentieth century, is exemplified in the belief that reality is driven by immutable natural laws and mechanisms, and is knowable, provided that the knower or inquirer remains distant, noninteractive and value free. This intellectual posture had its origins in the Enlightenment, and emphasised the separation of mind and body. The power of expert knowledge, knowledge that is objective and value free, assured the influence of the medical profession in understanding and treating mental illness.

In the twentieth century, we have seen the emergence of nonpositivist epistemologies (theories of knowledge). These are characterised by an increased valuing of personal knowledge and experience, and a recognition of the person as fundamentally self-interpreting. Here the notion of a positivist view of the progressive pursuit of a single valid truth through systematic method is largely discarded. This posture of presenting a model of multiple viewpoints, each with their own 'validity', is one of the characteristics of 'postmodern' philosophies.

Within the mental health field, this broadening of perspectives has added to our recognition of the complexity of the field, and has led to attempts to respond adequately and with a variety of approaches to mental distress.

## Modern psychiatry

Following Kraepelin, the development of a system of diagnostic categories describing psychopathology has become indispensable, both in general psychiatry and the field of psychiatric epidemiology. Epidemiological studies, with their dependence on classification systems, have enabled the undertaking of large-scale research studies into the prevalence, causes, consequences, and amount and effectiveness of care of the mentally ill (Robbins 1990). Undoubtedly this trend towards classification has had great benefits. However, it has also led, at times, to a reduction of the person to a description of his or her disorder, as in the practice of referring to 'schizophrenics'.

Throughout the twentieth century, other significant strands of thought have contributed to the underpinning of mental health practice. Sigmund Freud founded psychoanalysis as we understand it today, though it has undergone many changes since his pioneering work. Freud worked closely with people with mental disorders, accessing their inner lives through talk. The forces proceeding to mental disturbance were seen as being within the unaware, unconscious mind, and conflicts at this level produced disturbance in the aware self. By the beginning of the twentieth century, Freud was advancing a model of mental disturbance that no longer placed it as something alien, or the result of demonic possession. Instead, psychopathology could be seen as a part of everyday life, as the outcome of repressed trauma was present in everyone to some degree.

Through the early part of the twentieth century, the experimental science of psychology made great advances. Conditioned reflexes, as described by Pavlov, and operant conditioning, as first set out by Skinner, provided the core framework of behaviourism, which then developed through work on motivation and other aspects of psychology towards the complementing of behavioural approaches

with the cognitive approach. The sophistication of linkage between these approaches has progressively increased.

## Sociology of mental health and illness

During the early twentieth century, theoretical developments in sociology gave a different kind of access to the lived experience of people previously segregated: the mentally ill, criminals and people of different ethnic backgrounds. Mental disturbance came to be understood in terms of being an outcome of social processes as well as being described as illness.

### Ethnography in the mental hospital

In the 1960s and 1970s, the focus of research by Goffman and Helmreich (1961) and others, including Rosenhan (1973), was on the institutional treatment of mental patients in hospitals. It included striking studies on simulated patients. These volunteers expressed fairly limited psychiatric symptomatology, but often successfully secured hospital admission. Thereafter they found that, by virtue of their position as patients, their subsequent relatively normal behaviour was often described as pathological by the observing staff. This work has contributed significantly to our understanding of the relationship between social structures and roles, and the power of labelling to circumscribe the interpretation of behaviour.

### Structuralist perspectives

The structuralists are associated with critical and feminist theorists, who recognise that such factors as social regulation, an unequal distribution of resources and power relations influence social practices and life chances. In the mental health field, the most notable workers were the 'anti-psychiatrists' Laing, Cooper and Esterson, who analysed the power relationships they saw as influential in both the emergence of patients' symptoms and in psychiatrists' diagnostic and treatment practices. The power relationships within capitalist societies were held responsible for the disintegration of personality and for psychiatry itself becoming an actor in the perpetuation of

oppression. Such analyses provided arguments for challenges to the authority of the medical model in understanding deviance and mental illness. The meeting of this challenge was in part the force behind the emergence of broader synthetic models, such as the conceptualisation of the biopsychosocial model of mental illness, which will be discussed further in Chapter 3.

It is apparent that since the mid 1970s there has been a radical change in ways in which mental health problems have been thought about. These changes have created challenges to earlier epistemologies of practice and research.

### Feminist perspectives on mental illness

Feminist researchers and writers began to challenge dominant perspectives in the mental health field in the 1970s, proposing a different reading of the incidence, prevalence and meaning of women's mental illness. Emphasis began to be placed on understanding the conditions of women's lives as implicated in the causation of mental or emotional distress. Previous research and understanding of women's mental illness had focused on the belief that women were innately inferior to men, and had a biologically based tendency to mental pathology because of their reproductive and hormonal processes. Menstruation, childbirth and menopause were heavily implicated in creating a vulnerability to mental illness.

Against this explanation and viewpoint, feminist researchers have been critical of the adequacy of the evidence linking the impact of reproductive biology and specific mental states. In place of this link, arguments have been put that women's mental distress refers to the effect of the material, social and political constraints of their lives under the oppressive conditions of patriarchy. Their discontent is expressed through symptoms that have been interpreted as illness or disorder. The devaluing and disempowerment of women, which has been reflected throughout history, was understood to be present in tendencies to diagnose women as mentally ill more frequently than men, and in the apparently higher rates of depression prevalent among women. Feminist

perspectives proposed that women's madness might be better understood as a manifestation of the emotional frustration, narrowness and confinement of their lives (Al-Issa 1982; Astbury 1996; Busfield 1996; Chesler 1989, 1972; Jimenez 1997; Penfold & Walker 1983; Russell 1995; Saltman 1991; Stoppard 1999; Stoppard & McMullen 2003; Ussher 1992; Willie 1995).

In contemporary times, the mental health consumer movement and the women's movement have tended to develop their agendas separately although sharing some political views, particularly with regard to issues of power and prejudice. Lewis (2009) discussed the reasons for this in the UK, noting that the women's movement has been particularly successful in applying pressure for change in service provision in other sectors by advancing models of 'good' women-sensitive practice. In Victoria, policy concerning women's mental health services has not been directly addressed since the 1997 publication *Tailoring Services to Meet the Needs of Women* (Victorian Department of Human Services 1997). However, the Victorian Women and Mental Health Network <<http://www.vicserv.org.au/policy-networks/networks/alias.html>> has been active since 1988, most significantly continuing to advocate for women-only psychiatric wards. Importantly, in the last decade, the influence of feminist perspectives can be seen in more mainstream shifts towards placing a gendered lens on viewing the prevalence, course and impact of biological, psychological and social factors in the causation of mental illness among men and women (Judd et al. 2009).

## MENTAL HEALTH CONSUMER MOVEMENT

MERINDA EPSTEIN

Towards the end of the twentieth century the demand for human rights and citizenship by psychiatric patients began to grow, developing a more sophisticated critique and redefining a



knowledge base of its own. Demands were made both of services and of communities to respect the 'lived experience' (lives and aspirations) of people labelled with 'mental illness'. Around the world, many people diagnosed with 'mental illness' formed loose collectives, formalising into organisations and then a 'movement'. Many people abandoned the word 'patient', accusing the language of being colonised by medical doctors. They also criticised the word 'client'—colonised by psychologists and social workers. In a search for a clear defining name many terms came into prominence: survivors (of the mental illness system and/or 'mental illness'), users or service users, ex-patients and consumers. In Australia, the convention is for people to describe themselves as consumers. This word is used inclusively by people who refuse to have anything to do with mental health services as well as those who are 'patients'. Consumers claimed a perspective of their own, a particularly important and insightful way of viewing the world that takes advantage of seeing through the prism of personal experience. This perspective began to challenge more traditionally powerful ways of seeing 'mental illness': the medical perspective, the bureaucratic perspective, the 'helper' perspective, the scientific perspective and the 'carer' perspective.

Mentalism (which is sometimes called Sanism) grew out of the survivor-consumer movement in the USA. It describes the prejudice that operates in society to oppress people who have been diagnosed with a 'mental illness'. Like the other isms, it firmly locates this oppression within the social structures and institutions that make and remake the circumstances in which people play out their lives. Mentalism is as entrenched in the institution of health and mental health as it is in the media, education, the law and the family. Mentalism reflects a growing demand to rid decision-making and practice of tokenism towards consumers, intimating the possibility of paradigm change in the way in which mental disorder is understood, and service provision shaped or even revolutionised in response to consumer activism, expertise and leadership.

## INTO THE TWENTY-FIRST CENTURY

*FIONA McDERMOTT*

This new century is a time of accelerated change. The fast-paced discoveries delivered by neuroscientific research require us to think much more broadly about how we are to understand environment and the role which it plays in influencing consciousness and behaviour, no longer as 'merely' outside the body but as having, along with genetic factors, an integral influence on human biology and development. In the twenty-first century we are also experiencing the rise of globalisation and climate change, both of which are rapidly changing the physical, social, political and ecological character of our world, creating new health hazards in the emergence and spread of diseases. The migration of people is occurring on the broadest scale yet in human history, and the accompanying emotional traumas of war and forced migration are creating new social and environmental challenges, many of which are evident in mental distress and emotional trauma. The mental health consumer movement continues to be an active force in offering alternative and provocative (re)conceptualisation of mental disorder, in particular the concept of 'consumer perspective', which, like feminism in the 1970s, intimates the possibility of paradigm change in the way in which mental disorder is understood, and service provision shaped or even revolutionised in response to consumer advocacy and participation.

## RESPONDING TO MENTAL DISORDER

*FIONA McDERMOTT & GRAHAM MEADOWS*

The struggle to understand mental illness proceeded simultaneously with attempts to intervene and treat those experiencing it. Tensions and contradictions evident in these attempts highlight the mix of motives and beliefs as to the nature of mental illness

and the rights and responsibilities incumbent on those who intervened.

## TREATMENT AS AN EMERGENT IDEA

The belief characterising Enlightenment thinking that the social and natural worlds could be transformed by human intervention and need not be taken as ‘givens’ was reflected during the late eighteenth and nineteenth centuries in the sequestering of those identified as poor, insane or criminal. Indeed, as Giddens points out (1991, pp. 155–60), the notion of deviance was constructed out of the desire to achieve regulation in social life. Those who could not be regulated (the poor, the insane and the criminal) were constructed as deviants. However, this deviant status required that special settings (poorhouses, prisons and asylums) be established for them, whereby remedial treatment and regularised control could be asserted over them. An outcome of this was their increasing invisibility as they were excluded from social and community life. The threat that their disturbing modes of behaviour may have posed to the maintenance of social order had been, it was hoped, screened out.

Contemporary debates in the eighteenth century over the virtues of both medical and moral treatments (see Scull 1989) suggest that the Enlightenment philosophy of attaining cures and remedies for the insane was firmly in evidence. The mental hospital, as Giddens points out (1991, p. 159), had as its purpose the creation of a humane environment that would methodically correct for deficiencies and reform the afflicted personality.

## INNOVATION AND EXNOVATION

Following the increasingly systematic and experimental approach taken to medicine after the Enlightenment, a body of demonstratively effective treatments accumulated. This process gathered momentum during the twentieth century, because of developments of technologies and strategies for the empirical testing of treatments. As will be introduced elsewhere in this book, advances can be considered in terms of efficacy advances or practice

improvements (better tolerated or easier to prescribe treatments)—both forms of innovation. The term *exnovation* (Frank & Glied 2006) has been coined to describe abandonment of practice no longer seen as beneficial.

### Treatments for neurological diseases

Before 1900, the asylums had contained large numbers of people suffering not with what would now be seen as psychiatric disorders but with consequences of syphilis and uncontrolled epilepsy. This changed through the early part of the twentieth century, with increasingly effective treatments for these conditions.

For syphilis, salvarsan treatment was introduced in Germany in 1909, and from the 1940s and 1950s, penicillin treatment further improved the outcomes for people with this disorder.

For treatment of seizure disorders, barbitol in 1903, phenobarbital in 1912 and a host of other anticonvulsants since, have transformed these problems into predominantly manageable conditions.

### Physical treatments

#### Better drug treatments for mental illness

Research utilising randomised controlled clinical trial methodology has, since the 1940s, proved highly suitable for conducting trials of various psychotropic drugs. Significant outcomes were achieved in the development of medication for people suffering from schizophrenia, depression and bipolar mood disorders. Until these improvements in psychotropic drugs, the majority of people with serious mental illnesses received institution-based treatment, spending the greater part of their lives in hospitals and asylums.

There was a burst of activity in the production of new psychotropic drugs in the years after World War II, and in the 1950s many drugs still in wide use today were introduced. An early contribution to this was Australian: the introduction of lithium by John Cade for the treatment of mania in 1949. The drug was adopted widely in the 1960s after being shown to be effective in maintenance treatment of bipolar disorder. The first effective antipsychotic

medication was chlorpromazine, initially reported as effective in treating psychosis in 1952 in France, and coming into use more widely through the 1950s. The antidepressant effect of imipramine was reported in 1957, introducing the tricyclic antidepressants, and in the same year the first of the benzodiazepine tranquillisers (chlordiazepoxide or librium) was synthesised.

Recent years have seen significant additions to the range of drugs. Sometimes these new drugs offer increased effectiveness; for example, clozapine, a relatively newly adopted antipsychotic medication that can often treat schizophrenia effectively if it has not responded to other interventions. More commonly, the new drugs have similar effectiveness to the older drugs, but fewer side-effects, or are less dangerous in overdose. Hence, there are reduced terms of exchange surrounding the drug: the amount of side-effect that has to be undergone to attain the therapeutic effect, making the drugs much more attractive to many consumers. In this category we can put fluoxetine, sertraline and other drugs in this class of the serotonin-specific reuptake inhibitors for depression, and also risperidone, olanzapine, quetiapine and others as novel antipsychotics.

What we are describing here is by way of a pattern where a period of dramatic efficacy advances has been followed by developments more typically in the way of practice advances.

## ECT

Electroconvulsive therapy (ECT), an Italian invention dating from 1938, was first used in schizophrenia, but has proved most effective in severe depression. In ECT, passage of an electrical current through the brain causes a seizure, and it is this seizure that has therapeutic effect. When initially used on patients who were conscious before application of the shock, this technique was a desperate measure, horrifying in application and with high risks of broken bones from the unmodified seizures. Memory disturbance following the seizures could be severe. Understandably, ECT gained a reputation as a barbaric practice. The technique has been progressively refined and, with the use of anaesthetic and paralytic agents, brought into

line with appropriately humane modern standards. Measurement of the brain seizure response through monitoring of brain electrical activity with the EEG has added to the sophistication of the technique. It now ranks among the safest of medical interventions for depression. Understandably, though, in the minds of many, the practice still carries a fearful set of associations.

## Other physical treatments

Some previously widely used treatments have become understood to be ineffective or even potentially harmful and so have been subject to exnovation as termed here. Insulin coma therapy, deep sleep therapy and earlier crude forms of psychosurgery would fall in this category. New approaches, including deep brain stimulation and transcutaneous magnetic stimulation, are coming into wider use as demonstrably efficacious once hurdles to their dissemination are overcome.

## Psychological treatments

Psychological interventions have progressed dramatically in efficacy through the later part of the 20th century as the behavioural and cognitive revolutions brought new and often highly efficacious treatments into play and another wave of treatments is now finding its place. Psychodynamic therapy, though still having its place in treatments for some problems and being of value for personal development for many choosing to spend time in therapy, has been generally abandoned in regards to some of its earlier uses, such as in primary treatments of schizophrenia, this being another example of exnovation.

Who should do something to/for/with people with mental illness?

Questions concerning the best ways to respond to the problems posed by mental illness demonstrate the linkages between knowledge and interests of stakeholder groups. The history of developments in the mental health field over the last 250 years reflects a gradual opening up of a field of interests. These interests represent a broader base of involvement, demonstrated by the active participation of allied



health service providers, service users and carers. The move towards deinstitutionalisation has undoubtedly been driven by a number of historical forces, including, as set out above, treatments for neurosyphilis and epilepsy in the early part of the twentieth century, and better psychotropics, beginning in the 1950s.

Movements in the 1960s and 1970s aimed at ensuring civil rights of all citizens also played their part in the move towards community treatment, as did the empirical testing of models for delivery of care in the community in the 1970s and 1980s. Today, in many service settings, we can truly be seen as being in a postinstitutional stage of mental health practice, with many clinicians and clients never having had experience of working or being cared for in the large institutional asylum settings.

The achievements of psychotropic drug research and development have, as we have noted, generally enabled those experiencing mental disorders to spend less time in hospital, and then only for brief rather than long-term admissions. However, these advances have certainly not allowed psychiatry to bask in the glory of its therapeutic triumphs. The civil rights movements of the mid and late twentieth century have been critical of institutions, and the role of medicine in practices associated with them, which have been seen as oppressive and even abusive. In the USA, in particular, this played a part in provoking a neo-Kraepelinian revival in the 1970s (Klerman 1990). The neo-Kraepelinian paradigm emphasised the role of the psychiatrist as expert diagnostician, and held that 'psychiatry was the specialty of medicine, concerned with mental disorders and their scientific understanding, as well as with the diagnosis and treatment of individuals suffering from these disorders' (Klerman 1990, p. 29). Thus, in the US, psychiatry in many ways sought to 'remedicalise' and thereby regain some lost aspects of its reputation and credibility. This movement was much less pronounced in the UK, and the Australian position could be seen as lying somewhere between these strands.

The movement towards deinstitutionalisation and community care has meant that people

experiencing mental illness are now more visible and audible. The responsibility for their care (and control) has shifted to community-based clinical and rehabilitation services. Where previously services were provided almost solely by psychiatrists and hospital-based workers, the shift to community-based programs has opened up treatment and intervention provision to a range of service providers: social workers, occupational therapists, psychologists, nurses, general practitioners and psychiatrists. Each of these professions shows differing epistemologies of practice and research. Deinstitutionalisation and community-care initiatives have also meant that families are more frequently involved in the care and accommodation of mentally ill members, leading to difficulties, both for familial caregivers and the people themselves.

The rapid changes wrought by deinstitutionalisation and community care have presented a challenge for delivery of care through community agencies that are fragmented in ways in which the asylums, as total institutions, were not. There are three principal provider groups: professionals from a range of disciplines (including medical, allied health, legal, criminal justice and religious groups); family members and carers; and service user and/or consumer-survivor groups. Each interest group varies in the particular issues and concerns that motivate it. Professional groups differ in their perspectives on the place and the various merits of clinical treatment and psychosocial rehabilitation practices. Family and carer groups have been concerned to advocate improved services. Consumer-survivor groups have lobbied for a range of empowering services and the opportunity to establish and maintain self-help initiatives. Indeed, the involvement of consumers, service users and survivors in their own treatment and as a critical voice in evaluating intervention treatment responses, as will be discussed below, has been one of the most significant developments in the mental health field, and in contemporary times, offering increasingly sophisticated theoretical understanding, most notably the concept of 'consumer perspective', which is discussed here and in subsequent chapters.

## A CONSUMER PERSPECTIVE ON MENTAL ILLNESS

ANNE OLSEN & MERINDA EPSTEIN

As part of the examination of who should do something to, for or with mental disorder, we will next examine the changing role of the consumer in mental health practice. Arguably, only those who can speak with the experience of the consumer role can do justice to this subject, so this section is one of a number of consumer-written sections of this book.

### SPEAKING OUT

Medical and sociological debates concerning the definitions, causes and treatments of 'mental illness' have had little to do with encouraging active consumer participation in the development of policy and the delivery of services. For as long as people have been experiencing mental and emotional distress and society has sought to intervene or control the lives of these 'aberrant' individuals, voices have been raised in opposition to inhumane strategies and treatments. The 'Petition of the Poor Distracted People in the House of Bedlam', lodged in 1620, is one of the earliest recorded examples of protest against the abusive treatment meted out to mentally distressed people. If they are to speak out about needs, abuses and rights, individuals must first feel empowered.

### DISEMPOWERMENT

One of the critical factors giving rise to the disempowerment of people who suffer from 'mental illness' is what can be termed a failure of recognition—within the wider community and within services. There is a continuing tendency to identify the individual consumer with her or his diagnosis, resulting in dehumanisation of the person. This misrecognition encourages stereotypical understandings of what it means to be 'mad': weak and incompetent at best, and at worst, dangerous, evil or both.

This is not to suggest that consumers are victims, but rather that, as members of society, they themselves participate in dominant understandings and misunderstandings regarding 'mental illness' and 'mental health'. They are disempowered, at least in part, through sharing commonly held notions about inadequacy, incapacity and illegitimacy. It is important to emphasise here that an acknowledgment of participation does not mean that an individual is to blame for his or her own disempowerment; we (consumers, carers, practitioners and academics) are all participants in our own making, but we do not function in isolation or outside a material context.

### The social production of power

In the previous section, the terms empowerment and disempowerment have been used in relation to one another, but we have not considered the underlying concept of power as such. Power is not a tangible, measurable entity. It cannot be described or even identified within the paradigms established by positivist epistemologies. It could be argued that power does not exist except through the processes of human interaction; that is, power can be regarded as a dynamic and mutable product of human social relationships.

Because of its resistance to identification and control, power, as a social product, is frequently relegated to the margins in critiques or analyses of the relations that exist within the mental health sector. This is so particularly because the differential distribution of power is oddly invisible to those who enjoy its benefits. Within that field of human relations circumscribed by notions of 'mental illness' and 'mental wellness', those most likely to discern the (often subtle) workings of power are those who are, in some way or another, subordinate.

A problem that arises in trying to conceptualise power, disempowerment and empowerment is that, in the 'real' world, for any individual there are many different relationships—each with its own power differential—operating more or less concurrently. In one relationship an individual may feel in control, confident, useful, worthy; in another, the same individual may feel that she or he has no 'control'; that person may feel useless and unworthy and be

lacking the confidence to address these issues. It would be a mistake to suppose that any individual is either dominant or subordinate in each and every relationship in which she or he is involved.

## Power and mental health

The kinds of power relationships that operate within the mental health field are largely (still) constructed by and through institutions of social control. This means that the 'balances of power' in this field become entrenched, fixed and resistant to change.

Among the many things that consumers can teach service providers, the value of consumer empowerment may be one of the most important. The development of 'new and more empowering ways' of thinking about 'mental illness' and working with consumers will eventually be rewarding for consumers and providers—even if initially it is difficult to 'see how to achieve necessary changes' (Read & Wallcraft 1992, p. 22).

At a practical level, if providers are expected—by consumers or by management—to change their understandings and working practices, some kind of education must be provided. It has been suggested by some consumer groups that consumer-perspective education gives both providers and consumers the 'chance to step out of everyday roles and meet as equals on neutral ground'. For illustration of this, see Read and Wallcraft (1992, p. 22); also the board game *Lemon Looning* (Shaw & Epstein 1997).

Ideally, this will encourage honest and open discussion of what needs to change in the system, and ideas about how best to overcome obstacles to positive change can be shared on more equal terms.

## Self-advocacy and empowerment

Empowerment is a very difficult concept to define in a few words. It is probably easier to say what empowerment is not.

Contrary to what many well-intentioned people might believe, empowerment is not something that can be conferred upon others. Empowerment is related to the ability to make informed choices, the recognition of self-worth and an appreciation of the

right to self-determination; these are not gifts to be bestowed upon the marginalised, ill educated or down-and-outs by the more fortunate.

Social structures, community mores and expectations, and the lived realities of human beings are fundamentally implicated in creating the contexts within which individuals experience empowerment—or, indeed, disempowerment. For consumers, self-advocacy is one of the most significant outcomes of empowerment, as well as being a means to empowerment.

Self-advocacy is what happens when 'an individual or a group of individuals speak up for themselves or [for] a common cause' (Meagher 1995, p. 27). Examples of self-advocacy include people challenging decisions made about them—their treatment and their needs—without their input. Perhaps they have been asked to make decisions without having been made aware of all the alternatives; or perhaps they have not been given access to all the relevant information in a readily understandable form.

Obviously, it is not always easy for people to stand up for themselves. Often consumers are not taken seriously by 'carers'—whether these are family members, friends or professionals. Consumers therefore need support and encouragement in speaking on their own behalf. Where a group of individuals speaks up regarding common concerns, support comes from other group members. Group self-advocacy is carried out by unions, carer groups, parent groups, consumer groups and voluntary organisations (Meagher 1995, pp. 27–8).

There are groups that have been formed by and for consumers, and which take up social and political issues that affect their group. These groups may work with or without the collaboration of mental health workers, but essentially they are consumer driven. The kinds of issues tackled by consumer advocacy groups include stigma, prejudice, accommodation, civil rights and so on. This type of advocacy is usually concentrated on raising public awareness of these issues through various forms of campaigning.

## A FOCUS ON RECOVERY

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As was noted above, the need for new and more empowering ways of thinking about mental distress and working with consumers is urgent. One relatively new and particularly influential way of so doing is encapsulated in the concept and practice of what is termed *recovery*. Recovery as an idea is rooted in, and privileges, lived experience-based knowledge: expertise developed through firsthand experience of what life with mental health problems is like. Much has been written about recovery over the past two decades; the word ‘recovery’ has infiltrated mental health policy and services internationally but there are also concerns that it has been coopted and its meaning subverted (Davidson et al. 2005; Glover 2005; Onken et al. 2007; Ramon et al. 2007). Therefore, some discussion of its origins and the ideas that ‘recovery’ connotes may be a useful starting point for understanding.

### WHERE DID THIS INTEREST IN RECOVERY COME FROM?

The origins of the notion of recovery in the mental health field can be traced to at least three key influences:

- self-help movements, including notions of regaining sobriety and restoring one’s life originating in the addictions field
- the mental health consumer or survivor movement’s focus on first-person experience, claiming human rights and challenging discrimination
- psychiatric rehabilitation, with its focus on restoring a functional life and community reintegration, albeit that recovery has wider importance in mental health service systems (Amering & Schmolke 2009, Davidson et al. 2005; Onken et al. 2007).

It is informed by lived experience-based evidence from personal accounts of recovering (Barker 1999; Deegan 1993), consumer-led and other qualitative research exploring lived experiences of recovery (Davidson et al. 2005; Jacobsen 2001; Ridgway 2001),

which highlights that people can and do recover in the sense of rediscovering and reconstructing a satisfying, hopeful and contributing life beyond patienthood and the effects of symptoms (Davidson et al. 2005). Longitudinal outcome studies have also provided empirical data to ground hopes for recovery (Deegan 2001); to challenge mental health professionals to question previous assumptions about the prognosis for people with psychotic disorders in particular; and to think differently about what it is possible for people experiencing mental health issues to achieve (O’Hagan 2001; Davidson et al. 2005). So, in the sense that there were people living with and finding ways of self-managing and recovering long before the term became popularised (Cook et al. 2010), what is new is not so much the idea of recovery itself, but the awakening of mental health services to its implications for how to support people more effectively in recovery.

### WHAT IS RECOVERY?

The term *recovery* is a potential source of confusion or concern among consumers, families, carers and professionals (Repper & Perkins 2003; O’Hagan 2004). This is because in parts the term itself is open to misinterpretations, its origins are divergent and it is also not readily defined (Davidson et al. 2006; O’Hagan 2004; Repper & Perkins 2003). Every person who experiences mental health issues faces the challenge of maintaining or rebuilding a meaningful and satisfying life, whether these issues are time limited or ongoing, and whether or not the symptoms can be eliminated (Repper & Perkins 2003). So, in one sense, the challenge of recovering is shared irrespective of diagnostic labels and whatever understandings individuals come to for their situations (whether in philosophical, spiritual or scientific terms), but each person’s circumstances, what is most troubling and what makes life meaningful and satisfying also varies (O’Hagan 2001; Repper & Perkins 2003; Turner-Crowson & Wallcraft 2002). Thus, recovery, as clinically applied to mean the lessening of symptoms or their ‘cure’, needs to be distinguished from an understanding of recovering grounded in the experience-based knowledge of

people who have lived the challenges, struggles and triumphs over mental illness and distress (Glover 2005; Lapsley et al. 2002).

There are many available accounts of firsthand experiences that provide a rich source for further learning about what recovery means and can involve. There is limited scope here to draw on their words in depth; however, the following key ideas have been learnt and summarised to help address some sources of confusion or concerns about the notion of recovery:

- The cornerstone of the notion of recovery is, first and foremost, understanding that people who experience mental ill-health are human beings with feelings, values, hopes and aspirations, and no matter how devastating mental illness can be to their lives, the person and the mental illness are not one and the same (Davidson 2003; Deegan, 1996).
- Recovery is neither the restoration of a previous state, nor the disappearance of all suffering and symptoms (Deegan, 2001; Repper & Perkins, 2003): 'Recovery is happening when people can live well in the presence or absence of their mental illness, and the many losses that come in its wake, such as isolation, poverty, unemployment and discrimination. Recovery does not always mean that people will return to full health or retrieve all their losses, but it does mean that people can live well in spite of them' (O'Hagan 2001, p. 87).
- Recovery is a process of personal learning, growth and transformation, rather than an outcome (Deegan 2001; Turner-Crowson & Wallcraft 2002). In the words of two well-known consumer activists:

Recovery is an attitude, a way of approaching the day and the challenges I face. Being in recovery means I know I have certain limitations and things I can't do. But rather than letting these limitations be occasions for despair and giving up, I have learned that in knowing what I can't do, I also open up the possibilities of all I can do (Deegan 1993, p. 10).

Recovery is a journey as much as a destination ... for some people, recovery is a road they travel on once or twice, to a destination that

is relatively easy to find. For others, recovery is more like a maze with an elusive destination, a maze that takes a life time to navigate' (O'Hagan 2001, p. 87).

The notion of recovery implies change for the better, but must also address what people are recovering from (Onken et al. 2007). It is about a process of healing faced by people who experience differing kinds of losses, traumas and illnesses in the course of their lives (Spaniol et al. cited in Repper & Perkins 2003). Recovering then is not exclusive to people with mental ill-health, but many traumas associated with experiencing mental ill-health require such healing. These include traumas associated with symptoms; effects of medication and other treatments; devaluing and disempowering services; disconnection, discrimination and social exclusion (Lapsley et al. 2002; Onken et al. 2007; Repper & Perkins 2003). So, the challenges to recovering can include: losses of power, sense of self, a valued identity, meaning and hope that accompany these traumas (Spaniol et al., cited in Repper & Perkins 2003), but also barriers to participation and social inclusion imposed by society (Onken et al. 2007).

Each person's recovery journey then will be different and deeply personal: 'Each of us must find our own way and no-one can do it for us' (Deegan 1993). Appreciating this diversity of views and experiences is important, but so too is recognising that recovering is neither an exclusively individual responsibility, nor accomplished without allies and supports (Davidson et al. 2005; O'Hagan 2001; Repper & Perkins 2003; Ridgway 2001).

## ELEMENTS OF THE PROCESSES OF RECOVERING

The features of the processes that comprise recovery are described in varied ways in the literature (e.g. Andresen et al. 2003; Davidson et al. 2005, 2009; Onken et al. 2007; Repper & Perkins 2003). The three perspectives summarised in Table 1.1 serve to describe some of the ways in which these processes of recovering are presently



understood. Glover (2005) described five elements of individual recovery, drawing from her own and other Australians' lived experiences (Tooth et al. 2003), while Davidson and colleagues (2005, 2009) proposed components of being in recovery drawn from international qualitative research,

consumer-survivor accounts and other literature, and Onken and colleagues' (2007) review uses an ecological framework to describe person-centred and community-centred elements, and elements involving exchange between person and community.



TABLE 1.1 Elements of the process of recovering

<i>Glover 2005</i>	<i>Davidson et al. 2005; 2009</i>	<i>Onken et al. 2007</i>
The work of upholding <i>hope</i> (moving from despair to hope)	Renewing hope and commitment	Person-centred elements: hope, sense of agency, self-determination, meaning and purpose, awareness and potentiality  Re-authoring elements: coping, healing, wellness, thriving
The work of supporting <i>personal responsibility</i> (moving from others taking responsibility for me to taking personal responsibility)	Assuming control Incorporating illness Managing symptoms	
The work of unpacking <i>discovery</i> (moving from a sense of alienation and not knowing to discovery and meaning)		
The work of engaging an <i>active sense of self</i> (moving from passivity to activity)	Redefining self Finding one's niche in the community	Exchange-centred elements: social functioning and roles, power, choice among meaningful options  Community-centred elements: social connectedness and relationships, social opportunities, integration
The work of remaining <i>connected</i> (moving from a place of disconnection to connection with myself, relationships and the community)	Being supported by others	
	Becoming empowered and exercising citizenship Overcoming stigma (developing resilience and/or actively fighting discrimination)	



Each perspective in Table 1.1 offers a somewhat different view, but also highlights personal wellness, connecting to meaningful activities and communities as elements of recovering. Similarly, Andresen and colleagues' (2003) model of 'psychological recovery' identifies finding hope, reestablishing identity, finding meaning in life and taking responsibility for recovery are central processes. Indeed, the personal qualities and agency of individuals in recovery tend to be emphasised in much recovery literature, yet connection to culture in fostering recovery are relatively little discussed, and so too discrimination, disadvantage and barriers to participation (O'Hagan 2004; Onken et al. 2007).

Recovery is lived; that is, recovery unfolds within the context of everyday experiences of relationships, activities and environments, so that material and social circumstances and power are indeed central to processes of recovery (Borg & Davidson 2008).

The various elements of recovery outlined above may not have equal importance to every person experiencing mental health issues and, for some, it may be that this notion of 'recovery' is not even useful as a way to frame making sense of mental distress or troubles in their lives. Nevertheless, they offer some ideas about what recovery might mean, and what might be involved in travelling the road of recovering such that one can live well (O'Hagan 2001).

## **CONCLUSION**

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In this chapter, our purpose has been to sketch the history of the development of ideas that have been influential in shaping current understandings and practices within the mental health field in Australia. This historical context is characterised by change, as successive generations of interest groups grapple with the multiplicity of factors that surround mental

disorder and complicate its understanding. Each perspective, as it develops, illuminates part of the picture and obscures other parts. In the chapters that follow, we will pursue each of these directions to some degree. We will present as comprehensive and coherent an account of those parts of the mental health picture as possible, in a way that advances knowledge about and for practice for mental health professionals in Australia.