#### **Module Outline:**

#### Mental health problems Unit 1:

- What is a mental health problem? 1.1
- Experiencing a mental health problem 1.2

#### The politics of mental health Unit 2:

- 2.1 The political history of madness
- 2.2 Power in mental health

#### Unit 3: **Democracy and mental health**

- Democracy and participation 3.1
- The democratic challenge in mental health 3.2

#### **Investigating democracy in mental health services Unit 4:**

Student research project

#### **Module Introduction**

It might, at first, seem strange to suggest that democracy has anything to do mental health. Democracy is usually something we associate with a government, one in which the people choose their political representatives in elections. In a democracy, we are all equal politically, we all have one vote, and power is carefully divided and managed so that one group in society will not become too strong.

Yet politics and power are not things confined to the level of the nation state. They are also active in our daily lives. When we attend a school governors' meeting, when we complain about rail safety, when we lose our job, we are dealing with issues of power. Certainly, in our society, democracy is primarily a form of government. We do not, for the most part, have democracy in our hospitals, nor in our schools, nor in the firms for which we work. Yet power is active in all these places. As we shall see, in the area of mental health, power and politics are matters of vital importance. Today, people with mental health difficulties, carers, professionals and academics, are all debating these issues. Indeed, those who use mental health services are becoming increasingly vocal in their demands to be involved with decisions which effect them.

When we look at the organisations with which we interact most frequently in our everyday lives, however, issues of power and politics can be hard to see. Our task in this module is to improve our perception of the ways in which questions of power influence issues in mental health. Somehow, we must learn to see more clearly. In order to do so, we will use two methods. The first is to concentrate upon the words and experiences of those who have, themselves, experienced mental health problems. Their descriptions of how power operated in their experience enable us to recover a knowledge about mental health services that only they can provide. The second method will be to consider the history of our ideas about madness. By so doing, we seek to sharpen our perceptions of how issues of power effect the very ways in which we conceive of mental ill-health.

This module thus introduces individuals and groups to the growing debate in the field of mental health concerning issues of power and democracy. It provides an introduction to questions around the nature of mental health and an overview of how it has been conceived in history. It concludes with a survey of current democratic initiatives in mental health, including self-help groups, advocacy projects and innovations in the involvement of users in the design and delivery of services. Throughout, the module highlights the importance of questions of power in both past and present ideas about mental health. And it seeks to trace the ways in which these ideas have impacted upon services, treatments and everyday lives.

# **Learning Outcomes**

On completion of the module, students will be able to:

- 1. approach issues in mental health with greater understanding and sensitivity
- 2. demonstrate an understanding of the role of power in conceptions and treatment of mental health problems
- apply an understanding of democracy to the field of mental health **3.**
- 4. draw on a knowledge of recent democratic initiatives in mental health

#### Accreditation

What support will I get?

Your portfolio

How much time will I have to commit?

**Module symbols** 

#### **Mental Health Problems** Unit 1:

### Introduction

This section provides an introduction to how we think about madness and mental health.

Section 1.1 inspects the difficulties of defining and explaining mental health problems. Inspects the ways in which our ideas about madness affect how people are treated.

Section 1.2 focuses on what it feels like to have a mental health problem, and on what actually happens because of it.

#### Aims:

- To improve our understanding of what causes mental health problems
- To show the many difficulties involved in defining and explaining mental ill-health.

This first unit explores the practical implications of our ideas about mental health problems, particularly ideas about how madness is defined, explained and treated.

### 1.1 What is a mental health problem?

Words like 'mental health', 'madness' and 'normal' are extremely difficult to define. What is described as 'normal' behaviour in one time or place can be seen as abnormal in another. For example, in some cultures it is normal to laugh and feel joy at a funeral, whereas in others, this is seen to be inappropriate. Similarly, while some cultures believe people who hear voices have special powers, others see these voices as symptoms of mental ill-health. Where behaviour can be so differently interpreted, it is extremely difficult to define what we mean by a 'problem' in a person's mental health.

'Mental health problems' cause people to behave in ways that are seen as unacceptable. Each culture, each historical period, each place in the world, has different ideas about what behaviour is normal and what is abnormal. To experience a 'mental health problem' involves experiencing emotions that are different from those expected. We should not underestimate such an experience of difference. For an individual, and for those who interact with that individual, experiencing emotions which are different from what is expected is often deeply upsetting and frightening. Such feelings can seriously damage a person's ability to carry out his or her daily routines, and almost always, they are the cause of significant personal suffering. This suffering suggests that having a mental health problem is not only a matter of experiencing emotions that are unusual, different or creative. People who have had mental health problems, and those who care about those people, all attest to the profound distress which surrounds such experiences.

In fact, mental health problems remain one of the most important and controversial difficulties we face in modern society. Many people experience such problems, and there is evidence that numbers are on the increase. At present, the largest civilian institution in Europe is the British National Health Service. Within that service, more money and effort is expended on mental ill-health than on any other kind of health problem. The World Health Organisation recently concluded that mental health problems are now second only to heart disease as the leading cause of disability. We should, however, be aware of just how difficult it is to count the number of people who suffer from mental ill-health, for it depends on how such problems are defined and measured. Generally, though, the likelihood that a given individual will at some time experience significant mental health difficulties seems to be of around 20%.

It is hard to be certain about such numbers. They depend on what is seen to count as a mental health problem. Some estimates are as high as 28%.

It seems that about one out of five people will, at some point in life, experience a serious mental health problem.

**Stop and think:** look at the statistical data on the incidence of different types of mental health problems in the UK today. These figures come from the independent mental health charity MIND.

More than 6 million people seek help for mental health problems at some time in their lives Over 4,000 people take their own lives each year More than 2 million prescriptions are issued every year for tranguillisers and anti-depressants Over 200,000 people are admitted to psychiatric hospitals annually

More than 100,000 ECT (electro- convulsive therapy) treatments are administered every year Over fifty deaths a year may be caused by over-prescribing psychiatric medicines

WRITE DOWN THREE THINGS THESE FIGURES MAKE YOU THINK.

KEEP THESE NOTES IN YOUR PORTFOLIO

When we consider just how common such problems are, it is troubling to note that the experts often disagree about what a mental health problem actually is. With all the modern advances in medicine, we still find different experts offering quite different methods of treatment. At the heart of these disagreements are fundamentally different views about what causes a problem in mental health.

There are, generally, two schools of thought about the nature of mental ill-health. The first holds it to be primarily a physical and organic problem, like a medical disease of the brain or body. The second holds that mental ill-health is primarily a psychological and social problem, one caused by experiences in the world. While neither school completely dismisses the importance of the other, their respective explanations of mental ill-health retain a primary orientation to either physical/organic or psychological/social causes.

Today, we see these two different explanations of mental ill-health reflected in the institutions which offer help to sufferers. Treatment is often provided by two quite different kinds of institutions, one stressing physical/organic explanations, and the other the psychological/social.

Thus, health services offer primary points of contact with a medical doctor, drug treatments and hospital beds. In this way, they reflect a primarily organic approach to mental health problems. Social services and the voluntary sector, however, provide help of a rather different kind, such as case work and community support. This reflects a more social approach to mental health problems.

If we look across the range of expert opinion today, we can see that current thinking is that mental health problems are a response to the stresses and traumas that people experience in the course of their lives. What constitutes stress is different for all of us and may not be immediately obvious even as we experience it. Most people find stress difficult but they do not 'come apart', they do not experience what many people call a 'breakdown.' This notion, of coming apart, is an important one, for it allows us to see that mental health problems involve a kind of collapse. Such a collapse might be valuable, it might even be wholly understandable, but it nevertheless involves a serious disruption to a person's life. Now, as a person experiences a stressful situation, they find themselves responding with emotions or actions which may be surprising to them, and to the people around them.

Why, then, do some people respond to stress and trauma by coming apart, when others do not? Any answer to this question must begin by noting that almost everyone will come apart under sufficient stress. Simple sleep deprivation reduces everyone to a state of collapse. What causes one person to respond to the stresses they experience *in a particular way*, a way we have been calling 'a mental health problem', appears to be partly physical and organic, and partly psychological and social. It seems that some people have a physical tendency to respond to stress in ways that entail unexpected pain and emotion. What *triggers* these tendencies, however, are experiences of stress and trauma. The causes of mental health problems are, therefore, multiple. There are biological factors, and there are experiential and social triggers. For this reason, the best modern treatments for mental health problems combine elements of both approaches, the organic and the social, and involve co-ordination between both kinds of institution.

The problem of how to define mental health becomes more difficult still when we consider the many different ways in which people come apart under pressure. From the earliest times, observers noticed that while some patients became depressed, others saw visions, or were gripped by panic, or engaged in endless repetitive movements. The way we think about mental health problems is different in different times and places. While we know more about mental health problems today than we did in the past, there remain significant disagreements among experts around causes, definitions and treatments. Clearly, mental health is not like mechanics or chemistry. There is no single truth about what mental health is, nor about what we should do to treat it. Disagreements about how to explain mental health problems are important. They have practical affects. For example, the treatment offered to a person will reflect a particular explanation of mental ill-health.

Whether or not a person is seen to have a mental health problem is partly a matter of how serious that person's difficulties are, and how much distress they cause. It is also a matter of how long that difficulty lasts. For example, most people experience feelings of depression and anxiety at some point in their daily lives, often as a reaction to very real problems they encounter. Such emotions only become a mental health problem when they are overwhelming and last for a long

time. Finally, what is seen as being a mental health problem can be different in different times and places.

Some people experience serious mental health problems which last for a few days, while for others, a problem can last for many years. Short-term problems, particularly when they are obviously a reaction to a significant trauma, are referred to as "acute" problems. Those which last for many years are described as "chronic."

### 1.2 Experiencing a mental health problem

In trying to understand what it means to have a mental health problem, we are increasingly assisted by people's own accounts of their experience. In the early 1990's, MIND conducted a major survey of people who had received mental health services in the UK. What they found was both surprising and shocking. Time and again, people who had mental health problems reported how much suffering and disruption they experienced. Many claimed that the services they had received caused them additional difficulties.

Consider the following quotes from people describing what happened when they had a mental health problem.

- Family stress due to my mother's illness led to me having hallucinations."
- "I know from my own experiences that if more was known about mental illness and it was discussed in society I, for one, would have been saved a lot of pain and anguish. Right up to the day I was taken to a psychiatric hospital and sectioned under the Mental Health Act, I knew practically nothing about mental illness. I knew that I must be ill because I was very depressed, couldn't concentrate and was having weird experiences."
- "I had depression and phobias leading to attempted suicide... My doctor and family didn't understand me or help but my close friends were prepared to listen and to believe me."
- "I went round to my mum's for Christmas and the police were there waiting for me in the house. I had become very ill and my mum was ashamed. I was sectioned and kept in hospital for six months."
- "Eleven years ago, I spent about five months as a patient in six mental hospitals. The experience totally demoralised me. I had never thought of myself as a particularly strong person, but after hospitalisations, I was convinced of my own worthlessness. I had been told that I could not exist outside an institution. I was terrified that people would find out that I was an ex-patient and look down on me as much as I looked down on myself. For years I feared that any stress, any difficulty would lead to my total collapse."
- After I took an overdose, the staff nurse asked me if the stomach pump had been greased. When I said it had, she said that she would have left it ungreased because people taking overdoses should suffer."
- "I was given heavy medication then stripped and left locked up in a room for several days. I cried and cried but they would not let me out."

- "My friends acted as though I had the plague."
- "[My employers] got fed up with me having time off so I was dismissed."
- Once it was known that I had spend time in a 'nutters' hospital my neighbours gave me hell."
- "If I meet somebody who isn't or hasn't been in the hospital, then you don't mention that you're psychiatric and hope to God that nobody else mentions it in your family or whatever that meets them later. Because the attitude from people, some of them, they just... you can tell they're embarrassed and don't know what to say or anything... They think it's terrible. I think unless you've had somebody in your family who's had trouble, which a lot of people must have done, but some of course haven't and they have a very strange attitude towards psychiatric... it's taboo, you mustn't talk about it..."
- "[It was] the most terrible experience of my life."

These remarks highlight a number of the concerns we have been exploring, such as distress and suffering, coming apart, loosing the ability to do things, loosing control over one's life to others, stress upon carers, struggles over how to explain the problem and negative reactions from others.

Here, we should also note an additional way in which our ideas about mental ill-health have practical effects; specifically, they serve to increase the sufferer's difficulties. Most of us hold quite deep, and very negative, ideas about madness. For example, many people think that a person suffering from a mental health problem will be violent. In fact, this is not the case. When someone we know experiences a mental health problem, we make their lives still more difficult if we use such ideas to make judgments about them. There are, therefore, strong stereotypes about mental ill-health. These stereotypes are popular ideas about madness which have practical effects.

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<sup>&</sup>lt;sup>1</sup> Quotes are from J. Chamberlin, *On Our Own*, MIND, 1988; A. Rogers, D. Pilgrim and R. Lacy, *Experiencing Psychiatry: User's Views of Services*, Macmillan, 1993; P. Barham, *Closing the Asylum: the Mental Patient in Modern Society*, Penguin, 1992, http://www.vulliamy.demon.co.uk

#### **Stop and Think:**

Note down three stereotypes of madness

Where do you think these stereotypes come from?

To understand stereotypes of madness, we must look back at the history of human attempts to understand mental health. After all, the way we think is, in part, a product of how we have been taught to think, by schools, religions and institutions which are themselves the products of history. We now turn, therefore, to the history of our ideas about madness.

# **Unit 2: The politics of mental health**

#### Introduction

Unit 2.1 presents a brief history of our ideas about madness in order to sharpen our perception of the practices of power in different times and places.

Following this, Unit 2.2 clarifies the different kinds of power which operate in mental health services today, and closely inspects a particularly important event in the life of a person suffering from mental health difficulties, this being the moment they are given a medical diagnosis.

#### Aims:

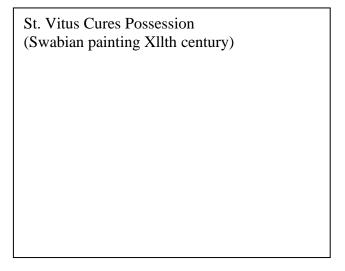
- To see how ideas about madness reflect relations of power within a society.
- To understand what power is and how it operates in relation to mental health issues

### 2.1 The political history of madness

The history of madness is really a history of *ideas about madness*. Our ideas about what madness is and how it is to be treated have changed significantly over time. We see this when we compare different beliefs from different historical periods. For example in the Eighteenth Century, madness was typically seen as a physical disease and treated accordingly. Yet in the Middle Ages, madness was often seen as sin, a belief which produced very different treatments and responses. When we look back, we not only see changing beliefs about madness. We also see that these beliefs reflect the dominant concerns of a particular society. The history of madness is, therefore, a history of power.

#### Madness as Sin

In the picture below, we see St. Vitus performing an exorcism in the Twelfth Century.



At the time St. Vitus administered this treatment, society was dominated by religion. Explanations of madness thus saw it as a spiritual and moral crisis, one brought on by sin, or the application of magic. With the cause of madness attributed to possession by the devil, or evil spirits, treatment took the form of exorcism of those spirits by a priest.

Here we see that ideas about madness reflect the power relations that exist within a society. When issues of power occur around questions of religion and a social order dominated by the church, mental health problems appear as a violation of that order. In this particular period of history, mental health problems were thought to be caused by sin. Their treatment required someone who upheld the religious order, such as a priest.

As we have already noted, our ideas about mental health are an expression of a particular time and place. Here, we see that such ideas are, in part, a product of the power relations and issues that dominate a particular society. If this is the case, then we would expect our ideas about madness to change as the power relations within a society change.

#### Madness as Physical Disease

Consider the following picture:

Picture: Drilling holes in a patients head.

In this picture, dating from the Sixteenth Century, we see a patient being treated by a physical method, and an extremely violent one at that. Such a method of treatment indicates that madness, within *this* time and place, has come to be seen as having an organic cause, as being a physical crisis rather than a spiritual one. This shift in how madness is explained reflects a more general struggle going on in this period between the old religious order and a newly emerging order of science. Once again, therefore, we see how ideas about madness reflect the relations of power within a society.

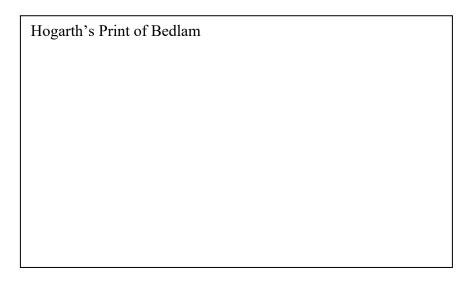
## The Victorian Asylums

By the middle of the Eighteenth Century, rapid changes in agriculture and industry combined to drive people from the land, forcing them to seek work in the cities. Here, in the new factories, science was being successfully applied to methods of production, and to the management of the workforce. It was also applied to the management of mental health problems. At this time, the first mental hospitals were built. These hospitals, filled with "pauper lunatics" who were often shackled, were the scene of terrible and cruel treatments. One of the most common was the "revolving chair" in which patients were strapped, then spun until blood came out of their ears and eyes.

Overseen by an expert doctor, these hospitals did witness advances in knowledge. For example, certain kinds of mental health problem, such as epilepsy and the last stages of syphilis were, for

the first time, shown to be directly caused by physical disease. Doctors, though they could now distinguish certain kinds of mental health problem from others, still presided over wards filled with patients whose symptoms they could neither understand nor treat. Often, patients admitted to mental hospital became worse rather than better, and once admitted, it was very difficult to get out.

In the following engraving by Hogarth, patients in the London Hospital called Bedlam are shown to be physically restrained and incarcerated in a place which is separate from the rest of society.



At the time this print was made, society was enjoying a period of unprecedented industrial and scientific advance. Such advances meant that power relations within society were once again changing. A 'normal' individual was now seen as one who could work and make a contribution to society. Those who could not make such a contribution were defined as social deviants, as mad, as something less than fully human. The huge Victorian asylums were thus places where patients were 'warehoused', excluded from society and dehumanised.

## **Hypnosis**

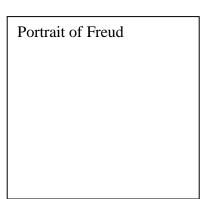
The Nineteenth Century saw many important advances in the explanation and treatment of mental health problems. Many doctors were experimenting with the new technique of hypnosis, first pioneered by a Viennese physician called Mesmer (as in Mesmerism). In Paris, a French psychiatrist by the name of Charcot employed hypnosis to treat female patients, often in front of an audience of medical students and the public.

Painting by Andre Brouillet, "A Clinical Lesson at La Salpetriere," 1887.

Hypnosis seemed to offer a way by which patients could recover lost memories, after which they reported an improvement in their condition. The idea that symptoms could be relieved by expressing hidden feelings led to the development of cathartic treatments – treatments where patients were encouraged to talk and act out their past experiences. The most famous practitioner of "the talking cure" was Sigmund Freud (1856-1939), who had attended Charcot's lectures in 1885.

#### Freud

In his clinic in Vienna, **Freud** was struck by the number of women who, when hypnotised, seemed to recover early experiences of sexual abuse. Unwilling to believe that these women had in fact been abused as children, Freud saw these memories as fantasies. This led him to suggest that while normal people went through a series of sexual changes as they grew up, those with mental health problems failed to go through these changes, and in fact became stuck in a particular stage of sexual development.



Freud's ideas, because they were about the repression of child sexuality were very controversial. Yet they enabled him to suggest that the human mind was divided into a conscious part, of which

one was aware, and an unconscious part, of which one was not usually aware. Madness was thus to be understood as an eruption, into the conscious mind, of frightening fantasies and images from the unconscious mind. Freud and his followers developed a a system of "psychoanalysis" which sought ways to express and analyse these unconscious images. In particular, Freud believed that these images could be recovered from the patient's dreams.

Freud was practicing during a time in which women were excluded from the public sphere and frequently forced into a life of domesticity. The frustration of being denied access to education, professions and the vote led in some cases to mental breakdown. These cases, alongside women's campaigns for access to public life, led to rebellious women being labeled as mad. Once again, then, we notice that the way madness is defined and treated reflects the dominant concerns and the relations of power within a society.

Freud's patients were mostly women, and they presented him with what were known as "hysterical" or "neurotic" symptoms. These included constant weeping, lethargy, panic and paralysis of parts of the body. Interestingly, many of these symptoms were observed by doctors treating traumatised soldiers during the First World War. These soldiers were given a diagnosis of "shell shock." Other symptoms Freud described, such as paralysis of the hands, are almost unheard of today. This suggests that even the symptoms of mental illness can change considerably as society changes.

# The Distinction Between Psychosis and Neurosis

Freud was also responsible for advancing our understanding of the different kinds of mental health problem, for he noticed that while "neurotic" symptoms could be treated by talking, another kind of problem did not respond to such treatments. From this observation, modern psychiatry learned to distinguish between neurosis and psychosis.

Neurosis is a way of responding to stress and trauma which involves symptoms like depression, anxiety and obsession.

Psychosis is a way of responding to stress and trauma which involves a profound separation from reality, serious delusions, dream-like imagery and magical thinking.

A mental health problem like *agoraphobia*, meaning a fear of open spaces, is thus an example of neurosis. A problem like *schizophrenia* however, because it involves delusional thinking, is an example of psychosis. Though this distinction can be over-stated (people labeled as schizophrenic, for example, are often also depressed), this is, nevertheless, an important difference in the way people respond to the pressures they experience in their lives.

Certainly, ideas about madness are expressions of the power relations within a society. Yet there do seem to be a variety of different kinds of mental health problem, requiring different kinds of responses. A description of modern categories of mental health problems can be found in the appendix at the end of this module.

#### **Closing the Asylums**

Despite of the use of talking treatments in the treatment of neurosis, the early Twentieth century saw the increasing dominance of medical science in the treatment of mental health problems. Still seen primarily as a physical disease, mental health problems continued to be treated by hospitalisation, and, after the 1950's, also by the use of drugs. By the 1960's, however, professionals began to question whether the exclusion of patients within asylums was the best way to treat such problems. Irving Goffman's work showed that asylums often made patients worse, cutting them off from society, making them dependent upon the asylum, and in fact preventing them from getting better. Goffman suggested that once people were labeled as mad, they became stigmatised, or permanently marked as different, so that it was almost impossible for them to overcome the exclusion and damage done to them *in the course of their treatment*.

From the 1970's, therefore, patients were increasingly treated in the community, receiving support from social workers and voluntary carers. Gradually, many large Victorian asylums were closed down. Unfortunately, the money saved was, all too often, not put into community services, so that sufferers found themselves freed from the asylum only to live impoverished lives in the community. Heated debates concerning the role of mental hospitals vs. the role of community care continue today.

This brief history of madness shows how our ideas have changed as the relations of power have changed. We certainly know more about madness today than we did in the past, and we no longer treat sufferers with the cruelty we formerly did. Yet many of the old ideas about madness remain. We still think of schizophrenia as a disease from which one can never recover. We still imagine that depression is a failure to try hard enough. We still fear those who have mental health problems. And, with over 40% of homeless people reporting mental health problems, we still fail to support sufferers and to bring them back into our communities.

Left over from the history of our ideas about madness, therefore, is a series of negative labels and stereotypes. When a person experiences a mental health problem today, they must constantly deal with these stereotypes, and with very powerful professionals and institutions, and with our continued inability to agree upon methods of treatment. This, then, has been a brief political history of madness. It is political precisely because it is a history of *power* and its application to people who are different. Those who suffer from mental health problems today have therefore

sought to regain some power over their experiences, to fight negative stereotypes and to recover their dignity. Inspecting the history of our ideas about madness has shown the way they reflect the relations of power in a particular time and place. We now turn, in section 2.2, to how power operates in mental health services today.

### **Stop and Think:**

What do you think you can tell about a society from the way it treats people with mental health problems?

#### 2.2 Power in mental health

Consider the following statement:

"It was the casting out, the stigma, that felt most damaging... Having been given, and accepted for lack of an alternative, a label of 'mentally ill', I did not feel that my opinions were valid. Many aspects of the treatments itself confirmed this view. Society's discrimination against people who have received psychiatric treatments, in not accepting us for proper jobs and proper housing, adds to this. Unlike criminals, society does not forgive our former diagnoses after a period of time... It is difficult for a person who has been treated for years as a 'mental patient' to realise that her (or his) thoughts and actions are valid and could make a difference. At this stage I have a vague awareness that I needed to join with others towards political action. The thought that I could play a part in bringing about change was alien to all that I had learned about my worthlessness during my upbringing and in the psychiatric system... One of the things that we service users have in common is this shared experience of total powerlessness. We learn to define ourselves by the roles and diagnoses given to us by psychiatrists, take them into ourselves and feel helpless to influence our lives... With powerlessness goes poverty of an enduring and humiliating nature."2

To understand the issues of power raised in this quote, we must first realise that power can take quite different forms and operate in different ways.

#### Physical power

Clearly, power can be a physical force. It can be applied by someone to someone else. It can force a person to do something they do not want to do. We see this physical power being used by police officers called out to take someone suffering from a mental health problem from their home to a hospital when they do not want to go. Similarly, physical power can be used to insure a person takes their medication, or to confine a person in wrist and ankle restraints.

<sup>&</sup>lt;sup>2</sup> Barham, Closing the Asylum, p. 116.

### Legal power

Of course, the police in first the example above are exercising this physical power according to law. The Mental Health Act (1983) allows for sufferers to be hospitalised if they as seen to be a danger to themselves or others. In such situations, the police have the legal power to detain a person. Under the Act, two doctors or one doctor and a social worker can detain, or "Section" a person to a mental hospital.

There are, of course, other Acts of law which give us basic civil rights, such as freedom of speech and freedom from arbitrary arrest. Nowadays, detention under the Mental Health Act is the *only* way one's basic civil rights can be violated without the judgement of a court. There is much debate about the provisions of the Mental Health Act at present, as it is being re-written for Parliamentary scrutiny in the next session. One of the most contentious aspects of the new Act is that it would allow for compulsory treatment in the community. For example, at this time, one can only be compelled to take medications when in hospital under Section. Taking them while living in the community, though strongly encouraged, cannot be compelled by law. If the new Compulsory Treatment Orders become law, people could be immediately Sectioned to hospital if they refuse to take their medication.

#### **Institutional power**

We see a somewhat different kind of power operating within the institutions which provide services for people with mental health problems. Here, hospital doctors and social work departments clearly have certain powers, and these powers can be physical and legal. But institutional power is more than simply the capacity of the institution to directly control a person. Institutions are settled organisations, they try to provide consistent, rule-governed activities, and to sustain themselves. This often means they become bureaucratised, they become separated from society as a whole, they grow internal cultures which profoundly affect those who work and interact with them.

# **Indirect forms of power**

Goffman's point about asylums, which we looked at in section 1.2 above, relates to this institutional power. The big hospitals, he argued, took away a person's independence and pride. They taught their inmates to think of themselves as being incurably mentally ill, and even allowed cruel treatments to be seen as morally acceptable. Here, then, we begin to notice more indirect forms of power. Modern institutions, like health and social services, each have developed complex and subtle forms of institutional power. It is often very difficult for those working within these institutions to see the dehumanising effects of institutional power. This is one of the main kinds of power that those suffering from mental health problems have fought to overcome.

## **Power over representations**

Once we recognise that power can have indirect forms, we notice that power can also be exercised over our everyday experience, over how we feel about ourselves and our lives. For example, indirect power can take the form of representations. Representations are images, stories and popular ideas. Even today, depictions of madness in the mass media and popular culture are frequently negative and ill-informed. Films, television programmes, and even news reports often resort to stereotypical images of madness, picturing it as stupidity, violence and associated with criminality. These images of madness have a powerful effect on popular conceptions of mental ill-health. As such, they must be included in our understand the subtle operation of indirect forms of power.

#### Power over how madness is described and explained

The power over how madness is described and explained has seldom been in the hands of mental health sufferers themselves. In our political history of madness (2.2 above), we saw how power has been exercised over our ideas and our explanations about what madness is. Here, we must note how difficult it is for people with mental health problems to enter into a fair discussion with professionals concerning their own experience. For example, it is not easy for sufferers to inspect their case files, to question the diagnoses they are assigned and to take an active role in treatment decisions. Also, many of those who use mental health services tell of times when they complained about their treatment, only to be told their complaint was another symptom. These are all examples of indirect power which is applied, often unintentionally, to the person with a mental health problem.

As we have already noted (1.1 above), the incidence of mental health problems in the general population is about 20%. Many groups, such as women, people from ethnic minorities, the poor, prisoners and the homeless, have little power in our society.

Here is some information on the incidence of mental health problems among such groups:

Women twice as likely to experience depression

Ethnic minorities

Poverty 4 times more likely

Prisoners 37% Homeless 33%

When we consider the disproportionately high incidence of mental health problems in people who have no power in our society, it does suggest that we may, today, be defining mental health in a way that once again expresses the power relationships within a particular time and place. Mental health diagnoses thus appear higher for women, racial minorities, the poor and the homeless.

Today, those suffering from serious mental health difficulties, and those who care for them, continue to be excluded from society, their services underfunded, their difference defined as

illness. Just as in our political history of madness, we still find difference being 'pathologised' by subtle and pervasive powers over how madness is to be defined, explained and represented.

Power has many dimensions. It can be direct and/or indirect. Direct forms include physical and legal power. Indirect forms include institutional, representational and explanatory power. The application of power may be intentional, or without any awareness at all. In the field of mental health, power is a pressing and recurrent issue.

**Table: The Dimensions of Power** 

DIRECT	INDIRECT
Physical	Institutional
Legal	Representational
-	Explanatory

**Stop and Think:** Give one example for each kind of power listed in the table above.

#### Power in the moment of diagnosis

We can see the various dimensions of power in the moment a person is given a diagnosis of their mental health problem. In the moment of diagnosis, a difficult problem is identified by a professional, one that begins a process of treatment. The individual gains an official explanation for a complex personal crisis, and perhaps also, real and much needed help. But all too often, people report that the services they receive are inadequate and even damaging. The moment of diagnosis is an entry into a set of descriptions, explanations, institutions and power relations. For many, it involves giving up power to a professional, a loss of independence and a loss of self-esteem. From this moment on, they will struggle with the label that has been attached to them.

In sharpening our perceptions of how power operates in the field of mental health, we should not forget that mental ill-health involves real suffering. This suffering is something more than just an effect of power. Our growing concern in this module is with the *political* question of how that suffering is to be understood, described and treated. As we can now see, there is little question that modern institutions for the treatment of mental health problems are shot through with power, so much so that some speak of themselves as being a "survivor" of those institutions. Yet when people have mental health problems, they need help, and there are many instances where health, social services and voluntary groups provide that help very well.

This module has used the words of mental health sufferers, a history of our ideas about madness and an analysis of power to sharpen our perception. Power is integral to contemporary questions around mental health. When we ask how services can be improved, we therefore ask also how

power is to be coped with, benefited from, managed. In the next unit, we explore the way we have learned to cope with power at the level of the nation state, this being democracy. Our interest here, therefore, it to see how democracy can be used to cope with questions of power in the field of mental health.

#### Activity: Power and mental health

Choose an example when you, or someone you know, or someone from a film, novel or television, sought help because of a mental health problem. Think carefully about this example, and answer the following questions:

- How would you describe the nature of the mental health problem featured in your example?
- How did the person in your example actually feel during the episode?
- How did others respond?
- What ideas about madness (past and present) were used by others to describe the episode?
- What conflicts took place over how the episode was to be described?
- What kind of help was offered?
- How successful was this help?
- In what ways do you think issues of power appeared in this person's experience?
- In what ways was this person disempowered by their experience?
- If there was one thing you could do to improve the way this episode was handled, what would it be?

### **Unit 3:** Democracy and mental health

#### Introduction

Unit 3.1 explores why democracy is seen as being the best strategy for coping with power at the level of the state. In particular, it stresses the importance of participation for democracy. Our concern then turns to the growing calls for more democracy in the field of mental health, and to the possibilities afforded by the participation and empowerment of those who have experienced mental health problems.

Unit 3.2 then surveys the wide range of current practical initiatives in democracy and mental health. This third unit, then, is an investigation into the question of how democracy can be used to cope with power issues that occur in the field of mental health.

#### Aims:

- To understand the role of democracy in the field of mental health
- To see the different ways in which democracy is being used in mental health

### 3.1 Democracy and participation

Power, of course, can be used for both good and bad, and nowhere is this more clear that in the history of the modern nation state. Democracy was developed precisely to remedy the abuse of power by Kings and aristocrats. By involving people in ruling themselves, by making sure one person or group of people were prevented from capturing power, democracy has become a universal aspiration for states around the world.

#### What is democracy?

Democracy is first of all an *ideal*. It is an ideal about people ruling themselves, or **popular sovereignty.** It holds that whoever is affected by a decision should be consulted about that decision. It also means that everyone should be **politically equal**, and **autonomous**. Being autonomous means being free to make our own decisions and able to be in charge of our own lives.

Democracy is also a *practical political arrangement*, a set of institutions, a way of governing a state. In the West, the political institutions we have today make appeal to the ideal of democracy in a number of ways. They hold elections, they have the representatives of the people make decisions in parliament, they give citizens an equal and single vote. These are not perfect reflections of the ideal, indeed, some argue they are barely democratic at all. But we do know that participation by the populace in the making of decisions is the best way we have ever found to cope with power at the level of the state.

# **Democracy in mental health**

One way to cope with power in our everyday lives, therefore, is democracy. In the field of mental health, voices who were formerly silent and excluded are at last being heard. People who were never consulted about decisions which affected them are, for the first time, seeking proper information and to have their views taken into account. They are resisting the removal of their autonomy that so often occurs when they receive treatment. They are attempting to stop the process of disempowerment that has characterized their experience of having a mental health problem. Those who use mental health services are, therefore, **empowering themselves** in a decidedly democratic way.

Ever since the first democrats in ancient Greece participated in their own government, writers have remarked on an extraordinary side-effect of empowerment and participation. Participation has always been seen as the best way to learn about power, to increase one's capacities and to improve one's judgment. **Participation "transforms" people.** In the field of mental health, this transforming effect has had the added importance of helping sufferers to recover their self-esteem, to learn again to value their own insights and experiences. Here, empowerment actually aids individual recovery from mental health problems.

The explosion of what used to be silent voices also makes available, to professionals and administrators, new knowledge about what those services are really like. Service users, having actually eaten the pudding, are its best judge. Just as involving the people in government improves the functioning of the state, so the participation of service users improves the quality of mental health services. It is to democratic initiatives to improve services that we now turn.

## 3.2 The democratic challenge in mental health

In the last thirty years, the field of mental health has faced a significant democratic challenge. Those who have used mental health services have begun to share their experiences, to insist that their voices be heard, to organise themselves and to act. Taken together, these activities are known as the "user movement." This movement encompasses a wide range of initiatives at local, state and international levels. User activities may take the form of campaigns and patients rights movements, self-help groups, community arts initiatives and advocacy projects. In this section we will be looking at some of the initiatives which make up the user movement.

Though user protests date as far back as the seventeenth century, the most recent user movement began in Northern Italy. In the early 1960's, some psychiatrists began to work more closely with hospital patients in order to address issues which were of importance to those patients. Organising around questions such as the quality of hospital food, private lockers and the openness of discussions with professionals, these early initiatives came to be known as "democratic psychiatry." In the United Kingdom, networks of mental health workers and patients began to demand a critical review of the explanations and treatment of "mental illness". Groups including *People Not Psychiatry* and the *British Network for Alternatives to Psychiatry* were influenced by the insights of contemporary radical psychiatrists such as R.D. Laing and Thomas Szasz.

Efforts to involve users in the design and evaluation of services received a significant boost when, in the USA, lawyers began to successfully argue that many hospitals were unfit for human habitation, and that patients were often denied the necessary knowledge to agree to treatments. This matter, referred to as "informed consent" resulted in user's voices being given more importance. A further step in the movement was the setting up of the British pressure and self-help network known as UKAN. From the mid-1980's local and national groups have had greater contact through the use of international conferences and increased access to new information technologies. Important meetings occurred in 1985 when the World Federation of Mental Health and the National Association for Mental Health (MIND) brought together users and workers from Italy, the United Kingdom, Holland and the United States.

The user movement has made significant advances in both our understanding of mental health problems and the nature of treatments and services. One very powerful idea introduced by service users was the idea of a 'survivor' of the treatment system. Indeed, the organisation *Survivors Speak Out*, formed in 1986, was the first national network of people who identified themselves as survivors.

As we have seen, all too often, services fail to help and can even make things worse. The user movement, by effectively breaking the silence that surrounded issues and practices in mental health, sought to increase the participation of users in the decisions which effected their lives, and to highlight and address problems in service delivery. The recovery of user solidarity and dignity was, therefore, also a learning process for professionals. For the first time, service providers received feedback on what it actually felt like to receive such services. This feedback has resulted in significant improvements in services and even changes in government policy towards people with mental health problems.

From the very beginning of the user movement, groups who sought to take back the power to help themselves faced hard decisions. Some decided to have nothing to do with the mental health system, and so developed their activities as separatist groups. Others built alliances with professionals, had professional members and sought mainstream funding. Groups also had to decide whether to campaign, offer informal support or to organise themselves to provide services. At the heart of these issues are questions around how best to balance the need for democratic self-determination with the need for expert knowledge and resources.

The following is a brief survey and description of democratic initiatives in mental health.

#### Self-help groups

Self-help groups are groups of individuals who meet to support each other. Having experienced a problem themselves, sufferers build up a significant understanding of particular mental health problems and available services. Self-help groups are a way of passing this knowledge on to others. Groups vary in their activities, ranging from talk and recreation to the highly organised provision of information and support. Though usually small and based within a particular community, some self-help groups are national organisations to which local groups affiliate.

Examples of self-help groups are:

- The Schizophrenia Survivors Group
- The Hearing Voices Network
- No Panic
- Carers' National Association.

Contact information on these groups is available in Appendix 4, at the end of this document.

#### **Advocacy projects**

Advocacy means speaking for another. Often, in receiving services, users report that they are not listened to by professionals, that their concerns are left out, that no one tells them what is going on. Advocacy projects provide an individual with an advocate, who accompanies a user to a meeting and helps them to articulate their views. Advocates are often users themselves, though many such groups offer training even to non-users in the skills of advocacy.

"The advocate has to ensure that s/he is properly reflecting the views and wishes of the client, not superimposing the advocate's view of what is best for the client... advocates may assist people in case reviews, community meetings or mental health tribunals, to give some examples."

Most large cities and local authorities now have mental health advocacy groups. Local groups can be located through the *UK Advocacy Network*.

#### Self-advocacy projects

Self-advocacy groups highlight the importance of users of services advocating for each other through a range of self-help and campaign initiatives. This is perhaps the most radically democratic of the various initiatives currently taking place in mental health. This is because it is the most concerned with self-determination and the empowerment of users. It is often highly critical of existing explanations and treatments of mental distress.

Self-advocacy may involve wide ranging campaigns for changes in mental health services which would benefit all users. At the same time, self-advocacy works to create space for differences between user groups. For example, the specific needs of women and ethnic minority users may be addressed by members of those groups advocating for each other. For this reason, self-advocacy groups are most directly engaged with questions of power, democracy and mental health.

One member of a self-advocate group describes her involvement in the following ways: 4

"I date my loss of power back to my first encounters with authority."

"For centuries we have been silenced by denial of our human rights, the shame of the stigma of madness, routine invalidation as self-determining human beings, the fear of punitive and damaging treatment, and the effects of treatments itself."

"Sharing our stories finally gave us the courage to believe that we are not mad: we are angry; that what we are saying is not all the result of deluded thinking:

<sup>&</sup>lt;sup>3</sup> J. Read, J. Wallcraft, Guidelines for Empowering Users of Mental Health Services, MIND/COHSE, 1992.

<sup>&</sup>lt;sup>4</sup> Quotes are from J. Wallcraft, "Empowering Empowerment: Professionals and Self-Advocacy Projects," *Mental Health Nursing*, 1994, April, 14/2, pp. 6-9.

distressing things really have happened to us, and our distress and anger is often a reasonable and comprehensible response to real life situations which have robbed us of our power and taught us helplessness."

Specific self-advocacy initiatives include the following:

- Patients Councils: Patients in hospitals have often organised around issues like food, personal safety and privacy, and tried to get hospital practices changed. Often, these groups call themselves Patients Councils.
- **Survivor Only Groups:** These groups believe that campaigning independently of professionals is of the utmost importance. The best known such groups are *Survivors Speak Out* and *MIND Link*.
- User Forums and User Involvement Initiatives: Users have often demanded that they be allowed more input into the design, provision and evaluation of local mental health services. There have also been many efforts made by professionals to increase user participation. As a result, we find users involved with a wide range of health and social service planning committees, service developments and evaluation efforts. In some places, such groups offer training in mental health issues to professionals.
- Campaigns: Users have been active in nationwide campaigns to influence government policy making. Examples include campaigns around prescription charges, compulsory treatment orders and votes for hospital patients. For more information.

Despite the many advances brought about by the user movement, there have also been instances in which professionals have attempted to thwart or even abuse democratic initiatives. Three examples deserve scrutiny, as they are so often mentioned by users and professionals alike.

The first occurs where professional bodies learn, in the name of democracy and user involvement, to make sure a token user is in attendance at a meeting, even though there is no intention of listening what they have to say.

The second involves professional bodies refusing to listen to user representatives on the grounds that they are not properly representative, i.e. they have not followed stringent procedures for selection and consultation.

The third is the tendency of an independent self-help group to be gradually invited into a decision making process, and to be given funding and professional 'allies' to such an extent that the independent quality of the group at last becomes seriously compromised. Somehow, professionals must find a way to benefit from interaction with an independent group without coopting that group.

We might sum up the whole idea of democracy in mental health with the following quote:

"Patients know themselves best, and should be experts in their care." 5

At the level of the state, achieving democracy has been a long and difficult journey, one that is by no means over even today. This is also true of democracy in mental health. There have been extraordinary advances, government policy has been influenced, institutions have been changed and professionals have become better at their work. Most of all though, individuals have empowered themselves, joined with others and decreased their suffering. In so doing, they have laid down a democratic challenge in the field of mental health which has raised profound questions around the relations of power within our own society. Learning to see how power operates in the field of mental health has, therefore, enabled us to see that the way people with mental health problems are treated says a great deal about a society.

#### **Stop and Think:**

A user group had been offered funds to write a report evaluating local mental health services. Give three arguments why they should accept, and three why they should not.

<sup>&</sup>lt;sup>5</sup> T. McDougall, "Patient Empowerment: Fact or Fiction?" *Mental Health Nursing*, 17/1, January 1997, pp. 4-5.

### Unit 4: Investigating Democracy in Mental Health Services

#### Introduction

Summary of two previous units Concepts and questions to be addressed by project

#### What kind of project?

#### Option One:

Asks you to study a mental health organisation with which you are involved or familiar. The task here is to investigate how democratic it is by interviewing one or more persons who are involved in the organisation and by observing how the organisation works. Some examples of organisations you might choose to investigate are:

- An NHS Psychiatric unit
- A voluntary sector organisation such as MIND
- A doctor's surgery
- A social services day centre
- A community care residential programme
- A self-help initiative or advocacy group

#### Option Two:

Asks you to choose a current area of debate around mental health service provision. The task here is to investigate discussions of a particular issue in both government and media publications. To what extent are these discussions democratic? i.e. to what extent do they include user voices, how aware are they of different points of view, issues of power, etc.? Some examples of debates you might choose to investigate are:

- Care in the Community
- The debate between SANE and MIND about enforced hospitalisation
- The new 'Compulsory Treatment Order'
- The new 'Supervision Register'
- ECT
- Voting rights for hospital patients

#### Option Three:

Asks you to choose recent media coverage of mental health issues. The task here is to investigate media reports and representations in order to assess the quality of democratic input to such reporting. To what extent did reporters interview service users? What kind of sources did reporters use? Who was treated as an expert and why? What images and myths of madness were being appealed to? What images accompanied the text?

Please note: The information, addresses and web sites given in these appendices do not necessarily represent the views of either authors or the publishers of this module. They are intended for information only.

### Appendix 1: Types of mental health problem

- **Depression** feelings of hopelessness and despair, often accompanied by loss of sleep and appetite which is prolonged and has significant negative effects upon a person's life and relationships. For more information.
- **Anxiety** feelings of apprehension and alarm ranging from minor to serious panic attacks which have significant negative effects upon a person's life and relationships. For more information.
- **Schizophrenia** a psychotic disorder of meaning and communication involving delusions which has significant negative effects upon a person's life and relationships. For more information.
- **Compulsive disorder** feeling compelled to do things in an obsessive way that is so serious as to have significant negative effects upon a person's life and relationships. <u>. For more information.</u>
- **Manic depression** or bi-polar affective disorder. A prolonged and repetitive swing in mood from euphoria and overwhelming energy to deep depression. For more information.
- **Dementia** a group of organic brain disorders usually affecting people in their old age. For <u>More information.</u>
- **Personality disorders** a life-long tendency to behave in ways that are continually seen as unacceptable, and which have significant negative effects upon a person's life and relationships. For more information.

More detailed information on different kinds of mental health problems, and local groups, is available from The National Association for Mental Health (MIND).

# Appendix 2: <u>Practitioner Roles</u>

**General Practitioner** – or GP. Medical doctor trained in general medicine and

community practice. Treats all ailments including mental health

problems. Can write prescriptions.

**Psychiatrist** - Medical doctor trained in general medicine, with additional

training in Psychiatry. Can write prescriptions.

**Psychologist** - Trained in clinical psychology. Provides psychological

treatment for mental health problems both in hospital and in the

community. Does not write prescriptions.

**Psychiatric nurse** – Trained as a medical nurse and in psychiatry. Cannot write

prescriptions but can administer medical treatment. In the community they are called Community Psychiatric Nurses.

Social worker - Usually employed by local authority Social Services

departments. Trained in social work, either generic or specialising in a particular client group. Psychiatric Social Workers can be Approved under the Mental Health Act to sign

Section papers.

**Voluntary worker -** Usually without formal training, volunteers work for self-help

and advocacy groups, in hospitals and community services.

Appendix 3: <u>Drugs</u>

[Scan in Blaug (1990) table.]

# Appendix 4: <u>Information on Democratic Initiatives.</u>

For access to a wide range of user led writing, opinion and information, see the on-line magazine First Person. This web site also contains extensive links to other valuable resources.

#### **National Self-Help Support Networks**

C/o National Self-Help Support Centre NCVO Regents Wharf 8 All Saints Street London N1 9RL Tel: 0171- 713-6161

It assists in setting up self-help groups wherever there is a shared experience. It co-ordinates national network meetings of self-help support staff and keeps a data-base of self-help activity.

#### **Hearing Voices Network**

91 Oldham Street Manchester M4 1LW

Tel: 0161 834 5768 (9am-5pm Mon-Fri Answerphone at all other times, leave your details and

they will get back to you)

Email: hearingvoices@care4free.net

A user led group helping people come to terms with their voices. Information pack, mailing list of self-help groups around the UK and publications available.

#### **UK Advocacy Network**

Volserve House 14-18 West Bar Green Sheffield S1 2DA

Tel: 0114 272 8171 (10am - 4pm Mon-Fri)

Federation of independent patients' councils, advocacy projects and user forums for mental health service users.

#### **Survivors Speak Out**

34 Osnaburgh Street London NW1 3ND Tel: 0171-916-5472

An organisation which aims to improve communication and contact between users and ex-users of psychiatric services, run by current and former users of mental health services.

#### **National Self-Harm Network**

c/o Survivors Speak Out. As above.

#### No Panic

93 Brandsfarm Way Telford Shropshire TF3 2JQ

Tel: 01952 590005 (office) 01952 590545 (helpline, 10am-10pm everyday)

Help for people with panic attacks, phobias and obsessive/compulsive disorders. Local groups and one to one telephone counselling available. Range of leaflets, video and audio-tapes also available.

#### **Triumph Over Phobia (TOP UK)**

PO Box 1831 Bath BA2 4YW

Tel: 01225 330353 (admin line, Mon-Fri 9.30am - 5pm)

Network of structured self-help groups run by trained, lay volunteers teaching sufferers from phobia and OCD how to overcome their problem. Leaflets available - please send SAE.

#### **Depression Alliance**

35 Westminster Bridge Road London SE1 7JB Tel: 020 7633 0557

Website: www.depressionalliance.org/

#### **MIND**

Granta House 15-19 Broadway London E15 4BQ

Tel: 020 8519 2122 Office (9.15am-5.15pm Mon-Fri)

Mind Information Line: 020 8522 1728 if you live in Greater London or 0345 660163 if you live

elsewhere (9.15am-4.45pm Mon - Fri)

Email: <a href="mail@mind.org.uk">email@mind.org.uk</a> Website: <a href="mail@mind.org.uk">www.mind.org.uk</a>

MIND works for everyone in emotional distress, campaigning for rights and developing locally based services. Mind's national Info Line covers all aspects of mental health including legal matters for service users, carers, family and friends, researchers, students, service providers and the public. Mind publishes a bi-monthly magazine and has a free quarterly newsletter as well as many other publications

#### **Manic Depression Fellowship**

Castle Works 21 St George's Road London SE1 6ES Tel: 020 7793 2600

Email: <a href="mdf@mdf.org.uk">mdf@mdf.org.uk</a> Website: <a href="mailto:www.mdf.org.uk">www.mdf.org.uk</a>

Self-help organisation for people with manic depression, their relatives and friends. Has a network of 150 support groups. Quarterly journal, factsheets and publications available. Telephone for free information pack.

Further helpful contacts are available from the Mental Health Foundation, here.