1

Introduction: barriers to social and occupational integration

The focus in this book is on people with serious mental illnesses, particularly psychoses, schizophrenia and manic-depressive illness (termed bipolar illness in the USA). Although less serious psychiatric conditions such as depression may also lead to social and occupational exclusion, the barriers are not as formidable or as extensive as with the psychotic illnesses. Perhaps this is because the latter often produce symptoms with which the person in the street cannot empathise. One of us (JL) was sharing the platform at a public meeting with Lewis Wolpert, who has written and spoken extensively about the severe depressive illness he suffered in the past and from which he has fully recovered. He told the audience that it took a great effort for him to overcome his reluctance to expose his experience to the public because of the considerable stigma accorded to depression. JL followed this confession by relating that when patients in his care who suffer from schizophrenia ask him how to explain the gaps in their work record to a potential employer, he advises them to say that they have been depressed.

1.1 Disabilities produced by the illness

The barriers are partly attributable to the effects of the illness and its management by professionals and partly to the reaction of the public. Both schizophrenia and manic-depressive illness commonly lead to delusions – false beliefs about the world – and hallucinations – seeing or hearing things that others do not experience. These symptoms can dominate patients' lives and interfere with their ability to interact with others, to attend to tasks and to think clearly.

Schizophrenia can also produce apathy, lack of interest, lack of motivation and a reluctance to engage with other people. These symptoms make it very difficult for the patient to undertake the search for a job, let alone to negotiate an interview, meet the demands of a job or form relationships with workmates. The symptoms also inhibit the activity of making and keeping friends. These negative symptoms, as they are termed, are much commoner in schizophrenia

than in manic-depressive illness, but they do appear in the depressed phase of the latter condition. Both positive and negative symptoms can respond to treatment, but all treatments have unwanted side effects.

1.2 Disabilities produced by professional care

The massive development of asylums in the UK in the nineteenth century was initiated as a solution to scandalous conditions in the private 'madhouses'. They became the centres of psychiatric care throughout the developed world and were exported to developing countries by the colonial powers. Although asylums were designed, with the best of intentions, to provide recreational spaces and the free circulation of air, they rapidly became overcrowded and understaffed. Constructed to house several hundred patients, many of them reached a peak of over two thousand. Those patients who could not be conscripted into a labour force to service and maintain the asylum were consigned to 'back wards', where they suffered neglect and inactivity. The lack of any occupation increased the severity of the apathy and inertia produced by their illnesses.

This was not the only deleterious effect of the institutions. They also came to represent to the public places into which disturbed patients disappeared, never to emerge again. Thus, they became readily identifiable icons of the stigma of mental illness. The introduction in the 1950s of effective medication to treat psychiatric disorders hastened the discharge of patients into the community, which had begun a few years earlier in the late 1940s. Unfortunately, these valuable drugs had side effects that produced conspicuous abnormalities of movement and behaviour. The mildest effects were shaking of the hands and a tendency to shuffle when walking, but patients could also suffer from major spasms of the head, neck and tongue, and even difficulties in breathing evenly and in speaking. Some patients were left with a constant flow of saliva, which dribbled from their mouths. These peculiarities marked the patients out as different from their healthy neighbours and compounded the stigma of their illnesses.

1.3 Attitudes of the public

Throughout the world, people with serious mental illnesses are viewed differently from those with physical illnesses. This is attributable partly to a perceived link with violence, which will be discussed below, and partly to difficulties in sharing and understanding the abnormal experiences that are induced by schizophrenia and manic-depressive illness. Members of the public wish to distance themselves

from people with such illnesses, as shown by their reluctance to work with them, marry them, live close to them, and have them as friends. In developed countries, a small minority of neighbours resist the establishment of sheltered housing in their streets and become very vocal in their resistance, sometimes defeating the efforts of service providers to sway the public towards acceptance.

Stigmatising attitudes vary with age and sex, older people being more prejudiced than younger people, and women more than men. Women with children are particularly fearful of people with mental illness, believing that their young ones are at risk of being harmed. Rejection by the public of people with psychiatric disorders leads to social isolation of the patients and results in their segregation with other people with similar mental health problems. It becomes very difficult for an individual to break out of this social ghetto.

1.4 Influence of the media

The media are very influential in the formation of public attitudes, and journalists working in newspapers and television have the power either to dispel or to reinforce misconceptions about mental illnesses. Journalists might be expected to be better informed than the general public about mental illness, but unfortunately this is rarely the case. Headlines and news stories tend to dramatise the rare occasions when a member of the public is harmed or killed by a person suffering from a mental illness. The language used is often pejorative, with slang terms such as 'weirdo' and 'nutcase'. The constant linking of mental illness with violence creates or strengthens an already existing stereotype.

Stigma in the community

They used to call me names. People that I met on the streets. They called me 'wing-nut' and stuff like that because of my mental illness. That kind of hurt me. It doesn't happen so much now.

Local newspapers can mount campaigns against the setting up of sheltered homes in a neighbourhood, especially if a group of vociferous citizens writes angry letters to the paper. On the other hand, the media have the potential to educate the public about mental illness and its effects, and responsible journalism and televised science programmes can combat ignorance and the prejudice it breeds.

The entertainment media are particularly influential in shaping the public's view of people with mental illness. Nearly three-quarters of mentally ill characters

in prime-time US TV dramas are portrayed as violent; over a fifth are killers (Signorelli, 1989). In such Hollywood movies as *Friday the 13th* and *The Silence of the Lambs*, people with mental illness are portrayed as fearsomely dangerous. Mentally ill people are often depicted as bizarre in appearance, vacant, grimacing, giggling and snarling. When the Academy Award-winning film *One Flew over the Cuckoo's Nest* was made at Oregon State Hospital in 1975, the producers had the opportunity to use hospital patients as walk-on actors. They rejected the idea, however, as real patients did not look strange enough to match the public image of mentally ill people (Wahl, 1995). Some more recent films, such as *Shine* and *A Beautiful Mind*, have shown a more realistic and optimistic view of mental illness; and, as we shall see later, advocacy groups have taken on the task of tackling the news and entertainment media about their inaccurate and derogatory portrayal of people with mental illness.

Speaking out

I think 'schizophrenia' is a word that still scares people – professional and non-professional. They think of mass murderers. It still has a bad name. It's like cancer or diabetes used to be. You know, 'cancer' used to be a bad word. I would love to be able to tell my employers, 'Hey, I'm schizophrenic and look at what a good job I'm doing and I'm schizophrenic; isn't that a great thing?' I would like to be able to say, 'Let's celebrate this!'

1.5 Self-stigmatising attitudes

Faced with stigma and prejudice from both the public and mental health professionals, it is no surprise that people with psychiatric illnesses begin to view themselves as inferior to others. They may accept the image that others hold of them as being dangerous and unpredictable. The impact on their self-image is then disastrous, leading to social withdrawal and lack of motivation to achieve their goals. This may be accompanied by depression. The professional attitude to patients with psychotic illnesses is that the more insight they can develop into the nature of their pathological experiences, the better. But for the patients, insight can be very painful, leading to a realisation of how disabled they have become and how much they have lost. Research now suggests that patients who resist the diagnosis of mental illness and who are, therefore, deemed to lack insight have higher self-esteem than those who accept the diagnosis.

Self-stigmatisation

When I got a job I got some criticism, but I didn't tell them I was sick. I didn't want them to know I was mentally ill. I could've been hired as a disabled person because I was mentally ill, but I was embarrassed about the fact that I'd done all these things, and I didn't want anyone to know I was mentally ill. So I never talked about it until just a few years ago. I didn't tell my boss about my history until I got to know her and I wanted her to get to know me as a person rather than for my illness.

1.6 Poverty and social disadvantage

Given the difficulties that people with serious mental illness have in obtaining and keeping jobs, the great majority are on some form of social benefit. Even in the most developed countries, the weekly amounts paid are barely sufficient for the basics of life, and the bureaucratic hurdles to claiming benefits are such that up to half the patients qualified to claim social welfare are not receiving the full amount to which they are entitled (McCrone and Thornicroft, 1997). As a result, patients cannot afford even relatively inexpensive entertainments such as attending sports events or going to the local cinema. Excluded by poverty from participation in such social activities, many patients have no recourse other than to watch endless television, often in a communal setting with other patients, where even the choice of programmes is not under their control.

Lack of money also prevents many patients from buying smart or fashionable clothes, so that their air of shabbiness becomes yet another feature marking them out as different. Some attempt to supplement their income by begging in the street, in competition with mentally healthy but homeless young people, thus becoming identified with the perceived lowest stratum of society.

1.7 Discrimination in housing and employment

Most of the patients who were discharged from long-stay care in psychiatric hospitals were unable to live independently in the community. Consequently, they were rehoused in homes that were staffed during the day and sometimes at night as well. Neighbours who learned that such a home was planned for their street varied in their reactions. The majority were welcoming, or at least accepting, of the new facility. However, a minority often formed determined opposition groups and took political action in order to prevent the home being established. At times, these people were successful and the planned home had to be sited in another locality.

Mentally ill people living in their own homes can be exploited or persecuted, particularly if they live in run-down neighbourhoods, being unable to live in a better environment. Studies have shown that contrary to the public image, people with serious mental illnesses are much more often the victims than the perpetrators of crime.

The difficulties in obtaining work have already been mentioned. These difficulties vary with the economic situation in the area in which the patient lives. When there is a high level of employment, people with a history of mental illness are more likely to find a paid job. However, when unemployment is high, they have very little chance in competition with people without such a history. They are usually more fortunate in agrarian societies with family enterprises, in which they can make a valued contribution, however small, to the family's income.

The working environment offers the opportunity of making friends, gives a structure to the day, increases the person's self-esteem, and provides an income, which enables the person to escape from the poverty trap. All these advantages are denied the person with serious mental illness who cannot find a sympathetic employer.

Discrimination in the workplace

I have to cheat to get a job. I have to make up a past, instead of telling them what's really going on, otherwise I wouldn't get hired. Actually, after I proved that I was a good worker, I once talked to my supervisor about having had a mental problem.

1.8 Human rights

The United Nations issued a Universal Declaration of Human Rights in 1948. Article 22 states: 'Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.' In the following chapters, we will expand on the themes introduced above, with the addition of remedial action that may be taken to enable the person with serious mental illness to enjoy the human rights guaranteed by the United Nations' Declaration.

Part I

The origins of stigma

2

The course of psychoses

2.1 The range of course and outcome

Emil Kraepelin (1896) was the first psychiatrist to distinguish between manic-depressive psychosis and what he called dementia praecox, now termed schizophrenia. He made this distinction largely on the basis of their different courses, with manic-depressive illness having a relatively benign outcome and dementia praecox, as the name suggests, entailing progressive deterioration. This formulation has continued to have its adherents, holding the view that a psychosis that resolves cannot be called schizophrenia. Thus, the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) of the American Psychiatric Association (1994) stipulates that schizophrenia can be diagnosed only if the symptoms have persisted for at least six months. A condition with exactly the same symptoms as schizophrenia but lasting less than six months is designated schizophreniform psychosis. Earlier diagnostic systems coined a variety of terms for short-lived illnesses with schizophrenic symptoms, including reactive psychosis, psychogenic psychosis, brief transient psychosis, schizo-affective illness, and the French term 'bouffee delirante'. Guinness (1992) conducted a follow-up study of these transient psychoses in Swaziland and found that some patients relapsed with the same type of transient condition, while between 10% and 20% developed long-standing illnesses that satisfied DSM-IV criteria for schizophrenia. There was nothing in the clinical presentation of the first episode that distinguished between patients with these disparate courses.

Although transient psychotic disorders are less common in developed countries than in developing countries, they do occur. A study of all patients with a psychotic disorder making a first contact with the services over two years was conducted in Nottingham (Singh *et al.*, 2004). The criteria in the International Classification of Diseases, 10th revision (ICD-10) for acute and transient psychotic disorders (ATPD) with a two-week period of onset were applied to the study sample (World Health Organization, 1992). Thirty-two patients satisfied these

criteria. The whole cohort of psychotic patients was followed up for three years and the outcome was compared for the various diagnostic groups. The patients with ATPD fared much better than those with a diagnosis of schizophrenia over the follow-up period. Three-quarters of the patients with ATPD had only a single episode of psychosis or multiple episodes with full remission between, compared with just over one-third of patients with an initial diagnosis of schizophrenia. At first contact, ten of the ATPD patients had symptoms indistinguishable from schizophrenia, and the symptom profile did not predict outcome. This finding confirms that of Guinness (1992) in her study in Swaziland and raises the question of whether these disorders represent a distinct diagnostic category or whether the concept of schizophrenia needs to be extended to include illnesses of very acute onset and rapid resolution.

The international epidemiological study mounted by the World Health Organization, Determinants of Outcome of Severe Mental Disorders (DOSMeD), of patients making first contact with the services for a psychotic illness, substantiated these findings (Jablensky *et al.*, 1992). A two-year follow-up of the samples of patients from a variety of developed and developing countries found that a substantial proportion of individuals with typical symptoms of schizophrenia recovered completely from the first episode of illness and remained well throughout the follow-up period. The importance of these findings cannot be overemphasised. They demonstrate that schizophrenia is by no means an illness that entails an inevitable deterioration. As we shall see later, the public's stereotype of schizophrenia includes the notion that no one recovers from this illness. Insistence by professionals that only chronic illnesses should be designated as schizophrenia reinforces the public's misconception of the condition.

Even patients with long-standing schizophrenia are not doomed to a dismal outcome. Manfred Bleuler (1978), whose father Eugen introduced the term 'schizophrenia', conducted the first follow-up study of patients with the illness that continued for several decades. Bleuler found that individuals whose illness was unremitting from the beginning showed a tendency to improve as time went on. This surprising result was confirmed by several studies in Europe (Huber *et al.*, 1975; Ciompi, 1980) and a study in the USA (Harding *et al.*, 1987). Some of these patients were considered to have a poor prognosis in the early years of their illness but were found to be working in paid employment decades later.

2.2 Outcome in developed and developing countries

Another key finding from the WHO international study of the onset and course of psychotic disorders was that the outcome over a two-year follow-up was very

much better for patients with a first episode of schizophrenia in developing countries than in developed countries. The best outcome was defined as complete recovery from the presenting episode and no further attacks of schizophrenia during the follow-up period. The proportion of patients falling into this category was 24–54% in India, Nigeria and Colombia (mean 37%) compared with 4–32% in developed countries (mean 16%). This is despite the fact that psychiatric resources in India and Nigeria are scarce compared with those in the West. For example, India has four psychiatrists and even fewer psychiatric nurses per one million population (World Health Organization, 2001). Patients with a rapid onset were more common in the samples from developing countries than in the other centres, but even when patients with this type of presentation was excluded the remaining patients fared better than those in developed countries. This makes it unlikely that the explanation lies in the type of illness being compared. It is much more probable that social and cultural differences between the centres account for the varied outcomes. If so, then there are opportunities to alter the patients' environment and, hence, improve their prospect for recovery. This would be an important step in changing the public's conception that people do not recover from schizophrenia.

A long-term international follow-up study has confirmed the findings of earlier long-term studies (Harrison *et al.*, 2001). The sample included 766 of the patients in the DOSMeD study, who were followed up for 25 years. Close to one-half of the patients were rated as globally recovered after this time, and 43% had not been psychotic in the final two years. In terms of social adjustment, 57% of those with a diagnosis of schizophrenia were working in paid employment or were engaged in housework. At an interim 15-year follow-up, 16% of those with schizophrenia showed evidence of late improvement, namely continuous symptoms initially followed by recovery. The overall rates of improvement were found to vary by location, confirming the two-year results, with the best outcomes in Nottingham and rural Chandigarh in northern India.

It would clearly be of practical importance to identify the reasons for the different course of schizophrenia between countries. Several follow-up studies in individual developing countries preceded the WHO DOSMeD study; some of these studies found a better outcome for patients in developing countries than in developed countries. In one study conducted in Sri Lanka, Waxler (1979) suggested that a possible reason was the relative ease with which patients could find useful and productive employment in family enterprises, which abound in rural pre-industrial societies. Waxler's view is supported by a finding made by an earlier WHO transnational follow-up study of schizophrenia (World Health Organization, 1979). These researchers observed that in developed countries it