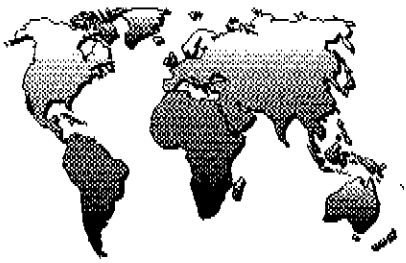
NATIONS FOR MENTAL HEALTH



WHO/MSA/NAM/97.6
English only
Distr.: General

Schizophrenia and public health

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Nations for Mental Health:
An Action Programme on Mental Health for Underserved Populations

Objectives of Nations for Mental Health

- To enhance the attention of people and governments of the world to the effects of mental health problems and substance abuse on the social well-being and physical health of the world's underserved populations. A first step is to increase awareness and concern of the importance of mental health through a series of key high profile regional and international events. Secondly, efforts will be devoted to building up the will of the key political authorities to participate. Thirdly, and finally, efforts are to be directed at securing political commitments by decision-makers.
- To establish a number of demonstration projects in each of the six WHO regions of the world. They are meant to illustrate the potential of collaborative efforts at country level, with the view of leading on to projects of a larger scale.
- To encourage technical support between countries for service development, research and training.

The implementation of the programme depends on voluntary contributions from governments, foundations, individuals and others. It receives financial and technical support from the Eli Lilly and Company Foundation, Johnson and Johnson, the Government of the United Kingdom of Great Britain and Northern Ireland, the Institute of Psychiatry at the Maudsley Hospital of London (United Kingdom), the Free and Hanseatic City of Hamburg (Germany), the Villa Pini Foundation (Chieti, Italy), Columbia University (New York, USA), the Laboratoires Servier (Paris, France) and the International Foundation for Mental Health and Neurosciences (Geneva, Switzerland).

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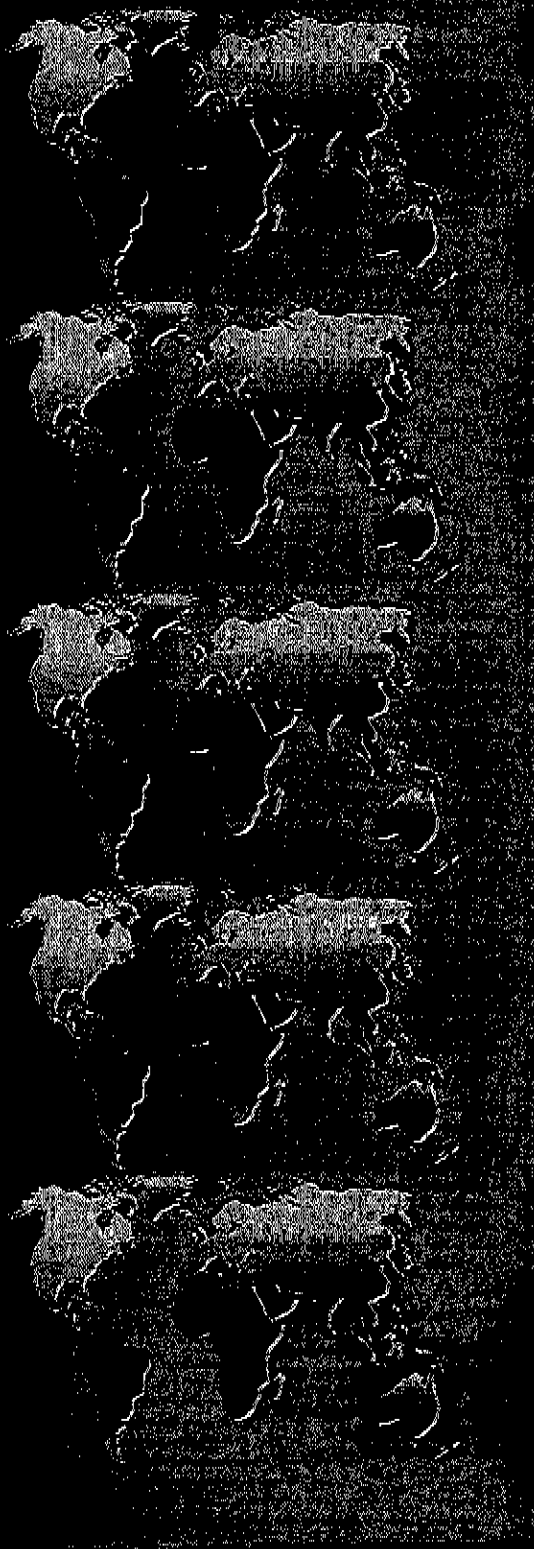

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Preface

The World Health Organization has established a new Action Programme on Mental Health for Underserved Populations. This programme, called 'Nations for Mental Health', has been created to deal with the increasing burdens of mental health and substance abuse worldwide. The main goal of the programme is to improve the mental health and psychosocial well being of the world's underserved populations.

Solutions to mental health and substance abuse problems entail a joint mobilization of social, economic and political forces as well as substantial changes in governmental policies related to education, health, and economic development in each country. This demands an intense and sustained effort from the nations of the world through joint cooperation between governments, nongovernmental organizations and the organizations within the United Nations system. The programme is of utmost importance to the work of WHO and WHO is willing to lead and coordinate this ambitious task. Several international meetings and launchings have been organized, in collaboration with other international organizations and academic institutions. A number of demonstration projects related to the programme have already been initiated in several countries. These projects are meant to illustrate and/or demonstrate the potential of collaborative efforts at country level, with the view of leading on to projects of a larger scale.

This document addresses important public health issues related to schizophrenia. It was written by Angelo Barbato, Centre 'Antonini', Milano, Italy.

I am very pleased to present this document as part of the global process of raising awareness and concern about the effects of mental health problems. It is hoped that this important document will help support health ministers, ministry officials, and regional health planners whose task is to deliver and improve mental health policy and services within a strategic context.

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Chapter 1
Introduction

The term *schizophrenia* was introduced into the medical language at the beginning of this century by the Swiss psychiatrist Bleuler. It refers to a major mental disorder, or group of disorders, whose causes are still largely unknown and which involves a complex set of disturbances of thinking, perception, affect and social behaviour. So far, no society or culture anywhere in the world has been found free from schizophrenia and there is evidence that this puzzling illness represents a serious public health problem.

Chapter 2
Clinical issues

2.1 Diagnosis

In the absence of a biological marker, diagnosis of schizophrenia relies on examination of mental state, usually through a clinical interview, and observation of the patient's behaviour. Table 1 shows the diagnostic guidelines according to the two major current classification systems.

As can easily be seen, the two systems overlap to a considerable extent, while retaining some differences. The ICD-10 represents a compromise between research findings and various diagnostic practices in different countries and is probably better suited for worldwide utilization.

Any approach to the diagnosis of schizophrenia should, however, take into account the following:

- Current operationalized diagnostic systems, while undoubtedly very reliable, leave the question of validity unanswered in the absence of external validating criteria. Diagnosis of schizophrenia should therefore be considered a provisional tool that organizes currently available scientific knowledge for practical purposes, but leaves the door open to future developments.
- Since the boundaries between schizophrenia and other psychotic disorders are ill-defined, differential diagnosis, particularly during the early stages, can be difficult. No single sign or symptom is specific of schizophrenia so the diagnosis always requires clusters of symptoms to be recognized over a period of time. Careful standardized diagnostic assessment, while useful for research, may not be necessary in clinical practice.
- The diagnosis of schizophrenia does not carry enough information for treatment planning. Symptoms suggestive of schizophrenia can be found in a number of neurological and psychiatric disorders. Therefore, differential diagnosis should consider the following conditions:
  - epilepsy (particularly temporal lobe epilepsy);
  - central nervous system neoplasms (particularly frontal or limbic);
  - central nervous system traumas;
  - central nervous system infections (particularly malaria and other parasitic diseases, neurosyphilis, herpes encephalitis);
  - cerebrovascular accidents;
  - other central nervous system diseases (leukodystrophy, Huntington's disease, Wilson's disease, systemic lupus erythematosus etc.);
  - drug-induced psychosis (especially related to use of amphetamines, LSD and phencyclidine);
  - acute transient psychosis;
  - affective disorder;
  - delusional disorder.

Table 1. Diagnostic criteria for schizophrenia

ICD-10	DSM-IV
A minimum of one very clear symptom belonging to any one of the groups listed below as (a) to (d) or symptoms from at least two of the groups referred to as (e) to (i) should have been clearly present for most of the time during a period of 1 month or more. a) Thought echo, thought insertion or withdrawal and thought broadcasting b) delusions of control, influence or passivity, clearly referred to body or limb movements or specific thoughts, actions or sensations; delusional perception c) hallucinatory voices giving a running commentary on the patient's behaviour or discussing the patient among themselves, or other types of hallucinatory voices coming from some part of the body d) persistent delusions of other kinds that are culturally inappropriate and completely impossible, such as religious or political identity, or superhuman powers and abilities (e.g. being able to control the weather or being in communication with aliens from another world) e) persistent hallucinations in any modality, when accompanied either by fleeting or half-formed delusions without clear affective content or by persistent over-valued ideas, or when occurring every day for weeks or months on end f) breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech, or neologisms g) catatonic behaviour, such as excitement, posturing, or waxy flexibility, negativism, mutism and stupor h) 'negative' symptoms such as marked apathy, paucity of speech and blunting or incongruity of emotional responses, usually resulting in social withdrawal and lowering of social performance; it must be clear that these are not due to depression or neuroleptic medication i) a significant and consistent change in the overall quality of some aspects of personal behaviour, manifest as loss of interest, aimlessness, idleness, a self-absorbed attitude and social withdrawal.	A. **Characteristic symptoms:** Two or more of the following, each present for a significant portion of time during a 1-month period, or less if successfully treated: 1) Delusions, 2) Hallucinations, 3) Disorganized speech, e.g. frequent derailment or incoherence, 4) Grossly disorganized or catatonic behavior, 5) Negative symptoms, i.e. affective flattening, alogia or avolition. *Note:* Only one criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other. B. **Social/Occupational dysfunction.** For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic or occupational achievement). C. **Duration.** Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet criterion A, i.e. active-phase symptoms, and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in criterion A present in an attenuated form (e.g. odd beliefs, unusual perceptual experiences). D. **Schizoaffective and mood disorder exclusion.** Schizoaffective and mood disorders have been ruled out because either (1) no major depressive, manic or mixed episodes have occurred concurrently with the active-phase symptoms or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods. E. **Substance/general medical condition exclusion.** The disturbance is not related to the direct physiological effect of a substance (e.g. a drug of abuse, a medication) or a general medical condition. F. **Relationship to a pervasive developmental disorder.** If there is a history of autistic disorder or another pervasive developmental disorder, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

Most neurological disorders can usually be ruled out by the presence of typical physical signs or by the findings of laboratory tests. However, the possibility of a neurological or medical disease should be suspected and carefully investigated at the first onset of psychosis, especially if this occurs in childhood or old age, in the presence of unusual features or when there is a marked change in quality of symptoms during the course of the disorder.

Differentiation between schizophrenia and other mental disorders requires consideration of the patient's history and clustering of symptoms, sometimes supplemented by longitudinal observation of the course of the illness.

2.2 Clinical picture

Although the clinical presentation of schizophrenia varies widely among affected individuals and even within the same individual at different phases of the illness, some of the following symptoms can always be observed:

- *Thought disorder:* usually inferred from abnormalities in spoken or written language, such as loosening of associations, continuing digression in speech, poverty of speech content and use of idiosyncratic expressions.
- *Delusions:* false beliefs based on incorrect inferences about reality, at odds with the patient's social and cultural background. Ideas of reference, control or persecution can often be observed.
- *Hallucinations:* sensory perceptions in the absence of external stimuli. Auditory hallucinations (especially voices) and bizarre physical sensations are the most common.
- *Abnormal affect:* reduction in emotional intensity or variation as well as affective responses inappropriate or incongruous with respect to the context of communication.
- *Disturbances in motor behaviour:* adoption for a long time of bizarre positions; repeated, aimless movement patterns; intense and disorganized activity or reduction of spontaneous movements with an apparent lack of awareness of surroundings.

In the seminal International Pilot Study of Schizophrenia, carried out by WHO, auditory hallucinations and ideas of reference were the most frequently observed symptoms, found in about 70% of patients (WHO, 1973). This, cannot hold true, however, in all social or cultural groups.

Furthermore, considerable empirical evidence points to a continuity between most psychotic symptoms and ordinary experience. The tendency to bizarre thinking and peculiar sensory experiences is spread across the population more widely than is usually acknowledged by clinicians (Claridge, 1990). Therefore, symptom assessment may be a threshold issue and should always be seen within the context of the person's overall emotional state and social functioning.

Various attempts have been made to classify symptoms of schizophrenia in order to define meaningful subtypes of the disorder. In the past 20 years the distinction between the two broad categories of *positive* and *negative* symptoms gained widespread popularity (Crow, 1980). However, more recent multivariate analysis has suggested not two but three symptom clusters: *reality distortion*, *disorganization* and *psychomotor poverty* (Liddle, 1987).

Chapter 3
Epidemiology

3.1 Incidence and prevalence

The distribution of a disorder in a given population is measured in terms of *incidence* and *prevalence*. *Incidence* refers to the proportion of new cases per unit of time (usually one year), while *prevalence* refers to the proportion of existing cases (both old and new). Three types of prevalence rate can be used: *point prevalence*, which is a measure of the number of cases at a specific point in time; *period prevalence*, showing the number of cases over a defined period of time (usually six months or one year); and *lifetime prevalence*, reflecting the proportion of individuals who have been affected by a disorder at any time during their lives.

Incidence studies of relatively rare disorders, such as schizophrenia, are difficult to carry out. Surveys have been carried out in various countries, however, and almost all show incidence rates per year of schizophrenia in adults within a quite narrow range between 0.1 and 0.4 per 1000 population. This has been the main finding from the WHO 10-country study (Jablensky et al., 1992).

Taking into account differences in diagnostic assessment, case-finding methods and definition of adulthood, we can say that the incidence of schizophrenia is remarkably similar in different geographical areas (Warner and de Girolamo, 1995). Exceptionally high rates that emerged from the Epidemiologic Catchment Area Study in the United States (Tien and Eaton, 1992) may be due to biased assessment. Although few data are available on incidence in developing countries, early assumptions on consistently lower rates outside the western industrialized countries have not been confirmed by recent thorough investigations in Asian countries (Lin et al., 1989; Jablensky et al., 1992; Rajkumar et al., 1991).

High incidence figures have recently been reported in some disadvantaged social groups - especially ethnic minorities in western Europe, such as Afro-Caribbean communities in the United Kingdom and immigrants from Surinam in the Netherlands (King et al., 1994; Selten and Sijben, 1994). Such findings, plagued by uncertainties about the actual size and age distribution of the populations at risk, still await convincing explanations.

In the last 15 years a variety of reports from several countries have suggested a declining trend in the number of people presenting for treatment of schizophrenia (Der et al., 1990). However, changes in diagnostic practices and patterns of care or more rigorous definitions of new cases as a result of improved recording systems, have not been ruled out as an explanation. So far, the case for a true decrease in incidence is suggestive but not proven (Jablensky, 1995).

Much wider variation has been observed for prevalence, which has been more extensively studied. Point prevalence on adults ranges between 1 and 17 per 1000 population, one-year prevalence between 1 and 7.5 per 1000, and lifetime prevalence between 1 and 18 per 1000 (Warner and de Girolamo, 1995). Variations in prevalence can be related to several factors, including differences in recovery, death and migration rates among the affected individuals.

Consistently lower point and period prevalence rates in almost all developing countries have usually been explained by most investigators as due to more favourable course and outcome of the disorder (Leff et al., 1992). However, other factors, such as increased mortality in patients with poor prognosis may contribute as well.

Pockets of high prevalence have been found in small areas of central and northern Europe, in some segregated groups in North America and in some populations living on the margin of the industrialized world, such as indigenous peoples in Canada or Australia (Warner and de Girolamo, 1995). Genetic isolation or selective outmigration of healthier individuals can explain such findings. However, it has been suggested that social disruption caused by the exposure of culturally isolated communities to western lifestyles, may have increased the risk of schizophrenia in vulnerable individuals (Jablensky and Sartorius, 1975). Given the above figures, the number of people with schizophrenia around the world can be estimated at about 29 million, of whom 20 million live in developing or least developed countries.

3.2 Course and outcome

In recent years refinements in methodology have given rise to significant advances in the study of patterns of course and outcome in schizophrenia. This is especially important since the first definitions of the disorder about a century ago relied heavily on deteriorating course and poor outcome as a hallmark (Berrios and Hauser, 1988).

Recent research has focused on prospective studies of representative samples of first-onset cases using standardized assessment tools, well-defined diagnostic criteria and repeated follow-up assessments (Ram et al., 1992; Thara and Eaton, 1996).

The mode of onset can be defined as acute, in which a florid psychotic state develops within days or weeks, or insidious, in which there is a gradual transition from premorbid personality through prodromal symptoms to overt psychotic illness.

Impairment of social and interpersonal functioning prior to the onset of the disorder can be found in up to 50% of patients. The frequency of different types of onset shows marked variations by location. In India and Nigeria acute onset has been observed in 70-80% of patients, in contrast with less than 50% in the United States and Europe (Jablensky et al., 1992).

A tendency to earlier onset in males with a peak incidence in the early twenties in contrast with the late twenties or early thirties in females, has been consistently asserted. However, this assertion is mainly supported by studies that equate age of onset with age of first contact with the treatment system, which can be related to various factors - such as gender differences in symptom severity, illness behaviour or social role expectations, other than true differences in onset. A milder course and better prognosis in females, however, is a well established finding.

Current estimates of the distribution of patients over broad patterns of medium-term course can be summarized as follows: about 45% recover after one or more episodes, about 20% show unremitting symptoms and increasing disability, and about 35% show a mixed pattern with varying degrees of remission and exacerbations of different length.

Such figures, however, hide a wide variation across geographical areas. In the WHO 10-country study at two-year follow-up, the percentage of cases with full remission after a single episode ranged between 3% in the USA and 54% in India, while the cases with continuous psychotic illness varied between 2% in Nigeria and 33% in Japan (Jablensky et al., 1992). A substantial body of evidence shows a more benign course and better outcome in developing countries. This observation, which has been one of the more striking conclusions of WHO studies, has been strengthened by prospective studies with long follow-up carefully conducted in Colombia and India (León, 1989; Thara et al., 1996). This undoubtedly means that environment plays a crucial role as an outcome determinant in schizophrenia. The factors that underlie higher improvement rates in developing countries, however, remain ill-defined, although better tolerance of the sick role, availability of suitable jobs, supportive family attitudes and extended family networks have been suggested as explanations (Leff et al., 1987; Leff et al., 1992; El-Islam, 1982).

Although generally worse than in developing countries, the outcome of schizophrenia in industrialized countries appears nevertheless better than previously described by classical psychiatry. Shepherd et al. (1989) reported the following five-year outcome data for a sample of first admission patients from a defined population in England: 22% had one episode with full remission, 35% several episodes with minimal impairment between episodes, 8% several episodes with continuous impairment, and 35% several episodes with increasing impairment.

Moreover, there is evidence that different dimensions of outcome, such as social functioning, clinical symptoms and cognitive performance, are often only weakly related, showing heterogeneity within individuals and leaving room for improvement in one area even though problems may persist in others (Davidson and McGlashan, 1997).

Given this wide spectrum of outcome, a number of studies tried to identify outcome predictors. Although the course in an individual patient remains very difficult to predict, some well-known features are related to good prognosis:

female gender, late onset, good premorbid social functioning and acute presentation with florid positive symptoms.

The greatest variability in clinical morbidity is found in the initial stages after the onset. After five years the course is less likely to display major fluctuations, although a slight trend towards clinical improvement in old age can be observed (Ciompi, 1980).

The more optimistic picture emerging from recent studies should not, however, lead us to overlook the fact that in about 60% of cases schizophrenia runs a prolonged course.

3.3 Risk factors

Risk factors for schizophrenia can be grouped according to Cooper (1978) in three categories:

- sociodemographic characteristics;
- predisposing factors;
- precipitating factors.

Within the first category, the association between lower social class and schizophrenia in urban areas of developed countries is one of the most robust epidemiological findings. This is currently explained mainly by the *selection-drift hypothesis*, according to which individuals vulnerable to schizophrenia or with insidious onset of the disorder are either prevented from attaining higher class status or move progressively downward (Eaton et al., 1988). However, it is possible that factors related to environmental conditions in lower class neighbourhoods, such as occupational hazards, poor maternal and obstetric care or high psychosocial stressors, can play a role in some subgroups of people with schizophrenia. Moreover, it should be noted that in non-western countries, such as India and elsewhere, the opposite pattern has been observed: prevalence of schizophrenia is greater in highest social groups (Nandi et al., 1980). The complex social class-related factors leading to varying patterns of occurrence of schizophrenia in different countries need further investigation.

The findings for marital status are remarkable as well. The risk ratio for unmarried individuals in comparison with their married counterparts is around 4 (Eaton et al., 1988). Although this is probably related to a selection process analogous to that described for social class, there are some suggestions that marriage, as well as any close interpersonal relationship, could act as a protective factor.

Among the predisposing factors, genetic ones are most important. Genetic contribution to liability for schizophrenia has been well established and is estimated around 60% (Kendler and Diehl, 1993), although models of genetic transmission, predisposing genes and the link between genetic factors and the phenomenology of schizophrenia are far from being identified. Available data

leave considerable room for environmental influences, as shown by concordance rates of less than 50% in monozygotic twins and lifetime risk of about 45% in children of two schizophrenic parents. Only 10% of people with schizophrenia have an affected parent (Gottesman, 1991). Given the heterogeneous nature of schizophrenic disorders, it is also possible that both genetic and non-genetic forms of the disorder exist.

The role of pregnancy and birth complications is less certain. Overall, the evidence suggests that a subgroup of people who later develop schizophrenia will have experienced a greater number of such problems (McNeil, 1995), although the strength of the association is not impressive. Moreover, this can simply be an aspect of a trend towards increased rates of psychopathology in persons who have suffered perinatal damage.

Among the variety of interpersonal, social and cultural variables postulated as precipitating factors, family environment remains the best documented. A large body of research shows that family interaction patterns characterized by unclear or fragmented communication, negative affective style, criticism, hostility and over involvement are strong predictors of relapse in schizophrenia, although evidence of their influence on onset is quite limited (Miklowitz, 1994). There are also indications that other less defined aspects of family environment may exert protective effects on vulnerable individuals (Tienari et al., 1989).

3.4 Comorbidity

In recent years, a number studies of diagnostic patterns in both clinical and community samples have shown that comorbidity among mental disorders is fairly common (Kessler, 1995). Schizophrenia is no exception: the risk in people with schizophrenia of meeting criteria for other mental disorders is many times higher than in the general population. In relation to treatment and prognostic issues, comorbidity with depression and substance abuse is especially relevant.

The percentage of people with schizophrenia showing at any point in time clinically significant depressed mood is at least 25% (Roy et al., 1983). Depressive symptoms can be observed mainly in the early stages of a psychotic relapse or following recovery from psychosis. Patients experiencing depression when in remission from a psychotic episode, at a time of increasing insight into their illness, are at high risk of suicide. This is especially true for young males with good premorbid functioning and high expectations, showing self-reported or perceived hopelessness (Caldwell and Gottesman, 1990).

Substance abuse associated with schizophrenia has emerged over the past few years as a major problem, particularly in western countries. In the United States lifetime prevalence of substance abuse or dependence in persons with schizophrenia has been estimated at over 30% for alcohol and around 25% for illicit drugs (Regier et al., 1990). Prevalence of smoking has been reported at

well above 50% (Masterson and O'Shea, 1984). There is some evidence that people with schizophrenia prefer, if available, activating drugs such as amphetamines, cocaine, cannabis and hallucinogens (Schneier and Siris, 1987).

The impact of comorbidity with substance abuse is significant in reducing treatment effectiveness, worsening positive psychotic symptoms, increasing social disability and raising the likelihood of violence (Cuffel et al., 1994).

Although medical comorbidity has been less investigated and is still often neglected, there is evidence that medical diseases, particularly if they run a chronic course, can be a serious problem in schizophrenia patients, leading to more morbidity and mortality. This is particularly the case for cardiovascular diseases (Jeste et al., 1996). Finally, in recent years HIV infection has been reported with increasing frequency, prevalence rates being around 7% (Sewell, 1996).

Chapter 4
Consequences of schizophrenia

4.1 Mortality

Although schizophrenia is not in itself a fatal disease, death rates of people with schizophrenia are at least twice as high as those in the general population. The excess mortality has been related in the past to poor conditions of prolonged institutional care, leading to high occurrence of tuberculosis and other communicable diseases (Allebeck, 1989). This may still be an important problem wherever large numbers of patients spend a long time in crowded asylum-like institutions.

However, recent studies of people with schizophrenia living in the community showed suicide and other accidents as leading causes of death in both developing and developed countries (Jablensky et al., 1992). Suicide, particularly, has emerged as a growing matter of concern, since lifetime risk of suicide in schizophrenic disorders has been estimated at above 10%, which is about 12 times that of the general population (Caldwell and Gottesman, 1990). There seems to be an increased mortality for cardiovascular disorders as well (Allebeck, 1989), possibly related to unhealthy lifestyles, restricted access to health care or the side-effects of antipsychotic drugs.

4.2 Social disability

According to the *International classification of impairments, disability and handicaps* (WHO, 1980) impairment represents any loss or abnormality of psychological, physiological or anatomical structure or function, while disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for an individual in his or her socio-cultural setting.

In mental disorders, such as schizophrenia, disability can affect social functioning in various broad areas (Janca et al., 1996), namely:

- self-care, which refers to personal hygiene, dressing and feeding;
- occupational performance, which refers to expected functioning in paid activities, studying, homemaking;
- functioning in relation to family and household members, which refers to expected interactions with spouses, parents, children or other relatives;
- functioning in a broader social context, which refers to socially appropriate interaction with community members, and participation in leisure and other social activities.

Data from European and North American studies show persisting disability of moderate or severe degree in about 40% of males with schizophrenia, in contrast with 25% of females (Shepherd et al., 1989). Substantially lower figures have been found in India, Africa and Latin America (Leff et al., 1992). Global assessment of disability, however, hides wide variations across life domains, which can be affected in different ways.

There is good evidence that for most patients nature and extent of social disability are more relevant as outcome indicators than clinical symptoms.

4.3 Social stigma

Social stigma refers to a set of deeply discrediting attributes, related to negative attitudes and beliefs towards a group of people, likely to affect a person's identity and thus leading to a damaged sense of self through social rejection, discrimination and social isolation (Goffman, 1963). Stigma is strongly linked with the label of mentally ill and is, to a certain extent, unrelated to the actual characteristics or behaviours of those stigmatized. Various adverse consequences may arise from the stigmatization process: use of pejorative language, barriers to housing or employment, restricted access to social services, fewer chances for marriage, increased mistreatment and institutionalization (Desjarlais et al., 1995).

Stigma is deeply rooted in the cultural background of society. Some observers have pointed out that it is less pervasive in most rural societies (Warner, 1985), but this assumption has been challenged by cross-cultural studies (Fabrega jr., 1991). There is no convincing evidence that there are cultures in which stigma is not attached to major mental disorders, whatever theories people hold about their causes, although the process of negative labelling may concern different groups across cultures and the level of stigma may vary.

Stigma operates however, not only in the larger community but within the mental health services as well. It may even be found at the level of the affected individuals as internalized negative self-perception (Carling, 1995).

Undoubtedly, stigma represents a major challenge with regard to the integration of persons with schizophrenia and other mental disorders into the community. Many first-person accounts from people with experience of mental disorder vividly portray the painful effects of stigmatization on their everyday lives (Leete, 1982).

Stigma also acts as a powerful barrier to treatment, not only because of the fear of being labelled as mentally ill, but also because too often mental health professionals and mental health services as a whole hold, often in a subtle way, negative or rejecting attitudes towards users and perpetuate practices fostering segregation, dependency and powerlessness (Deegan, 1990).

4.4 Impact on caregivers

The available data show that the proportion of persons with schizophrenia living with their relatives ranges between 40% in United States to more than 90% in China (Torrey and Wolfe, 1986; Xiong et al., 1994). Moreover, family involvement and distress is not necessarily lower when the sufferer lives away from home (Winefield and Harvey, 1993). Nevertheless, the burden that is often placed on families or others living in close contact with a mentally ill person has only recently been recognized (Fadden et al., 1987).

Various aspects of impact on caregivers should be considered, including:

- the economic burden related to the need to support the patient and the loss of productivity of the family unit;
- emotional reactions to the patient's illness, such as guilt, a feeling of loss and fear about the future;
- the stress of coping with disturbed behaviour;
- disruption of household routine;
- problems of coping with social withdrawal or awkward interpersonal behaviour;
- curtailment of social activities.

Various aspects of the caregiver's burden have been reported across a variety of geographical and social settings. Financial loss associated with schizophrenia has been noticed in countries as different as Laos and United Kingdom (Westermeyer, 1984; Davies and Drummond, 1994).

The manifold facets of burden hinder any overall evaluation, making it difficult to identify factors that are likely to influence it. A summary list includes patients' and caregivers' characteristics, family size and economic status, role expectations and illness-related beliefs. Such wide variability, combined with cross-cultural differences, leads to estimates of prevalence of family burden ranging between 30% and 80%.

There is a widely held belief that distress is more often related to patients' apathy, inactivity or failure to comply with social duties, than with more evident positive psychotic symptoms or behavioural disturbances (Leff and Vaughn, 1985). However, this may not be true in all social or cultural groups. According to a recent survey in Malaysia, in which subjective emotional burden has been found in 41% of families, hostility, violence and disruption of family activities was perceived as the main source of stress (Salleh, 1994).

4.5 Social costs

In recent years a major effort has been made towards the quantification of the global social burden of all illnesses and injuries, taking into account not only mortality but the extent of disability and allowing comparisons between

different categories of illness. The measure of disability-adjusted life years (DALYs) lost has been used as a health status indicator (Murray and Lopez, 1996). Although this approach may not be completely suitable for most mental disorders, including schizophrenia, because of their variable course and the fluctuating nature of the related disability, it enables social scientists and policy-makers to put the burden associated with schizophrenia within a comprehensive public health framework.

The loss in DALYs caused by schizophrenic disorders worldwide was estimated in 1990 at slightly below 13 million, which represents about 1% of the global burden of the disease deriving from all causes. Schizophrenia is 26th in the list of the diseases, ranked according to their contribution to the overall burden. However, if one takes into account the predicted modifications in social structure in most developing countries and the increase of populations at risk over the coming decades, schizophrenia is projected to be in 20th position by the year 2020, with more than 17 millions of DALYs lost, accounting for 1.25% of the overall burden (Murray and Lopez, 1996).

Estimates of economic costs of schizophrenia are available only for some industrialized countries. A broad distinction should be made between direct costs, i.e. money spent on providing care to affected individuals, and indirect costs, i.e. loss of resources and productivity due to morbidity and mortality. Direct costs of schizophrenia in western countries range between 1.6% and 2.6% of total health care expenditures, which in turn account for between 7% and 12% of the gross national product. This means £396 million in the United Kingdom and $18 billion in the United States (National Advisory Mental Health Council, 1993; Davies and Drummond, 1994). These costs, however, are very unevenly distributed among subgroups with differing severity of the disorder. According to a British study, if we consider a sample of people with schizophrenia from onset to death, it can be estimated that care of patients with long-term disabling course (which represent only 10% of the affected population) will absorb about 80% of the total lifetime direct costs. About 75% of these high costs are due to inpatient or residential care, while drugs represent less than 5% (Davies and Drummond, 1994). Therefore, any strategy aimed at reducing the costs of care for schizophrenia should target the small group of most disabled patients in order to improve, as far as possible, their independent living skills.

Less reliable data are available on indirect costs, which are much more difficult to assess and probably show more variation. They have been estimated at slightly below the direct costs in the United States and, in contrast, four times the direct costs in the United Kingdom.

An analysis conducted in the United States showed that the economic impact of schizophrenia, taking into account both direct and indirect costs, is close, in terms of per capita estimates, to that of a well known chronic disease such as diabetes. However, higher indirect costs indicate that prospects for potential gains by reducing morbidity and mortality through treatment are greater for schizophrenia than for diabetes (Report of the National Advisory Mental Health Council, 1993).

Chapter 5
Prevention, treatment and care

5.1 Preventive interventions

Primary prevention refers to an intervention that is intended to reduce the incidence of an illness in a population which is as yet unaffected by the disease. Two broad primary preventive strategies can be used within a public health framework: illness prevention and health promotion (Eisenberg, 1993). Illness prevention aims to establish specific interventions for specific disorders by modifying one or more risk factors, while health promotion aims to enhance health-promoting behaviours in the community to maintain well-being and prevent the onset of broad groups of disorders.

Secondary prevention aims at early identification of individuals with prodromal or early symptoms of an illness to reduce morbidity through prompt treatment.

A distinction between primary and secondary prevention depends on accurate knowledge of the natural history of the illness, with clear detection of prodromes, precursors and full-blown symptoms. At some point in time, when the onset of a disorder becomes inevitable, preventive strategies conceptually shift from primary to secondary (Eaton et al., 1995).

The complex multifaceted interplay that underlies the onset of schizophrenia, the low specificity of risk factors and prodromal symptoms, the lack of reliable methods to assess vulnerability to the disorder, and the uncertainties surrounding the pictures of its early course limit the development of targeted preventive interventions. Although the role of genetic transmission in liability to schizophrenia has been well documented, incomplete penetrance, the probable existence of non-genetic forms of the disorder and the absence of genetic markers make genetic risk prediction highly inaccurate. Moreover, only a small minority of people who develop schizophrenia come from families with a relative who is also affected. Such problems, in addition to ethical considerations, rule out the feasibility of genetic counselling.

It can be assumed that the prevention of obstetric complications, through the establishment of safer conditions for pregnancy and childbirth, could make a small contribution to the reduction of risk of schizophrenia, as well as of many other mental and neurological disorders. No data, however, are available to support this assumption.

Models for a psychosocial approach to the prevention of schizophrenia have recently been advocated (Laporta and Falloon, 1992; Birchwood et al., 1997). They involve various combinations of the following strategies:

- community education programmes about psychoses;
- integration of mental health services in primary care;
- detection by general practitioners and other community agencies of early warning signs of severe mental disorder;
- intensive home-based assessment and interventions targeted at people at risk and key persons in their social networks to enhance stress management strategies and problem-solving skills.

The underlying hypothesis is that the development of health-promoting coping attitudes in people showing at-risk mental states and in their social environment could prevent the onset of overt schizophrenic disorders, even through non-specific interventions. Moreover, active treatment can be started quickly if frank psychosis occurs.

Such approaches deserve attention insofar as they focus on the primary health care setting, thus reducing the stigma associated with psychiatric services and facilitating access to early treatment. All such aspects are particularly important, given that the treatment lag in first-episode schizophrenia has been estimated at one year or even more (Birchwood et al., 1997). Their value as truly preventive strategies, however, remains so far uncertain. More research is needed in this area.

5.2 Drugs

The place of medications in the treatment of schizophrenia has been firmly established for some 40 years. Given the recent advances in psychopharmacology, it is useful to distinguish between conventional and atypical antipsychotic drugs.

Most conventional antipsychotic drugs in common use are listed in Table 2. Although their chemical structures vary widely, their common mode of action is to block dopamine D_2 receptors mostly in mesolimbic and nigrostriatal brain areas. Their activity on psychotic symptoms is probably related to their action in the mesolimbic system. Although many are available, none has been shown to be more effective than any other, although for unknown reasons a particular patient may respond to one drug and be unimproved or even made worse by another.

Evidence for their efficacy in reducing acute positive symptoms (not only in schizophrenia, but in any disorder with psychotic features) is clear-cut, while their impact on negative symptoms looks modest. Findings from a large number of clinical trials indicate a substantial improvement within 6-14 weeks in 75% of patients with acute symptoms of schizophrenia treated at a dosage of 300-750 mg of chlorpromazine equivalents, in comparison with less than 25% treated with placebo (Dixon et al., 1995). Their efficacy in preventing relapse or recurrence after clinical remission, although well established, is less impressive. Risk of relapse during the first year following an acute episode in patients on antipsychotic medications is reduced to about 20%, in comparison with about 60% on placebo.

Data for more than one year are quite limited and relapse rates on placebo and on medications may become similar after two or three years. Therefore, drug therapy delays but does not suppress relapses. There is no consensus on how long treatment should be continued following an acute episode. For first-episode patients, in case of full remission, it has been suggested that medication should be tapered or discontinued within six months to two years (Dixon et al., 1995). For patients with multiple episodes or who show incomplete remission, there are no agreed guidelines; decisions about medication should be made on individual basis, balancing the costs and benefits of treatment.

With respect to maintenance doses, concern about unnecessary exposure to high amounts of medication, resulting in risk of tardive dyskinesia and other side-effects, led to the development of methods for determining the lowest effective dose. Two approaches are the focus of interest: targeted and low-dose strategies. So far, the use of low-dose strategy seems best supported by research (Schooler, 1991). In fact, the benefits of such drugs in real practice are limited by a number of problems.

Table 2. Conventional antipsychotic drugs

Class and generic name	Relative potency
Phenotiazines	
Chlorpromazine*	100
Thioridazine	100
Prochlorperazine	15
Perphenazine	10
Trifluoperazine	5
Triflupromazine	25
Fluphenazine	2
Fluphenazine decanoate[1]*	—
Thioxanthenes	
Thiothixene	5
Chlorprothixene	100
Flupentixol	2
Zuclopentixol	2
Butyrophenones	
Haloperidol*	2
Haloperidol decanoate[1]	-
Pimozide	2
Droperidol	4
Dibenzoxazepines	
Loxapine	10
Dihydroindolones	
Molindone	10

* Included in the World Health Organization's essential drugs list (WHO Expert Committee on the Use of Essential Drugs, 1995)

[1] Long-acting injectable preparations.

First of all, these drugs induce side-effects that are often distressing and sometimes dangerous. The most common are:

- sedation;
- extrapyramidal side-effects, such as tremors, acute dystonias, akathisia, akinesia, stiffness and shuffling gait;
- tardive dyskinesia;
- anticholinergic effects, such as dry mouth, blurred vision, urinary hesitancy, constipation;
- cardiovascular effects, such as tachycardia and postural hypotension;
- endocrine effects, such as amenorrhea, galactorrhea, breast enlargement in women and gynecomastia in men;

- weight gain;
- skin and eye effects, such as cutaneous rash, photo toxic skin reactions, pigmentary changes in skin, granular deposits in the cornea and lens;
- neuroleptic malignant syndrome, which is a rare but serious and potentially fatal complication. It is an idiosyncratic reaction, presenting initially as muscular rigidity and progressing to high fever, fluctuating consciousness and unstable vital signs. Mortality has been reported in 20% of cases (Guze and Baxter jr., 1985).

Although most side-effects are mild and time-limited, some represent serious problems and deserve special attention. Akathisia and other extrapyramidal symptoms, occurring to some degree in up to 70% of patients, are associated with considerable subjective distress that includes restlessness, anxiety, irritability and inability to feel comfortable. Some reports suggest that severe akathisia can result in aggressive or suicidal acts (Van Putten and Marder, 1987).

Tardive dyskinesia is a severe complication of long-term use of antipsychotics, characterized by a wide range of abnormal involuntary movements involving mouth, tongue, jaw or any other part of the body. Dyskinesia can be seriously disabling in its more severe forms and may affect walking, eating and breathing. Its incidence has been estimated at around 4% per year for 5-6 years of drug exposure and its prevalence in patients on maintenance treatment has been estimated to be at least 20% (Kane et al., 1988).

The effects of extrapyramidal symptoms and abnormal movements go beyond their medical consequences. According to research findings, strengthened by the personal accounts of patients, they may add to negative symptomatology even when unnoticed by clinicians and may impair, in more or less subtle ways, interpersonal skills (Estroff, 1981).

Treatment resistance is another relevant issue. Current data suggest that between 20-30% of patients fail to respond to acute treatment and the same proportion will relapse despite adequate maintenance therapy (Kane, 1996). No conclusive explanations are available for this finding.

Poor compliance with drug prescription is fairly common in the treatment of schizophrenia: about 50% of outpatients and 20% of inpatients fail to take prescribed medications. Even highly supervised settings and the use of depot injections cannot resolve the problem (Young et al., 1986). Explanations offered for noncompliance centre on several areas: staff-patient conflict, adverse reactions to drugs and side- effects, lack of insight due to psychotic disorder, inadequate information on drugs, and the patients' negative view of medications (Estroff, 1981).

Although any explanation, or combination of explanations, may be true for a single patient, the issue of compliance points to a major limitation of antipsychotics: the active refusal by a number of users to take medications and the unpleasant feelings and discomfort reported even by some who comply,

willing or not, with treatment. Such problems, overlooked by most clinical trials, came only recently to the attention of researchers and clinicians (Awad, 1992). Health professionals should listen carefully to the subjective experience associated with medications to discuss in a collaborative way with users issues related to long-term drug treatment.

In recent years great hopes have been raised by the introduction of so-called "new" or "atypical" antipsychotics, deemed free from most of the shortcomings of conventional ones. Atypical antipsychotics share two common features: action on mesolimbic neurons with little effect on nigrostriatal neurons, and higher 5-HT_2 than D_2 receptors affinity. This implies an effect on psychotic symptoms with a low incidence of extrapyramidal side-effects.

Clozapine is the first atypical antipsychotic to be introduced. It has been found to be as effective as antipsychotics on positive symptoms in both acute and maintenance treatment. Further, it has been found effective in improving psychotic symptoms in some 30-60% of schizophrenia patients who failed to respond to adequate dosage of conventional antipsychotics, and it is associated with a greatly reduced likelihood of developing extrapyramidal symptoms, neuroleptic malignant syndrome or tardive dyskinesia (Buchanan, 1995).

However, clozapine produces other serious side-effects. It is associated with a risk of agranulocytosis of 1-2%, which is most likely to occur within the first six months of treatment. Because agranulocytosis can be fatal if not detected and requires immediate discontinuation of the drug, patients on clozapine must undergo monitoring of white blood cell count weekly for the first 18 weeks and subsequently every four weeks as long as they take the drug. Other unwanted effects include seizures in up to 10% of patients, weight gain, hypotension, tachycardia and sedation.

Clozapine is very expensive: the average annual cost per patient has been estimated at around £2000 in the United Kingdom and $8500 dollars in the USA, i.e. 10 or more times higher than the cost of standard drugs (Fitton and Benfield, 1993). Although preliminary studies suggest that clinical benefits may lead to medium-term cost savings, primarily by reducing hospitalization, more investigations are needed to clarify this important issue. Moreover, it should be remembered that cost-benefit analyses can hardly be generalized across social and health care systems.

The need for regular blood sampling clearly limits the use of clozapine and may seriously affect patients' adherence to treatment, as shown by noncompliance rates of up to 50% found in some studies (Hirsch and Puri, 1993). The complexity of clozapine therapy seems at odds with the flexibility and easy access to treatment required by community care.

Other atypical antipsychotics that are currently being marketed or developed include risperidone, olanzapine and quetiapine (Pantelis and Barnes, 1996). Some promising data are available on risperidone, although further research is necessary to assess its efficacy both as a maintenance treatment and in non-responders. It

does not carry a risk of agranulocytosis but it induces dystonias and akathisia above a certain dose level. High cost is a problem with risperidone as well, as it will probably be for any other novel antipsychotic.

In summary, atypical antipsychotics represent to some extent the first innovation in biological treatment of psychoses in 40 years. However, many factors limit their widespread use at present. In the near future we shall see whether today's promises will be kept.

5.3 Family interventions

The causal role of dysfunctional child-rearing patterns and disturbed family communication was a cornerstone of early social theories of schizophrenia between the 1950s and the late 1970s. Such theories, although weakly supported by empirical data, enjoyed wide popularity among professionals, particularly in the USA and other western countries, unfortunately contributing to negative attitudes towards patients' relatives and adversarial relationships between professionals and families.

Subsequent research moved away from ambitious causal explanations to identify, within the framework of studies of expressed emotion, factors related to family interaction and family members' beliefs and expectations that are likely to influence the course of schizophrenia, and other mental and physical disorders (Leff and Vaughn, 1985).

This approach resulted in the development of family-based interventions designed to enhance the resources of the family unit in its caring function, relieve family burden, and modify family interactions and affective attitudes predictive of relapse. Such interventions, variously called "psychoeducational", "supportive" or "behavioural", share some common elements (Goldstein, 1995), namely:

- engagement of the family early in the treatment process in a "no fault" atmosphere;
- education about schizophrenia (the vulnerability-stress model, risk factors, variation in prognosis, rationale for various treatments, suggestions for coping with the disorder);
- communication training directed at enhancing the clarity of communication and improving the exchange of both positive and negative feedback within the family;
- problem-solving training aimed at improving ways of managing everyday problems, coping with stressful life events, and planning to deal with anticipated stressors, by generalizing problem-solving skills;
- crisis intervention at times of extreme stress or when signs of relapse are evident.

A number of studies conducted in various geographical and cultural settings show that the inclusion of culturally sensitive family interventions in the comprehensive care of people with schizophrenia significantly reduces the risk of relapse and increases patients' and relatives' satisfaction with service.

It is worth noting that some clinical trials supporting this evidence have been conducted in developing countries, such as China (Xiong et al., 1994). In fact, in many cultures in Africa, Asia and Latin America families do represent the core community support system and family members have always been considered primary caregivers for their ill relatives. Therefore, collaboration between them and health professionals has been the rule and conflicting relationships have rarely developed (Menon and Shankar, 1993).

The identification of family intervention as an important component of community care entails a conceptual and practical shift: family intervention should now be viewed, in most cases, as a long-term support rather than as a short time-limited treatment (Dixon and Lehman, 1995).

5.4 Other psychosocial interventions

For several decades insight-oriented long-term psychodynamic psychotherapy, stemming from the psychoanalytic tradition, has been the mainstay, particularly in France, the USA and to a lesser extent other European countries, of the psychological approach to treatment of schizophrenia. The psychodynamic model enjoyed high status and heavily influenced the training and professional attitudes of many clinicians, although it has never been within easy reach for the average patient. Over the last 20 years disappointing results of carefully designed clinical trials, high costs and limited flexibility and adaptability to community settings, led to widespread dissatisfaction with exploratory psychodynamic psychotherapy (Mueser and Berenbaum, 1990). Attention shifted to a variety of other psychosocial interventions, deriving from cognitive-behavioural models or developed within the framework of psychosocial rehabilitation.

Direct treatment of cognitive functioning through structured psychological interventions has been recently introduced as a byproduct of neuropsychological studies of schizophrenia. The goal is to remedy problems of basic information-processing skills, such as memory, attention and conceptual abilities. So far, no consistent conclusion can be drawn about the efficacy of such an approach, which has to be considered in the early stages of development. Moreover, it is uncertain to what extent improvements in the basic domains of cognitive functioning, detected by neuropsychological tests, can affect more complex social performances (Penn and Mueser, 1996).

Another, perhaps more relevant, cognitive approach focuses on subjective response to dysfunctional thoughts or perceptions. It attempts to modify beliefs associated with delusions and ways of coping with auditory hallucinations. The strength of this model lies in its purpose, which is to build on natural coping strategies already used by people with schizophrenia when faced with positive symptoms, thus linking professional intervention with self-help efforts. Moreover, it emphasizes that psychotic symptoms lie on a continuum of differences in thought or behaviour and do not arise from fundamentally different psychological processes, challenging a long-held belief about the

discontinuity between schizophrenia and ordinary experience (Chadwick et al., 1996). Preliminary results show that such techniques have promise. We should, however, await further investigations with more subjects across different settings (Penn and Mueser, 1996).

Other interventions are usually included under the heading of psychosocial rehabilitation and sometimes psychosocial rehabilitation itself is referred to as an intervention. This is misleading because psychosocial rehabilitation is not a technique, or a set of techniques, but an overall strategy encompassing not only health services but also legislation, social policy and economy (WHO, 1996).

It is more appropriate, therefore, to present such interventions, which are primarily addressed at the reduction of some aspects of disability and handicap associated with schizophrenia, as components of overall rehabilitation packages.

Social skills training refers to a class of interventions, based on social learning theories, that aim to teach the perceptual, motor and interpersonal skills deemed relevant to achieving community survival, independence and socially rewarding relationships. Complex behaviours are assessed and broken down into smaller discrete components taught through various behavioural techniques such as problem specification, instruction, modelling, role playing, behavioural rehearsal, coaching, reinforcement, structured feedback and homework assignment. The focus of social skills training programmes has recently moved from topographical features of overt behaviour to a more comprehensive range of communication and independent living skills (Halford and Hayes, 1992).

There is little doubt that people with schizophrenia can learn a variety of social skills, ranging from simple motor behaviours to more complex ones such as assertiveness and conversational skills. The improvement is evident for specific behavioural performances but is less pronounced for interpersonal and daily living skills. However, it remains unclear whether such effects transfer from the training environment to everyday life. Furthermore, the impact of social skills training on aspects of patients' outcome has not yet been demonstrated (Penn and Mueser, 1996).

Changes in social skills training methods, including implementation in natural settings by utilization of cues and prompts in everyday life, are probably necessary to overcome such limitations. Vocational rehabilitation has a long history and has traditionally been provided through hospital or clinic-based workshop activities. However, the value of such an approach has been questioned on the basis of consistently negative data on patients' employment following discharge. A subsequent evolution of the field, i.e. sheltered employment programmes, also failed to show any impact on employment outside the sheltered environment (Lehman, 1995).

More promising recent developments include vocational training linked to supported employment (Lehman, 1995) and the creation of self-sufficient enterprises to ensure permanent jobs for disabled people organized in a flexible way as workers' cooperatives, known in Italy *as social enterprises* (Savio and Angelo, 1993).

In judging the value of vocational rehabilitation, the patients' social context is of paramount importance. As previously stated, there are suggestions that in predominantly agrarian societies the greater availability of job opportunities provides grounds for people's reintegration into the labour market even without formal vocational rehabilitation programmes.

At the end of this review on psychosocial interventions it should be remembered that the failure of psychodynamic therapies to show their effectiveness should not tarnish the importance of the psychodynamic contribution in contacting the inner world of psychotic experience and building the supportive interpersonal relationship that is the core of any effective intervention.

Chapter 6
Service delivery

Any health care intervention takes place within the context of a service delivery system. For schizophrenia, ways of providing care, treatment settings and service organization are probably more important as outcome determinants than any single treatment modality. A few decades ago, care for schizophrenia was almost exclusively delivered in large institutions where most patients spent years. The negative effects of such an environment, particularly on social outcomes, have been well documented since the 1960s (Wing and Brown, 1970). Although custodial care is still a reality for many patients around the world, a broad array of community-based care services are currently judged by widespread opinion to be the best context for service delivery to people with schizophrenia (Santos et al., 1995).

Advanced models of community care have been described and implemented, to a greater or lesser extent, in countries as diverse as Australia (Hambridge and Rosen, 1994), France (Kovess et al., 1995), India (Menon and Shankar, 1993), Italy (Lesage and Tansella, 1993), the United Kingdom (Marks et al., 1994), the USA (Test, 1992) and many others. Although such models are known by a variety of names ("assertive community treatment", "training in community living", "community support programme", "assertive outreach", "continuous treatment teams", "comprehensive community care" and so on) and differ in many ways in relation to social, cultural and economic characteristics of the countries concerned, they share at least most of the following core elements (Santos et al., 1995):

- services are offered to the whole population in a well-defined catchment area;
- services are based on needs assessment and provide individualized treatment aimed at empowering users and building on their assets and strengths;
- services are primarily targeted at the most disabled and seriously ill patients;
- continuity of care over time and across treatment settings is provided;
- services are outreach-oriented, available where they are needed for as long as they are needed, preferably in the users' social environment;
- services are offered in the least restrictive setting and long-term hospitalization is avoided as far as possible;
- services are part of mainstream health services and are closely linked with primary health care;
- social and vocational rehabilitation is provided in a natural environment;
- service providers are accountable to the users and are monitored to ensure quality of care and relevance to users' needs;

- users and their caregivers are involved in planning, implementing and evaluating services;
- components of services include patient identification, crisis intervention and acute hospital admission, residential facilities, a full range of mental health care interventions, medical care, assistance with housing, income support, family and social support, and assistance with instrumental functioning in areas of work, social relations, leisure and daily living activities through skill teaching, support, environmental modifications and advocacy.

The above elements are steadily updated by ongoing innovations and the addition of new strategies. They need to be put in the conceptual framework of a biopsychosocial model of schizophrenia, which should be an integral part of the education and training of health and social professionals.

The balance of service provision between the primary care and specialist sectors or between direct care provision and the use of natural social networks, the range and type of professionals involved, and also the funding strategies will depend on the local conditions. Evidence from various countries is available to support both the feasibility and the benefits of comprehensive community care for people with schizophrenia and other severe mental disorders (Santos et al., 1995).

Last, but not least, no service, even one offering the most updated treatments, will ever be effective in the absence of major efforts to challenge, through political action and public education, the stigma associated with mental disorders and psychiatric treatment.

Chapter 7
Conclusion

Schizophrenia is a disorder associated with high levels of social burden and cost, as well as an incalculable amount of individual pain and suffering. However, there is evidence that the outcome of care can be as successful as it is in many other diseases treated by medical or surgical procedures (National Advisory Mental Health Council, 1993).

Implementation of an effective care system for schizophrenia, however, is more than a technical endeavour. It has to be sustained by a vision and must be put within a unifying overall frame of reference. The vision can be that of a *recovery-oriented mental health system*, i.e. a service oriented to promote recovery from mental disorders by fostering self-esteem, adjustment to disability, empowerment and self-determination (Anthony, 1993). *Psychosocial rehabilitation* can provide this vision with a frame of reference, linking mental health services to a complex and ambitious social perspective that encompasses different sectors and levels, from hospitals to homes and work settings, with a central aim of ensuring full citizenship for people irrespective of their disabilities (WHO, 1996).

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