CHAPTER 1

INTRODUCTION

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INTRODUCTION

Mental, physical and social health, are vital strands of life that are closely interwoven and deeply interdependent. Mental health is crucial to the overall well-being of individuals, societies and countries. Mental illness refers collectively to all of the diagnosable mental disorders. Mental disorders are characterized by abnormalities in cognition, emotion or mood, or the highest integrative aspects of behaviour, such as social interactions or planning of future activities. Mental and behavioural disorders are not exclusive to any special group: they are found in people of all regions, all countries and all societies. People with these disorders are often subjected to social isolation, poor quality of life and increased mortality. These disorders are the cause of staggering economic and social costs. About 450 million people suffer from mental disorders according to estimates given in WHO’s World Health Report 2001. One person in four will develop one or more mental or behavioural disorders during their lifetime (WHO, 2001). Mental and behavioural disorders are present at any point of time in about 10% of the adult population worldwide. One fifth of teenagers under the age of 18 years suffer from developmental, emotional or behavioural problems, one in eight have a mental disorder; among disadvantaged children the rate is one in five. Mental and neurological disorders account for 13% of the total Disability Adjusted Life Years (DALYs) lost due to all diseases and injuries in the world (WHO, 2004). Five of the ten leading causes of disability worldwide are
psychiatric conditions, including depression, alcohol use, schizophrenia and compulsive disorder (Murray & Lopez, 1996).

This chapter attempts to draw the study scenario in detail. The contents of the chapter delineate the concepts of mental health and mental illness, historical development in the understanding of the concepts, an overview of epidemiological trends in severe mental disorders, a brief account of treatment approaches, an overview of homelessness, theoretical framework of psychosocial rehabilitation, rehabilitation of homeless mentally ill and rehabilitation outcomes and voluntary efforts in rehabilitation of homeless mentally ill. This chapter also throws light into the significance of the study.

1.2 Mental Health & Mental Illness

1.2.1 Overview

Mental health includes subjective well-being, perceived self-efficacy, autonomy, competence, intergenerational dependence, and self-actualization of one’s intellectual and emotional potential, etc.

Mental illness or mental disorder is a health problem that significantly affects how a person feels, thinks, behaves, and interacts with other people. It is diagnosed according to standardized criteria. A mental health problem also interferes with how a person thinks, feels, and behaves, but to a lesser extent than a mental illness. Mental health problems are more common and include the mental ill health that can be experienced temporarily as a reaction to the stresses of life. Mental
health problems are less severe than mental illnesses, but may develop into a mental illness if they are not effectively dealt with.

“Mental health” and “mental illness” are considered as points on a continuum. Mental health is a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity. Mental health is indispensable to personal well-being, family and interpersonal relationships, and contribution to community or society.

Mental disorders are broadly classified as psychotic and neurotic disorders. The psychotic disorders like schizophrenia, bipolar affective disorders etc. run a chronic course and causes significant disability to the patient and distress to the care givers. The persons with psychotic illness will not have insight to their disease and would loose touch with reality. Neurotic mental disorders are minor mental illnesses and are milder in form and cause distress to the person affected and usually less disabling. The common types of neurotic mental disorders are Anxiety, Obsessive Compulsive Disorder, Panic Attacks etc. The ICD -10 (1992) and DSM –IV TR (2004) gives a detailed account of the classification of mental disorders.

1.2.2 Etiological Factors

The broad forces that cause mental disorders are biological, psychological, and social/cultural factors. Mental disorders are often
considered as a product of the *interplay* or *interaction* between biological, psychological, and socio-cultural factors. For some disorders, a biological predisposition is necessary but not sufficient to explain their occurrence. For other disorders, a psychological or socio-cultural cause may be necessary, but again not sufficient.

According to Engel’s model, biopsychosocial factors are involved in the causes, manifestation, course, and outcome of health and disease, including mental disorders (Engel G, 1977)\(^4\).

**1.2.3 Public Perceptions about Mental Illness**

The public perception on mental disorders has varied over time. In the 1950s, the American public viewed mental illness as a stigmatized condition and displayed an unscientific understanding of mental illness. Survey respondents typically were not able to identify individuals as “mentally ill” when presented with vignettes of individuals who would have been said to be mentally ill according to the professional standards of the day. The public was not particularly skilled at distinguishing mental illness from ordinary unhappiness and worry and tended to see only extreme forms of behaviour—namely psychosis—as mental illness. Mental illness carried great social stigma, especially linked with fear of unpredictable and violent behaviour (Veroff et al., 1981)\(^5\).

By 1996, a modern survey conducted in United States, revealed that people had achieved greater scientific understanding of mental illness. But the increases in knowledge did not defuse social stigma
The public learned to define mental illness and to distinguish it from ordinary worry and unhappiness. It expanded its definition of mental illness to encompass anxiety, depression, and other mental disorders. The public attributed mental illness to a mix of biological abnormalities and vulnerabilities to social and psychological stress. Yet, in comparison with the 1950s, the public’s perception of mental illness more frequently incorporated with violent behaviour (Phelan et al., 1997)\textsuperscript{6}. This was primarily true among those who defined mental illness to include psychosis (a view held by about one-third of the entire sample). The perception of people with psychosis as being dangerous is stronger today than in the past.

Stigma appears to be strong despite better public understanding of mental illness. This is attributed to the fear of violence: people with mental illness, especially those with psychosis, are perceived to be more violent than in the past (Phelan et al., 1997)\textsuperscript{6}.

1.2.4 Stigma and Seeking Help for Mental Disorders

Stigma related to mental disorders discourages a vast majority of persons with diagnosable mental disorders to seek treatment. Stigma surrounding the receipt of mental health treatment is among the many barriers that discourage people from seeking treatment and shown that nearly two-thirds of all people with diagnosable mental disorders do not seek treatment (Sussman et al., 1987\textsuperscript{7}; Cooper-Patrick et al., 1997\textsuperscript{8}, Regier et al., 1993\textsuperscript{9}; Kessler et al., 1996\textsuperscript{10}). Concern about
stigma appears to be heightened in rural areas in relation to larger towns or cities (Hoyt et al., 1997)\textsuperscript{11}.

1.2.5 Epidemiology of Mental Illness

1.2.5.1 Global Scenario:

According to WHO data, at least 40 million people suffer from severe mental disorders such as schizophrenia and severe depression. There are no demonstrable differences in figures between developing and developed countries. Disability associated with mental disorders ranks among the most widespread and severe of public health problems (WHO 2005)\textsuperscript{12}. The prevalence of Schizophrenia varies from 2-3/1000 all over the world.

1.2.5.2 Indian Scenario:

Indian studies revealed similar rates of prevalence of Schizophrenia ranging from 0.9 to 4.3/1000 (Sethi, et al., 1967\textsuperscript{13}, 1972\textsuperscript{14}; Dube, 1970\textsuperscript{15}; Elnagar, 1971\textsuperscript{16}). The estimates of incidence of Schizophrenia in India showed 3/10,000 in urban slums (Rajkumar, 1995\textsuperscript{17}); 4.4/10000 in rural areas and 3.8/10000 in urban areas (Wig et al, 1980\textsuperscript{18}). The above estimate amounts to approximately two million persons suffering schizophrenia at any given point of time.

A meta-analysis of 13 psychiatric epidemiological studies (n=33 572) yielded an estimated prevalence rate of 5.8\% (Reddy & Chandrasekhar, 1998\textsuperscript{19}). Organic psychosis (0.04\%), alcohol/drug dependence (0.69\%), schizophrenia (0.27\%), affective disorders (1.23\%), neurotic disorders (2.07\%), mental retardation (0.69\%) and
epilepsy (0.44%) were commonly diagnosed. Psychiatric morbidity was associated with residence (urban), gender (females), age group (35-44 years), marital status (married/widowed/divorced), socio-economic status (lower) and family type (nuclear). Epilepsy and hysteria were significantly more common in rural communities. Nandi et al (2000) reported that psychiatric morbidity decreased from 11.7% to 10.5% over 20 years in a rural setting.

1.3 Care of the Mentally Ill: Mental Health Services

The care of the mentally ill plays a pivotal role in the process of recovery for the mentally ill. The discussion on care should also include all services offered in the mental health care systems. The mental health services include promotion, prevention, and treatment approaches. The mental health promotion includes all interventions meant for enhancing the general well being all human beings. These interventions could be provided to all, irrespective of risks for mental health problems. The prevention interventions aims at prevention of mental disorders and is usually given to people at risk of developing mental health problems and curative mental health services are provided to all persons affected with a mental health problem or a mental disorder. This concept could be displayed in the figure:
1.3.1 Mental Health Promotion

Mental health promotion and mental disorder prevention can be an effective strategy to reduce the burden of mental disorders, and have shown to bring about health, social and economic development.
“Mental health promotion activities imply the creation of individual, social and environmental conditions that enable optimal psychological and psycho-physiological development. Such initiatives involve individuals in the process of achieving positive mental health and enhancing quality of life.

1.3.2 Mental Disorder Prevention

Preventive interventions work by focusing on reducing risk factors and enhancing protective factors associated with mental ill-health. Mental disorder prevention aims at “reducing incidence, prevalence, recurrence of mental disorders, the time spent with symptoms or the risk condition for a mental illness, preventing or delaying recurrences and also decreasing the impact of illness in the affected person, their families and the society” (Mrazek & Haggerty, 1994).21

Three Types of Prevention (Commission on Chronic Illness, 1957)22

- Primary Prevention, which seeks to decrease the number of new cases of a disorder or illness;
- Secondary Prevention, which seeks to lower the rate of established cases of a disorder or illness in the population (prevalence);
- Tertiary Prevention, which seeks to decrease the amount of disability associated with an existing disorder.
Three Levels of Prevention Proposed by Gordon (1987)\textsuperscript{23}

- Universal Measures are desirable for everyone in the eligible population. The benefits outweigh the costs for everyone;

- Selective Measures are desirable only when the individual is a member of a subgroup whose risk of becoming ill is above average;

- Indicated Measures are desirable for an individual who, on examination, is found to manifest a risk factor or condition that identifies them as being at high risk for the future development of a disease.

In the early 1990s, the Committee on Prevention of Mental Disorders, a sub-committee of the Institute of Medicine (IOM), was charged with preparing a report on the current research and policy recommendations for a prevention research agenda for mental disorders (Mrazek & Haggerty, 1994)\textsuperscript{21}. The resulting definitions of prevention are provided below. It should be noted that the definition of indicated prevention is different from Gordon’s definition in which the term is only for asymptomatic individuals.

- Universal Preventive Interventions are targeted to the general public or a whole population group that has not been identified on the basis of individual risk. The intervention is desirable for everyone;

- Selective Preventive Interventions are targeted to individuals or a subgroup of the population whose risk of developing
mental disorders is significantly higher than average. The risk may be imminent or it may be a lifetime risk;

- Indicated Preventive Interventions are targeted to high risk individuals who are identified as having minimal but detectable signs or symptoms foreshadowing mental disorder but who do not meet DSM criteria levels at the current time.

The primary prevention programmes adopts several measures including biological measures like prenatal and postnatal care; psychosocial measures such as providing education programmes, parent education and family based intervention programmes, peer group influence programmes, and self esteem enhancement programs.

The secondary prevention measures adopted are crisis intervention, community based education and early identification programmes, hotline counseling services, post disaster debriefing sessions etc.

The tertiary care programmes uses various treatment and after care programmes. The treatment approaches are discussed in the next section.

1.3.3 Treatment Approaches

Science and evidence based research has contributed to an armamentarium of efficacious treatments to ameliorate symptoms. In fact, for most mental disorders, there is generally not just one but a range of treatments of proven efficacy. Most treatments fall under
two general categories, biological and psychosocial. Moreover, the combination of the two—known as multimodal therapy—can sometimes be even more effective than each individually.

1.3.3.1 Biological Interventions

Biological treatments directly alter bodily processes. The common forms of biological treatment procedures are pharmacological treatment, electroconvulsive therapy and psychosurgery.

1.3.3.1.1 Pharmacological treatment:

Medication is the most common biological treatment. Tranquilizers and sedatives may be prescribed to reduce anxiety and distress. Antidepressants are sometimes used to treat affective disorders. Stimulants, which speed up bodily processes, have been used for depression and, ironically, overactivity in children. Antipsychotic drugs are used to reduce excitement, confusion, thought disorders, and hallucinations. Use of these medications has permitted many patients to return to the community rather than remain in institutions.

1.3.3.1.2 Electro Convulsive therapy:

Another biological treatment is electroconvulsive therapy (ECT), in which small amounts of electrical current are applied to the brain, triggering a brief seizure. ECT is most often used as a treatment for severe major depression which has not responded to other treatment, and is also used in the treatment of mania (often in bipolar disorder), catatonia, schizophrenia and other disorders. It was first
introduced in the 1930s and gained widespread use as a form of
treatment in the 1940s and 1950s; today, an estimated one million
people worldwide receive ECT every year, usually in a course of Six-
twelve treatments administered two or three times a week. ECT was
shown clinically to be the most effective treatment for severe
depression, and to result in improved quality of life in both short- and
long-term. After treatment, drug therapy can be continued, and some
patients receive continuation/maintenance ECT. The American
Psychiatric Association and the British National Institute for Health
and Clinical Excellence have concluded that the procedure does not
cause brain damage in adults.

1.3.3.1.3 Psychosurgery:

Psychosurgery is a biological treatment in which various nerve
centers in the brain are surgically severed, rendering the patient more
docile. Because such surgery is irreversible and usually develops no
new adaptive behaviours, it is rarely used.

1.3.3.2 Psychosocial Interventions

Comprehensive care for mental disorders involves not only
drug treatments, but also the provision of ongoing support, valid
information and, where appropriate, therapies or rehabilitative
strategies. The major purposes of psychosocial interventions are:
assessment, support, explanation and education, building
concentration, reinforcement of reality, help with relationships and
communication, treatment of non psychotic symptoms such as
anxiety and mood disturbance, dealing with challenging behaviours, e.g. aggression, self harm, structuring the day, attention to daily living skills, and working with families.

1.3.3.2.1 Education Programmes

Education Programmes are directed at either patients or carers/family members and have several aims. Improvement in knowledge of schizophrenia and its course and in compliance with treatment has been shown. There is also evidence of greater satisfaction with services provided. Some programmes go beyond the provision of information and take an educational approach to skills training or problem solving.

Education Programmes for patients may be undertaken in individual or in group settings. Simple information-giving is less effective than interactive sessions. The focus includes giving information about the course and management of the illness, including the importance of compliance with medication and the management of stress. Providing carer’s and family members with information on the likely course of the illness, the treatments available, the importance of compliance and the services available is an essential element of good practice. It may be undertaken as part of a Family Intervention programme.

1.3.3.2.2 Family Interventions

The aims of 'Family Intervention' include reduction of frequency of relapse into illness and reduction of hospital admissions,
reduction in the burden of care on families and carers, and improvement in compliance with medication. Some Family Intervention Programmes have targeted families where there are high levels of criticism, hostility and over-involvement. (Hogarty GE et al, 1991\textsuperscript{24}, Falloon, 1990\textsuperscript{25}). 'High expressed emotion' is a measure of these features and programmes which reduce this or reduce the amount of 'face to face' contact between the patient and family members have been shown to reduce the frequency of relapse.

1.3.3.2.3 Cognitive Behaviour Therapy (CBT)

Cognitive behavioral therapy (or cognitive behavior therapy, CBT) is a psychotherapeutic approach that aims to influence dysfunctional emotions, behaviors and cognitions through a goal-oriented, systematic procedure. CBT can be seen as an umbrella term for a number of psychological techniques that share a theoretical basis in behavioristic learning theory and cognitive psychology.

There is empirical evidence that CBT is effective for the treatment of a variety of problems, including mood, anxiety, personality, eating, substance abuse, and psychotic disorders (Ref). Treatment is often brief, and time-limited. CBT is used in individual therapy as well as group settings, and the techniques are often adapted for self-help applications. Some CBT therapies are more orientated towards predominantly cognitive interventions, while others are more behaviorally oriented.
Cognitive Behaviour Therapy for psychosis is a modification of standard cognitive behavioural therapy. The aim is to modify symptoms (e.g. delusions, hallucinations) or the consequences of the symptoms which may be cognitive, emotional, physiological or behavioural. The treatment programme is intensive (involving about 20 hours of individual treatment) and based on an individually tailored formulation which provides an explanation of the development, maintenance and exacerbation of symptoms and of pre-morbid mood, interpersonal and behavioural difficulties.

1.4 Mental Health Delivery

1.4.1 Global Scenario

The mental health delivery all over the world is delivered through four varied systems. The four sectors of the system are the specialty mental health sector, the general medical/primary care sector, the human services sector, and the voluntary support network sector. Specialty mental health services include services provided by specialized mental health professionals (e.g., psychologists, psychiatric nurses, psychiatrists, and psychiatric social workers) and the specialized offices, facilities, and agencies in which they work. Specialty services were designed expressly for the provision of mental health services. The general medical/primary care sector consists of health care professionals (e.g., family physicians, nurse practitioners, internists, pediatricians, etc.) and the settings (i.e., offices, clinics, and hospitals) in which they work. These settings were designed for the full
range of health care services, including, but not specialized for, the delivery of mental health services. The human services sector consists of social welfare, criminal justice, educational, religious, and charitable services. The voluntary support network refers to self-help groups and organizations. These are groups devoted to education, communication, and support, all of which extend beyond formal treatment.

The Mental Health Atlas (WHO, 2005)\textsuperscript{26} provides a clear picture of mental health facilities and resources in the world based on the assessment using WHO Assessment Instrument for Mental Health Systems.

### Psychiatric Beds and Professionals in Mental Health

<table>
<thead>
<tr>
<th></th>
<th>World</th>
<th>S-E Asia</th>
<th>India</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Psychiatric Beds per 10,000 population</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total psychiatric beds</td>
<td>1.69</td>
<td>0.33</td>
<td>0.25</td>
</tr>
<tr>
<td>Psychiatric beds in mental hospitals</td>
<td>1.16</td>
<td>0.27</td>
<td>0.2</td>
</tr>
<tr>
<td>Psychiatric beds in general hospitals</td>
<td>0.33</td>
<td>0.03</td>
<td>0.05</td>
</tr>
<tr>
<td>Psychiatric beds in other settings</td>
<td>0.20</td>
<td>0.03</td>
<td>0.01</td>
</tr>
<tr>
<td><strong>Professionals per 100,000 population</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of psychiatrists</td>
<td>1.20</td>
<td>0.20</td>
<td>0.2</td>
</tr>
<tr>
<td>Number of psychiatric nurses</td>
<td>2.0</td>
<td>0.10</td>
<td>0.05</td>
</tr>
<tr>
<td>Number of psychologists</td>
<td>0.60</td>
<td>0.03</td>
<td>0.03</td>
</tr>
<tr>
<td>Number of social workers</td>
<td>0.40</td>
<td>0.04</td>
<td>0.03</td>
</tr>
</tbody>
</table>

Source: Mental Health Atlas (WHO, 2005)
1.4.2 Indian Scenario

In India, mental health care is delivered through specialist mental health centers, general hospital psychiatric units and a variety of community care programmes as envisaged in the National Mental Health Programme (NMHP) (1982)\(^27\). The District Mental Health Programme provides care to a vast majority in the community. A few records of care facilities managed by families of mentally ill are also documented. The specialist care centers are set exclusively for the care of persons with mental illness with the support of a mental health team consisting of Psychiatrist, Psychiatric Social Workers, Clinical Psychologists and Psychiatric Nurses. The general hospital psychiatry units provide care to mentally ill in general hospital setting where the mental health delivery is offered in a medical specialty department with the services of mental health team. The community care programs under NMHP offers services to mentally ill through outreach clinics in locations accessible to people in their own neighbourhood. General health practitioners are also trained in dealing with emergency psychiatric conditions and follow up in the primary care facilities.

1.4.2.1 Hospital Based Services: Psychiatric Beds and Professionals

<table>
<thead>
<tr>
<th>Category</th>
<th>Per 10 000 Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total psychiatric beds</td>
<td>0.25</td>
</tr>
<tr>
<td>Psychiatric beds in mental hospitals</td>
<td>0.2</td>
</tr>
<tr>
<td>Psychiatric beds in general hospitals</td>
<td>0.05</td>
</tr>
<tr>
<td>Psychiatric beds in other settings</td>
<td>0.01</td>
</tr>
</tbody>
</table>
One third of mental health beds are in one State (Maharashtra) and several States have no mental hospitals. Some mental hospitals have more than 1000 beds and several still have a large proportion of long-stay patients. During the past two decades, many mental hospitals have been reformed through the intervention of the voluntary organizations (e.g. Action Aid India), media, National Human Rights Commission and Judiciary (courts), and yet a survey in 2002 showed that about a quarter had shortages in terms of drugs/treatment modalities and three quarters in terms of staff. The current emphasis is on general health psychiatry units that support voluntary admissions and encourage family members to stay with the patient. Some beds are allocated to treatment of drug abuse and for child psychiatry. Very few mental health professionals are based in rural areas. Most States allow public sector psychiatrists to have private clinics. Many mental health professionals have emigrated.

Non-Governmental Organizations NGOs are involved with mental health in the country. They are mainly involved in advocacy, promotion, prevention, treatment and rehabilitation. NGOs are involved in counselling, suicide prevention, training of lay counsellors and provision of rehabilitation programmes through day care, sheltered
workshops, halfway homes, hostels for recovering patients and long-term care facilities. Parents and other family members of mentally ill persons have recently come together to form self-help groups.

1.4.2.2 Community Based Care Facilities

Under the National Mental Health Programme (1982) mental health is provided as part of primary health care system. Actual treatment of severe mental disorders is available at the primary level. Mental health care in primary care is available in 100 districts out of about 600 districts.

In addition, various non-governmental organizations provide different types of services ranging from telephone hotlines to residential rehabilitative services. Further information is required about the quality of care provided through community facilities and the type of personnel involved in providing mental health care at the community level (Murali and Rao, 2004)28.

1.4.2.3 Mental Health Financing

There are budget allocations for mental health. The country spends 2.05% of the total health budget on mental health. Government funding for health services are provided both by the states and the center. Services provided at Government health centers are free. Certain industrial/governmental organizations provide health care schemes for their employees. The country has disability benefits for persons with mental disorders. Disability benefits have become available recently and in a limited way. The mental health
funding is significantly low and has deficits in meeting the needs of all mentally ill persons in the country.

Treatment for severe and chronic mental illness, in addition to medical management, comprises of a variety of therapeutic approaches, all aimed at helping the individual function at his/her optimal capacity. Psychiatric rehabilitation is the term used to represent this broad range of services that use a combination of learning procedures and environmental supports in a holistic and integrated manner to provide life long care for persons with mental illness. A large majority of severe mental illnesses run a chronic course and need long term treatment and rehabilitation.

1.5 Psychosocial Rehabilitation

Psychosocial rehabilitation is defined as "a therapeutic approach that encourages a mentally ill person to develop his or her fullest capacities through learning and environmental supports" (Bachrach, 1996).29

Psychosocial rehabilitation promotes recovery, full community integration and improved quality of life for persons who have been diagnosed with any mental health condition that seriously impairs their ability to lead meaningful lives. Psychosocial rehabilitation services are collaborative, person directed and individualized. These services are an essential element of the health care and human services spectrum, and should be evidence-based. They focus on
helping individuals develop skills and access resources needed to increase their capacity to be successful and satisfied in the living, working, learning, and social environments of their choice.

Psychosocial rehabilitation is a term used to describe services that aim to restore the patient’s ability to function in the community. It not only includes the medical and psychosocial treatment but also include ways to foster social interaction, to promote independent living, and to encourage vocational performance (Cook et al. 1996). Unlike past, now psychosocial rehabilitation aims to integrate patients back into the community rather than segregating them in separate facilities. The goal of Psychosocial rehabilitation is to teach skills and provide community supports so that the individuals with mental disabilities can function in social, vocational, educational and familial roles with the least amount of supervision from the helping professionals. The professionals must involve families in treatment planning and implementation. So rehabilitation is labor intensive and person-to-person venture. To help people with psychiatric disabilities become and remain integral members of society, rehabilitation, vocational training, and assistance in work settings are essential. Work is a key component, some would argue the most important component, of services designed to achieve community integration. In the context of Psychosocial rehabilitation, work can be seen both as an outcome and as a highly effective treatment modality in enhancing meaningful community integration (Ahrens, et al., 1999).
1.5.1 Psycho-social Rehabilitation: Theory

The concept of Psychosocial rehabilitation is associated with social psychiatry and is not based on a medical model of disability and the concept of mental illness.

Problems experienced by people with psychiatric disabilities are thought to include difficulties in understanding or dealing with interpersonal situations (e.g., misinterpreting social cues, not knowing how to respond), prejudice or bullying from others because they may seem different, problems coping with stress (including daily hassles such as travel or shopping), difficulty concentrating and finding energy and motivation.

Psychosocial rehabilitation services may include: supported accommodation, supported employment or education, social firms, assertive community (or outreach) teams assisting with social service agencies, medication management, housing, employment, family issues, coping skills and activities of daily living and socializing.

Psychosocial Rehabilitation (PsR) can be described as consisting of eight main areas of work: Psychiatric (symptom management); Social (relationships, family, boundaries, communications & community integration); Vocational and or Educational (coping skills, motivation); Basic Living Skills (hygiene, meals, safety, planning, chores); Financial (budgets); Community and or Legal (resources); Health and or Medical (maintain consistency of care); and Housing (safe environments).
Bennet (1983) described that the term rehabilitation has been borrowed by psychiatry from physical medicine. Bennet discusses the evolution of the term psychiatry and suggests that there have been six stages in the development of the concept,

1. a) Attempting to modify an individual’s psychiatric disability  
   b) Compensating for the disability by developing other abilities and then placing the person in an environment in which these abilities can be used.

2. Resettling psychiatrically disabled people in economic employment

3. Restoring psychiatrically disabled persons into their former stages, especially by taking them out of the psychiatric institutions

4. Returning or integrating the psychiatrically disabled person into a home, school and/or work community by developing his/her skills

5. Improving the competence and capabilities with an emphasis on coping not curing

6. The process of helping the psychiatrically disabled person to make the best use of his or her residual abilities in order to function at an optimum level in as normal a social context as possible.
Each of these stages in the development of the concept of rehabilitation has influenced, and been influenced by the models used in rehabilitation. Thus the overall mission of Psychosocial rehabilitation is to assist in the reintegration of the persons with mental illness to their respective communities.

1.5.2 Core Principles of Psychosocial Rehabilitation

International Association of Psychosocial Rehabilitation Services (1998) proposed the following principles of psychosocial rehabilitation

1. Recovery is the ultimate goal of Psychosocial Rehabilitation. Interventions must facilitate the process of recovery.

2. Psychosocial Rehabilitation practices help people re-establish normal roles in the community and their reintegration into community life.

3. Psychosocial Rehabilitation practices facilitate the development of personal support networks.

4. Psychosocial Rehabilitation practices facilitate an enhanced quality of life for each person receiving services.

5. All people have the capacity to learn and grow.

6. People receiving services have the right to direct their own affairs, including those that are related to their psychiatric disability.

7. All people are to be treated with respect and dignity.
8. Psychosocial Rehabilitation Practitioners make conscious and consistent efforts to eliminate labeling and discrimination, particularly discrimination based upon a disabling condition.

9. Culture and/or ethnicity play an important role in recovery. They are sources of strength and enrichment for the person and the services.

10. Psychosocial Rehabilitation interventions build on the strengths of each person.

11. Psychosocial Rehabilitation services are to be coordinated, accessible, and available as long as needed.

12. All services are to be designed to address the unique needs of each individual, consistent with the individual’s cultural values and norms.

13. Psychosocial Rehabilitation practices actively encourage and support the involvement of persons in normal community activities, such as school and work, throughout the rehabilitation process.

14. The involvement and partnership of persons receiving services and family members is an essential ingredient of the process of rehabilitation and recovery.

15. Psychosocial Rehabilitation practitioners should constantly strive to improve the services they provide.
In addressing the goals of the rehabilitation process, Murphy and Williams (1999) states: “The rehabilitation process is seen as a systematic approach to assessing and addressing the total needs of a person with disabilities. Each person is seen as a unique individual with assets that can be developed. The ultimate goal of the rehabilitation process is to promote functional independence where the individual is capable of economic self-sufficiency and integration into society”.

1.5.3 Historical development of Psychosocial Rehabilitation

The rehabilitation processes began with the parental concern for the mentally ill. The concern of the parents and significant other family members led to rehabilitation of the mentally ill. The family efforts were supported by institutions set up by government and non-governmental organizations. The first half of the 19th century was marked by the moral treatment which encompassed the first rehabilitation effort in many countries. In the small, private and state mental hospitals in which moral treatment was practiced, mentally ill patients were treated with compassion and concern. Treatment included three of four hours a day of variety of leisure activities, social gathering, educational and religious lectures and manual labor. The main goal of such interventions was to help the patients prevent morbid thoughts and reeducate them to prepare for their reintegration to families.
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In the midst of the moral treatment era, in 1841, Dorthea Lynde Dix began the remarkable 40 year crusade, devoted principally to the goal of building enough insane asylums to accommodate all mentally ill persons. Based on her investigation of negative experiences of mentally ill in almshouses and jails, she made great protest against the brutal ways of dealing mentally ill in these centers of confinement.

Introduction of family care in America was one of the positive development happened in the care of mentally ill. Some of the hospitals encouraged families to stay with the patients. Massachusetts was the first state to set up family care. Family care gave mentally ill persons an opportunity to live in the community and to experience participating in the life of family.

In the early part of the 20th century, Adolf Meyer, generally considered as the founder of modern psychiatry in the United states emphasized the need to understand the role of both the social environment and biological factors in determining psychopathology. Meyer supported Clifford Beers in establishing mental hygiene movement, whose goals included rehabilitation and the tenets anticipated many of the principles of community mental health movement.

British Psychiatrist John Wing contributed greatly to the conceptual aspects of Psychosocial rehabilitation. An important concept in rehabilitation is giving mentally ill person and sense of
mastery that is feeling that they can cope with their internal drives, their symptoms and the demands of the environment. The realization that all treatment and rehabilitation should be designed to help patients improve their ability to deal with and master both internal and external demands to the limits of their potential led to remarkable development in the field of rehabilitation.

During the last two decades, the field of psychosocial rehabilitation has developed a unique philosophy, knowledge base and technology as well as a number of well known programme applications. The term psychosocial rehabilitation has become pervasive in the mental health field; rehabilitation reflects the focus of the approach to improve functioning in a specific environment.

Rehabilitation has been described by Wing (1978)\textsuperscript{35} as having two components, enabling and caring: enabling is the sense of helping the individual to lead a normal life as far as possible in spite of his limitations; caring is helping to create various kinds of protected or supported environments adopted to these limitations.

1.5.4 Emergence of Rehabilitation services in India

Emergence and growth of psychosocial rehabilitation in India can be divided into two phases. In the first phase, comprising of the first 25 years since independence, most of the services were hospital based and largely confined to the government mental hospitals. The emphasis was on keeping the long-stay patient occupied with some form of work or activity. It is the second phase, from the early 70’s
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onwards that saw concerted efforts made to reintegrate the patient with the family and the community. This period is characterized by several initiatives taken by non-governmental organizations (NGOs). It is in this phase that rehabilitation, in the true sense of the term, emerged as a felt need. The developments in the delivery of rehabilitation services can, therefore, be viewed under 2 sections: Hospital based services and community based initiatives (Murali T, Rao 2004).

1.5.4.1 Hospital Based Services

Bhore Committee report (1946) strongly recommended occupational and vocational activities in the hospitals. The report also suggested the need for organized systematic work and an atmosphere of industry to be created in hospitals and to make occupation an activity that is approved by the patients" (Sharma, 1990). The Central Institute of Psychiatry (CIP) Ranchi had, at that time, the best occupational therapy unit in India and compared favourably with those abroad (Thomas & Bose, 1967). Persons were deputed for training to Ranchi and, as a result, vocational training units were set up in Mysore and Chennai. It is a sad reflection that, 50 years later, the National Human Rights Commission (NHRC) report (1999) on quality assurance in mental health care stated that rehabilitation services were practically non-existent in the 40 government hospitals situated in 18 states in India. While 64 % reported some rudimentary form of rehabilitation activity, only 4 hospitals had structured occupational therapy facilities in the form of day care centers. These
were at the National Institute of Mental Health & Neuro Sciences (NIMHANS), Bangalore, Karnataka Institute of Mental Health, Dharwad, Institute of Mental Health, Chennai, and Mental Health Center, Thiruvananthapuram).

Day care centers, especially those attached to psychiatric hospitals, tend to be used by more chronic patients with greater disability and from lower socio economic strata (Sharma, Gopinath & Reddy, 1987). Poor work performance is related to the persistence of residual symptoms (Gopinath et al, 1985). However, the use of activity therapy, behaviour modification techniques and monetary incentives for work reduces the behavioural problems and improves the social and occupational functioning of the patient (Rao, Barnabas & Gopinath, 1988a, Rao, Barnabas & Gopinath, 1989). Cognitive remediation can be used to improve the quality of life (George et al, 1996). The day care program is effective in reducing the burden on the family and gives them the much needed respite (Rao, Barnabas & Gopinath, 1988b).

The main reason that these efforts have not been replicated in many hospital settings is due to the paucity of mental health professionals other than psychiatrists. Most of the posts of clinical psychologists and psychiatric social workers lie vacant with little effort made to fill them (NHRC, 1999). This has resulted in hospital care becoming synonymous with medical management of the mentally ill. Mental hospitals provide mainly in-patient care with the number of long stay remaining constant, and the GHPUs provide
mainly out-patient based care with little time to attend to rehabilitation needs of the patient or concerns of the family.

1.5.4.2 Community Based Initiatives

The community based initiatives have largely come through Non-Governmental Organizations (NGOs). The first halfway home in India was started by the Medico-Pastoral Association in Bangalore in 1972, and the first day care center, also in Bangalore, was started by a group of housewives in 1974, coming together under the name of FRIENDS of NIMHANS. Today there are more than 50 such centers located in different parts of the country. Although, a majority is concentrated in the southern states, it is heartening to note that such facilities are available in Kolkata, Gauhati and Gurgaon. One of the centers in Kolkata (Paripurnata) is unique because it was primarily started to address the rehabilitation needs of women with mental illness in judicial custody. Yet another first is the starting of a day care center by family caregivers at Chennai (Aasha). In response to concerns expressed by caregivers, many of the NGO’s have started long stay residential facilities.

The quality of care, however, varies markedly across centers. Financial difficulties are the main constraints and, for most centers, pegging down running costs seems to be an uphill task. This has resulted in a class divide, with some facilities offering professional services and quality care at a price far beyond the reach of the average patient and family. While other centers, offer mainly custodial care
with patients being given food and shelter and engaged in routine, monotonous activities.

Thus, there is a need for better partnerships between mental health professionals, NGOs and the community at large. A success story here is the example of the MS Chellamuthu Trust, Madurai (TN) that has been able to provide low cost, but effective care and a comprehensive range of services. For the NGO sector to be viable, it would require active support and commitment from mental health professionals. There is however, a need to develop a cadre of well trained and qualified rehabilitation workers who have the basic aptitude and skills to work with persons with mental illness.

The community has several resources that can be tapped. A survey of involvement and participation of the community in Psychosocial rehabilitation (Ranganathan et al, 1996) showed that the community is willing to volunteer time, provide financial support, as well as avenues for income generation activity through self employment schemes, home based programs and sheltered employment. These resources are yet to be utilized optimally. The level of contact and interaction between the community and the mentally disabled must increase so that the community becomes more aware of the skills that they possess. Organizing educational programs, cultural activities to showcase skills and exhibitions to market the products made by persons with mental disability would be some of the ways of increasing the visibility of the recovered mentally ill.
Community based rehabilitation (CBR) is very appropriate in the Indian cultural setting, where social and community bonds are quite strong and deep-rooted. The challenge of CBR, and its success, depends on whether people with disabilities, their families and communities, and the concerned governmental agencies pertaining to health, education, welfare and social services can work together to make use of the resources in the community. The emerging view is that CBR programs for the mentally ill should integrate with existing community development programs, especially in the area of disability, so that there is no duplication and waste of resources.

1.5.4.3 Common Problems in Psychosocial Rehabilitation

Sheth, H.C. (2005) delineated the problems of psychosocial rehabilitation in developing countries. The problems discussed were Irregular Follow Up due to financial problems, Lack of medicines in governmental Institute, Difficulties in a Vocational Rehabilitation, Lack of Job Opportunities, Hospital as a Shelter, and Hospital as a dumping site, Societal Insensitivity, Lack of staff and over burdened Staff.

The inadequate facilities and incomplete treatment due to stigma and limited resources have contributed to low success rates in the care of the mentally ill. Many mentally ill were abandoned by families and a large number of them are dumped in to government psychiatric facilities. Persons with severe mental disorders compounded with their lack of resources lead a life of being abandoned without appropriate care, wander in the streets. This
scenario has added to the homelessness among mentally ill. The government and social welfare have limited facilities for the care of homeless mentally ill, who are wandering in the streets and live in precarious social situations.

1.6 Homelessness

1.6.1 Overview

Homelessness is one of the most serious consequences of the phenomenon of social exclusion. It affects an ever-increasing number of persons with severe mental disorders and groups that suffer serious conditions of poverty, marginalization and abandonment.

The term "homeless persons" refers to a group and a social problem with varied and heterogeneous characteristics, profiles and necessities, but with a series of common dimensions: severe poverty, social isolation, rootlessness, breakdown of social and family bonds, personal deterioration and lack of a place (a home) to cover needs of accommodation and social support. The phenomenon is a highly urban one, characteristic of large cities in which problems of poverty, rootlessness and isolation are exacerbated, and lead to exclusion processes (which form the basis of the problem) being expressed in the most extreme and inhuman way in situations of homelessness.

The following factors have resultant influence on homelessness among mentally ill. 1) The limited mental health care available in the public sector, lack of coordination of different caring groups, absence
of welfare system to meet the needs of mentally ill individuals and
their families. (Kumar, Sekar, Murthy, 2003) Mental illness leading to
homelessness is not always as the result of abandonment. Often, the
family is left with not too many options, especially among the lower
socio-economic groups where access to care and support is minimal or
non-existent. In most rural areas, the problem is often treated more as
spiritual and less as a psychological issue.

Persons with severe mental disorders are often dumped in
govt. hospitals. A study of the status of the mental hospitals
commissioned by the National Human Rights Commission revealed
gross inadequacies in all aspects of care, clinical services and
rehabilitation (National Human Right Commission, 1999). The
inadequate care facilities leave many in the streets with un-recovered
illness status.

Within the community of homeless persons living in the
streets or in hostels and shelters, cases of severe mental illness have
been detected. The homeless seriously mentally ill constitute an
especially marginalized group, and have given rise to considerable
social concern. This situation is particularly serious in all cities of the
World. Diverse studies carried out estimate that between 25% and
50% of adult homeless suffer from severe or chronic mental illness
(Lamb, 1984; Arce and Vergare, 1984; Bassuk, 1984 and 1986). However, many of the early studies presented various methodological
difficulties related to sampling biases, failure to use standardized
procedures, lack of a consistent definition of "mental illness", etc.,
which led to overestimations of the prevalence of these disorders among the homeless population. In recent years, several studies have been carried out using improved sampling systems and more appropriate diagnoses based on structured interviews such as the DIS or the CIDI (Composite International Diagnostic Interview). These studies indicate that between 25% and 35% of Homeless Persons present some kind of serious mental disorder (such as schizophrenia, severe depression, dysthymia or cognitive deterioration), and that 30% to 50% abuse alcohol or drugs.

Specific attention to the homeless chronically mentally ill in our country is scarce and inadequate. Given their situation and condition of severe social exclusion, many of the homeless mentally ill do not regularly use or take full advantage of mental health services – and the situation is much more serious among those living rough in the streets.

Calsyn & Morse, 1991a54, 1991b55; Morse, Calsyn, & Burger, 199156) from these early needs assessment studies, the following observations were made which influenced this study:

1. There are a core set of needs (e.g., emergency food and shelter, income supports, safety concerns, long-term housing, and employment) which affect all homeless individuals.

2. However, there is tremendous heterogeneity within the homeless population. No single program is likely to meet the needs of this population; therefore, multiple interventions which
focus on distinct subgroups of the homeless population are needed.

3. Although homeless men and women share many of the same problems, there are differences that must be considered in developing programs to meet their unique needs.

4. A significant percentage of the homeless population have experienced multiple episodes of homelessness. A more intensive strategy may be necessary to assist these individuals in exiting homelessness on a permanent basis.

5. Approximately two thirds of the homeless population have a significant substance abuse and/or mental health problem. One third of these have a substance problem only; another third have primarily a mental health problem; the final third have both a substance abuse and a mental health problem.

6. In the vast majority of these cases psychiatric hospitalization preceded the first episodes of homelessness. Thus, homelessness was not the cause of the psychiatric symptoms; rather, psychiatric problems had made individuals vulnerable to homelessness.

7. Although two thirds of the homeless population had a significant mental health problem, only 15% were currently receiving any form of mental health treatment.

8. Only a small percentage of the sample were willing to receive traditional psychiatric services such as psychiatric medication
(25%) or referral to a psychiatric clinic (35%), but a significant percentage were willing to be referred to case management (68%) and supportive housing (83%).

1.6.2 The Indian Scenario of Homeless Mentally ill

In India the situations of homeless and wandering mentally ill are not different. The homelessness results out of inadequate care facilities and inadequate resources of the family systems. The social security of homeless persons is restricted to occupying few beds in government psychiatric facilities. The government policy does not provide any provisions for protection of rights of homeless mentally ill. There is no studies reported on the specific issues of homeless mentally ill and no estimates of homeless are available. The homelessness was largely attributed to lack of care and not to deinstitutionalization. The streets of most of the large and small cities have a good number of homeless persons and informal reports estimate a high prevalence of psychiatric morbidity among these people.

1.6.3 Rehabilitation of Homeless Mentally ill

The dearth of financial resources and care facilities in developing countries causes the tremendous difficulties in rehabilitation of the patients. A study of the status of the mental hospitals commissioned by the National Human Rights Commission revealed gross inadequacies in all aspects of care, clinical services and rehabilitation (National Human Right Commission, 1999). In contrast to the slow and sporadic growth of psychosocial rehabilitation in the
hospital setting, the response in the community has been very encouraging. These initiatives have largely come through Non-Governmental Organizations (NGOs).

Current facilities for these patients vary from state to state. A small number of patients are admitted to mental hospitals, destitute homes and to facilities run by Non-Governmental Organizations. The conditions in these facilities are also varied in nature. There have also been community initiatives for the mentally ill that have been less visible. Several individuals and families in Kerala have been involved in providing food, clothing, shelter, medicine and occupational therapy free of cost for the homeless mentally ill. These are largely charitable efforts sustained by the active support, in cash and kind, of the local community (Murali, 2002)\textsuperscript{58}. These services need to be further examined with regard to the quality of care. The effectiveness of such programmes was not clearly estimated. The rehabilitation outcomes need to be understood in order to discuss the utility and effectiveness of such care facilities.

### 1.7 Measurement of Rehabilitation Outcomes

A review of the literature concerning outcome-based research and treatment interventions of persons with severe mental illness has used a variety of criteria to determine program effectiveness. Certain outcome criteria such as subjective quality of life, consumer satisfaction, and psychiatric re-hospitalization have witnessed a great deal of interest while other promising outcome measures using
empowerment and mastery indicators are limited. For instance, subjective quality of life is a general feeling of well-being and overall satisfaction with current aspects of one's life (Lehman, 198357, 198858).

Several health care and rehabilitation researchers have been advocating for the inclusion of quality of life in the framework for assessing rehabilitation health outcomes (Murphy & Williams, 199959; Renwick & Frielfeld, 199660)

1.8 Significance of the Study

There is a scarcity of information on the effectiveness of strategies for extending care to people with serious mental illness in rural communities in India and in other developing countries (Jacob, 2001)61. Community-based rehabilitation (CBR) is a form of care that has been implemented in the field of physical disabilities in low-income countries where specialized resources are scarce (Lagerkvist, 199262; Evans et al, 200163).

There have been efforts from a group of individuals to provide basic care for those wandering in the streets with mental illness. These isolated efforts have gradually grown into a movement of caring the homeless mentally ill through a rather semi-professional way. This movement played a pivotal role in the mental health care of the homeless mentally ill in the state of Kerala. The growth necessitated the documentation of the efforts and evaluating the effectiveness of the psychosocial rehabilitation programmes offered
by these centers. The knowledge and attitudes of care providers on various aspects of mental illness is important for the efficient care giving. The capacity building needs also needs to be explored in this context.

This study on Rehabilitation Facilities and Rehabilitation Outcomes of Homeless Mentally Ill in Kerala sought answers to seven research questions. What are the rehabilitation processes used by these care facilities?, What are the facilities provided at each center?, What is the quality of patient care services?, What are the personal profile of the chief functionary of the rehabilitation centers and their motivations for setting up and maintaining such facilities?, What is the level of knowledge and attitudes of care providers on mental illness?, What is the level of satisfaction of the residents?, How much is the quality of life and level of functioning of the homeless mentally ill?.

The current study focuses on the facilities available for rehabilitation of homeless mentally ill in Kerala with special reference to non-governmental organizations managed by non-professional individuals. The study also look at the effectiveness of such centers and estimate the rehabilitation outcome through the assessment of quality of life, level of functioning and patient satisfaction. The study further explores the mental health awareness and knowledge of rehabilitation among the volunteer care providers working in these centers.
An evaluation of relative treatment outcomes for these program models would demonstrate the effectiveness of this model to rehabilitate homeless mentally ill. These results would also enable program planners to create or modify existing programs to more effectively deal with homeless mentally ill. Using responsive evaluation methodologies, in which specific clinical program indicators are studied along with indicators chosen by the researcher, the programs under investigation in this study will not only derive efficacy data but will have a clear mechanism to continuously improve the quality of care. Thus, not only will there be data as to program model's effectiveness, but a quality improvement mechanism to improve health and mental health care in the future.
References


