Draft

Sambandh Health Foundation-A Framework for Mental Health System

Gurgaon, India Revised in 2018



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# PREFACE

The framework on mental health project presented here has emerged from personal needs and experiences of a few concerned and affected individuals and has evolved into a shared understanding for a holistic Mental Health Service.

The foundation that it is built upon is the belief that the individual with the mental illness (mi) needs to be an active participant and an equal partner in his/her recovery process. While the individual remains at the centre, he is supported by not only the mental health professionals and the family (caregiver) but by the larger community, as a whole. The goal being, to help this individual mobilize his own personal resources, move in the direction of recovery and live a meaningful, productive life in the community.

A very pertinent part of the agenda that emerges from here is the need for a change in the perspectives and mind sets of the society in terms of how a person with mental illness is viewed at large. Clearly there is a link between the lack of understanding which leads to lack of support for the individual. A support which could be crucial and perhaps even critical to the process of recovery and management of the illness.

Involving the community, besides the mental health professionals is of importance not just for the individual directly affected but also for the family members. The need for understanding the illness, de-stigmatisation, the real needs of a person with mental illness, necessary supports, ways of handling the person and hope are the key elements in a healthy approach to mental illness.

The ultimate goal as envisaged by this framework is to empower the individuals with mental illness (consumers) and provide an opportunity to integrate them into the social system rather than either incarcerating them or for that matter keeping them on the fringes.

# **INTRODUCTION**

Good health has a physical and a mental dimension, both equally important in living a happy and fulfilling life. While the physical dimension has been the centre of our concern, the mental dimension has been a relatively neglected area. In several countries mental health problems have lately been recognised and addressed to some extent. There has been a lot of progress in the medical treatment and provision of psychosocial supports and services. The inclusive approach of the community is paving the path to recovery.

### HISTORY OF MENTAL ILLNESS:

History shows that the mentally ill people in olden times were taken care of by their families, extended families and the community. The care was primarily in the area of sustenance. Then came a partial shift from home-based care to their isolation and institutionalization. But even in this there was no recovery. It was basically a transfer of responsibility from the family to the state. The fear and stigma of a person with mental illness, in the past, have prompted solutions which have been in the direction of management and control. The last couple of centuries have seen a movement away from long term institutionalization, back into the community, where each one of us rightfully belongs.

### VOICE OF CONSUMERS (Persons affected by mental illness):

Paul Carling, in reviewing a research that was completed on the experience of 'Recovery' by mental health consumers, states:

Studies raise major questions about the level of expectations we should hold about the potential of individuals with psychiatric disabilities for community integration. These findings counter the pervasive beliefs that many people with psychiatric disabilities are too symptomatic or too "low functioning" to benefit from recovery and integration. To be sure, many individuals are obviously in need of intensive assistance over an extended, or even lifelong period, if they are to take on employment, the independent management of a household, or other comparable productive activity. But this body of study suggests

that, with supports that are offered within the context of choice and community participation, there is reason to hold hopeful expectations for any individual.

### CONCEPTS AND TRENDS:

There is a near consensus in recognising the reality that if we hear the affected people carefully, what they are saying is that they desire a naturally fulfilling life in the community, drawing their supports from it and also making meaningful contributions to it. They would like to be in charge of their own lives. That merits a re-look at the previously held concepts and compels us to change our perspective of the illness. This would necessarily bring about a change in the way an affected person perceives himself and is perceived by the family, the society and the professionals. Consequently, it changes the general outlook on the kind of supports and services needed by the affected person for recovery.

The progress in the field of medical science makes mental illness treatable and manageable. The solutions that are emerging worldwide are in the direction of empowering the affected individuals to tap into their own strengths and capabilities and regain their lost social skills, and strengths. The person centred, community-based recovery approach can put a person back in control of his own life. Real life community interactions and supports help the recovery process and provide the affected person with an opportunity to make meaningful contributions, which is essential to one's feeling of self-worth. This promotes self-reliance and recovery. The needs and aspirations of the affected person are given prime importance. The affected persons, the families, the service providers, the medical professionals, act in coordination to decide on the supports needed, at the right time, to accommodate the fluctuating nature of the illness.

### PRESENT SCENARIO IN INDIA:

Looking at the MEDICAL ASPECT of mental health, we find that medical facilities and mental health professionals are inadequate in numbers. The benefits of the progress in the field of medical science does not reach the common man. With such limited numbers of professionals in the field of mental health and very few facilities, an average ill-informed family that encounters this illness considers itself doomed. They live fearful, isolated and a burdened life with a sense of hopelessness for the future.

Mental Illnesses includes common mental disorders (CMD) like mild depression and anxiety, and severe mental disorders (SMD) like schizophrenia, bipolar disorder, anxiety disorder, OCD and others. A large percentage of homeless people and attempts to suicides are associated with mental health issues.

There are approximately *5000 psychiatrists in the country*, which is grossly inadequate.

Looking at the PSYCHOSOCIAL ASPECT of mental health, the lack of awareness of the nature of the illness has a devastating effect on the affected individuals and their families and their interpersonal relationship. The impact of an uncertain family support, as the family usually does not understand mental illness, is unnerving for the affected person. There is practically no preparation in society what so ever to participate in the recovery process of a person with mental illness. The primary factor again being the inadequate and incorrect understanding of this illness. Social exclusion and isolation of the affected person and the families adds to multi-dimensional problems they are already facing.

# The First Indian Mental Health Policy 2014

Fortunately, in 2014, Ministry of Health and Family Welfare, Government of India, came up with a progressive Mental Health Policy for the first time in India.

Some key goals:

- 1. To reduce distress, disability, exclusion morbidity and premature mortality associated with mental health problems across life span of the person.
- 2. To enhance understanding of the mental health in the country.
- 3. To strengthen the leadership in the mental health sector at the national, state and district levels.

## The New Mental Health Care Act 2017

As a part of compliance with the United Nations convention on Rights of Persons with Disability (UNCRPD), which India had signed and ratified, the Ministry of Health and Family Welfare came up with the New Mental Health Care Act 2017.

The new Mental Health Care Act 2017 brings a ray of hope for changes that are humane and address the needs and rights of huge populations impacted by mental health issues in our country.

Some Key Features

- 1. All mental health services need to be provided in the least restrictive environment possible and in a manner that does not intrude on their rights and dignity.
- 2. Right of Persons with mental illness are lucidly defined and services need to be accessible to all people in the county in need of mental health interventions.
- 3. Advanced directive / Nominated representative
- 4. Decriminalization of suicides

'For the first time in India, universal mental health care is now a justiciable right following the enforcement of the Mental Healthcare Act (MHCA), 2017. As a watershed moment for the right to health movement in India, it is also for the first time that the law has recognised the right to access health care for citizens — and specifically for mental health.

According to the National Mental Health Survey (NHMS) of India, 2016, India spends less than 1% of its entire health budget on mental health. In a country where an estimated 150 million people need mental health care and treatment, up to 92% of them (no less than 105 million persons) do not have access to any form of mental health care. Further, stigmatisation and discrimination are serious causes of concern, with numerous documented cases of human rights violations as a result of poor quality of mental health care, forced admissions in mental health hospitals, and a denial of socio-economic rights. These facts point to an alarming a crisis in India's mental health system. Thus, the MHCA comes as a ground-breaking piece of legislation, especially if it is properly implemented. It mandates the government to provide accessible, affordable, acceptable and high-quality mental health care by integrating mental health-care services at each level of the public health system, establishing mental health facilities in proportion to the population in each State, and providing free mental health-care to socio-economically deprived sections of the population. Additionally, the government is duty-bound to design and implement mental health promotion and preventive programmes to create awareness about the MHCA using public media. While this sounds impressive on paper, it is a difficult task that cannot be achieved unless there is strong political will." – Soumitra Panthare and Arjun Kapoor, The Hindu, 26<sup>th</sup> August 2018

Mental health issues have traditionally been a taboo in India, but with the families and people living with mental illness firmly setting foot in the 21<sup>st</sup> century, discussions around mental health are finally surfacing and are being discussed in the mainstream.

Sambandh's progressive thinking is in sync with the provisions in the new law and upholds dignity, respect and an opportunity for least restrictive services in the spirit of UNCRPD, the Mental Health Policy and the Mental Health Care Act.

We are standing at a point in India where we can begin to successfully envision a mental health setup which would serve the needs of the many people affected by mental illness and their caregivers. Every country is bound to come up with some organic solutions to the same problem. However, the intrinsic human nature being very much the same, effective solutions are likely to work universally. It is possible for effective frameworks and working models to be extended to any part of the world, keeping in mind the cultural differences, the present-day scenario in terms of finances and human resources and the existing local mental health facilities in mind.

Though small in numbers, effective, independent models like day care centres, rehabilitation centres, counselling centres are doing good work in different parts of the country, but they are not part of an integrated system. Usually there are no follow up facilities. Many psychiatrists work in isolation without even counselling support. The need is for a continuous system to cater to the changing needs of the person suffering from

mental illness. Help is also needed in the areas of housing, vocational training, work etc., to address their basic needs. Experience demonstrates that unidimensional solutions, which address any one area of concern, do not meet the overall needs of people with severe and persistent mental health problems. Comprehensive, accessible, multidimensional service approaches are needed for the intended outcome of recovery.

Under the National Mental Health Plan, The Indian Government is in the process of implementing a District Mental Health Program (DMHP), started in 1996, in nearly 123 districts in the country and eventually in every district. Under this program primary healthcare people and health workers are being given short term training for diagnosis and treatment of prevalent common mental illnesses with the aid of limited number of drugs and also severe mental disorders with support and guidance from specialists. Each centre is to have a psychiatrist, a psychiatric social worker, a clinical psychologist and a psychiatric nurse. These centres apart from treating and counselling patients, work in the area of spreading awareness and acting as a backup referral service for the people visiting them. Future plans include proposals in the area of mental health promotion and prevention. This includes counselling and life skills education in schools, counselling in colleges and work places and suicide prevention.

- Funds are being allocated for creating Centres of Excellence which will train the manpower in the field of psychiatry and associated disciplines. Other functions will be provision of comprehensive mental health services and research. These will be linked with the existing mental health facilities like National Institute of Mental Health and Neuro Sciences (NIMHANS) - Bangalore, Central Institute of Ranchi etc.
- Replicating effective systems from our own country and from elsewhere and implementing new organic models, at the moment, faces many challenges:
- Lack of available funds for the cause.
- ✤ Acute shortage of medical professionals in the field of psychiatry.
- Lack of awareness of the illness amongst patients and their families. Hence lack of their effective participation in the recovery process.

- An ongoing stigma and fear of people related to mental health issues which leads to service approaches that seek to control and manage the affected person rather than empower them.
- This stigma also contributes to the lack of willingness of affected people to come out into the open with the problems they face. Hence the near absence of peer support. A sense of embarrassment causes them to cut themselves from their social circles, quite unaware of the impact of social and interpersonal factors on mental health.
- Lack of integration within the mental health system and primary healthcare and social systems. Hence the inability of support systems in addressing the overall needs of the person in a well-coordinated and accountable manner.

This creates the need for a well articulated framework which clearly identifies the real needs of a person affected by mi and his/her family and aims at addressing them effectively with the available resources and developing and evolving new resources. From this framework hopefully an integrated, holistic, community based mental health system will emerge, with consumers and families as full partners, along with mental health service providers and generic social groups, in the process of evolving and operating the system.

# THE FRAMEWORK

# THE PHILOSOPHICAL BASE AND CONCEPTUAL MODELS:

Clearly understanding the

## NEEDS

of a person with mental illness,

## the **RESOURSES**

needed to satisfy these needs and

their appropriate linkage is of primary significance and the basis of this framework.

## NEEDS

When we think in terms of the needs of people with mental illness, it is quite obvious that their BASIC HUMAN NEEDS would continue to remain the same as anybody else. The onset of mental illness is bound to create some ADDITIONAL NEEDS. We need to understand each one of these with clarity. The identification of needs here is done on basis of commonsense, general observations and reference to frameworks for mental health of some other countries.

### I) BASIC HUMAN NEEDS:

As humans we do have some basic needs and expectations.

### A) PHYSICAL NEEDS:

We need to satisfy our hunger and taste, wear suitable clothes and have a decent home. It gives us the feeling of prosperity. We like to be in a state of good health, which means access to healthy food and proper utilization of the body/exercise. This is essential for a sense of well being.

### B) EMOTIONAL/PSYCHOLOGICAL NEEDS:

In general people desire a fulfilling life in their family and community. We like to connect with our relatives, friends and society for which we need means of communication and travel. These needs are quite basic to our sense of belonging, feeling of being connected and sense of security. So are meaningful family and social relationships. mutual affection, trust and respect in these relationships can be a source of great joy to us. We are constantly drawing from the natural recourses around us and enriching our environment can be a very rewarding experience as well. We have certain expectations as citizens of a country and a desire to make a contribution. Experience shows that reciprocal relationships give us a feeling of satisfaction.

#### C) SPIRITUAL NEEDS:

To understand our own selves, others, our relationship with them, laws of nature, our relationship with the rest of nature, the purpose of life, goals in life etc., are questions that we are all constantly struggling with. The questions themselves differ for all of us. The journey may be different for every person. Our own personal experience and understanding, culture, tradition, family values, situation in life, inputs from various spiritual groups etc. contribute to our quest to understand life. The clearer our understanding, the clearer are our short term and long-term goals in life. This clarity gives a sense of purpose in life and a feeling of lasting happiness. Professionals and society need to be sensitive to this and the diversity that they might encounter from person to person in this area of need.

When the basic human needs are adequately addressed, they are likely to be a solid foundation for recovery. They also seem to be the basic elements for mental health promotion. Addressing these basic human needs will necessarily lead to both – promoting sound mental health and recovery from mental illness.



### **BASIC HUMAN NEEDS**

## SOLID FOUNDATION FOR RECOVERY/ELEMENTS OF MENTAL HEATH PROMOTION

PHYSICAL NEEDS	EMOTIONAL/ PSYCHOLOGICAL NEEDS	SPIRITUAL NEEDS
Food	Self - actualization	Understanding self, others, human-human relationships
Clothing	Reciprocal human-	
Shelter	human relationships	Understanding nature and our relationship with it
Means of travel, communication and leisure.	Enriching nature & environment while drawing our life supports from it etc.	Finding purpose and meaning in life
Good physical health etc		Gaining clarity on one's goals in life etc

## COMMONLY OBSERVED OUTCOME OF THE BASIC HUMAN NEEDS BEING ADEQUATELYADDRESSES:

- Feeling of prosperity and well being;
- ✤ Feeling of connectedness, security and satisfaction.
- ✤ Sense of purpose and meaning in life and of lasting happiness.

## **II) NEEDS OF A PERSON WITH MENTAL ILLNESS AND HIS/HER FAMILY:**

When it comes to physical illnesses, while they come with their own sets of discomforts and implications, it is a lot easier to deal with them since we understand them. We can find reasons to why they happen - germs, genes, hormones, age, lifestyle etc. Most illnesses don't even affect all areas of our lives either - for instance we can continue to have meaningful relationships, earn a living, have fun and learn to make a life in spite of or despite the illness. But when it comes to mental illness, especially severe/chronic mental illnesses like schizophrenia, bipolar disorder, anxiety disorders and OCD, the story changes. Firstly, we can't seem to pin it to any reasonable, logical cause. Which then leads to a lot of speculation. And since the manifestation of the disease shows up as behavioural changes, it more often than not, without proper understanding, ends up pointing to a dysfunctional family set-up. The natural outcome of this lack of proper understanding of the illness amongst families is feelings of fear, guilt, shame, blame, worry and denial. Secondly it seems to affect every possible aspect of one's life.

The need arises for healing not just for the affected person but for the entire family, at the physical, emotional, social and spiritual levels.

### A) BASIC HUMAN NEEDS:

It goes without saying that the basic human needs of the affected person continue to remain the same. Continuity of these needs being satisfactorily addressed can be a solid foundation for recovery. They also happen to be the elements of mental health promotion.

#### SPECIALISED NEEDS OF A PERSON WITH MENTAL ILLNESS:

Understanding and acceptance of mental illness; treatment and psychosocial supports; selfreliance and recovery.

#### B) UNDERSTANDING AND ACCEPTANCE OF MENTAL ILLNESS:

A genuine effort to understand mental illness is crucial for initiating the process of recovery. The affected person and the family need to understand the illness, its symptoms and manifestation, the options available for treatment and healing etc., to be able to make informed choices. The possible impacts on one's social situation and identity need to be confronted and dealt with.

There is a gap to be bridged between intellectual understanding and real acceptance. Real acceptance by the affected person and the family helps overcome internal stigma and qualitatively restore family relationships. Awareness and destigmatisation in society create

an atmosphere of social inclusion. overcoming stigma at all levels is a big mile stone in the path to recovery. Worry and desperation are transformed into hope.

#### C) TREATMENT AND PSYCHOSOCIAL SUPPORTS:

Early intervention – professional assessment, timely medication and the necessary psychosocial supports like therapies, supported education, vocational training, etc. can put the life of a person with mental illness, back on track.

Real life community interactions like participation in regular interest groups, spiritual and social groups are seen to play a significant role in the life of a person trying to recover from mental illness. The desire to seek informal supports and make contributions to the community seems quite natural. The thinking behind the mental health systems is fast changing. With the voice of the affected people and their families gaining strength, it is becoming clear that informal family and community supports go a long way in reducing the need for formal supports like therapies and hospitalization. It gives a sense of being in control.

#### D) SELF-RELIANCE AND RECOVERY:

A positive sense of self is a basic tool for dealing with mental illness. The important part is to separate the person from the illness, rather than seeing the illness as lifedefining and all consuming. This can help a person to continue to grow and be in a progress mode in life inspite of the illness. Developing one's skills and capabilities with necessary supports, helps people become self-reliant, being able to hold on to jobs/work in sheltered workshops, have an income, manage independent living, have a family life etc. Being able to find purpose and meaning in life and develop clarity on one's goals in life is a life transforming experience for a person with mental illness and paves the path to recovery.

## **NEEDS OF A PERSON WITH MENTAL ILLNESS**



### **BASIC HUMAN NEEDS:**

• Continuity of access to these needs

## **NEEDS RELATED TO MENTAL ILLNESS:**

Awareness, Practical Understanding and Acceptance of Mental Illness

- Understanding the illness symptoms & implications
- Real acceptance
- Understanding treatment options
- Understanding and confronting personal and social issues which surface

Treatment and Psychosocial supports:

- Professional assessment
- Medication
- Participation in choosing supports
- Continuity of real life community interactions

Self-Reliance and Recovery:

- Separating self from the illness
- Developing skills and capabilities
- Independent/supported work, housing etc.
- Freely drawing from family and community supports and making meaningful contributions.
- Inner transformation

# OBSERVED OUTCOME OF THE NEEDS OF A PERSON WITH MENTAL ILLNESS BEING ADEQUATELY ADDRESSED:

- ✤ A solid foundation for recovery
- Overcoming stigma; hope
- Sense of being in control of one's life
- ✤ A positive sense of self; resilience

The basic needs of the family of a person with mental illness are very much the same. Internal stigma and social stigma may lead to the family giving the affected relative the feeling of isolation or actually isolating them. It may also lead to their isolating themselves from their own social circles. This cuts them off from the social support systems as well. Understanding and awareness of mental illness, overcoming stigma, sharing their problems with near and dear ones and with others facing the same situation, peer counselling, education about mental illness and the options available, making informed choices, taking respite from care giving etc. are the specialised needs of the family. In the absence of these needs being met families experience burn out (a state of being completely stressed out).

# **RESOURCES:**

We have borrowed the conceptual models for resources, almost entirely from the Canadian Mental Health Association's third edition of "A Framework for Support" by John Trainor, Ed Pomeroy and Bonnie Pape. This framework has conceptualised the resources needed by a person with mental illness and the mental health system with great sensitivity.

There are of course changes to suit the Indian context and our thinking as a group. For instance, the families are the single largest group of life-long caregivers providing support to the mentally ill, in the absence of sufficient state supports in our country. Hence, we have given much more importance to understanding family resource. It is important to understand that this crucial resource, if not utilised effectively, could become a hindrance in the process of recovery. Also, the starting point with respect to awareness, understanding, financial and human resources, availability of professionals and service systems etc. are different in the Indian context.

The Framework Proposes Three Conceptual Models of Resources, to address the goal that -

"PEOPLE WITH SERIOUS MENTAL ILLNESS CAN LIVE A FULFULLING LIFE AS A NATURAL PART OF COMMUNITY."

### THE COMMUNITY RESOURCE BASE:

The paradigm shift in the way mental illness and the mentally ill are perceived today has naturally caused a shift in the kind of supports and services considered necessary for recovery. In keeping with the present- d a y paradigm of empowering the affected individuals, community resources needed must grow in magnitude and importance in the process of recovery. Service and non-service approaches like generic services which include treatment options, housing, education and jobs are recognised as part of solutions. This can ease the burden of the illness, on the affected individuals and the families.

In the absence of sufficient mobilization of the necessary community resources, families continue to be the most significant resource in the Indian context. Family relationships are very important to all of us. In majority of cases even today, the families continue to be the sole unit responsible for the treatment, caring, emotional and financial support of the affected people for their entire life time. It is a great challenge for this resource to be used effectively. If families work in isolation and try to take complete responsibility of their affected relative, they are likely to get burnt out. The affected person is likely to move in the direction of dependence, looking at himself as inferior and incapable. If the responsibility is taken sensibly with the correct understanding of the illness and community support, while facilitating the affected individual to tap into his personal resources and move in the direction of self-reliance, the family resource can be a great asset.

#### THE KNOWLEDGE RESOURCE BASE:

A wide variety of knowledge addresses the issue of mental illness. This includes medical scientific knowledge, social sciences, traditional and cultural knowledge, spiritual knowledge etc. The experiential knowledge of the consumers and their families which is an outcome of direct experience of the illness is a very rich knowledge base available to us today to understand their real needs and create systems to address them. The most important issue is to provide the space for the voice of consumers, families, professionals and society to be heard carefully and using this knowledge effectively.

#### THE PERSONAL RESOURCE BASE:

Consumers sometimes have limiting views of themselves and very often community has very limiting views of the consumers as well. The professional outlook of the past saw consumers as passive receivers of care. This outlook is now replaced by the observation that they are well capable of being active, alert participants in their own recovery process. The systems and supports need to be in the direction of bringing out their strengths and capabilities, so that they can identify their own needs and aspirations and work in the direction of fulfilling them with these supports. The first step in the direction is to broaden our mental horizons, as families, as a society, to facilitate the mobilization of this resource in an affected individual.

#### FEATURES OF THE SYSTEM PROPOSED BY THE FRAMEWORK

Understanding the nature of the illness, any framework for supports has to lend itself to a system which is psychologically and geographically *ACCESSIBLE*. Severe mental illnesses especially when they are chronic in nature, require systems that are *COMPREHENSIVE and CONTINUOUS*, addressing all aspects and phases of the illness. The present- d a y trend of focusing on *COMMUNITY BASED*, informal supports in addition to the formal supports that are needed, also makes the recovery process *COST EFFECTIVE*. The Framework suggests a model with a *SINGLE POINT OF COORDINATION AND ACCOUNTABILITY* that directly or indirectly (through referral/supported referral services) provides access to assessment, medication, formal and informal supports like therapies, rehabilitation, education, work, income, housing, communication, leisure, legal advice, real life community participation etc... This can be of invaluable help to the affected person and the family.

#### THE FRAMEWORK AND MENTAL HEALTH PROMOTION:

Good mental health could be looked upon as a state where one is able to deal with day to day pressures of life with satisfaction and without getting stressed out. Though this is to a great extent a personal state of being, dependent on one's own understanding, some basic determinants of health, a conducive environment and effective inputs can facilitate sound mental health.

The framework model, although developed largely outside the mental health promotion field, has many elements in common with mental health promotion. It recognizes the importance of the knowledge and experience of people with mental illness and their families, emphasizes participation in decision making as well as power and control, and focuses on the promotion of mental health and the journey to recovery rather than on simply treating the illness. It can accurately be seen as a mental health promotion model for people with mental illness.

### THE FRAMEWORK AND RECOVERY:

Academic research and writings by consumers have successfully challenged the traditional belief that serious mental illness must by definition follow a chronic and deteriorating course, the new perspective is more optimistic and recognizes the reality of recovery. Recovery from Severe Mental Disorders may coexist with ongoing symptoms.

William Anthony, a leader in the field of psychosocial rehabilitation, talks about how recovery involves the development of new meaning and purpose in life as an individual grows beyond the catastrophic effects of psychiatric disability. It can be seen as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and roles and as a way of living a satisfying, hopeful and contributing life. Because recovery is often described in terms of gaining control over one's life and the illness (rather than the illness having control over the individual), recovery has significant commonalities with mental health promotion.

The recovery perspective is fully consistent with the Framework. The elements that support recovery, including meaningful daily activity (such as work or education); positive family / peer / social relationships; medications, recovery-oriented mental health services, housing etc., are put in a conceptual context in the Framework model. The model also encompasses the idea of a new understanding of the illness and of the individual capacity to cope with the challenges it creates.

### THE FRAMEWORK AND POPULATION HEALTH:

We are of the view that the population health is largely dependent on the basic physical, emotional and spiritual needs being satisfactorily addressed. Hence there are personal, social and environmental factors that determine health. Access to work, income, education, housing, communication, travel, leisure, peer and family support, healthy community interactions, reciprocal relationships, participation in social, cultural and spiritual groups etc., are examples of population health factors. Working with these factors helps in reducing the burden on, more formal mental health systems.

## THE COMMUNITY RESOURCE BASE (CRB):

### Developing Comprehensive Services and Supports

Community Resource Base assumes the perspective of the person in the centre; the person who is actually living and coping with a serious mental health problem. The vast majority of persons with mental illness live most of their lives in the family and community and are impacted by a wide range of factors besides mental health services. By looking at the whole process of people's lives the Community Resource Base model introduces a more comprehensive notion of what policy should seek to influence.

The formal service models have been underdeveloped in India. Hence in the Indian context one does not need to think so much in terms of a shift from hospitalization or hospital like services in the community to a full life in the community. One can actually start with the new approach which is called the "community process paradigm". It fully recognizes the importance of mental health services but goes further to include the role of families and friends, generic services and supports and consumers working together on their own behalf. It also acknowledges the fundamental elements of community to which every citizen must have access: housing, education, income, and work. Taken together, the components of the Community Resource Base comprise the various elements that individuals with serious mental health problems need in order to live a full life in the community and to maximize their potential for recovery.

### The Person in the Centre

The person with a serious mental health problem, as the focus of concern of the Community Resource Base, is central in the model. The central position implies that the person has opportunities to be an active participant in the community and has decision-making power about not only mental health services, but also about the choice of which of the supports of the Community Resource Base, if any, are the most appropriate at any given point in time. The centrality of the person also implies that the person, not the system, must be the focus of policy.

### The Community Resource Base: Map

## **COMMUNITY RESOURCE BASE**



The Foundation of the Community Resource Base – Housing, Work, Education, Income and other basic elements of Citizenship; Reciprocal Relationships.

# SELF-HELP GROUPS AND CONSUMER ORGANIZATIONS

An important resource, now emerging is that of the families and the persons with mental illness themselves. With adequate financial support and organizational training where necessary, affected people and their families can collectively meet many of their mental health needs. While self help groups exist in many other areas related to health and social issues, they are still quite rare in the area of mental illness in our country, the primary reason being the stigma related to mental illness. Self-help groups are known to offer profound benefits. They not only provide the opportunity to share emotional and tangible support, but they make use of people's own strengths and capacities as sources of help for others. Based on principles of shared experience, joint ownership and leadership, and free of monetary considerations, self-help represents a fundamental tool to allow people to work together and take charge of their own lives.

In several countries, one can come across consumer-run advocacy groups and networks, consumer-operated businesses, consumers training other consumers in skills development, and consumers developing a base of knowledge for themselves. So the focus is not just on mutual support but on a whole lot of other activities.

These self-help groups/organizations are different from formal mental health services in that all the activities are generated by and controlled by the consumers/families themselves, working together.

## **MENTAL HEALTH SERVICES**

Mental Health Services consist of the various hospitals, community agencies, and privatepractice based options available in a particular community. This mental health system of physicians, nurses, social workers, psychologists, occupational therapists, and other professionals is an important resource. It not only provides treatment, but often supports recreation, housing, and other aspects of community life. There is an acute shortage of this resource in our country.

Until relatively recently, the prevalent professional view was that people with serious mental illness had no hope of recovery, and the main roles of the formal mental health system were maintenance and control. This is no longer the case. A range of recovery-oriented approaches, such as early intervention, timely psychosocial rehabilitation etc. are now available, in some places in India. If these models are multiplied and new models from other countries are adopted, the formal mental health system can play a vital role in community support. It can give the feeling of being in control of one's life.

### **FAMILYAND FRIENDS:**

Families are the single largest group of caregivers, often providing financial, emotional and social support especially in our country, although their role generally goes unrecognized. Families, when organized, have the potential not only to support their ill relative, but to provide support to one another and to other families as well. Despite the importance of the role families play and the burden they carry, they receive almost no social and financial support.

Family relationships are important to all of us. The affection, trust and respect of family members and their informal supports go a long way for a person to have a positive sense of self, a sense of belonging and security. It is also probably one of the most significant

resources available for recovery. On the other hand, it can also become a hindrance to the recovery process. This depends largely on the way the family perceives the illness itself and the affected relative and also the availability or non-availability of supports.

It is important for the caregiver to continue to be the centre of his own life rather than being so overwhelmed by the problem that his affected relative becomes the centre of his life. The support that the caregiver then extends would go in the direction of helping the relative to become self-reliant. The caregiver can continue to live his own life to the fullest, fulfilling his own desires and aspirations as well. This can be a satisfying experience for the caregiver and the relative. In this there is healing for both. This is possible only if along with the psychiatric professionals, the extended family and society accept the problem and share the responsibility of participating in the recovery process by providing the formal and informal supports and services needed by the affected person during the course of his life. The inclusive approach of the society also gives an opportunity to the affected person to express himself in terms of his skills and capabilities in real life community interactions.

The quality of relationship between a person affected by mental illness and their family / caregiver is conceptualised below:

## **Family Dynamics**

### Broadly There Are Three Possibilities:

I) Reciprocal / Mutually fulfilling relationship between the person affected by mental illness and the family.

- The affected person and the family understand and accept the illness and act out of this understanding.
- They give up stigma in their own hearts and share the problems they face with near and dear ones and caregiver groups and seek help in caring for the affected relative.
- The caregiver continues to be the centre of his own life, fulfilling his own desires and aspirations besides looking after the relative who is affected my mental illness.
- The family members and the affected relative continue to treat each other with love, affection, respect and trust. This can be a strong foundation for recovery.

- The family and the affected relative have the vision of recovery and the family continues to see the relative in terms of his strengths and capabilities.
- The family sees the affected relative at the centre, providing him with an opportunity to fully participate in the choice of supports and facilitating the relative to mobilize his personal resources for becoming independent and selfreliant.

## **DESIRABLE SITUATION**

- II) Stressed out family taking complete financial, social and emotional responsibility of the affected relative and making him completely dependent.
  - The family/affected person do not truly understand or accept the illness; is not able to overcome internal / social stigma.
  - The family sees the affected relative as incapable, inferior and dependent. There is no vision of recovery.



- The family isolates the affected relative and themselves from extended family and social circles.
- The family tries to hide the problem and to deal with all aspects of the problem themselves without sharing.
- Supports are not available

Usually in such cases the family is so stressed out that they stop living for themselves and the affected relative becomes the centre of their lives. In the process a lot of guilt and anger circulates. The affected person feels inferior, incapable and dependent and the family eventually can experience burn out.

## UNDESIRABLE SITUATION



III) Stressed out family disowns or isolates the relative.

The family and the affected person are both unable to understand or accept the illness.

- The family / affected person are unable to overcome internal / social stigma.
- The family is unable to cope with the affected person's emotional / financial/ physical needs and disowns or isolates the affected relative.
- Supports are not available.
- Consequently, the affected person is either homeless or incarcerated for life with no family support.

## **UNDESIRABLE SITUATION**

For many people, informal networks of friends or neighbours fill the same functions as families. These networks provide a variety of supports and the opportunity for reciprocal relationships not usually found in the system of formal services.

### **GENERIC COMMUNITY SERVICES AND GROUPS**



For many people, generic social services such as welfare benefits, public housing, and family services are even more important than formal mental health services. But there is practically no access to such services in our country yet. Generic social services should be figured into any discussion of community resources, as their role in the lives of people with serious mental health problems is significant. For example, when income supports are inadequate, or the episodic nature of mental illness is not recognized in income support policies, the impacts on people with mental illness can be devastating.

In addition to services, there is also a rich network of generic groups and organizations that contribute to life in the community. Spiritual organizations, addressing human life related questions; interest-based groups (such as gardening clubs, sports clubs), and service clubs (such as Rotary club) provide the opportunity for meaningful involvement in community life that is outside the realm of mental health or professional services.

#### THE FOUNDATION:

The foundation of the Community Resource Base is made up of the Elements of Citizenship, as also Reciprocal Relationships. People with serious mental health problems, like everyone else, need to be connected to the natural community through a web of supportive contacts. Without the fundamentals such as jobs or other productive activities, good housing, appropriate education, and adequate incomes, opportunity for reciprocal relationships, people are pushed to the margins of society and deprived of the kinds of support that they need if they are to survive the challenges of living with a mental illness. In addition to these basic needs, there are also other important factors, such as recreation and leisure, which contribute to a full life in the community.

The foundation, by underlying and giving context to the Community Resource Base, emphasizes the fact that all services and supports must work to enhance the individual's role as a human being, a family member and a citizen. It can also be seen as a grouping of social factors that determine mental health, consistent with the health determinants which satisfy the physical, psychological and spiritual needs of a person. **The Community Resource Base: Implications** 

### Shifting the Perspective

Community Resource Base suggests that the perspective of the person in the centre is paramount and must be considered by all the stake holders. Policy

development and program delivery has to start by listening to the people with mental illness.

### Drawing on a Range of Resources

The Community Resource Base is an ideal picture of the range of resources that should be available to a person with serious mental health problems. If a person is to live a full life in the community, all the resources in the Community Resource Base must be mobilized.

#### Moving Beyond the Service System

The Community Resource Base shows that many resources beyond formal services enrich people's lives. Equally important are the informal supports of family, friends and community, access to income, housing, jobs and education, and the solidarity that can come from membership in consumer groups and organizations. As a result, the Community Resource Base implies a shift from the services paradigm to the community process paradigm.

#### Forming New Partnerships

The presence of four balanced sectors implies that they work in partnership to support the person in the centre. While each sector provides its own unique kind of support, each must also recognize the importance of the others, and work to enhance the strength that all can provide together.

### Having the Power to Choose

The Community Resource Base is not just about support, but about participation and choice. The person in the centre has the power to make choices about which resources, if any, to utilize, and can participate fully at the decision-making level in all areas of community life.

#### Planning Mental Health Services

All the sectors of the Community Resource Base need to be involved in the mental health planning.

### Developing Comprehensive Strategies for Change

Those interested in mental health reform must remain aware of all aspects of the Community Resource Base when selecting targets for advocacy. Perhaps it is the service system that most needs to be in place and targeted for a paradigm change, but in other instances it may be generic community organisations, religious and spiritual groups, employers or educators who need to be targeted to promote access for people with mental health problems. In addition, action can be taken to help make generic services such as disability benefits more sensitive and accessible to people with mental health problems.

## THE KNOWLEDGE RESOURCE BASE (KRB):

### **Developing a New Understanding of Mental Illness**

Deinstitutionalization was a result of intended humane and idealistic goals but failed to achieve the desired result of recovery because though the people with mental illness were brought into sharper focus, they were seen as passive recipients of care and a charitable cause. They were not included as empowered partners in the ongoing process of providing services and supports. Now, in addition to receiving services, consumers are being recast as providers of these services, and as operators of their own base of organizations. The other reason that came in the way of recovery was the poverty of our vision. The answers to the fundamental questions – what is mental illness? How do we react to it? - play a crucial role in shaping our action. In our country professional support is not easily available. In most countries the tendency has been to assume that the answers come largely from professionals. The psychiatric and professional perspectives are very important, but other sources of knowledge exist and recognizing them can greatly enhance our understanding. There are other voices to be heard.

We need to understand mental illness in a richer, more complete fashion, and to understand it in a way that furthers our ability to support people affected by it, as fellow human beings and valued citizens. This means that building knowledge is not simply an abstract, academic pursuit. We need to build knowledge that is about something, and that something is people with mental illness living full lives in our communities.

For people with mental illness, who are often living on the margins of society and are subject to offensive and stigmatizing messages in day-to-day social life, the need for knowledge that can bring them a greater measure of freedom and dignity is a real and concrete issue. Thinking of research in this more focused way, and tying it to emancipation and empowerment, opens the door to building a richer understanding of mental illness.

The Knowledge Resource Base (KRB) is the conceptual foundation for building this richer understanding and is made up of the types of knowledge that are available to

understand and make sense of mental illness. The Knowledge Resource Base was developed using a mapping approach aimed at identifying all the sources of knowledge that we actually use in everyday life. It is an attempt to go beyond the notion that real knowledge is only in the hands of the clinical experts, and that others (such as affected people, families, and the public) have little to contribute. By recognising this wider field of knowledge, its goal is to promote a constructive dialogue that will lead to a more balanced and comprehensive understanding of mental illness.



### The Knowledge Resource Base: Map

The Foundation of the Knowledge Resource Base – Recognition of Diversity, Mental Health Literacy, An Enriched Range of Services and Supports, and Social Acceptance and Inclusion.

# MEDICAL / CLINICAL KNOWLEDGE:

The medical/clinical knowledge base pertains mostly to psychiatry and clinical psychology. Their findings are incorporated by social work and nursing. The emphasis is on drug treatment, and psychotherapy. Important work is being done in the area of understanding the brain and the underlying mechanisms that are at work. Clinical nutrition is beginning to contribute new knowledge. Many more disciplines are likely to emerge in future.

### SOCIAL SCIENCE KNOWLEDGE:

Social sciences such as anthropology, sociology and community psychology have developed important perspectives on mental illness. Social scientists study the influence of the social context. They are interested in such factors as social groups and classes, and the impact on mental health of variables such as unemployment, homelessness, and poverty.

While clinical approaches have traditionally used individual therapies to treat depression in women for instance, social scientific perspective, might look at the social factors that shape the lives of women and affect their mental health. High rates of poverty, job discrimination and psychological and physical abuse are seen as fundamental factors in explaining depression and in determining a practical course of action. In practice, many mental health professionals combine medical / clinical and social science perspectives.

### EXPERIENTIAL KNOWLEDGE:

Affected people live with mental illness and know it more intimately than scientists or professionals who lack direct experience. They know it from the inside. Their knowledge ranges from the immediate reality of symptoms to the impact of mental illness on their lives in the community. From this perspective, they know what mental illness is in a very important way. Though they are increasingly documenting their experience, this information is too often dismissed as anecdotal, rather than recognized as useful source of knowledge.

To a person suffering from mental illness, its symptoms are a profound personal

experience. While we often assume that the medical explanation tells the real story, and that the affected person's direct experience is just a result of a chemical imbalance, this is often not the case. If a person develops severe mental health problems as a result of life events such as childhood abuse, loss of loved ones, or other external factors, the real story of their symptoms is not just in the brain chemistry. It is also in their life. Even if, in another case, the direct cause of the illness has to do primarily with brain chemistry, the experiential component is essential to a full understanding of what is going on and to effective intervention.

The families of persons with mental illness can contribute in their own way to the experiential understanding. Although organized family groups have tended to adopt the medical / clinical perspective, as individuals, these same family members have extensive knowledge of the day-to-day realities of mental illness. They see the impact on loved ones, and what it means in a larger life context. This experience has led family organizations to become strong advocates for access to education, work, and full participation in community life in many countries. Their insight into the fact that a full understanding of mental illness includes recognizing the way in which illness and life circumstances interact is a valuable addition to our understanding.

### CUSTOMARY AND TRADITIONAL KNOWLEDGE:

This category refers to a variety of ideas and concepts about mental illness. Customary here means the kind of knowledge that people receive informally from family, friends, and their community, but not from organized formal systems such as medicine and social science. Included are such components as public attitudes and the conventional wisdom of understanding and responding to the people who are affected by mental illness.

Anyone, in any society, is exposed to customary and traditional ideas. If we talk to a cross section of people who have no direct experience as consumers and no scientific training, their knowledge and understanding of mental illness will reflect customary and traditional knowledge. For example, they might believe that people with mental illness need support from their family and friends, and meaningful tasks to occupy them during the day. Unfortunately, they might also hold rather derogatory or stereotype notions of mental

illness that will stand as barriers to meaningful integration of consumers into the community.

Also culture specific traditional knowledge like the knowledge of yoga in our country and its impact on the recovery process are being studied by various groups including NIMHANS (National Institute of Mental Health and Neurological Sciences, Bangalore). The tradition of introspection (through meditation) with its intention of getting in touch with unconditioned reality, and its impact on recovering from mental illness is also being experimented with and is a valuable source of traditional knowledge. Ayurveda is another rich source of traditional knowledge in medicine in India. Various countries are likely to experiment with traditional methods of healing, which can become a valuable source of knowledge for all.

### THE FOUNDATION

The foundation of Knowledge Resource base is made up of the outcomes of a more comprehensive approach to knowledge and of the impacts that such an approach will have. The foundation grounds the Knowledge Resource Base in ways that are helpful and practical to both people with mental illness, families and service providers.

### THE KNOWLEDGE RESOURCE BASE: IMPLICATIONS

#### Recognising Variety

The Knowledge Resource Base brings into focus the various types of knowledge that can contribute to an enriched understanding of mental illness. In the past, some of these have been ignored or undervalued.

### Building A Rich Resource

The components of Knowledge Resource Base represent a tremendous accumulation of experience and knowledge. Taken together, they form the base from which society can transform and enrich its understanding of mental illness.

### Developing a Critical Analysis

The components of Knowledge Resource Base, all have strengths and weaknesses, and there are many examples that illustrate the need for critical analysis. For example, medical/ clinical approaches have often stressed a narrow illness model. One result has been an inadequate understanding of the complex issues of day-to day life for the people with mental illness and an overriding emphasis on drug and hospital treatment. Another example is the negative aspects of some customary and traditional knowledge. Public attitudes to mental illness may have many inaccurate and dubious features, as well as positive and humane ones. All the components of the Knowledge Resource Base need to be analyzed for the positive contributions that they can make.

#### Taking Down the Barriers

By providing the map of the various types of knowledge that contribute to our understanding of mental illness and of mental health, Knowledge Resource Base highlights the need for better communication. The need for better communication highlights the need to remove the barriers that restrict our current thinking about mental illness. The full value of listening to other perspectives can come only if we actively attempt to integrate them into new and more balanced perspectives. Dialogue and mutual learning are the cornerstones of this process.

#### Moving Forward

The Knowledge Resource Base, with its emphasis on a balanced understanding of mental illness, sheds light on the most fundamental problem faced by the affected people today. On the one hand, the treatment standards, facilities, hospitals, rehabilitation centres, counselling centres are insufficient and geographically not accessible to large populations in need. Such people continue to be dependent on their families all their lives or are homeless. The prevalent picture is that of poverty, unemployment and despair. Society is predominantly rejecting of people with serious mental illness.

There is lack of awareness and commitment to building blocks of community life such as housing, income, work and an inclusive approach which would allow free community
acceptance. From the perspective of the Knowledge Resource Base, our limited understanding of people with mental illness as humans and citizens with the same hopes and dreams as anyone else lies at the heart of this contradiction. The current situation represents a biased and imbalanced use of the information available. The social, scientific, experiential, and traditional components have been largely ignored in favour of an overriding emphasis on medical/clinical knowledge and the institutional models, that it generates. At the street level, this has left large number of affected people living in poverty on a day-to-day basis. We are beginning to understand people with mental illness as patients, but only dimly as fellow human beings and fellow citizens.

Though a vast knowledge base is now available, the gap between understanding it in theory and actually translating the resource along with other resources, into an effective action plan and then implement it, is a challenge. From a variety of sources, including international research of schizophrenia, the writings of consumers, and research with families, it now seems clear that there is nothing more damaging to someone trying to deal with mental illness than the cut off from a meaningful life in the community. Even the best service system cannot overcome this. According to WHO, Western countries have worse outcomes for schizophrenia than some traditional areas in developing countries. Although treatment resources in these countries, as also in our country are very limited, the ability to include people, and to recognize their potential as well as their fundamental humanity, is enriched. This is seen largely in rural areas in India too where the affected people, as they lack social skills, are considered to be simple and gifted. Hence, they are included as natural part of the community.

## PERSONAL RESOURCE BASE (PRB):

Developing a New Understanding of the Personal Resources Needed to Deal with Mental Illness

People with severe mental illness carry the extra burden that the illness creates, while responding to personal needs and social expectations. The symptoms of depression, for example, or the cognitive problems associated with schizophrenia, in and of themselves creates challenges for the person coping with them. A second kind of burden is the negative social attitudes, discrimination, and stigma that are externally imposed and make success in personal and social life, even more difficult.

Common sense suggests that the affected people need to be equipped with significant personal resources to face the burdens imposed by mental illness. An enlightened mental health system would both treat illness and support the resiliency and personal strengths of those who deal with it. The past perspective painted people with mental illness entirely in terms of their illness and its deficits and saw them as passive recipients of care. The only positive characteristic that they could be perceived to possess was compliance.

The capabilities of persons with mental illness, to work, lean, form relationships, live independently, and to recover were underestimated by professionals, as was their ability to manage the illness and understand it. This poverty of imagination was shared with affected people and their families and created an atmosphere of disability that weakened the very resources that are most needed to survive and prosper.

This perspective is fast changing with the affected people, families and some progressive professionals creating other ways of seeing people with mental illness. The most significant critique is from the affected people themselves. They have written often and eloquently about the experience of facing life with a mental illness, and their words richly capture the struggles, victories and defeats of the process. They speak of hope and resilience, of strengths gained and increasingly, of recovery. The people with mental illness no longer see themselves as passive recipients of care, but rather as actors working to achieve understanding and control of their own lives.

The Personal Resource Base is a way of reflecting these important changes. Its goal is to consolidate the gains made and to support further progress. The Personal Resource Base creates a new model for how the affected people see themselves and how they can be seen by others. It is based on a balance between the reality; challenge of illness and the resources that are needed to deal with it and still live a full life. It graphically represents a fuller view of people with mental illness, by emphasizing more than just their mental health problem. The components, taken together, describe someone who feels a sense of control over their life – a critical element of mental health for all people. In this way the PRB directly reflects the approach to recovery that has been developed by the affected people themselves.

#### Personal Resource Base: Map



**PESONAL RESOURCE BASE** 

The Foundation of Personal Resource Base – Hope, Resilience, Confidence and Well Being

# A Practical Understanding of the Illness

People who have confronted the illness must make sense of the complex array of factors. The direct experience of the illness and the reactions the it elicits in family and peers need to be absorbed and understood. This process can help or hinder a person's ability to deal with the situation. Making sense of the experience involves at least three factors:

- The experience itself must be explained and classified;
- Its meaning for a person's sense of self and identity must be dealt with (for example, does the presence of the condition mean that one is damaged or inferior, or perhaps, as in some traditional cultures, that one is gifted);
- The impact on an individual's social situation and expectations must be confronted.

The result of this process of coming to grips with the illness are vitally important. As a person's own background and experience mix with input from family, friends, and professionals, an image of the illness and its impact begins to form. To do well, consumers need to develop a practical understanding of the illness. Doing this can lead to two positive results; strategy to stay well, and a plan of action when ill.

A practical understanding may involve more than simple illness education. A person with recurring bouts of serious depression will certainly need to know about the signs and symptoms of the illness, and what treatments will provide relief. If, however they are living in an abusive relationship, or have had a major loss in their lives, they also need to be aware of the impact that these contextual factors can have. In this sense, a practical understanding of the illness includes the kind of knowledge that will prevent a complex social situation being reduced to an isolated medical illness.

## A Positive Sense of the Self

Developing a positive sense of self is a basic tool for dealing with mental illness. Critical to this is the ability to separate the illness from the person. The labelling and stigmatizing of mentally ill people can result in an over-identification with the illness and a sense that it is all consuming and life-defining. To challenge this is not to underestimate the impact of psychiatric conditions, instead it follows the lead given by consumers in their effort for recovery and dignity. Many consumers end up with what has been called a damaged self – a sense that they are, as people, broken in some way. Putting the illness in its place is essential to counteracting this. A key part of the Personal Resource Base is the development of a sense of self that is separate from the illness and that is seen as having value and the chance to grow and develop throughout life.

### Purpose and Meaning

All people strive to make sense of their lives and to develop a sense of purpose and meaning. People with mental illness have the extra challenge of doing this in the face of an illness that has traditionally robbed them of self worth and dignity. A sense of coherence – sense that life generally is predictable and can be expected to work out reasonably well or, in other words, a feeling of some control – is vital to mental health as well as to coping with mental illness.

What comprises purpose and meaning for a particular individual may vary greatly. The development of spirituality, and understanding of life, of human values, an understanding of relationships, a feeling of contributing to collective life as a citizen, clarity of ones goals in life; all these and many other factors may enter the picture. The challenge for the professionals and the society to be sensitive to this. True social inclusion would mean free participation of the mentally ill in all spiritual, cultural and social groups to help them find their answers like the rest of us.

# Inclusion and Belonging

Mental illness is a very alienating experience for the people affected by it. Social rejection may combine with an inner sense of isolation to exacerbate the challenges posed by mental illness. A sense of inclusion and belonging, on the other hand, can limit the impact of the illness and its capacity to separate the affected person from full participation in social life. Inclusion and belonging are the result of a complex

interaction of factors: the illness, personal attitudes, and social circumstance as experienced by the affected person.

For most people a sense of inclusion is not simply a fixed characteristic of their personality but is dependent to an important degree on day-to-day interactions and messages received from others. Being in a position to receive these messages means being integrated into a series of social contexts. Our sense of inclusion and belonging is directly related to these social identities, for example in the workplace, in our families, and in settings such as religious and spiritual institutions and service clubs etc. In the past, the impact of mental illness was overestimated and many routes to inclusion and belonging were blocked. Work for example, which many people see as essential to a positive sense of inclusion, was considered unrealistic for people with serious mental illness. Other social roles were also considered closed with the result that the building blocks of inclusion and belonging were missing. Developing a range of positive social roles is an important part of changing this.

#### THE FOUNDATION

The foundation of the Personal Resource Base focuses on essential outcomes that contribute to recovery.

#### THE PERSONAL RESOURCE BASE: IMPLICATIONS

#### Recognising the Essentials of Mental Health

The mental health needs of people who have experienced a mental illness are no different from those of anyone else. We all need a home, a job, a family and a friend, a fact that has been articulated most clearly by the people affected by mental illness. The basic human needs remain very much the same. In addition, knowing that we are valuable and important to ourselves and others, having a sense of why we are in this world and what we are striving for, and feeling that we have a clear role and place to belong, all contribute to our mental health, no matter who we are. Even a practical understanding of the illness can be generalized to the broader population. No one gets

very far in life without experiencing setbacks, crises, and even tragedies. Having the tools for understanding and dealing with these challenges is another essential element of mental health. Thus, the categories of the Personal Resource Base describe resources that are essential for mental health in general, and hence are common to all people, not just those with mental illness.

## Building a Sense of Control

The feeling of being at the mercy of factors beyond our control is a recipe for stress, depression, and poor mental health in general. Unfortunately, this is too often the state in which people with mental illness find themselves. But all the components of the Personal Resource Base can add up to a sense of control over life. Even though not everything in life is controllable, with the right set of tools and resources in place it is still possible for people to make choices and take action on their own behalf. Knowing where we belong and where we want to go in life, feeling good about ourselves, and having the knowledge to deal with our particular challenges all contribute to a sense of control. And a sense of control, whether in regard to service options, workplace issues, or interpersonal relationships, is perhaps the most important element of mental health for all people.

## Drawing on the Community Resource Base

The Community Resource Base (CRB) helps to answer the question of how to ensure the various personal resources of the Personal Resource Base are in place. For example, what contributes to a positive sense of self, meaning and purpose, or inclusion and belonging? It could be connections to a faith community or interest groups (found in Generic Community Services in the Community Resource Base); it can be achieved through participation in the self-help movement, or through employment or education. How does a person gain understanding of the illness or of any mental health setback or challenge? It can come through education from the formal mental health system, through talking with family or friends, or through sharing experiences in self-help groups with others who have been through similar situations. The components of the Community Resource Base strengthen the resources of the person in the centre; the PRB highlights the person to describe these resources in detail.

# Taking into Account the Time of Illness and Time of Life

Mental illness can strike a person at any age, but whatever their stage of life, it is the initial stage of the illness which is crucial. This initial stage brings a series of challenges such as developing a relationship with the illness, dealing with its impact on sense of self and place in the world, and with its impact on family and friends. The Personal Resource Base provides a map to key areas that should be kept in mind in terms of the time or stage of illness.

Time of life is also important. The onset of a mental illness poses different challenges to a person who is sixteen than to a person who is sixty. The support offered needs to address the impact of the illness within the context of the time in the person's life. A young person may need focused support in completing the process of character formation and choice of roles, whereas a person in a later phase of life may need support in reconciling their established social roles to the new constraints posed by the onset of illness,

The Personal Resource Base is a way of looking more fully at a person at any point in time, but the particular point in time is very important and should take into account both the time of illness and a person's time of life or stage of development.

## CONCLUSION

As a human species, we need to clearly understand some very fundamental things like health and happiness. While most of us would agree that we desire to be healthy and happy, the effort and time we put in the direction of understanding these on an average, does not reflect this desire.

The starting point for this framework is mental illness but what we also need to understand clearly is our destination, which is sound mental health.

Disease or dis-ease is widely recognised today as a stressed-out condition, with a physical or mental manifestation. What is it that stresses us? Looking within and around us, some of the wide spread reasons seem to be – unhealthy food, lack of exercise, conflict in relationships, low self-esteem, challenges posed by the changing phases of life (adolescence, parenthood, old age etc,), competition in education and at work, peer pressure, tragedies, failures, poverty, homelessness, to count a few. Unfortunately, our education at home and at school is generally lacking in preparing us to deal with these common challenges of life. An understanding of mutually satisfying relationships, of self-worth, of the common roles we play in different stages of life, of excellence (in which the motivating force is from within and not from competition), of prosperity, of purpose and meaning in life etc. can be of valuable help, as it gives us clarity on where we want to be. This can possibly help release the dis-ease.

The modern hospitals that are coming up in our metropolitan cities are an evidence of an economically prosperous urban society and a wealth of medical expertise in treating illness, but it is certainly not an evidence of a healthy society. While a lot of effort has gone into understanding physical illnesses and treating them, and with an increasing awareness of mental illness the same kind of effort is now being initiated in several countries in this area, let us not lose sight of the fact that what we really need to understand is good health – physical as well as mental. The 'Community Process Paradigm' is indeed a reflection of this realisation. Carefully listening to the affected people has revealed their desire to live life as a natural part of the community as anybody else. This is at some level a reflection of their understanding of sound mental health. The clarity that they have independently or jointly gained about where they want to be, has been the guiding force behind the paradigm shift that is now driving the community based mental health systems. The movement appears to be in the right direction.

We have come a long way from dismissing people with mental illness as incapable and dependent for life. The poverty of this vision is the greatest obstacle we have overcome atleast partially. We need to identify the real constraints of the illness and address them, while releasing the constraints which are imposed from the outside world, like the fear, stigma and a limiting view of a person with mental illness.

As a society we need to reach a point where a person with mental illness is accepted in society as a person with any other health problem, where the problem is recognised and treated, necessary supports provided, and the person continues to live as a natural part of the community.

1. NATIONAL MENTAL HEALTH SURVEY of INDIA 2015-16 (Implemented by NIMHANS, Bengaluru; Supported by Ministry of Health and Family Welfare, Government of India)

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### WORKING GROUP

Sarfaraz Ansari (Capt. Robby) – caregiver; organiser and volunteer worker in mental Healthcare

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Sujata (Mona) Kanwal – a researcher

Neeta Kishore – over 30 years of coordinator in Ohio State Mental Health System

Sanjay Seth – advocate with management background.

Rita Seth – caregiver, active participant in a caregiver's self – help group called Roshni

# **RESOURCE GROUP**

An international group of well – wishers and advisors with years of experience in Mental Healthcare

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