#### Session 9

# Mental health and development model: 60 minutes

# Objectives:

- To learn to look at mental health as a Development issue.
- To understand the essential needs of PWMI.
- To share Basic Needs India's mission, approach and work with PWMI.

# Exercise:

- 1. Divide the participants into groups of 4-5 persons and ask them to list what they think might be essential needs of people with mental illness from their experience of knowing persons with mental illness.
- 2. Invite the groups to share their lists in the larger group.
- 3. From your own work with people with mental illness, from the past consultations, share what they have expressed to be their needs. Combine all the lists.
- 4. Summarize the discussion by presenting the 'Mental Health and Development Model' of Basic Needs
- 5. Describe some of the highlights from BNI work in partnership with other NGO's.

#### Session 9

### Mental health and development model

Mental health and development is an innovative model. Basic Needs India (BNI) believes that how ever poor or ill a person is, he has the capacity to manage his or her life. It believes that people with mental illnesses have rights and are entitled to being treated with dignity and respect.

### Vision and Mission of Basic Needs India

 Basic Needs India seeks to satisfy the essential needs of all people with mental illness in India and to ensure that their basic rights are respected and fulfilled.  To initiate programmes in India which actively involve people with mental illness and their carers and enable them to participate in their own as well as development of the larger society. In so doing, it hopes to stimulate supportive activities by other organizations and influence public opinion.

BNI's underlying conviction is that "Mental Health is a Development Issue". Hence it aims at the active participation of community in creating a caring and understanding environment to ensure fair treatment to PWMI in the community. A holistic approach would include implementing the existing policies and advocating for new ones.

# Objectives of Basic Needs India is:

- To restore mental health and human dignity to PWMI and ensure that their rights are protected.
- To alleviate poverty through economically viable income generation activities.
- To carry out action research and disseminate the information to try and influence public opinion.
- To work with government organizations and NGOs in fulfillment of these objectives.

# **Basic Needs India's Approach**

- "Inclusion of mentally ill in the development process".
- Work as collaborators with CBOs, NGOs and the Government.
- Holding consultations with PWMI to plan programmes concerning them.
- · Matching resources with needs.

With the active participation of persons with mental illness, their carers\ families and CBO's, BNI has evolved a training model- 'Mental Health and Development Model that comprises five modules. These are designed to facilitate social integration of people with mental illnesses and the community adopting 'development' practices.

### **Community Mental Health**

The purpose of Community Mental Health Care is to assist PWMI to attain an adequate level of functioning to enable them to participate in a sustainable, self-reliant programme leading. Staff of NGO's are trained to identify persons with mental health problems and design a need-based care programme. Training is provided by the staff of BNI along with some external resource persons and organisations.

### **Capacity Building and Animation**

As Basic Needs India works as a catalyst through NGO's, it is important to build the capacity of local organisations to independently manage their community mental health and development programme. Project holders and staff are trained on an ongoing basis. The training equips them with skills to manage all the capacity building elements of the programme. The focus of this work is mentally ill people themselves and their carers. It gives them opportunities to come together at regular intervals to talk about issues relevant to them and to assist them in developing appropriate strategies and sustainable livelihoods. Capacity building will equip them with knowledge about their illness and the coping mechanism. Ultimately, the aim is to erase the stigma attached to mental illness so that PWMI have their rightful place in the community.

### Sustainable Livelihoods

Poverty is a consequence and cause of mental illness. Therefore, we aim to involve people with mental illness and their family members in economically productive activities. Using a group animation approach, mentally ill people are encouraged to find practical solutions to the problems that they have identified. Economic development programmes, appropriate to the individual or his family members, are designed. The CBO's are trained in identifying local resources and trades and the capabilities of the PWMI. Savings and credit groups, comprising of mentally ill people and their carers, are formed and appropriate links made to micro finance organizations and/or to locally based schemes run by the Government for disadvantaged people.

#### Research

Action research will be planned and carried out along with people who have experience of mental illness to understand their lives in the community. The NGO's will document their learning and experiences and disseminate this information to other interested organizations and individuals. The end product of research is to obtain knowledge that can help bring change in the lives of PWMI as well as push for better of mental health programs- both by the Government and the NGO's.

### Session 10

# CBR and people with mental illness: 45 minutes

- 1. Invite the participants to share their experience of community based rehabilitation work with disabled persons.
- 2. Explain community mental health and development programme and the activities under it.
- 3. Ask the participants to identify similarities and differences in CBR and community mental health and development work.
- 4. Summarize the discussion sharing your experience of including community mental health activities in the CBR programmes of NGO's.

### Session 11:

# Why community mental health: 60 minutes

- 1. Ask the participants what they think could be the number of people with mental illness (what is the percentage of people with severe mental illness, common mental illness, epilepsy and mental retardation)
- 2. Provide the actual information on prevalence of mental illness in the Indian population.
- 3. Provide information on the available mental health infrastructure for the number mentally ill persons in the country.
- 4. Ask the participants to share about the attitude of the community about people with mental illness.
- 5. Share your experience of working with people with mental illness and how the quality of life has changed after the intervention.
- 6. Describe the District Mental Health programme (Bellary model to 11<sup>th</sup> five year plan)

### Session 11 a

# Why community mental health - some observations

Community Mental Health is concerned with early recognition and treatment of the mentally ill as close to their homes as possible. It should, preferably, be in the form of an out -patient or day patient clinic, in a centre situated in the middle of the community. A short term, in-patient treatment facility should also be part of the set—up in community -based rehabilitation.

- One in four people suffer from a mental or neurological disorder at some time during their life. About 450 million people are currently affected with mental illness in the country.
- It is a major public health burden. Around 30-40% of people who come to the Primary Health Centre could actually be having mental or psychological problems.

- Some of the mental health care skills can be easily taught to people like doctors, nurses, health workers and CBR workers, so that care can begin locally in their own immediate environment.
- Mental illnesses are very disabling.
- Depression is the number two public health problem in the world (121 million).
- The mental health infrastructure in the country is highly inadequate.
- There is a lot of stigma attached to mental illness, leading to isolation and marginalization of the PWMI and the family and it thus becomes a vicious circle of poverty and more illness.
- Many mental illnesses can be treated with simple, relatively inexpensive medicines.
- A very small percentage of the mentally ill require institutional care.
- Early diagnosis prevents complications and promotes recovery
- Most disorders can be treated in the community and promotes early recovery
- Most people with mental illness with adequate and appropriate care services will be able to lead normal life and take care of their own life.
- Un treated mental illness in the person leads to disability and increases the burden of care for the family and for the state
- When services are located locally it has more reach to meet the needs of vast majority located in the community
- People lock or chain up the mentally ill family member, under pressure from others and/or due to helplessness and ignorance of how to manage the person.

### Session 7

# Prevention and promotional strategies: 60 minutes

# Objectives:

- To understand the scale of mental illness and its implications for the society and the affected family.
- To understand the possible causes behind mental illness the circumstances that increase the chances of mental illnesses.
- To become aware of the factors that can help improve mental health and prevent mental illness.

#### Exercise:

- 1. Ask the participants to list out what they think are the causes of mental illnesses.
- 2. Ask the participants to reflect on the causes that can be prevented.
- 3. List the factors/strategies that promote mental health as shared by the participants.
- 4. Summarize the discussion using the points in the power point presentation on the factors that promote mental health and those that can prevent illnesses and relapse.

# Session 7 Prevention of Mental Disorders

About 450 million people suffer from mental and behavioural disorders worldwide. One person in four is likely to develop one or more of these disorders during his lifetime. Five of the ten leading causes of disability and premature death, worldwide, are psychiatric conditions. Mental disorders represent not only an immense psychological, social and economic burden to society, but also increase the risk of physical illnesses. Therefore, steps towards prevention are urgently needed.

Economic costs of mental ill-health are enormous and not readily measurable. They include health and social service costs, lost employment, reduced productivity, impact on families and caregivers, levels of crime and public safety and the negative impact of premature death. There are other, hard-to-measure costs, such as the negative impact of stigma and discrimination or lost opportunity to individuals and families that have not been taken into account.

To reduce the health, social and economic burdens of mental illness, it is essential that countries and regions pay greater attention to prevention and promotion in mental health at the level of policy formulation, legislation, decision-making and resource allocation within the overall health care system.

### 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

- a) reducing the incidence and recurrence of mental disorders or the risk conditions for mental illness:
- b) preventing or delaying recurrences; and
- c) decreasing the impact of the illness on the affected person, his family and the society.

Prevention needs to be a multi-pronged effort. Social, biological and neurological sciences have provided substantial insight into the role of risk and protective factors in mental disorders and poor mental health. Biological, psychological, social and societal risk and protective factors have been identified across the lifespan, from as early as fetal life. Many of these factors can be targeted for prevention and promotional measures.

### Effective prevention can reduce the risk of mental disorders

There is a wide range of tested, preventive programmes and policies available for implementation. These have been found to reduce risk factors, strengthen protective factors and decrease the onset of some mental disorders. They also improve positive mental health, contribute to better physical health and generate social and economic benefits. These interventions illustrate that prevention can be cost-effective. (WHAT AND WHERE ARE THEY?)

### Prevention needs to be sensitive to culture and to resources

Current opportunities for prevention of mental disorders and mental health promotion are unevenly distributed around the world. International initiatives are needed to reduce this gap and to support low income countries in developing prevention knowledge, expertise, policies and interventions that are responsive to their *needs*, *culture*, *conditions* and *opportunities*.

### Effective prevention requires linking up with different Departments

Prevention of mental disorders and mental health promotion need to be an integral part of public health and health promotion policies at local and national levels. Prevention and promotion in mental health should be integrated within a public policy approach that encompasses horizontal action through different public sectors, such as the environment, housing, social welfare, employment, education, criminal justice and human rights. This will generate "win-win" situations across sectors, including a wide range of health, social and economic benefits.

# Protecting human rights is a major strategy to prevent mental disorders

Adverse conditions such as child abuse, violence, war, discrimination, poverty and lack of access to education have a significant impact on the development of mental ill-health and the onset of mental disorders. Actions and policies that improve the protection of basic human rights represent a powerful preventive strategy for mental disorders.

### Risk factors

- Failure in exam and feeling excessively discouraged by it.
- Access to drugs and alcohol
- · Caring for chronically ill patients.
- Child abuse and neglect
- Chronic insomnia and chronic pain
- Displacement of the community.
- Early pregnancies.
- · Emotional immaturity.
- Excessive substance use
- Excessive exposure to aggression, violence and trauma
- Family conflicts or family disorganization
- Isolation and alienation.
- Extreme deprivation and poverty.

- · Chronic serious illness
- Chemical imbalance in the brain
- Parental mental illness
- Rejection by friends.
- Personal loss bereavement
- Poor nutrition
- Poor social circumstances
- Poor work skills and habits
- Racial injustice and discrimination
- Reading disabilities
- Sensory disabilities handicaps
- · Stressful life events
- Unemployment
- Pressure caused by urbanization
- Loss of family support by separation.
- War
- · Excessive work stress.

Trainer notes: It is important to emphasize the vulnerability of the adolescents or teenagers to mental illness as over 55% of severe mental illness is contracted at that age. One needs to be extra watchful of that age group, if the risk factors are high.

### Protective factors which have to be strengthened

- Ability to cope with stress
- Ability to face adversity
- Adaptability
- Self-dependence
- Early stimulation of thinking
- Ethnic minorities integration
- · Regular exercise, games, fun.
- Feelings of mastery and control
- · Feelings of security
- Literacy
- Positive interpersonal interactions

- Positive parent-child interaction
- Problem-solving skills
- Encouraging good social behaviour
- Improving self-esteem
- Training in skills for life
- Social and conflict management skills
- Encouraging social participation, social responsibility and tolerance
- Social services
- Social support and community networks
- Social support of family and friends

•	Stress management

### Session 8

### Child and adolescent mental health: 60 minutes:

# **Objectives:**

- To identify and understand signs of emotional disturbance / mental illness in children and adolescents.
- To learn about the various mental illnesses that affect children.
- To help parents/adults in the family understand a child's problems and look at him as an individual.
- To try and plan early intervention to lessen or avoid mental illness.

### **Exercise**

- 1. Divide the participants into groups of 4-5 persons and ask them to share their experiences of seeing a child/ adolescent with emotional problems.
- 2. Invite the groups to share highlights of their discussions in the larger group.
- 3. Summarize the discussion explaining the following text in your own, simple words.
- 4. Read up the mental health problems of children and equip yourself to answer questions regarding 'difficult' children that might come from the participants.

# Session 8 Mental health problems in children:

It's easy to know when your child has a fever. A child's mental health problem may be harder to identify, but you can learn to recognize the symptoms. Like adults, children and adolescents can have mental health disorders that interfere with the way they think, feel, and act. Untreated emotional problems in children can lead to failure at school, family conflicts, drug abuse, violence, and even suicide. Any of these problems in children can be very costly to families, communities, and the health care system.

Pay attention to excessive anger, fear, sadness or anxiety exhibited by children or adolescents. **Sudden changes** in your child's behavior can be indicative of a problem - behavior like exercising too much, or hurting others or oneself or destroying things. Emotional disturbances in children show up differently when compared with adults. The

ways in which they communicate their discomfort will be different. Or, more often, it may be to do with what the adults think about children. ('They cannot think', 'He is only a child, he cannot have a mental health issue', etc.)

Indeed, most parents are not abusive. But many may find it difficult to meet all that child care demands. Among the upper or middle classes, most parents want their children to get good/high marks in exams and always do very well in everything. The pressure they put on the children can cause stress beyond the children's ability to bear, affecting their mental health. Among the poor, their daily struggle or alcohol or substance abuse problems or violent relationships cause lot of stress in children. These are facts that are hard to reconcile with and waking up to them before it is too late is a challenge.

# Be aware of the following signs that point to a child/ adolescent having mental and/or emotional problems:

- Declining performance at school, although the child is intelligent.
- Losing interest in things that he once enjoyed.
- Unexplained changes in sleeping or eating patterns.
- Avoiding friends or family and wanting to be alone all the time.
- · Too much of daydreaming and not completing his tasks.
- · Feeling that life is too hard to handle.
- Hearing voices that cannot be explained.
- · Having suicidal thoughts.
- Poor concentration and unable to think straight or make up his mind.
- Inability to sit still and focus attention.
- Undue worry about being harmed, hurting others, or doing something "bad".
- A need to wash, clean things, or perform certain routines several times through the day.
- Having racing thoughts that are too fast to follow.

### Signs of Mental Health Disorders Can Signal a Need for Help:

Children and adolescents with mental health issues need to get help as soon as possible. A variety of signs may point to mental health disorders or serious emotional disturbances in children or adolescents. Pay attention if a child or adolescent you know has any of these warning signs:

# A child or adolescent is troubled by feeling:

- Sad and hopeless for no reason and these feelings do not go away.
- Very angry most of the time and crying a lot or over-reacting to things.
- · Feeling worthless or guilty often.
- · Feeling anxious or worried often.
- Unable to get over a loss or death of someone to whom he was close.
- Extremely fearful or having unexplained fears.
- Constantly concerned about physical problems or physical appearance.
- Frightened that his or her mind is either controlled by someone or is out of control.

#### Emotional disorders in children

A child might externalize his problem through difficult or aggressive behaviour or may internalize it through withdrawal and depression. It is important to know of both kinds of problems. The following are some of the Externalized problems:

# Attention Deficit Hyperactive Disorder (ADHD):

This is characterized by inattention, excessive and impulsive activities. This may be accompanied by depression, learning disorders, behaviour or conduct disorders and anxiety disorders.

ADHD produces two important consequences in children – falling behind in studies and lacking in social skills. At school, this problem is worsened by lack of attention to studies and assignments.

### Dyslexia:

Specific signs of dyslexia can be academic- in language and mathematics and motor

a. Academic The child may make spelling errors such as reversal of letters or words that look like a mirror image of each other such as 'no' and 'on' or omit letters or put wrong letters in a word. The hand writing is often untidy. Dyslexic children have difficulty in putting the order of multiplication correctly and get the results wrong.

<u>b. Motor signs</u> – the child may be restless or overactive. He may appear distracted and forgetful. He may be clumsy or have wrong orientation.

There may be all kinds of difficulties connected with attention deficiency as understanding instructions, reading a watch or telling a story.

# Conduct disorders (CD):

These children misbehave much more than normal, breaking important societal norms. The behavior typical of CD include aggressive acts that cause or threaten harm to people, animals or property, cheating, theft or serious rule violations. To infer that a child has CD, such behavior must have occurred repeatedly with the child expressing no regret for the same, when caught.

<u>Internalized Disorders:</u> Most important of these are being 'out of mood' or excess emotion. These are often overlooked or not brought to health worker's attention for long because they are no socially objectionable. Neither the parents nor the teachers may show concern about these.

### Separation anxiety disorder -

This is unique to children, they show excessive anxiety or even panic when they are not with known people (parents) or in familiar surroundings. This is normal to childhood and decreases by the age of 10. But if they persist beyond that age and are excessive, then it should be looked into.

### Other Anxiety disorders:

These are not specific but occur also in adults. They are social phobia, generalized anxiety disorder and Obsessive Compulsive Disorder (See under 'Common Mental Illnesses').

Social phobia: Children show excessive shrinking from contact with unfamiliar people that makes it hard for them to function normally in daily social contacts. However their relationships with familiar people like family members are generally warm and satisfying.

Depression: Although childhood is often pictured as a happy time with little responsibilities, endless play and infinite enjoyments, there may be some children suffering from Depression. They show withdrawal, volatile moods, over eating and over sleeping and suicidal thoughts. Failure to enjoy and have fun, low self esteem, fatigue, delinquent behavior, substance abuse and poor school performance are some of the manifestations.

Bed wetting: Where children wet the bed at an age when they should not. The commonest cause is a delay in this area of development of the child. Some children may start bed wetting after having learned how to control their urine. This is often due to the child becoming upset about something, such as fights in the family or arrival of a baby. Other less common reasons include urinary infections, child abuse, diabetes, physical problems in the urinary tract and some neurological problems.

Soiling: After having been toilet-trained, disturbed children might suddenly begin to dirty their clothes (pass stool in their underwear). This is a sign of seriously disturbed mind.

### Mental health problems in children

Certain types of mental health problems occur typically in childhood:

### Key features of mental illness in children

The key signs that suggest mental illness in children are:

- A child who is doing badly in studies even though she has normal intelligence
- A child who is always restless and cannot pay attention
- A child who is constantly getting into trouble or fights with other children
- A child who is withdrawn and does not play or interact with other children
- A child who refuses to go to school

#### Causes of mental illness

In many cultures, both medical and traditional explanations are used to understand the causes of ill health. Traditional models are often related to spiritual or supernatural causes, such as bad spirits or witchcraft. You should be aware of the beliefs in your culture. However, you should also be aware of the medical theories and use these to explain mental illness. It is useful to keep in mind the following main factors that can lead to mental illness:

Stressful life events: Life is full of experiences and events. Some of these may make a person feel worried and under stress. Most people will learn how to deal with such events and carry on with life. However, sometimes they can lead to mental illness. Life events that cause great stress include unemployment, death of a loved one, economic problems such as being in debt, loneliness, infertility, marital conflict, violence and trauma.

Difficult family background: People who have had an unhappy childhood because of violence or emotional neglect are more likely to suffer mental illnesses such as depression and anxiety later in life.

Brain diseases: Mental retardation, dementia and emotional problems can result from brain infections, AIDS, head injuries, epilepsy and strokes. No definite brain pathology has yet been identified for many mental illnesses. However, there is evidence to show that many illnesses are associated with changes in brain chemicals such as neurotransmitters.

Heredity or genes: Heredity is an important factor for severe mental disorders. However, if one parent has a mental illness, the risk that the children will suffer from a mental illness is very small. This is because, like diabetes and heart disease, these disorders are also influenced by environmental factors.

Medical problems: Physical illnesses such as kidney and liver failure can sometimes cause a severe mental disorder. Some medicines (e.g. some of those used to treat high blood pressure) can cause a depressive illness. Many medicines when used in large doses in elderly people can cause a delirium.

### Culture and mental illness

There are many ways in which culture can influence mental health issues

### WOMEN AND MENTAL HEALTH

#### **Objectives:**

• To understand the mental health problems of women.

- To look at the causes of mental disorders affecting women.
- To become aware of the position and conditions of women that makes them more vulnerable to these illnesses.

#### Exercise

- 1. Ask the participants if they have seen mentally ill women and what kinds of disorders or illnesses they have seen in the women in their community.
- 2. Ask the participants to think of the differences when a man in a family becomes mentally ill and when a woman becomes mentally ill. List the differences on the board.
- 3. Divided the participants into group of 4-5 persons and ask them to list the possible causes for the illnesses they have seen in women.
- 4. Ask the participants to come up with possible ways for the woman to come out of the problem.
- 5. Ask what they or the community can do to help the women get well.

### MENTAL HEALTH OF WOMEN - SOME FACTS TO BEAR IN MIND

All over the world, mental illnesses that affect women show a different pattern from that of men. For example, of the mentally ill women, about 30% are affected by Depression, whereas the figure for men is 12.6%. Among those affected by alcohol of substance abuse, men account for 31% while women account for 7%.

Poor women, in particular, experience harsher life situations and more chronic stress, whether it is due to poor housing, dangerous or rough neighbourhoods or difficult children. They are at much higher risk for becoming victims of abuse and violence-both domestic and sexual.

When men tend to externalize their suffering through substance abuse and aggression, the brunt of this has to be borne by the women. So depression and anxiety are common among women. Apart from these, psychological pain caused by the enormous burden and chronic stress makes women prone to nervous breakdowns and 'intrusion of spirits' (getting possessed).

The harmonal changes that occur during menstrual periods and pregnancy could make women sensitive and susceptible to the bad effect of stress during those periods. In the state of exhaustion after pregnancy and childbirth and nursing, women could be particularly vulnerable to mental health problems. This is compounded by malnutrition that is widely prevalent in that category of women.

Her low social status, illiteracy, patriarchal oppression and economic dependence put her at high risk for abuse and violent attacks. Although it is not readily acknowledged, sexual abuse of girls and women are much more common that we would like to believe. A lot of serious mental illnesses are caused by these circumstances in which poor women live.

Women who go out to work are affected by the double load of work at home and outside. It is worse when the atmosphere at home is unhelpful and hostile to her.

(I want to put some statistics concerning mental illnesses of women in India here.)

# Chapter 7

# **Project implementation**

# For trainees to gain understanding on

- 1. Advantages/ merits of including mental health in to development work
- 2. Consultation
- 3. Importance of home visits and Individual rehabilitation plan
- 4. Tracking changes through individual case files
- 5. documenting baseline
- 6. Reviews and evaluation
- 7. Understand the difference between ethics and life principles
- 8. Understand the different ethics involved while working with people and emotional issues.
- 9. Understand the need for empathy.
- 10. Understand some professional work ethics.

# Number of sessions: 8

Session 1: Merits of including mental health in development activities

Session 2: Consultation

Session 3: Importance of home visits and individual rehabilitation plan

Session 4: Tracking changes in the individual files

Session 5: Base line

Session 6: Networking and Alliance building

Session 7: Work ethics

Session 8: Reviews and Evaluation

### Session 1

# Including mental health in to development work -45 minutes

1. Divide the participants into groups of 5-6 persons.

2. Ask the group to discuss on whether mental health can be included in their CBR programmes. If yes, how would they include it in their existing CBR programme?

3. Small groups share their discussions in the large group.

4. Share BNI's experience with the partners including mental health in their CBR work.

### Session 1

# Community mental health and development approach:

People and the community are the biggest resources available for the community mental health services. Many of the mental health problems can be effectively dealt by the people and within resources available close to them. Large-scale dissemination of knowledge and skills to people would help in reducing stigma attached to mental illness. Building knowledge and awareness of families can make a real difference. It helps the PWMI become an integral part of the community, participating in all its social and cultural activities.

Strengths of development approach for meeting the needs of people with mental illness in their own communities:

1. Promotes community participation and community ownership of the programme. Community participation encourages planning, developing and monitoring the programme.

2. Actively involves of mentally ill people and their families in all the issues

concerning them, instead making them passive recipients.

3. Helps integrate mental health in the development process, including transfer of skills to the family and the community, minimising the need for engaging professionals. This would also make it more cost effective.

- 4. Medical approach alone is not a comprehensive approach. Unless special focus is given to the expressed needs of people with mental illness and their families, recovery will remain inadequate and unsatisfactory.
- 5. Promotes better social integration by ensuring that people with mental illness have access to the same benefits and services as others in the community where they are working.

6. Integration implies a high degree of collaboration between different

sectors. Such coordination works better locally.

- 7. Mental illness can be treated with relatively inexpensive drugs. Only a small percentage of them require institutional care. Hence a vast majority can be treated and taken care of in the community.
- 8. Early diagnosis prevents unnecessary expenses and promotes early recovery. This results in an attitude change in the community promoting treating of most disorders in the community.
- 9. More people can be serviced because interventions are decentralized.
- 10. Negative attitudes / stigma attached to mental illness will be challenged as there are more chances/opportunities for people with mental illness to recover and lead a better quality life.

### Session 2

#### Consultation

(Consultation should be handled (facilitated) by very experienced staff/workers. Newer community workers may participate as silent observers to learn how it is done.)

# Objectives:

 To get to know the people and their understanding of themselves, their present status.  To encourage the participants to express/voice their feelings, needs and aspirations.

(In the context of people with mental illness, the participants would include people with mental illness, their family members (caregivers) and community (health) workers.)

**Pre-consultation:** Notice of the meeting, its starting time, venue and the purpose should have reached the participants **well in** advance. Ensure travel plans and escort facilities as and where required. Ensure both women and men participate in the consultations.

**Logistics:** The right venue and environment help participants to interact with each other. Drinking water, toilet facilities, refreshments, enough newsprint, marker pens, etc., are other essential requirements. Participants feel comfortable preferably, completely at ease).

**Process:** A trained facilitator/animator should undertake the process. S/he should adhere to the topic guides. For the first consultation, topic guides will include:

- Greetings & ice breaking
- Introduction of the day's proceedings
- Introduction (self) of the participants
- · Asking for permission to document and photographs.
- Setting of Ground Rules for the conduct of the programme.
- "My World" constituency mapping exercise
- Explanation and debriefing of mapping exercise
- Needs discussion (group exercise) followed by presentation & discussion in a big group.
- "What Next?" again group exercise followed by presentation and discussion.
- Debriefing –involving the facilitator, key people from the organization and the process writer.

Process writer would be outside the circle and simply captures the content, context and even the movements and moods of people.

Facilitator/Animator sticks to a sequence, eliciting participation from every one. When required, asks the participants to repeat what s/he said so that the group understands the depth and intensity of the particular statement. Animator encourages reflections, debates among the participants without losing sight of the purpose and of the time. One has to be sensitive to the emotions expressed but, at the same time, not focus too long on one person lest the others lose interest.

Group size needs to be appropriate for every one to participate and their needs met in time. After each presentation clarifications to the queries have to be drawn from the participants themselves. Persons with behavior problems may get up and go out. Some one should mind them but not force them to conform in the group.

### Points for the facilitator to remember:

- Communicate in a common, easily understandable language.
- Do not misinterpret information/expressions- ask clarifications, if necessary.
- Listen with attention.
- Mind your body language- it should be calm and reassuring.
- Check for accuracy of the expectations/decisions made (eg., 'Did I hear you say 'you want to get married'?).

**Close:** Thank the participants for their frank sharing, especially for the commitments made/action plans arrived at and any other appropriate things done by them during the day. End with the hope they have brought in. All the materials presented by the participants get collected by the process writer.

**Debriefing:** The facilitator/animator, process writer and key staff from the organization sit for a debriefing to share their views and perceptions on every aspect of the day's proceedings. This too becomes a part of the process document.

### Session 3

# Home visits and Individual rehabilitation plan: 120 minutes

- 1. Divide the participants into 4 groups
- 2. Hand out the case studies and ask the groups to prepare a follow up plan for each, based on their experience.

- 3. Ask one of the groups to do a role play about visiting the house of the person described in the case study given to them. The CBR worker visiting them will try and design an individual rehabilitation plan together with the family.
- 4. Three groups may present their role plays in this manner.
- 5. Discuss each case, after the role play and help them to make an individual rehabilitation plan that reflects 'community mental health and development' ideas.
- 6. Ask the group to observe each role play and note the points that go into a good home visit.
- 7. Shares your own experience of the home visits- including some difficult ones.

### Session 3 a

# Case study I

Muniyamma is 45 years old married and living in one of the slum communities in Bangalore. She is originally from Tamilnadu and migrated to Bangalore a few decades ago. Her life started as a daily wage worker at construction sites. She lost her parents when she was very young. Life is very hard for an unmarried, single woman in the urban area. Her situation also made her to think and she decided to get married. The community in which she was living supported her and she got married to a person who was living in the same community who was an orphan living alone. After a few years, she gave birth to a baby boy and the family was a happy family. Some years later, unfortunately, the child developed some health problems and, in spite of all kinds of efforts, he could not survive and she lost her son. She was shattered by this death and became mentally disturbed.

She lost all joy in life and she became hopeless. Worsening the situation, her husband developed blood sugar and Asthma and he was struggling for his life. Poverty and lack of family support really shook the couple and they could not take proper care and treatment. Within a short period after the death of the child the husband also passed away. Muniyamma, who was full of sorrow from her childhood, could not face up to this situation and she became mentally ill. She developed severe mental illness and she started wandering in the streets, unmindful of personal hygiene and many times she was without clothes on her body. She would bring garbage from roadside into her house and the house was a stinking mess.

Though the community is sympathetic towards her it is not able to support her because even the community is confused about her behavior and situation. Some times, they give her some food and some old clothes. The Community is aware that her condition is serious and they also know the reasons for her situation. But they are not aware that she is having an illness. Looking at her wandering behavior and dirty appearance no body wants to talk to her. The police took her to a beggars' home, a few times, where they keep this kind of persons temporarily and send them back, after some time, to their communities. So to conclude she is mentally ill, living alone and though the community is aware of the situation they are not able to support.

# Case study II

Sunitha is a 34 year old married woman with two children. Her older daughter is 6 years and son is 3 years. Her husband, Raja, is a laborer in a whole sale market in Bangalore. His job is to load and unload goods from lorries. He is a hard worker and earns a reasonably fair amount of money every day. But he is addicted to alcohol and most of his earnings are spent on alcohol. He gives the remaining money to the family. They don't have a house and live in a shack by the roadside, next to the market. One day, Raja was beating Sunitha very badly and one of the shop owners, who was watching, went and stopped Raja and scolded him. But Raja suddenly reacted and said that she was mad and she never listened to him. At times, when she is out of control, he beat her. The next day, a development worker, belonging to the organization that was working for the laborers in the community, came to talk to Raja about this. He started narrating the story and said that Sunitha, some times, suddenly starts beating the children and shouting without reason. Throughout the night, she keeps talking to herself. Many times, when she went to the toilet, she would say that she saw her mother's spirit.

The story was interesting and the development worker asked Raja when she behaved like, how does he respond? He said that, some times he also feels she is possessed by her mother and had taken her to some faith healers and did what he could to have her treated. This had cost him a fair amount of money every time. So, instead of taking her to faith healers, he decided to give her the same 'treatment' of thrashing her with neem leaves and with his hands, whenever she behaved like that. Interesting as it was, it was at the same time saddening to hear about their understanding of her illness. Later, the worker spoke to Sunitha who narrated her story. When she was 14 years old she saw her mother dying. Sunitha's mother had extra marital relationships and her father could not accept the same. One day, he poured kerosene and set her on fire and Sunitha had seen her shouting in the middle of the flames. Though Sunitha saw this, she could not help her mother. This incident triggered her illness. Whether she developed mental illness after her marriage or when she was a child is not clear. But at present she is having a severe mental illness. She has hallucinations and feels she is possessed by her mother and is not interested in taking care of the children. She always shouts and guarrels with her husband. Raja is more worried about her behavior and their children. She also fears she may be sexually exploited in his absence when she is out of her mind as the place is full of alcoholics.

# Case study III

24 year old Shankarappa, who had studied up to PUC, suddenly started telling his family members that he could see God. Lord Venkateshwara and Narasimha are visible to him. Even in his dreams he could see the Tirupathi temple. At the same time, he also told them that he also sees a king cobra with 5 heads spitting blood and he is very afraid and unable to concentrate on his work and his daily activities. The family was astonished and confused at the same time not knowing what was happening with him. His brother Seenappa took him to a temple and they offered Pooja and the family thought that some rituals and religious rites will solve the problem. Even after performing some rituals and practices the situation continued to be the same. The family then thought that some body had done some black magic and some evil spirit had possessed Shankarappa. They approached faith healers and the outcome was the same.

At this juncture, the staff of one of BNI partner organizations identified the person and asked the family to attend a consultation meeting. During the consultation meeting Shankarappa expressed the same feelings and it was very clear that he had developed a severe mental illness. He was looking very afraid, aggressive and suspicious about his brother and the group. He was restless and agitated.

Later the development worker started to visit his family and interacted with the members. According to the information given by the family members Shankarappa is a very innocent and hard working man and after completing his 12<sup>th</sup> standard he had joined a private company where he has been working for the past two years. A few months ago, suddenly an astonishing change occurred in his behavior as mentioned above. Neither the family nor the neighbors were able to find out the reasons for his abnormal behavior. A few weeks later he was forcibly taken to a hospital. But as he was not willing to take medicines, his symptoms got worse. With great difficulty, the development worker was able to talk to Shankarappa and got to know that he left his job when a cheque got missing in the company where he was working for which the company suspected and blamed Shankarappa. So out of humiliation and frustration he left the job. He narrated another story that he was staying with four friends for about a year while working in that company and under the influence of his friends all the five of them had sex with a sex worker. Later he had developed some infection in his genital organ. So he was very confused and at the same time afraid.

# Case study IV

Lawrence, a 20-year-old boy discontinued his studies as he was not able to pass his 7<sup>th</sup> standard since the age of 15. He started working as a helper under a contractor at a construction site. He was honest in all his dealings and gave his

earnings to his parents. He had a lot of friends where he was living. His evenings were spent in the company of his friends, playing cricket, football etc. One of his friends was in love with a girl residing in the neighborhood. His friends used to tease that girl often. One day, a group of youths attacked Lawrence and his friends unexpectedly. Lawrence was also badly assaulted as he was part of the group. He had a head injury and was hospitalized. A few weeks later, he developed excessive fear and was not ready to go out of the house. He would scream constantly and sound very abnormal.

Lawrence's sister speaks of the incident and what followed. "He was an ok boy. Did not do well in the school and discontinued his studies. He started learning carpentry and the trainer was also a contractor. Hence, he had no problem in getting work. One day he did not feel normal. He was disoriented, speaking unnecessary things and behaving abnormally. We took him to various healers and offered prayers in the church but there was no improvement. One day he ran away from home. We searched all over but did not find him. After more than two months, his brother found him in another part of the town. When he was brought home, my heart sank and I wept. Every one was in tears. He was in his underwear and had an old coat on him. Even now if I think of that scene, some thing happens in my stomach."

### Session 3b

### Individual Rehabilitation Plan

Individual rehabilitation plan has to be developed for each individual taking into account the person's particular condition and needs. While planning the individual rehabilitation plan, one should involve the person and the family right from the initial discussion. The following aspects should be taken into account while planning for the Individual rehabilitation plan.

# The plan must include

- Information about the illness and the person's current situation.
- Details about treatment received previously and its outcome.
- Information on the functional impairment (abilities and handicaps) caused by the illness.
- Details about what needs to be done (goal, contact persons, follow-up methods and responsibility for care).

# Medical rehabilitation

- Identification of the person with mental illness.
- · Rapport building with the person and the family.
- · Educating the family about the illness.
- Assessment history of the illness
- Consultation of person with mental illness and in the larger groups (as described under 'Consultation').
- Referral for assessment, diagnosis and treatment
- Educating and motivating the family about the need for taking treatment.
- · Dealing with the side effects of medicines.
- Follow up services.
- Drawing up home based support
- Monitoring the medication
- Bare foot counselling and psychotherapy services
- Dealing with drop outs
- Identifying relapses and referring them back for care services
- Understanding and assessment family dynamics
- Attending caregivers meetings
- Documentation of individual files

### **Economic rehabilitation**

- Motivating the person to do household chores.
- Helping the person engage in productive work.
- Involving him in group activities.
- Encouraging the person to go back to his previous work.
- Discussing the situation of the person with his employer and persuading for reasonable accommodation.
- Involving the PWMI in income generation activities like animal rearing.

- Linking the SHG's to banks for micro credit loans.
- · Assessment of skills of the PWMI and caregiver.
- Referring for vocational training
- Encouraging or promoting savings

### Social rehabilitation

- Integrating into self help groups
- · Involving in family activities
- Involving in community activities
- Having awareness-raising programmes in the community.
- Accessing Poverty Alleviation Schemes and those meant for disabled persons.
- Celebration of events in the community, such as the World Mental Health Day or World Disabled Day etc.
- Educating community about the 'rights' of PWMI.
- Educating families and the communities about their entitlements and the Government's schemes for PWMI and Disabled persons.
- Formation of care givers forums
- Formation of wider-based group, federation or forum for raising their concerns more powerfully.

### Session 4

# Tracking changes through individual case files: 60 minutes

# Objectives:

- To learn about essentials of documentation- the kind of documentation that is necessary in Community Mental Health programme.
- To document in order to track changes in the mental health of the PWMI.
- To learn to track changes in the individual, the family and the community.

#### **Exercise**

- 1. Explain the kinds of documentation maintained in the community mental health and development programme (BNI model).
- 2. Explain the manner of maintaining individual files and how to track changes in the individual, the family and the community in the process of rehabilitation.
- 3. Distribute some formats for documentation in the local language and take the participants through the individual format, explaining the purpose of each column.

### Session 4

# Importance of documentation

Documentation has several purposes:

- (a) To keep track of the progress of PWMI due to the CMHD implementation; to provide good and correct service to the PWMI.
- (b) Use in advocacy and lobbying for getting services for the PWMI.
- (c) To assess the needs in a particular area/ for a group.
- (d) Use in awareness-raising and training of community workers.
- (e) To assess the quality of service rendered and make the necessary changes/ improvements.
- (f) Proper running of the rehabilitation programme.

# See the following examples:

- Records of the home visits made by the field staff helps to notice the overall progress of the client.
- Keeping a stock of medicines (at the clinic/ camp) helps to purchase medicines according to the need and to prepare a statement of budget to buy those medicines.
- Life stories will be a wealth of information narrating the process of interventions, efforts put in, results and impacts.
- Consolidation of reports at different levels provides information to make action plans and work out a budget allocation.
- A record of the impact of the work can be used in designing training. It becomes a resource in research and advocacy.

- Proper documentation at every level will help to run the programme smoothly. It sets a pattern and makes it is easy in transition when staff changes happen.
- The quality of service can be measured.
- Above all, information can be used for provoking new ideas and issues.

### The list of documents

- Profile of the service user\case history\photographs.
- The details of identification, treatment and level of stability.
- List of dropouts with reasons for each.
- Baseline data to use in advocacy.
- Photographs before and after stabilization.
- Individual intervention plans with follow-up details.
- Process documentation of the events.
- All training reports (consisting 5 W and 1H).
- Identification and Mapping of the organization.??
- Documenting the key learning at every stage of the implementation (impacts, failures and challenges).
- Review and Action plans.
- Evaluation report of the programme.
- Reports on the activities of sustainable livelihoods.
- Registers showing stock of medicines.
- Report of the existing knowledge and practices of the community, which later can be used as a base for research study.
- Annual Reports
- Records of the loans sanctioned.
- Video presentations, clippings and other training materials.
- Successful Life stories.

# Session 5

# **Objectives**

 To know about all the agencies, departments and public bodies that should be involved in CMHD for a successful implementation.

### Method:

- Explain the importance of collecting and making available information on the various agencies and structures in the Government implementing the schemes meant for disabled persons, including PWMI.
- Explain the various social, economic and health data that need to be collected in order to put forward the case of disabled persons effectively to public officials.
- With active participation of and contribution from the participants, put together a format for collection of such information.
- Alternatively, Government and other public officials can be invited to give details of the various schemes and facilities.

# Base line format:

- 1. Review of Literature
  - A. Policy Mental Health Policy 2002 (Government of India)
    - similar Policy at State Level (if available)
  - B. Legislation

Mental Health Act 1982

**PWD** Act

RCI act

**DMHP** 

(Who is responsible for implementation) State Government – Key People

- Ministers/State secretaries
- Government Departments
- Disability commissioners
- State level Co-ordination committees
- Task forces
- Any other state level committees
- Local MLA/MLC

# District Level - Key people

- District Commissioners
- Chief executive officers
- Chief secretaries for zilla panchayat
- District rehabilitation officer
- Asst dir. For women and child development
- Dt.Health officer
- Line department heads
- Corporation heads
- Special boards
- Judicial /police heads
- Any others

### Taluk Level Officials

Gram panchayat Level Panchayats, local MLAs and MLCs, MP

### C. Schemes

- a) SGSY
- b) JRY
- c) PMRY
- d) ICDS
- e) JANMABHOOMI
- f) ADHARA and ASHRAYA
- g) GANGA KALYAN YOJNA
- h) SCST BC CORPORATION
- i) PENSION
- j) RATION CARD
- k) ID CARD
- I) LIONS and ROTARY CLUBS
- m) VOLUNTARY NGO SCHEMES
- n) WOMENS DEVELOPMENT CORPORATION
- o) DRDA
- p) ANTHYOAYA
- D. Research Studies/Documents Published by Government / Related NGOs / Academic Bodies / Institutions) on the subject Project area maps / Govt. Administration maps
- 2. HEALTH RESOURCES Review of Existing General Health and Mental Health Services in the Area of Operation in relation to population

### Population

No of Psychiatrists/Clinical Psychologists/Psychiatric Social Workers/Nurses trained in psychiatry in the area (Give ratio per lakh population)

No. of Govt. Psychiatric Hospitals (No. of posts vs No. present)

No. of Pvt. Psychiatric Hospitals

No. of General Hospitals (Govt. and Private) (Give Bed strength, No of posts available and filled), District Hospitals, PHC, PHUs, peripheral centers, Health workers

No of General Physicians / Nurses/Dentists per lakh population

Note: Details such as distance from the area / transport facilities and frequency of visits of the personnel are important)

Traditional Healing methods operating in the area

Alternative Indian Medical Services - Homeopathy, Ayurveda, Others

- 3. Education resources Schools, facilities for disabled, Hostels, NGOs, Ashrams
- 4. Socio Economic Condition of the people

Indicators:

Per capita income

Persons below the poverty line

General literacy rate and female literacy rate

Number or percentage of girls in schools.

Local Human Development Index in relation to Indian average.

Local Poverty Index in relation to Indian average.

Housing Conditions in the area

Roads.

Communication - post office, telephones, computers, email facilities, fax

Water

Electricity

Drainage

Occupation and income levels

Livelihood options

Trade Analysis

Religious and culture practices

Customs/myths/traditions

### 4. NETWORKS IN THE PROJECT AREA

Review of all other services and the administrative links Government Departments, Schemes and Programmes to benefit the poor NGOs / Private and Corporate programmes for the poor operating in the area

Government Schemes (with brief information about each, also if any people with mental illness have accessed and benefited from these)

Sanghas

Youth clubs

Co-operatives

Committees

Associations

Informal panchayats

# **Community Leaders**

- 5. Review of the situation of Persons with Mental Illness
  - Number of persons identified
  - Issues/problems faced by them
  - Their needs
  - Practices in the family –religious. cultural, Human rights abuses, neglect, overprotection
  - Awareness and attitudes

### Session 6

# Alliance Building: 30 minutes

- 1. Ask the participants to think of the various institutions, groups and persons (also called stake holders) in the community who are connected with caring for PWMI.
- 2. Put down their responses on the black board.
- 3. You can also put it in the form of a web chart (See Page ---), keeping people with mental illness in the center and linking all the stakeholders in the web.

# Session 6

# **Networking and Alliance Building**

"Coming together is a beginning; keeping together is progress; working together is success."

# --- Henry Ford

To link up and build working relationships with every possible stake holder is the essence of alliance building. This is essential in advocacy, in the efforts to influence decision making and policy formulation or changes. To create a positive change in the society, organizations and individuals need to come together and collaborate to achieve common goals. This coming together and collaboration has been called by a variety of terms – alliances, coalitions and networks.

#### What are Networks?

Networks consist of individuals or organisations that share information, ideas and resources to accomplish individual or group goals. Networking is a process of acquiring resources and building power by using or creating linkages with other individuals, groups and organisations. Networks tend to be loose and flexible associations of people and groups, brought together by a common interest or concern. In networking there is multilateral co-operation with other persons or organisations. The following are some reasons for networking:

- · Building strength through numbers
- · Dissemination of information
- Dissemination of know-how
- · Coordination of activities
- · Capacity building of members
- Technical guidance and coordination
- Seeking social well being and social progress
- Making use of resources and skills, including specialists, of the network members

### What are Alliances?

Alliances are similar to Networks but tend to have a more formalised structure. Their 'permanent' nature can give them better clout and leverage. They can be working for a specific objective or goal.

Alliances may be local, regional, national or international. Some may be formed to achieve one short term objective. An alliance may be dissolved when the objective is achieved. There may be alliances working on a permanent basis for long term goals. Some that focus on more than one issue such as nutrition and health, population and environment, etc., tend to be permanent in nature. They recognize the value of mobilizing together for action, over a long time.

In terms of structure, some alliances may be formally organised and highly structured, while others could be more informal and flexible, relying on volunteers. Alliances are seen as a perfect vehicle for NGO collaboration. Alliances are usually strongest if they grow organically out of common interests. They are unlikely to survive when they are externally imposed. Working through alliances has many benefits:

Increased access to decision makers and other contacts

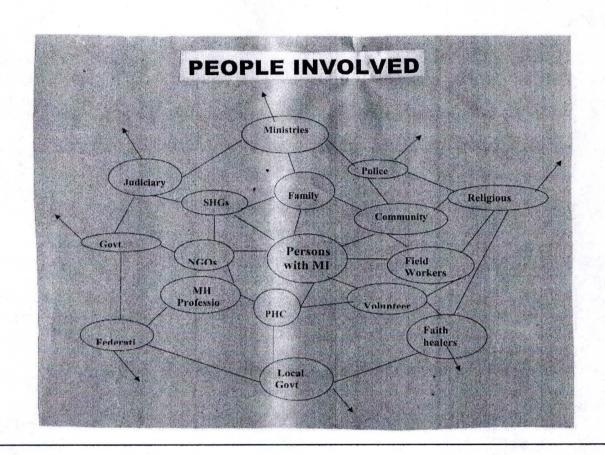
- · Improved credibility and visibility
- Opportunities to broaden public support

Different NGOs have different areas of expertise, varied resources and attract different stakeholders. Building a diverse alliance increases one's chances of success and proves to the decision makers in power that there is a broad social support for the desired policy change. Decision makers are also more likely to pay attention to alliances, as they have a stronger voice.

Alliance building in mental health work, should aim to fulfill the aspirations of persons with mental illness with respect for their rights. Their aim should also be help PWMI live a life of dignity.

# Various stake holders in the community

- Service users people who have mental health issues and are using the services.
- Caregivers and field staff
- SHG members
- Local group leaders like Panchayats leaders
- Local resource organizations
- Government bodies connected with:
  - Health sector PHC, Government Hospitals, Taluk and District health centres
  - Panchayats Raj institutions
  - Education Anganwadi workers, teachers, SDMC members, etc.
  - Law and Order Police
  - Social Welfare Department of Disabled welfare, Department of women and children
- Traditional healers and alternative healing systems and practitioners
- Religious institutions
- Donor agencies
- Media
- Hospitals private and government practitioners, Psychiatrists, Nurses
- Trained Community Counselors
- Women groups, youth groups, farmers groups and so on
- Volunteers and students from community
- Industries and Corporate sector that are socially responsible, to sustain the project
- Opinion makers



# Session 7

Work ethics - 120 minutes

Ethics & Emotions: (35 min.)

# **Activity:**

- Ask for 5 volunteers from the group for a small role-play. Do not reveal the story until you
  get the 5 volunteers. One plays the role of a counselor, another plays the role of a
  mentally ill woman who abuses her spouse as she suspects that her husband is having
  an extra marital affair; the others play the role of field staff wanting to take the person to
  visit the counselor. Give 5 minutes to act out the play.
- Ask the group if it is necessary to take prior consent before any commitment (conversation). Does prior informed consent make the person/s more involved and less uncomfortable? Try and link it with the right of a person to know what he is getting into beforehand.
- Give examples from the field where people are taken granted and decisions are made on their behalf: (a) denial of property rights and appropriation of the property by the siblings or relatives; (b) Family not taking interest in the treatment process; (c) mixing medicines for a PWMI in his food without his consent; (d) chaining, locking up PWMI;
- Ask the participants how they would like it if any of it happens to them. If participants say
  that such things are done in the interest of individual, ask questions like: (a) How can that
  be decided? (b) Who can decide that? (c) Is it the convenience of the care-givers or the
  PWMI? (d) Are the feelings and opinions of the PWMI ever asked?
- Now ask the role players to share any discomfort they felt in enacting the roles, especially that of the PWMI.

# You may ask the following questions:

- 1. Did you feel comfortable sharing your personal life and issues in front of the field staff?
- 2. What do you think people would do after listening to your story of abusing your spouse?
- 3. How would you role play this scène differently?
- Explain the importance of privacy and non-judgmental attitude towards clients.

# Empathy: (35 min.)

# Objectives:

- To understand empathy and attitudes that help in healing PWMI.
- To understand the importance of confidentiality and other ethics in CMH.

# **Activity:**

- Explain that an attitude of empathy helps you understand the individual's feelings and helps you to be non-judgmental.
- Explain that when we empathize we also maintain confidentiality.
- Explain the importance of confidentiality –how it is disturbing for any individual to know
  that incidents in his life are being discussed in public with others by people who say they
  want to help them.

- Empathy, respect and non-judgemental attitude help to build confidence-both in themselves and in those around them.
- This builds an atmosphere that helps a person overcome his illness.

# Professional Ethics – A Recap: (15 min)

Ask the participants to list what ethics were not followed in the following story:

"Shivanna is a 25 year old man. He has been suffering from schizophrenia for 5 years. He never really liked to go for treatment and counseling sessions that were arranged by a local social worker who was part of an NGO. He also did not want to take the bitter medicines that were given there. He was motivated to meet the doctor and was convinced to take medicines for few days. Later his family started mixing the medicines in his food. His symptoms reduced and he was 'stabilised' and he started to work on the farm.

A few weeks ago, when the social worker visited the village, he heard about Shivanna's marriage engagement. The social worker visited the family to find out about Shivanna. The family informed about the wedding, said that Shivanna had recovered now and that does not want to take medicines any more. The social worker was asked not to visit them after the marriage as the wife might then get to know about his illness. Shivanna's parents were happy that their son was getting married and the responsibility of caring for him would be shifted to his wife.

The social worker asked the family if they had informed the wife-to-be about Shivanna's illness. He also asked many questions including Shivanna's ability to manage life, wife and sexual abilities. Shivanna was hearing this entire conversation. He was nervous and uncomfortable as the social worker asked many personal questions when people around him were watching and listening. He could see other people already whispering among themselves. He felt ashamed, embarrassed and low. "

#### Hints:

- Name of individual mentioned
- 2. Medicine and Counseling compelled without consent
- 3. No Privacy
- 4. No confidentiality
- 5. Judgmental attitude
- 6. Empathy not found.

Wrap up by asking the participants to look at their own experiences at work and write a small essay to themselves on the above ethics and keep it for personal reflection.

## Session 7

## **Professional Ethics:**

There are some special norms and ethics in the relationship of a professional social worker with a PWMI. There is an obligation to prevent PWMI causing harm to themselves or others. Social workers are called upon to be especially attentive to the following ethical aspects in their work:

## 1. Social worker -patient relationship

This is at the heart of psychiatric practice. Many ethical principles have bearing on this relationship, including respect for the person and his autonomy. There should be honesty and confidentiality.

# 2. Professional competence

The social worker should try and maintain a sufficient level of professional competence through continually educating himself, through consulting experts as well as self-study. It is expected that the social worker will make referrals or delegate care only to persons who are competent to deliver the necessary treatment.

# 3. Confidentiality

Confidentiality is the obligation not to reveal a patient's personal information without his or her express permission. Respecting the patients' confidentiality is very important for social workers because patients entrust them with highly personal and often sensitive information. The patients' willingness to make painful, stigmatizing or embarrassing disclosures depends on their trust in the social worker that s/he will maintain confidentiality. There are ethical duties that arise from principles of promise-keeping, doing good and avoiding harm. Apart from all this, there is also a legal duty to keep private medical information confidential. Failure to do so can even invite punishment under the law.

## 4 .Honesty and Trust

Honesty and trust are fundamental values in this profession. Honesty entails the "positive" duty to tell the truth as well as the "negative" duty not to lie or intentionally mislead someone. Derived from core principles of trustworthiness, integrity and respect for PWMI, honesty and trust are fundamental expectations of a person seeking psychiatric care.

A social worker may be occasionally tempted to avoid or "soften" the truth in order to avoid harm to a patient. In general, omission (intentional failure to disclose) and evasion (avoidance of telling the truth) will affect the trust in the relationship between the social worker and patient and

is not appropriate. At the same time, out of respect for the patient's privacy, the social worker should reveal only the minimum information necessary in the presence of a third party.

#### 5. Informed Consent

Informed consent is an ethically and legally important process. It means telling the patient about the nature of his illness and the recommended treatment that is to be followed and obtaining his consent. Informed consent for assessment or treatment is said to be there if adequate information is disclosed, the patient is capable making a decision and does so voluntarily. In some cases, a valid informed consent may be obtained from the person in charge of him.

## 6. Keeping the Therapeutic Boundary

Boundaries may be described as defining the limits of a profession. It is necessary to maintain a professional distance and respect that ensures an atmosphere of safety and predictability. Therapeutic boundaries are also necessary for the therapy to be effective.

Social workers must never exploit or otherwise take advantage of patients. The unique position of power afforded by the therapeutic relationship can be used in ways that are unrelated to the treatment. The social worker must therefore limit the relationship with the patients to the therapeutic context only. This boundary requires that they avoid interactions with the patient that are aimed at fulfilling the psychiatrist's needs or impulses.

### 7. Relations with the team

The primary goal in the CBR programme is to provide highest standard of care. There should be no compromise on giving the maximum benefit and the *primary loyalty is always to the patient*.

# 8. Responding to unethical conduct of colleagues

Every person has an obligation to recognize and report any unethical behavior of colleagues or any member of the service providing set up. Unethical conduct includes a variety of behavior that violates professional standards. These may include exploitation of the patient, dishonesty, fraud or behavior meant to demean or humiliate the patient. The duty to report unethical conduct is an essential part of a profession's self-regulation. The members of a profession are in the best position to recognize unethical behavior from their colleagues. Unethical practices not only harm patients, but also damage the programme as a whole.

#### 9. Ethical issues in small communities

Small communities pose special ethical challenges to a social worker because of the interdependence of the members in the community. Many small communities face great limitations of health care resources. There may be other disadvantages such as weather, geography or lack of transportation in the placd. Social workers serving small communities may be treating patients who may be long-time neighbors, members of their extended family, local

officials, or civic leaders. Consequently, the ethical standard of separating personal and professional relationships may be difficult to achieve.

A social worker in a small community may experience greater difficulty in protecting the health information of their patients. When patients describe their own health-related experiences, they may indirectly disclose information about family or community members who may be well-known to them. The consequences of breach of confidentiality may be serious, particularly, given the stigma associated with mental illness. Certain communities may also require sensitivity to cultural practices that are unique to the group. Some practices and traditions (e.g., need to get family's rather than individual's consent) may require the social worker to consult them. Respecting these values may be useful in improving the relationship with the patient as well as with the entire community.

# Session 8: Reviews and Evaluations: 30 minutes

1. Explain the need for quarterly reviews to understand the problems at the field level and address them promptly. (It is not clear why and how this takes 30 minutes. Is there a format that is explained and discussed?)

Chapter 8

# **Exposure visits**

These are generally planned for two days. It is meant for the trainees to observe and learn from the CMHD activities in an area where an organization is successfully implementing the same.

# Objectives:

The trainees will be enabled to

- Observe the community mental health and development model as implemented in the field and interact with various stakeholders in the process.
- 2. Gain insight into a variety of perspectives in the field like gender, poverty, family dynamics, community participation and community mobilization.
- 3. Understand the activities of community groups like Self Help Groups, organisation of persons with disabilities and discuss their work, with specific reference to Community Mental Health and Development (CMHD) programme.

The field visit may be organized in this manner:

- The trainer and participants reach the project area of the host organization. The head of the organization and the staff make a presentation about their work to the visitors.
- The trainer divides the participants into three groups. Each group is taken by a representative of the NGO to a village.
- In the village, the group interacts with one community group and visits the homes of two persons with mental illness (preferably one male and one female) who are accessing the services of the community based mental health and development project.
- There should be some place where the participants can, later, gather for sharing, asking questions and clarifications or additional information if necessary.

# Activities on Day one:

- 1. Introduction of the participants and the organization
- 2. Experience sharing from the project director and the coordinators
- Interaction with the field staff and the trainees.
- 4. Two home visits to people with mental illness.
- 5. Interaction with the SHG members and discussion on livelihood interventions for people with mental illness.
- 6. Debriefing with the team
- 7. Street theatre, Cultural evening.

#### Activities in Day 2:

- 1. Interaction with the members of federation of disabled persons, understanding advocacy efforts of the group.
- 2. Awareness raising programme (community group meetings)
- 3. Consultation meeting
- 4. Caregivers meeting
- 5. Interaction with the volunteers
- 6. Debriefing with the group

# **Chapter 9**

# FIELD SUPPORT

# What is field support?

The trainer visits the programme to support the field staff/trainees to initiate community mental health and development activities. If the trainees' organization is already implementing the CMHD programme the field support will be aimed reviewing the activities.

# What are the guidelines for the field support?

Basic guidelines for field support

- 1. Need for consulting persons with mental illness.
- 2. Respecting and recognising the rights of people with mental illness and treating them with dignity.
- 3. "How ever ill/poor the person, he or she has the capacity to manage his or her life", is the watchword.
- 4. Voices of people with mental illness should guide the programme.
- 5. Inclusion of people with mental illness in the development processes.
- 6. Inclusion of people with mental illness in the existing self help groups and federations.
- 7. People with mental illness and their supporters should be encouraged and enabled to advocate with the authorities demanding meeting of their needs.
- 8. Mental health is a development issue, it needs to be included in all the development activities of the organizations
- 9. Need for active participation of community in creating/designing a caring, accommodative and understanding environment to ensure fair treatment to PWMI in the community.
- 10. Beyond meeting the treatment needs of PWMI, they also have a variety of psychosocial needs. These have to addressed through non-medical approaches.

# What to establish through Field Support?

The field staff should establish rapport with people with mental illness, gain their confidence and build a positive environment so the voice of people with mental illness are heard and respected more. The field staff should be sensitive to the needs of people with mental illness and should have an open mind. They need to be first open to learning themselves and examine their own ideas on mental illness and attitudes to PWMI. The field staff need to be oriented on why they should engage in community mental healthhow it would support their main activity, how it will be included in their development work and what are included in the community mental health and development activities.

# How will field support be provided?

The field support or on job training for the field staff needs to be given for 2 days, once in four months. The trainer visits the field of the partner organization and gives an on job training. The trainer spends one day in the field, facilitating and observing community mental health and development activities. The second day will be spent with whole team, providing inputs and understanding the difficulties faced by the field staff in their work, helping them in identifying alternatives to deal with the same.

Some of the support areas in the field are:

- 1. Demonstrating, through conducting consultation
- 2. Demonstrating animations skills
- 3. Observing their awareness raising programmes and giving suggestions for improvement

- 4. Visiting 'difficult' families to help them to understand the need for mental health care
- 5. Differentiation of mental illness and mental retardation
- 6. Understanding violent behavior, warning signs of violent behaviour
- 7. Demonstrating attitude of respect to people with mental illness and encouraging them to express themselves.
- 8. Similarities and differences between community mental health and development activities and community based rehabilitation activities.
- 9. How to interact with PWMI and the families.
- 10. Understanding individual and family needs motivating them to take treatment, join support groups etc
- 11. Understanding family dynamics to motivate neglected and difficult families.
- 12. Assessment of individuals with mental illness
- 13. Addressing misconceptions within the family
- 14. Organizing and facilitating caregivers' group meetings.
- 15. Organizing and facilitating community meetings to mobilize community support
- 16. Orienting community groups on mental health issues
- 17. Reviewing the documentation maintained by the organization.
- 18. Meeting government officials to sensitize them on the needs of people with mental illness
- 19. Setting short, medium, and long term plans together with people with mental illness and their families
- 20. Demonstration of trade analysis

In our experience, the following are some areas that require additional, theoretical inputs:

- 1. Assessment of people with mental illness.
- 2. Discussion on the misconceptions of people in the community and how the same can addressed effectively.
- 3. Need for drawing up individual rehabilitation plan for each identified PWMI.
- 4. Documenting-looking at individual files and other reports and giving suggestions.
- 5. Bare foot counseling/helping skills.
- **6.** Facilitating discussion on consultation.
- 7. Helping the field staff to create/use awareness-raising materials (eg., posters).
- 8. Differentiation of mental illness and mental retardation.
- 9. Discussion on the needs of the family members and PWMI, based on the field visits.
- **10.** Facilitating discussion on trade analysis, local market and livelihood options.
- **11.** Facilitating discussion with the partner organization on the need for inclusion of the CMHD module and networking with other groups.
- **12.** Facilitating discussion on engaging with the concerned government personnel for meeting the requirements and entitlements of PWMI.
- **13.** Sharing of the experiences and learning.
- 14. Orienting the heads of organizations and the board members on mental health issues.
- 15. Orienting field staff on the District Mental Health programme and National Rural Health mission.
- 16. Orienting field staff on community monitoring of CMHD.
- 17. Dealing with emotions and stress management

- 18. Demonstrating relaxations exercise
- 19. Base line documentation and need for the same
- 20. Demonstrating documentation through helping the field staff doing it.

# Chapter 10 List of energisers:

# 1. Chat Show (introduction)

Get the group to pair off and take turns in being a chat show host and guest. The chat show host has to find out 3 interesting facts about their guest. Switch the roles and repeat.

Bring everyone back to the big group and ask them to present briefly the 3 facts about their guest to the group. Maybe go round the group randomly so people are less aware of their turn coming up next and panicking about it.

Watch timing on this one as it has a tendency to go on too long if your group likes to chat too much.

#### 2. If I were a...

Ask each person to say what they would be and why, if they were a...

- A piece of fruit
- An historical figure
- · A household object
- A cartoon character
- · Any other off the wall group you can think of!

# Some examples:

I would be a pineapple as I am exotic, sweet and zingy. I would be a egg-beater as I like to stir things up. I would be horseas I rush around like a crazy creature

## 3. The Pocket/Purse Game

Everyone selects one (optionally two) items from their pocket or purse that has some personal significance to them. They introduce themselves and do show and tell for the selected item and why it is important to them.

For e.g people may have a picture of their family or their driving license. They need to explain why they have them in their wallet/hand-bag.

# 4. Paper Airplane Game

Everyone makes a paper airplane and writes their name, something they like and dislike on it (You may also want to add additional questions). On cue, everyone throws their airplane around the room. If you find an airplane, pick it and keep throwing it for 1-2 minutes. At the end of that time, everyone must have one paper airplane. This is the person they must find and introduce to the group.

## 5. Seven Up game

Every one counts the number starting from one, when it come to 7 or multiplication of 7, number ending with 7, they should clap, if they say the number than they are out of the game. Finally their will be one winner of the game. Trainer also would participate in the game

#### 6. Three in Common Game

Break the group into 3's. Their objective is for each group to find 3 things they have in common. But not normal things like age, sex or hair color. It must be three uncommon things. After letting the groups converse for 10 - 15 minutes, they (as a group) must tell the rest of the groups the 3 things they have in common.

## 7. Circle of Friends Game

This is a great greeting and departure for a large group who will be attending a seminar for more than one day together and the chances of meeting everyone in the room is almost impossible. Form two large circles (or simply form two lines side by side), one inside the other and have the people in the inside circle face the people in the outside circle. Ask the circles to take one step in the opposite directions, allowing them to meet each new person as the circle continues to move very slowly. If lines are formed, they simply keep the line moving very slowly, as they introduce themselves.

#### 8. Marooned Game

You are marooned on a island. What five (you can use a different number, such as seven, depending upon the size of each team) items would you have brought with you if you knew there was a chance that you might be stranded. Note that they are only allowed five items per team, not per person. You can have them write their items on a flip chart and discuss and defend their choices with the whole group. This activity helps them to learn about other's values and problem solving styles and promotes teamwork.

# 9. Decision making

You are in the middle of the sea in a big boat, the big boat started drowning due to technical problem. Along with you and your spouse, you have other co passengers like 17 year old disabled boy, 30 year old pregnant lady, 65 year old man and his wife 60 year old woman, 20 year old man. The boat was drowning, now only two people can escape by getting in to small boat which carries two people. If given choice for you whom do you send in that small boat and reason out why did you select them?, there is no right or wrong answer in this.

## 10 Story Time Game

The facilitator starts a story by saying a sentence. It then goes in a circle, each person adding a sentence onto the story-after repeating each sentence that's already been added.

#### 11. Ball Toss Game

This is a semi-review and wake-up exercise when covering material that requires heavy concentration. Have everyone stand up and form a resemblance of a circle. It does not have to

be perfect, but they should all be facing in, looking at each other. Through the ball to a person and have tell what they thought was the most important learning during the day. They then throw to other person explaining what they though was the most important concept. Continue the exercise until everyone has caught the ball at least once and explained an important concept of the material just covered.

# 12. Observe the opposite person

The participants will be asked to divide in to two groups of equal number. One group would act as observer and other group would be acting as statues. Both the groups would be asked to stand in line facing each other. The observer group is given 2 minutes for seeing the person in front of them. They are asked to go out of the room for 2 minutes. The statute group will be asked to make some changes in them (eg like changing the watch from left to right side, removing the buttons of the shirt, changing the hair style, changing the place of pen etc). The observer group is called, they would stand in the line facing their partner, they are asked to tell the changes in their partners.

# 13. Group untangle

The whole group will assemble in a circle with each person clasping a hand of someone different. (In other words, they will be holding one person's hand with their left hand and someone else's with their right hand) IMPORTANT! It cannot be the person next to them.

Now that they are in a complete jumble, blow the whistle and give them one minute to get untangled without letting go of each other's hands.

#### 14. Rebel Foot

Ask group members to sit comfortably. Then ask them to lift their right feet off the floor and make clockwise circles, while doing this, ask them to draw the number '6' in the air with their right hands. Their feet will change directions and there's nothing they can do about it. As we said, thinking controls behavior!

## 15. Blindfolded Animals

This activity can be used to separate people into pairs. With a small group, write the name of however many animals on two different pieces of paper and have the participants draw one out. With a large group, have students count off to a certain number and assign a certain animal for each number. When you say "go", participants will close their eyes and are only allowed to make

the noise of their animal in order to find their other group members. Animals such as cows, pigs, dogs, chickens, elephants, cats, and horses all make for a fun, and noisy, activity.

# 16. Trees Up Here Good -

Group repeats the words and motions of the leader

Leader: "Trees up here good!" Jumps up and puts hands high above head. Others: Repeat Leader: "Trees down here bad." Squats down and puts hands on ground. Others: Repeat Repeat this whole cycle 3 or 4 more times, then end on "Trees up here good.

## 17 Mixing the group with an exercise -

The group will be asked to sit comfortable on their chairs in a circle. Trainer will introduce the game by saying those people wearing slippers need to change their seats, when said all the participants wearing slippers should change, trainer would find his seat. The person who has not found the seat will have to ask people to change their seats giving options like (those who are wearing watches, those having money with them, those having gray hair etc)

# 18. Enactment what you did

Participants are given a doll asked them to pass it to the person sitting next to him, before passing they are asked to do some thing to the doll. Once they complete, participants are asked to repeat what they did to the doll to the person sitting next to them.

# 19. Joining together in Groups

The participants move about freely. The trainer calls out a number, for e.g. 'three' or 'seven'. The participants must immediately join together in groups corresponding to the number called out.. Those who are unable to join a group of the correct size are out of the game. The game continues until only two participants remain.

# 20. Knowing the names of all in the Group

Participants sit in a circle. The trainer asks one of them to start with his/her name. The next person repeats the first one's name and adds his/her own name. The participants go on until the last person repeats all the names.

#### 21. Statues

Participants form pairs. One partner is the clay. The other is the sculptor. The clay stands entirely relaxed, while the sculptor arranges him/her in certain posture. Neither may speak during the game. They then exchange roles. Sculptors may be left to choose the postures or the trainer may specify what is to be depicted, e.g., 'fear', 'anger', 'joy'.

## 22. Follow the Leader

Participants assemble in a circle. One participant is asked to volunteer to go out. The Trainer asks one to play the role of the leader. The leader performs an action which is followed by others (e.g. clapping hands). The leader changes actions from time to time. The volunteer participant is asked to come inside while the group is engaged in one action initiated by the leader. Volunteer's role is to identify the leader, who initiates /changes actions without being noticed. When the volunteer identifies the leader, he/she goes out. A few rounds may be played.

#### Session 5

Trade analysis: 60 minutes

# Objectives:

- To identify appropriate kinds of livelihood options for the PWMI and his family.
- · To look at the opportunities and risks of each identified option;
- To understand the implications of taking up an activity/ occupation- whether the PWMI and care giver can give the energy and time it demands.
- 1. Share the trade analysis format with the participants;
- 2. Divide the participants into three groups and ask them to identify an appropriate job/work for 3 mentally ill individuals. (Examples can be rearing a cow, opening a tailor shop and starting a welding/puncture repair service)
- 3. Invite the groups to present their analyses in the large group
- 4. Summarize the presentation focusing on the objectives and the points below.

Key issues: The analysis should look at possibilities (market and sale), risks, pressures and demands (maintaining quality, timely deliveries) that the occupation/job will entail on the PWMI and the care giver, consistently- has the PWMI stabilized sufficiently in his health for it.

# Session 5a Selection of an income generation activity

# The trade analysis should cover the following questions:

- What materials or equipment would be required for the production?
- How much would they cost?
- Who would buy the product?
- How much would they pay?
- Distance between the house and point of delivery of goods/services.
- Will there be transportation problems?
- Would any storage problems come up?
- What skills and knowledge would they need?
- What facilities or land would they require?
- How long would it take to get started?
- How long will it be before profit can begin to be made?
- Assistance available in the vicinity.
- What will be the long term and short term benefits to the family/person?
- How can the community be involved in the project?
- What will be the benefits to the community?

# Chapter 6

# **Documentation and Advocacy**

## Trainees should be able to:

- 1. Gain an overall understanding of documentation-types and importance
- 2. Develop format (individual file) for documenting
- 3. Learn and use the various legislations and provisions related to persons with mental illness
- 4. Have an understanding on human rights and international developments in disability (UNCRPD)

## Number of sessions: 6

Session 1: Need for documentation

Session 2: Individual file format and the quarterly report

Session 3: Advocacy

Session 4: Mental health legislations in India

Session 5: Provisions available for people with disabilities

Session 6: Human rights and UNCRPD

## Session 2:

# Individual file format and the quarterly report : 100 minutes Objectives:

 To introduce methods of collecting details about the person with mental illness, his family and circumstances.

- To try and trace and understand the history of the illness and its causes.
- To learn to listen with empathy and get quality information directly from the person affected with illness.
- To build up database that can be useful in community mental health programme.
- To build up data and evidence for public advocacy in CMHD.

## Exercise:

- 1. Introduce the concept of case study, individual files and life stories under the CMHD model.
- 2. Describe the reasons behind the formats used to collect details about the individual and family.
- 3. Share copy of the quarterly report and agree up on the quarterly report format; include a section for the "changes tracked (follow up information)" so that all partners have a common understanding on reporting.
- 4. Show an example of data base (display through LCD?) and how it is used in filling the quarterly report.

#### Session 2a

**CASE STUDIES:** In this context, it is an in-depth study of a person. In a case study, nearly every aspect of the subject's life and history is recorded to try and identify patterns and causes for his behavior. By an in-depth learning through this method of case study, one hopes to gain a general understanding of mental health and illness issues in a wider population.

**INDIVIDUAL FILES:** This includes comprehensive information about a person covering various aspects of his physical, mental, emotional and psychiatric details. The information collected should give an over all picture of the person's situation .The file must also include indicators that can be followed up on regular intervals to check if the person is making progress or not, for example, change in behaviour and symptoms etc.

**LIFE STORIES:** These are accounts of the series of events making up a person's life, as spoken and explained by the person himself. The idea is to bring out the qualitative information that tends to be missed out sometimes in case files. Life stories are written up in a reader –friendly format (see cases on Page---). This can then be used in awareness–raising and advocacy campaigns.

#### Session 2 b

# Guidelines for collecting information on the individual and the family/face sheet

a) Individual & family member's details like name, age, sex, marital status, education, occupation, number of children, number of earning persons and dependents etc.

# About individual illness

- a) History of illness when it started, since how many years, how it started
- b) Causes/triggering factors
- c) Symptoms
- d) Type of illness
- e) Understanding on the illness by the individual & the family
- f) Treatment process/efforts medical including local/faith healing

# Social aspects of the family

- a) Type of family nuclear or extended family
- b) Other social problems/difficulties like history alcohol/substances
- c) Single parent's family, broken families, marital conflicts if any, divorce and extra marital relationships etc.
- d) Cultural beliefs and practices of the family

# Family dynamics

- a) Relationships within the family
- b) Impact of positive and negative relationships on the individual
- c) Human rights violation like not providing treatment, property rights, abusing and assaulting, chaining and locking etc.

# Impact of the illness on the individual and the family

- a) Social impact stigma, marginalization/discrimination, isolation within the family and community
- b) Economic impact/burden earnings and expenditures, number of earning persons and dependents, savings, education of children, rent, family maintenance, food clothing etc.
- c) Due to mental illness any physical health hazards within the individual
- d) Psychological situation of the family

# Treatment process prior program intervention

- a) In depth understanding on the treatment process medical and other methods tried by the individual and the family, if he/she is on treatment which hospital, from how many months/years person is on treatment, whether it is satisfactory and supportive
- b) Why the efforts put by the family failed

# **Program interventions**

- a) Since how many years the family is in the program, how the individual and family is identified/ included in to the program
- b) Over all program interventions (Individual, family and community) like education & awareness on illness, right treatment and follow up, counseling, skill training/livelihood supports, self help groups, inclusion of PWMI and family members in to community groups, federations etc
- c) Impact and out come of the program interventions (Individual, family & community) in various areas like situation of illness, understanding on the illness, changes in the social aspects, family dynamics, economic situation, knowledge and information like part of self help groups, community groups and federation

# Chapter 5

# Livelihoods and income enhancement

# The trainees should be able to:

- 1. Understand relationship between mental illness and poverty
- 2. Understand family as a unit
- 3. Understand about the trade analysis
- 4. Understand about various livelihood options

# Key Issues:

Trainer notes: Need for independent living, self worth.

Number of sessions: 5

Session 1: Poverty and mental health

Session 2: Poverty: Cause and consequences of mental illness

Session 3: Sustainable Livelihoods

Session 4: Livelihood intervention

Session 5: Trade analysis

#### Session 1

# Poverty and mental health

# Prosperity: 20 minutes

- 1. Ask the participants what they think on poverty and poor people.
- 2. Write down the responses in the black board.

Some specific information on extent and effect of poverty in the country may be necessary – eg., reading of a status paper on poverty and an exercise to understand the implication of being poor.

WITHOUT ACCURATE STATISTICS, IT NOT POSSIBLE TO SAY POVERTY IS A CAUSE OF MENTAL ILLNESS.

## Self worth: 20 minutes

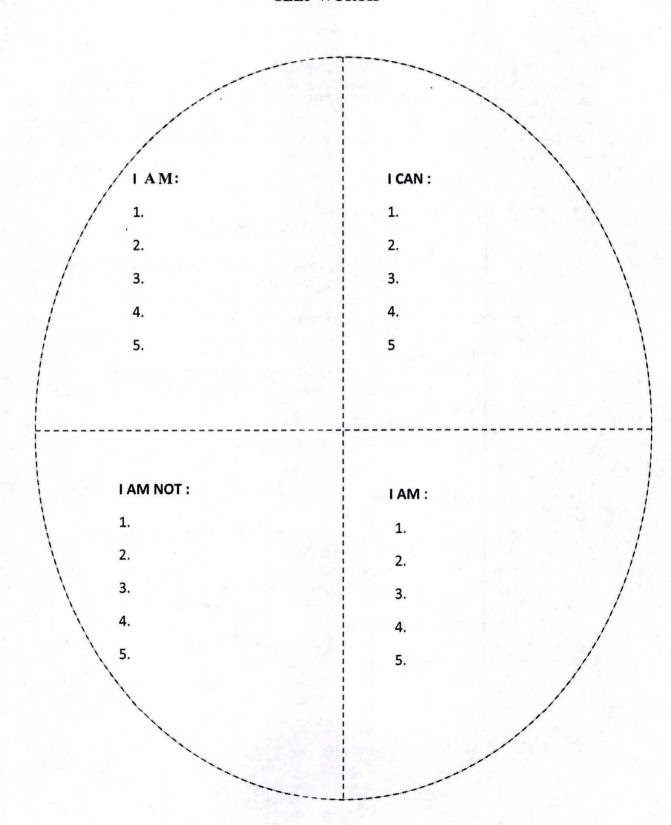
- 1. Divide the participants into groups of 5-6 persons and share their thoughts on one's self worth.
- 2. Introduce the paper on Looking at Self-Worth(SLB, Handout-2) to the participants. Ask the participants to fill the four columns, with a minimum five points under each.
- 3. On completion, invite the participants to share their views on the picture of themselves that emerges from the exercise.

# Leading to recovery: 20 minutes

- 1. Ask the participants to list the changes seen in PWMI on recovery.
- 2. Write the responses in the black board.
- 3. Describe the indicators of stabilization.
- 4. Describe the challenges and indicators of Relapse.
- 5. Explain the features of recovery.

Trainer's notes: Opportunities to socialize and engage in meaningful and productive activities that can increase the chances as well as speed up the recovery process. Being aware of the nature of the illness, providing a reasonable opportunity in sheltered workplaces would be essential.

# **SELF WORTH**



#### Session 1 d

# Recovery

Recovery is a process. It calls for a change in the way of life, in attitude and a new approach to meet life's challenges. The change has to come in the PWMI as well as everyone around him. The challenge is to rise above the limits of the illness/disability and establish a new sense of being valued and sense of purpose. The aspiration is to live, work and establish bonds in a community in which one lives.

# A person in the recovering phase will be:

- a. Free from the acute symptoms and problems that were caused by the illness.
- b. Able to understand the importance of care services, value the same and follow the instructions diligently.
- c. Able to take care of his personal hygiene.
- d. Able to involve himself in productive work in the family.
- e. Contributing towards the family income through engaging in livelihood activities.
- f. Participating in the self help group's meetings and activities.
- g. Making decisions or actively involved in making decisions concerning his life.
- h. In a position to understand and accept his life experiences.
- i. Taking active steps in promoting his own wellness.

# What recovery does not mean

- 1. Recovery does not mean a person will no longer experience the symptoms that he experienced before.
- 2. Recovery does not mean a person will no longer have struggles.
- 3. Recovery does not mean a person will not need medication.
- 4. Recovery does not mean a person will no longer need the care and services under community mental health.
- 5. Recovery does not mean a person will be completely independent in meeting all of his/her needs.

# Relapse

Sometimes, people with mental illness who have been "well" and carrying on with their life and work 'normally' can become ill again. This is called 'Relapse'. This can happen due to reasons such as these:

- Disturbing events occurring again: the kind of events that had originally caused the breakdown of mental health.
- Disturbing person (who was the original cause) reappearing on the scene.
- Decreased family support: It could be that the family decided to withdraw or lessen the support and care it was giving. Or, some additional stress that has burdened the family could have diverted its energy elsewhere.
- Most commonly, the person would have stopped taking the medicines (for a week or more).

The following signs and symptoms indicate a relapse:

\*Early signs: Anger, aggression, agitation, suicidal thoughts, sleeplessness or less sleep for 2-3 days.

\* Physical illness: an acute condition like vomiting or fever may indicate the beginning of the relapse.

Discontinuation of medicines: When there is a relapse the community health worker has to check whether the medicines have been discontinued. If that is the case, the person will not say it and the family also might not know about it. The community worker might even have to check the medicine packet and check with the person in whose presence the medicines were said to be taken.

# (This 'lesson' is newly introduced.)

#### Session 2

Poverty: Cause and consequences of mental illness: 60 minutes

# Objectives:

- To understand the consequence of having a PWMI in the family.
- To understand reasons behind the ability or inability to access resources necessary for the PWMI.

• To get an idea of the costs involved in caring for a PWMI.

#### **Exercise**

- 1. Divide the participants into groups of 5-7 persons.
- 2. Ask the participants to share case histories/stories, from their knowledge, of families having mentally ill members. The focus should be on their ability to access care services since the onset of the illness.
- 3. List out the cost involved in caring for a mentally ill person from the narrative of the case histories.
- 4. Summarize the consequences of having a PWMI for a poor family.

## **Key Issues:**

Some of the hidden cosst are cost for travel (often, more than one person accompanies the PWMI), the earning members losing wages, meeting expenses of 'treatments' like black magic, going to temples etc. The burden of care givers includes social, economic, psychological and emotional stress. Mental illness of one person affects the entire family. Therefore, for care services, the family has to be seen as a unit and not the individual mentally ill person.

# Session 2a

## Sustainable Livelihoods

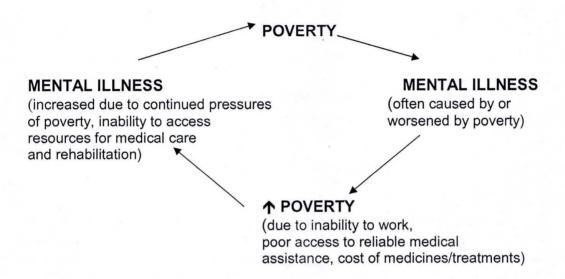
# A sustainable livelihood approach should operate at two levels.

One level of work is to directly provide poor people with better access to assets or ways of improving existing assets. The second level of work addresses the issues at a macro level, influencing policies in the private and public sector and promoting more effective functioning of the structures to ensure livelihood opportunities opening up to poor people, in a sustained manner. In its work with people with mental illness, Basic Needs India seeks to work at both levels.

## **Sustainable Livelihoods Programme**

## Sustainable Livelihoods and the mentally ill

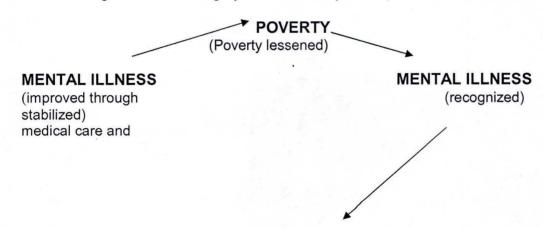
When dealing with poor people with mental illness, we have to consider not only their vulnerability due to their condition, but also the vulnerability brought about by poverty, which is a consequence and, to some extent, a cause of their condition. It is this cycle, which mental health and development programme aims to address, through its sustainable livelihoods interventions.



This is the reality of the debt trap of the family unit affected by a member's mental illness.

During our consultation process, caregivers always express a desire to address their financial burden caused by the cost of caring for the mentally ill person. There is a crying need to increase the family's income in order to cope with the additional stress created by the search for a 'cure', the need for regular medicines and the loss of a potential income source. The mentally ill people themselves express the wish to go back to their former work or take up a new income generating venture. The need is both to have an activity /engagement for the PWMI as well as to alleviate the stress on their families. It may not always be possible for a person to return to his former employment, though that must be an important priority. Alternatively, there is a need to explore other suitable and viable options, taking into account the individual's skills and capabilities as well as local opportunities and markets. Support is required to ensure long-term sustainability of the work/occupation or trade, not only in material/financial terms but also in the context of the person's illness.

The model outlined above demonstrates how a poor person can spiral downwards through mental illness. After the necessary intervention and support, we can imagine the following cycle of recovery and upward movement:



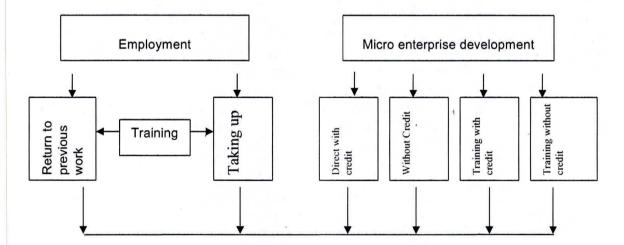


#### Sustainable Livelihoods: A definition

A meaningful work model demonstrates the concept of stabilization leading to reintroduction of choice for the mentally ill person. In our experience in the field, many have shown willingness, indeed eagerness, to exercise that choice and return to some form of employment. However, it is necessary to recognise that this choice is circumscribed by the limitations of poverty. It is imperative, therefore, that we work within the community to extend, in a sustainable way, the range of choices available to address poverty.

The whole thrust of the work therefore is to:

- (a) return mentally ill people to a range of options that exist in the community
- (b) wherever possible, collaborate with organisations/structures that are offering those options and get mentally ill people recognised as potential participants for the same.



# Meaningful work

Programme Focus

The primary unit for Basic Needs India's Sustainable Livelihood Intervention is the family of the mentally ill person, seen as a whole unit. The intention of the intervention is to enable the mentally ill person and her/his family to improve the family's assets in a way that directly enables the mentally ill person's own contribution and participation.

By family assets, we mean:

Asset Category	Breakdown
Natural	Land Water Livestock
Human	Aspirations Motivations Interests Capabilities Experience Knowledge Skills Networks
Financial	Income Savings Collateral

The programme's focus is to identify appropriate ways to enhance the stock of these assets in a manner that is sustainable, that has a qualitative and a quantitative impact on the family's life. It is crucial to enable the mentally ill person to make an identifiable and consistent contribution. This contribution should not only be seen to enhance the family's stock of assets, but should also support the PWMI in recovery from her illness. In other words, it should provide meaningful work which is recognised by the family for its usefulness and in a broad sense, be therapeutic as well to the PWMI.

## Approach:

The approach that Basic Needs is developing first recognizes the importance of stabilizing (the mental illness), by facilitating access to mental health services, promoting participation in the existing self help groups (SHGs) and providing support for the household.

Once stabilized, mentally ill people are encouraged to take up productive employment. But at the beginning, the person may be encouraged to help in 'non-remunerative' work, including, domestic chores. We recognize this as being

of intrinsic value as well as being an important stage of signaling to the family and the community that the person is stable and potentially available for employment or other income generating activities.

In our pilot projects, the ratio of people returning to their previous employment to those taking up a new, income generating activity is of the order of 3.5:1. We recognize that return to previous employment may be the simplest, least stressful and lowest risk option for a mentally ill person and is to be encouraged. We must, however, recognize that if poverty is a contributing cause to the development of mental illness and the family is under a great financial burden, the intermediary step of enhancing the family's assets through microfinance and training for possible employment should be seen as equally essential.

Where recovery takes longer or during relapses, we aim to involve the caregiver in income generation activities but inclusion of the mentally ill person, at all times, to the maximum extent possible, shall be part of the approach.

We aim to orient both SHGs, micro-finance and employment training institutions, so that they are encouraged to provide support, credit and savings and training to mentally ill people in ways that minimize stress and risk for them.

# Income expenditure analysis

# Model of income and expenditure analysis:

Expenditure of family X having two children - rough estimate of the monthly expenses

- 1. Expenses for the grains 500 Rs
- 2. Expenses for groceries 400 Rs
- 3. Expenses for milk 150 Rs
- 4. Expenses for snacks 160 Rs
- 5. Expenses for the vegetables 140 Rs
- 6. Expenses for firewood/kerosene 200 Rs
- 7. Expenses for Non veg food- 400 Rs
- 8. Expenses for flowers/agarbathi/camphor- 100 Rs
- 9. School and tuition fees 300 Rs
- 10. Expenses for buying fodder for the animals 800
- 11. House rent 500 Rs
- 12. Expenses for entertainment (cable charges, movies, exhibitions, circus)- 400 Rs
- 13. Expenses for ironing clothes 80 Rs ?
- 14. Expenses for washing clothes 120 Rs
- 15. Expenses for smoking/alcohol 500 Rs
- 16. Electricity bill/telephone bill/mobile bill /water charges- 350 Rs
- 17. Expenses for the travel 200 Rs
- 18. Expenses for buying face creams, powder & other make up equipments 150 Rs
- 19. Expenses for the cloths 300 Rs
- 20. Expenses for unpredictable things (illness, festivals etc)– 200 Rs

5800 rupees for one month

#### Income source

## Income for X family:

Income from agriculture: food grains worth rupees 18000 per year- 1500 rupees per month

Income from the coolie work (men) 100X15 days= 1500 rupees per month

Income from the coolie work (women) 80X12 days= 960 rupees per month Income from cows/buffalos 80X30= 2400 rupees per month

#### Session 3

# From Dependency towards Self Reliance - A Basic Needs India paradigm.

Poverty is more than low income and wealth is more than material possessions. Poverty being a cause and effect of mental illness has to be addressed from three stages that is the past, present and the future. Basic Needs India Trust, from its inception in 2001, has tried to tackle the issue of mental illness from a curative perspective- beginning with the identification of people with mental illness, treatment and follow up procedures. Working in partnership with other NGOs certainly has had a proven impact on the community..

This paper focuses on the experience of Basic Needs India in facilitating the community towards economic empowerment. Here the word "empowerment" conveys the meaning that people be enabled "to get what they want on their own". To base the program on local reality is the key to fundamental success. Based on the local reality, it is evident that starting a business or entrepreneur development services amidst the mentally ill population will be more difficult than in other, more favourable, contexts. It is important to keep this in mind, while initiating and implementing economic activities.

Society for Community Organization and Rural Development (SCORD), a partner organization of Basic Needs India, which works in the Thanjavur district of Tamilnadu, initiated the Micro Enterprise Development Program (MEDP) in its project area with help and support from Jan Sakthi Sansthan (JSS), a central government project. The preliminary discussions bore fruits whereby JSS identified the potential entrepreneurs for different trades and assured that the JSS team would provide training for the community. Some of the areas which were of interest to the community were:

- a. Sambrani /agarbathi (incense stick) production and sales unit.
- b. Animal Husbandry (Goat and Sheep rearing).
- c. Computer education.
- d. Tailoring and Embroidery.
- e. Color powder whole sale and retail business.

JSS has assured that training will be provided and appropriate support will be given during the initial phase.

The Government's step to collaborate with SCORD for the cause of the mentally ill, is a welcome measure. But, it is important to bear the special conditions of PWMI in mind.

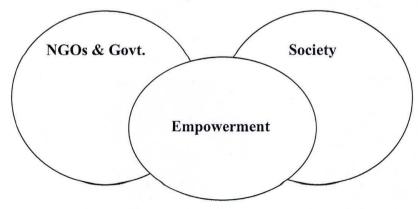
From a Mental illness perspective, Micro Enterprise Development Program has to be considered as a part of the rehabilitation process and not as a separate intervention. This means that MEDP would certainly promote recovery of the mentally ill but may not be totally successful in developing micro enterprises. Considering MEDP as a part of the rehabilitation process, may have to compromise on sustainability. It will be a Herculean task for stabilized people with mental illness to shift from a no-loss-no-gain enterprise to a profit-making one. Presumably, this shift can happen after a considerable period of time, if they survive in the midst of the competition in the market.

Identification of potential entrepreneurs from the community would be the first step. A set procedure has to be followed. Providing appropriate choices and preferences, through continuous motivational support, will invariably mean a "bottom-up" approach towards development.

In our pilot projects (Basic Needs India) the study conducted by Nicholas Coloff and Dr.Anil revealed that the ratio of people returning to previous employment to those taking up new income generating activities is of the order of 3.5:1. Comparatively speaking, the return to the previous employment may be the simplest, least stressful and lowest risk option facing a mentally ill person. This fact is recognized and encouraged by Basic Needs India. Though the previous employment reduces poverty to a certain extent it is felt that it is inadequate to meet the essential needs in the long run. In order to create a long term development outcome, emphasis should be given in areas like capacity building and motivational training, extracting more grant and credit facilities as support measures and collaboration with other departments and institutions.

It is essential to strike a balance between the rehabilitation model (considering the activities as activities in themselves, to keep the people with mental illness occupied) and the standard viable business model. A golden mean has to be arrived at, adopting the significant features from both the models.

A Micro Finance set up (SHG model) at the grassroots level already exists. The same can be used as a platform to carryout needs assessment and appropriate plans can be framed for the economic activities in consultation with the people with mental illness and their family members. A holistic approach, through sectoral coordination, as depicted in the following diagram, will be beneficial.





As a first step, the financial burden of the family will have to be analyzed. Next would be creating forward linkages with the banks and other financial institutions. Technology harnessed wisely through appropriate training will enhance human potential and people with mental illness are no exception to this. As already said, the ultimate goal of this venture is to restore the mentally ill persons to normalcy and get them integrated in the social mainstream. While doing so the guiding principle will always have to be "help to help themselves" as a permanent remedy and relief. Help in the form of Governmental, non-Governmental and technological aids will all be like crutches only. The crutches have to be removed at one stage and this will be for their own good.

## Session 4

## Livelihood Interventions: 60 minutes

- 1. Divide the participants into small groups of 5-6 persons.
- 2. Ask groups to list out the various livelihood options they have seen in their community.
- 3. Ask the participants to reflect on whether these interventions are able to meet the financial needs of the families.
- 4. Ask the group to discuss on why income generation activities provided was not able to meet the financial requirement of the individual/ families.
- 5. Have the groups present the summary of their discussions in the larger group.
- 6. Conclude the discussion stressing on how the livelihood interventions should meet the financial requirements of the family.

# Key Issues

Consultation with the affected person and the family is the key to successful intervention. Self employment, group activity, family occupations are the options. In the even of introducing a new activity, the affected person and/or the family should be given training in the necessary skills.

#### Session 4

Types of mental illness: 120 minutes

# Objectives:

- \* To learn that mental illness is a treatable condition that can be:
- a) healed resulting in complete recovery of the person; or
- b) managed, like many bodily illnesses, with medication on a long term or permanent basis.
- \* To learn the distinction between severe mental illnesses and common mental illnesses.
- \* To read simple descriptions of symptoms of some disorders (cases) to understand more about abnormal patterns in thinking.

#### **Exercise**

- Sive the cases (Page---), one or two for each small group to read.
- 2. Ask them to identify the differences between each one, if they can.
- 3. List down all the responses on the board.
- 4. Give four cases- one each on depression, anxiety, bipolar affective disorder and schizophrenia.
- 5. Ask if the participants know anyone with these features. Explain the main characteristics of each disorder.
- 6. Ask each group to do a role play based on the case. (HOW CAN THIS HELP PEOPLE UNDERSTAND THE ILLNESSES? BEFORE THE SESSION, THEY WILL NOT KNOW WHAT IT IS. After the session, it may come across as ridicule/ a practical joke. I suggest no role play)
- 7. After each role play, summarize clarifying on the symptoms of each of the type of mental illness.

## Session 4

# Types of mental illness

- **I. Severe mental illness:** In severe type of mental disorders, patients talk and behave very noticeably abnormally. The functions of the body and mind are severely disturbed, affecting the person's entire functioning and activities.
- II. Common Mental Disorders: Patients show either excessive or exaggerated emotional reaction to a stress or unhappy situation. They have symptoms like

anxiety, fear, sadness, vague aches and pains and other bodily symptoms. They are aware of their problems and seek help (but more often, for the physical symptoms).

- **III.** Alcohol and substance dependence: This is among the most common of mental illnesses although people may call them 'bad habits' and not illness. These are generally divided according to the substance involved alcohol, opium, marijuana, cocaine etc. They are also classified according to the clinical state in which the person is: addiction state, complications of use/abuse, and withdrawal symptoms.
- **IV. Childhood behavior problems:** These are mostly disturbances of behavior and conduct occurring in stressful family situations or as part of the child's development. The behaviour is not appropriate to the age or circumstances of the child.
- VI Psychosexual disorders: Psychosexual disorders are of two types: sexual dysfunction and sexual deviation. In sexual dysfunction, there is lack of normal sexual interest or response. In sexual deviation, the behaviour is unusual and violates the social norms of the society.

# VII Organic Mental disorder:

These disorders are caused directly by damage to the structures of brain. The underlying disease may be in the brain itself or may be in other parts of the body. The important symptoms and signs of the disorders are: disorientation to time, place and people, poor understanding and calculation, memory problems, emotional instability, self neglect and absence of awareness of the same

# Severe Mental Illnesses

This group of mental disorders consists of three main types of illnesses: Acute (brief) psychoses, Schizophrenia, manic-depressive disorder (also called Bipolar disorder). These illnesses are rare. However, they are characterized by marked behavioural problems and strange and unusual thinking. These are the disorders most typically associated with mental illness in people's minds. The majority of patients in psychiatric hospitals suffer from these psychoses.

# Some common features of severe mental illness are:

- Major mental disorders begin in young adulthood.
- They tend to be chronic and seriously disabling.
- Around one per cent of our population is affected by severe mental illness.

- · They have high risk of becoming homeless.
- They are a heavy emotional and financial burden for the caregivers
- They remain largely untreated.
- The illness affects their social and working life.

# The key features of schizophrenia

A person with schizophrenia will experience some of the following symptoms:

# Physical

 Strange complaints, such as the sensation that an animal or unusual objects are inside his body

# Feeling

- Depression
- A loss of interest and motivation in daily activities
- · Feeling scared of being harmed

# Thinking

- Difficulty thinking clearly
- Strange thoughts, such as believing that others are trying to harm him or that his mind is being controlled by external forces (such thoughts are also called 'delusions')

#### Behaving

- Withdrawal from usual activities
- Restlessness, pacing about
- Aggressive behaviour
- Bizarre behaviour such as hoarding rubbish
- · Poor self-care and hygiene
- Answering questions with irrelevant answers

# **Imagining**

- Hearing voices that talk about him, particularly nasty voices (hallucinations)
- Seeing things that others cannot (hallucinations)

## The key features of mania

A person with mania will experience some of the following symptoms:

## Feeling

- Feeling on top of the world
- Feeling happy without any reason
- Irritability

# Thinking

- Believing that she has special powers or is a special person
- Believing that others are trying to harm her
- Denying that there is any illness at all

# Behaving

- Rapid speech
- Being socially irresponsible, such as being sexually inappropriate
- Being unable to relax or sit still
- Sleeping less
- Trying to do many things but not managing to complete anything
- Refusing treatment

# **Imagining**

 Hearing voices that others cannot (often, these voices tell her that she is an important person who can do great things)

# The key features of acute or brief psychoses

The symptoms are similar to those of schizophrenia and mania. The key is that the symptoms begin suddenly and last less than a month. The typical symptoms seen are:

- · Severe behavioural disturbance such as restlessness and aggression
- Hearing voices or seeing things others cannot
- Bizarre beliefs
- Talking nonsense
- Fearful emotional state or rapidly changing emotions (from tears to laughter)

Session 4 c Common mental illnesses Common mental illnesses (also called Neuroses) cannot be easily defined. Unlike in severe mental illness or psychoses, in common mental illness, the persons do not lose touch with reality and they are able to meet the ordinary demands of every day living. For all purposes, they appear normal and carry on with their work and life. They generally have a good understanding of their problems. While they may not always cause much distress to others in the family, they do cause a lot of distress to the persons themselves. Though disturbed to varying degrees, the person usually is not disabled completely and is able to carry on with his/her work and social life.

The basic features of common mental illness are excessive mental tension and worry. All of us get tense or worried from time to time, especially when faced with difficult problems. However, we are able to cope with the situations and overcome these tensions or worry with passage of time. If the tension or worry is too intense or prolonged, they tend to interfere with our sense of well being and disturb our normal functioning.

Many persons with common mental illness, basically have feelings of inadequacy and inferiority – they lack self confidence. (Many a time, the feeling of 'inferiority' may be turned opposite into egotistic behaviour). This leads them to perceive common, every day problems as difficult and threatening. This constantly produces tension and worry and these individuals prefer to avoid facing these problems, ultimately resulting in physical or psychological complaints. Many persons with a common mental illness may have problems such as a difficult relationship, a family conflict, an unhappy marriage, difficulty at work place, persistent financial problems, serious and chronic physical illness in the family or a death of a close relative or friend.

Everyone experiences mental tension or unhappiness when faced difficult problems in life. But, in the case of persons with common mental illness, these tensions, worries and unhappiness become part of their life style, leading to constant feelings of insecurity and a need for support from others. The exact symptoms of common mental illness can vary markedly from one person to another.

# **Mental Illnesses**

There are six broad categories of mental illnesses:

- Common mental disorders (depression and anxiety);
- Panic, Phobia, Obsessive Compulsive Disorder, Post Traumatic Stress.
- 'Bad habits' such as alcohol dependence or drug misuse;

- Severe mental disorders (psychoses);
- Mental retardation;
- Mental health problems in the elderly;
- Mental health problems in children.

Common mental disorders consist of two types of emotional problems: depression and anxiety.

Depression means feeling low, sad, fed up or miserable. It is an emotion that almost everyone suffers sometimes in life. To some extent, it can even be called 'normal'. For example, following the death of a close friend or relative, one could be overtaken by grief and depression. But, there are times when depression starts to interfere with every day living. Then it becomes a problem. For example, everyone gets spells of feeling sad but most people manage to carry on with life and the feeling of depression fades off. Sometimes, the depression lasts for long periods, even longer than a month. It may be accompanied with symptoms such as tiredness and difficulty in concentrating. These feelings make it difficult for the person to work or look after children at home. The person may attempt suicide or talk of it. If depression begins to interfere with life and lasts for a longs period of time, then we can assume that the person is suffering from an illness.

If detected early and given appropriate care, medication or counseling and psychotherapy, the person can become completely normal. A person with Depression problem may have a tendency to get it again, when faced with a crisis and would require the necessary help again. In general, depression is higher in women than men. About 18 to 23% of all women and 8 to 11% of all men have 'depression episodes' at some time or the other in their lives. Of these, six per cent of the women and three per cent of the men may require hospitalization at some time.

## The key features of depression

A person with depression will experience some of the following symptoms

## Physical

- Tiredness and a feeling of fatigue and weakness generally.
- Vague aches and pains all over the body

## Feeling

- Feeling sad and miserable
- A loss of interest in life, social interactions, work, etc.
- Guilty feelings

## Thinking

- Hopelessness about the future
- Difficulty in making decisions

- Thoughts that he is not as good as others (low self-esteem).
- Thoughts that it would be better if he were not alive.
- Suicidal ideas and plans.
- Difficulty in concentrating.

## Behaving

- Disturbed sleep (usually reduced sleep, but occasionally too much sleep)
- Poor appetite (sometimes increased appetite)
- Reduced sex drive

## Anxiety

Anxiety is a sensation of feeling afraid and nervous. Like depression, this is normal in certain situations. For example, a person going to give a speech or going for a job interview or a student going for an examination will feel nervous, anxious and tense. Some people seem to be **always** anxious but yet seem to cope. Like depression, anxiety becomes an illness if it lasts long (generally more than two weeks) and interferes with the person's daily life.

Anxiety and Depression affect a large number of people. Generalized anxiety disorder is a condition that is commonly seen in people. According to a rough estimate more than 30% of patients attending medical or surgical problems have one or more symptoms of anxiety or depression. However, it is often unrecognized and not addressed because the attention is on the physical illnesses only. The characteristic feature of Anxiety disorder is excessive fear and worry. They fear that the worst might happen whether it is relationships, work, school, finances or health. The person suffering from Anxiety disorder finds it difficult to control the worry and fear and carry on with normal activities.

Most people with a common mental disorder have a mixture of symptoms of depression and anxiety. Most never complain of the feeling and thinking problems but instead experience physical and behavioural symptoms, as in case -----. This could be for many reasons. They may feel talking of their psychological symptoms will lead to them being labelled as a 'mental' case.

## The key features of anxiety

A person with anxiety will experience some of the following symptoms:

Physical

Feeling her heart is beating fast (palpitations)

- A feeling of suffocation
- Dizziness
- Trembling, shaking all over
- Headaches
- Pins and needles (or sensation like ants crawling) on her limbs or face

# Feeling

- Feeling as if something terrible is going to happen to her
- Feeling scared

# Thinking

- Worrying too much about her problems or her health
- Thoughts that she is going to die, lose control or go mad (these thoughts are often associated with severe physical symptoms and extreme fear)
- Repeatedly thinking the same distressing thought again and again despite efforts to stop thinking them

## Behaving

- Avoiding situations that she is scared of, such as market places or public transport.
- Poor sleep

In addition to depression and anxiety, the following three varieties of common mental disorders may be seen commonly with specific or unusual complaints:

#### Panic disorder:

**Panic** is when anxiety occurs in severe attacks, usually lasting only a few minutes The characteristic of Panic disorder is the *suddenness of fear* that comes and takes over the person. They are associated with severe physical symptoms of anxiety and make the sufferers feel terrified that something terrible is going to happen.

A person may complain of having a heart attack. But when investigated, no abnormalities are found. Panic disorder is a chronic but treatable problem. But the person's social and work abilities may be affected seriously. He may have a poor quality of life and frequent relapses. Often unrecognized, this problem is often treated with excessive use of medicines.

People under panic attacks are seen to breathe much faster than usual. This leads to

changes in the blood chemistry which cause physical symptoms. (Conscious and slow breathing can help in undoing the effect of the panic attack.)

#### **Phobic Disorders:**

Phobia is as an irrational fear where the person tries to avoid the feared object, activity or situation. The fear could be in relation to something like animal (cat or cockroach), or water or heights. The presence or thought of the feared object or animal causes distress in the person who also, usually, recognizes that his fear reaction is excessive. It disrupts his ability to function normally. Even if he knows his fear is silly and there is no reason for it, he still wants to avoid the object or situation.

Common situations that cause phobia or even a panic attack are crowded places such as markets and buses, closed spaces like small rooms or lifts, and in social situations such as meeting people. In severe cases, the person may even stop going out of the house altogether.

# Obsessive-compulsive disorder (OCD):

Many of us have habits and routines, which help to organize daily lives. But if a person develops a pattern of behavior which takes too much time and interferes with her daily life, then she is said to have OCD. OCD is an intriguing and often disabling syndrome characterized by two distinct phenomenon's obsessions and compulsions. Obsessions are unwanted and persistent ideas, images and impulses that run through the person's mind over and over again. Sometimes, these thoughts come only once in a while and are only mildly annoying. But at other times, the thoughts come constantly and cause noticeable distress. A Compulsion is a behavior that is performed in response to the obsessions. The individual puts his thoughts into actions as per the rules he has made for himself, even though the person knows these are unnecessary or stupid, in an attempt to control the distress caused by the obsession. The obsessions and compulsions can become so frequent that they affect the person's concentration and lead to depression People with OCD hide their problem to avoid embarrassment. Often this people are labeled as perfectionist/hygienic person. Studies have established that it is a fairly common syndrome with a prevalence of over 2%.

#### Post Traumatic Stress Disorder:

These symptoms appear in a person after an exposure to a traumatic, life threatening accident or a natural disaster like earth quake or floods or man-made disaster like a bomb blast and riots. Some people involved in or witnessing it develop a group of symptoms termed 'acute stress reaction'. These symptoms may go away gradually over a period of a month or so in most people. But in some susceptible individuals, these symptoms persist and cause severe distress and inability to function.

# The key features of alcohol dependence

A person with alcohol dependence will experience some of the following symptoms:

## **Physical**

- Stomach problems, such as gastritis and ulcers
- Liver disease and jaundice
- Vomiting blood
- Vomiting or sickness in the mornings
- Tremors, especially in the mornings
- Accidents and injuries
- Withdrawal reactions, such as seizures (fits), sweating, confusion

# Feeling

- Feeling helpless and out of control
- Feeling guilty about his drinking behaviour

# Thinking

- A strong desire for alcohol
- Continuous thoughts about the next drink
- Thoughts of suicide

# Behaving

- Sleep difficulties
- The need to have a drink in the daytime
- The need to have a drink early in the morning, to relieve physical discomfort

# The key features of drug misuse

A person who misuses drugs will experience some of the following symptoms:

# Physical

- Breathing problems, such as asthma
- Skin infections and ulcers if she injects drugs
- Withdrawal reactions if the drug is not taken, such as nausea, anxiety, tremors, diarrhorea, stomach cramps, sweating

## Feeling

- Feeling helpless and out of control
- Feeling guilty about taking drugs
- Feeling sad and depressed

# Thinking

- A strong desire to take the drug
- Continuous thoughts about the next occasion of drug use
- Thoughts of suicide

# Behaving

- Sleep difficulties
- Irritability, such as becoming short-tempered
- Stealing money to buy drugs; getting in trouble with the police

(These descriptions go into separate boxes)

## Session 5

## Mental illness and mental retardation: 30 minutes

# **Objectives:**

- To understand the signs and symptoms of Mental Retardation.
- To understand the differences between Mental retardation and mental illnesses.
- To help families understand mental retardation and work out a rehabilitation plan with them for the affected individuals.

## Exercise:

- 1. Ask the participants if they have any experience of working with children with mental retardation or have met or spent some time with them.
- 2. Ask if they know the difference between mental retardation and mental illness
- 3. Read the following information on mental retardation and explain the same to the participants, in your own words.
- 4. Explain the difference between mental illness and mental retardation.

# Session 5

## What is mental retardation (MR)

Mental retardation means that mental functions are not as well developed as expected for the age of the child. Children with mental retardation have difficulty with learning new things. The disability may affect all aspects of a child's development, from learning how to sit and walk to learning how to eat and talk. Mental retardation is not an illness, but a condition present from an early stage of life (usually from birth) which lasts for the rest of the person's life. There is no cure or treatment for mental retardation. However, there is much that can be done to improve the quality of life for the child and family. Mental retardation can be mild, moderate or severe. The vast majority of children with mental retardation have the mild variety. You can identify the degree of mental retardation from a careful history of the child's development.

# How does mental retardation affect the child?

Mental retardation affects a child's development in many aspects:

- > Physical functions, for example the child's ability to walk and using his hands;
- > Self-care, for example the ability to feed, bathe and use the toilet independently;
- > Communication with others by talking and understanding what is being said;
- > Social functioning, such as playing with other children;
- > Mental illness
- Physical disabilities and diseases (the more severe the mental retardation, the greater will be the chance of physical health problems such as seizures and physical disabilities);
- > Family problems caused by guilt, unhappiness and anger about the child's mental retardation

# When should you suspect mental retardation?

Suspect mental retardation if a child:

- Is delayed in achieving key milestones;
- ➤ Has difficulties in school work and playing with other children;
- > Is not able to carry out instructions

Suspect mental retardation if an adolescent:

- > Has difficulties in social relationships with other adolescents;
- > Shows inappropriate sexual behaviour;
- > Is not able to learn at the same rate as other students in class

Suspect mental retardation if an adult:

- > Has difficulties in everyday functioning (e.g. cooking, cleaning);
- Has problems in social adjustment (e.g. making friends, finding work).

Moderate to severe mental retardation is usually detected in a child under two years. When mental retardation is first detected in an adolescent or adult, it is usually mild. This is why it escaped being detected in childhood and showed up as a problem only when the person was faced with new responsibilities later in life.

## When mental retardation and mental illness occur together

Children with mental retardation are more vulnerable to mental illness. Children with mild mental retardation may become very aware of their limited abilities compared with other children and may show emotional and behavioural problems in the classroom (such as hyperactivity). As they grow older, their difficulty in making friends may make them depressed and angry. Sexual problems may arise. Children with more severe mental retardation often have brain damage, which can make them more vulnerable to psychoses. If a child with mental retardation shows a change in behaviour, you should suspect a mental illness.

## Questions to ask about the child

Asking the child questions and examining his abilities requires some training and practice. The main tool in detecting mental retardation is a careful history from the parent about the child's development and abilities. Ask what age the child did various things like sitting or standing up, walking and talking. If the child is old enough, you may ask about his worries (such as relationships with friend, studies and school performance, and so on). Knowledge of the kinds of problems the child is facing may make you think of mental retardation as a cause of these problems. You will also be able to judge the child's talking skill and get a sense of whether they are appropriate for his age.

Just because a child has MR, it does not mean he is not able to understand what is being said about him. Do not make the mistake of behaving as if the child were not present there at all. *Treat all children, no matter how severe the MR, with dignity and respect.* 

The first and most important thing is to be absolutely sure that the child has mental retardation. The label of mental retardation has a serious impact because it means that the child has a problem that is not curable. It is a label that can cause great unhappiness and worry, so use it with care. Get a second opinion from a child or mental health specialist.

Once you are very sure that the child has mental retardation, determine its severity. The abilities a child has will be an important indicator of how much progress he is likely to make in the years ahead. It is essential to educate the parents about what can be realistically expected of their child.

Most children with mild mental retardation will be able to go to school. Many children may manage in a regular school up to a level, especially if the teachers are sensitive to their needs. Others may need special schooling. Most children will be able to care for themselves and be fairly independent. These children will mainly have difficulties in making friends as they grow older and in finding jobs. Routine jobs may be the ideal kind of employment for them.

Most children with moderate mental retardation will need to be in special schools. They may need prompting and help with daily activities. For example, a child may learn to wash and go to the toilet on her own, but may need reminders and occasional checking. Most children will be dependent on their families for social interaction. Most will not be able to hold regular employment. However, some sort of sheltered employment in workshops may be possible. Sexual adjustment may become a problem in adulthood.

Children with severe mental retardation are likely to need care for most of their lives. They may suffer from physical disabilities and medical problems. Bladder and bowel control may not be achieved until very late. Such children may not be able to cope even in special schools. Employment is not a realistic possibility for them.

If the child has a specific medical problem, such as low thyroid function, or fits, refer him for specialist advice. Other than these special (and rare) situations, there are no medicines for the treatment of mental retardation. Do not use 'brain tonics' or other medicines supposed to help 'mental function'. These are not only expensive but will not be of any help.

Reassure the family that even though their child has limited mental abilities, she will be able to do many useful and productive things life. They must be prepared to accept the child's slowness and be realistic in what they expect their child to achieve. Specifically explain that there are no cures and that they should not waste money on false claims of cures.

Teach the parents how to help the child in daily activities such as toileting, dressing and feeding.

Things to remember when dealing with mental retardation

- Delay in development is most often because of mental retardation. Mental retardation is not a disease, but a condition that lasts the entire lifetime of the person.
- The majority of children with mental retardation look like other children.
- Mental retardation is not curable but may be preventable. Ensuring healthy pregnancies, childbirth and early child care and development will help prevent the majority of cases
- > Early detection is important because parent training may help improve the final outcome for the child.
- Mental retardation may not be detected until adolescence or even adulthood; usually, the mental retardation is mild in such situations.
- ➤ The parents will likely need information on how to care for the child and how to provide special education.
- Medicines have very little role to play in mental retardation except in the control of seizures (fits) and severe mental illnesses that can occur in some individuals.

Note: Many times, MR persons may also have mental illness of some kind (a) because of other problems along with MR; or (b) because of the way they are treated by the family and community, without understanding their condition. In such cases, the community worker has to find out the symptoms of the mental illness and have him treated for it.

# Mental Retardation and Mental Illness: What's the Difference?

Mental Retardation	Mental Illness
A Mentally retarded person has below average intelligence.	1. In Mental illness, a person's thinking, feeling, mood, ability to relate to others and daily functioning are affected. It is nothing to do with his
Mental retardation can be severe, moderate, mild and borderline or marginal.	intelligence.
	Mental illness can also range from very severe to very mild and it can be treated to bring the person to a normal functioning level.

2. Mental retardation is a condition. There is no treatment for recovery but they can be trained in daily living and some occupational skills.	2. Mental illness is an illness. If identified and provided with appropriate care the person can recover from illness and manage his/her own life.
3. National incidence of MR is said to be 3% of the general population.	
Mental retardation is present at birth or occurs during the period of development.	3. Mental illness disorders are widespread in the population with an estimated 1 % of the population having severe mental illnesses and 5-15% having common mental illnesses.
	4. Mental illnesses can affect persons of any age, caste or religion. They can be poor or rich, rural or urban. Mental illnesses are not the result of personal weakness, lack of character, or poor upbringing. Mental illnesses are treatable. Most people, including those with serious a mental illness, can get relief through treatment that may include medicines, counseling etc.
6. In mental retardation, the intelligence of the person is affected and this is a permanent condition.	6. In mental illness, the person's intelligence level can be as good as any one.
7. A person with mental retardation can be expected to behave rationally at his/her level though it may not be appropriate to his/her age.	7. A person with mental illness may fluctuate between normal and irrational behavior.
8. People with mental retardation can also experience different types of mental illnesses, such as, hallucinations, severe depression, phobias etc. In such a case, the illness can be treated.	8. Mental illness covers a wide variety of symptoms - emotional trouble, excessive moodiness, suspicion and mistrust, or poor emotional control.

You will notice that the 'lesson' on MR is long and has a lot of detail. I have often heard that health workers and trainers unclear about the distinction about MI and MR and these doubts seem to come back even after a year of working/training. I suggest, therefore, that these details be included for the trainers' benefit, perhaps, in Book II.

# Organizing care services

# a. Mental health Interventions 90 minutes

# Objectives:

- To understand the causes-effect link in mental illness.
- To understand the causes behind the disturbing behaviour, in order to create a better understanding in the family and in the community.
- To look at the different types of interventions necessary to help PWMI.

#### **Exercise**

- 1. Divide the participants into the same small groups as did before, for reading the cases and role plays.
- 2. Refer back to the role plays and the cases and explain how the effect, that is, MI, has causes underlying. (Insert the problem tree diagram here to clarify)
- Ask the participants to try and draw the problem tree (causes as roots and symptoms as branches) for the case given and present the same in the larger group.
- 4. Ask the participants to share their thoughts on the possible interventions to improve the quality of life of persons with mental illness and their families after each presentation.

(Note: Examples are awareness creation, identifying the nature of the illness, emphasis on need to respect the PWMI, administration of medicines, engaging in household chores, training in Activities of Daily Living (ADL), involving the PWMI in decision making)

- 5. Invite the participants to share their thoughts on how to change the attitude of the community towards PWMI. (Talking in community meetings on MI to create awareness.)
- 6. Summarize the list of interventions with examples from your own experience of working with PWMI.
- 7. Try and categorize the list of the interventions into those the community worker can do personally and those that need support/action from external sources.

# b. District mental health programme and National mental health programme: 30 minutes

## Objectives:

\*To understand the highlights of the Government's Mental Health Programme.

- \* To identify the role NGO's can ply in reaching the programme's benefits to the people.
  - 1. Explain in simple terms the objectives of the National Mental health programme of 1982
  - 2. Explain the objectives of District mental health programme with particular reference to the Bellary model.

The description/ note on DMHP- Bellary model and the 10<sup>th</sup> five year plan are not in the manual.

3. Invite the participants to come up with ideas of what role NGOs can play to make the DMHP programme effective.

# c. Multi dimensional approach:

# 60 minutes

# Objectives:

- To know about the various kinds of treatments available for mental illness.
- To help in choosing the most helpful treatments.
- 1. Divide the participants in to groups of 4-5 persons.
- 2. Distribute the article on Multi Dimensional Approach for them to read.
- 3. Ask the groups to say what they understood from reading the paper.
- 4. Sum up the discussion sharing from your own experience in community mental health and development programme.

# Session 6 Mental health care services

Mental illnesses are of various degrees and kinds. How long a person may suffer from Mental illness also varies widely. For a long time, (perhaps even now this may true with many people) it was believed that there is no specific treatment available for mental illnesses. People also commonly thought that mentally ill persons had to be admitted to a mental hospital for lifetime and that was the only way to care for them. This belief is due to seeing only serious and chronically ill patients that was difficult for the family to manage. In the last 50 years, specific treatments for many mental illnesses are available which are as effective as the treatments for physical illnesses like TB, leprosy, malaria and typhoid.

The following are among the different types of treatment and healing practices for mental illness:

- 1. Medicines: If treatment is started early and continued regularly, complete recovery is possible. These medicines are available in the form of tablets, capsules, syrups, and injections. Medicines are available for all severe and common mental disorders. (For a lasting cure, however, in most cases, there is need for therapeutic counseling as well.)
- 2. Electroconvulsive treatment (ECT): It is commonly believed to be "the final treatment" for all types of mental disorders when no other treatment helps. However, it is one of the effective and safe methods of treatment for some specific mental disorders when given appropriately by a team of specialists. In some cases, it can bring about a dramatic recovery, e.g., as in severe depression. The person/ family need to give consent for taking ECT.
- 3. <u>Psychological help</u> (psychotherapy): When faced with stressful situations, some people may experience feelings of deep distress. Such persons can be helped by simple methods like listening to their difficulties, talking to the family as a group and trying to bring a change in their attitude towards their situation. These efforts can bring greater harmony in their lives and thus improvement in their symptoms.

**Family Therapy**: Family therapy is a branch of psychotherapy that works with families and couples in intimate relationships to try and bring a change. It emphasizes family relationships as an important factor in psychological health. Family problems are seen to arise due to unhealthy and non-supportive interactions within the family. Instead blaming the individual members, the family therapists focus more on how the patterns in their interactions keeps the problem from being solved.

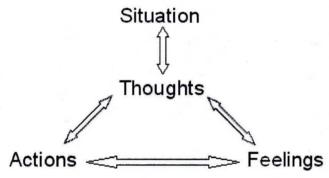
Family therapy has been used effectively where families or individuals in the family suffer from serious psychological disorders (eg schizophrenia anxiety depression, personality disorders, Attention Deficit Disorders and eating disorders.

Cognitive behaviour therapy: CBT can help you to change how you think ("Cognitive") and what you do ("Behaviour)". These changes can help you to feel better. Unlike some of the other talking treatments, it focuses on the "here and now" problems and difficulties. Instead of focusing on the causes of your distress or symptoms in the past, it looks for ways to improve your state of mind now. CBT can help you to understand large and overwhelming problems by breaking them down into smaller parts. This makes it easier to see how they are connected and how they affect you. These parts are:

- A Situation- a problem, event or difficult situation from this can follow:
- Thoughts
- Emotions
- Physical feelings
- Actions.

Each of these areas can affect the others. How you think about a problem can affect how you feel physically and emotionally. It can also alter what you do about it.

This is a simplified way of looking at what happens. The whole sequence, and parts of it, can also feedback like this:



This "vicious circle" can make you feel worse. You can start to believe quite unrealistic (and unpleasant) things about yourself. This happens because, when you are distressed you are more likely to jump to conclusions and to interpret things in extreme and unhelpful ways.

CBT can help you to break this vicious circle of altered thinking, feelings and behaviour. When you see the parts of the sequence clearly, you can change them - and so change the way you feel. CBT aims to get you to a point where you can "do it yourself", and work out your own ways of tackling these problems.

**Group therapy**: In group therapy approximately 6-10 individuals meet together with a group therapist. Members are encouraged to give feedback to others. Feedback includes expressing your own feelings about what someone says or does. Interactions between group members are encouraged as it provides each person with an opportunity to try out new ways of behaving; it also provides members with an opportunity for learning more about the way they interact with others. It is a safe environment in which members work to establish a level of trust that allows them to talk personally and honestly. Group members make a commitment to the group and its purpose of healing and recovery. They have to keep the content of the group sessions strictly confidential. It is not appropriate for group members to disclose events of the group to an outside person.

As the group members begin to feel more comfortable, the group member will be able to speak freely. The psychological safety of the group will allow the expression of those feelings which are often difficult to express outside of group. The group members will begin to ask for the support s/he needs. In a group, the member will probably be most helped and satisfied if given an opportunity to express and talk about his feelings.

<u>Couple/Marital therapy</u>: Couples therapy is a form of psychological therapy used to treat relationship problems for both individuals and couples. The purpose of couple therapy is to restore a better level of functioning in couples who experience distress in the relationship. The reasons for distress can include poor communication skills, incompatibility, psychological disorders that include domestic violence, alcoholism, depression, anxiety, and schizophrenia. The focus of couple therapy is to identify the cause of dissatisfaction and distress in the relationship and to devise a treatment plan and restore the relationship to a healthier level of functioning. Couples therapy can assist persons who are having complaints of intimacy, sexual, and communication difficulties.

<u>Rehabilitation</u>: Some persons with mental illness may not recover completely and may be left with longstanding impairments and disabilities. Such persons would benefit from rehabilitation programs, which include simple measures like involving them in recreational activities, teaching them simple, easy-to-do jobs, (eg. basket making, agarbathi making etc), social skill training, communication training, and including them in the daily household routines.

## Session 6 b

# Family interventions in community mental health programme

# Objectives:

- To become aware of the different aspects involved in family interventions.
- To understand the family's perspective, problems and possible thinking patterns.
- To identify and establish support structures for families having a PWMI.
- To work out a rehabilitation plan for the PWMI together with the family and the person.

## What are Family Interventions?

During family visits, the development worker provides support through creating understanding of the illness both for the affected individual and the family

members. The person with mental illness and his caregivers are consulted and involved in the entire process of assessment, diagnosis and planning of care services. This method helps the family in understanding the illness better. Family interventions also help the family to cope better with a chronically mentally ill member and help reduce their burden.

# Why involve the families in the care of their mentally ill members?

There are a number of reasons for this:

- **1.** Family members and relatives are the main care givers for people with mental illness.
- 2. The family supervises care services like medication, follow up with psycho social intervention and provide emotional, social and financial support to the affected member.
- 3. To deal with the fears and anxieties about the causes of mental illness and the affected member's future.
- 4. The family's lack of knowledge and understanding of the resources available for treating PWMI leads them to a helpless situation forcing them to resort to violation of the human rights of the PWMI.
- 5. If the family feels it is contributing to the affected member's problems, they may feel guilty and defensive. In such a case the engagement with the family will make them more supportive.
- 6. The presence of a PWMI changes the entire rhythm and routine of the family life. The family members have extra chores in caring for the affected member. Trying to keep the family life as normal as possible while simultaneously trying to help the affected member can be very frustrating and stressful. The care givers too often risk losing their livelihood opportunities.
- 7. The family may find the affected member's behaviour embarrassing and painful. They may avoid normal socializing with others due to the stigma of having a mentally ill member, leading to isolation of the family.
- 8. Families may feel angry with the affected member especially when they feel that the affected member is 'lazy' or not trying to control his behaviour.
- 9. Members in the family may experience severe stress, marital discord or depression associated with having a PWMI in the family. They often require attention from mental health professionals for their improving their own mental health.

- 10. The probability of the affected member relapsing is greater when the family's behaviour with him is over-protective, hostile, critical or otherwise very unhappy.
- 11. The environment in which the PWMI lives contributes markedly to improvement and recovery from the illness.
- 12. Due to the presence of a PWMI, families experience two kinds of burden:
- a) First is personal, emotional and social. It might give the family a sense of defeat, feelings of guilt, inadequacy, helplessness, confusion, hopelessness anger, disappointment and depression. On realizing that the affected member is not like a normal individual in the community, their expectations and dreams set on the individual get shattered.
- b) The second kind of burden includes a sharp decline in their financial condition. Expenses on medication, hospitalization, travel etc, and loss of earning and working days for the affected person as well as other family members can be very heavy. Interference with daily routines in the family, disruption in sleep and leisure time, difficulties in communicating with the affected member, strained family relationships and reduced social support etc.

# Why families need social support?

Families with a mentally ill member have fewer people to support them because of social stigma and the families isolating themselves. Families need to turn extended family members, neighbours, peer group, self help groups, federations, caregivers groups, community based organizations, NGOs, volunteers, staff of the NGOs, panchayaths, PHCs and health workers for emotional and practical support.

The advantages of having social contacts are:

- a) They can be useful and help distract the mind (even if temporarily) from the pain of having a severe mentally ill member.
- b) They provide general support and recreation to the family members and help relieve their tensions.
- c) They prevent the family members from focusing too much and spending too much energy on the affected member.
- d) They provide support in times of crisis.
- e) Care givers groups and self help groups provide a space to them to air their feelings and they are accepted and supported in these groups.

f) Caregivers forum provides a platform for them to raise their concerns through a collective voice and help them advocate for their rights.

# How effective are Family Interventions?

Family interventions are intended and designed to reduce the risk of relapse. They developed as a response to the burden experienced by the family members after hospitalization and in the treatment process. Many research studies have revealed that there is a substantial reduction in relapse rates due to family interventions and home based support given by the field staff. The experience of Basic Needs India also confirms this. Because of the clear relationship between expressed emotions and relapse, the interventions concentrate on diminishing the level of suppressed emotion through educating on the illness and care process, creating a platform for expressing their problems in these groups. The focus of the home visits and family interventions in Community Mental Health and Development programme are:

- · dealing with the side effects and negative symptoms;
- helping families to have realistic expectations from the PWMI;
- encouraging, consulting and engaging the mentally ill in the care process;
- · supporting caregivers to deal with their problems.

# What does Family Intervention involve?

The field worker visits the families and the PWMI:

- a) When the person has acute symptoms of the illness or relapse.
- b) When the person is in the recovering phase.
- c) During follow-ups when the person is doing well on treatment.

As the person may be in different phases of the illness, they may have different needs and expectations. The needs of the family will often differ from those of the PWMI. The family's needs could include:

- 1. Treatment for PWMI support for the travel and medicines.
- 2. Dealing with negative symptoms.
- 3. Referral services.
- 4. Psycho education.
- 5. Need for skill training for taking up a job or profession.
- 6. Economic empowerment needs such as housing, BPL card, voter or other ID's, Bus pass, Train pass, Disability ID card, pension for persons with mental illness, old age pension, widow's pension etc.
- 7. Day care/work therapy centers for the PWMI.
- 8. Institutional care for PWMI especially in families of single or aged parents.
- 9. Support for general health.
- 10. Legal support, related to property rights or maintenance.

## 11. Financial assistance from banks.

# Steps in treatment and rehabilitation

Once the person with mental illness has been identified in the community, the field worker starts working with the family, understanding its problems, assessing the situation, differentiating mental illness from mental retardation and stress symptoms. Field workers provide information about the available services for treatment. The field staff also encourage the families to attend caregivers meetings or meeting other families having similar experiences so that they understand the importance of getting regular treatment.

The field staff build rapport with the affected persons; consult them to understand their needs; educate the family about the illness and guide them or escort them for consulting mental health professionals for assessment and treatment. The field staff may need to explain about the medicines and the dosage. They may need to explain/warn about possible side effects from their experiences. When necessary, the field staff refer back to the mental health professional for guidance in managing the side effects. The PWMI will be encouraged to take up responsibilities at home and the families encouraged to involve the person in productive work.

The first step is to encourage the affected person and the family to engage the person in household activities. The second step is to encourage the person to go back to his previous work. In case this is not possible, encourage them to take up some income generating activities like agricultural work, animal rearing or some other skilled work.

## Session 4

# Types of mental illness

- **I. Severe mental illness:** In severe mental illness, the person talks and behaves very noticeably abnormally. The functions of the body and mind are severely disturbed affecting the person's entire functioning and activities.
- **II. Common Mental Disorders:** The PWMI show either excessive or exaggerated emotional reaction to a stress or unhappy situation. They have symptoms like anxiety, fear, sadness, vague aches and pains and other bodily symptoms. They are aware of their problems and seek help.
- **III. Alcohol and substance dependence:** These are generally divided according to the substance involved alcohol, opium, marijuana, cocaine etc. They are also classified according to the clinical state in which the person is: addiction state, complications of use/abuse, and withdrawal symptoms.
- **IV. Childhood behavior problems:** These are mostly disturbances of behavior occurring in stressful family situations or as part of the child's development. The behaviour is not appropriate to the age or circumstances of the child.
- V. Personality disorders: In personality disorder the person shows non-adjustment to his situation and exaggeration of some personal characteristics. Normally, the symptoms begin by late adolescence and continue more or less unchanged into old age.
- VI Psychosexual disorders: Psychosexual disorders are of two types: sexual dysfunction and sexual deviation. In sexual dysfunction, there is lack of normal sexual interest or response. In sexual deviation, the behaviour is unusual and violates the social norms of the society.

## VII Organic Mental disorder:

These disorders are caused directly by damage to the structures of brain. The underlying disease may be in the brain itself or may be in other parts of the body. The important symptoms and signs of the disorders are: disorientation to time, place and people, poor understanding and calculation, memory problems, emotional instability, self neglect and absence of awareness of the same

Three varieties of common mental disorders may present with specific or unusual complaints:

Panic is when anxiety occurs in severe attacks, usually lasting only a few minutes. Panic attacks typically start suddenly. They are associated with severe physical symptoms of anxiety and make sufferers feel terrified that something terrible is going to happen or that

they are going to die. Panic attacks occur because people who are fearful breathe much faster than usual. This leads to changes in the blood chemistry which cause physical symptoms.

**Phobias** are when a person feels scared (and often has a panic attack) only in specific situations. Common situations are crowded places such as markets and buses, closed spaces like small rooms or lifts, and in social situations such as meeting people. The person with a phobia often begins to avoid the situation that causes the anxiety, so that, in severe cases, the person may even stop going out of the house altogether.

Obsessive – compulsive disorders are conditions where a person gets repeated thoughts (obsessions) or does things repeatedly (compulsions) even though the person knows these are unnecessary or stupid. The obsessions and compulsions can become so frequent that they affect the person's concentration and lead to depression.

# The key features of alcohol dependence

A person with alcohol dependence will experience some of the following symptoms:

## Physical

- Stomach problems, such as gastritis and ulcers
- Liver disease and jaundice
- Vomiting blood
- Vomiting or sickness in the mornings
- Tremors, especially in the mornings
- Accidents and injuries
- Withdrawal reactions, such as seizures (fits), sweating, confusion

#### Feeling

- Feeling helpless and out of control
- Feeling guilty about his drinking behaviour

## Thinking

- A strong desire for alcohol
- Continuous thoughts about the next drink
- Thoughts of suicide

#### Behaving

- Sleep difficulties
- The need to have a drink in the daytime
- The need to have a drink early in the morning, to relieve physical discomfort

# The key features of drug misuse

A person who misuses drugs will experience some of the following symptoms:

# Physical

- Breathing problems, such as asthma
- Skin infections and ulcers if she injects drugs
- Withdrawal reactions if the drug is not taken, such as nausea, anxiety, tremors, diarrhorea, stomach cramps, sweating

# Feeling

- Feeling helpless and out of control
- Feeling guilty about taking drugs
- Feeling sad and depressed

# Thinking

- A strong desire to take the drug
- Continuous thoughts about the next occasion of drug use
- Thoughts of suicide

## Behaving

- Sleep difficulties
- Irritability, such as becoming short-tempered
- Stealing money to buy drugs; getting in trouble with the police

# **Severe Mental Illnesses**

The following are the commonly found severe mental illnesses:

Acute psychosis, Schizophrenia, Bipolar affective disorder

#### Some common features of severe mental illness are:

- Major mental disorders begin in young adulthood.
- They tend to be chronic and seriously disabling.
- · Around one per cent of our population is affected by severe mental illness.

- They have high risk of becoming homeless.
- They are a heavy emotional and financial burden for the caregivers
- They remain largely untreated.
- · The illness affects their social and working life.

# The key features of schizophrenia

A person with schizophrenia will experience some of the following symptoms:

# Physical

• Strange complaints, such as the sensation that an animal or unusual objects are inside his body

# Feeling

- Depression
- A loss of interest and motivation in daily activities
- Feeling scared of being harmed

# Thinking

- · Difficulty thinking clearly
- Strange thoughts, such as believing that others are trying to harm him or that his mind is being controlled by external forces (such thoughts are also called 'delusions')

## Behaving

- Withdrawal from usual activities
- Restlessness, pacing about
- Aggressive behaviour
- Very strange behaviour such as hoarding rubbish
- Poor self-care and hygiene
- Answering questions with irrelevant answers

# **Imagining**

- Hearing voices that talk about him, particularly nasty voices (hallucinations)
- Seeing things that others cannot (hallucinations)

## The key features of mania

A person with mania will experience some of the following symptoms:

# Feeling

- Feeling on top of the world
- Feeling happy without any reason
- Irritability

# Thinking

- Believing that she has special powers or is a special person
- Believing that others are trying to harm her
- Denying that there is any illness at all

# Behaving

- Rapid speech
- Being socially irresponsible, such as being sexually inappropriate
- Being unable to relax or sit still
- Sleeping less
- Trying to do many things but not managing to complete anything
- Refusing treatment

# *Imagining*

 Hearing voices that others cannot (often, these voices tell her that she is an important person who can do great things)

## The key features of acute or brief psychoses

The symptoms are similar to those of schizophrenia and mania. The key is that the symptoms begin suddenly and last less than a month. The typical symptoms seen are:

- Severe behavioural disturbance such as restlessness and aggression
- Hearing voices or seeing things others cannot
- Bizarre beliefs
- Talking nonsense
- Fearful emotional state or rapidly changing emotions (from tears to laughter)

# Session 4 c Common mental illnesses

# Types of common mental illness:

# Depression:

We have all experienced feeling of unhappiness sometimes or the other and also intense grief following the death of a close relative or friend. But these feelings go away with time. They, usually, do not require any treatment and also do not cause significant disturbances in our day-to-day affairs. But persons with depression would require appropriate care and attention for improving their functioning ability. Depression affects the quality of life of the individual remarkably and it can lead the person to harm himself or even commit suicide. If detected early and given appropriate care, medication or counseling and psychotherapy, the person can become completely functional. A person with Depression problem may have a tendency to get it again, when faced with a crisis and would require the necessary help again. In general, depression is higher in women than men. About 18 to 23% of all women and 8 to 11% of all men have 'depression episodes' at some time. Six per cent of those women and three per cent of those men may require hospitalization at some time.

# The key features of depression

A person with depression will experience some of the following symptoms

# Physical

- Tiredness and a feeling of fatigue and weakness
- Vague aches and pains all over the body

## Feeling

- Feeling sad and miserable
- A loss of interest in life, social interactions, work, etc.
- Guilty feelings

## Thinking

- Hopelessness about the future
- Difficulty making decisions
- Thoughts that he is not as good as others (low esteem)
- Thoughts that it would be better if he were not alive
- Suicidal ideas and plans
- Difficulty in concentrating

## Behaving

- Disturbed sleep (usually reduced sleep, but occasionally too much sleep)
- Poor appetite (sometimes increased appetite)
- Reduced sex drive

**Anxiety** 

Anxiety and Depression affect a large number of people. Generalized anxiety disorder is a condition that is commonly seen in people. According to a rough estimate more than 30% of patients attending medical or surgical problems have one or more symptoms of anxiety or depression. However, it is often unrecognized and not addressed because the attention is on their physical illnesses only. The characteristic feature of Anxiety disorder is excessive fear and worry. They fear that the worst will happen in the various events concerning relationships, work, school, finances or health. The person suffering from Anxiety disorder finds it difficult to control the worry and fear and carry on with normal activities.

The key features of anxiety

A person with anxiety will experience some of the following symptoms:

## Physical

- Feeling her heart is beating fast (palpitations)
- A feeling of suffocation
- Dizziness
- Trembling, shaking all over
- Headaches
- Pins and needles (or sensation of ants crawling) on her limbs or face

## Feeling

- Feeling as if something terrible is going to happen to her
- Feeling scared

## Thinking

- Worrying too much about her problems or her health
- Thoughts that she is going to die, lose control or go mad (these thoughts are often associated with severe physical symptoms and extreme fear)
- Repeatedly thinking the same distressing thought again and again despite efforts to stop thinking them

## Behaving

- Avoiding situations that she is scared of, such as marketplaces or public transport
- Poor sleep

## Phobia or fear:

Phobia is as an irrational fear where the person tries to avoid the feared object, activity or situation. The presence or thought of the object causes distress in the person who also, usually, recognizes that his reaction is excessive. It disrupts his ability to function normally. The sufferer would know that his fear is unfounded and there is no reason for it, but he still wants to avoid the object or situation. The commonly feared situations or objects include leaving home, being in a crowd or public places, speaking in public, entering small, enclosed places like a lift or seeing some pet animals (like a cat).

#### Panic disorder:

The characteristic of Panic disorder is the *suddenness of fear* that comes and takes over the person. It is rather like being under an attack by a frightening thing (such as an animal or a speeding vehicle). A person may complain of having a heart attack. But when investigated, no abnormalities are found. Panic disorder is a chronic but treatable problem. But the person's social and work abilities may be affected seriously. He may have a poor quality of life and frequent relapses. Often unrecognized, this problem is often treated with excessive use of medicines.

## Post Traumatic Stress Disorder:

These symptoms appear in a person after an exposure to a traumatic, life threatening accident or a natural disaster like earth quake or floods or man-made disaster like a bomb blast and riots. Some people involved in or witnessing it develop a group of symptoms termed 'acute stress reaction'. These symptoms may go away gradually over a period of a month or so in most people. But in some susceptible individuals, these symptoms persist and cause severe distress and inability to function.

## Adjustment disorders:

When a person is unable to adjust to a stress and shows marked distress even after a month after a stressful event, he is said to have adjustment disorder. The emotional and behavioral problems can be traced to an identified event. The symptoms usually do not last beyond 6 months. They could be like the following:

- 1) The distress is in excess of a normal response to the event:
- 2) There is significant inability in the person's social life and work or study...

## Obsessive-compulsive disorder (OCD):

Many of us have habits and routines, which help to organize our daily lives. But if a person has a habit or pattern of behavior on which he spends so much time that it affects his everyday life, then he/she is said to have OCD. OCD is a

puzzling often disabling problem, It has two distinct parts: obsessions and compulsions. Obsessions are unwanted ideas, thoughts or images that run through the person's mind over and over again. Sometimes these thoughts come only once in a while and are only mildly annoying. But, at other times, the thoughts come constantly and cause significant distress. Compulsion is a behavior that is performed in response to the obsessions or thoughts. The person puts his thoughts into action as per the rules he has made for himself. People with OCD hide their problem to avoid embarrassment. Often these people may be (mistakenly) called perfectionist or very hygienic. Studies show that OCD is a fairly common problem with over 2% of people suffering from it.

## What is mental retardation (MR)

Mental retardation means that mental functions are 'retarded' or, in other words, not as well developed as expected for the age of the child. Children with mental retardation have difficulty with learning new things. The disability may affect all aspects of a child's development, from learning how to sit and walk to learning how to talk and eat. Mental retardation is not an illness, but a condition present from an early stage of life (usually from birth) which lasts for the rest of the person's life. There is no cure or treatment for mental retardation. However, there is much that can be done to improve the quality of life for the child and family. Mental retardation can be mild, moderate or severe. The

vast majority of children with mental retardation have the mild variety. You can identify the degree of mental retardation from a careful history of the child's development.

# How does mental retardation affect the child?

Mental retardation affects a child's development in many aspects:

- > Physical functions, for example the child's ability to walk and using his hands;
- > Self-care, for example the ability to feed, bathe and use the toilet independently;
- > Communication with others by talking and understanding what is being said;
- > Social functioning, such as playing with other children;
- > Mental illness
- ➤ Physical disabilities and diseases (the more severe the mental retardation, the greater will be the chance of physical health problems such as seizures and physical disabilities);
- Family problems caused by guilt, unhappiness and anger about the child's mental retardation

# When should you suspect mental retardation?

Suspect mental retardation if a child:

- > Is delayed in achieving key milestones;
- Has difficulties in school work and playing with other children;
- > Is not able to carry out instructions

Suspect mental retardation if an adolescent :

- > Has difficulties in social relationships with other adolescents;
- > Shows inappropriate sexual behaviour;
- > Is not able to learn at the same rate as other students in class

Suspect mental retardation if an adult:

> Has difficulties in everyday functioning (e.g. cooking, cleaning);

Has problems in social adjustment (e.g. making friends, finding work).

Moderate to severe mental retardation is usually detected in a child under two years. When mental retardation is first detected in an adolescent or adult, it is usually mild. This is why it escaped being detected in childhood and showed up as a problem only when the person was faced with new responsibilities later in life.

## When mental retardation and mental illness occur together

Children with mental retardation are more vulnerable to mental illness. Children with mild mental retardation may become very aware of their limited abilities compared with other children and may show emotional and behavioural problems in the classroom (such as hyperactivity). As they grow older, their difficulty in making friends may make them depressed and angry. Sexual problems may arise. Children with more severe mental retardation often have brain damage, which can make them more vulnerable to *psychoses*. If a child with mental retardation shows a change in behaviour, you should suspect a mental illness.

# How to determine a child if mentally retarded

Asking the child questions and examining his abilities requires some training and practice. The main tool in detecting mental retardation is a careful questioning of the parents about the child's development and abilities -history to know at what age the child attained the various developmental milestones. Knowledge of the kinds of problems the child is facing may make you think of mental retardation as a cause of these problems. You will also be able to judge the child's verbal skills and get a sense of whether they are appropriate for his age.

Note the child's level of attention and involvement when you are talking. Children with mental retardation often have difficulty following long conversations as their mind tends to wander. They may look like they are daydreaming or not paying attention. They may have difficulty understanding simple questions and may give inappropriate answers.

Unusual physical findings are sometimes seen in children with mental retardation. These include a small or large head and physical disabilities. However, most children with mental retardation look just like any other child.

Some children may have a specific genetic syndrome that, in addition to producing mental retardation, also causes specific physical features. The commonest of these syndromes is Down's syndrome, where a child has slanting eyes, low ears, a short neck and, typically, a single prominent crease across the palms.

Special Note

Just because a child has MR, it does not mean he is not able to understand what is being said about him. Do not make the mistake of behaving as if the child were not in the room at all. Treat all children, no matter how severe the MR, with dignity and respect.

## What to do

The first and most important thing is to be absolutely sure that the child has mental retardation. The label of mental retardation has a serious impact because it means that the child has a problem that is not curable. It is a label that can cause great unhappiness and worry, so use it with care. Three useful strategies in being sure about the diagnoses are:

Ask the child to do some simple verbal or written tests that you would expect a child of that age to be able to do easily. For example, ask a child who is three years old to tell you her name.

For school-age children; ask for a teacher's report on school performance.

Get a second opinion from a child or mental health specialist.

Once you are confident that the child has mental retardation, determine its severity. The abilities a child has will be an important indicator of how much progress he is likely to make in the years ahead. It is essential to educate the parents about what can be realistically expected of their child.

Most children with mild mental retardation will be able to go to school. Many children may manage in a regular school, especially if the teachers are sensitive to their needs. Others may need special schooling. Most children will be able to care for themselves and be fairly independent. These children will mainly have difficulties in making friends as they grow older and in finding jobs. Routine jobs may be the ideal kind of employment for them.

Most children with moderate mental retardation will need to be in special schools. They may need prompting and help with daily activities. For example, a child may learn to wash and go to the toilet on her own, but may need reminders and occasional checking. Most children will be dependent on their families for social interactions. Most will not be able to hold regular employment. However, some sort of sheltered employment in workshops may be possible. Sexual adjustment may become a problem in adulthood.

Children with severe mental retardation are likely to need care for most of their lives. They may suffer from physical disabilities and medical problems. Bladder and bowel control may not be achieved until very late. Such children may not be able to cope even in special schools. Employment is not a realistic possibility for such children/adults.

If the child has a specific medical problem, such as low thyroid function, or fits, refer him for specialist advice. Other than these special (and rare) situations, there are no

indications for the use of medicines for the treatment of mental retardation. Do not use 'brain tonics' or other medicines supposed to help 'mental function'. These are not only expensive but will not be of any help.

Reassure the family that even though their child has limited mental abilities, he will be able to achieve many milestones in life. They must be prepared to accept a delay in these milestones and be realistic in what they expect their child to achieve. Specifically explain that there are no cures, and that they should not waste money on false claims of cures. Teach the parents how to help the child in daily activities such as toileting and feeding.

#### Things to remember when dealing with mental retardation

- > Delay in development is most often because of mental retardation. Mental retardation is not a disease, but a condition that lasts the entire lifetime of the person.
- The majority of children with mental retardation look like other children.
- Mental retardation is not curable but may be preventable. Ensuring healthy pregnancies, childbirth and early child care and development will help prevent the many cases. (However, community health workers are likely to meet the parents and MR child only after the birth of the child)
- ➤ Early detection is important because parent training may help improve the final outcome for the child.
- ➤ Mild mental retardation may not be detected until adolescence or even adulthood; The parents are likely to need information on how to care for the child and how to provide special education.
- ➤ Medicines have very little role to play in mental retardation except in the control of seizures and some other physical illnesses that are encountered in severe mental illnesses.

#### Session 6

#### Organizing care services

a. Mental health Interventions90 minutes

- 1. Trainer divided participants to go back to same groups (role plays and case vignettes)
- 2. Trainer refer back to the role plays and the case vignets and ask the participants to make a problem tree
- 3. Trainer invites participants to make presentation on the problem tree
- 4. Trainer ask larger group to share their thoughts on the possible interventions to improve the quality of life of people with mental illness and their families after each presentation
- 5. Trainer invites participants to share their thoughts on how to change the attitude of the community members
- 6. Trainer invites participants to summarize the list of the interventions
- 7. Trainer summarized with their experience of working with people with mental illness in the community
- 8. Trainer categorizes the list of the interventions in to what can community worker do and what support structures are needed for the care services from external sources.

# b. District mental health programme and National mental health programme:

#### 30 minutes

- Trainer shares about the objectives of National Mental health programme of 1982
- 2. Trainer makes presentation of the objectives of District mental health programme
- 3. Trainer makes a presentation of DMHP- Bellary model to 10<sup>th</sup> five year plan
- 4. Trainer distributes paper on the 11<sup>th</sup> five year plan and mental health programme
- **5.** Trainer invites participants to brainstorm How NGOs can take up complementary role in DMHP programme.

# c. Multi dimensional approach: 60 minutes

- 1. Trainer divides participants in to three groups
- 2. Trainer distributes the article on Multi Dimensional Approach
- 3. Trainer invites participants to read the article on multidimensional approach
- 4. Trainer invites the group to share the summary of the presentation
- 5. Trainer sums up the discussion sharing his/her experience of implementing community mental health and development programme.

# Session 6 Mental health care services

It has been seen that mental illnesses are of different types. Each of them affects the individual in varying degrees. Their duration also varies. So the available treatments also vary. It was often thought that no specific treatments are available for mental illnesses. This is not correct. This wrong notion occurs because people commonly believe that admission to a mental hospital, for lifetime, is the only means available to care for persons with mental illness. This belief is also the result of seeing only the chronically ill patients. In the last 50 years specific treatments for selected mental illnesses are available which are as effective as the treatments for physical illnesses like tuberculosis, leprosy, malaria and typhoid fever

The different types of treatment and healing practices are:

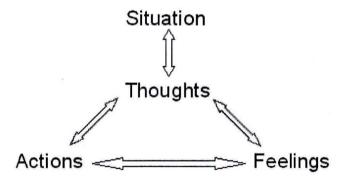
- 1. <u>Medicines:</u> If treatment is started early and is continued regularly complete recovery is possible. These medicines are available in the form of tablets, capsules, syrups, and injections. Medicines are available for all severe and common mental disorders.
- 2. Electroconvulsive treatment (ECT): It is commonly believed to be "the final treatment" for all types of mental disorders when no other treatment helps in recovery. However, it is one of the effective and safe methods of treatment for some specific mental disorders when given appropriately by a team of specialist. In few patients it can bring about dramatic recovery, e.g., as in severe depression. The person/ family need to give consent for taking ECT. It is given friction of second under the influence of anaesthesia.
- 3. <u>Psychological help (psychotherapy)</u>: Individuals faced with stressful situations experience psychological distress. Such persons can be helped by simple methods like listening to their difficulties, talking to the family as a group, bringing about change in their life situations. These efforts can result in greater harmony in their lives and thus improvement in their symptoms.
- a. Family Therapy: Family therapy is a branch of psychotherapy that works with families and couples in intimate relationships to nurture change and development. It tends to view these in terms of the systems of interaction between family members. It emphasizes family relationships as an important factor in psychological health. As such, family problems have been seen to arise out of systemic interactions, rather than to be blamed on individual members. Family therapists may focus more on how patterns of interaction maintain the problem rather than trying to identify the cause, as this can be experienced as blaming by some families. It assumes that the family as a whole is larger than the sum of its parts. Family therapy may also be used to draw upon the strengths of a social network to help address a problem that may be completely externally caused rather than created or maintained by the family.

Family therapy has been used effectively where families and or individuals in those families experience or suffer serious psychological disorders (eg schizophrenia anxiety depression, personality disorders, Attention deficit hyperkinetic disorders, additions and eating disorders.

- **b. Cognitive behaviour therapy**: CBT can help you to change how you think ("Cognitive") and what you do ("Behaviour)". These changes can help you to feel better. Unlike some of the other talking treatments, it focuses on the "here and now" problems and difficulties. Instead of focusing on the causes of your distress or symptoms in the past, it looks for ways to improve your state of mind now. CBT can help you to make sense of overwhelming problems by breaking them down into smaller parts. This makes it easier to see how they are connected and how they affect you. These parts are:
  - A Situation- a problem, event or difficult situation from this can follow:
  - Thoughts
  - Emotions
  - Physical feelings
  - Actions.

Each of these areas can affect the others. How you think about a problem can affect how you feel physically and emotionally. It can also alter what you do about it.

This is a simplified way of looking at what happens. The whole sequence, and parts of it, can also feedback like this:



This "vicious circle" can make you feel worse. You can start to believe quite unrealistic (and unpleasant) things about yourself. This happens because, when we are distressed, we are more likely to jump to conclusions and to interpret things in extreme and unhelpful ways.

CBT can help you to break this vicious circle of altered thinking, feelings and behaviour. When you see the parts of the sequence clearly, you can change

them - and so change the way you feel. CBT aims to get you to a point where you can "do it yourself", and work out your own ways of tackling these problems.

c. Group therapy: In group therapy approximately 6-10 individuals meet face-to-face with a group therapist. Members are encouraged to give feedback to others. Feedback includes expressing your own feelings about what someone says or does. Interaction between group members are highly encouraged and provides each person with an opportunity to try out new ways of behaving; it also provides members with an opportunity for learning more about the way they interact with others. It is a safe environment in which members work to establish a level of trust that allows them to talk personally and honestly. Group members make a commitment to the group and are instructed that the content of the group sessions are confidential. It is not appropriate for group members to disclose events of the group to an outside person.

As the group members begin to feel more comfortable, the group member will be able to speak freely. The psychological safety of the group will allow the expression of those feelings which are often difficult to express outside of group. The group member will begin to ask for the support needed. The group member will be encouraged to tell people what is expect of them. In a group, the member probably will be most helped and satisfied if given opportunity to express and talk about their feelings.

d. Couple/Marital therapy: Couples therapy is a form of psychological therapy used to treat relationship distress for both individuals and couples. The purpose of couple therapy is to restore a better level of functioning in couples who experience relationship distress. The reasons for distress can include poor communication skills, incompatibility, or a broad spectrum of psychological disorders that include domestic violence, alcoholism, depression, anxiety, and schizophrenia. The focus of couple therapy is to identify the presence of dissatisfaction and distress in the relationship, and to devise and implement a treatment plan with objectives designed to improve or alleviate the presenting symptoms and restore the relationship to a better and healthier level of functioning. Couples therapy can assist persons who are having complaints of intimacy, sexual, and communication difficulties.

Rehabilitation: Certain proportion of persons with mental illness may not recover completely and left with longstanding impairments and disabilities. Such persons would benefit from rehabilitation programs, which include simple measures like involving them in recreational activities, teaching them simple things repetitive type of jobs, (eg. basket making, agarbathi making etc), social skill training, communication training, and including them in the daily household routines.

#### Session 6 b

# Family interventions in community mental health programme:

#### What are Family Interventions?

During family visits, a development worker provides support and understanding of the illness for the affected individual and family members. Person with mental illness and their caregivers are consulted and involve them for the planning for assessment, diagnose and care services. This support helps the family in understanding of the illness. Intervention helps the person in gaining insight into the problems. Family interventions also help the family to cope with a chronically mentally ill member as well as reduce the burden faced by the families.

#### Why involve the families in the care of their mentally ill members?

There are a number of reasons for this:

- **1.** Family members and relatives are the main care givers of people with mental illness.
- 2. Family supervises the care services like medication intake, follow up of psycho social intervention and provide emotional, social and financial support for the affected member.

- 3. To deal with the fears and anxieties about the causes of mental illness and the affected member's future.
- 4. The family's lack of understanding of the resource available for treating their affected family member, lead them to helpless situation and force them to get involved in human rights violation.
- 5. Families may feel they are contributing to the affected member's problems, feel guilt and would be more supportive. They can become defensive in the treatment process.
- 6. The presence of an affected member changes the routine of the family life. The family members have extra household chores, as the affected member is unable to contribute. Trying to keep the family life as normal as possible while simultaneously trying to help the affected member is going to be frustrating more tedious/strainful. Due to caring their mentally ill family member would loose his or her livelihood opportunities.
- 7. The family may find the affected member's behaviour embarrassing and painful. They may avoid their normal socialization with others due to the stigma of having a mentally ill member, leading to self isolation of the family.
- 8. Families may feel angry with the affected member especially when they feel that the affected member is 'lazy' or not trying to control his behaviour (the negative symptoms).
- 9. Families may experience severe stress, or marital discord or depression associated with living with this illness, requiring attention from the mental health professionals for their improving mental health.
- 10. The probability of the affected member relapsing is greater when the family's behaviour with them tends to be over-involved, hostile, critical and dissatisfied
- 11. The environment in which person lives would contribute towards the prognosis of the illness.
- 12. Due to the mental illness in one of the family member, families would experience burden, it is seen at two levels, subjective and objective burden:
- a) What mental illness means to the family constitutes the subjective burden. It includes a sense of defeat, feelings of guilt, inadequacy, helplessness, confusion, hopelessness anger, disappointment and depression following the realization that the affected member is not like a normal individual like his or her fellow beings in the community. All their dreams set on the individual been unfulfilled because of the mental illness.

b). Objective burden such as decline in the economic status, as poverty is the cause and consequence of mental illness, (expenses on medication, hospitalizations, travel etc, and loss of livelihood opportunities for the affected person as well as the family member), sleep disruption, interference's with daily routines in the family, disruption of family's leisure time, difficulties in communicating with the affected member, strained family relationships and reduced social supports etc.

#### Why families need social support?

Families with mentally ill member have fewer people to support because of social stigma and families isolating themselves. Families need to turn for emotional or practical support from their networks which includes Immediate family members, neighborhoods, extended families, peer group, self help groups, federations, caregivers groups, care givers associations, community based organizations, NGOs, volunteers, staff of the NGOs, panchyaths, PHCs, health workers and etc.

The advantages of having social contacts are:

- a) Can be useful as temporary distractions from experiencing the pain of having a severe mentally ill member.
- b) They provide general support and recreation to help the family members relieve their tensions.
- c) Prevents the family member from focusing and spending too much energy on the affected member, and
- d) Provide support in times of crisis.
- e) Care givers groups and self help group helps them to ventilate their feelings, accepted as they are homogeneous groups
- f) Caregivers forum gives platform for them to raise their collective voices would help them for advocating for their rights

#### How effective are Family Interventions?

Family interventions designed to reduce the risk of relapse developed as a result of the burden experienced by the family members after hospitalization and in the treatment process. Many research studies, and the experience of Basic Needs India has revealed that a substantial reduction in relapse rates are due to family interventions and home based support given by the field staff. Because of the clear relationship between expressed emotion and relapse, the interventions concentrate on diminishing the level of expressed emotion through education on the illness and care process, creating a platform for expressing their problems in

a homogeneous groups, dealing with the side effects and negative symptoms during the home visits, helping families to have realistic expectations from their mentally ill family member, encouraging, consulting and engaging the mentally ill in the care process, supporting caregivers to deal with their problems would be the focus of family interventions in community mental health and development programme.

#### What does Family Intervention involve?

We will be seeing the families and the affected person during:

- a) When the affected member is acutely symptomatic or relapsed.
- b) When the affected member is in the recovering phase.
- c) During follow-ups when the affected member is maintaining well on treatment.

As the families that you meet may be in different phases of the illness, they may have different needs and expectations. The needs of the family per se will differ from that of the affected member's.

- 1. Treatment for PWMI support for the travel and medicines.
- 2. Dealing with negative symptoms.
- 3. Referral services.
- 4. Psycho education.
- 5. Need for skill training for taking up profession.
- 6. Economic empowerment needs (Housing, BPL card, Voters ID, Construction workers ID, Bus pass, Train pass, Disability ID card, Pension for persons with mental illness, Old age pension, Widow pension
- 7. Day care/work therapy centers for PWMI.
- 8. Institutional care for PWMI especially families of single parent and aged parents.
- 9. Support for general health.
- 10. Legal support related to property rights/separation.
- 11. Financial assistance from banks.

Once the person with mental illness had been identified in the community, the field worker starts working with the family, understanding the problems, assessing the situation, differentiating with mental retardation and stress. Field workers would provide information about the available services for treating people with mental illness. The field staff also would encourage the families to attend the caregivers meeting, or meeting other families having similar experiences so that they can get convinced about the need for regularizing treatment.

The field staff would build rapport with the affected persons; consult him to understand his or her needs. Educate the family about the illness and guide them or escort them for consulting mental health professional for assessment diagnosis and treatment services. The field staff would educate them about the

illness, and would inform them about the medicine intake. Field staff would visit the families, educate them about side effects, share his experiences of dealing with side effects, if necessary would refer back to the mental health professional for managing side effects. The affected person would be encouraged to take up responsibilities at home, motivate the families for involving in productive work along with the medicines.

Once the affected person and the family feels confidence of involving in productive work (household activities). Encourage them for going back to the previous work what he or she was doing (prior to illness). Incase if it becoming difficult, than encourage them for involving in income generation activities like agricultural work, animal rearing, skilled work.

# Chapter 4

Number of sessions: 8

**Session 1: Capacity Building** 

**Session 2: Animation** 

Session 3: Understanding barriers – Family and community

Session 4: Organizing people with mental illness and caregivers in to self help groups/associations

Session 5: Care givers needs

Session 6: Awareness generation

Session 7: Awareness materials

Session 8: Gender and mental health

#### Session 1

#### Capacity building

#### Objectives:

- To raise awareness in the community about mental illness, caring for PWMI and the rights of PWMI.
- To train different groups such SHG's, women's groups, Anganwadi workers and Panchayath members on Mental illness.
- To include the PWMI in SHG's and other community groups.
- To know the importance of networking caregiver's groups with other SHG's and to the Panchayath, District and State level organizations.
- To understand the method of accessing resources.

 To form pressure groups and other forums to advocate for the rights and entitlements of PWMI.

### Methodology

Wall writings, putting up posters, role plays and marking of special days, such as, Mental Health Week etc.

#### Session 3:

# Understanding barriers – Family and community: 120 minutes

- 1. Ask the participants to share their experience of
- 2. a. visiting the house of a person with mental illness and their interactions with the family members.
  - b. Talking with some community members about PWMI.
  - c. Meeting a local leader or Government official regarding the needs of PWMI.
- 3. During their sharing, ask someone to note the remarks/points that indicated supportive behaviour and those that appeared to be barriers in the interactions.
- 4. Divide the participants in to three groups and give the following topics for discussion to each of the groups.
- 5. Group one discusses the attitude of family towards the person with mental illness.
- 6. Group two discusses the attitude of the community towards people with mental illness.
- 7. Group three discusses the attitude of local government/local leaders towards the express needs of the people with mental illness.
- 8. Invite the groups to share their discussions in the larger group.

#### Session 3

Understanding barriers in the family

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#### Session 4:

Organizing people with mental illness and caregivers into self help groups or associations: 60 minutes

- 1. Ask the participants to share their views on including people with mental illness in the community's activities.
- 2. Note down the responses on the black board.
- 3. Share your own experiences of including people with mental illness in selfhelp groups of disabled persons with details of how they are working in some places.

#### Session 4

#### Caregiver's forum

Caregiver's forum consists of caregivers of mentally ill persons as well as PWMI whose condition has stabilized. These groups meet regularly for members to share their experiences. The sharing of experiences and sharing of their personal stories by stabilized PWMI, benefit the newcomers. It is a forum where people (caregivers) gain new insights that can help change their attitude towards mental illness and the PWMI in their family. They also gain courage to take action to solve their problems. For women carers, it is often an opportunity to come out of the isolation of their homes and share their problems with others in similar situations. Often, they gain confidence in speaking in a group, which can be an achievement in itself. Information's about medicines, their side effects, effective ways of administering the medicine to non-cooperative patients and such other things are learned from experienced carers. Over a period of time, the following changes in attitude are noticed in individual carers:

- trying out hospital medicines and sticking through the early difficulties with medicines.
- seeking government benefits.
- volunteering to help other affected families in simple ways.
- taking responsibility for the affected person (examples of 'shifting responsibility' by marrying off a PWMI, resulting in compounding of the problem are not uncommon).

The members learn to take responsibility for self help actions (an early one being holding the caregivers meetings regularly). Leadership and initiatives are fostered. Some groups decide to act on local community issues thereby contributing to the larger community leadership (eg getting municipality/panchayat authorities to attend to civic amenities)

The active members in the forum get identified over a period of time and get selected to be representatives in the larger apex body (federation).

They would be enabled through building capacity to function as effective representatives of PWMI.

(I do not know how the questions and this text of Session 4 are related. Are SHG's with PWMI included called Caregiver's Forum?)

# Session 5: Caregivers needs: 30 minutes

- Ask the participants to list out what they think could be the needs of caregivers of people with mental illness.
- 2. Invite some caregivers to the session and ask them to share their experience of being a caregiver (or show a video clipping)
- Explain the benefits of caregivers groups and meetings from your experience.
- 4. Summarize the discussion describing care givers associations and how they have included mental health issues in their activities.

#### Session 6

#### CARERS, THEIR ROLE IN HEALING

Severe mental disorders that are highly disabling affect nearly 1% of the population world wide. The illness is characterized by confused thinking, hallucinations, consequent behavioural problems and social isolation. In fact, more than 40 percent of people with severe mental disorders cannot participate in any structured activity on a regular basis.

Family members can play a crucial role in helping a person with severe mental illness. Before they can be helpful and supportive, they need to first understand and accept that mental illness is a disorder of the brain, just like diabetes is a disorder of the body. It is not anyone's fault and not an indication of moral or spiritual failure. Family members need to know this so that they do not blame their mentally ill relatives or think of them as lazy. People with mental illness are often unable to make any useful contribution to the family and are a drain on family's energy and resources. But this is not intentional behaviour on their part. They are, in many ways, victims as much as the family.

The most important thing family members can do to support their mentally ill relatives is to help them remain oriented to their task and routines. The family also should help them stay regular with their medications visit the doctor whenever necessary. Family members can help their mentally ill relative by helping them with personal care, eating a well-balanced diet and in getting regular exercise. Caring for mentally ill relatives is frequently painful and heartbreaking. Family members often need support and also a platform for sharing their problems and airing their frustrations. Participating in a self-help group of families of psychiatric patients reduces the family members' burden, loneliness and stress. It also provides them much needed support and encouragement to continue with the caring.

Poor people with mental illness and their families are affected worse by their inability to go to work and earn. The social stigma attached to mental illness further blocks community support and access to resources. For a female mentally ill person, the family's investment in her care is likely to be less as also other support needed for her recovery.

Because of the scarce mental health care facilities, the burden on the families is more. It is very important, therefore, to study the experiences of the families of PWMI to learn ways of support that can lead to recovery in people with mental illness.

#### Ideally, a good caregiver is one who has

- 1. Adequate time for the mentally ill family member:
- 2. Is a person who lives close by to mentally ill person;
- 3. Is a person with lot of patience;
- 4. A positive attitude towards the PWMI;
- 5. A firm belief that all problems can be solved;
- 6. The necessary motivation to care and also has capacity to motivate the person with illness.
- 7. Has the ability to create a favorable atmosphere for the person to be rehabilitated at home.

# A basic level of care required for person with mental illness includes

- 1. Follow up care- ensure the person takes his medicines regularly.
- 2. Providing adequate amount of nutritious food.
- 3. Encouraging the person to socialize with his acquaintances.
- 4. Motivating and monitoring the person to maintain personal hygiene.
- 5. Motivating the person to take on small responsibilities and carry them out.
- 6. Creating awareness in the community so that the person with mental illness is accepted and integrated into the community activities.
- 7. Engaging the person in income generation or productive activities.

In taking care of the people with mental illness, the carers play an important and difficult role, especially, when it is one with a severe mental illness. Their role is not recognized as much as that of the medicines and the doctor. This was evident in the findings of the annual reviews of Basic Needs, India. The carers have a responsibility which is quite heavy that might eventually affect their own physical and health and mental health as well.

#### Session 6:

#### Awareness generation: 60 minutes

- 1. Divide the participants into groups of 5-7 persons.
- 2. Ask each group to plan and do role play to raise awareness on mental health issues for the following groups of viewers:
  - a. ICDS/Anganwadi teachers.
  - b. Volunteers/ panchayath members
  - c. Their own community.
  - d. A women's group.
- 3. Each group shall pick one kind of audience and perform their role plays

- 4. Invite comments on the play from all the participants, after each role play.
- 5. Lead a discussion on areas that need to be improved while raising awareness on mental health issues.

#### Session 6

#### Awareness generation

In a community meeting the field staff share the following with the group:

- 1. Misconceptions and attitudes of people with regard to people with mental illness.
- 2. What is mental health?
- 3. Features of mental illness.
- 4. Causes of mental illness.
- 5. Need for including PWMI in the community's activities and in the self help groups.
- 6. Importance of regular and continuous treatment for mentally ill persons.
- 7. Treatment facilities available for mental illness in the locality.

Session 7:

Producing Awareness Raising material: 60 minutes

- 1. Ask the participants to go back to same small groups (as in role play) and design a poster or some awareness raising material that depict the message they want to give regarding mental illness.
- 2. Distribute sketch pens and chart paper and old magazines from which they can cut out pictures or whatever.
- **3.** Ask the group to discuss the posters/collages to be developed before beginning to make them.
- 4. Invite the groups to put up their posters and follow it up by a discussion.

#### Session 7

#### Awareness materials

A list of the awareness materials developed and maintained by our partners

- 1. Posters
- 2. Wall writings
- 3. Street theater scripts
- 4. Pluck cards
- 5. Banners
- 6. Handbook
- 7. Booklet on legislation concerning disability and mental illness.
- 8. Pamphlets/hand bills
- 9. Videos
- 10. Audio cassettes
- 11. Presentations??
- 12. Flip charts
- 13. Life stories and case studies
- 14. Resource directories
- 15. Calendars

Sample Posters on Mental health

POSTER -1

#### A person with good mental health

- Has clarity in his mind, is able to cope with his emotions and feelings and is able to carry out his daily work and lead a normal life.
- Has strength to face his regular problems, pains and disappointment.
- Is able to live in harmony with and to relate to people around him.
- Is able to keep his balance through the normal ups and downs in life.

#### A mentally ill person

- Might speak and behave differently from the normal way.
- Might have strange and dangerous thoughts.
- Might continuously find it difficult to do his/ her work and / or relate to others.

Causes of mental illness: Primary cause is unknown. But the following could cause mental imbalance and illness.

- Chemical change in the brain, caused by viral infection, tumor or blood clotting.
- Severe injury to the head to the nervous system.
- History of mental illness in the family.
- Excessive consumption of alcohol or drugs for a long period of time.
- A sudden shock due to an unexpected or big loss or tragedy.
- Very bitter experience in childhood and deeply disturbed family atmosphere.
- Social problems such as unemployment, extreme poverty and deprivation.
- Being subjected to serious and constant cruelty, violence and abuse.

#### Who can be affected by mental illness?

Men, women, Children, Literate, illiterate, poor or rich, those living in villages or cities- anyone can be affected by mental illness

#### POSTER - 2

#### Symptoms of mental illness

- Abnormal speech, behaviour or expression of feelings
- Disorder in sleep, hunger and sexual desire.
- · Lack of interest in looking after oneself.
- Baseless fears, anxiety and anger.
- · Sleeplessness and lack of appetite.
- Desire to be left alone and or/ wandering aimlessly
- Disinterest in normal social life.
- Confused mind and sometimes, loss of memory.
- Reduced ability to take appropriate and timely decisions.

#### Symptoms of common mental disorder

- Long term depression, feeling excessively nervous, anxious or scared.
- Lack of clarity in thinking and dealing with ordinary, everyday situations.
- Unusual behaviour, which may be embarrassing but harmless.

The person is aware of the reality and that he has a disorder

#### Symptoms of severe mental disorder

- Dangerous behaviour, being extremely quarrelsome or withdrawn
- Abnormal behaviour (Example. Laughing without reason, talking irrelevantly or talking to oneself)
- Being excessively suspicious, having wrong beliefs and a wild imagination.
- These persons may hear or see things that others cannot and may be confused because of that.
- Two contrasting kinds of behaviour in the same person such as depressed at times and highly excited at other times.
- Serious depression and thoughts of suicide.
- Lack of memory, lack of concentration, irregular in activities.

Usually, these persons are not aware that they are ill.

#### POSTER-3

#### Can mental illness be cured?

Yes, it can be...

- If it is identified at an early stage and treated
- · By taking treatment and medicines regularly.

Following are not correct or proper methods to cure a person with mental illness.

- Witchcraft
- Marriage
- Scaring, branding or chaining up the person

#### POSTER-4

Persons with mental illness need people who love and understand them.

They too have human rights like us.

#### What can you do?

- Increase their self-confidence by giving them affection, encouragement and support.
- Include them in the festivals you celebrate.
- Guide and encourage mentally ill persons to go to primary health centers or a hospital for treatment.
- Help them to get some vocational training.
- Create an opportunity for them to work and give them a job according to their abilities.
- Recognize and respect their rights. Help them get the benefits to which they are entitled, from government schemes.
- Ensure that mentally ill persons are involved in the discussions concerning them.

#### Session 3

#### Understanding human behaviour: 30 minutes

#### **Objectives:**

- To understand mental illness, the disturbances it causes in the body, mind and behaviour of the person;
- To reflect on the effect of hostile reaction to a person who is mentally ill.

#### **Exercise**

- 1. Divide the group into small groups of 5-6 persons.
- 2. Hand out the flip charts to each group. Ask the participants to create a story around the pictures.
- 3. Invite each group to present the discussion of their group.
- 4. Give your own observations on the chart.
- 5. Ask the group to think on the possible reasons for the odd/violent behaviour of people with mental illness.
- 6. List down the responses on the black board.
- 7. Ask the group why people look at a PWMI differently form a person with a physical illness or illnesses.
- 8. Ask each person to reflect on how s/he might feel when people laugh or tease or behave rudely with her/him.
- 9. Summarize explaining why mentally ill people become aggressive and how there is a cause behind the odd behaviour- eg., disturbance in thinking.

#### 30 minutes

# Exercise 2 Objective:

 To understand that the imbalance in mental illness is one of a degree of lack of control over one's behaviour.

#### Activity:

- a. Invite the participants to speak about one symptom/observation of a mentally ill person that they have seen/met.
- b. Write down all the words/responses of the participants on the board.
- c. Ask the participants if we too experience those symptoms sometimes.
- d. Ask the participants, if they ever use expressions like, "I am getting mad" "my mind is stuck". What do they mean?
- e. Summarize the discussion explaining the characteristics features of mental illness in a way that they can understand, using simple words and expressions.

1. Divide the participants into groups of 4-5 persons.

2. Give each group a case to read and discuss among themselves. Ask the participants if they can identify the mental illness in the given case and a possible cause for the same.

3. Explain the characteristics of mental illness and on the structural model of

mental health.

#### I suggest including these cases from Where there is no Psychiatrist

#### Voices from the edge

"It was so frightening when it first happened. I was sitting on a bus, when all of a sudden my heart stated beating so fast that I felt I was having a heart attack. I had difficulty breathing, and the then I started feeling as if ants were crawling on my hands and feet. My heart started pounding even faster, my body felt hot and I was trembling all over. I just had to get off the bus, but it was moving fast and I began to choke. My biggest fear was that I might collapse or go mad. Then the bus came to a stop and I rushed to get off even though I was still far from home. Since then, I have never been able to get on a bus....just the thought of using a bus makes me feel sick. For the past two years, I have stopped going out of the house because of this fear and now I have few friends and almost no social life...I didn't know what to do and I was too scared to see a psychiatrist....after all, I am not a mental case."

A 24-year-old woman with panic attacks and phobia

"I was only 17 when I first started hearing the voices. At first, I wasn't sure whether they were in my mind or real. But later, I used to hear strangers talking about me, saying nasty things. Once I heard a voice telling me to jump into a well and for days I would stand near the well feeling that I should obey the voice. I used to feel that my thoughts were being controlled by the TV and, sometimes, I was sure that my food was being poisoned and that gangsters were out to kill me. I used to get angry and it was when I lost my temper so badly and hit my neighbor that I was taken to the hospital."

A 23-year-old woman with depression

"I used to feel as if I had so much energy that I did not need to sleep at all. In fact, I hardly slept in those days. I would rush about with all my schemes and plans, but never really managed to finish any of them properly. I used to lose my temper if anyone tried to stop me. Once I got into a big fight with my business partners over one of my crazy schemes. But when I was high, I never realized how wrong I was. I even felt sometimes that I had special powers to heal others. The worst thing about my illness was how I would spend so much money that I almost bankrupted the family."

A 38-year-old man with mania

"I don't know what's happening. I seem to forget things so easily. The other day, my wife came to give me my morning tea and, for a moment, I did not know who she was. And then, I was walking home from the market and, even though I was in my village. I suddenly found I had no idea where I was. I always thought I was getting absent minded as I grew older, but this is too much... and then I remember my father who died after years of losing his memory and now I am scared that I may have the same problem."

A 68-year-old man with dementia

"My problems started at work when I started taking too much sick leave. I kept getting stomach upsets and, recently, I had jaundice. It was then that I started worrying about my drinking. What frightens me is that I wake up feeling terrible. It's like I must have a drink to get myself going in the day. These days I am starting to drink even before lunch. I don't know exactly how much I am drinking but it never seems to be enough."

A 44-year-old man with a drinking problem

(The following are cases given in the original text) **Session 3 – case studies** 

# Case study - 1

Ramalakshmama is a 30-year-old married woman who has studied upto grade XII, and was working in a garment factory as a helper. She has complained of dizziness and headaches for the past one year, but medical investigations revealed no physical illness. In course of sustained conversations with her, it has come to light that she is constantly thinking about various things, sleeping badly and occasionally having suicidal thoughts. She feels tired and not upto house hold chores. Her relationship with her husband worsened over time. A big cause for his displeasure has been that she has not borne a child and it has been two years since their marriage. He has been threatening to marry for the second time. To worsen matters, she also lost her job 3 months back as she was not able to concentrate on her work. She has no hope of securing another one given the way she is feeling. Currently she is feeling very lonely and helpless with no support system and has little hope of improving her situation.

# Case Study-2

A 24-year-old married woman witnessed a horrific accident involving a man falling off a running train. By nature she was an anxious and fearful person. Post witnessing this accident, her anxiety and fear have increased manifold. She now complains of extreme fearfulness while traveling in bus or train. She felt a wave of fear every morning when she traveled to go to her work place. Within a week she started avoiding the train and started going by bus. Within few days, she developed anxiety while traveling by buses too. The very thought of traveling would trigger episodes of severe anxiety, accompanied by trembling, sweating of the palms, feelings of suffocation, and get a feeling that she would die. Due to these problems she stopped going to work, and even the thought of going out of

the house brought on the same episodes of intense anxiety. Finally, over a period of two weeks, she started feeling sad, feeling fearful most of the time, felt a sense of loss of control over her life and began having suicidal thoughts. Her husband persuaded her to seek help from the counseling center.

# Case Study-3

Mrs Geetha, 35 year old housewife, has been complaining of repeated episodes of heart attacks. She recalls that her problems began 10 years back when she delivered her only child. The first attack occurred while she was working in the kitchen. She suddenly felt that there was a dramatic increase in her heart beat. She also felt an intense stabbing pain in her chest and had difficulty in breathing. She started sweating and trembling, felt dizzy and was rushed to a physician. An ECG was performed immediately and was reported to be normal. Since then, Mrs Geetha has complained periodically of such episodes of heart attacks with each episode lasting about 15-30 minutes. There have been nearly four episodes every month. During these episodes, she seeks medical help. Over the past 10 years she has undergone many medical investigations, each of them reconfirming and reassuring her that she has no cardiac disorder.

After her first few attacks, she has developed a fear of having an attack and not being able to access medical aid. Since then she avoids crowded places such as banks, marriage parties and cinema houses, where quick escape might be blocked and medical aid not easily available. The episodes still occur and are observed more frequently in those situations which she fears most. Mrs. Geetha recognizes that both her symptoms and her avoidance behavior are unreasonable and excessive, but nevertheless they dominate her life. She feels mildly depressed and restless and has difficulty falling asleep. Her confidence is low, and she is unable to focus on any activity.

# Case Study - 4

Mrs K is 45 years old, married for last 25 years. Her relationship with her spouse is strained and there is a severe marital conflict. For the past five years, Mrs. K has been having episodes of physical discomfort where she has difficulty in breathing, complaints of chest pain, sweating, and tremors. She has burning sensation in the chest and abdomen and feels that she is having heart attack. During this phase of discomfort, she has intense fear and cannot sit in a place and wants somebody to be with her. Each of such episodes lasts 5 to 10 minutes. Mrs. K has consulted a heart specialist, who after series of tests and examinations has reassured her that her heart is healthy. In spite of this she continues to have instances of discomfort and often visits her family physician and also approaches different doctors to find a solution. The frequency of such episodes has increased, affecting her daily routine and has also aggravated the marital discord.

# Case Study-5

Mr. Suresh, 36-year-old and married, working as a mechanic in a private factory. was of an energetic and pleasant disposition. His family comprised of his wife and two daughters. One day while returning from his factory, Suresh met with an accident in which he sustained an injury to his right leg. He was taken to a private hospital where the orthopedician tried to do restorative surgery. Unfortunately gangrene set-in after the surgery. Hence the specialist suggested to go for a below knee amputation. Suresh consented to the surgery after initial refusal. The surgery was done without any complications and postoperative-period was uneventful. Suresh was discharged within a week. A fortnight later, when Suresh was brought in for a follow up, he complained of uneasiness, decreased sleep and body aches. His family reported him to be withdrawn and irritable with frequent anger outbursts. His wife said that he was often fearful, had very little interest in pleasurable activities and even indulged in tears at times. mentioned that for two days before the consultation, he had spoken of suicidal thoughts. She revealed that all this had increased since listening to his colleague who mentioned that Suresh might lose his job on account of his condition. The wife also shared that all aspects of marital relationship had been affected post the accident. During the consultation Mr. Suresh started crying and asked the orthopedician for an injection which would put an end to his life without any pain. He shared a feeling of worthlessness and being a burden on the family as he couldn't return to his job. He expressed helplessness and hopelessness and a deep sense of life being unfair to him.

# Case Study-6

Lawrence, a 20-year-old boy discontinued his studies as he was not able to pass his 7<sup>th</sup> standard since the age of 15. He started working as a helper under a contractor at the construction sites. He was honest in all his dealings and gave his earnings to his parents. He had lot of friends where he was living. His evenings were spent in the company of his friends, playing cricket, football etc. One of his friends was in love with a girl residing in the neighborhood. His friends used to tease that girl often. One day a group of 5 youth attacked Lawrence and his friends unexpectedly. Lawrence was also badly assaulted as he was part of the group. He had a head injury and was hospitalized. Few weeks later he developed excessive fear and was not ready to go out of the house. He would scream constantly and sound very abnormal.

Lawrence's sister speaks of the incident and what followed. "He was an ok boy. Did not do well in the school and discontinued his studies. He started learning carpentry and the trainer was also a contractor. Hence, he had no problem in getting work. One day he did not feel normal. He was disoriented, speaking unnecessary things and behaving abnormally. We took him to various healers

and offered prayers in the church but there was no improvement. One day he ran away from home. We searched all over but did not find him. I think after more than two months his brother found him in another part of the town. When he was brought home, my heart sank and I wept. Every one was in tears. He was in his underwear and had an old coat on him. Even now if I think of that scene, some thing happens in my stomach."

# Case Study-7

Mrs Nagarathna, a 55 year old Telugu speaking retired employee from Hyderabad, was reported to have died in a railway accident. She was run over by a moving train and her body was found on the railway tracks. As she was often crossing the railway tracks, the neighbors surmised that she went wrong in her judgment while crossing the tracks on that day and met with an accident.

A doctor who was a friend of Mrs. Nagarathna, however, spoke to her daughter and elicited some information regarding her behavior during the past six months. Mrs. Nagarathna had opted for voluntary retirement the previous year and was not interested in taking up another job. She would spend her time reading, watching TV and helping her daughter in law in managing the house. She seemed to enjoy this new lifestyle for the first six months. However, subsequently her family began to notice considerable change in her behavior. She seemed worried and tense most of the time for no apparent reason. She would wake up at 3 in the morning and would find difficulty in going back to sleep. She tried taking sleeping pills on her own but it did not help her much. She would feel excessively tired throughout the day. She lost her appetite and ate nearly half her usual intake. As a result, she lost 10 kilos over a period of three months. She also complained of constipation very often. She stopped her morning walks, watching TV and reading books. She would often remark that she had wasted all her life for the sake of family. She would share her guilt for not saving enough money for her children. Gradually she started feeling more and more helpless about the lack of control over her life. She often expressed that life was not worthy to continue, and expressed death wishes. Finally she decided to end her life by going under the moving train.

#### Session 3

#### Mental disorders and its manifestations

The following changes are commonly found in persons with severe mental illnesses.

#### The symptoms of mental illnesses are broadly grouped as:

- Disturbances in bodily functions
- Changes in mental functions
- Changes in personal and social activities

#### Disturbances in bodily function:

- a) <u>Sleep:</u> The person finds it difficult to sleep. He stays awake and worries about his inability to sleep. He may have disturbed sleep through out the night or may not sleep at all. He does not feel fresh in the morning. Any of these types of sleep disturbance can be a sign of mental illness.
- b) Appetite and eating: The person does not have a proper appetite and eats less. At times, although appetite is normal, the person does not enjoy what he is eating. Sometimes, he may have more appetite and eat more. He may lose or gain weight.
- c) <u>Bowel and bladder functions</u>: The person may pass urine more frequently than usual. Sh/e may have loose motions or become constipated. Some patients may soil their clothes and remain unaware of it.
- d) <u>Sexual desire and activity</u>: They may lose interest in sex. Men may also complain of difficulty in sexual performance or inability to enjoy sex.
- e) <u>Bodily complaints:</u> The person may have continuous physical complaints or pains, without having a detectable physical illness. For e.g. person may complain of headache or body aches that whose cause cannot be found though investigations.

#### 2. Changes in mental functions:

- a) <u>Behaviour</u>: The person may behave in a peculiar and strange manner. His behaviour may irritate the family members and other people or place them in awkward and embarrassing situations. The person's behavior can be dangerous, at times, to himself and others. He may become overactive, restless and wander aimlessly. He may abuse and beat others for a trivial or no reason. Or, he may become very dull, inactive and lose interest in the day-to-day activities. He may sit or lie down for hours or at times, days together, refusing to move even to attend to the bodily needs.
- b) <u>Talk (thought process)</u>: The person may talk excessively and unnecessarily or may utter only a few words and remain silent for most part. At times, the talk becomes irrelevant and incoherent. The individual may express certain peculiar and wrong beliefs which are not shared by others. For example, he may say that somebody is spraying poisonous gas into his eyes; or that thousands of worms are crawling under his skin or that his food is mixed with poison.
- c) <u>Emotions</u> (feelings): The person may show excessive emotions of sadness or happiness that is not appropriate to the situation. In contrast, some may be unable to express any emotions at all and just sit like a statue. Others may laugh or weep.
- d) <u>Perception (understanding)</u>: the person's ability to understand what he sees or hears can be disturbed. He may misinterpret them. He may hear sounds that others do not hear or say things like, 'enemies are coming to kill him'. He may see figures that agitate him. Persons with Mental Illness can see things which are not present or which are not seen by others and react to them. This is known as "hallucination". When he hears some voices, he may start abusing or threatening the imaginary persons. On seeing someone with a tool or implement, he may run away to hide himself or attack others. A person

who is hallucinating can be seen talking to himself, laughing or weeping and wandering aimlessly on the streets.

- e) Memory: The memory of PWMI may be disturbed and they may forget what they saw, heard or experienced within a few minutes. They may be unable to remember where they kept articles of daily use such as money, clothes, keys, umbrella etc. They may not remember what they did a few days earlier or people they met a week ago. They may lose their capacity to remember their past and may even find it impossible to recall names of their children, where their brothers and sisters live etc. In severe cases, individual may lose his way, even in a familiar place.
- f) Intelligence and judgment: In some mental illnesses, intelligence and the ability to take decisions deteriorate. They may lose the capacity to think clearly and hence may commit mistakes in routine work. They may not be able to do even simple arithmetic and appear dull. With many PWMI, their ability to take appropriate decisions in many situations is impaired or lost. They may take wrong decisions that can result in difficulties for themselves and others. For example, they may keep quiet and do nothing when they see a child fall and get hurt.
- g) <u>Level of consciousness</u>: In some mental illnesses caused by brain damage, the person can become disoriented about time, place, day, date and people.

#### 3 .Changes in personal and social activities:

- a) <u>Personal</u>: A person with mental illness may neglect his bodily needs and personal hygiene like washing combing hair, bath or changing clothes. He may remain unclean for many days and not bother even when it causes discomfort to himself and others. At times, he may even soil his clothes and bed.
- b) <u>Social</u>: A person with mental illness may behave strangely with family members, friends, colleagues and others by insulting abusing or assaulting them. He may behave inappropriately in social situations and embarrass others. He may be rude to others annoying them or causing others to make fun of him.

#### Causes of mental illnesses

In many cultures, both medical and traditional explanations are used to understand the causes of ill health. Traditional models are often related to spiritual or supernatural causes, such as bad spirits or witchcraft. You should be aware of the beliefs in your culture. However, you should also be aware of the medical theories and use these to explain mental illness to the people who consult you. It is useful to keep in mind the following main factors that can lead to mental illness:

Stressful life events: Life is full of experiences and events. Some of these may make a person feel worried and under stress. Most people will learn how to deal with such events and carry on with life. However, sometimes they can lead to mental illness. Life events that cause great stress include unemployment, the death of a lover one, economic problems such as being in debt, loneliness, infertility, marital conflict, violence and trauma.

Difficult family background: People who have had an unhappy childhood because of violence or emotional neglect are more likely to suffer mental illnesses such as depression and anxiety later in life.

Brain diseases: Mental retardation, dementia and emotional problems can result from brain infections, AIDS, head injuries, epilepsy and strokes. No definite brain pathology has yet been identified for many mental illnesses. However, there is evidence to show that many illnesses are associated with changes in brain chemicals such as neurotransmitters.

Heredity or genes: Heredity is an important factor for severe mental disorders. However, if one parent has a mental illness, the risk that the children will suffer from a mental illness is very small. This is because, like diabetes and heart disease, these disorders are also influenced by environmental factors.

*Medical problems*: Physical illnesses such as kidney and liver failure can sometimes cause a severe mental disorder. Some medicines (e.g. some of those used to treat high blood pressure) can cause a depressive illness. Many medicines when used in large doses in elderly people can cause a delirium.

#### Culture and mental illness

There are many ways in which culture can influence mental health issues

What is a mental illness? Concepts about what a mental illness is differ from one culture to another. The group of disorders most often associated with mental illness is the severe mental disorders, such as schizophrenia and mania. The commonest mental health problems in general or community health care are the common mental disorders (depression and anxiety) and problems associated with alcohol and drug dependence. These disorders are rarely viewed as being mental illnesses. Although you should be aware of these mental illnesses, you need not add to the sufferer's problems by using labels with a potential stigma attached to them. Instead, you can use locally appropriate words to describe stress or emotional upset.

Priests, prophets and psychiatrists: What do people do when in distress? Sick people seek help from a variety of alternative, religious and traditional health care providers. Examples include: homoeopathy, Ayurveda, traditional Chinese medicine, spiritual healers, shamans, priests, pastors and prophets. This is for several reasons. First, medical health care does not have the answers for all health problems, and this is

especially true for mental illness. Second, many persons associate their emotional upset with spiritual or social factors and thus seek help from non-medical persons. Traditional treatment may help some people get better quicker than would medical treatments.

#### Things to remember about mental illness

- There are a number of different types of mental illness. Mental illness can produce severe disability and can lead to death.
- The commonest types of mental illness in the community or general health care settings are the common mental disorders, and disorders related to alcohol dependence; however, many patients and health workers may not consider these conditions as mental disorders.
- Schizophrenia, manic-depressive illness and acute psychoses are conditions that
  are most often recognized by the community and health workers as mental
  illnesses, because of the disturbed behaviour associated with them. Stressful
  events, changes in brain function and medical factors such as brain infections are
  the main causes of these mental illness.
- Some people may believe that spirits or supernatural factors cause mental illness.
   You should not challenge these beliefs but try to put forward the medical explanations for these problems
- It is not essential that you label a person with a mental illness diagnosis, what matters is that you recognize the existence of a mental health problem, attempt to identify the type of mental illness and then offer appropriate treatment.

File Name: course Materials
on Mental Health, MH-10
29/2/24

#### Session 3

# Advocacy: 30 minutes

- 1. Show the video(s) (name the videos) on mental health advocacy and ask the participants what they think about the video
- 2. Note down the responses on the board.
- 3. Explain the meaning of advocacy.
- 4. Invite participants to share some of their experiences on their advocacy activities (in any).

#### Session 3

#### ADVOCACY:

Advocacy is a means of supporting and helping people to speak up or act for themselves. The key aim of mental health advocacy is to empower people who use mental health services and to protect their rights and help them to get their views across. Empowerment is an essential aspect of advocacy. It supports and promotes people's rights to speak and act for themselves and get their entitlements.

Advocacy support is needed in the mental health services because people who use them can feel put off (disempowered) by the complex rules, procedures and the difficult attitude of the people providing the services. The issues could be:

- Being detained in a hospital under a section of the Mental Health Act.
- Being prescribed medication which has adverse side effects on the body.
- Not knowing how much money they are entitled to receive under any welfare scheme.
- Provision of suitable accommodation.

#### Advocacy can involve

- Listening and giving correct and relevant information.
- · Encouraging the PWMI or groups to speak for themselves.
- Liaise with different agencies- Governmental or otherwise.

- · Mediating to help individuals or groups understand one another.
- Representing or acting on behalf of individual or groups of PWMI.

#### Some situations that need advocacy:

#### In a hospital:

- Difficulties in communicating.
- · Feeling loss of respect and dignity.
- · Feeling powerless and unable to speak.
- Lack of information about medication, side-effects and entitlements.
- Lack of support when feeling confused, frightened or intimidated.
- Difficulties in getting a proper diagnosis.
- Supporting at (CPA's, Mangers Hearings??), Mental Health Review Tribunals.

#### In the community:

- Practical problems in accessing benefits, accommodation and other services.
- · Lack of understanding of severe mental illness.
- · Discriminatory attitudes and fear.
- Pressures at workplace, school, college and other environments.
- · Strained relationships in the family.
- Difficulty in getting a second opinion or a medical review.
- Problems with police and courts.

There are a number of ways of delivering advocacy services. The main ones are:

- Legal advocacy, which is provided by qualified advocates or lawyers.
- Citizen advocacy, which involves long-term, one-to-one partnership between the service user (or stakeholder) and the advocate. This kind of advocacy tends to be more common in the learning disability field than in mental health.
- Formal or professional advocacy refers to services run by professional groups which are not, usually, led by the users. Co-ordinators could be salaried staff of the agency and advocates are often paid. They usually are prepared to act for both carers and service users. Sometimes, they might help by explaining the available options to the clients who can make informed choices. These advocates may also mediate for their clients.
- Peer advocacy, where advocates are themselves mental health service users.
- Self-advocacy, which involves people speaking for themselves.

#### Session 4:

# Mental health act and People's with Disability Act: 60 minutes

1. Explain the concept of mental health in the legislation; list out the legislations related to mental health.

2. Explain the highlights of the Acts and distribute the summary of the Mental Health Act and Disability Act to the participants.

3. Divide the participants into groups of 4-6 persons and ask them to read and discuss the papers (summary of the two Acts).

4. Sum up the discussion explaining the relevance of these acts in the CBR context.