PROMOTING INDEPENDENCE OF PEOPLE WITH DISABILITIES DUE TO MENTAL DISORDERS
A Guide for Rehabilitation in Primary Health Care

H. Sell & V. Nagaswami

This document includes both a manual on psychosocial rehabilitation and eight practical fascicles, each one covering a different aspect, respectively: (i) general guidelines to work with a person with a disability due to a mental disorder, (ii) guidelines in providing help to persons with a mental disorder, (iii) working with the family, (iv) how to help a person with a personal disability, (v) how to help a person with a disability in the family role, (vi) how to help a person with a social disability, (vii) how to help a person with an occupational disability, and (viii) how to help a person with an emotional disability.

It is intended for mid-level health personnel who, in their work, come across people with psychiatric disabilities.

KEY WORDS: rehabilitation / psychosocial rehabilitation / mental health care / mental disorders / manuals / mid-level health workers / mid-level rehabilitation workers / psychoses / depression / mental retardation / epilepsy.

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FOREWORD

The rehabilitation of people with disabilities needs an intersectoral and interdisciplinary approach. The publication of this guide is the result of collaboration between the Mental Disorders Control Unit (Division of Mental Health and Prevention of Substance Abuse) and the Rehabilitation Unit (Division of Health Promotion, Education and Communication). This collaboration was requested in an attempt to apply what has been learned from the experience of community-based rehabilitation (CBR) to persons with disabilities and social disadvantages in urban slum communities.

This document is aimed to provide support to rehabilitation services who assist people with disabilities due to mental disorders. Its publication will facilitate the integration of rehabilitation and of mental health care into primary health care and will represent a major contribution to the improvement of both the quality of care and the quality of life of people with mental disorders, as well as of their relatives.

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This document has been tested in the field; however, it needs to be adapted to the local situation, upon which it could be freely translated and adapted to local language and usages upon information provided to WHO.

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INFORMATION TO READERS

This manual is divided into two components. The main manual comprises four chapters and covers symptoms, types and causes of mental disorders, their treatment, and the disabilities which can be caused by mental disorders. The main manual is accompanied by eight "Rehabilitation Booklets" which deal with different types of disability caused by mental disorders and means for the rehabilitation of persons disabled by them. Only certain severe mental disorders are addressed, although many other forms of less severe mental problems may also cause some disability.

This manual will tell you

- what the different types of mental disorders are;
- how they are caused;
- how you can identify them;
- what treatment is necessary for them;
- what disability such mental disorders can produce; and
- how you can help to rehabilitate such disabled persons.
1. INTRODUCTION

We are aware of the meaning of the term illness. It refers to a disturbance in the function of some part of the body for a variety of reasons. For example, tuberculosis is an illness where a part of the body, usually the lungs, is affected by a type of organism which causes the body to malfunction. This illness will have to be treated with medicines to kill these invading organisms. There are other types of illnesses which are caused, not by organisms, but by other factors. One example of such an illness is diabetes, where the body is unable to digest sugar that is taken through the food. Persons suffering from this illness need to reduce their sugar intake and take medicines regularly to ensure that the body is able to digest the sugar.

Just as the body is affected by illnesses, the mind can also be affected by illnesses. These are called mental disorders or mental illnesses. Usually persons with mental disorders show disturbances in behaviour that are easily recognizable by all of us. When a person whose behaviour is normal, either slowly or suddenly starts behaving strangely or abnormally, such a person is likely to be suffering from a mental disorder. Just like physical illnesses need to be treated, so too mental disorders require treatment. If mental illnesses are detected early enough and treatment given and continued over a prescribed period of time, most of them can be kept under control, and the individuals may be able to function in society like others.

Both mental disorders and physical illnesses can produce different kinds of disability. By this we mean that the illness has produced some changes in the person as a result of which the person is not able to discharge all the duties and social responsibilities that are usually expected. However, it is important to recognize the strengths and abilities of all ill persons. It is for this reason that persons who are disabled need rehabilitation. When we think of rehabilitation, we usually think of providing calipers for patients who cannot walk, hearing aids for persons who cannot hear well, glasses for people who cannot see well etc. Persons with mental disorders too need our help. They do not need sophisticated instruments, but they need our affection, understanding and additional assistance to help them to lead normal lives as far as possible. In addition, some environmental interventions (e.g. in the workplace, in school) contribute to what we call rehabilitation and, hence, to a greater integration and participation in family, in school or workplace and in community life. They can be rendered by all of us, provided we are trained in what to do. These efforts, combined with effective medicines can help the person disabled by a mental disorder to discharge many of his daily responsibilities and perhaps lead a normal life.
2. WHAT ARE MENTAL DISORDERS?

In this chapter you will learn about:
- symptoms of mental disorders;
- causes of mental disorders;
- treatment of mental disorders.

Mental disorders are not always easy to recognize particularly in the early stages. All of us have seen persons suffering from mental disorders, but we may not have recognized them as such. Each community has different names for these mental disorders. Usually persons suffering from these disorders are called mad or insane or possessed by evil spirits and so on. After you read this manual you will realize that persons who are called all these things really suffer from mental illnesses and that many of them can improve or even be able to function normally, with medicines.

The next chapter will tell you about the different types of mental disorders. But first we need to know and understand some general aspects of mental disorders.

PERSONS WITH SYMPTOMS OF MENTAL DISORDERS

Persons with mental disorders show behavioural changes most of which are easily recognizable. You may recognize somebody in your community who shows some or all of the following symptoms:
Disturbances in speech

The person may say things which cannot possibly be true, talk excessively or very little, or not at all, or speak in a way that nobody else can understand. Sometimes individuals may talk to themselves, even when nobody else is around, or what an individual says just does not seem to make sense.

Disturbances in mood and feelings

Some persons may be seen laughing or crying to themselves excessively and for long periods of time or become very irritable and angry without any reason. When asked they may not be able to give a reason. The person may be very sad and may weep for even the most trivial reason. Or, a previously cheerful person may be fearful or worried, refuse to talk, or may even think of committing suicide. Or, a person may become unreasonably cheerful and excited. There can also be apathy, as if all feelings have been lost. Feelings that are inappropriate to the situation may also be shown. For example, in the case of a death in the family, when everyone else is sad and cries, the ill person may be indifferent, or even laugh.
Disturbances in thoughts

Some people develop peculiar ideas which are not part of their usual way of thinking. They may believe/think that people hate them or want to harm them in some way, when everyone around them knows that this is not true. They may be suspicious that other persons, known or unknown, may be trying to poison them or take away their money. Some persons may suspect their spouse of having illicit relationships. And they will be firm about these ideas and beliefs even when everybody around them tries to convince them that these ideas and beliefs are false.

Example:

A man was brought to a hospital by some friends in a rather run-down state. He had refused to eat at home and later moved to a hotel, because he was convinced that his wife was trying to poison him. Later he refused to eat in the hotel because he was convinced that his wife, by having an illicit relationship with the hotel manager, had made him a partner in her deadly conspiracy. He lived only on bread which he bought from a wayside shop, but got so suspicious that even this he ate only after having fed some pieces to an animal and he drank water only from a public tap.
Disturbances in hearing

Some persons with a mental illness hear voices speaking to them even when no one is around, and, therefore, they may start speaking back to these voices. These voices are very real to them, and when they give orders as to what to do the person will act on them. So, in some instances, when persons show strange behaviour they may do this because they hear voices telling them to do so. This disturbance can be quite isolated, in an otherwise well functioning person.

Example:

A young woman was brought to a doctor because she had started to talk to herself and laugh for no apparent reason. Also, she had started to collect empty matchboxes whenever she would find them. On questioning she disclosed that a voice was telling her to do so. She agreed that these orders sounded rather silly but added that it must be "something sacred". Otherwise she continued to take care of her household chores and of her children perfectly well.
Disturbances in sleep and appetite

Many persons with mental disorders also have some disturbance of sleep. They may not be able to fall asleep; or if they fall asleep they keep waking up again and again during the night; or they may wake up very early in the morning and are not able to sleep after that. Some patients have excessive sleep. Some persons also have disturbances in appetite. They may lose interest in eating and lose weight, or they may make excessive demands for tea/coffee or cigarettes or they may start having an excessive appetite and gain weight uncontrollably.

Disturbances in personal hygiene

Some persons with a mental illness lose interest in basic personal hygiene like washing their hands, or having a bath or combing their hair. They may wear the same dirty clothes day after day and may even soil them. Their poor personal appearance does not bother them though others consider it disturbing or unacceptable.
Disturbances in social behaviour

Some persons suffering from mental illness behave in a manner that society finds difficult to accept. They may become abusive and assault people around them, especially when provoked, although they may not have felt provoked by the same or a similar situation before. They may stop doing any work and just wander around all day. The change may be gradual or sudden. They may show restlessness, may not be able to sit in one place, but may feel driven to pace up and down, or move the body forward and backward (rocking) for long periods of time. They may seem unable to think clearly, or may be excessively preoccupied with religious or supernatural matters. They may collect rubbish and keep it in their house or carry all kinds of strange things in bags wherever they go.

Example:

A 35 year old woman gradually stopped both cooking and looking after her children. She ran away from home and wandered around for increasing periods of time, not bothering about her appearance and the way she was dressed. When at home she would not allow anybody to enter her house. She used bad language and the neighbours found it difficult to put up with her and finally refused all contact with her.
NOTE

Some individuals who have epilepsy can also behave like a person with a mental disorder: they can do strange things or see things which are not really there. This is because both epilepsy and mental disorders are brain disorders. Epilepsy is not normally considered a mental disorder but rather a physical disease of the brain. This disease typically causes the person to have fits, but sometimes it can affect behaviour and sensations in other ways.
IDENTIFICATION OF PERSONS WITH MENTAL DISORDERS

After going through the symptoms listed above, you might think that you know many persons who have disturbances in sleep or suspicious thoughts or who behave in a way which you think is strange. You might wonder whether all these persons suffer from mental disorders. The answer to this is: "Yes." Currently a large number of ill persons are not identified. At the same time all persons with abnormal behaviour are not necessarily mentally ill. While some of them could have a mental illness, some may not. In determining whether a person has a mental disorder or not, you have to ask yourself three questions:

(1) Has the behaviour changed only recently? (Or has the person been like this for a long time, say, since youth).

(2) Has the behaviour change caused distress or disturbance to the person or the family or to the community where the person lives.

(3) Is the behaviour so strange and different from community norms that people agree that this person must be "ill"?

If the answer to all three questions is yes, then it is quite likely that the person suffers from a mental illness. If you are in doubt about the answers to these questions, it is always advisable to ask the doctor to examine the individual and confirm the presence or absence of mental illness. Because early identification is important for initiation of treatment which may be able to prevent the illness from getting worse, or perhaps cure it.

CAUSES OF MENTAL DISORDERS

We know very little about the causes of mental illness. Sometimes it is inherited. Be absolutely sure about what does not cause mental illness: there is nobody to blame, not the parents nor evil spirits nor the persons themselves.
TREATMENT OF MENTAL DISORDERS

Many people still believe that mental illnesses cannot be treated. Therefore, many persons with mental illnesses are never brought for treatment and suffer unnecessarily, together with their families.

It is very important that you help such persons to receive treatment if you know or hear of any. Because many of these persons, even if not all, can be cured, can get better with medicines. Let us now see what different kinds of treatment are available for persons with mental disorders.

TREATMENT MODALITIES

Medicines

The most common form of treatment of mental disorders are medicines. These are usually available at the primary health centre or can be obtained from a pharmacy. They are available in the form of tablets, liquid, or injections. Many persons may even need only one injection per month; most others will only need one type of medicine at night time. It is very important to remember that medicines should be taken regularly for as long a period of time
as the doctor recommends. The person may need supervision to make sure that the medicine is taken at the right time and for as long as needed. Some people may require medicines all their life.

Unfortunately, it is quite common to see a person with a mental disorder take medicines for a few days and then stop them without consulting the doctor. Persons may stop medicines because they feel better, because of side effects, or because there is no immediate improvement. This usually results in the person getting ill again, and each time this happens, improvement by medicines will become more difficult and less effective.

<table>
<thead>
<tr>
<th>When giving medicines to the patient, please remember the following:</th>
</tr>
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<tbody>
<tr>
<td>- The drugs are not addictive in nature.</td>
</tr>
<tr>
<td>- These are not sleeping tablets, but medicines to make the person feel better and to improve thinking.</td>
</tr>
<tr>
<td>- These medicines may cause adverse effects like dryness of mouth, drowsiness or muscle stiffness or cramps. Ask the doctor how these side effects can be managed. They can almost always be controlled by additional drugs with little change in effective drug regime.</td>
</tr>
<tr>
<td>- These medicines should be taken for as long as the doctor prescribes them. If they are stopped prematurely relapses can occur even if the person appears &quot;cured&quot;. In some cases treatment may have to last for many years or even for an entire lifetime.</td>
</tr>
<tr>
<td>- Early start of treatment gives the best outcome.</td>
</tr>
</tbody>
</table>
Counselling

In all types of mental disorders, affected persons and their families need to be understood by listening to them and counselling them about how they can deal with their problems. Quite often you can help a distressed person or members of the family very well by simply listening to him or her without passing judgement. If you are unable to help despite this, you can ask the doctor or a village elder to counsel the person.

Rehabilitation and Recreation Therapy

The following Booklets 1-8 will help you understand how to help persons who have a long standing mental disorder and their families to lead as normal a life as possible.
To summarize:

- Mental disorders can be recognized by disturbances in speech, in mood and feelings, in sleep and appetite, in thoughts, in hearing and seeing, in personal hygiene and in social behaviour; in short, by a significant change in behaviour or by strange ideas.

- These mental disorders can be treated by medicines given over a period of time, the duration of treatment partly depending on the duration of the illness at the time the treatment first started, and by rehabilitation and social therapy.

- Persons with mental disorders (whatever their form) are nevertheless able to actively participate in and contribute to the activities of their families and even of the community.
3. TYPES OF MENTAL DISORDERS

After having seen the general characteristics of mental disorders, let us now briefly consider the main types of severe illnesses affecting the mind or the brain that you are likely to come across in the course of your work in the community.

Types of mental/brain illnesses

- Psychoses
- Depression
- Mental retardation
- Epilepsy

PSYCHOSES

The term ‘psychoses’ refers to a group of severe mental disorders which all share some similarities. The main feature of psychosis is that people suffering from it lose touch with reality and exist in their own "fantasy" world. This is the condition that is usually referred to as madness or insanity. A person suffering from psychosis usually manifests some or more of the following symptoms:

- talks too much or not at all, says things which do not make sense or are not understandable;
- mood varies from irritability to apathy, exhilaration and crying spells without reason;
- sleeplessness/disturbance in sleep;
- expression of false beliefs, usually suspiciousness;
- talks to self or laughs to self without any reason;
- hearing of voices;
- neglect of personal hygiene, wandering away from home and family;
- may become angry for no obvious reason and may try to hurt people;
- poor work habits (e.g. going to work late, not finishing tasks) or refusal to do any work.
It is quite possible that you would have seen or heard of somebody in your community who behaves like this. Such a person suffers from psychosis (some doctors may call this schizophrenia).

In some cases, psychosis starts suddenly. In others it may start slowly over a period of time. The earlier we detect psychosis and start treatment, the better it will be for the person and the family. Most persons with a psychosis improve fast with medicines and do not need to be hospitalized. Psychoses need to be treated with medicines which may need to be taken regularly for a very long period of time. Even if the person gets better, and behaves normally, medication should not be interrupted without the doctor’s instructions. This is to prevent the illness occurring again. This is particularly important if violence has occurred and the family may refuse to look after the person if this happens again. Some medicines are available as an injection given only once a month. This can also make it easier to take treatment regularly and make it more acceptable.

### PLEASE REMEMBER THE FOLLOWING ABOUT MEDICINES FOR PSYCHOSES

- They are not sleeping tablets, but medicines to make the person feel better and function better.

- These medicines may have some undesirable side effects, like drowsiness or muscle cramps. Ask the doctor about these side effects and how they can be managed.

- These medicines should be taken for as long as the doctor prescribes them. If they are stopped, relapses can occur. In some cases treatment may have to last for many years or even a lifetime.

- Please advise the family members that these medicines should continue to be taken - even after the person becomes better - until the doctor advises that they should be stopped.

- In the case of a crisis situation, if the person refuses to see a doctor, or if there is agitation or violence, medicine can be administered in the form of drops in any food or drink. Ask the doctor about these.

- For many persons who need to take drugs for a long time, or refuse oral medicines, a monthly injection is sufficient. Talk to your doctor about this. Consider also ethical guidelines and legal requirements related to informed consent prior to initiating a drug treatment.
DEPRESSION

In this type of mental illness, the individual feels sad or angry and irritable for no apparent reason. There is often hostility specifically against previously loved ones and family members, which makes the person feel very guilty. The person might feel unable to do any kind of work, or may spend most of the time crying, and might even want to commit suicide. Everybody in the community will wonder why such a person feels so sad, and the person will not be able to say why. The following are the most important symptoms of depression:

- feeling sad, angry and miserable for no reason;
- crying without reason;
- not wanting to talk to other people, and withdrawing from others;
- feeling worthless and hopeless;
- talking about suicide and perhaps even trying to do it;
- loss of appetite;
- sleeplessness;
- multiple bodily complaints like body aches and pains;
- in severe cases, inability to work, to do the usual household chores or to look after the children.

You would have definitely seen some persons in your community who behave in this manner. If individuals are identified with some of the above symptoms, then the chances are that such a person is suffering from depression. And like psychosis, depression too needs treatment with medicines. It is important that treatment is started early. If treatment is delayed there may be the risk of suicide.

Example:

A woman of 32 years was a member of a happy and caring middle class family. Soon after the birth of her third child she started to be very irritable and got angry with her husband and the children very easily. Sometimes she would even slap a child which she had never done before. She felt very guilty about this but simply could not control her anger and hostility towards her family members. She found her household chores increasingly difficult, had difficulties falling asleep, and in the morning looked forward to the day with horror and despair.
As in the case of psychosis, the doctor will prescribe medicines for persons with depression. It is your responsibility to ensure that the person takes the medicines regularly. Remember, if the person does not take the treatment, both the person and family members will suffer, and there may be a real risk of the person committing suicide. Counsel the family to be alert for warning signals of this and request them not to leave the person alone if such risk is felt to exist.

In addition to medicines, some persons with depression need counselling, information about the nature of the disease and reassurance that they will get better. They need to have somebody to listen to their problems, understand them, and help them cope with the stresses of life. This is where you can help them a great deal. Being involved in meaningful activities will also help to divert the person’s excessive attention from the problem.

**PLEASE REMEMBER THE FOLLOWING ABOUT MEDICINES FOR DEPRESSION**

- They are not sleeping tablets, but medicines to make the person feel better, and function better.

- These medicines usually take 1 to 4 weeks to start being effective. So, please advise the person and wait for the treatment to show results.

- These medicines may have some undesirable side effects like dryness of mouth, drowsiness, or difficulties in urinating. Ask the doctor about these side effects and how they can be managed.

- These medicines should be taken for as long as the doctor prescribes them. If they are stopped too early, relapses can occur. In some cases, treatment may last for many years.

- Please advise the family members that these medicines should continue to be taken even after the person becomes better until the doctor advises otherwise.

- The participation in meaningful activities (including physical movements) will help in the absorption of the medicine and will also build up the person’s self-esteem.
MENTAL RETARDATION

Mental retardation refers to a group of different conditions which affect the brain. Although strictly speaking it is not a mental illness, in many countries mental health workers also deal with this and help people with mental retardation and their families. It is, therefore, briefly outlined here.

It is quite possible that you have seen some children in your community who do not behave like other children of their age. For example, a child who is 10 years old may appear not to be able to do what a five year old child can do. Such children do not learn and develop skills as fast as other children do. They are said to suffer from mental retardation. Please remember that mental retardation should not be confused with childishness. Most children behave a little childishly and are playful. This does not mean that they are mentally retarded.

Mentally retarded children will not sit, stand or walk at the age that other children do. They will not be able to learn as much as other children of their age, and will appear to be dull. They will not be able to participate in the childhood games that other children of their age usually play, and have difficulties with school activities. The following are the typical symptoms of mental retardation:

- slow overall development, when compared to that of other children;
- slow in learning;
- do not seem to understand what other people say;
- cannot concentrate properly;
- have difficulties in remembering even simple things;
- cannot follow instructions easily;
- cannot control their movements as well as other children of their age (e.g. sitting, standing and walking);
- simple activities like eating or dressing may be difficult.

Quite often children suffering from mental retardation also suffer from epilepsy, or become aggressive and violent. Only those children who suffer from epilepsy or from
aggressive outbursts should be treated with medicines and only to control the fits or outbursts. Keep in mind that mental retardation cannot be treated by medicines. This is very important because desperate parents may be wasting much money on medicines and charlatans, without any chance of improvement. You can provide some help by referring to the WHO Manual on Training in the community for people with disabilities, "Training package for a family member of a person who has difficulty learning", No. 22, "Training package for a family member of a child who has difficulty learning" No. 23, and "Training package for a family member of an adult who has difficulty learning" No. 24, all produced by the WHO, Geneva.

**EPILEPSY**

Epilepsy is a brain disease and, as such, resembles a mental illness. In some forms of epilepsy, symptoms similar to those seen in psychoses may appear, like seeing strange things or behaving in a bizarre way.

This is a condition that all of you must be very familiar with. You may have seen it in children and adults in your community. It is commonly called fits, and affects a large number of children and adults. In this illness, the affected person suddenly loses consciousness, falls to the ground, and starts having jerking movements of limbs and body. Usually these fits are accompanied by frothing at the mouth, biting of the tongue and injuries to the body. They last from a few seconds to a couple of minutes and after the attack is over, the person regains consciousness but appears confused for a few minutes. Irrespective of where they might be, these attacks can take place at any time of the day or night.

Hence, it is very important to ensure that the person with epilepsy does not go near water alone, does not drive a vehicle or ride a cycle or motor cycle on the highway or work near dangerous machinery. Also, that the person does not work at great height like a lineman, or does not cook over a stove or fire, without appropriate medical supervision. The patient with epilepsy needs mainly medical treatment. The doctor will prescribe medicines that will prevent the patient from getting more fits or at least less than before. And like in other disorders, these medicines too need to be taken for a long period
of time, even if the person does not get more fits. In fact, millions of persons with epilepsy all over the world take these medicines for the rest of their lives.

For further advice to the families, you may consult the WHO Manual on Training in the community for people with disabilities, No. 21 "Training package for a family member of a person who has fits - Information about the disability and what you can do about it", produced by the World Health Organization, Geneva, 1989.

PLEASE REMEMBER THE FOLLOWING ABOUT MEDICINES FOR EPILEPSY

- These are not sleeping tablets, but medicines to make the person stop having fits.

- These medicines may have some side effects like drowsiness, trembling, or swelling of the gums. Ask the doctor about these side effects and how they can be managed.

- These medicines should be taken for as long as the doctor prescribes them. If they are stopped, epileptic attacks can occur again. Treatment may have to last for many years, often a lifetime.

- Please advise the family members that these medicines should be taken even if the fits stop, until the doctor advises otherwise.
4. DISABILITY PRODUCED BY MENTAL DISORDERS

We have so far learned about mental disorders, how to identify them and how they are treated. Many, perhaps most, persons with a mental illness recover fully or live a meaningful life with the support of medication and a caring community. The remainder of this manual addresses itself to those who do not recover fully but continue to be disabled by a lasting mental disorder. You have to learn what role you can play in the treatment and rehabilitation of persons suffering from lasting mental disorders. In order to understand why persons with mental disorders need rehabilitation, we need to turn our attention to the disability resulting from mental disorders.

In this chapter you will learn:

- what disability is;

- the different areas in the person’s life that can be affected by disability: personal disability, disability in fulfilling the family role, social disability, occupational disability and emotional disability;

- how to assess disability.

Usually, all of us are able to behave in a manner that is acceptable to the society that we live in. This means that we all perform certain roles that are expected of us. Some we do well, and others we do not so well. But still we know what has to be done and how it is to be done. We know what to do to be a spouse, or a parent, or a worker. We all know what people around us will tolerate and what they will not; and since it is important that people accept us, we behave in a manner that is expected of us. We are able to do all this because our mental functioning is not disturbed.

However, some persons suffering from a mental disorder may not regain their normal functioning even after treatment with medicines and rehabilitation. Sometimes, they are unable to behave in a manner that people around them expect. They are unable to play the roles of a spouse, a parent, a worker, a friend, a citizen, or whatever people normally expect them to
do. This is disability. They behave in a socially unacceptable manner not because they do not care, nor because they hate society. They do so, because their illness has left behind some lasting problems, and as a result we call them disabled.

Does this mean that all individuals who experience mental illness will not be able to behave normally even after they are treated? Not at all. Many persons recover very well after treatment, and provided they take their medicines regularly, they will behave in a socially acceptable manner. However, some persons continue to behave in a disturbed way and are not able to do everything that is normally expected of them. They may be able to play some roles well, but not others. It is this disabled group of persons who require your special assistance. Most of the time these persons suffer from psychosis: some strange behaviour continues despite the best of medicines. Therefore, you need to educate and support families and the community to cope with and eventually tolerate these behaviours.

AREAS WHERE DISABILITY IS EXPERIENCED

There are different roles that people expect each of us to play. Disabilities are disturbances in playing any of the roles which contribute to a meaningful and independent life. To understand disability better, we can broadly consider disability to occur in the following areas:

- Personal disability
  - problems/difficulties in looking after oneself
  - low level of meaningful activity
  - restlessness
  - general slowness

- Disability in the family role:
  deficiencies in
  - participation in family life/role
  - marital role
  - parental role

1 Technically speaking, some of these areas should be properly be called impairments, and others, disabilities. However, for the sake of simplification they are generally referred to here, using only the term disabilities.
• Social disability
  - little meaningful contact with people
  - loss of general interest
  - friction in social contacts

• Occupational disability
  - loss of interest in the job
  - reduction in work performance, including household chores

• Emotional disability
  - apathy, unable to enjoy anything, loss of emotional responsiveness
  - inappropriate emotions.

Let us consider each of these areas in greater detail.

I. Personal disability

Looking after oneself: From a certain age onwards, all of us are expected to take care of ourselves and of our own personal hygiene. We are expected to go to the toilet regularly, keep our bodies clean, keep our clothes clean, eat in a tidy manner, and do some basic tasks in the house. But persons who experience personal disability will not be able to do all these tasks. They may do them once in a while, and quite often not unless they are asked to do so. The more severely disabled persons may not look after themselves at all and may need constant attention. Mildly disabled persons would make some effort to keep themselves clean but would still need some reminders to do so.

Meaningful activity: All of us like to keep ourselves mentally or physically occupied during the time we are awake. We either do some work in the house, or talk to our family and friends, or listen to the radio, or think about something. Rarely do we spend hours doing nothing at all. Some persons who suffer from a mental disorder seem to spend many hours in a day doing nothing. The more severely ill person can spend the whole day doing nothing, and may just sit in one room and keep staring the whole day or may go on repeating
meaningless gestures. Mildly disabled persons may do a few things, but would still need repeated coaxing and may make it clear that they would prefer to do nothing at all.

**Slowness:** Usually when we do some task or are asked to do a task, we do it at a pace that most persons may recognize as normal. Sometimes we do the tasks quickly, and sometimes, when we are feeling tired, we do them slowly. Persons who experience personal disability, usually find it difficult to do a task at what would be considered a normal pace. They do it at a slower pace than they usually would. The severely disabled person may not be able to do the task at all, and mildly disabled persons would do the task but do it at a much slower pace than would be expected.

II. **Disability in the family role**

All of us have a certain role and position in our family. There are some things that we do alone and there are some that we do together. Each family usually spends some time together every day, and when some major decisions have to be taken, family members usually talk about it or want at least to be told about it. In other words, every family develops its own style of doing things together and we all feel good about being part of a family. In the case of disabled persons, however, they may appear to have lost their sense of family. The severely disabled person may not show any interest in participating in any of the family's activities. Mildly disabled persons may participate in some family activities but not in others; and they may have to be encouraged and reminded about even those activities in which they participate.

**Marital role:** All of us know what we are expected to do as a spouse. We are usually more intimate physically and emotionally with our spouse than with any other person. Even if we have disagreements or misunderstandings with our spouse, we usually adjust to these problems because we consider our married life an important part of us. Each community may have different expectations of a spouse, but, wherever we come from, we usually know what is expected, and we try and behave in an appropriate manner with our spouse. Severely disabled persons may be unable to relate to their spouse as they used to before the illness, and they may therefore not do much of what is expected of them, or they may do some of the
things expected of them as spouses but not all, and this may cause considerable distress to the spouse. This lack of expression can be both sexual and emotional. Mildly disabled persons may express intimacy to the spouse to some extent, but will not do so as before the illness.

Parental role: If we have children, we spend a lot of our spare time with them, because we want our children to grow up happy and healthy. In other words, we are concerned about them, and each of us learns to show this concern in our own way. We play with them, we take them to school, we buy clothes for them, we make sure that they eat and sleep, we rush them to the doctor when they fall ill etc. But severely disabled persons may not appear to be concerned about the children. They may not do whatever they used to with and for them. The mildly disabled person will show some concern for the children, but not on a consistent basis, and may waver from time to time in the expression of concern for the children.

III. Social disability

Meaningful contacts with people: We all maintain meaningful relationships with some friends, relatives, or neighbours, who may play an active role in our life. Severely disabled persons, however, have difficulties in interacting with other people. They show little or no interest in meeting friends, relatives or neighbours. They may not respond to their attempts at contact or may actively avoid them, preferring to stay alone. Mildly disabled persons do not seek out friends, relatives and neighbours, but can be coaxed into meeting them, though they may not be able to maintain their usual relationships.

General interest: Other people that we relate to are the rest of the wider community. All human beings participate in some community activity. Usually, all of us are willing to do what is assigned to or expected of us because we want to belong to this community. Severely disabled persons may not show any interest in the community or what is happening in the world around them, or may show much less interest than they showed before the illness. They may also avoid people.

Friction in social contacts: Some disabled persons instead of withdrawing from social contacts may actually keep contacts with friends, relatives, neighbours and the rest of the
community. However, instead of maintaining a normal and friendly relationship the person will insist in an unacceptable way on the truthfulness of their strong ideas, accuse them of all sorts of wrong-doings, pick quarrels and may even fight. The severely disabled person will do this frequently, and the mildly disabled person only occasionally. As a result, very few persons in the community may want to maintain a relationship with the disabled person and new relationships are not formed.

IV. Occupational disability

Interest in the job: All human beings have a desire to spend some time purposefully or be gainfully employed. This may be a job outside of the house, or household tasks; in the case of a student, the occupation is studying and attending school/college. All of us will show interest in resuming our occupation if, for reason of illness, we are forced to take a break for a while. But the severely disabled person will show no interest in purposeful activities or in resuming his occupation. The mildly disabled person will show some interest, but only in a limited way and irregularly.

Work performance: Those persons who do show some interest in resuming their occupation and actually do try and start working again, may find it difficult to reach their previous level of performance. The severely disabled person may seem to have lost all his old skills, and the mildly disabled person may have lost some though not all skills.

V. Emotional disability

Apathy, inability to enjoy anything, loss of emotional responsiveness: these are problems quite common in people disabled by mental illness. Severely disabled persons may seem to be emotionally completely detached from everyday life and their environment. They may continue to have a rich emotional life, but this does not show in their dealings with the environment. Severely disabled persons may just sit around all day without much interest in what is going on around them. In milder forms of emotional disability only relatives may notice a blunting of emotional responsiveness compared to the state before the illness.
Inappropriate emotions: The person may show emotions as before the illness, but which do not seem to be in response to the environment. The person may laugh while people around are sad, or may cry while everybody else is happy or celebrating.

ASSESSMENT OF DISABILITY AND ABILITIES

It is important to understand how disability is to be assessed, because when you first see a disabled person, you have to assess in what areas and how severely the person is disabled. Only after you have done this, will you be able to develop a clear idea of how to help in the rehabilitation process. The following box summarizes rules for the assessment of disabilities.

RULES FOR ASSESSMENT

(a) Ask the questions given below for each area of disability, one after the other, slowly and clearly.

(b) Make sure that you ask these questions to the person or persons who are actually staying with the unwell person and have a chance to observe.

(c) You have to assess from the answer to each question whether the person is disabled or not. To do so, use the person’s behaviour before the disorder started for comparison, and not what you think should be the behaviour.

(d) If the person has had the illness for a very long time, the family member may not be able to recall the person’s behaviour before the illness. In such a case, use the behaviour of other members in the family for comparison.

(e) To assess the severity of disability, ask the family member whether the person is like this only occasionally and whether the changes in behaviour are mild (mild disability), or quite often but the changes are moderate (moderate disability), or most of the time and the changes are severe (severe disability).
You have to assess disability in each of the five areas of disability that you have learned about. The following are some questions, the answers to which will enable you to assess whether there is a disability in any of the five areas outlined. There is no need to assess the severity of the disability for each question. Just make an overall assessment whether there is mild, moderate or severe disability for each of the five areas, using the method described in the box on the previous page.

I. Personal disability

(1) Does the person wash regularly, keep the hair tidy and wear clean clothes like before the illness or like others in the family do?

(2) Does the person keep physically and mentally busy like before or like others in the family do or spend a lot of time doing nothing?

(3) Does the person do things at the same speed as before or like others in the family or are tasks dealt with more slowly?

II. Disability in family role

(1) Does the person take part in family activities as before the illness or as other family members do?

(2) Does the person have the same intimacy and closeness to the spouse as before the illness?

(3) Does the person have the same behaviour towards the children as before the illness?

III. Social disability

(1) Does the person still actively meet and talk to friends, relatives and neighbours as before the illness or like others in the family or is there an avoidance to meet friends, relatives and neighbours?
(2) Is the person overtly unfriendly, starting arguments or even picking fights with friends, relatives and neighbours more than before or more than others in the family do?

(3) Is the person as interested in what is happening in the community and the rest of the world as before, or as others in the family are?

IV. Occupational disability

(1) Does the person show an interest in getting back to work (if employed in the past), finding a job (if unemployed), doing household chores or returning to studies (if a student)?

(2) Is the performance at work/household chores/studies as good as it was before the illness, or as good as that of other members of the family?

V. Emotional disability

(1) Does the person show emotions as before, or as does anyone else in the family?

(2) Do the emotions the person shows have an obvious relation to the person's environment?

(3) Are the emotions the person shows appropriate to the situation?

This assessment is particularly important, because emotional disability can impose an especially severe burden on caregivers. The perception of family members will be particularly important in this disability. Take their feelings into account in the assessment as to whether there is severe, moderate or mild disability.

By now, you would have made your assessment of disability and would be ready to make a plan to help rehabilitate the person. In doing so, please follow the guidelines set out in the following box.
GUIDELINES FOR REHABILITATION

Please read carefully Rehabilitation Booklets 1 (General approach to a person with a mental disorder), 2 (General Guidelines in Providing Help to Persons Disabled with a Mental Disorder) and 3 (Working with the family). They will apply to all persons regardless of type and severity of disability.

To help a person who has a personal disability, please read Rehabilitation Booklet 4.

To help a person who has a disability with regard to the family role, please read Rehabilitation Booklet 5.

To help a person who has a social disability, please read Rehabilitation Booklet 6.

To help a person who has an occupational disability, please read Rehabilitation Booklet 7.

To help a person who has an emotional disability, please read Rehabilitation Booklet 8.

'Many people are involved when one person suffers a mental/psychiatric disorder - especially those who love him - and it is the level of coping with the situation which directly affects the success or failure of any treatment. That is, it is our responses which either reinforce the disorder, or minimize the dysfunction.....experience suggests that a compassionate detachment helps all concerned'.

From an article in a Newsletter of the World Schizophrenia Fellowship
BOOKLET 1

GENERAL GUIDELINES FOR WORKING
WITH PERSONS WITH A DISABILITY
DUE TO A MENTAL DISORDER

In this booklet you will learn:

- How communities perceive a person with a mental disorder.

- What you should do when you come across a person with a mental disorder.

- What you should not do when you come across a person with a mental disorder.
WORKING WITH A PERSON WITH A
DISABILITY DUE TO A MENTAL DISORDER

Now that you know what the symptoms of mental disorders are and what kind of
disability such persons may experience, let us try to learn what can be done for them in your
community. Let us first try and understand how we should approach the person with disability
from a mental illness.

THE COMMUNITY’S PERCEPTION OF PERSONS
WITH A MENTAL DISORDER

We must try and remember that very few persons in the community know much about
mental disorders. Even if they have seen persons suffering from mental disorders, it is very
likely that they are quite ignorant about them. This is not because they do not want to know,
but because they have not been informed about mental disorders. As a result of this most
persons are likely to have their own explanations about mental disorders. It is well known that
when faced with a person suffering from a mental disorder, most persons respond in one of
the following ways:

- **Fear**
  - because they assume that the person may be dangerous, break or destroy things or
    become violent;
  - because the person’s behaviour is unpredictable;
  - because they believe that the person has been possessed by evil spirits;
  - because they believe that the evil spirits may attack themselves;
  - because they are ‘different’ and, therefore, a nuisance.

- **Anger**
  - because the person’s behaviour is annoying or embarrassing;
  - because the person is sometimes unreasonable and may be difficult to control;
because people cannot understand why the person behaves in that way;
- because the family to which the person belongs gets involved in all the problems the person may cause, although they may be unwilling to accept personal responsibility for what the disabled person does.

- **Frustration and pity**

- because the person is suffering;
- because nobody knows how to help.

- **Disgust, avoidance and indifference**

- because sometimes the person is so dirty and unkempt;
- because of fear of harm and impulsiveness.

- **Amusement, curiosity, ridicule, teasing**

- because the person does strange things;
- because nobody can understand what the person says.

- **Social isolation, rejection, stigma**

- excluding the person from family life;
- keeping the person away from social situations.

- **Guilt**

- often family members have a feeling of guilt as if they were somehow responsible for the disabled person's plight;
- family members may think they are being punished for some wrong doing.
If you think back, you might be able to see that you also have reacted in some of the above ways when you saw a person suffering from a mental disorder. Remember that these are ‘normal’ reactions to something as strange as mental illness. If we educate people about mental disorders, they will slowly start changing their attitudes towards them. Very rarely, you might come across a person who truly understands what mental illness is. Such a person could be a good source of help for you.

WHAT TO DO WHEN A PERSON HAS A MENTAL DISORDER

It is very likely that in the course of your visits around the community, you will come across persons who show some of the symptoms of a mental illness. You will, with experience, be able to assess what type of disorder they suffer from. What should you do when you first see such a person?

1. First, ask yourself what emotions you feel. Do you feel any of the reactions mentioned above? If you do, tell yourself that the person is harmless, suffers from a mental disorder, and needs your help to get better.

2. Next, ask yourself what kind of mental disorder the person could be suffering from.

3. Then, ask yourself whether the person or the family has any immediate needs. Is first aid (e.g. immediate medical attention) needed? Is there a risk of suicide? Is the family very upset or agitated? Is the person a source of trouble for the rest of the family? Is there anybody in the family who can control the person if there may be violence? If there is a risk of suicide, or if there is violent and uncontrollable behaviour, take the person immediately to the nearest doctor. If the person is not very agitated, and if the behaviour does not trouble the family too much, you may plan a visit to the community health facility.

4. Talk to the person calmly and soothingly, indicating that you are a friend and want to help. It is very important that the person learns to trust you so that you can help in future rehabilitation efforts.
5. Let the person talk and listen with interest and respect, even if you are not able to make much sense out of what is being said.

6. Reassure the person of your harmless intentions, and that you understand the present situation. Also try and explain that there will be help from medicines.

7. Try to understand the person from the person’s point of view.

8. If the person wants to go to a faith healer or priest or temple, or if the family wants to take the person for a cure, do not oppose the idea. Let them realize that you are genuinely interested in helping both the person and the family. Along with the faith healing sessions, you can gently try and persuade person and family to see the doctor and in turn, where indicated by the doctor, ensure that the medicines are being taken. Make sure that practices that cause physical harm (e.g., beating, burning, starving) are not being used. If those practices are proposed by a traditional healer, you have to intervene forcefully.

9. Treat the person with the same respect and dignity that would be received without any mental illness. Remember that the person is a human being who has developed a mental illness through no personal choice.

10. **Spend a lot of time with the family if you are a health worker/carer.** Remember that the family members probably do not understand what is happening to the person. Try to be gentle and calm. Try to explain to them what mental illness is, and try to persuade them to see the doctor. If they prefer to seek religious help, go along with them, to convince them that you want to help, and at a later date you can perhaps persuade them to also take medical treatment. Remember that it is important to earn the family’s trust and cooperation if you are going to help in the rehabilitation of the person. They need your support to accept the nature of the disability which is affecting one of them.
WHAT NOT TO DO
WHEN A PERSON HAS A MENTAL DISORDER

1. Do not panic or make a fuss. A calm approach is essential.

2. Do not get angry with the person. Remember that the person is not fully in control of what is happening.

3. Do not laugh at the person who makes a bizarre statement.

4. Do not keep on talking. Just listen patiently.

5. Do not try and argue with a person who is expressing irrational beliefs. Just listen, and calmly assure that the problems will be solved and that you will help.

6. Do not frighten or threaten the person. Always be calm and listen before replying.

7. Do not try and change the person’s or the family’s attitude towards religious beliefs. If they believe in religious help, do not stop them unless this is physically harmful.

8. Do not tease the person or allow others to tease.

9. Do not promise the person or the family a total cure with medicines. Try and tell them that the medicines will help improve the illness but may not cure it completely.

10. Do not get angry with the family members’ statements or attitudes about the person. Remember, they do not understand what is happening, and they need your support. They may need your support to accept the nature of the disability that is affecting one of them.
To summarize:

- Most people when faced with a person who suffers from mental illness, react in one or more of the following ways: fear, anger, sadness and pity, disgust and avoidance, or amusement. This is usually so because they are ignorant about mental disorders.

- When you come across persons with mental illness, understand your own emotions, assess the kind of mental disorder, assess whether immediate medical attention is necessary and arrange for it, earn the person's trust by talking calmly and reassuringly, go with the person for religious help if the person or family members insist. You may even be able to persuade the healer to stress to the person and the family the importance of taking medicines. Try and gently persuade them to also take medicines. Spend some time with the family and earn their trust as well.

- Do not get angry or laugh at the person or argue or promise a total cure with medicines or oppose religious help.
BOOKLET 2

GUIDELINES FOR PROVIDING HELP TO PERSONS WITH A MENTAL DISORDER

In this booklet you will learn:

- How to select tasks which could be interesting for a person with a mental disorder.

- How to move towards a greater degree of independent and autonomous functioning of a person with a mental disorder.

- How to enlist families' collaboration.
PROVIDING HELP TO PERSONS WITH A MENTAL DISORDER

By now you have learned how to identify a person with a mental disorder, how to approach the person and the family, and how to make an assessment of the various kinds of disability that are being experienced. The next step is to understand how you can help such a person.

1. Remember that the person is disabled and that improvement is likely to be slow. Do not expect fast or dramatic results.

2. If the person’s improvement is slow, do not despair. Some persons take longer than others to become better.

3. Set realistic targets to be achieved. For example, if you are helping to restart some agricultural activity, you may propose starting with looking after a few head of cattle for a while, as a reasonable target.

   Select tasks which are simple and which could be interesting for the person. Break the task down into simple steps so the person can understand. For example, if the person goes shopping ask for one item only.

4. Initially, have the activity supervised. Slowly withdraw supervision, and let the person do the task unaided and unsupervised.

5. Slowly increase the target until you reach the optimum level, e.g., the person working as an independent herdsman.

6. Each time the person does something well be generous with praises and compliments. This will give the person the encouragement needed to continue.

7. Try to get help from members of the family in helping the person. Do not do all the tasks by yourself. The members of the family must learn how to help in the person’s management and rehabilitation.

When you are dealing with a person with mental illness, you have to do the following activities for all persons regardless of the area of disability, or severity of disability.
Keep in touch regularly

Make sure that you visit the person regularly, say once a week, even if there is nothing particular to talk about. If you promised to visit the person, make sure you keep the appointment; if for some reason you cannot, make sure that the person is informed in advance. If the person talks to you, listen attentively. If the person does not talk, speak to the person about the person's health and other general topics, even if no interest is shown.

Spend some time with the family

Remember that the family members may be very upset about the mental illness. So, try and spend some time with them talking about the positive qualities of the person, and also about neutral topics. The family should see you as a trusted friend who cares about their well-being and who tries to help them whenever necessary. Just to talk about their feelings may be helpful for the family.
Make sure of regular visits to the doctor

Usually the doctor will prescribe medicines for two weeks to a month. Make sure that the person or a family member goes to the Health Centre to collect the supply of medicine in time. If they are unable to go, you could offer to collect the medicines on their behalf, if it is convenient. The person should be seen by the doctor at least every three months.

Make sure the medicines are taken according to the instructions

Find out from the doctor or family members what type and dosage of medicine has been prescribed. Clearly explain this to the person and other family members. Check during each visit how much medicine is left. In this way you will know whether the medicines have been taken or not. If side effects from the medicines are present, reassure both the person and the family that this may seem dramatic, but it is not serious or harmful. Make sure that you know from the doctor how to control side effects before they happen.
Relate the use of medicines to improvement in symptoms. Stress the need for taking medication regularly or it may result in a relapse. Help the family to be alert in order to detect early signs of relapse.

Be firm and respectful to the person, but make sure that he does not stop his medicines. If he does stop, insist that he meets the doctor to discuss it. Think of the possibility of switching to a monthly injection.

Make sure that nobody is teasing or bothering the person

As you are aware, some people because of their reaction to mental illness, may make fun of or harass a person with mental disorders in some way or another. Try to see if this is happening. If it is, try to educate such people about mental disorders. Educate the family to help others to understand mental disorders. If children harass the person, talk to them, ask for their help; talk to school authorities/parents. Parents may ask: 'Why don't you keep the person inside?'. You may have to plead for their understanding and help. Involve the person in a festival/party, perhaps giving sweets to the children. Avoid the person dressing in clothes that draw attention. Try to prevent unacceptable behaviour from the person.
BOOKLET 3

WORKING WITH THE FAMILY

In this booklet you will learn:

- The family’s initial reaction to mental illness: usually a mixture of denial, fear, anger, sadness, guilt and, hopefully, a challenge to family cohesion.

- That once it is established that there will not be a full recovery but that some disability will remain, the family may go through a process of grief similar to the grief after the death of a loved one: they are losing a "normal" family member. This grief reaction often follows stages which you will be able to recognize: denial; anger, humiliation and hopelessness (demoralization); and, hopefully, acceptance. However, this acceptance may take the form of over-protectiveness, or there may be outright indifference.

- How to help them understand and deal with the illness and the resulting disability.
WORKING WITH THE FAMILY

As we are all aware, the most valuable source of support to all of us is our family. This is also the case for persons disabled by a mental disorder. But, we must remember that the family members are bound to find it difficult to deal with their disabled or mentally ill relative.

By and large you will find that most families are supportive if given enough help and support from you and the doctor. Never forget that the family needs your help as much as the person does. Let us first try to understand how they react to mental illness.

We will first turn our attention to the immediate or first reaction of the family members when the person starts showing symptoms of a mental disorder and then we will move on to their reactions once the disability becomes evident.

INITIAL REACTION OF FAMILY MEMBERS

We must remember that, as far as mental disorders are concerned, the family members usually know only as much about them as anybody else. So, they will share the usual apprehensions and misconceptions about mental illness that anybody else in the community has. Do not be surprised if even educated persons have the wrong ideas about mental disorders. It is your responsibility to educate persons about mental disorders.

Note

By family we mean here any person who is or was emotionally close to the person affected by disability. It includes members of the nuclear and extended family as well as close friends and other close relations.

When a person first begins to behave abnormally or show signs of mental disorder, the other members in the family can show one or more of the following reactions:

Denial

Many people deny that any problem exists and continue to go about their normal duties as if nothing has happened. Even if you try and point out to them that the person is
suffering from an illness, they will refuse to believe you or to agree with you, and will usually ignore the problem. They might believe:

- that the person is going through "stress" or "tension";

- that the problem will sort itself out, if the person is left alone;

- that marriage will cure a single person, or that a job will cure an unemployed person;

- that offering 'special prayers' in the local or other nearby 'special' temples or that some traditional healer will rid the person of the problem; or

- that a change of environment will help, for example by sending the person on a short trip or to visit some relatives.

They may spend a lot of time or money on such things, and since mental diseases do not normally stop on their own in a short period of time, and even less so mental disabilities, they will have cause to regret it later.

Example

An upper class family has a 22-year old daughter with a chronic psychosis, or disability from a mental disorder. This daughter has been in a private nursing home for 2 years.

Their 18-year old son also shows clear signs of disability from mental illness. He has dropped out of school although he used to be a brilliant student. He spends his days alone in his room, playing guitar, chain smoking and reading comics. His parents have taken him to a large number of traditional healers and temples and all sorts of quacks to help him overcome his "adolescent crisis". They have already sold one of the two houses they owned to pay for all these expenses.

Yet, they still dismiss the possibility that the second of their children also has a disability from mental illness; as proof he cannot be mentally ill, they point out that he is playing the guitar so well, "he is just an artist". They continue to refuse to accept that both their children are disabled. Or, in other words, to leave the stage of denial, and to enter the stage of hopelessness and demoralization, before entering the stage of acceptance.
Fear

After the denial phase is over and they do realize that something is indeed wrong with the person, some family members may experience fear. They do not understand what is happening to their loved one. They feel that all is due to some sins of the past, and they are afraid of what may happen. The family members may experience guilt and shame. They may seek the advice of elders or religious leaders in the community. They may go to faith healers who promise a cure or to far away places of worship which are renowned for healing properties for such problems. They may also avoid going close to the person for fear that something unexpected may happen.

Anger

After accepting that something is wrong with the person, some family members may experience anger. They get angry with the person for behaving abnormally, and overtly express their anger. They may get angry with "God" and wonder why their family is being "cursed". They may start believing that somebody is doing some "black magic" against them. And they may try and seek some relief by "counter black magic" agents.

They may also get angry at you if at this point you try and suggest that medicines can help the person, or that the problem is a medical one or that they should see a doctor. They may shout at you irrationally and get into fights with their neighbours and friends in the village. This anger, thus, is part of the denial that there is a medical problem with the functioning of the brain, just like diarrhoea is a problem with the functioning of the bowels.

Indifference

Some families, however, react very differently to the occurrence of mental illness or disability. These are otherwise "difficult" families, often very poor, which are also uncooperative in other ways. They tend to be neglectful and disorganized, one of the parents may have some mental disorder, or there may be an alcoholic or drug abusing father.

Such "risk households" may be unable or unwilling to face the additional challenge of a member disabled from mental illness. Such families may already pose a serious challenge to the health worker in terms of compliance with child spacing, immunization, and oral rehydration therapy etc. In short, they are the households which need the most support, but tend to get the least: families where your visits are not welcome, although they may be needed.
Or you may face a situation that a person disabled by a mental illness has already been thrown out by the family or has become homeless in other ways. You should be able to organize special help for these families. One way of doing this is temporary admission to some institution for short-term relief. Alternatively, you may be able to get on other community or family member to help out and, perhaps, give the family some time away from the situation.

**REACTION OF FAMILY MEMBERS**

**AFTER THE DISCLOSURE OF DISABILITY**

Once it is disclosed to the family that there will probably be a lasting disability, that the person will not fully return to former ways, your role will be even more important. Now the family has to face the definite loss of a loved one, a bereavement situation. The husband or wife or son or daughter will never be normal again. This is often more difficult to handle than if the person had actually died. In fact, you will often hear from family members how much better it would be if in fact the person was dead. Let us again look at what family members are likely to go through if they are faced with the reality of lasting disability.

**Denial**

Family members will refuse to accept that there is a disability; that there will never be a full recovery; that things will never be as they were before. They may take the person to temples and faith healers and charlatans again, or insist that "the Government must do something". It is easier to understand disability in a family member if the reason is obvious; if for example, someone has lost a leg in an accident. It is much more difficult to accept disability and adjust to it if it affects only the behaviour of a person, without any visible defect.

First of all, you yourself will have to understand that this "it can't be true" is a normal reaction in family members. If you have fully understood this you will have the patience to help family members to slowly give up denial and to stop looking for a cure. This may be a long and difficult process. Families do not accept and tend to deny the presence of lasting disability and waste fortunes looking for a cure from traditional healers and quacks of all sorts, or they may take the person to one specialist after another. They may need your continuous but insistent guidance on this.
Hopelessness, anger

Once the fact of disability has been fully recognized by the family members (like the final recognition that a beloved spouse is dead), there is likely to be a stage of hopelessness mixed with anger. They may get angry with "God" and wonder why their family is being "cursed". They may intensify their belief that somebody is doing some "black magic" against them. They may get angry at you if you suggest at this stage that the person could be helped by what you have learned as the steps of rehabilitation. This anger may turn into open hostility against the person who, in some families, may be fully rejected and thrown out of the house.

Note
There can be no meaningful steps towards rehabilitation involving the family as long as the family is in the stage of denial, or hopelessness and anger. Unless the family has reached the stage of acceptance of the disability in their member, efforts at family-based rehabilitation are likely to be harmful, adding feelings of guilt and incompetence to the feelings of hopelessness and anger. All you can do at this stage is to help the family to reach acceptance.

Over-protectiveness

In some cases you will find that family members are extremely protective of persons with a disability and want to do everything for them. They end up treating the person like a child. This attitude can also come in the way of recovery, as people treated in this way may find little or no scope to express themselves as an adult.

The overprotective family member may not allow the person to do any work or may refuse to allow the person to be exposed to the outside world for fear of a relapse or of being ridiculed, and so on. If you make further enquiries you will find that this overprotective behaviour was not present before the illness started and can be seen as an expression of extreme sympathy and sorrow felt by the family member. This pattern of behaviour is not helpful for the person.
HOW YOU CAN HELP

You would by now have realized that in order to help the person, you will also have to help the family members. To do this you will have to use the following guiding principles:

1. **Listen to them and earn their trust.** Remember that the family members have a need to be understood and want somebody to listen to their problems. If they are expressing anger, hostility or sadness, spend some time listening to them. **Do not judge them harshly even if they express negative thoughts about the person.** Always try to remember that they are a bereaved family and that they have to live every day with a serious problem, in addition to all the other problems they may have.

2. **Identify the feelings of important family members.** While listening to the family talking about the new situation they are in because of the disability of the family member, you will be able to describe what stage of bereavement (if any) the different family members are in. This is particularly important for the head of the household (if the previous head of the household himself is the disabled person, you will have to note who is now taking this role) and for the person who has taken on most of the care-giving.

   Note separately for each adult in the household whether there is denial, anger, hostility, hopelessness, guilt, humiliation, acceptance or over-protectiveness. Rate each of these feelings about the disabled person separately, since several may occur together, or a person may at times have one feeling and at other times another feeling. For probing: ask whether sometimes the person also gets angry, hopeless, etc. Reassure the family members that all these feelings are a normal part of the reaction to the loss of a "normal" family member. By talking about these stages of the grief reaction you will help the family to reach acceptance.

3. **Identify the major problems the family has in caring for their disabled member.** You will have understood by now that it can be very distressing for a family if a previously healthy member becomes disabled by mental illness. But the family may also face other problems. They may be very poor, making it difficult to care for an additional 'useless mouth', especially if the person had previously contributed to the family income. It may also be difficult for the family to pay for the prescribed treatment, especially if it is clear that it does not cure the person completely.
Parents may be worried about what will happen to an unwell child when they have died. They may feel that their social relationships are affected by the presence of the unwell child either because looking after the child takes too much time or because of the guilt, shame and feeling of humiliation due to the child's strange behaviour.

Family relationships may also be seriously strained by hostility or rejection of the person by some family members and caring and perhaps even over-protectiveness by others. Especially if there has been violence due to the illness, the family may continue to live in fear that violence may occur again. It is important that you assess the burden family members feel in caring for the person, and what specifically makes them feel this burden.

4. **Identify strengths and resources in the family.** The most important strength in a family with a disabled person is confidence in coping with the situation. Only if the family has accepted the disability and feels confident that they can cope with the situation, will they be able to fully participate in the process of rehabilitation. You may also be able to instill some feelings of pride and satisfaction in family members about being able to look after the person so well. Closeness within the family and support from neighbours and friends will also be helpful in caring. By talking to neighbours about the nature of the disability and about the family needs you may be able to help in finding this support.

It can be very helpful if families with members affected by disabilities from mental illness get together to share their problems and experiences. This will help them to clarify their feelings, to accept the disability, and to gain confidence that they can cope with the situation.

It may also help them to understand that they can help these persons by ensuring that they take medicines regularly (if only to prevent a relapse of the disease), that they should be involved in some activity in line with their capabilities, and by ensuring that they are not criticized, abused, ridiculed or ill-treated in any way.

Especially in the initial phase of the illness, and again after disclosure of lasting disability, much support is needed which can best come from self help/mutual aid groups of affected families. Such groups can not only be a source of emotional support, but they can also build financial and material resources for crisis situations and for care for disabled members if family carers are deceased.
BOOKLET 4

HOW TO HELP PERSONS
WITH A PERSONAL DISABILITY

In this booklet you will learn how to help a person
- who has problems with self-care.
- whose activity levels are low.
- who is slow in doing everything.
HOW TO HELP A PERSON WITH A PERSONAL DISABILITY

We will first turn to your role in helping a person who by reason of mental illness experiences personal disability: is deficient in self-care, is under-active and slow.

HELP FOR PROBLEMS WITH SELF-CARE

You will remember that the person with this disability will find it difficult to maintain personal hygiene. Here is what you can do to help.

Ensure that the person keeps clean

You can ask someone else in the family to help you. Try and persuade the person to wash regularly. For the severely disabled, try and ensure at least one bath, say, once a fortnight to start with, and gradually increase it. For the mildly disabled, ensure that the person washes daily with soap; that head and body are free of lice; that hair is combed and cut regularly and that general appearance is presentable and neat.
Ensure that the environment is kept clean

Help put away clothes and other personal belongings in a tidy manner. As for bathing, set targets: First, this is done once in a fortnight, gradually increasing to a daily routine. Make sure that things are not thrown around untidily.

Ensure that food is taken tidily

Share some meals with the person. This will create excellent opportunities to show how to eat cleanly and how to clean up after the meal. Set targets and move slowly towards them. Don't forget to express your appreciation whenever progress towards the targets is being made.
Some persons may show variable behaviour in different places. For example, they may eat properly only when given a dish of their choice. It is helpful to give small servings and to eat with others. Taking them to outside places and restaurants, if at all possible, may also be helpful.

HELP FOR PROBLEMS WITH UNDERACTIVITY

If you find a person who spends much time doing nothing, here is what you can do:

Spend time talking or reading to the person

By doing this you are achieving some form of mental activity. If the person shows clear and active disinterest in those sessions, keep them short in the beginning and make them gradually longer as you notice a decrease in disinterest.

Persuade family members and relatives to spend some time talking to the unwell person on a regular basis

Even if initially there does not seem to be an interest in this, family members can take turns. Once again set targets, but move slowly.
Persuade the person to come out for walks with you on a regular basis

In this way some physical activity is achieved. Suggest changes in dressing, behaviour, manners to avoid teasing by others. Again, set targets and move slowly towards achieving them.

Note
It is important that the health worker spends time exclusively with the person during the first few visits to build up a trusting relationship. The family should be seen/spoken to separately and not during the time allotted to the unwell person, as this one may resent being talked to in the presence of the family.
HELP FOR PROBLEMS WITH SLOWNESS

If the person is very slow at performing tasks, here is how you can help:

1. Make a list of basic tasks that the person must perform.

2. Find out those that are of interest and start with these.

3. Ask the person to do it at a comfortable pace.

4. Slowly increase the pace guiding the person through the activity at the increased pace.

5. Ask the person to practise the activity on a regular basis, so that mastery of the task can be achieved.

6. Make sure the person does not give up; the old pace will be regained in due course.

7. Do not despair if the first few attempts do not go off as planned. If you persist you will be rewarded with gratifying results.

8. Do not insist when you find that the person is getting upset and worked up. Have a break of a day or two, and then start again.
Example:

A 42 year old school teacher was discharged from a mental hospital after 9 months with the diagnosis of chronic psychosis and mental disability. His bizarre behaviour, talking to himself, and occasional outbreaks of violence, were well controlled by the monthly injection he received, with some resistance. He was extremely neglectful about himself and his environment and could only with great difficulty be made to participate in any activity in the home. He refused to leave the home or to do anything about his personal hygiene or cleanliness. He got angry with his wife and his mother when they tried to get him to do anything.

During a visit by a distant aunt he agreed to go with her for a walk. A little later he agreed to have a neighbour help him take a bath and wash his hair. Slowly, with the help of the aunt, the neighbour and the health worker, he accepted increasingly to take care of his personal hygiene and cleanliness. With their help and encouragement, he also started to do some work outside the house.

Although he never accepted help or encouragement from his wife or mother, he slowly but continuously improved in all activities through planned and patient encouragement from outsiders.
BOOKLET 5

HELP FOR PERSONS WITH DISABILITY IN THE FAMILY ROLE

In this booklet you will learn how to help a person who has difficulties in:

- participating in family activities.
- being a spouse.
- being a parent.
HELP FOR A PERSON WITH DIFFICULTIES IN PARTICIPATING IN FAMILY ACTIVITIES

Examples of family activities:
- having meals together;
- going out to cinema/functions together;
- talking together in the evening;
- making decisions together.

1. Have a discussion with the family members about all activities they used to do together with the person before the illness started.

2. Make a list of family activities in which the person used to participate but no longer participates.

3. Make sure that these are activities involve the whole family.

4. In drawing up the list, start with tasks that are easier, and slowly progress to more difficult tasks. Set targets for achieving each task. It may provoke anxiety, even panic, in a person with psychosis to participate in family activities. Discuss this with the doctor if you feel that this is what happens.

5. Discuss the list with the family members and obtain their cooperation. If they refuse to cooperate, do not push them. They may be afraid of the person becoming violent or abusive if this happened during earlier illness episodes. Discuss this with the doctor. Perhaps the medicines need to be adjusted to assure the family that abuse and violence will not recur as long as the person takes the prescribed medicines.

6. If despite repeated attempts the person refuses to cooperate, discuss it with the doctor, who will tell you what to do next.

7. After you have obtained the person's cooperation, ask both the person and the family to practice the activities identified in the list together on a regular basis. Initially try and be present for the first few attempts. Withdraw yourself slowly after the targets begin to be achieved.
8. Do not despair if the first few attempts do not go off as planned. If you persist you will probably be rewarded with gratifying results.

9. Stop pushing when you find that the person is getting upset and worked up. Have a break of a day or two and then start again.

Example:

A 37 year old housewife had lost all interest in her family following an attack of psychosis. Even her 10 and 7 year old children would not attract her interest and attention for more than brief moments. On the advice of the health worker, the family got a labrador dog and some exotic saplings. It turned out to be a very positive experience. The disabled person and the children took care of the dog and the saplings together, thereby slowly bringing them closer again.

HELP FOR A PERSON DISABLED IN THE MARITAL ROLE

Examples of marital role activities:

- being affectionate to each other;
- buying flowers or small gifts or special food for the spouse;
- talking with and listening to each other;
- dealing with family problems together.

1. Have a discussion with the spouse of the person about what they used to do together as husband and wife before the illness started. If the spouse is willing to discuss sexual matters, let the person do so, but do not push for information about this. Many persons with mental disorders lose interest in sex either because of the illness or as a side-effect of the medicines. If sexual problems exist, refer the couple to the doctor.
2. Make a list of marital activities in which the person used to participate but no longer participates.

3. Make sure that these activities involve both spouses together.

4. In drawing up the list start with things that are easier, and slowly progress to more difficult tasks. Set targets for achieving each task. It may provoke anxiety, even panic, in a person with psychosis, to participate in marital activities. Discuss this with the doctor if this is what you feel is happening.

5. Discuss the list with the person and obtain cooperation. If there is a refusal to cooperate, do not push. Try again after some time. Do this until you obtain the cooperation.

6. Discuss the list with the spouse and obtain cooperation. If there is a refusal to cooperate, do not push. The spouse may be afraid of the person becoming abusive or violent if this happened during previous illness episodes. Discuss this with the doctor. Perhaps the medicines need to be adjusted to assure the spouse that abuse and violence will not recur as long as the person takes the prescribed medicines.

7. If despite repeated attempts, the person refuses to cooperate, discuss it with the doctor, who will tell you what to do next.

8. After you have obtained the person’s and the spouse’s cooperation, ask both spouses to practise the activities identified in the list together on a regular basis. Initially try to be present for the first few attempts. Withdraw yourself slowly after the targets begin to be achieved.

9. Do not despair if the first few attempts do not go off as planned. If you persist you will probably be rewarded with gratifying results.

10. Stop pushing when you find that the person is getting upset and worked up. Have a break of a day or two and then start again.
HELP FOR A PERSON DISABLED IN THE PARENTAL ROLE

Examples of parental role activities:
- looking after the children and spending time with them;
- taking them to school;
- buying things necessary for them;
- playing with them;
- helping them with their homework.

1. Have a discussion with the spouse, other family members and grown up children about what activities the person used to do for the children before the illness started.

2. Try to explain the disability to smaller children in a way that they can understand. Perhaps identify another adult to whom they can go and talk if the parent is not well.

3. Make a list of parental activities that the person used to do but does not do any longer.

4. Make sure that these activities involve the care of the children.

5. In drawing up the list start with tasks that are easier, and slowly progress to more difficult tasks. Set targets for achieving each task.

6. Discuss the list with the person and obtain cooperation. If there is a refusal to cooperate, do not push. Try again after some time. Do this until you obtain the cooperation.

7. Discuss the list with the spouse, other family members and grown up children and obtain their cooperation. If they refuse to cooperate, do not push them. Try again after a few days. Do this until you obtain their cooperation.
8. If despite repeated attempts, the person refuses to cooperate, discuss it with the doctor, who will tell you what to do next.

9. After you have obtained the person’s cooperation, and that of the spouse, other family members and grown up children, ask that the activities identified in the list are practised on a regular basis. Initially try and be present for the first few attempts. Withdraw yourself slowly after the targets begin to be achieved.

10. Do not despair if the first few attempts do not go off as planned. If you persist you will probably be rewarded with gratifying results.

11. Stop insisting when you find that the person is getting upset and worked up. Have a break of a day or two and then start again.
BOOKLET 6

HELP FOR PERSONS WITH
A SOCIAL DISABILITY

In this booklet you will learn how to help a person who:

- is socially withdrawn.

- has little or no interest in what is happening in the world around him.
HELP FOR A PERSON SOCIALLy WITHDRAWN

A person who is socially withdrawn needs to be approached with particular care. You should first get the person to trust you as a valuable friend who wants to help. This you can do by spending time with the person in a very unobtrusive way. If you feel that your presence is upsetting, make these sessions shorter. Once you are sure that your presence does not bring out discomfort, you can slowly start taking the person out of the house in order to get used again to the environment and the neighbours.

Do not rush into social activities unless a desire to meet old friends, neighbours and relatives is expressed. Once the person trusts you, you will then be ready to undertake the following steps to overcome the social withdrawal:

1. Have a discussion with the person, the spouse, other family members, friends and relatives about the kind of social activities the person used to engage in, who were the people regularly met, etc., before the illness started.

2. Make a list of social activities in which the person used to participate but no longer participates.

3. Make sure that these activities involve exchanges with friends and relatives, without necessarily closer contact in the beginning, like gardening together, going together to the market, fetching water, etc.

4. In drawing up the list, start with things that are easy, and slowly progress to more difficult tasks. Set targets for achieving each task. It may provoke anxiety, even panic in a person with psychosis to participate in social activities. Discuss this with the doctor if this is what you feel is happening.

5. Discuss the list with the person and obtain cooperation. If there is a refusal to cooperate, do not push. Try again after a few days. Do this until you obtain the cooperation.
6. Discuss the list with the spouse, other family members and friends, relatives and neighbours, and obtain their cooperation. If they refuse to cooperate, do not insist. Try again after a few days. Do this until you obtain their cooperation. Remember that it is very important to obtain their cooperation. If they do not cooperate, it will be very difficult to get the person to socialize.

7. If despite repeated attempts, the person refuses to cooperate, discuss it with the doctor, who will tell you what to do next.

8. After you have obtained the person's cooperation, and that of the spouse, other family members, friends, neighbours and relatives, ask for activities identified in the list to be practised on a regular basis. Initially, try to be present for the first few attempts. Withdraw yourself slowly after the targets have been achieved.

9. Do not despair if the first few attempts do not go off as planned. If you persist you will be rewarded with gratifying results.

10. Stop insisting when you find that the person is getting upset and worked up. Have a break, of a day or two and then start again.
BOOKLET 7

HELP FOR PERSONS WITH AN OCCUPATIONAL DISABILITY

In this booklet you will learn how to help a person who:

- does not go to work or do housework or other work previously done, and has little or no interest in getting any work done;

- does some work or housework or goes for studies but is not able to do it well.
HELP FOR A PERSON WHO DOES NOT WORK 
AND HAS LITTLE OR NO INTEREST IN WORKING 
OR IN GAINFUL ACTIVITIES

It is quite possible that some of the people you meet may not go to work or may not do housework or other chores they used to do. If they are not able to get a job or if the family does not let them, then this is not a disability. But some persons may show little or no interest in getting a job or doing work even when the family or others expect them to do so. This is a disability, and for you to help such a person, you will need to have first obtained his trust by spending time with him. After you have done so, you can try the following steps:

1. Have a discussion with the person, the spouse and other family members, about the kind of work, housework and other chores which used to be done before the illness started.

2. Make a list of the kind of work that the person used to do, especially tasks enjoyed, and those not done any more.

3. Make sure that these activities are the ones the person used to do before the illness or enjoyed doing, and not some new task that would have to be learned.

4. In drawing up the list start with tasks that are easier, and slowly progress to more difficult tasks. Set targets for achieving each task.

5. Discuss the list with the person, family and colleagues from before the illness started and obtain their cooperation. If the person refuses to cooperate, do not insist. Perhaps you or the family can think of even easier tasks, especially if the person can do them alone, like watching cattle. Try again later. Do this until you obtain cooperation.

6. If the person does something well, make sure there is a reward - a small gift or praise or a token which later can be exchanged for some desired object.
7. If despite repeated attempts, the person refuses to cooperate, discuss it with the doctor who will tell you what to do next.

8. After you have obtained the person’s cooperation, ask for the activities identified in the list to be practised on a regular basis. Repetition of tasks will lead to the development of skills. Initially try to be present for the first few attempts. Withdraw yourself slowly after the targets have been achieved.

9. Do not despair if the first few attempts do not go off as planned. If you persist you may be rewarded with gratifying results.

10. Stop insisting when you find that the person is getting upset and worked up. Have a break, of a day or two and then start again.

Note

For many persons with a disability from mental illness it is easier to do things alone. To be with others, especially family members, may be stressful for them.

HELP FOR A PERSON WHO IS UNABLE TO WORK WELL

Some of the other people you visit may be willing to do some work, but find that they are unable to do their work as well or as fast as they used to. Such persons also need your assistance. Before you start to help such a person, check out with the doctor whether the difficulty in working well is a side effect of the medicine. If it is not due to the medicines and if you have already obtained the person’s trust, then take the steps as listed above. In this case, praise and reward for anything done well will be particularly important. Also the person may be happier to work with others and benefit from others as role models.

1. Have a discussion with the person, family members and the people with whom the person used to work about how well the work used to be done before the illness and what tasks were enjoyed.
2. Have also a discussion with the employer (if the person is employed) about what tasks the person is not doing well and request the support of the employer in helping the person.

3. Make a list of the tasks that the person is not doing well and which need improvement.

4. Make sure that these activities are the ones the person used to do before the illness and not some new task that would have to be learned.

5. In drawing up the list start with tasks that are easier and slowly progress to more difficult tasks. Set targets for achieving each task.

6. Discuss the list with the person and obtain cooperation. If there is a refusal to cooperate, do not insist. Try again after a few days. Do this until you obtain the cooperation.

7. If, despite repeated attempts, the refusal to cooperate persists, discuss it with the doctor who will tell you what to do next.

8. After you have obtained the person's cooperation ask for the activities identified in the list to be practised on a regular basis. Initially try to be present for the first few attempts. Withdraw yourself slowly after the targets have been achieved.

9. If the person does something well, make sure a reward is given in the form of a small gift or praise or a token which later can be exchanged for some desired object.

10. Do not despair if the first few attempts do not go off as planned. If you persist you may be rewarded with gratifying results.

11. Stop insisting when you find that the person is getting upset and worked up. Have a break and then start again.
Types of work that could be done by persons disabled by mental disorders

Income generating activities:

Poultry farming, fishing and fish farming, grazing cows and goats, milking cows, fetching water or fire wood for neighbours, feeding cattle, ploughing fields, harvesting paddy, growing vegetables and fruit, selling vegetables and fruits, working in tea shops, working in small shops, construction labour, unskilled labour.

Typing/Computers, Tailoring, Fax machines, Xeroxing, telephone operating, candle making, baking, screen printing etc.

Support activities:

Cutting vegetables, shopping, cooking, washing utensils, washing clothes, serving food, cleaning rice, fetching water or firewood, watching cattle, going to the post office.
BOOKLET 8

HELP FOR PERSONS WITH AN EMOTIONAL DISABILITY

In this booklet you will learn how to help a person who:

- shows very little emotion, or much less than before the illness.
- shows emotions which are not appropriate to the situation.
HELP FOR A PERSON WHO SHOWS APATHY, INABILITY TO ENJOY THINGS, LOSS OF EMOTIONAL RESPONSIVENESS

Emotional disability is often an early sign of the start of psychosis. In emotionally disabled persons, this disability may begin long before the other signs of psychosis appear. You must not confuse this with depression. Persons with depression suffer from uncontrollable irritability, hostility and anger towards loved ones, sadness and loss of the energy to do what could easily be done before. In contrast to this suffering which the person with depression will express readily, persons with emotional disability will say little if asked about their feelings, or may accuse others of interfering with their minds.

Social and emotional disability may seem rather unimportant to you, but family members may feel very burdened by the fact that a previously affectionate family member has stopped showing affection and emotional responsiveness. Family members may feel rejected and may react with rejection.

It is very important that you discuss these feelings with the family, and reassure them that their feelings of rejection are normal reactions to emotional disability.

1. You need great caution when discussing feelings and emotional responsiveness with the person, the spouse and other family members. Particularly for disabled persons this may be very stressful, although on the surface they may appear unconcerned.

2. Explain to the family that the lack of emotional responsiveness is a disability from mental disease, and through no fault of the person. It may also be made worse by the medicines the person takes.

3. Explain to the family patiently and repeatedly that showing feelings of affection as well as rejection can both be harmful to the person with an emotional disability.

4. Identify the family member who was most closely attached to the person. Practice with this family member how to react with calm and acceptance to not getting the emotional responses received from the person in the past. At first this family member may find such
exercises childish; but after some insistence on your part, it will be a gratifying experience to realize that by not insisting on emotional responses these will slowly come, at the affected person’s pace.

HELP FOR A PERSON WHO SHOWS EMOTIONS NOT APPROPRIATE FOR THE SITUATION

For persons with emotional disability, the rehabilitation work is not so much with the disabled person but with the concerned family: the less the family reacts to the emotional disability, the better the chances for improvement.

As is the case with persons who have lost their emotional responsiveness due to disability from mental illness, rehabilitation for persons showing emotions inappropriate to the situation will have to focus more on the family than on the disabled person.

1. Discuss with family members their feelings when confronted with emotions shown by the person which seem quite out of place and try to identify those situations. Discuss alternative ways of handling such situations in the future.

2. Help family members to identify and, if possible, describe their feelings when witnessing the person showing emotions clearly out of place. You will discover that family members may react to such situations with rejection, embarrassment, over-protection or denial.

3. You may be able to expose the person, perhaps in a relaxed and role-playing manner, to situations in which the person is likely to show inappropriate emotions. Give praise and recognition whenever an appropriate emotion is shown.
Example

The 18-year old brother of an emotionally disabled person has been killed in a traffic accident. In a well-intended effort for rehabilitation, the family invites the disabled person to join the funeral. At the height of mourning, the moment when the coffin is lowered into the grave, the disabled person starts laughing aloud and says: "I also was a cloud, you know. An evening thing". And then, laughingly to those standing next to him: "it's bad to dig holes into the earth. Only worms will come out of this". And laughing again.

It is a very laudable effort on your part to get the family to agree to have the disabled person attend the funeral as a gesture of social rehabilitation. However, you should have anticipated the possible expressions of emotional disability on such an occasion, and should have ensured with the family that everyone present would be able to face this situation without negative feelings.