



GUIDE 2.

How to reduce the impact of stigma

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 **NEGLECTED TROPICAL DISEASE
NGO NETWORK**
A global forum for nongovernmental organizations
working together on NTDs



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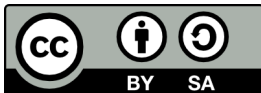
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International Federation of Anti-Leprosy Assosiations (ILEP)

ILEP is an international federation of NGOs working to achieve three targets related to leprosy: Zero Transmission, Zero Disability and Zero Discrimination.

Neglected Tropical Disease NGO Network (NNN)

The NTD NGO Network (NNN) is an international network of over 70 NGOs collaborating in the fight against NTDs. This includes reduction of NTD-related stigma and promotion of mental wellbeing of persons affected by NTDs and their families.



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Guide 2. How to reduce the impact of stigma

This Guide presents various ways to reduce the impact of stigma, discrimination and prejudice on individuals:

- At the individual level of persons affected by NTDs, by using psychosocial support to develop coping mechanisms and promote resilience and self-advocacy, and through role models or champions.
- At the group level of persons affected by NTDs, by creating a supportive environment through the development of support groups.
- At the family level, by reducing the impact of stigma on families through family psychosocial support and family support groups.



Photo credit: Jean Platteau, Damien Foundation

“Nobody asked me how I was feeling, everyone just told me what to do.”

— A statement from a leprosy-affected person

Learning objectives

After working through this Guide, you should understand:

- That there are various ways to reduce the impact of discrimination and prejudice on individuals. These can target different ‘levels’: individual, group and family.
- How psychosocial support can help a person to cope with mental health problems or any other hardship or challenges they might experience at a given time.
- The comprehensive guides that are available for giving psychosocial support.
- How to determine what type of support group (self-help, self-care and online) is most appropriate for a given situation.
- The different family-level interventions available.
- The role family plays in reducing or increasing the stigma and the distress individuals may experience.
- What referral is and when it is necessary to refer someone.

Credits

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1. From undetected disease to diagnosis to support

Time zero

Before the moment – ‘time zero’ – when a person is diagnosed with a neglected tropical disease (NTD), the person and their family may not feel they are ‘affected’ by the NTD. They may have noticed changes to their bodies, may experience pain and may have started to worry about what might be affecting them.

The golden hour



Photo credit: Layla Aerts, Damien Foundation

The ‘golden hour’ is the moment when the person affected receives the diagnosis. The person may or may not be in the company of family members, and may or may not suspect the diagnosis, but is certainly anxious to get a treatment for the condition and be cured right away. However, in the case of diseases associated with stigma and discrimination, the diagnosis may be perceived as bad news, not only because the treatment may be long, but also because the person may need to disclose the diagnosis to family members and contacts to get them examined for the same

disease. Many people may be ashamed of being affected by such a condition, which may lead them to conceal it. Others may simply reject or deny the diagnosis, especially if they have been to other doctors who have made a different diagnosis. Others may fall into a state of despair, running away, isolating themselves from everyone, or even considering suicide.

The golden hour is extremely important because it is through the medical diagnosis that the person and the family may feel like they lose their social status in the community and in the world. Actual loss of status may or may not occur, but the potential, anticipated loss enters the person’s life. The degree of perceived loss depends on several factors, including the way the person is addressed during this ‘golden hour’.

Whilst the moment of first diagnosis is very important, some conditions only become stigmatising when secondary effects such as physical impairments are apparent. This can happen many months or even years after diagnosis, but can have many of the same effects: shame, concealment, isolation and despair.

Exercise 1

In this exercise you are invited to ‘step into someone else’s shoes’. How does it feel to be stigmatised, to be excluded? Gain an in-depth understanding in this exercise.

➔ See Guide 2 Annex 1: Training exercises and tips for further details.

Case study from a psychologist working with leprosy patients in India

A woman came to the hospital along with her neighbour. They were both invited into the doctor's room, the doctor assuming the neighbour was a family member. He broke the news that the woman had leprosy and gave instructions about the treatment. The neighbour heard it all. A few days later, the patient came back to the hospital very upset, saying that her employer had fired her. Later she came again, this time having attempted suicide. She had been preparing for her daughter's marriage, but this had been cancelled by the in-laws once they heard that the mother of the bride had leprosy. The neighbour who had accompanied her to the hospital had told the whole village about her health condition.

If you are the health care provider, you should anticipate and be prepared to handle overwhelming emotional reactions from the person affected and/or family members. In managing and helping the person with their emotional reactions, it is important that you:

- Acknowledge and accept the reactions of the person, however strong they may be. For example, you might reply, 'I can see that you are upset'.
- Encourage expression of feelings. If people are crying or are angry, convey to them that they can feel free to express themselves and that they have reasons to feel the way they feel. Assure them of your understanding presence.
- After they settle down, help explore the reasons for their feelings, for example by asking questions such as 'What makes you feel this way?' and 'What is upsetting you?'
- Encourage the person to discuss the situation in detail.
- Help the person to explore options to manage the situation.

The golden hour is crucial in the course of the treatment as a key moment to promote adherence to treatment, promote contact examination and prevent mental health problems. Three points need to be considered during the 'golden hour':

- Communicating information sensitively and clearly about the diagnosis, treatment and progress of the condition.
 - Voluntary disclosure of the condition to others.
 - Communication with household members – what to tell family members and how to encourage them to help affected persons cope.
- Guide 2 Annex 2: Crucial points to consider during the 'golden hour' provides a detailed description of the points that need to be considered during the 'golden hour'. The Annex includes more information about important topics to consider and address, useful questions to ask and more general information about sensitive and clear communication.

2. Individual-level interventions

Promoting resilience

Diagnosis with an NTD can be distressing. If the diagnosis results in social exclusion and rejection, this may lead to mental health problems such as emotional stress, anxiety, depression, isolation and even suicide attempts. It is therefore important to build the capacity of the stigmatised person to deal with, withstand and overcome discrimination. Building resilience and psychological strength can help individuals to cope with hardship or challenges they might experience at any time.

Issues for which the individual might require individual/psychosocial support include:

- Accepting the diagnosis of a disease and its consequences.
- Coping with discrimination and prejudice from others.
- Difficulties in disclosing their disease status to others.
- Overwhelming or uncontrollable feelings that affect day-to-day life.
- Beliefs and fears about the disease.
- Acceptance of changes in appearance and body due to the disease.
- Adjustments to changes in lifestyle and status due to stigma.
- Adjustments to changes in family, marriage and social relationships.
- Coping with economic losses, inability to work as before and changing roles within the household because of loss of employment.

‘Resilience’ can be understood as ‘being strong and bouncing back’. In that way, resilience is like the bamboo that bends and bounces back, not like the tree that breaks in a storm. Bamboo survives in difficult conditions, still standing tall and staying green all year. When there is a storm, bamboo bends with the wind. When the storm is over, it resumes its upright position.

“ They keep my cutlery and kitchen utensils separate from theirs, this is very upsetting for me, I feel like taking poison and dying. ”

— Man with lymphatic filariasis, Bihar, India

Psychosocial support

Psychosocial support, sometimes referred to as counselling, psychological first aid or psychological help, is a helping relationship that involves a support partner working with a person to address the feelings (emotions), thoughts and beliefs, behaviours and relationships that are associated with the diagnosis and with the ongoing process of living with an NTD. The person is supported to understand and express their own thoughts and feelings about living with the condition, and to become empowered to deal with the issues that arise from their condition, leading to a better quality of life within family and community.



Photo credit: NLR

Psychosocial support should help the individual towards:

- Improved understanding and acceptance of themselves, including challenges and potentials.
- Improved understanding and acceptance of their situation and condition.
- Improved clarity about issues and awareness that something can be done about the problem.
- Improved self-esteem and confidence in their ability to handle their issues.
- Improved state of mental wellbeing.
- Realistic understanding of stigma.
- Motivation to resume meaningful participation in the family and community.

Whilst psychosocial support focuses on the individual, it can be beneficial to also work with the household and community when addressing the issues. This is described in chapters 3 and 4 of this Guide. Resources can be found in Guide 2 Annex 4: Resources for psychosocial support.

Good listening

Being an effective partner in the psychosocial support process is a combination of attitudes and personal qualities, skills and knowledge of the health condition, the cultural/social context and good ethics. Communication skills are especially crucial, as communication plays a major role in moving the psychosocial support process in the right direction. More than any other skill, good listening initiates positive change for the individual.

It takes understanding, self-awareness and practice to master the art of good listening. The purpose is to give the person a safe space to tell their story and to acknowledge, express and talk about their feelings, beliefs and thinking – and from this to understand, accept and solve some of the problems they experience. Good listening is about empowering people to understand and manage their own situation, both personal and social, and cope with the changes that the disease has brought into their lives.

Good listeners listen with their heart and mind, ears and eyes.

The heart and mind. The health worker or support partner's attitude to the person experiencing the NTD and its consequences is very important. Respect, empathy, acceptance and genuine listening can be the beginning of the journey towards emotional and mental wellbeing. In situations where any kind of stigma and discrimination is feared or has developed, the health worker may be the first person who shows a different reaction, one of giving value, seeing potential and creating hope. The personal character and attitudes of the health worker are often the first and most significant ingredient for helping a person experiencing emotional or psychological problems. This positive attitude is seen in factors like the warmth of the greeting, respectful seating arrangements, focus on the person without interruptions, encouragement and confidentiality and treating the person as someone of real value.

The ears. The health worker or support partner pays close attention to the words the person uses. The health worker listens to the person's story and the events and people in their life, listens for indications to their feelings and emotions, which may be expressed physically through tears or anger, and listens for what they believe and think, especially about themselves.

The eyes. The health worker or support partner pays attention to the person's non-verbal body language. This type of listening is about observing facial expressions, gestures, posture, amount of eye contact and breathing patterns. Body language conveys feelings, but the meaning may be

uncertain: it is necessary to check with the person, rather than assuming what the body language signifies.

Exercise 2. Practice exercise

In this exercise you can practice your communication skills. The objective of the exercise is to be aware of your own behaviour when you talk to someone who is affected by an NTD.

→ See Guide 2 Annex 1: Training exercises and tips for further details.

Domestic violence is a major issue that is often overlooked. It is a manifestation of stigma and severely affects a person's mental wellbeing. Guide 2 Annex 5: Domestic violence provides useful tools for health workers or support partners with regard to domestic violence.

Testimony from a psychologist working with leprosy patients in India

Ms. A. was diagnosed with leprosy during her late childhood. Her parents ignored the initial symptoms and she progressively developed disability in her hands. Her sister also developed leprosy, did not get access to treatment and suffered rapid onset of visible disability.

On the day of their brother's engagement, Ms A.'s sister was asked to stay back from attending the event. Her disability was more visible and the family didn't want the community to know leprosy was within their family. When the family returned home, they found she had committed suicide. After this terrible event Ms A. thought that her family would, from now on, treat her well, but her parents and other siblings continued to discriminate against her. She was asked to move to another family house in the countryside, as they didn't want her to be seen in the house in town. Unable to bear the rejection, Ms A. attempted suicide and was admitted to a leprosy hospital.

At the hospital, Ms A. had several counselling sessions with a psychologist and was encouraged to recognise her potential, her skills and her resilience and to move on with life. She met a man also affected by leprosy who asked her to marry him. Her family protested but Ms A. had the courage to stand up against her family and to go ahead with the marriage. She started life in another town because her family would not allow her in their town. Despite her family being quite affluent, she did not receive any money or property.

Ms A. and her husband went through many struggles, but she showed determination and resilience and wanted to prove herself to the family. Through regular counselling, she processed the trauma she had experienced and was able to see beyond. She became more stable psychologically. She and her husband adopted a boy and they started to be financially stable. Years later, she received a national award for her achievements. She decided to forgive her family and helped them when they went through health crises such as cancer.

Role models and champions

Champions – sometimes called patient advocates, change agents or role models – are people who work on a voluntary basis as advocates for persons affected by NTDs and their families. Often they have personally experienced the NTD. Their main aim is to combat stigma and discrimination and to improve the lives of persons affected. Champions serve as examples by positively influencing others and may provide a vision of whom people aspire to be.

Anyone can be a champion and anyone has the capability to become a role model. Some may be role models without knowing it. Traits of an effective champion often include confidence, communication skills to act as a change agent (raising awareness, fighting for rights, providing information and support), motivation to make a difference in the community and respect for other people. Guide 3 provides more information about (networks of) champions.

Self-advocacy

Effective role models and champions are self-advocates. This means they know about their rights and responsibilities, speak up for their rights and are able to make choices and decisions that affect their lives and may affect that of their peers. Self-advocacy is an important part of empowerment. Sometimes people affected by NTDs spend their lives being told what to do rather than being listened to. Decisions about their lives are made for them by other people. By learning self-advocacy skills, people can learn to assert their rights, take control of their lives and make the best decisions for themselves and their peers. It may mean that they speak out publicly about issues which are important to them and against stigmatising and discriminatory attitudes.

Testimonies from champions who were affected by leprosy (source: survey among members of the Global Leprosy Champions group, 2019)

Woman living in West Scotland, PhD student

'As a person affected by leprosy [living in Scotland, but originally from India], I have experienced stigma and discrimination over the years. I also lived in the constant fear of my family and me being classified as lower in the social hierarchy and thus being excluded from my society. I was deeply saddened by the unprofessional attitude of the doctor who started treating me for leprosy, when he wanted to know from where I got the disease. More so, as there is a myth in my society that leprosy is contracted through promiscuity. [...] Sometime in 2018, several of us who have been affected by leprosy formed ourselves into a group, calling ourselves Global Leprosy Champions. The group members have inspired me to stand for myself and believe in myself. [...] I also realise that the understanding of the disease also determines the kind of responses people affected get. For instance, in the UK, I have not been afraid to talk about leprosy because in my experience, people understand the disease and know that leprosy is curable.'

Man living in Paraguay, pastor

'I came to the realisation that I was very fortunate to have been treated [for leprosy] in time and that I did not experience any discrimination. I felt that I had somewhat of a duty to tell my story because it was so much easier for me than for most people affected that I knew. At one point I was even giving speeches about leprosy, but not from my personal perspective. I then realised that my story added another very valuable dimension. [...] However, when I started sharing my story, there was anxiety involved due to the myths and misconceptions that I believe people have about leprosy. I was afraid that people would reject me and treat me differently. [...] However, my fears were unfounded. I find that sharing is an empowering experience for me. I see that what I share has meaning and value and it encourages me to keep doing it.'

3. Group level interventions

Peer and group support

At diagnosis and during treatment, it is unlikely that the health worker will have the capacity or time to talk through all the potential psychological, social and economic implications of the condition. Nor will the patient be ready to engage with all of these at once. Diagnosis with a health condition is distressing for anyone, and the natural response is to seek support from close family and friends. However, engaging with family members is not always effective or possible. Family members may refuse to have anything to do with the person affected, they may be willing to help but feel overwhelmed by it or they may be unavailable – for example if the patient is a migrant labourer who is far from home.

The social rejection experienced as a result of stigma and discrimination can be devastating. Separation from home, spouse or children and loss of livelihood can leave someone not only alone, uncared for and destitute, but also feeling that they no longer have a purpose. Fear of such rejection by loved ones, and the consequent separation, can lead some people to try and hide their health condition. This makes people feel that they must face it alone, with the additional burden of carrying such a secret and the fear of discovery. Facing such a burden alone can be distressing, and the impact on mental wellbeing can easily lead to destructive behaviour ranging from poor treatment compliance and unexplained irritability with loved ones to self-harm and even attempted suicide.

Even where health or welfare interventions may address some of the immediate needs of a patient, they cannot replace the value of feeling wanted or needed, which typically comes from family or colleagues. In these scenarios, it is vital that people affected by NTDs understand that they are not alone. Newly diagnosed patients, and those who have had the disease for many years but may still be coming to terms with complications from it, will urgently need direct and personal support from others with similar lived experiences, especially if they are feeling rejected and stigmatised by their own family or community. It is vital that they be able to access this support when they need it, where they need it (i.e., without having to travel far to an urban health facility), and for as long as they need it.

Peer support between people affected has a reciprocal effect. The person being helped benefits from the empathy, experience and advice of someone who has faced similar issues and knows what they are now going through. The person helping also benefits, because they now have a new sense of purpose, and the knowledge that other people need their help can be a strong motivator and confidence booster.

Case study: 'Mental Motivators', Bangladesh

In Bangladesh, mental health services are not easily available for rural, poor people. This particularly affects those affected by leprosy and lymphatic filariasis (LF), who are prone to developing anxiety or depression.

The charity Lepira had already set up groups to promote physical self-care and to improve people's economic resilience and access to services. Lepira began to select 'Mental Motivators' from the groups – people who showed interest and good communication skills – and to train them in basic mental health care. The training covered basic counselling skills, the assessment of mental distress, the management of depression and anxiety, reporting and referring. A specific toolkit was developed for the Mental Motivators and they were also equipped with a mobile phone.

Mental Motivators offer counselling to people with a disability induced by leprosy or LF who have indicated they would like someone to talk to. Motivators also proactively look out for group members who seem to be struggling more than others and who might seem withdrawn or unhappy. Counselling takes place either on the phone or face-to-face. People were found to be anxious about their health, families, children's future, their future, social discrimination, their job etc.

Group counselling during the self-care group meetings has also been effective. Members are encouraged to share their feelings and the priority is to listen to them and to provide information on mental health. If a person needs more highly skilled help beyond what the peer-to-peer format can offer, the Mental Motivator refers them to a Lepira or government health worker for professional help.

Awareness meetings in the community are also led by Mental Motivators. They describe the importance of mental health and provide information on how to get support from community members and Mental Motivators.

Self-help and self-care groups

For some NTDs, treatment can be complex and cannot, on its own, guarantee complete protection from physical complications and disability. In these settings, self-care groups are an established approach to providing the training, materials, encouragement and supervision required to ensure that people are practising regular and effective self-care for their impairments. Self-care groups are increasingly being used as a vehicle for other actions too. Examples are:

- Economic: group members participate in savings/credit and livelihood activities (often referred to as self-help groups).
- Advocacy: group members are educated about their rights and how to stand up for them.
- Mental wellbeing: group members are encouraged to listen to each other and provide mutual support through peer counselling.
- Physical: group members learn to properly care for their affected body parts through hands-on activities (only relevant for some NTDs).

It can be effective to integrate self-care groups for a range of stigmatising NTDs. Such integration can boost solidarity and reduce stigma against individual diseases.

Guide 2 Annex 6: Creating an effective self-help or self-care support group provides details on creating an effective self-help or self-care support group.

People's organisations

Where self-care groups or self-help groups are not available or practical, people affected by NTDs may still need advice and support for overcoming stigma. People's Organisations (which may operate at state, national or international level) and disease-specific civil society organisations, typically operating at community or district level, can be valuable, and the two can work well together.

Case study from the Vimukti Leprosy Colony, Kakinada, East Godavari District, Andhra Pradesh

The 100 families residing in the Vimukti Leprosy Colony were facing attempts by a local politician to seize two acres from their colony, which, though once isolated, is now prime suburban land. The colony already had its own civil society organisation, developed in partnership with the NGOs Brighter Futures and The Leprosy Mission, which had been trained by two local lawyers about human rights. Faced with this land-grabbing from the elected representatives who were supposed to serve them, the colony needed more help and called on the state-level Society for Leprosy Affected Persons (SLAP), who brought leaders and other members to their aid. SLAP and civil society organisation members protested on the streets and blocked the vehicles of the Legislative Assembly, which attracted local media attention. SLAP leaders spoke forcefully on local television news and the lawyers helped to submit a case to the Human Rights Commission in Hyderabad. The Legislative Assembly backed down and the community retained their land.

Many individuals within the colony reported pride and greater self-confidence as a result of this experience. They know their rights and they know that others will help them fight for them when needed. One lady in another leprosy colony in Raebareilly in Uttar Pradesh, who had been blinded by leprosy, reported that she had not left her house for two years, but her neighbours had been attending civil society organisation meetings and they helped her to go too. For her, the very fact of being helped to attend a meeting and sit in a room with others discussing their needs was of much greater significance than the official goals of that meeting. When people affected by NTDs are mobilised to work together for specific tangible goals, numerous other benefits spring from the mutual support such activities involve.

Online support and social media

People in areas that have few people with the disease and/or that are very remote may struggle to meet in person with other people affected by NTDs, or to join them in self-care, self-help or advocacy-related groups or activities. For some people, the stigma perceived or experienced is so strong that they fear being seen or associated with other people affected by NTDs. However, with the ever-growing penetration of mobile phones, smartphones and affordable data packages, it is increasingly possible for people affected by NTDs to communicate with, and support each other, remotely using chat groups such as WhatsApp for mutual support.

4. Family-level interventions

Household members

Many people affected by NTDs receive love, care and support from family members (if not always the whole family). In such cases, the person does not feel rejected and therefore is less likely to develop serious mental health problems and physical complications. Some families are familiar with the disease and its consequences, but other families may find this a completely new and unknown experience and may themselves be shocked or scared. Those family members will need support and advice themselves.

Family psychosocial support

Family psychosocial support is a specific type of group support that focuses on the relationships within a household unit. The attitude of the family plays an important role in reducing or increasing the stigma and the distress the person may experience and in helping the person to come to terms with the health condition. It has been observed that people who have family support cope better with mental distress than those who do not.

The decision about whether to have family psychosocial support rests with the individual affected. Some people do not wish to disclose to family members that they have a health condition. However, if they agree to this disclosure, this kind of psychosocial support can be beneficial because family members themselves may also experience stigma because of the NTD. Also, as caregivers, they may have various psychological needs. It may sometimes be necessary to provide couple-oriented psychosocial support and/or to include children in the psychosocial support sessions.

Case study from TLM Champa Hospital, India

During the last decade, the hospital policy has been to admit leprosy patients together with a family member. Family members are those who take care of the patients at home. They can understand the processes used at the hospital and support the patients in dealing with all the administrative tasks. They also support patients in self-care activities, especially for simple ulcers in the hand or foot, and they learn about preventive measures against leprosy complications.

The experience during these years has been:

1. People admitted with family members are more cooperative, sleep better at night, talk more with the staff members and interact and share their thoughts with neighbouring patients more freely.
2. Self-care taught to the person affected along with the family member was implemented better at home. Where more severe complications were involved, those with a family member recovered faster, attended hospital appointments on time and were able to get back to work quicker.
3. Where no family member is available, support has often come from other leprosy-affected families, especially those who have overcome many of the challenges of leprosy and are now able to help others.

5. Referral

Deciding if referral is needed

Referral means recommending or directing a person in need of more advanced care to a facility where that care is available.

In order to decide if referral is necessary, it helps to learn more about the problem, family, current situation and related information about the person's life. This can be done by asking the person directly or by asking family members. The goal is to gain enough information to determine if the person should be referred to a specialist. If there is any doubt, it is safest to refer the person, so that the specialist can determine if the person needs treatment. Diagnosing a mental health condition should be done by a mental health professional; the role of general health staff is to recommend an evaluation and to inform the person affected and their family about the need for referral. It is important that the purpose of referral is made clear to the individual who is referred and that there is follow-up after the referral.

In many countries, access to specialised mental health care is poor and referring will not be an option for the general health staff. Some basic instructions for helping people cope with mental health problems can be found in chapter 2.

How to refer someone

The health worker needs a list of referral sources. The table below can help determine whether to refer and who to refer to.

Specialist to refer to	Suspected issue
Mental Health professional	<ul style="list-style-type: none"> Severe depression (there are tools available for screening - see Guide 4) Addiction, e.g., substance abuse
Physician	<ul style="list-style-type: none"> (Additional) health conditions
Social worker	<ul style="list-style-type: none"> Employment and career-related problems Government support, e.g., pension or disability support
Legal professional	<ul style="list-style-type: none"> Legal issues, e.g., exploitation of employer, domestic violence
Police	<ul style="list-style-type: none"> Abuse Domestic violence
NGO	<ul style="list-style-type: none"> Specific issues such as educational scholarships

Table 1. Referral

An important decision when deciding to refer a person is whether or not this is an urgent problem that needs quick attention because something bad can or did happen. This is called an emergency referral. Some of the times to make an emergency referral are when the person:

- Has had a very long convulsion or seizure (longer than 5 minutes).
- Has tried or threatened to kill him/herself.
- Has plans to hurt others or him/herself.
- Is experiencing domestic violence or physical, sexual or emotional abuse.
- Suffers from severe depression, delusions or panic attacks.

Follow-up

Referring someone does not guarantee that the person or their family will go to get an evaluation or more advanced care. It is important to check after a few days. If a person has not sought care yet:

- They may need additional information or explanation of how to go for an evaluation.
- They may be afraid of what will happen if they go. People may be afraid of being stigmatised if they seek care. People may also be afraid that going to get care means that they will be forced to get an injection or be locked up in a 'crazy home'. More education and reassurance about the process can address misconceptions and fears.

Exercise 3. Connecting cases to interventions

In this exercise you can practice deciding what intervention is the most appropriate in a given context. Several case studies are given and you have to decide what would be the most appropriate intervention. Critical thinking is crucial!

➔ See Guide 2 Annex 1: Training exercises and tips for further details.

Exercise 4. Critical thinking exercise

In this exercise you will be able to practice critical thinking, which is a crucial skill for a ‘helper’. The trainer will show you several statements about this Guide and you are asked if you agree or disagree with them.

➔ See Guide 2 Annex 1: Training exercises and tips for further details.

6. Further reading

- WHO’s Psychological first aid: Guide for field workers (PFA)
- WHO’s brief eLearning module on counselling in the leprosy context
- WHO’s package of training and guidance materials to promote rights and recovery...
- WHO’s Mental Health Gap Action Programme (mhGAP)
- The London School of Tropical Medicine and Hygiene’s Healthy Activity Programme...
- Mental Health Innovation Network’s (MHIN) Mental Health Resources

Additional guides in this series

This is guide 2 of the ILEP/NNN guides on stigma and mental wellbeing. Other guides in this series are available via stigmaguides.org

Guide 1. What are health-related stigma and mental wellbeing?

Guide 2. How to reduce the impact of stigma

Guide 3. How to reduce sources of stigma

Guide 4. How to assess health-related stigma and mental wellbeing

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Guide 2. Annex 1 – Training Exercises for guide 2

We do this to encourage you to use learner-centred approaches instead of lectures. Learning, especially on a topic like changing attitudes (on stigma), does not happen by lectures but demands a personal learning process. Most exercises therefore stimulate active participation and relating the material to the participants' own context.

This Guide is not a training course or programme. You can use the exercises which suit you, adjust them to your situation or let them inspire you.

At the start of each Guide you will find the most basic learning goals of the theme. You can adjust them to the specifics of your participants, add, remove or adjust.

There are no specific instructions for materials, as the contexts of users of this Guide differ. Make sure you have thought about:

- **Something on which you can write or draw big enough for the group to read** (digital) whiteboard, flipchart and felt pens, blackboard and chalk or even the wooden/concrete floor and chalk or sand and a stick).
- **Papers for the participants to write on** (Post-it notes, small paper and tape).
- **Something to allow the group to choose sides** (red and green papers to vote, tape or a rope to divide the room).

Learning objectives

After working through this Guide, you should understand:

- That there are various ways to reduce the impact of discrimination and prejudice on individuals. These can target different 'levels': individual, group and family.
- How psychosocial support can help a person to cope with mental health problems or any other hardship or challenges they might experience at a given time.
- The comprehensive guides that are available for giving psychosocial support.
- How to determine what type of support group (self-help, self-care and online) is most appropriate for a given situation.
- The different family-level interventions available.
- The role family plays in reducing or increasing the stigma and the distress individuals may experience.
- What referral is and when it is necessary to refer someone.

Exercise 1: Warming-up exercise

Participants come up with interventions to reduce the impact of stigma by putting themselves in the place of a stigmatised person. The objective of this exercise is to get into the topic and activate participants to think about it.

Steps

1. Draw a person in the middle of a flipchart or on the blackboard. Invent a name that suits your context. S/he has been diagnosed with an NTD 3 years ago and suffers from stigmatisation and discrimination because of the disease: lost job, and lost confidence because of the way people look at him/her.
2. Ask the group to add some phrases to the story: Imagine you are this person. How does it look like to have a life that is influenced by stigma because you have an NTD? What do you experience? How do you feel?
3. Write the key words around the person on the flipchart.
4. Ask the group what they think the person needs to deal with this situation. (Please note: we are talking about dealing with the stigma, not with the disease.)

4 Optional: You ask the group to step into your place as trainer: Please, advise me, I have 2 ways to ask you the question:*

What do you think the person needs to deal with this situation?

Or

What help does the person need?

What is the difference between the 2 questions? Have a short discussion on how 'helping' can add to feelings of being helpless and incompetent and that therefore the first question form might be better.

5. Let the group briefly discuss among themselves, perhaps in pairs and then in groups of 4.
6. Ask for ideas and write the down on the flipchart. Be open to all answers – the exercise is NOT to test knowledge but a warming-up exercise to get participants' minds set on the theme.
7. When you have plenty of words on the board/flip, explain to the group there are different types of interventions, all of which are described in the Guide. They focus on the individual person affected by the NTD, on groups of persons affected and on families and the community.

Exercise 2: Practice exercise

In this exercise the group can start exercising with skills they would like to practice. The objective of the exercise is to be aware of our own behaviours in discussion with patients and to practice in a safe context.

Note: This exercise takes place after you have explained what the ‘golden hour’ means.

1. Starting question: What are crucial skills from a health worker in the first discussion after a patient has been diagnosed (the golden hour) to reduce the chance of being stigmatised?
2. List them all on the flip/blackboard (e.g., not stigmatising as a professional, discussing disclosure, showing empathy without pity, making sure you plan a follow-up, assessing if the patient can still absorb information, etc.).
3. Ask the group to nominate 3 or 4 skills that they find crucial. You can allow every participant 2 votes or to have the groups discuss which they find most important. You can also choose them yourself.
4. Invite the group to do a simulation exercise. There is a health worker having a conversation with a patient, Mariana (or any other name). Mariana can be played by you or by participants, but be sure in the play Mariana reacts to the ‘health worker’ as realistically as possible.
5. Ask a learner to volunteer as the health worker. Give him/her the following instructions:
 - a. You are a health worker. You have just explained to Mariana that the test shows that she has a potentially stigmatising NTD. Show how the discussion continues.
 - b. You can stop the simulation and start again. It is OK to start again.
 - c. Here you can practice; it does not matter if it does not go well. It is not about an excellent performance; it is about trying out an approach in a safe manner (without a real patient).
6. After the exercise, ask the person who did the roleplay, ‘Looking at the skills we are practising, what went well, and what can be done better?’
7. Ask the group to give one piece of advice and one compliment. Make sure they reflect the skills you are practising and not acting skills or anything else.

Exercise 3: Connecting cases to interventions

In this exercise you have participants actively use what they have learned in Guide 2. The objective is to encourage critical thinking in deciding what intervention should fit best in a certain exercise.

Note: This exercise takes place after you have gone through the Guide.

Preparation

Make cards with the following cases. You need as many as you will have groups in the exercise. If needed, you can adjust the stories to your own context. NOTE: If you rewrite them, make sure you cover a variety of interventions.

Annamma, a woman patient, comes to your clinic. She suffers from lymphatic filariasis and has difficulties doing household chores such as cooking. Her mother-in-law is making her life very hard and she suffers a lot from it. Her husband was okay with her in the beginning but now seems to become harsher on her as well. She has bruises.

Moussa is an 18-year-old boy with disfigured hands because of leprosy. His family and school have always been very supportive to him. He feels confident. He is very bright and has gotten a scholarship to study in a nearby town. You meet him in your clinic, and you notice he is very afraid of the reactions he will receive in his new school.

Ebra lives in a middle-sized town. He used to be a taxi driver, but due to his disease he has disfigurements in his face. Customers do not come to his taxi anymore. Besides his family he has lost a lot of friends. He is losing income and feels very depressed. When he meets you, he talks about a person who killed himself last week. He says that in earlier days he would not have understood such an action, but nowadays he understands much better... He can't see how he is of use to anyone anymore.

Steps

1. Divide the group into smaller groups.
2. Ask the group to discuss the 3 cases and decide for each case what interventions they would think are best placed here and why.
3. Have a group discussion per case.

Exercise 4: Critical thinking exercise

In this exercise the group are encouraged to connect their own ideas and beliefs to what they have learned. The objective is to enlarge critical thinking in the health work. As a trainer, you need to create an open and safe space. Allow participants to express their own thoughts. Changing attitudes happens when people get inspired by other answers or after time; you cannot force it.






Preparation

Draw a line on the floor. Put a sign with 'AGREE' on one side of the line and a sign with 'DISAGREE' on the other side.

Steps

1. Project or write the first sentence for the group.
2. Ask participants to choose a side and wait till all have chosen.
3. Ask some people to explain their choice using concepts learned from Guide 2.
4. Allow participants to move from one side to the other if they change their opinion in the course of the exercise.
5. Repeat with the other sentences.

The sentences:

-  Not everyone can become a champion. For a 'champion' you need a certain type of person.
-  It is easy to minimise the stigma coming from the family. They love the person affected so they will be soft on him/her.
-  Domestic violence has nothing to do with stigma or having an NTD.
-  Some persons are not hurt so much by discrimination; they are the strong types.
-  Self-help groups are more for talking. They cannot achieve real changes.

Guide 2. Annex 2 – Crucial points to consider during the ‘golden hour’

The golden hour is crucial in the course of the treatment as a key moment to promote adherence to treatment, promote contact examination, and prevent mental health problems. Three points need to be considered during the ‘golden hour’

1. Communicating information about the diagnosis, treatment and evolution

The ability to communicate a diagnosis with sensitivity and clarity can be practised using tools such as the WHO’s Psychological First Aid guide, described in Annex 4. It is important to listen to the patient’s distress and address his/her questions with empathy and warmth as appropriate to the cultural setting.

Some topics must be addressed immediately: transmissibility, progress of symptoms and the treatment regimen. Starting the treatment right away instead of a few days or months later is extremely important to alleviate the fears in the mind of the patient. It is very important to keep an open door of communication for the patient and family member to come back as needed, but you should make every effort to provide all the key information at the golden hour because there might not be a second chance to do it.

When you explain the diagnosis to the person, keep the following in mind:

- Take the time the person needs. Do not rush this stage.
- Find out what the person already knows and suspects.
- Assess the gap between the person’s knowledge and reality.
- Provide just the necessary information.
- Allow the person to absorb the information.
- Encourage the person to express their feelings.
- Clarify doubts, misconceptions and fears.
- Briefly state the treatment plan in simple language, using use analogies from the patient’s daily life that they can relate to.
- Assure the person that you are available for further clarification.

2. Disclosure



The person affected must be given freedom to decide if they want to disclose their condition to others. Their decision must be respected. To come to this decision, they should be encouraged to talk about their fears of disclosure. When the person is ready to disclose their condition, the health care provider should offer help and assurance to talk to family members. The health care provider should ask the person affected if they prefer to be alone or with a family member when the diagnosis is discussed. Sometimes in-laws may force themselves to be present in the room, it can help to tell them that it is policy to talk to the affected person alone.

Useful questions to ask include: • Have you talked about your disease to anyone?

- Would you like any of your family or friends to know about your disease?
- If so, to whom do you want to disclose it?
- Would you want me to talk to them about it in your presence?
- What and how much would you want me to disclose?
- If you do not wish to disclose, do you want to discuss any issues related to keeping it secret?

An important part of disclosure is privacy. It is important to avoid unnecessary and involuntary disclosure. This can be done, for example, by ensuring that the service facilities to treat the patient are free of specific indication of the diagnosis (for example, more general labels such as 'tropical diseases' or 'dermatology' may be less stigmatising). Do not conduct home visits without the patient's prior informed consent. The connection to the disease name should be carefully thought out in order to avoid involuntary disclosure or linkage of the disease to the patient and the family.

In NTD programmes, house-to-house surveys are often conducted, in which health workers go to the neighbours of newly diagnosed patients and screen as many people as possible. This needs to be done in a manner that ensures confidentiality. Some health staff are known to the community as working with particular stigmatising diseases, so they must be careful before visiting any patient's house.

3. Communication with household members

Even if the individual allows you to disclose to those who are living in the same household, you should be cautious in what to tell family members. For example, in some situations if the individual fears that someone may react negatively it may be better to talk about the disease in more general terms and not mention its name, at least in the initial stages.

As caregivers to the patient, household members may also need psychological support once the disease is disclosed. It is essential to see household members and to help them to come to terms with the person's condition and hear their fears, doubts and reactions. Encourage household members to help the individual cope and to help with compliance and self-care issues.

Case study on the importance of nonverbal communication

'I was treated for leprosy 15 years ago but in the past six years I have noticed a loss of sensation on my left foot and pain on my right elbow similar to what I had before. I also have a minor loss of strength in my right hand. Despite having seen specialists twice during the period, none believed I had leprosy again until I saw the third specialist. She looked at my history and looked up the protocol for leprosy treatment. She concluded that I was not properly treated the first time (I was treated as a paucibacillary type of leprosy instead of multibacillary leprosy) and gave me her opinion right there, in front of the nurse. 'I was shocked but totally convinced by her reasoning, which she explained thoroughly, patiently answering my questions. As I expressed my fears of transmitting the disease to my family, colleagues and friends because there was no medication available, the nurse reached out to the window handle to open it wide. I realised she wanted to get some air into the room because of me being there. Leaving the room after discussing how to go about getting the medication, the physician reached out her hand to greet me goodbye and kissed my cheek (a common greeting gesture among females in Brazil). I was surprised by her gesture, which contradicted the nurse's previous one. Immediately I bonded to the physician and consequently to the service.' (A woman affected by leprosy, Brazil).

Guide 2. Annex 3 – Flowchart: from ‘time zero’ to intervention

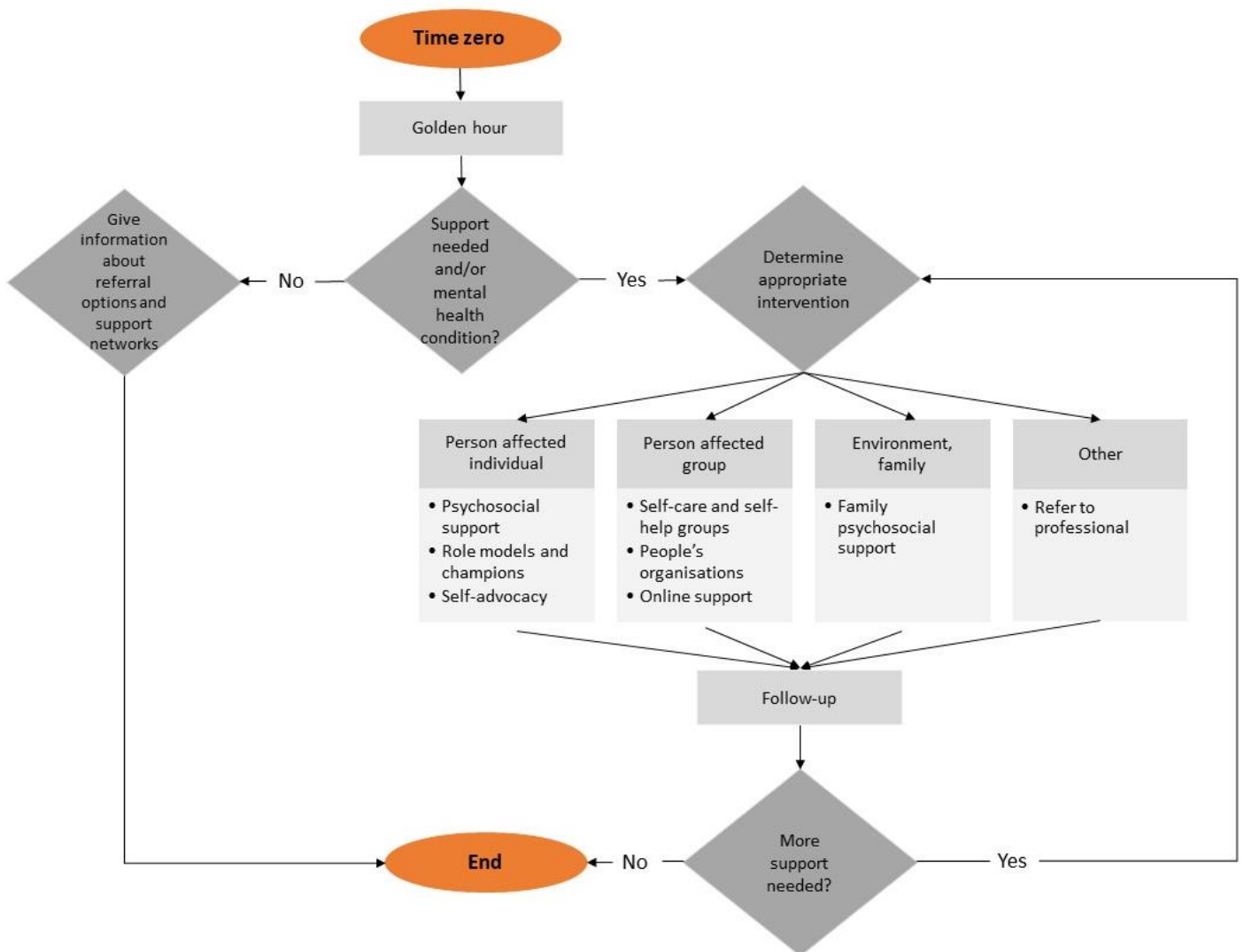


Figure 1: Flowchart, from ‘time zero’ to intervention.

Guide 2. Annex 4 – Resources for psychosocial support

Psychosocial support, often referred to as counselling, psychological first aid or psychological help, is a helping relationship that involves a support partner working with a person to address the feelings (emotions), thoughts and beliefs, behaviours and relationships that are associated with the diagnosis and with the ongoing process of living with an NTD. The person is supported to understand and express their own thoughts and feelings about living with the condition, and to become empowered to deal with the issues that arise from their condition, leading to a better quality of life within family and community.

Whilst psychosocial support focuses on the individual, it can be beneficial to also work with the household and community when addressing the issues.

Several comprehensive guides are available for giving psychosocial support. Many are available online, and in several languages, free of charge. One of these guides is the '**Psychological first aid: Guide for field workers**' developed by the World Health Organization. This guide covers humane, supportive and practical social and psychological support to individuals who suffer or have suffered from crisis events. It provides a framework for supporting people in ways that respect their dignity, culture and abilities. Psychological first aid (PFA) has been adapted for use in the Ebola outbreak. In 2020, a COR-NTD-supported project in India will develop a PFA version for use in NTDs called 'PFA-N'.

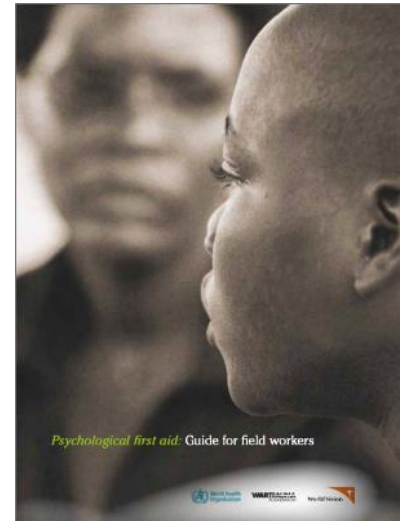


Photo credit: [WHO](#)

Information about counselling for leprosy (understanding counselling and best practices) can be found in the **WHO's brief eLearning module on counselling in the leprosy context**. The eLearning module is based on the WHO Guidelines for diagnosis, treatment and prevention of leprosy, but can also be used as background information for other stigmatised health conditions.



Photo credit: [WHO](#)

In case assistance is needed with mental, neurological and substance use disorders, the **WHO Mental Health Gap Action Programme (mhGAP)** has useful training manuals that support non-specialised health care providers to carry out tasks previously reserved for mental health specialists, who may not be available in many settings.

In case of depression, the **Healthy Activity Program (HAP)**, developed by the London School of Tropical Medicine and Hygiene, can be used as a practical guide. HAP provides health professionals with information about counselling patients with moderate-to-severe depression in primary care settings.

Sometimes psychosocial support, mhGAP or HAP may not be enough. The best way to help someone may be to refer them to a person who is licensed and trained to help people (e.g. a counsellor or psychologist). Information about referral is in chapter 5 of Guide 2.

Support needed	Appropriate resource	URL
Social and psychological support to individuals	Psychological first aid: Guide for field workers (PFA)	PFA guide
	WHO package of training and guidance materials to promote rights and recovery for people with psychosocial, intellectual or cognitive disabilities	Quality Rights tools
Assistance with mental, neurological and substance use disorders	Mental Health Gap Action Programme (mhGAP)	General information and training manual
Treatment of depression, support to Primary Health Care Centres	Healthy Activity Program (HAP)	Health Activity Program Manual
Urgent referral needed (e.g., risk of suicide or if the abovementioned guides are not sufficient)	Referral to professional counselling services	See chapter 5 of Guide 2

Guide 2. Annex 5 – Domestic violence

A major issue that may be overlooked in NTDs is domestic violence. Domestic violence severely affects a person's mental wellbeing and can be a barrier and disruption in treatment compliance and self-care. It can be from spouses but can also be from children and in-laws. Despite the link between domestic violence and mental ill health, mental health professionals don't always recognise the issue of abuse and may therefore be unaware of it. In addition, some people who experience domestic violence don't expect to be believed and may hide it.



It is important for health workers to be aware of the possibility of domestic violence. They need to be aware that people will often tell their experience of violence only when they are asked. Some may not even realise they are in an abusive situation, as in a cultural setting it may be 'normal'. It is important to be gentle when asking about abuse. Avoid direct questions such as 'Have you been abused by your spouse or anyone?'; instead, ask behaviour-specific questions, such as:

- Have you been injured in a conflict at home?
- Does anyone shout at you?
- What hinders you from coming to the hospital?

Violence and abuse can be physical, verbal, emotional and sexual, and all these types of abuse have a damaging effect on mental wellbeing. It is important to acknowledge and to help the person affected air the following feelings:

- Feelings of shame or embarrassment about these experiences.
- Self-blame and guilt, thinking they are responsible for the abuse.
- Fear of recurrent abuse.
- Fear of being judged and hesitation to ask for help.

The following can be done to help people who experience or have experienced violence or abuse:

- Encourage them to find friends with whom they can share their experiences.
- Ask them to include 'supporters' (e.g., children, siblings, parents) in psychosocial support.
- Ask them to invite the victimisers for counselling if they are willing.
- Train them on assertiveness skills.

In the case of abuse, tap on their resources which have helped them to cope and face the abuse. These resources can also be used to help them face stigma

Guide 2. Annex 6 – Creating an effective self-help or self-care support group

In a self-help or self-care group, ideally, the leader of the group should be a trained person who acts as a facilitator. A group may be as few as two people and may be composed of family, friends, stigma-affected individuals or members of the community. It can be helpful is to get homogeneous groups, for example of only spouses/partners, women or men, as in some culture women do not open up if it is a heterogeneous group.



Photo credit: The Leprosy Mission Trust India

The group needs to agree to abide by ground rules

1. Everything said in the group stays with the group, and only if there is potential harm to an individual (such as thoughts of suicide) should the confidentiality be breached.
2. The focus is on exploring their feelings and experiences of stigma, and ways of coping.
3. All members have an opportunity to share.
4. A person who does not want to speak should be respected and may be encouraged but not forced to speak.
5. Time is given to each member, but members should not interrupt or talk so much that time is taken from other members.
6. Any tendency in a group member to dominate, put down or control should be checked in a gentle way.
7. Everyone has a voice in the solution and should have the opportunity to express their thoughts and discuss feasibility and options in a non-threatening manner.



Photo Credit: Lepira, Bangladesh

The functions of the group leader

- Communicate with and listen to each member, direct and mediate the communication process and give background information when appropriate.
- Provide resources and referrals to community services or support networks.
 - Explain the ground rules.
 - Explain the reason and purpose of the group.
- Make sure that respect and time are given to each member – whoever dominates or takes up too much time should be gently dissuaded from continuing, or the counsellor should introduce a subject change, and should gently encourage reluctant or quieter individuals to participate. The leader should also be cautious not to talk too much him/herself.
- Help the group focus on exploring their feelings and experiences of stigma and ways of coping.
- Offer options and not solutions; give the group suggestions for solving issues.