



Guidelines to reduce stigma

Guide 4



Counselling to reduce stigma

2011

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Introduction

This Guide is part of a series of four Guides to reduce stigma. The Guides are for all managers, health and social workers and service staff who have to deal with stigma in leprosy and other health conditions. These Guides provide evidence-based and best-practice information from different disciplines, and recommendations for field workers on how to reduce stigma against and among affected persons and in the community.

This fourth Guide explains the use of counselling at a basic level in dealing with stigma. It provides an explanation of different techniques and approaches for counselling persons affected by stigma. The first Guide provides basic information on stigma, its causes, manifestations, and effects. The second Guide describes when and how to assess stigma using qualitative and quantitative methods and instruments. It also explains how to use the instruments. The third Guide provides recommendations on how to develop an approach for reducing stigma. Through the use of a roadmap, several steps are discussed for reducing stigma related to a particular health condition.

For supporting documents: www.infolep.org/stigma-guides

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

A statement from a leprosy affected person, showing the need for counselling

Abbreviations used:

CBR Community-Based Rehabilitation
CBT Cognitive-Behavioural Therapy

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1. Introduction to counselling

Counselling helps an individual cope with health-related stigma as described in the first Guide of this series. Stigma is a negative response to human differences. It has many faces. Stigma may manifest as self or internalised stigma, as negative attitudes and prejudice in society or as actual discrimination. Counselling is an intervention to understand and acknowledge and help with emotions, thoughts, and behaviour that arise for individuals or families who experience stigma when living with the health condition. The aim is to reduce stigma and improve the quality of life of those affected.

This booklet provides a basic introduction to counselling. It is intended for 'lay counsellors'. These are people who do not have a professional or clinical qualification in counselling but are working with people who are affected by stigma. They may be health workers, field workers, grass-roots workers, health educators or social workers. They may also be people offering peer counselling and support who themselves have personal experience of health-related stigma and have come to terms with the challenges it brings.

The need for counselling

Counselling helps an individual to cope with the stigma arising from a disease or disability. The counsellor supports the person to understand and express their own thoughts and feelings about living with the condition, so that the individual is empowered to deal with the issues that arise from stigma, leading to a better quality of life, within the family and community.

What is the impact of stigma?

Each person experiences the impact of a health condition, and any associated stigma, differently. However, experience and observation show some common ways in which stigma impacts on the lives of people.

Impact on emotions

Feelings such as fear, grief, depression, shame, guilt, anxiety, low self-esteem, hopelessness and anger, or inability to express such feelings

Impact on thoughts

Negative and pessimistic thoughts and beliefs about self, the world and the future. For example, 'I am a nobody'. These feelings lead to changes in behaviour such as avoidance, self-isolation and forced isolation and restricted social participation.

Impact on behaviour

Changes in emotions and thoughts can lead to changes in the individual's behaviour, such lack confidence, avoidance and self-isolation. These can keep a person from seeking help, which in turn can delay diagnosis and treatment and result in increased risk of disability.

Impact on relationships

Rejection, forced isolation and restricted social participation come into this category. These can be the result of social discrimination as well as defensive behaviours. These can, in turn, result in further problems such as unemployment.

The way a person responds to a stigmatising disease or condition, depends on the following factors:

- Society's negative or positive perception or understanding of the disease
- Support of family and community
- Visibility of the disease
- The extent to which it affects daily routine and life
- Personality and coping ability of the person

At the point when a person faces stigma they are likely to be vulnerable and needing acceptance, encouragement and emotional support. In a busy medical setting, individuals find it difficult to express their concerns. They wish that they could talk to someone who will understand. In view of the scarcity of mental health professionals, lay counsellors may be a good option to provide basic

support to individuals. In addition, people experiencing stigma may feel freer to approach a lay counsellor rather than a professional. Lay counsellors, being closer to the community, may also be more easily accessible to people who need counselling services.

The counselling relationship

Counselling is a helping relationship that involves working with the person to address the feelings (emotions), thoughts and beliefs, behaviours and relationships that are associated with the diagnosis and with the on-going process of living with a stigmatising condition. Whilst counselling focuses on the individual, it can sometimes be beneficial to work also with the family and community when addressing issues of stigma. Their support can be enlisted and their issues and questions addressed also.

The outcome of the counselling relationship

The counselling relationship and process should help the individual towards:

- Improved understanding of themselves – including challenges and potentials
- Improved acceptance of self and situation
- 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
- New decisions, new ways of coping and positive action plans
- Motivation to resume meaningful participation in the family and community

Issues for which the individual might require counselling help

- Acceptance of diagnosis of a disease and its consequences
- Coping with stigma from others and from within
- Difficulties in disclosing disease to others
- Overwhelming or uncontrollable feelings that affect normal living
- Beliefs and fears about the disease
- Changes in appearance and body due to the disease
- Adjustments to changes in life style and status due to stigma
- Adjustments to changes in family, marriage and social relationships



2. What it takes to be an effective counsellor

Being an effective counsellor is a combination of attitudes and personal qualities, skills, and knowledge of the health condition, the cultural / social context, and good ethics. The counsellor also requires support and continuing training and personal development.

Attitudes and personal qualities

An effective counsellor should have or develop the following qualities:

Empathy

This is an awareness of and understanding of the emotions and feelings of the other person. This is to try to imagine how we would feel if we were in the situation of the individual. It is distinctly different from sympathy. Effective empathy will help reassure the individual that the counsellor is sensitive and responsive to their thoughts and feelings. Empathy can be conveyed through warmth and understanding responses.

Non-judgemental attitude - unconditional acceptance and support

This means relating to each individual without any pre-conceived ideas of stigma or negative associations based on the counsellor's values and standards. Criticising, blaming or labelling should be avoided (e.g., 'alcoholic', 'drug addict', 'leprosy patient', 'HIV patient'), as should arguments, scolding, threatening or getting angry with the individual. The counsellor should be willing to accept and listen to the individual with an open mind and without expressing their personal point of view, even if the counsellor's ideas are different from those of the individual.

Respect

This means valuing the person as an equal human being, and respecting their unique experience with their own beliefs and worldview.

An intent to empower

This means supporting the individual to develop their potential and their capacity to handle their own issues and to achieve quality of life. A good counsellor does not direct or control the individual or solve their issues for them but helps them to grow to a position where they can do this themselves. It means ensuring that the individual does not become dependent on the counsellor.

Self-awareness

Be aware of your own limitations as a counsellor. You must know your own strengths and weaknesses and the way you handle your own problems. A good understanding of yourself will help you to understand others better.

Skills needed by an effective counsellor

Communication skills are the main tool in counselling. Communication in a counselling relationship plays a major role in moving the counselling process in the right direction. Effective counselling takes place only when the counsellor learns good communication skills.

Listening and observing

More than any other skill, good listening initiates positive change for the individual. Therefore it is the most important skill for a good counsellor, and it needs to be practised.

The skills of a good listener include:

- Give the person your undivided attention and availability.
- Be genuine and sincere in listening. Never pretend to listen.
- Listen to the feelings underlying the words of the individual. Focus on feelings rather than the problem.
- Look actively for non-verbal cues such as body language, facial expression, tone of voice etc. Sometimes these may be in contrast to the actual words said

and so need further exploration.

- Do not interrupt or try to complete the sentences for the individual. Do not assume what the individual is going to say.
- Avoid all personal biases and prejudices while listening.
- Avoid interruption while listening. Ground rules should be set to avoid distractions and disruptions to the counselling session.
- Do not be inquisitive or ask unnecessary questions while listening.
- Do not force the individual to talk when they are silent. Try to understand the silence.

Verbal and non-verbal communication skills

Communication takes place at two levels: verbal (with words) and non-verbal (without words). As a counsellor you need the skills to respond effectively to what you hear and observe about the individual. You may use verbal and non-verbal communication that will stimulate the individual to continue talking. Be sensitive to cultural expectations especially with regard to non-verbal communication.

Non-verbal communication skills

- **Posture and physical position**

Sit in a way that both the counsellor and the individual feel equal and make sure both are not too close or too far apart. The counsellor should be calm and not fidgety or restless. The counsellor may lean forward to convey interest.

- **Gestures including facial expressions**

Facial gestures should be appropriate. The counsellor may smile or nod appropriately to encourage further expression of problems.

- **Voice**

Be aware of the volume and tone of your voice as they can also convey happiness, sorrow, anger, and lack of interest, disappointment and other emotions. It does convey your attitude towards the individual.

- **Eye contact**

Eye contact means looking at the person's eyes while talking and not looking elsewhere. However, be aware of the individual's culture, and if NOT deemed disrespectful or threatening, maintain eye contact. This also conveys your attitude of respect and genuine interest in the individual's story. Note if the person has a tendency to avoid eye contact.

Verbal communication skills

Asking effective questions

Questioning is an important tool that facilitates an effective counselling process. The counsellor should carefully choose questions based on the situation as this will encourage the individual to express themselves freely. Open-ended questions are the most useful in basic counselling. It is important to avoid asking 'why' questions, as they may distress the individual and make them defensive.

There are three types of questions:

- **Open-ended questions:**

These are questions that open up discussions instead of provoking 'yes' or 'no' answers. Open questions encourage individuals to feel comfortable and talk freely, and bring out more detailed information.

Examples:

'How did you get here this morning?' (Instead of 'Did you come by bus?')

'What are your neighbours like?' (Instead of 'Are your neighbours good?')

- **Closed questions:**

These types of questions are sometimes necessary to get specific information. However, the counsellor should avoid repeated use of closed questions as it may make the individual irritable or uncomfortable.

Example:

'What is the issue that upsets you most?'

- **Indirect questions:**

Occasionally the counsellor may need to use indirect questions if the direct question may offend or hurt the individual. These types of questions try to get information without appearing to do so.

Example:

'Do people with this disease generally get the support of family?'

(Instead of directly asking if the individual's family is supportive)

Other verbal skills

- **Paraphrasing / repeating:**

The counsellor repeats in their own words what the individual said, to let the individual know that they have been heard. Paraphrasing helps to clarify issues.

Example:

'You are saying that you cannot believe that you caught leprosy.'

- **Reflection:**

The counsellor focuses on feelings, listens to the individual's description of the problem and reflects them back to the individual. This helps the individual to accurately identify and name the feelings they are expressing. It enables the counsellor to understand the individual's emotional state.

Examples:

'You seem to be worried about your inability to work as before.'

'You feel angry that your relatives are not visiting you these days.'

- **Summarising:**

After listening to and reflecting on the individual's feelings, the counsellor summarises in their own words the problem of the individual. This helps the individual to have a better understanding of the problem and also to know that the counsellor is interested in helping.



- **Silence:**

This may help the individual to relax, or to reflect and process information already discussed. Sometimes silence is needed if the individual is crying or expressing strong emotions: they may need the counsellor to just sit with them, showing that it is alright to have these feelings. You can tell the person that it is fine if they want to cry.

Skills to deal with emotions

An effective counsellor should remember that the individual may:

- Exhibit grief and strong negative feelings
- Be confused and find it difficult to make decisions
- Be distrustful of others and may even express mild hostility
- Look for hope and assurance from the counsellor and not so much a solution.

Handling emotions

In dealing with situations related to stigma and subsequent reactions, the counsellor should anticipate and be prepared to handle overwhelming emotional reactions from the person. These reactions may be intense, sporadic or sometimes even on-going. In managing and helping the person with their emotional reactions, the following steps should be considered.

- The counsellor should acknowledge and be willing to accept the reactions of the person, however strong they may be (for example: *'I can see that you are upset'*).
- **Encourage expression of feelings**
Never stop the person from expressing emotions. If they are crying or 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.**
Ask questions such as *"What makes you feel this way?"* *"What is upsetting you?"*
- Make sure your focus is on the person and not the issue
- Encourage the person to discuss the situation in detail
- Help the person to explore options to manage the situation

Before dealing with emotions that follow a diagnosis of a disease or issues related to stigma of diseases or disabilities, the counsellor should also be familiar with the steps in conveying information about the diagnosis. This will help create a better relationship between the counsellor and the individual as well as better compliance with treatment.

In cases where the counsellor is required to explain the diagnosis or the disease to the individual or if they ask the counsellor about their condition, the following steps should be considered.

- Find out what the individual already knows and suspects
- Assess the gap between the person's knowledge and reality
- Find out how much the person wants to know
- 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
- Assure the person that you are available for further clarification

Counselling ethics and professional support and development

Counselling ethics

Good practice in counselling requires confidentiality. This means it is unethical for the counsellor to reveal any information to anyone (including to health staff) without the individual's consent. The only exceptions are when the law requires disclosure, or when the individual reveals the intent of life-threatening harm to self (suicide) or to someone else. Confidentiality and its limits need to be explained to the individual at the beginning of the first counselling session.

Support and development for counsellors

Discussing others' problems can become an emotional burden to the counsellor. There needs to be emotional support available to enable the counsellor to deal with this emotional burden, and to continue personal learning and development so as to remain safe and effective. Support and development will include:

- 1. Self-reflection and evaluation**
- 2. A supportive peer counsellor network to share potential problems and the emotional burden**
- 3. Supervision with a professionally trained and accredited counsellor**

A supervisor, in this context, means someone from outside your workplace who meets with you from time to time to discuss issues that have arisen for

you in your counselling work (or your personal life) and to help you to deal with these so that you remain safe and effective for the people you work with. The supervisor may also help you evaluate your skills and need for further development.

4. Awareness about the issue of transference in counselling

Transference is a process of passing on, or transferring an emotion or attitude from the person being counselled onto the counsellor. Supervision is important in helping to deal with issues of transference and emotional dependence

Example:

An individual who finds comfort and acceptance from the counsellor may begin to view them as their parent because they never got these positive emotions from their own parent.

5. Refresher programmes to update knowledge and to share experiences and struggles in counselling.

3. The counselling process

In order for counselling to have any measurable effect in stigma reduction the attitudes, skills and knowledge of the counsellor and the on-going development of these are critical. In addition, change will only occur for the individual if the conditions for safety and confidentiality are met. It is also necessary that the counsellor allocate the time necessary for such work if it is expected to make a positive difference to the person affected by stigma issues. The following is a useful summary of the process. This process will take place over more than one appointment depending on the specific circumstances. An appointment should not last more than one hour or be too short to make any progress.

In addition, it is to be expected that change will only occur for the client if the conditions for safety and confidentiality are met. It is also necessary that the counsellor allocate the time necessary for such work if it is expected to make a positive difference for the person affected by stigma issues. The following is a summary of a useful process. This process will occur over more than one appointment depending on the specific circumstances. An appointment should not last more than one hour or be too short to achieve any progress.

Beginning stage

Prepare a safe and private setting

- Do the best you can in the context in which you work with the resources that are available and remember that privacy is important. This means making sure no-one else can overhear your conversation or disturb the counselling session.
- Be sensitive to cultural norms with regards gender issues and privacy

- Minimise any likely distractions, for example by turning off your telephone/mobile and informing other staff that you need uninterrupted time with the individual.

Counselling contact; attend to person and build rapport

- Make the individual feel welcome and at ease; provide comfortable seating levels, etc.
- Build rapport with a warm welcome, smile and attention
- Explain the purpose of counselling, typical timeframes, appointment duration and confidentiality
- Gather any necessary personal information, but this should be kept to a minimum
- Ask the individual if there are any particular concerns they would like to discuss (depends on whether they have been referred or have come voluntarily)

Middle stage

- Ask the individual to tell their story
- Listen and respond to help the person to explore their situation
- With the individual's consent you may take notes of key ideas, but do not allow this to divert you from listening
- Listen and observe for feelings. Encourage individual to identify and safely express these (remain non-judgemental). The individual should feel free and safe to express feelings fully in your presence without you stopping them with quick comfort. Sometimes silence is necessary here
- Listen and observe for thoughts and beliefs

- Listen and observe behavioural and/or relational issues
- Use responding skills to help the individual explore and allow them to determine the direction
- Summarise and reflect to clarify and reach a shared understanding
- Together identify what the person perceives as the initial issue. It may be an overwhelming feeling or a belief, thought, behaviour or relationship
- Together discuss the issue and develop goals to address it. The counsellor needs to help empower the individual and build them up rather than offer expert solutions. Remember the individual is the expert on their own life!
- Together initiate specific actions to help the individual with their issues. This may include support from a wide range of sources, for example family, community groups, learning and practising problem solving/social skills, other medical help, or community-based rehabilitation
- Subsequently these can be reviewed, refined and developed as changes begin to occur for the individual
- The counselling visits become less frequent as the individual increasingly experiences positive change in their situation and builds other supports outside the counselling setting

End stage

When the individual begins to experience the change needed to enable them to cope with or overcome the impact of stigma, the counselling is no longer required. It should be phased out gradually as progress is made. It is important that the individual has been empowered through the counselling experience so that they are more able to live their life with purpose and dignity. Termination may be difficult for the individual, but they must be:

- Congratulated on the efforts taken to change or cope
- Assured that they can return to counselling whenever there is a need.

When to consider referral?

Sometimes it will be necessary for the counsellor to refer the person to another professional (e.g. doctor, psychologist, physiotherapist, social worker, community worker, health educators, etc).

It may be helpful for the counsellor to have basic knowledge of the indicators to recognise a few psychiatric problems. You should refer the individual to the relevant professional immediately if you observe any of these symptoms:

1. Depression – lack of sleep and appetite, decreased energy, suicidal thoughts, overwhelming sadness or episodes of crying
2. Anxiety – fear, agitated state, palpitations, tremors in hands, restlessness
3. If an individual expresses a wish to die or says that they have had ideas of or have attempted suicide, they should be referred immediately to a doctor. The counsellor should also inform the family about an individual's suicidal thoughts.

4. When to use group counselling?

There needs to be a clear reason and purpose for undertaking group counselling. It may be so that peer support can be facilitated – that is, the members share personal stigma-related issues in order to solve mutual problems and support one another. Or it may be a family or community group where relationship dynamics are the focus. Guide 3 provides recommendations on how to develop a group approach for reducing stigma.



Group or family counselling has its own dynamics. However, many skills and exercises used for individual counselling can be used for group situations; hence they will not be repeated in this section. The leader of the group should be a trained person who acts as a facilitator and as a group counsellor.

Why group counselling may be useful

1. Cost-effective and time-effective
2. Individuals will realise that others also face issues similar to theirs
3. Communication skills can be developed and practised
4. Relationship skills can be developed and practised
5. Groups become a support system for each member
6. The facilitator has an added opportunity to see how an individual or group acts in group situations
7. An individual becomes more committed to the goals when others share the responsibility of achieving the goals

Who are the group members?

A group may be as few as two people and may be composed of family, friends, stigma-affected individuals or members of the community. Five to seven is a good size; ten should be the upper limit.

What are the ground rules?

The group needs to agree to abide by the ground rules:

1. Disclosure: everything said in the group stays with the group and only if there is potential harm (such as thoughts of suicide) to an individual 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. The individual 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 too much to be able to give time to other members.

6. Any tendency in a group member to dominate, put down or control, should be checked in a gentle way.
7. Solutions: everyone has a voice in the solution and opportunity should be given to express, discuss feasibility and options in a non-threatening manner.

Group facilitator

The roles of the counsellor as group facilitator are to:

1. 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.
2. Explain the ground rules.
3. Explain the reason and purpose of this group.
4. 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 gently encourage reluctant or quieter individuals to participate
5. Help the group focus on exploring their feelings and experiences of stigma and ways of coping.
6. Offer options and not solutions, gives the group suggestions for solving issues.

Potential issues to anticipate in group counselling

1. Skipping from topic to topic
2. Some participants try to dominate the discussion
3. Some participants may be shy and withdrawn
4. A participant may get angry with the leader
5. Some participants may get angry with one another
6. The leader or participants try to force each other to speak
7. A participant may be resistant, because they have been forced to attend
8. Participants do not like each other
9. Frequent changes in the group membership

5. When to use family counselling

Family counselling is a specific type of group counselling that focuses on the relationships within a family. Family plays an important role in reducing or promoting stigma in the individual. The attitude of the family is very important in helping the individual to come to terms with the disease. It has been observed that individuals with family support cope better with problems due to stigma.

The decision about whether family counselling takes place rests with the individual affected. Some people do not wish to disclose to family members that they have the disease. However, if they agree to this disclosure, family counselling can be beneficial because family members themselves can be affected by leprosy-related stigma. Also, as caregivers, they may have various counselling needs.

Disclosure

The individual must be given freedom to decide if they want to disclose the disease to their spouse or other family members. They should be encouraged to talk about their fears of disclosure, but their decision in this regard must be respected. When the individual is ready to disclose, the counsellor should offer them help and assurance to talk to family members.

Useful questions to ask:

- *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?*

Information about the disease or condition for the family

Even if the individual allows the counsellor to disclose to the family the counsellor should be cautious in what they tell the family member, depending upon the situation of the individual. For example, if the individual fears that their in-laws may react negatively it may be better to tell them that it is a bacterial disease and safer not to mention the name of the disease, at least in the initial stages.

Encouraging the family to support the individual

Once disclosed it is essential for the counsellor to encourage the individual to bring family members whenever possible. Time should be given to see family members and to help them express their feelings. As caregivers they too may need a lot of counselling support.

The counsellor should help family members to come to terms with the individual's condition and also help with their grief reactions. They should be helped to deal with their fears, doubts and misconceptions regarding the individual's condition. Family members should be encouraged to help the individual's coping and also to help with compliance and self-care issues.

Issues relating to couples

The individual may be hesitant to clarify doubts and fears related to marital issues including sexual relationships and the consequent problems. The counsellor should encourage exploration of problems in these areas, either with the individual or, if agreed, with both partners.

Useful questions to ask:

- *Would you like to discuss any issues related to physical contact with your spouse or children?*

- *Would you like to discuss any issues related to sexual relationships?*

Issues related to children

It may be beneficial to have a session with the individual's children to see if there is an impact in their lives due to a parent's disease. For example, if the child becomes a school drop-out due to the (parent's) disease or is rejected by the community. There may also be instances of ridicule and discrimination at school or in the neighbourhood due to associated stigma. The counsellor should encourage exploration of problems in these areas. In some instances it may be appropriate to discuss these with the child and their parents together.

6. Further reading

Please see the website www.infolep.org/stigma-guides for:

- Supporting documents
- Links to websites
- Further background reading
- Persons you can put your questions to
- Practical tools and guides



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