



Guidelines to reduce stigma

Guide 3



A roadmap to stigma reduction:
an empowerment intervention

2011

The Guidelines to reduce stigma are prepared on request of ILEP's Technical Commission and as an output of the Stigma Research Workshop, hosted in October 2010 in Amsterdam. The development of the Guidelines was financially supported by Netherlands Leprosy Relief.

The following people have been the main contributors to this guide on stigma interventions:
Hugh Cross, Miriam Heijnders, Miwako Hosoda, Mimi Lusli and Mike Idah.

These Guidelines to reduce stigma are licensed under a Creative Commons Attribution-Non-Commercial-ShareAlike 3.0 Unported licence. Any part of this work may be copied, distributed, transmitted and adapted, without permission from the authors or publishers, for non-commercial purposes and under similar licence only. The work must be attributed in the manner specified by ILEP. For any reproduction for commercial ends, permission must first be obtained from ILEP. Please send copies of adapted materials to ILEP.

Published by:

The International Federation of Anti-Leprosy Associations (ILEP) and the Netherlands Leprosy Relief (NLR), London / Amsterdam, 2011

Photographs by: Jan Joseph Stok (front page), NLR.

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 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. 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 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.

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

Contents

Introduction	3
Background to the design of a stigma reduction intervention	6
Road map: how to impact on stigma at multiple levels	7
1. Identifying and understanding the problem	8
2. How to plan and implement the project	9
3. How to mobilise appropriate resources	12
4. How to gain sufficient skill to facilitate individual and group empowerment	13
5. Monitoring and evaluating projects	14
6. How to raise community awareness	16
Further reading and practical tools	17

Abbreviations used:

CBO	Community-Based Organisation
CBR	Community-Based Rehabilitation
DPO	Disabled Peoples' Organisation
INGO	International Non-Governmental Organisation
MOU	Memorandum Of Understanding
NGO	Non-Governmental Organisation
PLA	Participatory Learning and Action

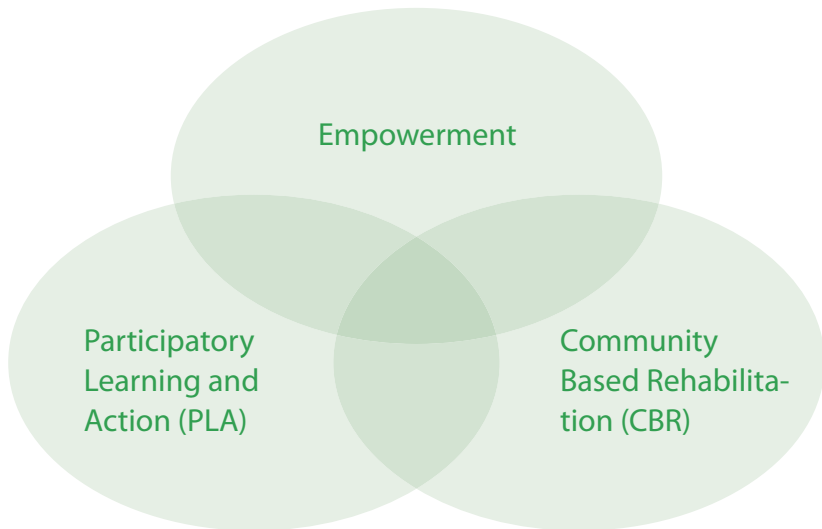
Background to the design of a stigma reduction intervention

In all leprosy programmes we are faced with stigmatising behaviour against people affected by leprosy. In many different places people have tried to implement stigma reduction interventions.

There are many approaches to targeting stigma so that it can be reduced. Researchers have tested a variety of different types of intervention. Guide 1 'What is health-related stigma?' explains stigma and suggests some ways that have been used for stigma reduction. We know, for example, that training health workers and teachers can be effective in helping them to understand what stigma is and how it works. Stigma can also be reduced when people who are stigmatised have opportunities to tell others about their lives and explain how the stigmatising actions of others have affected them (this is called a contact strategy or a contact approach). We still have much to learn about stigma reduction, but what we do know so far is that it is good to combine different approaches and to target people at multiple levels at the same time (for example: the patient, their family and health workers).

This road map leads readers through the steps required to implement an intervention in which people were motivated initially to participate in self-care groups. Successful self-care can lead people to an awareness of their own potential for change and to a desire to see positive changes in their environment. As they become change agents in their communities they lose the negative impression that their communities placed on them. This long term intervention combines multiple approaches to target stigma reduction; it is based on three concepts:

- Increasing self-esteem and self-efficacy; and stimulating positive identities through *Empowerment*,
- Improving social inclusion and social participation through *Community-Based Rehabilitation (CBR)*,
- Encouraging self-confidence and a sense of personal value through *Participatory Learning and Action (PLA)*.



By using this combination of concepts, an effective intervention was implemented which reduced the stigma of leprosy in Nepal – The Stigma Elimination Programme (STEP). STEP brought about a reduction in discrimination and enabled improvements in social participation for people who had been stigmatised by leprosy.

The Stigma Elimination Programme (STEP): transformation from “victims” to change agents

The first process in the STEP project was the selection of ten people disabled by leprosy. They were trained to be group leaders and were asked to set up self-care groups in their villages. People met regularly, practiced self-care together and discussed emotional and practical issues: how to deal with hostile families, what to do about getting water from shared wells, etc.

After a while the groups were encouraged to change their self-care groups into a self-help groups. At that time other people were allowed to become group members too. Together with a facilitator they discussed the needs in their villages and how their villages could develop. They got involved in many activities that benefitted their villages: they started informal literacy classes; they sourced funds to dig wells and to install water pumps; they did village clean-up programmes and began to improve the hygiene in their villages; they began to gain better access to health facilities. Some groups even became agents for leprosy control activities such as defaulter tracing. In this, and other activities, the co-operation and contact between leprosy disabled people, village development officers and others led to communities really valuing the self-help groups.

These actions and their consequences were responsible for affecting attitudes towards (persons affected by) leprosy in the community, between persons and for themselves. The ultimate effect of the combined approaches was that the social participation of people disabled by leprosy was significantly improved. This project in Nepal enabled persons to transform themselves from “victims” into agents of positive change agents.

Who is this road map for?

Project field staff » personnel with direct responsibility for planning, monitoring and evaluating projects.

Facilitators » personnel who will have responsibility for direct interaction with self-care or self-help groups on a routine basis. Their primary responsibilities are to: guide the groups so that they can achieve empowerment, guide the group members in the best self-care options, encourage the groups to commit to savings programmes, assist in finding access to resources, encourage groups to engage in community development activities, assist in advocacy.

Project administrators » personnel with responsibility for controlling budgets and accounting (the project manager or programme director is also in this category).



Empowerment

The main goal of empowerment is to gain an increase in conscious choice (Dignity is maintaining a sense of conscious choice).

There are four important things to consider if personal or community empowerment is to be facilitated

1. In all communities there is a need for an **identity: who we are, what we want and what we value**

Empowerment facilitators will not try to change what people value. They will identify and respect what people value and will work with them in the context of their values.

2. **How much people value and appreciate life itself**

It is commonly thought that “everyone wants to live”, but this is not true. For many people life is painful, hard or just plain boring.

3. **The presence of people’s dreams for a potential future where their needs are met and their values are respected**

A strong active desire to reach a better future is the driving force for empowerment. It is important to discover what people really want - not what we think they need.

4. **Access to resources – water, food, education, medical services, basic amenities etc**

In the absence of the first 3 considerations (identity, value of life and aspiration) even existing external resources are frequently not used to their full potential.

“External resources need to be placed within a psychological vessel of values, goals and identity. Without such a vessel, they usually drain away into the barren sand of good intentions.”

Participatory Learning and Action (PLA)

Participatory Learning and Action (PLA) is a method for learning about and engaging with communities. It combines an ever-growing toolkit of participatory and visual methods with natural interviewing techniques and is intended to facilitate a process of thinking and learning. The approach can be used for the identification of needs, planning, monitoring or evaluating projects and programmes. It is a powerful consultation tool, but it also offers an opportunity for communities to actively participate in the issues and interventions that shape their lives.

Community-Based Rehabilitation (CBR)

Community-based rehabilitation (CBR) focuses on enhancing the quality of life for people with disabilities and their families, meeting basic needs and ensuring inclusion and participation. CBR has evolved to become a strategy that involves collaborations between many different sectors with the aim of giving people with disabilities access to benefits from education, employment, health and social services. CBR is implemented through the combined efforts of people with disabilities, their families, organizations and communities, relevant government and non-government health, education, vocational, social and other services.

Suggestions for further reading on these concepts are shown at page 28

Road map: how to impact on stigma at multiple levels

If a programme is considering the above mentioned concepts (empowerment, CBR and PLA) for the reduction of stigma, we offer the below road map which can be followed. It is based on the STEP project in Nepal which proved to be successful in reducing the stigma of leprosy at multiple levels.

1. Identify and understand the problem

2. Plan and implement the project

3. Mobilise appropriate resources

4. Have sufficient skill to facilitate individual and group empowerment

5. Monitor and evaluate projects (appreciative learning and action)

6. Raise community awareness

1. How to identify and understand the problem

Who is responsible? » Project field staff and facilitators

Before starting to implement an intervention it is important to really understand what types of stigma exist in the area. For types of stigma please refer to Guide 1. It is important to understand how stigma affects people in the area and what the consequences of leprosy related stigma are. A short inventory could be made of any preconceived ideas, opinions and assumptions.

Planners should go into the community where there appears to be a problem, listen to what people are saying and discover what people affected by leprosy have experienced. When a general impression of the situation has been formed the following steps could be taken:

1.1 Establish a trusting and safe relationship with people who have a health condition leading to stigma

Tips:

- Visit and befriend stigmatised people
- Show interest in the issues they raise
- Offer services if available (or advice on how to access services) for immediate medical needs
- Do not raise false expectations and do not give in to material demands

1.2 Conduct PLA and build rapport with stakeholders in affected communities

- Use established PLA guidelines (please see Further reading #2). By using participatory approaches one can learn a lot from community members: how they define leprosy, if they are afraid of it or not, what they think are possible solutions to stop discrimination. The PLA is also a way to find out what the general issues are in the village and what is important to everybody.

1.3 Listen to what people are saying about discrimination, isolation, segregation, etc.

Tips:

- Find a friendly undisturbed place to talk
- Establish rapport (maintain eye contact, voice control, reflect on what people say)
- Encourage people to talk by asking open-ended questions (avoid giving opinions)
- “How” and “What” questions will give you information about the actual situation
- “Why” questions will help you understand what people believe to be true
- Appreciate their opinions without judgment
- Cross check – if in doubt ask people for clarification

1.4 Record what people are saying

Tips:

- If possible use a voice recorder to capture conversation (with permission)
- If you do not have a voice recorder you will need to take notes, but be careful not to let note taking spoil communication

1.5 Map where they are reporting stigma issues

- Draw simple maps of the general area and mark where stigmatised people live



2. How to plan and implement the project

Who is responsible? » Project administration, project field staff and facilitators

2.1 Within the project discuss results of early mapping exercises

Tips:

- Identify target areas (based on density of people reporting problems)
- Agree priority areas
- Make lists of probable resources that will be required

2.2 Assess the types and severity of stigma before starting the intervention

- This serves as a baseline for demonstrating the impact of the interventions at later stages
- If it is a project, use a survey. If it is an individual intervention or for a small group, it is also recommended to assess the type and severity of stigma.
- Please see Guide 2 'How to assess health-related stigma' for tips

2.3 Seek stakeholder support

Talk with stakeholders to convince them of the benefits that will follow if people in their communities are not stigmatised.

Who are “stakeholders”, other than the target population?

- Community Level – traditional leaders, local political leaders, religious leaders, head teachers, health centre in-charge
- District Officers – district development officers, public / community health officers, district education officers
- NGOs and CBOs – those local and national with a local presence in the target communities, DPOs

Tips:

- Share findings of listening surveys that demonstrate the extent of the problem
- Seek stakeholders who have a common agenda
- Learn what the mandates and strategies of government / NGOs are so that it can be shown how the intended project will contribute to achieving those goals.
- Find out whether it is necessary to have MOUs with significant stakeholders
- Clarify the roles / relationships expected of stakeholders
- Keep stakeholders updated on all decisions
- Inform resource holders of any problems

Who are the resource holders?

Some NGOs or CBOs may be resource holders (e.g. those that can gain access to materials or facilities), Government development officers, political leaders, INGOs / NGOs with local presence in target communities, DPOs

2.4 Identify potential group leaders

Group leaders will be among the most important people in the project and should be chosen with care. They will be responsible for encouraging people to join the group and to persevere in self-care. They will also help to solve problems between group members and will be the most likely spokespersons for the groups when they begin to access rights, benefits and other resources.

The most appropriate candidates to be leaders are:

- People who are directly affected by the stigmatising condition
- People who can commit their time
- People who show empathy
- People who demonstrate intuitive problem solving skills
- People who demonstrate communication skills (untaught)
- People who are creative or show some initiative

2.5 Facilitator training

Training should emphasise:

- Personal and group empowerment (See Further reading #1)
- CBR concepts
- Communication skills
- Participatory exercises

2.6 Assist the group leaders to form self-care groups

Who is responsible? » Facilitators

- Resort to medical or other records to find people who may be interested in becoming members (some people will not want to join groups; their intention should be respected)
- Check back on listening surveys and PLA to identify possible members
- Assist groups to find a venue for meetings
- Once enough people have been identified (minimum four; maximum 20), the first meeting should be called and the objectives of the self-care group explained. (The main objective is to control impairments. It has been found that when people begin to realize that they are not controlled by the effects of leprosy they begin to develop self-confidence)
- Supervise self-care groups closely for six months. (This is known to be important because it takes this length of time before people begin to see the results of self-care. They will need frequent encouragement to persevere until they can see that their own actions are producing results)

- During the first six month period, facilitators start to speak about development ideas to self-care groups. This can take the form of general discussions in the group where the facilitators begin to explain what other groups have managed to do (e.g. village hygiene projects) and what type of resources might be accessed (e.g. local government provision of basic toilets)
- After six months facilitators encourage the formation of self-help groups. Self-help groups are different from self-care groups because they include other people with disabilities or people who are marginalised for some other reason. Such other people may not benefit from self-care. The original self-care cell continues to be central to the self-help group and those who need to conduct self-care continue to do so together at group meetings. Those who do not need to do self-care should be asked to encourage and support those who do

3. How to mobilise appropriate resources

Who is responsible? » Facilitators

3.1 Develop the capacity of groups to advocate and access greater resources (e.g. donor funding, government provisions)

This will not be an early development. The group needs time to become confident. As the effects of self-care begin to be seen by the group members they will begin to develop self-confidence. Facilitators could begin to develop the groups' abilities to conduct discussions by first inviting local NGO members to group meetings. Group members are then encouraged to ask questions in an unthreatening environment. More ambitious opportunities can be facilitated as group members continue to grow in confidence.

3.2 Organise opportunities for interaction between group leaders and resource holders (government, NGOs, landowners, etc.)

If group members have not had sufficient experience in approaching officials they may need a facilitator to make the initial introductions. Facilitators should identify resource holders who can give access to the types of resources wanted by the group and then make preliminary inquiries regarding availability and terms. They should also assess the appropriateness of the resource and the access to it and should then discuss the situation with the group. The actual request for the resource should be made by representatives from the group with support from the facilitator. If a formal proposal is required, the facilitator or project field staff may be required to assist in drafting it.

4. How to gain sufficient skill to facilitate individual and group empowerment

Who is responsible? » Facilitators

For more details of facilitating individual and group empowerment please see 'An Action to Address Stigma: Self-Care Group Empowerment' (Further reading #1)

4.1 Essentials for the facilitation of individual and group empowerment

Develop:

- Listening skills of the group leaders
- Counselling skills of the group leaders
- Saving and socio-economic activities in the groups
- Networking skills
- Problem-solving skills
- Simple documentation skills (including book-keeping)

4.2 Essential objectives of group empowerment

- Build individual and group identities (See Further reading #1)
- Stimulate aspirations (See Further reading #1)
- Encourage the development of positive role models (see Further reading #1)
- Promote gender equality
- Non-formal education
- The initiation of community development activities (based on PLA)



5. How to monitor and evaluate projects

Who is responsible? » Project field staff

5.1 Learning and development

Monitoring and evaluating will help to give an assessment of how well the project is doing so that it can be improved even further. It is about asking what has happened and why – what is and what is not working. Effective evaluation will help personnel to learn from the project activities, and then to use what has been learnt to develop the programme for greater effect.

5.2 Accountability – showing others that the project is effective

Stakeholders need to know whether a project has earned their support. There may also be pressure from donors to provide them with evidence of success. Projects may have to respond to this demand in order to survive.

There may be some difficulties in co-ordinating both of these approaches but it is important to find ways in which both the need for accountability and the need for learning can be met. Stakeholders may be more interested not only in whether a project has worked, but why and how it worked.

The purpose of evaluation will change the type of questions asked. For accountability, the questions might be:

- *Has the project worked?*
- *How has money been spent?*
- *Should the project continue?*

For learning, the questions may be:

- *What are the project's strengths and weaknesses?*
- *What are the implementation problems?*
- *Why have things worked, or not?*
- *What are the good practice issues?*

Evaluation should not only answer questions; it should also prompt fresh thinking about the project for project staff and all the stakeholders. If the right questions are asked, an evaluation will reveal not only what has been achieved, but also how it was done and what was most effective. It will reveal the areas where improvement or change is needed, and help to identify ways to improve.

Guide 2 'How to assess health-related stigma' gives more tips for monitoring and evaluating the impact of your intervention. It describes how quantitative and qualitative methods can be useful in this.

5.3 Essentials of Participatory Learning and Action

Common principles of PLA:

- The focus should be on communal learning by the stakeholders through a system of joint analysis and interaction.
- Different perspectives are encouraged and recorded: equal importance is given to the various ways people understand what the realities of life are for them and to know the range of solutions for problems that different stakeholders use. Revealing this complexity of the world can only be done through group analysis and interaction.
- Wherever possible, methods should be designed or adapted to the local situation, preferably with the involvement of all actors.

- The role of outsiders (those who are not members of the community or group with whom they interact) is to guide local people in their decisions on what to do with information and the consequences of it. Outsiders may also choose to further analyse the findings generated by PLA so that they might influence policy-making processes at institutional or organisational levels. In either case, there should be commitment on the side of the facilitating organisations to do their best to assist or follow up on those actions that people have decided on as a result of PLA.
- The process of joint analysis and dialogue helps to define changes which would bring about improvement and seeks to motivate people to take action to implement the defined changes.

For access to further resources for PLA please see 'Further reading' (page 29)

6. How to raise community awareness

Who is responsible? » Project field workers

Community awareness is important because:

- It increases knowledge
- It makes people question their own beliefs and prejudices and makes them aware of false beliefs and hurtful attitudes.
- It gives the activities of the self-care groups a high profile (this demonstrates their courage)
- It encourages others to join the groups
- It gives self-care / self-help group members an opportunity to reveal the value of their actions to the community and other stakeholders

Start with this as early as possible preferably together with the planning and initiation of the self-care groups and continue the process throughout the duration of the project.

Tips on raising community awareness:

- Conduct village awareness campaigns (e.g. street theatre, puppetry etc.)
- Organise advocacy at government / religious institutions
- Gain access to public media

- Become involved in festival / public gathering planning
- Gain access to calendars or diaries of events from local government agencies, traditional authorities, NGOs
- Seek invitations to engage in planning
- Prepare and test materials for dissemination

Further reading and practical tools

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

- links to websites
- further background reading
- persons you can put your questions to
- practical tools and guides

The following documents contain further practical steps and can be found on the above website:

1. **An Action to Address Stigma: Self-Care Group Empowerment**

Useful practical guide that takes readers through a process that can be used to facilitate the empowerment of a self-care group.

2. **What is Participatory Learning and Action (PLA): An Introduction**

This introduction to PLA written by Sarah Thomas gives some basic easy-to-follow descriptions of PLA tools but is rather weak on how to use them.

3. **WHO / ILEP Technical guide on community-based rehabilitation and leprosy**

This is a comprehensive guide that will lead you to an understanding of the principles and practice of CBR.



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.

International Federation of Anti-Leprosy Associations (ILEP)

234 Blythe Road
London
W14 0HJ

Tel: + 44 (0)20 7602 6925

Fax: + 44 (0)20 7371 1621

E-mail: ilep@ilep.org.uk (all general enquiries)

