

# Guidelines for strengthening participation of persons affected by leprosy in leprosy services



**World Health  
Organization**

Regional Office for South-East Asia

# Guidelines for strengthening participation of persons affected by leprosy in leprosy services

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## Executive summary

The involvement of persons affected by leprosy in key activities of leprosy services has long been considered essential. Yet it has received scant attention by those delivering the services. There has been a lack of awareness among policy makers about the importance of including those individuals for whom the services are designed, as well as recognition of the significant contributions that people who have experienced leprosy have made to their communities and the world. However, during the last decade it has increasingly been recognized that people who have personally experienced the disease are important partners in their treatment. Ensuring that persons affected by leprosy are the central focus of the programme will have profound implications for the way that services are planned, delivered and evaluated.

These guidelines have been developed in consultation and active partnership with persons affected by leprosy. The change from a provider-centred approach, to an individual-centred one aimed at shared responsibility and shared decision-making is not simple; it requires greater commitment to and significant adjustment in programme structure and service delivery. It also recognizes that the family members of the person affected by leprosy also play an important role in assisting the individual in their daily lives and in addition help in the delivery of leprosy services. Through this re-orientation, the benefits could be enormous, with significant qualitative improvements in leprosy service and empowerment of persons affected by leprosy.

Several strategic issues have been identified, which have been classified as either primary or operational. The primary issues are stigma and discrimination; equity, social justice and human rights; and gender. The operational issues are information, education, communication; advocacy; counselling; training and capacity building; referral; prevention of disability; rehabilitation; and planning and management including monitoring of services; resource mobilization; research, and monitoring and evaluating the process of facilitating the involvement of persons affected by leprosy.

The central theme of the guidelines is to recognize the expertise of individuals who have had the disease and, through partnership, enable these individuals to support in the delivery of leprosy services. Efforts should be made to promote opportunities for each individual to realize ways in which they can be involved in leprosy services. This will ultimately lead to individuals affected by leprosy having equal access to quality services and being respected in their roles as contributing members of society.

It is essential for programmes to foster partnership with persons affected by leprosy and their families, and for civic groups to provide the means for capacity building through training and support, so that people affected by leprosy can effectively participate in leprosy services.

Facilitating the participation of persons affected by leprosy is not simple. It is essential to document the process and results, provide feedback on lessons learned, and disseminate the results to a wider audience to expand the process.

## **Definitions and terminology**

In the context of these guidelines, the term “persons” and “individuals” refers to all people currently under treatment for leprosy and individuals cured from leprosy. People no longer receiving treatment should not be referred to as “patients” outside of the medical setting.

It is important to always refer to individuals using the term “person” first. For example, say “a person affected by leprosy” or “a person affected by Hansen’s disease”. This is preferred to “leprosy-affected person” since using the term “person” first emphasizes a common humanity and makes leprosy secondary. When referring to a person affected by leprosy in other languages the concept of “person” first should be followed and appropriate translation made accordingly taking into account the local situation.

Offensive terms such as “leper” or the equivalent in any language or dialect should not be used.

Labels such as “victim,” “sufferer”, and descriptions such as “deformed”, or acronyms such as “PAL,” or “LAP” that do not recognize an individual as separate from the disease should not be used.

## **Acronyms**

IDEA	International Association for Integration, Dignity and Economic Advancement
IEC	information, education and communication
ILEP	International Federation of Anti-Leprosy Associations
NGO	nongovernmental organization
POD	prevention of disability
SMHF	Sasakawa Memorial Health Foundation
UNHRC	United Nations Human Rights Council
WHO	World Health Organization

## Introduction

*“Leprosy is not merely a disease, but a challenge to fellowship . . . There are things that speak to man with ancestral voices, demanding from the enlightened today the redress of the ancient wrongs of the dark past, and leprosy is one of them . . .”* Professor T.N. Jagadisan, India, editor, author, teacher and social worker who personally faced the challenges of leprosy.

The stigma associated with leprosy, which has prevailed in virtually every culture and has resulted in discrimination, stereotypes, labelling, and ultimately the exclusion of individuals affected by leprosy from equal participation in society. Adoption by the UN General Assembly on 21 December 2010 of the resolution on Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members was a milestone.

In June 2010, the World Health Organization conducted an historic meeting in Manila to formalize *Guidelines for strengthening the participation of persons affected by leprosy in leprosy services*. Half of the identified experts were individuals who had personally experienced the challenges of leprosy. The guidelines attempt to help programme managers identify areas where persons affected by leprosy can be involved and suggest relevant strategies to involve individuals to improve and strengthen leprosy services in endemic countries.

Actions directed at strengthening the involvement of persons affected by leprosy should become an integral part of the greater effort directed at the disabled in general which includes other disadvantaged persons also.

Of the 14 issues identified, three are considered primary: stigma and discrimination; equity, social justice and human rights; and gender. The remaining 11 are operational: information, education, communication; advocacy; counselling; training and capacity building; referral; prevention of disability; rehabilitation; planning and management; resource mobilization; research; and monitoring and evaluation. For each of these issues the guidelines provide a general description of essential features, suggest a defined set of strategic options, and propose a catalogue of activities to help place issues in the right perspective.

Total care involves ensuring opportunities for persons affected by leprosy to work in collaboration with healthcare and other service providers in delivering and providing equitable access to evidence-based services. When service users become participants, collaborators and facilitators, the programme realizes the potential benefit of health care. Participation of persons affected by leprosy and their family members is vital in removing imbalances by identifying needs, raising demand, establishing linkages and ensuring coordination.



By establishing a structure and an environment for improving the quality of life of people who have been diagnosed with leprosy, by improving services, and by providing equitable opportunities, healthcare providers will be promoting and protecting individuals' rights.

## **1. Primary issues**

### **1.1 Stigma and discrimination**

Stigma is a social process characterized by labelling, stereotyping, exclusion, rejection, fear, blame, devaluation and dismissal. Stigma in leprosy results in denial of equity, social justice and human rights. It is one of the major barriers to early case finding and treatment, often resulting in social and economic dislocation. Women and children are threatened even more by stigma and discrimination necessitating a special focus on their situation.

Overcoming and eliminating stigma as individuals and as a society is a critical step to full integration and participation of persons affected by leprosy and their family members into the mainstream of the community. It is important for both the person affected by leprosy and the community to have positive examples and to create a new frame of reference that replaces outdated beliefs and traditions.

#### ***Strategies***

➤ **Work with persons affected by leprosy, to identify and change negative attitudes, beliefs and practices that are negative**

Individuals and institutions responsible for health promotion should acknowledge the expertise and critical role of persons affected by leprosy and invite them to be part of the consultative group for planning the process. This involves elaborating a common goal, developing a mutual understanding of roles and responsibilities, and identifying the skills necessary for fulfilling the roles. It is also important that the media and community are held accountable for referring to the person affected by leprosy in a sensitive and dignified way.

➤ **Provide opportunities to share experiences, develop new attitudes and acquire new skills**

Some persons affected by leprosy may develop negative attitudes about themselves resulting in self-isolation. One way to address this is to organize empowerment workshops, which provide an opportunity for sharing successes and challenges, developing new perspectives and fostering an understanding of each person's potential and usefulness to society. A successful example is the

socio-economic empowerment workshops conducted by various organizations including those led by persons affected by leprosy.

Providing opportunities for individuals affected by leprosy to work in leprosy services can empower people and further increase self-esteem. Similarly, providing opportunities for such persons to improve their economic situation through income generation programmes, helps to promote social identity within the individual's family and society and improves self-worth. This is especially important for women. Persons who have successfully redefined themselves socially can become role models for others.

➤ **Work in partnership to promote the amendment or abolition of discriminatory laws**

In some countries discriminatory laws enacted years ago continue to be practised. It is important that individuals and programmes work together to develop alliances with administrators at various levels and lawmakers within local and national governments, to address this issue. *The Principles and Guidelines on the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members* adopted by the United Nations General Assembly in December 2010 is an important resolution that will help in addressing human rights issues in many countries.

## 1.2 Equity, social justice and human rights

Equity and social justice are basic tenets and the key to the realization of human rights. They are enshrined in the constitutions of many countries and in the Universal Declaration of Human Rights. Protecting human rights and promoting well-being are mutually reinforcing. It is important to co-ordinate medical, social and legal actions through the combined efforts of individuals who have personally experienced leprosy, their families, the government and the community. While supportive legislative framework is important, citizen action is essential.

### *Strategies*

➤ **Work with individuals and organizations representing persons affected by leprosy, to educate people who have experienced leprosy, programme staff and the community about human rights**

It is important to use the knowledge and talents of individuals who have overcome the challenges of leprosy to develop strategies that promote justice, equality, empowerment and participation. It is critical to develop partnerships with persons affected by leprosy and their organizations to develop educational programmes to help motivate the public to ensure that opportunities are created for all, irrespective of their health or social or economic status.

There are four United Nations documents that can provide information on human rights. They are: *Resolution on the Elimination of Discrimination Against Persons Affected by Leprosy and Their Family Members, approved by the United Nations Human Rights Council and the UN General Assembly (2010)*; *Convention on the Rights of Persons with Disabilities (2006)*; *Convention on the elimination of all forms of discrimination against women (1979)* and the *International Covenant on Economic, Social, and Cultural Rights (1966)*.

➤ **Encourage people to help identify and rectify human rights violations**

In an effort to identify and sensitize those who ignore the rights of persons affected by leprosy, individuals and organizations should be supported in their efforts to document and respond to all reported cases of human rights violations.

### **1.3 Gender**

In many parts of the world, leprosy affects twice as many men as it does women. However, it is generally acknowledged that stigma and discrimination are greater for women. In addition, in some societies it is more difficult for women to access services. Since women often have fewer financial resources, they face numerous barriers.

#### **Strategies**

➤ **Develop support groups**

Support groups are especially important for women. The power of women to encourage each other as they deal with diagnosis, treatment, and the social effects of the disease, has been proven to be an effective means to eliminate stigma and foster leadership. Choosing a meeting place where women feel comfortable is essential to the success of the group.

➤ **Work in partnership to advocate for equal rights and opportunities for men and women**

Identify female leaders who are affected by leprosy, so they can serve as role models and help educate women about their rights. Additionally, document their experiences so that they can be used to advocate for changes in practices that exclude women from opportunities and prevent equal rights.

Women's empowerment workshops, such as those held in Nepal, Brazil, and India, by associations of persons affected by leprosy are an important means of identifying problems and solutions, and developing leadership. It is important that women who are affected by leprosy are able to join other support groups that promote the empowerment of women and vice versa.

➤ **Promote participation of women in decision-making processes**

To incorporate gender sensitivity in all policies, at all levels and at all stages, it is essential to include the expertise of women who have overcome the challenges of leprosy and made significant contributions to their families, and local and international communities. On any matter related to the development of policies, delivery of services, or training, a basic question must be asked: “Have women affected by leprosy been consulted?”

It is important to facilitate the inclusion of women in self-help groups, so that they can play an influential role in changing the expectations of providers.

➤ **Promote participation of women in delivery of services**

Organizations co-ordinating or sponsoring leprosy services should be encouraged to include women in their delivery system. It is important to augment the awareness of the rights, knowledge, and skills of women, to enable them to participate in the planning and delivery of service. This could be accomplished through appropriate training and seminars.

## **2. Operational issues**

### **2.1 Information, education and communication**

Information, education and communication (IEC) encourages people to implement a range of voluntary activities to promote their well-being. Myths and misconceptions generate negative perceptions and attitudes which give rise to discrimination and human rights abuses. An informed community is better able to perceive the problem and is more likely to act in ways that benefit society. Persons affected by leprosy are the most appropriate persons to dispel misconceptions and bring about a change in attitudes. Their participation in IEC efforts is essential for bringing about improvements in awareness about the disease in the community. It is essential that in all aspects of IEC, terminology that promotes dignity is used. “People first” language, such as “a person affected by leprosy” must be used. Appropriate translation into other languages is encouraged based on this concept. As part of the IEC effort, the national programme should ensure that all educational materials depict a positive image of leprosy.

#### ***Strategies***

➤ **Provide opportunities for individuals to become leaders and serve as role models**

Promote forums where the leadership potential of individuals is identified and supported. Provide opportunities for individuals to share their experiences and

become role models for others, both within the world of leprosy and in general.

- **Provide opportunities for persons affected by leprosy to share their own experiences and to encourage the general public, health care providers, and various community leaders to think inclusively**

Sharing perceptions, experiences and expertise in public forums removes misconceptions and myths and increases awareness in the community that leprosy is a curable disease. This also helps to build self-esteem. Through interacting with the public, a person affected by leprosy can foster respect for persons affected by the disease.

- **Work in partnership to educate opinion leaders and the media**

Persons affected by leprosy can play a key role in disseminating information to the general public as well as to the media and others who help shape public opinion. Efforts should be made to promote coverage in the media on social issues such as justice, equity and inclusion of people affected by leprosy through press releases and editorials. These efforts can help to overcome educational, cultural, and social barriers to accessing services. This can be done individually or in groups in collaboration with health care, social work and media professionals.

- **Educate healthcare providers to have positive attitudes towards persons affected by leprosy**

Stigma and discrimination is prevalent not only in the community at large, but sometimes also among healthcare providers. This is expressed in various and often subtle ways. It is important to form partnerships with social action groups and other peer groups to initiate sustainable destigmatizing initiatives directed at healthcare providers. Providing forums for discussions, such as empowerment workshops, that include both individuals who have had leprosy and healthcare providers helps to remove barriers and misconceptions.

- **Develop educational materials with a social component**

The IEC activities created by healthcare providers for the general public often are limited to health issues and the information given is usually from the perspective of the provider of health services. It is important that those who have experienced the disease are involved in defining the appropriateness and content of educational materials and that their views and experiences are included.

## **2.2 Advocacy**

Advocacy, the process of seeking public support for a particular cause or policy, has been increasingly emphasized, since the social aspect of leprosy is equally important as the medical aspects of the disease. Influencing the opinions and attitudes of the public and policy makers is essential to advancing equity, social justice and human rights.

### ***Strategies***

➤ **Promote opportunities for individuals at local, national and international levels to become agents for positive change**

Many individuals affected by leprosy have great leadership potential but have not had the opportunity to realize this potential. It is essential to identify and provide opportunities for potential leaders to participate in workshops and training programmes to enhance their knowledge about organizational and community needs and processes.

It is also important to promote forums where individuals can share their expertise and wisdom and debate on important social, operational and programme issues that could lead to favourable changes in the delivery of services.

Organized efforts can bring about significant changes, such as the lobbying of parliamentarians done by an organization of persons affected by leprosy in India, which prompted action for fully assessing the needs of individuals with leprosy.

➤ **Develop partnerships to create awareness**

Conduct oral history interviews, use positive photographs that focus on ability rather than disability and focus on the wisdom and creativity of individuals to create awareness of how individuals have overcome challenges to become positive role models, not just for others with leprosy, but for the community in general. Promote opinion editorials and advertorials in newspapers. Encourage increase coverage in the media on social issues such as justice, equity and inclusion of people affected by leprosy.

➤ **Support organizations of people affected by leprosy to mobilize and build alliances**

Support and opportunities should be provided for groups, organizations and networks of people affected by leprosy to develop partnerships with other organizations such as NGOs or academia that work for similar causes.

## 2.3 Counselling

Psychological support and counselling are crucial to the successful treatment of people diagnosed with leprosy. Counselling can include general information on the disease, self-care, self-esteem and human rights. If leprosy control programmes do not have the resources to provide counselling, identify alternative options ranging from community-based agencies and instructional materials, to individuals who have experienced the disease. Peer counselling is the ideal option and therefore should be encouraged.

### *Strategies*

- **Involve persons affected by leprosy to ensure access to psychological support services at the time of diagnosis, during treatment and at other times, as needed**

Providing psychological support is essential, and someone who has also experienced leprosy is often the best source of support, for they can share information, help overcome fears, and direct people to community resources.

Persons newly diagnosed with leprosy can benefit from a support system of others who have had the disease, who can help maintain a continuous and significant link to the specific needs of each individual. Members of the support system made up of peer counsellors can share basic knowledge on the symptoms of leprosy; care of injuries and types of medications used for treatment of leprosy and complications; community resources for health and psychological services; venues for reporting instances of human rights violations; ability to identify potential barriers to proper care; and understanding of the importance of self-care.

- **Establish self-help groups led by persons affected by leprosy who have experience**

Self-help groups can also be an important resource for counselling and emotional support. Consistent positive messages coming from a group will produce a positive impact. It is essential to connect with a role model who has had similar problems.

## 2.4 Training and capacity building

The term training refers to the acquisition of knowledge, skills, and competencies as a result of the teaching of vocational or practical skills. Individuals affected by leprosy can benefit greatly by capacity building activities and can also in return train and help to build the capacity of others who provide services in the community. Training can be useful to foster capacity in counselling, self-care, resource mobilization, partnership development and role model and leadership development.

### **Strategies**

- **Promote opportunities for individuals and organizations to increase capacity to participate in relevant leprosy services**

Persons affected by leprosy should be included in the provision of services such as socio-economic rehabilitation, self-care, counselling, gender, and activities to address stigma, gender and human rights issues. Specific training courses should be developed, and made accessible to individuals.

- **Involve persons affected by leprosy in training programmes for project staff on how to involve other individuals who have experienced leprosy**

Individuals who have experienced leprosy have an important role to play in sensitising programme and project staff on social issues, as well as providing guidance on involving persons affected by leprosy in leprosy services. Persons affected by leprosy having expertise in key social areas of work can become part of the resource team of trainers, and compensated like other training professionals for their expertise.

## **2.5 Referral**

Referral is the process of assisting a person in accessing a specialized service or intervention which may not be available locally. It is one of the most important components of public health, based on the principle of providing total care to a person. It can range from providing counselling to integrating a person into society.

Holistic care goes beyond physical health and should accommodate all of the essential components that make life worth living. It is multisectoral involving health, education, livelihood, social issues, empowerment and the realization of human rights. Since the care of persons affected by leprosy has primarily been considered to be the primary responsibility of healthcare providers, individuals often receive little attention from other departments. This is a result of lack of awareness, lack of training and skill, lack of understanding and lack of co-ordination. Participation of persons affected by leprosy is vital in removing imbalances, raising demand, establishing linkages and ensuring co-ordination. A strong referral system can be created through the combined efforts of the people themselves, their families, communities, civic groups and service professionals.

### **Strategies**

- **Work in partnership with persons affected by leprosy to identify services and to be an advocate for referral**

Provide opportunities for persons affected by leprosy to become part of civil society groups that help develop a network of flexible, person-centred services to support individuals needing certain services not available locally. Persons



affected by leprosy can play an important role in building an inventory, site mapping services and disseminating information about these services.

Information on hospitals, treatment and the availability of rehabilitation services only in certain places, is often passed from one person to another. Establishing a network among persons affected by leprosy in different regions makes it easier for people to share beneficial information.

➤ **Work with persons affected by leprosy to support others who have leprosy**

Individuals can assist other persons affected by the disease in collaboration with civic groups and community-based organizations to help address financial, structural and personal barriers that limit access to care. Those who have experienced the disease can assist in developing local opportunities for education, vocational training and jobs, and also provide technical and emotional guidance and support in self-care, individually or through self-help groups.

➤ **Recognize individuals as an important resource for information on best practices**

Persons affected by leprosy are an important resource who, in strategic alliances with civic groups and community-based organizations, can help to create a platform for developing and disseminating best practices in different settings across the entire continuum of care.

➤ **Use individual expertise of persons affected by leprosy to sensitize service providers**

Social, educational and cultural differences between healthcare providers and persons affected by leprosy can become a barrier to access quality services. Recipients of services have a key role to play in the sensitization of healthcare providers.

## **2.6 Prevention of disability (POD)**

“Identify”, “train”, “support” and “integrate” are the main principles of prevention of disability. There are several ways in which persons with personal experience can contribute to increased effectiveness of POD. This includes participating in programmes to improve early diagnosis; assisting and encouraging others in practicing self care; and helping individuals access special services such as medical, social or economic services. This work can be done either individually or in self-help groups, in collaboration with healthcare providers and community-based organisations.

### **Strategies**

- **Involve persons affected by leprosy to encourage individuals to go for early evaluation**

Persons affected by leprosy often encourage others to seek early evaluation, diagnosis and treatment since they are acutely aware of the benefits. Opportunities and appropriate training should be provided for persons affected by leprosy to become formally involved in this process.

- **Formally engage persons affected by leprosy in the promotion of self-care and the identification of people in need of practising self-care**

Self-care is a person-centred, labour-intensive service. Those who have experienced and successfully overcome the challenges of leprosy can serve as effective role models for helping others with similar problems. Promoting opportunities for the improvement of skills, sharing experiences and encouraging others will increase a person's ability to promote self-care. Persons affected by leprosy can also become the first contacts for persons during follow-up after the completion of treatment.

- **Involve persons affected by leprosy in identifying individuals in need of aids and appliances such as protective footwear**

Persons affected by leprosy can learn to identify those who need special aids and appliances. They can liaise with the national programme, NGOs and private enterprises and get the necessary services delivered to those in need.

## **2.7 Rehabilitation**

Rehabilitation helps persons affected by leprosy to live productive lives with dignity, as integrated members of the community. Successful rehabilitation can be achieved through the combined efforts of individuals, their families, the community, and the appropriate health, educational, vocational and social services. It is aimed at enhancing quality of life by providing more equitable opportunities through social and economic empowerment. It also has a strong impact on reducing stigma and discrimination.

### **Strategies**

- **Promote involvement of persons affected by leprosy in identifying individuals who need physical and/or socio-economic rehabilitation and in participating in follow-up services**

People affected by leprosy have an important role to play in identifying individuals in need of services and helping to bring them to service points. Such rehabilitation activities should also include family members who are in

need. Projects providing rehabilitation services can be assisted very well by persons affected by leprosy at the community level.

➤ **Identify role models for others to encourage empowerment**

A person who has been socially and economically empowered can serve as a role model for others. It is important for service providers to identify role models in collaboration with local organizations of people affected by leprosy or self-help groups or through community-based organisations, and involve them in the process.

➤ **Encourage self-help groups to identify and work with rehabilitation programmes**

Self-help groups are started by like-minded people to support each other to live and work together for their common welfare. In some countries, self-help groups have many members and are therefore able to get loans from banks and grants from the government. They work together towards improving the living conditions of people in the groups. In due course, they become a strong voice in their community.

➤ **Encourage conducting socio-economic empowerment workshops**

Socio-economic empowerment workshops enable individuals to understand how to improve their lives and to build confidence. Many such workshops have been conducted successfully in various countries. People who have been marginalized or live apart from the community benefit extensively from these workshops. Government health officials and social welfare officers participate in the workshops and motivate individuals to avail themselves of government programmes. Sometimes, the workshops are primarily organized by people affected by leprosy themselves with the necessary financial support of NGOs.

➤ **Promote involvement with organizations that seek to address equal access and participation**

Being involved in other human rights-based organizations with similar issues and objectives provides the opportunity for sharing experiences and joining in the representation to governments to ensure that needs are met.

In recent years there has been more emphasis on integrating leprosy rehabilitation within rehabilitation services and programmes for persons with disabilities. Similarly, being involved with organizations that focus on issues of mutual concern such as women's issues and social justice issues provides the opportunity for sharing experiences that can help promote equal access and participation.

Vice-versa, leprosy-specific groups should also open up so that other individuals with disability in the community can join.

## 2.8 Planning and management of services

The personal experiences, knowledge and information that persons affected by leprosy have gained through having the disease must be recognized as a valuable asset to enhance the quality of leprosy services. Persons affected by leprosy are the best resource to identify their needs and problems, recommending policy and setting priorities. Over the years many persons affected by leprosy have demonstrated their potential to improve planning and management of leprosy services. National programme managers and NGO partners are encouraged to consider persons who have experienced leprosy as equal partners rather than 'consumers', 'recipients of services' or 'clients' and to recognize the rationale as well as the benefit of involving these individuals and their organizations as active partners in planning and management of services.

### *Strategy*

- **Recognize that people are experienced in particular social and medical aspects of the disease, and are knowledgeable about local culture, traditions, beliefs, and language and involve them in policy and planning**

Programme managers at all levels as well as NGOs and partners need to identify individuals or existing associations of persons affected by leprosy who can help to improve leprosy services by getting involved in the planning and management of services. The capacity of the persons affected by leprosy and their associations for planning and management can be developed through self-help groups and empowerment workshops where they identify their needs, understand ways to address them and solve problems and develop leadership capacity. It is essential that persons affected by leprosy are provided opportunities to participate at various forums for planning leprosy services. It is important that language barriers be addressed at these forums to ensure equal participation and strong communication.

## 2.9 Resource mobilization

Individuals who have faced the challenges of leprosy can be important catalysts for resource mobilization. They can be effective organizers as well as contributors because their active participation is in itself evidence of their strength and the positive changes occurring in the community. Mobilization of resources is not always limited to funds. It could also be increased opportunities for education, employment, social interactions and improved access to services. Resource mobilization will require carefully constructed plans and close collaboration with like-minded organizations.

### **Strategies**

- **Develop partnerships in which individuals advocate for resources with local governments and NGOs, and organize local fundraising events**

Persons affected by leprosy are in an eminently suitable position to raise awareness and funds by collaborating with like-minded civic groups. Involving individuals in fundraising events provides opportunities for public education. Individuals should also participate in the planning and monitoring process, because this provides the opportunity to lobby for increased funding.

- **Promote opportunities for persons affected by leprosy to be involved in decision-making bodies of funding organizations**

Involving individuals in decision-making and fundraising will ensure a higher level of sensitivity and awareness, which will improve the effectiveness of programmes and activities.

- **Work with persons affected by leprosy to raise awareness of people's ethics and rights in relation to fundraising strategies and materials**

Fundraising should be based on human rights, not simply the medical aspects of the disease. It is also important to ensure that fundraising organizations do not use negative images of leprosy. Involving organizations of persons affected by leprosy can ensure that strategies do not mistakenly promote stigma and discrimination.

## **2.10 Research**

In a constantly changing socio-economic environment and leprosy scenario, operational research becomes increasingly important and constitutes an essential part of leprosy services. It is essential for all individuals and organizations conducting research to consider the possibility of involving persons affected by leprosy who have the necessary skills, in various stages of research formulation and execution. Individuals should be respected as primary stakeholders, and efforts should be directed at building their capacity to conduct research, especially in the social aspects. They can also play a pivotal role in ensuring that ethical issues are not violated, as well as disseminating the results of research.

### **Strategies**

- **Promote participation of persons affected by leprosy in planning and execution of research**

It would be prudent to lobby with NGOs supporting leprosy work and research, to look for opportunities to build research capacity among persons affected by leprosy and encourage them to be involved as members of the research team.

It is also important to collaborate with relevant research institutes in organizing training on research ethics, research methods and other relevant topics and to promote the participation of representatives of organizations of persons affected by leprosy.

It would be highly relevant to organize meetings for programme managers, researchers at universities, NGOs and other partners to make them aware of the rationale of involving persons affected by leprosy in conducting research.

➤ **Promote training of organizations of persons affected by leprosy to conduct research themselves**

In collaboration with organizations of persons affected by leprosy and research institutes provide training and opportunities for individuals who have had leprosy to conduct research, especially with regard to social aspects such as measurement of stigma, self-care, counselling, and socio-economic rehabilitation.

## 2.11 Monitoring and evaluation

In recent years there has been a growing recognition in public health programmes of the importance of considering preferences of individuals in the development of services and active collaboration with individuals and organizations in the decision-making process. Willingness on the part of the national programme to encourage the participation of persons affected by leprosy in planning and monitoring, derives from pressures from funding agencies, rapidly changing professional attitudes towards care and the individuals' growing awareness of their rights. Participation of individuals receiving services in decision-making improves the quality of services and adherence and continuity of the treatment schedule. Participation also contributes to empowerment and improves self-esteem. It helps to induce social changes, such as reduction in stigma and discrimination.

Although a set of indicators would be the ideal way to measure success, it is important to be aware of the limitations of the information system, particularly in the context of integration. A more realistic option would be to collect examples of success and publish them periodically. Another option would be to look at three primary issues and elaborate on the strength and level of involvement of persons affected by leprosy.

### **Strategy**

➤ **Use the experience of persons affected by leprosy to help identify gaps in the public health system either before, during and after treatment**

The programme should receive continuous feedback from persons affected by leprosy. It is also desirable to work with persons affected by leprosy to evaluate whether the services provided promote dignity.

### **3. Acknowledgements**

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### **4. Recommended reading**

- (1) Arole S, Premkumar R, Arole R, Maury M, Saunderson P. Social stigma: a comparative qualitative study of integrated and vertical care approaches in leprosy." *Leprosy Review*. 2002; 73:186-196.
- (2) Bainsan KA, Van den Borne B. Dimensions and process of stigmatization in leprosy. *Leprosy Review*. 1998; 69: 341-350.
- (3) Brietha Olivia. *Olivia: my life of exile in Kalaupapa*. Honolulu: Arizona Memorial Museum Association, 1988.
- (4) Caron-Flinterman. *A new voice in science: patient participation in decision-making on biomedical research*. Amsterdam: Vrije Universiteit, 2005.
- (5) Coulter, A. What do patients and the public want from primary care? *British Medical Journal*. 2005; 331:1199-1201.
- (6) Crawford MJ, Rutler D, Manley C, Weaver T, Bhui K. Systematic review of involving patients in the planning and development of health care. *British Medical Journal*. 2002; 325:1263-1267.
- (7) Cunanan Arturo C, Maria Perpetua A. Eds. *Dignity regained*. Philippines, 2010.
- (8) Duff LA, Kelson M, Marriott S, McIntosh A, Brown S. Clinical guidelines: involving patients and users of services. *Journal of Clinical Effectiveness*. 1996; 1(3): 104-112.
- (9) Ghosh Rupak, Chowdhury Ujjwal K. Eds. *Dignity regained*. Maharashtra: ICONS Media Publication, 2005.
- (10) Grol R. Improving the quality of medical care: Building bridges among professional pride, payer profit and patient satisfaction. *Journal of American Medical Association*. 2001; 286:2578-2585.
- (11) Hirasawa Yasuji. *No despair in life: the memoirs of Yasuji Hirasawa*. Translation from Japanese. New York: IDEA Center for the Voices of Humanity, 2006.
- (12) Holman H, Lorig K. Patient as partners in managing chronic diseases. *British Medical Journal*. 2000; 320:526-527.
- (13) IDEA. *Quest for dignity: personal victories over leprosy/Hansen's Disease*. Louisiana: Franklin Press, 1997.
- (14) Morrison A. A woman with leprosy is in double jeopardy. *Leprosy Review*. 2000; 71:128-143.
- (15) Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews*. 2006; 3: Art No. CD004563.

- (16) Ohtani Fujio. *The walls crumble: the emancipation of persons affected by Hansen's disease in Japan*. Tokyo: Tofu Kyokai Association, 1998.
- (17) Ramirez José P. *Squint: my journey with leprosy*. Jackson: University Press of Mississippi, 2009.
- (18) Salmon P, Hall GM. Patient empowerment and control: a psychological discourse in the service of medicine. *Social Science and Medicine*. 2003; 57:1967-1980.
- (19) Soutar D. Leprosy and human rights. *Leprosy Review*. 2008; 79(3): 239-241.
- (20) Stein Stanley. *Alone no longer*. Revised edition. Louisiana: The Star, 1974.
- (21) Stigma, identity & human rights: the experience of leprosy in the era of HIV/AIDS, excerpts from International Conference held on Robben Island. *International Journal of Leprosy*. 2005; 73: 283-297.
- (22) Van Brakel WH, Anderson AM, Mutatkar RK, Bakirtzief Z, Nicholls PG, Raju MS, et al. The participation scale: measuring a key concept in public health. *Disabil Rehabil*. 2006; 28(4):193-203.
- (23) Van Brakel WH. Measuring health-related stigma -- a literature review. *Psychol Health Me.*, 2006; 11(3): 307-334.
- (24) Van de Bovenkamp HM, Trappenburg MJ. Reconsidering patient participation in guideline development. *Health Care Annal*. 2009; 17:198-216.
- (25) Varkevisser CM, Lever P, Alubo O, Burathoki K, Idawani C, Moreira TM, Patrobas P, Yulizar M. Gender and leprosy: case studies in Indonesia, Nigeria, Nepal and Brazil. *Leprosy Review*. 2009; 80: 65-76.
- (26) Vlassoff C, Moreno CG. Placing gender at the centre of health programming: challenges and limitations. *Social Science and Medicine*. 2002; 54:1713-1723.
- (27) Williams B, Grant G. Defining 'people-centred': making implicit explicit. *Health and Social Care in the Community*. 1998; 6: 84-94.
- (28) Williamson, C. The use of doctor-patient working groups. *British Medical Journal*. 1998; 317: 1374-1377.
- (29) World Health Organization, Regional Office for South-East Asia. *Developing guidelines to strengthen participation of persons affected by leprosy in leprosy services: report of the meeting 9-10 June 2010, Manila, Philippines*. New Delhi: WHO-SEARO, 2010. Document No. SEA-GLP-2010.3.



Guidelines to strengthen the participation of persons affected by leprosy in leprosy services were developed in consultation and active partnership of persons affected by leprosy. It promotes change from a provider-centred approach, to an individual-centred one aimed at shared responsibility and shared decision-making. It also recognizes that the family members of the person affected by leprosy also play an important role in assisting the individual in their daily lives and, in addition, help in the delivery of leprosy services. Through this re-orientation, the benefits could be enormous, with significant qualitative improvements in leprosy service and empowerment of persons affected by leprosy



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