

# Developing guidelines to strengthen participation of persons affected by leprosy in leprosy services

*Report of the meeting  
9-10 June 2010, Manila, Philippines*



**World Health  
Organization**

Regional Office for South-East Asia

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## 1. Introduction

A meeting to develop guidelines to strengthen the participation of persons affected by leprosy in leprosy services was held in WHO Regional Office for the Western Pacific Region in Manila, Philippines from 9 to 10 June 2010. The meeting was attended by over 35 participants representing various affected persons' organizations from the African, American, South-East Asian and Western Pacific Regions. In addition, national programme managers from eight countries and experts working in various fields of leprosy and partner organizations participated in this meeting. The meeting was opened by Dr Shin Young-Soo, Regional Director for the Western Pacific Region. Mr Sakae Saito read out the welcome address on behalf of Mr Yohei Sasakawa, who is the WHO Goodwill Ambassador for leprosy elimination.

In the inaugural session Dr Shin Young-Soo referred to the elimination of leprosy as a success story for public health. However, he said that elimination was only an intermediate goal. Cases will continue to appear for many years. The ultimate goal should be to reduce the disease burden further in all countries. Fear of leprosy is mainly due to ignorance about the disease. Stigma and social segregation are denial of basic human rights. Too often persons affected by leprosy cannot give voice to their cause. WHO's work is guided by the Enhanced Global Strategy 2011-2015. He acknowledged all the partners who have been involved in the initiative to improve the participation of persons affected by leprosy in leprosy services. WHO has formed a Task Force to develop guidelines to facilitate this initiative, which may set a trend for other disciplines.

On behalf of Mr Yohei Sasakawa, Mr Sakae Saito read out his message. It was pointed out that there has been a dramatic decline in the number of leprosy cases in the world thanks to the efforts of WHO, ministries of health and NGOs. Yet, there is a sizeable number of new cases being detected and treated each year. As early detection and treatment is the key to further reducing the number of cases, people need to know what the early symptoms are and where to go for treatment. An example of a motorbike was given whereby the front wheel represents the medical fight against the disease and the back wheel represents the efforts to tackle social stigma. For the bike to run smoothly, it was pointed out that both wheels must be of the same size. The guidelines that are being prepared hopefully will reflect the many constructive suggestions provided by affected persons. This unique initiative can have a major impact on leprosy services but to make it work will require understanding and cooperation of all concerned parties.

Mr Jose Ramirez was nominated as chairperson and Dr Alcino Ndeve as co-chairperson. Mrs Lourdes Nevis Mary, Mrs Yemelda Beauchamp, Dr Krishnamurthy and Dr Wim van Brakel were nominated as rapporteurs. Dr Myo Thet Htoon, Team Leader of the Global Leprosy Programme introduced the participants.

## 2. Objectives

The objectives of the meeting were:

- To review the draft guidelines to strengthen the participation of persons affected by leprosy in leprosy services; and
- To obtain endorsement for the guidelines.

## 3. Presentation of draft guidelines

Dr Wim van Brakel and Dr PK Gopal gave a short presentation on the draft guidelines aimed at helping national programme managers to strengthen the participation of persons affected by leprosy in various leprosy services. It was pointed out that in the Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy 2011-2015 under section 4.4 the role of persons affected by leprosy was highlighted. The aim of these guidelines is to help national programme managers in organizing and mobilizing the contributions that the affected person can make in improving the leprosy services at the community level.

Areas where people affected could be involved as partners and how they can support leprosy services were highlighted. The following potential areas were identified in the Enhanced Global Strategy:

- Training and capacity building
- Rehabilitation/CBR
- Stigma and discrimination
- Counselling (affected person and family)
- Gender issues
- Equity, social justice and human rights
- Advocacy
- Referral
- Information, Education and Communication (raising awareness)
- Prevention of Disabilities
- Research
- Planning and management of services
- Resource mobilization
- Monitoring and evaluation

#### **4. Presentations on experiences of working with leprosy control programmes in a specific area in leprosy services**

Dr P K Gopal and Mrs Lourdes Nevis Mary presented their work in India. Over 800 leprosy colonies have been identified in India and data on these colonies have been collected by affected people representing these colonies. Data has been presented to various state governments. The National Forum was started in 2005, involving people affected by leprosy in 700 self settle colonies. This was followed by holding national and regional conferences. At these conferences, a state chief minister or other minister from the state government was invited as chief guest.

The affected people through the National Forum have petitioned the Parliament to amend or repeal discriminatory laws. Members of Parliament have themselves visited leprosy colonies and have heard of their needs first hand. As a result, considerable changes for the better are taking place. Stigmatizing questions in a national sample survey were challenged and subsequently removed and replaced.

Training programmes for affected people on how to work with governments and organizations are essential and need to be instituted. Leaders should be identified and proper payment for time invested should be arranged. Regional and national meetings for sensitization need to be arranged.

Mr Michihiro Ko, President of Zen Ryo Kyo, the National Hansen's Disease Sanatoria Residents' Association in Japan, discussed about the 1907 segregation law and the forced isolation that was started in 1909 and the impact it had on the lives of affected people in the country till as recently as 1996. Over the years a total of 25 000 people died in the sanatoria where no policy for their release existed. The situation significantly changed in 2001, following a court decision which denounced government's prolonged isolation policy and ordered compensation for the residents. Currently, there are a wide range of partners that are supporting Zen Ryo Kyo on social issues relating to leprosy. This includes lawyers, members of parliament, the ministry of health, civil society (Citizen's Council on Hansen's Disease), and families of affected persons, those people affected but living outside sanatoria, the Hansen Disease Medical Association, media, schools and religious leaders. The ownership of the leprosy issues by society in general is bringing a fundamental change to the issues surrounding leprosy.

This was possible only due to the participation of the affected persons which began almost 60 years ago. Currently, the association has 2,400 members, most of whom are elderly.

Mr Hilarion M Guia presented the past history of Culion Lepers Colony and how after the segregation law of 1904 Cullion Island was designated as a leprosy colony. He spoke of his personal experiences as an inhabitant of Culion and the various developments in the treatment of leprosy that he had lived through. Culion is now a leprosy-free island: leprosy as a disease has been controlled, thanks to the introduction of MDT. The status of the island was changed to a municipality in 1992, thanks to the efforts



of leprosy- affected persons who advocated for this. When a radio programme using derogatory language was broadcaste, persons affected by leprosy made a strong protest against the producer, leading to a local government resolution banning such broadcasts.

Mr Adi Yosep from Indonesia presented progress regarding participation of affected persons in leprosy services. The presence of negative attitudes and discrimination at the field level is still high. Affected persons are seen only as beneficiaries of services and not as potential partners. Three years ago, PerMata was started as an association of persons affected by leprosy. They developed several self-help groups at the grassroots level. Their purpose is to promote equal opportunity, participation and access to basic services.

Mr Adi Yosep suggested that the involvement of persons affected by leprosy can lead to country-specific definitions and standards of the quality of services to be provided. They can also provide information on the quality of services on a regular basis.

Mr Gil-Yong-Lee and Mr Lim Seong from the Hansen Disease Welfare Association in Korea shared their experiences in promoting the rights of affected persons since 1963. Around 6000 affected persons lived in a colony on an island. They worked to promote equal opportunities and equal treatment. In 2009, the Prime Minister offered an official apology to leprosy affected people for the way the Korean government had treated affected persons in the past. The members of the association spoke out and organised public hearings repeatedly until a bill was passed in the National Assembly (Sept 2008). They also engage in fund raising.

## **5. Introduction of key topics from the draft guidelines**

### **5.1 Training and capacity building**

Mr Abdou Yohanna from Niger discussed developing skills and the learning process. He mainly focused on the draft guidelines and emphasized the importance of capacity building of health care providers and beneficiaries as an essential component of improving quality of services.

### **5.2 Advocacy**

On the topic of advocacy, Mr Coulibaly Oumar from Mali shared what he had learned from his father who is also an affected person that it is not necessary to beg to make a living. He passed on this message to others. There is an association of leprosy-affected people in Mali and 700 people have registered to do alternative activities to earn a living and have stopped begging. The association trained them in reading and writing. Already, over 300 people have been trained. Advocacy is needed also in the area of education against the mistreatment of children and in ensuring access to health services. Helping people to get back into society is another area where advocacy is needed. Housing is an example where in Mali, only last year land deeds were given to affected people in the city (Bamako) and every registered person received a plot of land.

Dr Zhiqiang Chen representing HANDA Rehabilitation and Welfare Association from People's Republic of China shared his experience with regard to how it is important for the people affected by leprosy to be part of an organization as this has helped people to talk to the public and even to university students about leprosy.

### **5.3 Rehabilitation and community-based rehabilitation (CBR)**

Mr Sophea Leng from Cambodia working in Kien Kleang Rehabilitation Centre, Phnom Penh told about his responsibilities in training people who are admitted at the centre with disabilities. Self-care training and giving activities of daily life support to help people after discharge from the centre was also provided. The rehabilitation centre also supports education of some children having difficulties attending school as a result of being impacted by leprosy. Those children are provided with scholarships for education and some are even sponsored for university education. Other social activities such as providing literacy skills and basic computer typing skills were also undertaken. Some affected persons are referred for vocational training (e.g. mechanics, electronics and mushroom cultivation skills) or receive financial support to set up their own business in their communities.

The importance of long-term sustainability of services in the area of rehabilitation was discussed. The need to improve the coverage of such services is often given too little emphasis in pilot projects, particularly in CBR.

### **5.4 Prevention of disabilities**

Ms Binti Khofifah from Indonesia gave the background about the strategies and implementation process with regard to prevention of disability in Indonesia. There is an emphasis on self-care and self-care groups. Persons affected by leprosy are recruited and trained in prevention of disability and they are then expected to start self-care groups in their own area. An example of a successful self-care group that has transformed itself into a self-help group with a range of socio-economic activities was also presented. An important point is to identify a good leader and provide this person with the necessary skills so that he/she can be a good facilitator for self-help groups and in monitoring the success of self-care.

Prevention of disabilities is an important aspect of capacity building for affected persons and it is an important area where they could be involved in the provision of services. The need to incorporate such activities as part of all aspects of the leprosy control programme and not to regard it as a totally separate activity was highlighted. From the programme aspects, it will need to know the magnitude of the disability problem and the needs of the affected persons. For that purpose, involving representatives of affected persons in planning meetings for prevention of disabilities will help in identifying the needs.

### **5.5 Counselling**

Ms Maria Graciela Baez from Brazil gave a short presentation on counselling based on her work. Counsellors should have the ability to listen and to establish a relationship which is

based on empathy. As such, the affected persons due to their own experience can be in a better position to help in understanding others. It was pointed out that only giving information is not sufficient to overcome fear. Sometimes a whole family is afraid of getting leprosy. We need to find out why they are afraid and address this specifically.

## **5.6 Information, education and communication (IEC)**

Mr Jackson Jonathan Nyarko from Ghana shared his experiences in school as a result of his disabilities and how he decided to help children with difficulties after finishing school. Personal contacts and interaction with the community is the most effective way to communicate with the public and to reduce fear and misunderstanding. There are many things that the affected person can do in the area of IEC. One example was on how the administrator of a general hospital which was formerly a leprosy hospital, invited Mr Nyarko to come and share his experience with students.

## **5.7 Equity, social justice and human rights**

Ms Zilda Borges from Brazil gave a presentation on the importance of inclusion of affected persons and how to see human rights in the hearts of the people and in the community. Promoting meetings with community members and family groups to discuss leprosy and human rights is one way to reduce stigma and discrimination. In some instances affected persons hide inside their houses and by contacting them personally on a one-to-one basis it is possible to bring them out and try to solve their problems.

The importance of focusing on responsibilities also, rather than only on rights was discussed. It was agreed that both rights and responsibilities are important and should be included in the guidelines. Working together with human rights organizations to project the cause of persons affected by leprosy is considered to be important to promote leprosy-related issues.

## **5.8 Stigma and discrimination**

Mr Michihiro Ko from Japan gave a presentation on stigma and discrimination. Hansen's Disease's stigma in the community is part of a larger stigma in society against anybody who appears different or dissimilar and persists long after the disease itself ceases to be a public health problem. Some people are also affected by internal stigma. In order to fight against stigma, every measure listed in the draft guidelines is important, but Mr Ko was not optimistic even if all these measures are put into practice. He said that stigma against leprosy is deep in people's mindset even after the affected people have left this world. The only way for stigma to vanish is when society acknowledges the ownership of the history of leprosy and makes it a part of its social conscience. For this to happen, social history of leprosy must be remembered beyond generations. In the case of Japan, Mr Ko believes he has found one partner, the Citizen's Council on Hansen's Disease, who will carry this mission forward.

The participants discussed an important aspect of stigma which is dismissal. The role of stigma as a function in the minds of those who stigmatize – it has a function of self-preservation or preserving an existing power balance. It was stated that fighting for human rights will not make stigma go away. Stigma can only be tackled by understanding what this function is, the reason why people stigmatise, even if they are not aware of it. Only if we understand the function, the reason, we can address this reason and render the negative attitude dysfunctional and it will become amenable to change. It was pointed out that stigma cannot be eradicated, but it can be ameliorated.

There are human rights violations occurring in every country and this problem can not be solved by laws alone and the threat of punishment. In order to bring various stakeholders such as national programmes, civil societies and affected persons to work together in this sensitive area, the principle of ‘human responsibilities’ must be used in order to address the problems.

## **5.9 Gender issues**

Ms Ymelda Beauchamp from USA made a presentation on gender issues. It was explained that gender is a cross-cutting issue. During a conference on ‘women affected by leprosy’, women started to speak up and were empowered in this process. More workshops to empower women should be conducted in different countries.

## **5.10 Planning and management of services**

Mr Sang Kwon Jung from the Republic of Korea shared experiences regarding affected persons managing their own affairs through self-reliance. A video was shown to illustrate this. The resettlement was a success as a result of government, NGOs representing persons affected by leprosy and other organizations working on social issues. The Korean government listened to the views of the affected persons very carefully which was the key to the success of the resettlement programme.

## **5.11 Referral**

Mrs Lourdes Nevis Mary from India presented how the affected persons are aware of the gaps in the leprosy services. Affected persons can also help new patients to go for diagnosis and treatment and sometimes this involves giving health education or counselling to those who are affected. Affected persons must be aware of the services that are available in order to guide others to the right place. Most importantly, the affected person can be the key person in helping to obtain appropriate care for diagnosis, treatment of complications and rehabilitation. Taking an active part in the referral process and being involved in the planning will also help the affected persons to learn about the decision-making processes which will, in return, help them to take decisions for themselves.

The need to take care of referrals for people who live far away is another important aspect of the referral system and it was mentioned that organizations of affected persons could be approached to support a person who needs referral but is unable to go.

## **5.12 Resource mobilization**

Mr Alhaji Shehu S/fada Gusau from Nigeria talked about resource mobilization. In general, for implementing leprosy services funds are being generated by the government, NGOs and also by persons affected by leprosy themselves. For affected persons to be able to mobilize resources more effectively they will need to be trained in self-reliance and accountability.

Another area where affected persons can play an important role in mobilizing resources is by networking with other social welfare programmes. A good example is how the persons affected by leprosy are included in the national convention of persons with disabilities in Nigeria. ILEP members could provide technical as well as financial support in helping associations of affected people raise resources for activities at grassroot levels.

Persons affected by leprosy should not have to fight their battle alone. There should be a tripartite approach which includes affected people, NGOs who work for leprosy and other NGOs who work for similar causes. An inclusive approach is needed. Stigma could also be perpetuated un-intentionally by working in organizations exclusively for leprosy. However, it is important to note that the first step in fighting for the rights of an affected person is to see that they organize themselves well so that they can join others having similar agendas. Encouragement should be given for organizations of affected persons to become members of general disability prevention organizations.

For fund raising purposes using stories and pictures that generate pity serve to perpetuate stigma. Instead, success stories should be used. Associations of affected persons need to work together with other organizations to develop sound strategies for resource mobilization that use acceptable means and messages in the media.

## **5.13 Research**

Mr Hilarion M. Guia from Philippines presented how affected persons can be involved in research. One important issue is for the consent forms for research studies to be made available in people's own language. The reasons for not having sufficient involvement of persons affected by leprosy on research committees are because of the requirement to be an expert in one of the related areas. Producing a list of affected people along with their area of expertise will help researchers in identifying the appropriate person to be selected in their research committees and who can contribute to the work of the committee.

## **6. Overall discussions on the draft guidelines**

Many comments were received to improve the current draft guidelines. An introduction mentioning the aim of the guidelines and an executive summary is to be added. In addition, it should be emphasized that the involvement of persons affected by leprosy will improve the quality of the services.

The following general comments regarding the draft guidelines were made by the participants:

- Introduce in the beginning why the document is laid out in the way it is. Try to make the document and the chapters readable 'in one go' – put things together that belong together.
- Simplify the implementation part and leave it to the national programme to base their national strategy and interventions on the simplified version of these guidelines.
- Add references for further reading and links to the internet.

Dr Maria Aparecida de Faria Grossi, National Programme Manager from Brazil, showed a comprehensive diagram of the political and operational components and stakeholders of the National Hansen Disease Programme. Organisations of persons affected by leprosy are stakeholders in every component of the programme (epidemiology, management, integrated care, communication, education and research). A booklet for the public about human rights and responsibilities has been produced. The national programme has also supported persons affected by leprosy in operational research.

Dr Lai Ky, National Programme Manager from Cambodia, shared experiences regarding involving affected persons in leprosy services. The first activity that was carried out is in prevention of disability. Another is in peer-education as they help affected persons to set up self-help groups and encourage people with signs of leprosy to report to the health centre. The national programme is able to provide some support to these volunteers, but cannot offer regular jobs. Training activities for persons affected by leprosy and their children are needed to improve their knowledge and livelihood skills.

Dr Christina Widaningrum, head of the Indonesian national programme, explained about how the programme started first by involving affected people in forming self-care groups. Affected persons were also invited to take part in the planning process for new project documents for provincial leprosy programmes. They are also helping in educating the community. The Commission on Human Rights which is part of the National Alliance for Elimination of Leprosy (ANEK) will be making a film on human rights and leprosy this year.

Dr Egwaga, the national programme manager from Tanzania, explained how the national programme is working closely with persons affected by leprosy and how mechanisms have been developed to provide referral to patients. Persons affected by leprosy are being involved in annual meetings.

## **7. Conclusion and recommendations**

During the final session, the draft guidelines document was unanimously endorsed by all participants.

## **Annex 1**

### **Agenda**

1. Opening Session
2. Key issues in the Enhanced Global Strategy 2011-2015
3. Presentation by Persons Affected by Leprosy on their experiences in relation to education, social, economic and human rights issues : India, Japan, China, Philippines, Nigeria and Nepal
4. Presentation of Draft Guidelines
5. Discussion on Training and Capacity Building; Advocacy; Rehabilitation and Community Based Rehabilitation (CBR); Prevention of disabilities and Counselling.
6. Discussion on Information, education and communication; Equity, social justice and human rights; stigma and discrimination and Gender issues.
7. Discussion on Planning and management of services; Monitoring and evaluation; Referral; Resource mobilization and Research.
8. Presentations of the Group Discussions.
9. Overall discussions on the Draft Guidelines
10. Conclusion and recommendations
11. Closing

## Annex 2

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A meeting to develop guidelines to strengthen the participation of persons affected by leprosy in leprosy services was held in Manila, Philippines from 9-10 June 2010. The objective of the meeting was to review the draft guidelines. The guidelines are aimed at helping national programme managers to strengthen the participation of person affected by leprosy in the various leprosy services carried out by the national programme and its partners. By mobilizing affected persons, it is hoped that they will be able to contribute towards improving the leprosy services at the community level. Areas where affected people could be involved as partners, and how they can support leprosy services, were highlighted during the meeting. Affected people make presentations on what has been done in the areas of reducing stigma and discrimination, counselling, support for referral of patients, improving community awareness and rehabilitation.



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