

Leprosy and Human Dignity- South East Asia

Draft Program Outlines

[Program Duration: November 2010 to Dec 2013]

1. Background

For centuries, leprosy, or Hansen's disease, has been a source of fear and suffering due to the severe disfigurement that can result if the disease goes untreated. In fact, for much of the disease's long history, an effective cure was unavailable, and there was a widespread belief that the disease was highly contagious. In the 1980s, leprosy became a curable disease with the development of multi-drug therapy (MDT). Thanks to the concerted efforts of health authorities, NGOs and the World Health Organization, over 16 million people have since been cured of leprosy. Where there were 122 leprosy-endemic countries in the world in 1985, the disease has been "eliminated as a public health problem" (i.e. less than 1 patient per 10,000 population) in all but two today -- Brazil and Timor-Leste.

Although leprosy is no longer a public health threat in South East Asia, the stigma attached to the disease remains deep-rooted, as is the case in other parts of the world. Because many people today are not properly informed about leprosy, they harbor misconceptions about the disease based on past stereotypes. As a consequence, people affected by the disease, and even their family members, face discrimination with respect to education, employment, marriage and many other aspects of their lives, and tend to live on the margins of society.

However, people affected by leprosy themselves did not remain silent altogether. As early as in 1951 an organization by the people confined in leprosy sanatoria in Japan formed their own association to fight for their own rights. The world saw another similar movement, MORHAN (Movement for Rehabilitation of people with Hansen's disease) in Brazil. Similarly, networks of affected people were formed in India, Ethiopia and many other countries. On this background, the world saw a new development when an NGO IDEA (Integration, Dignity, and Economic Advancement) was established in the United States as the first international network of people affected by leprosy. IDEA posed a challenge to the traditional, expert-oriented approach prevailing in the world of leprosy-related activities.

In 2005, another important step was taken in India, the creation of the National Forum, a national network of people affected by leprosy bringing together all the existing local association of the persons affected by leprosy. This National Forum provides the people with a platform on which to work on equal partnership with various stakeholders.

Within the region of South East Asia, PerMaTa, network of people affected, was born in Indonesia, and the Coalition of people affected and people who support those affected is being envisioned in the Philippines.

There are growing interests to form self help groups organized by people affected by the disease in many parts of the region, though they vary greatly in size and scope of their activities.

However, empowerment of people affected by leprosy itself is not enough to break the vicious cycle of stigma and discrimination. To end discrimination, we must instigate a mass movement for change. We need to reach every corner of society with the facts about leprosy.

The international community is also starting to take an interest in this issue. In June 2008, the UN Human Rights Council unanimously adopted a resolution to end stigma and discrimination against people affected by leprosy and their family members. It was the first time in history that governments debated leprosy as a human rights issue. The principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members has been drawn up by the UN Human Rights Advisory Committee, and unanimously adopted at the 15th Human Rights Council Meeting in September 2010 and the Plenary Meeting of 65th Session of the United Nations General Assembly in December 2010.

In an attempt to end stigma and discrimination against people affected by leprosy, The Nippon Foundation launched the first Global Appeal to End Stigma and Discrimination against People Affected by Leprosy in 2006. The Global Appeal, involving different sectors of society from religion to education to civil society, has been announced annually since 2006, encouraging everyone in society to take part in the fight against the deep rooted stigma and discrimination against leprosy and those who are affected by it.

Leprosy and Human Dignity- South East Asia Program sponsored by The Nippon Foundation is designed to end the vicious cycle afflicting people affected by leprosy over many generations in the South East Asia Region. It seeks to involve different sectors of society, with the principle of having people affected by leprosy as an equal partner, to raise awareness about the problems concerning people affected by leprosy and to create an environment in which people affected by leprosy and their families can live a dignified life.

2. Vision

To create a society in which all people affected by leprosy in the South East Asian region are assured a dignified life in an equitable and cohesive environment.

3. Mission

- To sensitize various sectors of society to the issues surrounding leprosy.
- To strengthen partnership among people affected by leprosy and various sectors of society to realize an inclusive society.

4. Principle

People, families and communities affected by leprosy participate in all decision-making processes that concern them.

5. Goal

To form a national/regional platform of people affected by leprosy and their partners in South East Asian countries.

The objective of the Goal have two folds; the first objective is to sensitize society at large on situations of leprosy and people affected by leprosy, and mobilize various sectors including non-leprosy NGOs / stakeholders and people's organizations to work together in the effort of empowering people affected by leprosy, eliminating stigma and discrimination against people affected by leprosy, and provide them opportunities in order to realize true participation in society. The second objective is to empower national networks of people affected by leprosy in each country in order to promote communication and cooperation among them for various activities.

6. The Potential Partners

- Existing groups/associations/organisation by the people affected by leprosy
- Government bodies
- Human Right Commission in each country
- Business community
- Media
- International agencies
- CBOs, NGOs, INGOs, including Disable People's Organisation
- Educational and research institutions
- Religious communities
- Entertainment sector
- Professionals (legal, medical, social welfare and others)
- All members of society

7. Strategies

The Program will seek to attain its goals by means of:

- 1) Sensitization / awareness and publishing workshop of society;
- 2) Partnership building with various sectors of society; and
- 3) Networking of people affected by leprosy;

8. Desired Outcome:

On the part of society

- a. General recognition and increased awareness of leprosy and human dignity
- b. Reduced stigma against people affected by leprosy
- c. Acceptance of and support for mainstreaming of people affected by leprosy
- d. Establishment of regional, national and local networks to promote the human dignity of people affected by leprosy

9. Perspectives

The Program is unique and innovative in its approach of embracing all members of society as active participants and contributors in the process of creating a new, more harmonious, more inclusive society.

The Program can propose to the international community a South East Asian model to eliminate stigma against people affected by leprosy and their families. The partnership and network that will help mainstream people affected by leprosy can also serve as an effective approach to solve other social problems.

10. Project Implementation

Leprosy and Human Dignity- South East Asia Program will be implemented covering the following steps:

- 1) Consultative Meeting
- 2) Publicizing Workshop
- 3) Identifying and Appointing National Networking Agencies and /or Country Coordinators
- 4) Project Applications
- 5) Review , Evaluation, Research and Documentation

1). Consultative Meeting

A consultative meeting for disseminating the goals and guidelines of the project will be held at an appropriate venue/country in October 2010. The participants of the meeting will include

- a) National Program Managers and NGOs from Indonesia, Philippines, Cambodia, Vietnam, Thailand and Malaysia
- b) Delegates representing people affected by leprosy from each of the above mentioned countries
- c) Program Director / Consultant and
- d) Officials from TNF and SMHF

2). Publicizing Workshop

Followed by the Consultative Meeting, a Publicizing Workshop will be conducted in Indonesia, Philippines, Cambodia, Vietnam, Thailand, and if required Malaysia by the Program Director, Consultant, and national network agencies and/or country coordinators.

The terms of reference (ToR) for the Publicizing Workshop are:

- a) To publicize the Program and its details.
- b) To sensitize other sector on the issue of leprosy and human dignity
- c) To encourage interaction between various stakeholders such as National Program Managers, Officials of leading Leprosy and Non-Leprosy NGOs, community leaders from areas where there are significantly higher incidence of the disease is reported, and people affected by leprosy.
- d) To identify potential NGO / Non NGO and other agencies for implementing viable projects for accomplishing the objects of the Program.

Schedule of Publicizing Workshop:

The workshops should ideally commence from January 2011 and should end by March 2011.

3). Identifying and Appointing National Networking Agencies and /or Country Co-coordinators

It is essential for the effective implementation of the Project in the South East Asian Countries, reliable and committed agencies and individuals must be identified in each country and enlists their cooperation for coordinating in the implementation of the project. They will serve as the liaison agency /individual and work closely with the Project Management Team.

4). Project Applications

NGOs and other interest groups will be encouraged to apply for Projects Grant in a prescribed Project Application form which will be sent to the applicants after ascertaining their interest and implementation capability.

Project Areas for Funding:

- **Sensitization of society**
 - Advocacy campaign
 - Media campaign
 - Awareness campaign
 - Legal literacy workshops
- **Networking of people affected by leprosy**
 - Collection of baseline data
 - Assistance to networking organizations
- **Partnership building with various sectors of society**
 - Media workshops
 - Inter and intra sector workshops

Projects that do not fall in the above mentioned areas are also eligible, if the project fulfils the vision, mission, principles and other conditions.

A Project Selection Committee (PSC) will be set up to review the applications and recommend them for grants.

5). Review, Evaluation and Documentation

The Project Coordination Office will conduct post funding review and evaluation of the projects approved for grants.

11. Implementation Schedule

No	Description	Year			
		2011	2012	2013	2014
1	Publishing workshop	Jan - March			
2	Call for Application and Summit proposal	March - Apr	April	April	
3	Project Screening and Selection	May	May	May	
4	Announce approve proposal and start implementation	June	June	June	June
5	Annual Report		July	July	July
6	Monitoring and Evaluation		August	August	August

*Please note the above schedule is subject to change.