

Social aspects and rehabilitation

Workshop 1—people affected by leprosy as working partners

‘To get rid of the stigma, we have to have self-confidence first’

Cheng-Li Wang, China

‘We used to say that if society changes, we will be able to change. But we should not rely on this. We should discard this attitude and adopt the belief that society will change because We Ourselves Change. Let us believe this and make our lives rich and rewarding ones’

Miyoji Morimoto, Japan

‘People affected by Hansen’s disease do not need charity, but the opportunity to show we are capable, and in so doing perhaps change the world’

Christiano Torres, Brazil

In order to achieve a world without leprosy, it is essential to harness the invaluable resource which is represented by persons affected by leprosy. We must all work together as partners in this global effort. Promotion of a positive self image and the projection of a positive image in society is at the core of the issue.

To this end, the use of non-labelling, non-stigmatizing language is of primary importance. Labels such as PALs, victims and sufferers must be avoided.

In some countries work has been initiated to address the social and economic aspects of leprosy and some organizations have made this a priority. However, much, much more needs to be done.

We have identified the following areas for action:

- Guidelines for appropriate terminology are needed.
- Self-confidence among persons affected by leprosy needs to be promoted.
- Discriminatory legislation and practices continue in many areas and present barriers to full participation.
- Every individual affected by leprosy has the right to information, both about the disease and treatment, and regarding available social and psychological support.
- People involved in leprosy-related work need to develop a greater level of commitment to working in partnership with persons affected by leprosy.
- Information and understanding on the part of the general public and health workers needs to be increased.
- Stigma and prejudice are still major problems in many countries and are often perpetuated by the media and fundraisers. It is important to work with people affected by leprosy to analyse and identify factors that influence the level of stigma. This will enable the

development of appropriate strategies to correct misunderstanding about the disease and misconceptions about those individuals affected by it.

- In many countries, there is need to change the attitude of health workers. Poor communication skills are a major problem which adds to stigmatization, low self esteem and hopelessness. Discriminatory attitudes of health personnel also need to be addressed.
- Attention to potential social and psychological problems is paramount. Training curricula of schools and universities should also include social and psychological aspects.
- Opportunities for self-expression are important for others to see that a person is more than his or her disease.
- The potential for self-stigmatization is high, even amongst persons with no visible disabilities, if support is not available.
- Attention to psycho-social issues by WHO and other influential organisations is of great importance.

RECOMMENDATIONS

1. Guidelines for appropriate terminology, taking into consideration cultural differences, should be developed with input from people affected by leprosy. These guidelines should be published and distributed.
2. Socio-economic improvement of persons affected by leprosy results in increased self-confidence and prevents marginalization. Skills development training and loan schemes aid in empowerment and in ensuring that individuals lead productive lives with dignity as fully participating members of the community.
3. An inventory of discriminatory legislation and practices throughout the world should be compiled. Individuals and associations of people affected by leprosy should be mobilized and unite with others for the repeal of these laws and discriminatory practices.
4. Information materials should be developed with input from persons affected by leprosy that address both medical concerns and social and psychological needs.
5. Creative strategies should be developed that will renew the commitment of policy makers to issues related to leprosy.
6. Stigma related factors should be researched and analysed to develop appropriate health education strategies and define specific messages. Full use of the media should be made and societies of professional journalists and the media in general need to be pushed to keep issues related to leprosy on the agenda,
7. Health education about leprosy for the general public and health workers should be intensified in order to prevent the distribution of erroneous information.
8. Training in communication skills should be required for every health care worker.
9. Curricula of schools and universities should include socio-psychological aspects of leprosy.
10. Writings, music, art and other forms of self-expression by people affected by leprosy should be encouraged and utilized to create a positive image.
11. People affected by leprosy with potential leadership skills should be identified to participate in self advocacy workshops. This will promote the creation of self-help support groups. In this way, individuals will be empowered to assist each other cope with feelings of fear, insecurity and hopelessness. This, in turn, will result in people who can effectively educate the public.
12. Efforts should be made to include leprosy-related issues on the agendas of meetings outside the scope of leprosy.

13. WHO and other influential organizations should create advisory boards which include people affected by leprosy to help in the formulation and implementation of policies directed at the elimination of prejudice and discrimination associated with leprosy.

‘We want to be a part of the process, to be in a position to help others as well as ourselves. It is our desire that our participation will be accepted as a giant leap forward towards the development of an international partnership aimed not only at the elimination of Hansen’s disease from the face of the earth, but also at reaffirming the humanity of all persons affected by Hansen’s disease. A Quest for Dignity’

Bernard Kawaka ‘Okalani Punikai’a, Hawaii, USA

Workshop 2—social and economic integration

The social and economic integration of persons affected by leprosy as an important means for promoting human dignity, reducing stigma, increasing economic independence and efficiently using limited community resources.

The level of integration achieved by people affected by leprosy differs widely around the world. While much progress has been made in integrating the medical care of people affected by Hansen’s disease into the general health care systems of their countries, less progress has been made in integrating them into established community based socio-economic support systems.

One possible reason for this is that the development of socio-economic support programmes fall outside the missions of the Ministries of Health and of the WHO which coordinate the medical aspects of Hansen’s disease work. In recent years, almost total concentration has been on the delivery of MDT in order to achieve public health goals. Another reason is the complexity of the socio-economic problems that need to be addressed for true integration to occur. Thirdly, most non-governmental organizations which have a strong leprosy focus have few professionals at headquarters level or in the field with much training and experience in socio-economic integration. Fourthly, there is little contact and cooperation between Hansen’s disease organizations and those international, national and local government and non-governmental organizations which do have expertise and programmes. And finally, of course, there are the problems of limited resources, remaining stigma and satisfaction with the status quo.

Considering the above situation, the Workshop on Social Integration recommends:

1. That the social and economic integration and empowerment of persons affected by leprosy become a priority for leprosy programme planners along with cure and prevention of disabilities.
2. That attempts be made by leprosy focused organizations and divisions to actively involve other appropriate UN agencies, government ministries, international, national and local NGOs with expertise and programmes in social and economic matters in the search for integrated, affective and efficient solutions to the medical and non-medical problems of persons affected by leprosy.
3. That persons with practical experience and training in socio-economic issues be designated within NGOs with a focus on Hansen’s disease to promote access to and creation of integrated, efficient and effective programmes at the national and local levels for education, vocational training and placement, small business development, care for

the severely disabled and destitute, housing, transportation and other important socio-economic needs.

4. That these socio-economic 'experts' have regular meetings under the auspices of ILEP at the international and national levels to share information about successful programmes and to interact with 'experts' in organizations from inside and outside the leprosy world on subjects of mutual interest.
5. That in project areas, surveys be made of the socio-economic needs of people affected by Hansen's disease and of individual, local and national resources for solving these in an integrated manner. The aim of such surveys is efficient and effective action to resolve them.
6. That people affected by leprosy be empowered to develop solutions to their problems in partnership with other community members.

The committee also warned against the following dangers:

1. Failure to consider socio-economic implications of medical decisions (for example, long internment for treatment, surgery, rehabilitation or research, causing institutionalization).
2. Goal confusion. Who is the primary beneficiary of a proposed programme? The institution or individuals affected by Hansen's disease? At times people affected by the disease are kept in an institution because they are more needed to guarantee the success of an institution's programme than because of their own needs.
3. Isolating people affected by Hansen's disease by establishing socio-economic programmes in former leprosy institutions rather than in the community.
4. Excessive paternalism: sometimes for aged and severely disabled, paternalism is needed. For others it can be deadly to the spirit and should be avoided. In some countries people affected by leprosy have more special privileges (pensions, housing, transportation, etc.) than people with similar problems. This can create resentment and segregation.
5. Exploitation: lack of fair payments for work performed by people affected by the disease. Also excessive exploitation of the leprosy image to bring in donations. This harms normalization.
6. Inadequate solutions for individuals. People are different. Some do better employed, some in setting up their own small business, some in cooperatives, others in sheltered workshops and others because of age and disability should be taken care of.
7. Not actively involving persons affected by leprosy and their families in the process of solving their medical and socio-economic problems.
8. Not considering other needs besides employment: what about transportation, day care, housing, aids for the disabled, all of which make employment possible?
9. Sustainability: creating non-viable programmes. How will the individual or the programme continue after the initial grant has dried up? There has to be a regular flow of cash return. That requires products that people want to buy with fair pricing and a fair profit margin. It means carefully calculating costs and returns before setting up a programme.
10. Evaluation. Programmes needs to be carefully and honestly evaluated in relation to clear, established objectives.

Workshop 3—changing community perceptions and ensuring community involvement

The Conference organizers had given the workshop four key phrases: changing community attitudes, community involvement, use of mass media and community action.

CHANGING COMMUNITY ATTITUDES

1. Opening the discussion, one of the PALs mentioned that change in the perception of PAL ought to be the first step in changing community attitudes. To quote 'when I was informed of my diagnosis as a leprosy patient, it was almost a declaration of a death sentence by a doctor. This was further endorsed by the priest when this was related to the sins in my earlier life. This was a real trauma and the beginning of a psychological battle.' If one has to overcome this factor, apart from building the psychological confidence of PAL, it is essential to orient religious leaders and others around the PAL in his family or community so that they understand the real and scientific nature of the disease. This process of demystifying the disease of leprosy must begin simultaneously with the clinical diagnosis of the case. This can be further supported by strengthening and modifying the attitudes of the family, peers, and the community so that PAL is reassured of his continued status in his community.
2. Empowerment of PAL. Discussing empowerment, the workshop believed that empowerment means enabling PAL to fully utilize all his rights—political, social and economic—like any other citizen. Empowerment also means provision of opportunities for upgrading the quality of life like any other citizen and to fully accomplish the developmental potential. There are positive and negative aspects of empowerment. There are laws, regulations and conditions that create obstacles and constraints in the process of empowerment. For example, right to education, communication, marriage, property or voting are all fundamental rights. Denial of any of them would spell denial of human rights. To overcome these negative factors, a special effort will have to be made so that the empowerment process is not hindered. To convert the negative factors into positive, involvement of the community and media will be very essential, but ultimately the goal will be equalization of developmental opportunities.
3. The Community Based Information and Education Campaign as thought of as the best method to provide education and enlightenment to community at large and to PALs in particular regarding the disease and its treatment, and also regarding the rights and responsibilities of PALs. It was felt that such a campaign should be organized at the local, state, and national level with a partnership between PAL, NGOs, and governments. The media support for such a campaign, along with non-governmental service organizations may go a long way to provide follow-up and sustainability to the campaign.
4. Media has a significant role in demolition of stigma. Narration of experiences from various countries indicated that many times electronic and press media does not have up-dated and scientific information on leprosy with the result that the image created is a stereotype resulting in social stigma. This may be unintentional but the fact remains that many meaningful efforts will have to be made to change and restructure the image of leprosy in the print and electronic media. The first step will be to evolve a media strategy. It was suggested that WHO may play a leading role along with country governments so that country-specific media strategy is developed. This strategy will answer what product we want to market, how we want to market, what is our audience, and what is our focus. The Workshop felt that the next step will be to develop orientation programmes for print and electronic communicators at the district level, rather than the national level so that feature writers, editors of Sunday editions, and producers of TV and radio documentaries can create the correct image. The third step would be to develop a data bank on leprosy and a collection of stories with human warmth and photographs that may be attractive to the press. Religious, socio-economic leaders and cult figures may be encouraged to undertake

an advocacy role on behalf of leprosy. For this campaign, use of folk lore, folk arts, and theatre may be very useful to suit the cultural context. It was discussed whether the negative image was created because of disability and disfigurement resulting in the stigma. The workshop, however, thought that the positive aspects expressed in the declining numbers of disability and lowering of percentages of active cases and disfigurement may be highlighted to create a positive image.

5. There was an extensive discussion on stigma. Stigma was defined as a social response on a continuum beginning from total rejection to total acceptance expressed in the form of social distance. Measurement of social distance and quantification of stigma are new researchable areas in the social sciences. It was felt by the participants that when stigma is overcome, it can serve as a positive element in the battle against leprosy.

COMMUNITY INVOLVEMENT

The members felt that the majority of the PALs in developing countries belong to agricultural rural communities. In these communities family either nuclear or extended and the self-contained society provide a safety net and security. If one is able to utilize this safety net, it can be an effective instrument in prevention, identification, treatment and rehabilitation, ultimately leading to community based rehabilitation. The bonds in rural society are strong and if appropriately used, the entire community could be involved in preventing dehabilitation of PAL. It was also pointed out that while the leprosy problem, looks very large globally, if it is seen as a community problem at the village level, it is likely to be manageable. The additional advantage is of using the traditional institutions, such as a church, Sunday school, or village panchayat. Discussing this issue further, it was felt that the level of the village there is a definite change in the role of the health worker. This change from a provider to a facilitator, or from provider to health educator and counsellor is an important change in our battle against leprosy, but to achieve this we will have to provide technical support to the community leaders who have their roots in the village itself. With the electronic revolution, the supply of information may not be the problem. The problem may be of selecting the right package for the right worker.

USE OF MASS MEDIA

While mass media is enlarging its scope to cover the rural and urban communities, it is struggling hard to cope with demands that are made on the limited space, either on the page or on the screen, or on the air time. Naturally leprosy will have to compete with many developmental priorities. While communicators are ready to help, efforts on the side of NGOs, governments, and WHO are also necessary. It was pointed out that a recent survey has indicated that the international press releases are either full of statistics or are diluted statements. The government communication are highly politicized. What is needed is a copy which is scientific, true and attractive to the reader to catch his attention. For this purpose, we have to use the three steps mentioned earlier about media strategy, orientation and data banks.

COMMUNITY ACTION

It was thought by the Workshop that community action is primarily in the area of decision-making. These decisions pertain to the future of PAL. This may be in the field of economics,

politics, or the social structures. For giving them the opportunity to make decisions, empowerment of the PAL is a prerequisite. The community participation or action is going to depend on awareness of the people. The workshop believed that awareness is not merely registering the information, but is critical awareness leading to social action. With a change of role of community health workers, they need to be oriented in basic skills of community organisation, counselling and communications. For this, support will have to be given to develop and disseminate a simple manual along with training modules for community participation and organization. Such manuals will have to be field tested before they are used for community involvement. It was also mentioned by the workshop that community action will also mean networking, not only at the local level but also at the national level. This networking need not be restricted only to organizations working in the field of leprosy or health, but the networking could include all developmental organizations such as the National Council of Women, Council of Child Welfare, Social Security Association, etc. Such a network would help develop interpolation of ideas and help strengthen a common front against leprosy.

Workshop 4—global needs and opportunities for rehabilitation

The Workshop made the following recommendations:

ESTIMATING THE GLOBAL NEED FOR REHABILITATION

1. A conceptual framework needs to be adopted by those involved in rehabilitation in the field of leprosy. The workshop recommends that the WHO International Classification of Impairments, Activities (Disabilities) and Participation (Handicaps), draft 2 (ISIDH-2) should be adopted for this purpose. This would facilitate communication and building alliances with those working in other areas of rehabilitation.
2. To assess the needs at the different levels of impairment, activity and participation, and to monitor and evaluate interventions at these levels, additional tools and indicators are needed. The workshop recommends that as far as possible existing tools should be used or adapted for use with leprosy-affected people. Examples: for impairment grading the WHO grading system, for ADL the questionnaire from the WHO disability training manual and for participation/handicap the grading developed by Dr P. K. Gopal or the assessment developed by Sr. Senkenesh in Ethiopia.
3. The Workshop recommends that a workshop should be convened in the near future to look at what tools are currently available (see 2), how they could be used or adapted for use in leprosy, and to make recommendations for their use. This should be done in coordination with the GLRA-organized workshop on socio-economic rehabilitation in May 1999.
4. The workshop recommends that a special study should be done in selected areas to devise a more accurate method to estimate the global needs in relation to rehabilitation.
5. The workshop recommends that a cohort-based system of assessment and reporting of impairment status of people registered in leprosy programmes should be urgently introduced. This should be included in the appropriate reporting formats of the WHO and ILEP. The aims are quality assessment of programmes and collection of data for advocacy purposes.

6. It should be recognized that people with impairments (even deformities) are not necessarily in need of rehabilitation. Rehabilitation should address problems in activities of daily living and social participation. People who do not experience problems in these areas may happily live with their impairments. However, many would still need to continue to prevent their impairments from getting worse. They need to learn how to do this and may be in need of certain protective devices.
7. Needs assessment should incorporate or be targeted at providing solutions. Interventions should follow such assessments. This is also the WHO approach to CBR. Community workers are trained in problem solving rather than in standard techniques for particular disabilities. Needs assessment should therefore not be done in a vacuum, but should take into account the resources (potentially) available for rehabilitation interventions in a given area. The workshop therefore recommends that detailed needs assessments, such as surveys should be undertaken in not too large, well-defined areas, where rehabilitation services can subsequently be offered or facilitated.
8. The one to define the (nature of the) need for rehabilitation should be the affected person him/herself. Experience has shown that the most successful rehabilitation programmes are those where people assess their own needs. A study in Ethiopia found that of people affected by leprosy only 20% identified themselves as needing rehabilitation. The workshop noted the need to raise awareness of rehabilitation opportunities among the target population, so that they could take well-informed decisions about their needs. Reaching those most in need may be the most difficult, for reasons such as lack of motivation.
9. Rehabilitation requires a process of understanding, which may need a process of growth in the affected people, before they are ready to participate. Motivation by (good) example is a powerful tool in this context. People who have initially rejected rehabilitation should also be given a chance to change their minds.
10. From the point of view of the affected person, their needs are physical, social, mental and spiritual. Our rehabilitation approach should therefore be holistic instead of compartmentalized.

IMPLEMENTATION OF REHABILITATION

1. Governments and organizations need to be stimulated/motivated at different levels to promote rehabilitation. This should be done with a multisectoral approach. Possibilities include the setting up of a multisectoral steering committee at the national level (e.g. Ethiopia) or decentralizing to more peripheral development programmes (e.g. Sri Lanka). In the experience of AIFO, achieving this at the district or provincial level is easier than at the national level. Each country or project needs to see which approach would be the most appropriate/effective in their situation.
2. The workshop noted the problem that people affected by leprosy needing rehabilitation are often spread out over a large geographical area. Modified CBR approaches may therefore be needed to address their needs.
3. Where services or infrastructure for leprosy work are established, there is a great potential for 'reverse integration' in relation to rehabilitation. General CBR services could be set up around existing leprosy services.
4. The workshop emphasized the importance of referral and support systems for rehabilitation without which CBR programmes cannot function. A network of available rehabilitation and referral facilities should be created.

5. Centres like ALERT could function as regional focal points for training and collection of experience and information and could serve as resource centres on rehabilitation.
6. The workshop recommends that leprosy workers should take advantage of documents such as 'The Standard Rules for Equalization of Opportunities for Persons with Disabilities' by the UN (1994). These should be studied to see how they would apply in the national or local situation, regarding people affected by leprosy.
7. Rehabilitation projects and proposals should be made gender sensitive. Women should be included as staff and volunteers, ideally proportional to the percentage of women needing rehabilitation.
8. The workshop stressed the importance of marketing awareness and research in relation to vocational rehabilitation. The expertise present in other organizations should be tapped.

Summary

MAJOR ISSUES

1. Equal rights and opportunities for people affected with leprosy to develop their full potentials is a matter of human rights.
2. Leprosy and its consequences are a complex human problem leading to discriminations, stigma and prejudices.
3. There is lack of complete understanding about global needs for rehabilitation.
4. Concentration on medical care of people affected with leprosy (MDT, surgery, etc.), though vastly beneficial, has led to highly inadequate psycho-socio-economic rehabilitation in a holistic manner resulting in poor quality of life.
5. People affected with leprosy have not been full partners and decision makers for their own development and lack self-confidence and opportunities for self-expression.
6. Community and health providers lack the right attitude and sensitivity, thus failing to assist in the empowerment of people affected with leprosy in an integrated manner.
8. There is insufficient coordination at international/NGOs/government levels to utilize scarce resources to allow full development of people affected with leprosy.

RECOMMENDATIONS

1. Estimation of global needs: using existing tools with necessary modifications, need assessment and relevant interventions in rehabilitation at global/national/field levels requires urgent attention to enable all concerned to take specific actions recognizing that not all require rehabilitation.
2. Change in perceptions and attitudes: using mass media and other tools like training, counselling, etc., changes in behaviour resulting in positive attitudes of communities, patients, their families and health providers are of paramount importance to ensure social amalgamation and reduction of stigma/prejudices.
3. Empowerment: provide information, education skills, resources and motivate people affected with leprosy to empower them to lead a dignified, self-reliant quality of life and achieve their full potential with access to equal opportunities.
4. Community based rehabilitation: CBR with modifications is appropriate in most of developing countries to provide sustainable self-employment and self-dependent living requiring simple skills and focusing on women who are excellent agents of change.

5. Community action: increase community awareness through use of better communications: field-based training and counselling to mobilize community support and participation in practical help to help people affected with leprosy in their social acceptance and rehabilitation.
6. Referral and support services: CBR will be successful provided diversified individual needs are met covering physical, medical and rehabilitative areas (but should avoid excessive institutional care) through referral and support services.
7. Discriminatory legislation: all discriminatory legislation must be repealed in countries/states where it exists. Appropriate terminology in relation to people affected with leprosy must be developed with their full consent.
8. Multi-sectorial approach: comprehensive rehabilitation with socio-economic emphasis is possible with involvement of relevant ministries of governments along with support of UN agencies and NGOs. The political commitment at governmental level is imperative.
9. Non-governmental agencies: non-governmental agencies, both at international (e.g. ILEP/ILU) and national levels (leprosy and non-leprosy) are critical in years ahead for their commitment and available resources in promoting rehabilitation. They need to strengthen their activities by acquiring well-trained rehabilitation experts and co-ordinating at field/central levels.
10. Research: ongoing research to find new effective and efficient rehabilitation methods, social aspect research, and market research can make significant improvements for the future.

C. S. WALTER (Moderator)