

## SOCIAL/ECONOMIC REHABILITATION

Dr. S. D. Gokhale  
Chairman  
International Leprosy Union  
Gurutrayer Smarak  
Bharat Scout Ground  
1799/84, Sadashiv Peth  
Pune 411 030, India

I would like to begin by bringing to you a quotation from Mahatma Gandhi, the great visionary of the last century. He says: "Leprosy work is not merely medical relief, it is transforming frustration of life into joy of dedication, personal ambition into selfless service. . . ."

### Background

Leprosy has a unique dimension. In no other disease are individuals made to leave their families and forced to live as outcasts. For many affected by leprosy, overcoming the infection is not sufficient to allow their return to a previous lifestyle.

Until recently, those abandoned by their families were cared for in institutions. Since the treatment lasted for many years, for them the institution was a point of no return. Such institutional approach was considered "rehabilitation." Now we consider it as chronic dependency with little possibility of reintegration. With advances in treatment procedures and surgery, this institution-based "rehabilitation" has become outdated. It gives diminishing returns. The longer one stays in the institution the lesser is the possibility of rehabilitation. Through social and economic rehabilitation, people cured of leprosy are helped to regain their dignity. They are helped to find productive employment, to contribute to the economy and to find their place in the community. There is a sea of change between these two concepts.

### Individual and not statistics

To understand leprosy one must have it; the next best thing is to live with people who have it. I lived for an unforgettable number of years among people who had leprosy.

Leprosy and, in turn, deformity and disability bring about deeper and fundamental changes in the character, personality and attitude of people. These changes remain even after the people are cured. Life will always be different for them because they have been "there." This change goes beyond the initial reactions of outrage, trauma and self-loathing. It is a change in the intrinsic human being. It is a change of soul.

In the field of leprosy there is little pretence, no sophistication, or concealment. Here we deal with raw human emotions which exist on the bedrock of life. Therefore, knowledge of prevalence rates and statistics is not enough. What is needed is "understanding" not only of the disease but also of the human face of leprosy.

### Present status

The Director General of the World Health Organization (WHO) in the recent regional meeting in Delhi in 2000 has reported: At present, five countries of the Region (Bangladesh, Bhutan, Maldives, Sri Lanka and Thailand) have achieved the elimination target of less than 1 case per 10,000 population at the national level and hope to achieve this target at the subnational level in the next few years. The leprosy situation in Indonesia shows a declining trend, and the country is expected to achieve the elimination target by the end of 2000. India, Myanmar and Nepal hope to achieve the elimination goal at the national level by 2003.

To sum up:

- Institutionalization gives diminishing returns. Longer a person stays, he/she develops an institutionalized personality

and chronic dependency. Institution must be used only as a last resort.

- Leprosy leading to deformity and disability brings about not only trauma but a change in the intrinsic human being.
- National averages are deceptive. In Bangladesh, Thailand, Sri Lanka and India there are still districts or pockets which are hyperendemic. For example, Bangladesh, which is declared to have achieved elimination, has still 13 districts which are hyperendemic. Similarly, Thailand which is declared as having achieved the elimination goal still has seven districts which are hyperendemic. Sri Lanka has three districts. India, which has not yet achieved the elimination goal, has only five states which are hyperendemic. Therefore, the question is when can we say that elimination is achieved? Should it be based on national average or on the district level statistics. What is needed is a new decentralized strategy focusing on the pockets of endemicity.
- Averages may be an easy indicator for statistics. But for the human being who is affected by leprosy, his suffering is 100% and not 1 upon 10,000. Therefore, while demographic projections are important ultimately it is the human face of leprosy that matters.
- Global alliance to be effective must have a very close collaboration with non-governmental organizations (NGOs) at the local level.

To enlist political commitment, WHO, The Nippon Foundation, Novartis and the International Federation of Anti-Leprosy Associations (ILEP) launched the Global Alliance for Leprosy Elimination at the Third International Conference held in Abidjan, Ivory Coast, in November 1999. Providing the last push is thus critical to success. This requires further strengthening of existing partnerships (Sasakawa Memorial Health Foundation, Nippon Foundation, ILEP, Novartis, DANIDA, World Bank) and the active involvement of both national and international NGOs.

WHO has estimated that at least a quarter of the total number of leprosy cases in the world have deformities. Leprosy is a far more serious problem than the sheer number implies, because disfigurement and dis-

ability lead to dislocation as a result of the social stigma.

Multidrug therapy (MDT) involves drugs which are expensive. However, the treatment periods are much shorter compared to the days when dapsone was used, in some cases, for life. Only in yesterday's state-of-the-art lecture on medicine we heard that perhaps with the new combination of drugs even one shot will be enough to cure leprosy. This is very heartening news.

In recent years great progress also has been made in the development of a vaccine against leprosy, which is currently undergoing field trials in Venezuela, Malawi and India.

To sum up:

- Leprosy is an ordinary disease with extraordinary social and economic implications
- Mere numbers do not adequately express the social and economic loss
- Killing of *M. leprae* in the human body alone cannot solve the problem

**Disfigurement and displacement.** Leprosy primarily affects the nerves. The damage is irreversible because the nerve cells do not possess the power of regeneration. This results in damage to hands and feet. The deformity consists of depression of the nose, loss of eyebrows, sagging of skin, claw hands and ulcerated feet. Most leprosy patients admit that improvement in appearance is as important as improvement in the function.

The important issue that needs to be clearly analyzed is: The incidence of deformity in leprosy is high and facial deformities are more common than those of the hands and feet.

To sum up:

- Disability due to leprosy must be treated as part of a total disability rehabilitation program
- LEP and MLEP must include prevention of disability and social and economic rehabilitation as an integral part
- The percent of debilitation is equal to the degree of disability and intensity of social stigma
- Measurement of the degree of disability must include social/psychological and economic factors.

**Situation of disability in developing countries of Asia.** According to the Economic and Social Commission of Asia and Pacific, it is estimated that there are some 450 million disabled persons of all categories in the world today, the vast majority of whom live in developing countries. It is a sad fact that in the developing countries a majority of the disabilities are preventable and are generally related to poverty, disease, malnutrition and ignorance. Most of the population in these countries is rural, agriculture based. Insufficient resources for medical prevention and care coupled with the lack of political will result in high prevalence diseases, leading to physical impairment and disability.

To sum up:

- Disability due to leprosy must be treated as part of a total disability and rehabilitation program
- LEP and MLEP must include a prevention of disability program and social and economic rehabilitation
- Prevention of debility and socioeconomic rehabilitation are neglected even now. WHO has not done adequate work in the area of rehabilitation of the leprosy cured. CBR movement has neglected leprosy where it is most required.

#### **Indian scenario**

How much has the profile of the rehabilitation including disability due to leprosy changed in the past two decades in India? The new Act on the "Rights of the Disabled" does not do justice to those disabled due to leprosy.

The Indian Ministries of Social Welfare and Health implement a number of programs/schemes to provide suitable rehabilitation services in order to enable all disabled to join the mainstream.

To sum up:

- Disability prevention services must form a part of the health care scheme.
- The Primary Health Workers need to be oriented in the skills of counselling, communications and community organizations.
- In all the programs, the advantages given to leprosy cured are less than 1%,

which shows the need to integrate leprosy work in the general health services.

**Discard the vertical programs.** It had been the Western model and practice to lift both the person and the problem out of the social context and to attempt to find a solution in a closed institutional setting. This process was supported by legislation restricting the life of the leprosy affected. In Japan, a legal case has been filed by cured persons who had to undergo inhuman treatment during their institutionalization, and this case of breach of human rights seeking compensation is attracting world-wide attention. Now in India, we have only slowly learned that a person with disability is basically a human being with equal rights. Therefore, to uproot a disabled person from his family is likely to endanger his dignity and destroy his future.

the creation of a separate vertical program for leprosy is an outcome of social stigma. Separate development has not only segregated the leprosy-affected but also the doctors and service providers. It may be interesting to note that a majority of the countries in which leprosy is declared as eliminated did not have a vertical program. Therefore, it is the need of the hour to demolish the vertical program as soon as possible and to treat leprosy rehabilitation as part of the overall disability rehabilitation.

To sum up:

- National averages are deceptive
- It is essential to focus on subregional and district levels

#### **Some definitions**

Impairment = concerned with abnormalities of body structure and appearance and with organ and system function, resulting from any cause. In principle, impairments represent disturbances at the organ level.

Disability = reflects the consequences of impairments in terms of functional performance and activity at the level of the person.

Handicap = concern with the disadvantage experienced by the individual as a result of impairments and disabilities; and reflects interactions with adaptation to the individual's surroundings.

Dehabilitation = means uprooting of an individual from his natural filial and socio-

economic environment and leads the person to isolation.

### What is rehabilitation

The term "rehabilitation" refers to a process aimed at enabling people with disabilities to reach and maintain their optimal physical, sensory, intellectual, and social functional levels, thus providing them with the tools to change their lives toward a higher level of independence. Rehabilitation may include measures to restore functions or compensate for the loss of a function.

Community-based rehabilitation (CBR) is defined in the ILO-UNESCO-WHO Joint Position Paper as follows: "Community Based Rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services."

### Targets set for Asia

The economic and Social Commission of the United Nations in April 1992 declared the period of 1993 to 2002 as the Asian and Pacific Decade of Disabled Persons. The Asian Decade of Disabled Persons focuses on the achievement of full participation and equality and has set the following targets: 1) Initiation in 1997 of public education campaign directed at the prevention of the five most prevalent preventable cases of disability; 2) Achievement by 2002 of a minimum 50% reduction in the incidence of three preventable causes of disability; 3) Inclusion by 1996 of persons with disabilities, in particular women, as active participants in the formulation of CBR strategies and in the implementation, and 4) Development of a national CBR strategy which will include training in CBR management so as to provide a framework for action with a special focus on rural and slum communities. However, it must be stated that these goals have not been achieved.

To sum up:

- "It is unfortunate that work on disability due to leprosy is yet at a very preliminary

stage in most of the Asian countries."

- The targets set are not yet achieved.

**People with disabilities.** An important objective of any campaign should be to increase public understanding of what disability is and an awareness of the problems it may bring. Many people today equate disability with restrictions in physical mobility. Disabled persons do not form a homogeneous group; they have different problems that demand different solutions.

The deformities associated with leprosy further increase the poverty of the people. People affected by leprosy are often the "poorest of the poor" due to stigmatization, dislocation and displacement, and loss of home, land, income and employment. These factors are often in direct proportion to the level of deformity among people affected by leprosy and form a vicious circle impossible for the individual alone to break through without societal help.

### Organizations of the disabled people.

In accordance with General Assembly Resolution 3447 (XXX), containing the declaration on the Rights of Disabled Persons, the United Nations has suggested that organizations of disabled person may be usefully consulted in all matters regarding the rights of disabled persons.

More than 500 million people in the world are disabled as a consequence of mental, physical or sensory impairment. They are entitled to the same rights and equal opportunities as all other human beings. Too often physical and social barriers in society hamper their participation. Because of this, millions of the disabled, including those due to leprosy, in the world often face a life that is segregated and de-based.

**Constraints.** Collection of data on the incidence and prevalence of disability, especially in leprosy, continues to be a critical issue. If disability issues are to get higher priority with governments for funding and action, accurate data must be collected and disseminated. To ensure data comparability, standard terminology in accordance with the international classification of impairment, disability and handicap should be used.

Development of training materials and programs of rehabilitation is not readily available.

### Social and economic rehabilitation

Social and economic rehabilitation is a unique task. Speaking at the International Leprosy Association (ILA) Conference in Beijing in September 1998, Dr. Arole, Director of the Jamkhed Project in India, identified the principles upon which that response should be based: "A change of paradigm is needed, recognizing people as subjects, not objects, and workers as enabling and not providers. Interventions must be supportive and responsive, empowering rather than diagnostic. They must include addressing the needs and resources of the community and extending its capacity."

A rehabilitation agency must recognize the impact of leprosy on the physical, psychological, social and economic life of the individual. It should be responsive to the concerns of individuals affected by leprosy. This requires a sensitive approach so as to restore dignity and self-respect; and ensure participation and empowerment. The rehabilitation agency should be aware of the concerns of the families and communities affected by leprosy who have an important role to play in rehabilitation.

To sum up:

- Rehabilitation agencies must focus on training community workers in counselling, communications and community organizations
- Kits for village workers
- People's participation is a must, especially by women as in Bangladesh and Myanmar
- Involve traditional healers like Dhama Zankari in Nepal and Vaidus in Maharashtra
- Use cured persons to mobilize the community

**The holistic principle.** "Holistic" means an awareness of, and responsiveness to, every aspect of life. It includes activities that address these aspects, and requires teamwork of different professionals toward prevention of disability, elimination of dehabilitation and achieves social integration.

Special attention has to be given to people whose self-esteem has been eroded by leprosy, actively involving them in decisions about improving their quality of life.

This leads to "empowerment." Empowerment is an ability of the client to make decisions and manage the transactions of everyday life. A community-oriented approach ensures that interventions to heal people affected by leprosy are acceptable to the community and, therefore, will lead to sustainability. Rather than creating special services for people affected by leprosy, one should use existing services through networking.

**Stigma and injustice.** Stigma may be due to color, race, disability, disfigurement or political and religious prejudices. Stigma is a social expression on a continuum of social reaction beginning with complete rejection. Stigma is the chief cause of dehabilitation or the social and economic dislocation that people affected by leprosy experience. Overcoming such stigma is an essential step toward reintegration in society.

The rehabilitation process must concentrate on overcoming the ignorance and prejudice that underline stigma. This can be done by running education campaigns. Activities may include exhibitions, leafleting drama, street-plays, posters, films and radio and TV programs. The media has a powerful role to play in this regard. Simple messages like: "Leprosy is Curable—All It Needs Is Your Support" "Do not fear it, treat it." This goes a long way to change community attitudes.

### Media's needs in leprosy elimination advocacy

Editors and print media generally express concern about the quality and regularity of information. Most of the material they receive consists either of dull statistics or long speeches on leprosy. These materials do not have any human warmth. What the newspapers want are stories with human warmth. They complain that they have rarely received any items of this nature which could command space on the front page.

To regularize the availability and quality of information on leprosy, in several countries the media seem very supportive of the idea to create a data bank on leprosy; a mechanism for orientation of communicators, and development of a feature service on leprosy. This three-pronged activity can be particularly appropriate for SAARC and WHO to support jointly with ILU, and other

NGOs. As South Asian countries contribute overwhelmingly to the global incidence of leprosy, it is important for SAARC, which is a very powerful regional political body, to support the LE campaign in the region. While SAARC has promoted health generally, so far it has done little to accelerate the antileprosy drive.

In this context, I would like to appreciate the efforts made by BBC/MPM in collaboration with the leprosy control program in Nepal and their department of communications. Similarly, the efforts made by BBC/MPM to develop suitable communication material for print as well as electronic media is very much appreciated. ILU and myself have been connected with these activities. I would particularly quote my experience in Nepal, where I requested the use of folk arts. In Nepal there is a group of people known as "Gayanis." These persons move around the villages every day singing songs of religious significance. We requested these Giyanis to prepare songs about leprosy and, similarly, we requested some of the creative persons in the electronic media to transmit the message to the people. I am tempted to quote a story depicted in the documentary. It's a three minute short film.

In the court of Yama the God of Death, a person is brought in. Looking at the person the Yamaraja, the God, says why has he come here? He is not yet due to die. The escorting person says that he is a leprosy patient and being tired of life he has committed suicide. Yamaraja looks at him very angrily and asks "Don't you know of MDT treatment? Now leprosy is curable and not contagious. It is like any other disease." The person replies, "Sir, it may be very costly." Yamaraja replies, "It is free." The person asks, "I may have to travel a long distance to get it." Yamaraja replies, "It is available next door in the nearest primary health center." The person starts arguing and Yamaraja replies with anger, "If you talk more I will throw you down. You have no reason to die because of leprosy." There are similar examples of the work done in India relating to Samba the son of Lord Krishna and many others. These efforts really pave a new way to persuade a community to change its attitude.

To sum up:

- Information must lead to awareness
- Critical awareness leads to action
- To inform, educate, create awareness the use of print, electronic media and folk art is essential
- NGOs need to be oriented in the skills of communication
- There is no data bank available for media, nor a media strategy developed by governments or NGOs
- Focus more on local newspapers, community television and newspapers in regional languages
- Work of BBC/MPM and ILU supports to create awareness

#### **Stigma and aborted media efforts**

Deep-seated prejudice sometimes mars media campaigns. This is evident from the following examples. In The Philippines, a popular actress was invited to appear on television to talk to a leprosy patient and educate the community on MDT. She was agreeable but after rehearsals were done, at the last minute, her agent objected to her appearance with a leprosy patient, suggesting that she risked losing all her future contracts. Later it was decided that she should appear in a poster displaying the MDT tables with the following slogan: "Leprosy is curable through MDT which is available free of cost in any health center."

The poster was sponsored by pharmaceutical company which felt that the mention of "leprosy" on the poster might affect its image. Therefore the word "leprosy" was deleted. Thousands of posters were then printed with the film star holding a product of tablets and stating, "Communicable diseases can be cured fast and MDT is available at every health clinic." The result was horrendous. The number of women viewers thought that this was an advertisement for a drug and wanted to have MDT for beauty treatment.

A TV spot on leprosy was prepared with the aid of the Health Department in Bangladesh. The spot showed a leprosy patient entering a boat to cross the River "Padma." People already sitting in the boat recognize him as a leprosy patient and refuse to have him in the boat. The boatman

who knows about leprosy tries to persuade the people by informing them that leprosy is not contagious and can be cured. The passengers are convinced and the patient is admitted in the boat to cross the river. The film fades out on the boat crossing the river.

To sum up:

- Community participation depends on empowerment
- Empowerment of the people cannot be imported, bought in a market or taught in a classroom—it must come from within
- Participation of people must be at the level of policy formulation, planning, implementation and sharing the fruits of action

**CBR successful experiments.** In The Philippines, a rehabilitation project (Samarina) is run by a home which admits two types of persons. One group is the elderly, disabled, destitute cured persons and patients who have nowhere to go and will be living there permanently, doing whatever little work their health can permit. The other category is 18–35-year-old, cured leprosy patients who are to be given vocational training so that they can go into the wider community and resettle themselves. While they are in the home, they are also supposed to help look after the other category of disabled residents. The director of the home is aware of the risk of chronic dependency, a product of institutionalization, but feels that it can be overcome if people work with faith and understanding and are given appropriate self-empowerment and support.

Nepal provides some instructive experience in transforming leprosaria. At one such institution cured persons are grouped with the disabled, disfigured, destitute and those who cannot return to society. For the last, an ashram or shelter has been set up where they stay permanently and are provided with some monthly food rations and a stipend. Medical care is also provided in the ashram as are occupational activities for those who are able to work. Cured persons, along with their families, who can stay independently are provided a small house (a room, kitchen) and kitchen garden, and are given a monthly allowance. They cultivate their gardens, and are engaged in beekeeping, goat rearing, dairy, etc. These houses

are located in and integrated with the larger community. Persons between 18 and 34 years of age are given vocational training and encouraged to apply for seed money to start their own business. Thus, resettlement approaches are geared to individual groups of persons classified by their rehabilitation needs and capability.

### **Lessons learned**

The partners who have a stake in the elimination of leprosy—such as international agencies like WHO, federal and estate governments, community-based organizations and those affected by leprosy—must network and understand the strengths and weaknesses of each other. During this process, we have learned several lessons that helped in redesigning not only the mission but the methodology.

**Rehabilitation.** Successful rehabilitation must be a three-way process involving the cooperation of the affected person, family and the community, and the socio-medical rehabilitation fraternity. A convincing illustration of this trilateral collaborative approach to leprosy elimination and rehabilitation comes from DANLEP, the DANIDA-assisted National Leprosy Eradication Program in India. This approach focuses on convincing people that leprosy-free communities are a reality, and community action and mobilization can result in desired attitudinal changes. Residential camps bring together health providers, patients and members of the community in an unstructured informal contract, aiming to change community attitudes and behavior.

How to achieve it? The state can provide the legal context and technical and financial support. The civil societies working in leprosy and other developmental fields must be involved in developing policy and laws.

**Empowerment.** Empowerment is a concept, political in content and economic in implication. Empowerment and participation are two inseparable aspects and without empowerment of people sustained development is not possible. It is the people themselves who must make decisions about all matters concerning their life. They should participate in: a) prioritizing the objectives; b) planning of actions; c) implementing the programs, and d) sharing the fruits of their efforts.

Very often a misconception exists that empowerment can be externally bestowed upon any individual or a group. Nothing can be further from the truth. Empowerment really germinates from within. It is an internal process related to the consciousness of rights and responsibilities. Empowerment must result in self-efficacy to discover one's capacity and develop the ability to share power as well as benefits with others in society. This presupposes awareness and political competence to make decisions, either individually or in coordination with others.

Empowerment aims to raise the self-esteem of clients and to extend their basic life skills. It changes attitudes so that clients become motivated to change. The key activities for empowerment are increasing the client's awareness through formal and informal education and giving support and encouragement.

"Awareness" is the level of understanding individuals have of themselves, their situation and the society in which they live. Increasing awareness involves developing new understanding and helping the client to recognize opportunities for change. Critical awareness is that which leads to social action.

**Community-based rehabilitation.** CBR implies a well-structured, smoothly functioning community that is capable of assessing its own needs, of determining its own priorities, of identifying its own resources and of achieving its own goals by community management of personnel and resources. CBR includes rehabilitation activities carried out within a community.

CBR is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and special services. (CBR for and with people with disabilities, Joint Position Paper ILO, UNESCO, WHO 1994.)

**Gender priority.** Another inescapably political dimension is that of gender, which is fast becoming an important theme worldwide in serious discussions on poverty and inequality. In the case of leprosy, it is a fact

that pregnancy suppresses the natural immunity of women to leprosy as well as to other diseases and may also precipitate episodes of reaction. Whether we like it or not, women suffer even more than men from the effects of leprosy, and their plight is compounded by their condition of social substatus and powerlessness. The problem of disabled or disfigured women becomes extremely acute, and they become subjects of harassment.

**Context of poverty.** Leprosy is an outcome of underdevelopment and poverty. Eradication of poverty can provide a major context, so we must move beyond the timidity that has hitherto kept our focus rooted on sheltered workshops or handicraft centers.

There are too many examples of leprosy hospitals and control programs that have set up schemes to create artificial jobs for people affected by leprosy. With the best of intentions, we ourselves have become a part of the problem of leprosy by a continuing dependence of people on our institutions—through subsidies, guaranteed jobs, markets and protection from the real world. It is high time that mere charity gives way to more realistic rehabilitation.

**Future of free colonies and "leprosy village/islands."** Leprosy care has changed from the leprosarium to being community-based, but colonies and/or villages still remain where a sizeable proportion of the population has had leprosy in the past. These free colonies are often near leprosy centers—often the only places where treatment could be obtained in the past and may be something of a haven because of reduced stigma and rejection. Once these free colonies got settled, dispersal to "home" areas after completing treatment becomes difficult or even impossible in some cases. Instead of considering such villages as totally negative, it is important to see how we can facilitate rehabilitation, screening, classifying and settling the families on land, as in Nepal. It is now essential to transform these institutions into referral centers.

By educating society about the disease, providing common services to persons affected and those not affected by leprosy may be another way to overcome the problem, as in South Korea.

**Priority for children.** Children brought up in the shadow of leprosy feel isolated

from the outside world. They may have a negative attitude toward society and their parents. They suffer from loneliness and lack of confidence. All of this contributes to a sense of dislocation from both society and family, often with the effect that the child's education is abandoned early. This commonly affects the children of people affected by leprosy also, so that they grow up in an atmosphere of rejection and inferiority. Their feelings of alienation and strangeness may result in antisocial behavior. Sponsorship of children in the shadow of leprosy is a major and successful experiment carried out by CASP in India and by similar agencies in Thailand.

**Strengthen the role of family.** The family plays a major role in the life of every human being and has a powerful influence on each person's image of self and the wider community. The disabled child or adult, and especially one affected by leprosy, may be helped to overcome a whole range of difficulties and encouraged to achieve as much as anyone else.

The most significant problem relates to marriage, which may be difficult both for the individual and other family members. This can lead to secrecy, ostracism and even sending away the person who has had leprosy. The family as a whole may be disadvantaged and suffer financially.

The family plays an important role in providing emotional support and acceptance. It provides for the basic needs of its members, namely, food, shelter, clothing, love and friendship and, as a consequence, helps to nurture self-respect. All of these activities of the family unit, especially its capacity to act as safety net, may be disrupted by leprosy. The reason seems to lie in the fear and ignorance that surround the disease, often entrenched by a long cultural tradition. The reactions lead to shame, rejection and secrecy which undermine the physical and emotional support which the family should be providing to each individual member. Therefore, how to strengthen the family to cope with leprosy should be our major concern.

**Economic independence—key to rehabilitation.** Self-employment is only one of a number of work opportunities most suitable for persons with disabilities, including those due to leprosy. It is the one that may

suit the largest number of people, especially persons affected by leprosy.

In urban projects, this is done through the establishment of cooperatives and self-help groups in which a revolving credit fund is created in combination with a member's savings and external grants. Credit facilities for the disadvantaged and poor need to be accessible with a minimum of formalities and red tape, and should be administered at the grass-root level by the poor themselves. Credit alone, without promoting saving and money management, actually tightens the poverty trap as people find themselves unable to repay the loan. Therefore, training in cooperation and preparing the leprosy cured for production, marketing and sales has to be promoted, as is done in Korea.

**Application of science and technology to rehabilitation.** This is a new area of work, and efforts to use technology in the development of artificial limbs appliances and aids of daily living are necessary. The information technology has revolutionized the concept of media and education. This can be very effectively used in the field of rehabilitation. Similarly in the social sciences, factors that appeared nonquantifiable are now being measured with the help of new research tools. Even the grading of disability is no more based on the physical ability or functionality. The social factors in measuring the degree of disability is a new area which is being developed. The new thrust on research in genetics is another area that is going to affect the field of communicable diseases.

The new approach.

- Support early identification and voluntary referral through a systematic campaign
- Raise awareness about the reasons for stigma and its resulting trauma to the victim
- Partner with local, national and international groups
- Update legislation and vigilant enforcement to assure the rights of those affected
- Orient action to prevent disabilities and debilitation
- Strengthen the family network
- Arrange meetings of people's representatives to build a political will

- Develop training modules and kits for frontline workers
- Undertake and support research evaluation and documentation

Before I conclude I would like to congratulate the young workers in the field of leprosy who have presented papers indicating the innovative efforts they have made in the fight against leprosy. I would like to congratulate all of these young workers. I was able to attend some sessions on the social and economic aspects of leprosy, media and training, rehabilitation and disability. I feel some of the papers are so important that the

International Leprosy Union should make an attempt to publish these papers in a book form because they reflect "the grass-root realities in leprosy."

At the last ILA Congress in the U.S.A. at Orlando, I was able to visit Disneyland. It's a wonderful place. But outside the Disneyland campus there is a board which says: "This work is incomplete and will remain incomplete as long as human imagination is there."

In the same tune, I would like to say that leprosy work is incomplete, and will remain incomplete as long as human suffering is there.