

# **The END of ISOLATION**

## **A Handbook for the Social and Economic Reintegration of Persons Affected by Leprosy**

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## Foreword

This book has taken several years to move from the conceptual phase to publication, for a number of logistic and technical reasons. It started life as the report of a workshop organised jointly by ALERT, the ILO and the Ethiopian Rehabilitation Agency, held in Addis Ababa in 1994, on the reintegration of people affected by leprosy. The editors have attempted to modify the report in such a way that it becomes a practical handbook, encouraging people everywhere to actually put into effect some of the ideas which were aired during the workshop.

The book is aimed at all levels of community workers involved in socio-economic reintegration. Although leprosy is the main topic, this book is not just for leprosy health workers. One of the problems with leprosy care is that it is often vertical and people affected by leprosy find themselves not just isolated within their community, but also isolated from the general rehabilitation services that could help with their reintegration. It is our hope, therefore, that this book will be read by those people working in the field of socio-economic reintegration so that they can consider how to involve people affected by leprosy into their programmes and end the isolation.

After setting the scene in the Introduction, the book is divided into two parts. Part one sets out a management approach to social reintegration and rehabilitation for people affected by leprosy. This will help you to analyse your situation and plan a variety of strategies to achieve reintegration and rehabilitation.

Part two looks more specifically at reintegration in an urban or rural setting and has some case studies of projects from various parts of the world. We do not pretend to have answers to all the problems but we hope that as you read you may be stimulated to think about your own situations and use some of the ideas to improve your programmes.

## **Acknowledgements**

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**Photographs by: © Pietro Cenini**

## **Introduction: Setting the scene**

### **Definitions and ground rules**

The theme of this book is "the socio-economic reintegration of people affected by leprosy." There are a number of technical terms used, but we will not get too involved in the whole question of definitions. "Rehabilitation," "Reintegration" and "Community based rehabilitation" - these three terms in themselves could provide material for several chapters. We will therefore take for granted certain broad definitions of these important themes, rather than become bogged down in narrow technical questions of definition.

For example, when we discuss Community Based Rehabilitation (CBR), let us be aware of the real world and of the needs of real people, rather than worry unduly about whether a given action was truly generated from within the community. CBR in its purest sense 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. In the real world it may not always be possible to execute each of these steps by the community's own unaided efforts.

CBR includes rehabilitation activities carried out within a community (as opposed to rehabilitation measures carried out within an institution) even if outside expertise and support provide the main stimulus for such activities. Similarly "rehabilitation" is often understood to include "reintegration" since rehabilitation involves both medical and physical issues, as well as the socio-economic issues which reintegration focuses on.

## **A practical approach**

If this book is to be characterised by a focus on what is practicable and achievable in the circumstances that we each face, perhaps it may be useful to point out ways in which individuals affected by leprosy are not much different from other categories of people. Rather than focusing on the disabilities of people who have had leprosy, it would be more helpful to focus on those factors shared by people who have had leprosy and other social groups.

As well as being "former patients" our partners are also members of families, members of a community. They are individual women and men with hopes and desires as well as fears, anxieties, problems and worries. In short, people affected by leprosy are human beings and we must concentrate on those characteristics shared by all of us, if we are to help reduce their isolation and their 'different-ness.'

It might therefore be more helpful to see the needs of people affected by leprosy for socio-economic reintegration as simply one strand in the overall need of society for effective community development. Not just the provision of more and better infrastructure such as housing, schools, roads and so on (though these are an undeniable necessity), but also in terms of empowering people to better direct their own lives and futures.

People who have previously had leprosy are often unbelievably poor, but we should view them as an integral part of a broader population of poor, disempowered individuals and

communities who also have their civil rights and their social obligations. The socio-economic reintegration of people affected by leprosy and the socio-economic development of poor communities are thus two sides of the same coin and should be pursued as parallel and complementary strategies.

### **The end of isolation**

Indeed just as it is becoming increasingly clear that leprosy as an issue of disease control should not necessarily be handled in an isolated manner but rather be pursued as a part of fully integrated health services, working for primary health care, it is also becoming clear that the socio-economic reintegration of people affected by leprosy should be seen in the broader context of integrated community development. A holistic and integrated approach to the resolution of all the myriad problems is thus an essential component of any realistic strategy.

We are all aware that leprosy is a mildly infectious, but curable, disease that is caused by *Mycobacterium leprae* which can fortunately be easily controlled with multi-drug therapy (MDT). But we are also aware that many of the problems created by leprosy are not susceptible to simple medical treatment, precisely because they are not simple medical problems.

Case detection often occurs late in the course of the disease thus causing often irreversible deformities. Deformities may occur even after the disease is arrested. Therefore, the strategy against leprosy must include a broad range of activities to promote community education and community awareness. To do that we need to enlist the help of journalists, writers, health educators, sociologists, social workers, anthropologists, religious leaders, teachers, psychologists and other members of the community.

## **Attack on three fronts**

Similarly, after the disease has been arrested and the person cured, there has to be provision for follow-up services: physical rehabilitation, occupational therapy, vocational training and socio-economic rehabilitation. We can therefore look at leprosy as needing to be attacked in three distinct phases:

- \* firstly, by intensive appropriate community education for early case detection:
- \* secondly, by effective, professional medical treatment and clinical control:
- \* thirdly, by compassionate and realistic strategies of support to a broad range of integrated activities that each contribute to the empowerment of people affected by leprosy in the determination of their contribution to society.

Offering a job to a person who has had leprosy may provide a salary for her and her family: it may help her to achieve some sense of dignity and worth. But whilst work mates, colleagues, family members and the wider society retain their prejudice and aversion to people affected by leprosy, the task of socio-economic rehabilitation is only half done. A holistic approach to the totality of leprosy related problems is the only realistic option.

## **Holistic approach**

Such a holistic approach has many practical implications. For example, surgeons may be required not just to advocate psychosocial assessment of people in hospital for reconstructive surgery, but actually to take into consideration the actual needs and circumstances of the person. It is easy to prescribe "bed rest for 6 weeks" to a person whose limb needs to be put in plaster, but if she is a daily wage earner, how will her husband and children get by without her support? When you tell a farmer not to put weight on his foot, how do

you expect him to provide for his family? Only by a teamwork approach between the patient, social workers, physicians, surgeons, occupational therapists, physiotherapists, nurses and health educators can we hope to tackle these vital problems successfully.

Socio-economic reintegration also poses new challenges. Unlike the treatment of leprosy as a disease which is a medical issue, socio-economic reintegration of people affected by leprosy into their society is a non-medical issue, which requires us to form coalitions of different specialists working together to help them to achieve their own goals. Since those goals will vary from individual to individual and from community to community no single strategy can be determined to meet those myriad different needs. Rather, your focus may be most helpful if it concentrates on ways of empowering people to achieve their own goals.

In the field of socio-economic rehabilitation we need to be facilitators rather than doers and we need to acquire skills in listening, in learning from others, in encouraging them and in counselling them rather than in providing services to them and for them.

Not only is the issue of socio-economic reintegration not a medical issue but a social one, but it is also a highly political issue. In any country or society, when you wish to help a disempowered and dispossessed underclass to achieve its liberation, its independence, its dignity, you may be perceived to be revolutionary and even subversive. You challenge the very assumptions of the entire society, with its intolerance of persons with disabilities and its comfortable amnesia about the unseen poverty that is consigned to hidden districts of its cities and rural areas.

If your work on behalf of people affected by leprosy is to be serious, it must be undertaken with a broad alliance of partners whose goal is to help them acquire real, meaningful power to change the socio-economic circumstances of their lives, the power to dream of a better future and to work towards the realisation of that dream.

## **Gender**

Another inescapably political dimension is that of gender, which is fast becoming an important theme world-wide 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 their leprosy and their plight is compounded by their wider condition of general social inferiority and powerlessness.

In a similar way when we discuss the socio-economic reintegration of people affected by leprosy we have to bear in mind the realities faced by women. If we help them to set themselves up as market women in the retail trade, are we sure that people will buy food and other goods from a visibly disabled and disfigured person? What measures can we take to empower women - as well as men - to overcome the many debilitating aspects of leprosy's stigma in the eyes of the wider society?

## **Poverty**

Just as the World Bank and other major funding agencies are - at long last - beginning to tackle the issue of the eradication of poverty, so we too must set ourselves a bold agenda and move beyond the timidity that has hitherto kept our focus rooted on sheltered workshops, on government-subsidised handicraft centres producing barely useful items for sale to tourists. Poverty alleviation is one step down the road, but surely it is the complete elimination of poverty that must be our goal.

There are too many examples of leprosy hospitals and control programmes that have set up cost-ineffective schemes to create artificial jobs for people affected by leprosy. Far too often and with the very best of intentions, we have ourselves become an integral part of the problem of leprosy by creating

and encouraging the continuing dependence of people on our institutions - for subsidies, for guaranteed jobs, for guaranteed markets and for guaranteed protection from the real world. It is high time that mere charity gives way to more realistic thinking, in order to devise more appropriate and sustainable strategies for long-term independence.

In conclusion, this book aims to be as practical as possible in helping you to design feasible strategies that can promote the socio-economic reintegration of people affected by leprosy into society. As the focus of the world moves away from leprosy as a disease - no doubt encouraged by the World Health Organisation's declared target of the elimination of leprosy as a public health problem by the year 2000 - it is our urgent task to place the social, the economic, the psychological, and the political aspects of rehabilitation firmly back on the public agenda.

We have a long way to go before we can comfortably forget about the continuing needs and hopes of the millions of people affected by leprosy in the world today. It is our duty to tackle the political agenda and to encourage the creation of grassroots associations of people affected by leprosy in a world-wide movement. Only when we accept this broader focus, only when we take an integrated and holistic approach can we be sure of moving beyond soothing words into meaningful actions.

## **Part 1**

### **A management approach to the reintegration of people affected by leprosy**

It is clear from the Introduction that there are many obstacles and difficulties in our path towards ending the isolation of people affected by leprosy. We are convinced that using ideas from the field of management is one of the most straightforward and practical ways of trying to tackle these problems and achieving some real change.

Chapters 1 - 6 therefore relate basic principles of management to the theme of the book: ending the isolation of people affected by leprosy.

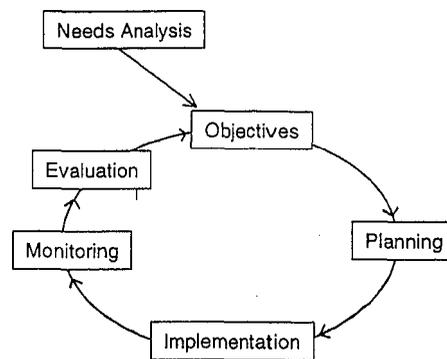
## **Chapter 1: Needs analysis**

### **Finding out where we are now**

Management is like going on a journey, first you have to find out where you are and then decide where you want to go. The planning for the journey will include ways to travel and roads to take, and all this is done before you actually start your journey.

In management terms a needs analysis is finding out where we are now, objective setting is deciding where we want to go, planning is looking at the ways and means of getting there and implementation is the actual going. The following diagram shows the management cycle.

*Diagram of the management cycle*



### **Needs analysis**

In a rational approach to social reintegration and rehabilitation, a needs analysis is a useful start. It will help you to look at the problem and the needs in your situation. You should be able to identify the following:

- \* the size of the problem
- \* the nature of the problem
- \* appropriate solutions

### **The size of the problem**

Routine statistics and data can help you to see the size of the problem. They should be able to tell you the number of people affected by leprosy who have disabilities. Leprosy data can tell you the levels of disability in your situation and those with the potential to get further problems. Leprosy programmes that concentrate on treatment alone will need to maintain a disability register for those people released from treatment. Many may continue to develop disability or a worsening of their wounds and ulcers even though they are no longer on treatment.

Surveys of leprosy villages can tell you how many people are under the poverty line, and begging. People affected by leprosy and in particular those who have loss of feeling in hands or feet, must be included in the house to house surveys for community based rehabilitation.

### **The nature of the problem**

Whilst statistics and data can tell you the "how much", a more qualitative approach is needed to find out the nature of the problem - the real felt needs. Many programmes have failed because "experts" have looked at the situation and decided on the needs. Development programmes are littered with unused appropriate technology that addressed the "need" as prescribed by an expert.

### **The "expert's" view**

*"People are not soaking their feet and seem unable to prevent wounds. The data show that 20% of people affected by leprosy have anaesthetic feet and that 12% have ulcers or wounds on their feet. Despite the shoe programme, the number of ulcers is not being reduced.*

*It is obvious to the expert that very little soaking of feet is being done. Indeed when he asks them if they soak their feet his analysis of the problem is only confirmed. The people are extremely poor and have no dishes, so he spends his rehabilitation budget on dishes for them. A year later there is no improvement in the wound count."*

### **The view of the person affected by leprosy**

*"Health workers are obsessed by our feet and wounds and this soaking. How can I sit and soak my feet for hours when I cannot buy food for my family. Perhaps I can sell this dish to get more food and then rest for a while. In the meantime, I need to walk to work so that my family will not starve. Yes, it is true I do not soak my feet but really it is not a priority, whereas my family and poverty are."*

In the above we can see that our priorities are often not those of the people we are trying to help. To find out exactly how they feel and what the real problem is may take much skill. We need to listen, observe and encourage the people to analyse their own situations. Semi-structured interviews of individuals can help but we must beware of bias in them. In our story above, the "expert" didn't find the real problem because he did not ask the right questions.

A needs analysis must contain qualitative as well as quantitative data. That is, as well as the numbers of people affected, we need interviews, case studies, and focus group discussions to gain information about what the problems are.

### **Appropriate solutions**

Having determined the size and nature of the problems, the next step is to find the right solutions. To avoid the misunderstanding which is often present in the "expert" approach, participatory methods must be used. By this we mean that people affected by leprosy must be encouraged to analyse their own problems and suggest solutions. These solutions must be practical and viable. They must be satisfactory to both the people themselves and those trying to help them.

A variety of participatory approaches to solutions can be used to encourage people affected by leprosy to describe their situations and the solutions that might help. The following table may help you, but for further information you should contact the *Sustainable Agriculture Programme*, mentioned under "Useful Addresses."

## *Different methods of needs analysis*

<b>Participatory mapping</b>	
Description	People are asked to make a map or model of their situation on paper or on the floor
General use	Shows number and locations. A good way to get people thinking. Helps to identify risk factors and vulnerable groups.
Use in social reintegration projects	People can map their areas showing different categories of people with disabilities by location and social group. Women can map their homes to identify problems and danger areas. Community facilities, hazards, problem areas can be mapped. Can show who uses services, who receives assistance, and where people with disabilities live.

<b>Seasonal diagram and analysis</b>	
Description	A calendar is made showing activities, climate changes, disease prevalence, seasonal differences in income, times of stress and difficulty.
General use	Useful in rural communities to see peak activity times. Shows how busy or free people are. Good for monitoring programmes.
Use in social reintegration projects	Farmers can outline the times in the year when they have the most work to do and relate this to wounds, ulcers and prevention. Wet and dry season activities and the variation in use of health facilities can be analysed.

<b>Matrix ranking and scoring</b>	
Description	People are invited to look at issues and give them a score and rank, either individually or as they relate to one another
General use	This helps to see the value people put on things (often very different from ours.) It is helpful for identifying priorities and options for action, targeting and allocating resources.
Use in social reintegration projects	People affected by leprosy can identify their problems and priorities and give scores to a variety of solutions. (For example, if low income is identified, people could rank sheltered workshops, self-employment, begging, credit schemes, etc.) People can compare disability vs income, or solutions vs income.

<b>Time-lines and trend analysis</b>	
Description	People affected by leprosy are asked to plot a time line of major events, incidence of disease, time spent in various activities or the progress of the project.
General use	Helpful on evaluation and monitoring. Helps people to make sense of what has happened and to build on previous success or learn from their mistakes.
Use in social reintegration projects	In evaluation the strategy, participants can map it out looking at major events, successes and failures. Individuals can be asked to plot the time spent doing various activities (such as begging, going to the clinic): these can be compared and learnt from.

Focus groups	
Description	Gather a group of about 6 to 8 similar people, (women, farmers, leaders) to discuss a certain issue. It can be used in conjunction with the more visual methods such as mapping and matrices. Sometimes starting with a picture is a useful way of getting the discussion going.
General use	Helps people to vocalise their situation in "safe" situation. Good for helping people to see that their knowledge is useful, helpful for expressing needs, preferences, perceptions and priorities.
Use in social reintegration projects	People affected by leprosy could be asked to discuss their situation in detail what areas do they find most difficult, where do they need help? Can also be used for monitoring - is the intervention working, if not why? What else should be done?

Case studies	
Description	Conduct an open interview encouraging the person to tell you his story, from beginning to end and in his own words
General use	Can provide useful ideas as to what it is like for the person, the history of his situation. Helps outsiders to learn
Use in social reintegration projects	Get the person affected by leprosy to tell you his story and describe the problems he meets due to disability and the problems he meets due to the attitudes of the society

Venn Diagram	
Description	Using circles, people are asked to show by size and proximity, the institutions and persons that are important to them and their relationships
General use	Shows resources and the support systems that are seen as important to individuals and groups
Use in social reintegration projects	People can list their support systems showing the links and the ones that they think are important. Barriers to networking and support can be identified

## Case studies

The following two case studies are from Ethiopia. They can help us to do a small needs analysis of their situations.

### Story no. 1

*"I caught this disease when I was eighteen. I was a grade 12 student and my parents didn't realise how serious it was. When I began to have difficulty controlling my hands and feet, my parents sent me to bathe in hot springs, in the hope that this would help. They also sent me to a wizard and I took traditional medicines, but nothing made any improvement.*

Eventually a family friend recommended I should go to the hot spring in Addis Ababa. Here my feet were completely submerged in the hot water, with the result that they were badly scalded and swelled up.

"At last, after 5 years, my parents took me to the leprosy hospital in 1958 and I was given a bed. After two months of continuous treatment the wounds dried up, but my fingers could not be flexed and I couldn't do anything with them as they became bent. My right leg was amputated.

"When I became better I left the hospital but didn't return to the place where I had been with my parents, because I felt they would feel ashamed of my disease. So I found a new life for myself in the outside world. In order to survive I became a messenger for prostitutes who worked in small bars. I became a drunkard and I took up smoking. Despite this, I was honest.

"I got a job as a guard in a tea room where I met a lot of people. Then one day an old gentleman asked me to teach his children during my leisure time. And it was through the help of this man that my future life started to become alright - my fingers began to work almost normally, and people started to call me by my own name instead of the name 'leper.'

"Then I started to look for a job in various government institutions, but because of my physical condition I wasn't accepted. I cursed the time I was born, but found comfort from reading Biblical stories which have some relation to my own situation. I continued to pray, and look for a job.

"Then a man who had helped to open a local school hired a 6 roomed building with a large campus. I managed to get hold of 6 old blackboards, various books, some school benches and started teaching, helped by two young people. A lot of students came to me through the help of the director of another school.

"Gradually I was able to employ 6 teachers, paying them from 100 to 150 Ethiopian Birr per month. It was a well-furnished school and it became famous for its academic status. The number of students soon exceeded those of the government schools in the district.

*"Its fame soon spread and the Emperor came to visit it twice. He told me he had heard of me - I was a small man with a big reputation! The school was recognised by the Ministry of Education and the students were able to sit for grade 6 National Examinations, It developed to grade 8 level, and I also started a typing school.*

*"I became very successful and made a lot of money, but because I was still very young I developed bad habits. I became a dancer and smoker. I also used to spend my nights in hired hotel beds - and I stopped the treatment which I had been having. I became sick again and was admitted to the hospital. I had to give up responsibility for running the school to one of my staff but he couldn't run it as I had done and it went bankrupt. After I got better and left the hospital I went to the railway station, where I had lived previously.*

*"I knew many people there and if anyone asked me to kick somebody I would kick them and got a lot of money. This didn't last long because I started a small clothes-washing business. I also became a broker or agent, arranging for people to do business with each other. In this way I managed to get some money together and opened an elementary school called Y. B. I opened a second school in L., gave responsibility for its management to other people, and came to the place where I am now. I opened another school which had 1100 students and 20 employees, but it was nationalised after the Emperor was deposed. Although I went away, the people in the area realised that it was only because I was there as Director that others would send their children to the school, so I was asked to come back, and I took up my previous position as Director. Today the school has about 3000 students, and over 59 employees working in shifts.*

*"I then opened another elementary school. It was licensed by the Ministry of Education and is still functioning. All this I was able to do with the help of God - and the assistance of various other people and government institutions.*

*"I did all this work once I had completed my education as an extension student, with the help of the German Cultural*

*Institute. I joined the Addis Ababa University and took a course which qualified me as a children's teacher. This was in 1965. In 1967 I completed the teachers training course.*

*"I have been married twice, and have children by both marriages. My first wife and I were divorced for purely personal reasons which had nothing to do with leprosy. My second wife is very supportive and so are my children. We do everything together and, in fact, my wife will not attend social functions if I don't go with her. My children are popular in our neighbourhood and are known to everyone by their pet names.*

*"Several of my neighbours have asked me to be godfather to their children and I have found no prejudice against me at all. I take a very active part in public and government affairs and also help organise sports activities for young people. To give you some idea of my life here are some of the things I do.*

*"I am a District Chairman. I am chairman of a public or District shop. I'm a member of the public court. I'm Chairman of the District Development branch. I'm cash collector of funeral associations as well as being a committee member of the church establishment. I'm also co-ordinator of a road building programme for my district which will cost 2,700,000 Ethiopian Birr. And finally, I'm organising 205 people in an attempt to solve their housing problems.*

*"I know some people who have had leprosy want to live in a community together because they feel they will not be discriminated against there, and they can support each other, but I think this is a short-sighted attitude. We should not be condemned for the rest of our lives to be ex-leprosy patients - nobody thinks of an ex-cancer patient in those terms. Once the disease is cured that's that! And if we live in ex-leper communities what will be the effect on our children? Are they to be condemned to be leper's children for the rest of their lives?*

*"I think the way we are treated is to some extent a reflection of our own attitudes. If we present ourselves well, if we are smartly turned out, lively and willing to take our place in the world at large, then we shall, I think, be treated accordingly.*

*"I am severely disabled, as you know from what I have told you, and yet I have never felt myself discriminated against. It seems to me that whenever new projects are being discussed I am one of those people always being called on for advice and help. I serve on all sorts of committees in various areas of my life and find it a rich and rewarding experience.*

*"Finally, I promise to organise people who have had leprosy, so that they will be able to lead their lives by working according to their ability, rather than leading the dependent life of a beggar."*

(Mr A B, 1994)

## **Story no 2**

*"After completing secondary school with vocational training, I was employed as a technician by what used to be called the Imperial Board of Telecommunication (now the Telecommunications Authority), on July 6, 1957. I was assigned to work at the J. R. Radio Broadcasting Station. After serving at the station for two years, I joined the advanced technician training course at the Tele Institute. After completing the two years training course successfully in 1961, I was assigned as an advanced technician at the Addis Ababa Radio Studio. In this capacity I was responsible for the public address system at the Imperial court. In addition I was also doing maintenance of the provincial telecommunication systems.*

*"In 1963 I was transferred to the Radio Receiving Station and served in the same place until I was pensioned in 1993. I enjoyed good health until 1965 when I started developing skin lesions on my face. I was then referred to a local hospital for investigation and treatment. The disease was not identified for two and half years, until I was referred to a specialist centre where Dr. M. diagnosed my disease as leprosy. Dr. M. also told me that I could have been treated and the disease could have been controlled by now had I gone to the right place earlier.*

*"After receiving the report from the specialist centre, the telecommunications clinic doctor referred me to the leprosy*

hospital. He in fact apologised to me that he had not been able to detect my disease in time. He said that his lack of experience was due to the fact that leprosy was eradicated in the country where he had his medical education. He never saw people with leprosy, but knew about leprosy only from the literature.

"The diagnosis was confirmed at the leprosy hospital and I was put on anti-leprosy treatment. All the lesions on my body disappeared after 9 months of treatment and I stopped my medications without being instructed to do so. Later I started developing loss of sensation in my extremities which was followed by clawing of my hands. I was then forced to go back to the leprosy hospital. In 1967 Dr. F. did successful reconstructive surgery on my hands and I was able to resume my job. However, because of lack of sensation I could not avoid the periodic injuries that happen to my hands.

"The abnormality that I had developed in my hands created suspicion amongst my colleagues, and those whom I supervised, that I could be contagious. The fear developed from a rumour to direct objection by the staff, who refused to work with me. The staff actually appealed to the Regional Telecommunication Manager that I should be removed.

"In 1972, I was instructed to produce a medical certificate to state that I was not infectious, or else lose my job. I was referred to the leprosy hospital and Dr. R., after reviewing my condition, certified that I had not carried leprosy germs for the past 3 years and that I was not contagious. The Tele Clinic Doctor then wrote to the Management based on the medical certificate I brought, and so I was able to remain in my job.

"In 1989, when the previous manager was replaced by a new one, the unrest among the staff was aggravated and they appealed again for my removal. I went back to the leprosy hospital and brought a certificate signed by the leprosy hospital medical board which stated that my disease was cured and that I was not infectious. This helped me again to remain in my job. However, due to a feeling of insecurity and the possibility of violence by the staff, my immediate branch chief

instructed me in 1989 to confine myself to one small room and avoid eating with other staff. I was also told that the management would not guarantee my safety. I was doing nothing but was being paid my salary from 1989 to 1993.

"My illness has also contributed to deprivation of my privilege for promotion during my 36 years of service under the telecommunications. My colleagues with whom I was trained and employed have various promotions. Some have become regional managers, others are branch and section chiefs. I remained as a supervisor for 30 years.

"I have made appreciable social contributions in the community where I live. I have served as Chairman of the School Committee for five years and set up and organised schools for which I was awarded a Certificate of Merit from the Ministry of Education in 1983. I have also served in my District, gaining recognition and respect from the community.

"With regards to family life, I am married and have seven children all of whom have completed secondary school education. My eldest daughter has studied computer science and is working in Greece. The second one has graduated with a diploma and has been working in the Sudan until her recent untimely death. The third one is a teacher. The other four young ones have completed secondary school, but could not find jobs. They still need my support and are living with me.

"I have some social problems within my family. After completing elementary school, my children did not want me to keep contact with the high schools they went to. Even though my children did not tell me openly, I could understand that they feel ashamed of me and do not want to be identified as my children. It was only their mother who contacted their schools. When I come across my children while they are with their friends, they avoid talking to me. I understand their problem and so try to avoid confronting them in such circumstances and hide myself. My wife also does not want to accompany me to funerals and other social events in my community."

(Mr A K, 1994)

## What can be learnt from the case studies?

An analysis of these two stories will consider both the individual and the community situation:

What contributed to these situations?  
How much success or failure was due to:

- \* the individual personality
- \* the social circumstances
- \* family support

What strategies could have helped the social rehabilitation?

In both these studies the people survived with the minimum of outside intervention. They were both able to find or hold on to jobs, although one was rather more integrated into his society than the other. It is clear that personality and in particular determination and persistence are important assets. Where stigma and fear are strong, however, people may be impeded from doing their jobs or living a normal life.

A normal life is defined by the community in which people live. This includes the family, the society and culture in which they live, and the economic and political situation. For medically trained people, this approach can be particularly difficult. They are more used to look at people from the point of view of signs, symptoms and biomedicine rather than as members of a community and influenced by its culture and beliefs. One of the problems of earlier attempts at rehabilitation for leprosy affected people, is that they increased their isolation rather than helping with reintegration.

In the two case studies, appropriate solutions directed at the community rather than the people affected by leprosy themselves, may have been needed. Early intervention in training and health education should have helped both young

men receive treatment at an earlier stage of the disease. Further health education for staff, colleagues and family may have helped the second person towards integration. Lobbying of his employers at a high level would have considerably improved his situation. **It is clear from these stories that the person's feeling of self-worth and the community stigma directed against the disease, are probably the biggest obstacles to social integration.**

## **Conclusion**

The role of the family, availability of employment, levels of stigma and disability are all important issues that need to be investigated in the needs analysis. If reintegration is to take place, the intervention must not isolate the person, but rather help him or her to be accepted and feel a part of the community. Where persons are completely without either hope or employment this becomes a much more difficult task. In the next chapter we shall consider the possible objectives that a rehabilitation programme might have, based on a variety of needs

## **Chapter 2: Setting objectives: Deciding where we want to be**

### **Introduction**

The setting of objectives is an essential step in the management cycle and often determines the success or failure of a project. Clear objectives are like a beacon or lighthouse - they help to show everyone the way forward.

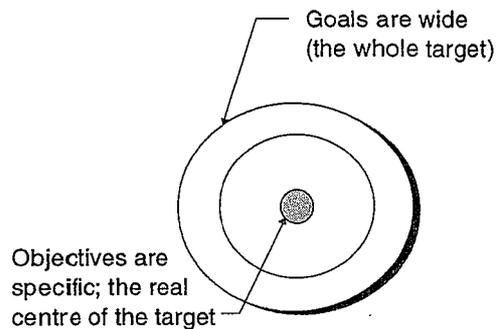
## Goals and objectives

Goals are wider than objectives and may not be restricted by time or measurability. For example, a reasonable goal might be “to minimise the physical and social constraints caused by leprosy” but to achieve it you may have to identify a number of smaller, contributory, objectives - such as:

1. that 50% of all people diagnosed as having leprosy should be able to take part in all activities in the village they live in, without instances of ostracism, within a period of 5 years;
2. that 20% of people disabled by leprosy should be incorporated into non-leprosy rehabilitation projects by the end of 2 years.

Another example of a broad goal of rehabilitation programmes might be that “persons affected by leprosy should be able to fulfil basic physical and psychological needs for themselves and their families in the community”. What kinds of specific, measurable and time-related objectives would be helpful in working towards the realisation of that goal?

### *Goals and objectives*



## **Setting objectives**

In order to be of maximum benefit, objectives need to have certain characteristics; the objectives of a rehabilitation programme should be:

### **1. Specific:**

The objective must relate to a specific outcome that you want to achieve, rather than to vague and imprecise concepts. "The rehabilitation of people affected by leprosy" is unhelpfully vague; "income-generation", "petty trade", "public education", and so on, are precise, specific and concrete outcomes.

### **2. Measurable:**

In order to be measurable, the objective should expect some kind of behaviour change by the end of the project's life, a change which can be seen and measured. For example, that people affected by leprosy should join groups of people with non-leprosy-related disabilities working for rehabilitation, is a measurable objective. Similarly, that people should participate in the planning of their own income generation projects, is a fully observable and measurable objective.

### **3. Agreed Upon:**

People affected by leprosy themselves and the staff involved, should help to set the objectives and agree as to what is worth doing in the programme.

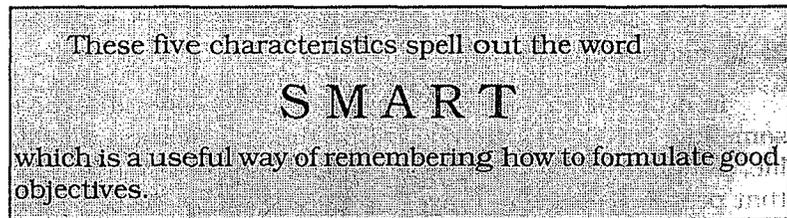
### **4. Realistic:**

The objective should be feasible and should not be too ambitious at the beginning. For example, it is not realistic to set up handicraft shops where no market research has been done and where certain products are not easily sold.

## 5. Time-related:

It is good to set a time-frame for objectives, and particularly useful to distinguish between long- and short-term objectives. Long-term objectives may be related to your expected outcomes in 5 to 10 years time, whereas short-term objectives may be what you expect from the project each year (or even after shorter periods of time, depending on the outcome).

For example, it may be useful to set up support groups for all people with severe disabilities due to leprosy as a long-term goal, and, in the first year, to set up a pilot study of 3 such groups, with the setting up of a further 7 groups being the objective in year 2.



## The relationship between objectives and a needs analysis

When we do a needs analysis, we identify the problems in the family and in the community. It is from this list of needs that we can easily derive our set of objectives. We look at each problem identified and then decide how far we would like to go to resolve that problem; this desired outcome then becomes our objective for that particular problem.

For example, during a needs analysis for social rehabilitation in leprosy, we may identify the following needs, for which we require written objectives:

**Problem 1:**

*The community members believe leprosy is spread by contact, so don't want to relate in any social way to people who have had leprosy.*

This could lead to the following objective being decided:

That people affected by leprosy should join in with the community at weddings/funerals/savings groups (i.e. anything that is socially appropriate for that particular culture), within a period of two years.

**Problem 2:**

*Many organisations are working in the same area, but their work is not co-ordinated; so some projects help the same people, while other people do not benefit at all.*

This could lead to the following objective being decided:

To create a network of NGOs (non-governmental organisations) and relevant Government agencies working in that area, so that tasks can be shared and co-ordinated - within a 12 month period.

**Problem 3:**

*People with disabilities cannot work as hard as able-bodied persons and therefore cannot find paid employment.*

This could lead to the following objectives being decided:

In the short-term:

- i) to place 20 people with disabilities in work each year;
- ii) to create co-operatives of people affected by leprosy to provide worthwhile paid jobs for 30 people per year.

In the long-term:

The Government should legislate that all organisations above a certain size should have - for example - 0.5% of their jobs filled by people with disabilities.

According to the overall aim or goal of the project, these objectives can then be prioritised so as not to attempt too much at once, and to spread the work load realistically over time.

## **Chapter 3: Planning and strategies**

### **How to get there**

Having decided on the needs and where we want to go, the next step is the “how” of getting there. The art of planning is in knowing who can do what and how much of various resources will be needed. Planning typically looks at three types of resource: personnel, materials and money. These must each be planned in detail for a specific project. In this chapter, we will focus on the different people and organisations involved in rehabilitation, who should be included in your social reintegration plan for people affected by leprosy. Part 2 of this book contains more detailed and specific strategies.

We start with your role, the role of the professional, the leader, the community worker. For many, a change in your own perspective and priorities may be needed.

## **The role of the professional**

### **Change from isolation to integration**

The role of the professional needs to change if reintegration is to replace isolation. People affected by leprosy have for too long been isolated from the community and culture on which they depend for existence and survival. In the past, many of our strategies for rehabilitation - special villages, leprosy farms and sheltered workshops - helped people affected by leprosy, but did little to reintegrate them into their own societies.

It may be that not all people can be reintegrated; some may continue to need specialised help and care, but our aim must be to increase independence and normality. The professionals' actions must help people affected by leprosy to analyse their own situation and to prioritise and select solutions. To do this we will have to empower them, that is, use rehabilitation methods that give them power over their situation rather than making them more dependent.

### **Change from experts to facilitators**

Previous models of assistance and intervention in rehabilitation were often based on experts coming in to analyse the situation and then prescribing a solution. Often the solutions were related only to the individuals and not to the surrounding society. Professionals were seen as the experts or providers, and people affected by leprosy as the receivers.

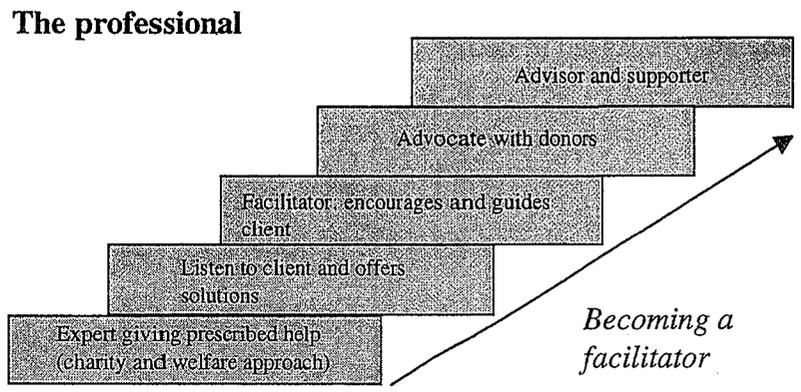
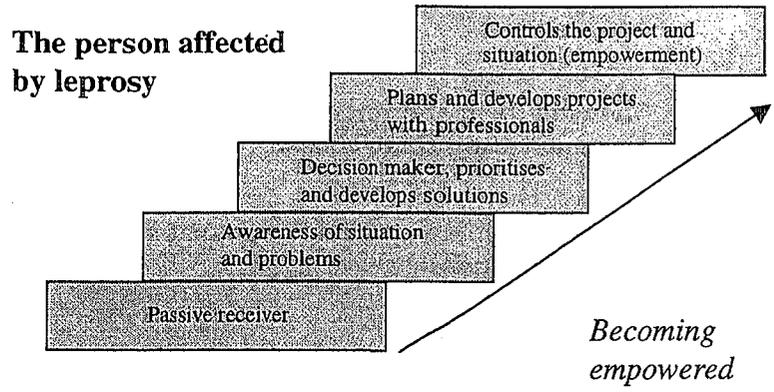
For sustainable help that empowers people we must start considering the expertise that people affected by leprosy already have. They know what they can do, and what is feasible in their own situations. When we help them to change from receivers to active participants we also give them more self-worth and help them to change from victims to people with ability. Our approach must be as facilitators. We facilitate their change, learning and growth.

We can facilitate in 5 ways:

1. **Listening** to the people affected by leprosy and helping them to vocalise their situation, ideas, hopes and expectations;
2. **Showing** them the sorts of solutions that are available and letting them choose;
3. **Guiding** them away from things that are not possible or sustainable;
4. **Assisting** them to set up or change the situation so that the solutions can be achieved;
5. **Mediating** between them, the funding agencies and other authorities.

The following diagrams show the process and some of the steps involved in going from expert to facilitator.

*Change from the viewpoint of both the person affected by leprosy and the professional.*



## Integration with CBR

Community based rehabilitation (CBR) is one of the most effective approaches for the rehabilitation of persons with disabilities.

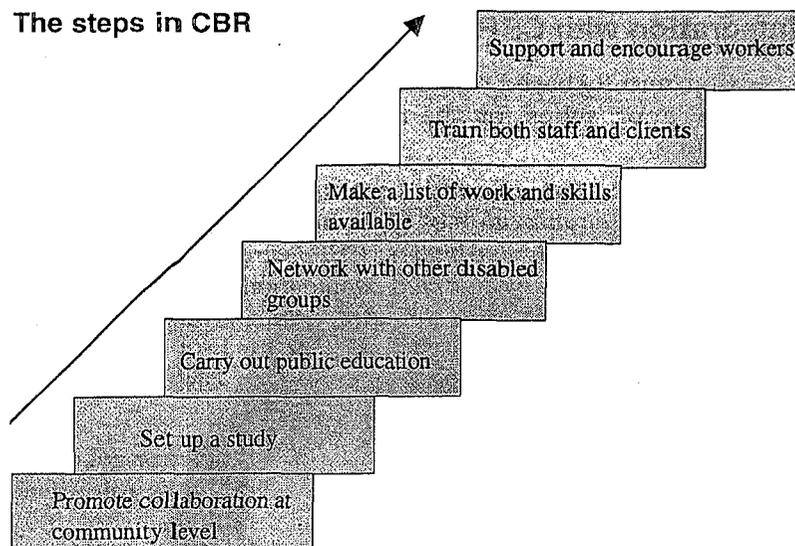
*“CBR is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education,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

In many countries, people with disabilities are generally given a low priority in the community. Therefore initiatives coming solely from the community are unlikely. They may however, react favourably to an initiative from outside, particularly if this benefits the community as a whole and not just the disabled person.

Stigma is the major problem when people affected by leprosy seek involvement in CBR programmes. Either the community does not want the person, or the person does not want the community, or both! Changing attitudes takes a long time, it involves re-education both of the person affected by leprosy and the community. CBR is not possible if the community does not accept the person affected by leprosy. Community awareness and health promotion campaigns will often need to precede an integrated CBR programme.

Sometimes self-stigma by leprosy-affected individuals can also be a major problem. If their self-esteem is low and they have experienced rejection, it will be difficult to persuade them that community based rehabilitation is appropriate. In this case, especially if they are living in leprosy communities, self care groups and leprosy community rehabilitation may be viable alternatives. If people affected by leprosy can be rehabilitated alongside other people with disabilities in the community, this will eventually improve community awareness about leprosy and restore social networks.

## The steps in CBR



## How to go about it

- \* Promote collaboration at community level so that all partners e.g. workers in health, social services, education and labour, take CBR seriously and co-ordination is facilitated.
- \* Study the socio-economic situation of the whole community. The following questions should be asked:
  - How many people with disabilities are there?
  - Are people with disability also disadvantaged in terms of getting jobs, education, etc?
  - Are they accepted in the normal social groupings of that area?
  - Are they poorer than other community members?
- \* Educate the public to ensure acceptance by the community.

- \* Network amongst all the groups of disabled persons to help them to understand each other and break the often self-imposed isolation. Eventually, the ideal situation would be to have a network of people with disabilities of all types supporting each other rather than individual groups of specific disabilities, such as a group for people affected by leprosy, a group for the deaf, or a group for the blind. Networks are useful for communication and facilitation of projects both within and between communities.
- \* Make a list of possible work opportunities and skills accessible to persons with disabilities, which will help in the setting up of projects and the choice of training provided.
- \* Train the people and start income-generating activities.
- \* Support the workers during implementation: this is important to iron out any problems encountered by the workers.

### **The role of the “leprosy village”**

Leprosy care has changed from the leprosarium to being community based, but villages still remain where a sizeable proportion of the population has had leprosy in the past. These villages are often near large leprosy centres - 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. Before the current era of effective, short-course therapy, people often came to reside near a leprosy centre because treatment took many years, but many then lost contact with their original home. Dispersal to “home” areas after completing treatment therefore became difficult or even impossible in some cases. Instead of considering such villages as totally negative, it is important for us to look at both the negative and positive aspects to see how we can facilitate reintegration for individuals in this situation.

### Positive and negative attributes of leprosy villages

Positive attributes	Negative attributes
<ul style="list-style-type: none"><li>* they provide a sense of belonging</li><li>* they help residents avoid stigma</li><li>* they facilitate the provision of services</li><li>* being in a group provides cohesion in voicing needs</li><li>* they can facilitate the exchange of ideas</li><li>* they provide a feeling of both emotional and social security</li></ul>	<ul style="list-style-type: none"><li>* they encourage dependency</li><li>* they encourage isolation from the general population</li><li>* they undermine self-confidence by isolating people from society</li><li>* they can become a haven for older people who will resist new ideas</li><li>* they make residents hypersensitive to the attitude of society</li><li>* they enforce the feeling of being different (self-stigma)</li><li>* they expose people affected by leprosy to discrimination</li></ul>

### Children

Children brought up in such villages may feel isolated from the outside world. They may have a negative attitude towards the society that has isolated them and their parents. They suffer from loneliness and a lack of confidence. They may reject or deny their parents. All of this contributes to a sense of dislocation from both society and family. Their feelings of alienation and strangeness may result in antisocial behaviour and delinquency.

## **Reintegration**

In order to cope with the numbers of people affected by leprosy in such villages, who have very little possibility of full social reintegration, the following must be addressed:

### **1. How to reduce the dependency created by leprosy villages**

Planners need to develop projects that encourage self reliance and empowerment. Service providers must plan for a future withdrawal of some of the non-sustainable help given. This must be time-bound and done in consultation with the residents themselves. Participatory groups need to be encouraged, with people taking the lead in their own rehabilitation.

Children must be educated and trained in normal schools and thus integrated as early as possible. After making satisfactory arrangements, existing special schools may be closed, or opened to non-disabled children. In this manner, the chance of stigma being attached to children of persons affected by leprosy can be reduced.

### **2. How to encourage the wider community around a village to integrate with it**

This can be done by educating the society about the disease, providing common services to persons affected and those not affected by leprosy. This may mean opening schools to everyone or inviting individuals unaffected by leprosy to join in certain projects. The end of isolation must be fostered by intercommunication between groups; for example the elderly can be linked with similar groups of people not affected by leprosy and women can be encouraged to join local community women's groups. People affected by leprosy will also need to be educated about their rights to live in an integrated environment. More than education, their confidence has to be restored through empowerment. Groups can be started where the people are encouraged to make decisions for themselves and come up with solutions for their own economic and social problems.

## **Patients' associations**

People affected by leprosy need to be listened to. Associations can provide a means by which their voice is heard, especially at the local level. Joining together people with similar problems e.g. housing, credit and savings or agricultural associations, may also be helpful. When it comes to lobbying and action at the national level, larger groupings of people with a whole variety of disabilities may be more effective. In areas where stigma is a major problem, however, people affected by leprosy are normally not accepted by other disabled groups. Evidence will have to be shown of mutual benefit from co-operation.

The numbers of associations of people affected by leprosy is on the increase. These associations should also be used as tools to educate people still undergoing treatment about the disease and its management. Leprosy associations may be considered as a step towards joining other general associations of persons with disabilities, although they may have to prove themselves before integration can take place. The particular problems associated with leprosy need to be specifically addressed by general disability associations for mutual benefit to take place.

Leprosy associations are not immune from political infighting and may be commandeered by the more vocal leaders for their own purposes. The primary purpose of associations is to voice opinions and promote advocacy amongst all people affected by leprosy. They must therefore be democratic and run by staff elected from the membership.

## **The role of the 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. A person's relationship with the family can lead on the one hand to a deep sense of security and self-worth or, on the other hand, to feelings of rejection and worthlessness. 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; or that person may be rejected and prevented from developing as an individual in society and contributing to it. While the nuclear family has the most powerful influence, the extended family has a larger and more varied membership, bringing a variety of influences onto the individual.

For the person affected by leprosy, a number of questions relating to the family can be raised.

**1. In what specific and practical ways is the family treated differently by the community?**

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. At school, the child affected by leprosy may be avoided or bullied and siblings may be affected, often with the effect that 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.

The family with a member affected by leprosy may thus suffer from limited social acceptance and social interaction affecting every part of life and as a whole, the family may be denied participation in community and social events.

**2. How may the person affected by leprosy be treated differently within the family itself?**

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 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. These reactions lead to shame, rejection and

secrecy which undermine the physical and emotional support which the family should be providing to each individual member.

### **How to help families with a member affected by leprosy**

Given the tremendous potential in the family for helping people affected by leprosy overcome their difficulties, how can support be given to such families?

There are three basic approaches:

1. Individual practical support of the family (for example training in coping with disabilities), so that they can overcome the problems of a member with disabilities. While giving help for physical problems, a caring and encouraging attitude will give emotional support to the family. (The "Therapeutic" approach).
2. Information and education for the leprosy-affected individuals themselves, their families and the community. This must be done on the basis of readily available information and using imaginative methods, with the aim of altering long-held beliefs and attitudes (The "Health Education" approach).
3. Assisting the economic development of both the family and the community in order to raise the standard of living, but perhaps more importantly raise the self-esteem of those involved, leading to improved inter-personal relationships in the family and the community (The "CBR" approach).

A further question related to those already dislocated from their families is, can reintegration be achieved? The answer is undoubtedly yes, but a number of potential problems must be resolved:

- a) Resistance on the part of the person affected by leprosy may be high, if the previous hurt and rejection have been severe.

- b) Because of a high level of suspicion on both sides, it will take time to build up trust and communication.
- c) Practical considerations of travel may need sorting out if families have split apart geographically.
- d) The longer the isolation, the more difficult reintegration is likely to be.

While various development agencies may be able to help, it is clear that those in the best position to help are those in regular and close contact with the people who have had leprosy and their families. This includes all grades of medical staff and others in the community with an interest in family welfare, such as social workers and teachers.

### **The role of the government**

In general, the government's role depends not so much on a needs analysis but on its own policies and approaches. There are however, five main areas in which governments can help in the social reintegration of people affected by leprosy:

1. Changing public attitudes
2. Legislation to combat discrimination and favour reintegration
3. Resource allocation
4. Facilitating networking between governmental and non-governmental organisations
5. Ensuring co-ordination of concerned departments and services

### **Changing public attitudes**

Prominent government figures who act as advocates for persons with disabilities can help to change public attitudes. Funding and backing for major education campaigns can also be provided. An inter-sectoral approach can be promoted,

such as the provision of school books for children which show people affected by leprosy in a positive light. Visits by Presidents and Ministers to institutions and projects can also help to change attitudes or bring social rehabilitation to the public's attention.

Public attitudes can also be changed through the following:

- \* Targeted public information to employers, community leaders, teachers, etc. with emphasis on the fact that leprosy can be easily and permanently rendered non-contagious.
- \* Highlighting success stories.
- \* Inviting people affected by leprosy to participate in community events and to be active members of the community.
- \* Promoting the changing of terminology.
- \* Changing isolation policies such as settlements, specialised hospitals and vertical programmes.
- \* Using the public media and preparing media campaigns.

Changing public attitudes is not solely the responsibility of the government. Changes in law and policy must be supported by the action of health workers, the media, community and religious leaders, prominent personalities, teachers and, most importantly, people affected by leprosy themselves.

## **Legislation**

The problems associated with legislation are that the bureaucratic machinery leads to a long decision making process. Often there are no disabled persons involved in policy making and there is a lack of resources such as finances, manpower, and equipment to put policy decisions into effect. Legislation can be produced to protect the rights of people with disabilities in employment, marriage, education, access

to welfare and services, etc. Legislation alone, however, will not lead to results - the provisions of legislation have to be enforced or implemented to be effective.

### **Resource allocation**

Matching funds can be set up between governments and NGOs or government and the community. Financial support for rehabilitation and reintegration programmes, public information and education is essential.

### **Facilitating networking**

Governments as co-ordinators and convenors of bodies such as national disability councils or rehabilitation agencies can facilitate networking amongst NGOs and their own institutions. They can organise committees and bodies in which organisations discuss the needs and problem-solving approaches that are appropriate in each situation. Government co-ordination may also prevent over-emphasis on certain areas of rehabilitation and a more balanced approach by agencies.

### **Networking**

Both people affected by leprosy, community workers and NGOs working in the disability field, need to be in contact with other organisations and people in similar situations; this means disabled persons organisations (DPOs), development workers and those working with or suffering from similar chronic diseases. Networking is a way of pooling resources, ideas and power.

Problem identification as part of the needs analysis is the first step in networking, followed by research into sources of help such as development agencies, community self-help groups, old peoples' organisations, disabled persons organisations and religious societies. New networks may need to be created or existing networks sustained. Mutual support can

be achieved and leprosy organisations have much to gain from groups who are much more experienced in problem-solving in social and developmental areas. Ongoing evaluation is necessary as to the value of the particular network. Some may become a hindrance to reintegration and new groups may need to be pursued. In the process of networking, creating a new network system may be more difficult than supporting an existing one. Experience shows that rather than creating vertical programmes, integration into existing systems should be the aim.

## Chapter 4: Implementation and obstacles

### Getting there

One of the most difficult sections of the management cycle is the actual implementation of the programme. You may be able to analyse and plan but when you get to implementation unforeseen obstacles mean that the programme runs into difficulties. Obstacles usually fall into two categories

1. Personnel problems
2. Resource problems

In a programme for reintegration of people affected by leprosy we can anticipate that the following will be obstacles to implementation. They need to be taken into account in your planning and dealt with.

## **Resistance by those who have had leprosy themselves**

Let us consider five reasons why integrated socio-economic rehabilitation may be resisted by the target individuals themselves.

1. Perhaps they don't understand what is being proposed, because they have not been involved in any discussions in the decision making process. When we try to make decisions for people but not with them this will lead to problems.
2. Perhaps they feel they will lose something with reintegration such as the special funds that have been available for leprosy or the feeling of camaraderie that people affected by leprosy share, or simply a fear of change and an unknown future.
3. Many have, as a result of the present beliefs about leprosy, a negative self image - they stigmatise themselves and are unwilling to integrate with others.
4. Most are aware of the negative socio-cultural beliefs regarding leprosy and are therefore frightened of not being accepted if reintegration occurs.
5. Many are satisfied with the status quo and resist any change towards an unknown future.

Encouraging participation and spending time with those we seek to help will reduce their resistance. Once they see that the programme works and helps them they will gradually join in. The keys are to involve them from the beginning, not to be too ambitious in your help or start anything that is non-sustainable, and to be patient.

## **Stigma in society**

Any disability can be stigmatising, but leprosy is particularly so, with many societies seeing it as the worst disease, a curse from God or the direct result of wrongdoing.

Society's attitude to leprosy may result in people affected by leprosy being seen as outcasts rather than people with disabilities who can be helped. Many societies are quite content to have leprosy dealt with in a separate programme and would actively oppose any integration. The need for health promotion that includes lobbying, advocacy, social marketing and not just traditional 'health education' cannot be over emphasised.

### **Lack of money**

The disease and the people affected by leprosy are generally associated with poverty and unfortunately 'socio-economic rehabilitation' for these people is also associated with a lack of financial commitment. Therefore for such projects to work, the strong commitment of all interested parties (government and donors), is essential.

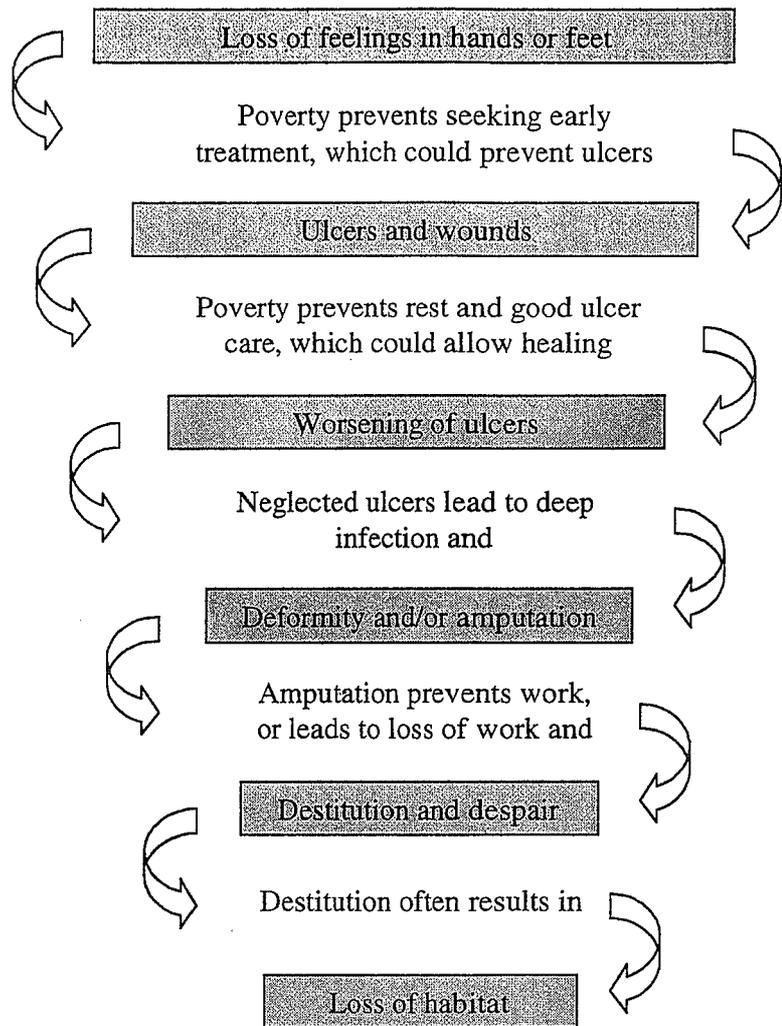
### **Poverty of the people**

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

- \* stigmatisation
- \* dislocation and displacement
- \* loss of home and land
- \* loss of income and employment

These factors are often in direct proportion to the level of deformity amongst people affected by leprosy and form a vicious cycle impossible for the individual to break without outside help. People affected by leprosy with anaesthetic limbs need to rest and take care of their wounds, but this is impossible where poverty means that they must farm, work or beg. This leads to a worsening of their disability, more wounds, more problems and perhaps ultimately amputation. The end of this downward spiral is almost certainly destitution and total dependency on external help or charity.

*Disability and poverty: a downward spiral*



## Poverty of financial assistance from donors/government

Whatever the situation of funding for leprosy in the wider world of fund-raising, it is certainly the case that funds for helping people affected by leprosy become active and useful members of their community is currently a low priority. The emphasis by the WHO is on elimination of leprosy by the year 2,000, so clinical aspects of the disease are still holding sway among policy-makers and the influential organisations in the leprosy world. The dignity, usefulness and basic human rights of people cured of leprosy - but who still face the harsh realities of daily life, with stigma, deformity and disability - are not yet on the world's agenda.

Reasons given for lack of assistance from donors are:

1. "socio-economic rehabilitation is a bottomless pit" meaning that the needs of persons affected by leprosy are without limit. But the needs of a developing country are also without limit (since societies continue to evolve whatever their current circumstances) - that has not stopped donors investing in rural development.
2. "it would be unjust to positively discriminate in favour of people affected by leprosy".

In other words, in a poor country there is no justification in helping the victims of one disease when victims of other diseases - and victims of poverty itself - are not extended such help. This is more an argument for developmental approaches to leprosy rather than inactivity. The needs of poor, disabled and stigmatised people in the world are many and pressing; so are their basic rights as human beings and citizens of their countries.

As previously mentioned in Chapter 3, the role of the professional and community workers has to change in order to meet the need for social integration and rehabilitation. This is also true of donors: their perspective and priorities need to change to encompass reintegration. Indeed, the utterly insufficient perspective of the clinical and public health

approaches - which both concentrate on the disease rather than on the person - should be obvious to all. In a poor country, with limited resources and perhaps non-existent provisions for widespread social security, releasing a person 'cured' of leprosy from treatment with no further support is a recipe for individual and social disaster. Begging and the informal economy may absorb some of these "medical outcasts" but in the long-term, the dangers of an explosive social situation arising from desperation and destitution are high.

## **Chapter 5: Monitoring and evaluation**

These activities are an essential and yet often neglected part of management. They are really an assessment of the project, seeking to find out if we have achieved the objective and if not, why not.

## Monitoring

Monitoring is the ongoing evaluation done whilst the project is happening. It seeks to answer the following questions:

- \* Are we going in the right direction?
- \* Is the project working?
- \* What are the problems?
- \* What are the obstacles?

Based on the answers to these questions, changes may have to be made to your planning and implementation strategies.

In any evaluation and monitoring effort you need to look at process and outcome indicators.

**Process** = The process is the **way** in which the activities are being carried out. Are all the steps in the project being done correctly? If most of the activities are being done properly and on schedule, it is more likely that the overall objectives will be achieved.

**Outcome** = The outcome of an intervention is the **change** or impact produced by that action. Have we got the results we really want? This can often be quite difficult to measure.

*For example:* If the objective is to place 100 people affected by leprosy in work by the end of the year, the evaluation of outcome will make a list of those working on December 31st to see if the total reaches 100. If the objectives are SMART (Chapter 2) it should be straightforward to evaluate outcomes. The evaluation of process, however, looks at activities such as training, assessing the market for potential self-employment opportunities, etc. Throughout the year these activities can be monitored - if they are being done successfully, the desired outcome is more likely to be achieved.

Monitoring has more to do with process than outcome. You need to look at:

### **1. Participation**

How many people affected by leprosy are joining in the programme? How many are voicing their opinions? Who is not participating and why? Are the people affected by leprosy satisfied with the programme? What do they think about the programme? Is it meeting their needs? How much reintegration has been achieved?

### **2. Strategies**

Are the strategies working? If not, why not? Which one is achieving the most? Which is achieving the least? What factors make the difference? What changes do we need to make? Are we meeting our targets?

### **3. Finances**

Do we have enough money to complete the project? Is the cash flow able to cover what we need. Are costs being recovered by participant fees or other charges? What further budgeting do we need for the future? What is not covered?

### **4. Other Resources**

Do we have adequate resources? What are we short of? What resources are not sustainable? How much of the resources are we getting from outside the country? What will we need for the future?

### **Timing of monitoring**

Monitoring occurs during the life of the project and not at the end. Some monitoring will occur naturally as you go along, but it is also good to schedule official times and set up a monitoring check list. Monitoring should take place at regular intervals, perhaps every 6 months. Some projects also require a mid-term evaluation half way through the project. This will look at outcome as well as process.

## Evaluation

This is when you analyse whether you have achieved your objectives. It is concerned with the outcome primarily, but may also use some process indicators. All these are dependent on your objectives. Since most of the objectives for social reintegration are related to participation and development, the following may be helpful:

- \* the percentage reduction in the number of dependent people affected by leprosy;
- \* number of children belonging to people affected by leprosy who regularly attend school, (this could be examined by sex and age group to give more information);
- \* number of people who are working;
- \* income levels amongst people affected by leprosy.

All these evaluate the project from the professional's point of view but the participant's opinion should not be neglected. Qualitative analysis should also be done.

- \* Does the project meet participant needs?
- \* How many people have dropped out? What are their reasons?
- \* Which groups are successful? What are the reasons for this?
- \* How do the participants see the future of the project? Where do they want it to go?

## Timing of the evaluation

An evaluation is usually done close to the end of the project, although for projects of longer duration, a mid-term evaluation may be beneficial. A mid-term evaluation may reveal targets which cannot be reached or which are not cost-effective. Such targets may be modified or abandoned, to concentrate on others. This will be used to make changes in the planning and implementation strategy.

## **Chapter 6: Conclusion: The plan of action**

A plan of action is a document which applies the principles of the management cycle to the proposed project. It will often be the basis for an approach to a donor for financial assistance or to a government department for approval to proceed. This chapter makes suggestions and recommendations as to what must be considered when a plan of action is being drafted for social reintegration projects for people affected by leprosy.

## **Building blocks for the future**

The following building blocks are considered to be the foundation on which specific socio-economic development projects can be developed:

- a. Psychosocial issues
- b. Public information
- c. Policy and Legislation
- d. Structures, networking and participation
- e. Enhancing work opportunities
- f. Front-line staff training and motivation.

All of these building blocks are necessary for social reintegration projects to be successful. In the following section we will look at the blocks individually, with recommendations for their implementation.

### **Psychosocial issues**

People affected by leprosy may not only have disability but also a very negative self-image. Their reintegration can be promoted by:

- \* training for health workers in the social skills of counselling and dealing with feelings;
- \* changing the attitudes of the individual, the family and the community so that those affected by leprosy are seen not as useless beggars, but instead are accepted as community members and given the right to participate and to make their own decisions;
- \* linking people affected by leprosy with community groups, including disabled persons organisations, so that wider issues such as gender and poverty alleviation can be dealt with;

- \* giving importance and priority to activities that help people affected by leprosy to gain vocational and economic skills;
- \* encouraging the treatment of people with active disease in their own community, to help them retain their independence and not become institutionalised;
- \* giving people with leprosy respect right from the start and in so doing, teaching them to have respect for themselves;
- \* identifying factors that can fight against stigma, for example public information campaigns via the media;
- \* inviting other professionals to share their experiences so that we approach the problem not just from a medical angle, but learn from the social sciences and other disciplines;
- \* stressing the role played by all sectors of the community.

### **Public information and advocacy**

Members of any community have concerns about the disease and avoid people affected by leprosy. These concerns and behaviours can be modified by:

- \* increasing coverage about leprosy, via the mass media, using media experts;
- \* making sure the media do not use leprosy information in the wrong way, and actually increase the stigma;
- \* educating the media personnel themselves;
- \* setting a good example by educating medical personnel to change their attitudes;

- \* identifying and recruiting influential people in public life to become advocates for people affected by leprosy. Public relations specialists exist for this purpose, and their use should be assessed. Their advice concerning getting information into schools should also be considered.

### **Policy and legislation**

Policies and legislation that specifically address the needs of people affected by leprosy are important. However, legislating for a minority in a way that is not supported by the majority is unlikely to be successful. Important principles include:

- \* Equal rights for all people regardless of gender, religion, race and disability should be part of the each country's constitution and/or legislation;
- \* Legislation prohibiting discrimination against persons with disabilities, including persons affected by leprosy, in all realms of life (health care, education, training, employment, etc.) should be a part of every country's legal code;
- \* Benefits available to persons with disabilities in general should be made available to those affected by leprosy (tax concessions, transport reductions, reserved jobs, etc.);
- \* Needed aids and appliances should be made available free of cost.

### **Structures, networking and participation**

In all structures and programmes the aim should be to encourage self-help amongst people affected by leprosy. Such help can be made more comprehensive by:

- \* encouraging the inclusion of persons affected by leprosy in all community development programmes;

- \* encouraging cross-disability organisations to include people affected by leprosy;
- \* encouraging persons affected by leprosy to form their own self-help groups;
- \* helping community associations to encourage the participation of persons affected by leprosy;
- \* promoting networking between development and disability organisations within a community.

### **Enhancing work opportunities**

Although all countries promote the creation of formal sector jobs and economic development, various schemes to support informal sector work opportunities also exist. Work opportunities for persons affected by leprosy can be enhanced by:

- \* giving NGOs the responsibility to organise appropriate income generating activities for individuals and groups of persons affected by leprosy;
- \* conducting a campaign directed at informal sector employers (to promote the training and employment of people affected by leprosy);
- \* helping persons affected by leprosy to develop vocational skills for work and self-employment;
- \* providing business skills training to individuals and groups;
- \* encouraging the establishment of micro-enterprise credit systems and lending to qualified individuals affected by leprosy;

### **Training and motivation**

The ongoing training of both institution personnel and community development workers in psychosocial skills, such as counselling, must be a priority. This can be achieved by:

- \* conducting regular in-service programmes;
- \* promoting the involvement of personnel from other sectors and disciplines;
- \* ensuring that workshops target 'front line' staff who may come into contact with people affected by leprosy;
- \* encouraging staff to specialise in counselling and other psychosocial skills;
- \* promoting networking in training programmes (get leprosy staff to attend appropriate socio-economic workshops, regardless of whether they deal with leprosy or not);
- \* ensuring appropriate follow-up of training programmes.

## **Part 2**

### **Social rehabilitation in practice**

Part 1 has set out a theoretical framework to enable you to start thinking about and planning projects for the socio-economic rehabilitation of people affected by leprosy. In this second part, Chapters 7 - 9, a number of different practical situations will be explored and examples of different ways of solving certain problems will be given. This is not a complete guide as to what is possible, but we hope it will give you some ideas as to what may work and what may not work in your own situation.

## **Chapter 7: Socio-economic reintegration in urban and rural settings**

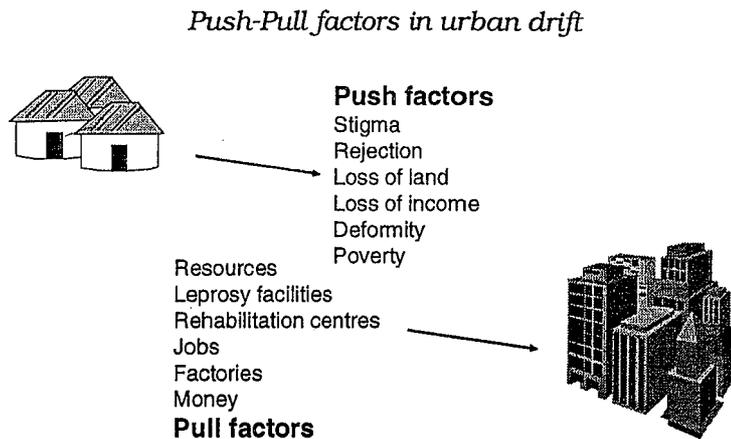
Persons affected by leprosy in developing countries live in both rural communities and in major cities. Effective strategies for socio-economic reintegration must be designed according to the circumstances of where one lives. What may work in a rural village or town may not be appropriate or effective in a city environment. Although the goal remains the same - economic self-reliance and participation in family and community life - different approaches are required, which are described in the following pages.

## The urban setting

### The problems

#### 1. Urban drift

Rejection and segregation leads to urban drift. Individuals are separated from their families without support or income. Reintegration needs to address the push-pull factors relating to leprosy.



Many people affected by leprosy cannot return to their home areas if they moved away many years ago. Some method of help for them has to be offered without encouraging urban drift for others.

#### 2. Poverty

Poverty, loss of income, housing, health, education, and sanitation are major social problems affecting most urban families. Often people who have had leprosy become the poorest of the poor, rejected and stigmatised even by those who have similar social problems.

General development measures can only help people affected by leprosy when stigma is dealt with and reduced. Specialised training, and creation of work opportunities may be regarded as possible solutions but only where other disadvantaged persons are involved in the schemes. Creating specialist help only for those who have had leprosy may impede their integration and lead to further stigmatisation.

### **3. Lack of political will**

Governments in developing countries often lack both the resources and the capacity to deal with urban problems. Laws and policies may be formulated but remain unenforced or unimplemented because of unpopularity and lack of voter appeal. Governments may resort to short term solutions such as slum clearance and resettlement.

Ignorance of the root causes of urban problems can lead to poor prioritisation and lack of clear policies. A lack of resources may lead governments to becoming donor dependent. This means that policies and solutions may become donor driven and unrelated to government priorities.

### **4. Top down approach**

Where countries have a strong top down development approach, cities and particularly capitals, will be provided with resources and become attractive to the poor. The urban clustering of resources and the educated elite will inevitably encourage begging and opportunistic moves of the poor to urban areas.

Development programmes that start from the bottom and work up will help people in rural areas and encourage equal countrywide distribution of resources.

## **Approaches**

### **1. Removing stigma**

Health promotion is as important in the urban setting as the rural. Only a comprehensive campaign will help to remove some of the prejudices that lead to urban drift. The educated elite of cities should be targeted using the mass media so that they can lobby the government for action. The use of mass media should be encouraged. Campaigns should address the urban problems experienced by many of the poor and disadvantaged, as well as the stigma and status of people affected by leprosy. In the urban situation lobbying public officials is one of the most important means of health promotion.

### **2. Development**

Development projects dealing with poverty and housing need to be opened to people affected by leprosy. The urge to treat leprosy as a "special case" needs to be replaced by a desire to look at the whole situation and associate leprosy programmes with existing developmental ones.

### **3. Work opportunities**

Programmes for the creation of work opportunities for persons with disabilities should be open to persons affected by leprosy. A holistic approach must be used. Sustainable programmes require:

*market research*, to ensure that services provided and products produced are demand-driven and essential to the population, and not just targeted for seasonal tourists;

*assessment* of the community and its needs, to determine the best approaches (self-employment, group employment, etc.);

*realism*; to ensure that projects are relevant to both the situation and the person affected by leprosy. Charity approaches create dependency rather than self-reliance.

## **The rural setting**

The aim of socio-economic reintegration is to allow the individual to be an independent member of his or her community. In most developing countries the whole population is poor, so it is best if help for people affected by leprosy is included as part of a package of assistance for the whole community.

It should, however, be remembered that people with disabilities find it difficult to find work and often cannot work productively enough on the land to compete with their neighbours. Therefore, criteria need to be established for aid that targets:

- \* heads of households, especially women, unable to feed their family members
- \* young people with no alternative but to become beggars

## **The problems**

The obstacles to the socio-economic reintegration of persons affected by leprosy in the rural setting are similar to urban ones:

1. Planning is usually done in a top-down fashion, so the people do not feel involved, and there is no sense of co-ownership.
2. The rural people are often less well-informed about which services are available from the Government.
3. Similarly, less education is available and they are less aware of their rights or about the options open to them.
4. Disability is often a low priority, so there are rarely any adequate services established to cope fully with the needs of persons with disability.

5. Rural communities depend mostly on agriculture, and this usually involves work and skills that are often difficult for a person with a disability. This is also true for people affected by leprosy, who may damage themselves by working in physically demanding situations with insensitive limbs.
6. Rural communities are more tradition-bound in their beliefs, and do not change their attitudes easily. This is a big obstacle to the reintegration of people affected by leprosy into the wider rural community.
7. It is difficult to remain anonymous in a rural community because of the close social networks that exist. Therefore it is difficult to hide a disease such as leprosy.
8. The prejudice against persons affected by leprosy is strong in rural communities and their segregation and non-participation in community life is often not perceived as unfair.

## **Approaches**

### **1. Public education**

To ensure acceptance of the people affected by leprosy - making use of existing structures e.g. village leaders, health workers, traditional healers and community groups.

### **2. Decentralised health services**

Village health workers are usually in the best position to know who needs help and can monitor people with complications more easily.

### **3. Extended family systems**

Most families, given the opportunity, are very happy to help their siblings or children who have a disability.

#### **4. Networks**

Many organisations are working towards the same goal. If they work together and help one another, the results will be better and more people can be assisted.

#### **5. Demonstration of abilities**

Show the community what a person affected by leprosy is capable of and ask them to uphold his or her rights of participation in community activities. When they see some people who have had leprosy able to live independently, they will become more accepting of others.

#### **6. Community development**

As any community develops - socially, as well as economically - it will be better placed to help the persons with disabilities within it.

#### **7. Economic assistance for self-reliance**

Any assistance given should benefit the community at large. This is where it is very important to have strict criteria as to who gets what.

#### **8. Support systems for carers of people affected by leprosy**

Self-help groups are an effective and inexpensive method of allowing carers to share their problems and solutions. Methods for providing expert help to assist carers need to be put into practice.

#### **9. Participation**

Involve the people affected by leprosy, both men and women, in changing public attitudes. Use them to teach the community about attitudes of tolerance, in creating awareness of their own circumstances, and in promoting inclusive policies and practices.

## **10. Land**

Land is a valuable capital resource. Many people who have had leprosy, own land and their property rights must be protected. Assisting people to make a living from their own land can be one of the most straight-forward and worthwhile methods of socio-economic rehabilitation.

### **Summary**

With all these approaches, it is important to look at the long-term results: activities may appear to be uncaring and rather harsh, but the overall, long-term objective must be to avoid creating dependence and to promote the development of autonomy. The objective must always be to help the person affected by leprosy, the family and, ultimately, the wider community to become responsible for meeting their own basic needs and for fulfilling their own aims and aspirations.

## **Chapter 8: Strategies for socio-economic reintegration**

In the following sections, specific strategies for economic reintegration are outlined in some detail. The strategies described are:

1. Self-employment
2. Group income generation
3. Co-operatives
4. Savings and credit schemes
5. Sheltered workshops
6. The holistic approach

## **Section 8.1: Self-employment**

Self-employment is only one of a number of work options for persons with disabilities but it is the one that may suit the largest number of this group of people, especially persons affected by leprosy. In developing countries, for every disabled person employed in the formal sector, there are at least 4 - 5 self-employed persons.

### **Advantages of self-employment**

- \* Self-employment depends on the individual's own decision making rather than someone else's.
- \* Jobs on the open labour market are becoming more and more scarce as population growth outstrips job creation.
- \* In economic terms, self-employment is perhaps the most cost effective method of creating new jobs, because 'start-up' costs are lower.
- \* The smaller the operation, the less it is dependent upon infrastructure (such as buildings or transport) which may not be available or effective.
- \* Self-employed persons tend to sell their products or services within a small area or community, thus providing a direct and needed service to people.
- \* Individuals can often operate from home and set their own working hours.
- \* When a person with a disability is involved in an enterprise, he or she tends to involve the whole family and this mutual support and security is especially suitable to such disadvantaged persons.

Self-employment is not for everyone. Not all persons affected by leprosy or affected by another disability have the ability to manage a small business activity. Those choosing this option may have to be trained in how to start and manage their own income-generating venture.

It is necessary to consider the following three things for successful self-employment:

1. Does the individual have the necessary combination of characteristics?
2. Does the individual have the physical requirements for the work?
3. What is the source of raw materials or products to be sold, and the demand for the product or service in the marketplace?

### **Assessment of participants**

Assessment of candidates for self-employment is often overdone with physical, mental, educational, intellectual analysis more detailed and comprehensive than for able-bodied persons. The important thing is to know the individual well and then make a judgement as to whether he or she has the basic aptitude, confidence, judgement, skills and enthusiasm necessary for self-employment. In this assessment the family can be a great help.

### **Choice of business**

An economic survey of the community should be carried out by the community worker. This should find out:

- \* What are the main products and/or services which are regularly in short supply?
- \* Is the population growing to increase demand for certain products or services?
- \* What raw materials are available locally?
- \* What is regularly coming into the community from outside?

When choosing a business, always work backwards from the market. The second biggest problem amongst self-employed persons after lack of finance is lack of customers!

Avoid influencing the individual into undertaking an activity just because it is what other disabled people have done before. There is far too much needlework and basket-work done, leading to vast stocks of unsold products piled up in store rooms.

When the individual chooses a form of self-employment, he or she should draw up a rough business plan with the help of the family. This will help to measure the level of enthusiasm and general business knowledge. Whatever activity is chosen, they should be encouraged to "start small," and do all the preparatory work themselves.

### **Training**

The individual may already have the necessary skills and need no training. He or she may need only some locally arranged business advice. If more training is necessary, there are a number of options.

The preferred option is a community apprenticeship in which the individual undergoes a short term (3-9 months) skills training programme with a local trades person. This will help him/her to learn both the technical skills and the business side of the trade. A small amount of money may be paid to the trades person to compensate for the training provided. A small training allowance may need to be paid to the trainee. This option gives a wide range of trade options to the individual, and will still be cheaper than most other alternatives.

The least preferred option is a skills training course for disabled persons that further isolates them from the community. This rarely gives the essential business knowledge necessary to market their skills effectively.

### **Capital**

In many studies in the developing world, lack of capital is the most commonly identified factor affecting self-employment projects for both disabled and non-disabled persons.

More money may not necessarily be the answer, if there is poor financial management. The importance of starting small cannot be over-emphasised.

Credit schemes, such as revolving loan schemes, are essential for the development of self-employment. They must always be accompanied by basic training in money management. Grants of money should be avoided or given sparingly, since they do not encourage self-sufficiency or a serious business attitude. Provision of credit through commercial channels is preferable to lending by charitable or business advisory services. When volunteers or advisers provide credit, loanees may avoid them and thus not benefit from their advice.

### **Community support**

Whilst we should aim for a situation in which self-employed people with disabilities succeed or fail on their own merits, some will need considerable assistance, especially in the start-up phase.

We should remember two factors that are nearly always present in successful examples of self-employed persons:

1. The individual is a self-confident person
2. The community is interested and involved in helping the individual to succeed.

It will be obvious that these two things present particular difficulties for people affected by leprosy. They are often ostracised by the community and suffer from a poor self-image. It may be that more time has to be spent in building up their self-confidence and educating the community, before self-employment projects can be commenced. The advantages of small projects such as petty trading, which give the person confidence as well as practice in business management are obvious.

## **Section 8.2: Group income generation**

*The example of the Women Fuelwood Carriers Project, Addis Ababa, Ethiopia*

### **Learning from previous failures**

Income generating projects for women's groups have often developed a bad reputation. They have been started in their thousands in every developing country but success stories have been few and far between. An income generating project has often come to imply a women's income generating project, and this has also contributed to the failure rates. There has been much research on the reasons for the failures.

The main characteristics of unsuccessful women's projects can be summed up as:

- \* they are under-funded, and often an appendix to a larger "mainstream" programme
- \* they promote "suitably feminine" skills, services and products, with no regard for their market demand
- \* they are guided and designed by community and social workers who have no business skills.

### **Six considerations for success**

When we search for the possibilities of helping people to earn an income on which they and their dependants can survive, the consideration of the following six conditions is crucial for a successful project.

#### **1. Individuals or groups?**

Many projects have concentrated on group efforts: the collective group production of items such as soap, or poultry have been encouraged. But the rationale for group income generating projects has not been based on what is best for

the business which the group operates. Group enterprises are difficult to operate for the following reasons:

- \* Group enterprises need more organisation. More effort may be spent on the "group dynamics" than on the business.
- \* Developing an enterprise which supports a large number of people is more difficult and ambitious than developing one that supports only one or two people and their families.
- \* Co-operation among the members is difficult to establish and maintain.

Basically a large group requires more capital and needs to generate more income. Large groups may have little chance of earning a meaningful income for their members, indeed the group may serve primarily a social purpose rather than a business one. The most promising option would seem to be small group enterprises operated by an individual or two or three people.

## **2. Choosing the type of enterprise**

The business idea should always originate with the operator, that is, the group or individual proposing the project. The operators can be guided and helped, and should be encouraged to ask themselves the following questions:

- \* Do I have the necessary skills or can I acquire them?
- \* Can the service or the product I plan be sold?
- \* Can I sell it at a profit?
- \* Can I earn an adequate income?

Only if the answer is yes to all four questions should that type of business activity be chosen. The operator should be encouraged to do his or her own research. This can be done by seeing how others are faring with the same activity; and by being helped to make the simple calculations of investment and working capital needs, costs, projected sales, income, etc.

### **3. Training**

New business operators do **need** some basic training in business and financial management, but it should not be forgotten that marketing, promotion, and quality control are at least as important as orderly financial records.

Training can provide useful tools for the would-be operator, but it cannot replace entrepreneurial spirit. Two important aspects of initial business training are: the development of the trainees' own problem solving capacities; and as many look-and-learn visits as possible.

### **4. Business support services**

The most successful small enterprise development programmes have built into them a regular support and advisory service. The Port Sudan Programme is an excellent example: extension agents trained in business management provide regular advisory services, for a small fee, to the operators. Regular visits ensure that financial records are kept and analysed. In this way any costing, pricing, or marketing problems can be detected as they appear, and prompt advice can be given to correct them. Social problems that affect the business can also be found and tackled.

Mutual support can also provide a beneficial service. In a Nigerian programme, for example, extension workers encouraged individual entrepreneurs to form small groups which met frequently. The members discussed any business problems they faced, and often other members of the group could give useful suggestions for solutions.

### **5. The capital base**

Groups may be given sewing machines or other equipment as a grant, but little attention is given to where the initial working capital will come from. Working capital needs are seldom met by donors - and women have struggled to make do with inadequate "seed money" for years. Similarly school leavers are given training in a craft, tools to set

themselves up, but cannot operate without working capital. Credit schemes for individuals initiating business activities can help provide necessary working capital.

## 6. The four Ps of marketing

These are:           Product  
                          Place  
                          Price  
                          Promotion

Marketing does not only mean identifying sales outlets. It means that the **Product** has to be right; the **Place** has to be accessible; the **Price** has to be attractive (but also provide a reasonable income) and the product must be **Promoted**. This last point has often been a difficulty in women's income generating projects.

In many societies women are not encouraged to be aggressive saleswomen. Their role is more passive and "gentle", but to sell you have to promote; to promote, you have to be active, you have to push your product and be visible. This is difficult for women and those stigmatised because of leprosy.

## Conclusion

Ultimately a combination of factors will determine whether a small business is successful or not. A good product or service, good training and support services, an adequate capital base (with access to credit, if possible) and good business management are all important. Subjective factors such as motivation, talent, and luck also play a part. To this mix must be added the time factor. It is unrealistic to expect small enterprises to break even immediately. In short, developing a successful small enterprise income generating programme takes time and much effort, and considerable financial and human resources input.

## Section 8.3: Co-operatives

### *A case study from Tibe, Ethiopia*

Tibe is a remote resettlement project to the west of Addis Ababa. It is set in fertile countryside and gives the impression of a well-established community. This is the result of almost 25 years of hard work by a group of people affected by leprosy.

The Tibe project began in 1971 with the help of some concerned individuals in Addis Ababa. The beneficiaries were all volunteers, who until then were living by begging on the streets of the capital, although many came from a farming background, before developing leprosy.

26 heads of households with their dependants were resettled at Tibe. Houses were constructed, they were given farm implements, some cattle and oxen for ploughing and cash for subsistence until the first harvest. They are now producing abundant crops including maize, beans and oil seeds.

The land is fertile and they have worked hard. As people affected by leprosy, they still need to look after their hands and feet. There is a partnership amongst them in their activities. If a man can do all farming activities except cutting grain with a scythe, he will be helped in this work by others.

One of the biggest problems has been acceptance by the wider community. Initially, the arrival of this group of people affected by leprosy was resented and local people would not mix socially with them. This was partly because the land given to them by the local government was taken away from others. The community also segregated them because of what they looked like; their deformities, and the way they dressed. This made selling their produce difficult because the community steered clear of them.

The resettled group worked hard to cultivate the land and provide for their needs and those of the community. Persistence on their behalf paid off and the group managed to

cope well and assimilate with the local people and a gradual increase of acceptance was obtained.

Some of the community's beliefs were changed as the local people observed this previously despised group. For example, in Ethiopia leprosy is believed to be hereditary, but the people realised that family members of these people did not have the same problem. Several relatives of group members came to visit and live with them. Data in 1994 showed that out of a total number of 175 settlers, only 28 were disabled by leprosy. Those affected by leprosy are still poor and their disabilities have worsened because of this, but they have learned to become productive and independent members of the community.

Three years after the start of the project, outside support ceased because of the change of government in Ethiopia. However, the group was well-motivated and hard working so that by the time of the severe drought and famine in Ethiopia in 1984, they were generally much more productive farmers than their neighbours. This led to recognition by the surrounding community, the allocation of more land and a fruitful link with the nearby rural technology centre.

The last ten years have been increasingly productive and new projects such as a maize mill are being considered. The mill is a joint project with a number of neighbouring villages but led by the Tibe group. These people who had leprosy a long time ago feel confident of their ability to live independently but also feel they are no longer ostracised by society because of their leprosy.

One additional sign of the socio-economic rehabilitation of this group is that they have been able to buy a house in Addis Ababa, so that their school age children can live together and attend the more prestigious schools in the capital. Their isolation has more or less ended, 25 years after leaving the streets of Addis Ababa.

## **Section 8.4: Savings and Credit Schemes (SACS)**

### *The example of Redd Barna - Ethiopia (Norwegian Save the Children)*

This project aims to improve the quality of life of children from low income families through financial support for income-generating activities. The objective is to enable families to secure sufficient income to cater for the basic needs of their children, throughout their up-bringing.

In urban projects, this is done through the establishment of Savings and Credit Co-operatives (SACC's), in which a revolving credit fund is created in combination with members savings and a grant from Redd Barna.

The following working principles are used:

- \* child, women and poverty oriented
- \* encouraging community participation
- \* cultural and ecological sensitivity
- \* maintaining low cost per unit of output

The ultimate goal is the economic empowerment of the target group to give back the social status and self-worth they have lost because of poverty.

### **The operation of a Savings and Credit Co-operative**

Credit facilities for the disadvantaged and poor need to be accessible with a minimum of formalities and red tape. They should be administered at grass roots 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.

It must be understood that the loan is not a grant and repayment, including a service charge, is part of the scheme. Credit schemes that fail to perpetuate themselves do not contribute to the alleviation of poverty. Financial viability of the scheme is one of the main guarantees for sustainability.

*Main features of Redd Barna's credit schemes:*

**1. Women orientation:** The credit schemes have a strong positive bias for poor women. The main essence of this orientation is that giving economic empowerment to women means feeding the whole family. Experience has also shown that women are more trustworthy than men, with higher repayment rates.

**2. Productive venture:** All schemes give credit for productive purposes that generate enough return to cover the loan repayment (including interest), plus an extra income to cover at least the basic life requirements of the borrowers. Credit is given for small scale trading services, production activities and for investments that increase agricultural productivity of a poor household. The types of undertakings for which credit is extended have to be individual/household level enterprises with a high profit prospect. The type of enterprise has to be decided by the individual borrower with advice given by the professional.

**3. Ownership and management:** The members are the owners of the scheme and it is managed by a democratically elected Executive Committee. Major decisions are made by the general assembly. In rural credit schemes, loans are decided during weekly or monthly meetings. All transactions such as loan approval, disbursement and repayments are conducted at group level.

**4. Collateral and loan repayment sanctions:** The relationship between members is characterised by trust and mutual understanding. As a result, there is no requirement for collateral (especially in our rural credit schemes). Seeking and gaining social acceptance has more weight than the written terms and conditions of an agreement. Peer group pressure is the main means of ensuring loan repayment and group discipline.

**5. Transparency of credit administration:** The scheme is operated in complete openness. All transactions are performed during weekly, biweekly, or monthly meetings. All recording and counting is done in front of members during

the regular meetings. During every meeting, each member is told the amount of outstanding loan and savings she has.

**6. Regular savings:** One of the disciplines required of a member is to save regularly. Failure to do so without acceptable reasons may entail penalties, and may ultimately result in dismissal from membership.

**7. Nucleus for extension work:** In most cases, credit and income generation alone may not make a significant impact on poverty alleviation. To add to its impact, the scheme is used as a contact point and a means to undertake basic extension work, such as primary health education, protection and preservation of the environment, reforestation, introduction of improved seeds, agricultural tools and techniques.

**8. Participatory approach:** The funds for the credit scheme are generated from the participants. Participants are encouraged to save so that their funds facilitate at least the first one or two rounds of loans. This exercise (if possible) should be done without creating expectation for financial grants from the sponsoring agency. A top-up grant is given where the members savings fall short of the demands for loans to engage in productive income generation activities. Under no circumstances are participants given all the funds required for a collective income generating activity. Grants are released in proportion to the funds mobilised by the participants of the scheme. Thus the participants are the ones who play the leading role and the external body is merely a supplementary resource.

**9. Social welfare activities:** Participation in a community mutual support network is as important as most human needs. For credit schemes, mutual support systems are an ideal means to further cement the sense of solidarity among members. As a result, such mutual support practices are encouraged as part of the savings and credit schemes. The mutual support networks have become a safeguard against borrowed money being spent to meet unexpected disasters in a family such as death, or loss of property by theft or fire.

## Supplementary policies for income generation

Successful income generation activities depend on the choice of the individual and a clear view of the basis of the proposal. The issue of profit and management must be addressed if people are to repay the loans without eating into their original capital and running at a loss.

**1. Co-operating partners:** These may be individuals or families. Community based interest groups such as service co-operatives, women's self-help groups and savings and credit co-operatives may also be targeted.

**2. Commercial vs. social objective:** There has to be some stress on the profit motive. If a heavy subsidy is given and operational costs are assumed by NGOs, the project will not be sustainable.

**3. Independent management:** Projects need to be independently managed. The sponsoring agency's role needs to be limited to technical assistance, and training.

**4. External security vs. own risk:** People must understand that the scheme is for income generating and not a charity. The person's knowledge and skills should be built upon and the risk that he/she takes made clear from the beginning. The NGO should not provide security for business failure.

**5. Training principle:** In order for the scheme to be successful, training must be built into it as part of an income generating promotion package. The training must be linked to employment opportunities, and focus on management skills.

**6. General economic development vs. immediate family income increase :** The aim is to help the family survive and overcome its poverty; therefore in the short run, schemes should increase family income. Individuals should be encouraged to focus on areas that give quick returns and look at small scale projects.

**7. Phasing in and phasing out:** Ultimately there must be a phasing out of the donor agency's contribution. This will avoid the dependency syndrome and create self-reliance. The ground work for phasing out must be laid at the planning stage for future sustainability.

## Section 8.5: Sheltered workshops

When considering any form of paid employment for disabled persons, it is necessary that their potential for rehabilitation is assessed by considering the following factors:

- \* Motivation to earn a living wage
- \* Desire to learn a skill
- \* Stability of mind
- \* The need for steady work

Any employment will depend on the physical capacity of the individual. The employer, in choosing a job for the individual, should not allocate work that he or she cannot do.

Sheltered employment is protected employment, provided for those with severe disabilities. It should not be regarded as permanent employment but as an intermediate employment with preparation for open employment. Sheltered employment could be in co-operative societies, dairy and arable farms, and in industry.

### Two examples from India

**Lingaraj** left home early in life, when he was sixteen, as soon as it was discovered that he had leprosy. He stayed in the New Life Centre for leprosy patients, attached to a hospital. Reconstructive surgery improved his hand function and being with others facing similar problems of stigma and isolation, gave him a feeling of belonging. There were some craft activities and involvement in these gave him some self-confidence. On the recommendation of his doctor, he was admitted to WORTH, a production workshop for persons with disabilities. Here he learnt to operate a lathe and use measuring instruments. Being able to earn a higher income and working amongst those who accepted and respected him, made him feel much happier.

When an open industry nearby offered to employ people affected by leprosy, he was one of the four who opted to go.

The workshop was nearby, so he could stay in the same rented place, keep his friends and earn a higher salary. He was interviewed and accepted. However, when he started work, he faced severe problems.

The workers in the factory did not accept him. They put notices on the machines he operated, saying that these machines were handled by a "leper" and were therefore dangerous. The management sought the advice of WORTH. The manager and a leprosy specialist met the workers a number of times and explained to them about leprosy - how those who are cured may still have deformities but there was no danger to others. The management took the view that those workers who refused to work with others affected by leprosy could leave and seek employment elsewhere. Many were convinced by the medical advice and others worked reluctantly, but none left.

Lingaraj was slowly accepted by the other workers and through his perseverance he was promoted and given more responsibility. The good income gave him a strong economic advantage. He could rent a house from people who earlier refused to accept him and he married a girl who had no disability - indicating social acceptance.

Today Lingaraj is awaiting retirement. He has built himself a house and has a relatively high income. His daughter completed secretarial training and is in full-time work. She is happily married. His son completed a tool-maker's course and earns more than his father.

Lingaraj takes part in all the social activities of the community. He frequently talks of his experiences and his happy life as a fully accepted member of the community. He says that his employment and good income made it all possible and that his disease and deformities are no longer of much significance.

**Velayudam** comes from a well-to-do family and has finished high school. On contracting leprosy at the age of sixteen, he left home without telling his family where he was going. Some said that he left because he did not want his

family to be ostracised and also to enable his sister to get married. That was thirty years ago.

A hospital where he was taking treatment referred him to WORTH, a sheltered workshop, and he was employed. He completed his training and worked as a tool grinder. Being smart and doing a skilled job, meant he was always among the higher paid workers.

When openings in other general industries came up, he refused to apply and thus lost the opportunity to be more closely integrated into the local community. He has no close friends to this day and has remained unmarried. He never speaks of his family to anyone and no member of his family seems to visit him.

### **Sheltered workshops and profitability**

A sheltered workshop is set up firstly to employ people with disabilities, while profit comes second. It may be established in a geographical area, supplementary to a larger mainstream industry. The area of specialisation should be such that operators can find employment in the surrounding industries. Because of the supportive nature of a sheltered workshop and its sub-contract work, the profit margin is usually low, offering very little opportunity for growth.

### **Meeting the needs of the few**

A sheltered workshop can offer employment to only a few people affected by leprosy. For effective supervision and control, it is vital that the workshop be kept small. If there is some preferential purchasing policy by government departments and other organisations, there may be some room for growth and the development of larger projects. In general, when allowing for the amount of investment required and the nature of the skills necessary, the potential for employment in a sheltered workshop is rather low, as is their sustainability.

## Section 8.6: The holistic approach

### Learning from past mistakes

Previous social reintegration approaches have often failed for the following reasons:

- \* The target groups (both people affected by leprosy and the community) did not participate in the decision making, planning and implementation
- \* No awareness creation was attempted to motivate or interest them in the project. (i.e. a top down approach was taken)
- \* The initial survey did not involve the target groups: they were the object and not the subject.
- \* The target group did not feel that they were the owners and therefore made no attempt to actively participate or keep the idea going.
- \* The different situations and needs of women and men affected by leprosy were not taken into account.

An integrated, holistic approach may go some way to removing some of these barriers to success. The holistic approach begins where it should begin, with the beneficiaries or target groups. They are asked, first of all, whether they want to be reintegrated or rehabilitated. If not, why not? If yes, why and how?

Even with this correct chronological order, beneficiaries may not rush to request a scheme that could change the quality of their life. The reasons for this are:

- \* The lack of trust in development workers, who may have preconceived ideas
- \* Habits that have been adopted for survival. The loss of dignity and self-worth may make change very difficult to accept. Beggars may not want to "rock the boat."

- \* Fatalistic outlook because of the repeated experience of failure.

To quote Paulo Freire in "Pedagogy of the Oppressed" -

*"Fatalism in the guise of docility, is the fruit of an historical and sociological situation, not an essential characteristic of a people's behaviour. It is almost always related to the power of destiny or fate or fortune - inevitable forces - or to a distorted view of God."*

- \* Their abject poverty, neglect and unjust treatment may make the poor see themselves as deserving poverty. Or, in the case of people affected by leprosy, they may see their misfortune as the inevitable result of a curse, sin, or the "will of God."
- \* They really may not know what options are available.

All this means that identifying needs and participating in decisions and implementation may be difficult for the benefactors of the project. A programme creating social awareness needs to be the first step in the project and this may take considerable time.

#### **Steps in developing a holistic programme**

- 1 Creating social awareness
- 2 Socio-economic and physical survey, done by both professionals and delegated members of the community, after training
- 3 Priority setting by the community using the results of the survey
- 4 Plans made

### **Sustainable development and time**

The holistic, participatory approach is the foundation for lasting development. With a group of people like those affected by leprosy, the change of attitude is not only one way. Community workers and the general public need a change in attitude and cultural values. People affected by leprosy cannot change from welfare seeking to dignified self-sufficiency over night. It can be attained, but it takes time.

### **More than just income generation**

The general view is that socio-economic reintegration equals income generation programmes. But in the integrated holistic approach, all programmes, including income generating are based on the priorities of the community. These priorities may be related to health, or education, or facilities, or physical structures as well as income. Having women and men identify their felt needs, and then planning the programmes and their implementation, is as important as the projected outcome. Problems should be seen as a whole; each component programme is integrated with all the other programmes.

### **Conclusion**

The holistic approach tackles problems through a community based approach, integrating all programmes to attack the root problems and addressing the needs of the whole person, the whole family and the whole community.

## **Chapter 9: Country projects**

It will be obvious from the preceding chapters that a mixed approach is the best way to deal with social reintegration. Income generation, health promotion, disability prevention, health care, welfare and psycho-social care go hand in hand. This being the case, we have chosen to share with you reports of three social rehabilitation programmes in Africa that have taken this approach. We are not advocating them as perfect, but rather a source of useful ideas for your own situation.

## 1. Tanzania

### *The Maisha Mazuri Programme*

This project was started in 1991. It started in a leprosy hospital, but has extended to the leprosy camp and villages.

The staff of the project work together to provide education to the people affected by leprosy on the quality of life they can achieve. The programme encourages people who have completed their anti-leprosy treatment to return to their home communities and begin income generating activities.

There are six main duties of Maisha Mazuri:

1. Leprosy education, including disability prevention, is taught by medical staff.
2. Education is provided on skill development and how to utilise local resources.
3. Individuals are prepared for reintegration into their home communities. Bridges are developed between the person and the family members. This process also involves educating family members and villagers on the causes and treatment of leprosy.
4. Financial assistance is also provided to enable the initiation of income generating activities. Some people are given revolving loans and others are given grants.
5. Orthopaedic assistance, in the form of crutches, prostheses and braces, is provided for people with disabilities.
6. Spiritual education is also given to encourage spiritual growth.

Maisha Mazuri today (October 1994) involves 185 people disabled by leprosy. They work on group and individual projects that require little skill, yet produce marketable items and a sense of self-worth.

**Ward activities**

Quilting; Table napkins; Table, floor and door mats; Gardening; Religious study.

**Leprosy camp activities**

Tie-dye and batik; Floor mats and baskets making; Gardening; Religious study.

**Village activities**

- \* *Group projects:* Gardening, flour and small fish selling, basket making, tree nursery and hammer mill;
- \* *Individual projects:* Shoe mending, bicycle repair, handicrafts such as baskets, plant-hangers, rope, pottery and crochet.

**Orthopaedic assistance****Informal group education**

Prepares children with disabilities for government schools; Educates mentally disabled adults to read and operate small businesses; Religious studies.

**Discharged person's activities**

Individual gardening projects, small scale farming.

**Leprosy education**

At the ward, the camp and all the surrounding villages.

## **2. Senegal**

### *Association Senegalaise D'Action Sociale et D'Assistance aux Lepreux (ASAL)*

This project is countrywide, and seeks to create a partnership between itself, the public services, the NGOs and the people affected by leprosy (both those living inside and outside of the social rehabilitation villages.)

#### **The programme for young people**

- \* Social and education activities, such as holidays and youth working camps, for the children in the social rehabilitation villages;
- \* Registration of the children of people affected by leprosy for school attendance;
- \* Granting scholarships for vocational training;
- \* Creating scholastic libraries in the villages and an itinerant book lending system;
- \* Equipping schools with books, benches and teaching material.

#### **Aid to the people affected by leprosy in Dakar**

- \* Creation of a community infrastructure to promote the economic activities of the people affected by leprosy. Trying to reduce the number of beggars and prevent urban drift;
- \* Setting up training and rehabilitation projects;
- \* Taking care of medical fees and the cost of other aids for people affected by leprosy.

#### **Adult literacy programme**

This village based project has been regularly attended by people affected by leprosy and their families. Training courses to adults have been given on:

- \* Market gardening;
- \* Sanitation;
- \* Family Planning;
- \* Management;
- \* Reforestation.

The courses have been given in the four main languages of the country and their aim is to help people affected by leprosy to be more independent and change their environment.

#### **Credit schemes**

The main projects for which credit has been given are:

- \* Buying of seeds for rainy season cultivation;
- \* Market gardening projects;
- \* Fish transformation projects;
- \* Cattle breeding micro projects;
- \* Training carpentry;
- \* Horse carts (for public transport).

#### **The social programme**

Two groups of staff are involved in this programme which caters for the social rehabilitation villages. They are

- \* Social animators;
- \* Health workers collaborating with the nurses from the major diseases sector who come to the village two or three times a week.

The achievements of this programme are:

- \* Improving the sanitary conditions of the villages by building latrines and rooms for foot bathing
- \* Building of dispensaries
- \* Giving of medicine

- \* Building and repairing of houses
- \* Building and equipping classrooms
- \* Creating community infrastructures to promote the economic activities of the people affected by leprosy
- \* A food assistance programme for 700 people severely disabled by leprosy.

### 3. Zimbabwe

#### *The Zimbabwe Self-Reliance Leprosy Trust (ZSRLT)*

This group was started in response to the needs of people made destitute by leprosy. It initially aimed to rehabilitate people from a leprosy settlement, but has since expanded and been registered as a welfare organisation. Initially land was obtained and agricultural training and support given to help the group become self-supporting and hence self-reliant. This improved both their economic situation and their participation in village production activities.

The trust has since expanded into other areas in response to other needs of the group. These are:

- \* Vocational training in a variety of skills
- \* Income generating projects on an individual basis for people affected by leprosy and their dependants.

#### **Community based care**

The ZSRLT uses a community based care programme, making use of community members and mobilising community resources. Agricultural co-operatives for people affected by leprosy have been established and supported. People are encouraged to assist their community and to strive for the development of their village by providing services such as dress making, and shoe repairs.

Community awareness programmes about leprosy are conducted to try and lessen the fear and stigma. Family

systems are strengthened and mutual assistance encouraged. Spiritual assistance and support is also offered by the ZSRLT, and through referral to other networks and agencies. This improves social integration. The ZSRLT also intervenes and mediates for equal and fair employment opportunities for people affected by leprosy. Employers are educated to try and remove fear and discrimination.

### **Self-reliance and integration**

Self-reliance is increased by ZSRLT's requirement that individuals should repay a percentage of the assistance they have received. This increases their sense of responsibility and helps to provide for future assistance to others. Surveys, looking at the results of the trust, have shown high levels of social integration and acceptance within the communities, and average levels of economic self-sufficiency and independence. Problems faced by people affected by leprosy tended to be those also faced by other community members, such as food shortages and drought. The assistance given by the ZSRLT had, in the majority of cases, improved their economic position and enhanced their integration in their community.

## Conclusion

Two major themes run throughout this book and seem to underpin any successful attempts at ending the isolation of persons affected by leprosy and enabling them to fully participate in their communities:

**Firstly, people affected by leprosy must be at the centre of our activities, with full involvement at every stage of the management cycle.** This is easy to say, but difficult to achieve in practice, partly because many people affected by leprosy have been excluded from educational and employment opportunities and therefore often lack the self-confidence to participate in the management process. However, we must persevere in our attempts to be inclusive, if we are to achieve anything in the long term.

**The second theme is that there is no single, correct approach to the re-integration of people affected by leprosy.** Different approaches must be used, with different groups of people; involve as many different players as possible, from a whole variety of organisations (NGO's, government offices, community groups, etc) and from a whole range of specialist fields (community workers, social workers, journalists, therapists, nurses, anthropologists, doctors, etc). Everyone has a part to play and can make a unique contribution.

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Werner D. *Nothing about us without us: developing innovative technologies for, by and with disabled persons.* Health Rights, Palo Alto 1998

## Useful Addresses

### **Action Aid**

Hamlyn House, Archway, London N19 5PG, UK

### **AHRTAG**

Farringdon Point, 29-35 Farringdon Road, London EC1M 3JB

Fax: +44 171 242 0041

Email: [ahrtag@gn.apc.org](mailto:ahrtag@gn.apc.org) or [ahrtag@geo2.geonet.de](mailto:ahrtag@geo2.geonet.de)

Produces several newsletters on health matters, including CBR News and is the home of the Disability Information Service (DIS).

### **All Africa Leprosy, Tuberculosis and Rehabilitation Training Centre (ALERT)**

P.O.Box 165, Addis Ababa, Ethiopia.

Fax: +251 171 1199

Email: [Alert@telecom.net.et](mailto:Alert@telecom.net.et)

### **Christoffel Blinden Mission**

Nibelungenstrasse 124, D-64625 Bensheim, Germany

### **Handicap International**

14 Ave Berthelot, 69361 Lyon Cedex 07, France

### **International Association for Integration Dignity and Economic Advancement (IDEA)**

200 Abney Circle Oak Hill, W. Virginia 25901, USA.

A newly organised international association of people affected by leprosy.

**International Federation for Leprosy Funding Agencies (ILEP)**

234, Blythe Road, London W14 0HJ, UK

Fax: +44 171 371 1621

Email: ilep@ilep.org.uk

ILEP co-ordinates grant giving, provides an information network and various advisory working groups including one on the social aspects of leprosy.

**International Health Exchange**

8-10 Dryden Street, London WC2E 9NA, UK

Fax: +44 171 379 1239

Email: info@ihe.org.uk

Produces a useful magazine (subscription only) called THE HEALTH EXCHANGE.

**International Labour Organisation (ILO)**

4 Route des Morillons, CH-1211 Geneva 22, Switzerland.

**Intermediate Technology Publications Ltd.**

103-105 Southampton Row, LONDON WC1B 4HH, UK.

Produces books on appropriate technology for developing countries.

**Oxfam**

274 Banbury Road, Oxford OX2 7DZ, UK

Produces an academic journal (subscription only) called DEVELOPMENT IN PRACTICE.

**The Leprosy Mission International (TLMI)**

80 Windmill Road, BRENTFORD, Middlesex TW8 0QH, UK

Fax: +44 181 569 7808

Email: friends@tlmint.org

Produces a free magazine for paramedical workers, called PARTNERS, dealing with all aspects of leprosy, both medical and sociological.

**Rehabilitation International**

25 East 21st Street, New York, NY 10010, USA

**Save the Children (UK)**

17 Grove Lane, London SE5 8RD, UK

**Sustainable Agriculture Programme**

IIED, 3 Endsleigh Street, LONDON WC1H 0DD, UK

Fax: + 44 171 388 2826

Produces Participatory Learning and Action (PLA) Notes. A useful resource for Participatory Rural Appraisal information.

**TALMILEP**

234 Blythe Road, London W14 OHJ, UK

Fax: +44 171 371 1621

Email: ilep@ilep.org.uk

Supplies a range of teaching and learning materials related to leprosy. A list of publications will be sent free of charge.

**Teaching Aids at Low Cost (TALC)**

P. O. Box 49, St Albans, Herts AL1 5TX, UK

Fax: + 44 1727 846852

A useful source of books on development and health issues.

**Tear Fund**

100 Church Road, Teddington, Middlesex TW11 8QE, UK

Email: imc@tearfund.dircon.co.uk

Produces a free magazine called FOOTSTEPS, on development issues.

**World Health Organisation (WHO)**

20 Avenue Appia, CH-1211 Geneva, Switzerland.