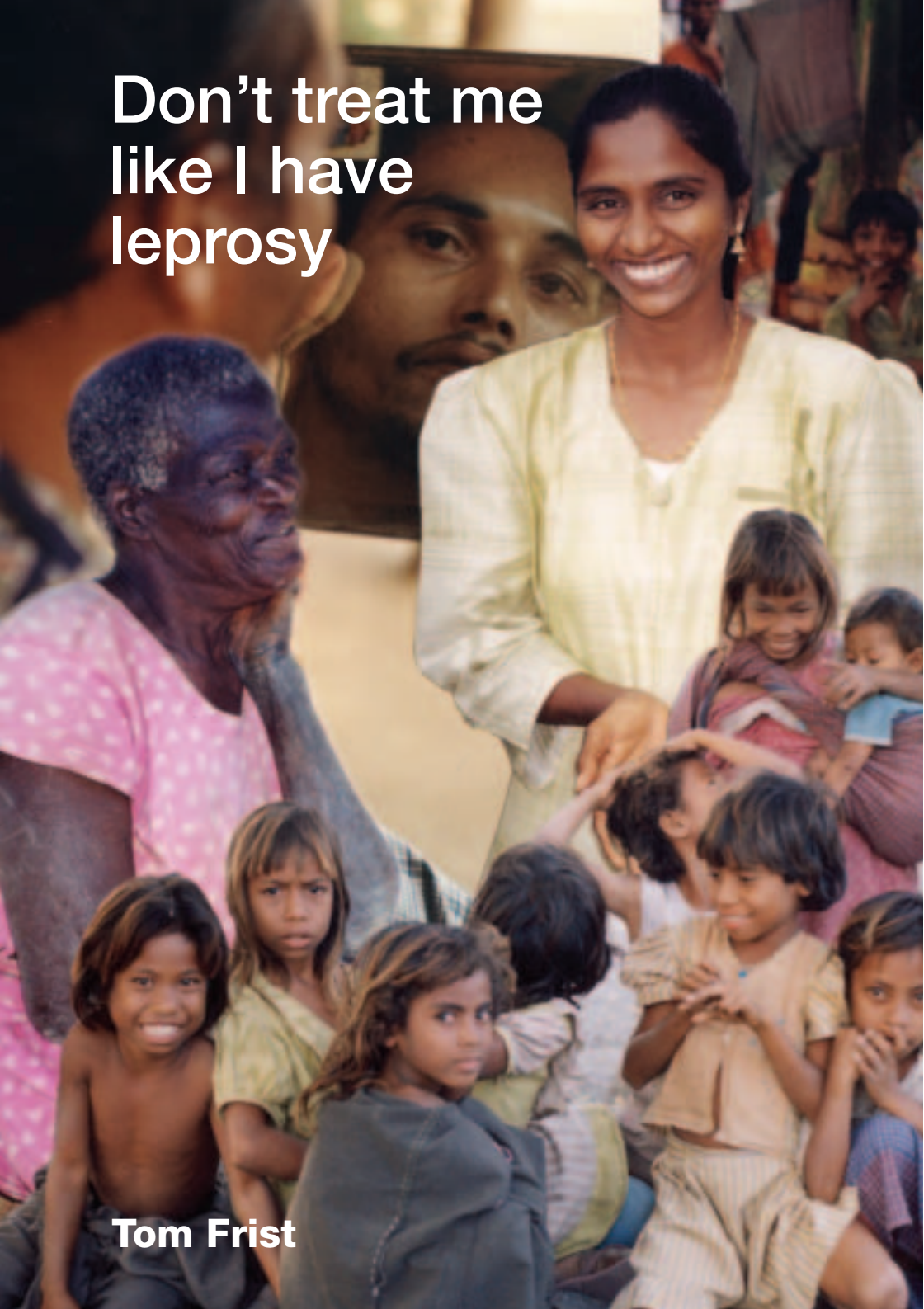


Don't treat me  
like I have  
leprosy



Tom Frist

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I would like to thank all the staff and members of ILEP who have supported the social aspects of leprosy work and have worked hard to update this new edition of 'Don't treat me like I have leprosy'. You have done an excellent job in making it into a shorter, simpler, clearer, and hopefully more useful overview of the social aspects of the disease.

### **Terminology**

In part because of a desire for clarity, the editors have chosen in this edition not to follow my scheme in the first edition of the book of using both the terms 'leprosy' and 'Hansen's disease' to describe the disease. While I understand their reasoning, I do want to register my opinion that the use of the term 'Hansen's disease' has had a positive effect in many countries in reducing the stigma of 'leprosy'. While I do not believe that terminology should be the dominant issue in addressing social stigma and integration, I do think it is an important one.

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**We all have prejudices.**

Even the most fair-minded of us will at times harbour irrational stereotypes of people who are in some way different.

# Introduction

We all have prejudices. Even the most fair-minded of us will at times harbour irrational stereotypes of people who are in some way different. And even the victims of prejudice may themselves stigmatise other people.

Throughout history, people affected by leprosy have been a perennial target for popular prejudice. The suffering caused by this disease is only partly physiological; there is also a host of psycho-social problems – deformity, poverty and social isolation. As a result, leprosy has for centuries been a symbol of all that is outcast and feared. This is a heavy burden to bear.

Fortunately, recent decades have seen remarkable progress in treating the physiological aspects of the disease. Today leprosy can be cured. It is not easily transmittable, and we have learned ways to prevent and even partially correct many of the disabilities associated with it.

## The justification for this book

Many valuable books and articles have been written about the medical aspects of leprosy. With their help, more than 12 million people have been cured of leprosy since the early 1980s – a remarkable victory.

Unfortunately, these medical advances have not been accompanied by similar progress in addressing the psycho-social problems caused by leprosy. There is little practical literature on the segregation, disability, stigma and poverty associated with the disease. So although they may be medically cured, many of the millions of people who remain affected by leprosy (through permanent disability for example) do not feel cured because all their other problems are still with them.

The purpose of this book, written with the encouragement of the International Federation of Anti-Leprosy Associations (ILEP), is to try to fill this gap in the literature.

# The target audiences

## This book is designed for three audiences:

**People already involved in leprosy work.** The aim is to help (for example) programme directors, fund-raisers, board members, medical and social care providers and people affected by the disease to look at leprosy from a non-medical standpoint.

**People with as yet little or no experience of leprosy work, but who are potential recruits to the cause.** Those affected by leprosy have for too long inhabited a closed world of specialists, segregated institutions and segregated programmes. But their problems cannot be solved without the help of generalist health and development agencies.

It is important to bring into leprosy work the experience of other stigmatised people in fighting poverty and social isolation.

**People interested in helping any other stigmatised group.** Although this book focuses on the stigmatisation arising from leprosy, the strategies it discusses are equally relevant to other conditions that result in social isolation.

## The structure of this book

Chapter One, 'An overview of leprosy', describes the causes, symptoms and treatment of leprosy; the current theories about how it is spread; and the infrastructure of institutions and organisations that has grown up around the disease.

Chapter Two, 'Progress in tackling the disease', looks at the physical, psychological, spiritual, social and economic objectives of leprosy work; at how to reconcile the interests of people affected by the disease, the general public and service providers; and at the progress currently being made in meeting the five objectives listed.

Chapter Three, 'Social integration and its implications', discusses issues in leprosy work that are equally relevant to other stigmatising conditions – for example, what integration will achieve; who should speak for stigmatised people; the role of different agencies; the best use of resources; and promoting an appropriate image of leprosy.

Chapter Four, 'Summary', summarises the challenges that remain in working towards the integration of people affected by leprosy.

The Appendix, 'Leprosy at a glance', presents some key facts and figures about leprosy.



**Somali woman  
cured of leprosy.**

(Photo: TLMI)

**Sarah Amongin,  
participant in  
socio-economic  
rehabilitation,  
Kumi, Uganda.**

(Photo: Geoff Crawford)



**Young woman  
affected by  
leprosy, India.**

(Photo: ALES)



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## **An overview of leprosy**

This chapter will describe the causes, symptoms and treatment of leprosy; current theories about how it is spread; and the infrastructure of institutions and organisations that has grown up around the disease. Much of the information about the physiological aspects of leprosy is drawn from the invaluable textbook *Leprosy*, edited by Dr Robert Hastings.

# Chapter One

## **The nature of the disease**

According to Webster's Third New International Dictionary, leprosy is "a chronic disease caused by infection with an acid-fast bacillus (*Mycobacterium leprae*) and characterized by the formation of nodules on the surface of the body and especially on the face, or by the appearance of tuberculoid macules on the skin that enlarge and spread and are accompanied by the loss of sensation followed sooner or later in both types by the involvement of nerves with eventual paralysis, wasting of muscle, and production of deformities and mutilations".

## **The cause**

Leprosy is one of the earliest diseases to have been recorded: some of its clinical signs have been identified from descriptions given in the ancient literatures of Egypt, India and Israel.

But it was not until 1873 that the Norwegian physician Dr G.H. Armauer Hansen discovered *Mycobacterium leprae* – the first bacterium to be identified as causing a major disease in man. Before (and even since) this discovery, many other theories were current about the cause of leprosy – that it was a curse from God or a punishment for one's own sins or the sins of others; that it was related to the law of karma or witchcraft; and that it was due to eating certain foods, hereditary disposition or even sudden changes of temperature.

## **The cure**

Historical theories about how to cure leprosy were equally unscientific. For example, those who regarded the disease as a sign of moral impurity felt the best remedy to be some kind of purification ritual, such as bathing in a holy river or touching the relics of saints.

From the early 1940s sulphone drugs such as promin, diasone and dapsone began to be used with considerable success to treat people affected by leprosy. But major problems remained. In some cases, clients had to continue the treatment for the rest of their lives; in others, the leprosy bacillus became resistant to sulphone drugs.

The search for more effective drugs was hindered by the fact that *Mycobacterium leprae* could not as yet successfully be cultivated in the laboratory; testing always had to be done on human volunteers. In the 1960s, however, it was discovered that the bacillus could be grown in mice and the nine-banded armadillo, and this enabled new drugs such as clofazamine and rifampicin to be tested.

Trials showed that a combination of these new drugs and the older sulphone drugs could cure leprosy relatively quickly. In 1981, the World Health Organization (WHO) therefore recommended the use of dapsone, rifampicin and clofazamine over two years to treat people with many bacilli in their bodies, and a combination of rifampicin and dapsone over six months to treat those with few bacilli. More recently the two-year regime has been reduced to twelve months. This Multi-Drug Therapy (MDT) was used all over the world with such remarkable results that WHO was able to make one of its major objectives the elimination of leprosy as a public health problem by the year 2000 and in many places this was achieved.

The search continues for even faster-acting and more convenient drugs. We can expect the time needed to cure someone of leprosy eventually to come down to a matter of weeks or days.

## How contagious is leprosy?

Because the bacillus *Mycobacterium leprae* can be transmitted to other people, leprosy is contagious. But it is not very contagious, for several reasons:

- Only people with large numbers of bacilli in their bodies can pass the disease on to others. These 'multibacillary' cases account for only around 40 per cent of the total. The remaining 60 per cent – the 'paucibacillary' cases – are not considered contagious.
- Only a small proportion of those exposed to multibacillary cases of leprosy ever catch the disease; an estimated 95 per cent of people have a natural resistance. This is shown by the fact that very few of the people who work with leprosy contract it.
- Multi-Drug Therapy kills most of the bacilli in a matter of days. This means that people undergoing treatment for the disease are not contagious.



How *Mycobacterium leprae* is passed from one person to another is still not entirely clear. However, since there is evidence that the bacillus can survive for some time outside the host, it is now thought that leprosy is spread through the respiratory tract. Multibacillary cases will have many bacilli in the mucous lining of the tract, and these can be expelled by coughing and sneezing.

One problem in leprosy work is the lack of a universally effective vaccine. The tuberculosis vaccine BCG has been moderately successful in preventing the disease, but cannot be considered a complete answer. Research must go on.

## **Where did the disease come from?**

As we have seen, leprosy was known in Egypt and the Middle East in ancient times, and the disease may have originated there. How it spread to Europe is not known; Alexander the Great's soldiers could have brought it back, or perhaps the Crusaders.

Leprosy became endemic in medieval Europe and thousands of lazarets were built to house people affected by the disease. Then suddenly, after about 1200 AD, leprosy went into sharp decline in most of Europe. This may have been due to improved economic conditions or to immunological relationships with other diseases (such as bubonic plague or tuberculosis), or because the forced isolation reduced the reservoir of infection. We do not know for sure.

As for the Americas, the evidence suggests that the disease was taken there by Europeans. Whatever its provenance, leprosy is today found mostly in Asia, Africa and South America. Europe now has very few cases, and most of the new cases in North America are among immigrants.

## **How many people are affected?**

Exact figures are impossible to obtain, but a conservative estimate is that at least six million people are currently affected by leprosy.

Of these six million, some have been cured and have few physical or psycho-social scars. These people probably no longer need medical services or socio-economic support. But many others will continue to need support after their cure; about three million people currently affected by leprosy have moderate to severe physical disabilities and many more have lost some physical sensation or have been affected socially, economically or psychologically by the disease. The scars of these people may not be visible, but they are just as real as physical disabilities. There is still much work to be done.

## Measuring progress

How do we monitor our progress in controlling the expansion of leprosy?

One method is to measure the 'prevalence rate'. Usually expressed in terms of cases per thousand or ten thousand of the population, this shows the total number of people affected by leprosy in a given geographical area at a given time. An estimated prevalence rate is obtained by dividing the number of registered cases of the disease in an area by the total population of that area, then multiplying the result by a somewhat arbitrary correction factor, depending on whether sampling shows that over-registration or under-registration is more likely.

In adopting the objective of "elimination of leprosy as a public health problem by the year 2000", WHO defined 'elimination' as a prevalence rate of one case per 10,000 people. By the year 2000, prevalence had come down to less than 1 per 10,000 when measured at a global level and many countries had also reached this 'target'. However, at least 15 countries still had overall prevalence rates of more than 1 per 10 000 and others have areas of high prevalence. Increased efforts are needed to reach WHO's current target of 'elimination' by the year 2005.

Another way of measuring progress is the 'case detection rate'. Also expressed in terms of cases per ten thousand or hundred thousand, this measures the number of new cases discovered over a specific period of time in a specific geographical area or population group.

As the prevalence rate of the disease declines, so too should the case detection rate, as there will be fewer people with active leprosy to act as sources of infection for the general population. However, the case detection rate for leprosy has recently held steady at about 6 – 700,000 new cases each year, which is a cause for concern.

WHO region	Number of cases registered at end of 2000 (rate per 10,000)		Number of new cases detected during 2000 (rate per 100,000)	
Africa	58 694	(0.9)	54 602	(8.6)
Americas	85 996	(1.0)	44 786	(5.5)
Eastern Mediterranean	8 525	(0.2)	5 565	(1.1)
Europe	197	(0.0)	111	(0.0)
South-east Asia	432 715	(2.9)	606 703	(40.2)
Western Pacific	11 105	(0.1)	7 563	(0.4)
<b>TOTAL</b>	<b>597 232</b>	<b>(1.0)</b>	<b>719 330</b>	<b>(11.9)</b>

Source: WHO Weekly Epidemiological Record Vol 77, No 1, 4 January 2002

## **Epidemiological trends**

By studying statistical trends, epidemiologists can give us some interesting information about leprosy.

For example, the multibacillary form of the disease is much more common in some countries than in others. Leprosy is about twice as likely to strike males as females, although the ratio can differ from country to country. There also seem to be differences between ethnic groups in their susceptibility to leprosy and in the form of the disease they generally contract; for example, in Brazil and South Africa, serious forms of leprosy are more likely to be found among white immigrants than among people indigenous to the area. As for age, leprosy strikes all age groups; it has been diagnosed in infants as well as in people over 70.

### **Is climate a factor?**

It is true that most cases of leprosy are today found in the warmer countries of the world. Yet climate cannot be a critical factor, as the disease was once particularly prevalent in the cold Scandinavian countries.

### **What about poverty?**

On the other hand, poverty probably has as much to do with the incidence of leprosy as it does with most other public health problems. Poor people seldom have access to healthy food, adequate sanitation and basic medical care. They also live in more crowded conditions. As a result, the disease is far more common among very poor people. Eliminating poverty would probably help to eliminate leprosy as well.

### **Is it hereditary?**

Leprosy tends to occur within families, and in the past this led many people to think that it was hereditary. Today, however, scientists think that these concentrations in families are due to the increased opportunity for intimate contact. Even then, only a small proportion of family members contract the disease.

## **Impairments, deformities and disabilities**

Although leprosy is seldom fatal, it can cause a whole range of impairments, deformities and physical disabilities: contracted fingers and toes, 'drop-foot' and 'drop-wrist', thickening skin (especially on the face and earlobes), nasal deformity, facial paralysis, loss of eyebrows, and blindness. Some of these problems are caused directly by the disease, others are its secondary results.

## **Primary impairments**

These are caused by leprosy bacilli invading the nerve fibres, the skin, the eyes and the mucous linings of the nose and other parts of the body. These concentrations of bacilli provoke a defensive reaction from the body and as a result the area under attack becomes thickened. This can so damage the body part in question that it becomes unable to perform its normal functions. Damage to the nerve trunks that control sensibility and motor functions is particularly common.

## **Secondary impairments**

As we have seen, leprosy bacilli can damage the nerves in the limbs, causing the hands and feet to lose their sensibility and become paralysed and contracted. If these extremities are not protected, they can easily incur further injury; the damaged nerves can no longer transmit pain and so an important warning mechanism is lost.

People affected in this way will not automatically withdraw their hands from the heat of the cooking fire or adjust their stride to avoid putting too much pressure on the ball of the foot. The burns and blisters that can develop as a result are often not cleaned because they do not hurt. But if they are not treated, fissures can open and infection set in, destroying tissue and bone and causing disabilities. The joints can also become frozen from lack of use and the build-up of scar tissue.

## **The infrastructure of leprosy**

A system of specialised institutions and organisations has been developed throughout the years to deal with people affected by leprosy. Let us look briefly at some of its principal components.

## **The institutions**

### **Leprosaria**

Today's leprosaria (also known as leprosy sanatoria, colonies, asylums or hospitals) are the descendants of the lazarets of medieval Europe.

The concept was taken to Asia, Africa and the Americas during the colonial centuries. By the early twentieth century there were hundreds of these institutions all over the world, and they were considered the first line of defence against the spread of the disease.

Although leprosaria have differed widely in their size, the services they offer and the organisations that sponsor them, they have all had two basic aims: to protect the general public and to meet the basic needs of people affected by leprosy.

A typical leprosarium was built on a large tract of land, which not only isolated the residents from centres of population but also enabled them to grow their own food. Since residents were confined for long periods – often for life – leprosaria had to provide for all their basic needs; there might be hospitals and dispensaries, houses for married couples and dormitories for single residents, places of worship, and electrical, sewing and woodworking workshops that enabled residents to support themselves. Recreation was not forgotten; some twentieth-century leprosaria had cinemas, libraries, parks, restaurants, ballrooms, sports stadiums and radio stations. Most leprosaria had their own cemeteries as well, as segregation continued even in death.

The director of a leprosarium often enjoyed considerable autonomy. In some places, under his jurisdiction he might have a ‘mayor’, a small police force, and a jail to confine troublesome residents. Special coins were sometimes minted for use in leprosaria so that the country’s normal currency would not be contaminated.

Leprosaria were set up and run by a variety of bodies: foreign missionary societies, national voluntary organisations, local, state or national governments or perhaps a combination of these. The staff of leprosaria were mostly drawn from among the residents, who carried out maintenance, security, teaching and nursing work. Residents might also be involved in small-scale income-generating activities such as farming, sewing, carpentry and printing. This ‘work therapy’ not only gave the residents something to do during their long internment but also provided cheap labour.

There were also staff who did not have leprosy. They lived in separate quarters from the residents, ate in separate dining halls and worshipped on different sides of the church. Some of these staff were attached to religious organisations; others were civil servants.

Current thinking about the contagiousness of leprosy determined the amount of contact residents were allowed with the outside world: at some periods, visitors were obliged to talk to residents across wide tables.

### **Preventoria and educandarios**

This fear of contagion often meant that children born in leprosaria were immediately separated from their parents and sent to relatives or to institutions created specially to care for them. These institutions, known as *preventoria* or *educandarios*, generally provided schooling and vocational training; contact between parents and child was usually infrequent and sometimes non-existent. When the children came of age, they were discharged from the *educandario* and helped to find employment, usually low-paid manual work. The psychological effect of institutionalisation on these children was often severe.

## **Leprosy dispensaries**

As knowledge about leprosy and its treatment increased, the restrictions on people affected by it were relaxed. Residents of leprosaria who showed no live bacilli after several tests were discharged. Special outpatient clinics were set up so that these discharged residents could continue to receive treatment. The clinics were often staffed by ex-residents with paramedical training and were regularly visited by a travelling leprologist. Whenever problems arose that were beyond the competence of the clinic, the person concerned was re-interred in the leprosarium.

## **Leprosy settlements**

Discharged residents often chose to live in settlements near the leprosaria. These were precarious communities, set up without planning or infrastructure. Sometimes the former residents were given land by the leprosarium, sometimes they bought it and sometimes they simply squatted on it.

People chose to live in these settlements for a variety of reasons. They could receive medical treatment that would be denied them elsewhere. They could escape from the rigid rules of the institution; for example, unmarried residents could live together if they wished. Above all, they would be among their own kind and would not face rejection.

There were also economic reasons. Land close to leprosaria was often cheaper than elsewhere. Many people in the settlement worked in the leprosarium or received benefits from it, such as food, clothing and medical treatment.

Ties between the leprosarium and the settlement were usually very close. People in the settlement continued to use the facilities of the leprosarium just as they had when they were residents, visiting friends whenever they chose. If a leprosarium closed down, this often spelt the end of the settlement as well.

## **Government intervention**

Initially, most leprosy institutions were set up as a result of local or private initiative, but in time national and state governments began to exercise their authority, co-ordinating the leprosy work being done in their territories.

Special 'leprosy divisions' were often set up, usually within the Department of Health, to meet both the medical and psycho-social needs of people affected by leprosy. These leprosy divisions were often responsible not only for medical services to clients but also for administering their pensions and setting up special prisons and psychiatric hospitals for them. Some divisions grew very large and enjoyed considerable autonomy, with their own budget, staff, vehicle fleets, libraries and publishing and training programmes.

## Special legislation

Another aspect of segregation was the special legislation introduced to deal with people affected by leprosy. Some of these laws were prejudicial, forcing people to be interned or limiting the types of jobs they could have, where they could live and who they could marry.

Other legislation favoured people affected by leprosy, however, exempting them from military service and property taxes or giving them special pensions. In some cases, politicians built their careers upon constituencies of people affected by leprosy, trying to win them special benefits in exchange for their votes.

## Voluntary organisations

Throughout the world, many voluntary organisations or special interest groups have been created around the theme of leprosy. Some were set up to meet the psychological and material needs of people affected by leprosy and their families. Others have focused on the medical aspects of the disease, recruiting, training and supporting medical or paramedical staff. Yet others focus on public education or fund-raising. There are also the client and professional associations set up to defend the interests of their members and to focus attention on the problems created by leprosy.

These organisations have played a vital role in the history of leprosy treatment. They have cared for people affected by the disease and have motivated others to do so. They have funded research into leprosy. The progress we have made is largely due to the pioneering efforts of these organisations at a time when few others were interested in the disease.



Photo: DAHW



**Osojo (on tricycle) at McKean Rehabilitation Centre, Thailand**

(Photo: TLMI)

**Client using eye protection, India.**

(Photo: TLMI)

**Local doctor training village health workers near Maimana, Afghanistan.**

(Photo: Joost Butenop)





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**Progress in tackling the disease**

In this chapter we shall look at the objectives of leprosy work and at the progress currently being made in meeting them.

# Chapter Two

## The interested parties

If leprosy work is to meet its objectives, it must achieve a compromise between the interests of the three major parties involved: the people affected by the disease, the general public and the service providers.

The interests of these groups usually overlap, but on occasions they can conflict.

### People affected by leprosy

People affected by the disease are usually concerned about:

- The prevention or relief of the physical problems caused by the disease.
- The impact leprosy will have not only on their self-image, but also on the image that family, friends and others have of them.
- How the disease will affect the way they are treated by the public and by service providers.
- The economic implications: the cost of medicines, orthopaedic devices, travel and time off from work; and how leprosy affects their ability to earn a living.
- How to obtain economic or other advantage from their condition to compensate for the physical, psychological, social and economic losses they feel they have suffered.
- A proper understanding of the disease. Why has it happened to them and not to others? What are the medical answers and psychological answers? What is the level of risk to others? What must they do to take care of themselves? What does the future hold for them? What people and programmes are available to help them? What medicines are effective?

## **The general public**

Where leprosy is concerned, the chief concern of members of the public is usually to protect themselves from contagion. This means that they are unlikely to co-operate with an assistance programme unless assured by the public health authorities that the disease will not be spread by people affected by it who are living and working in their midst.

Yet the public also has a social conscience and is usually willing to help people in need. This must be at reasonable cost, however; society is faced with many problems other than leprosy, and its resources are limited, especially in developing countries where the disease is most prevalent. The public will therefore want people affected by leprosy to be as self-sufficient as possible, and the programmes set up for them to be effective and efficient.

## **Service providers**

As well as being the mediators between people affected by leprosy and the public, service providers have their own concerns:

- To protect themselves from contagion.
- To enjoy job security and to receive a salary and benefits that will allow them to meet their personal needs.
- To meet their psychological needs; they want to help other people, to feel good about what they are doing, to do it well and to be respected by others for what they do. Some wish to rise to positions of influence and authority.

Because the needs of consumers, service providers and the public are so closely interwoven, it is imperative that each group should be aware of and respect the interests of the others. That is why dialogue is so important for the success of programmes. Whenever interests conflict, seek a compromise or an alternative.

## **The objectives of leprosy work**

This book is based on the proposition that the ultimate objective of leprosy work is to eradicate the disease and to help people affected by it to reintegrate into society. Social integration is an objective upon which the public, service providers and people affected by the disease can all agree, because it is based on natural justice rather than special privilege.

Integration must be a holistic process, because:

- It requires the involvement not only of the people affected by the disease, but also of service providers and the public.
- It cannot be achieved by addressing solely the physical problems of people affected by leprosy. We also need to help them solve their psychological, social and economic problems.

We have categorised the objectives of leprosy work under the following headings:

- |             |                  |              |
|-------------|------------------|--------------|
| 1. Physical | 2. Psychological | 3. Spiritual |
| 4. Social   | 5. Economic      |              |

The rest of this chapter will review recent progress towards meeting these objectives, and then consider what still needs to be done.

## **Progress towards physical objectives**

### **Objectives**

- To eliminate *Mycobacterium leprae* from the client's body as quickly as possible.
- To alleviate the physical suffering and disabilities caused directly or indirectly by leprosy.
- To eliminate the disease from the community, thus protecting others from its spread.

An estimated 20 to 25 per cent of people affected by leprosy have significant impairments leading to deformity and disability. The good news, however, is that most of them can now be prevented.

### **Preventing deformities and disabilities**

The best way to prevent deformities and disabilities is, of course, to cure people who have leprosy as quickly as possible, as this will stop the bacilli multiplying. Anti-inflammatory drugs can also reduce the inflammations that damage the nerves.

People affected by the disease can also learn simple techniques to care for the paralysed parts of their bodies. If they no longer have pain to warn them of danger, perspiration to lubricate their tissues or muscles strong enough to move their body parts, they must use other means:

## **Hands**

Hands can be protected by using pot-holders, gloves or insulated handles when cooking or taking hot drinks; by cigarette holders when smoking; and by gloves or smooth tools when working. Atrophied hand muscles can be exercised daily through delicate actions such as picking up grains of rice.

Hands can be soaked and oiled to reduce the dryness caused by the lack of perspiration. Tissue damage can be avoided by regulating the force of one's grip when holding tools, keys, handles or other objects. People should examine their hands daily for any redness, cuts, blisters or other damage and take remedial action.

## **Feet**

Recurring foot ulcers, a major problem with leprosy, can be avoided by choosing footwear that gives good protection, has straps that fit, no nails, and insoles that spread the weight over as wide an area of the foot as possible. People should take shorter steps, avoid walking for long distances, and take care to examine their feet daily. Any damaged areas must be cleaned and treated immediately.

## **Eyes**

An invasion of leprosy bacilli can damage the eyes, as well as the facial or orbital nerves that control the blinking and lubricating so necessary to protect them. Again, the best prevention is regular eye examinations and early treatment. People whose eyelids no longer blink spontaneously should blink deliberately so as to provide lubrication. Those who cannot fully close their eyelids should wear masks at night to protect their eyes from foreign bodies.

## **Surgery**

Surgical techniques have now been developed that can at least partially correct some of the disabilities associated with leprosy; for example, muscles and tendons can be re-routed to restore movement to eyelids, hands, fingers, feet and toes. Although motor functions can often be restored, the restoration of sensibility is still rare.

Surgery can also be used to transplant hair-bearing skin from other parts of the body to form new eyebrows; to reverse premature senility of the face; to correct sagging ear lobes; to remove hypertrophied mammary glands (the cause of gynaecomastia or enlargement of the breasts in men); to form new noses out of flaps of skin; and to remove segments of bone from the foot so that it is better able to bear weight.

## **Prosthetic and orthopaedic devices**

Braces can correct 'drop-wrist' and 'drop-hand'; individually designed orthopaedic shoes can prevent further injury to severely disabled feet; and artificial limbs can improve mobility. Artificial limbs, noses and eyes are also very valuable for cosmetic purposes.

Although we have been very successful in getting Multi-Drug Therapy to people affected by leprosy throughout the world, we have made far less progress in helping them to prevent disabilities. Very few government leprosy programmes have made the teaching of self-care a priority. A particular lack has been disability prevention programmes for people who have been cured of leprosy and no longer go to health centres for their drugs.

Setting up successful systems of disability prevention and care is one of the major challenges we still face. It is an area in which the concept of community-based rehabilitation may prove useful.

## **Progress towards psychological objectives**

### **Objectives**

- To combat negative stereotypes about leprosy among people affected by the disease, service providers and the general public.
- To encourage co-operation between these three groups to eliminate leprosy, alleviate its effects and promote genuine social integration.

Despite medical advances, people affected by leprosy are still stigmatised. Newspapers throughout the world continue to use the word 'leper' as a metaphor for whoever is feared and ostracised.

Even other stigmatised groups – such as people with AIDS or ex-prisoners – will complain of being 'treated like lepers'.

In countries where leprosy is common, any suspicion that a person has the disease can still bar their access to education, employment, housing, public transport and other activities. Once diagnosed with leprosy, many young women will still give up all hope of marriage.

It is therefore not surprising that people affected by leprosy continue to hide their condition from their employers, their colleagues and even their family. To avoid discovery, those who can afford to do so will avoid public clinics and pay for private treatment, even travelling to cities where they are not known. Many people bear this burden of secrecy because they feel that the alternative would be worse.

Saddest of all, even people affected by the disease will believe many of the myths about leprosy and as a result suffer from low self-esteem. This can show itself in self-destructive or antisocial behaviour, such as alcoholism. Research has shown that, in marriages where one partner has leprosy and separation occurs, it is often the spouse with the disease who initiates the split.

# **Why does leprosy lead to stigma?**

## **Visibility**

Untreated leprosy is often very visible: it can cause prominent skin patches and nodules, and in its advanced form, severe deformation of the face, hands and feet. A person suffering from the disease is easily stigmatised, perhaps because their appearance differs radically from society's idea of 'beauty', or because disabilities imply incapacity and disabled people are often viewed as a burden to themselves, their families and society.

## **Its progressive nature**

Leprosy rarely causes death, but if left untreated the disease can advance over the years – a phenomenon that can inspire fear in the beholder.

## **Its mystery**

Throughout the centuries leprosy has been the subject of innumerable legends. Until quite recently we understood very little about the disease: its cause, how it was transmitted, how it could be cured. This very mysteriousness of leprosy often provoked exaggerated feelings of insecurity in the public, and therefore an unwarranted fear of people affected by the disease.

## **Contagion and deformity**

Leprosy is feared not just because it deforms (after all, many other conditions cause deformation too) or because it is contagious (other diseases are far more contagious), but because it is both. This makes people feel vulnerable – leprosy could happen to them.

## **Religious associations**

In the past, most cultures explained away leprosy in religious terms. Man, nature and the spiritual world were often viewed as interdependent, and hence a physical disease in an individual could be seen as contaminating a whole community.

Leprosy could signify the worst that can happen to a human being: pain, deformity, poverty and rejection by one's fellows. Yet, paradoxically, it could also symbolise nobility: the ability of those affected by the disease to endure suffering and prejudice, and the capacity of others to overcome their natural fears and identify with, and care for, people who are rejected.

## **Links with poverty**

Although no social class is immune from leprosy, the disease today mainly affects the poorer developing countries and the poorer classes within those countries. This association with impoverished and powerless people helps to explain the negative

attitudes of the public and service providers towards leprosy and its neglect by health and social planners. People affected by leprosy are seldom consulted by policy makers, whereas those with other diseases and disabilities increasingly are.

### **Segregation**

The segregation that throughout the centuries has usually been the fate of people affected by leprosy has created a strong association in the mind of the public between the disease and ostracism. The longer such segregation persists, the harder this mental association will be to fight.

### **Reducing the stigma**

The only way to stop the stigmatisation of people affected by leprosy is to do away with the situations that caused the stigma in the first place. How successful have we been at doing this?

Although Multi-Drug Therapy has drastically reduced the number of people affected by the disease, we have had far less success in raising public awareness, educating clients or encouraging co-operation between people affected by the disease, care providers and the public. Nor has there been much progress in integrating leprosy work into non-medical programmes serving the general population.

If stigma is to be reduced, the public, the service providers and the clients must learn the new realities about leprosy: the cure is permanent, people undergoing treatment are not contagious, clients can prevent disabilities if they accept their own responsibility for doing so, and once a person has been diagnosed they should continue to live as normally as possible. Only then will attitudes and behaviour change.

## **Why haven't we been successful in transmitting this kind of awareness?**

### **Lack of time**

There is not enough time available in general training programmes to prepare professionals to deal with leprosy; similarly, the medical workers who hand out medicines and worry about innumerable other health problems are usually too busy to respond to the specific needs of people affected by the disease. And there is certainly insufficient time to go out into the community to resolve individual cases of discrimination.

### **Lack of resources**

There is never enough money to hire specialised health education workers or to buy media time to put over the message. Health education in leprosy has therefore had limited impact: surveys show that people know little about the disease, and are often astounded to discover it still exists.

### **Lack of influential spokespeople**

Leprosy is not a disease of the rich, powerful or famous, and therefore, unlike high-profile conditions such as AIDS, it has few well-known spokespeople. Articulate people affected by the disease do not want to admit the fact, for fear of jeopardising their social position. As a result, those who speak for leprosy are usually professionals who work with the disease or institutionalised people who have little to lose. The views of both these groups are perfectly valid, but they will be different from the views of people affected by the disease who are living and working in the community.

### **Insufficient consultation**

People affected by leprosy are rarely represented in fund-raising agencies, rarely consulted over the planning of programmes, rarely invited to conferences, and rarely allowed to join leprosy organisations. Such exclusion makes it impossible for us to acquire any real understanding of the social problems associated with the disease. Leprosy work still suffers from a blatantly paternalistic and segregationist approach that has disappeared from most other medical, disability and human rights movements.

### **Leprosy is a useful symbol**

Words like 'leper' are useful for writers, preachers and social activists who wish to conjure up images of the outcast and the ugly. Many of those who use such words have no idea that they are hurting real people by doing so.



## Progress towards spiritual objectives

### Objective

- To help people affected by leprosy to regain a sense of their own dignity and worth.

‘Spiritual’ is nowadays rather an unfashionable word, but it concerns nothing less than the deepest levels of a person’s identity: what they see as their reason for living, what they think is their place in the scheme of things. Research has shown that people’s spiritual beliefs have a major influence on their physical health. More and more care-givers are therefore rejecting artificial distinctions between the ‘physical’ and ‘spiritual’ aspect of individuals and are treating them in a holistic way.

In the past, the spiritual needs of people affected by leprosy were a major priority for those who set up assistance programmes, governments as well as religious bodies. Almost all leprosaria had places of worship.

Today, as treatment has shifted to community-based, government-sponsored health centres in increasingly secular societies, the spiritual needs of people affected by the disease have received less attention. Yet those needs still exist, and one hopes that they will be addressed by the religious bodies that serve the community as a whole.

Our spiritual objective should be to help people affected by the disease to see themselves as much more than just a ‘leprosy patient’ or ‘disabled person’. They need to realise their intrinsic worth as people, as well as their obligations to others. People affected by leprosy must be given opportunities to contribute as well as to receive, as this helps them to regain their dignity and become genuine members of their community.

## Progress towards social objectives

### Objectives

- To help people affected by leprosy to remain in their home communities, participating in the same activities, enjoying the same rights and carrying out the same duties as they would have done had they not contracted the disease.
- To end the segregation that places people affected by leprosy in specialised institutions, or that bars them from schools, churches, public housing, recreation facilities, hospitals, rehabilitation centres, homes for older and disabled people, etc.

In the past, segregation was often brutal: people thought to have leprosy were forced, sometimes at gunpoint, to leave their families and communities and to live behind the walls of institutions. Segregation today is less severe, but no less painful.

## **Why were people with leprosy segregated?**

### **To protect the interests of dominant groups**

A justification frequently put forward for segregation is the need to protect the interests of the dominant groups in society. Most people will agree that governments have a right, even a duty, to protect the well-being of the majority, even at the cost of restricting the rights of individuals or minorities. This reasoning is the basis of the quarantine laws that allow the state forcibly to segregate people whose continued freedom of movement and association poses a threat to public health.

Well into the twentieth century, the forced segregation of people affected by leprosy was considered necessary to prevent the spread of the disease. Since leprosy's mode of transmission was little understood, and effective drugs or vaccines were unknown, the segregation of the source of infection was thought to be the only way of containing it.

### **To protect the interests of the segregated minority**

Segregation is also carried out to protect the interests of the people being segregated. The thousands of leprosy institutions set up all over Europe during the Middle Ages, and in other parts of the world since then, have been monuments as much to compassion as to fear. These places were not only prisons, but also havens where people rejected by their families and communities could find the shelter, food, clothing, medical care, fellowship and spiritual solace denied them elsewhere.

### **To help the service providers**

Another reason for segregating people affected by leprosy has been to simplify the provision of services.

There have never been enough medical staff and funding available to cope with all the people needing treatment for leprosy. This has led to the centralisation of services. Unable or unwilling to deliver care to people in their communities, the service providers insisted that people came to them. When the treatment was prolonged – as it usually was with leprosy – people's ties with their families and communities would weaken and the result could be permanent segregation.

To a lesser extent, segregation has been caused by overspecialisation. Service providers have often focused on leprosy alone because they feel that otherwise they would be unable to keep up with current research and provide quality care. Such specialisation has resulted in professional categories such as leprologists, in special-interest professional and fund-raising societies, and in specialised institutions and programmes.

Some centralisation and specialisation of care is necessary, but it can be taken too far. If, for example, a client's general needs – not just those specific to leprosy – are

being treated by leprosy agencies, there will not just be physical segregation, but the idea that leprosy is a 'disease apart' will be reinforced in the minds of the client, the professional and the general public.

### **Because they choose to segregate themselves**

Segregation is not always imposed upon minorities; it can sometimes be a way of life that they freely choose. They may feel more comfortable living with people who dress, eat and think like they do and have had similar life experiences.

People affected by leprosy sometimes leave their families and their communities because they are afraid of infecting the one and being rejected by the other. Others prefer to live in leprosy institutions rather than in the community because life is easier there: they do not have to worry about food, clothing or shelter, they have security, friends and leisure, and they receive regular treatment. In fact, many people affected by leprosy strongly resist integration, as it would mean the loss of such privileges. Once the victims of the segregated system, some clients have now become its most fervent supporters.

## **The beginning of the end of segregation**

We have reached a transitional stage in our campaign to meet the socio-economic needs of people affected by leprosy. It has been a long time since they and their children were forced to live in segregated institutions. Nowadays, in fact, residents who wish to remain in leprosy institutions are sometimes forced to leave.

Most leprosy institutions have either closed down or have opened their doors to people with other conditions, such as tuberculosis, AIDS and disabilities. They have been forced to do so because the number of people affected by leprosy is diminishing and the demand for other types of service is increasing. They are also conscious of the psychological hazards of treating people for prolonged periods in segregated institutions.

Leprosy settlements are undergoing the same natural integration. As cities expand to swallow up their neighbours, these settlements are gradually becoming normal communities. Economics can also provide a powerful antidote to prejudice; people not affected by leprosy may make their home in a former leprosy settlement because it is convenient and affordable.

Leprosy treatment is increasingly being delivered through community health centres, as governments begin to take seriously their duty to provide basic health care to people affected by the disease. However, less progress has been made in integrating general hospitals, and many barriers remain to the acceptance of people with leprosy in non-medical institutions.

Many government leprosy divisions are now known by other names: for example, dermatology divisions, communicable disease divisions or public health divisions. Some of the non-medical work of former leprosy divisions is, very slowly and not very methodically, being transferred from ministries of health to ministries of social welfare.

Some leprosy fund-raising agencies have begun to raise funds for, say, people disabled by conditions other than leprosy and for general community development. Since many of the institutions and programmes that these agencies fund are now integrated, helping people with other diseases than leprosy, it is difficult for them to justify raising money for one disease alone.

There are now numerous movements of people affected by leprosy who set out to educate the public about the disease and to defend their own interests. For example, 1981 saw the founding in Brazil of MORHAN, a national organisation that brings together people affected by the disease, professionals and other interested parties to fight for better care. From the start, MORHAN has been integrated with the general disability movement in Brazil, and has grown to become the largest leprosy consumer/professional alliance in the world, with dozens of local chapters. More recently, IDEA (the International Association for Integration, Dignity and Economic Advancement) was set up, also in Brazil, to pursue similar aims at the international level. At long last, professionals are beginning to listen to the voice of people affected by leprosy.

Restrictive legislation is also disappearing. Laws that restrict marriage, voting rights, job opportunities, housing and transport for people affected by leprosy are now much less common (although some leprosy groups are still successfully lobbying for legislation that gives them special privileges).

Finally, leprosy is breaking up fewer families than before, partly because of increased public tolerance of the disease and partly because of the shift away from institutional care towards local, outpatient treatment. There is therefore less need for people affected by the disease to be separated from their families for long periods.

We have come a long way in meeting the social needs of people affected by leprosy, but there is still much to do. We must encourage them to overcome their shame, come out of hiding and fight for their rights. We must collaborate with others interested in eliminating disease and bringing about social integration, and we must set up the integrated support and fund-raising systems that will help to bring this about.

# Progress towards economic objectives

## Objectives

- To ensure that people affected by leprosy have the same access to jobs and vocational training as they would have enjoyed had they not contracted the disease.
- If the effects of leprosy have made it impossible for them to work, to ensure that they have the support of their family and receive help such as special vocational opportunities for disabled people and access to homes for destitute people and to any disability pensions available to the general population.
- Access to economic assistance should not be based solely on the criterion of being affected by leprosy, but on more specific factors such as age, extent of disability, financial need and availability of alternative sources of support.

In the past, people affected by leprosy often ended up as beggars. Shunned by their family, forbidden to work, they were forced to depend on charity. Even today, in the major cities of countries where leprosy is common, you may still see people displaying their gnarled hands or their foot ulcers in the hope of donations.

## How leprosy leads to poverty

Leprosy remains as closely associated with poverty as ever. The people who contract the disease are often very poor already, and it exacerbates their poverty in several ways:

- If they have insensitive hands and feet, they can injure themselves by carrying out the heavy manual labour generally associated with unskilled, low-paid jobs. Having these injuries treated also means time off work and a loss of wages or production.
- Even if they are capable of producing saleable goods, the public may not wish to buy these goods because of fear of contamination. This is especially true of agricultural produce.
- Many people affected by leprosy are unable to obtain paid work because of prejudice.
- Many older people affected by leprosy cannot depend upon the support of their family, either because they have lost contact with them or because their relatives are too poor (or too reluctant) to help.

- There are few vocational training and rehabilitation centres or sheltered workshops in the countries where leprosy is common, and many of those that do exist will not take people disabled by the disease.
- In developing countries, the social services safety net for all disabled people is flimsy, because governments can provide little economic support.

In view of these obstacles, begging is often the best paid and least physically damaging job for people disabled by leprosy.

## **The lack of economic support programmes**

Because of their bias towards the medical aspects of leprosy, planners have been slow to develop programmes for improving the economic prospects of people affected by the disease.

So far, most such programmes have been institution-based and have involved making and selling handicrafts (though there have also been examples of workshops making high-quality industrial and commercial products, such as Worth Industries in India).

People affected by leprosy have also set up co-operatives. The Han Sung Co-operative Association, for example, now controls a large proportion of the Korean egg market and employs many people not affected by the disease. However, members of the co-operative are reluctant to publicise the fact that they have had leprosy.

Organisations such as SORRI in Brazil have been set up to train people disabled by leprosy in useful skills, so that they can find employment in the general workforce of their community. Some of these organisations only serve people with leprosy or their relatives, whereas others are totally integrated and serve all disabled people.

There are a few housing and loan schemes, but their achievement is so far very limited compared with the vast numbers of people who need help.

To solve the economic problems of people affected by leprosy, the help of non-leprosy organisations – governmental, non-governmental and private – is essential. Without their help in training, work placements, micro-enterprise development, loans, transportation and housing, many people disabled by leprosy will be doomed to lives of poverty and isolation.



**Elderly village  
resident, Thailand.**

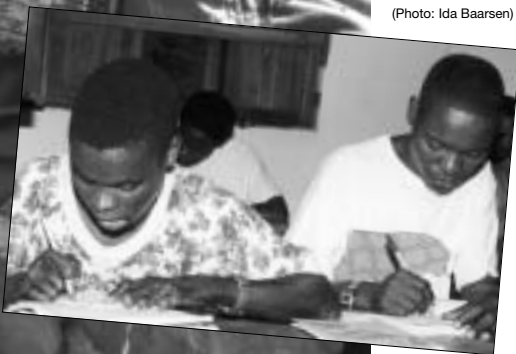
(Photo: Mike Heywood)

**Older woman  
working at a  
loom in China**

(Photo: Rolf Bauerdick)

**Boy cured of  
leprosy studying  
with his friend,  
Pemba,  
Mozambique**

(Photo: Ida Baarsen)





**Taking care of livestock**

(Photo: TLMl)

**Economic rehabilitation, India**

(Photo: ILEP Secretariat)

**Young girl in Inyatpur village, Uttar Pradesh, India**

(Photo: TLMl)





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## **Social integration and its implications**

This chapter will discuss some of the major questions connected with social integration. Most of these are relevant not only to people affected by leprosy, but also to other stigmatised and segregated groups.

# Chapter Three

## **What will integration achieve?**

How will integration help to solve the problems of people affected by leprosy? How far does it need to go? Does integration mean there should be no leprosy associations or specialised programmes at all?

We have stated that our overall objective in working with people affected by leprosy is integration. After years of hesitation, most professional workers and people affected by leprosy now support (at least verbally) the concept.

## **The arguments in favour of integration**

### **Medical and epidemiological**

A major obstacle to social integration has long been the public's fear of catching leprosy. As we have seen, this fear is vastly exaggerated.

### **Economic**

Segregation is expensive. An effective system for isolating people with leprosy requires an enormous outlay on buildings, food, clothing, staff and security. Even setting up a specialised, 'vertical' system for treating leprosy on a voluntary basis is usually much more expensive than an integrated system, because it duplicates the buildings, equipment, vehicles, staff and other resources already available elsewhere.

The segregation of people with leprosy is costly in other ways. Someone who is refused a job because they have the disease becomes an economic burden on their family and the community. This means a loss of production and a loss of taxes on the goods produced and the income of the worker. The family and the community are obliged to spend money to support someone who is forbidden to work.

The countries where leprosy is most common cannot afford to squander their scanty resources in this way. They must find the most efficient and effective way of stopping the spread of the disease and enabling the people affected by it to continue to work and to contribute to society.

### **Psychological**

Segregation reinforces stigma. Someone who is afraid to be identified as having leprosy will be reluctant to seek treatment, thus hampering efforts to control the disease. Isolation also saps morale: it is difficult to have a positive image of yourself when you are judged to be so dangerous to society that you are refused access to the services and institutions that others use.

Segregation also reinforces society's prejudices about leprosy. It confirms their suspicions that people affected by the disease are a threat to public health and need separate services. It makes the recruitment of qualified people for leprosy work more difficult. And while specialised leprosy institutions and programmes continue to exist, generalist medical and social institutions can argue that there is no need for them to open their doors to people with the disease.

### **Ethical**

Segregation is now morally indefensible. It was justified in the past as being the only effective way to halt the spread of leprosy, but recent advances in the treatment of the disease have made this argument invalid. The medical, economic, social and psychological costs of segregation are much greater than any benefits it might conceivably bring.

## **Resistance to integration**

Although the concept of integration has won the day, there is still debate about how far and how fast it should go. Here are some of the reasons why integration is still being resisted:

### **Tradition**

People are more comfortable with established ways of doing things. They fear that changing the methods of treatment will result in more complications, more work and more expense.

### **Quality**

Some service providers fear that the quality of treatment for people affected by leprosy will deteriorate in an integrated system. They think that other, more generalist professionals will not care for clients as effectively as they do, that they will have less control over staff and material resources and will have to compete for those resources with other special interest groups.

They also worry that, without specialised leprosy institutions or programmes, there will be too few concentrations of clients to provide medical workers with the experience they need to treat the disease adequately. If, as a consequence, the core group of experts were to shrink, we would be left without adequate defences were leprosy to come back to haunt us – as tuberculosis has done.

### **Confused messages**

Some fund-raisers worry that integration will dilute the mission of traditional leprosy organisations and thus send a confused message to donors and other collaborators. Leprosy is a powerful symbol in fund-raising, and organisations are reluctant to do anything that will weaken it.

There is also the fear of competition. If organisations that do not concentrate exclusively on leprosy start asking for donations to help treat the disease, this will mean fewer contributions to the specialist leprosy organisations.

### **Defensiveness**

Some people feel that to support integration is to concede that their previous approaches to treating leprosy were wrong. They feel the need to defend their past actions.

### **Loss of prestige**

Although professionals may be loath to admit it, they often fear that integration will diminish the prestige and power they currently enjoy in the circumscribed world of leprosy. Even worse, it may mean the loss of jobs – their jobs.

### **Loss of economic and social benefits**

Long-time leprosy clients may resist integration because it will bring to an end the protected way of life to which they have become accustomed. They are afraid of what they may encounter in the world outside the institution.

### **Outside resistance**

The outside world will often resist integration too. Some generalist organisations and government agencies would prefer to leave the socio-economic problems of people affected by leprosy to the care of specialists in the disease, because they do not want the extra work or the extra cost involved.

### **Lack of a strategy**

Finally, many people resist integration simply because they do not have an effective strategy for carrying it out. They are unsure about what to do and who should do it.

All these concerns have some validity. Like any social change, integration cannot be achieved without cost: to the people affected by the disease, to the professionals and to the institutions.

## **The potential benefits of integration**

During the transition to integration, the quality of leprosy treatment may well deteriorate. Clients may have to wait longer; specialists may lose prestige, yet at the same time have to cope with a larger workload; costs may increase, yet funding may decrease. And ways must be found to keep people interested and trained in leprosy work at a time when the number of clients is falling rapidly.

But we must weigh these temporary inconveniences against the enormous long-term benefit that integration will bring. An integrated system will be more effective and efficient, as well as more just and less likely to encourage stigma. Integration will mean that, in future, people affected by leprosy will be able to lead normal lives, living and working in their communities – they will no longer fear being ‘found out’.

Integration will mean that qualified professionals who currently have no connection with leprosy will involve themselves in research, training and service provision. It will mean that leprosy professionals and people affected by the disease will at last gain access to housing, vocational training, economic development and other services currently barred to them.

## **The future for specialisms**

Is there any longer a need for specialised leprosy agencies? After all, other conditions, such as cancer and heart disease, have their own special hospitals, associations and magazines.

The answer is, of course, that we still need national and international leprosy organisations that can speak with a powerful and united voice to governments and the public. We still need specialised publications in which workers involved with leprosy can share their research and experiences. We still need international leprosy federations, in which fund-raising and programme agencies working on different aspects of the disease and in different countries can share ideas and co-ordinate their activities.

We still need specialised research, training and treatment centres to increase our knowledge of leprosy, train future workers and treat clients with intractable problems.

An important difference between leprosy and other conditions (including other contagious diseases) is that the latter are usually treated not in specialised institutions, but via the services provided for the community at large. For example,

when someone being treated for tuberculosis needs dental work, housing advice or help with family problems, they do not have to go to a dentist, social worker or psychologist specialising in tuberculosis, but to any appropriate professional within their community. By contrast, people affected by leprosy who need this kind of help either have to find it within the closed world of leprosy or hide their condition and visit a local specialist.

Therefore we do not advocate the abolition of international organisations such as the International Leprosy Association (ILA), the International Federation of Anti-Leprosy Associations (ILEP) or the International Leprosy Union (ILU). On the contrary, we believe that they should be strengthened so that they can expand and diversify their membership, and thus address more effectively all concerns related to leprosy. As leprosy work becomes more integrated at the local level, these federations will be needed to bring together individuals and organisations at national and international level.

On the other hand, we do advocate that – for reasons of effectiveness, efficiency, client morale and ethics – almost all field services for people affected by leprosy, as well as the associations that raise money for them, should be integrated. This does not mean that all services at all levels of an organisation must be integrated; because of their complexity or the demand for them, some specialised services could be maintained within an integrated overall structure.

## **Who speaks for people affected by leprosy?**

Should it be the client, the service provider or the funder who decides what the needs are, which services should be provided, and how they will be organised and paid for?

As human rights become a live issue throughout the world, it is no longer acceptable for donors and service providers to impose their will upon clients without listening to their views first.

Developing countries increasingly resent the intrusion of donor countries and international agencies into what they regard as their area of authority; local authorities resent the intrusion of national or state government; and individuals resent what they consider to be the unreasonable demands of bureaucratic organisations that waste money which should have gone to resolving their problems. People want to have more control over their own destiny.

As people begin to stand up for their rights, the result is often tension between clients, service providers and funders. So far, this has not been as severe in leprosy programmes as it has in disability or AIDS work. But the seeds of conflict are there.

The fact is, some users of existing leprosy services feel that their needs are not being met, their opinions are not being sought and their dignity as individuals is being

compromised. They think that the image of leprosy presented to the public by donor agencies exploits them. They complain that far too much of the money raised goes on administration, leaving far too little to pay for actual services. They wonder why donor money has to be channelled through a succession of governmental or non-governmental agencies rather than being given directly to their own patient organisation or to them individually. They sometimes feel that, since they are the ones who are affected by leprosy, they are the best qualified to state their own case.

Service providers often think that they are the best spokespeople for leprosy because they have academic qualifications and practical experience. They feel that they can design and evaluate projects much more impartially and professionally than either donors or clients. They often feel unappreciated, underfunded and burdened by what they regard as the unreasonable expectations of clients and funders.

In practice, however, it is the funding agencies, governmental or non-governmental, that usually speak for leprosy. They are the ones that have to convince individual donors, corporations, foundations or legislative bodies to fund assistance programmes. Funding agencies often feel that neither the client nor the service provider fully appreciates the competitive nature of fund-raising, and the consequent need to present a case that is not only factual but will also motivate the public to keep on giving. Funding agencies need heart-rending stories and photos as well as statistics and factual accounts if they are to satisfy the diversity of groups and individuals who give them funds – they include kind-hearted old ladies as well as foundations that ask probing questions.

The answer, of course, is that all three – fund-raisers, service providers and clients – must speak for leprosy. They need each other's unique perspective.

Just because someone is a medical doctor who specialises in leprosy does not mean that they understand any better the physical pain, psychological suffering and poverty of people affected by the disease. Equally, just because someone has had leprosy, this does not make them an authority on drug treatments, the management of public health or economic development programmes. And just because someone knows that certain fund-raising techniques work better than others in certain situations, this does not excuse them from the obligation to base their appeals on true facts and to preserve the dignity of the people being portrayed.

These three groups should work together, actively seeking out and examining a range of different points of view as they design leprosy treatment and fund-raising programmes.

Having said that, the final say on finance will probably rest with those who hold the purse strings; the decision on what kind of programme can be delivered within the financial limits set by the funders will usually be taken by the service providers; and the decision on whether or not to participate in the programme will be taken by the client.

Each of these three groups has the means to present its point of view to society. It is best for the cause of leprosy if there is a consensus on the image of the disease presented.

## **The roles of different agencies**

What is the role of governments, non-governmental agencies and UN agencies in leprosy work?

Until fairly recently, responsibility for the care of people affected by leprosy was largely assumed by charitable agencies, otherwise known as non-governmental organisations (NGOs). These enjoyed considerable autonomy and there was little co-ordination between them.

In 1966 some of the major NGOs raising funds for leprosy decided to co-operate more closely, and set up what is now known as the International Federation of Anti-Leprosy Associations (ILEP). The currently 16 member organisations spend about \$60 million a year supporting work in over a hundred countries.

Although NGOs still play essential roles, the major players in leprosy work today are governments. In the past, most countries where the disease was common were content to allow NGOs considerable freedom of action in tackling it. Today, however, the governments of these same countries have assumed full responsibility for treating people affected by leprosy.

This has been partly due to the growth of national feeling and partly to the awareness among governments that only they have the resources and networks needed to tackle such a complex problem. NGOs welcome this new governmental concern about leprosy, but sometimes have difficulty in adjusting to the role of supporting government programmes rather than being in control.

A third major player in leprosy work today is the World Health Organization (WHO). Although WHO has few human and financial resources of its own (most of them come from NGOs), its programmes for the 'Elimination of Leprosy' have done much to promote Multi-Drug Therapy worldwide. By showing them exactly how it can be done, WHO has challenged governments to make the elimination of leprosy one of their policy objectives.

Although there are the inevitable frictions between NGOs, governments and WHO, the consensus is that these parties need each other if leprosy is to be eliminated.

Each party has its own strengths. WHO and other UN agencies have the influence to bring together top experts and to promote governmental action on leprosy. Governments have the power, the networks and the resources to bring leprosy work to the local community in an integrated fashion. NGOs have the flexibility, the

experience, the funds, the committed workers and the relationships of trust with communities that are vital when setting up new programmes.

The main challenge now is to involve yet more NGOs, UN agencies and government departments in the fight against leprosy.

## **The best use of resources**

Today there are thousands of organisations around the world trying to raise money for hundreds of causes. Health has to compete with the environment, social welfare, sport, culture, animal rights, politics, etc; and within the category of health there are groups seeking funds to fight AIDS, cancer, arthritis, heart disease and innumerable other conditions.

The reality is that leprosy is only one of the problems that afflict mankind, and it must compete for resources like all the others. In fact, competitors often envy the success leprosy organisations have had in raising funds. We shall now look at how this money can best be spent to achieve integration for people affected by leprosy.

## **Charity or development?**

Should organisations use their resources for development programmes rather than charitable work?

Charity has lost the positive image it once had. Nowadays, it is widely condemned as being paternalistic and degrading. Recipients see it as unreliable, because it depends on the whim of the giver. They feel that basic assistance is a human right and should not depend on charity.

Others criticise charity for making the recipient dependent upon the giver. “It is better to teach someone to fish than to give them a fish” is a Chinese proverb much quoted by development agencies. Funders are encouraging agencies to find ways not only of helping recipients to become more self-sufficient, but also of reducing their own dependence on grants from outside sources.

It is obviously important to help people and organisations to become as self-sufficient as possible, but we must not harbour unrealistic expectations. No one can be completely self-sufficient; we all depend on others for something. Nor is paternalism always wrong.

There are some situations where charity is the only answer, for example, in natural disasters such as famines, floods and earthquakes, as well as in personal crises such as severe illness or disability. Only after emergency aid has been given can self-sufficiency be considered.



Traditionally, leprosy has been treated in a very paternalistic way. People affected by the disease have been herded into closed institutions, forced to obey rules and regulations not of their own choosing, and given food, shelter, clothing and medical treatment free of charge. They have rarely been consulted about their personal needs and the nature of their treatment, and they have not always been taught to take care of themselves.

As a result, people affected by leprosy have sometimes become completely dependent. Through age, disability and the lack of viable alternatives, many have lost all realistic hope of becoming self-sufficient. These people could not survive for long without some type of charity.

The same is true of many of the local agencies that provide services for people affected by leprosy. They have been dependent on international bodies for so long that they have become almost incapable of surviving without their help. Where will they turn for resources? They can only cut their expenses by so much before their workers start looking for employment elsewhere and the people they are supposed to be helping rebel. Nor can these agencies support themselves fully by charging their clients, since these are usually the poorest of the poor.

The challenge for us is to distinguish between situations where charity is called for and those where development aid and encouraging self-sufficiency are more appropriate responses.

Planners and administrators should also promote self-sufficiency, of course, but they should not abruptly cut off support to partners and clients who have no realistic alternatives. They should first try to help them discover alternative sources.

## **Sophisticated services or basic care?**

What proportion of scarce resources should go to providing basic services for the many and what to providing more sophisticated services for the few?

For example, should \$150,000 be used to save one life through a heart transplant or to vaccinate thousands of children? Should all leprosy funding go towards curing people of the disease, or should some of it be used to restore useless hands or provide vocational training? Who makes this kind of decision, and on what criteria?

This issue is seldom simple. The world is becoming smaller; when disabled people in remote villages see on television or in magazines other disabled people using wheelchairs or artificial limbs, they are unlikely to remain content with a wooden stump. And when service providers learn of the existence of better equipment, even though it costs much more, they will naturally want to be able to use such equipment.

## **Institution-based or community-based?**

Should planners continue to finance expensive centralised institutions that care for only a few clients, or should they spend the money on simpler, community-based alternatives that can help many more people?

In recent years, certain UN agencies, NGOs and governments have called for the setting up of community-based rehabilitation programmes. Institution-based programmes have failed, they argue, because they serve only a small proportion of the people in need, and because their capital and maintenance costs eat up most of the budget available for helping disabled people. They believe that the local community, supported by the government, must be the main focus of disability work. This is a powerful argument that requires careful consideration.

The defenders of institutions point out that centres of excellence are essential for training, research and referral. These centres act as knowledge banks and provide stable back-up, without which the community-based programmes, with their high turnover of staff and constant need for training, would quickly disintegrate.

We take the middle view. Effective solutions can be neither exclusively community-based nor exclusively institution-based, but should be a mutually supportive combination of the two. The fear is often expressed that, even though the number of leprosy cases has fallen dramatically, the disease could return in strength. If that happens, we do not want a repeat of the situation with tuberculosis, where victory was declared too soon: research and training structures were prematurely dismantled and most experts were lost to other fields. To avoid this, we must continue to support some key institutions, programmes and people, even though, owing to the diminishing number of clients, there might not be a full-time demand for their services.

## **Competing aspects of leprosy work**

Within leprosy work, as in other disciplines, there is competition for funds between different specialisms. In the quest for integration, planners must carefully weigh the pros and cons of supporting one area over another.

### **Medical research**

Some people advocate medical research as the key to integration. They feel that devoting greater resources to discovering more effective treatments for leprosy will stop the spread of the disease. The public will lose its fear of the disease and the people affected by it – and social integration will be the result.

### **Controlling the spread**

Others feel that current drugs are effective enough, and that the emphasis should

be upon finding and treating new cases as quickly as possible. This too will halt the spread of leprosy and prevent disabilities, creating conditions favourable to social integration.

### **Physical rehabilitation**

Some specialists argue that one of the keys to social integration is the prevention and correction of physical deformities. These, they feel, are what really alarm the public and stigmatise clients. If we could train clients to prevent secondary deformities and we carried out more corrective surgery, this would do much to promote integration.

### **Economic rehabilitation**

Yet others give priority to training, work placements and the development of micro-enterprises. Their argument is that unless people are gainfully employed, they will never be fully socially integrated. It is through work that we make our principal social contacts, receive psychological satisfaction, develop an identity and receive the economic rewards that give us independence and social acceptance.

### **Public education**

Then there are those who think that the main obstacle is the misconceptions about leprosy among clients, professional workers and the public. They believe that integration will only happen when we get rid of these false notions of the disease. In particular, they would like to eliminate the word 'leprosy', with its negative and obsolete connotations, from our vocabulary and use 'Hansen's disease' or some equally neutral term instead.

### **Caring services**

Finally, there are those who point out that clients who are old or severely disabled have no chance of integration, and therefore that some of our resources should go to helping them live out their lives with dignity.

Once again, planners must strike a compromise between these competing views, as all of them contain some truth.

## Promoting an appropriate image

In view of the long history of leprosy and the present realities, what image of the disease and of the people affected by it will do most to help social integration?

The image that people have of leprosy will largely determine whether we can eradicate the disease and socially integrate the people affected by it. For example, this image influences:

- whether people seek treatment
- whether employers accept workers
- who people choose as marriage partners and how society views their offspring
- how people view themselves and take care of themselves
- whether or not professionals take up a career in leprosy work
- what governments decide about the allocation of resources
- whether individual donors give to leprosy work
- whether or not medical, religious, social and economic institutions open their doors to people affected by the disease.

## The good news

On the one hand, it is important to project a positive image, as great strides really have been made. People should be left in no doubt about the good news: leprosy is now curable – and seven million people have been cured in the last ten years. It is no longer the scourge it was once thought to be.

The new image of leprosy should allay public fears and make life more normal for people affected by the disease. This positive view has informed many recent health education campaigns and inspired WHO to choose the slogan, “The elimination of leprosy as a public health problem by the year 2000”. It has generated new funds for leprosy work and mobilised governments and the public to work towards the objective of elimination.

## **The cautious approach**

However, many people worry that this rosy picture of our progress in eliminating leprosy is unrealistic and could backfire. They argue that, although WHO may define 'elimination' as reducing the prevalence of the disease to one case in ten thousand people, the public understands the word as meaning the total eradication of leprosy – an impossibility with our current weapons.

If the public is to have an accurate picture of the present state of leprosy, certain less-than-positive aspects need to be mentioned. For example, although the number of people needing chemotherapy has dropped significantly, the number of new cases discovered each year has remained stable.

And it should be emphasised that the problems associated with leprosy do not stop once the bacilli are dead. Millions of people who have been cured of the disease still face physical disabilities or deformities, and will continue to need rehabilitation. Many others will need counselling and socio-economic support. In addition, there are relatives and others who are indirectly affected by leprosy and may need outside help.

Although we should beware of over-estimating the size of the 'leprosy problem', we should be just as careful not to underestimate it. Painting too positive a picture of our progress in eliminating leprosy could cause governments and the public to lose interest in the disease. This, of course, would be disastrous for leprosy work, which would lose the financial resources, the dedicated professionals and the commitment of governments and other agencies that it needs to eradicate the disease.

A decline in the allocation of resources has already been detected, and some organisations have concluded, rightly or wrongly, that this is due to the unduly positive image of leprosy currently being projected.

## **Differences in viewpoint**

The truth is that we have different viewpoints and objectives depending on our relationship to leprosy. Medical professionals are principally concerned with the physiological aspects of the disease and measure their success and failures in those terms. Social work professionals look more to the psychological, social and economic effects of the disease and measure success in terms of reducing these. Planners look at global statistics. And finally, individuals with the disease look at their own personal needs.

Fund-raisers and fieldworkers also look at leprosy in a different light. Fieldworkers emphasise that leprosy is a disease like any other. Their aim is to get rid of whatever sets the people with the disease apart from others – be it bacilli, disabilities, stigma or poverty. But fund-raisers, whose objective is to raise money,

not to educate, will often emphasise not the normality of people affected by leprosy but the ways in which they are different, on the grounds that if everything is going well for them, why should anyone want to give them money?

- Whereas the programme worker aims to emphasise the normality of the appearance of people affected by leprosy, the fund-raiser often uses images of deformity to demonstrate need.
- While the programme worker wishes to show economic success, the fund-raiser uses scenes of terrible poverty.
- Where the programme worker focuses on adults, because they are the most likely to have the disease, the fund-raiser focuses on children, because the public gives more generously to children's causes.
- Where the programme worker sees stigma in calling people 'leprosy patients' even after they have been cured, the fund-raiser sees the need to continue to identify people with the disease so as to raise money.

## **Basic principles**

So what image of leprosy should we use? Whatever the details, it should follow these three guidelines:

1. Do not compromise the dignity of people affected by the disease.
2. Always be truthful; do not exaggerate or manipulate.
3. Present as balanced a picture of leprosy as possible. For example, show both the medical and the psycho-social aspects of the disease; use both narrative and statistics; present both global and personal viewpoints; insist on the rights and responsibilities of all concerned; cite both the victories won and the challenges still to be faced; and when concentrating on the future, do not forget the past.

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**Changing medical and socio-economic support systems** will be a long and complex task, and both open and covert resistance to normalisation is to be expected.

# Chapter Four

## Summary

In summary, I should like to emphasise the following points:

1. Normalisation should be the ultimate aim of all leprosy projects. To normalise the life of the person affected by the disease within the community is the theme that should unite all research, control, rehabilitation and public education efforts, and success should be measured against this objective. Many of the strategies for integrating people affected by leprosy also apply to other stigmatised minority groups.
2. All systems for treating people and their disease, as well as all individual and institutional activities within such systems, should contribute directly or indirectly to achieving normalisation in an effective, efficient and non-stigmatising manner.
3. Unfortunately, the vertical, segregated systems that have characterised our treatment of leprosy are now mostly ineffective, inefficient and stigmatising. Instead of helping to maintain people affected by the disease in their families and communities, they have dislocated them. Instead of encouraging the integration of people affected by the disease with others having similar needs and interests, they have separated them in specialised organisations and programmes. Instead of promoting increased self-sufficiency, they have encouraged unnecessary dependency. Such segregated systems are expensive to maintain and reinforce the image of leprosy as a highly contagious condition, 'a disease apart'. They stigmatise people and hinder control programmes that depend on voluntary co-operation. They complicate the recruitment of professional workers and provide excuses for community institutions to discriminate against people affected by leprosy.

4. In order to change these systems of treatment, it will be necessary to integrate existing community programmes with organisations serving the general population, to create new integrated programmes and institutions, and to transform existing leprosy organisations. As much attention will have to be given to the social, economic, psychological and spiritual needs of people affected by leprosy as is now given to their physical problems and to protecting the community from the spread of the disease.
5. Bringing about major changes in support systems will require the co-operation of many individuals and organisations. We must therefore be aware of their differing points of view and the reasons why they differ. People are often willing to co-operate in achieving normalisation if their fears about leprosy are adequately addressed. Opposition to integration usually has little to do with prejudice against the disease or the patient. Rather, it is based on broader personal considerations concerning authority, salary level, prestige and comfort. Or it may be based on group interest, as demonstrated in the rivalries between the consumers and providers of services, between government and voluntary agencies, between the political right and left, and between professional specialisms and institutions.
6. Prime movers are essential if we are to change these support systems. The changes will not happen by themselves. These prime movers should have a global view of leprosy, not just a specialist's view of one or two of its aspects. Just as there are professionals for diagnosing and treating the physical and social problems of persons affected by leprosy, so there should also be capable people to diagnose and treat the problems of support systems.
7. Changing medical and socio-economic support systems will be a long and complex task, and both open and covert resistance to normalisation is to be expected.
8. Changing support systems from segregated to integrated, from vertical to horizontal, will not of course solve all the problems of people affected by leprosy. Nevertheless, transforming these systems will greatly help such people and their children to lead normal, useful lives with dignity within their communities.



## APPENDIX: LEPROSY AT A GLANCE

**Cause:** *Mycobacterium leprae* bacillus, identified by Gerhard Armauer Hansen in 1873.

**Numbers:** The number of people detected with leprosy in 2002 was 620,672. Between 1985 and 2002, around twelve million people were cured of leprosy with Multi-Drug Therapy (MDT).

**Distribution:** In 2002 the number of new cases detected was as follows:

WHO region	Number of new cases detected during 2002
Africa	48,248
Americas	39,939
South-east Asia	520,632
Rest of world	11,853
<b>TOTAL</b>	<b>620,672</b>

Statistical Source: WHO 7.10.2003, [www.who.int/lep/stat2002/global02.htm](http://www.who.int/lep/stat2002/global02.htm)

### Countries with largest number of cases detected in 2002:

**India** (473,658), **Brazil** (38,365), **Nepal** (13,830), **Indonesia** (12,377), **Bangladesh** (9,844), **Myanmar** (7,386), **Tanzania** (6,497), **Mozambique** (5,830), **Madagascar** (5,482), **Nigeria** (5,078) and **D.R. Congo** (5,037).

In addition, the following countries still had prevalence rates greater than 1 per 10,000 population: Angola, Cameroon, Central African Republic, Comoros, Congo, Guinea, Liberia, Papua New Guinea and Timor-Leste (see WHO source above).

### Transmission

Leprosy is a communicable disease, and the human being is the only known route through which other human beings can become infected. Although the process is not fully understood, it is thought that the bacillus is passed from one person to another through the skin and upper respiratory tract. People with untreated multibacillary types of the disease are the main sources of infection; the household contacts of these untreated multibacillary patients are the population most at risk.

**Incubation period**

For those who develop the disease, the average incubation period is two to five years.

**Immunity**

Most people have a good cell-mediated immune response to leprosy, and therefore if they become infected by *M. leprae*, they never develop the disease. Many others who contract leprosy are self-curing. Only a few seem to be unable to mount a reasonable defence and develop the disease. There are as yet no proven vaccines for the disease that give immunity, although BCG provides some benefits.

**Treatment**

After a few days of treatment with today's arsenal of drugs against leprosy, almost all bacilli become non-viable. The standard drugs used are dapsone, rifampicin and clofazimine, administered in combination to avoid the development of drug resistance; this is called Multi-Drug Therapy (MDT).

**Impairments**

About 20 to 25 per cent of people with leprosy are thought to have some type of impairment that can lead to deformity and disability. Primary impairments are those which are due directly to the disease, and secondary impairments are those that may occur as a result of primary problems. Most deformities and disabilities are secondary and can be prevented.

**Age**

Leprosy strikes all age groups.

**Sex**

Both sexes are affected, but males more often than females.

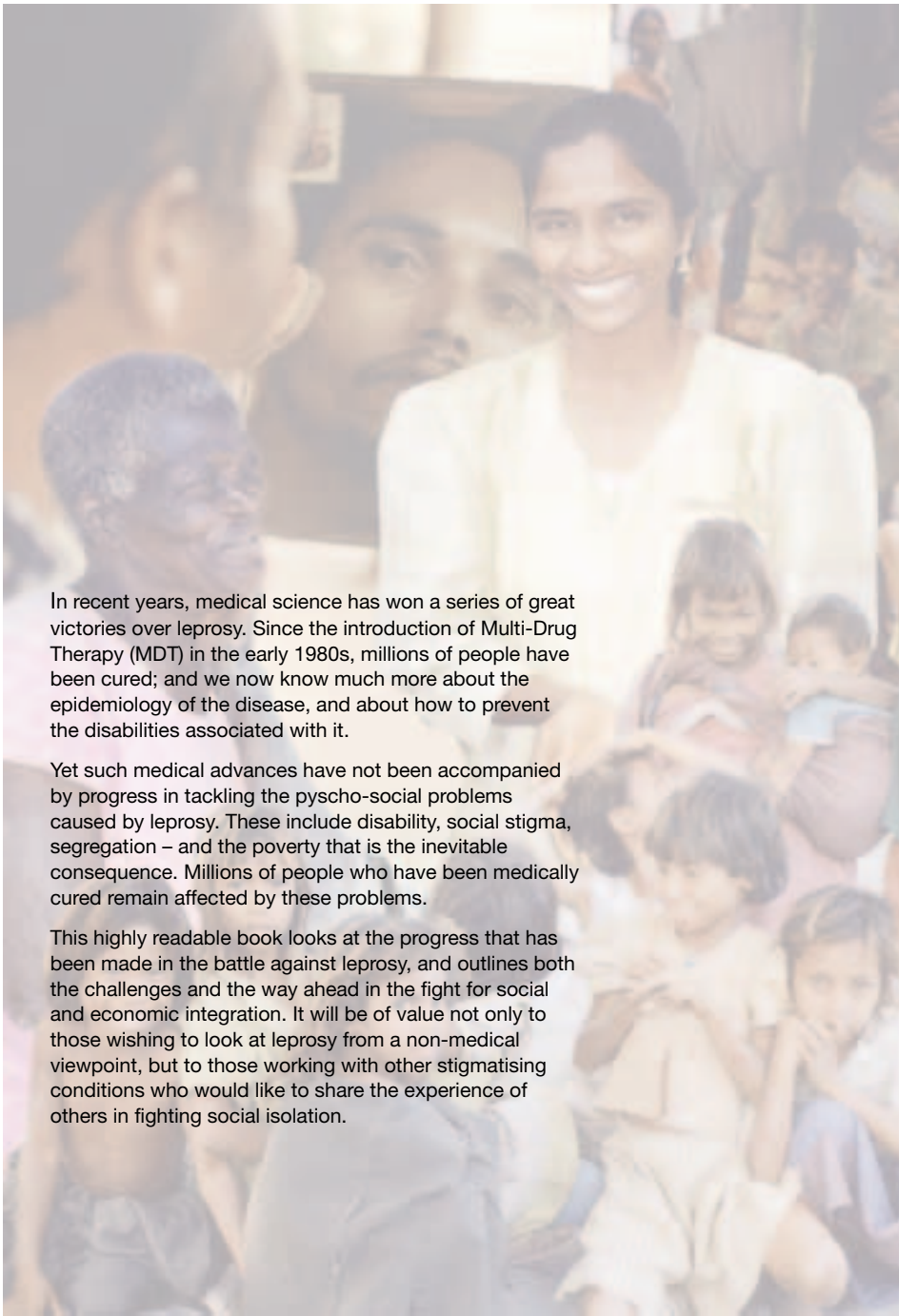
**Poverty**

Leprosy is primarily associated with poor living conditions.

**Mortality**

Leprosy is rarely the main cause of the death of a person.





In recent years, medical science has won a series of great victories over leprosy. Since the introduction of Multi-Drug Therapy (MDT) in the early 1980s, millions of people have been cured; and we now know much more about the epidemiology of the disease, and about how to prevent the disabilities associated with it.

Yet such medical advances have not been accompanied by progress in tackling the psycho-social problems caused by leprosy. These include disability, social stigma, segregation – and the poverty that is the inevitable consequence. Millions of people who have been medically cured remain affected by these problems.

This highly readable book looks at the progress that has been made in the battle against leprosy, and outlines both the challenges and the way ahead in the fight for social and economic integration. It will be of value not only to those wishing to look at leprosy from a non-medical viewpoint, but to those working with other stigmatising conditions who would like to share the experience of others in fighting social isolation.