WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE Elimination OF Leprosy

April 2010 • Number 43

- Leprosy is curable
- Free treatment is available
- Social discrimination has no place

The welcoming committee for Goodwill Ambassador Sasakawa when he visited Ho Polyclinic in Ghana in March.

MESSAGE

Good News from the BBC

I have repeatedly written letters to newspapers over the years to protest the use of the word "leper." Recently, I was delighted to learn that the BBC have added an entry to their style guide and will avoid using this word in future in favor of more dignifying terminology.

Ensuring that the media have a proper understanding of leprosy is an important task of the Goodwill Ambassador. Newspapers and TV broadcasts reach millions of people. That's why I never decline the opportunity to be interviewed when I visit a country, no matter how tight my schedule. The media are one of the biggest partners in my endeavors.

In India, I recall being interviewed 12 times in one day. I repeated the same messages until my throat was sore. But what is that discomfort compared to the discrimination suffered by people affected by leprosy?

However well-intentioned reporters and editors are in covering leprosy, and in faithfully reporting my call for an end to stigma and discrimination, more often than not the pejorative 'L' word creeps into the headline or is used in the body of the story. Recently this headline appeared on the website GhanaWeb: "Leprosy Ambassador targets discrimination against lepers". The article that follows goes on to report that I "cautioned against the use of derogatory terms such as lepers or its equivalent in other languages." On the one hand, my message is being conveyed; but on the other, it is being undermined by the insensitive choice of language used by journalists. Needless to say, this is not a problem limited to Ghana.

That said, thanks to media cooperation over the years, knowledge about leprosy is spreading and this has undoubtedly contributed to the dramatic fall in case numbers. For this, I thank the media for their cooperation and coverage. From now on, I urge all news organizations to take a leaf out of the BBC style manual and refer to people affected by leprosy in language that accords them the dignity and respect they are due.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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REPORT

CBR Guidelines Herald Change

New WHO guidelines will promote socio-economic inclusion, rights and dignity.

In October, new guidelines[1] on community-based rehabilitation (CBR) will be published that are designed to facilitate inclusive development for people with disabilities, including people affected by leprosy and their families. The guidelines will make "a huge change" to the way CBR has been practiced, according to the WHO's Chapal Khasnabis, one of the guidelines' architects.

As currently defined[2], CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. As such, it is highly relevant to the rehabilitation of people affected by leprosy, and the new guidelines will underline this with the inclusion of a supplementary chapter devoted to the subject of leprosy and CBR.

"The framework for the new CBR is a matrix with five major components: health, education, livelihood, social, and empowerment, with empowerment the strategy to make these sectors inclusive," says Khasnabis. "If we embrace this matrix, then even in the leprosy world, this will represent a change from the past more toward the social model, more toward inclusion."

"The basis of the social model is the idea that 'society makes me disabled, not my impairment. Therefore, I need to work with society not to make me disabled.' If the social model works in the disability sector, then why not also in the leprosy sector?"

To underline his point, he reads out two statements: 'Disability is mainly a socially created problem, and basically is a matter of full inclusion and participation of individuals into society.' 'Poverty, stigma, prejudice, systematic barriers, negative attitudes and exclusion by society are common experience of people with disabilities.' Replace the word 'disability' with 'leprosy' in the first, and 'people with disabilities' with 'people affected by leprosy' in the second, and these statements are still valid, he says.

A SECTOR APART

Leprosy has traditionally been excluded from mainstream rehabilitation and CBR, a fact that Khasnabis laments. The reasons include the way that persons with disabilities due to leprosy were usually referred to specific leprosy rehabilitation centers; the stigma attached to leprosy, which often made mainstream rehabilitation programs scared of taking people with leprosy and made people with disabilities due to leprosy hesitate to participate due to past experience of discrimination and self-stigma; a disconnect between leprosy and CBR programs from donors through the community level; and the attitude of leprosy leaders, their supporters and CBR implementers.

"Leprosy is not part of the disability movement, or disability development. This kind of segregation is not a healthy situation to change anything," says Khasnabis. "Leprosy leaders need to be part of the disability movement. Then the pace of change will be faster. If they remain isolated, they will remain isolated for ever."

Especially, the benefits of the Convention on the Rights of Persons with Disabilities should also reach to the people with disabilities due to leprosy, he says. "Partnership among disability leaders, leprosy leaders and CBR implementers can make this happen."

TOWARD INCLUSION

In order to include leprosy in CBR, much needs to happen. CBR programs and disabled persons' organizations including organizations of persons affected by leprosy need to work together to make them aware that they can be equal participants in CBR activities.

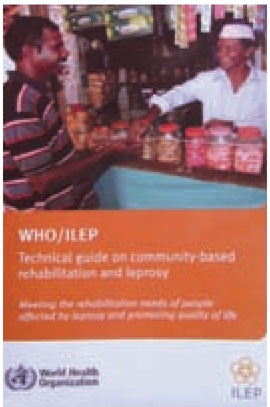
Awareness and training of CBR personnel is required, sensitizing them to the needs of people affected by leprosy and promoting their rights, while challenging their misconceptions, stigma and discrimination.

CBR implementers need to pay special attention to ensuring that, just like any other people with disabilities, people with leprosy and their family members are accessing all benefits of CBR with equal rights and opportunities.

The problem of poverty needs to be addressed. Skills training, income generation activities and decent work can provide a strong entry point for inclusion into society and is a mechanism for breaking the cycle of isolation, dependency and poverty associated with the leprosy. "I come from India," says Khasnabis. "India teaches that if you want to change leprosy, then you have to address poverty and its various facets."

In particular, it is important to involve people affected by leprosy in all aspects of CBR: planning, implementation and monitoring. "People affected by leprosy should be part of implementing CBR programs," says Khasnabis. "If they are only seen as beneficiaries, then change will never take place. Only when they are part of the whole system will change happen."

Indeed, under the guidelines, the aim is for all people with disabilities, irrespective of their causes or conditions, to be part of and benefit from all development initiatives — all people, including people affected by leprosy and their family members. ■



Paving the way: WHO/ILEP technical guide from 2007

Footnote

[1] The WHO CBR Guidelines will be launched at the 4th CBR Africa Network Congress in Abuja, Nigeria on 27 October 2010. They will complement the WHO/ILEP technical guide on community-based rehabilitation and leprosy published in 2007.

[2] The definition adopted by the International Labor Organization (ILO), United Nations Educational, Scientific and Cultural Organization (UNESCO), and the World Health Organization (WHO) in a 2004 position paper.

Supporting Economic Independence

Chamada Abibo is working to improve life for people affected by leprosy in Mozambique.

INTERVIEWEE:
Chamada Abibo

Chamada Abibo is General Director of ALEMO (Mozambique Assocation of Persons with Leprosy)

Goodwill Ambassador Yohei Sasakawa visits an ALEMO agricultural project in Nampula Province in 2005.

Chamada Abibo is General Director of ALEMO, an organization of people affected by leprosy in Mozambique. He first noticed symptoms of the disease at the age of 24, when the country was going through the turmoil of civil war, but he wasn't correctly diagnosed for another three years. Receiving treatment was extremely difficult. Every two months he had to cycle 150 kilometers to a hospital in Pemba, the capital of Cabo Delgado province, for his medication.

To earn a living, he worked as a farmer for seven years, before becoming a tree-cutter. Because of the deformity in his hands, the job was difficult for him and put him at risk of further injury. After six months, he was able to switch to an administrative position better suited to his condition. With friends, he started ALEMO in 2000. Today the organization consists of 46 groups, operating in four of Mozambique's 11 provinces — Cabo Delgado, Zambezia, Nampula, and Manica.

How did ALEMO begin?
ALEMO was established in 2000 with 13 members. It grew out of ADEMO, the Mozambican association of disabled people started in 1989.

What are ALEMO's main activities?
ALEMO supports people affected by leprosy to become economically independent. We organize small groups of people affected by the disease, and help them to engage in livelihood projects such as grinding maize, sewing, basket making, pottery and raising animals. There are also agricultural projects — growing maize, onions, tomatoes and many other crops. In addition, ALEMO emphasizes capacity building, where people go to other groups to train members who need more information and support.

Since the organization grew out of ADEMO, do you have a particular focus on persons with disabilities?
ALEMO supports the rehabilitation of persons with disabilities. If a person just sits around and does nothing because he or she has a disability, I believe their condition can get worse. It is important to find something they can do.

> "People try to find what work they can with their abilities."

How easy is it for people affected by leprosy in Mozambique to find work?
People try to find what work they can with their abilities. If a person can hold a broom, he or she might get a job as a cleaner. But given Mozambique's economic situation, there is a lack of employment opportunities in general, while disability caused by the disease is also a factor in the low levels of employment among people affected by leprosy. In urban areas, people often have to beg for a living.

What are your plans for ALEMO?
I would like to expand our activities nationwide. In particular, I want to tackle the issue of social stigma. I want to bring awareness to the public, work with the government, provide access to employment, and improve the lives of people affected by leprosy overall. ■

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Leprosy in the U.S.

With some 150 cases a year, leprosy is not a public health problem, but stigma lingers.

Yohei Sasakawa at Carville in October 2009

In early October 2009 the National Hansen's Disease Programs (NHDP)[1] was privileged to host Goodwill Ambassador Yohei Sasakawa. His time in Baton Rouge was very limited but Mr. Sasakawa was able to tour the NHDP research labs at Louisiana State University and the Carville Historic District[2] including the NHDP Museum.

While touring the NHDP laboratory he was given a briefing on basic research projects tied to more pragmatic goals, such as prevention (vaccine) and early detection of leprosy, development of molecular tools to study transmission, the cell biology and mechanisms of leprosy pathogenesis and development of the armadillo as an approachable animal model for the full clinical and histopathological spectrum of human leprosy.

The NHDP relocated from Carville to Baton Rouge in 1999. While touring the historical site at Carville, Mr. Sasakawa made a point to visit the spot on the Mississippi River where the first seven patients, exiled from New Orleans, were brought upriver on a coal barge and put ashore in 1894. At the Carville cemetery, Mr. Sasakawa spent a few quiet moments of reflection at the grave of Carville's patient No. 1, the first of over 4,500 registered since 1921 when the program was federalized.

He toured the NHDP museum where the exhibits and artifacts display the fascinating history of the care and treatment provided at the national leprosarium, tangible evidence of the stigma of leprosy and of the community and social life the patients made for themselves while confined there. Mr. Sasakawa was pleased to be able to visit with several of the 13 elderly residents, formerly patients, who regard Carville as their home and still reside in space leased from the State of Louisiana.

With only about 150 new cases each year in the United States, leprosy is not a public health problem. However, the lack of awareness of leprosy often results in delayed diagnosis and delay in initiation of treatment. To address this predicament, which is or will ultimately become problematic in other low endemic countries, the NHDP offers seminars and mini-symposia on "Increasing the Awareness of Leprosy in the U.S."

The awareness seminars are aimed at private sector physicians and nurses to raise the index of suspicion that leprosy can present in people who have lived in endemic areas as well as patients residing in the Texas / Louisiana Gulf Coast, where infected armadillos may be a reservoir of leprosy bacilli. With no diagnostic test for pre-clinical disease, attendees are taught that a presumptive diagnosis can be made based on history and examination for the cardinal signs of leprosy — especially chronic skin lesions with sensory loss, enlarged peripheral nerves, loss of eyebrows, swollen, nodular ears or a history of painless wounds or burns. Attendees are instructed to take a biopsy from the lesion and send it to NHDP for histopathological confirmation of their presumptive diagnosis and staging of the disease for the appropriate treatment regimen.

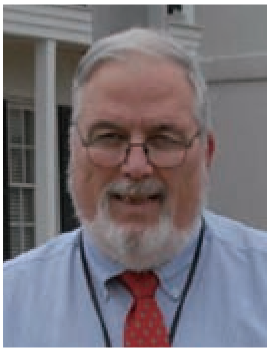
With the free NHDP-provided anti-leprosy drugs and consultations with NHDP physicians and therapists, these patients can be readily managed by local physicians. For management of complications such as unresponsive reactions, advanced wound care or reconstructive surgery, patients can be referred to the NHDP for appropriate treatment and follow-up care as out-patients.

UNWARRANTED FEAR

Mr. Sasakawa was interested in learning that the stigma attached to leprosy in other countries burdens many U.S. patients as well. As is the case elsewhere, the lack of understanding and unwarranted fear of leprosy indeed stigmatizes some individuals with leprosy. However, unlike the situation in many endemic countries, in the U.S. individuals with leprosy are not a homogeneous racial or cultural group so there is no typical U.S. attitude toward the stigma of the disease. Nevertheless, the individuals' concerns and the concerns of their friends, family, neighbors and employers can only be corrected through education that addresses these misconceptions. When local fears have arisen in the news media they have been rather effectively rebutted by facts issued by local and state health departments, often with NHDP input.

This was Mr. Sasakawa's first visit to Carville and the NHDP staff was delighted to finally meet the man who has made his life's work the elimination of leprosy and an end to discrimination faced by tens of millions of leprosy-affected people around the world. ■

AUTHOR:
James L. Krahenbuhl



James L. Krahenbuhl, Ph.D., is Director, National Hansen's Disease Programs, Health Resources and Services Administration, U.S. Department of Heath and Human Services.

Footnotes

[1] The National Hansen's Disease Programs is the center of leprosy care, research and information in the U.S. Based in Baton Rouge, Louisiana, it is part of the U.S. Department of Health and Human Services, Health Resources and Services Administration.

[2] Carville, in Iberville County, LA, is the site of the former National Leprosarium.

Professor Ji Baohong

Dr. Yo Yuasa, medical advisor to the Sasakawa Memorial Health Foundation, mourns the passing of colleague and friend Professor Ji Baohong.

One of the top-most experts on the chemotherapy of leprosy as well as Buruli ulcer died in Paris earlier this year from cancer. Professor Ji Baohong was my valued working partner as well as a close personal friend for nearly 30 years.

My first contact with Dr. Ji was in the late 1970s, when he spent some time at Kyoto University in Japan as a research professor under Professor M. Nishiura. Professor Nishiura was a close advisor to the Sasakawa Memorial Health Foundation (SMHF), of which I had become medical director in 1975.

Born in 1936, Dr. Ji worked for many years at Zeng Yi Hospital in Shanghai. It was there, single-handedly, that he developed an excellent mouse footpad laboratory for leprosy research, having had little direct contact with world-renowned experts in the field such as Dr. Charles Shepard of the U.S. or Dr. R.J.W. Rees of the U.K.

In 1989, he was invited by the World Health Organization to join the Leprosy Unit under Dr. S.K. Noordeen and serve as secretary of the THELEP (Therapy of Leprosy) Steering Committee. In 1994, after five years in Geneva, he moved to Paris at the invitation of Professor Jacques Grosset to join the Faculty of Medicine Pitié-Salpêtrière as a research professor, as well as to become a member of Fondation Raoul Follereau, one of the founding members of the International Federation of Anti-Leprosy Associations (ILEP).

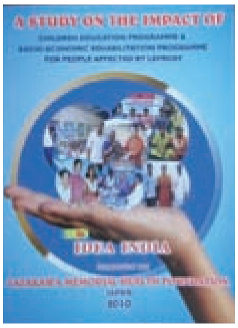
I had several occasions to work with Dr. Ji each year from the late 1980s up to 2003, either at WHO meetings or at ILEP meetings. I also had a chance to travel extensively with him in Vietnam, Cote d'Ivoire, and Madagascar. His greatest professional support to me came at an ILA (International Leprosy Association) Technical Forum that, as ILA president, I convened in Paris in February 2002, six months ahead of the 16th International Leprosy Congress (ILC) in Salvador, Brazil. This Forum was held in place of a meeting of the WHO Expert Committee on Leprosy, which was long overdue but which WHO refused to organize at that time. I believe the conclusions and evidence-based recommendations that emerged from the Technical Forum, which later became the recommendations of the 16th ILC, truly contributed to shaping current and future global leprosy activities in the 21st century.

Leprosy chemotherapy has now reached a critical stage, with measures being prepared to counteract a gradual increase in resistance to Rifampicin, one of the drugs used in multidrug therapy (MDT), as well the formulation of a shorter and more effective MDT regimen. Professor Ji had been expected to lead these efforts, so his loss will be keenly felt not only by chemotherapy specialists, but also among leprosy workers globally.

Doug Soutar, ILEP General Secretary, noted, “Dr. Ji was one of those rare people who was able to combine his technical and scientific expertise with a genuine empathy for those affected by leprosy and for the health worker in the field.” He is survived by his wife in Paris, a son and his family in the U.S. and another son and his family in China. ■

BOOK REVIEW

EDUCATION AND SOCIO-ECONOMIC REHABILITATION



Founded in 1997, IDEA India plays an important role in supporting the efforts of people affected by leprosy to rebuild their lives and overcome stigma. Among its activities, it offers educational assistance to children disadvantaged by leprosy and socio-economic support for persons affected by the disease.

A study published earlier this year by IDEA India looks at the impact of these two programs on 300 children and 115 self-employed adults selected for survey. For the purposes of the study, impact is defined in terms of jobs secured, improvement in living standards, reduction in social stigma and acceptance by society.

Showing the importance of education to securing employment, of 124 children who had already completed their schooling out of the 300 surveyed, only eight had yet to find a job. The study also examines the impact of such factors as caste, disability, and gender on outcomes, noting that women face more problems than men.

For more information, contact IDEA India: ideaind@sancharnet.in

A Week in Africa

Following a visit to Ghana, the Goodwill Ambassador heads to Mozambique to attend a partners' meeting in Maputo.

GHANA (MARCH 8-10)

In March, I was invited to Ghana to speak at the Hideyo Noguchi Africa Prize Memorial Symposium, named after the late Japanese bacteriologist who died in Ghana in 1928 while researching a vaccine for yellow fever. During my brief stay, I took the opportunity to update myself on the leprosy situation there.

Ghana has a leprosy prevalence rate (PR) of 0.29 per 10,000 population. At the end of 2009, there were 636 registered cases of the disease, with 580 new cases discovered during the course of the year. Of Ghana's 10 administrative regions, the Upper West Region has the highest PR (1.19). In the country as a whole, there are 10 high-endemic districts with a PR of between 1.0 and 4.69.

On March 8, I travelled from the capital Accra to Ankaful, near the Cape Coast. I was accompanied by Kofi Nyarko, the energetic president of IDEA Ghana, part of the IDEA network of organizations of and for people affected by leprosy. Kofi, who teaches at a school for children with disabilities in Ankaful, is working tirelessly to bring about an end to stigma and discrimination in his country.

My first stop was Ankaful Hospital. The hospital was a focal point of the government's leprosy program until the second half of the 1980s, when the program was decentralized. Today it serves as a general hospital but still has wards marked "Hansen's disease." Next I visited nearby Ankaful Camp, which came into being when people with leprosy first started coming to the hospital for treatment. The camp is home to about 68 families, although not all are affected by leprosy. Of the few people who have jobs, most work at the hospital or at a rehabilitation center known as Ahotokurom, which was started by American Franciscans in the 1970s. According to Kofi, people living in Ankaful Camp today do not face discrimination from the wider community.

With IDEA Ghana's president, Kofi Nyarko

Greeting residents of Ankaful Camp

The next day, I travelled to the Volta Region to visit the Ho Polyclinic. The polyclinic started out as a leprosarium, founded by missionaries in 1926. About 100 people affected by leprosy, clinic staff and other well-wishers were on hand to greet me. I was told that there are a number of people affected by leprosy living close to the former leprosarium who have been unable to return to their families because of stigmatization. As was the case in Ankaful, few people have work and most are receiving food support from the Catholic Church. On a positive note, the government of Ghana has registered all persons affected by leprosy under the national health insurance scheme, so that they can access health care without payment for services received.

MOZAMBIQUE (MARCH 11-12)

From Ghana I traveled via South Africa to Mozambique. This was my fifth visit to the country since 2005, when I began making regular visits in support of its leprosy elimination activities. Mozambique reached the WHO's elimination target of less than 1 case per 10,000 population at the national level in 2007. At the time, Health Minister Dr. Ivo Garrido said there would be no cause for celebration until this goal was reached at the state level too. This was duly achieved at the end of the following year.

After arriving in the capital, Maputo, I had meetings in the afternoon with Prime Minister Aires Ali, who assumed the post in January, and Vice President of the Assembly of the Republic Lucas Chomera. Accompanying me were Dr. El Hadi Benzerroug, the WHO's Mozambique representative, and Dr. Landry Bide of the WHO Regional Office for Africa. I congratulated the country's leaders on Mozambique's achievement of elimination and sought their cooperation

Scene from the partners' meeting in Maputo

in further reducing the number of cases of the disease. Later I met with former President Joaquin Chissano, whom I have known for many years through the Sasakawa Global 2000 Project to increase agricultural output.

On March 12 there was a partners' meeting at the Ministry of Health attended by representatives from six NGOs involved in leprosy work as well as ministry and WHO officials. From the NGO side were Dr. Charles Phaff, Netherlands Leprosy Relief; Ms. Genama Salvetti, AIFO; Dr. Jean Marie Nyambe, Damien Foundation; Mr. Candido Raphael, LEPRA UK; Mrs. Farida Gulamo, ADEMO; and Mr. Chamada Abibo, ALEMO — the latter having traveled from the very north of the country to attend.

Following the meeting, Health Minister Garrido gave a briefing on the current leprosy situation in the country in the presence of some 10 reporters from newspapers and TV. I learned that while leprosy has been eliminated as a public health problem in every state, the prevalence rate remains above 1 per 10,000 population in inland areas in a number of states. However, Mozambique is aiming to achieve elimination in every district while halving the number of patients in each district. Dr. Garrido said he would continue to lead these activities and carry on holding an annual meeting of all those concerned with leprosy work.

Concerning the situation in the north of the country, where there are still many cases, he said, "We cannot deal with leprosy simply as a problem of the poor. There must be a reason why certain areas have a high number of patients. We must analyze the situation and take appropriate steps."

In looking at Mozambique's achievement in eliminating leprosy as a public health problem, it is clear that political commitment has been most important. Soon after assuming his post, Health Minister Garrido indicated what must be done. He put the appropriate policies in place and, thanks to the determined efforts of the ministry, the WHO, and all the partners involved, achieved the desired result. I commend all who made this possible, despite limited manpower and funds, by dint of their persistent, patient work.

But the fight against leprosy is by no means over. As has been seen in other countries when elimination has been achieved and the number of leprosy cases declines, there is the very real fear that as leprosy comes to assume the status of a rare disease, medical workers become less aware of it, resulting in delayed diagnosis and treatment. Therefore, there must be no slackening off. Until the disease is completely eradicated, until the very last patient is treated and cured, appropriate diagnosis and treatment services must be sustained. To do this, the health services must continue to train health care workers to recognize and correctly diagnose leprosy.

Socio-economic inclusion is another key item that remains on the agenda.

The socio-economic inclusion of people affected by leprosy is another key item that remains on the agenda. In terms of discrimination against people affected by leprosy, Mozambique is no exception. In towns and cities especially, there are said to be many affected persons whose only recourse is to beg as they can't find jobs. Given Mozambique's economic situation, it is difficult to call for work for every affected person; but at the very least, people capable of working should not be denied the opportunity on the grounds that they once had leprosy.

Until the day comes when not just the disease but also the associated discrimination are eradicated and Mozambique is truly free of leprosy, the health ministry, the WHO and all NGOs involved must continue to work together closely. I intend to play my part and look forward to visiting Mozambique again in support of these efforts. ■

Leprosy FACT

- Of 538 new cases reported in Ghana in 2009, 16 (2.7%) presented with Grade 2 disability, and 34 (6.07%) new cases were children.

India Looks to Fill Gaps

Shortage of program personnel prompts action

Concerned about the shortage of program personnel in the National Leprosy Eradication Program, India's Ministry of Health and Family Welfare has instructed states to fill vacancies in the NLEP during program review meetings attended by the State Health Secretaries and Program Managers.

According to reports, only nine states — Andhra Pradesh, Gujarat, Goa, Jharkhand, Karnataka, Kerala, Orissa, Tamil Nadu and West Bengal — have dedicated leprosy officers in place. At the district level, 116 posts out of 311 posts in 523 districts in 20 states are vacant.

At the beginning of 2009, there were 86,331 registered cases of leprosy in India, or a prevalence rate of 0.72 per 10,000 people at the national level. For the year 2008, a total of 134,184 cases were detected.

WHO LEPROSY FACT SHEET

An updated leprosy fact sheet has been published in the *Weekly Epidemiological Record* (No.6, 210, 85). The fact sheet notes that the global burden of leprosy has declined dramatically, from 5.2 million cases in 1985 to 805,000 in 1995 to 793,000 at the end of 1999 to 213,036 cases at the end of 2008.

In order to reach all patients, treatment of leprosy needs to be fully integrated into general health services, "the key to successful elimination of the disease," the document says.

Concerning the age-old stigma attached to leprosy, which remains an obstacle to self-reporting and early treatment, the image of leprosy "has to be changed at the global, national and local levels," it says. "A new environment, in which patients will not hesitate to come forward for diagnosis and treatment, must be created."

IDEA 'DAY OF DIGNITY'

IDEA (Integration, Dignity, and Economic Advancement) celebrated its 12th annual International Day of Dignity and Respect on March 11. The event, which was established in 1999 to focus on the dignity inherent in every human being, was marked by activities conducted by members of the IDEA network in different countries around the world. ■

FROM THE EDITORS

INCLUSIVE DEVELOPMENT

Over the past two decades, more than 14 million people have been cured of leprosy. However, it is estimated that there are more than 2 million people in the world who have disabilities resulting from the disease. Another 2 million are thought to have loss of sensation in their hands and feet, putting them at risk of developing impairment.

People diagnosed with leprosy still face discrimination. For those with disabilities, the discrimination can be especially pronounced, compounded by the misconceptions and misrepresentations that continue to surround the disease. Yet the disabilities associated with leprosy are not unique. And people with disabilities, whatever their cause and condition, are still people.

The long-awaited WHO guidelines on community-based rehabilitation (CBR) that are to be launched this autumn in Nigeria (see p. 2) are aimed at all persons with disabilities, including people affected by leprosy and their families. There will even be a supplementary chapter on leprosy and CBR.

The new guidelines are based on the notion of community-based inclusive development. In this model, all benefit from development initiatives, all live in the community with choices equal to others, all enjoy equal human rights and all live with dignity.

The WHO's Chapal Khasnabis, who has worked long and hard on preparing the guidelines, has described them as "new CBR for a new millennium". He is keen to stress their relevance and applicability to people affected by leprosy and their families, and is anxious for people affected by leprosy to seize the opportunity that the new guidelines provide.

For that to happen, leprosy needs to be part of the disability movement, he says. Otherwise, leprosy will remain in isolation, "a social puzzle," and the pace of change will be slow.

FOR THE ELIMINATION OF LEPROSY

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