LEPROSY
Learning from success
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A disease, shrouded for centuries in stigma and shame, could now come out into the open with a fresh new face: hard to catch, easy to cure. A new era in the age-old fight had begun.

Of all the diseases that continue to plague humanity, leprosy has the most notorious history as a cause of deformity, disability, loathing and fear. From ancient times until the recent past, the disease was considered both highly contagious and impossible to cure. Victims were universally shunned, their physical suffering compounded by the misery of being treated as social outcasts. Even at the medical level the sole option for control was the isolation of patients in colonies or leprosaria. As recently as 1897, an international conference of experts concluded that leprosy could not be cured.

All that would change within the short span of a few decades, slowly at first, and then with thrilling speed. The initial breakthrough came with the discovery of dapsone in 1941, introducing the first prospects for cure. Within eight years, the drug's suitability for use in mass campaigns was clear. Countries now had an option: patients could be treated and cured, often in their homes, rather than banished to institutions. Treatment was, however, lifelong in most cases. The spread of resistance to dapsone, which first appeared in 1964, put an end to the hope that leprosy might be defeated.

Science responded to this setback by stepping up its quest for a better tool. Results came in 1981 when a WHO group of experts issued its recommendations for an unbeatable cocktail of drugs: multidrug therapy, with rifampicin and clofazimine bolstering the original dapsone. The results were spectacular. Treatment could be reduced from decades to a matter of months. The drugs were so safe they could be taken by pregnant women. Patients under treatment quickly lost the ability to infect others. Disabilities could be prevented by early detection and complete cure.
The number of cases plummeted. Progress was so impressive that, in 1991, government delegations at WHO’s World Health Assembly resolved to eliminate leprosy as a public health problem by the end of the century. The international community, notably the Nippon Foundation, came forward with generous financial support.

Control programmes could now begin to reach the remaining pockets of disease—in sprawling urban slums and remote village dwellings—with an offer of cure that was not only safe and effective, but also free. Another major logistical boost came in 1998 when a WHO group of experts announced innovations that vastly simplified leprosy control, reduced its costs, and pushed the world dramatically closer to the goal of forcing leprosy to disappear.

The momentum continued to swell in 1999, when WHO formed a global alliance of partners determined to see leprosy eliminated by the year 2005. Members include representatives of countries where the disease remains a problem, Danish International Development Assistance, the International Federation of Anti-Leprosy Associations, the Nippon Foundation, Novartis and the Novartis Foundation for Sustainable Development, WHO and the World Bank. The partnership aims specifically to bring down the number of cases to a level so low that natural interruption of transmission will occur.

As the stories that follow show, the straightforward WHO blueprint for leprosy elimination is flexible as well as effective. Elimination programmes have been smoothly implemented in countries having a host of distinct problems and dramatically different health systems.

Using the recommended WHO strategy, even an extremely poor country like Burkina Faso has been able to reach all of its people with the best drugs and treatment protocols the world has to offer.

And, as one country after another has learned, the best the world has to offer works extremely well to produce swift and spectacular results. Venezuela, which had one of the worst leprosy problems in all of Latin America just 15 years ago, eliminated leprosy in 1997. Viet Nam, which has suffered from leprosy since at least the 6th century and had pockets of disease where an astonishing 30% of the population were affected, reached the elimination goal in 1995.

Thailand, where leprosy was once the rampant and dreaded “disease of social loathing”, fully integrated control activities into its general health services, brought treatment close to people’s homes, and vanquished the disease in 1995.
In Togo, procedures for diagnosis and treatment, firmly entrenched at the local and district level, proved tough enough to withstand years of political turmoil. The elimination of leprosy was proudly announced in 1997.

A mass public awareness campaign in Sri Lanka virtually eliminated the stigma attached to leprosy, encouraging people who previously hid their symptoms out of fear of ostracism to come out in the open for early diagnosis and cure. Leprosy was eliminated in 1995. Benin, a small country distinguished by its very large number of leprosaria, also used a fully integrated approach to reach elimination in 1997. The doors of its many leprosaria are now reopened as health centres serving the general population.

Taken together, these country experiences clearly demonstrate the decisive power of commitment and determination to bring victory, even under circumstances that are far from ideal. With the support of presidents, prime ministers, kings, well-trained and motivated health staff, generous donors and dedicated voluntary groups, leprosy can—and will—be completely vanquished from our world. And very soon, too, for a disease that has been one of humanity's oldest and most notorious foes.

There is no doubt that the use of improved technologies such as multidrug therapy, added to the possibility of cure, is producing positive changes in public attitudes to leprosy and leprosy patients.

- WHO Expert Committee, 1988
The great promise that dapsone would cure leprosy and lead to its control prompted the Ministry of Health of Sri Lanka to introduce the country’s first antileprosy programme in 1954. Patients, banished to asylums since the 17th century, could now be treated in special clinics. Government-trained paramedicals were appointed to conduct surveys and information campaigns in villages and local communities, resulting in a three-fold increase in case detection. But treatment took decades, dapsone resistance emerged, and progress proved slow and fragile.

As elsewhere, the breakthrough came with the advent of multidrug therapy, which was introduced in Sri Lanka in 1983. Although all registered cases were receiving treatment within the short span of a year, transmission continued at a disturbing rate, making it clear that many hidden cases were not being reached. Active case detection via house-to-house searchers was considered far too expensive and, moreover, might actually increase the fear and stigma attached to the disease.
The government looked for another solution.

This came in 1990 when the Ministry of Health, assisted by a Swiss charity organization and the Novartis Foundation for Sustainable Development, launched a professional, powerful, and broad-based advertising campaign aimed at nothing less than changing the public image of leprosy. By portraying leprosy as just another treatable disease, the campaign hoped to motivate people with suspicious lesions to come forward for early diagnosis and free cure. Apart from being much less costly, such “passive” case detection, with its reliance on self-reporting, attracted strongly motivated patients who could be counted on to follow treatment carefully.

The campaign was launched in February 1990 on a big scale—and in big-time fashion. Messages were beamed to the masses via radio and TV spots, serials, and popular soap operas. Billboards, buses, and walls were plastered with positive slogans and images. Collaboration at the grassroots level was secured through health education training for close to 5 000 carefully selected opinion-leaders, teachers, and village women. Letters and health education materials were sent to the nation’s clergy. School-teachers were provided with flip charts to help them get the word out to children. In remote areas beyond the reach of radio and TV, week-long education sessions were held and supported by “skin camps”, which combined leprosy detection activities with the lure of free treatment for skin ailments.
But motivation to seek treatment was only part of the goal. The campaign also aimed to make sure that patients seeking treatment would find it easily, close to home, and of the best quality. The country doubled the number of clinics and extended their opening hours. Pocket calendars giving district clinic schedules were distributed to residents to improve clinic attendance and facilitate referrals. Blister packs were introduced to simplify the dispensing of medicines and improve patient compliance. As an added benefit, they also created the impression that a new treatment was available, thus bringing excitement and immediacy to the good news that leprosy could be cured.

The links between the leprosy control services and the general health services were improved. All primary care staff, medical officers working in hospital outpatient departments, and medical staff on plantations were given special training to increase their diagnostic and treatment skills. Since many patients, hoping to avoid stigma, preferred to consult private practitioners, the country’s general practitioners were also reached with information on how to diagnose and treat the disease. Collaboration with the private sector was further secured by donating blister packs to dermatologists, who provided statistics on their patients in return.

The results were spectacular.

In less than a year, case detection had increased by 150%. Even more impressive was the vast increase in self-reporting. While in the year prior to the campaign, only 9% of new cases were self-reported, the figure rose to 50% by 1991 and has remained high in subsequent years. Since the start of the campaign, more than 20 000 patients have been detected and treated. Awareness of the first signs of leprosy and the availability of a cure is now widespread. The image of leprosy has moved from one of fear and loathing to one of hope and cure.

With greater self-reporting and strengthened services, Sri Lanka was gradually able to clear the backlog of cases and reduce the pool of infection.
In 1995, the national prevalence rate dropped below 1 per 10,000 population, meeting the WHO definition for the elimination of leprosy as a public health problem. As the number of new cases is expected to continue to decrease, the vertical programme that made leprosy elimination possible has been reoriented. Leprosy control activities are now fully integrated into the general health services, which are competent, equipped, and motivated to maintain the country’s triumph over leprosy.
At the start of the 20th century, leprosy was a rampant and dreaded disease in Thailand. Social attitudes were strongly coloured by the religious notion of leprosy as an incurable disease brought on by sinful acts—an unclean affliction. Even among health workers, leprosy was known as “the disease of social loathing.” Healthy people wanted patients kept at a distance. Isolation and segregation were the main method of control, and many leprosaria were established to care for patients.

In 1953, the largely vertical national leprosy control programme was launched. That same year, a random survey produced alarming statistics: around 140,000 cases and a prevalence rate of 50 per 10,000 inhabitants. Treatment with dapsone began in 1955 when the country introduced a modern control programme based on case finding, health education, and domiciliary treatment. Activities were carried out in provincial leprosy units. With this system, close to 80% of the detected cases were eventually treated. By 1971, the prevalence had declined from 50 to 12.4 per 10,000 population.
A major change came when the country unveiled its Third National Health Development Plan covering the period 1972–1976. The plan called for the dismantling of the vertical programme and the integration of leprosy control activities into provincial primary health care services. Appropriate training was provided, information systems were developed, and 10 regional leprosy control centres were established to supply technical guidance and support.

At the end of 1976, partial integration of leprosy services had been achieved in all but six highly endemic provinces, where the vertical system of control was maintained.

Coverage reached 89% of the total population.

Integration brought other advantages as well. By avoiding the suspicions and stigma aroused by attendance at special clinics, it encouraged patients to seek treatment at an early stage. It also allowed patients to be treated closer to home, thus facilitating the continuity of care. Moreover, since leprosy control activities in general health services are less dependent on donors, they are easier for governments to sustain.

In line with WHO recommendations, multidrug therapy was introduced in 1982, largely in response to the spread of dapsone resistance, and was initially confined to three hyperendemic provinces.
Progress was so impressive that the government began a drive to extend coverage to the entire country—a process that was greatly facilitated by the integrated infrastructure. The dramatic cure rates and the drastic reduction in the duration of therapy brought an added bonus: costly and time-consuming registration procedures could be vastly simplified.

By 1989, multidrug therapy had completely replaced dapsone monotherapy.

The decline in the number of cases accelerated. Leprosy was clearly in retreat. The government stepped up its drive to defeat the disease and to further reduce the stigma that kept victims from seeking care until it was too late. Thailand’s highly revered king, Bhumibol Adulyadej, established a leprosy foundation and urged the public not to treat victims as outcasts. By 1995, the prevalence of leprosy had been reduced from the mid-century high of 50 per 10,000 population to below 1 per 10,000. Thailand had reached the goal of eliminating leprosy as a public health problem.

While support from nongovernmental organizations played a major role in this achievement, the decisive factors were sound technical guidance from WHO and strong determination on the part of the government, which showed persistence in mastering new problems with population-wide solutions. As in many developing countries, leprosy had exacted a heavy economic toll in Thailand owing to the costs associated with permanent and progressive disabilities, loss of productive work force, and the utter social and economic destitution that was so often the lot of patients and their families.

A strong tenet of the Buddhist faith is its compassion and mercy for those who are less fortunate. In Thailand, where staunch government commitment was backed by dedicated NGO support, compassion and mercy prevailed to banish this “disease of social loathing” not to another sanatorium, but to the past.
By 1995, the prevalence of leprosy had been reduced from the mid-century high of 50 per 10,000 inhabitants to below 1 per 10,000 population.
The history of leprosy elimination in Burkina Faso, one of the world’s poorest countries, provides proof that the disease can be conquered despite poverty, high rates of illiteracy, a fragile economy, drought-prone terrain, and a population that migrates to neighbouring countries in search of seasonal work. The country registered its peak number of cases in 1965, when 140 000 patients were recorded. For two decades, control relied on dapsone monotherapy with all its imperfections.

With the advent of multidrug therapy, the government looked to WHO for advice on the best way to bring the benefits of this spectacular new tool to its people. Proverbs are popular in this rural country and one favourite piece of folk wisdom carried very good advice for leprosy control: “Don’t test the depth of a river with both feet”. In 1983, Burkina Faso introduced multidrug therapy on a pilot basis, testing the ability of health services and staff to meet the WHO strategy of early case detection and complete cure of patients. That river proved so shallow and easily crossed that the country’s leprosy control activities began moving with both feet—on the run.
Guided by WHO’s technical recommendations and with the support of dedicated nongovernmental organizations, the government developed a plan to extend coverage with multidrug therapy to the entire population. The plan also included precise measures for ensuring that staff would be adequately trained, supervised and monitored, that the necessary laboratory backup services would be available and functioning properly, and that the drugs would be readily accessible and correctly dispensed. Since the country could never afford active case detection, patients would need to be lured to health centres by the prospect of first-rate care.

The country set up a well-organized and determined leprosy control programme characterized by a strategy of training, supervision, data collection and reporting that took centrally-agreed procedures to the provinces, and then to the peripheral areas. Health workers received local training in diagnosis and treatment. Laboratory technicians, centrally trained and supervised by specialists, became experts in the confirmation of diagnosis and monitoring of treatment response.

The national programme supervised work at the provincial level every 6 months; supervisors from the provincial services then fanned out to check work in peripheral areas every 1–3 months. Data on registered cases and results were compiled at the peripheral level on a monthly basis and reported to the provincial services. Consolidated reporting to the national level took place quarterly.
The low level recorded in 1994 had been maintained, and Burkina Faso joined the ranks of countries that have reached the goal of leprosy elimination.
This decentralized structure was further solidified in 1990, when the national programme appointed health directors for each province and provided training in the elaboration of a provincial plan of action. Thorough training allowed decentralization of authority to the provincial level, where health directors were given full responsibility for situation analysis, priority setting, planning, and budget management. One unexpected outgrowth of this provincial “ownership” was the creation of fierce competition between directors, who struggled to outdo each other with the best plan for efficient management and good results.

The structure was remarkably effective.

Coverage with multidrug therapy soared. In just 11 years, the prevalence rate plummeted from more than 40 per 10 000 inhabitants in 1983, to less than 1 per 10 000 in 1994. In 1991, the country reached another milestone: the carefully maintained reporting system revealed that 100% of all registered patients were receiving modern treatment. Most importantly, the number of newly detected cases declined from 3 per 10 000 inhabitants in 1985 to less than 1 per 10 000 in 1993, offering good evidence that the pool of infection was shrinking.

In 1997, the prevalence rate dipped down to 0.76 per 10 000. The low level recorded in 1994 had been maintained, and Burkina Faso joined the ranks of countries that have reached the goal of leprosy elimination. Though constant vigilance is required to maintain geographical coverage, the country’s health services are blessed with well-trained and motivated staff who are proud to have achieved so much in a setting where so few resources are the norm. In this final stage of vigilance, Burkina Faso’s fund of folk wisdom again has pertinent advice: “When you fall, look where you slipped, not where you land”. It may be something of this mentality that explains why one of the world’s poorest countries never stumbled for long—whether at the level of central planning or in the performance of local health workers—in its steadfast determination to see leprosy defeated.
In 1961, Togo had over 31,000 registered leprosy cases, making the disease one of the country’s most important public health problems. A determined effort to combat leprosy began in 1967, when case control activities based on dapsone monotherapy were rigorously implemented. Mobile teams mounted on bicycles and mopeds combed the country for cases and quite literally delivered the drugs to the doors of patients’ homes. The programme was remarkably successful. During the dapsone era, over 26,500 cases were detected and treated, and large numbers were cured.

When the great promise held out by multidrug therapy appeared, the country had a good base to build on. Apart from the success with dapsone and the growing perception in communities that leprosy could be treated and cured, Togo had an excellent infrastructure for the introduction of multidrug therapy into general health services. The population was blessed with relatively easy access to health services, and qualified personnel existed throughout the whole country.