

INSTITUTE OF MEDICINE

Shaping the Future for Health



ENDING NEGLECT

THE ELIMINATION OF TUBERCULOSIS IN THE UNITED STATES

It is said that opportunity knocks only once. But when it comes to the opportunity to eliminate tuberculosis in the United States, we have been given a second chance. If the country now fails to seize this moment, the losses—in terms of both health and economics—are certain to be great.

Tuberculosis (TB) is an infectious disease caused by a type of bacteria called *Mycobacterium tuberculosis*. TB is spread from person to person through the air, as someone with active tuberculosis of the respiratory tract coughs, sneezes, yells, or otherwise expels bacteria-laden droplets. When inhaled by another person, some of these invaders can go on to establish sites of infection throughout the body.

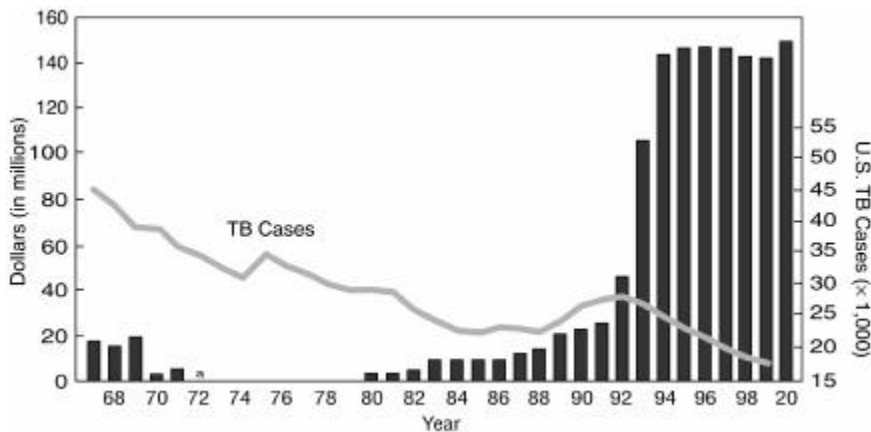
TB has plagued humanity since before recorded history, and it remains the leading infectious cause of death worldwide—even though the disease is both preventable and, in most cases, treatable. In the United States, tuberculosis had been brought under tighter control by the 1960s, thanks to improving social and economic conditions, as well as the development of effective drugs. At that time, the prevalence of TB had been reduced greatly, and its occurrence had been confined to small geographic pockets. As a result, public health experts renewed calls—first issued in the 1930s—to develop a comprehensive plan for eliminating tuberculosis in the United States by the 1980s.

However, none of these calls was heeded. On the contrary, federal funding specifically targeted for TB was eliminated, and prevention and control efforts at all levels of government were reduced if not dropped entirely.

The price of this neglect was a nationwide resurgence of TB by the mid-1980s. Particularly troubling was the appearance, for the first time, of cases of ‘multidrug-resistant’ tuberculosis, which is difficult and costly to treat, at best, and often proves fatal. In addition to claiming more lives, the resurgence also exacted an economic price—in New York City alone, for example, the monetary cost of losing control of TB proved to be in excess of \$1 billion.

Faced with this increasingly troubling situation, federal, state, and local governments again increased their tuberculosis control activities. Beginning in

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1992, the decline of TB resumed, and all-time lows in both the total number of cases and the number of new cases diagnosed annually have been achieved.

Remarkable success, indeed. But the issue now confronting the nation is whether we will allow another cycle of neglect to begin or, instead, whether we will take decisive action to eliminate tuberculosis. History is clear about the

consequences of not acting: The incidence of TB, including multidrug-resistant tuberculosis, will rise, more lives will be lost, and it will be both more difficult and more expensive when we are next forced to take action.

Tuberculosis funding, Centers for Disease Control and Prevention, Fiscal Years 1960–1993. NOTE: During Fiscal Years 1972–1982, categorical grants ceased; funds to states were in block grants not specific for TB.

Source: CDC and OTA

What Can Be Done

The Institute of Medicine (IOM), an arm of the National Academy of Sciences, released a report in May 2000 that lays out an action plan for eliminating tuberculosis in the United States. (Elimination is defined as an incidence rate of less than one TB case per 1 million persons per year.) Called *Ending Neglect*, the report details a number of intertwined steps that involve all levels of government, as well as the private sector. If all parties will join in implementing this plan, its goal is well within reach.

As a key part of the plan, new TB treatment and prevention strategies must be developed that are tailored to the current environment. Among today's hallmarks:

- Tuberculosis now occurs in ever-smaller numbers in most regions of the country.
 - Higher numbers of cases are concentrated in pockets located in major metropolitan areas, and this increased prevalence is due, in large part, to the increased number of people with or at risk for HIV/AIDS infection.
 - Foreign-born people (both legal and undocumented immigrants) coming to the United States from countries with high rates of TB now account for nearly half of all TB cases.
 - Other groups, such as HIV-infected people and the growing population of prison inmates, the homeless, and intravenous drug abusers, are emerging as being at high risk.
 - And, finally, the private sector—especially through managed care organizations—is becoming increasingly involved in TB treatment and prevention.

While implementing intensified, carefully designed control programs will help increase the current annual rate of decline in TB cases, more is needed. Eliminating tuberculosis will require accelerated research and the development of new tools. Fortunately, the recent mapping of the entire genetic code of the bacterium that causes TB sets the stage for important advances.

Given the global face of tuberculosis, the United States also must increase its engagement with other nations' efforts to control the disease—for both altruistic reasons and to help reduce the total “reservoir” of infection. Such efforts should include participation in multilateral projects with many countries, as well as in bilateral projects with particular countries that have high rates of TB infection or that present special circumstances regarding the influx of foreign-born people.

Underlying these steps, there must be a concerted effort to build and sustain the public and political support necessary to ensure that sufficient resources are made available for what must be a long-lasting effort. As the number of TB cases declines, such “social mobilization” by countless groups and individuals may be all that prevents a shift of attention and resources to other perceived needs—and thus all that prevents the onset of yet another period of neglect.

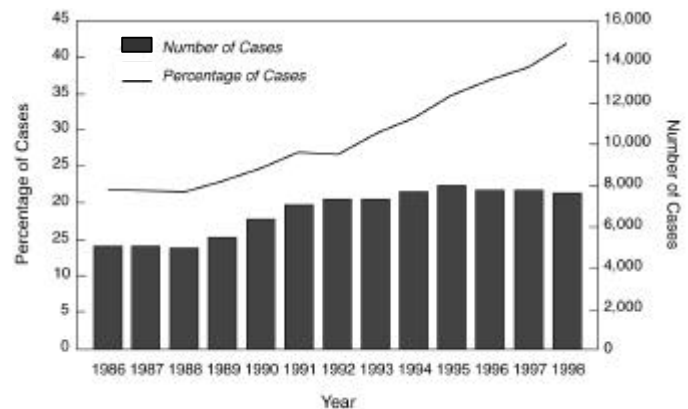
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The Federal Role

In many ways—and perhaps most notably in terms of financial support—the federal government should set the pace in fostering efforts to manage and prevent tuberculosis. The IOM report identifies a number of areas in which the federal government could take action. To list a few:

- **Provide adequate “categorical” funding that is targeted specifically at tuberculosis.** Categorical funding for tuberculosis, at least at the federal level, is needed to ensure that the disease is not neglected. In the years since 1995, the peak funding year, federal support for TB control has been essentially flat at approximately \$140 million annually. When adjusted for inflation, the current level of support actually reflects the equivalent of a 15 percent reduction from the peak spending.

- **Develop targeted programs that use skin tests to detect “latent” tuberculosis.** One program should focus on skin testing immigrants from countries with high rates of TB as part of the visa application process that occurs prior to arrival in the United States. Individuals found to have latent infection (infection in individuals who do not have any symptoms but ultimately may develop active disease) should be required to complete an approved course of treatment, in the United States, before they will be granted their Alien Registration card, or “green card.” Skin testing, coupled with treatment of latent



Trends in tuberculosis cases among foreign-born people in the United States (the 50 states, the District of Columbia, and New York City), 1986–1998.

Source: CDC

It is estimated that a person with a new case of TB comes in close contact with approximately nine other individuals while infectious, and that, on average, three of those contacts will become infected.

infection, also should be required for all inmates of correctional facilities, and testing and treatment programs should be increased for other high-incidence groups, such as HIV-infected people, the homeless, and intravenous drug abusers.

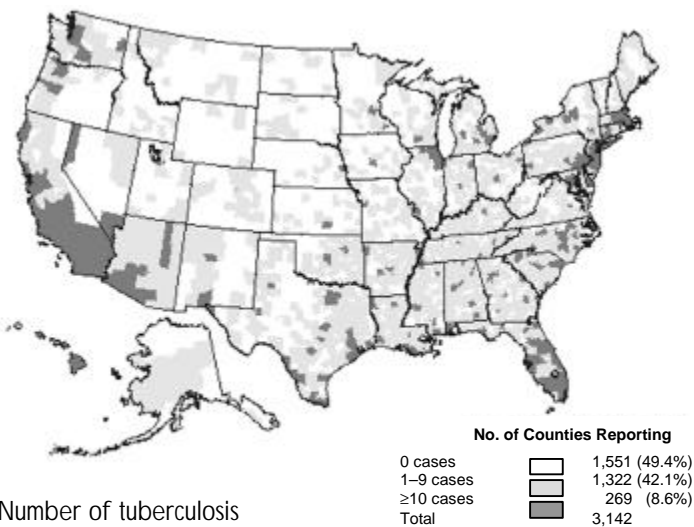
- **Develop more effective methods to identify people who have been exposed to new cases of tuberculosis.** It is estimated that a person with a new case of TB comes in close contact with approximately nine other individuals while infectious, and that, on average, three of those contacts will become infected. Thus, the examination of contacts is one of the most important ways of identifying and treating people who have latent infection or who have progressed to active disease. As cases of TB have retreated, in large measure, into defined pockets—for example, in big cities and among people who engage in high-risk behaviors—it is becoming increasingly necessary to modify traditional contact-tracing methods in order to address the specific circumstances of these vulnerable populations.

- **Expand research programs.** To support the necessary research, the federal research budget should be roughly tripled (to approximately \$280 million annually). One of the greatest needs is to devise better tests to diagnose latent TB infection and to identify individuals who are at greatest risk of developing active tuberculosis. From a global perspective, perhaps the most compelling need is to develop improved TB vaccines. To advance this work, the plans outlined in the *Blueprint for Tuberculosis Vaccine Development*, published by the National Institutes of Health (NIH) in 1998, should be fully implemented. Expanded research on new diagnostics, new drugs, and on social science issues is also essential.

- **Promote the regionalization of tuberculosis services.** As the incidence of TB declines, it makes sense to invest limited resources in public health units and other facilities that serve larger geographic areas. This cooperation may bring to-

gether several jurisdictions within a state, or bring together several states, to provide better access to and more efficient use of clinical, epidemiological, and other technical services. The federal Centers for Disease Control and Prevention (CDC) can facilitate such regionalization by conducting pilot programs in conjunction with states, as well as by maintaining experienced personnel who can provide back-up during outbreak situations and complex investigations within a particular area.

- **Support national training programs.** Much of the current success in tuberculosis control is due to the presence of experienced personnel, especially in public health departments, who not only carry out their duties but also transfer their knowledge to less experienced staff. But as TB cases decline in number, there will be fewer such experts to contribute to the system's "core competency," particularly in assessing and managing



Number of tuberculosis cases reported, by county, 1998.

Source: CDC

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difficult diagnostic or treatment issues. One direct solution to this problem is increased training of health care providers, especially in the private sector, in the management of tuberculosis. A blueprint for developing and conducting such activities is available in *the Strategic Plan for Tuberculosis Training and Education*, released in January 2000 as a joint project of the CDC and the National Tuberculosis Centers. This plan should be fully funded and implemented. Among its recommendations, the plan calls for special training efforts to be focused on physicians serving the impoverished and new arrivals to the United States.

- **Develop educational programs for tuberculosis patients and their significant others.** Although the populations at greatest risk for tuberculosis infection have been identified, behavioral studies are still needed to clarify such vital issues as how to tailor interventions for each group and how to improve the adherence of TB patients to therapy.

- **Encourage businesses to develop tuberculosis-related products.** Although some companies already participate in this market, many firms have been reluctant to take part. To foster additional development efforts, federal agencies should support a number of “seed grant” projects that will encourage companies, both small and large, to undertake the translation of basic scientific knowledge generated in public laboratories into promising commercial products. Agencies also should take the lead in identifying the global market for TB diagnostic kits, drugs, and vaccines, and should take steps to facilitate access to these markets.

- **Strengthen the U.S. role in global efforts to control tuberculosis.** The government should contribute to these efforts through targeted use of financial, technical, and human resources, as well as through expanded research efforts. In particular, the government should continue its active role and support of the Stop TB Initiative, a partnership hosted by the World Health Organization. To guide such global involvement, the U.S. Agency for International Development, the NIH, and the CDC should jointly develop and publish strategic plans.

The State and Local Role

While the federal role in managing tuberculosis is vital, often it is at the state and local levels that funding is translated into programs, programs are put into practice, and practice results in improved health for countless people. Thus, the IOM report identifies a number of steps that state and local governments and agencies should take. For example:

- **All states should ensure that adequate resources are available for tuberculosis control and prevention, even as TB cases in their regions decline.** States should work with the CDC to develop protocols that public health departments can use to assess their resource levels. To maximize their resources available for supporting TB programs, states should take advantage of a 1993 amendment to the Medicaid Act that allows them to obtain Medicaid funding for low-

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income people who test positive for tuberculosis, and they should more aggressively bill private insurers to offset costs for TB diagnostic and treatment services, including directly observed therapy to ensure that patients comply with prescribed treatments.

- **Many public health departments should integrate tuberculosis control with other programs.** Such merged efforts can include incorporating TB reporting and surveillance with similar activities involving HIV/AIDS, and integrating TB contact investigations into the job descriptions of staff members who contact the partners of individuals who have a sexually transmitted disease. The departments also should support and participate in efforts to develop regionalized laboratory, training, and other facilities—a process that often will require the identification and elimination of bureaucratic obstacles that stand in the way of resource sharing.

- **Where cost effective, public health departments should hire private providers to supply tuberculosis services.** The departments should develop well-designed contracts that specify providers' performance measures and responsibilities, but it will remain the departments' responsibility to ensure, by monitoring on a case-by-case basis, that patients are receiving appropriate treatment.

- **Health agencies should require completion of therapy (completion to cure) for all patients with active tuberculosis.** The agencies also should ensure that all treatment is administered in the context of patient-oriented programs that are based on the individual patient's circumstances.

- **Health agencies should expand their activities to treat latent TB infection.** Such programs often will require close collaboration with organizations, such as community groups and neighborhood health centers, that already provide medical care to the infected individuals, who typically have other health problems as well.

- **All public health departments should evaluate their performances regularly.** Evaluation should be done using the new program standards being developed by the CDC. To aid in evaluation, the departments should develop standardized, flexible case-management systems that are designed to meet local, state, and federal data needs, and that will yield the information needed to ensure that all patients are receiving care of a uniformly high quality. Such evaluation tools will become increasingly important as the level of staff experience becomes more unpredictable.

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The Private Role

Nongovernmental organizations also have important contributions to make, as the IOM report identifies.

For example, private foundations often can fill a crucial catalytic niche in many realms of medical research. In particular, these funders can move quickly to address new needs, undertake higher-risk projects that hold potential for high

payoffs, and test novel funding mechanisms that may serve as a model for other private or public funders. For now, though, private support for tuberculosis research remains limited, especially in light of the scope of the problem. However, the recent announcement by the Bill and Melinda Gates Foundation of a 5-year, \$25 million grant for TB vaccine development may signal new interest in tuberculosis research among foundations.

Nongovernmental organizations also are well situated to collaborate with international partners in developing training and educational materials related to disease management.

But private organizations may prove most valuable by energizing social mobilization to increase public and political support for tuberculosis control programs. In a notable example, the American Lung Association, with support from the Robert Wood Johnson Foundation, established in 1991 the National Coalition for the Elimination of Tuberculosis (NCET). The coalition is credited with playing a major role in bringing about the next year's significant increase in federal support for TB control. The challenge now facing NCET is to expand its partnerships at the federal, state, and local levels, as well as with nontraditional partners, in order to accelerate social mobilization. Other nongovernmental organizations also should support the coalition's efforts and help in advocating for the additional resources needed to advance toward the elimination of tuberculosis in the United States.

For More Information . . .

Copies of *Ending Neglect: The Elimination of Tuberculosis in the United States* are available for sale from the National Academy Press; call (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area), or visit the NAP home page at www.nap.edu. The full text of the report is available on line at www.nap.edu/readingroom.

For more information about tuberculosis, visit www.nationalacademies.org/includes/tb.html.

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