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EMERGING INFECTIOUS DISEASES

National Surveillance System Could Be Strengthened

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Emerging Infectious Diseases: National Surveillance System Could Be Strengthened

Mr. Chairman and Members of the Subcommittee:

We are pleased to be here today to discuss our report on public health surveillance of emerging infectious diseases, which you are releasing today.[1] As you know, the spread of infectious diseases, once a problem thought to be largely under control, remains a serious public health threat. While some diseases are controlled through the use of antibiotics, new ones, such as AIDS, are constantly emerging and others, such as tuberculosis, re-emerge in drug-resistant forms. Surveillance—the monitoring of infections to identify them and their source—is essential to public health efforts to control or prevent the spread of infectious diseases. Recently, many experts have voiced concerns about the adequacy of our nation's surveillance, particularly for antibiotic-resistant diseases.

In light of these concerns, we examined the nation's surveillance system, with a focus on the role of laboratories. New technology makes laboratories increasingly important in identifying pathogens, patterns of antibiotic resistance, and sources of outbreaks. In my remarks today, I will describe the nation's surveillance network—which includes public health agencies, private health care providers, and laboratories—and the extent to which states conduct surveillance and laboratory testing of six emerging infections.[2] I will also discuss the problems state public health officials face in gathering and using laboratory-related data in surveillance and the views of state officials on the assistance that the Centers for Disease Control and Prevention (CDC) provides for surveillance. For two of the six infections we studied—*Streptococcus pneumoniae* and tuberculosis—antibiotic-resistance is a concern. My statements today are based on data we gathered through nationwide surveys of state public health laboratory directors and epidemiologists[3] and from information provided by health officials and experts in 30 states and at CDC.[4]

[1]Emerging Infectious Diseases: Consensus on Needed Laboratory Capacity Could Strengthen Surveillance (GAO/HEHS-99-26, Feb. 5, 1999).

[2]The six diseases or pathogens we studied are tuberculosis, virulent strains of *E. coli* that produce Shiga-like toxin and include *E. coli* O157:H7, pertussis (whooping cough), *Cryptosporidium parvum*, hepatitis C virus, and penicillin-resistant *Streptococcus pneumoniae*.

[3]Epidemiologists study the causes and distribution of disease or injury in a population.

[4]Our surveys included programs in all 50 states, 5 territories, the District of Columbia, and New York City. Throughout this statement, we refer to this group collectively as "states." We received responses from all 57 laboratory directors and from 55 epidemiologists, for response rates of 100 percent and 97 percent, respectively.

In brief, we found that surveillance of and testing for important emerging infectious diseases are not comprehensive in all states. We found that most states conduct surveillance of five of the six emerging infections we asked about, and state public health laboratories conduct tests to support state surveillance of four of the six. However, over half of state laboratories do not conduct tests for surveillance of penicillin-resistant *S. pneumoniae* and hepatitis C. Also, most state epidemiologists believe their surveillance programs do not sufficiently study antibiotic-resistant and other diseases they consider important.

Many state laboratory directors and epidemiologists reported that inadequate staffing and information-sharing problems hinder their ability to generate and use laboratory data in their surveillance. However, public health officials have not agreed on a consensus definition of the minimum capabilities that state and local health departments need to conduct infectious diseases surveillance. This lack of consensus makes it difficult for policymakers to assess the adequacy of existing resources or to evaluate where investments are needed most. Accordingly, our report recommends that the Director of CDC lead an effort to help federal, state, and local public health officials create consensus on the core capacities needed at each level of government.

Most state officials said CDC's testing and consulting services, training, and grant funding support are critical to their efforts to detect and respond to emerging infections. However, both laboratory directors and epidemiologists were frustrated by the lack of integrated information systems within CDC and the lack of integrated systems linking them with other public and private surveillance partners. CDC's continued commitment to integrating its own data systems and to helping states and localities build integrated electronic data and communication systems could give state and local public health agencies vital assistance in carrying out their infectious diseases surveillance and reporting responsibilities.

Background

Emerging infectious diseases pose a growing health threat to people everywhere. Some emerging infections result from deforestation, increased development, and other environmental changes that bring people into contact with animals or insects that harbor diseases only rarely encountered before. However, others are familiar diseases that have developed resistance to the antibiotics that brought them under control just a generation ago.

Infectious diseases account for considerable health care costs and lost productivity. In this country, about one-fourth of all doctor visits involve infectious diseases. The number of pathogens resistant to one or more previously effective antibiotics is increasing rapidly, reducing treatment options and adding to health care costs.

Surveillance Is the Primary Public Health Tool to Detect and Monitor Infections

Surveillance is public health officials' most important tool for detecting and monitoring both existing and emerging infections. Without adequate surveillance, local, state, and federal officials cannot know the true scope of existing health problems and may not recognize new diseases until many people have been affected. Health officials also use surveillance data to allocate their staff and dollar resources and to monitor and evaluate the effectiveness of prevention and control programs.

The states have principal responsibility for protecting the public's health and, therefore, take the lead role in surveillance efforts. Each state decides for itself which diseases physicians, hospitals, and others should report to its health department and which information it will then pass on to CDC. Most state surveillance programs include infections from the list of "nationally notifiable" diseases, which the Council of State and Territorial Epidemiologists (CSTE), in consultation with CDC, reviews annually. Nationally notifiable diseases are ones that are important enough for the nation as a whole to routinely report to CDC. However, states are under no obligation to include nationally notifiable diseases in their own surveillance programs, and state reporting to CDC is voluntary.

The methods for detecting emerging infections are the same as those used to monitor infectious diseases generally. These methods can be characterized as passive or active. Passive surveillance relies on laboratory and hospital staff, physicians, and other relevant sources to take the initiative to provide data to the health department, where officials analyze and interpret the information as it comes in. Under active surveillance, public health officials contact people directly to gather data. For example, health department staff could call clinical laboratories each week to ask if any samples of *S. pneumoniae* tested positive for resistance to penicillin. Active surveillance produces more complete information than passive surveillance, but it takes more time and costs more.

Infectious diseases surveillance in the United States depends largely on passive methods of collecting disease reports and laboratory test results. Consequently, the surveillance network relies on the participation of

health care providers, private laboratories, and state and local health departments across the nation. Even when states require reporting of specific diseases, experts acknowledge that the completeness of reporting varies by disease and type of provider.

Surveillance usually begins when a person with a reportable disease seeks care and the physician—in an effort to determine the cause of the illness—runs a laboratory test, which could be performed in the physician's office, a hospital, an independent clinical laboratory, or a public health laboratory. Reports of infectious diseases generated by such tests are often sent first to local health departments, where staff check the reports for completeness, contact health care professionals to obtain missing information or clarify unclear responses, and forward the reports to state health agencies.

At the state level, state epidemiologists analyze data collected through the disease reporting network, decide when and how to supplement passive reporting with active surveillance methods, conduct outbreak and other disease investigations, and design and evaluate disease prevention and control efforts. They also transmit state data to CDC, providing routine reporting on selected diseases. Many state epidemiologists and laboratory directors provide the medical community with information obtained through surveillance, such as rates of disease incidence or prevailing patterns of antimicrobial resistance.

Federal participation in the infectious diseases surveillance network focuses on CDC activities—particularly those of the National Center for Infectious Diseases (NCID), which operates CDC's infectious diseases laboratories. CDC analyzes the data furnished by states to (1) monitor national health trends, (2) formulate and implement prevention strategies, and (3) evaluate state and federal disease prevention efforts. CDC routinely provides public health officials, medical personnel, and others information on disease trends and analyses of outbreaks. CDC also offers an array of scientific and financial support for state infectious diseases surveillance, prevention, and control programs.

Laboratories Play an Essential Role in Surveillance of Emerging Infectious Diseases

Public health and private laboratories are a vital part of the surveillance network because only laboratory test results can definitively identify pathogens. In addition, test results are often an essential complement to a physician's clinical impressions. According to public health officials, the

nation's 158,000 laboratories are consistent sources of passively reported information for infectious diseases surveillance.[5]

Every state has at least one state public health laboratory that conducts testing for routine surveillance or as part of special clinical or epidemiologic studies. State public health laboratories also provide specialized testing for low-incidence, high-risk diseases, such as tuberculosis and botulism. Testing they provide during an outbreak contributes greatly to tracing the spread of the outbreak, identifying the source, and developing appropriate control measures. Epidemiologists rely on state public health laboratories to document trends and identify events that may indicate an emerging problem. Many state laboratories also provide licensing and quality assurance oversight of commercial laboratories.

State public health laboratories are increasingly using advanced technology to identify pathogens at the molecular level. These tests provide information that can enable epidemiologists to tell whether individual cases of illness are caused by the same strain of pathogen—information that is not available from clinical records or other epidemiologic methods. Public health officials have used advanced molecular technology to trace the movement of diseases in ways that would not have been possible 5 years ago. For example, DNA fingerprints developed by laboratories in a CDC-sponsored network showed that drug-resistant strains of tuberculosis first found in New York City have spread to other parts of the country. The fingerprints also showed that tuberculosis can be transmitted during brief contact among people—an important discovery that improved treatment and control programs.

CDC laboratories provide highly specialized tests not always available in state public health or commercial laboratories and assist states with testing during outbreaks. Specifically, CDC laboratories help diagnose life-threatening, unusual, or exotic infectious diseases; confirm public or private laboratory test results that are difficult to interpret; and conduct research to improve diagnostic methods.

[5]U.S. laboratories include about 90,000 laboratories in physicians' offices; 5,800 independent clinical laboratories; 9,000 hospital laboratories; and 53,000 other laboratories, such as those in state and local health departments, nursing homes, and other health care facilities.

Not All States Conduct Surveillance and Testing for Important Emerging Infections

While state surveillance and laboratory testing programs are extensive, not all include every significant emerging infection, leaving gaps in the nation's surveillance network. Our surveys found that almost all states conducted surveillance of tuberculosis, pertussis, hepatitis C, and virulent strains of *E. coli*; slightly fewer collected information on cryptosporidiosis. About two-thirds collected information on penicillin-resistant *S. pneumoniae*. Similarly, state public health laboratories commonly performed tests to support state surveillance of tuberculosis, pertussis, cryptosporidiosis, and virulent strains of *E. coli*. However, over half of the laboratories did not test for hepatitis C, and about two-thirds did not test for penicillin-resistant *S. pneumoniae*.

Over three-quarters of the responding epidemiologists told us that their surveillance programs either leave out or do not focus sufficient attention on important infectious diseases. Antibiotic-resistant diseases, including penicillin-resistant *S. pneumoniae* and hepatitis C, were among the diseases they cited most often as deserving greater attention.[6]

Moreover, our surveys found that about half of the state laboratories used a molecular technology called pulsed field gel electrophoreses (PFGE) to support state surveillance of the diseases we asked about. State and CDC officials believe that most, and possibly all, states should have PFGE because it can be used to study many diseases and greatly improves the ability to detect outbreaks.

Officials Report That Staffing Constraints and Weak Information Sharing Impede Surveillance of Emerging Infections

As part of our surveys and field interviews, we asked state officials to identify the problems they considered most important in conducting surveillance of emerging infectious diseases. The problems they cited fell principally into two categories: staffing and information sharing.

State epidemiologists and laboratory directors told us that staffing constraints prevent them from undertaking surveillance and testing for diseases they consider important. Furthermore, laboratory officials noted that advances in scientific knowledge and the proliferation of molecular testing methods have created a need for training to update the skills of current staff. They reported that such training was often either unavailable or inaccessible because of funding or administrative constraints.

[6]One state epidemiologist reported taking steps to add hepatitis C and penicillin-resistant *S. pneumoniae* to the state's list of reportable diseases. Another state epidemiologist reported adding hepatitis C to the list of reportable diseases, and a third reported adding penicillin-resistant *S. pneumoniae*.

We found considerable variability among states in laboratory and epidemiology staffing. During fiscal year 1997, states devoted a median of 8 staff years per 1 million population to laboratory testing of infectious diseases, with individual states reporting from 1.3 to 89 staff per 1 million population. The variation in epidemiology staffing was even greater, ranging from 2.1 to 321 in individual states, with a median 14 staff years per 1 million population.

Lack of Equipment and Cumbersome Systems Hinder Information Sharing

Epidemiologists and laboratory officials alike said that public health departments often lack either basic equipment, such as computers and fax machines, or integrated data systems that would allow them to rapidly share surveillance-related information with public and private partners. For health crises that need an immediate response—as when a serious and highly contagious disease appears in a school or among restaurant staff—rapid sharing of surveillance information is critical. Officials most often attributed the lack of computer equipment and integrated data systems to insufficient funding.

Without such equipment, some tasks that could be automated must be done by hand. In some cases, the lack of equipment has required data in electronic form to be reverted to paper form. For example, representatives from two large, multistate private clinical laboratories told us that data stored electronically in their information systems had to be converted to paper so it could be reported to local health departments.

Our survey responses indicate that state laboratory directors use electronic communications systems much less often than do state epidemiologists. Although most laboratory directors use electronic systems to communicate within their laboratories, they often do not use them to communicate with others. For example, almost 40 percent reported rarely using computerized systems to receive surveillance-related data, and 21 percent used them very little to transmit such data.

Even with adequate computer equipment, the difficulty of creating integrated information systems can be formidable. Not only does technology change rapidly, but computerized public health data are stored in thousands of isolated locations, including the record and information systems of public health agencies and health care institutions, individual case files, and data files of surveys and surveillance systems. These independent systems have differing hardware and software structures and

considerable variation in how the data are coded, particularly for laboratory test results.

CDC alone operates over 100 data systems to monitor over 200 health events, such as diagnoses of specific infectious diseases. Many of these systems collect data from state surveillance programs. CDC's patchwork of data systems arose, in part, to meet federal and state needs for more detailed information for particular diseases than was usually reported.

Public health officials told us that the multitude of databases and data systems, software, and reporting mechanisms burdens staff at state and local health agencies and leads to duplication of effort when staff must enter the same data into multiple systems that do not communicate with one another. Further, the lack of integrated data management systems can hinder laboratory and epidemiologic efforts to control outbreaks. For example, in 1993, the lack of integrated systems impeded efforts to control the hantavirus outbreak in the Southwest. Data were locked into separate databases that could not be analyzed or merged with others, causing public health investigators to analyze paper printouts by hand.

Public Health Consensus on Core Capacities Needed to Conduct Surveillance Does Not Exist

Although many state officials are concerned about their staffing and technology resources, public health officials have not developed a consensus definition of the minimum capabilities that state and local health departments need to conduct infectious diseases surveillance. For example, according to CDC and state health officials, there are no standards for the types of tests state public health laboratories should be able to perform; nor are there widely accepted standards for the epidemiological capabilities state public health departments need. Public health officials have identified a number of elements that might be included in a consensus definition, such as the number and qualifications of laboratory and epidemiology staff; the pathogens that each state laboratory should be able to identify and, where relevant, test for antibiotic resistance; and laboratory and information-sharing technology each state should have.

CSTE, the Association of Public Health Laboratories, and CDC have begun collaborating to define the staff and equipment components of a national surveillance system for infectious diseases and other conditions. They plan to develop agreements about the laboratory and epidemiology resources needed to conduct surveillance, diseases that should be under surveillance, and the information systems needed to share surveillance

data. According to state and federal officials, this consensus would give state and local health agencies the basis for setting priorities for their surveillance efforts and determining the resources needed to implement them.

CDC Services Are Wide-Ranging and Generally Perceived as Valuable

CDC provides state and local health departments with a wide range of technical, financial, and staff resources. Many state laboratory directors and epidemiologists said such assistance has been essential to their ability to conduct infectious diseases surveillance and to take advantage of new laboratory technology; however, a small number of laboratory directors and epidemiologists believe CDC's assistance has not significantly increased their ability to conduct surveillance of emerging infections. Yet many state officials indicated that improvements are needed, particularly in the area of information-sharing systems.

Laboratory Testing, Consultation, and Training Assistance Are Viewed as Critical

Many state laboratory directors and epidemiologists told us that CDC's testing, consultation, and training services are critical to their surveillance efforts. More than half of those responding to our surveys indicated that these three services greatly or significantly improved their state's ability to conduct surveillance. State officials indicated that CDC's testing for rare pathogens and the ability to consult with experienced CDC staff are important, particularly for investigating cases of unusual diseases, and that CDC's training was even more significant for improving their ability to conduct surveillance of emerging infections.

Over 70 percent of epidemiologists responding to our survey said that when they need assistance, knowledgeable staff at CDC are easy to locate, but many noted that help with matters involving more than one CDC unit is difficult to obtain. Many state officials said that this problem arose when staff in different units did not communicate well with one another. One official described CDC's units as separate towers that do not interact. State officials and survey respondents also said they would like CDC to provide more timely test results in non-urgent situations and additional training in new laboratory techniques.

Most Respondents See Substantial Value in Grant Assistance Programs

Most survey respondents said that NCID's disease-specific grants and epidemiology and laboratory capacity grants had made great or significant improvements in their ability to conduct surveillance of emerging infectious diseases. For example, after state laboratories began receiving

funds from CDC's tuberculosis grant program—which go to programs in all states and selected localities—they markedly improved their ability to rapidly identify the disease and indicate which, if any, antibiotics could be used effectively in treatment. State laboratory officials attributed this improvement to the funding and training they received from CDC.

In contrast, only eight states receive CDC funding for active surveillance and testing for penicillin-resistant *S. pneumoniae*. Where almost all states and most state laboratories reported that they monitor antibiotic-resistance in tuberculosis, far fewer reported monitoring penicillin-resistant *S. pneumoniae*. Moreover, while all but one state require health care providers to submit tuberculosis reports, fewer than half require reporting of penicillin-resistant *S. pneumoniae*.

Information-Sharing Systems Need Improvement

Over the past two decades, CDC has developed and made available to states several general and disease-specific information management and reporting programs. State and federal officials we spoke with said CDC's systems have limited flexibility for adapting to state program needs—one reason states have developed their own information management systems. Officials told us that two systems used by most laboratory directors and epidemiologists often cannot share data with each other or with other CDC-or state-developed systems. CDC officials responsible for these programs said that the most recent versions can share data more readily with other systems, but the lack of training in how to use the programs and high staff turnover at state agencies may limit the number of state staff able to use the full range of program capabilities.

Many state officials complained about a substantial drain on scarce staff time to enter and reconcile data into multiple systems, such as their own system plus one or more CDC-developed systems. The inability to share data between systems also hinders identifying multiple records on one case and undermines efforts to improve reporting by providers.

In response to state and local requests for greater integration of systems, CDC established a board to formulate and enact policy for integrating public health information and surveillance systems. The board brings together federal and state public health officials to focus on issues such as data standards and security, assessing hardware and software used by states, and identifying gaps in CDC databases.

CDC and the states have made progress in developing more efficient information-sharing systems through one of CDC's grant programs: the Information Network for Public Health Officials (INPHO). INPHO is designed to foster communication between public and private partners, make information more accessible, and allow for rapid and secure exchange of data. By 1997, 14 states had begun INPHO projects. Some had combined these funds with other CDC grant moneys to build statewide networks linking state and local health departments and, in some cases, private laboratories. Integrated systems can dramatically improve communication. For example, in Washington, electronic information sharing systems reduced passive reporting time from 35 days to 1 day and gave local authorities access to health data for analysis.[7]

Mr. Chairman, this concludes my prepared statement. I will be happy to answer any questions you or other members of the Subcommittee may have.

[7]J. Davies and D. B. Jernigan, "Development and Evaluation of Electronic Laboratory-Based Reporting for Infectious Diseases Surveillance" (Atlanta, Ga.: International Conference on Emerging Infectious Diseases, 1998).

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