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SEPTEMBER 11

**Problems Remain in
Planning for and Providing
Health Screening and
Monitoring Services for
Responders**

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Highlights of [GAO-07-1253T](#), a testimony before the Committee on Homeland Security, House of Representatives

Why GAO Did This Study

Six years after the attack on the World Trade Center (WTC), concerns persist about health effects experienced by WTC responders and the availability of health care services for those affected. Several federally funded programs provide screening, monitoring, or treatment services to responders. GAO has previously reported on the progress made and implementation problems faced by these WTC health programs, as well as lessons learned from the WTC disaster.

This testimony is based on previous GAO work, primarily *September 11: HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders* ([GAO-07-892](#), July 23, 2007). This testimony discusses (1) status of services provided by the Department of Health and Human Services' (HHS) WTC Federal Responder Screening Program, (2) efforts by the Centers for Disease Control and Prevention's National Institute for Occupational Safety and Health (NIOSH) to provide services for nonfederal responders residing outside the New York City (NYC) area, and (3) lessons learned from WTC health programs.

For the July 2007 report, GAO reviewed program documents and interviewed HHS officials, grantees, and others. In August and September 2007, GAO updated selected information in preparing this testimony.

To view the full product, including the scope and methodology, click on [GAO-07-1253T](#). For more information, contact Cynthia A. Bascetta at (202) 512-7114 or bascettac@gao.gov.

SEPTEMBER 11

Problems Remain in Planning for and Providing Health Screening and Monitoring Services for Responders

What GAO Found

In July 2007, following a reexamination of the status of the WTC health programs, GAO recommended that the Secretary of HHS take expeditious action to ensure that health screening and monitoring services are available to all people who responded to the WTC attack, regardless of who their employer was or where they reside. As of September 2007 the department has not responded to this recommendation.

As GAO reported in July 2007, HHS's WTC Federal Responder Screening Program has had difficulties ensuring the uninterrupted availability of screening services for federal responders. From January 2007 to May 2007, the program stopped scheduling screening examinations because there was a change in the program's administration and certain interagency agreements were not established in time to keep the program fully operational. From April 2006 to March 2007, the program stopped scheduling and paying for specialty diagnostic services associated with screening. NIOSH, the administrator of the program, has been considering expanding the program to include monitoring—that is, follow-up physical and mental health examinations—but has not done so. If federal responders do not receive monitoring, health conditions that arise later may not be diagnosed and treated, and knowledge of the health effects of the WTC disaster may be incomplete.

NIOSH has not ensured the availability of screening and monitoring services for nonfederal responders residing outside the NYC area, although it recently took steps toward expanding the availability of these services. In late 2002, NIOSH arranged for a network of occupational health clinics to provide screening services. This effort ended in July 2004, and until June 2005 NIOSH did not fund screening or monitoring services for nonfederal responders outside the NYC area. In June 2005, NIOSH funded the Mount Sinai School of Medicine Data and Coordination Center (DCC) to provide screening and monitoring services; however, DCC had difficulty establishing a nationwide network of providers and contracted with only 10 clinics in seven states. In 2006, NIOSH began to explore other options for providing these services, and in May 2007 it took steps toward expanding the provider network. However, as of September 2007 these efforts are incomplete.

Lessons have been learned from the WTC health programs that could assist in the event of a future disaster. Lessons include the need to quickly identify and contact responders and others affected by a disaster, the value of a centrally coordinated approach for assessing individuals' health, and the importance of addressing both physical and mental health effects. Consideration of these lessons by federal agencies is important in planning for the response to future disasters.

Mr. Chairman and Members of the Committee:

I am pleased to be here today to discuss our work on the implementation of federally funded health programs for individuals affected by the September 11, 2001, attack on the World Trade Center (WTC), as well as lessons learned from responses to that disaster.¹ Tens of thousands of people served as responders in the aftermath of the WTC disaster, including New York City Fire Department (FDNY) personnel, federal government personnel, and other government and private-sector workers and volunteers from New York and elsewhere. By responders we are referring to anyone involved in rescue, recovery, or cleanup activities at or near the vicinity of the WTC or the Staten Island site.² These responders were exposed to numerous physical hazards, environmental toxins, and psychological trauma. Six years after the destruction of the WTC buildings, concerns remain about the physical and mental health effects of the disaster, the long-term nature of some of these health effects, and the availability of health care services for those affected.

Following the WTC attack, federal funding was provided to government agencies and private organizations to establish programs for screening, monitoring, or treating responders for illnesses and conditions related to the WTC disaster; these programs are referred to in this testimony as the WTC health programs.^{3,4} The Department of Health and Human Services (HHS) funded the programs as separate efforts serving different categories of responders—for example, firefighters, other workers and volunteers, or federal responders—and has responsibility for coordinating program efforts. Officials involved in the administration and implementation of the WTC health programs have derived lessons from their experiences that could improve the design of such programs in the future.

¹A list of abbreviations used in this testimony is in app. I.

²The Staten Island site is the landfill that is the off-site location of the WTC recovery operation.

³In this testimony, “screening” refers to initial physical and mental health examinations of affected individuals. “Monitoring” refers to tracking the health of individuals over time, either through periodic surveys or through follow-up physical and mental health examinations.

⁴One of the WTC health programs, the WTC Health Registry, also includes people living or attending school in the area of the WTC or working or present in the vicinity on September 11, 2001.

We have previously reported on the implementation of these programs and their progress in providing services to responders,⁵ who reside in all 50 states and the District of Columbia. In 2005 and 2006, we reported that one of the WTC health programs, HHS's WTC Federal Responder Screening Program, which was established to provide one-time screening examinations for responders who were federal employees when they responded to the WTC attack, had accomplished little.⁶ HHS established the program in June 2003, suspended it in March 2004, and resumed it in December 2005. In September 2006, we reported that the program was registering and screening federal responders and that a total of 907 federal workers had received screening examinations.⁷ We also reported that the National Institute for Occupational Safety and Health (NIOSH), the component of HHS's Centers for Disease Control and Prevention (CDC) responsible for administering most of the WTC health programs, had begun to take steps to provide access to screening, monitoring, and treatment services for nonfederal responders who resided outside the New York City (NYC) metropolitan area.⁸

In September 2006 we also testified that CDC had begun, but not completed, the process of allocating funding from a \$75 million appropriation made in fiscal year 2006 for WTC health programs for responders.^{9,10} This was the first appropriation specifically available for treatment for responders. We reported that in August 2006 CDC had awarded \$1.5 million from this appropriation to the FDNY WTC Medical Monitoring and Treatment Program and almost \$1.1 million to the New York/New Jersey (NY/NJ) WTC Consortium for treatment-related

⁵See, for example, GAO, *September 11: HHS Has Screened Additional Federal Responders for World Trade Center Health Effects, but Plans for Awarding Funds for Treatment Are Incomplete*, [GAO-06-1092T](#) (Washington, D.C.: Sept. 8, 2006). A list of related GAO products is included at the end of this testimony.

⁶See GAO, *September 11: Monitoring of World Trade Center Health Effects Has Progressed, but Not for Federal Responders*, [GAO-05-1020T](#) (Washington, D.C.: Sept. 10, 2005), and *September 11: Monitoring of World Trade Center Health Effects Has Progressed, but Program for Federal Responders Lags Behind*, [GAO-06-481T](#) (Washington, D.C.: Feb. 28, 2006).

⁷See [GAO-06-1092T](#).

⁸In general, the WTC health programs provide services in the NYC metropolitan area.

⁹Department of Defense Appropriations Act, 2006, Pub. L. No. 109-148, § 5011(b), 119 Stat. 2680, 2814 (2005).

¹⁰See [GAO-06-1092T](#).

activities. We also reported that CDC officials told us they could not predict how long the funding from the appropriation would support four WTC health programs that provide treatment services.

My testimony today is primarily based on our report issued in July 2007.¹¹ As you requested, I will discuss (1) the status of services provided by the WTC Federal Responder Screening Program, (2) NIOSH's efforts to provide services for nonfederal responders residing outside the NYC metropolitan area, (3) NIOSH's awards to grantees for treatment services, and (4) lessons learned from WTC health programs.

To assess the status of services provided by the WTC Federal Responder Screening Program, we obtained and reviewed program data and documents from HHS, including applicable interagency agreements. We interviewed officials from the HHS entities involved in administering and implementing the program: NIOSH and two HHS offices, the Federal Occupational Health Services (FOH)¹² and the Office of the Assistant Secretary for Preparedness and Response (ASPR).¹³ To assess NIOSH's efforts to provide services for nonfederal responders residing outside the NYC metropolitan area, we obtained documents and interviewed officials from NIOSH. We also interviewed officials of organizations that worked with NIOSH to provide or facilitate services for nonfederal responders residing outside the NYC metropolitan area, including the Mount Sinai School of Medicine in NYC and the Association of Occupational and Environmental Clinics (AOEC)—a network of university-affiliated and other private occupational health clinics across the United States and in Canada. To assess NIOSH's awards to grantees for treatment services, we obtained documents and interviewed officials from NIOSH. We also interviewed officials from two WTC health program grantees¹⁴ from which

¹¹See GAO, *September 11: HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders*, GAO-07-892 (Washington, D.C.: July 23, 2007).

¹²FOH is a service unit within HHS's Program Support Center that provides occupational health services to federal government departments and agencies located throughout the United States.

¹³ASPR coordinates and directs HHS's emergency preparedness and response program. In December 2006 the Office of Public Health and Emergency Preparedness became ASPR. We refer to that office as ASPR throughout this testimony, regardless of the time period discussed.

¹⁴NIOSH provides funds to the programs through cooperative agreements, but refers to award recipients as grantees. Therefore, in this testimony we use the term grantee when referring to NIOSH's award recipients.

the majority of responders receive medical services: the NY/NJ WTC Consortium¹⁵ and the FDNY WTC program. In addition, we interviewed officials from the American Red Cross, which has funded treatment services for responders. In our review of the WTC health programs, we relied primarily on information provided by agency officials and contained in government publications. We compared the information with information in other supporting documents, when available, to determine its consistency and reasonableness. We determined that the information we obtained was sufficiently reliable for our purposes. To identify lessons learned, we relied on previous work, for which we conducted interviews with HHS officials, WTC health program officials, and experts in public health.¹⁶ We also reviewed our previous work on the safety and health of workers who responded to Hurricane Katrina.¹⁷ We performed the work for the July 2007 report from November 2006 through July 2007—and updated selected information in August and September 2007. We performed the work to identify lessons learned from July 2005 through September 2005 and updated this information in February 2006. All work was conducted in accordance with generally accepted government auditing standards.

In brief, we reported in July 2007 that HHS's WTC Federal Responder Screening Program had had difficulties ensuring the uninterrupted availability of screening services for federal responders and that NIOSH, the administrator of the program, was considering expanding the program to include monitoring but had not done so. We also reported that NIOSH had not ensured the availability of screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area, although it had recently taken steps toward expanding the availability of these services. As a result of our assessment of these programs, we recommended that the Secretary of HHS expeditiously take action to ensure that screening and monitoring services are available for all responders, including federal responders and nonfederal responders residing outside of the NYC metropolitan area. As of September 2007 the department has not responded to this recommendation. We also reported

¹⁵In previous reports we have also referred to this program as the worker and volunteer WTC program.

¹⁶See [GAO-05-1020T](#) and [GAO-06-481T](#).

¹⁷See GAO, *Disaster Preparedness: Better Planning Would Improve OSHA's Efforts to Protect Workers' Safety and Health in Disasters*, [GAO-07-193](#) (Washington, D.C.: Mar. 28, 2007).

that NIOSH had awarded and set aside treatment funds totaling \$51 million from its \$75 million appropriation for four NYC-area programs. Finally, important lessons have been learned from the WTC health programs that could assist in the event of a future disaster. These include the need to quickly identify and contact responders and others affected by a disaster, the value of a centrally coordinated approach for assessing individuals' health, and the importance of addressing both physical and mental health effects.

Background

The tens of thousands of individuals¹⁸ who responded to the September 11, 2001, attack on the WTC experienced the emotional trauma of the disaster and were exposed to a noxious mixture of dust, debris, smoke, and potentially toxic contaminants, such as pulverized concrete, fibrous glass, particulate matter, and asbestos. A wide variety of health effects have been experienced by responders to the WTC attack, and several federally funded programs have been created to address the health needs of these individuals.

Health Effects

Numerous studies have documented the physical and mental health effects of the WTC attacks.¹⁹ Physical health effects included injuries and respiratory conditions, such as sinusitis, asthma, and a new syndrome called WTC cough, which consists of persistent coughing accompanied by severe respiratory symptoms. Almost all firefighters who responded to the attack experienced respiratory effects, including WTC cough. One study

¹⁸There is not a definitive count of the number of people who served as responders. Estimates have ranged from about 40,000 to about 91,000.

¹⁹See, for example, Centers for Disease Control and Prevention, "Mental Health Status of World Trade Center Rescue and Recovery Workers and Volunteers—New York City, July 2002-August 2004," *Morbidity and Mortality Weekly Report*, vol. 53 (2004); "Physical Health Status of World Trade Center Rescue and Recovery Workers and Volunteers—New York City, July 2002-August 2004," *Morbidity and Mortality Weekly Report*, vol. 53 (2004); and "Surveillance for World Trade Center Disaster Health Effects among Survivors of Collapsed and Damaged Buildings," *Morbidity and Mortality Weekly Report*, vol. 55 (2006). See also G. I. Banauch et al., "Pulmonary Function after Exposure to the World Trade Center in the New York City Fire Department," *American Journal of Respiratory and Critical Care Medicine*, vol. 174, no. 3 (2006); G. Izbicki et al., "World Trade Center 'Sarcoid Like' Granulomatous Pulmonary Disease in New York City Fire Department Rescue Workers," *Chest*, vol. 131 (2007); and K. Wheeler et al., "Asthma Diagnosed after September 11, 2001 among Rescue and Recovery Workers: Findings from the World Trade Center Health Registry," *Environmental Health Perspectives*, <http://dx.doi.org/10.1289/ehp.10248> (downloaded Aug. 27, 2007).

suggested that exposed firefighters on average experienced a decline in lung function equivalent to that which would be produced by 12 years of aging.²⁰ A recently published study found a significantly higher risk of newly diagnosed asthma among responders that was associated with increased exposure to the WTC disaster site.²¹ Commonly reported mental health effects among responders and other affected individuals included symptoms associated with post-traumatic stress disorder (PTSD), depression, and anxiety. Behavioral health effects such as alcohol and tobacco use have also been reported.

Some health effects experienced by responders have persisted or worsened over time, leading many responders to begin seeking treatment years after September 11, 2001. Clinicians involved in screening, monitoring, and treating responders have found that many responders' conditions—both physical and psychological—have not resolved and have developed into chronic disorders that require long-term monitoring. For example, findings from a study conducted by clinicians at the NY/NJ WTC Consortium show that at the time of examination, up to 2.5 years after the start of the rescue and recovery effort, 59 percent of responders enrolled in the program were still experiencing new or worsened respiratory symptoms.²² Experts studying the mental health of responders found that about 2 years after the WTC attack, responders had higher rates of PTSD and other psychological conditions compared to others in similar jobs who were not WTC responders and others in the general population.²³ Clinicians also anticipate that other health effects, such as immunological disorders and cancers, may emerge over time.

²⁰Banauch et al., "Pulmonary Function."

²¹Wheeler et al., "Asthma Diagnosed."

²²R. Herbert et al., "The World Trade Center Disaster and the Health of Workers: Five-Year Assessment of a Unique Medical Screening Program," *Environmental Health Perspectives*, vol. 114, no. 12 (2006).

²³For example, see R. Gross et al., "Posttraumatic Stress Disorder and Other Psychological Sequelae among World Trade Center Clean Up and Recovery Workers," *Annals of the New York Academy of Sciences*, vol. 1071 (2006) and M. Perrin et al., "Differences in PTSD Prevalence and Associated Risk Factors among World Trade Center Disaster Rescue and Recovery Workers," *American Journal of Psychiatry*, vol. 64 (2007).

Overview of WTC Health Programs

There are six key programs that currently receive federal funding to provide voluntary health screening, monitoring, or treatment at no cost to responders.²⁴ The six WTC health programs, shown in table 1, are (1) the FDNY WTC Medical Monitoring and Treatment Program; (2) the NY/NJ WTC Consortium, which comprises five clinical centers in the NY/NJ area;²⁵ (3) the WTC Federal Responder Screening Program; (4) the WTC Health Registry; (5) Project COPE; and (6) the Police Organization Providing Peer Assistance (POPPA) program.²⁶ The programs vary in aspects such as the HHS administering agency or component responsible for administering the funding; the implementing agency, component, or organization responsible for providing program services; eligibility requirements; and services.

²⁴In addition to these programs, a New York State responder screening program received federal funding for screening New York State employees and National Guard personnel who responded to the WTC attack in an official capacity. This program ended its screening examinations in November 2003.

²⁵The NY/NJ WTC Consortium consists of five clinical centers operated by (1) Mount Sinai-Irving J. Selikoff Center for Occupational and Environmental Medicine; (2) Long Island Occupational and Environmental Health Center at SUNY, Stony Brook; (3) New York University School of Medicine/Bellevue Hospital Center; (4) Center for the Biology of Natural Systems, at CUNY, Queens College; and (5) University of Medicine and Dentistry of New Jersey Robert Wood Johnson Medical School, Environmental and Occupational Health Sciences Institute. Mount Sinai's clinical center, which is the largest of the five centers, also receives federal funding to operate a data and coordination center to coordinate the work of the five clinical centers and conduct outreach and education, quality assurance, and data management for the NY/NJ WTC Consortium.

²⁶Project COPE and the POPPA program provide mental health services to members of the New York City Police Department (NYPD) and operate independently of the NYPD.

Table 1: Key Federally Funded WTC Health Programs, June 2007

Program	HHS administering agency or component	Implementing agency, component, or organization	Eligible population	Services provided
FDNY WTC Medical Monitoring and Treatment Program	NIOSH	FDNY Bureau of Health Services	Firefighters and emergency medical service technicians	<ul style="list-style-type: none"> Initial screening Follow-up medical monitoring Treatment of WTC-related physical and mental health conditions
NY/NJ WTC Consortium	NIOSH	Five clinical centers, one of which, the Mount Sinai-Irving J. Selikoff Center for Occupational and Environmental Medicine, also serves as the consortium's Data and Coordination Center (DCC)	All responders, excluding FDNY firefighters and emergency medical service technicians and current federal employees ^a	<ul style="list-style-type: none"> Initial screening Follow-up medical monitoring Treatment of WTC-related physical and mental health conditions
WTC Federal Responder Screening Program	NIOSH ^b	FOH	Current federal employees who responded to the WTC attack in an official capacity	<ul style="list-style-type: none"> One-time screening Referrals to employee assistance programs and specialty diagnostic services^c
WTC Health Registry	Agency for Toxic Substances and Disease Registry (ATSDR)	NYC Department of Health and Mental Hygiene	Responders and people living or attending school in the area of the WTC or working or present in the vicinity on September 11, 2001	<ul style="list-style-type: none"> Long-term monitoring through periodic surveys
Project COPE	NIOSH	Collaboration between the NYC Police Foundation and Columbia University Medical Center	New York City Police Department (NYPD) uniformed and civilian employees and their family members	<ul style="list-style-type: none"> Hotline, mental health counseling, and referral services; some services provided by Columbia University clinical staff and some by other clinicians
POPPA program	NIOSH	POPPA program	NYPD uniformed employees	<ul style="list-style-type: none"> Hotline, mental health counseling, and referral services; some services provided by trained NYPD officers and some by mental health professionals

Source: GAO analysis of information from NIOSH, ATSDR, FOH, FDNY, the NY/NJ WTC Consortium, the NYC Department of Health and Mental Hygiene, the POPPA program, and Project COPE.

Note: Some of these federally funded programs have also received funds from the American Red Cross and other private organizations.

^aIn February 2006, ASPR and NIOSH reached an agreement to have former federal employees screened by the NY/NJ WTC Consortium.

^bUntil December 26, 2006, ASPR was the administrator.

⁶FOH can refer an individual with mental health symptoms to an employee assistance program for a telephone assessment. If appropriate, the individual can then be referred to a program counselor for up to six in-person sessions. The specialty diagnostic services are provided by ear, nose, and throat doctors; pulmonologists; and cardiologists.

The WTC health programs that are providing screening and monitoring are tracking thousands of individuals who were affected by the WTC disaster. As of June 2007, the FDNY WTC program had screened about 14,500 responders and had conducted follow-up examinations for about 13,500 of these responders, while the NY/NJ WTC Consortium had screened about 20,000 responders and had conducted follow-up examinations for about 8,000 of these responders. Some of the responders include nonfederal responders residing outside the NYC metropolitan area. As of June 2007, the WTC Federal Responder Screening Program had screened 1,305 federal responders and referred 281 responders for employee assistance program services or specialty diagnostic services. In addition, the WTC Health Registry, a monitoring program that consists of periodic surveys of self-reported health status and related studies but does not provide in-person screening or monitoring, collected baseline health data from over 71,000 people who enrolled in the Registry.²⁷ In the winter of 2006, the Registry began its first adult follow-up survey, and as of June 2007 over 36,000 individuals had completed the follow-up survey.

In addition to providing medical examinations, FDNY's WTC program and the NY/NJ WTC Consortium have collected information for use in scientific research to better understand the health effects of the WTC attack and other disasters. The WTC Health Registry is also collecting information to assess the long-term public health consequences of the disaster.

Federal Funding and Coordination of WTC Health Programs

Beginning in October 2001 and continuing through 2003, FDNY's WTC program, the NY/NJ WTC Consortium, the WTC Federal Responder Screening Program, and the WTC Health Registry received federal funding to provide services to responders. This funding primarily came from appropriations to the Department of Homeland Security's Federal Emergency Management Agency (FEMA),²⁸ as part of the approximately

²⁷The WTC Health Registry also provides information on where participants can seek health care.

²⁸FEMA is the agency responsible for coordinating federal disaster response efforts under the National Response Plan.

\$8.8 billion that the Congress appropriated to FEMA for response and recovery activities after the WTC disaster.²⁹ FEMA entered into interagency agreements with HHS agencies to distribute the funding to the programs. For example, FEMA entered into an agreement with NIOSH to distribute \$90 million appropriated in 2003 that was available for monitoring.³⁰ FEMA also entered into an agreement with ASPR for ASPR to administer the WTC Federal Responder Screening Program. A \$75 million appropriation to CDC in fiscal year 2006 for purposes related to the WTC attack resulted in additional funding for the monitoring activities of the FDNY WTC program, NY/NJ WTC Consortium, and the Registry.³¹ The \$75 million appropriation to CDC in fiscal year 2006 also provided funds that were awarded to the FDNY WTC program, the NY/NJ WTC Consortium, Project COPE, and the POPPA program for treatment services for responders. An emergency supplemental appropriation to CDC in May 2007 included an additional \$50 million to carry out the same activities provided for in the \$75 million appropriation made in fiscal year 2006.³² The President's proposed fiscal year 2008 budget for HHS includes \$25 million for treatment of WTC-related illnesses for responders.

In February 2006, the Secretary of HHS designated the Director of NIOSH to take the lead in ensuring that the WTC health programs are well coordinated, and in September 2006 the Secretary established a WTC Task Force to advise him on federal policies and funding issues related to responders' health conditions. The chair of the task force is HHS's Assistant Secretary for Health, and the vice chair is the Director of NIOSH. The task force reported to the Secretary of HHS in early April 2007.

²⁹See Consolidated Appropriations Resolution, 2003, Pub. L. No. 108-7, 117 Stat. 11, 517; 2002 Supplemental Appropriations Act for Further Recovery from and Response to Terrorist Attacks on the United States, Pub. L. No. 107-206, 116 Stat. 820, 894; Department of Defense and Emergency Supplemental Appropriations for Recovery from and Response to Terrorist Attacks on the United States Act, 2002, Pub. L. No. 107-117, 115 Stat. 2230, 2338; and 2001 Emergency Supplemental Appropriations Act for Recovery from and Response to Terrorist Attacks on the United States, Pub. L. No. 107-38, 115 Stat. 220-221.

³⁰Pub. L. No. 108-7, 117 Stat. 517.

³¹The statute required CDC, in expending such funds, to give first priority to specified existing programs that administer baseline and follow-up screening; clinical examinations; or long-term medical health monitoring, analysis, or treatment for emergency services personnel or rescue and recovery personnel. It required CDC to give secondary priority to similar programs coordinated by other entities working with the State of New York and NYC. Pub. L. No. 109-148, § 5011(b), 119 Stat. 2814.

³²U.S. Troop Readiness, Veterans' Care, Katrina Recovery, and Iraq Accountability Appropriations Act, 2007, Pub. L. No. 110-28, ch. 5, 121 Stat. 112, 166 (2007).

WTC Federal Responder Screening Program Has Had Difficulties Ensuring the Availability of Screening Services, and NIOSH Has Considered Expanding the Program to Include Monitoring

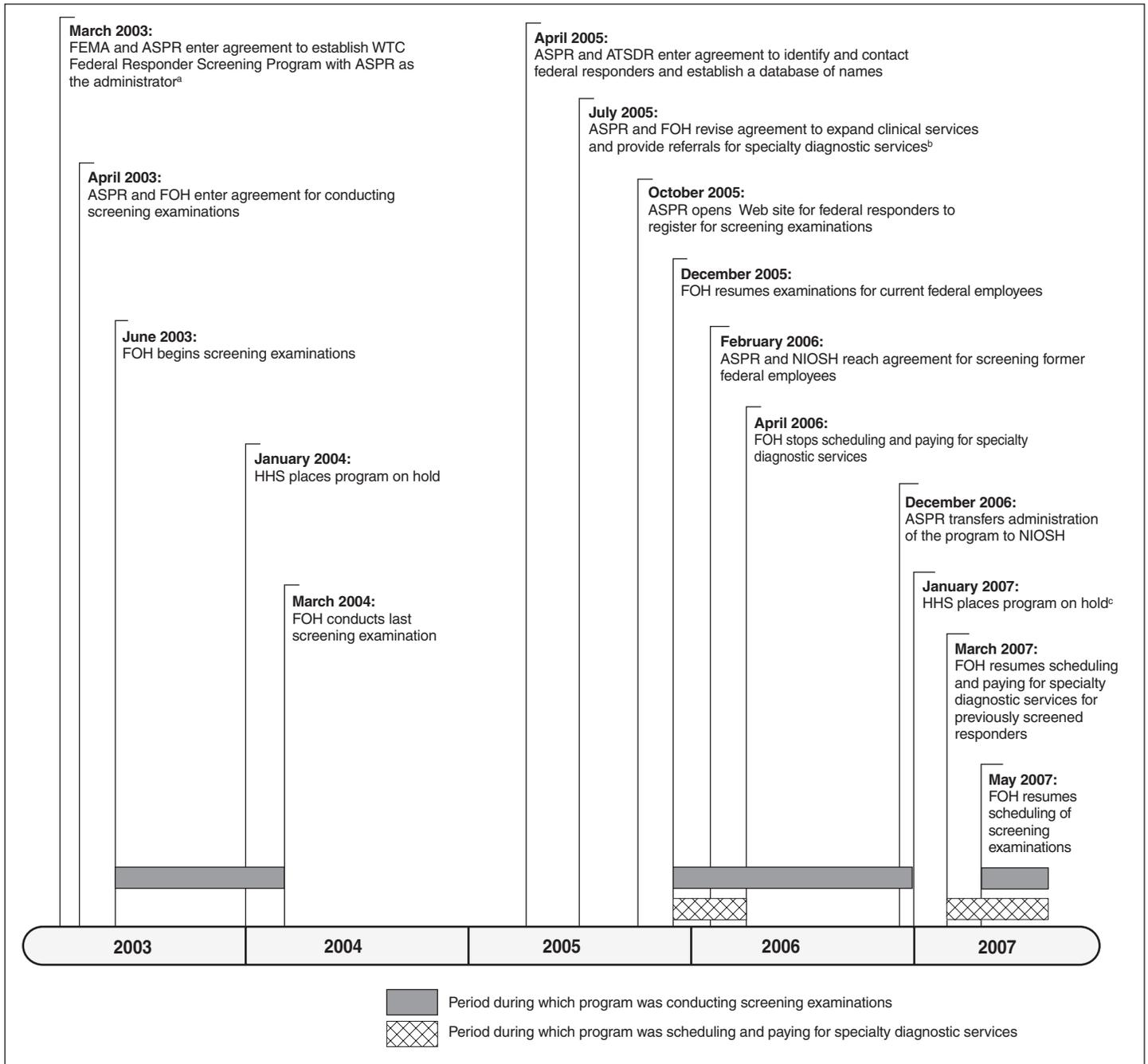
HHS's WTC Federal Responder Screening Program has had difficulties ensuring the uninterrupted availability of services for federal responders. First, the provision of screening examinations has been intermittent. (See fig. 1.) After resuming screening examinations in December 2005³³ and conducting them for about a year, HHS again placed the program on hold and suspended scheduling of screening examinations for responders from January 2007 to May 2007. This interruption in service occurred because there was a change in the administration of the WTC Federal Responder Screening Program, and certain interagency agreements were not established in time to keep the program fully operational. In late December 2006, ASPR and NIOSH signed an interagency agreement giving NIOSH \$2.1 million to administer the WTC Federal Responder Screening Program.³⁴ Subsequently, NIOSH and FOH needed to sign a new interagency agreement to allow FOH to continue to be reimbursed for providing screening examinations. It took several months for the agreement between NIOSH and FOH to be negotiated and approved, and scheduling of screening examinations did not resume until May 2007.³⁵

³³The program previously suspended examinations from March 2004 to December 2005. See [GAO-06-481T](#).

³⁴The agreement was a modification of ASPR's February 2006 interagency agreement with NIOSH that covers screenings for former federal employees.

³⁵Before an agreement between NIOSH and FOH could be signed, the agreement between ASPR and NIOSH required several technical corrections. The revised ASPR-NIOSH agreement extended the availability of funding for the WTC Federal Responder Screening Program to April 30, 2008.

Figure 1: Timeline of Key Actions Related to the WTC Federal Responder Screening Program



Source: GAO analysis of information from ASPR, FOH, NIOSH, and FEMA.

Note: The WTC Federal Responder Screening Program serves current federal employees who responded to the WTC attack in an official capacity. In February 2006, ASPR and NIOSH reached an agreement to have former federal employees screened by the NY/NJ WTC Consortium.

^aIn December 2006 the Office of Public Health and Emergency Preparedness became ASPR. We refer to that office as ASPR throughout this figure, regardless of the time period being discussed.

^bIn providing referrals for specialty diagnostic services, FOH schedules and pays for the diagnostic services.

^cAfter HHS placed the program on hold, FOH completed examinations that had already been scheduled.

Second, the program's provision of specialty diagnostic services has also been intermittent. After initial screening examinations, responders often need further diagnostic services by ear, nose, and throat doctors; cardiologists; and pulmonologists; and FOH had been referring responders to these specialists and paying for the services. However, the program stopped scheduling and paying for these specialty diagnostic services in April 2006 because the program's contract with a new provider network did not cover these services.³⁶ In March 2007, FOH modified its contract with the provider network and resumed scheduling and paying for specialty diagnostic services for federal responders.

In July 2007 we reported that NIOSH was considering expanding the WTC Federal Responder Screening Program to include monitoring examinations—follow-up physical and mental health examinations—and was assessing options for funding and delivering these services. If federal responders do not receive this type of monitoring, health conditions that arise later may not be diagnosed and treated, and knowledge of the health effects of the WTC disaster may be incomplete. In February 2007, NIOSH sent a letter to FEMA, which provides the funding for the program, asking whether the funding could be used to support monitoring in addition to the one-time screening currently offered. A NIOSH official told us that as of August 2007 the agency had not received a response from FEMA. NIOSH officials told us that if FEMA did not agree to pay for monitoring of federal responders, NIOSH would consider using other funding. According to a NIOSH official, if FEMA or NIOSH agrees to pay for monitoring of

³⁶In April 2006, FOH contracted with a new provider network to provide various services for all federal employees, such as immunizations and vision tests. The contract with the new provider network did not cover specialty diagnostic services by ear, nose, and throat doctors; cardiologists; and pulmonologists. Although the previous provider network had provided these services, the new provider network and the HHS contract officer interpreted the statement of work in the new contract as not including these specialty diagnostic services.

federal responders, this service would be provided by FOH or one of the other WTC health programs.

NIOSH Has Not Ensured the Availability of Services for Nonfederal Responders Residing outside the NYC Metropolitan Area

NIOSH has not ensured the availability of screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area, although it recently took steps toward expanding the availability of these services. Initially, NIOSH made two efforts to provide screening and monitoring services for these responders, the exact number of which is unknown.³⁷ The first effort began in late 2002 when NIOSH awarded a contract for about \$306,000 to the Mount Sinai School of Medicine to provide screening services for nonfederal responders residing outside the NYC metropolitan area and directed it to establish a subcontract with AOEC.³⁸ AOEC then subcontracted with 32 of its member clinics across the country to provide screening services. From February 2003 to July 2004, the 32 AOEC member clinics screened 588 nonfederal responders nationwide. AOEC experienced challenges in providing these screening services. For example, many nonfederal responders did not enroll in the program because they did not live near an AOEC clinic, and the administration of the program required substantial coordination among AOEC, AOEC member clinics, and Mount Sinai.

Mount Sinai's subcontract with AOEC ended in July 2004, and from August 2004 until June 2005 NIOSH did not fund any organization to provide services to nonfederal responders outside the NYC metropolitan area.³⁹ During this period, NIOSH focused on providing screening and monitoring services for nonfederal responders in the NYC metropolitan area. In June 2005, NIOSH began its second effort by awarding \$776,000 to the Mount

³⁷According to the NYC Department of Health and Mental Hygiene, about 7,000 nonfederal and federal responders residing outside the NYC metropolitan area have enrolled in the WTC Health Registry.

³⁸Around that time, NIOSH was providing screening services for nonfederal responders in the NYC metropolitan area through the NY/NJ WTC Consortium and the FDNY WTC program. Nonfederal responders residing outside the NYC metropolitan area were able to travel at their own expense to the NYC metropolitan area to obtain screening services through the NY/NJ WTC Consortium.

³⁹In early 2004, AOEC applied to NIOSH to use its national network of member clinics to provide screening and monitoring for nonfederal responders residing outside the NYC metropolitan area, but NIOSH rejected AOEC's application for several reasons, including that the application did not adequately address how to coordinate and implement a monitoring program with complex data collection and reporting requirements.

Sinai School of Medicine Data and Coordination Center (DCC) to provide both screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area. In June 2006, NIOSH awarded an additional \$788,000 to DCC to provide screening and monitoring services for these responders. NIOSH officials told us that they assigned DCC the task of providing screening and monitoring services to nonfederal responders outside the NYC metropolitan area because the task was consistent with DCC's responsibilities for the NY/NJ WTC Consortium, which include data monitoring and coordination. DCC, however, had difficulty establishing a network of providers that could serve nonfederal responders residing throughout the country—ultimately contracting with only 10 clinics in seven states to provide screening and monitoring services.⁴⁰ DCC officials said that as of June 2007 the 10 clinics were monitoring 180 responders.

In early 2006, NIOSH began exploring how to establish a national program that would expand the network of providers to provide screening and monitoring services, as well as treatment services, for nonfederal responders residing outside the NYC metropolitan area.⁴¹ According to NIOSH, there have been several challenges involved in expanding a network of providers to screen and monitor nonfederal responders nationwide. These include establishing contracts with clinics that have the occupational health expertise to provide services nationwide, establishing patient data transfer systems that comply with applicable privacy laws, navigating the institutional review board⁴² process for a large provider network, and establishing payment systems with clinics participating in a national network of providers. On March 15, 2007, NIOSH issued a formal request for information from organizations that have an interest in and the capability of developing a national program for responders residing

⁴⁰Contracts were originally established with 11 clinics in eight states, but 1 clinic discontinued its participation in the program after conducting one examination. The 10 active clinics are located in seven states: Arkansas, California, Illinois, Maryland, Massachusetts, New York, and Ohio. Of the 10 active clinics, 7 are AOEC member clinics.

⁴¹According to NIOSH and DCC officials, efforts to provide monitoring services to federal responders residing outside the NYC metropolitan area may be included in the national program.

⁴²Institutional review boards are groups that have been formally designated to review and monitor biomedical research involving human subjects, such as research based on data collected from screening and monitoring examinations.

outside the NYC metropolitan area.⁴³ In this request, NIOSH described the scope of a national program as offering screening, monitoring, and treatment services to about 3,000 nonfederal responders through a national network of occupational health facilities. NIOSH also specified that the program's facilities should be located within reasonable driving distance to responders and that participating facilities must provide copies of examination records to DCC. In May 2007, NIOSH approved a request from DCC to redirect about \$125,000 from the June 2006 award to establish a contract with a company to provide screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area. Subsequently, DCC contracted with QTC Management, Inc.,⁴⁴ one of the four organizations that had responded to NIOSH's request for information. DCC's contract with QTC does not include treatment services, and NIOSH officials are still exploring how to provide and pay for treatment services for nonfederal responders residing outside the NYC metropolitan area.⁴⁵ QTC has a network of providers in all 50 states and the District of Columbia and can use internal medicine and occupational medicine doctors in its network to provide these services. In addition, DCC and QTC have agreed that QTC will identify and subcontract with providers outside of its network to screen and monitor nonfederal responders who do not reside within 25 miles of a QTC provider.⁴⁶ In June 2007, NIOSH awarded \$800,600 to DCC for coordinating the provision of screening and monitoring examinations, and QTC will receive a portion of this award from DCC to provide about 1,000 screening and monitoring examinations through May 2008. According to a NIOSH official, QTC's providers have begun conducting screening examinations, and by the end

⁴³Department of Health and Human Services, *Sources Sought Notice: National Medical Monitoring and Treatment Program for World Trade Center (WTC) Rescue, Recovery, and Restoration Responders and Volunteers*, SSA-WTC-001 (Mar. 15, 2007).

⁴⁴QTC is a private provider of government-outsourced occupational health and disability examination services.

⁴⁵Some nonfederal responders residing outside the NYC metropolitan area may have access to privately funded treatment services. In June 2005 the American Red Cross funded AOEC to provide treatment services for these responders. As of June 2007, AOEC had contracted with 40 of its member clinics located in 27 states and the District of Columbia to provide these services. An American Red Cross official told us in September 2007 that funding for AOEC to provide treatment services would continue through June 2008.

⁴⁶As of June 2007, DCC identified 1,151 nonfederal responders residing outside the NYC metropolitan area who requested screening and monitoring services and were too ill or lacked financial resources to travel to NYC or any of DCC's 10 contracted clinics.

of August 2007, 18 nonfederal responders had completed screening examinations, and 33 others had been scheduled.

NIOSH Awarded Funding for Treatment Services to Four WTC Health Programs

In fall 2006, NIOSH awarded and set aside funds totaling \$51 million from its \$75 million appropriation for four WTC health programs in the NYC metropolitan area to provide treatment services to responders enrolled in these programs. Of the \$51 million, NIOSH awarded about \$44 million for outpatient services to the FDNY WTC program, the NY/NJ WTC Consortium, Project COPE, and the POPPA program. NIOSH made the largest awards to the two programs from which almost all responders receive medical services, the FDNY WTC program and NY/NJ WTC Consortium (see table 2). In July 2007 we reported that officials from the FDNY WTC program and the NY/NJ WTC Consortium expected that their awards for outpatient treatment would be spent by the end of fiscal year 2007.⁴⁷⁻⁴⁸ In addition to the \$44 million it awarded for outpatient services, NIOSH set aside about \$7 million for the FDNY WTC program and NY/NJ WTC Consortium to pay for responders' WTC-related inpatient hospital care as needed.⁴⁹

⁴⁷In August 2007 a NIOSH official told us that NIOSH did not expect that all of these funds would be spent by September 30, 2007.

⁴⁸In addition to funding from NIOSH, the FDNY WTC program and the NY/NJ WTC Consortium received funding in 2006 from the American Red Cross to provide treatment services. In September 2007 an official from the American Red Cross told us that it was the organization's understanding that most of the clinics in the NY/NJ WTC Consortium had expended the American Red Cross funds but that one of the Consortium's clinics was expected to request a no-cost 6-month extension up to the end of calendar year 2007. The American Red Cross had already granted a similar extension for the same period to the FDNY WTC program.

⁴⁹Of the \$24 million remaining from the \$75 million appropriation to CDC, NIOSH used about \$15 million to support monitoring and other WTC-related health services conducted by the FDNY WTC program and NY/NJ WTC Consortium. ATSDR awarded \$9 million to the WTC Health Registry to continue its collection of health data.

Table 2: NIOSH Awards to WTC Health Programs for Providing Treatment Services, 2006

Dollars in millions		
WTC health program	Amount of award ^a	Date of award
NY/NJ WTC Consortium	\$20.8	October 26, 2006
FDNY WTC Medical Monitoring and Treatment Program	18.7	October 26, 2006
Project COPE	3.0 ^b	September 19, 2006
POPPA program	1.5 ^c	September 19, 2006
Total amount of awards	\$44.0	

Source: NIOSH.

^aAmount is rounded to the nearest \$0.1 million.

^bNIOSH will provide \$1 million annually to Project COPE beginning in September 2006 through September 2008, for a total award of \$3 million.

^cNIOSH will provide \$500,000 annually to the POPPA program beginning in September 2006 through September 2008, for a total award of \$1.5 million.

The FDNY WTC program and NY/NJ WTC Consortium used their awards from NIOSH to continue providing treatment services to responders and to expand the scope of available treatment services. Before NIOSH made its awards for treatment services, the treatment services provided by the two programs were supported by funding from private philanthropies and other organizations. According to officials of the NY/NJ WTC Consortium, this funding was sufficient to provide only outpatient care and partial coverage for prescription medications. The two programs used NIOSH's awards to continue to provide outpatient services to responders, such as treatment for gastrointestinal reflux disease, upper and lower respiratory disorders, and mental health conditions. They also expanded the scope of their programs by offering responders full coverage for their prescription medications for the first time. A NIOSH official told us that some of the commonly experienced WTC conditions, such as upper airway conditions, gastrointestinal disorders, and mental health disorders, are frequently treated with medications that can be costly and may be prescribed for an extended period of time. According to an FDNY WTC program official, prescription medications are now the largest component of the program's treatment budget.

The FDNY WTC program and NY/NJ WTC Consortium also expanded the scope of their programs by paying for inpatient hospital care for the first time, using funds from the \$7 million that NIOSH had set aside for this purpose. According to a NIOSH official, NIOSH pays for hospitalizations

that have been approved by the medical directors of the FDNY WTC program and NY/NJ WTC Consortium through awards to the programs from the funds NIOSH set aside for this purpose. By August 31, 2007, federal funds had been used to support 34 hospitalizations of responders, 28 of which were referred by the NY/NJ WTC Consortium's Mount Sinai clinic, 5 by the FDNY WTC program, and 1 by the NY/NJ WTC Consortium's CUNY Queens College program. Responders have received inpatient hospital care to treat, for example, asthma, pulmonary fibrosis,⁵⁰ and severe cases of depression or PTSD. According to a NIOSH official, one responder is now a candidate for lung transplantation and if this procedure is performed, it will be covered by federal funds. If funds set aside for hospital care are not completely used by the end of fiscal year 2007, he said they could be carried over into fiscal year 2008 for this purpose or used for outpatient services.

After receiving NIOSH's funding for treatment services in fall 2006, the NY/NJ WTC Consortium ended its efforts to obtain reimbursement from health insurance held by responders with coverage.⁵¹ Consortium officials told us that efforts to bill insurance companies involved a heavy administrative burden and were frequently unsuccessful, in part because the insurance carriers typically denied coverage for work-related health conditions on the grounds that such conditions should be covered by state workers' compensation programs. However, according to officials from the NY/NJ WTC Consortium, responders trying to obtain workers' compensation coverage routinely experienced administrative hurdles and significant delays, some lasting several years. Moreover, according to these program officials, the majority of responders enrolled in the program either had limited or no health insurance coverage. According to a labor official, responders who carried out cleanup services after the WTC attack often did not have health insurance, and responders who were construction workers often lost their health insurance when they became too ill to work the number of days each quarter or year required to maintain eligibility for insurance coverage.

⁵⁰Pulmonary fibrosis is a condition characterized by the formation of scar tissue in the lungs following the inflammation of lung tissue.

⁵¹The NY/NJ WTC Consortium now offers treatment services at no cost to responders; however, prior to fall 2006 the program attempted when possible to obtain reimbursement for its services from health insurance carriers and to obtain applicable copayments from responders.

According to a NIOSH official, although the agency had not received authorization as of August 30, 2007, to use the \$50 million emergency supplemental appropriation made to CDC in May 2007, NIOSH was formulating plans for use of these funds to support the WTC treatment programs in fiscal year 2008.

Lessons from WTC Health Programs Could Assist with Response to Future Disasters

Officials involved in the WTC health programs implemented by government agencies or private organizations—as well as officials from the federal administering agencies—derived lessons from their experiences that could help with the design of such programs in the future. Lessons include the need to quickly identify and contact responders and others affected by a disaster, the value of a centrally coordinated approach for assessing individuals' health, and the importance of addressing both physical and mental health effects.

Officials involved in WTC monitoring efforts discussed with us the importance of quickly identifying and contacting responders and others affected by a disaster.⁵² They said that potential monitoring program participants could become more difficult to locate as time passed.⁵³ In addition, potential participants' ability to recall the events of a disaster may decrease over time, making it more difficult to collect accurate information about their experiences and health. However, the time it takes to design, fund, approve, and implement monitoring programs can lead to delays in contacting the people who were affected. For example, the WTC Health Registry received funding in July 2002 but did not begin collecting data until September 2003—2 years after the disaster. From July 2002 through September 2003, the program's activities included developing the Registry protocol, testing the questionnaire, and obtaining approval from institutional review boards. Our work on Hurricane Katrina found that no one was assigned responsibility for collecting data on the total number of

⁵²See, for example, [GAO-06-481T](#).

⁵³The extent of the challenge of locating potential participants varied among WTC health programs, depending on the population involved. For example, FDNY had contact information for all potential participants in its monitoring program because they were employed by FDNY during or after the disaster. In contrast, the NY/NJ WTC Consortium and the WTC Health Registry had to expend considerable effort to identify people who were eligible to participate and inform them about the programs.

response and recovery workers deployed to the Gulf and no agency collected it.⁵⁴⁻⁵⁵

Furthermore, officials from the WTC health programs told us that health monitoring for future disasters could benefit from additional centrally coordinated planning. Such planning could facilitate the collection of compatible data among monitoring efforts, to the extent that this is appropriate. Collecting compatible data could allow information from different programs to be integrated and contribute to improved data analysis and more useful research. In addition, centrally coordinated planning could help officials determine agency roles so important aspects of disaster response efforts are not overlooked. For example, as we reported in March 2007,⁵⁶ federal agencies involved in the response to the Hurricane Katrina disaster disagreed over which agency should fund the medical monitoring of responders. We recommended that the relevant federal agencies involved clearly define their roles and resolve this disagreement so that the need may be met in future disasters. In general, there has been no systematic monitoring of the health of responders to Hurricane Katrina.

Officials also told us that efforts to address health effects should be comprehensive—encompassing responders’ physical and mental health. Officials from the NY/NJ WTC Consortium told us that the initial planning for their program had focused primarily on screening participants’ physical health and that they originally budgeted only for basic mental health screening. Subsequently, they recognized a need for more in-depth mental health screening, including greater participation of mental health professionals, but the program’s federal funding was not sufficient to cover such screening. By collaborating with the Mount Sinai School of Medicine Department of Psychiatry, program officials were able to obtain philanthropic funding to develop a more comprehensive mental health questionnaire, provide in-person psychiatric screening, and, when necessary, provide more extensive evaluations. Our work on Hurricane Katrina found problems with the provision of mental health services during the response to the disaster. Not all responders who needed mental

⁵⁴See [GAO-07-193](#).

⁵⁵Ten federal agencies, however, estimated the number of federal workers each deployed to the Gulf, and six of the ten also tracked the number of workers employed by their contractors.

⁵⁶See [GAO-07-193](#).

health services received them. For example, it was difficult to get mental health counselors to go to the base camps where workers lived during the response and to get counselors to provide services during off-hours to workers who did not have standard work schedules.

Concluding Observations

Screening and monitoring the health of the people who responded to the September 11, 2001, attack on the World Trade Center are critical for identifying health effects already experienced by responders or those that may emerge in the future. In addition, collecting and analyzing information produced by screening and monitoring responders can give health care providers information that could help them better diagnose and treat responders and others who experience similar health effects.

While some groups of responders are eligible for screening and follow-up physical and mental health examinations through the federally funded WTC health programs, other groups of responders are not eligible for comparable services or may not always find these services available. Federal responders have been eligible only for the initial screening examination provided through the WTC Federal Responder Screening Program. NIOSH, the administrator of the program, has been considering expanding the program to include monitoring but has not done so. In addition, many responders who reside outside the NYC metropolitan area have not been able to obtain screening and monitoring services because available services are too distant. Moreover, HHS has repeatedly interrupted the programs it established for federal responders and nonfederal responders outside of NYC, resulting in periods when no services were available to them.

HHS continues to fund and coordinate the WTC health programs and has key federal responsibility for ensuring the availability of services to responders. HHS and its agencies have recently taken steps to move toward providing screening and monitoring services to federal responders and to nonfederal responders living outside of the NYC area. However, these efforts are not complete, and the stop-and-start history of the department's efforts to serve these groups does not provide assurance that the latest efforts to extend screening and monitoring services to these responders will be successful and will be sustained over time. Therefore we recommended in July 2007 that the Secretary of HHS take expeditious action to ensure that health screening and monitoring services are available to all people who responded to the attack on the WTC, regardless of who their employer was or where they reside. As of September 2007 the department has not responded to this recommendation.

Finally, important lessons have been learned from the WTC disaster. These include the need to quickly identify and contact responders and others affected by a disaster, the value of a centrally coordinated approach for assessing individuals' health, and the importance of addressing both physical and mental health effects. Consideration of these lessons by federal agencies is important in planning for the response to future disasters.

Mr. Chairman, this completes my prepared remarks. I would be happy to respond to any questions you or other members of the committee may have at this time.

Contacts and Acknowledgments

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Appendix I: Abbreviations

AOEC	Association of Occupational and Environmental Clinics
ASPR	Office of the Assistant Secretary for Preparedness and Response
ATSDR	Agency for Toxic Substances and Disease Registry
CDC	Centers for Disease Control and Prevention
DCC	Data and Coordination Center
FDNY	New York City Fire Department
FEMA	Federal Emergency Management Agency
FOH	Federal Occupational Health Services
HHS	Department of Health and Human Services
NIOSH	National Institute for Occupational Safety and Health
NYC	New York City
NY/NJ	New York/New Jersey
NYPD	New York City Police Department
POPPA	Police Organization Providing Peer Assistance
PTSD	post-traumatic stress disorder
WTC	World Trade Center

Related GAO Products

September 11: HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders. [GAO-07-892](#). Washington, D.C.: July 23, 2007.

Disaster Preparedness: Better Planning Would Improve OSHA's Efforts to Protect Workers' Safety and Health in Disasters. [GAO-07-193](#). Washington, D.C.: March 28, 2007.

September 11: HHS Has Screened Additional Federal Responders for World Trade Center Health Effects, but Plans for Awarding Funds for Treatment Are Incomplete. [GAO-06-1092T](#). Washington, D.C.: September 8, 2006.

September 11: Monitoring of World Trade Center Health Effects Has Progressed, but Program for Federal Responders Lags Behind. [GAO-06-481T](#). Washington, D.C.: February 28, 2006.

September 11: Monitoring of World Trade Center Health Effects Has Progressed, but Not for Federal Responders. [GAO-05-1020T](#). Washington, D.C.: September 10, 2005.

September 11: Health Effects in the Aftermath of the World Trade Center Attack. [GAO-04-1068T](#). Washington, D.C.: September 8, 2004.

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