SEPTEMBER 11

Improvements Needed in Availability of Health Screening and Monitoring Services for Responders

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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.

This testimony is based on and updates GAO’s report, September 11: HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders (GAO-07-892, July 23, 2007). In this testimony, GAO discusses the status of (1) 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) NIOSH’s awards to WTC health program grantees for treatment services.

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.

What GAO Found

In July 2007, following a re-examination 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 early 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.

NIOSH has awarded treatment funds to four WTC health programs in the NYC area. In fall 2006, NIOSH awarded $44 million for outpatient treatment and set aside $7 million for hospital care. The New York/New Jersey WTC Consortium and the New York City Fire Department WTC program, which received the largest awards, used NIOSH’s funding to continue outpatient services, offer full coverage for prescriptions, and cover hospital care.
Mr. Chairman and Members of the Subcommittee:

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). 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. 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. 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.

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1 A list of abbreviations used in this testimony is in app. I.
2 The Staten Island site is the landfill that is the off-site location of the WTC recovery operation.
3 In 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.
4 One 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, 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 onetime screening examinations for responders who were federal employees when they responded to the WTC attack, had accomplished little. 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. 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.

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. 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 services.

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5 See, 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.


7 See GAO-06-1092T.

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


10 See 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.\textsuperscript{11} As you requested, I will discuss the status of (1) 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, and (3) NIOSH’s awards to grantees for treatment services.

To assess the status of services provided by the WTC Federal Responder Screening Program, we obtained and reviewed program data and documents from HHIS, including applicable interagency agreements. We interviewed officials from the HHIS entities involved in administering and implementing the program: NIOSH and two HHIS offices, the Federal Occupational Health Services (FOH)\textsuperscript{12} and the Office of the Assistant Secretary for Preparedness and Response (ASPR).\textsuperscript{13} To assess the status of 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 the status of NIOSH’s awards to grantees for treatment services, we obtained documents and interviewed officials from NIOSH. We also interviewed officials from two


\textsuperscript{12}FOH is a service unit within HHIS’s Program Support Center that provides occupational health services to federal government departments and agencies located throughout the United States.

\textsuperscript{13}ASPR coordinates and directs HHIS’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.
WTC health program grantees\textsuperscript{14} from which the majority of responders receive medical services: the NY/NJ WTC Consortium\textsuperscript{15} 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. We conducted our work from November 2006 through July 2007—and updated selected information in August and September 2007—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 early September 2007 the department has not responded to this recommendation. Finally, we also reported that NIOSH had awarded and set aside treatment funds totaling $51 million from its $75 million appropriation for four NYC-area programs.

\textsuperscript{14}NIOSH 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.

\textsuperscript{15}In previous reports we have also referred to this program as the worker and volunteer WTC program.
Background

The tens of thousands of individuals 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. 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 suggested that exposed firefighters on average experienced a decline in lung function equivalent to that which would be produced by 12 years of aging. 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. Commonly reported mental health effects among responders and other affected individuals included symptoms associated with post-traumatic stress disorder (PTSD).

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16There 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.


18Banauch et al., “Pulmonary Function.”

19Wheeler et al., “Asthma Diagnosed.”
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. 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. Clinicians also anticipate that other health effects, such as immunological disorders and cancers, may emerge over time.

### 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. 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

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22 In 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.
(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. 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.

The 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.

Project 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>
<thead>
<tr>
<th>Program</th>
<th>HHS administering agency or component</th>
<th>Implementing agency, component, or organization</th>
<th>Eligible population</th>
<th>Services provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>FDNY WTC Medical Monitoring and Treatment Program</td>
<td>NIOSH</td>
<td>FDNY Bureau of Health Services</td>
<td>Firefighters and emergency medical service technicians</td>
<td>• Initial screening &lt;br&gt; • Follow-up medical monitoring &lt;br&gt; • Treatment of WTC-related physical and mental health conditions</td>
</tr>
<tr>
<td>NY/NJ WTC Consortium</td>
<td>NIOSH</td>
<td>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)</td>
<td>All responders, excluding FDNY firefighters and emergency medical service technicians and current federal employees*</td>
<td>• Initial screening &lt;br&gt; • Follow-up medical monitoring &lt;br&gt; • Treatment of WTC-related physical and mental health conditions</td>
</tr>
<tr>
<td>WTC Federal Responder Screening Program</td>
<td>NIOSH</td>
<td>FOH</td>
<td>Current federal employees who responded to the WTC attack in an official capacity</td>
<td>• Onetime screening &lt;br&gt; • Referrals to employee assistance programs and specialty diagnostic services⁵</td>
</tr>
<tr>
<td>WTC Health Registry</td>
<td>Agency for Toxic Substances and Disease Registry (ATSDR)</td>
<td>NYC Department of Health and Mental Hygiene</td>
<td>Responders and people living or attending school in the area of the WTC or working or present in the vicinity on September 11, 2001</td>
<td>• Long-term monitoring through periodic surveys</td>
</tr>
<tr>
<td>Project COPE</td>
<td>NIOSH</td>
<td>Collaboration between the NYC Police Foundation and Columbia University Medical Center</td>
<td>New York City Police Department (NYPD) uniformed and civilian employees and their family members</td>
<td>• Hotline, mental health counseling, and referral services; some services provided by Columbia University clinical staff and some by other clinicians</td>
</tr>
<tr>
<td>POPPA program</td>
<td>NIOSH</td>
<td>POPPA program</td>
<td>NYPD uniformed employees</td>
<td>• Hotline, mental health counseling, and referral services; some services provided by trained NYPD officers and some by mental health professionals</td>
</tr>
</tbody>
</table>

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.

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

⁵Until December 26, 2006, ASPR was the administrator.
FOH 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. 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), as part of the approximately

25The WTC Health Registry also provides information on where participants can seek health care.

26FEMA 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. 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. FEMA also entered into an agreement with 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. 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. 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.


29The 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.

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 2005 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. 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.

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31The program previously suspended examinations from March 2004 to December 2005. See GAO-06-481T.

32The agreement was a modification of ASPR’s February 2006 interagency agreement with NIOSH that covers screenings for former federal employees.

33Before 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.
March 2003: FEMA and ASPR enter agreement to establish WTC Federal Responder Screening Program with ASPR as the administrator.

April 2003: ASPR and FOH enter agreement for conducting screening examinations.

June 2003: FOH begins screening examinations.

January 2004: HHS places program on hold.

March 2004: FOH conducts last screening examination.

April 2005: APR and ATSDR enter agreement to identify and contact federal responders and establish a database of names.

July 2005: ASPR and FOH revise agreement to expand clinical services and provide referrals for specialty diagnostic services.

October 2005: ASPR opens Web site for federal responders to register for screening examinations.

December 2005: FOH resumes examinations for current federal employees.

February 2006: ASPR and NIOSH reach agreement for screening former federal employees.

April 2006: FOH stops scheduling and paying for specialty diagnostic services.

December 2006: ASPR transfers administration of the program to NIOSH.

January 2007: HHS places program on hold.

March 2007: FOH resumes scheduling and paying for specialty diagnostic services for previously screened responders.


Period during which program was conducting screening examinations.

Period during which program was scheduling and paying for specialty diagnostic services.

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.

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

*In providing referrals for specialty diagnostic services, FOH schedules and pays for the diagnostic services.*

*After 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. 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 onetime 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 federal

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*In 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.*
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.\(^{35}\) 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.\(^{36}\) 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.\(^{37}\) 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

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\(^{35}\) According 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.

\(^{36}\) Around 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.

\(^{37}\) In 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. 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. 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 board 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 outside the NYC metropolitan area.

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38Contracts 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.

39According 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.

40Institutional 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.\textsuperscript{41} 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.,\textsuperscript{42} 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.\textsuperscript{43} 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.\textsuperscript{44} 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


\textsuperscript{42}QTC is a private provider of government-outsourced occupational health and disability examination services.

\textsuperscript{43}Some 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.

\textsuperscript{44}As 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.\(^45\)\(^46\) 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.\(^47\)

\(^45\)In August 2007 a NIOSH official told us that NIOSH did not expect that all of these funds would be spent by September 30, 2007.

\(^46\)In 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.

\(^47\)Of 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

<table>
<thead>
<tr>
<th>WTC health program</th>
<th>Amount of award</th>
<th>Date of award</th>
</tr>
</thead>
<tbody>
<tr>
<td>NY/NJ WTC Consortium</td>
<td>$20.8</td>
<td>October 26, 2006</td>
</tr>
<tr>
<td>FDNY WTC Medical Monitoring and Treatment Program</td>
<td>18.7</td>
<td>October 26, 2006</td>
</tr>
<tr>
<td>Project COPE</td>
<td>3.0</td>
<td>September 19, 2006</td>
</tr>
<tr>
<td>POPPA program</td>
<td>1.5</td>
<td>September 19, 2006</td>
</tr>
<tr>
<td><strong>Total amount of awards</strong></td>
<td><strong>$44.0</strong></td>
<td></td>
</tr>
</tbody>
</table>

Source: NIOSH.

*Amount is rounded to the nearest $0.1 million.

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

NIOSH 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 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, 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. 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.

48Pulmonary fibrosis is a condition characterized by the formation of scar tissue in the lungs following the inflammation of lung tissue.

49The 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 co-payments 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.

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 early September 2007 the department has not responded to this recommendation.

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

Contacts and Acknowledgments

For further information about this testimony, please contact Cynthia A. Bascetta at (202) 512-7114 or bascettac@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this statement. Helene F. Toiv, Assistant Director; Hernan Bozzolo; Frederick Caison; Anne Dievler; and Roseanne Price made key contributions to this statement.
## Appendix I: Abbreviations

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