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SEPTEMBER 11

HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders





Highlights of [GAO-07-892](#), a report to congressional requesters

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Why GAO Did This Study

Responders to the World Trade Center (WTC) attack were exposed to many hazards, and concerns remain about long-term health effects of the disaster and the availability of health care services for those affected. In 2006, GAO reported on problems with the Department of Health and Human Services' (HHS) WTC Federal Responder Screening Program and on the Centers for Disease Control and Prevention's (CDC) distribution of treatment funding.

GAO was asked to update its 2006 testimony. GAO assessed the status of (1) services provided by the WTC Federal Responder Screening Program, (2) efforts by CDC'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 grantees for treatment services and efforts to estimate service costs. GAO reviewed program documents and interviewed HHS officials, grantees, and others.

What GAO Recommends

GAO recommends that the Secretary of HHS expeditiously ensure that screening and monitoring services are available for (1) federal responders and (2) nonfederal responders residing outside the NYC area. In its comments on a draft of GAO's report, HHS said that the report was generally accurate. HHS did not comment on GAO's recommendations. www.gao.gov/cgi-bin/getrpt?GAO-07-892.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Cynthia Bascetta at (202) 512-7114 or bascettac@gao.gov.

What GAO Found

HHS's WTC Federal Responder Screening Program has had difficulties ensuring the uninterrupted availability of services for federal responders. From January 2007 to May 2007, the program stopped scheduling screening examinations because there was a change in the administration of the WTC Federal Responder Screening Program, and certain interagency agreements were not established in a timely way to keep the program fully operational. In April 2006 the program also stopped scheduling and paying for specialty diagnostic services because a contract with the program's new provider network did not cover these services. Almost a year later, the contract was modified, and the program resumed scheduling and paying for these services in March 2007. NIOSH is considering expanding the WTC Federal Responder Screening Program to include monitoring—follow-up physical and mental health examinations—and is assessing options for funding and service delivery. 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 7 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, these efforts are incomplete.

NIOSH has awarded treatment funds to four NYC-area programs, but does not have a reliable cost estimate of serving responders. 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. Program officials expect that NIOSH's outpatient treatment awards will be spent by the end of fiscal year 2007. NIOSH lacks a reliable estimate of service costs because the estimate that NIOSH and its grantees developed included potential costs for certain program changes that may not be implemented, and in the absence of actual treatment cost data, they relied on questionable assumptions. It is unclear whether the estimate overstates or understates the cost of serving responders. To improve future cost estimates, HHS officials have required the two largest grantees to report detailed cost data.

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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
EPA	Environmental Protection Agency
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

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United States Government Accountability Office
Washington, DC 20548

July 23, 2007

The Honorable Christopher Shays
Ranking Member
Subcommittee on National Security and Foreign Affairs
Committee on Oversight and Government Reform
House of Representatives

The Honorable Vito J. Fossella
House of Representatives

The Honorable Carolyn B. Maloney
House of Representatives

Tens of thousands of people served as responders in the aftermath of the World Trade Center (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.¹ These responders were exposed to numerous physical hazards, environmental toxins, and psychological trauma. More than 5 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 report as the WTC health programs.^{2,3} The Department of Health and Human Services (HHS)

¹In this report, “responders” refers to anyone involved in rescue, recovery, or cleanup activities at or near the vicinity of the WTC or Staten Island site, the landfill that is the off-site location of the WTC recovery operation.

²In this report, “screening” refers to initial physical and mental health examinations of responders. “Monitoring” refers to tracking the health of responders over time, either through periodic surveys or through follow-up physical and mental health examinations.

³One 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.

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. We have previously reported on the implementation of these programs and their progress in providing services to responders,⁴ 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 lagged behind the other programs and accomplished little.⁵ HHS established the program in June 2003 and then suspended the program’s activities in March 2004, in part because of difficulties identifying eligible federal responders and providing any necessary diagnostic services related to responders’ screening examinations. After taking steps to address these concerns, HHS resumed the program in December 2005; when we testified 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.⁶ We also reported that the National Institute for Occupational Safety and Health (NIOSH), a component of HHS’s Centers for Disease Control and Prevention (CDC) responsible for administering most of the WTC health programs for responders, had begun to take steps to provide access to screening, monitoring, and treatment services for nonfederal responders who reside outside the New York City (NYC) metropolitan area.⁷

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

⁴GAO, *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); *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); *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: Health Effects in the Aftermath of the World Trade Center Attack*, [GAO-04-1068T](#) (Washington, D.C.: Sept. 8, 2004).

⁵See [GAO-05-1020T](#) and [GAO-06-481T](#).

⁶See [GAO-06-1092T](#).

⁷In general, the WTC health programs provide services in the NYC metropolitan area.

responders.^{8,9} This appropriation was available to provide health care treatment for responders, the first time an appropriation was specifically available for this purpose. We reported that in August 2006, CDC had awarded \$1.5 million to the FDNY WTC Medical Monitoring and Treatment Program from this appropriation and almost \$1.1 million to the New York/New Jersey (NY/NJ) WTC Consortium for treatment-related 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, in part because of uncertainty about the cost of providing these services.

You requested that we update information provided in our September 2006 testimony. Specifically, in this report we assess 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, as well as efforts to estimate the cost of serving responders.

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)¹⁰ and the Office of the Assistant Secretary for Preparedness and Response (ASPR).¹¹ 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 who reside outside the NYC metropolitan area,

⁸Department of Defense Appropriations Act, 2006, Pub. L. No. 109-148, § 5011(b), 119 Stat. 2680, 2814 (2005).

⁹See [GAO-06-1092T](#).

¹⁰FOH 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.

¹¹ASPR 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 report, regardless of the time period discussed.

including the Mount Sinai School of Medicine 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 and efforts to estimate the cost of serving responders, we obtained documents and interviewed officials from NIOSH, HHS's Office of the Assistant Secretary for Health, and HHS's Office of the Assistant Secretary for Planning and Evaluation.¹² We also interviewed officials from two WTC health program grantees¹³ from which the majority of responders receive medical services: the NY/NJ WTC Consortium¹⁴ and the FDNY WTC program. In addition, we interviewed officials from the American Red Cross, which has funded treatment services for responders. We reviewed a 2007 report submitted to the mayor of New York City that included an estimate of the cost of providing health services to responders,¹⁵ and we attended a briefing by a NYC official who participated in compiling that estimate. To do the work for our review, we relied 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 in accordance with generally accepted government auditing standards.

Results in Brief

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. After resuming screening examinations in December 2005 and conducting them

¹²The Assistant Secretary for Health is chief public health advisor for the Secretary of HHS; the Assistant Secretary for Planning and Evaluation is the principal advisor to the Secretary on policy development and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis.

¹³NIOSH provides funds to the programs through cooperative agreements, but refers to award recipients as grantees. Therefore, in this report we use the term grantee when referring to NIOSH's award recipients.

¹⁴In previous reports we have also referred to this program as the worker and volunteer WTC Program.

¹⁵See World Trade Center Health Panel, *Addressing the Health Impacts of 9-11: Report and Recommendations to Mayor Michael R. Bloomberg* (New York: January 2007).

for about a year, the program again 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 a timely way to keep the program fully operational. Second, the program's provision of specialty diagnostic services by ear, nose, and throat doctors; cardiologists; and pulmonologists has also been intermittent. The program did not schedule and pay for these specialty diagnostic services from April 2006 to March 2007 because the program's contract with a new provider network did not cover these services. A NIOSH official told us that NIOSH is considering expanding the WTC Federal Responder Screening Program to include monitoring examinations—follow-up physical and mental health examinations—and is 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.

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. NIOSH made two initial efforts to provide screening and monitoring services for these responders. The first effort, in which NIOSH arranged for AOEC to provide screening services, began in late 2002 and ended in July 2004. From August 2004 until June 2005, NIOSH did not fund any organization to provide services to nonfederal responders outside the NYC metropolitan area. In June 2005, NIOSH began its second effort by awarding funds to the Mount Sinai School of Medicine Data and Coordination Center (DCC) to provide both screening and monitoring services. However, DCC had difficulty establishing a network of providers that could serve responders residing throughout the country—ultimately contracting with only 10 clinics in 7 states. In early 2006, NIOSH began exploring how to establish a national program that would expand the network of providers to provide services for nonfederal responders residing outside the NYC metropolitan area. However, these efforts are incomplete. In May 2007, NIOSH and DCC arranged for a national network of providers to screen and monitor nonfederal responders, and according to DCC officials, the national network will implement a pilot program consisting of 20 examinations in summer 2007. NIOSH is still investigating how to provide and pay for treatment services for nonfederal responders who reside outside the NYC metropolitan area.

CDC's NIOSH awarded and set aside funds totaling \$51 million from its \$75 million appropriation for four WTC health programs located in the NYC metropolitan area to provide treatment services to responders, but does not have a reliable cost estimate of serving responders. In fall 2006, NIOSH awarded \$44 million to four programs to provide outpatient treatment services to responders enrolled in their programs. NIOSH made the largest outpatient treatment awards to the two WTC health programs from which almost all responders receive medical services, the FDNY WTC program and the NY/NJ WTC Consortium. NIOSH made smaller awards to two WTC health programs that provide mental health services to members of the New York City Police Department (NYPD), Project COPE and the Police Organization Providing Peer Assistance (POPPA) program. The FDNY WTC program and NY/NJ WTC Consortium used NIOSH's awards to continue to provide outpatient treatment services and to expand the scope of treatment by offering full coverage for prescription medications. NIOSH also set aside \$7 million for the FDNY WTC program and NY/NJ WTC Consortium for providing inpatient hospital care to responders. Officials from these two programs expect that their awards for outpatient treatment will be spent by the end of fiscal year 2007. Efforts by NIOSH and its grantees in 2007 to estimate the cost of monitoring and treating responders in several of the WTC programs have not produced reliable results because the estimate included potential costs for certain program changes that may not be implemented as well as some costs that were mistakenly included, such as a double counting of indirect program support costs. In addition, in the absence of actual treatment cost data, the estimate is based in part on questionable assumptions. For example, NIOSH and its grantees adjusted the estimate to account for different treatment utilization levels—the complexity or volume of care provided to responders based on their medical needs—but NIOSH and its grantees did not have data to support the accuracy of the specific cost adjustments they made. It is unclear whether the 2007 cost estimate overstated or understated the annual costs of monitoring and treating responders. To improve the reliability of future cost estimates, HHS officials required the NY/NJ WTC Consortium and the FDNY WTC program to begin reporting detailed cost and treatment data, which the programs began submitting in February and March 2007, respectively.

HHS continues to fund and coordinate the WTC health programs and has key federal responsibility for ensuring the availability of services to responders. We are recommending 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.

In commenting on a draft of this report, HHS stated that our report was generally an accurate and appropriate account of its activities and accomplishments concerning health services for responders to the WTC disaster. HHS did not comment on our recommendations.

Background

When the WTC buildings collapsed on September 11, 2001, an estimated 250,000 to 400,000 people in the vicinity were immediately exposed to a noxious mixture of dust, debris, smoke, and potentially toxic contaminants, such as pulverized concrete, fibrous glass, particulate matter, and asbestos.¹⁶ Those affected included people residing, working, or attending school in the vicinity of the WTC and emergency responders. In the days, weeks, and months that followed the attack, tens of thousands of responders were involved in some capacity.¹⁷ These responders included personnel from many federal, state, and NYC government agencies and private organizations, as well as volunteers.¹⁸

Health Effects

A wide variety of physical and mental health effects have been observed and reported among people who were involved in rescue, recovery, and cleanup operations and among those who lived and worked in the vicinity of the WTC buildings.¹⁹ Physical health effects included injuries and

¹⁶More than 20,000 residences in Lower Manhattan may have been affected by the dust that blanketed the area. On June 20, 2007, GAO testified on the Environmental Protection Agency's (EPA) second program to address indoor contamination. See, GAO, *World Trade Center: Preliminary Observations on EPA's Second Program to Address Indoor Contamination*, [GAO-07-806T](#) (Washington, D.C.: June 20, 2007).

¹⁷There 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.

¹⁸The responders included firefighters, law enforcement officers, emergency medical technicians and paramedics, morticians, health care professionals, construction workers, iron workers, heavy equipment operators, mechanics, engineers, truck drivers, carpenters, telecommunications workers, and day laborers.

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).

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.²⁰ 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.²¹ 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.²²

Clinicians also anticipate that other health effects, such as immunological disorders and cancers, may emerge over time. Clinicians at the FDNY WTC program found an increased incidence of sarcoid-like pulmonary disease involving inflammation of the lungs. Of 26 cases of this sarcoid-like

²⁰Banauch et al., "Pulmonary Function."

²¹R. 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).

²²R. 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).

pulmonary disease, 13 cases were identified during the first year after the WTC attack and 13 cases were found during the next 4 years.²³

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 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. Each program uses a variety of approaches, such as Web sites, toll-free numbers, and community forums, to conduct outreach to eligible populations.

²³G. Izbicki et al, "World Trade Center 'Sarcoid Like' Granulomatous Pulmonary Disease in New York City Fire Department Rescue Workers," *Chest*, vol. 131 (2007).

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 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
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 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"> Onetime 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	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	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, NY/NJ WTC Consortium, NYC Department of Health and Mental Hygiene, 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.

^cFOH 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 these 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 does not provide in-person screening or monitoring, but consists of periodic surveys of self-reported health status and related studies, 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. Clinicians who evaluate and treat responders to the WTC disaster told us they expect that research on health effects from the disaster will not only help researchers understand the health consequences, but also provide information on appropriate treatment options for affected individuals.

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

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 \$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, 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

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

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 New York City. Pub. L. No. 109-148, §5011(b), 119 Stat. 2814.

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 has two subcommittees, one examining finance issues (cost and financing of WTC-related health programs) and the other examining the scientific evidence on the health effects of the WTC disaster. The task force reported to the Secretary of HHS in early April 2007.

WTC Federal Responder Screening Program Has Had Difficulties Ensuring the Availability of Screening Services and Is Not Designed to Provide Monitoring

HHS's WTC Federal Responder Screening Program has not ensured the uninterrupted availability of screening services for federal responders. Since the beginning of the program, the provision of screening examinations has been intermittent (see fig. 1). After the program resumed screening examinations in December 2005³³ and conducted them for about a year, HHS again placed the program on hold in January 2007. From January to May 2007, FOH, the program's implementing agency, did not schedule screening examinations for federal responders. 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 a timely way 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

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).

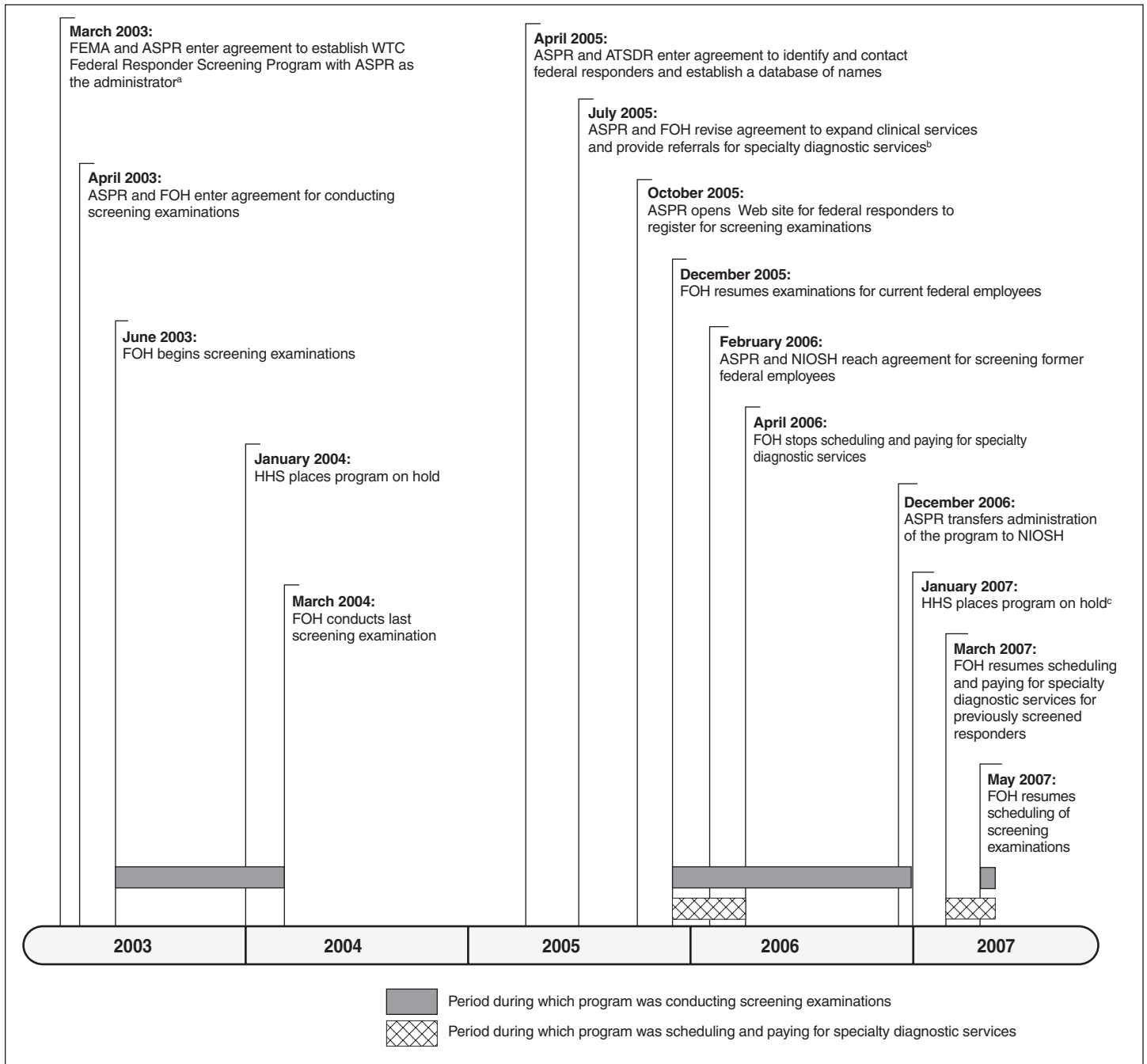
³³The program previously suspended examinations from March 2004 to December 2005. See [GAO-06-481T](#).

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

months for the agreement between NIOSH and FOH to be negotiated and approved.³⁵ After both agencies signed the agreement, FOH resumed scheduling screening examinations for federal responders in May 2007. At that time, there were 28 federal responders waiting to be scheduled for screening examinations.

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 service.

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

The WTC Federal Responder Screening Program's provision of specialty diagnostic services has also been intermittent. The health effects experienced by responders often result in a need for diagnostic services by ear, nose, and throat doctors; cardiologists; and pulmonologists. When these diagnostic services are needed after the initial screening examination, FOH refers responders to these specialists and pays for the services.³⁶ The WTC Federal Responder Screening Program stopped scheduling and paying for these specialty diagnostic services for almost a year, from April 2006 to March 2007. This occurred because in April 2006, FOH contracted with a new provider network to provide various services for 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. FOH was therefore unable to pay for these services for federal responders and stopped scheduling them in April 2006. Almost a year later, in March 2007, FOH modified its contract with the provider network and resumed scheduling and paying for specialty diagnostic services for federal responders. FOH estimated that at that time, 104 responders were waiting for appointments for these services.

The WTC Federal Responder Screening Program was designed to provide a onetime screening examination; however, NIOSH officials told us they want to expand the program to offer monitoring examinations—that is, follow-up physical and mental health examinations—to federal responders.³⁷ Clinicians involved in the monitoring of responders have

³⁶These services are for diagnostic purposes only. FOH does not initiate or pay for treatment.

³⁷Federal responders can currently obtain monitoring through the periodic surveys of the WTC Health Registry.

noted the need for long-term monitoring because some possible health effects, such as cancer, may not appear until many years after a person has been exposed to a harmful agent. NIOSH officials have said that to expand the WTC Federal Responder Screening Program to include monitoring, NIOSH would need to secure funding and determine who would provide the monitoring services. A NIOSH official told us that one option for funding would be for NIOSH to use some of the \$2.1 million of the existing FEMA-ASPR funding to have the WTC Federal Responder Screening Program include monitoring. For this to happen, the NIOSH official said, FEMA, which originally provided the funding to ASPR to establish the program, would have to agree to change the scope of the program. In February 2007, NIOSH sent a letter to FEMA asking whether the funding for the program could be provided directly to NIOSH and whether the funding could be used to support monitoring in addition to the onetime screening examination the program currently offers, but as of June 2007, NIOSH had not received a response from FEMA. NIOSH officials told us that if FEMA does not agree to this arrangement, NIOSH will consider using other funding to pay for monitoring. According to a NIOSH official, if NIOSH either reaches a new agreement with FEMA or decides to pay for monitoring of federal responders by itself, NIOSH would have to either negotiate a new agreement with FOH to provide monitoring, which FOH officials said they would consider doing, or it would have to make arrangements with another program, such as the NY/NJ WTC Consortium, to provide monitoring.

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. NIOSH made two initial efforts to provide screening and monitoring services for these responders. The first effort, in which NIOSH arranged for AOEC to provide screening services, began in late 2002 and ended in July 2004. From August 2004 until June 2005, NIOSH did not fund any organization to provide services to nonfederal responders outside the NYC metropolitan area. In June 2005, NIOSH began its second effort by awarding funds to Mount Sinai's DCC to provide both screening and monitoring services. However, DCC had difficulty establishing a network of providers that could serve nonfederal responders residing throughout the country. In early 2006, NIOSH began exploring how to establish a broader national program that would provide screening and monitoring services, as well as treatment, for nonfederal responders residing outside the NYC metropolitan area. However, these efforts are incomplete. In May 2007, NIOSH and DCC arranged for a national network of providers to

screen and monitor nonfederal responders, and a pilot program consisting of 20 examinations was scheduled to begin in summer 2007.

NIOSH's Initial Efforts to Provide Screening and Monitoring Services for Nonfederal Responders Residing outside the NYC Area Did Not Ensure Availability of These Services

In November 2002, NIOSH began its first effort to provide services for nonfederal responders outside the NYC metropolitan area.³⁸ The exact number of these responders is unknown.³⁹ 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. AOEC then subcontracted with 32 of its member clinics across the country to provide screening services. For its part, AOEC was responsible for establishing a network of providers nationwide through its member clinics, referring nonfederal responders to the AOEC member clinics for screening examinations, working with Mount Sinai to determine responders' program enrollment eligibility, ensuring proper billing, and reimbursing its member clinics for services. From February 2003 to July 2004, the 32 AOEC member clinics screened 588 nonfederal responders nationwide.

An AOEC official told us AOEC experienced challenges in providing the screening services nationwide through its member clinics. This official said, for example, that many nonfederal responders—especially those residing in rural areas—did not enroll in the program because they did not live near an AOEC member clinic. In addition, the process to reimburse AOEC member clinics for clinical examinations required substantial coordination among AOEC, AOEC member clinics, and Mount Sinai. After a nonfederal responder was examined by an AOEC member clinic, Mount Sinai had to review the responder's medical records and determine that all aspects of the examination were completed before AOEC could issue a payment to its member clinic.

³⁸ Around that time, NIOSH was providing screening services for nonfederal responders in the NYC metropolitan area through the NY/NJ WTC Consortium and FDNY's 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.

³⁹ 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.

From August 2004 until June 2005, NIOSH did not fund any organization to provide screening or monitoring services outside the NYC metropolitan area for nonfederal responders. Mount Sinai's subcontract with AOEC to provide screening services ended in July 2004 when NIOSH was establishing cooperative agreements to provide both screening and monitoring services for nonfederal responders nationwide. A NIOSH official told us that from July 2004 until June 2005, NIOSH focused on providing screening and monitoring services for nonfederal responders in the NYC metropolitan area because the majority of nonfederal responders reside there. NIOSH had requested applications from organizations to provide both screening and monitoring services for nonfederal responders and awarded funds to the FDNY WTC program and NY/NJ WTC Consortium to provide these services in the NYC metropolitan area. AOEC applied 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.⁴⁰ AOEC was the only organization that applied to provide screening and monitoring services to these responders.

In June 2005, NIOSH began its second effort to provide services for nonfederal responders residing outside the NYC metropolitan area. Specifically, NIOSH awarded about \$776,000 to DCC to coordinate the provision of screening and monitoring services for these responders.⁴¹ DCC spent about \$387,000 of these funds on providing screening and monitoring services for these responders. In June 2006, NIOSH awarded an additional \$788,000 to DCC to provide screening and monitoring services

⁴⁰According to a NIOSH official, AOEC's application did not adequately address how to coordinate and implement a monitoring program with complex data collection and reporting requirements. In addition, NIOSH officials identified other reasons the application was rejected by reviewers, including the fact that the application lacked an overall statement of programmatic goals or specific aims, the administrative and clinical evaluation plans described in the application were too vague, and the proposed leadership for the program did not include trained mental health professionals.

⁴¹DCC received this amount as a part of its award continuation for DCC's second year of funding. DCC's second year award continuation totaled about \$3,778,000 and was for its role as coordinator for the NY/NJ WTC Consortium. The award continuation was used to pay for all data management, data analysis, and program coordination activities performed from June 2005 through May 2006.

for nonfederal responders residing outside the NYC metropolitan area.⁴² According to a NIOSH official, DCC budgeted about \$393,000 of the \$788,000 for providing these services, and received approval from NIOSH to redirect the remaining amount (\$395,000) for other purposes. 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 7 states to provide screening and monitoring services.⁴³ DCC officials said that as of June 2007, the 10 clinics were monitoring 180 responders.

According to a NIOSH official, there have been several challenges involved in establishing 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 board⁴⁴ process for a large provider network, and establishing payment systems with clinics participating in a national network of providers.

⁴²DCC received this amount as a part of its award continuation for DCC's third year of funding. DCC's third year award continuation totaled about \$3,924,000 and was for its role as coordinator for the NY/NJ WTC Consortium. The award continuation was used to pay for all data management, data analysis, and program coordination activities performed from June 2006 through May 2007.

⁴³Contracts were originally established with 11 clinics in 8 states, but 1 clinic discontinued its participation in the program after conducting one examination. The 10 active clinics are located in Arkansas, California, Illinois, Maryland, Massachusetts, New York, and Ohio. Of the 10 active clinics, 7 are AOEC member clinics.

⁴⁴Institutional 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.

NIOSH Has Recently Taken Steps to Establish a National Program for Nonfederal Responders to Provide Screening, Monitoring, and Treatment Services, but Its Efforts Are Incomplete

Since 2006, NIOSH has been exploring how to establish a national program that would expand the availability of screening and monitoring services, as well as provide treatment services, to nonfederal responders residing outside the NYC metropolitan area.⁴⁵ NIOSH officials have indicated that they would like to expand the availability of screening and monitoring services by establishing a network of providers with locations convenient to all nonfederal responders. NIOSH officials have also indicated that they would like to offer the same set of services to these responders that is offered to nonfederal responders in the NYC metropolitan area—screening, monitoring, and treatment services. NIOSH has considered different approaches for this national program. For example, in early 2006, NIOSH officials considered funding AOEC and its network of 50 member clinics to administer a national program and instructed DCC to discontinue efforts to establish new contracts with clinics nationwide. However, in February 2007, NIOSH officials decided that AOEC would not administer the national program.⁴⁶ 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.⁴⁷ 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 took steps toward establishing the national program, but its efforts are incomplete. 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.

⁴⁵According 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.

⁴⁶A NIOSH official told us that an AOEC network of 50 member clinics would not be sufficient by itself to provide the three services to nonfederal responders nationwide.

⁴⁷Department 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).

Subsequently, DCC contracted with QTC Management, Inc.,⁴⁸ one of the four organizations that had responded to NIOSH's request for information. QTC has a network of providers located across all 50 states and the District of Columbia and will use internal medicine and occupational medicine doctors in its network to provide these services. In addition, QTC will identify and subcontract with providers outside of the QTC network to screen and monitor nonfederal responders who do not reside within 25 miles of a QTC provider.⁴⁹ 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 2008.⁵⁰ According to DCC officials, they are working with QTC to establish examination protocols and administrative systems needed to begin conducting screening and monitoring examinations, and they will begin a pilot program consisting of 20 examinations in summer 2007. 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.⁵¹

⁴⁸QTC is a private provider of government-outsourced occupational health and disability examination services.

⁴⁹As of June 2007, DCC identified 1,151 nonfederal responders residing outside the NYC metropolitan area who requested screening and monitoring services but were too ill or lacked financial resources to travel to NYC or any of DCC's 10 contracted clinics.

⁵⁰In addition to this award, according to a NIOSH official, NIOSH approved DCC's request to use the funds remaining from the June 2005 award, about \$389,000, to provide screening and monitoring services to nonfederal responders residing outside the NYC metropolitan area. Therefore, as of June 2007, a total of \$1,189,600 is available for this purpose. In addition, when NIOSH receives DCC's financial status report in summer 2007, it will decide if any unused funds from the June 2006 award will be made available to DCC for providing these services.

⁵¹Some 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. The initial grant from the American Red Cross will be expended by June 30, 2007, but American Red Cross officials told us that funding may be provided into 2008.

CDC's NIOSH Awarded Funding for Treatment Services to Four WTC Health Programs, but Does Not Have a Reliable Estimate of Service Costs

In fall 2006, CDC's NIOSH awarded \$44 million to four programs in the NYC metropolitan area for providing outpatient treatment services to responders. Officials from the FDNY WTC program and NY/NJ WTC Consortium used some of the funds to provide full coverage for prescription medications. NIOSH also set aside \$7 million for the FDNY WTC program and NY/NJ WTC Consortium to provide inpatient hospital care. Officials from these programs expect that the funds they received from NIOSH for outpatient services will be spent by the end of fiscal year 2007. NIOSH has worked with two of its grantees to estimate the cost of monitoring and treating responders; however, the most recent effort, in 2007, has not produced reliable results because the estimate included potential costs for certain program changes that may not be implemented as well as some costs that reduced the estimate's accuracy. In addition, in the absence of actual treatment cost data, the estimate was based in part on questionable assumptions. To improve the reliability of future cost estimates, HHS officials have required some of the WTC health programs to report detailed cost and treatment data.

NIOSH Awarded \$44 Million in Outpatient Treatment Funding, Which Is Expected to Be Spent by End of Fiscal Year 2007, and Set Aside \$7 Million for Hospital Care

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.⁵² 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). Officials from the FDNY WTC program and NY/NJ WTC Consortium expect funds they received from NIOSH for outpatient treatment services to be expended by the end of fiscal year 2007.⁵³ 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

⁵²Federal responders are not eligible for services through these four programs.

⁵³In addition to funding from NIOSH, the FDNY WTC program and NY/NJ WTC Consortium received funding in 2006 from the American Red Cross to provide treatment services. Officials from the American Red Cross expected that the funds it provided would be expended by June 30, 2007, except for the Mount Sinai Clinical Center's funding, which is expected to be expended by July 31, 2007. American Red Cross officials told us that their organization is ending its support of the two health programs and does not plan to renew treatment funding.

WTC Consortium to pay for responders' WTC-related inpatient hospital care as needed.⁵⁴

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

WTC health program	Amount of award ^a (in millions)	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

⁵⁴Of 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.

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. As of June 1, 2007, there were 15 hospitalizations of responders, 13 of whom were referred by the NY/NJ WTC Consortium's Mount Sinai clinic and 2 by the FDNY WTC program. Responders have received inpatient hospital care to treat, for example, asthma, pulmonary fibrosis,⁵⁵ and severe cases of depression or PTSD. If not completely used by the end of fiscal year 2007, funds set aside for hospital care could be 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.⁵⁶ 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

⁵⁵Pulmonary fibrosis is a condition characterized by the formation of scar tissue in the lungs following the inflammation of lung tissue.

⁵⁶The 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.

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.

NIOSH and Its Grantees Have Estimated Costs of Providing Monitoring and Treatment Services, but These Efforts Have Not Produced a Reliable Estimate

NIOSH has worked with two of its grantees—the FDNY WTC program and NY/NJ WTC Consortium—to estimate the annual cost of monitoring and treating responders. In December 2006, the agency and its grantees estimated that the annual cost of monitoring and treating responders enrolled in the FDNY WTC program and NY/NJ WTC Consortium, including associated program costs,⁵⁷ was about \$257 million. In January 2007, NIOSH revised the estimate to also include the cost of monitoring and treating responders enrolled in the WTC Federal Responder Screening Program and nonfederal responders residing outside the NYC metropolitan area who participate in the WTC health programs. The estimate did not include the cost of providing mental health treatment services through Project COPE and the POPPA program.⁵⁸ The January 2007 estimate projected that aggregate annual costs for providing monitoring and treatment services, along with associated program expenses, could be approximately \$230 million or \$283 million, depending on the number of responders who receive treatment services.⁵⁹

To develop an estimate of outpatient treatment costs, which are generally higher than monitoring costs, NIOSH and its grantees projected the incidence of WTC-related health conditions among responders and the number of responders who would likely obtain treatment. Based on this number, they projected that in a given year,

⁵⁷ Associated program costs include expenses for data analysis and program administration.

⁵⁸ The estimate also did not include the cost of providing baseline medical screenings.

⁵⁹ NIOSH and its grantees estimated that monitoring and treatment costs could be about \$230 million annually if 75 percent of the responders projected to need medical treatment in a given year received such services and that these costs could be about \$283 million annually if 100 percent of the responders projected to need medical treatment in a given year received such services. To estimate the annual cost of monitoring, NIOSH and its grantees estimated that the cost of examining a responder not receiving medical treatment from a WTC health program would be \$1,500 and the cost for a responder receiving treatment would be \$500. (NIOSH officials explained that the cost of conducting a monitoring examination is lower for a responder who is receiving care on a regular basis because some diagnostic procedures needed for monitoring will have already been performed.) The January 2007 estimate projected that annual monitoring costs would account for about \$35.7 million of its \$230 million estimate and for about \$30.7 million of its \$283 million estimate.

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- 25 to 30 percent of participating responders will have aerodigestive (combined pulmonary and gastrointestinal) disorders that require treatment,
 - 25 to 35 percent of participating responders will have mental health disorders that require treatment, and
 - 1 to 4 percent of participating responders will have musculoskeletal disorders that require treatment.

To estimate treatment costs for these conditions, NIOSH and its grantees multiplied the estimated per patient cost of providing outpatient services by the number of responders projected to need these services in a given year. They did not have actual cost data on these services because the WTC health programs had not been required to report such data when private organizations were funding the programs' treatment services. In the absence of actual cost data, NIOSH and its grantees relied on workers' compensation reimbursement rates for specific services⁶⁰ as a proxy for outpatient treatment costs. They adjusted the proxy rates to reflect different treatment utilization⁶¹ levels—routine, moderate, or extensive outpatient care—and used their best judgment, based on experience, for the distribution of responders into the three treatment utilization levels. Specifically, they used the proxy rates to represent moderate utilization, reduced the proxy rates by one-third to represent routine utilization, and increased the proxy rates by one-third to represent extensive outpatient care. Outpatient treatment costs were further adjusted to account for the differences in treatment protocols and medication costs at the FDNY WTC program and NY/NJ WTC Consortium.⁶² After estimating the cost of providing outpatient services, NIOSH and its grantees estimated other treatment-related expenses—inpatient care, medical monitoring, indirect costs,⁶³ language translation, data analysis, and expenses incurred by NIOSH such as for travel and telephone service. They added these

⁶⁰NIOSH and its grantees used New York State workers' compensation reimbursement rates.

⁶¹Treatment utilization is the volume or complexity of care provided to patients based on their medical needs.

⁶²NIOSH and its grantees assumed that other providers' treatment costs would be equivalent to those of the NY/NJ WTC Consortium.

⁶³Indirect costs are for functions that indirectly support a program, such as administrative activities, utilities, and building maintenance.

estimated expenses to the estimate for outpatient services to arrive at a total annual cost amount.

Several factors reduced the reliability of the January 2007 estimate. It is unclear whether the overall estimate overstated or understated the costs of monitoring and treating responders. First, the estimate included potential costs that reflect certain program changes that may not be implemented. For example, when NIOSH and its grantees projected the cost of medically monitoring responders, the estimate assumed a more frequent monitoring interval, which has been discussed by program officials but has not been adopted.⁶⁴ Similarly, they included costs for providing monitoring and treatment services to federal responders, who are not now eligible for such services.

Second, NIOSH mistakenly included certain costs in the estimate. According to NIOSH officials, the estimate included a calculation for indirect costs associated with monitoring and treating responders. However, NIOSH officials later learned that the workers' compensation reimbursement rates that were used as a proxy for outpatient treatment costs already contained an adjustment for indirect costs. As a result, total indirect costs were overstated. In addition, the estimate included the cost of monitoring services provided by the FDNY WTC program and NY/NJ WTC Consortium without taking into account that these services were already funded through mid-2009 by other NIOSH funds.

Finally, in the absence of actual data on the cost of providing treatment services, the estimate was based in part on two questionable assumptions. First, when NIOSH and its grantees used the assumption that adjusting the proxy rates up or down by one-third would account for the differences in treatment utilization levels, there were no data to support the accuracy of such adjustments. As a result, it is unclear whether the projections of treatment costs have resulted in an overestimate or underestimate of treatment costs. Second, the assumption used to estimate the cost of medical monitoring was not consistent with the historical participation rates reported by the NY/NJ WTC Consortium. NIOSH and its grantees based the estimate on the assumption that every responder would keep his or her appointment for periodic medical monitoring. However, NY/NJ

⁶⁴The WTC medical monitoring protocol calls for an in-office assessment of a responder's physical and mental health every 18 months; the estimate assumes that these visits occur every 12 months. NIOSH officials told us that they assumed a 12-month interval because that is what clinicians prefer for optimal identification and treatment of illnesses.

WTC Consortium officials told us that the rate at which responders have kept scheduled appointments is 50 to 60 percent.⁶⁵

HHS Officials Have Taken Steps to Develop More Reliable Cost Estimates

To improve the reliability of future efforts to estimate the cost of providing services to responders, NIOSH officials and the Assistant Secretary for Health—in his capacity as chairman of the HHS WTC Task Force—have required the FDNY WTC program and NY/NJ WTC Consortium to report detailed demographic, service utilization, and cost information. The information requested from each program includes

- the number of responders monitored and treated,
- diagnoses of responders monitored and treated,
- medical services provided and the cost of those services, and
- responders' occupations and insurance coverage status.

These data are to be reported on a quarterly basis, and the first reports were received from the NY/NJ WTC Consortium in late February 2007 and from the FDNY WTC program in March 2007. These reports included data covering 2 quarters—July through September 2006, when treatment funding was provided by the American Red Cross, and October through December 2006, when treatment funding was provided by NIOSH and the American Red Cross.⁶⁶

According to an HHS official who is a member of the HHS WTC Task Force, some of the cost reports submitted in February and March were incomplete and therefore did not provide sufficient information to support a reliable estimate of the annual cost of medical services provided by the

⁶⁵In an effort separate from the estimation effort of NIOSH and its grantees, an NYC mayoral panel that reviewed WTC health effects issued a report in February 2007 that contained an estimate of the cost to provide medical services through the FDNY WTC and the NY/NJ WTC Consortium programs. This effort resulted in a lower estimate of the cost of providing medical services through these two programs—approximately \$107 million in fiscal year 2008. The NYC effort was affected by some of the same factors that limited the reliability of the estimate of NIOSH and the grantees, such as the lack of actual treatment cost data. See World Trade Center Health Panel, *Addressing the Health Impacts of 9-11: Report and Recommendations to Mayor Michael R. Bloomberg*.

⁶⁶These data were not available when NIOSH and its grantees made their estimate of WTC costs in January 2007.

WTC health programs. For example, some clinical centers submitted expense reports for only 1 quarter instead of 2. Furthermore, a NIOSH official told us that some of the data that were compiled manually were not accurate. According to the task force member, HHS will need at least 4 quarters of complete and accurate data before it can make reliable estimates. This would mean that HHS may not have data needed to develop a reliable estimate of costs until October 2008. NIOSH officials told us, however, that as they, the FDNY WTC program, and the NY/NJ WTC Consortium gain experience and as report data are automated, the quality of the data they develop and the reliability of cost estimates will improve.

Conclusions

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 are eligible only for the initial screening examination provided through the WTC Federal Responder Screening Program and are not eligible for federally funded follow-up monitoring examinations. In addition, many responders who reside outside of 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, it is important for HHS to make a concerted effort, without further delay, to ensure that health screening and monitoring services are available to all people who responded to the attack on the World Trade Center, regardless of who their employer is or where they reside.

Recommendations for Executive Action

To ensure that comparable screening and monitoring services are available to all responders, we are recommending that the Secretary of HHS expeditiously take two actions: (1) ensure that screening and monitoring services are available for federal responders and (2) ensure that screening and monitoring services are available for nonfederal responders residing outside of the NYC metropolitan area.

Agency Comments and Our Evaluation

HHS reviewed a draft of this report and provided comments, which are reprinted in appendix I. HHS also provided technical comments, which we incorporated as appropriate.

HHS commented that overall, our report is an accurate and appropriate account of its activities and accomplishments concerning health services for responders to the WTC disaster. However, HHS stated that an inaccurate understanding of our findings would likely result if a reader read only the summary information about the WTC Federal Responder Screening Program and services for nonfederal responders residing outside the NYC area in the Highlights and Results in Brief. Where appropriate, we revised the language in the Highlights and Results in Brief to be consistent with the findings in our report. HHS also stated that our description of the services available to nonfederal responders residing outside the NYC metropolitan area did not acknowledge that over 60 percent of these responders have been examined by the DCC network or by AOEC. However, because the total number of nonfederal responders residing outside the NYC metropolitan area is unknown, we believe it is not possible to determine what percentage of these responders has been examined.

In its comments, HHS raised concerns about our use of the terms HHS, CDC, and NIOSH with respect to their role in particular activities. We modified the report where appropriate to clarify respective agency responsibilities. Finally, HHS acknowledged that the estimate of the costs of monitoring and treating WTC responders was imprecise. HHS also noted, as we have reported, that the clinical centers of the NY/NJ WTC Consortium and the FDNY WTC program have begun submitting quarterly

cost and treatment reports and that this information will be used to improve cost estimates. We believe this is an important step toward the development of a reliable estimate.

HHS did not comment on our recommendations.

As agreed with your offices, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days after its issue date. At that time we will send copies of this report to the Secretary of Health and Human Services, congressional committees, and other interested parties. We will also make copies available to others upon request. In addition, the report will be available at no charge on the GAO Web site at <http://www.gao.gov>.

If you or your staffs have any questions about this report, please contact me 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 report. GAO staff who made major contributions to this report are listed in appendix II.



Cynthia Bascetta
Director, Health Care

Appendix I: Comments from the Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Assistant Secretary
for Legislation

Washington, D.C. 20201

JUL 16 2007

Cynthia Bascetta
Director
Health Care
U.S. Government Accountability Office
Washington, DC 20548


Dear Ms. Bascetta:

Enclosed are the Department's comments on the U.S. Government Accountability Office's (GAO) draft report entitled, "HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders" (GAO-07-892).

The Department has provided several technical comments directly to your staff.

The Department appreciates the opportunity to comment on this draft before its publication.

Sincerely,


for Vincent Ventimiglia
Assistant Secretary for Legislation

COMMENTS FROM THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE U.S. GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT: HHS NEEDS TO ENSURE THE AVAILABILITY OF HEALTH SCREENING AND MONITORING FOR ALL RESPONDERS (GAO-07-892)

General Comments

While the entire report is generally an accurate and appropriate account of activities and accomplishments, the "Highlights" page and the "Results in Brief" do not provide the same degree of objectivity. As an example, in the first paragraph of the Highlights, the second sentence ends with the words: "... to keep the program operational." However, the same sentence on page 17 is worded: "... to keep the program fully operational." Similarly, the first sentence in paragraph two states: "NIOSH has not ensured the availability of screening and monitoring services for nonfederal responders residing outside the NYC area." However, over 60% of such responders have been examined either by the DCC network or by AOEC, and there is now a mechanism in place for these examinations. Thus, if a reader only looks at the summary information, an inaccurate understanding will likely result.

References to HHS, CDC, and NIOSH are sometimes mismatched with respect to certain activities. For the most part, NIOSH has served as the primary operational component for this program. However, NIOSH has had interactions with CDC offices and other HHS components, as well as FEMA, in the conduct of this program. In most places, it would be more accurate to refer to CDC/NIOSH" rather than either "CDC" or "NIOSH" separately.

Cost estimates were based on grantee information and are unquestionably imprecise. NIOSH has required all six clinical centers to report their expenses and their patient numbers on a quarterly basis in order to monitor the progress of the program. This information, along with other information on medical protocols is being used to improve cost estimates.

Appendix II: GAO Contact and Staff Acknowledgments

GAO Contact

Cynthia A. Bascetta, (202) 512-7114 or bascettac@gao.gov

Acknowledgments

In addition to the contact named above, Helene F. Toiv, Assistant Director; George Bogart; Hernan Bozzolo; Frederick Caison; Anne Dievler; and Krister Friday made key contributions to this report.

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