

May 2008

SEPTEMBER 11

HHS Needs to Develop a Plan That Incorporates Lessons from the Responder Health Programs





Highlights of [GAO-08-610](#), a report to congressional requesters

Why GAO Did This Study

Following the World Trade Center (WTC) attack, the Congress appropriated more than \$8 billion to the Department of Homeland Security's (DHS) Federal Emergency Management Agency for response and recovery activities. The Department of Health and Human Services (HHS) received some of this funding to establish health screening and monitoring programs for responders to the disaster and later received additional appropriations to fund treatment. In total, about \$369.2 million has been appropriated or awarded for the WTC health programs. GAO previously reported on problems that these programs have had in ensuring the availability of services for all responders.

GAO was asked to examine lessons from the WTC health programs that could guide future programs. GAO examined (1) lessons from the programs' experience and (2) HHS actions or plans that incorporate the lessons. GAO interviewed WTC health program officials and other experts and reviewed DHS and HHS documents.

What GAO Recommends

GAO recommends that the Secretary of HHS develop a department-level plan for responder screening and monitoring services that defines the roles of HHS components and incorporates the lessons from the WTC health programs. In its comments on a draft of GAO's report, HHS did not comment on GAO's recommendation.

To view the full product, including the scope and methodology, click on [GAO-08-610](#). For more information, contact Cynthia A. Bascetta at (202) 512-7114 or bascettac@gao.gov.

SEPTEMBER 11

HHS Needs to Develop a Plan That Incorporates Lessons from the Responder Health Programs

What GAO Found

GAO identified five important lessons from the experience of the WTC health programs that could help with the development of responder health programs in the event of a future disaster. First, registering all responders during a response to a disaster could improve implementation of screening and monitoring services. Second, designing and implementing screening and monitoring programs that foster the ability to conduct epidemiologic research could improve the understanding of health effects experienced by responders and help determine the need for ongoing monitoring. Third, providing timely mental health screening and monitoring that is integrated with physical health screening and monitoring could improve the ability to accurately diagnose physical and mental health conditions and prevent more serious mental health conditions from developing. Fourth, including a treatment referral process in screening and monitoring programs could improve the ability of responders to gain access to needed treatment. Fifth, making comparable services available to all responders, regardless of their employer or geographic location, could ensure more equitable access to services for responders and help ensure that data collected about responders' health are consistent and comprehensive.

HHS has taken steps to facilitate responder registration, but has not developed a department-level plan for responder health programs. HHS's Agency for Toxic Substances and Disease Registry has developed a survey instrument that state and local entities can adopt to register responders and other individuals exposed to a disaster. In a separate effort, HHS's Office of the Assistant Secretary for Preparedness and Response is taking steps to establish a system to register HHS employees and other federal public health and medical personnel who are deployed to a disaster, but it has not completed this effort. HHS has not developed a department-level plan for designing and implementing responder health programs that incorporates the five lessons from the WTC health programs. As a result, HHS has not indicated whether its policies and actions following a disaster or emergency would apply these lessons. Another consequence of not having a plan is that HHS has not described its components' roles and responsibilities for designing and implementing responder health programs. It has not identified which HHS components would be involved in responder health programs, which component would take the lead, how the expertise of various components would be used, or how efforts would be coordinated. In the absence of a department-level plan, HHS's National Institute for Occupational Safety and Health developed a proposal in February 2008 for a project to develop strategies to ensure responder safety and health. While GAO concluded that this proposal is a step in the right direction for addressing responder health issues, it noted that the proposal does not fully address the lessons that have been identified from the WTC health programs.

Contents

Letter		1
	Results in Brief	4
	Background	5
	Five Important Lessons Can Be Drawn from the Experience of the WTC Health Programs	13
	HHS Has Taken Steps to Facilitate Responder Registration, but Has Not Developed a Plan for Responder Health Programs	21
	Conclusions	24
	Recommendation for Executive Action	24
	Agency Comments and Our Evaluation	25
Appendix I	Key Federally Funded WTC Health Programs, May 2008	27
Appendix II	Comments from the Department of Health and Human Services	28
Appendix III	GAO Contact and Staff Acknowledgments	31
Related GAO Products		32
Table		
	Table 1: Services Provided to Responders through WTC Health Programs as of December 31, 2007	8

Abbreviations

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
DHS	Department of Homeland Security
ESF#8	Emergency Support Function #8
FDNY	New York City Fire Department
FEMA	Federal Emergency Management Agency
FOH	Federal Occupational Health Services
HHS	Department of Health and Human Services
NDMS	National Disaster Medical System
NIEHS	National Institute of Environmental Health Sciences
NIMH	National Institute of Mental Health
NIOSH	National Institute for Occupational Safety and Health
NRF	National Response Framework
NRP	National Response Plan
NYC	New York City
NY/NJ	New York/New Jersey
OSHA	Occupational Safety and Health Administration
POPPA	Police Organization Providing Peer Assistance
PTSD	post-traumatic stress disorder
RRR	Rapid Response Registry
RTI	Research Triangle Institute International
WTC	World Trade Center

This is a work of the U.S. government and is not subject to copyright protection in the United States. The published product may be reproduced and distributed in its entirety without further permission from GAO. However, because this work may contain copyrighted images or other material, permission from the copyright holder may be necessary if you wish to reproduce this material separately.



United States Government Accountability Office
Washington, DC 20548

May 30, 2008

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

Following the September 11, 2001, attack on the World Trade Center (WTC), the Congress appropriated more than \$8 billion to the Department of Homeland Security's (DHS) Federal Emergency Management Agency (FEMA) for response and recovery activities.¹ As part of this assistance, the Department of Health and Human Services (HHS)—the lead federal agency for public health and medical disaster preparedness and response activities under the National Response Framework (NRF)²—received funding to establish programs in collaboration with local government and private organizations to address health concerns related to the WTC disaster. In October 2001, HHS began funding programs to screen and monitor the health of tens of thousands of WTC responders,³ who were exposed to numerous physical hazards, environmental toxins, and psychological trauma as a result of their work. HHS also provided funds to the New York City (NYC) Department of Health and Mental Hygiene in July 2002 to establish the WTC Health Registry to monitor for self-reported health problems among responders, as well as among people who were

¹Response activities address the immediate and short-term effects of an emergency or disaster. Recovery activities address long-term impacts of an emergency or disaster.

²The NRF establishes a framework of how the federal government coordinates with state, local, and tribal governments and the private sector during an emergency or disaster.

³In this report, “responders” refers to anyone involved in rescue, recovery, or cleanup activities at or near the vicinity of the WTC or the Staten Island site, the landfill that is the off-site location of the WTC recovery operation. Responders included New York City Fire Department personnel, federal government personnel, and other government and private-sector workers and volunteers from New York and elsewhere.

living or attending school in the area of the WTC or were working or present in the vicinity on September 11, 2001. In fiscal year 2006 the Congress first appropriated funds that were specifically available for treatment programs for certain responders with health conditions related to the WTC disaster.

We have previously reported on the implementation of the federally funded WTC responder health programs—referred to in this report as the WTC health programs⁴—and their progress in providing services to responders.⁵ In the course of this previous work, we found that HHS had problems ensuring the availability of screening and monitoring services for all responders.⁶ However, in designing, administering, and implementing these services, officials from HHS and the WTC health programs gained valuable experience that could guide future federal efforts to develop programs for responders following a disaster or emergency that overwhelms state and local response capabilities.

As part of its responsibilities as the lead federal agency for public health disaster preparedness and response, HHS is directed by the NRF to develop policies and plans governing how it would provide resources to carry out its role. In the years since the WTC disaster, HHS has taken some steps to prepare for disasters and other public health emergencies, including participating in planning activities with DHS and other federal agencies, conducting research, developing a strategic plan and other initiatives, and providing grants and technical assistance to states⁷ and localities to support their efforts to prepare for disasters and public health emergencies.

You requested that we determine what lessons have been learned from the WTC health programs that could help with the development of responder health programs in the event of a future disaster. Specifically, in this report we (1) identify lessons from the experience of the WTC health programs

⁴See appendix I for a description of the key federally funded WTC health programs.

⁵A list of related GAO products is provided at the end of this report.

⁶In 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.

⁷In this report, the term state includes the District of Columbia and the territories.

and (2) determine whether HHS has taken actions or developed plans that incorporate the lessons from the WTC health programs.

To identify lessons from the experience of the WTC health programs, we reviewed our previous work on the WTC health programs and interviewed individuals who are experts in this area. Those experts included officials from the HHS components involved in administering and implementing the programs: the Office of the Assistant Secretary for Preparedness and Response (ASPR),⁸ the Centers for Disease Control and Prevention's (CDC) National Institute for Occupational Safety and Health (NIOSH),⁹ the Agency for Toxic Substances and Disease Registry (ATSDR),¹⁰ and the Federal Occupational Health Services (FOH).¹¹ We also interviewed experts from HHS's National Institute of Mental Health (NIMH)¹² and the National Institute of Environmental Health Sciences (NIEHS),¹³ agencies that funded WTC-related research. Other experts that we interviewed included officials from three of the key WTC health programs—the New York City Fire Department (FDNY) WTC Medical Monitoring and Treatment program, the New York/New Jersey (NY/NJ) WTC Consortium, and the WTC Health Registry—and researchers in occupational and environmental health. In addition, we reviewed published and unpublished reports and articles that examined lessons from the WTC disaster. To determine whether HHS has taken actions or developed plans that incorporate the lessons from the WTC health programs, we interviewed ASPR, ATSDR, FOH, NIEHS, NIMH, and NIOSH officials. We also reviewed documents from DHS, HHS, and the Congressional Research Service and reviewed relevant disaster-related statutes. Our review focused on the

⁸ASPR coordinates emergency preparedness activities among HHS agencies; other federal departments, agencies, and offices; and state and local officials.

⁹NIOSH conducts research on and makes recommendations for the prevention of work-related injury and illness.

¹⁰ATSDR performs functions concerning the effect on public health of hazardous substances in the environment, including designing and conducting surveillance programs and establishing and maintaining registries of persons exposed to toxic substances.

¹¹FOH provides occupational health and safety services to federal agencies located throughout the United States.

¹²NIMH supports research on the diagnosis, treatment, and prevention of mental disorders.

¹³NIEHS conducts and funds research and training on environmental health. The agency has two programs, the Worker Education and Training Program and the Superfund Basic Research Program, that specifically relate to the effects of the environment on the health and safety of workers, including responders.

physical and mental health needs of responders following a disaster. We did not examine HHS's efforts to prevent physical or psychological harm to responders during disaster response, which are important but beyond the scope of this report. We conducted this performance audit from November 2006 through May 2008 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Results in Brief

We have identified five important lessons from the experience of the WTC health programs that could help with the development of responder health programs in the event of a future disaster. First, registering all responders during a response to a disaster could improve implementation of screening and monitoring services. Second, designing and implementing screening and monitoring programs that foster the ability to conduct epidemiologic research—that is, scientific research designed to understand the distribution and determinants of disease or health status in a population—could improve the understanding of health effects experienced by responders and help determine the need for ongoing monitoring. Third, providing timely mental health screening and monitoring that is integrated with physical health screening and monitoring could improve the ability to accurately diagnose physical and mental health conditions and prevent more serious mental health conditions from developing. Fourth, including a treatment referral process in screening and monitoring programs could improve the ability of responders to gain access to needed treatment. Fifth, making comparable services available to all responders, regardless of their employer or geographic location, could ensure more equitable access to services for responders and help ensure that data collected about responders' health are consistent and comprehensive.

HHS has taken steps to facilitate responder registration, but has not developed a department-level plan for responder health programs. ATSDR has developed a Rapid Response Registry (RRR) survey instrument that state and local entities can voluntarily adopt to register responders and other individuals exposed to a disaster. In a separate effort, ASPR is taking steps to establish a system to register HHS employees and other federal public health and medical personnel who are deployed to a disaster under the authority of the Secretary of HHS, but it has not completed this effort. HHS has not developed a department-level plan for designing and implementing responder health programs that incorporates the lessons

from the WTC health programs. As a result, HHS has not indicated whether its policies and actions following a disaster or emergency would apply these lessons. Another consequence of not having a plan is that HHS has not described its components' roles and responsibilities for designing and implementing responder health programs. According to the NRF, agencies should clearly define roles and responsibilities in their disaster preparedness plans, but HHS has not identified which components would be involved in responder health programs, which component would take the lead, how the expertise of various components would be used, and how efforts would be coordinated. In the absence of a department-level plan, NIOSH developed a proposal in February 2008 for a project to develop strategies to ensure responder safety and health. This proposal is a step in the right direction for addressing responder health issues, but it does not fully address the lessons that have been identified from the WTC health programs.

To ensure that effective programs are developed to deal with the health effects that responders may experience in the event of a future disaster, we recommend that the Secretary of HHS develop a department-level responder screening and monitoring plan that defines the roles and responsibilities of HHS components and incorporates the five lessons identified from the experience of the WTC health programs. In its comments on a draft of this report, HHS provided additional information about ASPR's responsibilities and activities, as well as technical comments, which we incorporated as appropriate. HHS did not comment on our recommendation but said that any overall HHS plan should include guidance on treatment referral processes and methods to ensure comparable treatment services across all responder groups.

Background

When a disaster or emergency overwhelms state and local response capabilities, the federal government can provide assistance with response and recovery efforts. FEMA, the federal agency responsible for coordinating federal disaster response efforts, collaborates with HHS on health issues related to disasters. Following the September 11, 2001, attack on the WTC, FEMA provided funding to HHS to establish certain WTC health programs. HHS's disaster response and recovery activities operate within an administrative and legal framework that helps to define federal agency roles and responsibilities and gives HHS certain authorities.

Overview of WTC Health Programs

Following the attack on the WTC, the Congress appropriated approximately \$8.8 billion to FEMA, over several years, for response and recovery activities.¹⁴ FEMA entered into interagency agreements with HHS agencies, such as NIOSH, ASPR, and ATSDR, to distribute funding to government and private organizations to implement health screening and monitoring programs for responders and other affected groups. In fiscal year 2006, the Congress appropriated \$75 million to CDC that was available for monitoring and treatment services for certain WTC responders.¹⁵ The Congress made additional appropriations to CDC available for the same purpose in fiscal years 2007 and 2008.¹⁶ Federal funds appropriated or awarded for the WTC health programs from October 2001 through December 2007 have totaled about \$369.2 million.

There are four key WTC health programs that currently receive federal funding to provide voluntary health screening, monitoring, or treatment services to responders at no cost for illnesses and conditions related to the WTC disaster.¹⁷ The four programs are the FDNY WTC Medical Monitoring and Treatment Program; the NY/NJ WTC Consortium, which comprises

¹⁴See 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.

¹⁵Department of Defense Appropriations Act, 2006, Pub. L. No. 109-148, § 5011(b), 119 Stat. 2680, 2814 (2005) (available for personnel involved in emergency services or rescue and recovery activities) (available until expended).

¹⁶In fiscal year 2007 the Congress appropriated an additional \$50 million to CDC, which was also available for monitoring and treatment of responders involved in emergency services or rescue and recovery activities. See U.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) (available until expended). In fiscal year 2008 the Congress provided an appropriation of about \$108.1 million for monitoring and treatment of responders involved in emergency services. See Consolidated Appropriations Act of 2008, Pub. L. No. 110-161, 121 Stat. 1844, 2172 (also available for residents, students, and others related to the WTC attack) (available until expended).

¹⁷Another program, 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.

five clinical centers in the NY/NJ area;¹⁸ HHS's WTC Federal Responder Screening Program; and the WTC Health Registry.¹⁹ Unlike the other key programs, the WTC Health Registry does not provide in-person screening or monitoring services. Instead it uses periodic surveys of self-reported health status to collect health information on responders, as well as people who resided, worked, attended school, or were present in the vicinity of the WTC.²⁰ (See app. I for more information about these key WTC health programs.)

HHS funded the WTC health programs to serve different categories of responders (e.g., firefighters, federal responders, and other workers and volunteers). The programs also varied in their geographic coverage. For example, the FDNY WTC Program and the NY/NJ WTC Consortium primarily serve, respectively, firefighters and other workers and volunteers who reside in the NYC area or travel to that area for services. HHS's WTC Federal Responder Screening Program provides screening services to federal responders nationwide through its network of FOH clinics. In addition, beginning in late 2002, NIOSH funded services for nonfederal

¹⁸This program was formerly known as the worker and volunteer WTC Program. The five clinical centers are 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 School of Medicine 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.

¹⁹In addition to these four programs, two smaller programs, the Police Organization Providing Peer Assistance (POPPA) program and Project COPE, have received federal funding to provide mental health services through hotline, counseling, and referral services to NYC Police Department employees and their family members. POPPA and Project COPE are private programs that operate independently of the NYC Police Department.

²⁰The WTC Health Registry has collected baseline health data from over 71,000 people. In the winter of 2006, the registry began its first follow-up survey of adults, and as of June 2007 over 36,000 individuals had completed the follow-up survey. The WTC Health Registry also provides information to participants on where they can seek health care.

responders residing outside the NYC metropolitan area.²¹ Table 1 provides information on the numbers of responders who have received various health services. NIOSH is the HHS administering agency for all the WTC health programs, except the WTC Health Registry,²² and 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.

Table 1: Services Provided to Responders through WTC Health Programs as of December 31, 2007

Responder category	Initial screening examination^a	Follow-up monitoring examination^b	Physical health treatment^c	Mental health treatment^d
Firefighters	14,620	17,569	2,456	2,453
Workers and volunteers	22,748	11,315	7,288	3,131
Nonfederal responders residing outside NYC area	818	176	70	70
Federal responders	1,355	Not applicable ^e	Not applicable ^e	Not applicable ^e
Total	39,541	29,060	9,814	5,654

Source: NIOSH.

Note: NIOSH based these data on reports from the programs that provided the services, with the exception of treatment services for nonfederal responders residing outside of the NYC area. Data for this category are estimates based on data NIOSH obtained from the Association of Occupational and Environmental Clinics. The Association of Occupational and Environmental Clinics provides physical and mental health treatment to WTC responders who reside outside the New York City area with funds provided by the American Red Cross.

^aCumulative number of initial screening examinations performed since program began.

^bCumulative number of follow-up examinations performed since inception of monitoring; some responders have received multiple monitoring examinations.

²¹From late 2002 to July 2004, NIOSH funded the Association of Occupational and Environmental Clinics to provide screening services to nonfederal responders outside the NYC area. In June 2005, NIOSH began funding the Mount Sinai School of Medicine Data and Coordination Center to provide screening and monitoring services to nonfederal responders outside the NYC area, and in May 2007 the Data and Coordination Center contracted with QTC Management, Inc., to provide these services. QTC is a private provider of government-outsourced occupational health and disability examination services.

²²ATSDR is the HHS administering agency for the WTC Health Registry.

^cNumber of responders who received treatment for physical health conditions, January 1, 2007, through December 31, 2007.

^dNumber of responders who received treatment for mental health conditions, January 1, 2007, through December 31, 2007.

^eResponders enrolled in the WTC Federal Responder Screening Program are eligible for an initial screening examination only.

Information collected by the WTC health programs and other researchers has helped to identify the physical and mental health effects of the WTC disaster. 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.²³ Almost all firefighters who responded to the attack experienced respiratory effects, including WTC cough. One study conducted by researchers affiliated with the FDNY WTC Program found that exposed firefighters on average experienced a decline in lung function equivalent to that which would be produced by 12 years of aging.²⁴ A study conducted by WTC Health Registry researchers found that responders' risk of newly diagnosed asthma increased with greater exposure to the WTC disaster site, as indicated by arriving at the site at an earlier date or working there for a longer duration.²⁵ The Mount Sinai School of Medicine clinical center of the NY/NJ WTC Consortium found that about half of the participants in its screening program met the threshold criteria for being referred for a clinical mental health evaluation.²⁶ Commonly reported mental health effects among responders and other affected individuals included symptoms associated with post-traumatic stress disorder (PTSD),

²³See, for example, S.M. Levin et al., "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, no. 35 (2004), and R. 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).

²⁴G. I. Banauch et al., "Pulmonary Function after Exposure to the World Trade Center Collapse in the New York City Fire Department," *American Journal of Respiratory and Critical Care Medicine*, vol. 174 (2006).

²⁵K. Wheeler et al., "Asthma Diagnosed after 11 September 2001 among Rescue and Recovery Workers: Findings from the World Trade Center Health Registry," *Environmental Health Perspectives*, vol. 115, no. 11 (2007).

²⁶R.P. Smith et al., "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, no. 35 (2004).

depression, and anxiety.²⁷ Behavioral health effects such as increased alcohol and tobacco use were also reported.²⁸

In previous reports we noted limitations of the WTC health programs and problems with their implementation.²⁹ For example, we reported that federal responders were eligible only for screening services and did not receive monitoring services as other responders did. We also reported on the service interruptions in the WTC Federal Responder Screening Program. HHS established the program in June 2003, suspended it in March 2004, resumed it in December 2005, suspended it again in January 2007, and resumed it in May 2007. Similarly, NIOSH's services for nonfederal responders residing outside the NYC area were not continuously available for all responders. In addition, some of the screening and monitoring programs initially faced difficulties referring responders for treatment. Throughout the history of these programs, program officials have raised concerns about whether the duration of federal funding would be adequate.

Administrative and Legal Framework for HHS's Disaster Response Activities

HHS's disaster response activities, including efforts to address the health of responders, operate within an administrative and legal framework. In response to the attacks on September 11, 2001, the Congress enacted the Homeland Security Act of 2002, which established DHS and required the department to consolidate existing federal government response plans into a single coordinated national response plan.³⁰ In December 2004, DHS issued the National Response Plan (NRP), which detailed missions, policies, structures, and responsibilities of federal agencies for

²⁷R.P. Smith et al., "Mental Health Status;" and M.A. Perrin et al., "Differences in PTSD Prevalence and Associated Risk Factors Among World Trade Center Disaster Rescue and Recovery Workers," *American Journal of Psychiatry*, vol. 164, no. 9 (2007).

²⁸R.P. Smith et al., "Mental Health Status;" D.Vlahov et al., "Increased Use of Cigarettes, Alcohol, and Marijuana among Manhattan, New York, Residents after the September 11th Terrorist Attacks," *American Journal of Epidemiology*, vol. 155, no. 11 (2002); and M.P. Bars et al., "Tobacco Free With FDNY: The New York City Fire Department World Trade Center Tobacco Cessation Study," *Chest*, vol. 129, no. 4 (2006).

²⁹See GAO, *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), and *September 11: HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders*, [GAO-07-892](#) (Washington, D.C.: July 23, 2007).

³⁰Pub. L. No. 107-296, §§ 101, 502, 116 Stat. 2135, 2142, 2212-13.

coordinating resource and programmatic support to states, localities, and other entities. The NRF was to be invoked when the President issued a major disaster or emergency declaration under the Stafford Act.³¹ The NRF was first invoked in August 2005 in response to Hurricane Katrina and was subsequently updated in May 2006. In January 2008, DHS issued the NRF to supersede the NRP.³²

The NRF is intended to provide a coordinated approach to disaster and emergency response and short-term recovery. FEMA is responsible for assigning work and providing funding to other federal agencies for performing operations included in the NRF. To execute this responsibility, FEMA uses mission assignments, which are interagency agreements with other federal agencies intended to meet immediate and short-term needs. When a disaster or emergency is declared under the authority of the Stafford Act and FEMA issues a mission assignment, a federal agency has 60 days after the declaration to complete tasks described in the mission assignment, unless time is extended by FEMA due to unusual or extenuating circumstances.³³

Under the NRF, HHS is the primary agency for coordinating the federal government's public health and medical response, and the Department of Labor's Occupational Safety and Health Administration (OSHA) is the lead agency for responding to worker safety and health concerns, with HHS as a cooperating agency. HHS's responsibilities for public health and medical response are described in the NRF's Public Health and Medical Services Annex, also known as Emergency Support Function #8 (ESF#8). Under ESF#8, HHS can deploy its public health and medical personnel, including civilian volunteers, to the affected area. In addition, HHS can request an appropriate organization supporting ESF#8, such as the Environmental Protection Agency or the American Red Cross, to activate and deploy its public health and medical personnel. HHS can also assist state, tribal, and local officials in establishing a registry of potentially exposed individuals and conducting long-term monitoring for potential health effects. HHS's ASPR coordinates ESF#8 actions. OSHA's and HHS's responsibilities for worker safety and health are described in the NRF's Worker Safety and

³¹Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act), Pub. L. No. 93-288, 88 Stat. 143 (1974) (as amended) (codified as amended at 42 U.S.C. §§ 5121-5207).

³²The NRF became effective March 22, 2008.

³³44 C.F.R. 206.208 (2007).

Health Support Annex.³⁴ Under the Worker Safety and Health Support Annex, OSHA, in coordination with HHS, is responsible for providing technical assistance, advice, and support for medical surveillance and monitoring and for evaluating the need for longer-term medical monitoring of response and recovery workers. OSHA and NIOSH have established an interagency agreement that broadly describes NIOSH's role in carrying out the Worker Safety and Health Support Annex. However, NIOSH would receive funding specifically to carry out activities related to the Worker Safety and Health Support Annex only if, after a disaster, FEMA issued a mission assignment to OSHA for such activities and OSHA in turn assigned activities to NIOSH.³⁵

In addition to the NRF, there are certain statutes that are relevant to HHS's responsibilities concerning responder health. According to the Pandemic and All-Hazards Preparedness Act, HHS is the lead federal agency for public health and medical responses to emergencies and disasters. The act specifies that ASPR must carry out certain functions during a response, including registering federal public health and medical personnel who are deployed under the authority of the Secretary of HHS.³⁶ These personnel include members of the National Disaster Medical System (NDMS).³⁷

³⁴The Worker Safety and Health Support Annex indicates that HHS's responsibilities are to be carried out by three HHS agencies—ATSDR, NIEHS, and NIOSH—and indicates that OSHA and NIOSH are to collaborate in all areas of the annex.

³⁵In the aftermath of Hurricane Katrina, FEMA did not issue a mission assignment to authorize OSHA to receive reimbursement for evaluating the need for and providing medical surveillance and monitoring. Federal agencies involved in the response disagreed over which agencies should fund medical monitoring of responders, and in general there was no systematic monitoring of the health of responders to Hurricane Katrina. See GAO, *Disaster Preparedness: Better Planning Would Improve OSHA's Efforts to Protect Workers' Safety and Health in Disasters*, [GAO-07-193](#) (Washington, D.C.: Mar. 28, 2007) and *September 11: Problems Remain in Planning for and Providing Health Screening and Monitoring Services for Responders*, [GAO-07-1253T](#) (Washington, D.C.: Sept. 20, 2007).

³⁶Pub. L. No. 109-417, §§ 101, 102, 120 Stat. 2831, 2832-2833 (2006). The other functions that the act assigns to ASPR include credentialing, organizing, training, and equipping federal public health and medical personnel who are under the authority of the Secretary; the act also gives ASPR the authority to deploy these personnel.

³⁷Under ESF#8, NDMS is a federally coordinated system to supplement an integrated national medical response capability for assisting state and local authorities in the event of a disaster. Components of the system include medical response to a disaster area in the form of personnel, supplies, and equipment; patient movement from the disaster site to unaffected areas of the nation; and medical care at participating hospitals in unaffected areas.

Section 709 of the Security and Accountability for Every Port Act of 2006 (also known as the SAFE Port Act) provides that the President, acting through HHS, may establish and implement a program to provide screening and monitoring services for certain individuals affected by a presidentially declared disaster, including responders. The act specifies that such a program may include collecting exposure data, developing and disseminating information and educational materials, performing baseline and follow-up clinical and mental health evaluations, establishing and maintaining an exposure registry, studying short- and long-term health effects through epidemiologic and other health studies, and providing assistance to individuals in determining eligibility for health coverage and identifying appropriate health services. The act also authorizes the President, acting through HHS, to establish cooperative agreements with a medical institution, including a local health department or a consortium of medical institutions, to carry out this program.³⁸

Five Important Lessons Can Be Drawn from the Experience of the WTC Health Programs

We have identified five important lessons from the experience of the WTC health programs. These lessons relate to activities during the response to a disaster as well as during the recovery period, when follow-up monitoring or treatment may be needed. Although some of the difficulties encountered by the WTC programs resulted from the unique nature of the WTC disaster, applying these lessons could help to improve the response to and recovery from future disasters.

Lesson 1: *Registering all responders during a response to a disaster could improve implementation of screening and monitoring services.*

During the WTC disaster response, neither NYC nor the federal government developed a registry of all responders who worked at the WTC disaster site. Therefore WTC health program officials subsequently had to compile a list of responders who were potentially eligible to receive services—a difficult, time-consuming, and costly task that was only partially successful.³⁹ WTC Health Registry officials and WTC Federal Responder Screening Program officials tried to compile a list of potentially eligible responders by contacting government agencies, private-sector employers, and volunteer organizations to locate employees who had

³⁸Pub. L. No. 109-347, § 709, 120 Stat. 1884, 1947.

³⁹There is no definitive count of those who served as responders. Estimates have ranged from about 40,000 to about 91,000.

responded to the WTC disaster. According to an ATSDR official, some government agencies and many employers did not cooperate with program officials, primarily because of concerns about confidentiality.⁴⁰ According to an ATSDR official, the effort to compile a list of responders potentially eligible for the WTC Health Registry cost about \$1 million and took about 19 months.

Not registering responders during disaster response efforts affects outreach activities and hinders efforts to plan services. An official from the NY/NJ WTC Consortium said that without a definitive list of responders, the program had to issue widespread and costly public service announcements to identify and enroll eligible responders. The lack of a complete registry with demographic and exposure information also made it difficult to quantify the needs for screening, monitoring, and treatment services for responders. For example, a WTC health program official told us that not knowing where responders are located around the country has made it difficult to determine how to design services and allocate resources for the responder population living outside the NYC metropolitan area.

Without a complete registry of responders, it is difficult to accurately determine the incidence⁴¹ and causes of health problems experienced by the responder population. An epidemiologist involved in the NY/NJ WTC Consortium told us that efforts to determine the incidence of health effects among responders were complicated because the number of responders who were exposed is not known. The WTC health programs have been able to collect information only on responders who seek out their services or fill out their surveys. Because these responders constitute a self-selected population, program officials have not been able to determine the incidence of health effects among the total population of responders. In addition, because there was no registry with reliable information on the amount, duration, and types of exposure (e.g., physical hazards, environmental toxins, psychological trauma) experienced by responders, it has been difficult to determine the relationship between level of exposure and changes in physical and mental health. The WTC

⁴⁰In addition, some federal agency officials believed that medical screening was not necessary for their employees, and some agencies had instituted their own screening efforts.

⁴¹Incidence is a measure of new cases of disease, illness, or condition during a specified time period.

health programs have had to rely on participants' recollection of their exposure. Most of the federally funded WTC health programs were not started immediately, but rather months after the disaster, which affected the ability of participants to remember their exposures accurately. For example, WTC Health Registry officials told us they did not begin surveying responders until 2 years after the WTC disaster.

WTC health program officials told us that registering responders during a response to a disaster would help ensure that responders are contacted before some scatter and become more difficult to locate. Having a complete registry could improve the ability of responder health programs to conduct outreach for screening and monitoring services, improve efforts to plan services and allocate resources, and provide data for epidemiologic research.

Lesson 2: *Designing and implementing screening and monitoring programs that foster the ability to conduct epidemiologic research could improve the understanding of health effects experienced by responders and help determine the need for ongoing monitoring.*

Despite an accumulation of evidence about the health effects experienced by responders, researchers have acknowledged that there remains some uncertainty and controversy about the health risks associated with the disaster, especially the long-term health effects.⁴² In addition to a lack of information about the number and identity of responders and their exposures, another serious limitation to understanding the health effects of the WTC disaster is the fact that the WTC screening and monitoring programs were not explicitly designed and implemented to conduct research, in particular epidemiologic research. Therefore, certain opportunities to collect and analyze data were lost. NIOSH officials told us that the FDNY WTC program and the NY/NJ WTC Consortium were not designed to conduct epidemiologic research but rather were established as clinical programs focused on the health of individual responders.⁴³ For example, the programs were not designed to test specific hypotheses about health effects or to compare participants' health with the health of a comparison group.

⁴²J.M. Samet, A.S. Geyh, and M.J. Utell. "The Legacy of World Trade Center Dust," *New England Journal of Medicine*, vol. 356, no. 22 (2007).

⁴³The WTC Health Registry was designed to conduct epidemiologic research. However, the data collected by this program are self-reported and not clinically verified.

A NIOSH official told us NIOSH did not design and implement FDNY's and the Consortium's monitoring programs to conduct research because of restrictions that FEMA placed on the funding for the programs. Because FEMA primarily provides funding for programs to address the short-term effects of a disaster, in its interagency agreement with NIOSH to establish the monitoring programs, FEMA specified that the funding it provided could not be used for research. HHS's Federal Responder Screening Program also was not designed to collect any information on responders' health for the purposes of research. The interagency agreement between FEMA and ASPR to establish the program limited the program to a onetime screening examination, and HHS officials said they did not have the resources to conduct epidemiologic research with the federal responder population. HHS officials told us that, in hindsight, such research clearly would have provided useful data and benefited the program.

Because of the restrictions on the use of federal funding for research, the FDNY WTC program and the NY/NJ WTC Consortium relied on other resources to conduct research, and the programs vary in the type and amount of studies they have published. Many of the studies have been descriptive, such as reports of the incidence of upper and lower respiratory symptoms among responders. The FDNY WTC program initiated its own research on the health effects of the WTC disaster on firefighters and quickly published a series of papers about the health effects experienced by firefighters in peer-reviewed journals.⁴⁴ It was able to do this because the FDNY WTC program is based in FDNY's Bureau of Health Services, which has an established research infrastructure. In addition, the bureau had baseline medical data on all firefighters, and all firefighters are required to have an annual physical examination. In contrast, the NY/NJ WTC Consortium has had more difficulty conducting research. There have been fewer studies conducted by researchers affiliated with the Consortium, and it has taken longer for the studies to be published. The NY/NJ WTC Consortium serves a more heterogeneous responder population of workers and volunteers and lacks baseline health

⁴⁴See, for example, D.J. Prezant et al., "Cough and Bronchial Responsiveness in Firefighters at the World Trade Center Site," *New England Journal of Medicine*, vol. 347, no. 11 (2002); G.I. Banauch et al., "Persistent Hyperreactivity and Reactive Airway Dysfunction in Firefighters at the World Trade Center," *American Journal of Respiratory and Critical Care Medicine*, vol. 168 (2003); G.I. Banauch et al., "Pulmonary Function after Exposure to the World Trade Center Collapse in the New York City Fire Department," *American Journal of Respiratory and Critical Care Medicine*, vol. 174 (2006); D.J. Prezant, "World Trade Center Cough Syndrome and Its Treatment," *Lung*, vol. 186, suppl. 1 (2008).

status information on this population. In addition, in our discussions with clinicians and researchers affiliated with the NY/NJ WTC Consortium, they raised concerns such as the program lacking sufficient in-house experience for conducting research or lacking data collection and management tools to facilitate conducting research. For example, it did not have an adequate electronic medical records system. In addition, information collected by the program had to go through a protracted data cleaning process before it could be analyzed.

WTC health program officials and others also noted that there was a lack of previously tested, scientifically based protocols for conducting physical and mental health screening, making it difficult to obtain conclusive data to conduct research about the health effects of responders. One clinician noted that the mental health protocol used by the NY/NJ WTC Consortium focused on delivering good clinical services but that there was not enough emphasis on making the protocol scientifically sound for drawing definitive conclusions about the mental health effects experienced by responders.

Officials involved in the WTC health programs and other experts have learned that screening and monitoring programs need to be able to scientifically document the health effects of a disaster. They have observed that to achieve this goal the programs should be designed to have the capacity to conduct epidemiologic research, such as by having research hypotheses, using data collection protocols that will produce information useful for understanding health effects, and studying comparison groups of people not affected by the disaster. In addition, conducting scientific research of health effects can help public health officials determine whether long-term monitoring is needed. In 2007, NIOSH officials identified a need for additional funding to allow the monitoring programs to conduct research and answer important scientific questions about the health of WTC responders.

Lesson 3: *Providing timely mental health screening and monitoring that is integrated with physical health screening and monitoring could improve the ability to accurately diagnose physical and mental health conditions and prevent more serious mental health conditions from developing.*

Responders to the WTC disaster were at high risk for mental health problems. They experienced an unprecedented, highly traumatizing event. Many workers and volunteers worked for extended periods of time without sufficient respite. Some of them did not have training in disaster response and were therefore more vulnerable to the stress of the event.

Despite the early recognition of the need for mental health services, the mental health status of responders did not receive as much attention initially as their physical health status. For example, when the Mount Sinai School of Medicine, one of the clinical centers in the NY/NJ WTC Consortium, implemented its federally funded screening program in July 2002, the emphasis was on conducting a thorough physical health assessment. The mental health status of responders was initially assessed with a short written questionnaire, and depending on a person's score, individuals were referred for an in-person clinical mental health evaluation. Recognizing the seriousness of mental health problems among responders, the Mount Sinai School of Medicine Department of Psychiatry sought private funding from the Robin Hood Foundation⁴⁵ to develop a broader mental health component to the screening program. With the additional funds, the program was able to develop and use a more extensive mental health questionnaire and have a trained mental health professional conduct in-person interviews.

Screening and monitoring programs that integrate physical and mental health assessments can have several benefits. According to clinicians and researchers, such programs can improve the ability to accurately diagnose and differentiate physical and mental health conditions because mental health conditions sometimes present as physical symptoms. For example, gastrointestinal problems can sometimes be a sign of psychological stress. Timely mental health screening and monitoring can also prevent some mental health conditions from progressing to more serious disorders. For example, obtaining treatment for mild depression might prevent a major depressive disorder from developing, or treating depression might prevent alcoholism.

Lesson 4: *Including a treatment referral process in screening and monitoring programs could improve the ability of responders to gain access to needed treatment.*

⁴⁵The Robin Hood Foundation is a charitable organization based in New York City.

Before federal funding became available in fiscal year 2006 to pay for treatment of responders' health effects, WTC health program officials told us that it was a challenge to find providers who would treat responders whose screening or monitoring examination indicated a need for treatment. As clinicians at the FDNY WTC program and the NY/NJ WTC Consortium began screening responders, they immediately recognized that some responders required additional diagnosis or treatment for physical or mental health conditions. Although the FDNY WTC program was able to refer firefighters to its Bureau of Health Services, which provided treatment, the NY/NJ WTC Consortium did not have a similar option. Officials from this program said that identifying providers available and willing to treat participants was a major part of their operations and was especially difficult when participants lacked health insurance, which was often the case. For example, 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 required to maintain eligibility for coverage.

HHS officials, clinicians involved with the WTC health programs, and other experts said that an integral part of screening and monitoring is the establishment of a linkage to treatment services. Some indicated that as professionals they also felt an ethical obligation to be able to refer people in need of care to treatment services. An NIMH official told us that a working group of agency officials and other experts examining responder mental health issues concluded that providers who identified a need for treatment during screening examinations acquired a responsibility to provide access to care.

Lesson 5: *Making comparable services available to all responders, regardless of their employer or geographic location, could ensure more equitable access to services for responders and help ensure that data collected about responders' health are consistent and comprehensive.*

Screening and monitoring programs for responders to the WTC disaster were set up as separate programs on the basis of the responder's employer and geographic location, and the types of services available and information collected about responders varied by program. For example, the WTC Federal Responder Screening Program provided an initial screening examination for federal responders, while the FDNY WTC program and the NY/NJ WTC Consortium provided an initial screening examination followed by monitoring examinations every 18 months for firefighters and other workers and volunteers. Additionally, from 2002

until summer 2007, NIOSH did not consistently ensure the availability of screening and monitoring services for nonfederal responders residing outside the NYC area. For example, 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. Responders who traveled to NYC from around the country following the attack have testified before the Congress about having difficulty receiving services. Finally, because the WTC Federal Responder Screening Program collected only limited data, less is known about the health effects experienced by federal responders than is known about other categories of responders.

Officials involved with the WTC health programs have recognized the value of designing responder health programs that provide comparable services to all responders and of centrally coordinating these services, and they have been making efforts to provide comparable services to all WTC responders. For example, NIOSH took steps to increase the availability of services to nonfederal responders outside the NYC metropolitan area when in June 2007 it arranged for QTC Management, Inc., to provide screening and monitoring examinations nationwide for 1 year. In March 2008, CDC issued a request for organizations to indicate their interest in coordinating a national program for WTC responders that would ensure that all WTC responders who reside outside the NYC metropolitan area have access to federally funded screening, monitoring, and treatment services.

In the event of a future disaster, providing comparable services to all responders would ensure more equitable access to services; that is, no group of responders would be unable to obtain certain services on the basis of who their employer was or where they reside. This could help ensure that responders receive timely care for conditions and illnesses related to the disaster. In addition, ensuring consistency in program design could help ensure that programs collect data that are consistent and comprehensive.

HHS Has Taken Steps to Facilitate Responder Registration, but Has Not Developed a Plan for Responder Health Programs

HHS has taken steps to ensure that responders are registered, but it has not developed a department-level plan for responder health programs. ATSDR has developed a survey instrument that state and local entities can voluntarily adopt to register responders. ASPR is also taking steps to establish a system to register HHS employees and certain other volunteers, but it has not completed its effort. HHS has not developed a department-level plan for designing and implementing responder health programs that incorporates the lessons from the WTC health programs. In addition, HHS has not described the roles and responsibilities of its components in designing and implementing responder health programs. In the absence of a department-level plan, NIOSH developed a proposal for a project to develop strategies to ensure responder safety and health. NIOSH's project would address some aspects of the lessons from the WTC health programs.

HHS Has Taken Some Steps to Ensure That Responders Are Registered Following a Disaster, but These Efforts Are Incomplete

Using experience gained from the WTC disaster, HHS's ATSDR has developed and tested a Rapid Response Registry (RRR) survey instrument that state and local entities can voluntarily adopt to register responders and other individuals exposed to a disaster. The RRR survey instrument, a two-page form that can be distributed in paper or electronic format, is designed to collect information that would enable officials to inform individuals about follow-up health services and facilitate research studies. It contains 38 questions that are intended to collect basic demographic and health information, including contact information; exposure information; and information on exposure-related health effects, immediate health and safety needs, and health insurance.

In October 2005, ATSDR established a contract with Research Triangle Institute International (RTI)⁴⁶ to support state and local efforts to implement the RRR survey instrument during responses to disasters. RTI's responsibilities include providing information to the entire at-risk population on how to enroll in the RRR.⁴⁷ RTI is also responsible for identifying individuals who left the disaster area before being enrolled in the RRR. According to an ATSDR official, data would be collected and

⁴⁶RTI is a private corporation that conducts research and provides technical assistance to government agencies and businesses.

⁴⁷ATSDR officials told us they provided the RRR instrument in response to several requests during Hurricane Katrina. However, they do not know whether the RRR was implemented to any significant extent after the hurricane.

maintained by state or local entities with ATSDR's and RTT's assistance. ATSDR has shared the instrument with other federal agencies, all state health departments, and local response organizations; an ATSDR official told us that as of February 2008, 21 states had included the RRR survey in their disaster planning.⁴⁸

NIOSH has also taken some steps that relate to the registering of responders. In 2005, NIOSH posted interim guidance on its Web site to help occupational health and other clinicians conduct postexposure medical screening of workers leaving hurricane disaster recovery areas. The guidance states that all responders should receive some basic screening services and that their identity and contact information should be obtained on their completion of or return from response activities. The guidance outlines minimum screening information needs, including contact information, health status information, type of response work, exposure information, and injuries or symptoms.

Finally, although ASPR is required under the Pandemic and All-Hazards Preparedness Act to register federal public health and medical personnel who are deployed under the Secretary of HHS's authority, it has not completed efforts to ensure that these responders would be registered in the event of an emergency or a disaster. As part of its efforts, ASPR recently established the Center for Responder Safety, Health, and Risk Management, which is working to develop a system to register responders and record their health problems and make referrals. An ASPR official told us that the Center is exploring how to adapt two existing electronic record systems used by NDMS for this purpose: the Joint Patient Tracking System and the Electronic Medical Record.

HHS Has Not Developed a Plan That Incorporates the Lessons from the WTC Health Programs

HHS has not developed a department-level plan for designing and implementing responder health programs that incorporates the five lessons from the WTC health programs. As a result, HHS has not indicated whether its policies and actions following a disaster or emergency would apply these lessons, such as by building epidemiologic research into the design of screening and monitoring services. Another consequence of not having a plan is that HHS has not described the roles and responsibilities

⁴⁸According to an ATSDR official, the 21 states are Arizona, California, Colorado, Connecticut, Florida, Georgia, Guam, Kentucky, Massachusetts, Michigan, Minnesota, Nebraska, New Jersey, New York, North Carolina, Oklahoma, Oregon, Rhode Island, South Carolina, Tennessee, and Texas.

of its components in designing and implementing responder health programs. According to the NRF, agencies should clearly define roles and responsibilities in their disaster preparedness plans, but HHS has not identified which components would be involved in responder health programs, which component would take the lead, how the expertise of various components would be used, and how efforts would be coordinated.

In the absence of a department-level plan describing the roles of all relevant HHS agencies with regard to responder health programs, NIOSH developed a proposal in February 2008 for working with some of the relevant HHS components to develop strategies to ensure responder safety and health. A NIOSH official told us that the purpose of the project would be to help HHS determine how it would respond to an activation of the NRF and how it would implement the SAFE Port Act. One of the objectives of the project would be to produce a guidance document for federal, state, and local governments and private businesses and organizations to assist them in providing services to responders. A second objective would be to develop a responder surveillance system to document and integrate data on exposures and health effects to identify ways to control potential hazards and determine the need for long-term monitoring. NIOSH partnered with other HHS components, such as ASPR and NIEHS, to develop the proposal. As part of the project, NIOSH officials plan to meet with ATSDR officials about adapting the RRR and other surveillance tools to collect more specific information about a responder's occupation and exposure. In addition, to obtain other perspectives on the project, NIOSH officials plan to meet with state health department representatives in May 2008 and to conduct a focus group with risk managers with an interest in responder safety and health in June 2008.

NIOSH's project would address some aspects of the lessons from the WTC health programs. For example, regarding the first lesson—registering all responders during the response to a disaster—the proposed guidance document would include guidelines for tracking responders during an event, including their activities, exposures, and physical and mental health effects. In addition, the project's objective to develop a responder surveillance system acknowledges aspects of the second lesson—ensuring that screening and monitoring programs are designed to foster epidemiologic research.

Conclusions

Thousands of responders to the WTC disaster have experienced serious physical and mental health problems as a result of their response and recovery efforts. Over the past several years the federal government has provided significant resources to support screening, monitoring, and treatment services for these responders, and designing and implementing these services has involved many challenges. We have identified lessons from this experience that include both practical issues, such as the need to develop a list of responders, and policy approaches, such as the importance of ensuring comparability of services for all responders. Although HHS has taken some steps to apply the first lesson concerning registering responders, it has not completed work to adopt a system to register responders who are deployed to an emergency or a disaster under the Secretary's authority. Timely implementation of such a system, prior to a disaster or emergency occurring, is important. Although NIOSH's proposal for a project to develop strategies for addressing responder health issues is a step in the right direction, HHS has not developed a department-level plan that incorporates the five lessons from the WTC program and defines the roles and responsibilities of all HHS components with regard to planning and implementing responder health programs. Until HHS completes this work, responders to a future disaster could be left vulnerable if they experience health problems as a result of carrying out critical response and recovery activities.

Recommendation for Executive Action

To ensure that effective programs are developed to deal with the health effects that responders may experience in the event of a future disaster, we recommend that the Secretary of HHS take the following action: develop a department-level responder screening and monitoring plan that defines the roles and responsibilities of HHS components and incorporates the five lessons identified from the experience of the WTC health programs. Specifically, this plan should facilitate the registration of all responders and ensure that screening and monitoring services are designed to foster epidemiologic research; provide timely mental health screening and monitoring that is integrated with physical health screening and monitoring; include a treatment referral process; and make comparable services available to all responders, regardless of their employer or geographic location.

Agency Comments and Our Evaluation

HHS reviewed a draft of this report and provided comments on our findings. HHS's comments are reprinted in appendix II. HHS did not comment on our recommendation that HHS develop a department-level responder screening and monitoring plan, but acknowledged that any overall HHS plan should include guidance on treatment referral processes and methods to ensure comparable treatment services across all responder groups.

In its comments, HHS provided additional information about ASPR's responsibilities and activities under the Pandemic and All-Hazards Preparedness Act, which we incorporated as appropriate. For example, HHS discussed ASPR's establishment of the Center for Responder Safety, Health, and Risk Management to address health issues related to public health emergencies. HHS also said that the recommendations and guidance that it plans to develop through NIOSH's project for responder safety and health are intended to reach a larger audience than HHS and that NIOSH has held or is planning meetings with state health department representatives, risk managers with an interest in responder safety and health, and other federal organizations, such as the United States Army Corps of Engineers, to obtain their perspectives on the project.

Finally, HHS said that it was possible to infer from our draft report that long-term monitoring and treatment, including referral for treatment, are appropriate each time a Stafford Act declaration occurs following a disaster. However, our discussions of the lessons on the importance of registering responders and of designing responder health programs to foster epidemiological research noted that implementing these lessons would help public health officials determine whether a specific disaster resulted in health effects and whether long-term monitoring was necessary.

HHS also provided technical comments, which we incorporated as appropriate.

As agreed with your offices, unless you publicly announce its contents earlier, we plan no further distribution of this report until 7 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 on 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 III.



Cynthia A. Bascetta
Director, Health Care

Appendix I: Key Federally Funded WTC Health Programs, May 2008

Program	HHS administering agency or component	Implementing agency, component, or organization	Eligible population	Services provided
New York City Fire Department (FDNY) World Trade Center (WTC) Medical Monitoring and Treatment Program	National Institute for Occupational Safety and Health (NIOSH)	FDNY Bureau of Health Services	Firefighters and emergency medical service technicians	<ul style="list-style-type: none"> Initial screening Follow-up medical monitoring Treatment of WTC-related physical and mental health conditions
New York/New Jersey (NY/NJ) WTC Consortium	NIOSH	Five clinical centers, one of which, the Mount Sinai-Irving J. Selikoff Center for Occupational and Environmental Medicine, also serves as the consortium's Data and Coordination Center	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	Federal Occupational Health Services (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)	New York City (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

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

Note: Some of these federally funded programs have also received funds from the American Red Cross and other private organizations. In addition to the four programs listed in this table, two smaller programs, the Police Organization Providing Peer Assistance (POPPA) program and Project COPE, have received federal funding to provide mental health services through hotline, counseling, and referral services to NYC Police Department employees and their family members. POPPA and Project COPE are private programs that operate independently of the NYC Police Department.

^aIn February 2006, the HHS Assistant Secretary for Preparedness and Response (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.

Appendix II: 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

MAY 19 2008

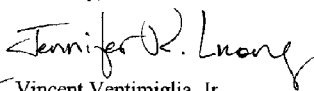
Cynthia A. Bascetta
Director, Health Care
U.S. Government Accountability Office
441 G Street, NW
Washington, DC 20548

Dear Ms. Bascetta:

Enclosed are the Department's comments on the U.S. Government Accountability Office's (GAO) draft report entitled: "September 11: HHS Needs to Develop a Plan that Incorporates Lessons from the Responder Health Programs" (GAO 08-610).

The Department appreciates the opportunity to review and comment on this report before its publication.

Sincerely,


for Vincent Ventimiglia, Jr.
Assistant Secretary for Legislation

Attachment

**COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)
ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT
ENTITLED: HHS NEEDS TO DEVELOP A PLAN THAT INCORPORATES LESSONS
FROM THE RESPONDER HEALTH PROGRAMS (GAO 08-610)**

When the Pandemic and All-Hazards Preparedness Act (PAHPA) was enacted to amend the Public Health Service Act in December 2006, the Secretary of Health and Human Services (HHS) was tasked with leading the Federal public health and medical response to public health emergencies and incidents covered by the National Response Framework. PAHPA also established the position of the Assistant Secretary for Preparedness and Response (ASPR) to carry out functions, subject to the authority of the Secretary, related to public health and medical preparedness and response for public health emergencies. Among other functions, PAHPA tasks the ASPR with registering, credentialing, organizing, training, equipping, and having the authority to deploy federal public health and medical personnel under the authority of the Secretary. To support this function, ASPR is developing an objective methodology to create a system intended to address the needs of future disaster responders.

PAHPA also tasks ASPR to coordinate with relevant federal officials to ensure integration of federal preparedness and response activities for public health emergencies, with promoting improved emergency medical services medical direction, system integration, research, uniformity of data collection, treatment protocols, and policies with regard to public health emergencies, and with carrying out other duties determined appropriate by the Secretary. ASPR has coordinated efforts to address the needs of disaster and emergency responders with CDC, CDC/NIOSH, OSHA, FOH, and OSG/OFRD. In March 2008, ASPR tasked its National Disaster Medical System (NDMS) Office of the Chief Medical Officer (OCMO) with building on these efforts and creating a Center for Responder Safety, Health, and Risk Management. Among other things, the NDMS is charged with carrying out ongoing activities necessary to prepare for the provision of services to respond to the needs of victims of a public health emergency when it is activated.

The NIOSH Project Plan was developed late 2007 and approved by the NIOSH Director February 2008. At that time, NIOSH staff began the process of researching the tools and programs currently available to meet the needs of responders during a disaster. Recommendations and guidance were intended to reach a larger audience than HHS alone. Meetings were held with the National Institute of Environmental Health Sciences (NIEHS), Office of the Assistant Secretary for Preparedness and Response (ASPR), United States Army Corps of Engineers, and other partners. In conjunction with CDC's Disaster Surveillance Working Group, a workshop will be held for State health department representatives in May 2008. The workshop is designed to discuss disaster surveillance, and includes a one-day breakout session on responder safety and health. NIOSH, in partnership with NIEHS, will be sponsoring this breakout session to help determine needs at the State level. NIOSH staff will also conduct a focus group with risk managers with an interest in responder safety and health in June 2008 to get a different perspective on the Project Plan. These are the first steps taken in determining available tools, where opportunity exists to build on current infrastructure, and determine where the largest gaps exist. NIOSH staff plan to discuss the Rapid Response Registry and other surveillance tools with ATSDR.

**COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)
ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT
ENTITLED: HHS NEEDS TO DEVELOP A PLAN THAT INCORPORATES LESSONS
FROM THE RESPONDER HEALTH PROGRAMS (GAO 08-610)**

There may be opportunity to build on the fundamentals of this registry to better capture the increased detail of occupational and exposure information necessary for a responder population.

The WTC health program is a unique instance where NIOSH was designated to lead health programs. This is not a usual mission of NIOSH. As such, when the NIOSH Project Plan was developed, it was not intended to include guidance on treatment referral processes or methods of ensuring comparable treatment services across all responder groups, although these topics should be included in any overall HHS plan.

Finally, with respect to implications that could be drawn from the report that monitoring and treatment, including referral for treatment, are appropriate each time a Stafford Act declaration occurs, we note that neither the Congress nor the Executive Branch has determined that long-term monitoring and treatment will be appropriate each time a disaster declaration is made; and indeed the circumstances for such events will vary enormously. In fact, the HHS authorities under the SAFE Port Act of 2006 allow for case-by-case consideration of the circumstances of each disaster.

Appendix III: 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 Roseanne Price made key contributions to this report.

Related GAO Products

September 11: Improvements Still Needed in Availability of Health Screening and Monitoring Services for Responders outside the New York City Area. [GAO-08-429T](#). Washington, D.C.: January 22, 2008.

September 11: Improvements Needed in Availability of Health Screening and Monitoring Services for Responders. [GAO-07-1229T](#). Washington, D.C.: September 10, 2007.

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

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

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

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

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

GAO's Mission

The Government Accountability Office, the audit, evaluation, and investigative arm of Congress, exists to support Congress in meeting its constitutional responsibilities and to help improve the performance and accountability of the federal government for the American people. GAO examines the use of public funds; evaluates federal programs and policies; and provides analyses, recommendations, and other assistance to help Congress make informed oversight, policy, and funding decisions. GAO's commitment to good government is reflected in its core values of accountability, integrity, and reliability.

Obtaining Copies of GAO Reports and Testimony

The fastest and easiest way to obtain copies of GAO documents at no cost is through GAO's Web site (www.gao.gov). Each weekday, GAO posts newly released reports, testimony, and correspondence on its Web site. To have GAO e-mail you a list of newly posted products every afternoon, go to www.gao.gov and select "E-mail Updates."

Order by Mail or Phone

The first copy of each printed report is free. Additional copies are \$2 each. A check or money order should be made out to the Superintendent of Documents. GAO also accepts VISA and Mastercard. Orders for 100 or more copies mailed to a single address are discounted 25 percent. Orders should be sent to:

U.S. Government Accountability Office
441 G Street NW, Room LM
Washington, DC 20548

To order by Phone: Voice: (202) 512-6000
TDD: (202) 512-2537
Fax: (202) 512-6061

To Report Fraud, Waste, and Abuse in Federal Programs

Contact:

Web site: www.gao.gov/fraudnet/fraudnet.htm

E-mail: fraudnet@gao.gov

Automated answering system: (800) 424-5454 or (202) 512-7470

Congressional Relations

Ralph Dawn, Managing Director, dawnr@gao.gov, (202) 512-4400
U.S. Government Accountability Office, 441 G Street NW, Room 7125
Washington, DC 20548

Public Affairs

Chuck Young, Managing Director, youngc1@gao.gov, (202) 512-4800
U.S. Government Accountability Office, 441 G Street NW, Room 7149
Washington, DC 20548