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SEPTEMBER 11

Monitoring of World Trade Center Health Effects Has Progressed, but Not for Federal Responders

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Highlights of [GAO-05-1020T](#), a testimony before the Subcommittee on National Security, Emerging Threats, and International Relations, Committee on Government Reform, House of Representatives

Why GAO Did This Study

After the 2001 attack on the World Trade Center (WTC), nearly 3,000 people died and an estimated 250,000 to 400,000 people who lived, worked, or attended school in the vicinity were affected. An estimated 40,000 people who responded to the disaster—including New York City Fire Department (FDNY) personnel and other government and private-sector workers and volunteers—were exposed to numerous physical and mental health hazards. Concerns remain about the long-term health effects of the attack and about the nation's capacity to plan for and respond to both short- and long-term health effects in the event of a future attack or other disaster.

Several federally funded programs have monitored the physical and mental health effects of the WTC attack. These monitoring programs include one-time screening programs and programs that also conduct follow-up monitoring. GAO was asked to assess the progress of these programs. GAO examined (1) federally funded programs implemented by state and local government agencies or private institutions, (2) federally administered programs to monitor the health of federal workers who responded to the disaster in an official capacity, and (3) lessons learned from WTC monitoring programs. GAO reviewed program documents and interviewed federal, state, and local officials and others involved in WTC monitoring programs.

www.gao.gov/cgi-bin/getrpt?GAO-05-1020T.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Cynthia A. Bascetta at (202) 512-7101 or bascettac@gao.gov.

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Monitoring of World Trade Center Health Effects Has Progressed, but Not for Federal Responders

What GAO Found

Three federally funded monitoring programs implemented by state and local governments or private organizations after the WTC attack have provided initial medical examinations—and in some cases follow-up examinations—to thousands of affected responders to screen for health problems. For example, the FDNY medical monitoring program completed initial screening for over 15,000 firefighters and emergency medical service personnel, and the worker and volunteer program screened over 14,000 other responders. The New York State responder screening program screened about 1,700 state responders before ending its examinations in 2003. Most state responders have not been informed that they are now eligible to participate in the worker and volunteer program, and New York State responders could miss the opportunity for continued monitoring. These monitoring programs and the WTC Health Registry have collected information that program officials believe researchers could use to help better understand the health consequences of the attack and improve treatment. Program officials expressed concern, however, that current federal funding arrangements for long-term monitoring may be too short to allow for identification of all future health effects.

In contrast to the progress made by other federally funded programs, the Department of Health and Human Services' (HHS) program to screen federal workers who were sent by their agencies to respond to the WTC disaster has accomplished little and is on hold. The program—which started about one year later than other WTC monitoring programs—completed screening of 394 of the estimated 10,000 federal workers who responded in an official capacity to the disaster, but HHS officials suspended examinations and the program has not screened anyone since March 2004. The program's limited activity and the exclusion of federal workers from other monitoring programs because of the assumption that they could receive screening examinations through the HHS program may have resulted in many federal responders losing the opportunity to identify and seek treatment for their WTC-related health problems.

Officials involved in WTC health monitoring programs cited lessons from their experiences that could help others who may be responsible for designing and implementing health monitoring efforts that follow other disasters, such as Hurricane Katrina. These include the need to quickly identify and contact people affected by a disaster; to monitor for mental health effects, as well as physical injuries and illnesses; and to anticipate when designing disaster-related monitoring efforts that there will likely be many people who require referrals for follow-up care and that handling the referral process may require substantial effort. HHS and New York State officials provided comments on the facts contained in this testimony and GAO made changes as appropriate.

Mr. Chairman and Members of the Subcommittee:

Thank you for inviting me to participate in today's hearing to discuss issues related to the health effects that people continue to experience in the aftermath of the September 11, 2001, terrorist attack on the World Trade Center (WTC).¹ After the collapse of the WTC buildings, nearly 3,000 people died, and an estimated 250,000 to 400,000 people who lived, worked, or attended school in the vicinity were affected. An estimated 40,000 people responded to the disaster, including New York City Fire Department (FDNY) personnel and other government and private-sector workers and volunteers from New York and other locations across the nation. These responders,² as they took part in various rescue, recovery, and cleanup activities in the days, weeks, and months following the attack, were exposed to numerous physical hazards and environmental toxins due to the destruction caused by the attack. The magnitude and unprecedented nature of this event also exposed responders and many other people to considerable psychological trauma.

Four years after the destruction of the WTC buildings, concerns remain about the long-term physical and mental health effects of the attack. Several recent studies of responders report that many of them have high rates of physical and mental health symptoms, of which respiratory problems are the most persistent physical effects.³ While the nature and severity of a future terrorist attack cannot be predicted, our prior work on the health effects of the WTC attack, the 2001 anthrax attacks, and bioterrorism preparedness, as well as reports by other organizations, highlight the importance of ensuring the nation's capacity to plan for and respond to the short- and long-term health consequences likely to result in

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

²In this testimony, the term "responders" refers to anyone involved in rescue, recovery, or cleanup activities at or near the vicinity of the WTC site and Staten Island Fresh Kills landfill (the off-site location of the WTC recovery operation).

³See, 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); Centers for Disease Control and Prevention, "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 Gisela I. Banauch and others, "Bronchial Hyperreactivity and Other Inhalation Lung Injuries in Rescue/Recovery Workers after the World Trade Center Collapse," *Critical Care Medicine*, vol. 33, no. 1 (2005).

the event of a future attack or other disaster, such as the destruction recently caused by Hurricane Katrina.⁴

As we testified in September 2004, in the aftermath of the WTC attack, five key federally funded programs were implemented to assess the short-term, and in some cases long-term, effects on people's physical and mental health. These programs include the FDNY WTC Medical Monitoring Program, WTC Medical Monitoring Program (worker and volunteer program),⁵ New York State responder screening program, WTC Health Registry, and the Department of Health and Human Services' (HHS) WTC Federal Responder Screening Program. You asked us to provide information on the progress of these monitoring programs.⁶ My testimony today will focus on (1) progress made by federally funded programs that are implemented by state and local government agencies or private organizations and were established to monitor the health of people in the aftermath of the attack, (2) progress made by federally administered programs established to monitor the health of federal workers who responded to the disaster in an official capacity, and (3) lessons from WTC monitoring programs that could assist those who may be responsible for future disaster-related health monitoring efforts.

To conduct this work, we obtained and reviewed program documents dating from the beginning of the programs, including grantee progress reports, budget documents, clinical protocols, health screening and other assessment tools, and selected peer-reviewed articles based on information collected by WTC monitoring programs. We also interviewed federal, state, and local officials and others involved in administering WTC monitoring programs, including officials from HHS and the Department of

⁴See, for example, GAO, *September 11: Health Effects in the Aftermath of the World Trade Center Attack*, [GAO-04-1068T](#) (Washington, D.C.: Sept. 8, 2004); GAO, *Bioterrorism: Public Health Response to Anthrax Incidents of 2001*, [GAO-04-152](#) (Washington, D.C.: Oct. 15, 2003); GAO, *Public Health Preparedness: Response Capacity Improving, but Much Remains to Be Accomplished*, [GAO-04-458T](#) (Washington, D.C.: Feb. 12, 2004); and Institute of Medicine, *Preparing for the Psychological Consequences of Terrorism: A Public Health Strategy* (Washington, D.C.: 2003).

⁵This program was formerly known as the WTC Worker and Volunteer Medical Screening Program. In this testimony, we refer to the program as the worker and volunteer program.

⁶In this testimony, we use the term monitoring program to refer to both one-time screening programs and programs that include initial screening and periodic follow-up monitoring.

Homeland Security (DHS);⁷ New York State Department of Health; New York City Department of Health and Mental Hygiene; and FDNY. Within HHS, we interviewed officials from the Agency for Toxic Substances and Disease Registry (ATSDR); the Centers for Disease Control and Prevention's (CDC) National Center for Environmental Health and National Institute for Occupational Safety and Health (NIOSH); Federal Occupational Health Services (FOH);⁸ and the Office of Public Health Emergency Preparedness (OPHEP). We also obtained information from the Department of Defense (DOD) and the Department of Justice (DOJ). We interviewed medical professionals affiliated with the New York University School of Medicine, FDNY's Bureau of Health Services, Long Island Occupational and Environmental Health Center, Mount Sinai-Irving J. Selikoff Center for Occupational and Environmental Medicine, Mount Sinai School of Medicine Department of Psychiatry, and the University of Medicine and Dentistry of New Jersey's Robert Wood Johnson Medical School. We relied on data provided by agency officials and contained in government publications and did not independently verify the data we obtained. In our judgment the reliability of the information we obtained was adequate for our purposes. HHS and New York State officials provided comments on the facts contained in this statement, and we made changes as appropriate. We conducted our work from July 2005 through September 2005 in accordance with generally accepted government auditing standards.

In summary, three federally funded programs implemented by state and local governments or private organizations in the aftermath of the WTC attack have provided initial medical examinations—and in some cases follow-up examinations—to thousands of affected responders to screen for health problems. For example, the FDNY program completed initial screening for over 15,000 firefighters and emergency medical service personnel, and the worker and volunteer program has screened over 14,000 other responders. The New York State program screened about 1,700 state responders before ending its screening examinations; in general, it has not informed state responders that they are now eligible to receive continued monitoring from the worker and volunteer program. These three programs and the WTC Health Registry have collected information that monitoring program officials believe could be used by

⁷The DHS officials we spoke with were from the Federal Emergency Management Agency, which became part of DHS in March 2003.

⁸FOH is a part of HHS's Program Support Center.

researchers to help better understand the health consequences of the attack and improve treatment, such as by identifying which types of treatment are effective for specific conditions. Officials of programs that plan to conduct long-term health monitoring are concerned that current federal funding arrangements may be too short to allow for identification of all the health effects that participants may eventually experience.

In contrast to the progress made by federally funded programs implemented by state and local governments or private organizations, the program that HHS implemented to screen federal workers who were sent by their agencies to respond to the WTC disaster has accomplished little. The program—which started later than other WTC monitoring programs—completed screening of 394 of the estimated 10,000 federal workers who responded in an official capacity to the disaster and were not eligible for any other WTC health monitoring program. HHS placed the program on hold in January 2004, when it stopped scheduling new examinations. It has not screened anyone since March 2004. We identified two federal agencies that, in the aftermath of the WTC attack, have implemented programs to assess the health of their own employees who responded to the disaster.

Officials involved in WTC health monitoring programs cited lessons from their experiences that could help others who may be responsible for designing and implementing disaster-related health monitoring efforts in the future. These include the need to quickly identify and contact people affected by a disaster; to monitor for mental health effects, as well as the more obvious physical injuries and illnesses; and, when developing health monitoring efforts in the wake of disasters, to anticipate that there will likely be many people who require referrals for further diagnostic and treatment services and that handling the referral process may require a substantial level of effort.

Background

When the WTC buildings collapsed on September 11, 2001, an estimated 250,000 to 400,000 people were immediately exposed to a noxious mixture of dust, debris, smoke, and potentially toxic contaminants in the air and on the ground, such as pulverized concrete, fibrous glass, particulate matter, and asbestos. Those affected included people residing, working, or attending school in the vicinity of the WTC and thousands of emergency response workers. Also affected were the estimated 40,000 responders who were involved in some capacity in the days, weeks, and months that

followed, including personnel from many government agencies and private organizations as well as other workers and volunteers.⁹

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.¹⁰ Physical health effects included injuries and respiratory conditions, such as sinusitis, asthma, and a new syndrome called WTC cough, which consists of persistent coughing accompanied by severe respiratory symptoms. Almost all firefighters who responded to the attack experienced respiratory effects, including WTC cough, and hundreds had to end their firefighting careers due to WTC-related respiratory illnesses. The most commonly reported mental health effects among responders and others were symptoms associated with posttraumatic stress disorder—an often debilitating disorder that can develop after a person experiences or witnesses a traumatic event, and which may not develop for months or years after the event. Behavioral effects such as alcohol and tobacco use and difficulty coping with daily responsibilities were also reported.

Several federally funded programs monitor the health of people who were exposed to the WTC attack and its aftermath. The monitoring programs vary in such aspects as eligibility requirements, methods used for collecting information about people's health, and approaches for offering referrals. Of the four programs that offer medical examinations to WTC responders, the only one that is open to federal workers who responded to the disaster in an official capacity is the one implemented by HHS. (See table 1.) None of the monitoring programs receives federal funds to provide clinical treatment for health problems that are identified.

⁹The responders included firefighters, law enforcement officers, emergency medical technicians and paramedics, morticians, health care professionals, and other workers and volunteers, including those in the construction and ironwork trades, heavy equipment operators, mechanics, engineers, truck drivers, carpenters, day laborers, and telecommunications workers. Numerous federal, state, and New York City agencies sent personnel to respond to the WTC disaster (see app. II).

¹⁰[GAO-04-1068T](#).

Table 1: Key Federally Funded WTC Health Monitoring Programs

	Implementing agency or organization	Federal administering agency	Eligible populations	Monitoring methods	Treatment referral
FDNY WTC Medical Monitoring Program^a	FDNY Bureau of Health Services (FDNY-BHS)	National Institute for Occupational Safety and Health (NIOSH)	Firefighters and emergency medical service technicians	Medical questionnaire and examination	Refers to FDNY-BHS
WTC Medical Monitoring Program (worker and volunteer program)^a	Five clinical centers, one of which, the Mount Sinai-Irving J. Selikoff Center for Occupational and Environmental Medicine, also serves as a data and coordination center ^b	NIOSH	Rescue and recovery workers and volunteers, except for federal workers who were official responders and New York City (NYC) firefighters ^c	Medical questionnaire and examination	Refers to privately funded programs available to responders; some privately funded treatment provided at the clinical centers
New York State responder screening program^d	New York State Department of Health	National Center for Environmental Health	New York State employees and National Guard personnel who responded to the WTC attack in an official capacity	Medical questionnaire and examination	Instructed participants to see their primary care physician or a specialist
WTC Health Registry	NYC Department of Health and Mental Hygiene	Agency for Toxic Substances and Disease Registry (ATSDR)	Responders and people living or attending school in the area of the WTC, or working or present in the vicinity on September 11, 2001 ^e	Telephone-based health and exposure interview	Provides information on where treatment can be sought; ^f refers participants to LIFENET ^g for mental health services
WTC Federal Responder Screening Program	Department of Health and Human Services' (HHS) Office of Public Health Emergency Preparedness	HHS	Federal workers who responded to the WTC attack in an official capacity	Medical questionnaire and examination	Instructs participants to see their primary care physician; in future, may refer participants with mental health symptoms to a Federal Occupational Health Services employee assistance program

Source: GAO analysis of information from ATSDR, FDNY, Mount Sinai, National Center for Environmental Health, New York City Department of Health and Mental Hygiene, New York State Department of Health, and NIOSH.

^aThe FDNY WTC Medical Monitoring Program and the WTC Medical Monitoring Program constitute the WTC Responder Health Consortium. NIOSH established the consortium in March 2004 to coordinate the health monitoring of the two programs and to facilitate data sharing.

⁸The other clinical centers are located at the Long Island Occupational and Environmental Health Center, the New York University School of Medicine, the City University of New York's Queens College, and the University of Medicine and Dentistry of New Jersey's Robert Wood Johnson Medical School. The responsibilities of the Mount Sinai data and coordination center include coordination of the clinical centers, outreach and education, quality assurance, and data management.

⁷The worker and volunteer program excludes responders who were paid as federal workers or as NYC firefighters for their WTC work; these employees are eligible for other programs. The program initially excluded responders who were paid as New York State employees for their WTC work and were eligible for the New York State responder screening program. That program ended its screening examinations in November 2003, and as of February 2005, New York State responders became eligible for the worker and volunteer program.

⁴The New York State program ended its screening examinations in November 2003.

⁵Participants in the other WTC monitoring programs may also participate in the registry program.

⁶The registry program provides enrollees with a resource guide of occupational, respiratory, environmental, and mental health facilities where they could seek treatment. Some of the services provided by these facilities require payment, while others are free of charge.

⁹LIFENET is a 24-hour mental health information and referral service provided by the New York State Office of Mental Health. In cases where WTC Health Registry interviewers think a person is experiencing moderate distress, they can immediately transfer the call so the person can speak to a LIFENET counselor.

The majority of federal funding for these monitoring programs was provided by DHS's Federal Emergency Management Agency (FEMA),¹¹ as part of the approximately \$8.8 billion in federal assistance that the Congress appropriated to FEMA for response and recovery activities after the WTC disaster.¹² One fiscal year 2003 appropriation specifically authorized FEMA to use a portion of its WTC-related funding for screening and long-term monitoring of emergency services and rescue and recovery personnel.¹³ Generally, however, FEMA may fund only short-term care

¹¹FEMA is the agency responsible for coordinating federal disaster response efforts under the National Response Plan.

¹²FEMA provided funds to HHS to support screening and long-term monitoring efforts from funds appropriated for disaster relief and emergency response to the September 11, 2001, terrorist attacks. See 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.

¹³Pub. L. No. 108-7.

after a disaster, such as emergency medical services, and not ongoing clinical treatment.¹⁴

FEMA entered into interagency agreements with HHS to fund most of these health monitoring programs. HHS is the designated lead agency for the public health and medical support function under the National Response Plan and is responsible for coordinating the medical resources of all federal departments and agencies. HHS's Office of Public Health Emergency Preparedness (OPHEP) coordinates and directs HHS's emergency preparedness and response program.

Health Monitoring Programs Implemented by State and Local Governments or Private Organizations Have Made Progress

Three federally funded programs implemented by state and local governments or private organizations—the FDNY WTC Medical Monitoring Program, WTC Medical Monitoring Program (worker and volunteer program), and New York State responder screening program—have made progress in monitoring the physical and mental health of people affected by the WTC attack. Federal employees who responded to the WTC disaster in an official capacity were not eligible for these programs because it was expected that another program would be developed for them. The New York State program stopped providing examinations in November 2003, and state workers are now eligible for initial or continued monitoring through the worker and volunteer program. In general, the state program has not informed state responders that they are eligible for the worker and volunteer program. All three programs and the WTC Health Registry have collected information that could contribute to better understanding of the health consequences of the attack and improve health care for affected individuals. Officials from the FDNY, worker and volunteer, and WTC Health Registry programs are concerned that federal funding for their programs could end before sufficient monitoring occurs to identify all long-term health problems related to the WTC disaster.

¹⁴The Robert T. Stafford Disaster Relief and Emergency Assistance Act, as amended, authorizes FEMA to, among other things, make appropriated funds available for disaster relief and emergency assistance. Pub. L. No. 93-288, 88 Stat. 143 (1974), as amended. The Stafford Act does not specifically authorize ongoing clinical treatment.

Three WTC Monitoring Programs Provided Medical Examinations to Identify Responders' Health Problems

Three federally funded programs implemented by state and local governments or private organizations have provided medical examinations to identify physical and mental health problems after the WTC attack. (See table 2.) Two of these programs—the FDNY WTC Medical Monitoring Program and the worker and volunteer program—are tracking the health of WTC rescue, recovery, and cleanup workers and volunteers over time. The third program, the New York State responder screening program, offered one-time screening examinations to state employees, including National Guard personnel, who participated in WTC rescue, recovery, and cleanup work. Federal employees who responded to the WTC disaster in an official capacity were not eligible for any of these programs because it was expected that another program would be developed for them.

Table 2: Monitoring Activities and Associated Federal Funding for WTC Monitoring Programs Implemented by State and Local Governments or Private Organizations

	Completed monitoring activities	Planned monitoring activities	Federal funding ^a
FDNY WTC Medical Monitoring Program	Through June 2005, 15,284 firefighters and emergency medical service technicians received screening examinations, and 522 of these participants completed a follow-up examination.	By June 2009, conduct three follow-up examinations of each participant.	\$4.8 million was provided beginning in October 2001 for initial program; additional \$25 million is available through June 2009.
WTC Medical Monitoring Program (worker and volunteer program)	Through June 2005, 14,110 people received screening examinations, and 1,699 of these participants completed a follow-up examination.	By July 2009, conduct three follow-up examinations of each participant.	\$15.9 million was provided for initial program; ^b additional \$56 million is available through July 2009.
New York State responder screening program	As of November 2003, 1,677 of approximately 9,800 eligible employees and National Guard personnel received screening examinations.	No further examinations are planned. Participants are now eligible to participate in the worker and volunteer program.	\$2.4 million was provided in January 2002 and is available through January 2006. ^c
WTC Health Registry	As of November 2004, the program completed baseline data collection through interviews with the 71,437 people who enrolled in the registry; ^d registry officials estimate that about 385,000 people had been eligible to enroll. In 2005, the program updated contact information obtained at the time of enrollment.	In 2006, conduct follow-up survey of participants. Registry officials are developing plans to track participants' health through 2023.	\$20 million was provided beginning in July 2002, ^e and additional funding of about \$3 million has since been provided. ^f

Source: GAO analysis of information from ATSDR, FDNY, Mount Sinai, National Center for Environmental Health, New York City Department of Health and Mental Hygiene, New York State Department of Health, and NIOSH.

^aExcept as noted, FEMA provided these funds to the federal administering agency for each monitoring program.

^b\$11.8 million of this amount was provided beginning in July 2002 through funds appropriated to CDC. An additional \$4.1 million was provided in fiscal year 2003 through an interagency agreement with FEMA.

^eThe primary program activity since November 2003 has been data analysis.

^fRegistry officials told us that final enrollment numbers may be revised pending internal verification of data.

^gThe grant agreement is between ATSDR and the New York City Department of Health and Mental Hygiene. However, ATSDR contracted directly with Research Triangle Institute (RTI), a private not-for-profit organization, for most of the work to establish the registry, and about \$16 million of the \$20 million went directly from ATSDR to RTI.

^hThe Environmental Protection Agency provided \$2 million of these funds. In addition, CDC and ATSDR provided \$500,000 each.

The FDNY program completed initial screening for over 15,000 firefighters and emergency medical service personnel, and the worker and volunteer program completed initial screening for over 14,000 other responders. In both programs, screenings include physical examinations, pulmonary function tests, blood and urine analysis, a chest X-ray, and questionnaires on exposures and mental health issues. Both programs have begun to conduct follow-up examinations of participants and continue to accept new enrollees who desire initial screening. Current plans are to conduct a total of three follow-up examinations for each participant by 2009. As part of their federally funded activities, both programs provide referrals for participants who require treatment. FDNY employees and retirees can obtain treatment and counseling services from the FDNY Bureau of Health Services and the FDNY Counseling Services Unit, or they can use their health insurance to obtain treatment and counseling services elsewhere. The worker and volunteer program also provides referrals for its participants, including referrals to programs funded by the American Red Cross and other nonprofit organizations.

The New York State program screened about 1,700 of the estimated 9,800 state workers and National Guard personnel who responded to the WTC disaster. Officials sent letters to these responders to inform them about the program and their eligibility for it.¹⁵ For each participant, the screening included a health and exposure questionnaire and physical and pulmonary examinations. Participants who required further evaluation or treatment after screening were told to follow up with their personal physician or a specialist. The program stopped screening participants in November 2003, in part because the number of responders requesting examinations was dwindling, and no follow-up examinations are planned.

¹⁵When state officials contacted the estimated 9,800 state responders, some of them informed the program that they were not interested in participating. Officials sent follow-up letters to state employees who did not respond to the initial mailing. National Guard personnel were sent only an initial letter.

In February 2005, worker and volunteer program officials began to allow New York State responders to participate in that monitoring program. The officials determined that the worker and volunteer program would have sufficient funding to accommodate state workers who want to join the program.¹⁶ The state program has not notified the approximately 1,700 workers it has screened that they are now eligible for continued monitoring from the worker and volunteer program. Program officials relayed this development only to those state responders who inquired about screening or monitoring examinations following the decision to permit state responders to participate in the worker and volunteer program. Worker and volunteer program officials told us that, through August 2005, no state workers who responded to the WTC disaster in an official capacity had received examinations from the worker and volunteer program. According to worker and volunteer program officials, any state worker screened by the state program would need a new baseline examination through the worker and volunteer program because the screening data collected by the state program differ from the data collected in the worker and volunteer program. For example, the worker and volunteer program offers a breathing test not provided by the state program.

Programs Provide Data for WTC-Related Health Research

In addition to providing medical examinations, these three programs—the FDNY program, the worker and volunteer program, and the New York State program—have collected information for use in scientific research to better understand the health consequences of the WTC attack and other disasters. A fourth program, the WTC Health Registry, includes health and exposure information obtained through interviews with participants; it is designed to track participants’ health for 20 years and to provide data on the long-term health consequences of the disaster (see table 2). Physicians who evaluate and treat WTC responders 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.

¹⁶As of September 1, 2005, the worker and volunteer program was in the process of establishing a network of providers to serve responders outside the New York City metropolitan area. State responders had been eligible for monitoring at existing New York City area clinics since February 2005, but they will not be able to visit providers in Albany and other areas of New York until the network is established.

Both the FDNY program and the worker and volunteer program have been the basis for published research articles on the health of WTC responders. For example, the FDNY program reported on the injuries and illnesses experienced by firefighters and emergency medical service workers after responding to the attack.¹⁷ In addition, the worker and volunteer program published information on the physical and mental health of responders in 2004.¹⁸ Officials from both programs plan to publish additional findings as they track participants' health over time. Although the New York State program has stopped offering examinations, program officials are continuing to analyze data from the program with plans for eventual publication.

The WTC Health Registry program has collected health information through interviews with responders, people living or attending school in the vicinity of the WTC site, and people working or present in the vicinity on September 11, 2001. The registry completed enrollment and conducted interviews with over 71,000 participants by November 2004. Officials updated contact information for all participants in 2005, and they plan to conduct a follow-up health survey of participants in early 2006. Registry officials would like to conduct subsequent follow-up surveys periodically through about 2023—20 years after the program began in 2003—but have not yet secured funding for long-term monitoring.¹⁹

The registry is designed to provide a basis for research to evaluate the long-term health consequences of the disaster. It includes contact information for people affected by the WTC attack, information on individuals' experiences and exposures during the disaster, and information on their health. In November 2004, registry officials published preliminary results on the health status of registry participants, and officials expect to submit several research papers for publication within the next year. In addition, in May 2005, registry officials published

¹⁷See, for example, CDC, "Injuries and Illnesses among New York City Fire Department Rescue Workers after Responding to the World Trade Center Attacks," *Morbidity and Mortality Weekly Report*, vol. 51 (2002), and Elizabeth M. Fireman and others, "Induced Sputum Assessment in NYC Firefighters Exposed to World Trade Center Dust," *Environmental Health Perspectives*, vol. 112 (2004).

¹⁸CDC, *Morbidity and Mortality Weekly Report*, vol. 53, p. 807, and CDC, *Morbidity and Mortality Weekly Report*, vol. 53, p. 812.

¹⁹Program officials told us that the registry was designed as a 20-year program because most long-term health effects that might result from the WTC disaster would likely begin to appear in the population within that period of time.

guidelines for allowing registry information to be used in scientific research,²⁰ and they have since approved three proposals for external research projects that use registry information. These proposals include two studies of building evacuations and a study of psychological responses to terrorism.

Program Officials Are Concerned That Current Federal Funding Arrangements Will End before Needed Monitoring Is Complete

Officials from the FDNY, worker and volunteer, and WTC Health Registry programs are concerned that current federal funding arrangements for programs designed to track participants' health over time may be too short to allow for identification of all the health effects that may eventually develop. ATSDR plans to fund the WTC Health Registry through April 2008, and NIOSH plans to fund the FDNY program and the worker and volunteer program through mid-2009. ATSDR's 5-year cooperative agreement with the New York City Department of Health and Mental Hygiene to support the WTC Health Registry went into effect April 30, 2003, and extends through April 29, 2008. Similarly, NIOSH awarded 5-year grants in July 2004 to continue the FDNY and worker and volunteer programs, which had begun in 2001 and 2002, respectively. Health experts involved in these monitoring programs, however, cite the need for long-term monitoring of affected groups because some possible health effects, such as cancer, may not appear until decades after a person has been exposed to a harmful agent. They also told us that monitoring is important for identifying and assessing the occurrence of newly identified conditions, such as WTC cough, and chronic conditions, such as asthma.

HHS's Program for Screening Federal Responders Has Accomplished Little and Is on Hold

HHS's OPHEP established the WTC Federal Responder Screening Program to provide medical screening examinations for an estimated 10,000 federal workers who responded to the WTC disaster in an official capacity and were not eligible for any other medical monitoring program. OPHEP did not develop a comprehensive list of federal responders who were eligible for the program. The program began in June 2003—about a year later than other monitoring programs—and completed screenings for 394 workers. No examinations have occurred since March 2004, because officials placed the program on hold, temporarily suspending new examinations. The program is still on hold, and OPHEP officials are taking actions intended

²⁰Under the guidelines, a review committee consisting of public health scientists and stakeholder representatives evaluates each proposed research project based on criteria such as the proposal's scientific and technical merit, funding, and contribution to a community or individuals.

to lead to restarting the program. We identified two federal agencies that established screening programs for their own personnel who responded to the disaster.

HHS Program Screened Few Federal Workers and Has Been on Hold for over 1 Year

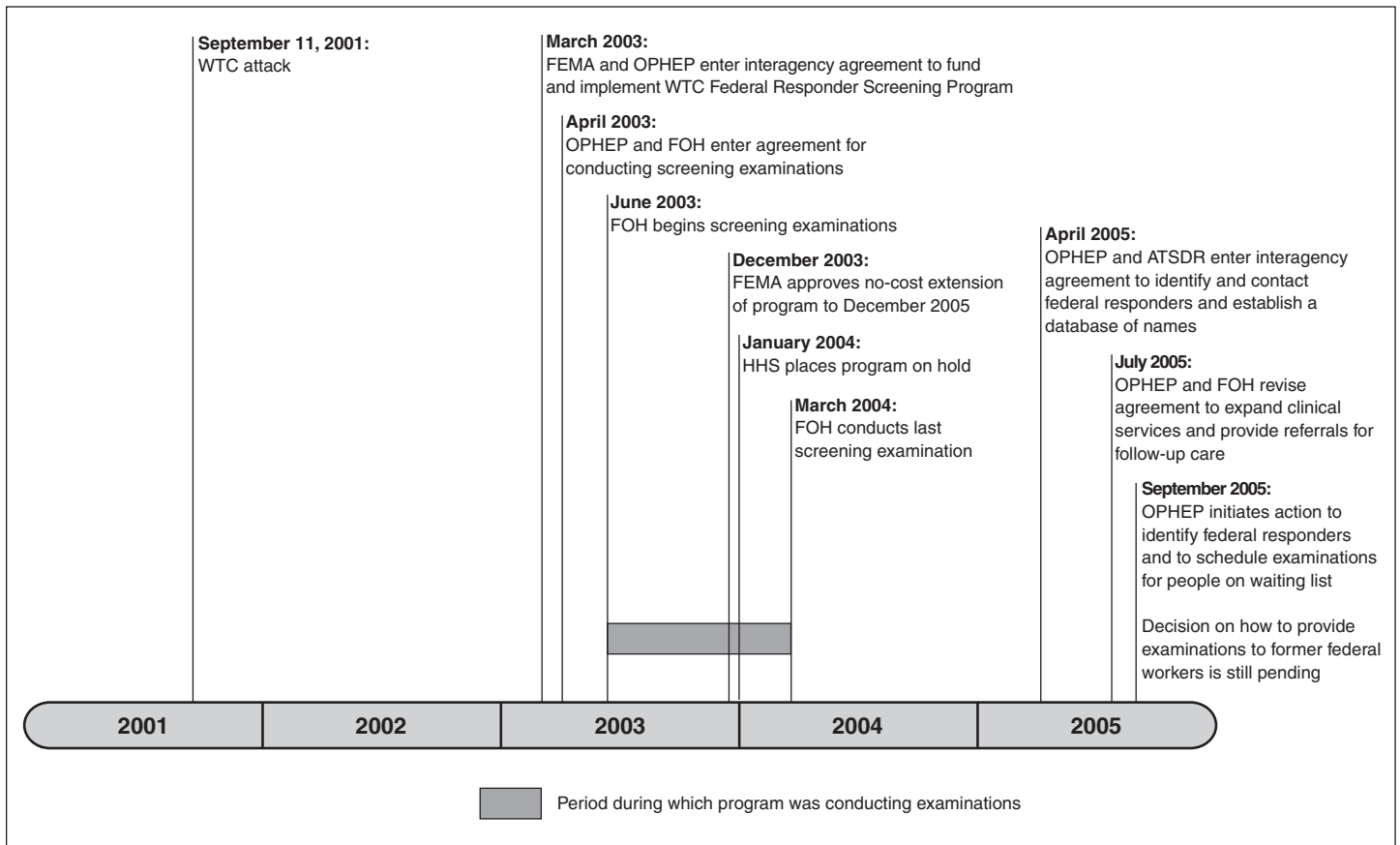
HHS's WTC Federal Responder Screening Program was established to provide free voluntary medical screening examinations for an estimated 10,000 federal workers²¹ whom their agencies sent to respond to the WTC disaster from September 11, 2001, through September 10, 2002, and who were not eligible for any other monitoring program.²² FEMA provided \$3.74 million through an interagency agreement with HHS's OPHEP for the purpose of developing and implementing the program. OPHEP entered into an agreement with HHS's FOH to schedule and conduct the screening examinations.

The launching of the federal responder screening program lagged behind the implementation of other federally funded monitoring programs for WTC responders. For example, the medical screening program for New York State employees and the worker and volunteer program started conducting screening examinations in May 2002 and July 2002, respectively. However, OPHEP did not launch its program until June 2003. (Figure 1 highlights key actions in developing and implementing the program.)

²¹For this program, a federal worker is defined as being either a permanent, temporary, or intermittent federal employee.

²²According to a FEMA official, federal workers who did not receive official orders from their agencies to respond to the WTC disaster are not eligible for this program. According to an official of the worker and volunteer program, federal workers who volunteered on their own in the aftermath of the disaster were eligible to participate in that screening program.

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



Source: GAO analysis of information from HHS's OPHEP and FOH, and FEMA.

OPHEP did not develop a plan for identifying all federal agencies and their personnel that responded to the WTC disaster or for contacting all federal personnel eligible for the screening program. Although OPHEP and FEMA developed a partial list of federal responders—consisting primarily of HHS and FEMA personnel—OPHEP did not have a comprehensive list of agencies and personnel, and so could not inform all eligible federal responders about the WTC screening program. The program’s principal action to communicate with the federal responders was to place program

information and registration forms on FEMA's National Disaster Medical System (NDMS) Web site.²³

The screening program had operated for about 6 months when OPHEP officials decided in January 2004 to place it on hold by temporarily suspending examinations. FOH officials told us that they completed 394 screening examinations²⁴ from June 2003 through March 2004,²⁵ with most completed by the end of September 2003. According to FOH, a total of \$177,967 was spent on examinations.²⁶ As of September 7, 2005, the program remained on hold, with 37 people on the waiting list for examinations,²⁷ and OPHEP has not set a date for resuming the examination process.

OPHEP officials told us that three operational issues contributed to the decision to suspend the program. First, OPHEP could not inform all eligible federal responders about the program because it lacked a comprehensive list of eligible federal responders. Second, there were concerns about what actions FOH clinicians could take when screening examinations identified problems. Based on the examinations that had been completed before the program was placed on hold, FOH clinicians determined that many participants needed additional diagnostic testing and follow-up care, primarily in the areas of respiratory functioning and mental health. However, under the existing interagency agreement there was no provision for providing follow-up care and no direction for

²³NDMS provides medical care to victims and responders to domestic disaster, including acts of terrorism and natural disasters. According to HHS officials, when NDMS was transferred to FEMA in 2003 as part of the formation of DHS, key NDMS staff involved in the initial planning of the screening program were also transferred. During the transition period, these NDMS staff continued to carry out some tasks related to the screening program, including working to identify agencies that had sent employees to the WTC disaster, developing a list of federal responders, and placing information about the program on the NDMS Web site. Officials said that overall program management responsibility and funding remained with HHS.

²⁴FOH officials told us that although FOH clinicians had seen approximately 460 federal personnel, not all of them completed the entire examination process.

²⁵FOH continued to schedule and conduct examinations for those people who had requested an examination before the program was placed on hold in January 2004.

²⁶FOH officials told us that this amount includes spending on the 394 completed examinations and on examinations that were not completed.

²⁷FOH officials told us that these 37 applications were received after the screening program was placed on hold in January 2004.

clinicians on how to handle the provision of further diagnostic tests, treatment, or referrals. FOH officials told us that they were concerned about continuing to provide screening examinations without the ability to provide participants with additional needed services. Third, although the screening program had been established to provide examinations to all federal responders regardless of their current federal employment status, HHS officials told us that the department determined that FOH does not have the authority to provide examinations to people who are no longer in federal service. OPHEP officials told us in September 2005 that they were exploring avenues for providing examinations to federal responders who were no longer federal employees.

OPHEP has begun to take action to prepare for offering examinations again. In April 2005, program officials enlisted the assistance of ATSDR—which had successfully developed the WTC Health Registry—to help develop the needed lists of federal agencies and personnel for the federal responder program. OPHEP executed an agreement with ATSDR that allocated about \$491,000 from the program’s remaining allocation from FEMA to ATSDR.²⁸ Under this agreement, which is scheduled to run through April 2006, ATSDR is working with the contractor it used to develop the WTC Health Registry to develop a new registration Web site, develop and implement a comprehensive recruitment and enrollment plan for current and former federal workers, and establish a database containing the names of federal responders. On September 1, 2005, OPHEP sent a letter to 51 federal agencies requesting them to provide ATSDR’s contractor with contact information on the employees they sent to respond to the WTC disaster.

In July 2005, OPHEP and FOH executed a new agreement so that when the program begins examining responders again, FOH clinicians will be able to make referrals for follow-up care. For example, they will be able to refer participants with mental health symptoms to an FOH employee assistance program for a telephone assessment. If appropriate, the participant will be referred to an employee assistance program counselor for up to six in-person sessions. If the assessment indicates that longer treatment is necessary, the participant instead will be advised to use health insurance to obtain care or to contact a local Department of Labor Office of Workers’ Compensation to file a claim, receive further evaluation, and possibly

²⁸According to OPHEP, as of August 22, 2005, about \$3 million of the original \$3.74 million allocated by FEMA for this screening program remained.

obtain compensation for mental health services. The new agreement between OPHEP and FOH also will allow FOH clinicians to order additional clinical tests, such as special pulmonary and breathing tests.

Two Federal Agencies Established Their Own Screening Programs

We identified two federal agencies that established medical screening programs to assess the health of the personnel they had sent to respond to the WTC disaster. One agency, the Army, established two screening programs—one specifically for Army Corps of Engineers personnel and one that also included other Army responders. The Army Corps of Engineers established a voluntary program to assess the health of 356 employees it had sent to respond to the disaster.²⁹ The program, initiated in November 2001, consists of sending employees an initial medical screening questionnaire covering physical health issues.³⁰ If questionnaire results indicate symptoms or concerns that need further evaluation, the employee is offered a medical examination.³¹ As of August 2004, 92 Corps of Engineers employees had participated in the program, with 40 receiving follow-up examinations. The Army's Center for Health Promotion and Preventive Medicine initiated a program—the World Trade Center Support Health Assessment Survey—in January 2002. It was designed as a voluntary medical screening for Army military and civilian personnel, including contractors. From January 2002 through September 2003, questionnaires were sent to 256 employees.³² According to DOD, 162 employees completed and returned their questionnaires. In addition, the U.S. Marshals Service, within the Department of Justice, modified an existing agreement with FOH in 2003 for FOH to screen approximately 200 U.S. Marshals Service employees assigned to the WTC or Pentagon recovery sites. The one-time assessment includes a screening

²⁹The screening program has no closing date, and employees can request a screening examination at any time.

³⁰The questionnaire collects information on prior and WTC-related occupational exposures and prior and current physical health status.

³¹The medical examination includes a comprehensive history and physical examination, chest X-ray, and pulmonary function, blood, and urine tests.

³²The Army's questionnaire was distributed to active-duty service members, activated members of the Reserves and National Guard, civilian employees, and civilian contractors. These included 125 New Jersey Army National Guard members. The 474 active-duty members of the New York Army National Guard who responded to the WTC disaster were not included due to their eligibility to participate in the medical screening program established for New York State workers.

questionnaire and a medical examination.³³ FOH officials said that as of August 2005, 88 of the 200 U.S. Marshals Service employees had requested and obtained examinations.³⁴

Lessons from WTC Health Monitoring Programs Could Assist Future Monitoring Efforts

Officials involved in the WTC health monitoring programs implemented by state and local governments or private organizations—including officials from the federal administering agencies—derived lessons from their experiences that could help officials design such programs in the future. They include the need to quickly identify and contact people affected by a disaster, the value of a centrally coordinated approach for assessing individuals' health, the importance of monitoring both physical and mental health, and the need to plan for providing referrals for treatment when screening examinations identify health problems.

Officials involved in the monitoring programs emphasized the importance of quickly identifying and contacting people affected by a disaster. They said that potential monitoring program participants can become more difficult to locate as time passes.³⁵ In addition, potential participants' ability to recall the events of a disaster may decrease over time, making it more difficult to collect accurate information about their experiences and health. However, the time it takes to design, fund, approve, and implement monitoring programs can lead to delays in contacting the people who were affected. For example, the WTC Health Registry received funding in July 2002 but did not begin collecting data until September 2003—2 years after the disaster. From July 2002 through September 2003, the program's activities included developing the registry protocol, testing the questionnaire, and obtaining approval from institutional review boards and

³³The medical examination includes an occupational exposure history and physical examination, chest X-ray, blood and urine tests, pulmonary function test, audiogram, and electrocardiogram.

³⁴FOH officials told us that under the terms of the agreement, eligible employees can still request a screening examination.

³⁵The extent of the challenge of locating potential participants varied among WTC monitoring programs, depending on the population involved. For example, FDNY had contact information for all potential participants in its monitoring program because they were employed by FDNY during or after the disaster. In contrast, the worker and volunteer program and the WTC Health Registry had to expend considerable effort to identify people who were eligible to participate and inform them about the programs.

the federal Office of Management and Budget.³⁶ This delayed the collection of information from participants. To prevent similar delays during the response to future disasters, ATSDR officials are developing a questionnaire, known as the Rapid Response Registry, to allow officials to identify and locate potentially affected individuals immediately after a disaster and collect basic preliminary information, such as their current contact information and their location during the disaster.³⁷ ATSDR officials expect that using this instrument would reduce delays in collecting time-sensitive information while officials take the time necessary to develop a monitoring program for disaster-related health effects.

Furthermore, officials told us that health monitoring for future disasters could benefit from additional centrally coordinated planning. Such planning could facilitate the collection of compatible data among monitoring efforts, to the extent that this is appropriate. Collecting compatible data could allow information from different programs to be integrated and contribute to improved data analysis and more useful research. In addition, centrally coordinated planning could help officials determine whether separate programs are necessary to serve different groups of people. For example, worker and volunteer program officials indicated that it might have been possible for that program to serve federal workers who responded to the disaster in an official capacity, which might have eliminated the need to organize and administer a separate program for them.

Officials also stated that screening and monitoring programs should be comprehensive, encompassing both physical and mental health evaluations. Worker and volunteer medical monitoring program officials told us that the initial planning for the program had focused primarily on screening participants' physical health, and that they did not originally budget for extensive mental health screening. Subsequently, they recognized a need for more extensive mental health screening, including greater participation of mental health professionals, but the program's

³⁶Institutional review boards are groups that have been formally designated to review and monitor biomedical research involving human subjects. Under the Paperwork Reduction Act, agencies are required to submit proposed information collections to the Office of Management and Budget for approval. See, 44 U.S.C. § 3507.

³⁷The Rapid Response Registry has been approved by CDC's Institutional Review Board and has undergone initial review by the Office of Management and Budget.

federal funding was not sufficient to cover such screening. By collaborating with the Mount Sinai School of Medicine Department of Psychiatry, program officials were able to obtain philanthropic funding to develop a more comprehensive mental health questionnaire, provide on-site psychiatric screening, and, when necessary, provide more extensive evaluations.

Many participants in the monitoring programs required additional testing or needed treatment for health problems that were identified during screening examinations. Officials told us that finding treatment sources for such participants is an important, but challenging, part of the programs' responsibility. For example, officials from the worker and volunteer program stated that identifying providers available to treat participants became a major part of their operations, and was especially difficult when participants lacked health insurance. The officials said that planning for future monitoring programs should include a determination of how best to help participants obtain needed treatment.

Concluding Observations

Federally funded programs implemented by state and local governments or private organizations to monitor the health effects of the WTC attack on thousands of people who responded to the disaster have made progress. However, the program HHS established to screen the federal employees whose agencies sent them to the WTC after the attack has accomplished little, completing screenings of fewer than 400 of the thousands of federal responders. Moreover, no examinations have occurred for over a year. Because of this program's limited activity, and the inability of federal workers to participate in other monitoring programs because of the assumption that they would have the opportunity to receive screening examinations through the HHS program, many federal responders may not have had an opportunity to identify and seek treatment for health problems related to the WTC disaster. For state responders, the opportunity for continued monitoring could be lost if they are not informed that they are now eligible to participate in the worker and volunteer program.

Based on their experiences, officials involved in the monitoring programs have made a number of useful observations that will apply to future terrorist attacks and natural disasters such as Hurricane Katrina. For example, screening for mental as well as physical health problems in New Orleans and along the Gulf Coast will be critical to the recovery of survivors of Hurricane Katrina and the responders to the disaster. The federal, state, and local government officials who are responsible for

planning and implementing health monitoring activities in the aftermath of disasters could improve their effectiveness by incorporating the lessons learned from the World Trade Center experience.

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

Contact and Acknowledgments

For further information about this testimony, please contact Cynthia A. Bascetta at (202) 512-7101 or bascettac@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this statement. Helene F. Toiv, Assistant Director; George H. Bogart; Alice L. London; Roseanne Price; and William R. Simerl made key contributions to this statement.

Appendix I: Abbreviations

ATSDR	Agency for Toxic Substances and Disease Registry
CDC	Centers for Disease Control and Prevention
DHS	Department of Homeland Security
DOD	Department of Defense
DOJ	Department of Justice
FDNY	New York City Fire Department
FDNY-BHS	New York City Fire Department Bureau of Health Services
FEMA	Federal Emergency Management Agency
FOH	Federal Occupational Health Services
HHS	Department of Health and Human Services
NDMS	National Disaster Medical System
NIOSH	National Institute for Occupational Safety and Health
NYC	New York City
OPHEP	Office of Public Health Emergency Preparedness
RTI	Research Triangle Institute
WTC	World Trade Center

Appendix II: Government Agencies That Sent Responders Following the World Trade Center Attack

Through our work, we identified the following agencies that sent employees to respond to the World Trade Center attack of September 11, 2001.

Federal Agencies

Department of Defense
Department of Energy
Department of Health and Human Services
 Agency for Toxic Substances and Disease Registry
 Centers for Disease Control and Prevention
 National Institutes of Health
 Substance Abuse and Mental Health Services Administration
Department of Homeland Security
 Federal Emergency Management Agency¹
 U.S. Coast Guard²
Department of the Interior
 National Park Service
Department of Justice
 Federal Bureau of Investigation
 U.S. Marshals Service
Department of Labor
 Occupational Safety and Health Administration
Environmental Protection Agency

New York State Agencies

Department of Environmental Conservation
Department of Health
Division of Military and Naval Affairs
Emergency Management Office
Office of Mental Health

¹At the time of the World Trade Center attack, the Federal Emergency Management Agency was an independent agency.

²At the time of the World Trade Center attack, the U.S. Coast Guard was in the Department of Transportation.

New York City Agencies

Department of Design and Construction
Department of Environmental Protection
Department of Health and Mental Hygiene
Department of Sanitation
Fire Department
Metropolitan Transportation Authority
Office of Emergency Management
Police Department

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