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SEPTEMBER 11

Improvements Still Needed
in Availability of Health
Screening and Monitoring
Services for Responders
outside the New York City
Area

Statement of Cynthia A. Bascetta
Director, Health Care





Highlights of [GAO-08-429T](#), a testimony before the Subcommittee on Government Management, Organization, and Procurement, Committee on Oversight and Government Reform, House of Representatives

Why GAO Did This Study

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

This testimony is based primarily on GAO's testimony, *September 11: Improvements Needed in Availability of Health Screening and Monitoring Services for Responders* ([GAO-07-1229T](#), Sept. 10, 2007), which updated GAO's report, *September 11: HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders* ([GAO-07-892](#), July 23, 2007). In this testimony, GAO discusses efforts by the Centers for Disease Control and Prevention's National Institute for Occupational Safety and Health (NIOSH) to provide services for nonfederal responders residing outside the New York City (NYC) area.

For the July 2007 report, GAO reviewed program documents and interviewed Department of Health and Human Services (HHS) officials, grantees, and others. GAO updated selected information in August and September 2007 and conducted work for this statement in January 2008.

To view the full product, including the scope and methodology, click on [GAO-08-429T](#). For more information, contact Cynthia A. Bascetta at (202) 512-7114 or bascettac@gao.gov.

SEPTEMBER 11

Improvements Still Needed in Availability of Health Screening and Monitoring Services for Responders outside the New York City Area

What GAO Found

In July 2007, following a reexamination of the status of the WTC health programs, GAO recommended that the Secretary of HHS take expeditious action to ensure that health screening and monitoring services are available to all people who responded to the WTC attack, regardless of where they reside. As of January 2008, the department has not responded to this recommendation.

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

Mr. Chairman and Members of the Subcommittee:

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

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

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

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

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

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

We have previously reported on the implementation of these programs and their progress in providing services to responders,⁵ who reside in all 50 states and the District of Columbia. We also previously reported that one of the WTC health programs, HHS's WTC Federal Responder Screening Program, which was established to provide onetime screening examinations for responders who were federal employees when they responded to the WTC attack, has had difficulties ensuring the uninterrupted availability of services.⁶ 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 2007.⁷ We also reported that the National Institute for Occupational Safety and Health (NIOSH), the component of HHS's Centers for Disease Control and Prevention responsible for administering most of the WTC health programs, had begun to take steps to provide access to screening, monitoring, and treatment services for nonfederal responders who resided outside the NYC metropolitan area.⁸

My testimony today is based primarily on testimony we issued in September 2007,⁹ which in turn was based on a report we issued in July 2007.¹⁰ As you requested, I will discuss the status of NIOSH's efforts to provide services for nonfederal responders residing outside the NYC metropolitan area.

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

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

⁷See [GAO-06-481T](#) and GAO, *September 11: HHS Needs to Ensure the Availability of Health Screening and Monitoring for All Responders*, [GAO-07-892](#) (Washington, D.C.: July 23, 2007).

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

⁹See GAO, *September 11: Improvements Needed in Availability of Health Screening and Monitoring Services for Responders*, [GAO-07-1229T](#) (Washington, D.C.: Sept. 10, 2007).

¹⁰See [GAO-07-892](#).

To assess the status of NIOSH's efforts to provide services for nonfederal responders residing outside the NYC metropolitan area, we obtained documents and interviewed officials from NIOSH. We also interviewed officials of organizations that worked with NIOSH to provide or facilitate services for nonfederal responders residing outside the NYC metropolitan area, including the Mount Sinai School of Medicine in NYC and the Association of Occupational and Environmental Clinics (AOEC)—a network of university-affiliated and other private occupational health clinics across the United States and in Canada. In our review of the WTC health programs, we relied primarily on information provided by agency officials and contained in government publications. We compared the information with information in other supporting documents, when available, to determine its consistency and reasonableness. We determined that the information we obtained was sufficiently reliable for our purposes. We conducted our earlier work from November 2006 through July 2007, updated selected information in August and September 2007, and conducted work for this statement in January 2008. We conducted this performance audit 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.

In brief, as we testified in September 2007, NIOSH has not ensured the availability of screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area, although it has taken steps toward expanding the availability of these services. As a result of our assessment of the WTC health programs, we recommended in our July 2007 report that the Secretary of HHS expeditiously take action to ensure that screening and monitoring services are available for all responders, including federal responders and nonfederal responders residing outside of the NYC metropolitan area. As of January 2008, the department has not responded to this recommendation.

Background

The tens of thousands of individuals¹¹ who responded to the September 11, 2001, attack on the WTC experienced the emotional trauma of the disaster

¹¹There is not a definitive count of the number of people who served as responders. Estimates have ranged from about 40,000 to about 91,000.

and were exposed to a noxious mixture of dust, debris, smoke, and potentially toxic contaminants, such as pulverized concrete, fibrous glass, particulate matter, and asbestos. A wide variety of health effects have been experienced by responders to the WTC attack, including 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. Commonly reported mental health effects among responders and other affected individuals included symptoms associated with post-traumatic stress disorder, depression, and anxiety. Behavioral health effects such as alcohol and tobacco use have also been reported.

There are six key programs that currently receive federal funding to provide voluntary health screening, monitoring, or treatment at no cost to responders.¹² The six WTC health programs, shown in table 1, are (1) the FDNY WTC Medical Monitoring and Treatment Program; (2) the New York/New Jersey (NY/NJ) WTC Consortium,¹³ which comprises five clinical centers in the NY/NJ area;¹⁴ (3) the WTC Federal Responder Screening Program; (4) the WTC Health Registry; (5) Project COPE; and (6) the Police Organization Providing Peer Assistance (POPPA) program.¹⁵ The programs vary in aspects such as the HHS administering agency or component responsible for administering the funding; the implementing agency, component, or organization responsible for providing program services; eligibility requirements; and services.

¹²In addition to these programs, a New York State responder screening program received federal funding for screening New York State employees and National Guard personnel who responded to the WTC attack in an official capacity. This program ended its screening examinations in November 2003.

¹³In previous reports we have also referred to this program as the worker and volunteer WTC program.

¹⁴The NY/NJ WTC Consortium consists of five clinical centers operated by (1) Mount Sinai-Irving J. Selikoff Center for Occupational and Environmental Medicine; (2) Long Island Occupational and Environmental Health Center at SUNY, Stony Brook; (3) New York University School of Medicine/Bellevue Hospital Center; (4) Center for the Biology of Natural Systems, at CUNY, Queens College; and (5) University of Medicine and Dentistry of New Jersey Robert Wood Johnson Medical School, Environmental and Occupational Health Sciences Institute. Mount Sinai's clinical center, which is the largest of the five centers, also receives federal funding to operate a data and coordination center to coordinate the work of the five clinical centers and conduct outreach and education, quality assurance, and data management for the NY/NJ WTC Consortium.

¹⁵Project COPE and the POPPA program provide mental health services to members of the New York City Police Department (NYPD) and operate independently of the NYPD.

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

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

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

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

^aIn February 2006, HHS's Office of the Assistant Secretary for Preparedness and Response (ASPR) and NIOSH reached an agreement to have former federal employees screened by the NY/NJ WTC Consortium. ASPR coordinates and directs HHS's emergency preparedness and response program. In December 2006 the Office of Public Health and Emergency Preparedness became ASPR.

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

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

The WTC health programs that are providing screening and monitoring are tracking thousands of individuals who were affected by the WTC disaster. As of June 2007, the FDNY WTC program had screened about 14,500 responders and had conducted follow-up examinations for about 13,500 of these responders, while the NY/NJ WTC Consortium had screened about 20,000 responders and had conducted follow-up examinations for about 8,000 of these responders. Some of the responders include nonfederal responders residing outside the NYC metropolitan area. As of June 2007, the WTC Federal Responder Screening Program had screened 1,305 federal responders and referred 281 responders for employee assistance program services or specialty diagnostic services. In addition, the WTC Health Registry, a monitoring program that consists of periodic surveys of self-reported health status and related studies but does not provide in-person screening or monitoring, collected baseline health data from over 71,000 people who enrolled in the registry.¹⁶ In the winter of 2006, the registry began its first adult follow-up survey, and as of June 2007 over 36,000 individuals had completed the follow-up survey.

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

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

¹⁶The WTC Health Registry also provides information on where participants can seek health care.

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

NIOSH has not ensured the availability of screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area, although it has taken steps toward expanding the availability of these services. Initially, NIOSH made two efforts to provide screening and monitoring services for these responders, the exact number of whom is unknown.¹⁷ The first effort began in late 2002 when NIOSH awarded a contract for about \$306,000 to the Mount Sinai School of Medicine to provide screening services for nonfederal responders residing outside the NYC metropolitan area and directed it to establish a subcontract with AOEC.¹⁸ AOEC then subcontracted with 32 of its member clinics across the country to provide screening services. From February 2003 to July 2004, the 32 AOEC member clinics screened 588 nonfederal responders nationwide. AOEC experienced challenges in providing these screening services. For example, many nonfederal responders did not enroll in the program because they did not live near an AOEC clinic, and the administration of the program required substantial coordination among AOEC, AOEC member clinics, and Mount Sinai.

Mount Sinai's subcontract with AOEC ended in July 2004, and from August 2004 until June 2005 NIOSH did not fund any organization to provide services to nonfederal responders outside the NYC metropolitan area.¹⁹ During this period, NIOSH focused on providing screening and monitoring services for nonfederal responders in the NYC metropolitan area. In June 2005, NIOSH began its second effort by awarding \$776,000 to the Mount Sinai School of Medicine Data and Coordination Center (DCC) to provide both screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area.²⁰ In June 2006, NIOSH awarded an

¹⁷According to the NYC Department of Health and Mental Hygiene, about 7,000 nonfederal and federal responders residing outside the NYC metropolitan area have enrolled in the WTC Health Registry.

¹⁸Around that time, NIOSH was providing screening services for nonfederal responders in the NYC metropolitan area through the NY/NJ WTC Consortium and the FDNY WTC program. Nonfederal responders residing outside the NYC metropolitan area were able to travel at their own expense to the NYC metropolitan area to obtain screening services through the NY/NJ WTC Consortium.

¹⁹In early 2004, AOEC applied to NIOSH to use its national network of member clinics to provide screening and monitoring for nonfederal responders residing outside the NYC metropolitan area, but NIOSH rejected AOEC's application for several reasons, including that the application did not adequately address how to coordinate and implement a monitoring program with complex data collection and reporting requirements.

²⁰This award and subsequent awards for this purpose were made under a 5-year cooperative agreement between NIOSH and Mt. Sinai, which began in 2004.

additional \$788,000 to DCC to provide screening and monitoring services for these responders. NIOSH officials told us that they assigned DCC the task of providing screening and monitoring services to nonfederal responders outside the NYC metropolitan area because the task was consistent with DCC's responsibilities for the NY/NJ WTC Consortium, which include data monitoring and coordination. DCC, however, had difficulty establishing a network of providers that could serve nonfederal responders residing throughout the country—ultimately contracting with only 10 clinics in seven states to provide screening and monitoring services.²¹ DCC officials said that as of June 2007 the 10 clinics were monitoring 180 responders.

In early 2006, NIOSH began exploring how to establish a national program that would expand the network of providers to provide screening and monitoring services, as well as treatment services, for nonfederal responders residing outside the NYC metropolitan area.²² According to NIOSH, there have been several challenges involved in expanding a network of providers to screen and monitor nonfederal responders nationwide. These include establishing contracts with clinics that have the occupational health expertise to provide services nationwide, establishing patient data transfer systems that comply with applicable privacy laws, navigating the institutional review board²³ process for a large provider network, and establishing payment systems with clinics participating in a national network of providers. On March 15, 2007, NIOSH issued a formal request for information from organizations that have an interest in and the capability of developing a national program for responders residing outside the NYC metropolitan area.²⁴ In this request, NIOSH described the scope of a national program as offering screening, monitoring, and

²¹Contracts were originally established with 11 clinics in eight states, but 1 clinic discontinued its participation in the program after conducting one examination. The 10 active clinics are located in seven states: Arkansas, California, Illinois, Maryland, Massachusetts, New York, and Ohio. Of the 10 active clinics, 7 are AOEC member clinics.

²²According to NIOSH and DCC officials, efforts to provide monitoring services to federal responders residing outside the NYC metropolitan area may be included in the national program.

²³Institutional review boards are groups that have been formally designated to review and monitor biomedical research involving human subjects, such as research based on data collected from screening and monitoring examinations.

²⁴Department of Health and Human Services, *Sources Sought Notice: National Medical Monitoring and Treatment Program for World Trade Center (WTC) Rescue, Recovery, and Restoration Responders and Volunteers*, SSA-WTC-001 (Mar. 15, 2007).

treatment services to about 3,000 nonfederal responders through a national network of occupational health facilities. NIOSH also specified that the program's facilities should be located within reasonable driving distance to responders and that participating facilities must provide copies of examination records to DCC. In May 2007, NIOSH approved a request from DCC to redirect about \$125,000 from the June 2006 award to establish a contract with a company to provide screening and monitoring services for nonfederal responders residing outside the NYC metropolitan area. Subsequently, DCC contracted with QTC Management, Inc.,²⁵ one of the four organizations that had responded to NIOSH's request for information. DCC's contract with QTC does not include treatment services, and NIOSH officials are still exploring how to provide and pay for treatment services for nonfederal responders residing outside the NYC metropolitan area.²⁶ QTC has a network of providers in all 50 states and the District of Columbia and can use internal medicine and occupational medicine doctors in its network to provide these services. In addition, DCC and QTC have agreed that QTC will identify and subcontract with providers outside of its network to screen and monitor nonfederal responders who do not reside within 25 miles of a QTC provider.²⁷ In June 2007, NIOSH awarded \$800,600 to DCC for coordinating the provision of screening and monitoring examinations, and QTC was to receive a portion of this award from DCC to provide about 1,000 screening and monitoring examinations through May 2008. According to a NIOSH official, QTC's providers began conducting screening examinations in summer 2007.

Concluding Observations

Screening and monitoring the health of the people who responded to the September 11, 2001, attack on the World Trade Center are critical for identifying health effects already experienced by responders or those that may emerge in the future. In addition, collecting and analyzing information

²⁵QTC is a private provider of government-outsourced occupational health and disability examination services.

²⁶Some nonfederal responders residing outside the NYC metropolitan area may have access to privately funded treatment services. In June 2005 the American Red Cross funded AOEC to provide treatment services for these responders. As of June 2007, AOEC had contracted with 40 of its member clinics located in 27 states and the District of Columbia to provide these services. An American Red Cross official told us in September 2007 that funding for AOEC to provide treatment services would continue through June 2008.

²⁷As of June 2007, DCC identified 1,151 nonfederal responders residing outside the NYC metropolitan area who requested screening and monitoring services and were too ill or lacked financial resources to travel to NYC or any of DCC's 10 contracted clinics.

produced by screening and monitoring responders can give health care providers information that could help them better diagnose and treat responders and others who experience similar health effects.

While many responders have been able to obtain screening and follow-up physical and mental health examinations through the federally funded WTC health programs, other responders may not always find these services available. Specifically, many responders who reside outside the NYC metropolitan area have not been able to obtain screening and monitoring services because available services are too distant. Moreover, HHS has repeatedly interrupted its efforts to provide services outside the NYC area, resulting in periods when no such services were available.

HHS continues to fund and coordinate the WTC health programs and has key federal responsibility for ensuring the availability of services to responders. HHS and its agencies have taken steps to move toward providing screening and monitoring services to nonfederal responders living outside of the NYC area. However, these efforts are not complete, and the stop-and-start history of the department's efforts to serve these responders does not provide assurance that the latest efforts to extend screening and monitoring services to them will be successful and will be sustained over time. Therefore we recommended in July 2007 that the Secretary of HHS take expeditious action to ensure that health screening and monitoring services are available to all people who responded to the attack on the WTC, regardless of where they reside. As of January 2008, the department has not responded to this recommendation.

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

Contacts and Acknowledgments

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

Appendix I: Abbreviations

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

Related GAO Products

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.

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

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

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