CHAPTER 3

The Public Health Response to the World Trade Center Attack and Its Aftermath by the New York City Department of Health and Mental Hygiene

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The destruction of the World Trade Center (WTC) posed immediate and long-term public health and mental health challenges to the City of New York, some of which are still prominent a decade later. This chapter will review (a) emergency management immediately following the attacks of September 11, 2001 (9/11), (b) its effect on preparedness for the New York City Department of Health and Mental Hygiene (the Department), and (c) two projects to address long-term problems that emerged after the immediate response: Project Liberty and the World Trade Center Health Registry. (See also Chapter 4.)

At the time of the attack, the Department consisted of two separate mayoral agencies: the New York City Department of Health (DOH) and the New York City Department of Mental Health, Mental Retardation and Alcohol (DMH)—although both were overseen by the same commissioner. This chapter will present the activities of both agencies and the department created by the merger of the two agencies in 2002.

EMERGENCY PREPAREDNESS BEFORE 9/11

The 1999 West Nile virus outbreak and the then-imminent concerns about possible computer problems at the start of 2000 (Y2K) spurred DOH to formally organize an emergency response framework. By New Year's Eve of 1999, a rudimentary incident command system and an internal emergency operations center were

established. From 2000 to 2001, other advances included informing all employees of their emergency response duties, enhancing relationships with other emergency response agencies, and expanding communicable disease surveillance. From 2000 until 9/11, there were no activations of the DOH incident command system. DMH had a crisis services unit, comprising four staff members, who responded to immediate crises, such as fires and large-scale vehicle crashes. There were no requirements for disaster planning by the hundreds of contracted mental health programs. The DOH and DMH response to 9/11 developed in this context.

THE WORLD TRADE CENTER ATTACK: IMMEDIATE RESPONSE

Public Health Activities

The DOH emergency operations center opened immediately after the 9/11 attacks and began many activities. School health nurses were deployed to American Red Cross shelters. Twelve sites opened, and 140 displaced persons were housed at the peak of sheltering operations. The shelters operated for 12 days, with 130 public health nurses working at these sites. The vital records department was moved from Lower Manhattan to another site to assure continuity of operations. DOH notified funeral directors about the move by telephone. Communication with the Office of the Chief Medical Examiner was strengthened to process death certificates and burial permits for bodies recovered at the WTC site.

A surveillance system to document and describe victims presenting to hospitals was initiated, with Departmental personnel being stationed at hospitals near the WTC site. Using a common data-collection form, they abstracted information from survivors' hospital charts for a 2-day period starting on the morning of 9/11. During this period, 790 survivors were treated for injuries (Fig. 3-1). The most common injuries were inhalation injuries (49 percent of survivors), ocular injuries (26 percent), lacerations (14 percent), sprains or strains (14 percent), and contusions (12 percent). Among the patients, 29 percent were first responders. Few deaths occurred among those presenting to hospitals because the vast majority of those who died succumbed at the WTC site. Ultimately, 2,617 persons died during or immediately after the attacks. A plurality of victims were young men between 35 to 39 years of age. Of the total deaths, 344 were firefighters; 23, police; 37, security guards and Port Authority personnel; and three, emergency rescue workers.

DOH environmental health staff members measured ionizing radiation levels at the WTC site on September 11 and 13. No ionizing radiation above background level was identified. Later, the Department of Energy tested at the WTC site and the Fresh Kills landfill on Staten Island and also found no ionizing radiation above background level.[1]

Stressful conditions characterized the immediate response. The DOH building is several blocks from Ground Zero, so some employees coming to work witnessed the planes crashing into the World Trade Center towers, people jumping from the buildings, and escapees and vehicles covered with debris. Unexpectedly, at about 10:00 a.m., emergency medical service workers brought victims into the lobby of the

Figure 3–1: People make their way amid debris near the World Trade Center approximately 1 hour and 40 minutes after the first attack. (AP/Wide World Photos)

DOH building. DOH staff quickly organized a response, bringing in physicians and basic medical supplies. Forty-five patients were seen; none were hospitalized. That afternoon, just outside the DOH building, workers were hammering together wooden palettes to transport bodies. Throughout that day, large crowds gathered outside the DOH building seeking to volunteer. Since the DOH lacked plans for using volunteers, staff members redirected them to hospitals to donate blood, which exacerbated hospital crowding. After 9/11, staff members distributed personal protective equipment to the rescue workers and witnessed the dead being removed. Although exposures of Department staff members to the events pale in comparison to those of the first responders at Ground Zero, the attack had a profound impact on them.

Neither land-line nor mobile phones worked normally, making communication difficult. All roads and subways to Lower Manhattan were closed by the New York Police Department, denying access to DOH employees who had not yet reported to work. On September 12, because of restricted access and difficulties in communications, the DOH relocated to the Public Health Laboratory, about 30 blocks uptown. Therefore, most DOH personnel working on the response had to contend with working in an unfamiliar building.

The DOH established three additional surveillance systems to inform the response:

1. DOH performed hospital needs-assessments in collaboration with the Greater New York Hospital Association.
2. DOH established a syndromic surveillance system, based on stationing Epidemic Intelligence Service officers from the Centers for Disease Control and Prevention

(CDC) at area hospitals to collect data in order to detect a possible bioterrorist attack. There was no evidence of such an attack.

3. DOH helped establish surveillance of injuries to recovery workers in order to help guide the cleanup effort. Data were collected from medical centers near the WTC site and at five federal disaster medical assistance team (DMAT) sites, which were providing medical care to the rescue workers.

The collapse of the World Trade Center towers caused an environmental catastrophe (Fig. 3-2). In response, the DOH helped create new air-sampling strategies for multiple pollutants. It worked with other government agencies to combine and analyze environmental data. Substances monitored included asbestos, particulate matter, dioxins, polychlorinated biphenyls (PCBs), carbon monoxide, heavy metals, and volatile organic compounds (VOCs). Samples were taken from air, bulk dust, and water.

The Department delivered fact sheets on safe reoccupancy to residents of Lower Manhattan. It made worker safety a priority and, with OSHA, distributed personal protective equipment to recovery workers at Ground Zero.

Other environmental work included inspection of food services for recovery workers and cleaning seemingly abandoned restaurants near the WTC site. Tons of spoiled food from restaurants and supermarkets were removed. Enhanced rodent abatement was started. And additional surveillance of mosquitoes around the WTC site was performed for West Nile virus.

Communication to the general public and to the medical community became a major focus of the Department's work. Topics of press releases included mental

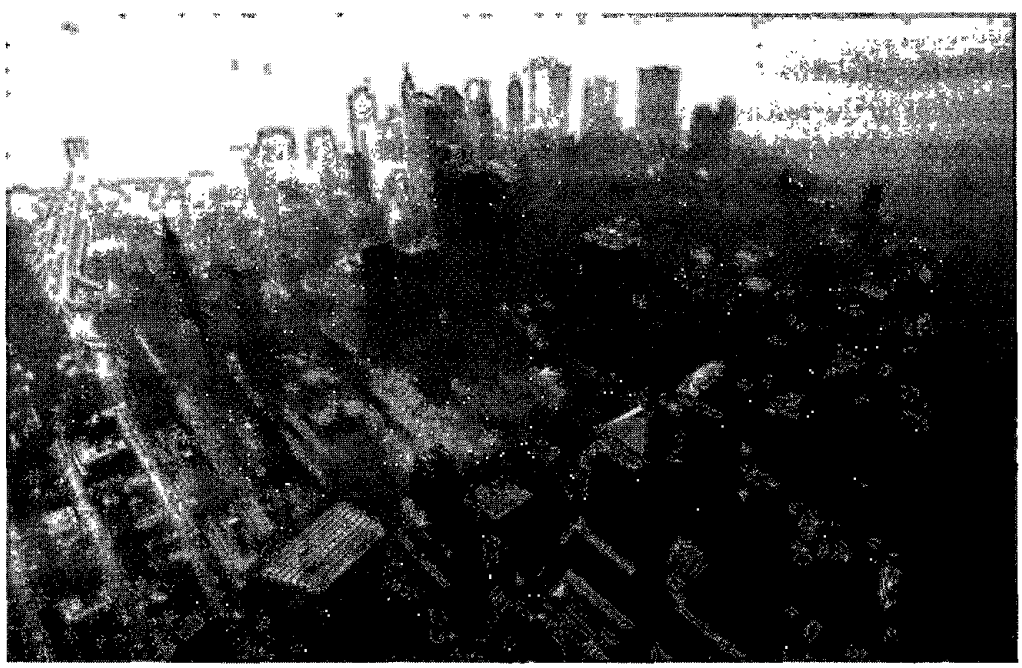

Figure 3–2: Aerial view of devastation at the World Trade Center site as it appeared on October 4, 2001. (Photograph by Andrea Booher/FEMA News Photo)

health counseling services, relocation of the Department's headquarters, the health of rescue workers, and revised ways of obtaining birth and death certificates. Topics of broadcast faxes sent to hospitals included surveillance advice, mental health needs, exposures of rescue workers to body fluids, health risks from decomposing human remains, and the health effects of asbestos and other dust.

Mental Health Activities

Soon after 9/11, the city government established the 69th Regiment Armory (located at 68th Street and Lexington Avenue) as the primary information site for family members and rescue workers. The Department then coordinated its clinicians (master's-level social workers, psychologists, and psychiatrists) and those of its contracted agencies, and then dispatched them to the Armory.

There they were available for emotional support for people who were searching for the names of loved ones on lists of those hospitalized or were bringing DNA samples to match with remains. Hundreds of people were seen. Other volunteer clinicians met with firefighters and police officers coming to the Armory after shifts at the WTC site. This type of volunteer staffing continued as the city government opened its Family Assistance Center, which consolidated services for victims' families at Pier 94 on the west side in midtown Manhattan.

The number of calls to the Department-funded Lifenet mental health telephone hotline helped us track the overall level of stress. This toll-free information and referral service contracted with the Department in 1996 for English speakers, in 1998 for Spanish speakers, and in 2000 for Chinese speakers (with translation available for other languages, as needed). Lifenet calls spiked dramatically after 9/11 and have never decreased (Fig. 3-3). Soon after 9/11, Lifenet received additional special funding from city and state government, coordinated through the Department and the September 11 Fund. (See Chapter 7.)

Lessons Learned

The following lessons learned still influence emergency management at the Department. The incident command system (ICS) in place on 9/11 was not well understood by many staff members, which led to inefficiencies in the response. For example, because of a lack of incident action plans, at times two groups worked independently on the same project, such as tracking personal protective equipment supplies. Emergency operations meetings were crowded and disorganized. About a month after 9/11, the Department had to respond to the anthrax outbreak. Following that response, the Department redesigned its ICS structure and trained key personnel in its use. And during subsequent activations, it has worked much better, with the introduction of job action sheets and incident action plans as well as better tracking of resources and assignments.

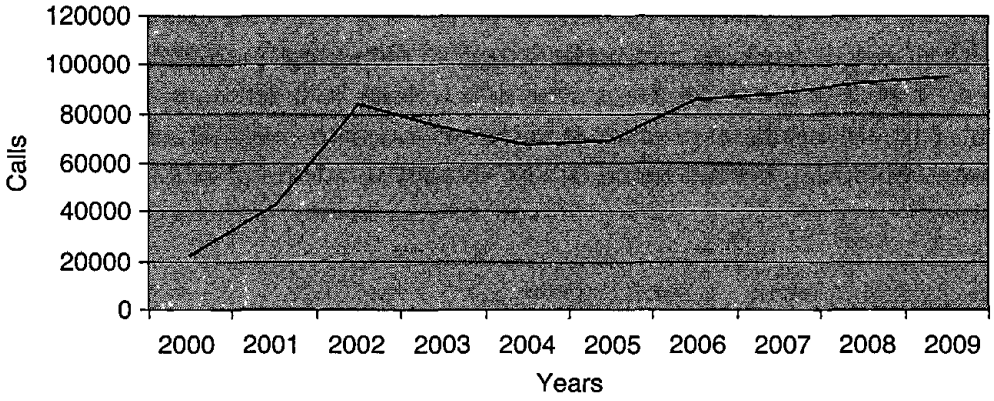

Figure 3–3: Lifenet calls per year, 2000–2009.

Before 9/11, the Department's emergency operations center (EOC) had been located in a conference room at its headquarters building in Lower Manhattan. When the Department relocated to the Public Health Laboratory (PHL) on September 12, the EOC continued its operation in a conference room and what had been administrative offices. Today, the EOC is located in dedicated space at its headquarters, and a secondary EOC is located in another borough of the city.

On 9/11, communication was severely compromised. The Department has since improved its communications capacity by purchasing satellite and cell phones, 800-megahertz radios, and other portable electronic devices, such as Blackberries. It has also improved the content of its communications by providing training on communication during crises to key personnel, creating information sheets for possible emergencies, and printing brochures that address mental health issues.

The Department has also developed staff surge capacity since its experience in the aftermath of 9/11. From 9/11 until the end of 2001, the Department continuously addressed three major New York City emergencies: the World Trade Center attack; the anthrax outbreak, starting on October 12; and the crash of an American Airlines flight shortly after taking off from Kennedy International Airport on November 12. Responding to these emergencies exhausted many Department personnel. The Department has since adopted a "five-deep" policy for leadership positions in emergencies, so that five people can each assume a specific leadership position in an emergency. The PHL has done extensive cross-training with its staff, so that it can quickly shift priorities for laboratory testing to address an emergency, without relying on more-distant public health laboratories.

In addition, the Department has greatly expanded its collection of emergency department data to determine possible exposure to biological agents, on which syndromic surveillance in New York is based. Seven days a week, it electronically obtains and analyzes surveillance data from emergency departments. Syndromic surveillance now includes data from retail pharmacies, outpatient clinics, and school health nurses. This system has been used in subsequent health emergencies in New York, such as the 2003 blackout and the 2009 H1N1 influenza pandemic.

The Department needed to strengthen its collaboration with a wide spectrum of health care organizations, first-responder groups, and state and federal agencies. To help respond to emergencies, it created the New York City Medical Reserve Corps (MRC), which now has 9,300 volunteer licensed professionals. It actively participates in meetings and collaborative projects with the New York State Department of Health, the CDC, and relevant mayoral agencies in the city. And it participates in the Citywide Incident Management System, which integrates the response of mayoral agencies during emergencies.

Before 9/11, there was no formal relationship between the Department and hospitals in New York. Supported by federal government funding, there have since been joint projects, tabletop exercises, and drills, leading to better coordination of the health response to an emergency. Issues addressed by this collaboration have included surge capacity in response to a mass casualty event, extensive planning for pandemic influenza, and planning for serving emergency needs of special populations, such as children, older people, and burn victims.

Emergency Activations Since 9/11

Anthrax: On October 1, 2001, the Department learned that an NBC News employee who recalled handling letters with white powder had developed a skin lesion suspicious for cutaneous anthrax. The powder tested negative for anthrax spores. However, on the morning of October 12, the Department learned that the results of a biopsy that had been performed on the lesion were consistent with cutaneous anthrax. The Department's incident command center was quickly activated. An onsite investigation began at the headquarters of NBC News, and its employees were informed. That afternoon, the first distribution site for prophylactic antibiotics was set up.[2] Soon after, a second letter with white powder that had been sent to NBC News was found to contain anthrax spores. Unfortunately, poor handling led to the contamination of the testing laboratory and two of the three lab workers who had been trained to perform anthrax testing. Then, three more cases suspected of being cutaneous anthrax were reported—all associated with major media outlets in New York, leading to investigations at ABC News, CBS News, and the *New York Post*. (See Chapter 5.)

On October 28, the Department learned of a woman critically ill with anthrax who had delivered supplies in a New York hospital. She subsequently died of inhalational anthrax.[3] The Department performed an intensive epidemiological and environmental investigation, which included her home, her workplace, New York postal facilities, and the subway system. But no source of her exposure was found.

The impact on the Department's public health laboratory was profound.[4] The contamination of the laboratory and its personnel on October 12 resulted in an acute shortage of space and personnel just as the Department received 3,200 environmental samples and 2,700 nasal swabs, causing an extreme strain on staff. Many members of the Fire Department of New York (FDNY) hazardous materials (hazmat) teams who had been trained in the proper packaging and transport of

white powder had died on 9/11. Inappropriate submission of specimens hindered laboratory work. Fortunately, the U.S. Department of Defense provided personnel and equipment to address these challenges.

Smallpox Vaccination Campaign: The Department activated its incident command system to support the logistics of the smallpox vaccination campaign in 2003. The campaign included components to increase community awareness, to educate clinicians, to train vaccinators, and to develop a smallpox response plan for New York. The campaign vaccinated 369 Department employees, health care professionals, and first-responders. (See Chapter 11.)

The Northeast Blackout: In August 2003, New York and many other places in the Northeast United States and part of Canada experienced a blackout.[5] The ICS was activated immediately to respond to possible health effects due to lack of electricity in the midst of a hot summer. An early concern was a concomitant terrorist attack. Because syndromic surveillance relied on electronic transfer of data from New York hospitals—not possible during the blackout—Department personnel were sent to hospitals to collect the data manually. The PHL relocated its critical "Biowatch" functions (filter testing for biological agents of terrorism) to an outside laboratory and maintained its normal daily laboratory testing. Overflow of sewage from waste treatment plants resulted in beach closures. The Department disseminated public messages on food safety, beach closures, and the harmful effects of heat.

The Republican National Convention: In 2004, the Republican National Convention took place in New York for one week, during which the Department activated emergency operations to help coordinate activities, including increased surveillance, sanitary inspections, and laboratory testing of biowatch filters. Department personnel also participated in three other emergency operations centers organized by the Office of Emergency Management, the New York Police Department, and the Federal Bureau of Investigation.

Anthrax in a Drummer: In February 2006,[6] *Bacillus anthracis* was isolated from a New York resident hospitalized in Pennsylvania. The patient, a dancer, had recently made drums with African hides. Because anthrax spores represent a potential bioterrorism agent, the Department activated its ICS to help determine the mode of transmission and to notify law enforcement agencies. Terrorism was quickly ruled out. The drummer had manipulated hides in both his apartment and in a warehouse. Samples from both locations were found to be positive for *B. anthracis*, and both locations were cleaned. The Department offered post-exposure prophylaxis to several other people it had determined were potentially at risk for anthrax. It also provided information to other building occupants, physicians, and veterinarians, and information to the general public.

Hepatitis A Prophylaxis: In 2008, after the investigation of an acute case of hepatitis A in a bartender, the Department decided to offer hepatitis A prophylaxis to at-risk employees and patrons of the restaurant where the bartender had worked. Points of distribution (POD) sites were set up, and prophylaxis was given on three consecutive days to 184 restaurant patrons. The ICS provided the Department with a management framework to organize, obtain resources for,

and set up and monitor the PODs. This experience was valuable practice for Department staff in setting up H1N1 influenza vaccine POD operations in the fall of 2009.

Pandemic Influenza: On April 23, 2009, a school health nurse in Queens notified the Department that she had seen about 100 students with flu-like illness.[7] The next day, Department personnel took nasal swabs from nine sick students, and, by April 26, CDC confirmed that the specimens contained H1N1 2009 virus. The Department activated its ICS from April 24 through June 2009.[8] The Department conducted surveillance by monitoring emergency department visits for flu-like illness, deaths due to influenza, the number of H1N1 specimens tested in the PHL, and telephone surveys. Eventually, there were an estimated 750,000 to one million cases of flu-like illness in New York. The Department provided information to hospitals on H1N1 influenza virus and infection control. It developed guidelines on infection control for schools, day care centers, a jail, and homeless shelters.

In the spring of 2009, a total of 55 schools were closed because of clusters of flu-like illness. In the fall of 2009, H1N1 cases were generally mild, no schools were closed, and the Department did not activate the ICS. The Department vaccinated school-age children, and conducted an extensive communication campaign on hygiene and staying home if sick.

EVOLUTION OF EMERGENCY PREPAREDNESS SINCE 9/11

Emergency preparedness activities at the Department have expanded and evolved since 9/11. Although the Department cannot anticipate all possible emergencies, it has developed all-hazards and incident-specific plans to address public health emergencies. Key preparedness activities include the training of staff members and their participation in tabletop exercises and drills. All employees are assigned to an emergency-preparedness section based on their competencies for potential activation. They are given a phone number to call to get their assignments. Department leaders participate quarterly in reviews of emergency protocols and tabletop exercises and receive extensive training on the ICS. Physicians and other staff members are available at all times to begin the Department's response, if necessary. Following an emergency response, the Department performs a rigorous self-critique of its efforts and sets up a plan to avoid mistakes and improve future responses.

Public health surveillance by the Department relies on electronic reporting of laboratory results, syndromic surveillance, and traditional reporting by health care providers—all of which decreases the time needed to identify outbreaks. The Public Health Laboratory has a Biosafety Level 3 facility, which has greatly expanded its capacity for testing biological agents. In addition, the Department supports a mental health preparedness unit, which works with other organizations to provide mental health counseling in crises and psychological first aid to affected populations. The Department's environmental section, which has extensively prepared for radiological emergencies, has the capability to identify and characterize releases of radiation or radioactive materials.

Health care preparedness has expanded beyond hospitals to include community health centers, mental health facilities, adult homes, and dialysis centers. Since 2001, the Department's capacity for medical countermeasures has grown substantially; it can now support 200 pre-selected POD sites. It is also working with organizations that represent vulnerable populations who would be unable to come to PODs, in order to be able to provide medical countermeasures for them. The Department has also developed extensive contingency plans for operational continuity, if necessary during an emergency.

Project Liberty

Because a terrorist incident seems senseless, uncontrollable, and unpredictable, it violates the attacked population's fundamental sense of "how things should be."[9] The events of 9/11 were experienced by many more people than the family members, co-workers, and friends of the more than 2,600 who died. Terrorist attacks, which cause fear and chaos, are destabilizing to the mental health of individuals and communities, in both the short and the long term. In addition to the emotional stress of mass casualties, the 9/11 attacks subsequently caused much economic distress, as thousands of jobs disappeared from Lower Manhattan, creating huge challenges for individuals and families.

While clinicians addressed mental health needs throughout New York, Department administrators prepared the documentation necessary to obtain funding from the Federal Emergency Management Agency (FEMA) for mental health services, including a crisis counseling program. This FEMA-supported initiative, called Project Liberty, sought to address the significant psychological distress of New York residents. It became the largest public mental health campaign up to that time. It required unprecedented coordination and cooperation among the Department, the State of New York, various federal agencies, and several nonprofit charitable operations.

At the start, the campaign needed to estimate how many people were suffering and needing crisis counseling. Approximately 2.1 million adults and children in the city were projected to benefit from crisis counseling services.[10]

Project Liberty offered community-based, often one-time, short-term crisis counseling. Crisis counselors also facilitated public education sessions—in senior centers, schools, and other community settings—to provide information about typical responses to a traumatic event, signs of more serious mental health disorders, and places to receive help for ongoing symptoms. Services were designed to help people return to their level of functioning before 9/11 by enabling them to recognize that their stress frequently was a normal response and by referring those who needed additional assistance. All services were offered free of charge. The program issued public service announcements, including suggestions to turn off television sets with continuous reporting on the disaster.

Crisis counselors, working for 122 public mental health agencies, the Department of Education (DOE), and the FDNY, delivered these services. They included both

mental health professionals and nonprofessional community members. They encountered people at bus stops, barber shops, special events, and housing complexes to ask about their well-being and to offer support, reassurance, and referral for additional services. Counseling initially focused on family members of victims, residents of Lower Manhattan, and those who worked at or near the World Trade Center.

Crisis counseling was not considered treatment or case-management. Crisis counselors could not provide benefits, such as food or money; however, they could offer referrals for those in need. They were often the first to provide mental health services for people who were suffering. Counselors met repeatedly with people who were in distress—until they forged sufficient trust so that clients would accept, if necessary, referrals for mental health or substance abuse treatment.

In order to mobilize adequate mental health resources quickly, the Department first allowed all licensed providers to bill for mental health services provided in the first 45 days after 9/11. The amount of services needed, the range of providers, and contracting rules necessitated creative approaches. Counselors provided services where people frequently gathered, such as memorial gatherings, senior centers, and even the Staten Island Ferry Terminal.

Community-based providers knew well their service neighborhoods and the diverse populations who lived there. Therefore, Project Liberty contracted with many of these providers—rather than a few large agencies. Providers were encouraged to utilize personnel from their own communities. Services were especially focused on older people, physically and mentally disabled people, first responders, children, families of victims, and workers at the WTC site.

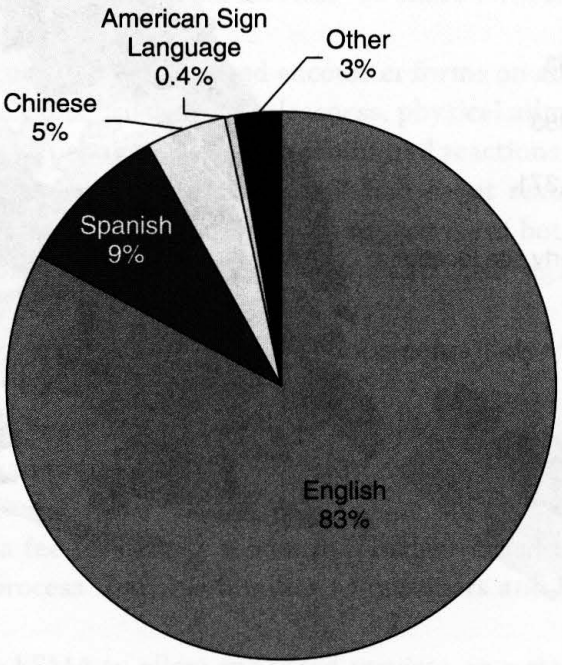

Figure 3–4: Languages for Project Liberty clients.

More than 1.3 million people received services under Project Liberty: 513,000 in individual or family crisis counseling, 211,000 in group counseling, and 604,000 in group public education. Crisis counseling was accessible to people of many cultures and languages—17 percent in languages other than English, including Japanese, Korean, Polish, Russian, Arabic, Hindu, Urdu, French, Farsi, Hebrew, Italian, German, Turkish, Yiddish, Haitian-Creole, Greek, and Cambodian (Fig. 3-4).

Project Liberty's services were provided to about 400,000 children and adolescents and their family members, primarily through the New York City Department of Education, which allocated over $30 million for services within schools. Each of the 40 school districts in New York developed a plan for serving its students, and each was allocated funds based on need. Crisis counseling services were provided either by school personnel or in some cases by contracted service providers (some of whom were providing services under the broader Project Liberty program) (Fig. 3-5).

Project Liberty was the first U.S. initiative in which a public mental health strategy addressed the psychological consequences of a terrorist attack. A multifaceted media campaign was conducted by the Department and the State of New York Office of Mental Health. It used a variety of media approaches tailored to the populations it served, including billboards, subway ads, television and radio announcements, ads on "take-out" coffee cups in Lower Manhattan, newspaper ads and feature stories, and postcards in bars, restaurants, and gyms (Fig. 3-6). Brochures, printed in five languages, were modified as the needs of the communities changed; for example, the brochure on the third anniversary of 9/11 focused on resilience.

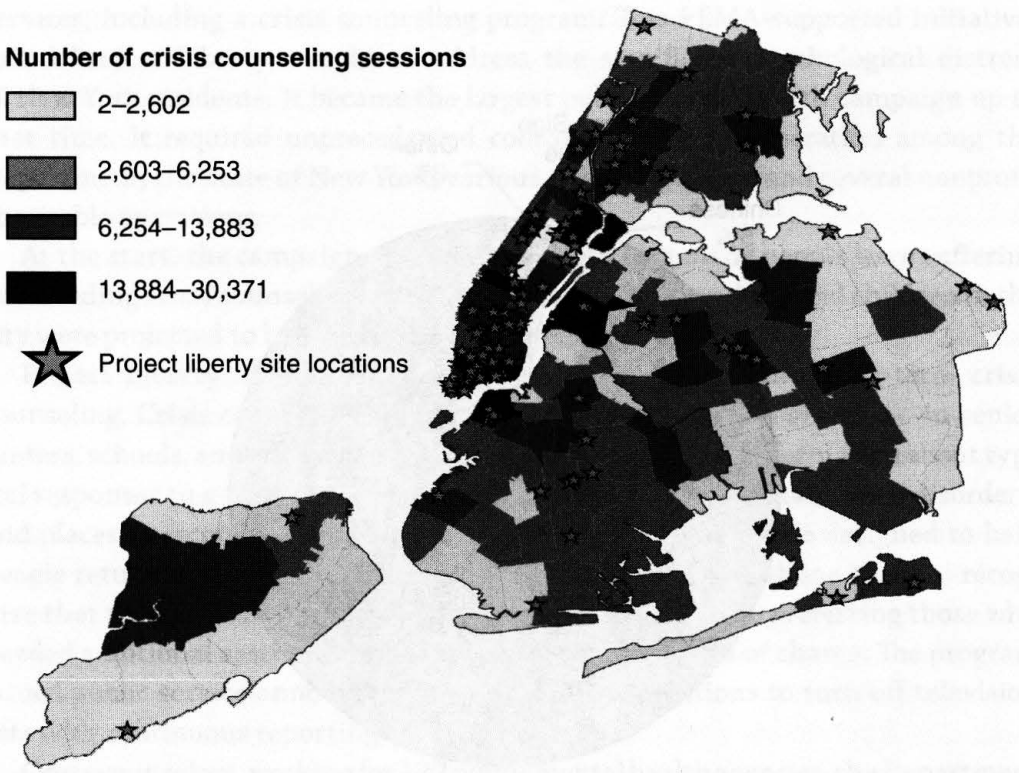

Figure 3–5: Geographic distribution of crisis counseling sessions and locations.

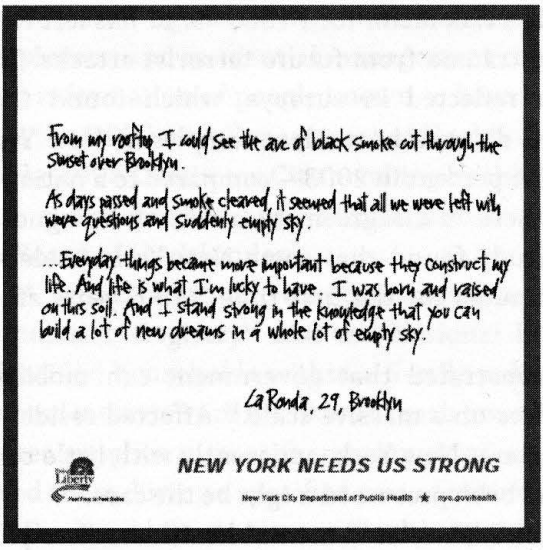

Figure 3–6: Project Liberty advertisements.

Over time, it became apparent that many people needed a higher level of care. In 2002, FEMA approved "enhanced services" of short-term mental health treatment for children and adults.

Project Liberty counselors completed encounter forms on all clients, which documented "event reactions," such as sleeplessness, physical ailments, and intrusive memories. Among the people served, 26 percent had reactions suggestive of post-traumatic stress disorder (PTSD), 16 percent had event reactions suggestive of depression, and 8 percent had event reactions suggestive of both.[11]

Project Liberty provided valuable lessons about structuring services:

- Linking reporting documents to claims documents helped ensure good data collection
- Contracting with mental health service providers who met broad qualifications—rather than issuing requests for proposals—sped the process of providing services
- Changing from a fee-for-service model to a budget-based reimbursement system created a process that was familiar to providers and allowed them to do much outreach
- Advocating with FEMA to allow enhanced services, in a standardized manner, allowed Project Liberty to help many more people

Because previous exposure to trauma is a risk factor for PTSD,[12] 9/11 has left New York residents especially vulnerable to trauma from future terrorist attacks. The lingering effects of 9/11 have been reflected in surveys, which found that the 30-day prevalence of psychological distress in random samples of New York residents was 6.4 percent in 2002 and 5.1 percent in 2003—compared to a national estimate of about 3 percent. While there is disagreement about the diagnosis of late-onset PTSD,[13] a Department study found that some New York residents reported symptoms of psychological trauma for the first time 5 to 6 years after 9/11.[14]

The Department's experience demonstrated that government can mobilize quickly to provide mental health services on a massive scale.[15] Affected residents accessed mental health services throughout New York, apparently with little concern for social stigma, as previously had been presumed might be the case.

For some city residents, the need for 9/11-related mental health services persists. The Department's 9/11 Mental Health and Substance Abuse Services benefit pays out-of-pocket mental health and substance-abuse treatment expenses to people still experiencing psychological effects from the attacks. Since its inception in 2008, over 5,000 people experiencing symptoms of depression, anxiety, or PTSD related to 9/11 have enrolled for this benefit.

Recognizing the importance of mental health disaster preparedness, the Department created the Office of Mental Health Disaster Preparedness and Response in 2005. The Office continues to assess mental health needs related to 9/11 and coordinates appropriate responses.

The World Trade Center Health Registry

The World Trade Center Health Registry, the largest disaster registry in U.S. history, has enrolled 71,465 people. It is the major source for epidemiological follow-up of 9/11 survivors. Managed by the Department, it employs nearly 40 staff members and has an annual budget of $3 to $7 million. The Registry has responded to the health care needs and concerns of enrollees and other affected populations—estimated to number over 400,000—by providing 9/11-related resource information, referrals for care to 9/11 Centers of Excellence, and guidelines for physicians caring for adults and children exposed to the World Trade Center attack.

In the weeks following 9/11, a proposal for a registry was first discussed by officials of the Agency for Toxic Substances and Disease Registry (ATSDR), the National Institute for Occupational Safety and Health (NIOSH), FEMA, and the Department. The Department believed that a registry would protect affected people from being barraged by researchers, but would encourage legitimate research. A comprehensive registry that would include all those exposed could also serve public health purposes.

Several options to recruit enrollees for the registry were considered. These included modifying the New York City health code to require reporting of exposed persons, akin to notifiable disease reporting requirements. Reporting would

specify that agencies, organizations, hospital emergency departments, unions, employees, and residential management companies would provide names and contact information of people known to have been exposed to the attack. A precedent was the Oklahoma Department of Health requiring the reporting of people injured in the 1995 Oklahoma City bombing by their treating practitioners.[16] This approach was not adopted because it would have required complex definitions and a change in Board of Health rules.

A census approach was considered, as used in the Three Mile Island (TMI) Population Registry[17] and the National Exposure Registry (NER).[18] The former identified households within a 5-mile radius of the TMI nuclear facility and conducted interviews of members of each household. The latter identified residences on water supplies in specific communities, and collected data from people who had lived there during a specified period of time.

The World Trade Center Health Registry was established with the following objectives:

1. To provide a complete picture of health effects among targeted populations, including acute injuries and mental health effects as outcomes
2. To create a comprehensive sample for periodic matching with death registries, cancer registries, and other registries
3. To provide denominator information
4. To be a source for the selection of study samples for future research
5. To provide future notification of identified health risks to affected individuals and general public
6. To provide information for preventive measures and for public policy concerning future natural or terrorist attacks.

Recruitment and enrollment was done by obtaining lists of potentially eligible persons through contact with employers, government agencies, unions, residences, schools, and other sources. Proposed modes of data collection included phone interviewing, mailed questionnaires, and onsite interviews. A scientific advisory committee was established. It has met every 3 months since February 2002.

In July 2002, ATSDR announced a $20 million award for establishing the Registry, authorized by FEMA. By September 2002, a data-collection instrument was completed (modeled after the ATSDR National Exposure Registry), RTI International (of the Research Triangle Institute) was selected as the contractor for recruitment and data collection, a protocol was completed and submitted to New York City Institutional Review Board, and a mechanism for funding the Department through a cooperative agreement was established.

RTI International built a data system that could manage registrant information in real time. Once it obtained information on potentially eligible enrollees, 300 staff members used computer-assisted telephone interviews and person-to-person interviews to obtain and immediately transfer information to a database.

Major media and outreach campaigns were conducted to attract registrants. The Department's Office of Public Affairs worked closely with the Registry on

planning, designing, and composing advertising announcements and press releases (Fig. 3-7). College students working as aides and interns distributed materials in Lower Manhattan, attended summer fairs, and answered questions and distributed material at key locations, such as train station entrances and apartment building lobbies.

Four primary target groups were defined, based on the nature of their exposure to the attack:

- 362,092 people exposed to the attack and its immediate aftermath (passersby and persons who were in damaged or destroyed buildings)
- 91,469 workers and volunteers involved in rescue, recovery, and cleanup of the WTC site or other operations related to disaster cleanup
- 57,571 residents who lived close to the WTC site
- 15,197 children, teachers, and staff members in schools close to the WTC site[19]

The Registry was officially launched in September 2003. Enrollees were either self- or list-identified. Self-identification involved either preregistering on a Web site (with a subsequent interview) or calling the advertised toll-free number (and participating in an interview at the time of the call). List-identified enrollment used contact information obtained from lists, which led to calls for interviews.

Figure 3–7: World Trade Center Health Registry advertisement.

Most interviews were conducted by telephone, with only 5 percent done in person. A process called "locating and tracing" found and verified incomplete contact information.

Wave 1 (W1, or the baseline enrollment interview) contained a series of screening questions to determine eligibility, followed by questions on exposure specific to each eligibility group. All interviewees were asked (a) if they were caught in the dust/debris cloud or witnessed the events on 9/11; and (b) if they had 9/11-related injuries, symptoms, and diagnosed conditions. They were also asked screening questions. Additional contact information and consent to be part of the Registry—for future studies and matching to other registries—were included in the last portion of interview. (See questionnaire at http://www.nyc.gov/html/doh/wtc/downloads/pdf/wtc/wtc-questionnaire.pdf.) Interviewers who spoke English, Spanish, Cantonese, and Mandarin were available. Parents and guardians served as proxies for children under 18 years of age. (For more information on the Registry, see http://www.nyc.gov/html/doh/wtc/downloads/pdf/wtc/wtc-datafile-manual.pdf.)

Completion of Baseline Enrollment (Wave 1)

During the first year of data collection, 61,087 interviews were completed. The characteristics of this sample were described in "Data Snapshot," published in November 2004 (http://www.nyc.gov/html/doh/wtc/downloads/pdf/wtc/wtc-report2005-0131.pdf). This Department publication also provided the first release of Registry health data on 9/11-related injuries, new and worsening health conditions, and psychological distress. Data collection was extended beyond 1 year because several large lists were obtained late in the data collection period, including lists of security personnel and additional volunteers. In addition, permission was obtained to conduct person-to-person recruitment of NYC firefighters at their firehouses in the fall of 2004, which led to several thousand additional FDNY personnel being enrolled.

The final enrollment in the Registry was 71,437 after multiple interviews for the same individual were reconciled:

- 14,665 who had been residents in Lower Manhattan on 9/11
- 30,665 rescue and recovery workers and volunteers who worked at least one shift at the WTC site, at the Staten Island Recovery Center, or on barges
- 43,487 persons who had been south of Chambers Street on 9/11, of whom 3,271 were in the World Trade Center towers at the time of the attacks
- 2,075 students who were enrolled in schools south of Canal Street on 9/11
- 571 teachers and staff members in these schools

Twenty-eight percent were members of more than one eligibility group.[20] Of the 3,251 enrollees younger than 18 on 9/11, 2,635 proxy interviews of their parents were conducted. (For more detailed information, see http://www.nyc.gov/html/doh/wtc/downloads/pdf/wtc/wtc-outcome-explanation.pdf.)

Follow-up Surveys (Wave 2)

Two years after the completion of the W1, a survey of registrants who were adults in April 2006 was conducted to: (a) assess the current health status of adults in the Registry; (b) obtain enhanced exposure information relative to W1; and (c) obtain additional information on several important topic areas not addressed in W1, including quality of life, health care access, and alcohol consumption. Over 68,000 adults were eligible for W2, which was conducted from November 2006 through December 2007. Paper questionnaires, Web-based surveys (by e-mail invitation), and computer-assisted telephone interviews resulted in an overall 68 percent response rate.

A survey of child registrants was conducted in 2007 and 2008 by mailed questionnaire. Parents completed all questions for children younger than 12; adolescents were instructed to complete a portion of the questionnaire themselves. About 2,000 children were eligible for this survey; a 50 percent response rate was achieved.

Challenges

There were several challenges that were faced during the development of the Registry:

- Incomplete or absent exposure data for defining eligibility criteria
- The use of geographical boundaries of Canal Street (for residents) and Chambers Street (for persons on the street or in buildings), because there has been no definitive information on the extent of exposure to dust from the collapse of the buildings

Operationally, these boundaries were useful because they were easily understood and recognized by most New Yorkers, but the Department recognized that there were people outside these boundaries who had probably been exposed.

After 9/11, there was much suspicion and distrust about the government's response to the attacks and even rumors that government officials had deliberately misinformed the public about health hazards. This was a difficult challenge to address. The primary strategy for allaying suspicion was to release findings as soon as possible about the effects of the 9/11 attack. The first data report was released in October 2003, only 1 month after the start of data collection. Reports were disseminated quarterly until data collection was completed. The Registry has continued to focus on transparency by having regular meetings with community and labor advisory committees and on dissemination of reports via the Internet and by mail.

A legitimate criticism of the Registry was the lack of early community input in the early stages of its design—largely because constituencies and their representatives were not apparent then. Survivors from the buildings and next of kin of those who died were the most prominent constituencies in the first several

months after 9/11, as were rescue and recovery workers. The Registry involved these groups in selecting content for the survey. The groups most vocal about the lack of community involvement comprised residents of Lower Manhattan and members of unions of municipal employees. Their claims did not emerge until the Registry had already begun operating. The Registry addressed this problem by setting up community and labor advisory committees, which helped to develop follow-up surveys and other initiatives.

Other Registry Activities

Other major activities included maintaining accurate and up-to-date contact information; matching Registry data to data in vital records and cancer registries; encouraging, reviewing, and approving external studies that have used the Registry as a source of subjects; performing community-focused referral; and offering tobacco cessation programs. A vital part of these activities has been conducting community outreach and personalized communication with registrants. The Registry also conducts quarterly community and labor advisory committee meetings, which enable participants to provide input on survey content and analysis. As of early 2011, the Registry was designing Wave 3 (W3) adult and pediatric surveys, expected to begin later in the year.

Findings from Registry-based Studies

Mental health and physical health studies have been based on the Registry. Unlike any other cohort that has focused on 9/11-related health issues, the Registry has reported findings from a wide range of populations affected by 9/11, including survivors from buildings, rescue and recovery workers, office workers who returned to the area after 9/11, residents, and children. (See Table 3–1.)

Table 3–1 summarizes the published reports from the Registry. Two reports provided results on multiple population groups.[14,24] Others focused on one group and conducted an in-depth of analysis of one or more health outcomes.[19,21–28]

The first paper published by the Registry focused on 8,418 survivors from collapsed and damaged buildings.[19] People who were in the WTC towers and other nearby damaged or destroyed buildings on 9/11 witnessed events and were exposed to the dust and debris cloud. Many survivors also lost work colleagues and had homes and offices that were near the WTC site that were damaged and contaminated.

The dust and debris cloud was the most significant exposure among survivors of collapsed and damaged buildings. Sustaining an injury on 9/11 was four times more likely among persons who were caught in the dust and debris cloud and the rate of eye injury or eye irritation was more than five times greater among these people. Among those who evacuated from buildings, a higher proportion of people on highest floors at the time of the attacks reported sprain or strain injuries; burns and

Table 3–1: SUMMARY OF PUBLISHED REGISTRY-BASED STUDIES

Year Published:	06	07	08	09	10	RRV	Residents	Occ/ Trans	Children
Paper topic	**1st author**								
Health outcomes–building survivors	Brackbill[19]	X						X	
PTSD in rescue/recovery workers	Perrin[21]		X			X			
Asthma in rescue-recovery workers	Wheeler[22]		X			X			
Coverage measurement	Murphy[20]		X			X	X	X	X
Asthma in children	Thomas[23]			X			X		X
Health overview	Farfel[24]			X		X	X	X	X
PTSD in Lower Manhattan residents	DiGrande[25]			X			X		
Estimating population denominator	Murphy[26]				X	X	X	X	X
PTSD in police	Bowler[27]					X	X		
PTSD in WTC tower survivors	DiGrande[28]					X		X	
Diagnosed asthma and PTSD	Brackbill[14]				X		X	X	

RRV: Rescue/recovery and volunteer workers; Occ/Trans: Occupants of buildings and persons in transit on 9/11.

concussion injuries occurred most frequently among those present on the lowest and the highest floors.

Among those who were caught in the dust and debris cloud, wheezing was three times more likely, newly diagnosed asthma twice as likely; stroke six times more likely; and heartburn, gastroesophageal reflux disorder, and severe headaches significantly more prevalent.[19]

Among those caught in the dust and debris cloud, 69 percent reported depression, anxiety, and emotional problems after 9/11; and 14 percent reported severe psychological distress (compared to 6 percent of those who were not in the dust and debris cloud). Persons who survived collapsed buildings also had significantly more mental health problems.[19]

The Registry enrolled 3,271 civilian WTC tower survivors—21 percent of the estimated number of people there.[26,28] Only three survivors reported being at or above the level of impact at any time in the North Tower, compared to nearly 400 in the South Tower. Over 90 percent of these survivors witnessed traumatizing events, such as people jumping from a building, and 32 percent had one or more types of injury. Two to three years after 9/11, 15 percent of WTC tower survivors screened positive for PTSD, using a conservative definition.

Among survivors of the North Tower who had started evacuating during the collapse of the South Tower or had sustained an injury, 28 percent screened positive for PTSD. There was an inverse relationship between income level and probable PTSD—hypothesized to result from marginalization, lack of resources, powerlessness, or coping with negative life events.[28]

Less-educated residents and residents who were divorced, widowed, or separated had a higher prevalence of probable PTSD.[25] Prevalence was highest among residents who lived within 1,000 feet of the WTC site (17 percent), those in a World Trade Center tower on 9/11 (16 percent), and rescue and recovery workers (20 percent). Almost 20 percent of residents who had evacuated and stayed away for a long period developed PTSD.[25]

Prevalence of probable PTSD varied considerably among WTC rescue and recovery workers, ranging from 7 percent among police to 25 percent among unaffiliated volunteers.[21] Occupational groups with more experience or training in disaster response were less vulnerable to psychological sequelae.[21] However, female police officers had almost 14 percent prevalence of PTSD, compared to 7 percent among male police officers.[27] The strongest risk factor for probable PTSD was sustaining an injury on 9/11.[27]

PTSD remains a significant problem among people most highly exposed on 9/11. Two to three years after 9/11, 16 percent of adult enrollees screened positive for probable PTSD and 8 percent for psychological distress.[14,19] Among respondents to the first two Wave surveys conducted by the Registry, 24 percent screened positive for probable PTSD.[14] Five to six years after 9/11, passersby or persons on the street south of Chambers Street on 9/11 had the highest prevalence of chronic PTSD (13 percent)—defined as having screened positive on both Wave surveys—while rescue and recovery workers and volunteers had the highest prevalence of late-onset PTSD symptoms (11 percent).[14]

Lower and upper respiratory problems arising from exposure at the WTC site occurred especially among rescue and recovery workers who arrived there early.[29–31] Of Registry enrollees, 67 percent reported new or worsening respiratory symptoms, such as persistent cough, shortness of breath, and wheezing.[24] Among workers who worked on "the Pile" at the WTC site on 9/11, 88 percent reported these symptoms.[24] Rescue and recovery workers and volunteers had a 12-fold higher 3-year risk of diagnosed asthma (3.6 percent) than the general population (0.3 percent).[22] Workers who arrived on 9/11 and worked more than 90 days had a 7 percent 3-year risk of diagnosed asthma; the risk of diagnosed asthma increased 2 to 3 percent for every 10 days of additional work at the WTC site.[22] There was also a direct relationship between how long a worker waited to use any kind of respiratory protection and the risk for asthma, ranging from 4.9 percent prevalence for using respiratory protection without any delay to 16 percent prevalence for never using protection.[22] Residents and office workers who reported exposure to heavy dust at their homes or offices after 9/11 and those who had an intense dust and debris cloud exposure on 9/11 had a 50 percent increased risk of (self-reported) diagnosed asthma.[14] Longitudinal data from the Registry, however, show that asthma prevalence 5 to 6 years after 9/11 decreased to the prevalence of the general

population—although there has remained a small, but significant, association between 9/11 exposure and asthma diagnosed after 2004.

About 25,000 children were either residing or enrolled in a school south of Canal Street on 9/11. A Registry study found that about 50 percent of these children, regardless of age, had a new or worsened respiratory symptom after 9/11.[23] Eleven percent of children under age 4 developed diagnosed asthma after 9/11. The prevalence of new-onset asthma in other age groups ranged from about 3 to 6 percent. Children who had been in the dust and debris cloud had twice the risk of newly diagnosed asthma.

Clinical Guidelines

The Department continues to regularly issue reports and medical guidelines related to important public health problems. These publications are disseminated primarily to health care providers through a departmental publication, *City Health Information* (*CHI*). In 2008 and 2009, it published, through *CHI*, clinical guidelines related to the WTC attack—one focused on adults[32] and the other on children and adolescents.[33] These reports resulted from the collective work of medical researchers, clinicians, and community representatives throughout New York. The adult guidelines provided evidenced-based information on diagnosis and treatment of 9/11-related disorders, including chronic rhinitis and rhinosinusitis, irritant-induced asthma and reactive airways dysfunction syndrome (RADS), gastroesophageal reflux disorder (GERD), and laryngo-pharyngeal reflux disease (LPRD). These guidelines also provided clinical diagnostic tools and treatment regimens for mental disorders that may have resulted from 9/11 psychological trauma, including PTSD, major depression, and generalized anxiety disorder.

The clinical guidelines for children and adolescents focused primarily on mental health and behavioral problems that could occur in children as a result of the 9/11 attack. The guidelines included key exposure questions to assess potential disorders related to the WTC attack and a list of age-specific reactions to disasters for preschool, early-school, pre-adolescent, and adolescent children. Guidelines for using a pediatric symptom checklist were included. The report focused on anxiety disorders (such as PTSD, generalized anxiety disorder, separation anxiety, agoraphobia, and panic disorder); mood disorders (such as major depressive disorder); and substance abuse and substance dependence.

Currently, Registry-based research is focusing on GERD, co-morbidity of post-9/11 PTSD and respiratory symptoms, health care access and unmet health care needs, diagnosed asthma among children 5 to 6 years after 9/11, the current health status of those injured on 9/11, and an assessment of mortality due to the 9/11 attacks.

CONCLUSION

Mitigation of the short- and long-term health effects of the World Trade Center attack was achieved by the cooperative work of many public health agencies.

The experience transformed emergency preparedness and response within the Department and other agencies and organizations. We believe that the experience and lessons learned will improve the response to future public health emergencies.

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