

2008 Annual Report on 9/11 Health

September 2008



LETTER TO MAYOR BLOOMBERG

September 2008

Dear Mayor Bloomberg:

Last year you appointed a WorldTrade Center (WTC) Medical Working Group, whose diverse membership extends beyond City government, to advise you about health issues that are related or potentially related to the September 11, 2001 terrorist attacks on the WorldTrade Center. We were charged with writing an annual report that can help policy makers and others with an interest in 9/11 health better understand the complexities of research that has been published to date and make recommendations about research and service needs to improve the state of 9/11 health.

Research on WTC health impacts, much of it based on clinical studies of people in treatment, is considerable. More than 40,000 rescue and recovery workers have been screened nationally, primarily at New York City's three WTC Centers of Excellence. Of these, more than 10,500 have received federally funded treatment for physical health conditions including respiratory problems, asthma and gastroesophageal reflux disease, and more than 5,500 have been treated for mental health conditions such as posttraumatic stress disorder (thousands of others have been treated with private funding). In addition, nearly 2,700 Lower Manhattan residents and area workers—including those who worked in Lower Manhattan, though they may live elsewhere—have sought treatment for these same conditions from New York City's Health and Hospitals Corporation. Some of these people have recovered, but others have not.

In recognition of your strong belief that New York City must target resources to those who are in need, this report presents an overview of clinical findings to date in populations exposed to the WTC collapse and results from population-based research. Understanding clinical service needs and, more broadly, the types and magnitudes of 9/11 health impacts is essential in helping make important policy decisions regarding future services and resources given the current uncertainties in federal funding.

The WTC Medical Working Group is well qualified and uniquely positioned to review the emerging evidence. We are committed to helping you and other policy makers make sense of this complex body of information, and to share our work with other stakeholders. With this report, we hope to provide a balanced summary of 9/11 health risks that will be used to educate, inform and assist those affected by the disaster.

Linda Gibbs, Co-Chair

New York City Deputy Mayor

for Health and Human Services

Thomas R. Frieden, MD, MPH, Co-Chair

New York City Health

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KEY/FINDINGS

The WTC Medical Working Group, a group of physicians and researchers appointed by Mayor Bloomberg in 2007 to assess the state of 9/11 health and related services on an annual basis, reviewed more than 100 scientific articles that have been published since the 2001 attack on the World Trade Center. Our key findings from these studies published as of June 2008 are presented below. Recommendations follow to guide policy makers, researchers and other constituencies with an interest in 9/11 health.

Both clinical studies and population-based surveillance indicate that symptoms of posttraumatic stress disorder are highly prevalent among rescue and recovery workers and Lower Manhattan residents, two directly affected populations. Studies of rescue and recovery workers also indicate that respiratory problems, asthma and gastroesophageal reflux disease are common among this group, particularly those who arrived early at the WTC site and those who worked there for long periods of time. Similarly, Lower Manhattan residents and area workers—including those who worked in Lower Manhattan, though they may live elsewhere—have reported elevated levels of respiratory problems and new onset asthma. Studies are ongoing to characterize the kinds of exposures that may have contributed to this illness and to determine its persistence.

This review of research to date also makes clear that significant questions remain unanswered. For example, how extensively did the disaster affect the health of residents, area workers, and students in Lower Manhattan, and what kinds of exposures increased their risks? How persistent are the mental and physical health symptoms in thousands of rescue, recovery and clean-up workers? How effective has treatment been among the people who have received it?

From our review of services, informed by the medical directors of New York City's three Centers of Excellence who are members of this group, current health care resources are adequate for the more than 10,000 WTC-exposed individuals who have sought treatment for conditions related or potentially related to 9/11 exposure. What is not clear, however, is if all the people eligible for these programs are aware of them. Monitoring and treatment services available through the Centers of Excellence would be strained if greater awareness of these programs—particularly among Lower Manhattan residents, area workers and students—significantly increased demand.

Furthermore, uncertainty in the availability of ongoing federal support for 9/11-related health care means that the people currently in these programs don't know if they will continue to receive their treatment and medications free of charge. Both FDNY and the New York/New Jersey WTC Clinical Consortium are funded through 2009 only, and the New York City Health and Hospitals Corporation's (HHC) WTC Environmental Health Center has not received any federal funding to date.

PHYSICAL TRAUMA AND RESPIRATORY HEALTH

- 2,751 people were killed in the WTC attack. Other victims were treated for burns and injuries, some of which have substantially affected the quality of their lives in the years since.
- In the first weeks and months after 9/11, respiratory symptoms were common among people who breathed in the dust, smoke and fumes released by the WTC collapse.
- Clinical studies of exposed rescue and recovery workers show that respiratory symptoms subsided over time for many workers but have persisted for others. While nearly all responding NYC firefighters experienced respiratory symptoms on the day of the WTC attacks, symptoms have persisted for approximately 25% of firefighters two to four years later. Prior to 9/11, fewer than 5% of NYC firefighters had chronic respiratory symptoms.
- In surveys conducted two to three years after 9/11, rescue and recovery workers, Lower Manhattan residents and area workers all reported levels of new asthma that were two-to- three times higher than national estimates.
- For several worker groups, pulmonary function tests have documented decline in lung function or high prevalence of abnormal lung function after 9/11.

- Compared to pre-9/11 levels, new diagnoses of sarcoidosis (an inflammatory condition of lung and often other organs) or sarcoid-like lung disease were elevated among NYC firefighters in the first year after the disaster. Since then, rates have subsided to pre-9/11 levels.
- Gastroesophageal reflux (GERD) symptoms are common among WTC-exposed populations, especially in conjunction with upper and lower respiratory symptoms, but it is difficult to draw conclusions about the relationship between GERD and WTC exposure because GERD occurs frequently in the general population.

MENTAL HEALTH

- Posttraumatic stress symptoms and disorders were common in the first six months after 9/11 among people both directly and indirectly exposed to the WTC disaster.
- Early symptoms of posttraumatic stress resolved quickly for most people, particularly for those who were not directly exposed.
- However, among directly exposed populations, rates of PTSD were elevated two-to-three years after 9/11: 12% of rescue and recovery workers and 13% of Lower Manhattan residents reported symptoms of PTSD, which is three times higher than would be expected if the WTC attacks had never occurred.
- In the general New York City population, rates of depression and abuse of alcohol or other substances are not persistently elevated as a result of the WTC disaster.
- Among groups directly exposed to the WTC disaster, depression and substance abuse have not been well studied.

OTHER PHYSICAL HEALTH AND MORTALITY

- A small number of studies on women pregnant on 9/11 have suggested that exposure to the disaster may have impacted birth outcomes, such as increased risk of lower birth weight or shorter length at delivery. These impacts were small in magnitude and of unclear clinical significance. No studies to date have identified if these birth outcomes had subsequent clinical implications, such as developmental delays.
- One national study of individuals not in physical proximity to the 9/11 attacks showed that those who experienced acute stress as a result of the attacks were at increased risk for new onset hypertension and heart problems.
- Studies have been initiated to examine the possibility of WTC-related cancers and to measure overall patterns of mortality among people with exposure to the WTC collapse, but results are not yet available. These and other late-emerging effects are not expected to be clearly evident for at least a decade after exposure. A small number of other health conditions are also now being studied.

KEY/RECOMMENDATIONS

I. Funding

- Advocate for long-term federal funding so that the following critical activities can continue:
 - treatment of WTC-exposed populations including rescue, recovery and clean-up workers,
 Lower Manhattan residents, area workers (including commuters living outside of New York City)
 and students for illnesses related to WTC exposure at the Centers of Excellence
 - regular monitoring of firefighters, police, correction, sanitation and other rescue, recovery and clean-up workers for WTC-related mental and physical health conditions
 - tracking the health of 71,000 people enrolled in the WTC Health Registry, who now reside in all 50 states

II. Research and Evaluation

- Expand research on the prevalence of WTC-related conditions and determine their persistence
- Document WTC-related treatment needs and effectiveness by:
 - determining the extent to which people with potential WTC-related health conditions are receiving treatment, and by identifying coverage gaps
 - evaluating the effectiveness of treatment among patients with WTC-related mental and physical health conditions
 - estimating the number of people who may seek mental and/or physical health treatment to help policy makers project future treatment costs
- Determine whether cancer, chronic illnesses and other late emerging diseases are elevated among WTC-exposed populations by comparing incidence and mortality rates among WTC-exposed populations to estimated background rates for New York City
- Expand research on the impact of 9/11 on mental health and substance use by:
 - collecting additional data on the prevalence of WTC-related depression, suicide and substance use among WTC-exposed populations
 - assessing the impact of chronic WTC-related physical health conditions on long-term mental health
 - studying the impact of tobacco use on WTC-related respiratory conditions
- Increase research on mental and physical health effects on vulnerable populations who were exposed to the WTC collapse including children who went to school or who lived in the area, had first responder parents, or lost family members on 9/11

III. Education

- Increase awareness of WTC-related symptoms and the availability of clinical resources among people who were exposed to the disaster
- Increase awareness of *Clinical Guidelines for Adults Exposed to the WTC Disaster*¹ among health care professionals, especially in areas where large numbers of WTC-exposed individuals may reside
- Develop and disseminate clinical guidelines for children exposed to the WTC disaster
- Educate policy makers, the media and the public about the difficulty in establishing a direct cause-effect relationship between WTC exposure and any one individual's illness for most diseases, especially those that are relatively rare

INTRODUCTION

The September 11, 2001 attack on the WorldTrade Center (WTC) resulted in the largest loss of life caused by an act of terrorism committed on American soil. This attack killed 2,751 people, including more than 2,200 civilians, 343 NYC firefighters, 23 NYC police officers and 37 Port Authority police officers.

Beyond the immediate deaths and injuries attributable to the event, the attack and its aftermath affected the mental and physical health of thousands of people, including responders, volunteers, people who lived and worked in the area and schoolchildren.

The full extent of the health impacts resulting from the WTC attack is unknown. Medical evidence suggests a variety of short- to medium-term health consequences, including posttraumatic stress disorder (PTSD), anxiety and depression, upper and lower respiratory illnesses and gastroesophageal reflux disease (GERD). Many people have recovered, but others continue to experience a range of symptoms. Concern also exists that chronic diseases, including cancer and pulmonary fibrosis, may be linked to WTC exposure in the years ahead, though it may take many years to fully understand the long-term health effects of WTC exposure.

Mayor's Medical Working Group Formation

In September 2006, Mayor Michael R. Bloomberg asked Deputy Mayors Linda Gibbs and Edward Skyler to lead a panel of City agencies to examine the known health effects of WTC exposure and to assess the adequacy of available resources to address these effects. The panel's report, *Addressing the Health Impacts of 9-11: Report and Recommendations to Mayor Michael R. Bloomberg*, was released in February 2007. Among the panel's recommendations was the creation of the Mayor's WTC Medical Working Group (MWG), which is charged with writing an annual report on the state of 9/11 health and related services.

Co-chaired by the Deputy Mayor for Health and Human Services and the Commissioner of the Department of Health and Mental Hygiene, the MWG comprises academic leaders in the fields of public health, mental health, medicine and research, as well as medical representatives from the NYC Fire, Police, Correction and Health Departments, the three WTC treatment Centers of Excellence and the Office of the Chief Medical Examiner. It meets regularly to review existing and emerging scientific data about the health effects of the WTC collapse. A primary purpose of this review is to identify clinical risks and translate them into useful information for policy makers, and to provide perspectives on communicating health risks to people with WTC exposure. The MWG also assesses the adequacy of resources available to address the mental health and physical health needs of affected people.

This report serves as the first Annual Report of the Mayor's Medical Working Group.

OVERVIEW OF THE DISASTER

On the morning of September 11, 2001, terrorists crashed two hijacked airplanes into the North and South Towers of the World Trade Center. Within two hours, both 110-story buildings collapsed, followed by 7 World Trade and three other large buildings. This left an enormous pile of burning rubble.

Both airplane crashes resulted in massive combustion of jet fuel and produced smoke plumes. The collapse of the buildings and subsequent fires released a complex mixture of potential contaminants including asbestos, particulate matter (pulverized concrete, smoke, dust, and combustion materials), lead and polychlorinated biphenyls into the environment. An enormous dust cloud enveloped many people as they evacuated Lower Manhattan.

On that day, 2,751 people were killed in New York City and thousands of others escaped death or injury while fleeing the area. Hundreds of thousands of people also witnessed traumatic events such as airplanes striking one or both towers; buildings collapsing; and people fleeing, jumping, falling, suffering injury or dying. Millions of other people saw these events repeatedly on their televisions.

Immediately following the attack, first responders, rescue workers, volunteers, contractors and others from around the country rushed to Lower Manhattan to take part in the search for survivors. Thousands more participated in the recovery and clean-up efforts that followed. Although the exact number is not known, an estimated 90,000 people were involved in operations that lasted for months at the former WTC site, the NYC Morgue, the temporary morgues on pier locations on the west side of Manhattan, and on the barges between the west side and the Fresh Kills Landfill.

Tens of thousands of Lower Manhattan area workers, residents, schoolchildren and commuters were evacuated and had their lives and livelihoods disrupted. Many residents returned to their homes to find them covered in dust.

Though concentrations of airborne particulates were highest immediately following the attack and dropped substantially within days, fires burned for months near the WTC site. Dust and smoke settled on many indoor spaces and outdoor sites.

KEY SOURCES OF INFORMATION

In preparing this report, the WTC Medical Working Group reviewed more than 100 articles from the peer-reviewed literature on the mental and physical health impacts of 9/11. Much of the published research was drawn from data collected by 9/11-related programs in New York City. A brief description of these programs is provided below.

WTC Treatment Centers of Excellence in New York City

Specialized treatment services are available to people in the New York area who may have developed physical and mental health problems as a result of their exposure to the WTC disaster. A combination of funding from city, federal and private sources has made treatment, medications and counseling available free-of-charge through three WTC treatment Centers of Excellence. Clinical research conducted through these programs has contributed to the body of WTC scientific literature and to an understanding of health conditions experienced by those affected. The three WTC treatment Centers of Excellence are:

1) World Trade Center Medical Monitoring and Treatment Program at the Fire Department of **New York (FDNY)**

This program is funded by the National Institute for Occupational Safety and Health (NIOSH) to monitor and treat active and retired FDNY-firefighters and FDNY-EMS workers who were exposed to the WTC disaster. FDNY monitors the health of workers enrolled in the program

during annual WTC physical exams. Because nearly all NYC firefighters responded to the disaster, and because FDNY has always required pre-employment and periodic physicals during employment, the data collected through this program have been extremely valuable to patients, clinicians, researchers and policy makers interested in the health effects of 9/11 on a highly exposed, homogenous cohort.

Currently, 14,700 FDNY active and retired firefighter and EMS workers are being monitored in the program, which represents nearly all workers eligible for services. More than 12,000 have received at least one follow-up exam. The program treats an average of 2,500 patients annually for mental health conditions (primarily depression, prolonged grief and PTSD) and approximately 2,000 patients annually for physical health conditions (primarily upper and lower respiratory diseases).

2) <u>World Trade Center Medical Monitoring and Treatment Program coordinated by</u> Mount Sinai School of Medicine

This program, formally known as the New York/New Jersey WTC Clinical Consortium, is also funded by NIOSH. It provides health monitoring to more than 24,000 workers and volunteers who participated in the rescue, recovery and clean-up operations at the WTC site and three other locations, and it treats those who may have developed medical problems as a result. All participants enrolled in this program are asked to return at 18-month intervals for monitoring examinations. The majority of 8,500 patients currently receiving treatment are under- or uninsured and many non-English speakers participate. Services for the diverse patient population are available at seven locations in the greater New York area, including Long Island and Westchester County, and in New Jersey.

3) <u>World Trade Center Environmental Health Center at Bellevue Hospital Center, Gouverneur</u> Health Care Services and Elmhurst Hospital Center

This program, begun with private funds and expanded in 2007 by New York City, is a treatment program for local residents, area workers (including commuters living outside of New York City) and people who report exposure to WTC dust or fumes and who are experiencing symptoms that may be related to this exposure. As of July 2008 this included nearly 2,700 adult and child residents of Lower Manhattan and some areas of Brooklyn; students who were attending schools and colleges in Lower Manhattan in 2001–2002; increasing numbers of people who worked in the area near the World Trade Center; and volunteers and individuals involved in debris removal. The Center is not a screening program for individuals who do not have physical or mental health symptoms. Patients are seen regardless of their insurance status.

World Trade Center Health Registry

In 2003, the NYC Department of Health & Mental Hygiene (DOHMH) and the federal Agency for Toxic Substances and Disease Registry (ATSDR) launched the World Trade Center Health Registry. The Registry, funded by the federal government, periodically collects information about physical and mental health effects from more than 71,000 adults and children who were exposed to the WTC collapse. The Registry is the largest effort in U.S. history to study the health effects of a disaster. Enrollees currently reside in all 50 states. Comprehensive, self-reported health surveys of this unique cohort have been conducted twice to date, and focused clinical sub-studies are underway.

New York Police Department

The New York Police Department (NYPD) has documented, evaluated, monitored, tracked and referred to treatment members who have come forward with WTC-related symptoms since 2001. NYPD has a large work force that was exposed to the disaster and has an ongoing five-year follow-up study of its Emergency Services Unit personnel with pre- and post-9/11 data.

STRENGTHS AND LIMITATIONS OF WTC-RELATED RESEARCH

Much of the research presented in this report was gathered by a select number of institutions that recognized the need to monitor the health of individuals affected by the WTC collapse early after the disaster.

Particular strengths of this body of research include the fact that many different studies have found similar physical and mental health effects across exposed groups, and that the research includes data gleaned from several large longitudinal cohorts, in addition to numerous one-time surveys. Some of the largest study groups include:

- Nearly all FDNY responders who responded to the disaster. All have pre- and post-9/11 medical records and the group receives ongoing clinical monitoring.
- A large cohort of responders enrolled in the New York/New Jersey WTC Clinical Consortium for clinical screening, monitoring and treatment. This Consortium collects similar data to FDNY to facilitate comparisons across worker groups.
- The WTC Health Registry, the largest post-disaster exposure registry in U.S. history, enrolling more than 71,000 exposed individuals to be tracked for a period of at least 20 years.

Several significant challenges also affect the ability to conduct accurate research on 9/11 health effects. Prior to reviewing the findings presented here, it is helpful to highlight the limitations that characterize most published studies:

- The exact size and composition of the population affected by the disaster remains unknown, although estimates have been developed and published.
- It is difficult to measure how much and what type of exposure different people had to traumatic or environmental impacts of 9/11. More is known about exposure among some groups (rescue and recovery workers) than among others (residents and area workers), but all exposure measurements remain imprecise.
- Many studies are conducted on volunteer or clinic-based samples, which may not be representative of the true population of exposed people and may over-represent those who are ill.
- Many studies rely on self-reports of symptoms and conditions, some of which can be difficult to verify.
- Studies are laborious to conduct, analyze and publish, leaving policy makers with limited up-todate information, particularly regarding persistence of conditions over time.

MENTAL HEALTH FINDINGS

Posttraumatic Stress Disorder (PTSD), Depression and Substance Abuse

- Posttraumatic stress symptoms and disorders were common in the first six months after 9/11 among people both directly and indirectly exposed to the WTC disaster.
- Early symptoms of posttraumatic stress resolved quickly for most people, particularly for those who were not directly exposed.
- However, among directly exposed populations, rates of PTSD were elevated two-to-three years after 9/11: 12% of rescue and recovery workers and 13% of Lower Manhattan residents reported symptoms of PTSD, which is three times higher than would be expected if the WTC attacks had never occurred.
- In the general New York City population, rates of depression and abuse of alcohol or other substances are not persistently elevated as a result of the WTC disaster.
- Among groups directly exposed to the WTC disaster, depression and substance abuse have not been well studied.

Posttraumatic Stress Disorder (PTSD)

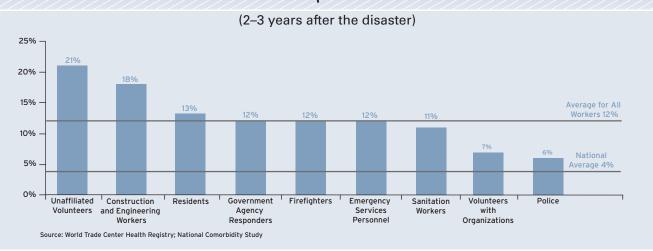
PTSD may develop in individuals exposed to traumatic event(s) where the threat of serious injury or death occurs and the individual's response involves intense fear, helplessness, or horror. PTSD is characterized by all of the following symptoms that either arise immediately or after a delayed period, and cause significant distress or impaired functioning:

- Re-living of the traumatic event in the form of nightmares and flashbacks; and
- Avoidance of reminders of the event, such as places, activities, and people, or feeling emotionally detached or numb; and
- Hyperarousal such as insomnia, irritability, hypervigilance, or exaggerated startle reaction.

PTSD often co-exists with other psychological disorders such as depression.



Probable PTSD in WTC-Exposed Workers and Residents



Prevalence and Exposures That Increase the Risk of PTSD

Residents

Among NYC residents, early surveys indicated that adults directly affected by the disaster were more likely to have developed post-trauma stress symptoms and PTSD than those indirectly affected. According to one representative telephone survey conducted six months post attack, 15% of those directly affected screened positive for PTSD compared to 4% of those not directly affected.² Examples of individuals who were directly affected are those who were in the WTC complex, were injured or feared injury during the attacks, had a friend or relative killed, lost possessions, became unemployed, or were involved in the rescue effort. Added risk factors for PTSD included low levels of social support or high levels of lifetime stressors before and after 9/11.²

The World Trade Center Health Registry enrolled a large sample (12,654) of Lower Manhattan residents who lived below Canal Street on 9/11. Results from a standardized survey of these enrollees suggested that approximately 13% of adult residents had probable PTSD two to three years after 9/11.³ Though the sample size for this study was large, these estimates may not be representative of the entire Lower Manhattan community because enrollment in the Registry was voluntary and may therefore over-represent individuals suffering from mental or physical conditions.

No national estimate of WTC-associated PTSD is available but general mental health surveys indicate that at any point in time, approximately 4% of the adult population screens positive for PTSD-like disorders due to a variety of traumas.^{3a} PTSD is typically more common in women, people with Hispanic ethnicity, and those with low socioeconomic status. These same associations were observed in studies of people exposed to the WTC disaster.⁴⁹ Other 9/11-specific risk factors include having sustained an injury, evacuating one's home, or directly witnessing horrific events.

Children

An early study of NYC schoolchildren, conducted in the first six months after 9/11, found that 11% of children surveyed had symptoms of PTSD.¹⁰ The same study identified a higher risk of negative mental health outcomes among children who were directly affected by the disaster, had parents who were directly affected, or who previously suffered from PTSD or depression. Agoraphobia, the fear of being in places from which escape might be difficult or help might not be available if needed, and separation anxiety were the two most common negative outcomes.^{10, 11}

A recent study of 115 Lower Manhattan preschool children identified that children with a combination of trauma exposure prior to 9/11 and WTC-related trauma exposure had an increased risk of clinically significant behavioral problems, whereas preschool children with no other trauma exposure history did not experience such problems after 9/11 exposure. This suggests that children with prior trauma exposure may be particularly in need of mental health services.¹²

Rescue, Recovery and Clean-up Workers

Post-disaster studies from the World Trade Center and other disasters have consistently identified that PTSD levels vary among rescue, recovery and clean-up workers, even when work experiences are similar. This suggests that workers in different occupation groups have varying degrees of susceptibility to trauma-related psychological distress. In a large sample of 28,962 workers and volunteers from the World Trade Center Health Registry who worked at the WTC site, a total of 12% had probable PTSD, and rates ranged from 6% among police to 21% among volunteers. The study identified that workers in occupational categories with less training in disaster rescue or recovery operations (e.g. sanitation or construction workers), or who worked outside of their areas of training, were at increased risk for PTSD. Other risk factors specific to 9/11 included having sustained an injury, being exposed to the dust cloud resulting from the collapsing buildings, beginning work on or immediately after 9/11, or working at or near the site for 90 days or longer. 13, 14

A recently published study by the NewYork/New Jersey WTC Clinical Consortium found similar results: 11% of more than 10,000 rescue, recovery and clean-up workers, the majority of whom arrived at the WTC site within one week after the attacks, met the criteria for probable PTSD in the month prior to being screened over a five-year period. Half of the workers with PTSD also had either probable depression, panic disorder or both. They also were twice as likely as those without PTSD to have an alcohol problem.¹⁵

Treatment for PTSD

A range of psychotherapy and pharmacotherapy treatments are used by primary care and mental health providers to treat patients diagnosed with PTSD. Exposure therapy helps to reduce the arousal and distress associated with memories of trauma and has proven effective in treating PTSD. Further research is needed to confirm the efficacy of other cognitive and behavioral therapies.¹⁶ The U.S. Food and Drug Administration has approved two drugs (both are antidepressant selective serotonin reuptake inhibitors, or SSRI's) to treat PTSD. Pharmacotherapy for PTSD may also include other antidepressant medications, mood stabilizers, anti-adrenergic agents, anti-anxiety agents, and antipsychotic medications.

Little information exists with respect to treatments offered by NYC mental health providers for PTSD, or with respect to mental health services utilization. One population-based study of adult New Yorkers found that in the year after the attack, self-reported use of mental health services did not increase substantially in the general population; however, service use did increase among two subgroups of New Yorkers: those who had been directly affected by the disaster and those who had been receiving mental health care at the time of the attack.¹⁷

Depression and Substance Abuse

A telephone survey of 2,700 residents of the New York metropolitan area conducted six months after the disaster found that while the prevalence of depression among the general population was significantly elevated shortly after September 11, 2001, six months later it had returned to a level that was within the expected background range. Among those who were directly affected by the attacks which included those who experienced the death of a friend or relative, were in the WTC complex, suffered an injury, participated in the rescue efforts, or lost possessions, property or a job—the sixmonth prevalence of depression was higher than expected: 6% were depressed six months later, compared to ranges of 2.2% to nearly 4.9% in a non-traumatized population.¹⁸

Six to nine months after September 11, 2001 researchers found that compared to the month before the attack, Manhattan residents reported significant increases in alcohol consumption (17.5%), cigarette smoking (10%), and marijuana use (3%). In the same study, current PTSD was associated with increased cigarette smoking and current depression was associated with increases in alcohol consumption and cigarette smoking. 19 Another study found that greater direct exposure to the WTC disaster increased the likelihood of binge drinking or alcohol dependence among NYC residents.²⁰ No research has been published to show whether binge drinking or alcohol dependence among directly exposed residents remained elevated after the first year.

Few studies have systematically examined the burden of depression and substance abuse and dependence in WTC-exposed groups over longer periods.

Depression

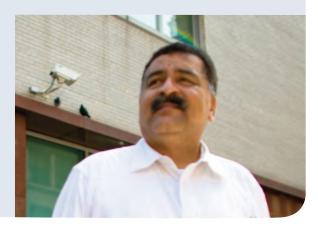
Depression is a disabling condition that affects many aspects of a person's life and overall functioning. People who directly witnessed the WTC attacks and those who participated in the rescue and recovery efforts may be at increased risk for developing depression, with or without PTSD. Depression is typically characterized by many or all of the following: feelings of extreme sadness, anhedonia (taking no pleasure in usually enjoyable activities), guilt, helplessness, hopelessness, insomnia, inability to concentrate, loss of appetite, and thoughts of suicide and/or death. There may be only one episode, but depression is more commonly a recurring condition.

Simple screening tools to detect depression are readily available.

Substance Abuse and Dependence

Substance abuse is a pattern of use that leads to significant impairment or distress (including problems at work, school or home) but without the physical dependence or loss of control over intake that characterize substance dependence.

Substance dependence or addiction involves a preoccupation with a substance, diminished control over its consumption and persistent behavioral consequences. The hallmarks of dependence are *tolerance and withdrawal*.



PHYSICAL HEALTH FINDINGS

Physical Trauma

■ 2,751 people were killed in the WTC attack. Other victims were treated for burns and injuries, some of which have substantially affected the quality of their lives in the years since.

In the WTC attack, 2,751 people were killed (NYC Office of the Chief Medical Examiner). Of these, more than 400 were rescue workers. In the first 24 hours after the attacks, nearly 250 FDNY rescue workers were treated and released from emergency departments (ED) for eye irritation, respiratory tract irritation, exhaustion, dehydration, and/or chest pain. A smaller number of workers experienced bone and spine fractures, and several life-threatening inhalation injuries that required intubation.²¹

An analysis of medical records from the five nearest hospitals indicated that by September 13, more than 1,100 ED visits were likely to have been WTC-related. Medical records indicate that 810 individuals were treated for mild inhalation and/or eye irritations and released. More serious injuries, such as fractures, burns, head injuries, crush injuries and/or inhalation injuries required hospitalization.²²

Respiratory Symptoms

- In the first weeks and months after 9/11, respiratory symptoms were common among people who breathed in the dust, smoke and fumes released by the WTC collapse.
- Clinical studies of exposed rescue and recovery workers show that respiratory symptoms subsided over time for many workers but have persisted for others. While nearly all responding NYC firefighters experienced respiratory symptoms on the day of the WTC attacks, symptoms have persisted for approximately 25% of firefighters two to four years later. Prior to 9/11, fewer than 5% of NYC firefighters had chronic respiratory symptoms.

Common Upper and Lower Airways Symptoms Associated with WTC-Exposure

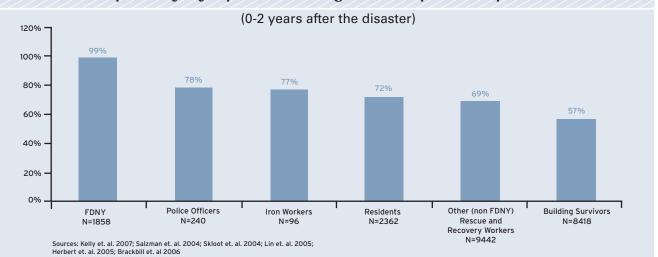
Upper respiratory symptoms can include cough, sinus congestion, sinus pain, post-nasal drip, runny nose, headache, sore throat, ear pain and hoarse voice. Clinical terms include chronic rhinosinusitis and sinusitis.

Lower respiratory symptoms can include cough, chest tightness, wheezing, shortness of breath and asthma symptoms. The presence of upper respiratory symptoms may worsen lower respiratory symptoms.

Gastroesophageal reflux disease (GERD), or a burning feeling in the throat or chest, often accompanies these symptoms (see GERD below).



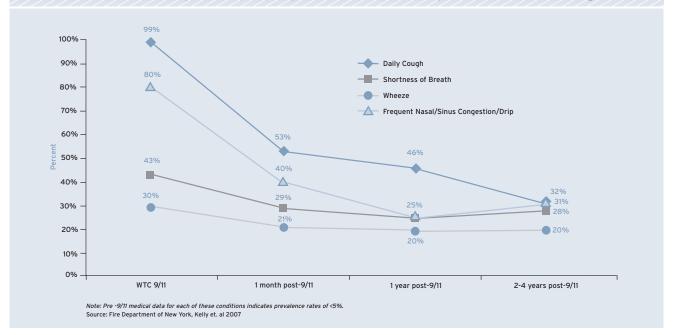
Respiratory Symptoms Among WTC-Exposed Populations



Studies of certain groups exposed to the WTC attacks measured self-reported respiratory symptoms after 9/11. Most of these studies showed high levels of symptoms in the weeks and months that followed, ranging from 99% among firefighters who arrived on the morning of 9/11 to 57% among building survivors. One symptom, coughing, ranged in frequency from 65% among iron workers to 41% among residents and to 31% among New York State personnel.²³⁻²⁵

Among workers, several aspects of their experience at WTC disaster sites are linked to higher levels of respiratory symptoms, such as exposure to the dust cloud, early arrival at the WTC site and longer duration of time spent working at the site. 13, 28-38 Those who actually worked on top of what was known as "the pile" (of debris) at the WTC site had higher reported rates of lower respiratory symptoms.³⁴ Most studies were not able to adequately measure the use of protective respiratory equipment, but three studies indicate that reported use of a respirator reduced the likelihood of developing respiratory symptoms.23, 33, 36

Persistence of Respiratory Symptoms in WTC-Exposed FDNY Firefighters



A study comparing Lower Manhattan residents to a control group living outside the WTC area after 9/11 showed an increase in upper and lower respiratory symptoms. ²⁴ One publication from this study also identified an association between exposure to WTC dust and odors in the home and respiratory symptoms eight to 16 months after 9/11. ²⁷ However, the response rate to this study was low and it did not determine if being caught in the dust cloud on 9/11 had any impact on the link between symptoms and exposure to WTC dust in the home environment. A new clinical study of residents and area workers now underway may help clarify whether or not the presence of WTC dust in homes and offices had any impact on respiratory health.

Treatment of firefighters for WTC cough in the early months after 9/11 was highly effective.²⁸ Subsequent monitoring of NYC firefighters, nearly all of whom reported respiratory symptoms on 9/11, suggests that while these symptoms have decreased and resolved for most, 25% continue to report upper and lower respiratory symptoms two to four years later.³⁹ This is a substantial number for a group that had a prevalence of less than 5% of chronic respiratory conditions prior to 9/11.

Asthma

■ In surveys conducted two to three years after 9/11, rescue and recovery workers, Lower Manhattan residents and area workers all reported levels of new asthma that were two-to-three times higher than national estimates.

Asthma

People with asthma may experience episodes of shortness of breath, chest tightness, wheezing, cough, and/or phlegm. These symptoms can be triggered by upper respiratory infections, seasonal allergies, exercise, irritants or extreme temperature, humidity, or emotional upset. Diagnosis can be difficult and is usually prompted by the symptoms a patient describes to a physician. Often, though not always, asthma can be determined by medical tests.

Asthma most commonly begins in childhood, but may start at any age. Some patients with occupational asthma continue to have symptoms long after their exposure ceases.



Both adults and children exposed to the WTC disaster report higher than expected rates of newly diagnosed asthma. One large survey of 25,748 previously asthma-free rescue and recovery workers enrolled in the WTC Health Registry asked participants if a doctor had newly diagnosed them with asthma during the first two-to-three years after 9/11. Nearly 1,000 of these workers (3.6%) reported a new diagnosis of asthma.36 In this sample, levels of new asthma increased with reported level of exposure to either the 9/11 dust cloud or increased length of time spent working at WTC sites.

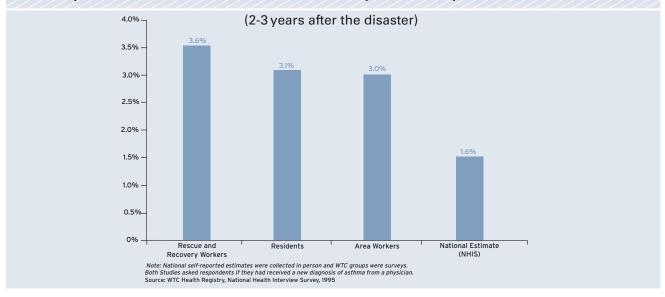
Lower Manhattan residents and area workers enrolled in the WTC Health Registry also reported similar, though slightly lower, levels of newly diagnosed asthma during the same period. 36a Because as many as 28% of WTC Health Registry enrollees can be classified in more than one category (with the most significant overlap occurring among the rescue and recovery worker and area worker categories), it is difficult to draw clear conclusions about what types of WTC exposures may have contributed to these new asthma diagnoses. The reported rates among all three groups, however, are two-to-three times higher than would be expected among the general adult population over the same time period.

Health findings among children also indicate that WTC exposure increased the likelihood of a new asthma diagnosis two to three years after 9/11. Young children whose parents said they had been caught in the dust cloud were twice as likely to have been diagnosed with subsequent asthma as children not caught in the dust cloud. In total, parents of approximately 6% of children under the age of five enrolled in the WTC Health Registry reported that their child had been diagnosed with asthma after 9/11, a rate that may be twice as high as the regional (northeastern) rate for the same age group.36b

These findings all suggest a substantial elevation in the incidence of asthma among populations exposed to the WTC disaster compared to national background rates but two significant limitations must be considered in their interpretation: 1) the data are self reported which is considered less reliable than information gathered from a documented medical examination; and 2) the difficulty in calculating the expected background incidence of asthma.

National estimates of the incidence of new onset, physician-diagnosed asthma vary according to type of study and no NYC-specific data are available for either adults or children. One recent national study, also based on self-reported information, projected an annual rate of 0.52% for new onset asthma among adults. A 2000–2001 study in Massachusetts identified a rate of 0.4% among center city dwellers (in general, asthma prevalence in adults is higher among center-city dwellers than in suburban and rural populations). All 2004 Based on these findings two-to-three year rates of new onset asthma for the general population would range from 0.8%–1.6%, below the 3.0%-3.6% rates reported among adults exposed to the WTC disaster.

Self-Reported New-Onset Asthma in WTC-Exposed Groups and National Estimates



Gastroesophageal Reflux Disease

Gastroesophageal reflux (GERD) symptoms are very prevalent among WTC-exposed populations, especially in conjunction with upper and lower respiratory symptoms, but it is difficult to draw conclusions about the relationship between GERD and WTC exposure because GERD occurs frequently in the general population.

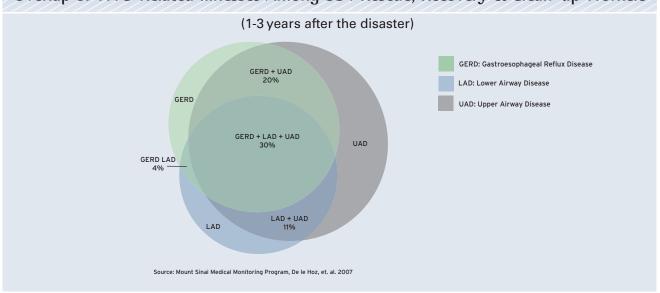
Gastroesophageal Reflux Disease (GERD)

Symptoms of GERD include heartburn, sore throat, regurgitation, chest pain, hoarseness, and/or other digestive symptoms. The causes of GERD and its relationship to respiratory ailments are unclear.



Along with respiratory disease, several studies have found a high prevalence of self-reported gastroesophageal reflux disease, or GERD, among those exposed to the WTC disaster. Among firefighters and other rescue and recovery workers, estimates of GERD range from 87% six months after 9/11 to 58% one to three years later.^{28, 35} A study of collapsed building survivors two to three years after 9/11 indicated that 28% experienced GERD. These symptoms are commonly found in conjunction with upper and/or lower respiratory symptoms, and clinical experts recommend looking for GERD and treating it in conjunction with the respiratory conditions.⁴³ One study of more than 500 rescue and recovery worker patients identified that more than half (53%) of patients had both respiratory and GERD symptoms.35 No study has verified that these levels of GERD are elevated in comparison to other similar groups of workers with no WTC exposure.

Overlap of WTC-Related Illnesses Among 554 Rescue, Recovery & Clean-up Workers



Pulmonary Function Loss

■ For several worker groups, pulmonary function tests have documented decline in lung function or high prevalence of abnormal lung function after 9/11.

Several studies have documented loss of lung function or abnormal lung function among rescue and recovery workers. With the exception of firefighters, however, most workers did not have their lung function measured before and after 9/11, making it difficult to quantify the exact impact of WTC exposure.

In the most comprehensive finding to date, a longitudinal study of more than 12,000 NYC firefighters with pre-9/11 pulmonary function tests (PFTs) on record found an average annual reduction of 372 milliliters—roughly the volume of a 12-ounce soda container—in the first year after 9/11. This annual reduction was 12 times greater than that found over the five years before 9/11 when the average annual loss was 31 milliliters. Despite the increased post-9/11 reduction, PFT measurements remained normal—within the three-to-four liter range—for most of these workers.

Other studies could not test loss of lung function but instead examined how many participants had abnormal lung function in comparison to persons of similar age, gender and height. In all these studies, spirometric values were within normal parameters for the majority of participants, but significant abnormality in lung function was identified in some. National studies suggest that approximately 13% of never-smoking men have abnormal lung function.

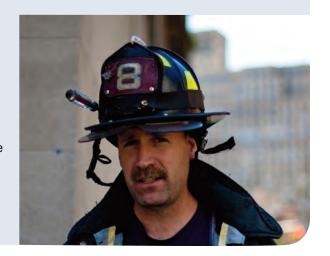
In a Mount Sinai study of nearly 9,500 responders who sought monitoring and treatment 28% had abnormal spirometry.³⁸ In a 2002–2003 study of New York State personnel who responded to the WTC collapse, 14% had abnormal PFT results.²⁵ In a clinical sample of the first 1,575 residents, area workers and others treated at the WTC Environmental Health Center of Excellence, almost 20% had a reduced lung volume and 18% had reduced airflow.⁴⁴ It is unknown whether these individuals will regain lost lung function, plateau, or continue to deteriorate. Although important to help characterize and diagnose respiratory symptoms, spirometry does not detect all aspects of lung function. Additional studies may help further describe the respiratory symptoms in exposed populations.⁴⁵

Measuring Pulmonary Function Loss

Pulmonary function tests (PFTs), such as spirometry, are screening tools that assess whether lung function is normal in comparison to persons of similar age, gender and height. Spirometry measures both the amount of air that a person breathes out, as well as the force of exhalation.

PFT results alone are not used to diagnose disease, although abnormal PFTs generally indicate lower respiratory problems. But because they are not especially sensitive, PFT results may be normal even in the presence of respiratory symptoms. A physical examination which includes an assessment of how well a patient functions, in conjunction with PFT results, is a more reliable overall indicator of a patient's respiratory health.

Nevertheless, PFTs offer an objective and quantitative way to determine the severity and impact of WTC exposure on the respiratory system over time. PFT use in longitudinal monitoring can help determine the stability or progression of respiratory disease.



Sarcoidosis

■ Compared to pre-9/11 levels, new diagnoses of sarcoidosis or sarcoid-like lung disease were elevated among NYC firefighters in the first year after the disaster. Since then, rates have slowly subsided to pre-9/11 levels.

Sarcoidosis: Description & Causes

In patients with sarcoidosis, inflammatory lesions appear in one or more organs, most commonly the lungs, bronchi, or thoracic lymph nodes (these are known as granulomas).46 The exact cause of sarcoidosis is unknown, but it has been linked to environmental exposures, including wood burning stoves and inorganic particles.

The severity of sarcoidosis varies and it often resolves on its own. Many people with the illness have no symptoms and are diagnosed only through screening chest radiographs. Less commonly, others are symptomatic with progressive involvement of the lungs leading to fibrosis.

Sarcoidosis mainly affects people between 20 and 40 years of age, with African-Americans three times more likely to develop the condition than Caucasians, and women twice as likely to develop it as men.



Before 9/11, one study showed a slightly higher than expected number of sarcoid cases among NYC firefighters, suggesting that firefighting posed some increased risk for the disease.⁴⁷ After 9/11, another study documented 13 cases of new-onset sarcoidosis or sarcoid-like diseases among NYC firefighters, an increase roughly six times higher than pre-9/11 levels. 46 The rate subsequently declined to near-baseline levels, with 13 additional cases identified over the next four years.

Studies of a possible 9/11 connection to sarcoidosis are difficult to interpret, because the frequently asymptomatic nature of the condition means that the increased use of chest radiographs after 9/11 may have identified cases that normally would have been undetected.

Nonetheless, it seems likely that exposure to WTC dust led to the development of a small number of sarcoidosis cases.

Birth Outcomes, Cardiovascular Disease, Late-Emerging Diseases, Cancer and Overall Mortality

- A small number of studies on women pregnant on 9/11 have suggested that exposure to the disaster may have impacted birth outcomes, such as increased risk of lower birth weight or shorter length at delivery. These impacts were small in magnitude and of unclear clinical significance. No studies to date have identified subsequent clinical implications, such as developmental delays.
- One national study of individuals who were not in physical proximity to the 9/11 attacks showed an association between increased risk for new onset hypertension and heart problems among those who experienced acute stress as a result of the attacks.
- Studies have been initiated to examine the possibility of WTC-related cancers and to measure overall patterns of mortality among people with exposure to the WTC collapse, but results are not yet available. These and other late-emerging effects are not expected to be clearly evident for at least a decade after exposure. A small number of other health conditions are also now being studied.

Birth Outcomes

A limited number of studies have examined whether physical exposure to the environmental impacts of 9/11 during pregnancy affected birth outcomes. In each, small detrimental effects were identified, but the clinical relevance of such findings regarding impact on a child's health or neurocognitive development remains unclear. In one study, women delivering at certain NYC hospitals were surveyed about their exposure to 9/11, and women with 9/11 exposures were compared to those without. Among newborns of exposed women, higher levels of intrauterine growth restriction (poor growth of a fetus) were observed.⁴⁸ In another study, babies born to women residing within a two-mile radius of the WTC site had lower birth weight and birth length than those in a comparison group.⁴⁹

A more recently published study examined the impact of stress from 9/11 on birth outcomes. NYC babies born the week of 9/11 were compared to those born in the same week during previous years; babies born immediately after 9/11 were more likely to be low birth weight. In the same study, the authors also found there were more low birth weight babies in NYC and throughout the state around January 2002 and 33–36 weeks after the disaster, suggesting that mental stress experienced at different times during pregnancy may impact birth outcomes.⁵⁰ Finally, another study found that babies born to mothers with WTC-related PTSD had lower levels of cortisol, a hormone involved in the body's reaction to stress, than babies born to healthy mothers.⁵¹

Cardiovascular Disease

Few studies have examined the impact of 9/11 on cardiovascular disease. In one national prospective study, researchers found a higher rate of physician-diagnosed cardiovascular ailments among individuals who reported high levels of posttraumatic stress symptoms compared to those with lower levels during the three years following the 9/11 attacks.⁵² Another study examined hospital billing records and found an increase in acute heart attacks among patients to New Jersey area emergency department patients in the six months after 9/11 compared to the six months before.⁵³

Late-Emerging Diseases

Clinicians are carefully monitoring WTC-exposed populations for cancer and other late-emerging diseases. Instances of rare lung diseases such as pulmonary fibrosis, which inflames and scars the lungs, and which can be related to different kinds of occupational exposures, are being investigated among rescue and recovery workers. Myositis, an autoimmune disease that affects skeletal muscles, is also being investigated. Because no pathologic markers for WTC disease have been found, long-term population surveillance among exposed groups and clinical studies at the WTC treatment Centers of Excellence will be necessary to determine if a causal link between WTC exposure and these conditions exists.

Cancer

No studies have been published with information on whether rates of cancer or death are elevated among WTC-exposed populations compared to expected background levels, but a number of large studies are currently underway.

To date, there is no evidence for or against a causal connection between WTC exposure and any form of cancer. Literature suggests that most cancers, including lung cancer and mesothelioma (both of which can be caused by inhaling asbestos) have latency periods of more than ten years. Such a connection is likely to be identified sooner with hematological cancers, in particular leukemia or multiple myeloma, than with many solid tumor malignancies because these conditions are more easily detected through routine blood tests, and their latency periods may be shorter. Hematological malignancies have been associated with environmental exposures such as benzene, a product found in jet fuel and present at the WTC site.

It is important to note that the occurrence of blood cancers (or other serious conditions) already seen by some clinicians among rescue, recovery and clean up workers with WTC exposure is not definitive evidence that WTC exposure caused these conditions. Every year a certain percentage of the population will develop a condition such as a blood cancer. Based on the latest information available from the New York State Cancer Registry, from 1994 through 2004, there was a yearly average of 289 leukemia cases in New York City among adults from the ages of 25 to 64 (an age range comparable to that for rescue and recovery workers), and an average of 183 multiple myeloma cases.

However, the observation of blood cancer cases among some rescue, recovery and clean-up workers increases the urgency of cancer surveillance now being conducted by the WTC Health Registry (the largest representative sample of people with WTC exposure) and the WTC treatment Centers of Excellence (FDNY and the New York/New Jersey WTC Clinical Consortium). Because cancer diagnoses are reportable by law in most states, researchers are matching enrollee names against state cancer registries in states where large numbers of enrollees currently reside. This will help them verify these diagnoses and compare cancer rates in the WTC-exposed population against a background or expected rate among people of the same gender and age group. If higher than background rates of specific cancers are detected in a WTC-exposed population, the WTC treatment Centers of Excellence will add cancer screening and treatment to existing program protocols.

Overall Mortality

The media has reported the deaths of at least ten people—primarily first responders—who were directly exposed to the WTC collapse and presumed by some to die of WTC-related causes. Determining the precise relationship between the death of any single individual and WTC exposure is difficult. Pre-existing conditions, the effect of subsequent exposures and other factors complicate determination of causality. Complexities in analyzing individual cases emphasize the importance of epidemiologic studies.

The <u>WTC</u> Responders Fatality Investigation program at the New York State Department of Health has identified more than 360 fatalities among responders and volunteers. Information is being collected on cause of death from death certificates, medical records and autopsies. This information will be compared with expected death rates to determine if mortality is elevated within this population.

Another study currently underway at the WTC Health Registry will compare overall mortality rates among people who were exposed to the WTC collapse to rates among similar demographic and occupational groups, as well as to the population as a whole. These different efforts will help determine if the death rate is higher than what would be considered typical if the WTC attack had never occurred.

HOW NEW YORK CITY IS MEETING CURRENT NEEDS

In 2006, Mayor Bloomberg appointed a special panel of City agency leaders to recommend a course of action to support 9/11 health needs. After a thorough examination of relevant issues, including extensive interviews with service providers, labor unions and community groups, among others, the panel released *Addressing the Health Impacts of 9/11*, a comprehensive strategy to ensure that New York City could "take care of its own."

The report noted that private funding for many WTC-related health services was coming to an end and that the federal commitment to fund monitoring and medical treatment for workers through programs at the Fire Department of New York and the New York/New Jersey WTC Clinical Consortium remained uncertain. It also found that services for Lower Manhattan residents and area workers (including commuters living outside of New York City) exposed to the WTC disaster were limited to a small, privately funded clinic at Bellevue Hospital.

The report asserted that the federal government had a moral and ethical responsibility to fund 9/11 health services because the terrorist attack on the WorldTrade Center was an attack on the nation, and that the City should advocate vigorously for this funding. It also called for the City to help ensure medical care for everyone experiencing WTC-related health problems. The Mayor agreed to implement the report's 15 recommendations, and pledged a financial commitment of nearly \$100 million to do so.

As a result, in 2008, WTC-related mental and physical health treatment and medication are accessible to more New Yorkers than ever before. In addition, information about the latest scientific research and services are widely available to anyone with an interest in 9/11 health. The Mayor's 9/11 initiatives include:

- Expanding HHC's World Trade Center Environmental Health Center, which began as an asthma clinic at Bellevue Hospital, by adding locations in Lower Manhattan and Queens. Nearly 2,700 adults and children who were exposed to the WTC disaster have been treated, most of whom were able to receive health care from physicians with specific knowledge of 9/11-related health conditions for the first time.
- Launching the NYC 9/11 Benefit Program for Mental Health & Substance Use Services which began enrolling residents of all five boroughs in April 2008. The program provides coverage of mental health services and will ensure continuity of services for thousands of New Yorkers directly affected by the attack on the WTC whose financial assistance had ended under a similar, privately funded program.
- Distributing <u>Clinical Guidelines for Adults Exposed to the World Trade Center Disaster</u> released in 2006 by the NYC Department of Health and Mental Hygiene. Written and recently revised in collaboration with WTC medical experts, including representatives from the three WTC treatment Centers of Excellence, these guidelines are among the few resources that can assist in diagnosing and treating people who were exposed to the WTC disaster no matter where they live now.
- <u>Launching a "one-stop shopping" website</u> so that all affected groups, including City employees, can guickly find the latest information about services and scientific research.

Today, more federal dollars for WTC-related treatment are available than when the Mayoral panel released *Addressing the Health Impacts of 9/11* eighteen months ago. Due to the efforts of the New York Congressional delegation, vigorous lobbying by the City and strong support from organized labor, Congress appropriated \$108 million for the 2008 fiscal year including dollars earmarked to treat residents, area workers and students for the first time. At the time this report went to print, the Centers for Disease Control announced that it expected to award up to \$30 million over the next three years to provide access to health screenings, diagnostic services and treatment for residents, students and other "non-emergency responders" whose health may have been adversely affected by the WTC attacks.

The WTC Medical Working Group believes that sustaining 9/11 health programs and research is vital. While existing programs appear to be meeting current needs in the New York City area, treatment and research cannot be sustained over the long-term without a sustained commitment from the federal government. The <u>James Zadroga 9/11 Health and Compensation Act (H.R. 6594)</u> would fulfill such a commitment by establishing a long-term funding stream for 9/11 health care and research.

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