Good morning and thank you for including me in the session this morning on Emergency Response Issues.

Given the caliber of the three speakers for this session, I know that you will hear some excellent presentations. Since I am not an expert in emergency response issues, what I thought I would do is to share with you some of my thoughts after coordinating the Department of Health and Human Services’ World Trade Center Health Programs.

The WTC disaster triggered a massive emergency response involving thousands of early-arriving responders and volunteers—both previously trained volunteers and “spontaneous” or “unaffiliated” volunteers. Many of these responders escaped from, or witnessed the collapse of, the WTC Twin Towers. Thousands of later-arriving responders and volunteers engaged in search and rescue activities to free those who were trapped in the rubble of the collapsed towers.

Over the ensuing days and months, many more thousands of responders and volunteers from all over the United States worked tirelessly in activities involving the recovery, cleanup and restoration of the WTC site itself and the streets, residences and commercial buildings in Lower Manhattan; the transport of debris to barge stations located along the west side of Lower Manhattan; the receipt and handling of debris at the Staten Island Landfill; and the forensic examination of human remains at the New York City Medical Examiners Office. From the time of the collapse until the last fire at the WTC site was extinguished on December 20, 2001, responders—and others in the nearby residential and commercial building communities, as well as passersby—were exposed to debris, dust and smoke composed of several different types of hazardous substances.

The exposure environment consisted of significant concentrations of many
agents known to be toxic on their own, but also to mixed concentrations of multiple toxic agents whose effects in combination are relatively unknown. During the early hours and days of the WTC disaster, responders and other exposed populations in Lower Manhattan had less than optimal respiratory protection. Even during the subsequent months of the clean up and recovery, adequate respiratory protection was often difficult to achieve in practice.

**World Trade Center Responders**

Although the exact number of individuals who comprise the responder group is unknown, one estimate of how many workers and volunteers may have been involved in the WTC response is 91,469 individuals. However, I believe that, based on the enrollment history of the WTC Medical Monitoring and Treatment Program over the past six years, the total number of workers and volunteers who are likely to seek medical monitoring services is closer to 65,000 than to 90,000.

As of December 31, 2007, 50,300 responders have enrolled in the WTC Medical Monitoring and Treatment Program and are currently being contacted and scheduled for an initial screening examination and a total of about 39,348 responders have had an initial medical screening examination and/or a follow-up monitoring examination by either the New York City Fire Department (FDNY)(14,620) or through a consortium of NYC-NY Metropolitan Area clinics coordinated by the Mt. Sinai School of Medicine’s Center for Occupational and Environmental Medicine (22,728).

Of the 39,348 responders in the WTC Medical Monitoring and Treatment Program that have received an initial screening via a clinical center in the New York City-New Jersey Metropolitan Area, 9,744 have received treatment for a combination of respiratory and gastrointestinal system conditions, such as sinusitis, laryngitis, chronic cough, asthma, interstitial lung disease and gastroesophageal reflux disease, and 5,674 have been treated for mental health conditions such as persistent post-traumatic stress disorder. The availability of treatment for both physical and mental WTC-related health conditions announced in late 2006 has encouraged more responders to enroll and continue participating in the WTC Medical Monitoring and Treatment Program, which will enable HHS to better understand and help treat the long-term effects of their WTC exposures.

Among the total number of WTC responders and volunteers are those who came to New York City from across the United States to serve in the response effort. After their response work was completed, these “national responders” returned to

---

their place of residence. The exact number of national responders is also unknown, but is estimated to be between 5,000 and 10,000. As of February 2008, 3,993 responders residing outside the NYC-NJ Metropolitan Area have enrolled in either the Federal workers program (1,915) or the WTC Medical Monitoring and Treatment Program (2,078).

Based what we know about the health effects from exposure to single WTC toxins agents such as asbestos, and the clinical findings to date, it is likely that the most significantly exposed members of the WTC responder groups, and similarly exposed members of the community groups, may present with additional health conditions later in life.

**Resources**

Agencies within HHS have received funding for what you might call post-emergency response medical surveillance in a rather piecemeal and uncoordinated way.

In 2002, $12 million was appropriated for one-time medical screening of WTC responders. In 2003, Congress directed $90 million appropriated to FEMA as part of the Emergency Response Fund to be reserved for “clinical reexaminations and long term health monitoring and analysis for emergency services personnel and rescue and recovery personnel.”

Finally, in FY 2006, Congress appropriated $75 million for treatment of responders. During the interim four years, many responders had sought care at charitable funded clinics, and at alternative medicine spas and scientology centers.

In FY 2007, in the U.S. Troop Readiness, Veterans’ Health, Katrina Relief and Iraq Accountability Appropriations Act, 2007, Congress appropriated an additional $50 million for screening, monitoring, and medical treatment for responders.

In 2008, Congress appropriated $109 million “to provide screening and treatment for first response emergency services personnel, residents, students, and others related to the September 11, 2001 terrorist attacks on the World Trade Center.” The FY08 provision of funds is the first time resources had been provided for the community members of the World Trade Center affected populations. Yet, despite what appears to be appropriations totaling nearly a quarter of a billion dollars, the absence of dedicated, multi-year funding has made institutional commitment hard to achieve and has exacerbated the worries of ill responders that care will not be long-lasting.
Last week, Senator Clinton introduced an amendment to the FY09 budget bill making its way through the Senate that would provide, for the first time, a deficit-neutral reserve fund for multi-year funding for WTC Health Programs.

World Trade Center Affected Community Members

Funding for community medical surveillance in 2008 provides us with an opportunity to assess the effect of the WTC disaster on groups other than responders.

The exact number of individuals who comprise the community group is also unknown, but one estimate includes 57,511 individuals whose primary residence was south of Canal Street on September 11, 2001, 15,197 students and staff of nursery/daycare, elementary, middle or high schools located south of Canal Street, and 62,092 worker occupants of collapse and damaged buildings for a total of 134,800. Additional building occupants from contaminated but undamaged buildings using 14th Street from river to river may bring the total number of members of the community group closer to 300,000. I believe that even though the estimated number of affected community members may range up to 300,000, the proportion who received exposures likely to cause adverse health effects is expected to be considerably less.

Lower Manhattan is home to many thousands of residents. People living in public housing, apartments, co-operatives and condominiums near the WTC site experienced an acute and intense indoor exposure to dust on September 11, 2001. For several months afterwards, they experienced persistent exposure to dust re-suspended by recovery operations and the activities of daily living, as well as exposure to smoke from the fires at Ground Zero. Dust and smoke gained entrance to residences through windows, building cracks, and ventilation systems. Their past exposures, and their belief in continued, low-level exposures, has been a difficult environmental issue for both residents and the government to deal with.

Soon after September 11, 2001, researchers at Bellevue Hospital, the New York University School of Medicine, and the New York State Department of Health initiated surveys to determine if there was an increase in the rate of new respiratory symptoms in Lower Manhattan residents. Within 8 to 16 months after September 11, 2001, residents within one mile of Ground Zero were surveyed about whether they had any new onset respiratory symptoms. The analysis of

---


nearly 3,000 residents of Lower Manhattan revealed that 55.8 percent (compared to 20.1 percent among residents living five miles away from Ground Zero in Manhattan) reported new onset respiratory symptoms, such as cough, wheezing, or shortness of breath at any time following September 11, 2001. These respiratory symptoms resulted in an almost two-fold increase in unplanned medical visits and use of asthma medication in persons living near Ground Zero compared with others. The study also addressed whether these symptoms were resolved right after the WTC attacks or if they persisted by asking whether symptoms were still present in the month immediately preceding completion of the survey (8 to 16 months after September 11th) with a frequency of at least twice per week. Newly onset lower respiratory symptoms were present in 27 percent of exposed residents versus 8 percent of controls—a threefold increase in persistent respiratory symptoms.

In addition to these early self-reports of symptoms in a non-responder population, there is also clinical evidence of illness in residents and others. The WTC Environmental Health Center at Bellevue Hospital has medically examined over 1,000 residents, commercial building occupants, and cleanup workers. Although many of these residents and workers were apparently healthy before the WTC exposure, the WTC Environmental Health Center at Bellevue has noted that many of the same patients now manifest persistent, difficult-to-treat, respiratory conditions, such as reactive airways disease and asthma, while “others have a process in their lungs that we do not fully understand and may consist of a granulomatous disease of the lung like sarcoid, or fibrosis, which is scarring in the lungs.” These survey and clinical findings in residents are remarkably consistent with the findings seen in studies of firefighters and other rescue, recovery, and cleanup responders.

WTC Health Registry

Another source of information about the health effects seen in responder and community groups is the World Trade Center Health Registry, located in the New York City Department of Health and Mental Hygiene, which was established to identify and track the long-term health effects of tens of thousands of responders, residents, school children and Lower Manhattan workers, who were the most directly exposed to smoke, dust, and debris resulting from the WTC collapse.

WTC Health Registry registrants will be interviewed periodically (over a period of 20 years or more) through the use of a comprehensive and confidential health survey to assess their physical and mental health. At the conclusion of baseline

---

4 Interview with Joan Reibman, M.D., Medical Director, Bellevue/New York University School of Medicine World Trade Center Health Center, New York, N.Y. (February 4, 2007).

data collection in November 2004, 71,437 interviews had been completed, establishing the WTC Health Registry as the largest health registry of its kind in the United States.

The findings reported in early symptom surveys of Lower Manhattan residents performed within 16 months of the WTC attacks were corroborated by the initial WTC Health Registry’s survey of nearly 9,000 survivors of collapsed or damaged buildings done 24 to 36 months after the attacks. These baseline survey findings, published in 2006, concluded that “two or three years after September 11th, survivors of buildings that collapsed or that were damaged as a result of the WTC attacks reported substantial physical and mental health problems” and recommended that long term follow-up of residents, building occupants, and others enrolled in the Registry should be maintained, particularly those persons most exposed to the dust cloud.

In 2007, the Registry launched a second or follow up survey of enrollees to determine whether respiratory and mental health symptoms still persist five to six years following the WTC collapse.7

**Lessons Learned from the World Trade Center Response**

In December 2001, NIOSH convened a conference to explore lessons about preserving the safety and health of emergency responders in the context of terrorist attacks, organized and led by the RAND Science and Technology Policy Institute in New York City.

This conference and three subsequent NIOSH evaluations of response efforts to large-scale disasters concluded that there is a critical need for:

- Accessibility to protective and practical personal protective equipment (PPE) and hazard monitoring technologies;
- Interagency training to aid in the effective implementation of health and safety measures and PPE enforcement;
- Quick and effective establishment of a command authority over the disaster site and perimeter control; and
- Rigorous tracking of responders.

---


Each of these four reports is available on the NIOSH website.

In addition to the NIOSH reports, the most important lesson I have learned from the World Trade Center health disaster aftermath is that when structuring emergency preparedness and response, it is critical to ensure that responder safety and health is treated with as much importance as victim rescue and site recovery.

If you fail to achieve parity between victims and responders, you create the “after-disaster.” It is the World Trade Center after-disaster that I spend quite a bit of my time responding to.

An equivalent proportionality between victim and responder needs to be built into our national response culture. I base this lesson on the evidence that I have seen of continuing health issues for World Trade Center responders, volunteers, and the nearby community of residents and other building occupants.

The World Trade Center Health Programs are generating a body of knowledge that indicates the importance of ensuring the safety and health of disaster responders before they are deployed, while they are deployed and after deployment.

**Before** deployment, as we all recognize, it is critical to provide pre-event training about likely hazards and hands-on instruction in the use of personal protective equipment. Adequate preparation is especially important for “spontaneous” or “unaffiliated” responders who volunteer their services during an emergency. As seen in the wake of the WTC response, these responders are often more adversely affected by their exposure, possibly due to a lack of health and safety training. Interviews conducted two to three years following the WTC attacks show that the overall prevalence of PTSD among WTC responders was 12.4 percent with the greatest risk of developing PTSD found in those responders who were not professional rescue personnel, e.g., construction and sanitation workers and unaffiliated volunteers.8

**While** responders are deployed, it is critical:

(1) To compile a list of responders and their individual disaster-site exposure profile;

(2) To reinforce training with on-scene instruction (especially for spontaneous or unaffiliated responders who volunteer their services);

---

(3) To establish an integrated safety management structure among all responding agencies, not just consensus-achieving meetings of like-minded responders;

(4) To set up tight disaster site perimeter control;

(5) To rigorously track responder entry and exit from the site;

(6) To conduct real-time, area and personal exposure assessment and hazard control; and

**Note:** During the deployment stage, when responders are actively engaged in the response effort, it is critical to track responders’ access to the disaster site and conduct real-time exposure assessment. Knowing where responders have gone, and their exposures, will enable us to more accurately assess post-disaster health effects and determine their post-deployment needs. The absence of this knowledge for World Trade Center responders will hamper any longitudinal study looking for causal factors for the burden of disease now being seen in many responders and further social benefits.

(7) To monitor responders—especially those engaged in long-response operations—for signs that their mental health resiliency is waning.

**After** deployment, it is critical to screen responders for physical and emotional health effects based on during-deployment, area and personal exposure assessment findings or the occurrence of symptoms. Positive findings should then lead to long term monitoring and treatment, as necessary.

An important policy step in ensuring the highest level of professionalism during large-scale national disaster response would be for the Worker Safety and Health Annex to be elevated to an Emergency Support Function within the National Response Plan, so that OSHA (with NIOSH technical support), not FEMA, would determine when the Annex would be activated, and that the operational objectives of excellence in responder safety and health could be achieved in parallel with excellence in victim rescue and recovery. OSHA and NIOSH made an attempt at accomplishing that important policy change this year but failed. Nevertheless, it is the right thing to do, whether or not FEMA—with its own investment in safety and health cadres—thinks it so.

Thank you for your attention.