

A nighttime photograph of a city skyline, likely New York City, viewed from a rooftop. In the foreground, several rooftop HVAC units and pipes are visible. In the middle ground, a large, multi-story building with many lit windows stands out. In the background, the city skyline is visible, with two bright, vertical light beams rising from the ground, representing the 9/11 Memorial. The sky is dark with some clouds.

# ***WE COUNT!***

Documenting the 9/11 Health Crisis 8 Years Later



**9/11 ENVIRONMENTAL ACTION**

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**9/11 *ENVIRONMENTAL ACTION***

[www.911ea.org](http://www.911ea.org)



[www.beyondgroundzero.org](http://www.beyondgroundzero.org)

**BGZ GROUPS INCLUDE:**

**Commission on the Public Health's System**

**National Mobilization Against Sweatshops**

**Chinese Staff and Workers' Association**

**Community Development Project of the Urban Justice Center**

**Asian American Legal Defense and Education Fund**

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**September 2009**

# I. INTRODUCTION

The collapse of the twin towers on September 11, 2001 sent more than 1.2 million tons of hazardous contaminants and toxins into lower Manhattan and western Brooklyn, penetrating buildings and setting off massive fires that would pollute the area for months.<sup>1</sup> Eight years after the World Trade Center (“WTC”) disaster, tens of thousands of workers, residents, and students in the New York metropolitan area continue to suffer profound health consequences. *WE COUNT!*, a 9/11 community health survey, aims to document the myriad impacts of 9/11 toxic air and dust on local communities.

Despite the progress that has been made in the fight for 9/11 health, the *WE COUNT!* survey indicates that many residents, workers, WTC first-responders, and children are chronically ill. Survey responses demonstrate the need for the federal government, in collaboration with the medical community, to further research 9/11 health conditions and for those suffering from 9/11-related health problems to better understand the effects of the toxins on their bodies. Residents and workers have also voiced their need for innovative, quality treatment and ongoing medical monitoring.

The *WE COUNT!* survey is a joint project by the Beyond Ground Zero network (“BGZ”) and 9/11 Environmental Action (“9/11 EA”). This survey represents a community effort to investigate the extent and scope of the 9/11 health crisis in the absence of an adequate government response. In sharing these survey results at a time when Congress and President Obama are considering both national healthcare reform and 9/11 health legislation, BGZ and 9/11 EA call on the federal government to formulate a just and comprehensive long-term response to this ongoing public health disaster.

## **Beyond Ground Zero and 9/11 Environmental Action**

BGZ is a coalition of community-based organizations that came together shortly after September 11, 2001 to address the severe health and economic impacts of the WTC’s collapse on the low-income and immigrant communities in New York City, particularly the Lower East Side and Chinatown.<sup>2</sup> The member groups of BGZ are the Asian American Legal Defense and Education Fund, Chinese Staff and Workers’ Association, Commission on the Public’s Health System, National Mobilization Against Sweatshops, and the Community Development Project of the Urban Justice Center. BGZ has organized thousands of residents and workers to fight for relief benefits, health insurance, and quality treatment for their 9/11-related health problems. Thanks to the organizing and advocacy of affected workers and residents organizing through BGZ, an early form of the World Trade Center Environmental Health Center (“WTC EHC”) began serving 9/11-affected patients free of charge.<sup>3</sup> Years later, BGZ still represents many residents and workers who are patients in the WTC EHC. These community members continue to experience evolving 9/11-related health problems—which began with respiratory, mental health, gastrointestinal, and dermatological problems, and have now expanded to cardiac, skin, eye, and gynecological problems, as well as cancers.

9/11 EA is a community-based organization of downtown residents, school parents, and occupational-safety and environmental-health advocates that formed in April 2002 to end the federal Environmental Protection Agency’s (“EPA”) cover-up of the toxic substances released in the WTC disaster. For the past seven and a half years, 9/11 EA has fought for comprehensive clean-up of WTC contamination by the federal EPA and for federally funded medical monitoring and healthcare for everyone harmed by exposure to WTC smoke and dust.

## **Why *WE COUNT!***

To date, government and academic studies have failed to document the extent and scope of 9/11-related health problems affecting those excluded from the WTC Health Registry (see below). While many 9/11 health studies have been conducted,<sup>4</sup> the vast majority address the health impacts on first-responders. The relatively few studies of residents, area workers, and students have examined only a limited cohort of those affected. In addition, research has focused exclusively on well-established WTC respiratory, gastrointestinal, and mental health impacts, ignoring a host of other health problems that may be 9/11-related. After years of organizing and advocacy, workers and residents are currently able to receive quality, expert treatment at the WTC EHC sites in the Bellevue, Gouverneur, and Elmhurst hospitals, but this treatment is not enough. Patients face increasingly complex and debilitating health problems that have already left a growing number of them unable to work, and neither existing health clinics nor the New York State Workers’ Compensation are fully responsive to these concerns. If, at this crucial time of congressional debate over health legislation, 9/11-affected workers and residents do not renew their call for long-term health care, monitoring, compensation, and support services, the federal government will continue to downplay their 9/11-related health and economic needs.



## II. BACKGROUND

### Failures of the 9/11 Response

When the WTC towers collapsed, the local, state, and federal governments failed to warn or protect New Yorkers from the overwhelming environmental threat to public health. Top federal officials, including former EPA Administrator Christine Todd Whitman, and Mayor Giuliani encouraged the return of hundreds of thousands of workers, residents, and students to lower Manhattan without first ensuring that the air was safe to breathe.<sup>5</sup>

In 2003, the New York City and federal governments jointly established a “health registry” in the face of community outrage at the governments’ failure to clean up lower Manhattan or to track and treat those who became sick. When the registry was announced, residents and workers demanded the inclusion of everyone exposed to the environmental disaster in order to document the nature and scope of 9/11-related health impacts and unmet needs. However, as discussed below, the resultant New York City WTC Health Registry effectively minimized the 9/11 health crisis by excluding many affected workers and residents from its purview.

### WTC Health Registry and Limited Geographic Boundaries

The New York City Department of Health’s WTC Health Registry began with a large-scale telephone and mail survey that purported to identify and gather information about 9/11-related exposures and long-term mental and physical health effects.<sup>6</sup> Due to geographic and other restrictive eligibility criteria, however, the program has excluded many people whose health was greatly diminished by the disaster. The information gathered is therefore inadequate and presents a myopic view of the range and scope of health impacts.

The WTC Health Registry arbitrarily set Canal Street as its northern boundary, cutting out significant segments of the affected population.<sup>7</sup> This continues to define the eligibility area, notwithstanding studies showing that many residents north of this boundary line were also affected by 9/11 toxic dust and air.<sup>8</sup> Historically, residents and workers, especially community members of the Lower East Side and Chinatown, have been underserved or excluded from 9/11 relief programs, clean-up programs, and federally funded treatment, and the Health Registry has been no exception. In addition, the Registry restricts eligibility for office workers, accepting only those who were south of Chambers Street on 9/11. The Registry’s future longitudinal research will continue to exclude the experiences and health impacts of many people living and working in Chinatown and on the Lower East Side. *WE COUNT!*, therefore, demonstrates a community-based, symbolic rejoinder to the Registry’s neglect.

### World Trade Center Environmental Health Center

The WTC EHC, the only government-funded treatment and study program available to residents, students, and area workers (non first-responders), was won through community organizing and advocacy. Notably, the WTC EHC utilizes 14th Street as its northern eligibility boundary and serves residents throughout the New York City metropolitan area, as many residents and workers have moved out of lower Manhattan since 9/11. Had workers and residents not organized to demand such a program, the current federal legislation (see below) would not include a “community program.” Even in its current form, this legislation reflects a too-narrow view of the “community” patient population. Thus, the future of the only 9/11 health treatment and study program for workers and residents is far from secure.

### Federal 9/11 Health Legislation

After years of fighting for federal recognition, workers and residents have succeeded in pushing Congress to propose legislation that could fund a 9/11 community health program. Companion versions of the “James Zadroga 9/11 Health and Compensation Act” (HR 847 and SR 1334) are currently being debated in the House and Senate.<sup>9</sup> Significant components of these bills include:<sup>10</sup>

- Establishing the World Trade Center Health Program:
  - a medical monitoring and treatment program for WTC responders and
  - a medical monitoring, screening and treatment program for the community (area workers, students, and residents);
- Providing funding for research into 9/11-related conditions;
- Supporting New York City Department of Health and Mental Hygiene programs; and
- Reopening the September 11th Victim Compensation Fund (“VCF”) to again provide financial compensation to family members of deceased victims as well as to injured persons meeting certain criteria.<sup>11</sup>

As discussed later in this report, although these bills represent a significant step forward, they omit certain segments of the affected population and do not guarantee that all 9/11-related illnesses will be covered, which ultimately excludes people from obtaining needed healthcare. New York City's police union, the Patrolman's Benevolent Association, has similarly observed that the bill "has many flaws, the most serious being its failure to include cancer and blood disorders as qualifying medical conditions entitling the victim to treatment and compensation."<sup>12</sup>

In August 2009, Mount Sinai-based clinical researchers reported higher than expected cases of a bone marrow cancer, multiple myeloma, in WTC first-responders, with an unusual number of cases in police officers under 45 years of age. An additional eight cases in WTC first-responders are in the process of being verified. Researchers point to dust samples taken from lower Manhattan as confirming that "the air contained many known carcinogens," and caution that exposures to combinations of the toxic substances released as a result of the disaster may have "new and unexpected health effects," including altered disease patterns.<sup>13</sup>

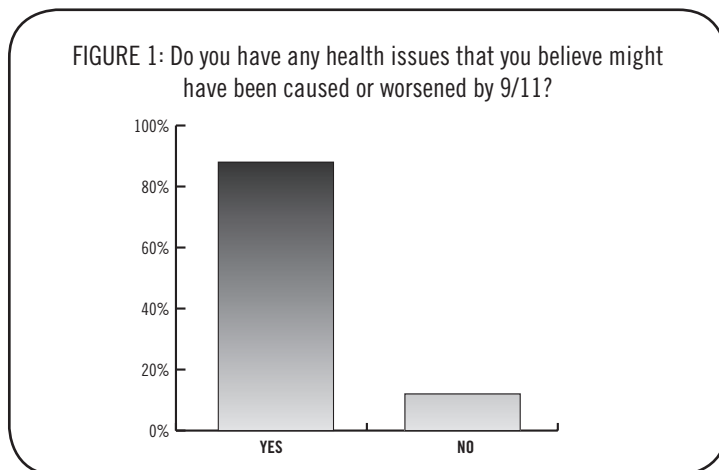
### III. METHODOLOGY

Over approximately 18 months, BGZ's and 9/11 EA's used the *WE COUNT!* survey to conduct outreach to residents, workers, and students in various locations across New York City, but with a focus on lower Manhattan. The survey was designed to capture a snapshot of some of the health and economic problems faced by workers, residents, WTC first-responders, and children exposed to 9/11 toxins. The findings confirm and build upon BGZ and 9/11 EA's collective knowledge of the staggering health impact of the 9/11 environmental disaster and echo the medical literature. In total, 211 surveys were completed and form the basis of the analysis in this report. Unless a subset of the respondent pool is specified, the statistics and percentages below reflect responses to each question by the total surveyed pool of 211 people. BGZ continues to collect additional surveys and will conduct ongoing monitoring of the health and economic impacts of 9/11 on affected communities.

## IV. FINDINGS

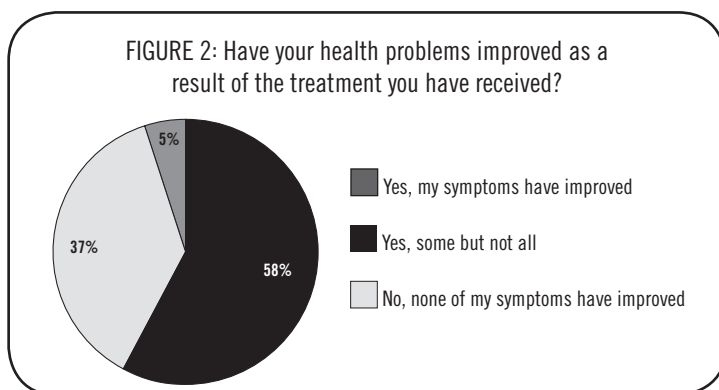
### 1. The health of many workers and residents suffering from 9/11-related health problems is not improving.

Diverse 9/11-related health problems continue to devastate the health of affected workers and residents. Of those surveyed:



- **88%** state their health symptoms may have been caused or worsened by 9/11.
- **81%** with 9/11-related symptoms have seen a doctor concerning their symptoms.

Workers and residents report that, despite receiving ongoing treatment, their 9/11-related health symptoms have not improved at all or only some symptoms have improved. Of those surveyed:



- Only **5%** state that their symptoms have fully improved.
- **58%** state that only some of their symptoms improved.
- **About 1 in 3** state that none of their symptoms have improved.

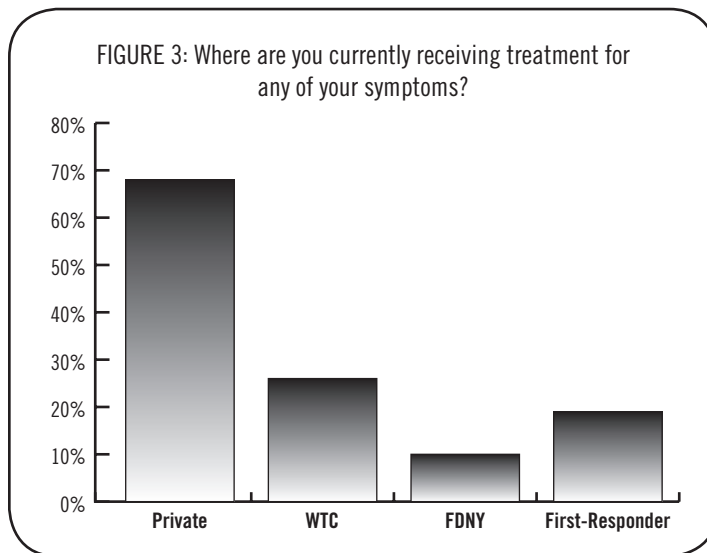
Scientific studies support these *WE COUNT!* survey findings. For example, a study published in the *Journal of American Medicine* entitled “Asthma and Posttraumatic Stress Symptoms 5 to 6 Years Following Exposure to the World Trade Center Terrorist Attack,” found that people directly exposed to the 9/11 attack were approximately four times more likely than the general population to report post-traumatic stress symptoms.<sup>14</sup> The study also found increased reports of psychological symptoms between 2003 and 2007.<sup>15</sup> In addition, researchers found that in the first year after 9/11, asthma was being diagnosed in residents and workers exposed to smoke and dust at six times the normal rate for New York City; while the rate has declined since then, it has still not returned to normal.<sup>16</sup> For many, asthma and other respiratory illnesses have become chronic. A study of the residents and workers being treated at the WTC EHC found that they are suffering from new and persistent respiratory symptoms and lung function abnormalities five or more years after 9/11.<sup>17</sup>

#### **Summary and Analysis of Finding 1**

Most workers and residents suffering from 9/11-related health problems are chronically ill, with more than one-third stating that their symptoms have not improved at all after receiving treatment. Patients’ symptoms may not be improving for a number of reasons. Chronic illnesses do not go away with treatment, which may only have a stabilizing effect. In addition, as 9/11 toxins and their effects on the human body are not yet fully identified, workers’ and residents’ health problems appear to be evolving at a faster rate than the medical community’s knowledge of how to treat these illnesses.

## 2. Many 9/11-affected workers and residents are not seeking treatment at the WTC EHC or other 9/11-specific Centers of Excellence.

Although treatment at the WTC EHC is free to patients, a significant percentage of surveyed workers and residents with 9/11-related symptoms choose to see private doctors or seek treatment at clinics that are not part of the Centers of Excellence.<sup>18</sup> At present, the three WTC EHC clinical sites of Bellevue, Gouverneur, and Elmhurst have provided treatment to approximately 4,100 residents and clean-up workers,<sup>19</sup> despite the many thousands who may have been affected. Of those surveyed who have seen a doctor for symptoms related to 9/11, only **39%** have exclusively visited WTC EHC doctors, compared to **72%** who have seen a private doctor either exclusively or in conjunction with a Center of Excellence.<sup>20</sup> Of those surveyed who are currently receiving medical treatment:



- Only **26%** are visiting the WTC EHC.
- **68%** are visiting private doctors.
- **10%** are visiting the FDNY Clinic.
- **19%** are visiting Mt. Sinai's World Trade Center Medical Monitoring and Treatment Program.<sup>21</sup>

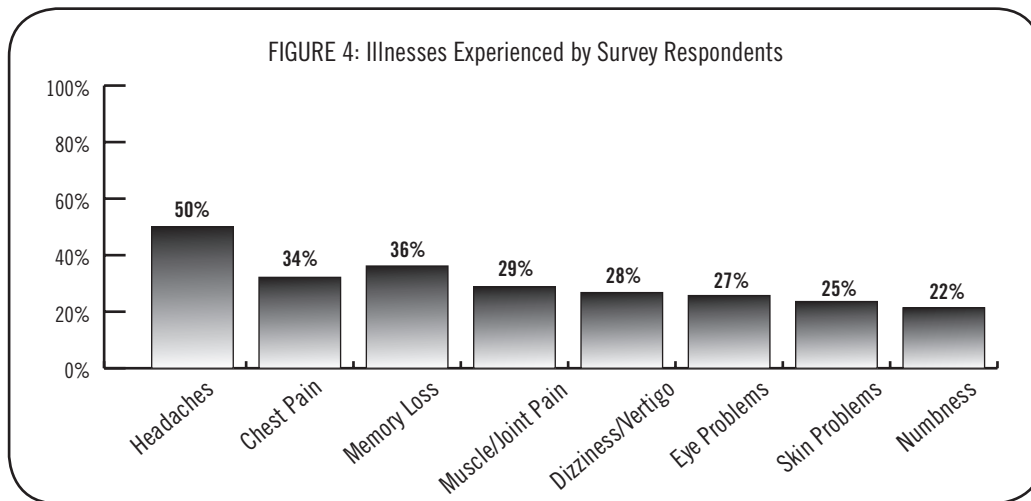
### Summary and Analysis of Finding 2

A surprising majority of surveyed workers and residents, many of whom are unaware of the WTC EHC, report going to private doctors either exclusively or in addition to a Center of Excellence for their 9/11-related health problems. This finding has two important ramifications. First, since Congress uses the WTC EHC patient population, not those treated by private doctors, as the basis for determining entitlement to treatment and monitoring in the community program, the affected population is being undercounted. Second, those exclusively seeing private doctors are not being included in the ongoing studies undertaken by the Centers of Excellence and are not receiving specialized 9/11 health treatment and monitoring.<sup>22</sup> This finding demands further investigation, as it may reflect patients' frustration with traditional treatment at the WTC EHC or patients' cultural or logistical preferences for their family physicians. As the economic crisis persists and as more workers become so sick they can no longer work, patients with employer-based health insurance will need to seek treatment at the WTC EHC.<sup>23</sup> The government must be prepared to adequately support this increased need by expanding services at the WTC EHC. Moreover, recognizing that many people will prefer continuing to see their private doctors in the community, the WTC EHC should establish a network whereby its physicians and psychologists can advise community doctors on 9/11-related illnesses and refer patients for evaluation and collaborative delivery of quality health services.

### 3. Workers and residents exposed to 9/11 toxins are experiencing a wide range of illnesses, some of which are not recognized as 9/11-related.

Although there has been some recognition of evolving health problems related to 9/11, such as digestive and mental health problems, many other conditions reported by workers and residents are not recognized by the government as such and have not been adequately investigated by the medical community. Many symptoms reported by *WE COUNT!* respondents—including headaches, memory loss, muscle/joint pain, and cardiac problems—are not listed as 9/11-related in the current 9/11 health legislation.

Workers and residents in the survey report other 9/11-related health problems such as:



Other reported symptoms include gynecological problems, sarcoidosis, and even potentially 9/11-related cancers.<sup>24</sup> It is difficult to obtain proper medical care and workers' compensation benefits for symptoms and illnesses not recognized by the government and medical community as connected to 9/11, and private physicians do not have the resources or patient base to investigate these connections. Workers and residents suffering from emerging health problems need specialized care from doctors who have the resources to determine whether these illnesses are in fact 9/11-related.<sup>25</sup>

#### **Summary and Analysis of Finding 3**

Many people exposed to 9/11 toxic air and dust are suffering from illnesses not officially recognized by governments and other bodies. More research must be done to determine if these conditions are linked to 9/11. In the absence of such research, the victims of 9/11 will be underrepresented. In addition, if community members perceive the WTC EHC and other Centers of Excellence as being open to broadened research, they are more likely to seek treatment at those clinics and to contribute to the studies. A long-term response to the 9/11 health crisis demands the "community-health partnership" behind the WTC EHC must continue, with affected workers and residents playing a central role in identifying and implementing new treatments and care for evolving health problems.<sup>26</sup> The leadership and participation of directly affected workers and residents must be recognized in the face of imperfect scientific understanding of the disastrous fallout of 9/11.



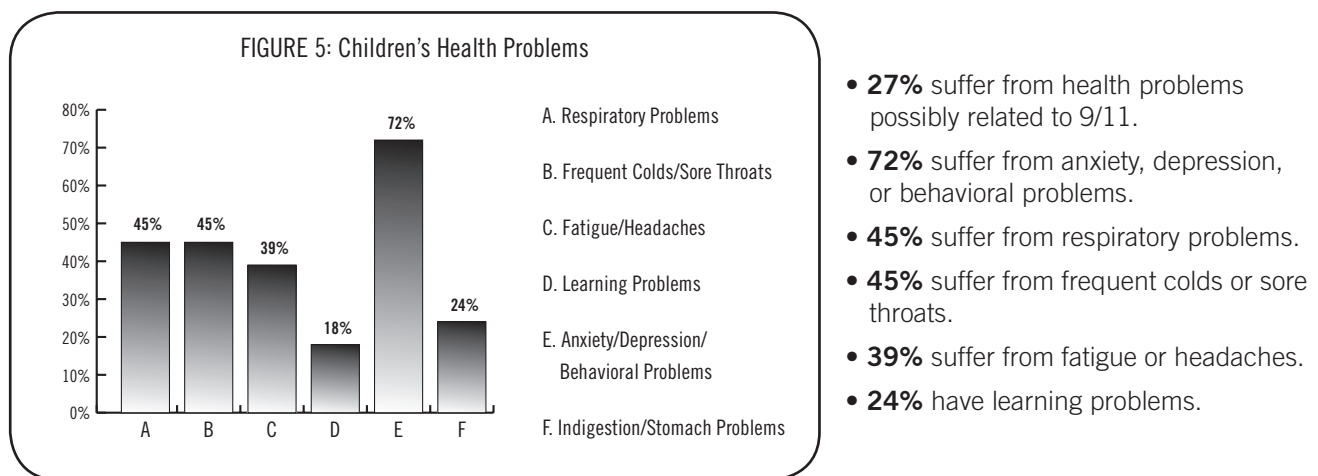
#### 4. Children affected by the WTC health disaster suffer from health symptoms but are not being adequately addressed.

The 9/11 disaster exposed as many as 46,000 schoolchildren to toxic air, dust, fumes, and smoke.<sup>27</sup> Even though children are more susceptible to harm from toxic environmental exposures, from the first days following 9/11, the government expressly denied the risks to children who lived or attended school downtown. Though it is now clear from a small number of studies that children have developed respiratory illnesses and other conditions, their 9/11-related medical problems are the least studied of any exposed population.

It was not until 2008 that the WTC Health Registry published a study based on its “child survey,” finding that children under five years old who had been attending school or living in lower Manhattan were getting asthma at twice the rates for the northeastern U.S.<sup>28</sup> There was no specialized treatment available to children until 2008, when the WTC EHC Pediatric Program opened, and only in 2009 did the City Health Department release its WTC pediatric guidelines. For the last eight years, both parents and pediatricians have lacked both accurate information and appropriate WTC health resources for children.

At this juncture, it is difficult to track and record 9/11-related health symptoms among affected adolescents and young adults, a population that has become more dispersed since 9/11.<sup>29</sup> Many parents do not know about the pediatric program at the Bellevue site of the WTC EHC, so outreach is still needed. Moreover, those who utilize the program must continue to push for family-friendly scheduling of appointments—outside of school hours and on the weekends.

To research possible pediatric health effects, *WE COUNT!* included questions aimed at gathering information about survey participants’ children. Of the children of those parents surveyed:



Like 9/11-affected adults, some children seen by doctors have experienced improvements in their health. Of the children of those parents surveyed:

- **12%** have seen all of their symptoms improve.
- **64%** have seen some of their symptoms improve.
- **39%** have seen none of their symptoms improve.

#### Summary and Analysis of Finding 4

Children are suffering from serious, persistent 9/11-related health problems. Studies of babies born to mothers in the months after 9/11 show that *in-utero* exposures resulted in reduced fetal growth, which is associated with cognitive deficits and future health risks.<sup>30</sup> A Mount Sinai School of Medicine report observes that the incidence of substance abuse is higher among teens who were exposed to the attacks than those who were not.<sup>31</sup> And children whose mothers were depressed or had posttraumatic stress disorder because of the 9/11 attacks were more likely to act out than their peers.<sup>32</sup> Even with these studies, the full scope and nature of the pediatric health impact has yet to be accurately documented. Without this base of knowledge, many parents remain unaware of their children’s 9/11-related illnesses; and without adequate monitoring, children, youth, and young adults will not receive the attention they need to address evolving 9/11-related health problems.

## 5. Among surveyed workers and residents who are currently unemployed, most are unable to work due to their 9/11-related health problems.

9/11-related health problems have taken a significant toll on workers' and residents' ability to support themselves and their families. Nearly half (43%) of respondents reported they are not currently working, and a majority of these workers and residents (57%) are not working due to their 9/11-related health problems.<sup>33</sup>

Unfortunately, many affected workers are ineligible for workers' compensation because they were downtown "area workers," as opposed to cleanup or rescue/recovery workers, in the wake of 9/11. The 9/11-specific section of the New York State Workers' Compensation Law (Article 8-A) does not cover employees who were exposed to dust outside the normal course of their employment; thus, only strictly cleanup, rescue, and recovery workers are eligible—not area workers who breathed in toxic air and may have cleaned dust from their workspaces. Unsurprisingly, then, **66%** of workers surveyed have not filed a C-3 claim form (which begins a case) with the New York State Workers' Compensation Board.

### ***Summary and Analysis of Finding 5***

There is a close connection between physical/mental health and financial well-being. *WE COUNT!* survey respondents report the challenges they continue to face in dealing with their 9/11-related illnesses, and their financial need will only increase as workers and residents become sicker.<sup>34</sup>

While 9/11 cleanup, rescue, and recovery workers are eligible for workers' compensation benefits, downtown office and area workers are not, notwithstanding their participation in cleanup of their workspaces. Nor can area residents, by definition, apply for workers' compensation benefits, even if they were excluded from the Victims Compensation Fund. Some of these community members may have recourse to the social security disability system, but they must fight for benefits in an often impenetrable venue that has little understanding of 9/11-related health problems.

The economic needs of residents and downtown workers have been shockingly absent from discussion of the 9/11 health crisis. For injured 9/11 cleanup workers eligible for workers' compensation, it has not been easy to secure compensation. An unprecedented 76% of injury claims have been "controverted" (challenged) by workers' compensation insurance companies, a rate more than triple the average.<sup>35</sup> Moreover, the median number of days from filing to receipt of benefits in a case of permanent partial disability is 309, nearly one year,<sup>36</sup> and appeals in 9/11 workers' compensation cases take an average of 133 days, during which time the worker receives no benefits.<sup>37</sup> Shamefully, the employers from the 9/11 cleanup, large contractors and small subcontractors alike, were contracted by the government to clean WTC debris from commercial, residential, and government buildings, as well as schools and churches. While profiting from the labor of exploited workers, these companies and their insurance carriers relentlessly fight the workers' claims for minimal compensation.

## V. POLITICAL CONTEXT: THIS LEGISLATIVE MOMENT

In February 2009, Congresspersons Carolyn Maloney (D-NY 14) and Jerrold Nadler (D-NY 8), together with 68 other sponsors, introduced the James Zadroga 9/11 Health and Compensation Act of 2009 (HR 847) in the House of Representatives.<sup>38</sup> This is the first bill that would provide extensive federal funding to treat the 9/11-related health problems of affected first responders, clean-up workers, students, and residents.

In the U.S. Senate, New York Senators Gillibrand and Schumer, with New Jersey Senators Lautenberg and Menendez, introduced the James Zadroga 9/11 Health and Compensation Act of 2009 (S 1334).<sup>39</sup> As the companion and virtual twin to HR 847, this Act would also provide federal funding for 9/11 clinics serving community members as well as first responders.

Although these bills are overdue and welcome, HR 847 and S 1334 are inadequate to meet the needs of all those whose health has been negatively affected by 9/11. The bills do not encompass all potentially related medical symptoms or illnesses, nor do they provide for all workers, residents, and students who have been affected.<sup>40</sup> Below is a chart summarizing the current provisions and shortcomings of the House and Senate bills:

FIGURE 6

BGZ and 9/11 EA demand that:	HR 847 and S 1334 provide that:	How the bills should be amended
Arbitrary geographic boundaries do not limit healthcare access.	Residents, clean-up workers, and area workers are only eligible if they lived/worked south of Houston or in Brooklyn within a 1.5 mile of the WTC towers.	At the very least, extend the northern eligibility boundary to 14 <sup>th</sup> Street, which is in line with medical data and does not exclude communities of color from the Lower East Side.
Community members must be involved in decision-making about their health.	The Administrator of the program must consult the WTC Community Program Steering Committee, which includes representation of, among others, “hard-to-reach populations,” but only has 11 spots.	Clarify to ensure that directly affected community members and WTC EHC patients, not just large “community” groups, participate on the Steering Committee.
Community members contribute to defining “WTC-related health condition.”	The definition of <i>causally related</i> physical or mental illness is broadly defined but then narrowed by a restrictive list of “aerodigestive disorders” and “mental health conditions.” “Musculoskeletal conditions” are not considered 9/11-related for persons who were not first-responders.	Expand the list and provide for accommodation of evolving health conditions.
Community members should receive their fair share of funding and resources.	The first-responder program is allocated hundreds of millions more in funding than are community programs.	Funding must be justly distributed for all those suffering from medical conditions caused by the attacks, first-responders and workers/residents alike.

While BGZ and 9/11 EA support these bills and the hard work of residents, workers, responders, and elected officials who have fought for a federal program to track and treat 9/11 illnesses, it is clear that the legislation does not provide for the current or future burdens of the affected population. Even if these bills are passed, it will be up to the workers and residents affected by 9/11 to stand up for their rights to quality healthcare, to take advantage of the treatment available at the WTC EHC, and to push for studies and medical decisions that speak to the causality of their 9/11 diseases. It is the hope of BGZ and 9/11 EA that the *WE COUNT!* community survey can contribute to these ongoing efforts.

## VI. RECOMMENDATIONS

Findings from the *WE COUNT!* survey confirm that workers and residents still suffer from severe 9/11-related health problems, that their symptoms are not improving, that many health problems go unrecognized as 9/11-related, and that children are affected as well. Increasing numbers of workers and residents can no longer work because of the severity of their illnesses.

Congress and President Obama must bring justice to 9/11-affected workers, residents, students, and their communities. After eight years of neglect, they must finally investigate the full extent and scope of the 9/11 health crisis and respond to the health and economic needs of workers, residents, students, and first-responders. Based on the *WE COUNT!* survey findings, and understanding that federal leadership is needed in response to the 9/11 health crisis, BGZ and 9/11 EA make the following recommendations:

### ***Fashion a Holistic Public Health and Economic Response to the 9/11 Health Crisis.***

1. The WTC EHC and other Centers of Excellence should create a network to enable 9/11-specialist physicians, psychologists, and staff to educate doctors in the community as to diagnosis and treatment of 9/11-related conditions and to establish a referral path to the WTC EHC. The Centers of Excellence should work with local private doctors to ensure that all those affected by 9/11 are included in ongoing studies and continue to receive the highest quality care possible, and to explain the importance of doctors' sending their patients to the WTC EHC for long-term monitoring, an essential epidemiological tool for recognizing new patterns of disease.
2. Recognizing that many 9/11-affected workers and residents can no longer work due to their 9/11-related health problems, Congress and President Obama must guarantee all those unable to work due to their 9/11-related health problems—whether past, present, or future—compensation for lost income as well as medical and other support services, including home-healthcare services.
3. Recognizing workers' and residents' chronic, worsening 9/11-related health problems, Congress and President Obama must instruct and fund the Centers of Excellence to explore alternative therapies and treatments for 9/11-affected workers and residents.
4. Congress and President Obama should recognize the critical role played by the “community-health partnership” between the WTC EHC, the current or former workers and residents who are its patients, and community stakeholders, including BGZ and 9/11 EA. Affected workers and residents seeking treatment in federally funded 9/11 health programs should be regarded as non-medical experts in assessment and monitoring of 9/11-related conditions, and funding should be provided for continued outreach to affected populations.

### ***Guarantee Treatment for and Expand Knowledge of Emerging Illnesses, Conditions, and Health Problems Reported by 9/11-Affected Workers and Residents.***

1. Congress and President Obama must direct the Centers of Excellence and provide resources to screen, treat, document, describe, and track the progress of all 9/11-related illnesses, including emerging illnesses, conditions, and health problems not currently recognized as 9/11-related but reported by 9/11-affected workers and residents.
2. Barring timely additions to the list of illnesses and WTC-related conditions in the proposed 9/11 legislation, Congress and President Obama should guarantee retroactive reimbursement for the treatment of emerging illnesses, conditions, and health problems not covered by the legislation but later found to be WTC-related.
3. Congress and President Obama must increase federal funding for further long-term research into WTC-related conditions and mandate that a significant portion of that research focus on emerging conditions (*i.e.*, symptoms and illnesses not currently recognized as 9/11-related) reported by 9/11-affected workers and residents.
4. Congress and President Obama must provide incentives for academics and medical professionals to engage in longitudinal research in partnership with 9/11-affected communities, the Centers of Excellence, and local governments and agencies (e.g., the NYC Department of Education) on the connections between 9/11-related toxic exposures and the health problems of workers, residents, students, and first-responders.

# ENDNOTES

- <sup>1</sup> Nordgren, Megan D., Eric A. Goldstein, and Mark A. Izeman. *The Environmental Impact of the World Trade Center Attacks: A Preliminary Assessment*. The Earth's Best Defense, Feb. 2002. Web. 11 Sept. 2009. <<http://www.nrdc.org/air/pollution/wtc/wtc.pdf>>.
- <sup>2</sup> See Urban Justice Center. "The Ripple Effect: The Crisis in NYC's Low-Income Communities After September 11th." *www.beyondgroundzero.org*. N.p., Sept. 2002. Web. 8 Sept. 2009. <[www.beyondgroundzero.org/files/RippleEffect.pdf](http://www.beyondgroundzero.org/files/RippleEffect.pdf)>.
- <sup>3</sup> "HHC - WTC Environmental Health Center." Web. 11 Sept. 2009. <<http://www.nyc.gov/html/hhc/html/services/wtc-cac.shtml>>.
- <sup>4</sup> See, e.g., NYC government. *9/11 Health*. N.p., n.d. Web. 8 Sept. 2009. <[www.nyc.gov/html/doh/wtc/html/home/home.shtml](http://www.nyc.gov/html/doh/wtc/html/home/home.shtml)>. Pallarito, Karen. "Dust exposure after 9/11 linked to high asthma rates." *CNN.com*. CNN, 5 Aug. 2009. Web. 8 Sept. 2009. <<http://www.cnn.com/2009/HEALTH/08/05/dust.exposure.asthma/>>.
- <sup>5</sup> DePalma, Anthony. "Whitman Defends Air Quality Assurances Made After 9/11." *The New York Times*. June 26, 2007.
- <sup>6</sup> "9/11 Health - WTC Health Registry." Web. 11 Sept. 2009. <<http://nyc.gov/html/doh/wtc/html/registry/registry.shtml>>. The Registry reports "tracking the health of 71, 437 people directly exposed to the WTC disaster." ("World Trade Center Health Registry 2008 Annual Report." *NYC Health*. Apr. 2009.)
- <sup>7</sup> "[Community and labor] representatives have noted that the geographic boundaries used by the registry exclude office workers below Chambers Street who were not at work on September 11 but returned to work in the following weeks; office workers, including several groups of city employees, working between Chambers and Canal Streets; and Brooklyn residents who may have been exposed to the cloud of dust and smoke." United States. U.S. Government Accountability Office. *September 11: Health Effects in the Aftermath of the World Trade Center Attack*. *www.GAO.gov*. U.S. Government Accountability Office, n.d. Web. 8 Sept. 2009. <<http://www.gao.gov/htext/d041068t.html>>.
- <sup>8</sup> See, e.g., Szema, Anthony M., et al. "Clinical deterioration in pediatric asthmatic patients after September 11, 2001." *Journal of Allergy and Clinical Immunology* 113:3 (Mar. 2004): 420-426.
- <sup>9</sup> See Open Congress. "H.R.847 - James Zadroga 9/11 Health and Compensation Act of 2009." *OpenCongress.com*. N.p., n.d. Web. 8 Sept. 2009. <<http://www.opencongress.org/bill/111-h847/show>>.
- <sup>10</sup> United States. Cong. House. *Summary of H.R. 847, the 9/11 Health and Compensation Act in the 111th Congress*. *maloney.house.gov*. Rep. Carolyn B. Maloney, 24 Feb. 2009. Web. 8 Sept. 2009. <[http://maloney.house.gov/documents/911recovery/20090224\\_Summary%20of%20911%20HC%20Act.pdf](http://maloney.house.gov/documents/911recovery/20090224_Summary%20of%20911%20HC%20Act.pdf)>.
- <sup>11</sup> Representative Carolyn Maloney stated, "The 9/11 Health and Compensation Act, which Congressmen Nadler, King, McMahon and I introduced with the support of the entire New York Congressional delegation, would reopen the federal Victim Compensation Fund to help those who lost their livelihoods as a result of the 9/11 attacks." "Maloney Statement on Today's 9/11 Health and Compensation Hearing." *maloney.house.gov*. Rep. Carolyn B. Maloney, 31 Mar. 2009. Web. 8 Sept. 2009. <[http://maloney.house.gov/index.php?option=com\\_content&task=view&id=1822&Itemid=61](http://maloney.house.gov/index.php?option=com_content&task=view&id=1822&Itemid=61)>.
- <sup>12</sup> Paul, Ari. "PBA Bucks Other Unions in Opposing Zadroga Bill." *www.thechief-leader.com*. Civil Service Leader, 4 Sept. 2009. Web. 8 Sept. 2009. <<http://www.thechief-leader.com/news/2009/0904/news/005.html>>.
- <sup>13</sup> See Moline, Jacqueline M., et al. "Multiple Myeloma in World Trade Center Responders: A Case Series." *Journal of Environmental Medicine* 51(8) (Aug. 2009): 896-902.
- <sup>14</sup> HealthDay News. "For Many, 9/11-Linked Trauma Emerged Years Later." *www.AJC.com*. N.p., 4 Aug. 2009. Web. 8 Sept. 2009. <<http://www.ajc.com/health/content/shared-auto/healthnews/asth/629697.html>>.
- <sup>15</sup> Ibid.
- <sup>16</sup> Brackbill, R.M., et al. "Asthma and posttraumatic stress symptoms 5 to 6 years following exposure to the World Trade Center terrorist attack." *Journal of the American Medical Association* 302(5): 502-516 (Aug. 2009).
- <sup>17</sup> Reibman, J., et al. "Characteristics of a residential and working community with diverse exposure to World Trade Center dust, gas, and fumes." *Journal of Occupational and Environmental Medicine* 51(5): 534-541 (May 2009).
- <sup>18</sup> Recognized by Congress as representing the authority on 9/11 health screening, monitoring, and treatment, the Centers of Excellence provide specialized testing and treatment for 911-related health conditions. The Centers of Excellence include the WTC EHC, the NY Fire Department's WTC Medical Monitoring and Treatment Program, and Mount Sinai's WTC Medical Monitoring and Treatment Program.
- <sup>19</sup> Miles, Terry. "World Trade Center Environmental Health Center Update." Presentation to HHC Strategic Planning Committee. 15 Sept. 2009.
- <sup>20</sup> Wagner, Victoria, Marleen Radigan, Patrick Roohan, Joesph Annarella, and Foster Gesten. "Asthma in Medicaid Managed Care Enrollees Residing in New York City: Results From a Post World Trade Center Disaster Survey." *Journal of Urban Health* 82.1 (2005): 76-89. Print.
- <sup>21</sup> "Mount Sinai - World Trade Center Programs FPA." *Mount Sinai - Home*. Web. 11 Sept. 2009. <<http://www.mountsinai.org/Education/School%20of%20Medicine/Faculty%20Practice%20Associates/Practices/World%20Trade%20Center%20Programs%20FPA>>.
- <sup>22</sup> One respondent admitted as much, saying, "My private doctors are not trained to recognize the connection (to 9/11)." -Respondent #192.



- <sup>23</sup> As survey respondent #206 stated, “My COBRA runs out in 6 months and I don’t know what I’ll do after that.” While some are losing their healthcare, others are paying high out-of-pocket costs on their 9/11-related health problems. In fact, 16% of people surveyed have spent more the \$5000 total on 9/11 related health costs.
- <sup>24</sup> See *supra*, on myeloma (Moline). The sponsors of the House bill released a statement in response to the myeloma study, stating, “The fact that the authors of this cancer study say the results are inconclusive only reinforces the urgent need for an established, long-term monitoring program for 9/11 responders and treatment for illnesses that result from exposure to toxins at Ground Zero.” (“Media Center.” *Online Office of Congressman Michael E. McMahon*. Web. 11 Sept. 2009. <[http://mcmahon.house.gov/index.php?option=com\\_content&view=section&layout=blog&id=16&Itemid=160&limitstart=10](http://mcmahon.house.gov/index.php?option=com_content&view=section&layout=blog&id=16&Itemid=160&limitstart=10)>.)
- <sup>25</sup> The need for better research was echoed by survey respondent #184: “Some illnesses are acknowledged as 9-11[-related], others are denied.”
- <sup>26</sup> See Kim, E. Tammy and Jei Fong. “The Beyond Ground Zero Network: A model for grassroots public health responses following an urban environmental disaster.” *Advancing Climate Justice: Transforming the Economy, Public Health & Our Environment* conference (Jan. 2009). On file with authors.
- <sup>27</sup> Landrigan, Philip J. “Impacts on the Health of Children of the September 11 Attacks on the World Trade Center.” Testimony before the Subcommittee on Clear Air, Wetlands, and Climate Change, Committee on Environment and Public Works; United States Senate. 11 Feb. 2002. <[http://epw.senate.gov/107th/Landrigan\\_021102.htm](http://epw.senate.gov/107th/Landrigan_021102.htm)>.
- <sup>28</sup> Thomas, Pauline, Robert Brackbill, Lisa Thalji, Laura DiGrande, Sharon Campolucci, Lorna Thrope, and Kelly Horning. “Respiratory and Other Health Effects Reported in Children Exposed.” *Environmental Health Perspectives* 116.10 (2008): 1383-390. Web. 11 Sept. 2009. <<http://www.ehponline.org/members/2008/11205/11205.pdf>>.
- <sup>29</sup> Some parents reported in the survey that their children suffer from *in utero* 9/11 effects: “(My) wife became pregnant during my time working there during 9/11 . . . our child was born with a growth disorder which was not related to genetics.” (Survey respondent #113.)
- <sup>30</sup> See Perera, FP, et al. “Prenatal airborne polycyclic aromatic hydrocarbon exposure and child IQ at age 5 years.” *Pediatrics* 124(2): 195-202 (Aug. 2009). Choi, H., et al. “Prenatal exposure to airborne polycyclic aromatic hydrocarbons and risk of intrauterine growth restriction.” *Environmental Health Perspectives* 116(5): 658-665 (May 2008). Perera, FP, et al. “Relationship between polycyclic aromatic hydrocarbon-DNA adducts, environmental tobacco smoke, and child development in the World Trade Center cohort.” *Environmental Health Perspectives* 115(10): 1497-1502 (Oct. 2007). Perera, FP, et al. “Relationships among polycyclic aromatic hydrocarbon-DNA adducts, proximity to the World Trade Center, and effects on fetal growth.” *Environmental Health Perspectives* 113(8): 1062-1067 (Aug. 2005).
- <sup>31</sup> Mt. Sinai School of Medicine. “Substance use and functional impairment among adolescents directly exposed to the 2001 World Trade Center attacks.” *www.ncbi.nlm.nih.gov*. N.p., 31 Oct. 2008. Web. 9 Sept. 2009. <<http://www.ncbi.nlm.nih.gov/pubmed/19178553>>.
- <sup>32</sup> Mt. Sinai School of Medicine. “Effect of Maternal Psychopathology on Behavioral Problems in Preschool Children Exposed to Terrorism: Use of Generalized Estimating Equations to Integrate Multiple Informant Reports.” *www.ncbi.nlm.nih.gov*. N.p., June 2009. Web. 9 Sept. 2009. <<http://www.ncbi.nlm.nih.gov/pubmed/19487609?dopt=abstractplus>>.
- <sup>33</sup> Survey respondent #84 stated, “(My) health is worsening and I cannot hold a job.” Survey respondent #189 commented on the need for economic support: “I was let go from my job and told due to my health issues since 9/11 and continued absence from work I was no longer effective in my position. I am now on social security disability due to my numerous health issues.”
- <sup>34</sup> The WTC Registry has also found event-related loss of spouse or job to be associated with PTSD five to six years after 9/11.
- <sup>35</sup> New York State Workers’ Compensation Board. “World Trade Center Cases in the New York Workers’ Compensation System.” Pp. 7, 33, 34. Sept. 2009. <<http://www.wcb.state.ny.us/content/main/TheBoard/WCBWTCReport2009.pdf>>.
- <sup>36</sup> *Ibid.* p. 43.
- <sup>37</sup> *Ibid.* p. 38.
- <sup>38</sup> Open Congress. “H.R.847 - James Zadroga 9/11 Health and Compensation Act of 2009.” *OpenCongress.com*. N.p., n.d. Web. 8 Sept. 2009. <<http://www.opencongress.org/bill/111-h847/show>>.
- <sup>39</sup> United States. Cong. House Committee on the Judiciary. *Joint Hearing on: H.R. 847, the “James Zadroga 9/11 Health and Compensation Act of 2009.”* *judiciary.house.com*. U.S. House of Representatives Committee on the Judiciary, n.d. Web. 8 Sept. 2009. <[http://judiciary.house.gov/hearings/hear\\_090331.html](http://judiciary.house.gov/hearings/hear_090331.html)>.
- <sup>40</sup> “HR 847.” *THOMAS (Library of Congress)*. Web. 11 Sept. 2009. <<http://thomas.loc.gov/cgi-bin/bdquery/z?d111:h.r.00847:>>. “S 1334.” *THOMAS (Library of Congress)*. Web. 11 Sept. 2009. <<http://thomas.loc.gov/cgi-bin/bdquery/z?d111:SN01334:>>.

## **9/11 *ENVIRONMENTAL ACTION***

[www.911ea.org](http://www.911ea.org)



[www.beyondgroundzero.org](http://www.beyondgroundzero.org)

### **BGZ GROUPS INCLUDE:**

**Commission on the Public Health's System**

**National Mobilization Against Sweatshops**

**Chinese Staff and Workers' Association**

**Community Development Project of the Urban Justice Center**

**Asian American Legal Defense and Education Fund**