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Lessons Learned from the World Trade Center Disaster:

Emergency Preparedness for People with Disabilities in New York

September 9, 2004

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Finally, we would like to recognize the spirit, resilience, and creativity of the many people with disabilities who survived and are acting with others in their communities to improve things for all of us.

Susan M. Dooha, JD
Executive Director

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SUMMARY OF REPORT

There were a number of lessons learned during and immediately after 9/11 about preparation and accommodations for people with disabilities. The most prominent and disturbing conclusion was that despite the fact that many of these lessons had been learned before 9/11, systemic preparation conceived of or conducted by mainstream emergency responders and relief agencies did not consistently take into account the specific needs of people with disabilities.

Every individual is entitled to equal access to available services, particularly those related to emergency response and recovery activities. As such, relief agencies and other service providers are responsible for ensuring appropriate accommodations that allow people with disabilities the same chance as other members of the public to survive and recover from disasters. To achieve this equity, the following recommendations are made:

- **Emergency responders, as well as relief and other service agencies, must incorporate into their planning and operations an appropriate strategy for ensuring equitable access to response and recovery services for people with disabilities.** Emergency planning by individual employers, landlords, and organizations should include purchasing and training staff in the use of evacuation and other emergency equipment appropriate for people with disabilities. Emergency professionals should rely on the disability community to advise them on which types of equipment are best.
- **Relief agencies cannot wait until they are in the middle of a disaster to start training their staff in disability awareness.** Train volunteers and staff ahead of time in basic disability awareness and etiquette, and in how to accommodate needs that commonly arise for people with disabilities.

- **The day after a disaster is too late for agencies to start doing outreach to make their services known to people with disabilities.** It is necessary to communicate with members of the disability community:
 - * On an ongoing basis, as part of a preparedness outreach effort
 - * Before an event, to warn about an emergency
 - * During an event, to give information and instruction about the emergency
 - * After an event, to give information about recovering from the emergency.

- **During the recovery phase, there must be a priority to restore or address those services and needs most critical to people with disabilities, especially related to access to home attendants, assistive equipment, medication, accessible transportation and temporary shelter, and food delivery.**

INTRODUCTION

Any disaster will, by definition, disrupt lives. Still, some response and recovery issues are predictable, common to many disasters and crisis situations: these are the ones that can be successfully minimized through pre-crisis planning and preparation.

For people with disabilities, however, existing disaster response and recovery measures are significantly less successful, given that little systemic preparation is conceived of or conducted by mainstream emergency responders with their specific needs in mind. In fact, most of the planning related to emergency measures for people with disabilities consists of lists of things that consumers and their advocates should do—a practical first step, but one that clearly requires additional substantial support by emergency responders who have incorporated into their planning and operations an appropriate strategy for ensuring equitable access to response and recovery services.

The Center for Independence of the Disabled in New York (CIDNY) supports all efforts to help people with disabilities prepare themselves for emergencies, an approach that coincides with its fundamental mission of assisting consumers in achieving maximum independence. CIDNY has distributed thousands of brochures with advice and checklists on disaster preparedness to consumers and sister agencies working with the disability community. CIDNY actively provides technical assistance to government and other social service agencies on ways in which to assist people with disabilities during and after emergency situations. To strengthen this effort, this report focuses on what relief agencies and other service providers can do—and have done—to give people with disabilities the same chance as other members of the public to survive and recover from disasters.

[Former Executive Director] Susan Scheer says CIDNY has realized it has a large constituency of people with disabilities who are not traditionally considered independent living consumers.

“We’ve come to know a lot of people,” she says, “who were doing their own things and had successfully created their own support networks. When their support systems crumbled—as they so dramatically did [on 9/11]—many still thought they could work things out themselves. But as things dragged on, they found they needed assistance.”

“9-11 Offers Important Lessons in Disaster Preparedness,”
Richard Petty, *ILRU Network*, January 2002

SECTION 1: THE CENTER FOR INDEPENDENCE OF THE DISABLED IN NEW YORK'S RESPONSE TO THE WORLD TRADE CENTER DISASTER

Like most New Yorkers, Susan Scheer, the former executive director of CIDNY, remembers September 11 very clearly:

When the first plane hit, we were in a staff meeting at CIDNY. We heard something about the World Trade Center before we went into the meeting. When we came out, there was all this news about the building being on fire and people evacuating. Everybody got on the phone to call our consumers, and I had the staff print out everything they could—I had a feeling we might not be able to get to the computers for a while. We wrote down each other's phone numbers and beeper numbers. Then I told people they could go home. Those who couldn't make it home arranged to stay with staff members who lived nearby.

It quickly became clear that, as the Independent Living Center closest to the World Trade Center, CIDNY would be the leading service coordinator for people with disabilities who were affected by the September 11 attacks. In addition to helping individuals with disabilities—whether they were disabled before or as a result of the WTC incident—CIDNY became a leading source of information on disability issues for the many private and public entities participating in the massive response and recovery effort.

CIDNY was located just inside the border of the so-called Frozen Zone. On September 12, CIDNY staffers were not allowed back in the building that housed their office until late in the day. There were no phones, no electricity.

“For the first few days,” Scheer recalls, “we were just ‘putting out fires.’ We began hearing from our consumers, and then they started telling us about other people in their buildings who were in trouble All our deaf consumers showed up right away, to find out what was happening. There was this chaos on TV and they didn’t understand what it meant.”

Traumatized, forced to evacuate their own headquarters, and limited by disrupted phone services and other utilities, CIDNY’s staff was in no position to launch an immediate emergency response. At the same time, state agencies that [Brad] Williams [Executive Director of the New York State Independent Living Council] thought would be involved in responding to people with disabilities during the crisis seemed to be waiting for someone to tell them what to do. Frustrated, Williams called the National Council on Independent Living (NCIL) for help.

NCIL’s Marcie Roth called the White House disability liaison who, in turn, began contacting federal agencies and the New York governor’s office. Finally, Williams says, the state agencies kicked into gear—“ten days to two weeks after the attacks.”

“NYSILC Crisis Response Plan Focused on Communication, Coordination—and Returning Control as Soon as Possible,”
ILRU Network, January 2002

In immediate response to the disaster, CIDNY played a central role in gathering information about the needs of people with disabilities and communicating that information to the media and to agencies and authorities controlling the delivery of disaster recovery services. CIDNY further advised local hospitals treating survivors of the attack to refer to the agency those who were newly disabled.

CIDNY's small staff was stretched to its limit by the addition of so many new consumers with urgent and complex needs. Volunteers were soon recruited, along with a dedicated coordinator, to manage CIDNY's disaster recovery efforts, including the logistics of storing and distributing an outpouring of donated assistive equipment and medical supplies. Several new counselors were hired, and other staff diverted much of their time to counseling and other activities related to the WTC incident.

Meanwhile, hundreds of consumers not directly affected by September 11 still counted on the agency for assistance. According to Sharon Shapiro, CIDNY's then assistant director, it was a struggle to maintain the agency's regular programs during the initial disaster recovery period.

"Landlords didn't stop evicting tenants, and hearings with Social Security and HRA kept coming up," stated Ms. Shapiro. She also noted that CIDNY's regular clients—those who were not directly involved in the disaster—were fearful and had a greater need for counseling after the attack, mirroring the unease and anxiety experienced by all New Yorkers.

The agency rapidly developed a Disaster Relief Services program, encompassing three major functions:

- Direct services, particularly case management for people with disabilities affected or who were newly disabled by the WTC incident
- Education, training, and technical assistance to relief and other service-providing agencies
- Outreach to people with disabilities who did not come forward seeking help in the first weeks or months after the attack.

Direct Services for People with Disabilities Affected by September 11

1. Case Management and Other Direct Services

CIDNY's staff provided a broad array of services in assisting people with disabilities in the aftermath of the WTC incident:

- Comprehensive situational assessments of consumer needs, in such areas as health care, finances, mobility, transportation, assistive technology, child care, family relations, emotional and mental health, employment, and legal matters
- Crisis intervention, providing immediate assistance in urgent situations, including service coordination for accessing federal, state, and private disaster relief programs
- Peer counseling and referrals to specialized mental health services as needed
- Referral and advocacy for consumers and their families for appropriate benefits, entitlements, and services provided by other governmental and private agencies
- Home visits to consumers requiring peer support and/or needing help to complete applications for disaster relief and environmental cleanup services.

KR, a twenty-one-year-old woman with an existing traumatic brain injury, was expecting a visit from the Homebound Unit of NYC's Human Resources Administration (HRA) on September 11, to determine her eligibility for public assistance. She lived close enough to the site to see the attack and was highly traumatized by what she saw. Just when she needed assistance the most, HRA canceled its visit because of the disaster.

She contacted CIDNY in early October 2001, needing emergency food and cash assistance. The agency sent a volunteer to her apartment, bringing food and money, as well as helping her apply for assistance from various relief agencies.

Within two weeks, the Red Cross gave her food, clothing, and a "comfort kit," and agreed to help her find alternative housing. In the meantime, they did not assist with rent in her existing apartment, so she ran the risk of eviction. CIDNY assisted KR with obtaining rental assistance from FEMA and signing up for Section 8 housing, which normally has a waiting list of up to ten years. She was not eligible for emergency income replacement because she had no income before the disaster.

CIDNY consumer case file

2. Services for Newly Disabled People

Newly disabled people faced social isolation, often stemming from mobility issues and mental health concerns like depression, anxiety, and stress. Those who found their way to CIDNY were advised about making housing adaptations; using the vocational rehabilitation system; assistive technology; managing medical concerns and costs; learning to consider accessible facilities and transportation in planning daily life; and acquiring retraining or assistance with basic activities like personal care, household tasks, communication, and travel.

NM was a temporary employee located in a World Trade Center office. She never arrived at work on September 11; she was trampled by the escaping crowd, which knocked her unconscious, broke her collarbone, and badly bruised her legs and back.

At first, NM managed, on her own, to obtain Disaster Unemployment benefits, a month's rent, and \$50 for food from the Red Cross, as well as coverage for her prescriptions from the Crime Victims Fund. She contacted CIDNY a week after the attack, asking for help in applying for Disaster Relief Medicaid; at this point, she felt overwhelmed by the physical and emotional effects of her ordeal and unready to navigate the bureaucratic process of seeking additional assistance. She had not yet thought about long-term needs for health coverage, transportation, and finding new employment.

CIDNY consumer case file

JC is a forty-five-year-old Hispanic man who was working as a hotel employee in the World Financial Center on September 11, 2001. The father of four, JC became unemployed after the WTC incident, not only because of the destruction of his place of employment, but also due to a severe injury to his legs and the exacerbation of an existing liver condition caused by the attacks. His health was further worsened by the onset of post-traumatic stress.

At the time he was referred to CIDNY, JC's case had been closed by another disaster relief agency due to that agency's determination that he had failed to comply with a service plan. Over the course of three months, CIDNY assisted JC in (1) successfully reapplying for disaster relief funds from Safe Horizon, (2) completing an application for the American Red Cross Additional Assistance Program, and (3) receiving information and counseling about refinancing his mortgage with a low-interest rehabilitation loan. In addition, as JC begins his transition from disaster relief assistance to longer-term case management, CIDNY continues to work with him on issues related to Social Security Disability recertification and access to public health insurance for himself and his family.

CIDNY consumer case file

3. Removing Barriers to Full Integration by Relief and Service-Providing Organizations

From the outset, lack of appropriate access and accommodations for people with disabilities seeking response and recovery services in the aftermath of the WTC attack was evident, reflecting, among other factors, methods of program administration that disregarded needs specific to those with physical, medical, cognitive, or psychiatric conditions. Through its work with WTC

consumers, CIDNY identified a series of administrative procedures that resulted in inappropriate service denials with a wide range of public and private agencies. CIDNY also observed that agencies lacked disability-related information.

In particular, people with disabilities affected by the WTC attack were unable to access services because, for example, they could not read signs, they lacked access to American Sign Language (ASL) translation at service and disaster sites, there was no teletypewriter (TTY) system set up for reaching specific hotlines, there was a disregard for reimbursement of assistive technology destroyed in the attack, and there was a lack of effort to make visits to homebound consumers to assist with disaster relief paperwork.

CIDNY received a call from a displaced Battery Park City resident with a mobility impairment. She had called FEMA to register and assess damage to her apartment. FEMA regulations required that she meet the FEMA representative at her apartment to assess damage. For the consumer, this was physically impossible, particularly given debris and other barriers situated around the vicinity of the WTC attack. When she was unable to comply, FEMA closed her case. CIDNY successfully advocated with FEMA to establish a waiver of this requirement for people with mobility impairments.

CIDNY consumer case file

MR, a person living with mental illness and an orthopedic disability, lived downtown. She had received the offer of a new job in the downtown area and was on her way to a meeting about the job on September 11. When the attack occurred, MR was near the collapsing buildings and was knocked over by people fleeing the scene, sustaining back and ankle injuries that exacerbated her existing orthopedic condition. Moreover, MR and her son were displaced from their apartment for many months, which was covered with dust and debris from the disaster.

MR came to CIDNY in late September 2001. Due to her physical disability, it was impossible for her to register for assistance with the Red Cross, as applicants were expected to stand in long lines to meet with relief workers in person. She had asked for an accommodation, but was told that she would have to wait with the other applicants if she expected help. In response, CIDNY arranged for MR to be registered at the Carmine Center, the only accessible site among all the locations dispensing disaster relief assistance.

CIDNY consumer case file

Education, Training, and Technical Assistance to Other Relief Agencies

As indicated, through direct services to consumers—and from inquiries and reports from other service providers—CIDNY was able to track systemic and policy issues affecting service delivery to people with disabilities. The agency responded to these issues by:

- Participating in the United Services Group (USG), a coalition of disaster relief and service-providing agencies that met periodically to share information, discuss policy, and plan actions. CIDNY participated in the USG's Case Management Working Group, Technology Committee, Training Committee, Public Relations Committee, and Service Coordinator Steering Committee

- Creating and distributing basic informational materials to other agencies about disability issues, benefits, and resources, as well as materials specific to serving “hard-to-reach” populations
- Offering education and training workshops to other agencies, and assisting them in integrating materials on disability awareness and the impact of having a newly acquired disability into their own training and orientation programs
- Answering questions from individual service coordinators at other agencies about disabled World Trade Center consumers among their caseload, and accompanying consumers to meetings with other service or benefits providers as their advocate.

In the first months after the attack, CIDNY conducted daily conference calls with FEMA and the Red Cross. One major issue was the need for accommodations at the Disaster Assistance Centers, where people applied for assistance from dozens of government and private relief agencies. Multiple visits were often required. Many people with disabilities were unable to apply for benefits because they could not stand on line for the long periods of time required. At the start, there were no chairs at centers, and people were not allowed to send representatives to file applications on their behalf, even if they were homebound prior to the attack.

FEMA did not see a need for accommodations because, as one CIDNY staffer recalled, “They said they had received 10,000 applications and none were from people with disabilities. But they had taken the question on disability out of their screening interviews to save time.” Eventually, FEMA restored the disability screening question, making it possible for them to track applications from people with disabilities.

CIDNY staff notes

One relief agency sponsored a support group for survivors and family members experiencing posttraumatic stress disorder (PTSD). Meetings were held in a location that was not accessible to wheelchair users. CIDNY advised the agency on how to serve people with both mobility impairments and PTSD, including strategies for attaining cooperation of the building management in making meeting space accessible or relocating the meetings, as well as the benefits of telephone-based support groups for those unable to attend in person due to psychiatric symptoms.

CIDNY staff notes

People at the Red Cross were polite and interested, but everything had to be brought to their attention. Their volunteers were from all over the country. They didn't understand transportation issues for people with disabilities in New York City. They would say, "Can't they get a neighbor to drive them?" and we'd have to keep telling them that the neighbors don't have cars.

Recollection from Susan Scheer, June 24, 2004

Outreach Activities

CIDNY's outreach activities reflected four principal strategies: direct outreach to potential consumers and their advocates; media outreach through articles and public service announcements; distribution of "tip cards" offering key information; and outreach through the Internet.

1. Direct Outreach

After the first few weeks, it became clear that many people with disabilities were not coming forth for assistance, for reasons CIDNY identified as:

- Being more isolated than the public at large, due to mobility impairments and limited access to communication
- Not feeling welcome at organizations that make no obvious effort to reach or include them
- Not considering themselves to be “people with disabilities,” despite needing and being entitled to services or benefits based on a disabling condition.

CIDNY began outreach to identify consumers and engage them in services. In late October, efforts were made to identify overlooked groups of elderly and/or disabled people living in the downtown/Chinatown area. In November, several Mandarin-speaking volunteers were recruited, and written outreach materials began to be translated into Mandarin. CIDNY staff explained disaster relief issues for people with disabilities to groups of employees from other agencies, including those at a Disaster Preparation Conference held at the Manhattan Veterans’ Administration Hospital and to caseworkers attending a conference of the United Services Group, both in January 2002. Other efforts included:

- In-person distribution of written materials related to disaster relief programs and CIDNY services in the lobbies of housing facilities, as well as to building management offices, health clinics, and neighborhood community centers
- Discussions with building managers to help identify tenants known to them to be homebound or disabled and then distributing disaster relief materials to those persons
- Attending consumer-initiated group meetings to provide support and disaster relief information
- Working with the American Red Cross and FEMA representatives to arrange to identify dedicated liaisons on their staff to work with elderly and/or disabled Lower Manhattan residents

- Distribution of letters with instructions on how to register with the EPA for environmental inspections and assistance to every person in CIDNY's consumer records database residing in designated zip code areas.

Other outreach sites included hospitals and clinics specifically serving World Trade Center-affected populations, including several large hospitals providing health screening and medical care to World Trade Center recovery and volunteer workers with emerging respiratory difficulties, skin lesions, post-traumatic stress syndrome, and other problems. CIDNY worked closely with Mt. Sinai's Selikoff Center for Occupational and Environmental Medicine, whose social workers began to refer consumers to CIDNY's WTC Service Coordination Program and benefits-related workshops.

2. Media and Public Relations

Articles and public service announcements were targeted to media accessible to consumers of varying sensory capacity, including those speaking languages other than English. CIDNY assisted reporters covering the disaster.

- Newspapers: *The Wall Street Journal*, *the New York Times*, *ABLE*
- A story recounting ongoing issues for a CIDNY consumer was broadcast on 44 New York State radio stations on September 10, 2003. The story was picked up by CBS Radio News Network and broadcast nationwide on another 726 stations.
- Information posted on CIDNY's and other metropolitan New York Independent Living Centers' Web sites, as well as on the USG's public Web site.

A mother in Queens had two daughters. The older daughter worked in the World Trade Center and died in the attack. The younger daughter requires full-time care because she has autism. The older daughter had supported the family financially and helped her mother care for her autistic sister.

By the time the mother contacted CIDNY, she was “at the end of her rope.” Caregiving for her remaining daughter kept her so busy that she had no time to apply for benefits for victims’ families, but she had heard about CIDNY in the local news. CIDNY helped her to get assistance for her daughter and connected her with support groups in Queens for parents of autistic children.

CIDNY consumer case file

3. Tip Cards

These introduced CIDNY as a resource for people who needed help related to the WTC incident. The cards were produced in English, Spanish, and Mandarin, and included information on how to contact CIDNY. They were directly provided to:

- Health and hospital settings, including emergency rooms, trauma, psychiatric and rehabilitation units, information desks and waiting areas; community health clinics, mental health centers
- Social and human service agencies (including disaster relief providers like Safe Horizon, Catholic Charities, American Red Cross), homeless shelters, food pantries and hunger-related organizations or programs, houses of worship, senior citizen and other community centers, public schools
- NYPD community relations personnel and local precincts, Fire Department community relations personnel and local engine and ladder companies, Emergency Medical Service, etc.

4. Outreach through the Internet

CIDNY posted tip cards on its Web site (www.cidny.org) and asked other Independent Living Centers to do the same. CIDNY also provided the ILCs with information to disseminate about CIDNY's disaster relief services and disability-related workshops. Additional entities contacted to request assistance in Internet outreach included:

- Disability organizations: United Cerebral Palsy of New York, Multiple Sclerosis Society—New York Chapter, Blindness Resource Center, New York State Independence for the Disabled (NYSID), National Spinal Cord Injury Association, Coalition of Voluntary Mental Health Agencies
- 9/11 relief providers: the United Services Group, Safe Horizon, the American Red Cross
- E-mail lists originated by Lower Manhattan tenants' organizations, displaced Battery Park residents, and others.

In spring 2002, a man with quadriplegia who lived near Ground Zero called CIDNY seeking financial aid to purchase an air filter. Though he had experienced respiratory problems severe enough at one point to need hospitalization, his apartment had not yet been cleaned of the dust and debris of 9/11. As he could not leave his home, he went unnoticed by outreach personnel of agencies providing relief in the downtown area and was unaware of how to seek help until, by chance, he learned of CIDNY.

CIDNY consumer case file

SECTION 2: HOW THE IMPACT OF DISASTERS ON PEOPLE WITH DISABILITIES DIFFERS FROM THE IMPACT ON THE GENERAL POPULATION

Changes from normal life due to disasters hit people with disabilities harder

1. Disasters Create New Physical Barriers and Eliminate Services Used by Everyone

For people with disabilities, the disaster and its aftermath may take away their ability to do tasks that they can usually do and, as such, keep them from responding to the disaster as others do.

- Rubble, debris, cracks, flooding, and other changes in the surface of a street make walking difficult for people without disabilities; they make it near impossible for people with mobility impairments or blindness to travel at all.
- Elevators not working are an inconvenience to people who can walk, and are a distinct barrier to those who either cannot walk or have difficulty doing so.
- Loss of communication systems for people who are homebound, mobility impaired, visually impaired, and hearing impaired is especially isolating and a threat to their safety, as they are then often unable to seek outside assistance or obtain important emergency-related information.
- Most New Yorkers can adapt to the loss of certain bus and subway transportation options. People with disabilities, however, are often unable to switch to alternatives used by those without disabilities, particularly since many alternatives are not accessible (e.g., private cars, taxis, bicycles).

- Poor environmental conditions—including toxic or poor air quality—are dangerous to everyone, but for people with breathing-related medical conditions, they keep them from being able to go outside or open windows at all.

Stories came in [to CIDNY] about people with mobility disabilities that were not readily visible, having to explain repeatedly why they could not flee the scene of the tragedy in order to get lifesaving assistance.

CIDNY staff notes

LM did not evacuate from her Battery Park City apartment, although she knew others were leaving, because she was afraid to go outside into the clouds of dust and debris. She had a traumatic brain injury, facial paralysis, and hearing and speaking difficulties. Because one of her eyes didn't close easily, she knew it might be injured by the debris in the air. She believes she stayed in her apartment for thirty-six hours, waiting for the air to clear.

CIDNY consumer case file

HARRIS: Davis-Chanin family members. . . . lived near Battery Park, but they've been in a single-room hotel for the past two months . . . I can't imagine how all four of you plus the four . . . guinea pigs . . . have . . . been living in . . . a one-room hotel room.

LAURA DAVIS-CHANIN: It's very, very difficult . . . managing children and it's also a smaller room than normal because I [need to] have a handicapped-access bathroom. So it's smaller and it's really, really difficult. Plus with my scooter, it's a very small space.

"Displaced New York Family Copes with Living in One Room After September 11," CNN transcript, November 22, 2001

At all stages after the attack, transportation was one of the most common problems for which consumers with disabilities sought CIDNY's assistance. iCan News Service reported that many people with disabilities living in Lower Manhattan were not getting to health-care appointments because they could not find transportation or were afraid to leave their homes. Those with blindness or low vision and their guide dogs had to spend hundreds of hours learning how to navigate the rearranged city, on foot and by rerouted public transportation. The League for the Hard of Hearing found that 50 percent of its clients were either canceling appointments or just not showing up.

The Port Authority Trans-Hudson has been ferrying passengers under the Hudson River for decades. It was one of the first modes of transportation in the area to comply with the Americans with Disabilities Act. With the key stations equipped with elevators, travel to New York was, according to Hudson County resident James Stoney, a “breeze.” Getting places in New Jersey has always been difficult, if not downright impossible, for wheelchair users. For many individuals with disabilities, Manhattan provided a variety of opportunities. When the twin towers fell, PATH service between cities in Hudson County and downtown New York ended.

“Paradise Lost,” by Marianne Valls, from the Web site of the New Jersey Developmental Disabilities Council

(It took over two years for PATH service to the World Trade Center site to be restored.)

2. Disasters Disrupt Daily Life Arrangements for All, but People with Disabilities Have More Trouble Putting Things Back Together

- Many disabled residents could not clean the hazardous dust and debris from their apartments themselves nor were their caretakers, who could have assisted with this task, allowed into the Frozen Zone for many days.
- Some people with disabilities who had to leave their homes had even more trouble than people without disabilities finding new affordable housing in New York City’s extremely tight and expensive real estate market. In addition, New York City’s rental housing stock, being older than that in most areas around the United States, is composed of less accessible units for people with mobility impairments.
- People with disabilities tend to face multiple obstacles to finding work. It is difficult for them to get essential skills and education, to find

employers who will hire them, and to find jobs that provide the accommodations they need to function. Those who lost jobs due to the WTC attack faced even tougher job searches than all other New Yorkers who became unemployed during the post-disaster economic slump.

- Computer systems governing public assistance, food stamps, and Medicaid failed, as central offices of city agencies were in the area damaged by the attack. Some food stamp recipients whose benefits were cut off by computer failures were able to walk to food pantries and soup kitchens to get groceries. People who couldn't walk far enough, or couldn't wait in line and carry home a load of groceries, were unable to get emergency food.

GM was a resident of Battery Park City who had paraplegia. When forced to leave his apartment, he found a new one. However, to be accessible to him, it needed modifications, and his landlord would not allow him to make them. This was a violation of fair housing rules, which permit tenants to modify their apartments for accessibility as long as they agree to return them to their original condition when they move out.

CIDNY consumer case file

MY is a self-employed professional with a neurological condition, who had to leave his scooter at his apartment in Battery Park City during the evacuation. At first, he stayed at his parents' home, where his sixty-year-old father carried him up and down stairs. When he learned it would be three months before he could move back into the apartment that also served as his office, he moved to a hotel.

To resume his work, he needed a computer, which he requested from the Red Cross. He was told to find a computer to borrow. As his condition had worsened after the attack, he did not have the physical or emotional stamina to locate a computer to borrow. According to his caseworker at CIDNY, "RC [the Red Cross] doesn't get it, says 'he does not feel (up to) doing anything about it now.'"

What the Red Cross did not understand was that the loss of mobility (caused by not having an electric scooter), combined with the loss of his home and work, undermined the foundations of MY's independence. It was hard enough to ask the Red Cross for help; he did not want to also ask his friends and acquaintances to lend him a computer.

CIDNY consumer case file

3. Disasters Interrupt Specialized Services Essential to People with Disabilities

In the aftermath of the WTC incident, and reflecting the disregard for people with disabilities in response and recovery planning and operations, many vital services remained disrupted or disallowed, even after it became clear that this circumstance placed people with disabilities at risk.

- Delivery of food, medication, and oxygen and home-care services

were unavailable for many people in the Frozen Zone for a prolonged period of time.

- Access-A-Ride and other transportation for people with disabilities were interrupted, thereby causing many people with disabilities to be captive in their homes and unable to get out for appointments, food, and services.
- Closed-captioning for the deaf on television was suspended for some period of time, causing immense confusion for the hearing impaired, who could not obtain accurate or timely information on what was happening during and after the attack. Exacerbating this situation, Telecommunications for the Deaf reported that telephone relay centers (which translate typed messages from deaf callers into spoken words to the people they are calling, and vice versa) were unprepared for the deluge of calls on September 11, so that many callers were unable to communicate with friends and family.¹

New York City Transit, which runs the Access-A-Ride paratransit service, is taking reservations only one to two days in advance, instead of the usual four days. Buses . . . cannot go below the Frozen Zone near the attack site . . . Some subway stations remain closed and are being rerouted, which may cause complications for people with mobility impairments who depend on catching the train at a specific stop, or for people who are blind and rely on their routine.

“Disability Community Struggles in Aftermath of Attacks,”
Nicole Bondi, iCan News Service, September 18, 2001

Citymeals-on-Wheels, which provides food for the homebound elderly, saw service disrupted last week when meal vans could not make it into the city after the attacks ... Citymeals-on-Wheels program coordinator Alison Leavitt said 100-200 clients did not get meals on either Tuesday or Wednesday . . . All the agency’s clients have been contacted and emergency supplies went out last week to those who needed it most, Leavitt said.

“NYC Disabled Community Faces Hardships After Attack,”
Long-Term Rehab News, November 2001

The Response to Disaster by Relief Agencies Is Experienced Differently by People with Disabilities

1. Disaster Services Are Not All Accessible to People with Disabilities

As evidenced in the aftermath of the WTC incident, emergency response and recovery measures did not accommodate people with disabilities.

- Warnings and instructions were not routinely communicated in ways that can be seen, heard, and understood by people with disabilities.
- Most shelters and Disaster Assistance Centers were not accessible to people with mobility impairments, and the centers did not have signs and printed materials that were readable by the blind and visually impaired.
- Many relief agencies did not have—or failed to publicize—TTY numbers and most had no American Sign Language interpreters for the deaf and hearing impaired.
- People with disabilities were not always able to travel to sites providing relief services and supplies, reflecting the widespread absence of accessible modes of transportation.

- Alternative methods of outreach—for example, home visits or information sessions held at local community centers rather than out-of-neighborhood locations—were not conducted, even though there were people who were homebound or who had cognitive or psychiatric conditions that precluded them from obtaining assistance from relief agencies directly.

Some people with disabilities were left behind in evacuated buildings because rescue agencies didn't fully understand how someone could not be aware of the evacuation effort. Relief workers often had difficulty understanding why the public transportation shutdown prevented people from accessing emergency assistance. Emergency housing and shelters were not adequately equipped for people who need accessible lodging. Trauma counselors didn't always fully appreciate the experience of trying to remain independent when routine services and supports have gone to hell.

“Manhattan CIL Rebounds in Aftermath of Attacks with Help from IL Community,” Kaye Beneke, *ILRU Network*, January 2002

DM, a Battery Park City resident, uses crutches and has asthma. When a shuttle bus began operating to link the housing complex to the streets outside the Frozen Zone, she found the shuttle was a small yellow school bus with no lift, which made it inaccessible to her. She had to take taxis instead. CIDNY contracted with two car services to provide transportation for World Trade Center survivors to medical appointments and other essential destinations.

CIDNY consumer case file

2. There Is a Lack of Disaster Services Specifically Needed by People with Disabilities

Many of the disaster response and recovery efforts were not structured to meet specific needs of people with disabilities.

- Methods of outreach, both for evacuation immediately after the disaster and for overcoming the isolation that kept people uninformed of available help and how to get it, did not take into account ways in which to reach people who were homebound or with limiting cognitive or psychiatric conditions.
- There lacked mental health professionals experienced in working specifically with people with disabilities.
- Knowledge of benefits as they relate to people with disabilities—such as SSI, SSDI, Medicaid, housing accommodations—was not incorporated into initial disaster relief efforts.
- There were no planned programs for assisting with the replacement of durable medical and other related equipment and medicine destroyed, lost, or left behind.
- There were no planned programs dealing with reimbursement for accessible transportation or accessible hotel accommodations.

An employee at the World Trade Center saw nineteen of her co-workers die before she escaped. The trauma triggered a stroke, which made her blind. She had no idea that she was eligible for financial assistance as a survivor of 9/11 until she got in touch with CIDNY seven months after the World Trade Center disaster. The consumer was referred to CIDNY by her daughter, a California resident, after her employer notified her that she would be fired if she did not return to work by the end of the month.

CIDNY consumer case file

When a Red Cross nurse asked RG if she had left her crutches behind and needed new ones, she said “no”—because she uses a scooter. She had to leave it behind when she evacuated her Battery Park City apartment. But the Red Cross never asked if she needed a replacement scooter. They reported to CIDNY that all her needs were being met, even while she was staying in a friend’s apartment, where she couldn’t take a shower because the tub was not accessible.

CIDNY consumer case file

Things really improved . . . when Rosemary Lamb, representing the Office of Advocate for Persons with Disabilities, convinced public information officials at the NYC emergency control center to air vital contact information about assistance for people with disabilities.

“NYSILC Crisis Response Plan Focused on Communication, Coordination—and Returning Control as Soon as Possible,”
ILRU Network, January 2002

3. Shortcomings Were Evident in Response to Requests Regarding People with Disabilities

Most relief and other service agencies were quick to remedy problems once CIDNY and other disability advocates identified and offered suggestions on dealing with them. However, this did not necessarily help people with disabilities who were discouraged before the problem was fixed and did not return for assistance.

- All city, state, and federal agencies are required to have an employee to ensure compliance with regulations regarding disability issues. Many large nonprofit organizations also have them, since they are required to comply with the Americans with Disabilities Act. Nonetheless, many organizations involved in relief efforts did not have

an identifiable person with knowledge of disability needs or the responsibility to act as liaison with the disability community.

- Members of CIDNY's staff reported that relief agencies appeared to believe that disability was "not our issue," so that they did not have to meet the needs of people with disabilities.
- After September 11, the disability liaison at the New York Police Department was promoted. Despite requests from Independent Living Centers for contact information for her replacement, the department did not name a replacement for over a year.

After the 1993 bombing, many tenants of the World Trade Center and the building management for the complex were aware that evacuation plans for people with disabilities were needed. Unfortunately, the evacuation plan for people with disabilities was lethal to them: It consisted simply of requiring them to go to pre-determined meeting sites within the building and wait for evacuation assistance.

Two wheelchair users escaped from the World Trade Center disaster, using evacuation chairs with inexperienced helpers, because they broke the rules and left before being found by rescue workers. Most who did what they were expected to do, that is, wait to be rescued, died, according to June Kailes.

"Evacuation Preparedness: Taking Responsibility for Your Safety—A Guide for People with Disabilities and Other Activity Limitations," 2002

One man's final image as he left the eightieth floor and made it to safety was that of a roomful of people using wheelchairs and walkers waiting to be rescued by the firefighters who were coming up the stairs. They all perished as the building collapsed shortly after.

"The Day the World Changed," Angela Miele Melledy,
ABLE, October 2001

4. Security Measures Create Barriers for People with Disabilities

- Blocking areas off can keep people with disabilities from traveling through or around an area.
- During searches of people with disabilities at airports, upon entry into buildings, and elsewhere, security staff often do not realize that such individuals may have unfamiliar objects among their assistive equipment, that standing up for a wand examination can be difficult, and that some metal detected on their persons may be part of a prosthesis or medical device that cannot be removed.
- People with medical conditions may need to carry needles for insulin injections, scissors for changing bandages, or other items not usually permitted in shelters. To preserve their safety, these individuals must not be separated from their service animals or from assistive equipment.
- People who have communication impairments or cognitive disabilities can be seen as threatening or uncooperative by untrained security personnel. In turn, guards demanding identification or explanations can intimidate and discourage people with posttraumatic stress disorder, chronic mental illness, mental retardation, or communication impairments.

Security personnel at airports and other highly secure locations should be aware of people with hearing loss when they do not respond to all the questions and when they carry items such as pagers, hearing aids, TTYs, or cochlear implant processors. There was an incident when a plane was diverted because a deaf passenger went to the bathroom not knowing he was supposed to stay seated.

“Lessons Learned from September 11,” presentation by Claude L. Stout of Telecommunications for the Deaf, Inc., at the State of Science Conference at Gallaudet University, October 30, 2001

Agencies serving people with disabilities reported great difficulty in making sure their consumers were able to get home on the day of the disaster. Michael, a man with mental retardation who worked at the World Trade Center, was able to get out of the downtown area along with everyone else. However, he could not get home alone from Midtown in the chaos of that first afternoon, when the subways were not running. His cell phone stopped working, and it was hours before he could get to a pay phone to call his sister, to tell her he was waiting for her husband Jake at the Port Authority:

[Jake] called and promised to get to Michael as quickly as he could. But his attempts to rescue his brother-in-law became a race against time.

“Michael called me back and said, ‘I’m so scared. Where’s Jake?’” Pleeter [his sister] said. “He told me that the police were clearing the area because it was a potential bomb site. I said, ‘Tell them that you’re mentally handicapped and somebody is coming to get you.’ Jake Pleeter reached Michael just before the Port Authority was shut down.”

“Agency Teamwork Helps Locate WTC Survivor,”
C. J. Miller, *The Journal*, January 2002

Residents’ prescription and other medical needs became a serious issue. Stores were closed. Mail delivery was suspended. Nonresidents could not enter the area and people weren’t allowed to return if they left.

Our City Council Representative at the time “smuggled” the owner of our area drugstore into the neighborhood. Tenants volunteered to run the cash register and manage the store as he filled residents’ prescriptions. Some of our board members delivered the prescriptions to those unable to leave their apartments. It was amazing teamwork that allowed him to stay open and we were grateful that there was a source for what was life-sustaining medication for many people.

“Neighbor to Neighbor—The Downtown Solution:
IPNTA’s Guide to Community Healing,”
Independence Plaza North Tenants Association, 2003

EXAMPLE 1: ACCESS TO THE FROZEN ZONE AFTER 9/11

For security reasons, the streets around the World Trade Center were shut down in a pattern that changed repeatedly during the five months following September 11. The map on page 36, generated by the New York City Office of Emergency Management, shows the dates on which sections of the Frozen Zone opened to traffic. It does not show when pedestrians, as distinct from vehicles, were allowed into closed areas. There was great confusion about this, as individual police officers guarding the perimeter of the site were not consistently informed of changes in the boundaries or of changes in rules regarding who was or was not allowed to cross them. This confusion was particularly harmful to people with disabilities, for some of whom communication with police guards was difficult or impossible and detouring for blocks around a closed street was unmanageable.

On the map, the area at the left-hand edge of the site, below Chambers Street, represents Battery Park City, a high-density residential development that was home to many people with disabilities in September 2001. The rest of the Frozen Zone blocked travel to and from Battery Park City. Residents with disabilities faced ongoing disruptions of their lives beyond those experienced by other residents.

- A temporary shuttle bus that carried residents through the Frozen Zone out to the open streets was not accessible to people with mobility impairments.
- Taxis were considered “emergency vehicles” and allowed in, but Access-A-Ride vans were not given “emergency” vehicle clearance until several weeks had passed.
- Often, home health aides were not allowed in to care for consumers, and delivery people bringing prescription drugs and medical supplies were kept out.
- In the first days after the disaster, residents of the Frozen Zone were allowed into their apartments for just fifteen minutes, to feed pets and

gather clothing, documents, and other essential items. People with limited mobility had to turn to CIDNY in order to get permission to bring an assistant with them so they could accomplish this task within the fifteen minutes allotted.

- When bus service was restored in Battery Park City and the areas just outside the Frozen Zone, many bus stops were blocked by police cars and other emergency vehicles. As a result, passengers in wheelchairs needing to use the bus lifts could not do so, because the buses stopped too far out in the street.



What took the most time was getting Access-A-Ride back in operation. First they had to get their computers working again. Then the police wanted to have security on every van—a police officer—but of course they didn't have enough police officers at that time. Then there was the issue of checkpoints and permits for the vans, and when we got all that worked out with the city and the police, the FBI overruled them and said the Access-A-Ride vans couldn't come in.

Recollection by Susan Scheer, June 24, 2004

EXAMPLE 2: MENTAL HEALTH NEEDS

Needs of People who Already Have Mental Illness

It is important to treat people with mental illness on an ongoing basis, so that they have the capacity to function well if a disaster strikes. The passages below highlight the importance of having uninterrupted access to prescription medication, which requires pharmacies to be open, a mechanism for authorizing prescriptions, and a source of payment for medication.

Clinical field experience has shown that disaster survivors with mental illness function fairly well following a disaster, if essential services have not been interrupted. Many demonstrate an increased ability to handle this stress without an exacerbation of their mental illness, especially when they are able to maintain their medication regimens. However, some survivors with mental illness have achieved only a tenuous balance before the disaster. The added stress of the disaster disrupts this balance; for some, additional mental health support services, medications, or hospitalization may be necessary to regain stability. . .

Having sufficient financial resources and being able

to benefit from a social support network buffer the potentially devastating effects of a disaster and greatly assist the recovery process. An additional resilience factor includes the ability to tolerate and cope with disruption and loss. In contrast, vulnerability factors include preexisting health or emotional problems and additional concurrent stressful life events . . . Survivors who have significant concurrent psychosocial, health, or financial problems are at greater risk for depression, anxiety, posttraumatic stress symptoms, or an exacerbation of their preexisting condition.

Training Manual for Mental Health and Human Service Workers in Major Disasters, Deborah J. DeWolfe, PhD, MSPH for the Federal Emergency Management Agency and the Center for Mental Health Services at the Substance Abuse and Mental Health Services Administration, 2000

Needs of People with Disabilities Other Than Mental Illness

Having to evacuate is unsettling for everyone, but especially unsettling for people with visual, hearing, or cognitive impairments, because they rely on familiar sights and routines to orient themselves. Moving from one temporary shelter to another seems to raise the stress level of evacuees much more than moving to the first shelter.² People with disabilities are more likely than others to have to leave their first shelter placement because it is not accessible to them. If they stay or return to their own homes, they may not be able to arrange for repairs or cleanup, due to financial, physical, or mental limitations.

Some stress is caused by the recovery rather than the event itself, such as the frustrations and challenges of dealing with bureaucratic relief agencies or losing a job, mirroring that which is experienced by people without disabilities. People with disabilities, however, often have low incomes, reduced physical stamina, and/or mobility impairments that decrease the amount of time and energy that they can use in recovery activities.³

Needs of People with Newly Acquired Mental Health Impairments

New York City received approximately \$125 million over a three-year period for crisis counseling and short-term therapy. “Within twenty four hours of the World Trade Center collapse, DMH [Department of Mental Health] informed the media that its mental health counseling and referral information line—LIFENET—was up and running in English, Spanish, and Asian languages,” announced the public relations office of New York City’s DMH. The LIFENET Hot Line received 29,900 calls in five months.⁴ Although it played an essential role, the hotline was primarily a referral system that could not guarantee the quality or appropriateness of the care.

Previous research indicated “the vast majority of disaster survivors recover from the initial shock and trauma of a disaster usually within weeks or months of the event.”⁵ The city’s Department of Health & Mental Hygiene also found that about two-thirds of people who developed PTSD symptoms recovered fairly quickly. One out of three had persistent PTSD symptoms, especially those who suffered another loss or trauma after the World Trade Center disaster, such as losing a job or acquiring a disability. Another group developed PTSD symptoms months or years after the attack; these people also went through another loss or trauma. Project Liberty administrators found that FEMA funding would not help people with long-term PTSD and related anxiety and depression, who required traditional mental health care, including therapy, medication, and/or case management.⁶

AC is a forty-eight-year-old, African American woman who was working on the seventy-eighth floor at One World Trade Center on September 11. On that day, she evacuated herself, as well as a co-worker who was on fire, out of the building. Since that time, AC has suffered from severe posttraumatic stress, comprised of frequent and ongoing flashbacks and nightmares and chronic symptoms of depression. Her condition has been exacerbated by financial problems resulting from loss of her employment since the World Trade Center attacks.

Since becoming a consumer at CIDNY, AC has been helped with ensuring receipt of much-needed financial assistance from previously available disaster relief programs and with procuring health-care insurance that will meet her ongoing psychiatric needs. AC also felt safe enough at CIDNY to participate in the agency's Project Liberty support group, co-sponsored with the Jewish Guild for the Blind. Most recently, AC received help in applying for the Red Cross Additional Assistance program. On a longer-term basis, CIDNY is working with AC to develop a strategy for returning to the world of work.

CIDNY consumer case file

Health professionals flooded Lower Manhattan, sometimes to the consternation of those at Ground Zero, many of whom told volunteer therapists to go elsewhere . . . Mt. Sinai operated a twenty-four-hour hotline for two weeks, using eight phone lines to offer telephone counseling to community residents “too frightened to leave their homes.” New York Presbyterian Hospital helped a variety of companies and organizations to provide onsite group counseling and follow-up counseling to their employees . . .

It became clear that the short-term response was inadequate for the longer-term impact on the city’s population . . . “Project Liberty,” the federal and state emergency program set up to fund emergency services and counseling at workplaces, schools, and homes in the metropolitan region, provided \$22.7 million, with \$14 million reserved for use in New York City.

As late as June 2002, Jack Krauskopf of the USG [The 9/11 United Services Group] was concerned that although there was a system “for crisis counseling and short-term mental health assistance,” it was “not clear if there is enough support for the long-term counseling and treatment needs that people who have been severely affected emotionally have.” . . . One major problem was the lack of an adequate system of public and private insurance to cover mental health services, which made any planning for long-term psychotherapy virtually meaningless without a huge influx of federal and state monies.

“The Frail and the Hardy Seniors of 9/11: The Needs and Contributions of Older Americans,” interview with Myrna I. Lewis, PhD, of the Mt. Sinai School of Medicine, at Johns Hopkins University, Center for Civilian Biodefense Strategies, 2003

SECTION 3: LEARNING FROM EXPERIENCE—SUCCESSFUL STRATEGIES FROM 9/11 AND THE 2003 BLACKOUT

Having a plan that specifically acknowledges the needs of people with disabilities, knowing what is needed and how to supply it in the event of disruptions, and practicing evacuation—these are a few of the factors that help limit both physical and psychological injury during and in the immediate aftermath of a disaster.

United Cerebral Palsy of NYC’s executive and administrative offices were at 80 Maiden Lane, only three blocks from the World Trade Center site. While all staff were safely evacuated following the collapse of both towers, many faced long walks home due to the closure of mass transit in Manhattan and the lockdown of major bridges and tunnels. Hundreds of children and adults with disabilities attend UCP/NYC programs citywide. Most have some degree of physical impairment, and many use wheelchairs or walkers for mobility purposes. Some live in one borough and attend a day program in another.

Manhattan facilities at 23rd Street and Park Avenue South faced getting both very young children and adults of all ages safely home. Some staff members were able to utilize agency vans to drive people home. Other groups of participants, accompanied by staff, headed to buses and subways still operating. Private transportation companies, which transport many children and adults from their homes to programs and back, stayed on the job long past normal hours.

Paula Willingham, supported employment specialist with UCP/NYC, contacted families to arrange meeting places, then escorted each consumer to that meeting place

via public transportation. In Brooklyn, staff members stayed overnight with two Manhattan women who attend day programs in Brooklyn. They were able to arrange accommodations, fill medical prescriptions, and obtain changes of clothing for the women as they made them comfortable at nearby Belsky House.

“UCP/NYC Family Responds to September 11th Tragedy,”
UCP Image, Fall 2001

After the 1993 World Trade Center bombing, at the suggestion of the local emergency management office, The Associated Blind (a local service provider for low- and no-vision clients) worked with the New York City Fire Department to develop a building evacuation plan and drill for their staff, most of whom have limited or no vision. The Associated Blind wanted a plan for their staff members covering the range of problems that could occur during a disaster. On September 11th, their efforts paid off. The entire staff calmly and safely evacuated their building’s 9th floor, a success they attribute directly to the customized advance planning and drills.

Also on September 11th, a wheelchair user who worked on the 68th floor of the World Trade Center was safely carried from the building, thanks to a specialized chair purchased after the 1993 bombing. A Port Authority of New York and New Jersey employee escaped from the 70th floor because his prosthetic leg allowed him to keep pace with nondisabled workers on the emergency stairs—and, he says, because of experience gained in the building’s frequent fire drills since 1993.

During the attack on the Pentagon, equipment previously installed to help employees and visitors with low or no

vision to evacuate the facility in the event of an emergency made it possible for dozens of sighted individuals to flee the smoke-filled corridors as well.

“Emergency Preparedness Initiative Guide on the Special Needs of People with Disabilities,” National Organization on Disability, 2002

Metro New York Developmental Disabilities Services Office (DDSO) had to get medications for the relocated individuals to them in their temporary quarters. It did not appear possible to return to residences, even to pick up medications.

At about 6:00 p.m., Laurie Gamza called Med World, a pharmacy in Rockland County that serves these houses. Based upon doctors’ orders on record, Med World filled 2-day supplies of medications and delivered them to Metro DDSO’s Bronx office at about 10:00 p.m. Laurie Gamza and Mitch Liner sorted the medications into envelopes according to the new residences and the people receiving them, and attached “Ready-to-Go” packets. These “Ready-to-Go” packets listed vital information such as names of correspondents and diagnoses for each individual.

Given the seriousness of their task, Mr. Daniels was authorized to use [the State Office of Mental Retardation and Developmental Disabilities’] Safety and Security vehicle, marked “Police.” Although traffic continued to be very bad, the “police” designation allowed him access to all thoroughfares.

“Metro NY DDSO on the Front Lines—Assuring the Safety of the People We Serve,” *The Journal*, January 2002

“Of the more than 2,800 people killed in the World Trade Center attacks, not one was a person with a developmental disability,” according to a documentary by the Institute on Community Integration, called We Watch the City: Stories in the Shadow of 9/11. In the film, survivors and witnesses of the attacks with developmental disabilities share their stories of the attack on the World Trade Center.

Training conducted for people with developmental disabilities before the disaster, not for escaping but for being able to work, paid off on September 11. In addition, a tracking system established in preparation for Y2K made it possible to keep track of people with disabilities in the hours and days immediately after the attacks. The database includes names, zip codes, and medication information.

“9 /11 Documentary on New Yorkers with Developmental Disabilities Premieres in Minnesota,” press release from the University of Minnesota, November 21, 2002

The U.S. Transportation Security Administration has developed new procedures it says will increase airline security while making travel more appealing to passengers with disabilities. The new guidelines were developed by the agency with help from disability groups, and are to be followed by all TSA screeners across the country.

Sandra Cammaroto, the first manager of the TSA Screening of Persons with Disabilities Program, explained: “Screeners will talk to blind passengers, help them to empty their pockets of metal, and make sure they gather their belongings at the end of the X-ray machine. Screeners will no longer remove harnesses from service animals and guide dogs, but will inspect them by hand. Passengers using

wheelchairs who can't walk through the metal detectors will be offered a private area where a screener can search them by hand."

"New Security Measures for Airline Passengers with Disabilities,"
Dave Reynolds, *Inclusion Daily Express*, May 28, 2003

After the 2003 East Coast blackout, New York City senior center staff:

- Went to apartments to retrieve medication for those seniors who were stranded at the centers
- Traveled by foot and on bike to bring water and food to frail and isolated clients
- Checked up on senior center members, many of whom were scared and confused.

"Emergency Preparedness for Agencies Serving Older People: Lessons from September 11, 2001, and Other Recent Emergency Situations," Igal Jellinek, Council of Senior Centers & Services of New York City, before the City Council Aging Committee, September 18, 2003

SECTION 4: LEARNING FROM EXPERIENCE—LESSONS THAT SHOULD HAVE BEEN LEARNED BEFORE SEPTEMBER 11

It is essential for mainstream emergency planning and response agencies to educate themselves about disability issues, so that past failures to learn the same lessons are not perpetually repeated. In this section, an examination of the literature that was available before September 11, 2001, regarding disasters and people with disabilities is presented. Following the description of each incident before 9/11, there is an example of incidents following the World Trade Center attack that could have been prevented if the preceding lesson had been learned.

During Hurricane Floyd, the Northridge earthquake, and after the 1993 World Trade Center attack, people who were elderly or had severe health conditions or disabilities were left stranded, sent to shelters that couldn't accommodate their needs, or lost access to their aides and medications—creating massive problems for rescue/relief workers, not to mention for the people who were stranded.

*

New York City, 9/11/2001, people who were elderly, with severe health conditions or disabilities, were left stranded, sent to shelters that could not accommodate them, or lost access to their aides and medications—creating massive problems for rescue/relief workers, not to mention for the people who were stranded.

In addition, during the Nebraska tornado in the 1970s, people who were deaf or hearing impaired had no access to emergency information or relief and emergency services. During the 1995 earthquake in Japan, many people with

mobility and hearing impairments were trapped in their homes, could not hear rescuers' voices, and found it impossible to evacuate.

*

New York City, 9/11/2001, people who were deaf or hearing impaired had no access to emergency information or relief and emergency services. Many, including those who were mobility or hearing impaired, were trapped in their homes, could not hear rescuers' voices, and found it impossible to evacuate.

EXAMPLE 1: LEAVE NO ONE BEHIND

Along with its torrential rains, Hurricane Floyd—the monstrous hurricane that churned up the U.S. East Coast last fall—brought a mass of public health problems to North Carolina . . .

People with health conditions or disabilities were left stranded in flooded homes, creating a massive burden on rescue workers who were already faced with a huge task . . .

People with health conditions were brought to shelters that could not accommodate their needs . . . “To prevent a repeat of the problem, a special task force has been formed to coordinate how to evacuate and shelter people with special needs during the next flood or hurricane,” Baluss said.

“Health Experts Evaluate the Medical Side Effects of Hurricane Floyd,” May 24, 2000, Stephanie Kriner, of DisasterRelief.org

One Year Later, in New York City

A Red Cross employee on an outreach team found residents with disabilities who were overlooked in the evacuation of their apartment buildings:

Buller remembered one resident who had schizophrenia and had been alone since the attacks. We also discovered a blind resident still stuck in his apartment, and two others who had multiple sclerosis.

“One of the MS patients was paralyzed and had been alone since September 11,” Buller continued. “She told me she’d heard both planes explode, but then the power and phones went out, so she couldn’t watch television or contact friends. She was stuck in the dark for two days, not knowing if we had gone to war. She had not bathed during that time because her home-care aide was unable to get in, and she could not get to the bathroom on her own.”

“Immediate Outreach,” interview with Dr. Kelly Buller, Red Cross Coordinator of Disaster Volunteers, by Christina Ward, DisasterRelief.org, October 3, 2001

Three Years Later, in New York City

MB has multiple sclerosis and requires home-care to get dressed and fed in the morning. He lives below 14th Street, which had been designated as a Frozen Zone post-9/11. Due to security procedures that excluded all nonresidents from the area, home-care attendants were unable to enter the area to provide care to homebound clients. On and following September 11, MB had to get himself out of bed with great difficulty, wheel himself around the apartment naked, without assistance until days had passed. The incident left him feeling highly anxious, depressed, and angry.

CIDNY consumer case file

EXAMPLE 2: ACCESS FOR THE DISABLED IS MANDATORY

After the January 1994 earthquake in Northridge, California, one of the biggest problems was the failure of electrical power and its repercussions for those dependent on motorized wheelchairs, respirators, and other pieces of equipment. Other problems identified at that time included:

- Evacuation centers that were fully or partially inaccessible
- Distribution of food, water, and other supplies from inaccessible locations
- Procedures that did not take persons with disabilities into account, or relief workers (often hastily trained volunteers) who were not aware of those procedures that might have:

- * A man with a hearing impairment was denied shelter because personnel could not understand sign language.
- * Persons with cerebral palsy were not served because shelter volunteers thought they were on drugs or alcohol.
- * A quadriplegic man could not take a shower for a week because the shelter was not equipped with an accessible stall.
- * A wheelchair user was forced to leave a fifth-floor apartment because of damage to the elevator. FEMA turned her down for emergency housing because the building had been judged safe.
- * Disabled people were turned away from shelters and told to go to hospitals by staff members who assumed that they were sick or injured.

“Disaster!” Douglas Lathrop
Mainstream magazine, November 1994

Seven Years After These Discoveries, in New York City

Mary is the deaf wife of a firefighter. Prior to 9/11, he was stationed at the firehouse closest to the WTC. When the towers were attacked, the military took over the frequency that provides closed-captioning. She was therefore unable to communicate with the outside world for over thirty-six hours, could not find out what was happening on the news without closed-captioning, and had no idea about her husband’s whereabouts or condition until he miraculously returned home thirty-eight hours later.

CIDNY consumer case file

EXAMPLE 3: EMERGENCY INFORMATION MUST BE ACCESSIBLE

On August 13, 2001, the Commission released a Public Notice reminding the public and video programming distributors of the distributors' obligation to provide emergency information in a format accessible to people with hearing disabilities. At that time, the Commission noted that it had received a number of complaints from residents of California, Colorado, Florida, Indiana, Louisiana, Maryland, Michigan, Minnesota, Missouri, New York, North Carolina, Ohio, Oklahoma, and Texas asserting that video programming distributors had failed to make local emergency information accessible to viewers with hearing disabilities.

Definitions:

- These rules apply to: “video programming distributors, including broadcasters, cable operators, and satellite television services.”
- Emergency information is defined as that which “helps to protect life, health, safety or property, and can include . . . specific details about the geographic areas affected, evacuation orders, detailed descriptions of areas to be evacuated, specific evacuation routes, approved shelters or ways to take shelter in one’s home, instructions on how to secure personal property, road closures, and how to obtain relief assistance.”

“Reminder to Video Programming Distributors of Obligation to Make Emergency Information Accessible to Persons with Hearing or Vision Disabilities,” FCC memorandum DA 02-1852, released July 31, 2002

One Month Later, in New York City

Not only did people who are deaf not understand what was happening at the time, but they also missed out on the twenty-four-hour television news broadcast, which did not include real-time captioning. Most cable news channels scrolled headlines along the bottom, but that scroll was not directly tied to what they were discussing onscreen. No emergency phone numbers included TTY or TDD lines.

*“U.S. Disability Community Struggles in Aftermath of Attacks,”
Nicole Bondi, iCan News Service, September 18, 2001*

CIDNY’s telephone number was not publicized for at least two days after the attack. When it was finally broadcast, it appeared only in the “footer,” the printed crawl going across the bottom of the television screen. I do not recall hearing any reporters or city officials announce CIDNY’s number or any other resource for people with disabilities affected by the disaster.

The CIDNY number was the only one they put out, and we were just not staffed for that response . . . People [staff] were really burned out after a month.

Recollection of Susan Scheer, June 24, 2004

EXAMPLE 4: PLAN AHEAD TO SERVE PEOPLE WITH DISABILITIES

During the 1970s, the Administration on Aging made major efforts to prepare the aging network to respond to the special needs of older disaster victims. An interagency agreement was negotiated between the Administration on Aging and the Federal Emergency Management Agency (then the Federal Disaster Assistance Administration), which dealt with mutual expectations relative to program and fiscal activity.

One of the services that must be established quickly is called “Disaster Advocate and Outreach Services.” Over the years, this service has been identified as the most critical service that can be provided by the aging network for older disaster victims. Disaster advocates are persons who volunteer or are employed to work on a one-to-one basis with older persons once a Disaster Application Center (DAC) is established or even prior to that time.

During the response to the Omaha, Nebraska, tornado of 1975, older persons crowded into disaster centers along with the general population. It was discovered that older persons were exiting the center without understanding what had just happened to them. They were simply confused. One of the major factors was hearing loss, which makes it extremely difficult to hear certain tones. When a great deal of background noise is present, as in a disaster center, it becomes almost impossible for a person with that kind of difficulty to understand what is being said. If the

older person has difficulty in reading print that is too small, they have for all purposes been cut off from communication with the very people that they depend on for assistance.

Emergency Preparedness Manual, March 1995, Fernando M. Torres-Gil, Assistant Secretary of the United States Administration on Aging, and Joanne Hurst, Secretary of the Kansas Department on Aging

Six Years Later, in New York City

There were special problems for the hearing impaired. A number were evacuated without their hearing aids. They missed the emergency information usually relayed verbally. They had to rely on their own wits, as they told us . . .

Organizations like FEMA, the Red Cross, the Salvation Army, and local health and aging services organizations need to develop specific coordinated plans to locate and assist the older people and the disabled, rather than relying as we had to in New York on ad hoc systems. And when we interviewed some of the representatives of these organizations, we learned they had really no formal plans before 9/11 to reach these populations.

“The Frail and the Hardy Seniors of 9/11: The Needs and Contributions of Older Americans,” interview with Myrna I. Lewis, PhD, of the Mt. Sinai School of Medicine, at Johns Hopkins University, Center for Civilian Biodefense Strategies, 2003

EXAMPLE 5: “THE BEST PREVENTION OF HUMAN TRAGEDY IS INTEGRATION INTO THE COMMUNITY”

On January 17, 1995, a severe earthquake rocked most of the western section of Japan’s main island of Honshu . . . The Great Kobe Earthquake . . . caused over 8,500 deaths and many casualties, and at least 450,000 houses were destroyed or damaged . . . Everyone had to evacuate to emergency places such as schools, community centers, churches, etc. Over 70,000 citizens lived in temporary shelters for several months.

Persons with orthopedic disabilities were unable to evacuate from their living quarters to designated evacuation sites due to the lack of accessibility. Inside their apartments, the refrigerators, tables, chest of drawers, and beds were rearranged; dishes and glass were all over the floor. Of course, wheelchair users were immobilized. Citizens with visual disabilities were unable to identify the exit to evacuate due to the displacement of furniture. Persons with hearing impairments trapped in their homes could not hear the rescuers’ voices. Persons living in high-rise apartments especially found it almost impossible to evacuate by themselves since there was no electricity either.

The majority of citizens with disabilities had to move from one evacuation site to another.

One year after the earthquake, Kobe City conducted research on all of Kobe’s residents. The result shows that 5.2% of the citizens were isolated from the community—in other words, had no friends in the community. However, 14.7% of persons with physical and/or mental challenges were totally isolated. This clearly shows that when a natural

disaster occurs, persons with disabilities might not be identified by community persons to facilitate a rescue. Therefore, the best prevention of human tragedy is integration into the community and neighborhood network.
[Emphasis added by CIDNY]

The research also shows that 22% of persons with physical disabilities and 15% of the mentally challenged persons lost their jobs after the earthquake. Again, the government continues to focus on medical and housing needs, and transportation for victims with the least effort put on creating an awareness of people with disabilities.

“The 1995 Kobe Earthquake,” Professor Akiie Ninomiya, Japan, in *Disability International*, spring 1997

Six Years Later, in New York City

During the day of September 11, news broadcasters used “crawls” across the bottom of the television screen to give written information to the public. These blocked the only way [closed-captioning] that deaf people could get information from television. There was uninterrupted coverage of the event for days afterward, during which authorities repeated the same information and instructions to the general public over and over. Yet there were no specific instructions and information regarding people with disabilities, such as a central number they could call for assistance. There was no discussion of which facilities were accessible for people using wheelchairs, or how to get immediate replacement of essential medications and equipment.

CIDNY staff notes

The majority of older people lived alone or with an older spouse, [and a] significant number of these, especially the emotionally and the mentally frail, remained hidden behind the doors of their apartments and houses. They were located only after relief workers and volunteers began going door to door checking on every resident . . . There was some initial work done, but solidly going through these buildings didn't really take place until the beginning of the second week . . .

A number of older persons were found in deteriorated conditions with dwindling food, water, medical supplies. Some required immediate medical care, emergency medical care. The Visiting Nurse Service reported incidents of heart attacks and strokes that appeared to be directly related to 9/11 . . .

"The Frail and the Hardy Seniors of 9/11: The Needs and Contributions of Older Americans", interview with Myrna I. Lewis, PhD, of the Mt. Sinai School of Medicine, at Johns Hopkins University, Center for Civilian Biodefense Strategies, 2003

For our providers who had to find shelter for their clients, each one said that they needed to have a list of shelters available in an emergency, but that no such list existed. Many of our members told us they were never told of any emergency shelters during the tragedy of 9/11 and its aftermath.

"Lessons Learned from Our City's Aging Services Providers from the Tragedy of September 11, 2001," statement by Igal Jellinek, executive director, Council of Senior Centers & Services of New York City, before the U.S. Senate's Special Committee on Aging, February 11, 2002

SECTION 5: RECOMMENDATIONS⁷

Relief agencies cannot wait until they are in the middle of a disaster to start training their staff in disability awareness. Train volunteers and staff ahead of time in basic disability awareness and etiquette, and in how to accommodate needs that commonly arise for people with disabilities.

Examples:

- Volunteers and staff at relief agencies or service providers may be asked to provide services or items that seem to be luxuries in time of crisis, but are actually indispensable to the everyday lives of people with disabilities (e.g., food delivery, door-to-door transportation, electrical backup, etc.).
- Operators on the city's 311 information line could be trained to respond to certain predictable inquiries.
- Community groups or other local organizations could be enlisted and trained to provide assistance and follow-up and check personally on callers.

TRAINING RESOURCE

Staff at emergency response agencies can take a 2-1/2-day course, "Emergency Planning for Special Needs," developed by FEMA after September 11. FEMA recommends that training sessions have an audience half composed of emergency personnel and half of people with disabilities.

For more information, contact the National Emergency Training Center at (301) 447-1000 and ask for the Special Needs Course Project Manager.

The day after a disaster is too late for agencies to start doing outreach to make their services known to people with disabilities. It is necessary to communicate with members of the disability community:

- On an ongoing basis, as part of a preparedness outreach effort
- Before an event, to warn about an emergency
- During an event, to give information and instruction about the emergency
- After an event, to give information about recovering from the emergency.

Examples:

- Television stations must broadcast closed-captioning in emergencies. If they run a text message “crawl” across the television screen, it should not cover the area reserved for closed-captioning.
- Emergency hotlines should offer a TTY/TDD number, or the instruction “TTY callers use relay.”
- Essential information should be repeated often in a simple form easily understood by those with cognitive disabilities.

During the recovery phase, there must be a priority to restore or address those services and needs most critical to people with disabilities.

Examples:

- Provide access around blockades and to shelters and other impacted areas for attendants, home health aides, visiting nurses, guide animals, and other individuals essential to the lives of people with disabilities
- If electricity or telephone service is interrupted, evaluate the effects on people with disabilities requiring respiratory equipment, telephone text messaging, recharging for electric scooters
- Provide accessible shelters and temporary housing
- Address how people with disabilities who are employed by businesses that are able to open after a disaster will get to work

- Shelters must meet minimal accessibility levels so that all members of a community can find safety
- Para-transit vans should be included in disaster plans, giving them emergency vehicle status.

Emergency planning by individual employers, landlords, and organizations should include purchasing and training staff in the use of emergency equipment appropriate for people with disabilities. Emergency professionals should rely on the disability community to advise them on which types of equipment are best.

Examples:

- Evacuation chairs
- Transfer-height cots
- Communication boards
- Reverse 911 notification systems.

DISASTER PREPAREDNESS FOR PEOPLE WITH DISABILITIES

- **People with disabilities must prepare themselves (FEMA and Red Cross offer specific instructions)**
- **Individual workplaces must also devise a plan to safely evacuate all employees with disabilities**
- **Disaster facilities and services must be accessible**
- **All types of disabilities must be considered**
- **Local, state, and national government agencies need to also appoint people with disabilities to boards that oversee public safety**
- **Emergency personnel must be trained on how to work effectively with people with disabilities.**

“The Impact of 9/11 on People with Disabilities,”
Kathleen Kendall-Tackett, PhD, in Disability Issues in Psychology,
for the Committee on Disability Issues in Psychology,
of the American Psychological Association, 2002

NOTES

- ¹ “Lessons Learned from September 11,” panel presentation by Claude L. Stout of Telecommunications for the Deaf, Inc., at the State of Science Conference at Gallaudet University, October 30, 2001.
- ² The Disaster Recovery Process: What We Know and Do Not Know from Research, E. L. Quarantelli, for the Disaster Research Center at the University of Delaware, 1999.
- ³ Psychosocial Aspects of Disaster Recovery: Integrating Communities into Disaster Planning and Policy Making, David Hutton, Institute for Catastrophic Loss Reduction, 2001.
- ⁴ Crain’s Health, February 14, 2002.
- ⁵ Hutton, op. cit.
- ⁶ Testimony by Lloyd I. Sederer, MD, of the New York City Department of Health & Mental Hygiene before the New York City Council on April 15, 2004.
- ⁷ Most of these are based on the National Organization on Disability’s Emergency Preparedness Initiative Guide on the Special Needs of People with Disabilities, 2002.

