

ILRU Network

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9-11 offers important lessons in disaster preparedness

...by *Richard Petty, IL Net Director*

More than three months after Sept. 11, many of us are still trying to comprehend a tragedy that seems too big to be real. We've seen and heard countless stories of courage, determination and selfless heroism in the aftermath of the terrorist attacks. None are more inspiring than those about our friends and colleagues in the New York and New Jersey independent living communities.

The Center for Independence of the Disabled in New York (CIDNY) is located just a few blocks from Ground Zero in Manhattan. Staff members there watched in horror as the World Trade Center collapsed. It might have been easy to become immobilized by their personal reactions to the tragedy. But—within hours—the CIDNY staff was hard at work trying to figure out how to restore and maintain services and support for hundreds of consumers in an unprecedented crisis.

Meanwhile, staff members at New Jersey's Progressive Center for Independent Living were dealing with their own crisis. PCIL's executive director, Colleen Fraser, was aboard the hijacked plane that crashed in Pennsylvania. Her untimely death left a painful hole in the hearts of her coworkers, associates and friends. Knowing that Fraser would expect nothing less, they were determined to keep the programs and services she so strongly believed in operating smoothly.

The strength and determination exhibited by these CILs is nothing short of heroic. But they are the first to say they could not have done it alone. The outpouring of emotional, logistical and financial support from the entire independent living community, they say, made it possible to move forward.

The independent living community includes people with vastly diverse interests, beliefs, attitudes and philosophies. Sometimes our differences

divide us. Sometimes we're so busy we forget we are part of a community. But, as proven in the weeks since Sept. 11, we are a strong and caring community that can accomplish great things by working together.

As important as that reminder is, there are other—more practical—things to gain from this experience. It does not require a terrorist attack to wreak disaster. Hurricanes, tornadoes, floods and fires can be equally disruptive—especially to people with disabilities who rely on a sometimes complex and fragile system of services and supports. How do you plan for that? What do you need to be prepared with an

effective response?

The folks at CIDNY and Progressive CIL tell us they're still figuring some of that out. Nonetheless, what they've learned so far provides the rest of us with critical information about preparing for and responding to a disaster. With everything else they have going on, staff from these centers and others who played a major role in the emergency response took time out to reflect on what they've learned in the weeks since Sept. 11. We are grateful for their assistance in putting together this issue of *ILRU Network*. And we hope the information will be useful in assessing your own organization's disaster preparedness.

Down—but not out

Manhattan CIL rebounds in aftermath of attacks with help from IL community



Susan Scheer says she's usually pretty good at anticipating all the things that might go wrong in a given situation. It's a survival skill that has served her well—personally and professionally—when things don't go as originally planned.

Nonetheless, she and her colleagues at the Center for Independence of the Disabled in New York (CIDNY) are astounded at the number of things they didn't—and couldn't—anticipate in the aftermath of the Sept. 11 attack on the World Trade Center. The weeks since have been marked by a continuous stream of learning experiences for New York's oldest CIL and, Scheer says, may be a wake up call for the entire independent living community.

From their office a mile away, Scheer, CIDNY's executive director, and several staff members and colleagues visiting from another CIL watched the skyscrapers collapse. Fighter jets circled overhead. "It was totally scary," Scheer remembers. "An act of war happened down the street from us! We were all in shock."

As an unprecedented act of terrorism, the disaster took an especially strong toll on peoples' nerves and emotions. "We couldn't help but wonder if they were coming back—if something else was going to happen," Scheer says.

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Manhattan CIL rebounds with help from IL community

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Otherwise, in terms of damage and disruption, the tragedy could be compared to other types of major disasters—hurricanes, floods, blizzards, earthquakes or fires:

- Thousands were forced to evacuate their homes and offices.
- Utilities—electricity, gas, water and telephone services—were disrupted, in some areas for several days.
- There was little to no public transportation.
- Closed captioning, TDD and relay services for people who are deaf or hearing impaired stopped operating.
- Intense security measures played a large role in how and when residents and workers moved around the city—and complicated everything.

It was unsettling, unpleasant and downright scary for everybody. For many people with disabilities, however, Scheer says the situation was much more serious—even life threatening.

CIDNY acted quickly to try to assure that people with disabilities were not overlooked as the city attempted to regain some semblance of safety and normalcy. Forced to evacuate their office—and many unable to get to their own homes—the staff was in touch with emergency officials within hours of the attacks. Their efforts were bolstered, Scheer says, by an incredible show of support from the New York Statewide Independent Living Council (NYSILC) and others throughout the state and nation. (See story-p.3)

Even so, it was a frustrating and tedious process. CIDNY had been in a “building mode” for the past couple of years, Scheer says, and had been expanding its programs, services and budget. Still, she says, the center was simply not prepared to handle a disaster of this magnitude. “I think we were on the right track with everything we’ve been doing,” she says, “but I wish we had been further along.”

“I wish we’d had a stronger relationship with all the other community-based agencies so we could coordinate efforts,” Scheer says. “The time to build relationships is not in the middle of a crisis. I wish we’d paid more attention to efforts to include people with disabilities in disaster planning. I wish we’d had better mechanisms in place to get the word out that we exist and what we can do for people who need help.”

Prior to Sept. 11, Scheer says CIDNY did know the city’s disability liaison and

the state advocate for people with disabilities. But the CIL had no relationship with the big players—the Federal Emergency Management Agency (FEMA), Red Cross and many other local, state and federal assistance agencies. Scheer says it quickly became obvious these agencies don’t “get it” when it came to addressing the needs of people with disabilities.

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.” Relief volunteers—many of them from other states—were unfamiliar with Manhattan and unable to offer reliable assistance.

Scheer is quick to point out that the responsibility for understanding these and other issues does not lie entirely with the disaster relief agencies. The independent living community, she says, has a responsibility to educate and work with these agencies on an ongoing basis.

In the past, Scheer says, CIDNY was invited to participate in various emergency preparedness meetings; but in the day-to-day reality of providing independent living services, those meetings didn’t get much priority. That’s changed now, and Scheer says the CIL hopes to build on the relationships and learning that have occurred since September.

THANKS

“One thing that has absolutely warmed everybody’s hearts is the support from the IL community. We often refer to ourselves as a community, but we don’t always feel like one. I felt so proud to be part of this movement in a way I’ve never felt before. There was such depth of feeling, concern and assistance from CILs small, large and in-between—they were on the phone; they were on the Internet; they sent staff, money, and supplies. That was great, and it did so much to alleviate the feeling that we were out there alone.”

—Susan Scheer, CIDNY

CIDNY will also pay more attention to helping consumers develop personal emergency preparedness plans. “Imagine that someone tells you that—as of this moment—you will not be able to go back to your home for three months,” Scheer suggests. “Think about all the things you need and don’t have with you. Think about all the arrangements you’d need to make. That’s what our folks were dealing with. You can’t imagine all the pieces of that.”

In addition to these “lessons learned,” 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—many still thought they could work things out themselves. But as things dragged on, they found they needed assistance.”

Scheer says many of these “new consumers” were relieved to discover CIDNY, even though it was difficult for them to admit they needed help. Meanwhile, the CIL is becoming acquainted with still another new population—people who were injured and/or disabled in the disaster.

The center is making a concerted effort to reach out to these folks and their families, Scheer says. But the efforts may be limited by another grim reality stemming from the attacks. “It’s really challenging to be asked to do all this extra work at a time when our budget is being cut,” Scheer says.

New York City, facing a huge budget

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NYSILC crisis response plan focused on communication, coordination—and returning control as soon as possible

Brad Williams was on the phone with Susan Scheer within an hour after the World Trade Center vanished into a cloud of debris and smoke. Williams, executive director of the New York Statewide Independent Living Council (NYSILC), was mostly interested in making sure the folks at the Center for Independence of the Disabled in New York (CIDNY) were okay. Scheer, CIDNY's executive director,

was still badly shaken by the terror she and staff members had just witnessed a few blocks away. But she recalls telling Williams they were already concerned about people with disabilities in the areas that were being evacuated.

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. Nonetheless, a crisis service plan was operational within hours— thanks to Williams and a cohesive and determined local, state and national IL community.

“We started with the reality that no one had a functional plan,” says Williams. “The state emergency management office may have had one to provide some guidance on evacuation procedures, but nothing that had ever been tested under the circumstances we were in.”

In contrast to the overwhelming nature of the crisis, the response plan Williams crafted that afternoon was short and simple—focusing on communication and coordination in the short term. The immediate goals:

- help CIDNY regain control of its operations as quickly as possible, and
- assure that people with disabilities— whether they were CIDNY consumers at the time of the attacks or not—were out of harm's way and fully included in all recovery and relief activities.

The CILs in greater New York City— geographically close by and familiar with Manhattan's service environment—were the logical first-responders. Williams drew heavily on their advice and resources to create a plan that would be practical and proactive. “It was a matter of making contact with the New York City network to assess how things were and what was needed,” says Williams.

“Then we started looking around to see who could help out with various resources. We just went down the list of issues and delegated who was going to work on them,” he adds. “Who can we forward CIDNY's telephone calls to? Who will check out the evacuation situation? Who's going to assess transportation? Who's going to make sure closed captioning and TDD relay service is back up? And so on.”

The day after the attacks, Williams and the NYC network finalized the plan over a conference call. By the next day, it had been circulated to the statewide CIL network “to keep them informed and ready to participate when needed.” Keeping people in the communications loop, Williams believes, is an important part of an effective crisis response.

With so much happening and so much information to circulate, Williams says it would have been impossible for one



Shortly after Sept. 11, CIDNY staff and volunteers started a detailed log to keep track of the multitude of contacts and requests for assistance. The following is a small sampling of notations included on the Nov. 5 log. They serve as an eye-opening chronicle of the diverse ways people with disabilities were affected when New York City's complex system of services and supports collapsed in the aftermath of the attack on the World Trade Center. —Ed

...young architect has multiple sclerosis...uses a scooter that he had to leave behind...went to parents' home...60 year-old father carrying him up and down stairs daily...

...has CP...uses walker...was told he would have to walk from Brooklyn Bridge or Canal Street to his school...

... had to stay in the hospital because there was no way to get back and forth for dialysis...

...her one good suit and briefcase were destroyed...

...21-year-old woman with significant traumatic brain injury...witnessed WTC collapse and is traumatized...has no food/income...is scared and highly vulnerable...

...has moved into her office...Red Cross installed a bed and gave her a TV...walls are too thin for grab bars...

...car was destroyed, along with handicap sticker...workplace also destroyed...has replacement car, but needs help replacing handicapped parking permit and other permits...

...consumer says “they (volunteer relief workers) are a bunch of well-meaning women with white hair from Colorado who don't know what is going on here”...

...claims she has made 36 trips to four different Red Cross centers...

...consumer with lung and brain cancer was displaced from her home...currently staying in hotel...needs transportation to her medical appointment next week...

...refuses to go home without her new (orthopedic) shoes...

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CAUTION

**Disasters happen.
Failure to prepare
may be hazardous
to your health.**

includes detailed guidance and instructions for each of the items presented here, as well information for specific disabilities and situations. Check it out at www.ilrcsf.org.

**Developed and distributed by Independent Living Resource Center San Francisco in cooperation with June Kailes, Disability Consultant, through a grant from the American Red Cross Northern California Disaster Preparedness Network*

San Francisco CIL shares lessons learned from 1989 earthquake

On October 17, 1989, a major earthquake rocked the San Francisco Bay area. The Loma Prieta quake—which lasted 20 seconds and measured 7.1 on the Richter Scale—resulted in 62 deaths, approximately 3,700 injuries, displacement of more than 12,000 people and an estimated \$10 billion in damage and business interruption.

The catastrophe—particularly its impact on people with disabilities—caused the Independent Living Resource Center San Francisco (ILRCSF) to take a hard look at its own ability to respond to a crisis, along with ways to help its constituency be better prepared.

ILRCSF, working with a consultant and a coalition of disability, community and disaster relief organizations created a series of fact sheets, checklists and tips intended specifically for people with disabilities and senior citizens. While some of the guidance is specific to earthquakes—a constant threat to people living in the area—much of it is easily applicable to any natural or man-made disaster in any part of the country.

The print materials are available on the CIL's website (www.ilrcsf.org). Herb Levine, ILRCSF program director, encourages anyone who finds them useful to copy and adapt them, as needed.

Recalling his own center's experience developing the materials, Levine suggests that organizations that use them would do well to incorporate different viewpoints in

The emergency preparedness information featured on these two pages is provided courtesy of the Independent Living Resource Center San Francisco (ILRCSF). It's been edited to allow us to provide a sampling of the variety of comprehensive information available on ILRCSF's website.* The site

deciding what works best in their community. "It was a painstaking process because we had a core group of advisors and we also asked people who had specific disabilities to review the specialized tips. Some of them hadn't thought too much about it before. But, once they got started thinking, they started thinking about a lot of issues and ideas." Levine says the dialogue may have slowed the process somewhat, but it was really useful in developing thoughtful and reliable advice.

The materials are just a part of ILRCSF's emergency preparedness activities. Other efforts include:

- promoting a volunteer *Disaster Registry Program* operated by the local health department;
- participating in a coalition that educates consumers about emergency preparedness;
- working with the fire department to include more people with disabilities in training for Neighborhood Emergency Response Teams (NERT); and
- chairing the committee for the San Francisco Mass Care Shelter Task Force that is working to improve disabled access to emergency shelters and services.

Contact Herb Levine, ILRCSF program director, by phone at 415-543-6222 or e-mail at herb@ilrcsf.org.

Checklist: Things to have, know and do

- Establish a *personal support network*.
- Customize an *emergency health information card* (see sample on p. 5). Keep copies in wallet, purse and emergency supply kits.
- Complete an *emergency contact list*
- Collect *emergency documents*
- Store *emergency documents* in emergency supply kits, wallet, safe deposit box and give copies to personal support network and out of area contact.
- Conduct an *ability self-assessment*.
- Collect "carry-with-you" supplies to keep with you at all times.
- Collect *disability-related supplies* for emergency kits.
- Maintain a seven-day supply of *essential medications*.
- Keep *important equipment and assistive devices* in consistent, convenient and secured place.
- Write out *instructions for things you will need help with* in an emergency.
- If you use a *service animal* see *Tips for Service Animal and Pet Owners*.

Seven important things about support networks

- 1 Make arrangements, prior to an emergency, for your support network to immediately check on you after a quake and, if needed, offer assistance.
- 2 Exchange important keys.
- 3 Show where you keep emergency supplies.
- 4 Share copies of your relevant emergency documents, evacuation plans and emergency health information card.
- 5 Agree on and practice a communications system regarding how to contact each other in an emergency. Do not count on the telephones working.
- 6 You and your personal support network should always notify each other when you are going out of town and when you will return.
- 7 The relationship should be mutual. Learn about each other's needs and how to help each other in an emergency.

Preparedness group lists “most important things” in disasters

Source: Bay Area Emergency Preparedness Coalition

In the event of a serious disaster everyone should be self-sufficient for at least three days without help or emergency services, with streets closed and with no stores open. There may be no electricity, gas, water or telephone service. Remember your home is the best place to stay—if it is not too badly damaged to be safe. The most important things to have:

- Bottled water (3 gals. per person in small, easy open bottles)
- Several flashlights (by the bed and around the house)

- One-week supply of medicines (rotated regularly) and instructions for use— dosage, frequency, doctor's name and phone; post this information on your refrigerator under the heading EMERGENCY INSTRUCTIONS.
- First aid kit
- Shoes under the bed (to protect feet from broken glass—windows, lamps, etc.)
- Fire extinguisher (know how to use it)
- Smoke alarm (check batteries yearly)
- Battery operated radio or TV
- Whistle or loud bell (to attract attention)
- Wrench for gas turn-off (only if you or someone else smells gas)

- Garbage bags (for personal waste)

The Coalition maintains an expanded list of other “important” and “good to have” things in its website: www.preparenow.org. —Ed.

Update emergency documents regularly!

A good time to review them is the same day you adjust your clocks for Daylight Savings. .

Bright Idea!

Things to keep with you or have handy in a crisis

- Emergency Health Information Card.
- Instructions on personal assistance needs and how best to provide them.
- Copy of emergency documents.
- Essential medications/copies of prescriptions (at least a week's supply).
- Flashlight on key ring.
- Signaling device (whistle, beeper, bell, screecher).
- Small battery-operated radio and extra batteries.
- Disability-related supplies to add to regular emergency kits*

**You won't carry your extra disability-related supplies with you all the time—but do keep them where you can get to them easily. Plan for enough disability-related supplies for up to two weeks (medication syringes, colostomy, respiratory, catheter, padding, distilled water, etc.). Don't expect shelters or first aid stations to meet your supply needs.*



SERVICE ANIMAL EARTHQUAKE KIT (FOR 7 DAYS)

- Water and food bowl(s)
- Food • Blanket for bedding
- Plastic bags and paper towels for disposing of feces
- Neosporin ointment for minor wounds • Medications or other items recommended by vet
- Favorite toy • Extra harness

Emergency Health Information + Emergency Health Information +

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Emergency Health Information + Emergency Health Information + Emergency Health Information + Emergency Health Information + Emergency Health Information +

Name _____

Street Address _____ City/State/ _____

Phone: Home _____ Work _____ Fax _____

Birth Date ____ / ____ / ____ Blood Type _____
Day Month Year

Social Security Number _____

Health Insurance Carrier _____

Individual Number _____ Group Number _____

Physician(s) Name _____ Physician(s) Phone _____

Emergency Contact(s) Name _____ Contact(s) Phone _____

Conditions/Disability _____

Medications _____

Assistance Needed _____

Allergies _____

Immunization Dates _____

Communication/Equipment/Other Needs _____

Emergency Health Information + Emergency Health Information + Emergency Health Information + Emergency Health Information + Emergency Health Information +

An emergency health information card communicates to rescuers what they need to know about you if they find you unconscious or incoherent—or if they need to quickly help evacuate you. Make multiple copies of this card to keep in emergency supply kits, emergency carry-with-you kits, car, work, wallet and purse (behind drivers license or primary identification card) wheelchair pack, etc. The form above can be folded down to wallet size.



Preparedness Pointers

No two disasters are exactly alike, so there's probably no way to plan for everything that will happen during or after an emergency. Still, we can learn from folks who have actually been through the experience. With that in mind, we offer the following tips—listed in no particular order—gathered from interviews with CIDNY Executive Director Susan Scheer and Brad Williams, NYSILC executive director, as they reflected on their own preparedness in the aftermath of Sept. 11. —Ed

- The best preparedness plans include a “Plan B”—just in case the situation makes “Plan A” impossible. For example, a plan that relies on telephoning consumers to check on their safety will be useless if phone lines aren’t working or are overloaded.
- Even if transportation systems are not damaged, emergency response personnel may restrict travel for security or other reasons. For example, personal vehicles were not allowed into Manhattan for a period of time after the attacks. Without public or special transit, people who had medical appointments or needed to travel to apply for relief benefits or other important business had no way to get into town.
- If emergency shelters and temporary housing are not accessible, they’re of no use to many people with disabilities. It’s not enough to plan to evacuate folks—they’ve got to be able to get in and around emergency lodging.
- When closed captioning and TDDs go down, many people who are deaf have no access to critical information about evacuation, emergency shelter, medical services, relief assistance, etc. Restoring and maintaining communications to this population should be a priority in any emergency response plan.
- People who provide services to consumers may be impacted by the crisis, too. For example, a personal assistant may be injured, stranded, cut off from communication or otherwise affected by the disaster—just like everybody else. Emergency response plans need to take this into account and provide for some type of backup arrangements.
- Don’t assume that emergency and relief agencies understand accessibility, accommodations, communication, transportation issues or any other aspect of disability or independent living. If you haven’t worked to raise their awareness before the emergency, plan to spend a lot of time educating them in the midst of the crisis.
- If you’re near the state line, your emergency response may need to include two states. Learn in advance what needs to happen to account for differences in services and systems.
- The news media is a valuable resource in reaching out to constituents in a time of crisis. Include a media plan in your overall emergency response plan.

Crisis plan...continued from page 3

person to do it alone. “This was a huge effort with people helping out whenever asked,” he says. “I’m especially grateful to our SILC office manager, Stephanie Lawton, and the folks at the CILs in Albany and Troy for their part in the communications and coordination.”

Their efforts extended to the national level as government and private relief organizations resisted the CILs’ attempts to discuss or be involved in efforts to identify and assist people with disabilities affected by the crisis. “The emergency management people seemed to take offense to it,” Williams says, “like we were insinuating they weren’t doing their jobs. The lowest point was when they were paying more attention to rescuing animals than they were to us.”

At the same time, state agencies that Williams 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. We helped some of them

make a connection with the emergency management organizations,” he adds, “so they could coordinate things.”

Things really improved, Williams says, 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.

It didn’t take long to realize that CIDNY was going to need a lot more money to respond to the increased need for its services. “Suddenly, they had quadruple the need,” Williams says. The SILC worked with Robert Gumson of the Office of Vocational and Educational Services for Individuals with Disabilities (VESID) to allow unspent dollars from other New York CILs to be channeled to CIDNY’s service budget. Meanwhile, donations were already coming in from other organizations and individuals.

On Sept. 21, just 10 days after the catastrophe, CIDNY was in place and in control again. That’s not to say all the problems are resolved—far from it. And it’s not to say the SILC has completely stepped out of the picture. Williams says the SILC has relinquished its emergency coordination responsibility and now plays a more supportive role.

Before this experience, Williams says, it had never occurred to the SILC to have an

emergency response plan. “We plan to keep one maintained now,” he adds, “and we’ll use the one we developed after Sept. 11 as a starting point.”

When asked if emergency preparedness planning is an appropriate role for SILCs, Williams is quick with a definite “yes.” Based on their experience, though, he and Scheer agree there is a fine line between a SILC providing support and assistance—and taking over completely.

Scheer credits Williams and the NYSILC with knowing exactly where the line is, and being sensitive to CIDNY’s desire to control—as much as possible—the response to its own constituents. “They found just the right balance between being a liaison and providing support,” Scheer says. “They helped us connect—to do our job effectively—without making us feel we were being controlled.”

Williams suspects that few states are any better prepared for a big emergency than his state was. For those that want to be better prepared, he thinks there’s plenty of work to go around.

CILs, Williams offers, can be reaching out to their local emergency management offices “to make sure they are aware of who you are, what you do and how you can be of assistance in emergency situations.” SILCs, he suggests, should be

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Crisis plan...continued from page 6

working with their network of CILs to develop a plan that would help establish communications, assess the need and address some system issues in an emergency environment.

SILCs can also introduce themselves to state level emergency management officials. "They need to know about your network and what you plan to do in an emergency. In our case, that connection was not there," Williams says.

Emergency preparedness planning may be a new and strange experience for the IL community. But Williams says it's a good fit with the IL philosophy. "We provide services to individuals, but we also have to address systems," he observes. "In the aftermath of the tragedy, the sooner we fixed the infrastructure, the sooner we reduced the number of people who needed assistance."

To contact Brad Williams for more information, call 518-427-1060, ext. 12, or send e-mail to bradsw@adelphia.net or nysilc@nysilc.org.

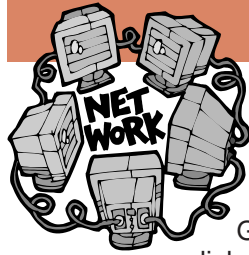
CIDNY...continued from page 2

deficit following the attacks, has already cancelled one of CIDNY's contracts—retroactively. "That's the part of the future that's very worrisome," Scheer says. "We want to build on what we've accomplished so far, but we'll need the financial resources to do it."

Speaking of finances, Scheer says CIDNY has received—and is extremely grateful for—nearly \$30,000 in donations from CILs, SILCs and other organizations and individuals throughout the country. Those funds are going out to people who lost their jobs, had their benefits disrupted or need food, medications or similar types of assistance as a result of the disaster.

Meanwhile, the center's ability to handle longer term issues stemming from the crisis got a major boost with a \$200,000 grant from the United Way's September 11th Fund. Scheer says the first attempts to get the relief organization's attention were hampered by the general lack of understanding about people with disabilities' diverse and sometimes complex needs. The funding organization was finally convinced after CIDNY submitted an explicit grant application detailing real-life examples of the problems people are facing and the CIL's unique capability to understand and assist in resolving them.

Susan Scheer will leave CIDNY in early February to work at Columbia University. To contact CIDNY, call 212-674-2300 (V) or 212-674-5619 (TTY), or send e-mail to info@CIDNY.org. The CIL's website is www.cidny.org.



CRISIS RESPONSE FORUM

Want to know what others are doing to spruce up their emergency response plans? Do you have a great idea for helping consumers take charge of their personal preparedness? Check out the **Virtual IL Coach** discussion board and share ideas and strategies for disaster preparedness. Go to www.ilru.org/online/forum.html#Virtual and follow the links to the **Virtual IL Coach** discussion board.

Progressive CIL staff vows to "keep on keepin' on" as Fraser would want it

Kate Blisard and Colleen Fraser served as Progressive's disability policy consultant, shares office space with Progressive Center for Independent Living. Fraser was the New Jersey CIL's executive director for nearly two years. She was also a passenger on ill-fated United Flight 93—the plane that crashed in Pennsylvania on Sept. 11

Since mid-October, Blisard has served as Progressive's interim director while the board searches for a new director. She says it feels "kind of strange" to sit in Fraser's office and try to carry on the work that was so important to her.

"Sometimes I laugh at what Colleen would say about some of the things that have happened," says Blisard. "An article about the plane crash featured Colleen and her disability advocacy activities. It appeared in the same *Vanity Fair* that had Brad Pitt on the cover. She would have loved that!"

As hard as it is some days, Blisard and Progressive's board and staff members believe that carrying on is the best thing they can do to honor Fraser's memory. "The staff went home on Sept. 11 and decided to take the next day off because things were in such turmoil," Blisard recalls. "But everybody came back on Sept. 13, and we've been fully operational since. We have not had to cease or decrease our services."

"Everybody came together and divided up tasks that needed to be done. The board and staff worked together," Blisard says. "Looking back, that was so important; but it surprised me a little bit because our board members have other lives. They've always been 'hands on'; but this time they really went the extra mile to help."

As might be expected, Blisard says, morale was a major concern in the days and weeks after the tragedy. The small and close-knit staff found solace

in talking about their feelings with one another—something they did pretty often in the beginning. "It helped everybody feel we were all together and we had a job to do," Blisard says. "It really helped just to say 'we're upset, we're sad, we have to plan a funeral and memorial service; but we're going to do this because Colleen believed in all this and we do, too.'"

The Progressive staff's resolve to keep moving forward got a major boost from scores of independent living colleagues throughout the nation, Blisard adds. "It was so heartwarming," she says. "It helped us feel we were not alone at all."

Fraser's sister asked that memorial contributions be made to Progressive CIL. Blisard says the response is impressive—and humbling. "Donations came from the statewide council, from CILs we know couldn't afford very much and from national organizations, too. They're still coming in. Our board is considering how to best use the donations to advance Colleen's vision for independent living."

In addition to the financial donations, Blisard says the IL community flooded the CIL with generous offers of help and support—a fact that provided an important lesson. "I used to feel like it might be an imposition to accept an offer to help. But, I learned that people needed to help. So, if they asked, I gave them something to do."

For the Progressive board and staff, the next challenge will be moving ahead with a new director who may not be anything like the beloved Fraser. "Colleen set the bar pretty high," Blisard says. "We'll make it so the new person doesn't feel like they have to fill her shoes. They're going to be able to do things their own way. We don't expect them to do like Colleen."

To contact Kate Blisard, acting director at Progressive CIL, call 609-530-0006 or send e-mail to the CIL at susan.yochim@pcil.org.

Floods give rise to concerns about “survival of the fittest”

Randy Sorenson, executive director of Options Interstate Resource Center for Independent Living, still vividly remembers the 1997 floods that wreaked such havoc in the rural Minnesota and North Dakota communities his center serves. It’s not easy to forget. Even now—five years later—people in the communities are still recovering and rebuilding.

While it was a raging river that destroyed and disrupted so much, Sorenson’s account of the catastrophe’s impact on people with disabilities is unsettling in its similarities to other types of disasters in other parts of the country. Emergency management personnel did not already understand people with disabilities’ needs—and they weren’t especially interested in having to learn about them in the middle of a crisis.

Sorenson says, “It startled me to see how quickly rights were violated with the attitude that people with disabilities should be able to rough it like the rest. People didn’t understand that in some cases it wasn’t roughing it—the accommodations were needed to survive. People with disabilities should not take their own survival for granted in the case of a national tragedy. They need to be active participants, insuring they have plans to get out of buildings, plans for evacuation from their homes/apartments and plans for how to get the things they need.”

For more information, call Randy Sorenson at 218-773-6100 or send e-mail to randy@rrv.net.

■■■ Looking for disaster preparedness resources? The **National Organization on Disability (NOD)** has a comprehensive list

NetNotes

of websites and resources for a variety of emergency response issues. They’re also reporting the results of an interesting NOD/Harris Poll which reveals that the majority of people with disabilities don’t feel sufficiently prepared for another crisis. Check out the Emergency Preparedness Directory from the NOD home page: www.nod.org

■■■ Still looking for disaster resources? The **Job Accommodation Network (JAN)** website is another good cyberstop where you’ll find information about safety procedures and equipment, ADA requirements for employment safety and the like. Go to: www.jan.vvu.edu.

■■■ Still not enough? Try San Francisco’s **Community Preparedness Website Project**: www.preparenow.org. Or check out **DisabilityDirect.gov’s Emergency Preparedness** section: www.disabilitydirect.gov.

■■■ Look for IndependenceFirst’s Leslie Meyers interesting personal account of *Thirteen Days at CIDNY, Ground Zero of New York’s Disability Community* in the current newsletter section of the CIL’s website: www.independencefirst.org.

■■■ The 2002 SILC Congress passed two resolutions focusing on improving disaster preparedness in the IL community. Check them out at **ILRU NetWork Online**: www.ilru.org.

ilru NetWork

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