

**A Quarterly Newsletter of the National
Alliance for Direct Support Professionals**

Frontline Initiative

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We Watch the City Stories in the Shadow of 9/11

We Watch the City: Stories in the Shadow of 9/11, a video documentary and booklet about New Yorkers with developmental and other disabilities and those who support them in the aftermath of September 11, 2001, began shortly after the terrorist attack. The Administration on Developmental Disabilities, Federal Department of Health and Human Services, was interested in exploring the responses of people with developmental disabilities who were caught in the middle of this catastrophic event. The Research and Training Center on Community Living (RTC) at the

University of Minnesota's Institute on Community Integration was asked to work on this project because they had produced documentary projects, involving the participation of people with developmental disabilities in the past. By mid-October of 2001, the project was underway and dozens of people with disabilities, Direct Support Professionals, administrators, and allies were contacted to participate. Due to time and budget considerations, this project was limited to the events of New York City.

We could not begin interviewing people in New York until April of 2002, because

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Coping with Disaster
Frontline Initiative Newsletter

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Sokie Brumfeld was sorting mail in the World Trade Center when she heard the planes crashing into the buildings.



Frontline Notes

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Do you remember what you were doing on September 11, 2001? Most of us remember exactly where we were and what we were doing when we heard about the terrorist attacks on the Pentagon and the World Trade Center. Did hearing the news change anything in your life? There are many stories about ordinary people who found they were heroes not by choice but rather because of the attack. While news media covered the attacks and kept Americans informed, they did not share the stories about countless Direct Support Professionals (DSPs) who made sure every person they supported was safe and accounted for. The story about individuals with developmental disabilities who were working in the area when the plane struck the Pentagon was not told. The fact that everyone on this crew made it out of the building safe and uninjured was due to the dedication of the DSPs supervising the crew.

The story about people with developmental disabilities who worked at the World Trade Center was not told. None of these stories were even mentioned by the media. In this issue of *Frontline Initiative* our cover story shares excerpts from “We Watch the City” a video documentary and booklet about what September 11th meant to the Americans with disabilities who were personally touched by the terrorist attack.

Disaster, natural or man made, can happen at any time, anywhere. What would you do if disaster struck? Would you know how to cope if your home or place of employment was destroyed by floods, fire or other natural disasters? As a DSP would you be ready to sup-

port someone with developmental disabilities through a disaster that could take away their home? The article on Project Cope has some practical advice about preparing someone you support to cope with and survive disasters. Across the country there are snow and ice storms, floods, earthquakes, tornados, fires and other natural disasters that profoundly effect people with developmental disabilities and the people that support them.

Whether it is giving day-to-day support or helping stabilize someone's world after disaster strikes, DSPs have a profound influence on the quality of life for the people they support. This influence needs professional recognition and national attention. Read the article about ANCOR's National Advocacy Campaign to improve wages and benefits for DSPs. This effort will increase public awareness regarding the important role DSPs play in the lives of Americans with disabilities. Finally, it is our hope that by offering practical advice on emergency preparedness, advising you of important national campaigns to improve the status of direct support professionals and by telling the stories from “We Watch the City” all Americans will know that what you do is important and matters every day.

— The Editors

NADSP Member Organizations and State Contacts

Frontline Initiative is a product of the National Alliance for Direct Support Professionals. The NADSP is a collaboration between organizations who are committed to promoting the development of a highly competent human services workforce that supports individuals in achieving their life goals. The following are some of those organizations —

- Administration on Developmental Disabilities
- American Association on Mental Retardation
- Association of University Centers on Disabilities
- American Network of Community Options and Resources
- The Arc of the United States
- Association of Public Developmental Disabilities Administrators
- Association for Persons in Supported Employment
- CARF...The Rehabilitation Accreditation Commission
- Consortium for Citizens with Disabilities
- JFK Jr. Institute for Worker Education
- Council for Standards in Human Service Education
- Human Services Research Institute
- Institute on Community Integration (UCEDD), University of Minnesota
- International Association of Psychosocial Rehabilitation Services
- Irwin Siegel Agency, Inc.
- National Association of State Directors of Developmental Disabilities Services
- National Association of State Directors of Vocational Technical Education
- National Center on Educational Restructuring and Inclusion
- National Center for Paraprofessionals in Education
- National Organization of Child Care Workers Association
- National Organization for Human Service Educators
- National Resource Center for Paraprofessionals
- New Jersey Association of Community Providers
- President's Committee on Mental Retardation
- Program in Child Development and Child Care, University of Pittsburgh, School of Social Work
- Reaching Up
- Self-Advocates Becoming Empowered
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Join NADSP and Represent Your State

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Frontline Initiative is available in alternate formats upon request.

The Real Scoop

Welcome to *The Real Scoop*. Clifford is a self-advocate who has been politically active for years. He's here to give you his spin on how to deal with issues you face as you forge ahead in your role as a Direct Support Professional (DSP). Seth has been a DSP for many years, and he loves to give advice. He may ruffle your feathers, but hey, it's for your own good! Clifford and Seth tackle this one with a few suggestions.

Everybody Needs a Plan!

Dear Seth and Cliff,
I am a DSP and I work in a home where I support three people who use wheelchairs. Lately, I have been very concerned about being prepared in case something happens on my shift. I sometimes work alone and worry that I would not be able to get all three people out safely if there were a fire or disaster. I also worry that maybe the agency I work for is not as concerned as I am about having an emergency or disaster preparedness plan. What should I do so I am ready in case there is an emergency when I am alone? Any advice?

— Alone and Worried

Dear Alone and Worried,

R - U kidding me!!! How can there NOT be a safety plan already in place. Speak immediately with your supervisor and his/her supervisor until you get to top management and the bottom of what's going on.

— Seth

Dear Alone and Worried,

Talk with your supervisor to develop an evacuation plan in case of a fire. Your plan should be simple and straight forward and your first priority should be getting the guys out of the house. Consider how accessible the house is and if some of the people you support are able to wheel themselves out of the house without your help. Having a plan in place and practicing getting out should help you and the people you support feel more prepared in case of a fire. As for a disaster preparedness plan... I believe your agency has to come up with a disaster preparedness plan to comply with state and federal regulations. Your agency should have a plan in place in case of fire, tornadoes and a variety of other possible disasters. Find out if your agency has a plan and if not start developing one by talking to your supervisor about what you can do to help create a disaster preparedness plan at your site. Check out the article from Project Cope in this issue for ideas on developing your plan.

— Cliff

Ask Clifford and Seth

Do you have a burning question about direct support, but don't know who to ask? Submit it to —

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Please include your name, day phone for verification, and alias, if desired.

Project Cope

Hope for the Best, Prepare for the Worst

The events of September 11 had a big impact on Americans; certainly adults with cognitive disabilities were no different. While we hope nothing like this will ever happen again, we are reminded that disasters come in many forms and can strike at any time. The sudden and unanticipated nature of the attacks made us realize how important it is to prepare for disaster. Reflecting on how individuals with disabilities reacted to September 11 can help prepare us to respond to future traumatic events.

Project Cope was started one week after September 11 in recognition that some individuals with disabilities faced unique coping challenges in the aftermath of disaster. A major goal of the project is to develop support systems for individuals with developmental disabilities and their families. In the first month, we asked how adults with intellectual disabilities and their support providers were affected. We found that the reactions depended on three things: first, their understanding of the disaster; second, the reactions of important people in their lives; and third, their previous experience with trauma. We found that Direct Support Professionals (DSPs) played pivotal roles in recognizing traumatic stress reactions and in supporting coping recovery.

This article summarizes our current understanding of how people with intellectual and developmental disabilities reacted to the September 11 attacks and subsequent events. We then provide a number of steps that can be taken *now* to prepare for a future disaster. We also describe

some ways of supporting people with disabilities should a disaster occur.

How did people react to the September 11 attacks?

After the September 11 attacks, many adults with cognitive disabilities reacted with sadness, anxiety, and anger, clearly understanding

We found that DSPs played pivotal roles in recognizing traumatic stress reactions and in supporting coping recovery.

what happened. Some who showed no specific awareness of the events were upset by the reactions of others in their households. Others showed no reaction at all. Some specific examples included —

- **Fear.** A common reaction was concern for family members and a desire to call them. Some were upset if they could not make immediate contact. Others were afraid to take public transportation or were worried that their homes were not safe.
- **Misunderstanding.** Some did not understand the scope of the event, but were frightened by the images on television, just as they would be of a scary movie. Others thought the attack was recurring each time

it was shown on television.

- **Upset about disruption of routine.** Some were distressed when preferred activities were cancelled or favorite television programs were not shown.
- **Increase in problem behaviors.** Outbursts and other challenging behaviors sometimes occurred, especially when others discussed the attack. Examples included two men who began to hit themselves, a woman who kept repeating, “I didn’t do it,” and another man, prone to angry outbursts, who threw a chair.
- **Distractibility.** Some reported having difficulty focusing on chores at home and tasks at work.
- **Disturbed sleep.** Several people reported difficulty in falling asleep, staying asleep, waking up too early, or having disturbing dreams.

What can you do now?

We can not predict if or when a disaster might happen. We do know that the time to prepare for a disaster is before they happen by developing an evacuation plan. We offer the following suggestions for DSPs when preparing individuals with intellectual and cognitive disabilities for potential disasters —

- **Develop disaster and resident support plans.** Have a checklist of essentials for each member of the household or work environment, with medicines, favorite possessions, names and phone numbers of family members, and whatever else might be taken on an over-

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night trip. Reassure those who use wheelchairs, have difficulty walking, or are visually impaired that someone will assist them. For each shift, assign staff members to assist each individual. Ensure that people know or have access to the home and work locations of loved ones; on September 11th, some were perplexed and fearful because they were unsure of where family members worked in lower Manhattan. People who live in supported apartments may not have a DSP on site when they need to evacuate. It is important that they have their own checklist and know exactly what to do in case of emergency.

• **Rehearse the evacuation plan.**

Understand that practice may initially *increase* anxiety because it is a change in routine or a reminder of unpleasant events. Practice the plan so it becomes familiar. With practice, the plan becomes automatic and anxiety usually diminishes. During rehearsal, practice remaining calm when stressed and using coping skills.

• **Actively develop coping skills.**

Set up opportunities to teach and practice coping skills. Like everyone else, adults with intellectual and cognitive disabilities benefit from learning progressive relaxation techniques and helpful self-talk (positive coping statements). If you are not experienced in teaching stress management, locate professionals and other resources in your agency or community who can help. During rehearsal, ask questions like “What should you do when you are upset?” “Who can help you with that problem?” Look for answers like “Use my relaxation” and “Call this number.”

Ensure that people know or have access to the home and work locations of loved ones; on September 11th, some were perplexed and fearful because they were unsure of where family members worked in lower Manhattan.

What should you do if something bad does occur?

A stressor such as car accident, fire, death of a family member, or the illness of a co-worker will cause anxiety. In addition, news reports about war, terrorism, or airplane accidents may evoke strong feelings for people who reacted to the events of September 11th. If potentially upsetting events do occur, consider the following —

• **Be aware of individual reactions.**

Know how people typically respond to stress and watch for its signs. Discuss upsetting events individually rather than in groups. Group discussions can be upsetting for some individuals as levels of understanding may vary. Tune into their body language. Provide opportunities for individuals to express their feelings in ways that feel comfortable for them, but don't force people to talk if they do not wish to.

• **Acknowledge fears.** Check on what people are feeling. Use pictures for those who have trouble

with verbal expression. Correct misunderstandings that may be contributing to fears. Determine whether talking about a “fear” might have developed into a way to get attention or avoid an activity. If so, schedule specific times to discuss these fears.

• **Check understanding.** Ask and answer questions using language the person understands. Listen carefully to conversations and check for misconceptions. Repeat correct information often. For public disasters, listen to statements from authorities and follow their advice.

• **Maintain routines.** Continue scheduled activities and familiar routines. Try not to cancel activities unnecessarily.

• **Family contact.** During stressful times, encourage individuals to contact family members or friends on a regular basis. Direct support staff should have a list of family contacts available. Should there be an evacuation, immediately contact the family.

• **Limit exposure to upsetting material.** Repeated viewing of a public disaster can increase fear. If world events result in continuous news coverage, watch a videotape, or turn off the television and play a board game. Avoid watching the news for a long time or before bed. This is especially important for people with sleep problems. Structure any exposure to traumatic events that does occur. Talk about what was seen.

• **Monitor the household environment.** Support staff, family members, co-workers, and

How DSPs Can Prepare for Disaster

housemates have their own stress reactions. Watch for the effects this may have on individuals with cognitive disabilities. Take care of yourself.

Other Suggestions for Direct Support Professionals

Direct support professionals play a significant role in the way people with disabilities handle traumatic events. They are often in a unique position to recognize people's reactions first-hand and can support the immediate use of the coping strategies. It helps for caregivers and family members to be aware of their own reactions and understand how these affect others. Strong reactions can cause distress for everyone in a household. Calm and caring responses to a traumatic event produce the opposite result.

This guide is a product of Project Cope of the Westchester Institute for Human Development (WIHD), a University Center for Excellence in Developmental Disabilities Education, Research, and Service at the Westchester Medical Center in Valhalla, NY. The guide was written by Marilyn Vitale, M.A., Daniel Crimmins, Ph.D., and Anne Farrell, Ph.D. Visit <http://www.projectcope.net> for more information.

Throughout this edition of *Frontline Initiative* we have heard stories of how Direct Support Professionals (DSPs) and people with disabilities have worked together to cope in the case of terrorist attacks, ice storms and winter storms. DSPs and the people they support should prepare for all types of disasters including earthquakes, floods, droughts and tornados. The American Red Cross urges everyone to prepare for disasters and offers a framework that DSPs can follow. Use the guidelines below to facilitate discussions to plan for the types of disasters that could potentially occur in your area.

- **Talk** with the people you support about disasters that can occur in your area and the need for preparing. Calmly discuss the dangers of the potential disaster and decide on individual responsibilities. If verbal communication presents a problem then use an alternative way to discuss this like pictures, story books or videos.
- **Plan** where to meet after a disaster and how each of the individuals you support will be transported or rescued depending on their mobility (escape route). Arrange for a contact person who everyone can call and update on their whereabouts.
- **Learn** about your community's emergency warning signals including what they mean and what you should do when you hear them. Practice using the fire extin-

guisher and identify the safe spots in the building.

- **Check** supplies making sure you have adequate food, water and medical supplies in case of a disaster. It is a good idea to have three to five day supply of canned goods available in case of an emergency. Check the batteries in smoke alarms in all rooms at least twice a year.
- **Tell** all your co-workers and the people you support where the emergency contact information is kept and make copies for everyone. Post emergency contact numbers by the phones.
- **Practice** fire and earthquake drills, and evacuation routes. Update emergency contact information and disaster supplies. Review and practice your disaster plans regularly.

Types of Disasters

Drought

Do your part to prevent drought by conserving water. If a drought condition occurs in your community water use may be restricted at certain times or for certain uses (i.e. watering your lawn). Discuss the potential restrictions with the people you support and work together to adjust your daily lives to reflect the changes. For more information specific to your community, contact your local water authority.

Earthquakes

Develop a plan to prepare for potential earthquakes by identifying a safe place within every room

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under a sturdy object where you and the people you support would be safe from falling objects. If an earthquake occurs DROP, COVER, AND HOLD ON to protect yourself. Avoid going outside and being near windows until the shaking stops. After the shaking stops check yourself and those you support for injuries. Check for possible gas leaks as a result of the earthquake.

Fires

Plan and practice your escape routes in case of fire including evacuation plans for those in wheelchairs. Plan to meet at a neighbor's house and call the fire department from there. If there is fire or smoke in your escape path take an alternate route, if this is the only option stay low and check all doors for heat before opening them. If you are trapped keep doors closed and wave a bright colored cloth like a bed sheet or curtain, out of a nearby window.

Floods

Learn about your community's risk for floods. If it has been raining for several hours or days know that the occurrence of the flood is possible. Tune into local radio or television stations to learn about potential flood warnings. If you need to evacuate do so quickly and move to higher ground enacting the evacuation plan you have developed.

Heat Waves

A heat wave is defined by the American Red Cross as a prolonged period of excessive heat and humidity. The National Weather Service steps up its procedures to alert the public during these periods of excessive

heat and humidity. DSPs and the people they support should avoid excessive activity, stay hydrated and spend time in air conditioned areas when available. Monitor for heat exhaustion and heat stroke.

Terrorism

Identify the potential for terrorist attacks in your area. In the event of a terrorist attack stay calm and follow the instructions of local emergency officials. Develop an emergency communications plan for everyone to follow and identify a place to meet in case the area that you work in is affected. Compile a disaster supply kit that includes food and water. Have kits for each person you support that include items that are essential for each individual like medicines.

Thunderstorms

If you suspect a storm is approaching listen to the radio for updates on the weather conditions. Avoid running water, unplug appliances and do not use your phone. Draw the blinds to protect glass breakage from entering the room. Locate a safe room away from windows. If you are outdoors find shelter immediately.

Tornado

Decide where you and the people you support will go in the case of a tornado. Choose a basement or hallways and internal rooms if a basement is not available. Have food, water, a battery-powered radio, flashlight, and extra batteries handy to take to your protected location. Listen to the radio to get information about tornado warnings and watches.

Winter Storms

Listen to the radio for winter storm watches and warnings. Have warm clothes including hats and mittens for yourself and each person you support. Avoid going outdoors and driving. Make sure you have adequate supplies of food, water and medicine in case you are unable to go out. As with a tornado, have a battery-powered radio, flashlight, and extra batteries on hand.

For more information about how to prepare disasters visit the Disaster Safety section of the American Red Cross Web site at <http://www.redcross.org>.

Michelle Trotter is research assistant at Institute on Community Integration, University of Minnesota.

DSP Perspective

A Time for Ice and Snow

Winters in Kansas City are usually pretty predictable with relatively small amounts of snow. The only obstacle is the bitter cold from December to mid-February. From time to time, however, Mother Nature throws us a curve that can leave even the best prepared person wondering what just hit. This is a story from a Direct Care Provider's point of view about the events that happened in Kansas City in January 2002 and how a few workers with a common goal provided supports for persons with developmental disabilities.

My name is Jim, and I have worked in direct care for about 10 years. I started working with persons with special needs in McPherson, Kansas. It was the first job I ever had that I didn't wonder what it would be like to be somewhere else. There was a level of acceptance that I can not describe and a genuine spirit of goodness that I always received for being there, providing supports and caring for others. Over the course of several years and three relocations I found myself in Kansas City working for a very progressive company called Johnson County Developmental Supports (JCDS). I felt at home and really enjoyed the relationships being built with the people I supported and fellow employees. I am currently a "Live-in", and along with my full time position I provide supports that can range from helping someone at night if they are ill to assisting in an emergency situation.

It was Thursday, January, 2002 and it was cold and nasty. The weather had turned pretty rough that week and the days that followed were very challenging for everyone

and everything in the Kansas City area. It had been snowing off and on with periods of sleet and freezing rain since Wednesday. Getting from one place to another was extremely challenging and the weather wasn't letting up. I remember coming home around 4 p.m. to the usual greeting from the women that live at 154th Street, "Hi Jim." We visited briefly and I retired downstairs to

Suddenly, a loud electrical explosion filled the air followed by a greenish blue glow, lighting up the sky like the 4th of July.

my living quarters. The electricity had flickered several times through the early evening and about at 5:15 p.m. the lights went out and stayed out. I came upstairs where a colleague, Sheri, was rounding up flashlights and candles and assuring Peggy, Cheryl, Dee and Jamie that all would be ok.

It was getting dark outside and the rain and ice mix was still coming in full force. We made several phone calls to the power company with a cell phone, a great tool to have on hand when the power goes out. We found ourselves sharing stories and jokes, listening to the weather radio, and enjoying each other's company. We started hearing a very eerie sound of distant crack-

ing. I walked into the back yard and discovered that with every gust of wind tree branches were buckling under the pressure of the mounting ice. Suddenly, a loud electrical explosion filled the air followed by a greenish blue glow, lighting up the sky like the 4th of July. It took awhile for all this to start making sense but we were seeing and hearing electrical transformers explode. We counted half a dozen or so and were all amazed with the beauty of the distant light show in every direction.

We received a phone call from the Residential Coordinator, Patty, shortly after the power went off. She shared with us that people all over the Kansas City area were losing power and she was going to call us back with a plan just in case the power stayed off. Occasionally we would see a utility truck passing by with their strobe lights on, going up and down the street just beyond our backyard. We just knew that it wouldn't be long before they had our power back on and all would be fine. Meanwhile, Patty called us with a plan. After discussing options with her supervisor they decided that we were to go to the Holiday Inn with the women, and check in so we would have heat. Patty had called ahead and the booked us the last several rooms.

After de-icing the van, packing clothes, medicine, extra blankets, and flashlights, we were ready to meet the others at the Holiday Inn. After arriving, we were shocked to find that the hotel had lost power just five minutes before we arrived. All the while, the rain and ice continued. We were able to move our reservations from that hotel to

another Holiday Inn nearby.

Once we arrived at the second location and were checking in, I remember wondering just how many people were without power. Some people were showing up with reservations, and some were just coming in and asking if there were any rooms. In order to keep our group together we were forced to be on the fourth floor. This didn't make us too happy because we had two people in a wheelchair, one person that used a walker. The person on duty assured me this was the best they could do to keep our group together. We accepted the rooms and began to check into the hotel.

Unloading the vans proved to be quite a tricky task. The men and women who walked were escorted arm in arm with staff over the icy parking lot while the vans that had wheelchair lifts were in front of the hotel unloading. During this process, and on several other occasions, I remember thinking, these guys are doing incredibly well for having to change their living arrangements at a drop of a hat! I was very impressed at how well everyone worked together. Final trips were made by staff to get clothes and medications, a few extra items and then park the vans with lifts before everyone could regroup and enjoy a bit of warmth.

Approximately thirty minutes after our check in we were faced with yet another obstacle, this hotel lost power, too. A diesel generator started up shortly after the place went black but was only running the lights in the hallways. Everyone was getting a little restless but remained calm in our newest circumstances.

A couple of staff went downstairs to check on the situation and it wasn't very hopeful. Not only were we without power, but the genera-

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tor outside was only able to run the hallway lights within the hotel. The lobby now looked like a tomb and was darker than the hallways running above it on the other floors. We were again in a situation where there was no heat or electricity. Since the elevator wasn't working we couldn't get the men and women who were in wheelchairs out the way we came in. The people working the front desk didn't have any news other than that they had called the power company and like everyone else in the city, they would have power as soon as possible.

Despite the events everyone remained calm. Most of the people being supported simply decided that sleep was the best idea. A couple of staff went to the van to get some emergency flashlights and made a phone call to Patty to advise her of our situation. It was approaching eleven o'clock and a couple of staff came to the hotel to relieve the shift before them. We had eleven people sleeping in beds and the staff were keeping a watchful eye, by sitting in the dimly lit halls leaning against walls or doorways to each room.

Electronic swipe cards operated the doors so we were very careful not to close the doors.

It was close to midnight and was getting colder. All of the extra blankets we brought were being used so a couple of staff went downstairs and asked about getting more blankets. They gave us the last two blankets and said that was the best they could do. I was upset and explained that we had men and women with special healthcare needs on the fourth floor and since the power went out, about two hours earlier, no one from the hotel has been up to check on the safety of persons staying there! The employees gave little reassurance, but one person encouraged me to speak with management the next morning and perhaps they could "discount" our stay.

Everyone made it through the night, and in the early hours of the morning hours we ran to Lamar Donuts and brought back donuts and juice for all of us. Nothing had changed with the situation of the hotel and by mid morning we were all ready to check out - but how were we going to get the people in wheelchairs out without an elevator?

After discussing the situation with our supervisor and colleagues, it was decided that the people from the homes that had power could go back home and a couple of staff would remain behind with Steve who was in the power chair. Additional arrangements of getting him out were to be made by calling the Fire Department for an evacuation once everyone else was out.

Attending staff proceeded to warm the vehicles and escort people one by one down four flights of stairs. We carried one person down the stairs and returned her to

Participant Empowerment in Action

How One DSP Helped Two Women Feel Safer

I am a Direct Support Professional (DSP) and I work with Diane and Tamira. After the terrorist attack of September 11, I noticed that they often talked about being afraid and were scared that someone might blow up the building where they worked. I talked with them a lot about their fears but they continued having nightmares. I told them they were safe and the job coach would help them get out of the building safe. They wanted to know what would happen if the job coach got hurt. What would they do? I knew it was serious and they really felt bad. I wanted them to feel safe, so I talked with my supervisor and got permission to meet with them once a week to help them make their own safety plans.

In the first meeting we talked about their fears and I asked them to tell me their greatest fears. They asked why someone would want to blow up the World Trade Towers? They told me they were afraid someone might do that at the big hotel where they worked. They didn't know what they would do and they were scared that something bad might happen to their job coach. Then who would help them?

We talked a lot at that first meeting and I kept encouraging them to tell me as much as they could about how they were feeling. I thought it was important that they have someone they trusted to talk to about their fears. At the end of the meeting we all agreed to work on making a plan that they could follow, just in case something bad happened at work.

At our next meeting, one of the women baked cookies to surprise her job coach, who was also invited to attend. I knew it was important for the job coach to be a part of any plan. Between meetings I had taken time to find some pictures that represented the things they

We talked a lot at that first meeting and I kept encouraging them to tell me as much as they could about how they were feeling. I thought it was important that they have someone they trusted to talk to about their fears.

said made them fearful. Pictures were important because the women couldn't read. We took the pictures and started pasting them into a scrap book, and started talking about things that made them feel safe. They drew pictures and cut out photos from magazines of things that made them safe. We put these in the scrap book too.

We met at the library a week later to see if there were any books or movies about safety. We did find a couple of videos and some books so Diane and Tamira decided to check these out and bring them home. During the next week they

watched the video several times and asked me to read the books to them. The job coach asked the women if they wanted her to take pictures of them at the hotel and they said they thought that was a great idea. So after work one day the job coach took pictures of Diane and Tamira doing their job, finding the exits, going down the stairs, even standing in the parking lot by the tree that would be their designated safety spot. We also checked the local Red Cross and Community Safety Department to see if there were other safety resources they could look at.

At our final meeting, the women took the pictures their job coach had taken of them, pasted them in the scrap book, and decided to call it their *Safety Plan Book for Work*. That is the title we put on the cover with a picture of them where they felt safe. Inside we had a section that described in, pictures and drawings, how they felt about their fears, things that make them feel safe and finally what to do at work in case something bad happened. I asked the women to read me their book and when they said they couldn't read I said that was okay they didn't have to because we made the book out of pictures and all they had to do was tell me what they saw in the pictures. They giggled as they "read" their very own *Safety Plan Book* to me and the job coach. I know this helped empower Diane and Tamira to feel safer because they stopped having nightmares. The job coach said that every month or so she asks them to read their book to her and show her what they would do if

Personal Stories

From *We Watch the City*

The following are excerpts from the stories captured by Jerry Smith and his crew for *We Watch the City: Stories in the Shadow of 9/11*. The individual's stories are in their own word.

From Chapter 1: September 11, 2001

Steven Maiman

Steven lives in a supportive apartment on West 23rd Street and works at the Securities Training Corporation at Battery Place.

"Tuesday, September 11, 2001 turned out to be a very nice morning. As I got to work about 8:15am, and I was up front in the reception area checking people in. We had classes that morning. And then about 8:46 am or so, we saw on the T.V. that a plane had hit the World Trade Center. And we thought it was an accident. Then about ten minutes later, another plane went in, and we knew that it wasn't an accident, that it was a terrorist attack."

"So, myself and some of my colleagues went down the stairs and out into the park. There were a lot of people in the park. And then all of a sudden, the first building collapsed, then the second building collapsed, and we were all running for our lives. We didn't know what was going to come down next. It was like an apocalypse. It became dark and we were all full of soot and we were all black and everything. And we all ran towards the ferry and I was standing with one of my co-workers and then I left him for a minute to get something to drink because it was very hot that morning. The beautiful morning, that turned out

to be a disaster. And then I lost my co-worker, and I was like by myself."

"Afterwards, I just kept on running. About twenty minutes later, I ran into one of my other co-workers. We just stood together for about twenty to twenty-five minutes. And then it became, the air became a little clearer. It got a little lighter. So, I ran across the park and then I, with about six or seven of my co-workers, and then we just hugged each other and broke down. And then we all got into the subway doors. We were all in there because it was just so dark and there was debris all over the entire place and then we just stood there for a while."

From Chapter 2: The Response

Steven Maiman

"A lot of people were trying to get in touch with me. My family from New Jersey, my family from Florida, my father and my brother and my sister, about fifteen people tried to get in touch with me. But, I was just so shaken up, I was just in shock, I couldn't call anyone back at that time. I was just in shock."...

... "I have a lot of friends who helped me through it. It'll never ever be the same, it will never ever be the same. I'm very scared everyday when I'm down and around Battery Park. But, it'll never be the same, some nights I still wake up, I have nightmares about it. But, I know that, I feel safe in my apartment, you know. I have a lot of people who are helping me and working with me. You know, of course, I still feel that sacredness, I still feel afraid



Michael Spielberg, who called the Direct Support Professional who worked with him several hours after the attacks, and said, "What you want babe? I'm home and safe."

when I'm down there. Because I witnessed it, I was right down there in the park that morning. It was very devastating, very scary, I thought I was going to die that day. I thought it was going to be the end of my life." ...

... "It was very eerie and very scary. We all talked a little bit, then we all kind of got into our work. Which was the best thing to do. It felt very strange (to be back). It felt very strange to be down there. But, I realized that I have to go on with my life. Unfortunately, it's very sad. A lot of people lost their lives. Fortunately, I have my life and I have a job to do. I have an apartment to pay for, I have to eat, I have bills to pay, so I had to go back to work."

From Chapter 2: The Response

Kathy Broderick, Associate Commissioner

"We had a group of ladies and gentlemen [with disabilities] who had this very desperate need to be a part of and to do something, to give back, to do, to whatever. So, a friend of mine, that night, we took his van. It is an 18-passenger vehicle, it's huge. We took out the seats and between the consumers and the staff and this friend of mine, we hit every store. And wiped them out of everything.. We do a lot with Special Olympics, so I had Special Olympic uniforms, they went in the van. Socks, flashlights, batteries, everything, got put in this van. And Friday morning, a group of us drove it down to [an emergency response] center and as we pulled in. There were National Guard and police with rifles. One of the gentlemen that was with me, jumped up and said, 'Not to worry! We're from the Office of Mental Retardation and Developmental Disabilities



Elizabeth Sterling, seen here walking with her friend Tony Phillips, wonders why someone would fly planes into the World Trade Center.

(OMRDD).’ The cop looks at me and says, ‘Omar who!’ I said, ‘Oh my God!’ I tried to explain it, but then I said forget it, forget it. It’s just a group of people that really wanted you to know that we’re thinking of you and this call came out on the radio that you need these supplies. So here it is.”

You know, but that was just one indication of their needs. Groups have been formed now that are volunteering, they established choral groups that sing at nursing homes and day care centers. We have consumers that were part of photography clubs that took pictures. I’m trying to think, I cannot even, getting people across the (Verisano Bridge) when (Staten) Island was on lock down. I mean they were on lock down, nobody could get in, and nobody could get out. People couldn’t leave their house. The trauma that our consumers and our staff were subjected to and they just

kept rising and rising.”

(The Journal: Dedicated to OMRDD’s Heroes: Special September 11, 2001 Commemorative Edition 14(1) pp 3-4. Albany, NY: OMRDD).

From Chapter 3: The Day After

Steven Maiman

“After six months, I still feel scared down there, but I know there is much much more security down there now. There’s a lot of security in my building. We have to show IDs now. So, I don’t feel 100% safe, which I don’t think I ever will. I feel maybe 60% safe.”

From Chapter 4: Lessons Learned and Advice

*Office of Mental Retardation and Developmental Disabilities
Thomas A. Maul, OMRDD
Commissioner*

Continued on back cover

Helping People You Support Cope with War and Terrorism

1. Be honest and give age and developmentally appropriate explanations about the traumatic event. Only provide answers to questions that the people you support are asking and do not overwhelm them with too much detail. Use language that is appropriate for the people you support. Monitor your own and the people you support's exposure to visual images that are terrifying in the newspapers or television. Use adaptive ways to communicate with the individuals you support.
2. Help the people you support to express how they are feeling about what they have seen or heard. If the person you support has difficulty verbally expressing their feelings, work with them to find another outlet for expression. Ask the people you support, "What is the scariest or worst thing about this for you?" or "What is worrying you the most?"
3. Tell the people who you support that what they are feeling (e.g., anger, anxiety, helplessness) is normal and that others feel the same way.
4. Reassure the people who you support that you or another trusted direct support professional will be there to help them through any traumatic event.
5. Help the people who you support to release their tension by encouraging daily exercise and activities.
6. Structure and routine are very important to many people with disabilities, so try to keep daily routines on schedule and close to what people are used to doing.
7. Recognize that war or a tragic event could elevate psychological or physical symptoms (e.g., headaches, abdominal pain or chest pain, nightmares). Anger and symptoms of illness can be a signs of anxiety. Check with a health care professional if escalation in symptoms persist beyond a couple of weeks.
8. Use this opportunity as a time to work with the people who you support on their coping skills. Use coping strategies which you know are typically helpful for the people you support since each person copes in a way that is best for him or her (for example, prayer, doing things to help other people, listening to music).
9. Remember that emotions are contagious. If you are highly upset or anxious, there is a chance that the people around you will feel the same way. If you are having difficulty coping with stress or with what is going on in the world around you, it is important to talk with someone who can help you to cope.
10. Remember that this can be an opportunity to build future coping and life skills.

Adapted with permission from Bernadette Mazurek Melnyk, PhD, CPNP, NPP, FAAN, founder and chair of NAPNAP's KySS (Keep your children/yourself Safe and Secure). Bernadette can be reached at Bernadette_Melnyk@urmc.rochester.edu

Highlighting America's Quiet Heros

The American Network of Community Options and Resources (ANCOR), with the support of its 700 member agencies, launched a National Advocacy Campaign in September 2001 to address the critical issues facing private providers that threaten the stability and viability of community-based supports and services for people with disabilities. The objectives of this campaign are —

- To obtain wage and benefit enhancements for direct support staff.
- To create awareness of the need for a national policy to address the workforce shortage, i.e., make this a national priority issue.
- To demonstrate the critical role DSPs make in enhancing the lives of Americans with disabilities.
- To secure incentives for solidifying a career path for DSPs.
- To build the level of public awareness of the depth of private provider services.

This unprecedented effort has begun to bear fruit with recent developments, showcased at the ANCOR Governmental Activities Seminar this past September.

- Secretary of Labor Elaine L. Chao addressed the ANCOR audience and pledged support
- Representatives Pete Sessions and Lois Capps introduced a congressional resolution focusing on Direct Support workforce crisis.
- BDO Seidman released workforce research data validating significantly decreased labor purchasing power for private providers.

Secretary Chao Pledges Support

Secretary of Labor Elaine L. Chao demonstrated a clear command of the recruiting and retention issues facing private providers and their impact on advancing community inclusion; the challenges of direct

Private agencies serving the developmentally disabled cannot attain and retain qualified employees when wages in competitive markets are increasing at a much faster rate.

support work; and the contribution made to the fabric of American communities everywhere. She added her endorsement of the ANCOR National Advocacy Campaign, calling the industry the “heart of the American spirit.” Secretary Chao promised the enthusiastic support of the Department of Labor, working with the Department of Health and Human Services, to address the national direct support labor crisis. This initiative will identify methods to attract, train and maintain a skilled and committed workforce.

BDO Seidman Research Data

Joe Lubarsky, a partner with the prestigious accounting and consulting firm

BDO Seidman, shared data supporting the growing crisis in the direct support workforce. The results presented by Lubarsky derive from research underwritten by the ANCOR National Advocacy Campaign. Of note is that wages have increased only \$0.82 over a nine-year period versus \$3.16 and \$2.11 increases for “public” direct support workers and fast food workers, respectively. The percentage increases over that same period for public direct support and fast food workers were 200-300%.

“Private agencies serving the developmentally disabled cannot attain and retain qualified employees when wages in competitive markets are increasing at a much faster rate,” stated Lubarsky. The wage increases for direct support workers over an eight-year period are roughly one-third of the percentage increase in spendable income nationally over the same time period. Lubarsky also shared comparative data on benefits packages and noted that the next phase of the research will focus on expanding comparative benefits data.

For detailed research graphs and narrative on this research go to the ANCOR Web site (http://www.ancor.org/dev/Activities/National_Advocacy_Campaign.htm select the “Research” button).

Representatives Sessions and Capps Introduce Resolution on Behalf of Direct Support Workforce

At a national news conference on September 24, held in conjunction with the ANCOR Governmental Activities Seminar, U.S. House of Representatives members Pete Sessions (R-TX) and Lois Capps (D-CA) announced the joint introduction of a resolution to Congress, H. Con. Res. 477, which addresses the direct support professional workforce crisis. (For a full text of the resolution, go to: <http://www.ancor.org/dev/issues/Workforce/HR477.pdf>). The resolution states that the federal government and the states should “make it a priority to ensure a stable, quality direct support workforce for individuals with mental retardation or other developmental disabilities that advances our nation’s commitment to community integration for such individuals and to personal security for them and their families.” Since its introduction, numerous other representatives have signed on as co-sponsors.

“These direct support professionals are great for our country,” Congressman Sessions told the news conference attendees. “They need to be honored for what they do every day.” Congresswoman Capps added, “This population of caregivers with tremendous dedication and skills is held hostage by dwindling budgets and shrinking resources.”

Sessions and Capps were joined on the podium by individuals with disabilities, direct support staff and parents. Speaking on behalf of direct support professionals was Tonya Simmons, an employee of Spectrum Support in Maryland, an ANCOR member. Ms. Simmons is

a single mother with eight-year-old twin daughters and is a junior at Coppin State University. She works 140 hours every two weeks as a job developer and coach. “I am working in an underpaid position working 140 hours biweekly to support adults with disabilities,” she stated. “I enjoy what I do and look forward to going to work each and every day. Why? Disabilities does not mean inability and I believe in what we do...”

Ms. Simmons stressed that direct support workers should be acknowledged and respected for the challenging work they do every day, and that the respect should be translated into a decent wage. A father from Kentucky spoke about the critical role direct support professionals have played in enhancing his daughter’s life and supporting her in reaching her full potential.

The resolution has also garnered support from the following national organizations: American Association on Mental Retardation, The Arc of the United States; National Association of State Directors of Developmental Disability Services; The Council on Quality and Leadership and United Cerebral Palsy.

We encourage direct support professionals to champion the resolution by sending a letter to their congressperson requesting support of the resolution. You can either complete and fax the model grassroots resolution support letter prepared by ANCOR (download the letter from the ANCOR Web site at http://www.ancor.org/dev/Activities/National_Advocacy_Campaign.html / *GRLetter.doc*) or fax a letter to your member of Congress. If you do not know your House member, fax your letter to ANCOR, and we will fax to your congressperson for you.

We also urge you to request a meeting with your House member to discuss the resolution and the importance of the direct support workforce.

Sinclair Broadcast, which operates in over 60 media markets across the country, has pledged its support in broadcasting public service announcements in prime time slots. Funding is being sought to develop at least two public service announcements to begin airing in 2003. The focus of these service announcements would be to highlight the critical role direct support professionals play in the lives of people with disabilities.

The workforce issue carries huge social ramifications and ANCOR is committed to moving it forward onto the national action agenda.

Renee L. Pietrangelo is CEO for the American Network of Community Options and Resources (ANCOR). She can be reached at: 1101 King St., Suite 380, Alexandria, VA 22314, or 703.535.7850. The ANCOR Web address is <http://www.ancor.org>.

Frontline Resources

American Red Cross Disaster Preparedness for People with Disabilities

[http://www.redcross.org/
services.disaster/beprepared/
prep.html](http://www.redcross.org/services.disaster/beprepared/prep.html)

The booklet was designed to help people who have physical, visual, auditory, or cognitive disabilities to prepare for natural disasters and their consequences. Anyone who has a disability or anyone who works with, lives with, or assists a person with a disability can use this booklet. It contains information that can help you organize a personal disaster plan and includes plans for the care of service animals and/or pets during a disaster. The booklet is designed with checklists and extra space for people to use to organize information that will help them prepare for a disaster. You may copy these pages from the booklet as needed to distribute or post somewhere handy. The booklet is in a pdf file format and require Acrobat Reader Software.

Communication Picture Board New York City Mayor's Office of Emergency Management & The New York Community Trust

The communication picture board is for use by emergency service personnel and frontline intake staff to better enable effective communication with the public. The booklet helps staff determine an individual's primary language (Albanian, Arabic, Chinese, Greek, Hindu, Italian, Haitian/Creole, Japanese, Korean, Polish, Russian, Spanish, Yiddish and American Sign Language). There are a series

of pictures with the corresponding English and Spanish words that help individuals to express their needs in times of disasters or other emergency situations. People are able to simply point to the picture or phrase that represents his or her situation or identifies an item she/he needs. To obtain a copy, call the New York City Mayor's Office of Emergency Management at 212-788-2830.

Emergency Plans that Include Workers with Disabilities

Nan Hawthorne
[http://www.esight.org/
View.cfm?x=364&ov_id=-1](http://www.esight.org/View.cfm?x=364&ov_id=-1)

In the wake of the September 11 disasters in the United States, there's an unspoken question on many minds: How can we include an employee with a disability in our emergency and evacuation plans? Here are some answers to allay your darkest fears. Topics include —

- What will happen to our disabled workers if there is an emergency
- Strategies that save lives
- Tools and help before you need it
- Related links

Federal Emergency Management Agency

[http://www.fema.gov/library/
disprepf.htm](http://www.fema.gov/library/disprepf.htm)

Provides information related to disaster preparedness for people with disabilities and assisting people with disabilities in a disaster.

National Organization on Disability

<http://www.nod.org>

Site provides a wide range of information on emergency preparedness for people with disabilities.

One Step Ahead of a Disaster: A Guide to Developing a Disaster Preparedness Plan (1994)

Irwin Siegel Agency, Inc.
Risk Management Department
25 Lake Louise Marie Road
Rock Hill, NY 12775
1-800-622-8272

of the upheaval in New York City after the attacks on the World Trade Center. This delay certainly changed the nature of the interviews as most people responded rather stoically to our questions about 9/11. New York City itself changed dramatically during this time as well, as recovery and construction crews worked tirelessly through the devastation of the trade center site, referred to as “ground zero.” By spring of 2002 the site had become a large hole, most of the debris had been removed. Still, thousands of people came each day to look at the site where the towers once stood. The area had become a memorial and a shrine.

Once we received approval to begin interviewing, a number of provider agencies came forward and provided us with essential assistance by connecting us with people whose lives were deeply affected by the events. YAI- National Institute for People with Disabilities, Lifespire, Job Path, FEGS, United Cerebral Palsy of New York, and other organizations shared our concern that stories should be gathered and delivered to a wide audience.

Tony Phillips of Self-Advocacy Association of New York State, who is a deacon in his church, and an Americorps volunteer, helped during most of the on-camera interviews. Not only did Tony seem to know most everyone in the city, but his knowledge of the service delivery system evoked many questions we might never have asked. Beyond exploring personal stories of 9/11 and after, Tony would often ask Direct Support Professionals how they benefited from their involvement with the people they support. “Who helped you on 9/11?” “In what ways did the people you support help in the days following 9/11?” Through

Tony’s involvement, we gained a better understanding of what Direct Support Professionals experienced and a deeper appreciation of the bonds people developed. These were not stories of a tragic day, but of friendships, of deeply felt relationships that transcended labels of “staff” and “consumer.”

Over course of interviewing and shooting footage, perhaps the most striking part of this project was how similar people’s stories of 9/11 were to those without disabilities. The desire to help others, New Yorker pride, the anger toward the terrorists, the outpouring of grief, and the willingness to get back to work — all of these were present in the comments most everyone we interviewed. Perhaps at some time in the future, news media will include stories of people with disabilities and a project such as this will not be necessary. But we are not there yet, as Tony and I discovered when we asked reporters on the anniversary of 9/11 if they were covering the reaction of people with disabilities. These stories of 9/11, of people with disabilities and those who support them, are really just stories of ordinary people who, like other New Yorkers on that day, experienced tragedies and responded by rising to extraordinary levels. These stories stand out as unique and different because no one else has told them.

Jerry Smith is a project coordinator and filmmaker at the Institute on Community Integration, University of Minnesota. He can be reached at 612.624.4336 or smith495@umn.edu. To order, call 612-624-4512 or visit <http://lici.umn.edu/publications>.

her chair at the bottom. Another person, who uses the assistance of a walker, walked arm in arm and hand in hand with staff down all four flights. This was an incredible accomplishment for her and was a powerful statement of determination for everyone that witnessed it.

We made another phone call to Patty roughly an hour after we started and reported that the first step of our evacuation was done and two staff were waiting for the Fire Department to arrive and help carry Steve and his chair downstairs. Within minutes of that call our help arrived and we carried him separately from his chair to the bottom landing where he thanked everyone for helping him. “Thank-yous” and handshakes were graciously exchanged and our heroes were off to another call. We officially checked out around 1pm on Friday. The hotel was still without power.

According the newspapers some 800,000 Metro residents were without power and full power was finally restored until mid February. The men and women we are responsible for either returned to their own homes, their parents’ homes, or arrangements were made for other temporary homes until power was restored.

This story shows how Direct Support Professionals and the people they support can work together to adapt and cope during a disaster. To plan for winter storms stock up on blankets and supplies. When elevators are unavailable, consider all options before moving people who use wheelchairs using the stairs.

Jim Hardin is a DSP at Johnson County Developmental Supports. He can be reached at 10501 Lackman Road, Lenexa, Kansas 66219-1223, 913.492.6161 (ext.252), or jim.hardin@jocoks.com.

How One DSP Helped Two Women Feel Safer, continued from page 10

something bad happened at work, and they do.

Community Supports Skill Standards

Competency Area I: Participant Empowerment

The competent community-based support human service practitioner (CSHSP) enhances the ability of the participant to lead a self-determining life by providing the support and information necessary to build self-esteem, and assertiveness; and to make decisions.

Participant Empowerment in Action

As a DSP, think of ways in which you can involve the people you support when planning for disaster or emergencies. Provide or find information together about ideas on how to make emergency or disaster preparedness plans. Encourage the people you support to help in making decisions on how to carry out these plans. Practice using the plans in a way that involves the people you support. With their help, being safe in a disaster will be easier!

For more information on the nationally validated Community Supports Skill Standards, visit <http://www.nadsp.org/training/csss.html>.

If you have a story that shows how you demonstrated one of the skill standards, please send it to Nancy McCulloh, FI Editor, mccul037@umn.edu.

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Personal Stories From We Watch the City,
continued from page 12

“As I traveled around New York City after September 11, I couldn’t help but recall all the times in the past I had talked about our staff, especially our direct care staff, being special people. I have certainly meant it, they are indeed special, and over the years they have given me many reasons to believe it is true. But, until you have experienced the kind of tragedy they have experienced, I don’t think that you realized how really special these people are.”

“I have used the word heroes when referring to these incredible people, and there certainly isn’t a better use of that word. I feel that way because indeed it takes a special person to place the welfare and the needs of others above their

own needs and above their own concerns at a time of crisis. That’s what so many staff people did on September 11 — at both state level and at voluntary provider agency programs.” ...

... “I think we should always remember the World Trade Center. I say that not in terms of the human devastation and sorrow and the suffering, but I think that we should remember the World Trade Center in terms of the people who raised themselves about levels that we would have ever anticipated. People who are heroes, people who addressed the needs of others, people who showed that caring was the most important of the human commodities. If we remember that lesson, we will indeed have a better

world” (*The Journal: Dedicated to OMRDD’s Heroes: Special September 11, 2001 Commemorative Edition*, 14(1) pp 2,4. Albany, NY: OMRDD).

Excerpts from: *We Watch the City, September 11, 2001 and Its Aftermath: Experiences of Persons with Developmental Disabilities*, by Mary F. Hayden, K. Charlie Lakin, and Jerry Smith, Rehabilitation and Research Center on Community Living, Institute on Community Integration (UCEDD), College of Education, University of Minnesota, 214 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. <http://rtc.umn.edu>

Visit the DSP Web site at <http://rtc.umn.edu/dsp>

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