

**Emergency Management and People with Disabilities:
Before, During and After**

**Congressional Briefing
November 10, 2005**

Hosted by The National Council on Disability, the National Council on Independent Living, the National Organization on Disability, the National Spinal Cord Injury Association and the Paralyzed Veterans of America.

Room 2168, Rayburn House Office Building, Independence Avenue

1:30 p.m. on November 10, 2005

Total Time: 2 hours

Agenda

Panel Discussion (1:30 – 3:20)

Opening Remarks

The Honorable Jim Ramstad, Co-Chair, Bipartisan Disabilities Caucus

The Honorable James Langevin, Co-Chair, Bipartisan Disabilities Caucus

Lee Page, Associate Advocacy Director, Paralyzed Veterans of America

Presentation by Panelists:

Hilary Styron, Director, Emergency Preparedness Initiative, National Organization on Disability

Marcie Roth, Executive Director/CEO, National Spinal Cord Injury Association

Claudia Gordon, Attorney Advisor, Office for Civil Rights and Civil Liberties, U.S. Department of Homeland Security

John Lancaster, Executive Director, National Council on Independent Living

Natalia Mason, Interim Manager, Partner Services, American Red Cross

Patricia Pound, Vice Chair of the National Council on Disability

NOTE: The **Federal Emergency Management Agency (FEMA)** was invited, but did not appear.

Q&A with Panelists (3:20- 3:50)

Closing

Lee Page, Associate Advocacy Director, Paralyzed Veterans of America.

Minutes

Jim Ramstad: We'll begin today's briefing. I want to welcome all of you here. My name is Jim Ramstad from Minnesota. Along with James Langevin from Rhode Island, who will be coming shortly. Together, James and I co-chair the Bipartisan Disabilities Caucus. It's a real pleasure to welcome all of you here today. I particularly want to thank several people for their hard work in putting this briefing together. These people include: Jeff Rosen and Mark Seifarth from the National Council on Disabilities; Susan Prokop from the Paralyzed Veterans of America; Daniel Davis from the National Council on Independent Living; Mary Dolan from the National Organization on Disability; and Deb Fulmer from the Department of Homeland Security. I also want to thank our panelists for joining us today.

The audience will hear friends and eyewitness accounts from Hurricane Katrina and Rita that are compelling, gripping, and horrifying. These accounts will demonstrate the need to include people with disabilities in emergency management planning preparedness. As co-chair of the Bipartisan Disabilities Caucus, I want to thank all of you for being here today to discuss such an important subject. I'm sure all of you agree we need to knock down barriers wherever we can. That's why it's absolutely unacceptable, that in a time of national emergencies, people with disabilities face barriers and roadblocks to their very own survival. Many of us saw that played out on television during the rescue efforts. Some of our panelists are going to talk about being on a phone with a person in a chair as he or she tried to make the last effort to escape the rising water only to meet their demise.

Certainly, the disaster in the Gulf Coast region exposed the enormous gaps in the emergency planning preparedness and management for people with disabilities. Amazingly, this was not the first time that the federal government has been alerted to the need for better emergency management for people with disabilities. In a truly remarkable show of foresight, the National Council on Disability (NCD) released a report last April outlining steps that the federal government should take to include people with disabilities in emergency preparedness, disaster relief, and homeland security. In addition, with the emergency evacuation at Capitol, House and Senate office buildings in June, one would think that the federal government would take some action in this matter. In response, the Committee on House Administration held a hearing on accessibility of the House complex for persons with special needs. The co-chair of the Bipartisan Disabilities Caucus, Jim Langevin, testified at the hearing on the pressing need to do more in emergency preparedness for people with disabilities. But, despite all these warnings, the federal response in the Gulf region before, during, and after Katrina was seriously lacking.

One example of a dire story is the one of the Louis Armstrong Airport full of wheelchairs because wheelchairs had to be left behind. People with disabilities were separated from their service animals, from their medication, from their life-saving dialysis. Other stories that did not receive much press attention also show severe problems that people with disabilities faced. Another example of a case that I found particularly compelling and gripping was of a medical unit being placed on the second floor of a building; this limited access for people with impaired mobility who could not reach the second floor. Despite this setback, local officials were able to connect them with medical services. In response, they relocated doctors and other medical professionals to the first floor. But again, due to lack of preparedness, lack of planning, lack of thoughtfulness, the medical services were placed on the second floor of a building, which housed people with disabilities.

Jim and I believe that it is long past due for the federal government to do the right thing, which is to place the highest priority on helping people with disabilities by making these escapes and relief efforts accessible to people with disabilities. Jim has pointed out that evacuation plans for people with disabilities exist here at the Capitol in the event of an emergency situation; such as an elevator that will run if the power supply is interrupted. However, what's lacking, as Jim Langevin has pointed out to many of us, is directions to the elevator for people with disabilities or designated personnel to help people with disabilities find the elevator. There might be an elevator that will provide you with an escape mechanism, those of you in chairs, but what good does it do if you don't know where it is or if nobody's providing directions to that elevator. This is really unacceptable. It's time to learn the lessons that are so obvious, or should be so obvious.

As we move forward in rebuilding, we need to keep in mind the accessibility of first aid stations, mass feeding areas, portable pay phone stations, portable toilets, and temporary shelter. We need to insure that people will not be separated from their wheelchairs or service animals, and certainly not for extended periods of time. We need to ensure that FEMA and other disaster management agencies not only purchase adequate trailers for short-term housing, but also new housing and new buildings that are accessible for the long-term need.

In conclusion, I think we all agree, as this large turnout today indicates, that this briefing is clearly needed. I am grateful to all of you for your continuing efforts to help people affected by Katrina, Rita and other natural disasters. I hope the Federal Government will finally heed your urging. All of you know, like Jim and I know, that it's axiomatic in Washington, on Capitol Hill, that the squeaky wheel gets the grease. We have to be the squeaky wheel so that the federal government does finally heed your urging. We must adequately prepare and include people with disabilities in emergency management. We must adequately prepare and include people with disabilities in the emergency management. So thank you again, all of you, for being here. Thank you to our panelists. It's now my pleasure to turn it over to my distinguished co-chair, my good friend from Rhode Island, Jim Langevin.

James Langevin: Your comments, Jim, were great. Thank you for your leadership and your partnership to the Bipartisan Disabilities Caucus. Your experience and your instincts are invaluable. Let me begin by thanking all the groups that are represented here today for such an important issue.

Because the Disability Community is so diverse, this panel represents the scope of our knowledge, our challenges, and our experiences. I am also thrilled that the National Council on Disability, The National Spinal Cord Injury Association, and National Council on Independent Living, The Paralyzed Veterans of America and the National Organization on Disability have come together to present to the Bipartisan Disabilities Caucus their impressions and findings about the effects of Hurricane Katrina and Rita on people with disabilities. I am also grateful for the participation of representatives from the Department of Homeland Security and the Red Cross.

We have all heard the very upsetting stories about the plight of American families in the Gulf Coast. Some of the most tragic are those stories that were completely avoidable. For me, the stories about the paralyzed and physically disabled people being left in their homes to die are very personal. I can sympathize with them because I know what supports that I need in order to maintain my independence on a day-to-day basis. I know quite clearly that if those things break down or things don't come together like they should that people can be in trouble. And, clearly, this is what happened in the Gulf region for people with disabilities. Every American has the right to expect that these supports in an emergency situation will be present. And when there's no plan for evacuating people with disabilities, we find ourselves unable to reunite even a person with their wheelchair; in these types of cases, we truly have failed. In other words, we failed too many Americans in the Gulf Coast this year. And the sad part is that the failures could have been prevented.

Following the hurricanes, Katrina and Rita, my colleagues and I worked quickly to pass emergency funding bills, to accelerate TANF payments for those affected by Katrina, to waive student loan repayments for students attending schools, and to increase the available federal funds to pay claims under the National Flood Insurance Program. In the coming weeks and months, Congress will continue to deal with these kinds of issues.

But, as we move forward, I think that it is crucial not to neglect issues of accessibility and inclusion in our planning because the problems can surface later and they will be even more complicated, more expensive; and in some extreme cases, they will cost people their lives. I understand this panel has some concrete recommendations to put forth as to how we can better prepare for the future events that may take place. I also understand the panel will discuss the ongoing needs of people with disabilities who were evacuated from the Gulf Coast region. Such needs include accessible housing and accessible health care.

I just want to thank you for your quick and efficient work on identifying these needs. And I want you to know that I pledge, along with my colleagues, Jim Ramstad and others, to work with you and all Americans with disabilities as we move forward. Finally, I want to thank this panel for highlighting to all of us here today how very important it is to keep the needs of *all* of our constituents in mind before, during, and after these catastrophic events. In my years of policymaking, I have tried to stress that the needs of people with disabilities must be a forethought, not an afterthought. This has never been clearer than it is today, as we discuss what happened to persons with disabilities in the tragic days and weeks surrounding the Gulf coast hurricanes. I just want to thank you for all your hard work for being here today and for putting this together. I know we're all going to learn a lot. And now we also need to use this as a

call to action to put those recommendations into place so we can address effects of disasters in the future. I will turn the panel over to Lee Page.

Lee Page: Thank you very much, both Congressmen, Jim Ramstad and James Langevin for kicking off the program with such great statements. You really set the stage as to what we really need to talk about, especially recognizing that it was just two short months ago that Katrina and Rita basically devastated the Gulf region areas leading to a strain on FEMA, Red Cross, and all the other voluntary agencies that are out there responding to the needs of the general public. However, we have not necessarily seen what people with disabilities or those with chronic illnesses or the most vulnerable have gone through.

I know that for us, Paralyzed Veterans of America (PVA), our Bayou Gulf state's chapter took a direct hit. It is located in the Louisiana area; however, all that is left is the cement slab of the facility. We had over nine hundred members of the organization that were hit and felt some sort of effect via the hurricanes. In addition, we had 25 members that specifically lost everything including their housing. All of the members are spinal cord injury veterans, who use wheelchairs a hundred percent of the time. In some instances, the VA medical center located in Gulf Port, Mississippi was evacuated leading to many of the patients and members being transferred to different facilities throughout the region. In some cases, we had members transferred to the V.A. in Memphis and in Houston. Unfortunately because everything was done in such a hurry due to the evacuation, a lot of things did get left behind; these include people's wheelchairs, assistive technologies, and medications needed for them to continue their independent lifestyle. But, fortunately, because the V.A. is a very well organized part of the government that provides assistance to veterans of the armed services, most of the services have been returned to our members, and to many other veterans. However, what is lacking is accessible housing. I have received a statement that our executive director from the Bayou chapter found out that when FEMA or the other organizations that were distributing housing or materials, it was basically on a first come first serve basis. In addition, the concern about whether it was accessible or not accessible or whether it met your needs was not considered. In other words, if the evacuees did not take what they were given, whether it met their needs or not, they were placed on the back of the list. As a result, some of our guys had to camp out in their homes in makeshift tents or shelters, while waiting for accessible trailers. But, what would have even helped more was if they had just plywood and sheetrock dropped off that would have allowed them to either fix the damage themselves or have someone fix the damage. But with that, I will pass it on to some of the other panelists, including Patricia Pound from the National Council on Disability, Natalia Mason from Red Cross, myself from PVA, John Lancaster from NCIL, Hilary Styron from NOD and the director of the Emergency Preparedness Initiative, Marcie Roth from National Spinal Cord Injury Association, and Claudia Gordon from the Office for Civil Rights and Homeland Security. I'd like to turn it over to Hilary so she can speak a few words. She has actually been down to the Bayou area and seen face-to-face activity of what's going on, especially how people with disabilities have been affected.

Hilary Styron: Good afternoon, everybody, I am Hilary Styron with the National Organization on Disability and director of the Emergency Preparedness Initiative, which

is one of the only emergency based programs with a disability organization in the country and was founded and started after 9-11 by Allen Reich, who passed away on Tuesday morning. This is certainly a sad time and we send condolences to his family.

I deployed rapid assessment teams after Katrina hit in the Gulf region. We had four teams in Louisiana, Houston, Texas, Alabama and Mississippi, primarily to assess what was happening with the disability and special needs community in this region as well as what was not happening. We couldn't really ask federal responders to make changes if we didn't have a real handle on the truth. I went to Louisiana after coming back from the deployment for the special needs teams. I was redeployed at the mayor's request to the city of New Orleans and worked at the EEOC for a week in the direct impact zone to help them address their special needs issues. I've been a first responder for over fifteen years. I've been on the back of ambulances as a paramedic, working in the Gun and Knife club of the Midwest. I've worked floods, tornadoes, earthquakes and hurricanes. By far, this is one of the worst disaster scenes I've ever been on. The members of my team who were survivors from 9-11 say it was worse than 9-11 after getting out of the rubble.

Some of the shelter assessments and information is in the back of the room for you, I will direct your comments that were on the shelters in Louisiana that had a special needs portion of the second floor that was inaccessible to some people with disabilities. I personally went to that shelter, ready to bear arms; unfortunately, I had to be dressed in Kevlar to enter that shelter of five thousand people. The reason that it was on the second floor was because of the crime and the violence unfolding on the first floor and the need to maintain control and security of five thousand people in a two thousand person room. Eventually that special needs shelter was moved out of that facility and taken to a hospital.

So, I just caution us all as the only emergency manager on the panel that we're thinking about all of the special needs; and I do not disagree that this is not new information because this has been going on for 25 years and perhaps even longer than that. This has been an issue ever since the first disaster, but it has not been effectively addressed. It's not part of the national response plan or part of the FEMA agenda; however, it will be now. The Emergency Preparedness Initiative is actively talking with emergency managers, elected officials at all levels of government throughout this country, and working strongly with the disabilities leaders in this room, on this panel and across the country.

So, you are going to hear some wonderful information as well as some tragic information. I have voice mails on my cell phone and home phone number from people calling and saying: Do you think I'm going to make it? I have water in my apartment, I have this or that, am I going to make it? Those people did not make it. There's no reason for the after-action reports of 9-11 or any of the other natural disasters in this country to not be made into action. This is your chance to no longer be a passive consumer and encourage your members of Congress and your advocates to protect your life safety. If we're going to argue about Medicare or the price of gas, then you need to be arguing about your personal preparedness and whether you can access the system.

85.7 percent of the community-based organizations that provide services to people with disabilities and aging senior citizens did not know who their emergency

manager was in the Gulf region. They thought it was 911. 911 is not your emergency manager.

By far the hardest community hit in this disaster was the deaf and hard of hearing. Over 80 percent of the shelters did not have access to TTY; 60 percent of the shelters did not have captioning TV capabilities. Less than 30 percent had access to sign language interpreters.

When an individual with disabilities or special needs went into a general needs/general population shelter, the people working in the shelter did not know how to recognize if someone had a special need because of the lack of pre-management training. Some disabilities are hidden. For example, if someone is deaf, they don't understand what you're saying to them; or if they have a cognitive or learning disability, they may not be able to understand the directions. And because of that lack of communication due to the absence of accessible communications devices, they had delayed care. There were deaths as a result; this increased fatalities. The largest population suffering from this disaster is over the age of 60; many of them have a disability. Seventy-five percent of them are from nursing homes, including the 34 from the nursing home in Bernards.

When I talk to emergency managers, as recently as last weekend, in Orlando, I was told that this population is acceptable "loss and collateral damage." I asked a major in the army national guard how his mother was doing in the nursing home. Oh, she's just fine. Congratulations, you just killed her because she's an acceptable loss. This has happened for too long. As an emergency manager we have failed to get you what you need. We've had to respond with terrorism grants that are not fully accessible. We have failed this population and I need to know how much longer. We've all lost friends. We've lost our businesses. We've lost a lot. And it will continue to happen until there is a regulation or until there are compliance standards or until there is money tied to it. There's enough money in this country to rebuild other countries. We need to protect this one first. The assets of the human person in this country are our most critical and we are not protecting them. So, I ask you Congress: What are you going to do after this session today? Thank you for your time.

Lee Page: Thank you very much. Marcie, why don't we hear some comments from you.

Marcie Roth: Good afternoon, I'm Marcie Roth. I'm the Executive Director and CEO of the National Spinal Cord Injury Association, which is the nation's oldest and largest organization serving civilians with spinal cord injuries and diseases since 1948. I'm here representing NCIA, but I want to be very clear that we have been working on behalf of all people with disabilities, including those with sensory, intellectual disabilities, mental illness and other psychiatric disabilities. And although I am focusing on efforts to assist Americans with disabilities in disasters today, NCIA is also wholly committed to working with our colleagues to address the needs of all people with disabilities in disasters in other parts of the world.

I want to thank the Disabilities Caucus for the opportunity to provide you and your colleagues with this briefing, especially representatives Congressmen Langevin and Jim Ramstad for your leadership and support. I want to thank my colleagues, both those in the private sector and those representing government, for the opportunity to work

alongside you over the past ten weeks as we have shared our knowledge, resources, and deep commitment to meeting the needs of as many people with disabilities as we possibly could. We have demonstrated a kind of partnership I celebrate now and I will do all I can to maintain this partnership in all aspects of my work as we move forward. We have truly worked as a team and 56 million Americans are better off for our efforts.

On September 13, 2001, I first became involved in navigating between the federal systems and private sector in an effort to address the urgent needs of people with disabilities who had survived the terrorist attacks two days earlier. I quickly learned that a lifetime of knowledge of the additional needs of people with disabilities was being called into action as I found myself in the breach, navigating between the very real needs of very real people and the limited federal systems poorly designed to address those needs. In the months and years after those terrible days, I participated in, but did not lead efforts to assist people with disabilities to prepare for another emergency.

I saw the creation of the US Department of Homeland Security, the relocation of FEMA and the National Disaster Medical System and many other visible signs that indicated to me that high level planning for the next national disaster was in good hands. I did my part, but trusted that even though I couldn't see it, we were ready. I joined much of America as we watched with more than a little alarm as Hurricane Katrina took a bite out of Florida and then made its way into the Gulf. On the morning of August 29, I received a call that I will never forget, and once I tell you about it, I hope you will never forget it either. My friend and colleague, former appointee to the Social Security Administration, Susan Daniels called me to enlist my help because her sister-in-law, a quadriplegic woman in New Orleans had been unsuccessfully trying to evacuate to the Superdome for two days. In my naïveté, I thought a few phone calls to the right people would help and I was sure I knew whom to call. After many calls to the right people, it was clear that this woman, Benilda Caixetta, was not being evacuated. I stayed on the phone with Benilda, for the most part of the day, assuring her that I was doing all I could to make sure help would be coming as soon as possible. She kept telling me she'd been calling for a ride to the Superdome since Saturday; but, despite promises, no one came. The very same paratransit system that people can't rely on in good weather is what was being relied on in the evacuation. It's no surprise that didn't work. I was on the phone with Benilda when she told me, with panic in her voice "the water is rushing in." And then her phone went dead. We learned five days later that she had been found in her apartment dead, floating next to her wheelchair. Sometimes things like this can't be prevented. This was not one of those times. Benilda did not have to drown.

Charles, a man with a good job, his own home in New Orleans, and flood insurance hasn't been able to bathe in ten weeks. He's quadraplegic and homeless. The lack of personal care has landed him in the hospital twice. He now has a staph infection as a result of his last hospitalization. His insurance will pay over one hundred thousand dollars to repair his accessible home, but his community is destroyed. There's no public transit system, no grocery store, no health care system. He can't afford to keep paying the mortgage and taxes on a home he can't live in; and he can't afford to move to Baton Rouge where he could continue working and access health care and other disability related services. A hundred thousand dollars won't pay off his mortgage and it won't allow him to buy a new home in Baton Rouge. The cost of housing is just too high there. What is he to do?

Selena, also quadriplegic, started in her own home in Bayou La Batrie, Alabama. She had chosen to pay for college rather than pay for homeowners insurance. On August 29 she evacuated first to family, then to a crowded, understaffed special needs shelter where she slept in her wheelchair. When the shelter was unexpectedly shut down, she was sent to a bed and breakfast without an accessible bathroom. Her skin couldn't take the abuse. She ended up with a life threatening pressure sore. Yesterday, she was transferred to a nursing home. Selena survived the hurricane. She now faces surgery and months of recovery. She's living in a nursing home and has no place to go.

We worked around the clock for weeks to try to get disability experts into the shelters to assess the needs of people with disabilities who couldn't hear the announcements over loud speakers or see the signs that directed them to assistance, or who were losing critical stability because they didn't have access to medication to treat their mental illness, or whose eyes, kidneys and hearts were being attacked because they didn't have insulin, or who didn't understand what they needed to do to get food and water because of an intellectual disability or who couldn't stand in line for seven hours, or seven minutes, because they lost their wheelchair in the evacuation.

I have worked with others to rescue dozens of sophisticated mobility hardware left at the New Orleans airport and reunite them with their owners. I had to raise money from the Muslim Public Affairs Council when we couldn't get any money from FEMA to move durable medical equipment and supplies into the Gulf States to simply get people a wheelchair, feeding tube or sterile catheter. The disability community and our partners came together to try to take care of our own. In addition, we were excluded from the larger relief community despite repeated assurances that we would just be in the way and make things worse. I received report after report about the Red Cross shelters turning people with disabilities away or separating them from caregivers or service animals, then sending them to nursing homes when they couldn't maintain their independence.

When I inquired about the sheltering needs of people with disabilities, one Red Cross operations official told me, "We aren't supposed to help these people. The local health department does that. We can hardly deal with the intact people," she said. "Don't you understand that we're taking volunteers off the streets to run these shelters?" The very same housing crisis that has kept hundreds of thousands of people in restricted living environments is now putting previously independent and self-sufficient disaster survivors in hospitals and nursing homes for lack of appropriate housing that allows them to use a bathroom and sleep in a bed.

We're still working to get to the tables where key decisions are being made about temporary and permanent housing. We've been trying to get to those tables since it first became apparent that housing would be a critical need. Even today, housing decisions are being made that will result in discrimination, further limited options and institutionalization of people that could and should be in our communities and in our work force. Groups like the New Urbanists, who fantasize a community filled with high porches and high price tags and who are at the table we are being denied access to. Along with everyone else, I have learned over the past two months that for all of the planning that has gone on, people with disabilities are not in good hands. Without immediate and bold steps, their needs will remain entirely unmet just as soon as the next disaster strikes.

I wish that generic systems were capable of holding the very specific and complex needs of people with disabilities in the foreground as they make quick and sweeping decisions. But in a country that still thinks nursing home placement trumps community based care for people with disabilities on a sunny day, we can't rely on generic decision makers to make smart decisions for people with disabilities in the midst of disaster. Just as we cannot expect well intentioned medical and public service personnel to adequately address the needs of people with disabilities in day-to-day situations without a deep and thorough understanding of the tenets of independent living and self-determination or absolute clarity of the human and civil rights of people with disabilities, we can't expect these dedicated community members to understand the complexities of meeting the additional needs of people in the midst of disaster.

With some smart investment, not only can people with disabilities begin to trust that their needs will be better met in future disasters, taxpayers and the general public can rest assured that we're maximizing limited resources and minimizing unnecessary waste. In fact, amid all of the projections of huge additional costs to meet the real needs of our citizenry in a disaster, there's clearly an opportunity for visionary policy makers to save tax dollars while maximizing limited resources. Now, who could possibly argue against that?

It is in Benilda's memory, and with deep appreciation toward those who have worked tirelessly over the past ten week in the Gulf States, here in Washington, and around the country that I make the following recommendations. Number one, we need an independent task force convened immediately to focus on the specific issues facing hurricane survivors with disabilities, the ongoing needs for preparedness, rescue, mitigation and recovery specific to the additional needs of people with disabilities and always with an eye toward protecting those whose needs would be further sidelined as scarce resources are redirected to those perceived to have more immediate needs.

Number two, we need an Office on Disability, well resourced and with real decision-making capability within the US Department of Homeland security and one in FEMA. Our Office on Disability at the US Department of Health and Human Services needs far more resources and far more decision-making power and this need exists in each of the Cabinet and Sub-Cabinet agencies who currently participate in the Interagency Coordinating Council on Emergency Preparedness for People with Disabilities. Without this, there'll continue to be waste and unintended consequences when those ill-equipped to make decisions on meeting the needs of people with disabilities are the only ones able to call the shots.

Within FEMA national disaster medical system, there's an exquisite model that I strongly recommend that we consider to create a prototype to create disaster disability assistance teams. The model uses highly trained and practiced state-based teams ready to deploy to the site of a disaster upon request from FEMA to meet a clearly defined need. Small teams of disability experts could be ready at all times to address the disability specific needs of disaster survivors with disabilities before, during and after.

Within the US Department of Health and Human Services, the Surgeon General's office is working to develop a volunteer corps to supplement FEMA medical teams. This corps, under the command of Commander Dan Beck, could use our many experts with specialized knowledge of the unique needs of people with disability in a disaster and a real willingness to volunteer that expertise in times of need. Organizations for people

with disabilities who already operate without adequate resources have had to use their limited funds to address the needs of disaster survivors with disabilities as well as their usual constituency.

Supplemental funds need to be given to these groups to help them serve our communities now and in the future. These groups, independent living centers, local chapters etc, are at the heart of the solution. We know this. Let's make sure we support what is working. Please listen to us when we come to you, members of Congress and your staff, to talk about Medicaid, housing, and other federal programs. Cutting Medicaid won't save money. It will cost money. Failing to fund accessible housing solutions does not save money.

We can appreciate that members of Congress are confused like everybody else about what is best for people with disabilities. We are very familiar with the pervasive bigotry of low expectations. Please listen to those who know best, not those that have a financial interest in filling nursing home beds or denying basic medical equipment that maximizes health and independence. We can help make Medicaid and Medicare, housing programs and other programs work better for people with disabilities and save a lot of taxpayer dollars in the process. And please, do not allow anyone to convince you to compromise the civil rights of people with disabilities.

Our rights remain fragile even today, and these rights are easily overlooked or dismissed in the time of emergency. This is illegal; but if that isn't enough, it's also costly. Be good stewards of tax dollars. Just say no to limiting or violating the civil rights of people with disabilities. Finally, join us in calling for a similar briefing for the Senate and for immediate action and resources to address the urgent needs of people with disabilities before the inevitable next disaster strikes.

We have the knowledge and the solutions to alleviate a lot of unnecessary suffering and maximize very limited resources. We have demonstrated an ability to lead and solve difficult problems. Please give us the power and the resources to do what needs to be done. We will make this country and our world a better place for our efforts. It's the least we can do for Benilda and others like her who perished because of our lack of leadership. Thank you.

Lee Page: Thank you, Marcie. Claudia, if we could hear some comments from you that would be great.

Claudia Gordon: Good afternoon. It's my pleasure to be here today to join this distinguished panel. Also I see many of our Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities partners here in the audience, and I particularly want to thank them. And I especially want to thank Congressmen Langevin and Ramstad for hosting this event today. I'm going to take a bit of a different approach. I'm speaking here on behalf of the Department of Homeland Security, the Office for Civil Rights and Civil Liberties. At the Department of Homeland Security, we have the pleasure of chairing the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities. This Council was established about one year ago by Executive Order 13347 and signed by President Bush. We recognize the issue of Emergency Preparedness for people with disabilities is not new. Much of what we've heard today is really just an example of an ongoing problem. However, recent

series of events have increased the level of visibility and afford the issues a more prominent place on the national agenda. For that we should be thankful. At the Department of Homeland Security, we believe that people with disabilities should be safe and secure in their home, workplace, and communities, just as safe and secure as individuals without disabilities would be in that situation. That's really what drives the work of the Interagency Council. The Interagency Council is made up of 24 different federal government agencies and departments. The primary vision of the Council is for the Federal Government to ensure that the needs of individuals with disabilities are fully incorporated in to all aspects of the emergency preparedness, response, and recovery efforts. We have focused on eight major areas: emergency communication, emergency transportation, emergency preparedness in the workplace, technical assistance and outreach, the state, local, tribal government coordination, research, private sector coordination, and health. We have placed great emphasis on coordinating issues with the private sector and state and local government entities. If an emergency or disaster strikes, the first responders...the first people who need to mobilize are likely at the state and local government level. So we have to invest a substantial amount of time working and coordinating with the state and local emergency managers.

In fact, last year, Secretary Ridge specifically sent a letter to state and territorial governors emphasizing their emergency preparedness responsibility to their constituents with disabilities and asking them to take several specific steps. He asked them to ensure that their Emergency Preparedness plan is comprehensive as possible regarding the needs of individuals with disabilities. We have a web site and some of this is also included in our Annual Report to the President. What I will do now is go into the activities that we have been engaging in immediately after Hurricane Katrina.

We began to mobilize just a few days after the hurricane and some of Interagency Council members and individuals here from the private sector like Marcie Roth worked through the weekend, collaborating with my boss, Daniel Sutherland and responding to emerging issues. What we found was prior to Hurricane Katrina; our role was mainly one of policy making. We were preparing to implement recommendations proposed in our first Annual Report, and so forth, we found ourselves in the position where we were receiving lots of contacts from individuals that were affected who needed answers and guidance. There was a need for leadership; and we assumed a role that was operational. We began to have teleconference calls with local service providers in the affected region and tried to respond to their needs.

We also began to provide advice to the Secretary and immediately created an Incident Management Team to respond to the many urgent and unique needs of individuals with disabilities and ensure that they were timely and adequately addressed. The team consists of about nine members that represent different agencies and departments, including Health and Human Service, Federal Communications Commission, Departments of Education, Transportation, Labor. We met on a daily basis as we tried to respond to the immediate, urgent, critical needs of individuals with disabilities that were affected.

We also had a subject matter expert in the affected region, Texas and Louisiana; this had been requested by the Secretary of the Department of Homeland Security in a memo that he then issued to the Admirals leading the operation in the affected region. We also had several ICC representatives tour several shelters throughout country. In fact,

we had ICC representatives visiting Houston, Dallas, Tulsa, Louisiana and Mississippi shelters to determine the conditions of individuals with disabilities and whether their needs were being met and do whatever they could to make sure their needs were being responded. .

One problem that arose immediately after the hurricane was the fact that people were moving from Louisiana to other states and many of them had a critical, immediate, and urgent medical need that required medication. Out-of-state pharmacies would not accept their Medicaid card. The ICC was able to resolve this working with our partner in Health and Human Services. We were able to get the Center for Medicaid Assistance to repeal that issue so the individual could get their life saving medication at pharmacies outside of their home state.

The FCC also issued a reminder to television stations about the need to provide closed captioning of emergency broadcasts. We delivered a truckload of durable medical equipment to the Houston Astrodome. Some of you saw it play out on television where many individuals with disabilities, the elderly and other special need had to leave their equipments behind when they evacuated from shelters, boarded a bus to go to another shelter or another safe haven...they were forced to leave their equipment behind. In response, we were able to work with the Incident Management Team and partner in the private sector to facilitate the delivery of durable medical equipment.

We also work in partnership with the DHS Web site personnel to update a Web site designated for donations to include durable medical equipment, hearing aids, communication access/interpreters for the deaf and hard of hearing, and other items that individuals with disabilities need at that time. In the beginning that Web site included no categories of items specific to what individuals with disabilities needed. We also found that several Web sites for disaster relief, like the FEMA web site, had issues with regards to Section 508 compliance; in response, we were able to resolve those issues---Working with FEMA and the DHS 508 Program office.

We had representatives from the Department of Transportation provide advice on the transportation needed because that was and still is critical area of need. In addition to accessible transportation, another major issue is accessible housing, is a priority of ours. I was deployed to Baton Rouge in Louisiana and I worked there for one month. It was an eye opening experience. I think being there on the ground really put into perspective what we mean when we say the needs of individuals with disabilities must be fully integrated in emergency management. We saw a system that tried to deal with the disability issue on the sideline...as an afterthought, and I believe that is where a lot of work needs to be done. Eventually, we brought in a disability accessible architect expert from the Department of Justice who was able to work side by side with the FEMA housing officer offering advice and input. DOJ and HUD working in partnership with the ICC also revised the one of FEMA's manufactured specifications so that accessibility will be incorporated into the design of future procurement as opposed to retrofitting post design. This will help to ensure that families with mobility or other kinds of disabilities were able to acquire accessible transitional housing.

We are currently working with the leadership of the Department of Homeland Security to address the challenges ahead, such as accessible housing, accessible transportation, and identification of people with disabilities. Where are they now? Who are they? We know that a lot of individuals who were otherwise living independently in

the community are being placed in nursing homes. And that's another priority of ours to address, these people need to be returned to the community in accessible housing.

We are also working to ensure that in future disasters there will be ways to self-identify as a person with a disability in the beginning phase of intake or registration for disaster assistance. Because, as we learned with this disaster...we no longer know where some of those individuals are located. We can't get a specific grasp on the number. One thing I found that happened again and again in Louisiana, the housing contractors, the housing leaders want to know how much accessible housing is needed. What number? We can't provide that number. So I think a system will need to be in place in the future where we can identify individuals. And if not, we still need to have a systematic approach that will serve as a guideline for adequately responding to the need for accessible housing.

The Interagency Coordinating Council and partners in this room, whom some of them I see, we look forward to working in partnership with all of you, especially with Congress to improve where we are on this issue. And, Secretary Chertoff, my boss...Daniel Sutherland, is committed to this issue and we will continue to stress the importance of this issue with the appropriate leaders within the Department of Homeland Security. Thank you.

John Lancaster: Thank you Congressman Ramstad. Thank you for hosting this event. The same thanks goes to Congressman Langevin. The National Council on Independent Living is an association made up of centers for independent living all around the country. We serve, support, and advocate with some of the most severely disabled people in this country that live independently and productively in the community.

We have learned many things from this terrible disaster. In all deference to the remarks from Claudia from the Department of Homeland Security, we appreciate your efforts personally and those things the Department has done. However, the bottom line is that these efforts were way too little, way too late and it is still late. In addition, there was basically nonexistent, non-coordinated and clueless execution of evacuation efforts and emergency rescue and relief at every level possible. It is a situation that as you address what needs to be done must be approached in conjunction with the Disability Community in this country. Relief efforts need to be carefully coordinated with them by retrieving their input and placing people with disabilities who know what they're doing in charge of this stuff.

We have learned a lot of things. We feel that the Red Cross and FEMA need to take responsibility for doing in-take and referral in a manner that is consistent with the civil rights and personal choices of people with disabilities. Many folks with severe disabilities were referred to institutional settings without an appropriate, consistent assessment process or even a record of why they were being sent there, even though they had previously been living independently in the community. Even CMS is only somewhat aware of who has been placed in what institutions. These people were placed in nursing homes as far away as Utah, Idaho, Pennsylvania, and the Carolinas leading to an extra caseload onto protection, advocacy systems and centers for independent living all over the country, not just in Louisiana, Mississippi, and Texas. Advocates for people with disabilities were repeatedly denied access to these nursing homes and shelters and

displaced people with disabilities were separated from service animals and durable medical equipment.

No clear approach has been outlined as to how people with disabilities that are eligible for FEMA aid are receiving this aid. We've heard reports of many problems in shelters and reports of FEMA's failure to provide key communications in alternative formats. That it is not even to mention the issue posed by the fact that people placed in nursing homes have not been informed of FEMA assistance or the application process. In fact, people don't even know where many of these people are. Reports are fragmentary as to how many people were involuntarily institutionalized as a result of Katrina and Rita. But from Alabama and the Atlanta metropolitan area alone, we can conservatively say that four hundred were placed in institutions in those areas. Project this over the 29 states to which evacuees from Katrina were dispersed and the numbers are potentially quite staggering. We know from Rebecca Tuttle, one of our folks down in Alabama, that two hundred persons with disabilities were institutionalized in the Atlanta, Georgia metropolitan area. So 200 of those four hundred came from Alabama. Yavonka Archaga recently put critical housing need in the disability community in the New Orleans - Baton Rouge area at conservatively at least two hundred. Yavonka is the center director for the New Orleans Center for Independent Living. Christy Dunaway of LIFE in Mississippi confirms that the stock of accessible housing is virtually nonexistent in Mississippi.

Though some of the accessible trailers based on the DOJ approved design have reached Mississippi, they are not suitable for many who require larger temporary housing due to mobility aids. Furthermore, we know that very recently 120 people, predominantly people with disabilities remain in Baker, Louisiana. The shelter was substandard, temporary housing built in the area to provide accessible housing. And many of those in the Baker shelter were on their fifth or sixth or seventh shelter having been shuffled around from place to place to place.

FEMA and Red Cross have failed to meet the housing needs of people with disabilities, leaving many people in dire need of housing or people being shuffled around all over the place, though HUD has taken recent steps in the form of their Katrina Disaster Housing Assistance Program voucher. FEMA, on the other hand, has been extraordinarily slow to meet the housing and shelter needs of people with disabilities. Though persons with disabilities were technically supposed to be the first priority to get housing, in practice they have often been the last to get their housing needs met. And in many cases, they're still waiting for desperately needed assistance. The system of closing shelters and shuffling people around at the request of a particular jurisdiction is proving dehumanizing. Moreover, when temporary shelters were placed, for example, the Baker one, they were not even placed in a site with the capacity to lay down concrete so that the shelters could be made accessible.

When accessible trailers are made available, our NCIL directors in Mississippi report that many of those made available only meet the needs of people with certain types of mobility impairments.

NCIL is dismayed by policy calls for across the board cuts and budget reconciliation to offset the cost of hurricanes. NCILs, Protection and Advocacy Systems, NOD, PVA, and some of the others, like National Spinal Cord Injury Association, that have been working hard on these issues, have now stepped up to the plate and spent

significant portions of their own, very limited budgets to fill gaps that the federal government has been totally unable to address. And at the same time, some of us receive some federal funds through contracts or grants, directly or indirectly. I know with NCIL, part of our budget is a federal government contract to provide much needed technical assistance and training to centers for independent living and people with disabilities around the country. And now all of these things are in threat of being cut. And our centers, most of which receive some federal financial assistance are probably going to have their budget cuts at the same time all this extra work is being dumped upon them.

At the same time, you're talking about a reconciliation bill where people who are on Medicaid now need to co-share or co-pay when they don't have a job or a house anymore. I mean this is like a double whammy for people with disabilities. First you throw a hurricane on top of them, don't bother to evacuate them; then those that do manage to survive, you don't provide them any services. Then at the same time, you start fleecing their pockets. It's pretty darn disgusting. And I'll tell you one thing, it says a lot of where we've come in this country in terms of civil rights for people with disabilities and other people who are economically disadvantaged. Not very far! Instead of being lauded for it and given additional resources, meaning the Disability Community for the way we've stepped up, Congress is contemplating across the board cuts that will diminish our capacity to respond. Funding for accessible transportation that could get those with disabilities out of harms way during future hurricanes or disasters, as well as funding for assistive technology that in many cases people with disabilities lost during Katrina or never had to start with and might have given them the warning they needed, are not going to be there. What kind of message is this? Somehow this sort of forethought planning for the next natural disaster is lacking.

Furthermore, NCIL opposes the House's budget reconciliation bill. The House promotes drastic changes to home and community based services in section 3131 of that bill. These changes were not developed in the consultation with disability community advocates. In addition, many believe it threatened to undercut the only steady principle around deinstitutionalization. At the same time, we now know that thousands of people with significant disabilities are institutionalized as a result of these disasters that weren't before. How are they going to get out? We do not understand why they have failed to embrace such provisions as Money Follows the Person, which would allow, particularly in this time when people are in such great need, the ability to get some control back in their lives to be able to access the health care and personal assistance services they may need. Why isn't that being supported by the House?

So, we have tremendous problems that play into the issues. They say they need to lower budgets because of these disasters, in a way that just adds another kick in the face to people with disabilities. It's a disaster and it's going to be a worse disaster if this budget reconciliation bill goes through. I want to add a personal note, say that NCIL would have had the director of the New Orleans center sitting here to talk to you today if we could have arranged it. She frankly said I cannot leave the work I am doing now in New Orleans and Baton Rouge. Actually she's in Baton Rouge, her center got wiped out in New Orleans and they don't have a place to go. She has been talking to me regularly and Daniel Davis on our staff. And right from the get-go, they had over a hundred severely, significantly disabled people with disabilities that they were serving and supporting in living independently and productively in some of the worst neighborhoods

of New Orleans, ones that were totally inundated when the levees broke. And at that time, a hundred and three people that they were actively following were in their homes. The center had worked with the authorities in New Orleans and the state under evidently some FEMA regulations or guidelines to actually have an evacuation program plan in place for all those individuals in the event of a terrible disaster such as this or in the event of some sort of terrorist attack in which an evacuation would be necessary. They all had an assigned evacuation number; they were all on an evacuation pick-up route. They had a number to call if they weren't being picked up. But none were ever picked up.

As Yavonka and her staff were buttoning down their center and evacuating, trying to get some computers out and evacuating to Baton Rouge, they started getting calls from these people. Nobody's picked me up. Nobody's answering the number I'm supposed to call. What do we do? Can you get us? The plan was never executed. And of those hundred and three people, they still have not located or identified 45 of them. No idea whether they're dead or alive; and if they're alive, where they are? They do know that some have passed away. One of the 45 people has a body that is unidentified. And, they can't officially identify her despite having an idea who she is because the authorities won't release the body to the family because the family happens to be out of the country. So there's nobody they can really, really get in there to identify her.

So, it's a terrible situation, Yavonka suspects that many of those 45 people just simply never made it; like the woman that Marcie described who was a good friend. And there was a plan set up. But nobody even attempted to execute it. Systems totally failed when it came to the evacuation. And Yavonka says, in her words, right now, the situation in terms of assisting people, locating them, providing housing, providing personal assistant services is ridiculous and virtually nonexistent.

However, what is getting done is being done by people with disabilities themselves with scant resources. Her center and staff is overworked and extremely stressed. In addition, they are working extremely long hours, while receiving virtually no help from any government source. She said the state of Louisiana is crumbling in her opinion and is totally nonfunctional when it comes to any issue relating to people with disabilities. She also said, she has a tremendous need for personal assistants and personal care attendants to assist people that they have identified as well as relocate them to their home areas. She has people who want to become personal care attendants that have lost their other jobs because of the disaster and are willing to do this kind of work, but she cannot identify anybody in the state that will approve and license them because the state has cut all those services financially. And, the Medicaid monies that were there to pay those personal care attendants is not present. She said the situation for people with disabilities in New Orleans is really, really bad.

So, we hope that the situation is going to start getting addressed, and seriously addressed on two fronts. Number one: What do we do about folks now that desperately need services as we sit here and speak? And number two: How are we going to prevent this from ever happening again? And, the disability community needs to be at the table for those conversations.

Lee Page: Thank you for that eloquent and very frank perspective. You've already heard some of the thoughts that I spoke about, what PVA's gone through in our chapter

down in the Bayou area. But I want to turn over to Natalia Mason who is here from the Red Cross and so we can hear some of her thoughts at that time.

Natalia Mason: Again, I'm Natalia Mason, I'm the manager for partner services; and I'd like to thank Congressman Jim Ramstad and Congressman Langevin for hosting this event to give us an opportunity to listen to the stories that you've shared, to help inform how we address persons with disabilities in the entire cycle of a disaster; in preparedness in recovery, in response, as well as mitigation.

I'd like to introduce my colleague, Mary Lou. She's with our Office of General Counsel. She's our point of contact for the ADA issues. As well as Lynn Crab, who is our manager of mass care. I think it's important for me to take a moment to review with all of you the role of the Red Cross in a disaster. I'd like to start there, and then speak with you specifically about what we are interested in doing with regard to partnering so that we are able to address the issues of persons with disabilities.

The Red Cross is a humanitarian organization led by volunteers and people guided by its congressional charter and the fundamental principles of the national Red Cross movement that provides relief to victims of disaster and helps people prevent, prepare for and respond to emergencies. Our organization is not a federal government organization, but a non-governmental organization. And we're a voluntary organization charged with helping people prepare for and respond to disasters. With regard to our role in the national response plan, we are the emergency support function number six, which means mass care.

Mass care specifically means feeding, sheltering, first aid, disaster welfare information. So, that's our mandate, and we provide those services in the immediate aftermath of a disaster. I'd like to share with you some statistics that will really help emphasize the catastrophic nature of this particular disaster compared to any disaster that the Red Cross has encountered in its almost 125 year history of dealing with disasters. The scale with which we provided immediate relief services to the victims of Hurricane Katrina and Rita, again, it's unprecedented; overnight stays in shelters, for example, 3.4 million as of November 2. And let's compare that to the 2004 hurricanes, which at that time was the largest disaster event in the history of the Red Cross. At that time, 519,000 clients were housed in shelters. With regard to meals and snacks served, during Hurricanes Katrina and Rita, we provided 49 million meals. In the 2004 hurricanes, we provided 16 million meals. As far as family assistance cases that were opened during Hurricanes Katrina and Rita, 1.4 million cases were opened, supervised, managed financial assistance. So, in addition to providing shelter and providing meals and snacks, there were needs beyond those two areas that we took on as well and provided some basic immediate financial assistance. During the 2004 hurricanes, that number was 73 thousand. So, at one point, I understand the long hours and the immense pressures that all of us have been under working 18 hour days.

I work in many disaster-operation centers at the national headquarters. I think that this past weekend, because it was my anniversary and my birthday, I was able to take the weekend off. But it was the second weekend that I had off since August 23. And, it was only because I was able to have someone actually relieve me who finally had some rest. But, I say that to say that I was among about 200,000 workers that had been

recruited to help support this particular disaster. And, if we compare that to the hurricanes of 2004, the total number of workers we had out in the field was just 34,000.

So, many of the issues I've heard today have much to do with bringing 200,000 volunteers into the most catastrophic disaster that the Red Cross has ever had to deal with. And, my particular area of expertise, or my particular area that I'm responsible for is community relations. Community relations, for the Red Cross, insures that the interest, concerns, needs and resources of individuals and organizations representing the diverse population in the communities affected by disaster are considered on the relief operation.

So, this is just one of the many areas that partner services in my particular area handles. And, I think that the response to Katrina and Rita, based on my having told you what it is we do, is far beyond the scope of any one organization. We are here to reinforce how important we know our partnerships are with the organizations that represent persons with disabilities. We are not so arrogant to believe that we have been able to address the issues of persons with disabilities in this particular disaster, and that we know everything there is to know with regard to providing services in a catastrophic disaster or any other kind of disaster.

During the time that Katrina and Rita was consuming our relief efforts, we were also responding to... on an annual basis we respond to 70 thousand disasters. So in the midst of the worst disaster of the history of the Red Cross and the history of this country, we were also addressing disasters all across the country that were a part of our purview. But, I wanted to make sure to provide that perspective to everyone, and, specifically with regard to organizations that represent persons with disabilities.

I am new to this particular role. My interest is in learning as much as I possibly can. This is a new beginning for partner services with working with persons with disabilities as far as my role is concerned. We've already begun our partnerships with the Interagency Coordinating Council of which Claudia is representative of that organization. As a result of the meetings that we've conducted with them, we came away from our initial meetings with some very concrete actions. We also look forward to future meetings with the other folks that are sitting here on this panel. I think that we are where we need to be right now. I personally am committed to learning as much as I can and also working with our partners to ensure that we implement actions in a systematic way to help us deal fairly and equitably with persons with disabilities in the cycle of disaster.

With the Interagency Coordinating Council, we took their advice. We did provide guidance to our volunteers and specifically to our shelters with respect to general information on how to identify persons with disabilities in order to provide the appropriate services. That wasn't enough. Based on the advice that we received from the Interagency Coordinating Council, we have refined that guidance and expect to publish that guidance broadly and incorporate that guidance, and any advice that the panel here can provide us, into a number of different places. With regard to preparedness, we do have materials that we provide for persons with disabilities on how to prepare for disaster. We need to do more. With regard to responding to disaster, training obviously had a critical gap.

With regard to identifying, appropriately, people who should, in fact, have been allowed into shelters, my commitment is to ensure that we provide information and training on persons with disabilities as broadly and as specifically as we possibly can, both on disaster operations in general and across the organization. I agree with what I've

heard regarding how specialized the knowledge is that persons providing services to persons with disabilities needs to be; and I'm in complete agreement. And we have spoken with our staffing folks about the possibility of creating a specialty track that would allow that type of support in a disaster. I understand that it was difficult for persons who are deaf or deaf and blind to understand what was going on in shelters. We need to do better with that. We welcome any suggestions that you would have with regard to how to incorporate technology in the midst of a disaster so that we can do that before a disaster occurs. This is an opportunity to take a look at that. In my particular role, it's my job to encourage chapters to know their community demographics so that we're able to anticipate where the needs are in the community prior to a disaster. So that when there is a disaster, we can probe appropriately and adequately address those needs. That includes identifying who the persons with disabilities are in their communities. And finally, it's particularly important for me to re-emphasize just how important it is for us to all understand that Katrina and Rita was an unprecedented disaster in the history of the Red Cross and in the history of this country. And, again, the response and the recovery that we are faced with, which is going to be several years in the making, is beyond the scope of any one organization. We welcome your advice. We welcome your joint action as we move forward. Thank you very much.

Lee Page: Thank you very much Natalia. That was great. Our last speaker is Patricia Pound from the National Council on Disability.

Patricia Pound: Thank you, Lee. I appreciate the hosting of this meeting by the Congressmen. The National Council on Disability is an independent federal agency that makes recommendations to the President and Congress to enhance the quality of life for people with disabilities. Our April 2005 report, *Saving Lives: Including People with Disabilities and Emergency Planning*, reviews the status of emergency services and people with disabilities in America.

The hurricanes this fall certainly provided dramatic, real life demonstration of the need for disability policy and leadership in this area. Today, I would like to share some examples of progress, challenges and recommendations for the future. I address progress because sometimes the problems seem too immense that they don't seem solvable.

In my experience with getting people within governmental and nonprofit structures to move is to show them that it is possible to build on what progress we have. We saw that governors in Mississippi and Texas, along with several federal officials had sign language interpreters as they provided critical hurricane information. We also think that captioning of emergency information appeared to be improved, partly because of one state's association of broadcasting reminding television stations of their legal obligation to do so.

Some state and local leaders made commitments to assist people with disabilities to evacuate and upheld these commitments. State and local disability organizations provided evacuation disability services for people with disabilities. Examples of assistance provided to the evacuees included replacement of wheelchairs, availability of transportation, replacement of canes, Braille writers, eyeglasses, hearing aids, hearing aid batteries, and in the case of one gentleman, even a replacement of an artificial leg. Some also received home health services, respite care, substance abuse counseling, etc.

The flexibility of shelter workers was amazing. In one shelter the age range was six months to 102. In fact, the request of one of the 102-year-olds was for a bed in front of the big screen TV. I suspect maybe she had low vision. One of the buses that arrived in one of the cities in need of shelter contained 80 individuals who had autism and three nuns. We really were appreciative of the three nuns. Yes, the hurricanes this fall highlighted awareness that the relationship between emergency management and people with disabilities is far from what it needs to be.

Obviously, we've heard a lot about that today. Challenges revealed included people with disabilities that were unable to leave their homes, hospitals, nursing homes, without significant assistance. Some received that assistance; others did not. Available public transportation was sometimes limited and the degree of accessibility was often unknown. The amount or availability of personal care attendants and sign language interpreters was often inadequate or in the case of people who didn't evacuate, nonexistent. The communication about evacuation instructions and instructions in shelters was difficult for people with hearing disabilities without video phones, relay service, captioning or sign language interpreters.

Some people became separated from life critical aids such as care givers, medication, or services such as dialysis, as well as equipment. In light of the serious implications the hurricanes continue to have on people with disabilities, the National Council on Disability recommends a coordinated federal plan for hurricanes be developed that focuses on the needs of people with disabilities. It should include accessible disaster facilities and services, accessible communications and assistance, and accessibility of rescue efforts.

Immediate actions that DHS could take include: establishing a point person on disability reporting to the Secretary to provide guidance, coordination and leadership; developing and implementing a coordinated federal disability hurricane recovery plan; and establishing a disability advisory group targeting resources to make critical needs of survivors with disabilities accessible, especially affordable accessible housing.

More long-term actions that NCD recommends DHS do is ensure that the reconstruction rebuilding efforts have the resources, medical equipment, and supplies to address the needs of people with disabilities; educate and train emergency personnel during all phases of operations on how to support the independence and dignity of people with disabilities; follow accessibility requirements and universal design principles during all the reconstruction phases; rely on disability organizations for ongoing advice and guidance; and provide funding for them to provide such aid.

NCD's report, *Saving Lives*, provides further advice about the steps the Federal Government should take to build a solid and resilient infrastructure that will enable the government to include the diverse populations of people with disabilities in emergency preparedness, disaster relief and planning

Some of the major findings of the report include: people with disabilities frequently encountering barriers to physical facilities, communications, and programs in shelters and recovery centers and elsewhere during the disaster. Many barriers are not new. Lessons learned are frequently not communicated across agencies and they're not communicated across disasters.

People with disabilities are too often left out of preparedness and planning activities related to emergencies, including the analysis and documentation of the

potential impact of possible emergencies on life and property; disaster preparedness and response systems are usually designed for people without disabilities who can rely on walking, running, seeing, hearing or quickly responding to instructions; and access to emergency public awareness or public warnings is often not available to people with hearing and vision disabilities.

The strength that community-based organizations can provide in emergency planning is frequently not utilized. The DHS offices do not get many complaints from people with disabilities, but this is inconsistent with the stories that we hear about the true experiences. Key recommendations from the *Saving Lives* report include: DHS should establish a disability access advisory group separate from the organizations coordinating council; DHS should integrate information about people with disabilities into all materials as well as advise people where they can locate more customized materials; DHS should issue guidance to state and local governments about meeting the responsibilities of Sections 504, 508, Rehabilitation Act and the Americans with Disabilities Act; the FCC should strengthen the enforcement mechanism to insure video distributors comply to make emergency information accessible to people with vision disabilities and they should act on violations quickly, as well as promote Section 255 hearing aid compatibility; DHS should develop and offer technical assistance and guidance materials for grantees regarding the grantee's responsibility to comply with Sections 504 and 508 and ADA. They should proactively review compliance efforts of grantees and publish such information where people can understand what's happening on compliance; and DHS should collect and aggregate information about compliance efforts and also make that information available.

Lastly, I want to share that our chairperson, Lex Frieden has written a letter to the President talking about the tremendous opportunity that we have in the rebuilding, reconstruction and resettlement efforts. We will be rebuilding homes that could be designed by universal design elements. We'll be rebuilding schools, hospitals, medical facilities, government infrastructure, all of which need to meet ADA standards for the rebuilding. We also could make our communities, as we rebuild them, more livable. Also, earlier this year the National Council on Disability published a report on livable communities for adults with disabilities. It describes many aspects of livability that exists around our country, things that could be modeled as we rebuild. Each livable community is one that promotes the independence, productivity, safety, security, inclusion and choice for all people within the community. We have an opportunity to apply those concepts and use the information that is already gathered and consistent so that people can use and make our communities useful to us all. I hope that we will come out with some actions that we can all be proud of a year from now, if not sooner.

And, I would like to say too, that in the handout in the back of the room there's a number of internet addresses for the two reports mentioned, as well as all the work the National Council has done related to emergency management. Thank you.

Lee Page: Thank you, Patricia for those words and what NCD is doing. At this time, that concludes what the panel has to say. As you can tell, we've covered a lot of bases of what people with disabilities face in the light of Hurricanes Katrina and Rita. And our time is short now, but we do have time for some questions and answers, and I do see

some hands going up. So I'll start over here. And just if you can ask your question, or maybe come up and use the microphone. I will leave it open to anyone on the panel to please answer at their discretion.

Edwina Schula: I'm an advocate for people with disabilities fire and life safety. I don't work for any agency, been an advocate on my own, and I know most of the people at the table. I'd like to specifically address this question to Hilary Styron of NODPDI, the national organization of disabilities recognized on the 18th of September, 2001 created in response to the disability community rising up and saying that we needed to address these issues for us. I think 9-11 was the bell for them that got their attention. Mr. Reich, who passed away on Tuesday called that meeting on September 18, just several days after 9-11. What came out of it was their Emergency Preparedness Initiative. To my knowledge and I've been around doing this for more than thirty years, it's the only disability-based organization that has ever tackled the problem of disabilities in Emergency Preparedness. So, that being said, I'd like to ask Hilary, who is the newest person in the field here.

Hilary Styron: No.

Edwina Schula: But has a comprehensive background. I'm hearing things I've been hearing over and over and over again and what can happen now to change things? I know Claudia and her organization has done massive amounts of work, but how are we going to get government to support what we're doing? This is a very simple question.

Hilary Styron: It's a simple question, but it's not a simple answer. It's going to take everyone to become self-reliant, self-prepared, and personally accountable. It is also going to take all levels of government recognizing that this is a critical part to emergency management planning. I may be new at this table as far as we are concerned being everybody else has been up here for 20 years in their organizations, but I've been in emergency management for the last fifteen years and spending years on Capitol Hill doing their accessible emergency planning and working with the house committee, it is ownership that we're fighting right now, politically, who owns it, is it the mayor's job, the governor's job? It's everyone's job. It begins at your house. Preparedness is every day. It is not one month a year. It needs to be tied in to federal funding, minimal meet or exceed compliance regulations. We have OSHA, but we don't have anything that regulates emergency management for people with disabilities.

The national response plan was written, we're not in there. If you're written in to emergency management plan, special needs are usually part of an annex. You're thought of afterwards. Government needs to open their blind minds and think outside the box; and bring disability leadership and emergency managers to the table to work through this problem that we continue to have.

We can set up effective operations, we can make this change; and it can happen. There will be loss of life, I understand that, but I do not want to go in to another room and be told by a first responder or an emergency manager or a general or a major that the special needs population is automatically collateral damage. I will not hear that again and you should not either.

Edwina Schula: One last thing, you mentioned government is for all people.

Hilary Styron: The government is for all people, and we elect these people to protect us.

Carl Vaughner: I am with Fairfax county government. I'm just wondering if anybody on the panel knows of a local jurisdiction whether it be state, county, city that has done a good job, at least on paper of including people with disabilities and the issues facing them in emergency planning development and management. At least as far as strategic plans go.

Hilary Styron: Working with the national capital region for several years now in emergency planning there are several local jurisdictions that actually are in good practices. They are working on redeveloping and reanalyzing their plans. There has been, for the last several years a push to focus on terrorism preparedness and we lost sight of some of those issues.

The national capitol region has recognized that within each county they need to re-evaluate strongly what they're doing for the special needs population. As part of this last fall's September national preparedness month activities, they produced a survey where they interviewed the population of people with disabilities and nondisabled individuals; it was a general, random survey. They were able to assess people's level of preparedness. They're incorporating those answers, which by the way are not good. How many people in this room have a plan right now? Do you know how to get out of this room? Five hands. Have fun.

Now, this is the House, we're working on getting accessible elevator use and planning, we're getting there, I'm working on it. They're definitely re-evaluating their plan. They'll be incorporating this in their plans because I'm meeting with them on the 29th of November. I will be meeting with the DC mayor and the emergency management director and Tom Lockwood with DHS; so we'll be doing things regionally.

Lee: Claudia did you have a response?

Claudia: A brief response to the man that asked the question about city, county, if I understand the question correctly. I had the pleasure of traveling to Tulsa, Oklahoma and you would be interested in what they're doing there. They've been doing an excellent job for the whole community on individual preparedness, but have also incorporated people with disabilities in their work. And I have several examples. Is there a safe room because Tulsa is very susceptible to tornado? Were they able to work and get a safe room that is accessible to an individual with a physical disability. They also partner with the Tulsa speech and language hearing association to provide sign language interpreters for individuals who are deaf or hard of hearing. Another example of their work is that they're partnering with NOAA to develop a radio with flashing alert for people that are deaf or hard of hearing so that they could receive a warning. So, Tulsa is a model in this area, I believe.

Bill Parsons: I am with Congress Chris Van Hollen's office. I have a question that I think should be addressed to Claudia. When Hurricane Katrina hit, we had a constituent

caller who had a son in an ICMFR facility; and he was concerned about similarly situated people in the impact zone. We called FEMA, HHS, and CMS to double check the locations of nursing homes and of ICFMR facilities as a matter of basic protocol of first responders who were in the position to go to geographic locations where these people are. I can't tell you how many people I talked to and nobody could confirm for us that was done as a matter of basic protocol. It struck us and the Congressman that it would make good sense to do something that certainly could be done beforehand as a matter of preparedness. Can you tell us today whether or not that is part of basic protocol; if it's not, whether you think that would be advisable.

Claudia: Let me see if I understand the question. You are asking about what happens when taking this person to a shelter?

Bill Parsons: No, what I'm talking about is a matter, as part of preparedness planning, are the first responders, the actual people who are in a position to go to facilities and in particular, in this context, I'm talking about nursing homes ICFMR facilities that are going to be housing people. It's safe to assume many of whom are not in a position to evacuate themselves necessarily, are the physical locations of those facilities as a matter of course provided to first responders for purposes of evacuation in the event of a disaster.

Claudia: We try to promote community preparedness as a part of outreach and education. Nursing home, group home, and individuals with disabilities themselves should make information available to their local emergency manager about their location and the need they have in case of emergency or disaster so that in the event of a disaster, like Katrina, they can respond and know where to find the individual. But it has to be in place before and that's part of outreach that we intend to push even further and more aggressively giving the lessons that we have learned.

Bill Parsons: If you ask me, we have no assessment date, mandate in the state or local facility emergency management entity to do that.

Hilary Styron: There is no law that requires that nursing home facilities are at the table with the emergency management planners and vice versa. Those hardened facilities and locations obviously we know where they are, but the responders have to know to ask where they are. In New Orleans, the responders, the people working in the operation center, did not know based on zip code of what the break down was of the disabled in their community. And that is rampant across this country. There is not a law that requires it. It should be common sense, one would think. But it's not.

Claudia: If we need to pass a law to make that happen. we should probably pass a law. My suspicion is there's nothing that prohibits it.

Hilary Styron: There's nothing that prohibits. It has to occur. They both have to come to table.

Claudia: I'm offering that as a suggestion.

Marcie Roth: I'm going to respond to that as well as a resident of Montgomery County, Maryland. I know we're doing a dismal job on a daily basis of meeting the needs of people with disabilities. As a parent of two children with disabilities, I know we're not making huge progress on that front. I know for sure I cannot rely on my community to do an adequate job of meeting my children's needs, my family's needs, in case of an emergency. I know that's not happening. If that's not happening in Montgomery County, Maryland, I'm sure it's happening even less in other parts of the country.

Kathy Hardgan: I'm a member of the President's Committee for People with Intellectual Disabilities. I appreciate Marcie acknowledging that the population exists and are under the radar. Every meeting I ever attended when they talk about disabilities, they talk about mainstream disabilities. They forget there are people with developmental disabilities who cannot plan for themselves. They're dependent on their stakeholders, families, group home providers, whoever does the plan for them. Many of these people have cognitive disabilities. That's not what brought me up here. What brought me up here is an understanding I have that many families were separated when they were evacuated and that they are still separated. And I want to know who is taking responsibility for finding those families and reuniting them now.

Hilary Styron: I understand that cognitive and intellectual disabilities take a different level of planning. We're reaching out to their care providers and constituents that are responsible for advocating and protecting those individuals. We developed training materials for individuals themselves but also their care providers. It's a very different approach, and I'm not denying or negating that issue exists. I absolutely acknowledge that it does.

Natalia Mason: Evacuees and those trying to restore their family links with folks that have been dispersed, actually there's a vehicle that's called our family links registry; it's on www.RedCross.org. You can go to the family link at www.KATRINASAVE.com. That's a resource. I don't know whether that resource allows for family members to self-select in any way to identify themselves other than their predisaster address and some contact information.

Marcie Roth: I don't believe that web site is accessible. And I also think for people who don't read or for people for that matter who don't have access to a computer, it's not an option.

Jeff Rosen: I just have a quick question. I work at the National Council on Disability. My question is to the American Red Cross. We work with the Red Cross trying to set up more of a stronger response that's more accessible; and we continue to collaborate. One thing that I continue to hear is that we tend to talk about the response in terms of providing guidance, but that's not enough. Until you dedicate personnel, resources, funding, you're never going to achieve your objective. I haven't heard the Red Cross once commit to doing that because accommodations cost money. You need money to

pay for interpreters; you need money to get access to different shelters. And when you don't have the resources available or set up, then things fall apart and they continue to. When are you going to commit those resources? When are you going to agree that that is necessary? When are you going to send somebody who's a responsible person who serves in that community?

Natalia Mason: Thank you for your question. With regard to personnel, it is my responsibility, in fact, to identify and actually hire someone to address the needs of persons with disabilities. I strongly believe, and I know the Red Cross strongly believes that in order to provide service delivery to our evacuees, clients, and victims of disaster in general, our service volunteers need to look like the people they are serving and need to be like the people they are serving. So, that is one thing that I can say that I can do. With regard to other resources and funding, again, this is not a disaster that we can address on our own. We need to reach out to our partners. To leverage all of the resources that are available so that we can approach this situation productively and efficiently.

Lee Page: Yes, question? Come on up. Feel free, come on up.

Bonnie: I work with Claudia in the Interagency Coordinating Council. I do appreciate all of your efforts to work with us and get guidance from us. In follow-up to Jeff's suggestion, I'm just wondering/recommending that the Red Cross undertake a comprehensive approach to training staff across the country so that the staff and volunteers can work in collaboration with the civilian community. I know you've been working on guidance, but do you have more comprehensive training than you do?

Natalia Mason: There is a need for more comprehensive training, but also a need for some very specific training that can address the specific needs of persons with disabilities. I think that one area that could serve the persons with disabilities particularly well are the representatives or volunteers that we have in community relation organizations. They are specifically tasked with going out into the community and identifying persons whose needs are beyond the scope of our standard services. So, that's one area that I know we can impact. We have had discussions internally regarding incorporating training into many of the different curricula that help our volunteers provide services on a disaster. So that means not only are we considering providing some specialized training and considering a specialty track, because we've heard that a number of times, that's really something that's necessary. But, ensuring that exposure to and knowledge about working with persons with disabilities happens across all of Red Cross training for all of our volunteers.

Marcie Roth: It's critically important that as a part of that process, certainly people with disabilities need to be hired and brought in to the team.

Natalia Mason: Yes.

Marcie Roth: It's not enough to have a disability. It needs to be absolute top experts on facilitating, resourcing, responding, information referral, and those kinds of skill sets. So, it's beyond training because people who have been trained will come and go.

Natalia Mason: I agree.

Lee Page: Okay, any more questions. Seeing none – yes.

Speaker from the floor: It was mentioned earlier about emergency managers. Who are they, and how do we find out who they are in the area?

Hilary Styron: Emergency managers, depending on your jurisdiction will vary. It could be a mayor as a designated emergency manager. It could be the fire chief in your community. It could be secretary of the principal federal officer on a disaster. The emergency manager as your designated official will vary depending on what level of government is involved. If you want to know who your emergency manager is in your community, you should visit the community's web site. If they have one, call the city administrator's office or the fire department. A non-emergency number, please. And ask them who their emergency manager is. If they cannot tell you, then you can call me and I will find out and tell you. I have a list of all emergency managers in the country at different levels of government and will be able to access that for you if your own community cannot tell you. We did have that experience recently here in a local jurisdiction that couldn't spell it out for us, so we spelled it out for them.

Lee Page: I'd like if you could give a big hand. Thanks, of course, Congress Langevin and Jim Ramstad and Amy Judge for the room here today. I guess in closing, you know, we've discussed a lot of heavy topics today. You know, here we are two months out after Hurricanes Katrina and Rita devastated the gulf region and the biggest void in the room is that there's nobody here from FEMA, but which is the federal emergency management response. But, saying that we are all trying to do our best, one of the things that we must recognize is responsibility starts at home with people with disabilities and all citizens themselves first. Whether you live in the Gulf States region or California where earthquakes are, or where tornadoes are, or where there's a fire or whatever, the responsibility starts with us first. We've had systems that failed from the top and the bottom and the middle and the side. We need better communication, better coordination and obviously people with disabilities need to be involved from the beginning. So, having said that, thank you for coming. Thank you for being here and we're adjourned.

Adjournment

Meeting ended at 3:50 p.m.