Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities

2nd Quarterly Meeting December 15, 2004

Meeting Participants

Participants included representatives from the following organizations.

Lawrence W. Roffee, Jr., Access Board

John Carroll Surina, Department of Agriculture

Jeff Nulf, Department of Commerce

Clarissa Lara, Department of Commerce

Susan Aramaki, Department of Commerce

K. Dane Snowden, Federal Communication Commission

Cheryl King, Federal Communications Commission

Denis Legel, Department of Defense

John Hager, Department of Education

Dr. Thomas Finch, Department of Education

Christopher Kuczynski, Equal Employment Opportunity Commission

Mildred Rivera, Employment Opportunity Commission

Ken Ringlein, Equal Employment Opportunity Commission

David Pegram, Department of Energy

Russell Shearer, Department of Energy

Wesley Carpenter, Environment Protection Agency

Dr. Margaret Giannini, Department of Health and Human Services

Anne E. Norwood, Department of Health and Human Services

Susan Dunaway, Department of Health and Human Services

Ollie Cantos, Department of Justice

Wilbur Roy Grizzard, Department of Labor

John Kim Cook, Department of Labor

Brian Parsons, Department of Labor

Anne Rader, National Council on Disability

Jeff Rosen, National Council on Disability

John Martin, Office of Personnel Management

Cynthia Giler, Social Security Administration

Michael Trujillo, Department of Transportation

John Patrick Benison, Department of Transportation

Sally Atwater, President's Committee for People with Intellectual Disabilities

Dr. George Bouthilet, President's Committee for People with Intellectual Disabilities

Kathy Hargett, President's Committee for People with Intellectual Disabilities

Hilary Styron, National Organization on Disability

Elizabeth Davis, National Organization on Disability

Mary Dolan, National Organization on Disability

Seville Allen, National Federation of the Blind

Jim McCarthey, National Federation of the Blind
Ericka Rose, National Citizen Corps Council
Wendy Walsh, National Citizen Corps Council
Cheryl Heppner, Deaf and Hard of Hearing Consumer Advocacy Network
Rosaline Crawford, Deaf and Hard of Hearing Consumer Advocacy Network
Helena Berger, American Association of People with Disabitilies
Daniel Sutherland, Department of Homeland Security
Claudia Gordon, Department of Homeland Security

Michelle Parnes, Sign Language Interpreter Anne Leahy, Sign Language Interpreter Sherry Knox, CART Writer

Welcome and Introductions

Dan Sutherland, Department of Homeland Security, Officer for Civil Rights and Civil Liberties

Mr. Sutherland welcomed participants to the meeting and thanked K. Dane Snowden, Federal Communications Commission, for hosting the meeting. Mr. Sutherland said that a discussion of some baseline numbers – where are we in terms of emergency preparedness as we start – was first on the agenda Second, updates on progress of the Interagency Council Subcommittees would be reviewed. Third, he asked for input from some of the disability consumer organizations about how they view some of the issues.

Presentation on the National Survey on Emergency Preparedness & People with Disabilities.

Mr. Sutherland then introduced Mary Dolan, National Organization on Disability (NOD) and World Committee on Disability. He commented that the Department of Homeland Security (DHS) gave NOD a grant to perform a survey and obtain baseline numbers with regard to emergency preparedness and people with disabilities.

Ms. Dolan acknowledged the work of her colleagues Elizabeth Davis and Hillary Styron who were in the room and also worked on the project. She said that the NOD had never worked on emergency preparedness until after 9/11. In 2004, in partnership with a grant from DHS the organization studied emergency managers themselves and how they incorporated the needs of people with disabilities into their plans. She mentioned that the presentation was an abridged version of the complete survey and encouraged the audience to visit the website at www.nod.org.

The NOD commissioned Harris Interactive to conduct a study among emergency management officials at the state and local level in the United States about how they have incorporated the emergency needs of people with disabilities in their emergency plans. Key objectives of the study were to:

- Understand whether the needs of people with disabilities have been incorporated into emergency planning
- Identify the elements of emergency plans for people with disabilities
- Measure the level of involvement by people with disabilities in the planning process
- Understand the adequacy of resources.

The data was collected in August and September 2004.

The findings state that 69 percent of emergency managers surveyed said they have incorporated the needs of people with disabilities into their plan. Ms. Dolan added that the number represents national representation of all emergency managers across the country.

Of State emergency managers, 65 percent said they have incorporated the needs of people with disabilities. She noted that 77 percent of big city managers, 69 percent of mid-city managers, and 66% of small cities surveyed have incorporated the needs of people with disabilities in their planning. Also, 22 percent said they did not have a plan currently but planning was under development.

Ms. Dolan said NOD was concerned with the finding that 54 percent surveyed said they have included schools for people with disabilities into their plans. And 39 percent state they have included dialysis or other clinic care, off-site clinics into their plans. Ms. Dolan observed that these numbers indicate a bit of a breakdown of the real inclusion of people with disabilities into emergency plans, despite the fact many are saying that they have included people with disabilities in their plans.

Ms. Dolan characterized some of the findings as "seeing the glass half full or half-empty." The total number for those who have included people with disabilities into their planning process was 55 percent. At the state level, 66 percent have included people with disabilities in their planning process; big cities, 62 percent; mid-sized cities, 53 percent; and small cities 49 percent. Ms. Dolan noted that this finding indicates small cities are dragging behind in reaching out to the community and including them in the planning process.

Ms. Dolan explained other findings that NOD thought were revealing. Although 61 percent said they have purchased specialized equipment, when drilling down to other questions about equipment they found some cause for concern. For example, only 49 percent of the managers said they had purchased TTY and TDD machines. Only 29 percent indicated they purchased evacuation chairs; 14 percent, alpha pagers; and 39 percent said they hadn't purchase any specialized equipment.

Roughly six out of 10 officials have a public outreach campaign in place or under development. Ms. Dolan said this was one of the more alarming numbers. While 42 percent say they have a public awareness campaign in place, only 16 percent state that it

exists in accessible formats such as Braille, close-captions, cassette, large type, etc. That is a number that is of great concern to NOD.

Additionally, only 14 percent of emergency planners said they had received funding specifically for emergency planning for people with disabilities. And only 10 percent said they plan to receive funding in the future. Out of total respondents, only 18 percent said that they felt their resources were adequate.

Findings also suggest that more can be done such as including the voice of the disability community in the planning process and establishing channels of communication to provide emergency information with people with disabilities.

A lack of resources also appears to be a barrier. Emergency officials are far more likely to feel that resources available to them are inadequate than they are adequate. And most officials say they have not received funding and do not plan to receive funding for addressing the emergency needs of people with disabilities

Concluding her presentation, Ms. Dolan said research findings revealed that steps are being taken to ensure that the needs of people with disabilities are being accounted for in emergency planning. Specifically, the majority of officials claim to currently have a plan or have one under development that incorporated their needs. Further, there are many types of groups and facilities included in the plan. However, findings also suggest that more can be done such as including the voice of the disability community in the planning process and establishing channels of communication to provide emergency information with people with disabilities.

Since Emergency planning will be a public issue, Ms. Dolan noted, the results can serve as a benchmark for future investigation.

The audience members interposed the following questions or comments:

- *Is the survey on the website?* Ms. Dolan responded that the presentation and all the data from the survey is on the website at www.nod.org
- It's apparent that smaller cities do not have the wherewithal. Is there any reason given in the leverage of cost? The survey did not drill down to that level. That would be the kind of question we would need to get at with the next level of survey.
- How did you define disabilities? Disability is defined as the Census Bureau defines it. This survey was of emergency managers themselves but with the recognition of the full scope of disability.
- The survey seems to assume that you're either black or white, that you're either with a disability or not with a disability...does this survey assume that the questions are about the extra effort, the differential of work that's being done for people with disabilities? I think what this survey finds is again, as I put it, the glass is half empty. We are finding that on the surface emergency managers are including people with disabilities, but when you drill down into these other

- questions and we see they have not included schools for children with disabilities, that is a concern.
- Of the 42 percent who indicate they have an emergency preparedness campaign, is that local, smaller level, or state level? This is general preparedness information for all people in the jurisdiction. We were concerned about the issues of access. The concern is if the information is there for all of us to be prepared, how can we be assured that it's reaching the people that we want it to so that they may take action.

Mr. Sutherland then summarized the status of the subcommittee's work. He noted that seven different subcommittees or working groups have been formed in various areas. He explained that there was a strong possibility that another subcommittee would be added. Dr. Giannini, Department of Health and Human Services, is working on health and social service issues that people with disabilities face at the time of emergencies.

Mr. Sutherland explained that each of the seven committees would have five minutes to provide an overview. He expressed a special thank you to Claudia Gordon who is coordinating the program and doing a terrific job.

Department of Transportation, Emergency Transportation Subcommittee

Michael Trujillo, Director, U.S. DOT/Departmental Office of Civil Rights, commented that the Subcommittee met twice and made substantial progress with formalizing their charter, with the help of the Office for Civil Rights and Civil Liberties. Mr.Trujillo then turned the presentation over to John Dennison who, he noted, is a nationally recognized expert in the area of persons with disabilities.

Mr. Dennison explained that the purpose of the subcommittee: 1) to develop policies and programs that are related to the transportation needs of individuals with disabilities during an emergency 2) to advise the Council and the Secretaries of Transportation and Homeland Security on transportation matters during emergencies that pertain to individuals with disabilities. He noted the federal agencies that comprise the subcommittee and the resources they bring to the effort.

He commented that outreach to the transportation community and the disability community has just begun. An emergency transportation website is being built with plans to launch it by the end of January. Two audiences have been targeted: members of the traveling public with disabilities and transportation providers. He pointed out that national guidelines designed primarily for transportation providers and emergency first responders would be included on the website.

Mr. Dennison also addressed the issue of emergency preparedness in the workplace. He explained that in August 2003, DOT developed guidelines on emergency preparedness in the workplace for their employees. He was asked to chair a work group that is going to document best practices in federal agencies and in private organizations that will be added to the Department of Labor's primary deliverable.

Mr. Sutherland then called upon Assistant Secretary Roy Grizzard to report on the Emergency Preparedness in the Workplace Subcommittee. Mr. Grizzard said the first meeting of the Subcommittee was held on November 18, with 12 agencies attending. The group informs the Council on related areas of emergency preparedness in the workplace including first responders strategies, employer and employee responsibilities, and legal considerations.

The Subcommittee will develop a template of guidelines of effective practices to be distributed to federal agencies as their first deliverable. They also intend to provide this type of information in an electronic format, working with the technical assistance subcommittee for inclusion in the web-based tool kit they are developing. He informed the audience that the next meeting was January 13, 2005. Mr. Grizzard credited Brian Parsons and Kim Cook from ODEP for the yeomans work they have done.

Federal Communications Commission, Emergency Communications Subcommittee

Mr. Dane Snowden addressed emergency communication issues. He acknowledged Cheryl King, Deputy Chief, Office of Disability Rights, and provided an update of the activities of the communication subcommittee. Mr. Snowden said the subcommittee is focusing on short-term and long-term goals.

With regard to short-term goals and accomplishments to date, the subcommittee began a program with Telecommunications Relay Service (TRS) Centers around the country to obtain telecommunication service priority during emergencies. The network for TRS Centers will receive designation for priority restoration of circuits during and after a disaster so individuals with disabilities can communicate through the public switch telephone network as well.

Another initiative of the committee is to ensure that key personnel in all federal agencies, offices, and commissions have government emergency telephone system or GETS cards. Additionally, the subcommittee wants to collaborate with the Partnership with Public Warning (PPW) to select appropriate items developed in PPW's needs assessment and Plan for Action. The organization is committed to improving the nation's warning capability.

For the long term throughout 2005, the Subcommittee will assist the FCC with the Emergency Alert system rulemaking proceeding by reviewing comments that include references to persons with disabilities. The Subcommittee is also planning organizing a national event that develops from collaboration with the Partnership for Public Warning.

The audience members interposed the following questions or comments:

• Thank you for the Summit you convened on accessibility to communication during emergencies. One of the issues debated during the summit was the enforcement power that the FCC might have to assure that effective communication practices, in place but

not always implemented during an emergency, can take priority to other enforcement issues. Is there any progress in that area? Our enforcement bureau has been looking at the issue that you raise and we have noticed that in times of emergency, for example when the hurricane season begins or when we had the sniper incident, certain things were not captioned. We are currently looking at how we can do a faster job on that.

- You talked about an emergency alert rule making process. I'm not quite sure where that process is. We have been advocating for a long time to make greater access to emergency alerts through public broadcasting media and that hasn't really had traction in the FCC. Can you comment on that? The comment period has just closed. The staff is reviewing all the comments and no determination has been made just yet. I know we received a healthy amount of comments on that item and we are in the review process right now.
- I would urge the Chairman to meet with Tom Lockwood over at the Department of Homeland Security. He is heading up the National Capital Region effort. They have done a lot with the emergency communication alert warning system and other practical methods that reach out to many neighborhoods in Washington, D.C. You raise a great point. FCC plays a role in the emergency alert system and we have to work with FEMA. Also, on 9/11, the President chose to go to the airwaves. That is another issue we have to look at. In the 21st century, what type of emergency alert system will work in this world? I'll be happy to pass these comments along.

Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) Subcommittee on Research

The discussion was turned over to Lt.Governor John Hager who then asked Dr. Tom Finch, Rehabilitation Administration, who serves as primary staffer for the initiative, to provide a report on research. He said the subcommittee held their first meeting on December 8. The subcommittee is unique because it is part of a larger entity co-chaired by Dr. Giannini at the Department of Health and Human Services and Steve Tingus, Director, National Institute on Disability and Rehabilitation Research.

During the first meeting the subcommittee reviewed four major goals: 1) promoting coordination and cooperation among Federal departments and agencies conducting research on topics related to emergency preparedness and emergency management 2) identifying, assessing and coordinating all Federal programs 3) developing a compendium of programs, activities and project outcomes to share with all agencies and post online so it will be accessible to federal partners, state and local entities, as well as the disability community at large 4) receiving input from the disability community atlarge in order to develop research priorities that may be undertaken by entities in the federal government.

Dr. Finch commented that within this framework are subgoals. One is to ensure that the research being performed targets the needs of individuals with disabilities, has an appropriate balance between applied and basic research as well as outcomes research and focuses on projects that cover a wide array of topics. Regarding outcomes, Dr. Finch said the subcommittee envisioned 1) devising methods and strategies to coordinate the research activities among all federal partners, 2) assisting in the development of new

research priorities, to address and identify gaps and 3) reviewing, gathering, analyzing and synthesizing federal reports dealing with emergency preparedness research.

Dr. Finch added that the subcommittee's work during the next few weeks will be to review this framework of ideas, receive approval from the subcommittee members, and set guidelines for future work. He said the goals he outlined have short and long-term benchmarks. Specific tasks and action steps will be addressed and a time line for securing accomplishments.

Department of Justice, Technical Assistance & Outreach Subcommittee

Mr. Sutherland asked Ollegario "Ollie" Cantos, Special Assistant to the Assistant Attorney General for Civil Rights, to provide an overview. Mr. Cantos explained that the committee aims to reach out to people with disabilities in organizations that serve them, such as emergency preparedness professionals, first responders, employers in all sectors and schools. The ultimate goal is to help ensure that people with disabilities become integrally involved in emergency planning and become a part of the emergency preparedness solution.

Mr. Cantos stated that as the subcommittee centralizes previously developed material, they will identify gaps that need to be filled and be in a better position to prevent duplication of effort. The subcommittee expects to promote cross-organizational collaboration between government agencies, nonprofit organizations, and the private sector and pave the way for a close-knit community of emergency preparedness experts who will drive emergency preparedness activities to a new level of effectiveness and coordination and the private sector.

To accomplish these goals the subcommittee developed an Education and Action Tool Kit on Emergency Preparedness on People with Disabilities. Mr. Cantos said the subcommittee plans to post the tool kit online by July 26, 2005, the 15th anniversary of the signing of the Americans with Disabilities Act. Mr. Cantos explained that the tool kit will cover disasters as well as terrorist attacks, address the needs of people with disabilities as a whole, while also focusing on specific disability populations.

Additionally, the subcommittee has obtained listings of 1,450 disability media contacts to inform individuals in every part of the country about the tool kit. The tool kit will become a living document to be updated periodically as new effective practices emerge in the field.

Department of Homeland Security, State, Local and Tribal Government Coordination Subcommittee

Mr. Sutherland then presented his report on State, Local and Tribal Government Coordination. Mr. Sutherland stated that he and Claudia Gordon met with Secretary Ridge to chart the subcommittee's course and framework. Secretary Ridge has addressed both the Republican Governors Association and the Democratic Association to encourage them to include people with disabilities in their thinking as they spend government funds. The Secretary expects to draft a letter to all Governors on this point. Sue Menser,

Executive Director, Department of Homeland Security Office of State and Local Government Coordination and Preparedness, is assisting with this as well.

The other subcommittee priority will be to identify best practices that exist at the state and local level. Mr. Sutherland said if there is a city that is recognized for its best practices, they would publicize that also.

Department of Homeland Security, Private Sector Coordination

Mr. Sutherland directed attention to the final subcommittee and the private sector coordination developing through the National Citizen Corps Council. The Council established a subcommittee that focuses on individuals with disabilities in emergency preparedness. And they have organized consumer organizations and advocacy groups to provide input to the subcommittee. The group met on October 19, 2004. The meeting minutes were included in the materials.

Mr. Sutherland noted that the advocacy groups have two ways of providing input. First, to provide input to decision makers. Second, a smaller delegation of the larger group are members of the National Citizen Corps itself, so they are integrating into that work as well.

National Citizen Corps Council, Subcommittee on Individuals with Disabilities in Emergency Preparedness

Mr. Sutherland then turned the presentation over to Hillary Styron, Emergency Initiative Officer, National Organization on Disability, who represented the Citizen Corps and their subcommittee.

Ms. Styron explained that the subcommittee intends to be a resource tool to the National Citizen Corps Council to work together to accomplish some of the challenges for meeting the needs for integrating emergency preparedness for people with disabilities. The subcommittee established a format to address key issues in order to prevent duplicative efforts.

She noted the importance of communication – crafting and communicating appropriate messages to the public. And she explained that a message is continuously communicated before the event, during the event, and after the events, and needs to be in alternate formats and accessible.

Other challenges include transportation and research, accessible shelters or areas of refuge, and plans for massive evacuation. Ms Styron commented that some additional questions for consideration include determining whether accessible phone lines exist in the shelters.

Regarding public awareness campaigns, Ms Styron queried whether messages were properly customized to fit the targeted audience keeping the end user in mind.

She implored the subcommittee and the audience to change the criteria used to develop Homeland Security exercise evaluation material to add mandatory requirements that people with disabilities be included in the planning process. If they are not included in the planning, how are you to effectively respond to their needs, she asked.

She stated that another challenge associated with the emergency and medical needs for people with disabilities involves the strategic national stock pile. There may be special medication that is not generally in the generic strategic national stock pile, she noted. Depending upon the emergency, an individual with a special medication may not be able to secure that medication and may need some solutions to have their needs met. Therefore, we might be looking at how to address that issue.

Ms. Styron presented some views on how Community Emergency Response Teams (CERT) may include people with disabilities. She suggested integrating people with disabilities into an already established team; yet, having a variety of different groups become a team. This would increase manpower for volunteers and the people on the ground who are available to help. It also provides a person with a disability an opportunity to understand what is happening and obtain general awareness.

Ms.Styron pointed out that there is a new Council establishing itself almost every week across the country, in every city and community, working to improve emergency preparedness and response for people with disabilities, and that includes about 1500 Citizen Corps Councils. This is a grassroots campaign that can take the accomplishments at the Federal level to the grassroots and integrate it at the community level, she said. Ms Styron announced that the next meeting of the subcommittee is January 19, 2005 and concluded by reminding the audience that if emergency preparedness meets the needs of people with disabilities, it meets the needs of everyone. And everyone must be involved in preparedness.

Mr. Sutherland thanked Ms. Styron and told the audience they need to prod government officials, provide input, and let them know if they are not moving fast enough. He mentioned that the report is due to the President this summer. He commented that the summer would be interesting because the 15th Anniversary of the Americans with Disabilities Act will be commemorated and the work of the Interagency Council is likely to be closely scrutinized, as is most work in the disability arena.

He requested participants to provide input to the development of the contents of the final report. Mr. Sutherland noted that a good time line will need to be developed so that the final publication is produced in a timely manner.

Claudia Gordon thanked everyone for their participation thus far and mentioned that there were several new agencies on board. Mr. Sutherland said the next meeting would occur in the March time frame. At that time, some of the products discussed will start to be delivered. After that, there will be a meeting just prior to the anniversary of the ADA to wrap up the first year of work. Mr. Sutherland thanked everyone for their good work.