U.S. Department of Education

Emergency Management Research and People With Disabilities

A Resource Guide

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April 2008

Point of Contact

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April 2008

This report is available on the U.S. Department of Education's Web site at: http://www.ed.gov/rschstat/research/pubs. It also is available on the Interagency Committee on Disability Research (ICDR) Web site at http://www.icdr.us, the National Center for the Dissemination of Disability Research Web site at http://www.ncddr.org/new/announcements.html and the National Rehabilitation Information Center (NARIC) Web site at http://www.naric.com/public/pubs.cfm.

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Introduction

The National Institute on Disability and Rehabilitation Research (NIDRR) is pleased to provide this online resource guide on emergency management research and people with disabilities. This resource guide is the culmination of cooperative efforts by NIDRR, the Department of Education, the Research Subcommittee of the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC), and the New Freedom Initiative Subcommittee of the Interagency Committee on Disability Research (ICDR).

The guide provides a listing and description of research projects funded by the federal government and nonfederal entities, research recommendations that have come out of conferences on emergency management and disability, and a bibliography of relevant research publications. Each item listed in the table of contents is a hyperlink to its location in the document. This has been done to facilitate navigation throughout the document.

Many federal agencies participated in the effort to identify research projects and conference recommendations. In all, we were able to identify 16 federally funded and four nonfederally funded research projects specific to emergency management and people with disabilities. Conference recommendations identified a multitude of knowledge gaps that need to be filled. Clearly there is a need for increased research.

It is our hope that this guide will facilitate the development and implementation of a nationwide research agenda on emergency management and people with disabilities, so that we can develop a strong evidence base about the best ways to ensure the safety and security of people with disabilities in emergency and disaster situations.

Research Projects

Federally Funded Research

Information about specific research projects came from a variety of sources, including: the National Rehabilitation Information Center (http://www.naric.com), which catalogues NIDRR grants and provides abstracts from grant applications; other Web sites, and responses from federal partners, grantees and others to inquiries about relevant research projects (see Appendix E: Methodology for further details).

Access to Emergency Alerts for People With Disabilities

Institution: WGBH National Center for Accessible Media (NCAM)

Principal Investigator: Marcia Brooks

Funding Source: U.S. Department of Commerce, Technology Opportunities Program

Funding Years and Amount: Fiscal Year (FY) 2005 - FY 07. Total = $550,000.

Grant Number: 25-60-04026

Contact Information: Marcia Brooks, WGBH National Center for Accessible Media (NCAM), WGBH Educational Foundation, 125 Western Ave., Boston, MA 02134

E-mail: marcia_brooks@wgbh.org

Telephone: 617-300-3431

Fax: 617-300-3431

Web sites: http://ncam.wgbh.org/alerts, and http://www.incident.com/access (last accessed March 28, 2008)

The National Center for Accessible Media (NCAM) is leading a collaborative initiative to enhance the nation's emergency warning systems to better serve people with sensory disabilities. Although emerging systems, services and products are developing a range of text and audio alert capabilities which could meet this need, most are inconsistent in terms of fully supporting appropriate modalities and accessible interfaces.

NCAM and partners have established a working group that is developing an information model and recommendations as to how message components, data preparation, transmission practices and technologies could be adapted to better serve people with disabilities. This work will result in recommended accessibility extensions to emergency system protocols, technologies and services for wired, wireless, DTV- and IP-based delivery systems. End-

user testing will identify key usability factors. This work is supported by an advisory board comprising representatives from organizations serving the deaf, hard of hearing, blind and visually impaired communities.

Access to Locally Televised On-Screen Information: Auditory Messaging and Captions During Emergency Broadcasts

Institution: WGBH National Center for Accessible Media (NCAM)

Principal Investigator: Geoff Freed

Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research

Funding Years and Amounts: FY 05 = $150,000; FY 06 = $150,000; FY 07 = $150,000

Grant Number: H133G050278

Contact Information: Mary Watkins, WGBH National Center for Accessible Media (NCAM), WGBH Educational Foundation, 125 Western Ave., Boston, MA 02134

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Telephone: 617-300-3700

Fax: 617-300-1020

Web sites: http://ncam.wgbh.org, and
http://www.naric.com/nidrr/grantees/record.cfm?pn=H133G050278
(last accessed March 28, 2009)

Although local television broadcasts serve as the primary source for emergency alerts, weather warnings, local traffic problems and school closings, much of this information remains inaccessible to people with sensory disabilities. To better serve viewers who are blind or have low vision, NCAM is researching DTV systems and procedures that will enable real-time processing and conversion of on-screen text crawls into speech output. To better serve viewers who rely on captions, NCAM is addressing display conflicts between captions and on-screen graphics by developing methods of tagging and prioritizing text and graphics messages within automated broadcast display systems.

After refining solutions in WGBH studios, NCAM will conduct a demonstration model within the newsroom facilities at the ABC network affiliate station WCVB-TV Channel 5, the flagship station of the Hearst-Argyle Television Group, located in Boston, Mass. Project guidelines and technical solutions will be immediately useful to the nation's broadcasters and will have a significant impact on broadcast procedures and future equipment capabilities.

Assessing the Impact of Hurricane Katrina on Persons With Disabilities

Institution: Research and Training Center on Independent Living, University of Kansas

Principal Investigator: Glen White

Funding Source: U. S. Department of Education, National Institute on Disability and
Rehabilitation Research

Funding Year and Amount: FY 05 = $162,000

Grant Number: Supplement to H133B000500

Contact Information: Glen White, University of Kansas, Research and Training Center on
Independent Living, 1000 Sunnyside Ave., Room 4089, Dole Center, Lawrence,
KS 66045-7555

E-mail: rtcfpil@ku.edu

Telephone: 785-864-4095; 785-864-0706 (TTY)

Fax: 785-864-5063

Web site: http://rtcil.org/products/NIDRR_FinalKatrinaReport.pdf
(last accessed March 28, 2008)

The Research and Training Center on Independent Living at the University of Kansas received
from the National Institute on Disability and Rehabilitation Research (NIDRR) a one-year
research grant to assess the impact of Hurricane Katrina on persons with disabilities.
Specifically, the researchers and NIDRR sought to fill a void in our national understanding by
documenting the experiences of staff and consumers at centers for independent living (CILs)
along with those of local emergency management personnel in the Gulf Coast following
Hurricane Katrina.

The research focused on understanding how persons with disabilities prepared for, reacted to,
and recovered from the devastating impact of the storm in portions of the Gulf Coast most
affected. In addition, this work sought to understand the roles and relationships that CILs played
in all phases of the disaster, with a special emphasis on their relationship to the emergency
management system.

The primary tasks of the project were to:

1) Assess the impact of Hurricane Katrina on CIL staff and consumers;
2) Identify the barriers faced by CILs and emergency management personnel in locating and
assisting persons with disabilities in the affected areas and relocation centers;

3) Identify future independent living needs among CIL consumers during and after disasters; and

4) Identify resources, including training, information, equipment and facilities that CIL and emergency management personnel state as being most useful to them in the event of future large-scale emergencies.

The project's goal was to provide policy- and program-level recommendations that can be used to improve the services provided to persons with disabilities in future disasters and emergencies.

Findings from the study revealed three significant gaps in areas affecting persons with disabilities: 1) ineffective pre-disaster planning by CILs, persons with disabilities, and emergency management; 2) poorly developed pre- and post-disaster communication and information-sharing within and between these three entities; and 3) underdeveloped pre- and post-disaster coordination between these three entities and other elements of support within communities.

Bottom-Up Modeling of Mass Pedestrian Flows: Implications for the Effective Egress of Individuals With Disabilities

Institution: Utah State University, Center for Persons With Disabilities

Principal Investigator: Keith Christensen

Funding Source: U.S. Dept. of Education, National Institute on Disability and Rehabilitation Research

Funding Years and Amounts: FY 03 = $150,000; FY 04 = $150,000; FY 05 = $150,000

Grant Number: H133G030013

Contact Information: Keith Christiansen, Utah State University, Center for Persons With Disabilities, 6800 Old Main Hill, Logan, UT 84322

E-mail: keithc@cpd2.usu.edu

Telephone: 435-797-3997

Fax: 435-797-7219

Web site: http://www.naric.com/nidrr/grantees/record.cfm?pn=H133G030013
(last accessed March 28, 2008)

The purpose of this research project is to improve the exit of individuals with disabilities from buildings and other settings in emergencies. The project researches the effect of the current and proposed *Americans with Disabilities Act Accessibility Guidelines* (*ADAAG*) for the built-environment on the egress of individuals with disabilities during the mass pedestrian flows

(MPFs) triggered by health-safety events, and the effect of security-oriented design methods on the egress of individuals with disabilities during health-safety event triggered MPFs. The objective of the project is to measure the emergent behaviors of the diverse sample populations of six representative built-environments (an airport, high school, conference center, multi-story office building, federal development, and secured federal development) during simulated health-safety events. An intervention (modification of the design character of the built-environment) is applied to eliminate conditions occurring during MPFs, which adversely affect the egress of individuals with disabilities.

Emergency Preparedness Demonstration Program for Disadvantaged Communities

Institutions: Center for Urban and Regional Studies of the University of North Carolina–Chapel Hill; MDC

Principal Investigators: David Dodson, John Cooper, Philip Berke, Jim Fraser, and David Salvesen

Funding Source: Department of Homeland Security

Funding Years and Amount: FY 05 - FY 08. Total = $2 million

Grant Number: DHS-GRANTS-122304-001

Contact Information: John Cooper, MDC, 400 Silver Cedar Court, Suite 300, Chapel Hill, NC 27516; and Philip Berke, Professor of City and Regional Planning Faculty Fellow, Center for Urban & Regional Studies, University of North Carolina–Chapel Hill, NC 27599-3140

E-mail: jcooper@mdcinc.org, and pberke@unc.edu

Telephone: 919-968-4531 (Cooper, MDC) and 919-962-4765 (Berke, UNC–Chapel Hill)

Fax: 919-929-8557 (Cooper, MDC)

Web sites: http://www.planning.unc.edu/grant/fema/about.htm, and http://www.mdcinc.org (last accessed March 28, 2008)

The purpose of this project is to identify and overcome barriers for increasing awareness of disasters and building capacity for emergency preparedness in disadvantaged minority communities in the District of Columbia, Delaware, Maryland, North Carolina, Pennsylvania, Virginia and West Virginia (i.e., areas that were impacted by Hurricane Isabel in 2003).

The three core objectives are to: 1) build community capacity to undertake coordinated action to develop and implement emergency preparedness plans; 2) raise awareness and knowledge levels of community residents about their potential vulnerability to harm from future disasters and the

measures they can take to reduce their vulnerability; and 3) reduce community vulnerability to harm from disasters while respecting local needs.

Emergency Preparedness for Special Populations

Institution: Columbia University Mailman School of Public Health

Principal Investigator: David S. Markenson

Funding Source: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality

Funding Years and Amount: FY 04 – FY 06; amount not available

Grant Number: 1R13HS014556-01

Contact Information: Irwin Redlener, MD, Associate Dean and Director of National Center for Disaster Preparedness, Mailman School of Public Health, Columbia University, 722 W 168th Street, 10th Floor, New York, NY 10032

E-mail: ir2110@columbia.edu

Telephone: 212-305-0338

Fax: 212-342-5160

Web sites: http://www.ncdp.mailman.columbia.edu, and
http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6813881&p_grant_num=1R13 HS01455601&p_query=&ticket=24090706&p_audit_session_id=132170999&p_keywor ds=
(last accessed March 28, 2008)

Despite the recent attention to disaster, terrorism, and public health emergency preparedness, little attention has been given to vulnerable populations. Current efforts have focused primarily on the needs of the average adult population. Based on the preliminary work done in the Pediatric Disaster and Terrorism Preparedness: A National Consensus Conference on both content and in establishing a format for conducting this type of evidence-based consensus process, the National Center for Disaster Preparedness proposes to conduct a conference that has the purpose to address the needs of vulnerable populations in disasters, terrorism, and public health emergencies.

The two selected vulnerable populations to be addressed are children and people with disabilities. The specific goals of the conference are: 1) build a collaboration among individuals with expertise in people with disabilities, terrorism preparedness, public health, and emergency management, including disaster planning, management, and response; 2) review and summarize the existing data on the needs of people with disabilities in disasters, terrorism, and public health

emergencies, including planning, preparation, and response; 3) develop consensus on the needs of people with disabilities in disasters, terrorism, and public health emergencies; 4) create a research agenda to answer knowledge gaps based on the limited data that exist on the needs of people with disabilities in disasters, terrorism, and public health emergencies; 5) review the recommendations and treatment guidelines from the Pediatric Disaster and Terrorism Preparedness National Consensus Conference for the need for revision based on new data and new governmental and nongovernmental initiatives; and 6) develop recommendations and treatment guidelines on the needs of children in disasters, terrorism, and public health emergencies in the areas identified in the prior meeting as requiring further clarification from the coalition supplemented by those with specific expertise in these areas.

The areas identified are: school preparedness; child congregate facility preparedness; sheltering needs of children; pediatric needs for public health emergency preparedness; children with special health care needs and technologically assisted children; decontamination of children; biological terrorism prophylaxis and treatment of emerging agents; and family-centered preparedness.

Emergency Preparedness Training Software With Universal Access

Institution: Vcom3D, Inc.

Principal Investigator: Amber Emery

Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research

Funding Year and Amount: FY 02 = $74,830

Grant Number: H133S020076

Contact Information: Amber Emery, 3452 Lake Lynda Drive, Suite 260, Orlando, FL 32817

E-mail: ambere@vcom3d.com

Telephone: 407-737-7310, ext. 117

Fax: 407-737-6821

Web site: http://www.vcom3d.com
(last accessed March 28, 2008)

This project develops a Web-based software program that assists people who are deaf or hard of hearing in learning self-advocacy and survival skills for life-threatening situations. The software uses 3-D animated signing characters employing SigningAvatar technology in an interactive virtual-reality environment. Effectiveness and user acceptance is evaluated in school environments.

Evacuation Methodology and Understanding Behavior of Persons With Disabilities in Disasters: A Blueprint for Emergency Planning Solutions

Institution: West Virginia University

Principal Investigator: George Trapp (Through May 15, 2008); Brian Gerber (May 16, 2008 – end of project)

Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research

Funding Years and Amounts: FY 07 = $443,035; FY 08 = $449,963; FY 09 = $436,016

Grant Number: H133A070005

Contact Information: George Trapp or Brian Gerber, West Virginia University, VMC/Homeland Security Programs, P.O. Box 6270, Morgantown, WV 26506.

E-mail: George.Trapp@mail.wvu.edu; Brian.Gerber@mail.wvu.edu

Telephone: George Trapp: 304-282-8629; Brian Gerber: 304-293-2614

Fax: George Trapp: 304-293-7199; Brian Gerber: 304-293-8814

This project quantifies and interprets the unique challenges of persons with disabilities and special needs during emergency/disaster evacuations in order to improve the management of such events. The Virtual Medical Campus (VMC)/Homeland Security Programs at West Virginia University and the Center for Disability and Special Needs Preparedness operated by Inclusion Research Institute are surveying people with disabilities, the elderly, emergency managers and other local service providers to understand emergency evacuation experiences and behaviors; they then will develop, pilot, and disseminate best practice guidance.

Making In-Flight Communications and Entertainment Accessible

Institution: WGBH National Center for Accessible Media (NCAM)

Principal Investigator: Larry Goldberg

Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research

Funding Years and Amounts: FY 05 = $150,000; FY 06 = $150,000; FY 07 = $150,000

Grant Number: H133G050254

Contact Information: Larry Goldberg, WGBH National Center for Accessible Media (NCAM), WGBH Educational Foundation, 125 Western Ave., Boston, MA 02134

E-mail: larry_goldberg@wgbh.org

Telephone: 617-300-3486

Fax: 617-300-1035

Web site: http://www.wgbh.org/ncam
        (last accessed March 28, 2008)

Full-featured embedded or handheld media and communication systems are fast becoming two common services offered to travelers via next-generation, in-flight entertainment systems (IFEs). These systems offer passengers Internet connectivity and access to satellite TV and video-on-demand, and allow them to independently access up-to-date flight information on arrival times, connections, delays and gate changes. NCAM is working with the World Airlines Entertainment Association, Matsushita Avionics Systems and the National Center for Accessible Transportation at Oregon State University to develop solutions that can make IFEs accessible to people with sensory disabilities.[1]

National Organization on Disability (NOD) Emergency Preparedness Study, 2004

Institution: National Organization on Disability

Chairman: Tom Ridge

Funding Source: U.S. Department of Homeland Security, Domestic Preparedness Training and Technical Assistance

Funding Year and Amount: FY 04 = $200,000

Grant Number: 2004-TH-TX-0003

Contact Information: Hilary Styron, National Organization on Disability, 910 Sixteenth St. N.W., 6th Floor, Washington, DC 20006

E-mail: StyronH@nod.org

Telephone: 202-293-5960; 202-293-5968 (TTY)

Fax: 202-293-7999

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[1] Although this project does not pertain directly to emergency management, it is included in this resource guide because the technologies developed may be applicable to emergency situations.

Web site:
　　http://www.nod.org/index.cfm?fuseaction=page.viewPage&pageID=1430&nodeID=1&FeatureID=1422&redirected=1&CFID=10167718&CFTOKEN=92931920
　　(last accessed March 28, 2008)

Commissioned by the National Organization on Disability (NOD) through a grant from the U.S. Department of Homeland Security, this study surveyed emergency managers in states and in cities of all sizes to determine if officials considered the needs of people with disabilities in their emergency plans and included people with disabilities in the planning process.

The findings indicated that 69 percent had incorporated the needs of people with disabilities into their emergency plans; an additional 22 percent had a plan in development. However, of those cities that had a preparedness plan in place or in development, 50 percent did not have a special-needs registry that includes people with disabilities; 59 percent did not have plans for the pediatric population; and 76 percent did not have a paid expert aware of preparedness concerns for people with disabilities. Additionally, only 42 percent had a public awareness campaign to provide information to people with disabilities, and only 16 percent had the plan available in alternative formats.

Nobody Left Behind: Disaster Preparedness for Persons With Mobility Impairments

Institution: Research and Training Center on Independent Living, University of Kansas

Principal Investigators: Glen W. White; Michael Fox

Funding Source: Centers for Disease Control and Prevention, through the Association for
　　Prevention Teaching and Research

Funding Years and Amount: Total funding FY 02 – FY 05. Total = $615,000

Grant Number**:** TS #-0840

Contact Information: Cathy Rooney, 1000 Sunnyside Ave., Dole Center, Room 4089, Lawrence,
　　KS 66045

E-mail: catr@ku.org

Telephone: 785-864-3791

Fax: 785-864-5063

Web site: http://www2.ku.edu/~rrtcpbs/
　　(last accessed July 16, 2007)

The mission of this research is to investigate 30 randomly selected counties or cities in the United States that have recently experienced a natural or man-made disaster to: 1) determine if disaster plans and emergency response systems for homes, businesses and the community include the health, safety and survival needs for persons with mobility impairment; 2) identify the morbidity and mortality of persons with mobility impairments in these disasters; 3) assess any post-disaster changes to address the needs of persons with mobility impairments; and 4) develop best practices models for counties to assist in disaster plans and emergency responses to meet the needs of persons with mobility impairments to prevent injuries, save lives and assure that nobody is left behind.

Project Safe EV-AC: Safe EVacuation and ACcommodation of People With Disabilities

Institution: West Virginia University

Principal Investigator: Richard Walls

Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research

Funding Years and Amounts: FY 04 = $149,970; FY 05 = $149,949; FY 06 = $149,884

Grant Number: H133G040318

Contact Information: Beth Loy, West Virginia University, Job Accommodation Network (JAN), 224 Spruce St., Morgantown, WV 26506

E-mail: evac@icdi.wvu.edu

Telephone: 304-293-7186

Fax: 304-393-5407

Web sites: http://evac.icdi.wvu.edu, and
http://www.naric.com/research/record.cfm?search=1&type=all&criteria=Project%20Safe%20EV-AC&phrase=no&rec=1428
(last accessed March 28, 2008)

The Project Safe EV-AC: Safe EVacuation and ACcommodation of People with Disabilities team, which includes the Job Accommodation Network (JAN) and the National Organization on Disability's Emergency Preparedness Initiative, develops high-quality, comprehensive, easy-to-use safe evacuation materials for people with disabilities. The team researches prior safe evacuation studies and training products; coordinates a network of expert and end-user adviser groups; and produces comprehensive, cost-effective, safe evacuation education and training tools using the most appropriate technology for the material.

Project Safe EV-AC targets people with disabilities and emergency responders. It uses a continuous improvement model with enhanced feedback loops to ensure that the products created are rigorously evaluated by those who use them. The end products include a final report for the National Institute on Disability and Rehabilitation Research (NIDRR) articulating the existing gaps in knowledge and product development in the field of safe evacuation and accommodation for people with disabilities.

Rehabilitation Engineering Research Center for Wireless Technologies

Institution: Georgia Institute of Technology

Principal Investigator: Helena Mitchell

Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research

Funding Year and Amount: FY 06 = $949,999; FY 07 = $949,999; FY 08 = $949,998; FY 09 = $949,999; FY 10 = $949,999

Grant Number: H133E060061

Contact Information: Helena Mitchell, Georgia Institute of Technology, Center for Advanced Communications Policy, 500 Tenth Street, NW, Atlanta, GA, 30332-0620

E-mail: rerc@cacp.gatech.edu

Telephone: 404-385-4651

Fax: 404-385-0269

Web sites: http://www.wirelessrerc.org, and http://www.naric.com/research/pd/record.cfm?search=1&type=type&display=detailed&criteria=Rehabilitation%20Engineering%20Research%20Centers%20(RERCs)&rec=1671 (last accessed March 28, 2008)

The Rehabilitation Engineering Research Center (RERC) for Wireless Technologies' mission is to: 1) promote equitable access to and use of wireless technologies by persons with disabilities; and 2) encourage adoption of Universal Design in future generations of wireless technologies. The RERC contains a number of research and development projects. Two development projects, "Development of Wireless Emergency Communications" and "Ensuring Access to Emergency Assistance," both focus on the area of wireless emergency communications for people with disabilities; developing wireless communication technology to be used by emergency personnel to contact individuals with disabilities, and by people with disabilities to signal the need for assistance.

Rehabilitation Engineering Research Center on Telecommunications Access

Institution: University of Wisconsin/Madison

Principal Investigator: Gregg C. Vanderheiden; Judy Harkins

Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research

Funding Years and Amounts: FY 04 = $850,000; FY 05 = $924,988; FY 06 = $850,000; FY 07 = $850,000; FY 08 = $850,000

Grant Number: H133E040013

Contact Information: Gregg C. Vanderheiden, University of Wisconsin/Madison, Trace Center, College of Engineering, 2107 Engineering Centers Building, 1550 Engineering Drive, Madison, WI 53706

E-mail: info@trace.wisc.edu

Telephone: 608-265-4621, 608-263-5408 (TTY)

Fax: 608-262-8848

Web sites: http://trace.wisc.edu/telrerc, and http://www.naric.com/research/pd/record.cfm?search=1&type=type&display=detailed&criteria=Rehabilitation%20Engineering%20Research%20Centers%20(RERCs)&rec=1435 (last accessed March 28, 2008).

Accessible Emergency Notification and Communication State of the Science Conference: http://tap.gallaudet.edu/emergencycommconf.htm (last accessed March 28, 2008).

The mission of the Telecommunications Access RERC is to advance accessibility and usability in existing and emerging telecommunications products for people with all types of disabilities. A key application of the RERC's research and development is in the area of emergency communications – both directly and through the development of telecommunication infrastructure that will support text and video in mainstream telecommunications. In 2005, one RERC project was directed specifically at identifying issues and recommendations pertaining to alerting people about possible emergencies and ensuring accessible communication in emergency or crisis situations.

The RERC's State of the Science Conference on Accessible Emergency Notification and Communication, held Nov. 2-3, 2005, resulted in 32 recommendations for research, development, evaluation and technical assistance targeted at accessible emergency

communication systems; 23 recommendations for public policy; and five recommendations for information and training. (Recommendations for research are listed in the first entry of the next chapter on page 23.)

Saving Lives: Including People With Disabilities in Emergency Planning

Institution: National Council on Disability

Chairman: Lex Frieden

Funding Source: National Council on Disability

Funding Year and Amount: FY 03 – FY 04. Total = $30,000

Grant Number: Not available

Contact Information: Lex Frieden, National Council on Disability, 1331 F St. N.W., Suite 850,
        Washington, DC 20004

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Telephone: 202-272-2004; 202-272-2074 (TTY)

Fax: 202-272-2022

Web site: http://www.ncd.gov/newsroom/publications/2005/saving_lives.htm
        (last accessed March 28, 2008)

This report: 1) describes the disaster experiences of people with disabilities; 2) details the contributions and efforts of community-based organizations (CBOs); 3) examines the nascent work of the U.S. Department of Homeland Security's (DHS) Directorate of Emergency Preparedness and Response (EP&R), which includes the Federal Emergency Management Agency (FEMA) and its federal, state and private sector partners as well as DHS' Office for Civil Rights and Civil Liberties (CRCL); and 4) touches on the ongoing work of the Federal Communications Commission (FCC) in specific areas that relate to issues of homeland security and emergency preparation.

While other federal agencies play important roles in this effort, efforts by the DHS and the FCC represent some of the most critical operations on behalf of Americans with disabilities. Given the nature of most disasters, general and disability-specific programs and services span many different governmental and nongovernmental organizations.

The report also examines the following broad areas:

- ▪ The disaster experiences of people with disabilities and activity limitations and how their access to disaster services could be improved;

- ▪ The disaster experiences of CBOs and how partnerships with those organizations can help people with disabilities and activity limitations; and
- ▪ How an effective, disability-related homeland security and emergency preparedness infrastructure may be developed.

The report's recommendations urge the federal government to influence its state and local government partners, as well as its community-based partners, to assume major roles in implementing key recommendations.

Sound Alert: A Centralized System Capable of Alerting People Who Are Deaf or Hearing Impaired of Critical Sounds in Their Environment

Institution: CreateAbility Concepts, Inc.

Principal Investigator: Stephen M. Sutter

Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research

Funding Years and Amounts: FY 07 = $250,000; FY 08 = $250,000

Grant Number: H133S060109

Contact Information: Stephen M. Sutter, CreateAbility Concepts, Inc., 5610 Crawfordsville Rd., Suite 2401, Indianapolis, IN 46224

E-mail: support@createabilityinc.com

Telephone: 317-536-2815 or 866-210-6662

Fax: 317-536-2815

Web sites: http://www.createabilityinc.com, and
http://www.naric.com/research/pd/record.cfm?search=1&type=type&display=detailed&criteria=Small%20Business%20Innovative%20Research%20(SBIR),%20Phase%20II&rec=1698
(last accessed March 28, 2008)

This research and development will result in a comprehensive system that delivers natural warning and communication mechanisms for people with hearing loss. The SoundAlert system offers a unique approach to enable individuals who are non-hearing to: 1) initiate and receive emergency communications, 2) receive alerts in the workplace or home environments on a single pocket-sized device through innovative sound discrimination techniques able to identify specific sounds with accuracy, and; 3) combine this functionality with supplementation or replacement of other alerting technologies for convenience on the same single platform. The system enables outbound and inbound communication with emergency services in response to such events as

evacuation or rescue information when needed, thus alleviating a major concern of this population for their personal safety.

Nonfederally Funded Research

The Harris Poll #60: *Many People Unprepared for Terrorist Attacks or Other Disasters*

Institution: Harris Interactive Incorporated

Chair: Humphrey Taylor

Funding Source: Charles Stewart Mott Foundation

Funding Year and Amount: FY 01; amount not available

Grant Number: Not available

Contact Information: Tracey McNerney, Harris Interactive Public Relations, 60 Corporate
        Woods, Rochester, NY 14623

E-mail: TMcNerney@HarrisInteractive.com

Telephone: 585-214-7756

Fax: 585-214-7686

Web site: http://www.harrisinteractive.com/harris_poll/index.asp?PID=272 and
http://www.nod.org/index.cfm?fuseaction=page.viewPage&pageID=1430&nodeID=1&FeatureI
D=507&redirected=1&CFID=3645752&CFTOKEN=81135247
(Last accessed March 28, 2008)

A Harris Interactive survey, conducted Nov. 14-20, 2001, interviewing 1,011 people by
telephone, 15 percent of whom indicated they had disabilities. Results from the survey, done on
behalf of the National Organization on Disability, showed that most of the country's 54 million
citizens with disabilities do not feel sufficiently prepared for future crises. According to
the survey:

- 58 percent of people with disabilities said they do not know whom to contact about
  emergency plans for their community in the event of a terrorist attack or other crisis.
- 61 percent said that they have not made plans to quickly and safely evacuate their home.
- Among those who are employed full or part time, 50 percent say no plans have been
  made to safely evacuate their workplace.

The survey results showed these percentages were higher than for those without disabilities: 51
percent reported not knowing whom to contact about community emergency plans, 58 percent
said no plans were in place for evacuating home, and 44 percent said none in place for work.

December 2003 Follow-Up to the Harris Poll #60: New Poll Highlights Need for More Emergency Planning for and by People With Disabilities

Institution: Harris Interactive commissioned by the National Organization on Disability (NOD)

Chairman: Humphrey Taylor, Harris Interactive

Funding Source: Harris Interactive

Funding Year and Amount: FY 2003; amount not available

Grant Number: Not available

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http://www.nod.org/index.cfm?fuseaction=page.viewPage&pageID=1430&nodeID=1&FeatureI
D=1245&redirected=1&CFID=7154392&CFTOKEN=44289573 (last accessed March 28, 2008)

More than two years after terrorist attacks focused national attention on the importance of planning ahead for disasters, Americans with disabilities remain insufficiently prepared, and are anxious about their safety, according to a Harris Interactive survey commissioned by the National Organization on Disability (NOD).

In the event of a terrorist attack, natural disaster, or other crisis, only 44 percent of people with disabilities said they knew whom to contact about emergency plans for their community. Just 39 percent had made plans to evacuate quickly and safely from their homes. These figures barely changed from Sept. 11, when Harris conducted the same survey following the terrorist attacks.

This survey found a noteworthy improvement, however, in the workplace preparedness of people with disabilities. Sixty-eight percent said that plans have been made to quickly and safely evacuate from their jobs, a dramatic increase from 45 percent in 2001.

The Harris Interactive survey interviewed 993 people, 19 percent of whom reported having disabilities, by telephone Dec. 10-16, 2003. NOD's Emergency Preparedness Initiative will continue to monitor and report on the disability community's preparedness level.

National Report: Emergency Preparedness and Emergency Communication Access: Lessons Learned Since 9/11 and Recommendations

Institutions: Northern Virginia Resource Center for Deaf & Hard of Hearing Persons (NVRC); Deaf and Hard of Hearing Consumer Advocacy Network

Point of Contact: Cheryl Heppner, NVRC

Funding Source: Northern Virginia Resource Center for Deaf and Hard of Hearing Persons

Funding Years and Amount: FY 01 – 04. Total = $10,000

Grant Number: Not applicable

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Web site: http://www.nad.org/site/pp.asp?c=foINKQMBF&b=264081
(last accessed March 28, 2008)

This national report calls attention to serious weaknesses in the nation's emergency preparedness infrastructure that compromise the safety and security of 28 million Americans who are deaf or hard of hearing. It identifies priorities for remedying the problem and makes recommendations on how to build a national network of support for individuals with hearing loss in the event of an emergency.

NOD/Harris Survey on Emergency Preparedness: Workplace Preparedness of People With Disabilities Down— Personal Preparedness on the Rise

Institution: Harris Interactive Commissioned by the National Organization on Disability (NOD)

Chairman: Humphrey Taylor, Harris Interactive

Funding Source: Multiple private sources

Funding Year and Amount: FY 2005; amount not available

Grant Number: Not available

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Web site: http://www.nod.org/index.cfm?fuseaction=page.viewPage&pageID=1430&nodeID=1&FeatureID=1562&redirected=1&CFID=25124092&CFTOKEN=37905663 and http://www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=1474 (last accessed March 28, 2008)

Four months after hurricanes Katrina and Rita ravaged the Gulf Coast and almost five years after Sept. 11, emergency preparedness in the workplace is on the decline, but personal preparedness for people with disabilities is on the rise, according to this Harris Interactive survey commissioned by the NOD's Emergency Preparedness Initiative. Furthermore, the disabled community has yet to experience the comparable decrease in their anxiety levels about their own personal safety that the population without disabilities has experienced.

This survey also reports a marked decrease in workplace preparedness for people with disabilities. Survey results reveal that 57 percent of people with disabilities indicate that they have a workplace plan, a figure that is down from 68 percent in 2003.

This telephone survey was conducted by Harris Interactive among a national cross-section of 1,001 adults aged 18 or over from Dec. 15 - 18, 2005. The sample size for adults with disabilities is 161 and for adults without disabilities is 829.

Research Recommendations from Conferences on Emergency Management and People With Disabilities

This section lists conferences on emergency management and people with disabilities that took place from 2003 through 2005, and it includes recommendations for research that were formulated and discussed at these meetings. All recommendations are reprinted verbatim from conference records.

Accessible Emergency Notification and Communication: State of the Science Conference

Sponsored by the Rehabilitation Engineering Research Center (RERC) on Telecommunications Access.
Held at Gallaudet University, Washington, D.C., on Nov. 2-3, 2005.

The research recommendations below are from the conference report, Accessible Emergency Notification and Communication: Research and Policy Recommendations, Pages 6-11. The full report is available at http://tap.gallaudet.edu/EmergencyCommConf.htm (last accessed March 28, 2008)

Recommendations for Research

Accessibility of Mainstream Personal Technologies Used for Communications and Information

► R-1. Development of techniques to make mainstream technologies used for notification and communication usable by people with disabilities, including inability to use without vision, lack of text communication features and phone complexity. Technology accessibility affects the ability of people with disabilities to be notified of important information prior to and during an emergency and during recovery; and to engage in emergency communications. If the basic technologies are not accessible, then emergency and recovery messages will be missed and people will be prevented from communicating in order to seek help or give help to others.

► R-2. Inclusion of disability access in research on next generation emergency notification technologies. Researchers that are specializing in projects on emergency communications have an obligation to coordinate with researchers working on the broader accessibility issues, as sometimes these two will overlap.

► R-3. Development of accessible communications devices for persons who are deaf-blind. At our conference, the limitations in accessibility of current technology vis-à-vis deaf-blind persons were a particular concern. Most in this group have visual and hearing impairments that prevent them from being able to use television, radio or cell phones. Thus they cannot use typical visual or auditory warning and communication devices. This group is growing in size as the U.S. population ages.

Research, Development, Evaluation, and Technical Assistance Targeted at Accessible Emergency Communication Systems

► R-4. Conduct a systems engineering analysis to determine:
- Needs regarding emergency communications, including coverage at various times of day and for various types of emergency situations.
- Capabilities assessment, including evaluation of performance under load.
- Requirements analysis and assumptions, including requirements matrix (specifications which can be realized in solutions/ products).
- Long-term solutions and not merely incremental approaches.

► R-5. Assess accessibility of current and proposed/planned emergency notification and communications, particularly during situations where people with disabilities are disproportionately vulnerable to missing alerts or information, and target research and standards development there. Some examples of situations where individuals with disabilities would be particularly vulnerable in emergencies:

- while driving if unable to listen to radio or call 9-1-1;
- while sleeping if unable to hear alerting sounds;
- while out in a public place if unable to see what others are doing or hear what they are saying;
- in a power outage if dependent mainly or solely on a computer for communications and information;
- in any situation if deaf-blind.

► R-6. Gather information using regional expertise of both consumers and emergency management personnel, in successfully providing accessible and timely communications during various types of emergencies. Document best practices and recommend models for federal, state and local governments to follow.

► R-7 Sponsor participation of accessibility technical experts in emergency communications standards and guideline development, and in industry and government advisory groups. Examples:

- wireless technology consortia developing specifications for location-based notification
- government's integrated Public Alert and Warning System (iPAWS)
- 9-1-1 government/industry partnerships addressing technology migration

► R-8. Development of methods to apply advanced technologies such as intelligent agents to automatically ensure emergency information generated in one format is available in all formats. Such technologies could also be applied to simplify complex messages to reduce cognitive load.

► R-9. Conduct lab and field tests of promising technologies for improved accessibility of emergency communications, working with partners in the public and private

sectors and involving people with disabilities. In particular, assessments need to be made to determine the extent to which the various methods of information delivery being considered in projects being coordinated by FEMA as well as local governments' systems, will achieve accessibility.

Government to Individual Communications and Broadcast Coverage of Emergencies

► R-10. Research the concept of streaming text over radio data channels to deliver emergency text messages through radio displays. Radio is frequently depended upon by the public for emergency and recovery information, particularly when driving or when there is an extended power outage. Radio is inaccessible to people who are deaf and some who are hard of hearing.

► R-11. Develop technology for conversion of text-based information to auditory information, such as text displayed on television screens during emergencies (e.g., school closing information and local telephone numbers to call for help). (Note**:** This area of research is being funded by NIDRR through a Field Initiated Research grant to WGBH.)

► R-12. Assess commercial products that perform emergency telephone notification functions ("reverse 9-1-1") against a list of accessibility features needed for people with disabilities and publish the information in an accessible format on the web and promote its availability to local and state governments, professional associations, industry trade associations, and disability organizations.

► R-13. Determine the most effective way of making EAS television alerts accessible to people who are blind. Current methods provide only an audio alert squawk, and not spoken information, when the television distributor sends the message in text only. The audio alert is sometimes accompanied by a spoken direction to tune to another channel, but the emergency information is not necessarily provided on that other channel. (Note: This issue is being considered by the FCC at this time, although no research is being carried out. Policy recommendations regarding the EAS can be found in the next section of this report.)

► R-14. Evaluate speech recognition technology for the specific application of automatically and accurately transcribing audio messages when spoken announcements are made, e.g., in public places such as airports and for automated telephone notification systems. If the additional step of separately typing in messages is required during an emergency, there is a greater likelihood that it will not happen and a text version will not be sent.

► R-15. Address technical problems in timeliness of message delivery, spam filters terminating emergency messages, and other issues that can affect whether people with disabilities obtain emergency information. Although these problems are shared by non-disabled people, mobile e-mail is more relied upon by people with hearing disabilities than those without disabilities.

► R-16. Research liability issues with non-emergency service providers that are in the path between the alerting organization and the public. Examples: wireless carriers, other servers of information. Liability issues may hamper the ability of local governments to work with carriers to provide highly localized alerts (e.g., chemical spill, road closure) to wireless users. If legal barriers would present problems, these would need to be addressed.

► R-17. If national and satellite radio takes over much of the broadcast radio market–research techniques for getting local alerts while listening to national/satellite radio. Radio is often the first place people who are blind will seek information. Competition from national radio sources may change the marketplace for radio. The accessibility implication is that local emergency information may be harder to come by via radio.

► R-18. Research use of streaming video (to mobile devices that can support video) for sign language alert and recovery information.

► R-19. Assess accessibility of NOAA Weather Radios on the market to people with visual disabilities including deaf-blind persons.

Individual to Government Communications

► R-20. Study technologies and operational procedures for network security and control during emergencies that can hamper access to useful technologies such as video and text. For example, e-mail alerts are already losing effectiveness due to spam control procedures and a lack of priority setting for e-mail. Video and instant messaging often disallowed or blocked by firewalls in many organizations. Recommend solutions to these problems.

► R-21. Build in accessibility to planned changes in 9-1-1 architectures. The migration of the nation's Public Safety Answering Points (PSAPs) to packet-switched technologies is a wonderful opportunity for better accessibility but if accessibility concerns are not considered, it could be a missed opportunity. In this endeavor, NIDRR could coordinate and perhaps co-fund projects with the U.S. Department of Transportation, which has been designated the point agency for the development and testing of next-generation technology for 9-1-1.) PSAPs need to be able to receive voice, data or video transmissions in real-time, and then be able to pass along the information received to specific emergency responder networks. Technology coordination is needed so that accessibility occurs shoulder to shoulder with upgrades to 9-1-1, without repeated changes to PSAP requirements overtime.

► R-22. Study methods for TTY functionality in wireless PDAs and other methods that may be short-term solutions to E9-1-1 access with mobile location finding and coverage equal to that of voice users. The TTY devices on the market are quite large and not really mobile devices, so they are not being used by deaf people. In contrast, wireless PDAs using Internet-based services are widely used. Companies should

build TTY functionality into phone devices that have QWERTY keyboards so that direct calls to 9-1-1 are possible without any specialized equipment. The networks already support TTY; this is a last step to achieving direct 9-1-1 access in the short term.

► R-23. Study and demonstrate options and issues for relay services' handling of 9-1-1 calls. Research in this area could provide informed decisions for call handling in the future and may enable improved handling of relayed calls to 9-1-1. Recent FCC rules indicate that new forms of relay services will soon be required to handle 9-1-1 calls. Research investment is needed to move this area ahead quickly, as many text users have abandoned the PSTN and TTY due to the availability of text and video over broadband. IP-based and video relay centers need to be able to determine the correct PSAP, based on the caller's locations, and be capable of exchanging information with PSAPs. IP-based forms of speech-to-speech relay service and CapTel are forthcoming; these also will need to be compatible with 9-1-1. Tests of this concept, as well as one-step calling might include the use of one or more specialized relay centers for routing and relaying these calls.

► R-24. Demonstrate and evaluate methods of connection and call handling to 9-1-1 using IP text and IP-based relay services. For direct calling to 9-1-1 by people who cannot use the voice phone, continued support of standard, reliable and interoperable real-time text communication will be needed. However, the antiquated TTY technology of the PSTN should not be perpetuated in new systems that operate over IP networks.

Individual to Individual Communications (including residential situations and communications within facilities and campuses)

► R-25. Research effective and accessible methods of communicating egress or shelter instructions in buildings and building complexes. There are basically two situations: one in which the person being alerted has some relationship to the building, such as an employee or a student, and the building management can to some degree control the situation; and one in which people are transient, such as stores, restaurants, rail stations, or airports. One concern is that with terrorism and biohazard incidents more of a threat, we do not have ways to communicate the specifics of what people with disabilities need to do in an emergency: exit, shelter in place, move to another area, etc. Another concern is that, even for routine egress, better use of technology could be made to signal the direction to exit if a person cannot see as a result of blindness or smoke in the building.

► R-26. Study and evaluate technologies for finding people with hearing and/or speech disabilities in a collapsed structure or other rescue situation where speech and hearing would routinely be used to communicate between rescuer and rescuee—for example, after an earthquake or bomb detonation.

► R-27. Study methods of awakening people with hearing disabilities while sleeping. Recent research involving awakening people from sleep indicates that guidelines for accessibility are inadequate for awakening a large percentage of people who cannot hear or cannot hear well. Further study should include additional signals (such as low or variable frequency sounds); and specific products and technologies should be evaluated against these requirements. The possibility that some persons could sleep through vibrations or other signals after habituation should be studied. Guidelines may need to be changed as a result of this research.

► R-28. Improve alerting interfaces; Implement standard connections in emergency systems for external flashing/loud audio/vibrating device. Develop and transfer to the private sector a portable vibrating alerting device with standard connector and battery backup. This simple type of device would permit people who cannot be alerted by an auditory signal to move from location to location and plug in a vibrating device to an alarm.

► R-29. Study human factors issues related to audio alerting and hard of hearing people while awake. For example, people who have progressive hearing loss and who may not be attuned to seeking visual information, due to age or late onset of disability. What are the most effective forms of audio alerts?

► R-30. Study human factors issues around alerting people who are deaf-blind. Deaf-blind people are not served by most technologies that are on the market. Special attention needs to be paid to emergency communications access for people who are deaf-blind, and for whom most communications technologies are inaccessible.

► R-31. Study information needs and communication specific to certain disability groups and identify effective practices for peer-oriented communications and help. Networking and self-help within disability groups has been an important recovery tool during severe and widespread disasters such as hurricanes Katrina and Rita. What specialized emergency information is needed by people with various disabilities in an emergency? How and by whom does such information get produced now and how should it be produced in the future? How can such information best be delivered? What role should non-profit relief organizations have, and how can they coordinate and work with disability-specific groups? Should institutions serving specific groups effectively (e.g., state schools for deaf children) have official roles as shelters?

► R-32. Demonstrate and test the use of IVR (Interactive Voice Response—telephone menus) to make emergency information on the web more accessible to people when not in the presence of a computer or smartphone, and to make the information more easily and universally accessible to people who are blind. For example, a blind person could dial a phone number, listen to a list of categories and chose the topic of interest to receive more information.

Conference on Emergency Preparedness for People With Disabilities

> Sponsored by the National Capitol Region with the support of the U.S. Department of
> Homeland Security and in partnership with the National Organization on Disability
> Held at the Hyatt Regency–Crystal City, Arlington, Va., on Sept. 22-24, 2004.

The conference was dedicated specifically to the systems-level examination of disability and
emergency preparedness and represented a cumulative effort by several individuals,
organizations and agencies to highlight aspects of their projects that each were already working
on individually.

While the conference report does not include a compilation of research recommendations, it lists
key concepts that came up repeatedly during the conference. Because they are pertinent to the
development of a research agenda on emergency preparedness and people with disabilities, they
are reprinted below. The full *Conference on Emergency Preparedness for People With
Disabilities: Conference Report* is available at: http://www.nod.org/epiconference2004
(last accessed March 28, 2008). Excerpts below are from Pages 3-4 of this online report.

> ► 1. Including disability issues in disaster drills enables the capture of lessons-learned,
> which become criteria for improvement. People with disabilities must be permitted on
> the exercise design teams, as well as participants in the drills, and/or as evaluators of
> the drill. In addition to the preplanning of disaster drills, people with disabilities
> should be included in the after-action evaluation and reporting on that drill. Tested
> measures around disabilities must get past the "victim" model and beyond a medical
> nexus in order to reflect the freedom of participation in all levels and activities of
> society that people with disabilities are guaranteed in this nation. Further, the
> improvements made as a result of the lessons-learned, must be tied into future
> funding evaluation and award merits to foster continued positive change.

> ► 2. Recognize that local performance measures will lead to accountability. Require
> special needs issues to be mandated parts of grant applications for funding, requests
> for proposals (RFPs), and even extended to the negotiated language in service
> contracts with vendors. The concern with this is that without the proper guidance
> from experts, the actual RFP language will not be such as to solicit the proper
> outcomes in replies. Without expert involvement in the review process, inappropriate,
> or at the very least inconsistent, awards will be granted.

> ► 3. A debate over terminology still exists in both the emergency and disability
> communities as to the use of a generalized term like "special needs". But until a
> resolution emerges with consensus, careful definition of terms and planning
> assumptions must be commonplace. Data collection for validation is important and is
> often tied to funding but the presentation of educated and defensible assumptions, as
> not to delay the planning process, should be accepted once clearly articulated as such.

> ► 4. Beyond the merit of data collection, hard research is desperately needed in this area
> of disability and emergency. Apparently research would impact use criteria and

standards for equipment developed for people with disabilities and emergency application. Research would also validate funding opportunities, as mentioned above, by identifying the potential impact if preemptive actions are not enabled. And finally research would ensure the codification of rules and regulations by demonstrating that legislation must keep up with the ever-changing new technology platforms used by both the emergency and disability communities.

► 5. There must be designated simple and common access areas to share information about funding and research opportunities, and learning opportunities, etc. so to break down the prevalent paradigm of working within our own spheres. Without such ability to share information and knowledge across all involved disciplines, duplicative efforts will continue, solutions will be long to replicate, and safety results will be delayed to the intended audiences.

Considerations in Emergency Preparedness: A Two-Track Conference

Sponsored by the National Center for Disaster Preparedness, Mailman School of Public Health, Columbia University.
Held at the Watergate Hotel, Washington, D.C., on Dec. 13-15, 2005

This conference had two tracks: one on pediatrics and one on people with disabilities. The research recommendations below are from the track pertaining to people with disabilities. The conference report *Emergency Preparedness: Addressing the Needs of People With Disabilities*, Page 39. The full report is available at
http://www.ncdp.mailman.columbia.edu/files/DISABILITIES.pdf
(last accessed March 28, 2008).

Research Priorities:

► 14.1 Evaluate effectiveness of community-based "special needs registries" or REVERSE 911® systems.

► 14.2 Evaluate effectiveness of evacuation messages for people with disabilities, including analysis of how messages are understood and of modality and messaging techniques.

► 14.3 Evaluate effective activation of local transportation networks to serve individuals with special needs before, during, and after an emergency or disaster, including the willingness of these individuals to report to duty after a disaster.

► 14.4 Evaluate effectiveness in cross-training disability and emergency preparedness communities.

► 14.5 Determine factors that affect caregivers and medical professionals' willingness and ability to report to work during times of disaster.

► 14.6 Consider the advantages, disadvantages, and unintended consequences of developing segregated versus unsegregated sheltering systems.

► 14.7 Determine relationship between standing orders for patient care in EMS settings, including and especially for adults and children with disabilities, and health outcomes during a disaster.

► 14.8 Evaluate EMS readiness to care for people with disabilities, including the surge capability of EMS to respond with appropriate equipment and knowledge to the needs of people with disabilities.

► 14.9 Quantify the benefit of telehealth for people with disabilities in providing instruction and health care to homebound individuals before, during, and in recovery periods.

Product Research and Development Needs:

► 14.10 Emergency evacuation devices including elevator systems that operate during emergency situations, wheelchairs that climb up or down stairs and portable ventilators for use during power outages.

► 14.11 Considerations on the use of elevators for building evacuation when the integrity of the system is intact and it is reasonably safe to do so (e.g., "hardening" of a dedicated elevator and/or bank, as well as a protocol for its use).

► 14.12 Decontamination protocol and equipment for adaptive technology for people with disabilities, as well as for people who have physical limitations that prevent them from either walking or lying on a backboard for decontamination, or for people with service animals.

Emergency Evacuation of People With Physical Disabilities From Buildings

Sponsored by the Interagency Committee on Disability Research, Interagency Subcommittee on Technology.
Held at the Doubletree Hotel, Rockville, Md., on Oct. 13-14, 2004.

Conference presenters and attendees exchanged information and ideas during panel presentations and breakout sessions. Among the 85 presenters and participants were: federal employees involved in emergency preparedness; first responders and emergency management personnel; building and life safety code practitioners; manufacturers of evacuation devices; people with disabilities who have used evacuation devices; and leading researchers in mobility devices, human factors and egress modeling.

Listed below are the research recommendations, by category, issued in *Emergency Evacuation of People With Physical Disabilities From Buildings: 2004 Conference Proceedings*, Pages 47-53. One category of recommendations ("Cross-Train People with Disabilities as Emergency

Responders") is not listed as research recommendations. However, we include it here because it is pertinent to the development of a research agenda on emergency preparedness and disability. The full report is available at: http://www.icdr.us/documents/pwd-emergency-evac.pdf. (last accessed March 28, 2008).

Buildings: Design, Codes and Construction

Recommendations for research:

> ► Find a safe way to use elevators in existing buildings by occupants in emergencies.

> ► Member agencies of the ICDR should fund the development of guidelines for emergency plans for all occupancies and building types.

> ► Member agencies of the ICDR should fund research on effective means of communicating emergency information that is communicated to everyone, including people who are deaf or hard of hearing.

Emergency Management and First Responders

Recommendations for Research:

> ► Identify the best strategies for keeping people with disabilities safe during an emergency event.

> ► Appropriate provisions for people with disabilities need to be tested.

> ► Identify the best way to communicate with people with disabilities during an emergency.

> ► Identify strategies for coordination of the dynamics of simultaneous evacuations of individuals and groups.

> ► Address the specific issues of people with multiple disabilities.

> ► Identify gaps (disconnects) between planners, responders and occupants.

> ► Find out how many first responder personnel it takes to complete a rescue (need for better data and times).

Tools and Model-Building

Recommendations for Research:

> ► Identify an agreed upon set of experimental studies and needed data to improve the models.

► Involve many different fields and organizations under coordination and leadership from appropriate groups (e.g., disaster research centers).

► Set up funding in three phases, beginning at $250,000, and working up to $1 million. This would lead to more comprehensive, substantiated and effective decisions by all parties in a position to influence outcomes.

Lessons Learned—Literature Review and Syntheses

Recommendations for Research:

► Collect from repository of lessons learned: after-action reports, civil rights complaints, anecdotal evidence from disability communities, and syntheses of nationally and internationally published studies that are cross incident.

► Use a team composed of cross-disability groups, first responders and the U.S. Department of Justice and start the funding amount at $5 million. Lessons learned are translated into effective practice and cross-training material.

Data Before and During Events

Recommendations for Research:

► Develop data collection points for a response profile for first responders as they arrive at a facility for disasters:
  o Anticipate resource needs for a response based on who will be there (the number and composition of occupants, including people with disabilities).
  o While on-site, employ effective procedures to assess the evacuation of people with disabilities that has occurred thus far, and determine who might be left behind.
  o Track the impact of the disaster on people with disabilities, first responders and others.

Cross-Train People With Disabilities as Emergency Responders

Other recommendations:

Design a four-hour curriculum to be included in training to orient fire and rescue personnel to special needs.

► Two hours in class studying:
  o A list of disabilities: physical, visual, cognitive, psychiatric, and deaf and hard-of-hearing; and
  o The demography of disabilities: residential or commercial.

► Time considerations:
  o Assessment;

     o Rescue;

     o Fire; and

     o Additional resources (i.e., rescuers and treatment).

► Assistive technology: raise the awareness for first responders of the importance and value of these tools:
  o Assistance to service animals;
  o Wheelchairs; and
  o Computers.

► Two-hour hands-on training to cover:
  o Equipment information;
  o Backboard transfer methods;
  o Surface issues;
  o Manpower; and
  o Lifting techniques.

► Design a two-hour course presented to the disability community titled "Response, Rescue and Treatment."
  o Qualify the individuals;
  o Include information as to how first responders operate;
  o Include best practices;
  o Work through advocacy organizations; and
  o For each case (i.e., hotels, libraries, etc.), state that training and applicability may vary.

Current State of Research of Evacuation Equipment and Mobility Devices

Recommendations for Research:

► The ICDR should develop and coordinate a federal strategy for the development of technical standards for evacuation devices and a program to develop and provide consumer information on evacuation devices and standards. RESNA develops voluntary standards for wheeled mobility devices and could be an interested partner.

► Support the federal development, implementation and maintenance of a consumer database on evacuation technology. Include the development of technical and performance standards for several types of devices in collaboration with industry, RESNA and the FDA.

► Provide comprehensive consumer information on device usability from a single federal source. Comprehensive and comparable information on the characteristics, use and performance of evacuation devices—including stair, building and operator requirements—is not currently available to assist consumers and procurement staff with the purchase of appropriate devices. Some devices are currently regulated by the FDA, but most are not.

Conference attendees estimated that a budget of $3.5 million over seven years for standards development and an additional $4 million dollars for consumer information would be needed. It was anticipated that the industry would maintain the consumer database once it was developed.

During the conference, a wide range of device types were identified:

► Rigid sleds, stretchers and chairs used by emergency responders;

► Transfer-to devices operated by responders or workplace volunteers;

► Emerging aftermarket technologies that could transform an individual mobility device into a stair-descending evacuation device, for use with or without assistance; and

► Portable elevator and lift technologies.

Human Factors and Egress Modeling

Recommendations for Research:

► The United States needs better evacuation models that can model elements that influence behaviors during evacuations. To identify actual behaviors, certain datasets are needed, including multiple sets, hazards and scenarios.
  o Quantitative, qualitative and video data, especially in the stairs (group behavior first hand); and
  o Occupancy specific data, not just building specific data.
    ▪ What about tunnel evacuations?

► It is important to understand people's responses to their environments (i.e., fire, debris, etc.) It is also important to understand and model groups and emerging leaders (in addition to first responders), especially people with disabilities.
  o In emergencies, most people give up their individual agendas.
  o Consider counter flow of traffic—people encountering evacuation devices inside the stairwells—and how this affects stair movement.
  o Simulate a broader range of disabilities
  o Consider the effect and response of ongoing communication—utilize ongoing decision-making as new information on the behavior of the occupants becomes available.
  o Consider behavior of occupants in different types of hazards (e.g., occupants evacuating while wearing chemical masks.)
  o Implement/utilize models that take into account the actual decision-making process of people with disabilities during an evacuation.
  o Study data on evacuation and relocation.
  o Foster an awareness of one's surroundings—people do not often think while walking into a building, "What will I do if an emergency occurs?"

► There is a need to fill the gaps between the factors (independent variables and predictors, such as people running frantically in certain incidences) that affect egress decisions and the trainers or decision makers that design the plan.
- o It is essential to bring research to practice.
- o Research exists from different disciplines. How can planners use this data to create a model? What about decision-making analysis models (a collection of past data on decision-making in emergencies put into a usable model for plan-makers)?
- o Data are needed from other disciplines, bringing them together during emergencies.
- o Data are needed on the number of hours of training necessary for occupants to provide a successful response (following proper procedures during drills and actual evacuations). How many hours of training (education) are necessary for occupants to retain emergency procedure information?
- o Multiple-test scenarios and an understanding of the knowledge gained and retained from each hour of training are needed.

► Emergency planning: What factors influence emergency preparedness?
- o Best practice checklist for evacuation, specifically of people with disabilities.
  - ▪ Improve plans for federal buildings.

- o Can we rely on the national preparedness standard NFPA 1600, which is a template listing questions to answer when developing a plan?
  - ▪ Not necessarily required for buildings as of yet.

- o What does emergency planning have to do with human factors modeling?
  - ▪ How people respond is a result of the information that they obtain or receive during an emergency.
  - ▪ The information is affected by a specific warning system.
  - ▪ Should a warning system and corresponding information be part of an evacuation plan?
  - ▪ What should the system entail?

Pediatric Preparedness for Disasters and Terrorism: A National Consensus Conference

Sponsored by the National Center for Disaster Preparedness, Columbia University Mailman School of Public Health.
Held at the Wyndham Hotel, Washington, D.C., on Feb. 10-12, 2003.

The goals of this national conference were to: 1) build collaboration among individuals with expertise in all areas of pediatric care as well as in emergency management; 2) review and summarize the existing data on the needs of children in disasters; 3) develop a consensus on the needs of children in disasters; and 4) create a research agenda to address knowledge gaps.

The following excerpted recommendations were largely based on expert opinion due to the limited amount of pediatric research currently available. They offer a proposed research agenda and a description of funding needs for terrorism and disaster preparedness efforts for children.

The recommendations below are from *Pediatric Preparedness for Disasters and Terrorism: A National Consensus Conference* (Page 19). The full report is available at: http://www.bt.cdc.gov/children/pdf/working/execsumm03.pdf (last accessed March 28, 2008).

Emergency Preparedness

Children With Special Health Care Needs (CSHCN)

> ► Incorporate considerations for CSHCN in all disaster and terrorism planning at the national, state and local levels (e.g., water, dialysis and medication).

> ► Identify all CSHCN to ensure each child has a medical home, adequate medical coverage and support mechanisms before a disaster or terrorist event.

> ► Ensure that all CSHCN are considered in emergency preparedness plans of the U.S. Department of Homeland Security.

> ► Develop mechanisms for identification of and community planning for children with increased vulnerability in disasters, including CSHCN and their families, at the national, state and local levels.

> ► Provide federal, state and local government funding for emergency preparedness planning and implementation of services to meet the needs of CSHCN. This funding must be timely, immediately accessible and of sufficient duration.

> ► Explore, within government agencies, development of nontraditional, community-based support systems for CSHCN and their families (e.g., independent living centers, faith-based groups and parent-based groups).

> ► Mandate continuity of operations and mutual aid planning among community health facilities to address disaster and terrorist events for pediatric populations, including CSHCN.

Workshop on Building Occupant Movement During Fire Emergencies

> Building and Fire Research Laboratory, National Institute of Standards and Technology
> United Technologies Research Center.
> Held at the National Institute of Standards and Technology, Gaithersburg, Md., on June 10-11, 2004.

This workshop on occupant behavior and movement during building emergencies was organized in response to renewed interest in how buildings should be evacuated during fires after

Sept.11, 2001; and it provided a forum for the exchange of experiences among the fire and non-fire communities working on emergency egress.

The research recommendations below are from the conference report *Workshop on Building Occupancy During Fire Emergencies, June 10-11, 2004, National Institute of Standards and Technology* (Pages 15, 55, 62, and 98). The full report is available at: http://fire.nist.gov/bfrlpubs/fire05/PDF/f05023.pdf (last accessed March 28, 2008).

[Below is from Page 15]

Protected Elevators for Egress and Access During Fires in Tall Buildings

Development of Operating Procedures

Prior research and recent advances can address all of the technology issues identified as critical to the safe and reliable operation of elevators during fires. The remaining piece is the development of operating procedures for access, egress, and rescue of the disabled that are sensitive to the human factors issues and to the need for these activities to occur simultaneously in tall buildings. Thus the systems must be designed and used such that they do not interfere with all these uses.

[Below is from Page 55]

4 Data Needs for Predictive Building Movement Models

The usefulness of a model-based predictive capability is heavily dependent on an understanding of its accuracy and limits of applicability. However, the current situation is such that small amounts of data exist and that they are not generally available to groups studying this topic. Additional experimental data gathering efforts are needed in order to quantify current and future egress predictive capabilities. Areas of interest may include pre-evacuation timing and behavior, disabled occupant responses to fires, exhaustion on stairs and interaction of occupants and building systems with the environment of the event.

[Below is from Page 62]

Available Data and Input into Models

Research Needs

In order to better understand human behavior in fire, to enhance the effectiveness and completeness of evacuation models, and to provide better information for the users of evacuations model, additional study is needed in a range of areas.

The areas of study involve the need for more data on all the time components of behavior, particularly those that are not a simple matter of speed and distance; data on the variability of those time components; and data or models on the factors driving behavior choices and the

variability in time to perform certain actions. Some of the more specific areas are listed and described here:

- movement capabilities of a wide cross-section of society: how much do we know about variations in movement capability by age or by walking impairment?

- evacuation of disabled people: how are wheelchair users expected to evacuate and how long with that take; how might their evacuation impact the overall evacuation flow?

[Below is from Page 97]

5 Workshop Summary

5.2 Specific Needs Obtained From Workshop Participants

There is a need to include the impacts of human behavior in predictive models. Currently used evacuation models lack certain behavioral aspects of an evacuation, including group behavior and accurate representation of the disabled population.

Appendix A: Executive Order 13347: Individuals With Disabilities in Emergency Preparedness

By the authority vested in me as President by the Constitution and the laws of the United States of America, and to strengthen emergency preparedness with respect to individuals with disabilities, it is hereby ordered as follows:

Sec. 1. *Policy.* To ensure that the Federal Government appropriately supports safety and security for individuals with disabilities in situations involving disasters, including earthquakes, tornadoes, fires, floods, hurricanes, and acts of terrorism, it shall be the policy of the United States that executive departments and agencies of the Federal Government (agencies):

(a)   consider, in their emergency preparedness planning, the unique needs of agency employees with disabilities and individuals with disabilities whom the agency serves;

(b)   consideration of the unique needs of employees and individuals with disabilities served by State, local, and tribal governments and private organizations and individuals in emergency preparedness planning; and

(c)   facilitate cooperation among Federal, State, local, and tribal governments and private organizations and individuals in the implementation of emergency preparedness plans as they relate to individuals with disabilities.

Sec. 2. *Establishment of Council.* (a) There is hereby established, within the Department of Homeland Security for administrative purposes, the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (the ''Council''). The Council shall consist exclusively of the following members or their designees:

(i)   the heads of executive departments, the Administrator of the Environmental Protection Agency, the Administrator of General Services, the Director of the Office of Personnel Management, and the Commissioner of Social Security; and

(ii)   any other agency head as the Secretary of Homeland Security may, with the concurrence of the agency head, designate.

(b)   The Secretary of Homeland Security shall chair the Council, convene and preside at its meetings, determine its agenda, direct its work, and, as appropriate to particular subject matters, establish and direct subgroups of the Council, which shall consist exclusively of Council members.

(c)   A member of the Council may designate, to perform the Council functions of the member, an employee of the member's department or agency who is either an officer of the United States appointed by the President, or a full-time employee serving in a position with pay equal to or greater than the minimum rate payable for GS–15 of the General Schedule.

Sec. 3. *Functions of Council.* (a) The Council shall:

(i) coordinate implementation by agencies of the policy set forth in section 1 of this order;

(ii) whenever the Council obtains in the performance of its functions information or advice from any individual who is not a full-time or permanent part-time Federal employee, obtain such information and advice only in a manner that seeks individual advice and does not involve collective judgment or consensus advice or deliberation; and

(iii) at the request of any agency head (or the agency head's designee under section 2(c) of this order) who is a member of the Council, unless the Secretary of Homeland Security declines the request, promptly review and provide advice, for the purpose of furthering the policy set forth in section 1, on a proposed action by that agency.

(b) The Council shall submit to the President each year beginning 1 year after the date of this order, through the Assistant to the President for Homeland Security, a report that describes:

(i) the achievements of the Council in implementing the policy set forth in section 1;

(ii) the best practices among Federal, State, local, and tribal governments and private organizations and individuals for emergency preparedness planning with respect to individuals with disabilities; and

(iii) recommendations of the Council for advancing the policy set forth in section 1.

Sec. 4. *General.* (a) To the extent permitted by law:

(i) agencies shall assist and provide information to the Council for the performance of its functions under this order; and

(ii) the Department of Homeland Security shall provide funding and administrative support for the Council.

(b) Nothing in this order shall be construed to impair or otherwise affect the functions of the Director of the Office of Management and Budget relating to budget, administrative, or legislative proposals.

(c) This order is intended only to improve the internal management of the executive branch and is not intended to, and does not, create any right or benefit, substantive or procedural, enforceable at law or in equity by a party against the United States, its departments, agencies, instrumentalities, or entities, its officers or employees, or any other person.

/s/

THE WHITE HOUSE,
July 22, 2004

Appendix B: *Excerpts from Individuals With Disabilities in Emergency Preparedness, Executive Order 13347: Annual Report, July 2005*.

Excerpts below are from the Executive Summary, the Research Subcommittee chapter, and Recommendation 7 of the *Individuals With Disabilities in Emergency Preparedness, Executive Order 13347: Annual Report, July 2005*, published by the U.S. Department of Homeland Security, Office for Civil Rights and Civil Liberties, on behalf of the Interagency Coordinating Council on Emergency Preparedness and Individuals With Disabilities (ICC).

The full report is available at:
http://www.dhs.gov/xlibrary/assets/CRCL_IWDEP_AnnualReport_2005.pdf
(last accessed March 28, 2008).

[Below is from Page 3]

I. Executive Summary

Background

The September 11, 2001, terrorist attacks significantly increased awareness of the need to be prepared for all kinds of disasters and emergencies. As a nation, we are much more conscious of our vulnerabilities, not only to natural disasters such as tornadoes, fires, floods and hurricanes but also to acts of terrorism. We are more keenly aware of the compounded vulnerabilities and challenges the approximately 54 million Americans with disabilities face in time of disasters and emergencies. Yet disaster and emergency mitigation, preparedness, response and recovery planning efforts often overlook people with disabilities. Ensuring that people with disabilities become and remain an integral part of the nation's disaster and emergency mitigation, preparedness, response and recovery efforts requires a concerted approach to address a myriad of complex issues.

Implementation of the Executive Order

Recognizing that individuals with disabilities should feel as safe and secure in their communities and work environments as individuals without disabilities, President George W. Bush issued Executive Order 13347, Individuals with Disabilities in Emergency Preparedness. This Executive Order, a copy of which is provided as Appendix 1, sets forth the role of the Federal Government in effectively tackling these issues in a coordinated fashion. To ensure this, the President created the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities, directing multiple Federal executive departments and agencies to work together to ensure that emergency preparedness plans are as comprehensive as possible with regard to the issues presented by individuals with disabilities.

The Council has concentrated its work in eight major areas:

    (1) Emergency Communications;
    (2) Emergency Preparedness in the Workplace;
    (3) Emergency Transportation;
    (4) Health;
    (5) Private Sector Coordination;
    (6) Research;
    (7) State, Local and Tribal Government Coordination; and
    (8) Technical Assistance and Outreach.

[Below is from Pages 26-28)

F. Research Subcommittee

Summary of Objectives

There are many questions about how best to secure the safety and security of people with disabilities in emergency situations. The broad array of disabilities, the breadth of possible emergency scenarios and the interactive nature of certain disabilities with social environments (and disruption of those environments) means that research efforts may be required to address the many factors with the potential to impact individuals with disabilities in the context of a life-threatening disaster.

Decisive answers to these complex issues remain uncertain. Sufficient empirically-based research focusing on disability is not available to guide the many efforts underway to prepare for potential terrorist attacks, natural disasters and other emergencies. For example, the NCD reports that while there is a wealth of anecdotal accounts, meeting minutes and unpublished reports in the popular press, there is scarce research on the experiences of people with disabilities in disaster activities.[11]

The mission of the Research Subcommittee is to assess, coordinate and promote Federal research related to emergency preparedness for individuals with disabilities. Primary objectives of the Research Subcommittee include: assessing the state-of-the-art on emergency preparedness and disability, identifying research gaps; coordinating Federal emergency preparedness research activities; and soliciting public input on an as needed basis. This includes, but is not limited to, gathering input from the disability community and other public and private stakeholders, developing, maintaining and disseminating to the public a compendium of Federal emergency preparedness research, and creating a research agenda on emergency preparedness and individuals with disabilities.

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[11] Saving Lives: Including People with Disabilities in Emergency Planning. National Council on Disability Web site. Available http://www.ncd.gov/newsroom/publications/2005/saving_lives.htm (May, 2005).

Scope of Research Subcommittee

The Subcommittee is identifying Federal department and agency representatives vested with responsibilities associated with research on emergency preparedness and disabilities. It is working with these representatives to identify Federally-funded projects on emergency preparedness and disabilities. To date, participating Federal agencies and departments include:

- Department of Education;
- Department of Labor;
- U.S. Access Board;
- Department of Justice; Department of Transportation;
- Department of Agriculture;
- Department of Homeland Security;
- Department of Veterans Affairs;
- Department of Interior;
- Office of Personnel Management; and
- Department of Health and Human Services (including the Agency for Healthcare Research and Quality, the Office on Disability, the Administration on Aging, the Centers for Disease Control, and the National Institute of Mental Health);
- Department of Commerce (including National Institute of Standards and Technology);
- The National Science Foundation; and
- The National Council on Disability.

The Research Subcommittee continues to broaden this partnership across the Federal Government in order to establish a comprehensive assessment of activities while still avoiding duplication of efforts.

Administration

The Research Subcommittee is chaired jointly by representatives from the NIDRR in the Department of Education (ED), and the ODEP in the DOL. The Research Subcommittee operates as a Task Force under the Interagency Committee on Disability Research (ICDR), Interagency Subcommittee on the New Freedom Initiative (ISNFI). The Chair of the ICDR is Mr. Steven James Tingus, who also is the Director of NIDRR, located within ED's Office of Special Education and Rehabilitative Services (OSERS). The Assistant Secretary for OSERS, Mr. John H. Hager, represents ED on the Interagency Coordinating Council.

Projects Initiated

The Research Subcommittee is currently spearheading the following initiatives:

Assessing the State-of-the-Art in Research on Emergency Preparedness and Disability
The Subcommittee has launched a number of activities to assess the state-of-the-art in research on emergency preparedness and disability. An initial scan of several engineering, education, psychology, medicine and other databases yielded numerous "how to" guides, checklists,

reviews of legislation, conference proceedings and catalogs of technologies useful for people with disabilities in emergency situations, but few research-specific articles.

Similarly, preliminary documentation from the Subcommittee's federal partners suggests that little federal support has been available for research specific to emergency preparedness and disability. Emergency preparedness has, for the most part, focused on the general population; attention to disability issues is recent. Below are some examples of federal and Federally-funded research projects and conferences related to emergency preparedness for people with disabilities. Funding sources and grantee information are provided in footnotes.

Research Projects:
- ***Disaster Planning, Mobility Impairment, and Best Practices:***
  - Determining whether areas that have experienced natural disasters include people with mobility impairments in their disaster plans and emergency response systems, identifying morbidity and mortality of persons with mobility impairments in disasters and identifying emerging or best practice models for individual counties.[12]

- ***Emergency Evacuation:***
  - Developing comprehensive, easy-to-use safe evacuation education materials and training tools that include people with disabilities.[13]
  - Developing standards to improve the ability of persons with disabilities to get out of buildings during mass evacuations triggered by health or safety emergency events.[14]

- ***Self-Advocacy and Survival Skills:***
  - Developing a Web-based software program that assists people who are deaf or hard of hearing in learning self-advocacy and survival skills for life threatening situations.[15]

- ***Emergency Managers:***
  - Studying emergency management officials at the State and local level in the United States to determine how they have incorporated the emergency needs of people with disabilities in their emergency plans.[16]

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[12] Funding Source: Centers for Disease Control and Prevention through the Association of Teachers of Preventative Medicine; Grantee: Research and Training Center on Independent Living, University of Kansas; Project Name: Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments.

[13] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research; Grantee: West Virginia University; Project Name: Project Safe EV-AC.

[14] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research; Grantee: Utah State University Center for Persons with Disabilities; Project Name: Bottom-Up Modeling of Mass Pedestrian Flows: Implications for the Effective Egress of Individuals with Disabilities.

[15] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research; Grantee: Vcom3D, Inc; Project Name: Emergency Preparedness Training Software with Universal Access.

[16] Funding Source: U.S. Department of Homeland Security; Grantee: National Organization on Disability; Project Name: Emergency Preparedness Survey.

- *Directions for the Federal Government:*
    - o Providing an overview of 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 homeland security programs. This infrastructure would incorporate access to technology, physical plants, programs and communications. It also would include procurement and emergency programs and services.[17]

- *Conferences:*
    - o A National Consensus Conference was held in 2003 focusing on Pediatric Preparedness for Disasters and Terrorism. This conference dealt with issues relevant to children with disabilities, including: mental health needs and children with special health care needs. A follow-up consensus conference on Emergency Preparedness was held in September 2005, with a dual focus: pediatrics (including children with disabilities) and people with disabilities across the lifespan.[18]
    - o A conference was held in 2004 on Emergency Evacuation of People with Physical Disabilities from Buildings.[19]

Surveying and Compiling Federal Research Activities

To ensure the continued and thorough investigation of Federal and Federally-funded research, the Research Subcommittee collaborated with DHS and the Interagency Coordinating Council's State, Local and Tribal Government Subcommittee to develop a survey focusing on emergency preparedness and disability.[20] The purpose of the survey is to develop a comprehensive compilation of programs, activities and initiatives of Federal departments and agencies that support safety and security for individuals with disabilities in emergency situations. This survey requests information related to funding (grants and contracts), training and outreach, and research. The Research Subcommittee developed the research-related questions. This survey will be sent first to Federal agencies and later to nonprofit entities and State, local and tribal governments.

Soliciting Public Input

The Research Subcommittee is committed to seeking input on research needs from public and private stakeholders (e.g., the disability community, first responders, and industry representatives) and has initiated a number of projects to further this goal. First, the Research

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[17] Funding Source: National Council on Disability; Grantee: June Isaacson Kailes; Project Name: Saving Lives: Including People with Disabilities In Emergency Planning.

[18] Funding Source: Agency for Healthcare Research and Quality; Grantee: Columbia University; Project Name: Emergency Preparedness for Special Populations. Proceedings from this conference indicate that current adult models and guidelines cannot be applied to disaster preparedness for children. Furthermore, a review of the literature in the area of pediatric preparedness yielded very little data. Conference proceedings indicate that this lack of data has resulted in policy statements that are based on a "best advice" approach rather than research findings.

[19] This was an activity of the Federal Interagency Committee on Disability Research (ICDR). Formal recommendations from this conference are forthcoming, but cover areas such as: (a) building design, codes, and construction; (b) first responders; (c) the involvement of people with disabilities in emergency preparedness activities; (d) evacuation equipment and mobility devices; and (e) human factors and egress modeling (evacuation models that take into account human behavior).

[20] The Interagency Committee on Disability Research Web site. Available: http://www.icdr.us (April, 2005).

Subcommittee has established a public input link on the ICDR Web site, which invites comment on research needs in the area of emergency preparedness and disability. Second, the Research Subcommittee is working with the Interagency Coordinating Council's Private Sector Coordination Group to identify methods of securing public input. Third, the Research Subcommittee has established a collaborative effort with Columbia University's National Center on Disaster Preparedness at Columbia University in New York. At the September 2005 Consensus Conference on Emergency Preparedness, the Research Subcommittee and the ICC provided information on the activities of the ICC and at the same time will seek input from conference attendees to assess more fully the range of research questions and needs.

Future Goals

- Complete a comprehensive literature review and develop a discussion of research gaps.

- Create, maintain and update a list of federal agency representatives who have responsibility for emergency preparedness research affecting people with disabilities.

- Create, maintain and update a listing of federal research projects related to emergency preparedness and disability.

- Solicit input from the disability community and other public and private stakeholders regarding research gaps in the area of emergency preparedness and disability.

- Identify research needs in the area of emergency preparedness and disability.

Conclusion

There is a plethora of guides, checklists, tip sheets and plans related to emergency preparedness and disability, but a noticeable lack of empirical research to back up those guides, plans and practices. The nation's emergency preparedness efforts will be more effective in protecting the lives of approximately 54 million Americans with disabilities if they are based on solid research. It is critical to transition from suggestions and ideas to empirically-based research that provides evidence for what works. By doing this, people with disabilities, first responders, the health care industry and other stakeholders will receive the information they need to answer critical questions.

[Below is from Pages 38-39.]

V. Recommendations

Executive Order 13347 directs the Interagency Coordinating Council to submit to the President recommendations for advancing the policy set forth in the Executive Order. It requires that the Council identify future actions that the executive departments and agencies can undertake to ensure that the Federal Government appropriately supports safety and security for individuals with disabilities in situations involving disasters, including earthquakes, tornados, fires, flood, hurricanes and acts of terrorism.

Recommendation 7: Coordinate evidence-based Federal research into the effectiveness of audio, visual and/or tactile protocols and technologies related to emergency preparedness, alerting, warning and response for individuals with disabilities. In order to ensure that all persons are alerted to and warned about disasters or emergencies, accessible technologies are indispensable. The ICC is uniquely positioned to accelerate research that guides the development and integration of appropriate technologies into the Nation's emergency warning systems and practices. These technologies identified from research will guide contract procurement and technical assistance, and translate findings into guidelines. Findings will also result in information on promising new practices for alerting and warning individuals with disabilities.

Appendix C: Excerpts from the *Individuals with Disabilities in Emergency Preparedness, Executive Order 13347: 2005-2006 Progress Report*.
(In-Press Copy)

Excerpted below is the Research Subcommittee chapter of the *Individuals with Disabilities in Emergency Preparedness, Executive Order 13347: 2005-2006 Progress Report*. Washington, D.C., in-press, 2008. This document was in-press on the date this guide was published by the U.S. Department of Education. The in-press report is being published by the U.S. Department of Homeland Security, Office for Civil Rights and Civil Liberties, on behalf of the Interagency Coordinating Council on Emergency Preparedness and Individuals With Disabilities (ICC). Once published, the document will be available at http://www.disabilitypreparedness.gov.

[Below is from Page 30.]

Research Subcommittee

Background

People with disabilities are at particular risk during emergency and disaster situations. Typical ways of accommodating disabilities (e.g., wheelchair users descending buildings in elevators; people with vision impairments following a specific route home through the city; people who are deaf communicating via sign language interpreters) often get disrupted during times of crisis and infrastructure damage.

Research is needed to demonstrate disability-related interventions, technologies, standards, methods, and procedures that are safe, effective, and compatible with overall emergency management efforts. Answers are needed to address a multitude of questions, such as how to communicate with, evacuate, shelter, transport, and provide health and mental health services to people with physical, mental, and sensory impairments over the course of a disaster. Research efforts should focus on ways to incorporate disability considerations into standard operations rather than on methods that segregate people with disabilities from the general population during times of disaster. Finally, research is needed across the life cycle of disaster and emergency situations, covering the whole spectrum of emergency management (i.e., preparedness, mitigation, response and recovery).

Administration

The Research Subcommittee is chaired by the National Institute on Disability and Rehabilitation Research (NIDRR) in the Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education. Former Assistant Secretary of OSERS, Mr. John H. Hager, was the Department of Education's principal ICC representative during the time period covered by the information included in this section. The Research Subcommittee operates as a Task Force under the Interagency Committee on Disability Research (ICDR), Subcommittee on the

New Freedom Initiative. The Chair of the ICDR during this time period was Mr. Steven James Tingus, who also was the Director of NIDRR.

Mission and Objectives

The mission of the Research Subcommittee of the U.S. Department of Homeland Security's (DHS) Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC) is to assess, coordinate, and promote federally-funded research on emergency management as it relates to people with disabilities. Primary objectives of the Research Subcommittee include: assessing the state-of-the-art in emergency management research as it relates to people with disabilities; identifying research gaps; soliciting public input; disseminating materials; and coordinating and promoting federal funding efforts.

Accomplishments

The Research Subcommittee has spearheaded federal initiatives in each area within its mission: assessment, coordination, and promotion of federal research. This section outlines progress within each of these areas.

Assessing the State-of-the-Art in Disability-Related Emergency Management Research
The Research Subcommittee conducted multiple projects aimed at gaining a comprehensive understanding of the state-of-the art in research on emergency management issues related to people with disabilities. This included: developing a research bibliography; compiling relevant conference recommendations; surveying federal agencies to determine what federal research projects currently are being funded; and soliciting public input. All of these activities are ongoing in nature and are being used to develop a comprehensive federal research agenda in emergency management and disability. The Research Subcommittee is working to disseminate results from these projects in order to enhance coordination among federal funding agencies and stimulate further research.

Bibliography
The Research Subcommittee developed a bibliography of research articles specific to emergency management related to people with disabilities.

Conference Recommendations
The Research Subcommittee is engaged in ongoing efforts to compile, synthesize, and disseminate research recommendations from major conferences on emergency management issues relevant to people with disabilities. Relevant conferences have included, but are not limited to:

- Pediatric Preparedness for Disasters and Terrorism: A National Consensus Conference, Columbia University, National Center for Disaster Preparedness, February 2003.[9]

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[9] The pediatric preparedness conference included a focus on children's mental health and children with special health care needs. Information is available at: http://www.ncdp.mailman.columbia.edu and http://www.pediatricpreparedness.org.

- Emergency Preparedness for People With Disabilities: An Interagency Seminar of Exchange for Federal Managers, U.S. Department of Labor, December 2003.[10]
- Workshop on Building Occupant Movement During Fire Emergencies, National Institute on Standards and Technology (NIST), June 2004.[11]
- Conference on Emergency Preparedness for People With Disabilities, National Organization on Disability (NOD), September 2004.[12]
- Emergency Evacuation of People With Physical Disabilities from Buildings, Interagency Committee on Disability Research (ICDR), Subcommittee on Technology, October 2004.[13]
- Accessible Notification and Communication: State of the Science Conference, Gallaudet University, November 2005.[14]
- Considerations in Emergency Preparedness: A Two Track Conference, Columbia University, National Center for Disaster Preparedness, December, 2005.[15]

Current Federal Research

In collaboration with DHS, the Research Subcommittee developed and administered a survey to federal agencies that examines current Federally-funded research focusing specifically on the intersection of emergency management and issues affecting people with disabilities. Ten Federally-funded projects emerged from this survey and other efforts to identify relevant federal research projects. These projects were funded by four federal agencies: the Department of Education, the Department of Commerce, the Centers for Disease Control, and the National Council on Disability. The projects include:

- Access Alerts: Making Emergency Information Accessible to People With Disabilities.[16]
- Access to Locally Televised On-Screen Information: Auditory Messaging and Captions During Emergency Broadcasts.[17]
- Assessing the Impact of Hurricane Katrina on Persons With Disabilities.[18]
- Bottom-Up Modeling of Mass Pedestrian Flows: Implications for the Effective Egress of Individuals With Disabilities.[19]
- Making In-Flight Communications and Entertainment Accessible.[20]

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[10] The Department of Labor summary report and other information is available at: http://www.dol.gov/odep/programs/emergency.htm.

[11] Information about the NIST conference is available at: http://fire.nist.gov/bfrlpubs/fire05/art023.html.

[12] Information about the NOD conference is available at: http://www.nod.org/epiconference2004.

[13] The ICDR *Emergency Evacuation of People with Physical Disabilities From Buildings: 2004 Conference Proceedings*, including research recommendations, are available on the ICDR Web site at http://www.icdr.us.

[14] Gallaudet conference materials are available at http://tap.gallaudet.edu/emergencyconf.htm. Research recommendations are forthcoming at that location.

[15] Columbia University's research recommendations are forthcoming.

[16] Funding Source: U.S. Department of Commerce. Grantee: WGBH National Center for Accessible Media. Total Funding: $550,000.

[17] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research. Grantee: WGBH National Center for Accessible Media. Total Funding: $450,000.

[18] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research. Grantee: Research and Training Center on Independent Living at the University of Kansas. Total Funding: $162,500.

[19] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research. Grantee: Utah State University Center for Persons with Disabilities. Total Funding: $450,000.

- Nobody Left Behind: Disaster Preparedness for Persons With Mobility Impairments.[21]
- Project Safe EV-AC: Safe Evacuation and Accommodation of People With Disabilities.[22]
- Saving Lives: Including People With Disabilities in Emergency Planning.[23]
- Rehabilitation Engineering Research Center on Telecommunications Access[24]*
- Rehabilitation Engineering Research Center for Wireless Technologies[25]*

Public Input

The Research Subcommittee has sought, and will continue to seek, public input on research needs. In May 2006, the ICDR conducted a public comment meeting in which it invited and received input on the federal research agenda in disability and rehabilitation research, including emergency preparedness and disability. Among the comments received were suggestions from representatives of Columbia University's National Center for Disaster Preparedness on areas for future research based in part on recommendations from the December 2005 Columbia Consensus Conference, "Considerations in Emergency Preparedness." The comments will be incorporated into the ICDR and the ICC's synthesis of research needs. In addition, the ICDR Web site has an ongoing public comment section specifically requesting input on emergency preparedness research needs (http://www.icdr.us). Information about both of these opportunities for public input is publicized through the ICDR and through the newsletter of the ICC. The Research Subcommittee will review and analyze all public input, and incorporate findings into efforts to coordinate and promote federal research in emergency preparedness and disability.

Coordinating and Promoting Federal Research

Interagency Coordination

The Research Subcommittee has conducted extensive discussions with multiple federal agencies regarding research needs in emergency management and disability, and has worked with these agencies to define specific areas in need of funding. Some examples of the multitude of questions still needing resolution include but are not limited to:

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[20] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research. Grantee: WGBH National Center for Accessible Media. Total Funding: $450,000. *Note: This project does not focus on emergency issues, but the general focus on accessible in-flight communications would assist communications in the event of an emergency.

[21] Funding Source: Center for Disease Control and Prevention through the Association of Teachers of Preventative Medicine. Grantee: Research and Training Center on Independent Living at the University of Kansas. Total Funding: $622,408.

[22] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research. Grantee: West Virginia University. Total Funding: $450,000.

[23] Funding Source: National Council on Disability. Grantee: June Kailes. Total Funding: $25,000.

[24] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research. Grantee: University of Wisconsin/Madison. Total Funding: $4,324,988.* Note: This project does not focus exclusively on emergency issues, but does include a focus on accessible emergency alerts and communications.

[25] Funding Source: U.S. Department of Education, National Institute on Disability and Rehabilitation Research. Grantee: Georgia Institute of Technology. Total Funding: $4,749,994. Note: This project does not focus exclusively on emergency issues, but does include a focus on wireless emergency communications.

- What methods, technologies, and standards are appropriate for communicating with people with hearing, vision, cognitive, and other impairments during emergency preparedness, response and recovery efforts?
- What are the most effective interventions and methods for emergency preparedness, response, and recovery with respect to people with mental disabilities?
- What methods, technologies, and standards are appropriate for evacuating people with disabilities from buildings, transportation systems, and cities?
- What technologies, standards, and interventions are effective for emergency preparedness, response, and recovery when applied to infants and children with disabilities and/or chronic health care needs?

Promotion of Federal Research

NIDRR has provided strong leadership across federal agencies to promote federal funding in emergency management and disability. Based in part on the findings of the Research Subcommittee, NIDRR has announced two proposed priorities for Fiscal Year 2007 that focus on research needs related to the intersection of emergency management issues and people with disabilities.

In addition, NIDRR, for the first time, has included emergency preparedness and disability in its Long-Range Plan for Fiscal Years 2005–2009. The Plan, which presents a five-year research agenda, now incorporates emergency preparedness in the discussion of the national policy context for NIDRR research. The Plan is available at http://www.ed.gov/legislation/FedRegister/other/2006-1/021506d.html.

Future Goals

The Research Subcommittee continues its efforts in a multitude of areas, including but not limited to:

- Soliciting public input from the disability community and other public and private stakeholders to gain a comprehensive understanding of critical research needs.
- Developing a comprehensive federal research agenda in the area of emergency management and people with disabilities.
- Coordinating and promoting federal funding efforts.

Conclusion

The Research Subcommittee/ICC survey of federal research projects found that across the whole federal government there appear to be only 10 federal research projects focusing on emergency management and disability. In addition, the Research Subcommittee literature review revealed a dearth of published literature in emergency management and disability, and research recommendations from conferences also reveal numerous questions needing resolution. Until empirical research provides answers to these questions, our nation will be left with good intentions and efforts that may or may not be effective.

Research necessary to providing answers is, for the most part, at the earliest stages of development. The Research Subcommittee intends to help bridge this gap by soliciting input on research needs, developing a comprehensive federal research agenda, and coordinating and promoting federal funding efforts. Commitments from other agencies to fund research will be an important step in closing the gap.

Finally, the incorporation of disability-related research into ongoing research on emergency management will be an important means of ensuring that people with disabilities, and disability considerations, are fully integrated into emergency preparedness, mitigation, response, and recovery efforts.

Appendix D: List of Interagency Collaborators

Representatives from the agencies below participated in meetings of the Research Subcommittee of the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC) and the New Freedom Initiative Subcommittee of the Interagency Committee on Disability Research (ICDR), which led to the development of this document.

U.S. Access Board
U.S. Department of Agriculture
U.S. Department of Commerce
U.S. Department of Education
U.S. Equal Employment Opportunity Commission
U.S. Federal Aviation Administration
U.S. Federal Communications Commission
U.S. Department of Health and Human Services
U.S. Department of Homeland Security
U.S. Department of Housing and Urban Development
U.S. Department of the Interior
U.S. Department of Justice
U.S. Department of Labor
U.S. Office of Personnel Management
U.S. National Council on Disability
U.S. National Science Foundation
U.S. Social Security Administration
U.S. Department of Transportation
U.S. Department of Veterans Affairs

Appendix E: Methodology

This appendix provides information on the methodologies used to identify the research projects, conference recommendations and bibliographic references provided in this document.

Research Projects

To locate research projects specific to emergency management and disability, we first searched the National Institute on Disability and Rehabilitation Research's database of projects known as NARIC, the National Rehabilitation Information Center (http://www.naric.com). This search yielded all projects funded by NIDRR.

We then researched publicly available Web sites and databases to identify additional public, private and international research projects in emergency management and disability. These included Web sites such as: the National Organization on Disability; the National Science Foundation; the U.S. Department of Homeland Security; the National Institute on Standards and Technology; Doctors Without Borders; the World Health Organization; the Pan American Health Organization; the United Nations, Oxfam International, and the United Nations Educational, Scientific and Cultural Organization. We also searched databases such as the Computer Retrieval of Information on Scientific Projects (CRISP), Ovid, REHABDATA and ABLEDATA, and databases sponsored by the Trace Center and the National Center for the Dissemination of Disability Research. Examples of key search terms included: "research," "research grants," "emergency evacuation," "emergency preparedness" and "emergency management and disability."

Additionally, we surveyed all members of the ICDR in May 2005 to continue our search for research projects funded by federal agencies. Steven Tingus, former director of NIDRR, sent a letter to the ICDR membership requesting assistance identifying research projects in this area. We included the list of projects we had identified thus far, and requested any additions. We also included a questionnaire we had developed in conjunction with a broader DHS survey of emergency preparedness activities. The research questionnaire provided a definition of "research activities" and "development activities," and asked for information about past, current and planned projects funded by each ICDR agency.

Finally, we again searched multiple Web sites to locate any additional funded projects.

Conference Recommendations

We searched Web sites and conference reports from conferences on emergency management and disability for research recommendations. We then compiled a preliminary list of conferences, sent it out for comment to ICDR members and asked them for assistance in identifying additional conferences that may have issued research recommendations. However, no further conferences were identified as a result of that effort.

Research recommendations from the proceedings of identified conferences are reprinted verbatim in this guide; however, we did make minor changes to the formats and fonts in order to provide consistency in this document.

Bibliography

The process of compiling bibliographic citations for research on emergency management and disability included several venues. First, we performed searches on general search engines (Google, Google Scholar and various disability and emergency management Web sites). Second, we searched numerous databases, including Engineering Village 2 (Compendex), FirstSearch (WorldCat), PubMed, EBSCo Information Services, ERIC, Books in Print, ISI Web of Knowledge and IgentaConnect. Examples of major search terms included "disability," "emergency," "emergency management and disability" and "emergency preparedness and disability." Third, we contacted NIDRR grantees and other researchers known to be working in the areas of emergency management and disability and asked them to send us lists of their research publications. Fourth, we searched both the Project Safe EV-AC Library Database (available at http://evac.icdi.wvu.edu) and the *American Association on Health and Disability Annotated Bibliography on Emergency Preparedness and Response for People with Disabilities* (available at http://aahd.webchoices.us/site/static/pdfs/bestPractices/emergencypreparedness.doc.) These last two sources yielded an extensive list of guidelines, fact sheets, checklists, reports and other planning information. Finally, we reviewed bibliographies from relevant studies and projects.

The bibliography in our report does not reprint the citations for the many "how to" guides to preparing for an emergency, nor does it include every newspaper article on emergency management and disability. It focuses on research, other scholarly articles that relate to emergency management and disability, and government publications of relevance. References are from both the United States and abroad. Web links are provided where available.

Note to reader: The three Web sites given in this appendix were last accessed on March 28, 2008.

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