

Report And Recommendations Of The National Working Group On The Needs And Priorities Of People With Disabilities In Emergency Preparedness and Response



University of Kansas



American Association on Health and Disability



University of New Mexico

March, 2005

Members Of The National Workgroup

Organizational affiliations are listed for identification purpose only, and do not imply that the findings or recommendations contained in this report have been approved by these organizations or represent the official opinions or conclusions of these organizations. Members of the workgroup did not attend the working meeting held in Albuquerque on which this report is based as official representatives of their organizations.

Anne Pascarelli Barraza

New Mexico Department of Health

Anthony Cahill, Ph.D.

University of New Mexico

Roger Chapman

Iowa Department of Health

Michael Collins

California State Independent Living Council

Marcie Davis

Davis Innovations, Inc.

Alexandra Enders

University of Kansas

Susan Gray

New Mexico Department of Health

Judith Liddell

University of New Mexico

Cathy Rooney

University of Kansas

Michael Spoerri

Rhode Island Department of Health

Glen White, Ph.D.

University of Kansas

Mary Beresford, Ph.D.

New Mexico Governor's Commission on Disability

Roberta Carlin

American Association on Health and Disability

Alan Clive

Federal Emergency Management Agency

Juliana Cyril

Centers for Disease Control and Prevention

Elizabeth Davis

Michael Fox

University of Kansas

June Isaacson Kailes

Disability Policy Consultant

Theresa Paeglow

New York State Department of Health

Sandy Sands

Montana Department of Health and Human Services

Hilary Styron

National Organization on Disability

Mary Helen Witten

Centers for Disease Control and Prevention

■ Introduction

The terrorist attacks of September 11, 2001 and the subsequent series of anthrax attacks served as a catalyst for staff of federal, state and local agencies charged with the responsibility for planning emergency services to take action in case of possible future emergencies. Numerous federal agencies, including the Federal Emergency Management Agency (FEMA), the Department of Homeland Security, the Centers for Disease Control and Prevention (CDC) and the Health Research and Services Administration (HRSA), provided states with funds to assess their preparedness planning and develop or revise policies, programs and services.

Since 2001, numerous issues have arisen around the ability of public and private organizations involved in emergency planning or response to incorporate the needs and priorities of people with disabilities in the event of a terrorist, natural or man-made disaster. There appears to be a false sense of security on the part of too many policy makers, service providers and individuals with disabilities alike. Many service providers seem to have an attitude of “one size fits all” and a misplaced confidence that current disaster plans already accommodate individuals with disabilities. By the same token, many individuals with disabilities have a perception that a safety net exists within existing emergency-related programs and services in their communities. In fact, reality fails to match these expectations.

...Unfortunately there seems to be a false sense of security regarding emergency preparedness and individuals with disabilities. One size does not fit all...”

*Glen White, Ph.D.
University of Kansas*

In the years since the September 11, 2001 attacks, a relatively few organizations throughout the country, including university-based organizations; federal, state and local agencies; and non-profit associations have been considering various aspects of the issue of people with disabilities and emergency preparedness and response. However, these efforts have generally not been coordinated with one another, nor has there been sufficient information sharing among the various organizations

involved in these efforts. There is a clear need to overcome this fragmentation and duplication and assess how a coordinated, systematic effort can be made to incorporate the needs and priorities of people with disabilities in current and future emergency preparedness planning.

In early 2004, the American Association on Health and Disability, the Center on Development and Disability at the University of New Mexico and the Research and Training Center on Independent Living at the University of Kansas convened a meeting of invited individuals from state, federal, university-based and other organizations who have been working in the area of emergency preparedness and people with disabilities.¹

The meeting, which occurred in Albuquerque, New Mexico in June of 2004, was designed to bring experts in emergency preparedness and emergency response for people with disabilities together to:

- Identify key barriers to including the needs and priorities of people with disabilities in emergency preparedness and response;
- Recommend specific policies, practices and procedures;
- Draft preliminary plans for materials containing guidelines, best practices and compilations of resources for staff of state health and public safety departments;
- Identify specific research questions in the area of emergency preparedness and response for people with disabilities and recommend possible funding streams to support efforts to address those questions; and
- Determine next steps to plan and implement further activities including involving partners from additional organizations, including federal and other public agencies, consumer and advocacy organizations, and others as appropriate.

Prior to the meeting participants were asked to complete pre-conference worksheets that identified:

- activities participants were involved in or aware of in the general area of emergency preparedness and people with disabilities;
- both key barriers as well as facilitators that participants had experienced in their work; and

¹ Participants can be found on the inside front cover of this report.

- priority areas that needed to be addressed.

Participant responses to these questions were utilized to create the meeting agenda and to assist in defining the areas of need regarding disaster preparedness and emergency response to people with disabilities.

■ Focus Areas

Based on the pre-conference worksheets, seven focus areas were identified by participants that need to be addressed in order to ensure effective emergency planning and response that includes people with disabilities:

- Emergency Preparedness and Planning
- Evacuation
- Communication
- Shelter
- Recovery
- Training
- Funding

Emergency Preparedness/Planning

The enthusiasm for emergency preparedness exhibited in the weeks and months immediately following September 11, 2001 has noticeably diminished. This growing complacency increases the vulnerability and risk of individuals both with and without disabilities in any emergency situation. Lessons learned from prior emergencies validated the fact that necessary preparedness skills must be evident before, during and after a disaster to facilitate survival and recovery.

Of great concern in current emergency preparedness planning is the failure to include qualified individuals with disabilities in all aspects of the planning and response processes including training and training simulations, policy development, emergency plans and evacuations. Too many people involved in these areas suffer from the mistaken belief that people with disabilities are not

qualified to participate in emergency planning and disaster response. Furthermore, federal policy does not mandate that people with disabilities be included in the planning processes and little guidance on the topic exists in many federally-funded grant programs. There was an overwhelming consensus for the need to replace the current paradigm of working “for” people with disabilities to working “with” people with disabilities.

A second concern that surfaced during the meeting was the extensive duplication of emergency

preparedness efforts of federal, state and local agencies as well as non-profit and other groups. The level of fragmentation at all levels and agencies tasked with emergency planning means that many agencies are not aware of what other groups are doing and are thus ignoring valuable resources and frequently “reinventing the wheel.”

A third concern was the “top-down” nature of much emergency preparedness planning, including that for people with disabilities. For example, early planning in many federal, state and local public agencies focused on establishing centralized registries of people with disabilities to be used in the event of an emergency. Gradually, a new focus has emerged that is consistent with current emergency management theory: “all response is local,” and effective response begins in the locality where the disaster or emergency situation occurs.

The challenge of identifying, locating and providing services to individuals with disabilities can best be met by adopting an approach in which state and federal resources are used to assist community-based groups and organizations. These “naturally occurring local networks” are powerful tools that can be tapped in the event of an emergency, particularly in the many rural parts of the state. They include clubs, transportation agencies, Health Maintenance Organizations (HMOs), fraternal

...Effective and appropriate emergency planning and response cannot be accomplished without the active participation of qualified individuals with disabilities...nothing about us, without us.”

*Mary Beresford, Ph.D.
New Mexico Governor's
Commission on Disability*

organizations, faith-based organizations, and neighborhood associations. However, these types of organizations are not as fully involved in emergency preparedness planning as they could or should be.

Evacuation

Participants at the meeting agreed there is inadequate evacuation planning specific to individuals with disabilities at the local, state and federal levels. Problems identified included inadequate awareness of modern evacuation technology and procedures, lack of accessible transportation in evacuation areas, and difficulty locating people with disabilities especially in rural areas.

Communication

Two broad problems were discussed in relation to communication issues before, during and after an emergency has occurred. The first was that of communication issues between service providers. Workshop participants expressed frustration over a lack of coordination and information exchange between planning agencies and service providers at all levels of government. Bureaucracies that make it difficult to coordinate efforts and cross agency jurisdictions too frequently result in information that is outdated, fragmented and insufficient.

The second problem focuses on communication breakdowns between service providers and individuals with disabilities. People with disabilities often encounter communication barriers. Currently, much emergency information is not provided in alternative formats such as Braille, closed captioning, real-time captioning, qualified sign language interpreters, audio format and languages other than English. Local 911 systems cannot adequately address the influx of requests for assistance and information in the event of an emergency, nor do they have alternative forms of communicative devices.

Clear, truthful and timely information is critical for all people affected by a disaster to reduce panic and enhance personal safety. Emergency preparedness plans that do not adequately address the various communication needs of individuals with disabilities further endanger their safety and heighten personal risk.

Shelter

Shelters, by nature, are designed to accommodate large numbers of individuals on a short term basis. These temporary facilities must provide the general public with food, housing, restrooms and other daily living accommodations. In even best case scenarios, individuals with disabilities may face additional obstacles while staying in a shelter. Issues identified by the participants at the working meeting included:

- Physical inaccessibility;
- Inadequate understanding of the role of a service animal and accommodations for the service animal;
- Lack of accessible transportation to a shelter;
- Insufficient communication in alternative formats, i.e., absence of certified interpreters;
- Shortage of durable medical equipment, i.e., wheelchairs, hospital beds, oxygen, etc.;
- Deficient mechanisms and infrastructure to reunite separated family members; and
- Inadequate quarantine and isolation accommodations.

Recovery

Once a disaster has occurred, recovery efforts can go on for long periods of time. Temporary housing, relocation to permanent housing, counseling, medical services, and other social service needs specific to individuals with disabilities must be addressed. There must also be a continuation of services individuals with disabilities were receiving prior to the disaster.

Training

Fourteen years after the enactment of the Americans with Disabilities Act, ignorance of disability issues can no longer be used as an excuse for the inadequate attention being paid to ensuring that people with disabilities are included in emergency preparedness and response. While various training modules developed by federal, state and non-profit organizations exist, much of the information contained in them is inappropriate, insufficient or fragmented.

Training needs expressed included:

- Utilizing people first language versus “special needs populations” or other negative connotations specific to people with disabilities;
- Skill building for first responders regarding appropriate service and communication with people with disabilities;
- Disaster preparedness for an individual’s residence;
- Increase first responder’s awareness to people with disabilities;
- Reducing fear and ignorance on the part of all parties regarding issues of emergency preparedness for people with disabilities; and
- Addressing the psychosocial impact of disasters on people with disabilities.

“Fourteen years after the enactment of the ADA, ignorance can no longer be used as an excuse for inadequate emergency preparedness and planning.”

June Isaacson Kailes
Disability Policy Consultant

At least three major barriers to developing and implementing training programs that address the needs of people with a wide range of disabilities. The first is that emergency preparedness training is not mandated for federal programs serving people with disabilities. Secondly, insufficient funding and time constraints for first responders and other emergency preparedness personnel, including health care providers, frequently prevents them from participating in the training that does exist. Finally, many emergency preparedness training federal grant programs, including those by HRSA to develop training for health care providers, first responders and others, do not include people with disabilities as a focus area.

Funding

A cohesive, systematic effort is needed to influence national policy to maximize funding and reduce duplicative efforts for emergency preparedness programs and services. Cost effective funding strategies include:

- Capitalizing on partnerships;
- Seeking matching funds;
- Avoiding fragmentation that hampers effective distribution of funds;
- Providing community incentives; and
- Stipulating that individuals with disabilities be included as a funding requirement.

The challenge is to develop a more effective method of channeling funds to the local level and to ensure funds are appropriately spent on

disability-related emergency preparedness materials and programs. This effort would require funding be attached to a mandate to work with existing emergency planning groups and that the funding be consistently allocated through a stable funding

Governmental fiscal and programmatic support is essential for successful emergency preparedness for people with disabilities.

*Anne Pascarelli Barraza
New Mexico Department
of Health*

channel in each state. Improved communication between counties and citizen groups who have first hand knowledge of the needs and resources in their communities and the state governments who exercise funding discretion is essential.

■ Recommendations

Participants at the working meeting expressed agreed that there is an urgent need to prepare local communities, states and the nation to effectively respond to the needs and priorities of people with disabilities in emergency preparedness and response. Essential to the success of this effort is the

inclusion of people with disabilities and those familiar with disability issues in all emergency planning efforts. These include developing disability culturally appropriate training materials; maximizing funding streams; and reducing the damaging levels of duplication and fragmentation that currently exist.

One important step in accomplishing these objectives is to consider the creation of a **National Task Force on Emergency Preparedness and Disaster Planning for People with Disabilities**. The Task Force would not seek to duplicate the efforts of others, but would serve as a mechanism to share information; promote disability issues in existing public policies, programs and services related to emergency preparedness and response; and serve as a vehicle to reduce the fragmentation and duplication that currently exists at the local, state and national levels. Membership on the Task Force should be broad-based, and include disability and advocacy organizations; government entities at the national, state and local levels; university researchers; non-profit organizations such as the Red Cross, and others.

Possible roles for the Task Force include:

- Developing a coordinated education plan for first responders, emergency managers, health care professionals and others that incorporates planning for people with disabilities in national, state and local state plans;
- Increasing awareness among people with disabilities and disability advocacy organizations about emergency preparedness and disaster planning by providing more user friendly and coordinated information;
- Working with the Department of Homeland Security to develop a response-specific Annex that addresses the needs of persons with disabilities and integrate the Annex as a part of the National Response Plan;
- Communicating and advocating with policy makers at the federal, state and local levels about the need to incorporate disability issues when discussing emergency preparedness and disaster planning for the general population;
- Providing disability-related technical assistance to funding agencies that are developing grant programs on emergency preparedness and response;

- Establishing a coordinated Information Clearinghouse containing materials on emergency preparedness and disaster planning for people with disabilities;
- Assisting in the development of training materials, including developing case specific training scenarios and simulations, a “train-the-trainer” program, and talking points and tip sheets for first responders, primary health care providers and other emergency preparedness personnel;
- Reviewing current and future training materials for disability cultural sensitivity and best practices;
- Monitoring emerging emergency preparedness and disaster planning research and disseminating the results to people with disabilities, advocacy organizations, national, state and local governments, task force partners and the public at large;
- Partnering with and serving as a resource for national, state and local organizations, including emergency planning and emergency response committees, to develop and present workshops regarding emergency preparedness and post incident response for individuals with disabilities; and

These activities represent an ambitious agenda that clearly cannot be realized all at once.

Nevertheless, the Task Force and these potential activities represent an opportunity to include and integrate disability-related issues into emergency preparedness planning and response in a meaningful way.