
A Report Prepared for The Public Health Emergency Preparedness Unit Of The New Mexico Department Of Health In Response To The Cooperative Agreement Between The New Mexico Department Of Health And The Centers For Disease Control And Prevention For Public Health Preparedness And Response For Bioterrorism

Center for Development and Disability
Health Sciences Center
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The opinions expressed in this report are those of the authors, and do not represent the official opinions of the New Mexico Department of Health or the University of New Mexico.
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INTRODUCTION

The terrorist attacks in New York City on September 11th, 2001 and the subsequent series of anthrax attacks along the eastern seaboard and in the Midwest served as the catalyst for staff of federal, state and local agencies charged with the responsibility for planning emergency health services in case of possible future attacks. Both the Centers for Disease Control and Prevention (CDC) and the Health Research and Services Administration (HRSA) provided states with funds to assess their health-related emergency preparedness planning in light of possible future attacks.

In New Mexico, the New Mexico Department of Health was charged as the lead agency in this process. In the first year of the project, the primary task was to conduct an assessment of existing plans and resources. Unlike most other states, the New Mexico Department of Health made a clear commitment to formally recognize the needs of a wide variety of populations in the assessment and planning process. These included people with physical and cognitive disabilities, seniors, people who are chronically mentally ill, substance abusers and children with special health care needs. As the assessment process began, a workgroup was established with representatives of numerous public and private organizations representing these constituencies, as well as agencies involved in providing services in the event of a public health emergency. (See Appendix A for a list of members of the workgroup).

In addition, the Department of Health asked the Center for Development and Disability at the University of New Mexico to undertake several tasks in support of the workgroup. Among these was completion of an assessment of the needs and priorities of these populations that provided answers to several research questions developed by Shaening and Associates, the prime contractor for the Department of Health in preparing the overall statewide assessment. This re-
port contains those findings, along with several recommendations directed to the Department. Some of these recommendations are broad in scope, directed at policies of the Department, while others are directly related to the research questions developed by Shaening Associates.

In preparing this report, CDD staff and contractors utilized several types of information. First, interviews were conducted with staff of several New Mexico agencies involved in services or advocacy including the:

- New Mexico Developmental Disabilities Planning Council;
- New Mexico State Agency on Aging;
- New Mexico Commission for the Blind;
- New Mexico Commission for Deaf and Hard of Hearing Persons;
- New Vistas Independent Living Center;
- New Mexico Department of Health Long Term Services Division;
- New Mexico Home Health Association;
- New Mexico Department of Vocational Rehabilitation;
- New Mexico Department of Health Behavioral Health Services Division;
- Recovery of Alcoholics Program; and the
- New Mexico Chapter of the National Alliance for the Mentally Ill.

Other sources used to prepare this report include:

- a national review of best practice prepared by the Governor’s Committee on the Concerns of the Handicapped;
- a related search by CDD staff and contractors of materials from public and private agencies including the Federal Emergency Management Agency (FEMA), the American Red Cross and the Administration on Developmental Disabilities of the federal Department of Health and Human Services; and
meetings with the Department of Health’s emergency preparedness communications consultant. (See Appendix B for a list of reports, web sites, presentations and other products used in the preparation of this report).

KEY ISSUES IN EMERGENCY PREPAREDNESS FOR PEOPLE WITH DISABILITIES, SENIORS, PEOPLE WHO ARE CHRONICALLY MENTALLY ILL, SUBSTANCE ABUSERS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

As discussions at meetings of the workgroup progressed, three key issues emerged. First, how can people with disabilities, seniors, people who are chronically mentally ill, substance abusers and children with special health care needs be identified in the case of an emergency? There is no single place in which people with these conditions are registered. Some receive services from one or more public agencies, but many do not. Even in those cases in which services are provided, names and other identifying information that exist in the administrative databases of public agencies are not easily available, particularly in a large-scale emergency in which non-emergency personnel may not be in their offices and communication services may be erratic.

Second, how can the unique needs of these populations be identified in advance and made known to those who will have first contact with them, including fire and police personnel and emergency management services personnel? In the event of a large scale emergency requiring voluntary or mandatory evacuations, movement of large numbers of people to temporary shelters, and provision of health services such as inoculations or primary health care services, there will be little time to brief first responders on needs unique to individuals in these populations. In these circumstances, there is also likely to be a great deal of confusion and difficulty in communications.

Finally, how can services be provided that meet the needs of individuals in these populations? During any large-scale emergency, there will of necessity be an emphasis on common
sets of pre-planned procedures, policies and programs. In the event of an emergency requiring the movement and/or provision of health services to large numbers of people, there may be few opportunities to vary from routines and procedures to ensure that the needs of one individual – whether a member of one of these populations or not – are met.

KEY FINDINGS RELATED TO EMERGENCY PREPAREDNESS FOR PEOPLE WITH DISABILITIES, SENIORS, PEOPLE WHO ARE CHRONICALLY MENTALLY ILL, SUBSTANCE ABUSERS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

During numerous discussions of the workgroup, four themes emerged which drove subsequent work and helped to shape the findings and recommendations contained here.

The Need For An “All-Hazards” Approach

The original mandate of the federal agencies providing funding for emergency preparedness health planning was on responding to bioterror attacks such as smallpox and anthrax. Early meetings of the workgroup (as well as the overall statewide assessment) also followed this emphasis. Over the course of the assessment process, however, it became clear to workgroup members that a singular focus on bioterrorism was too narrow and confining. Many of the principles and issues involved in preparing for and responding to the health needs of New Mexicans in a possible bioterrorist attack are identical or highly similar to issues involved in any major interruption of normal life in some or all of the state. For example, the Hantavirus outbreak of 1993, the Menin-

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1 For example, the CDC grant program under which this report was prepared was titled “Public Health Preparedness and Response for Bioterrorism”.

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Policy Issues in New Mexico For Emergency Preparedness for People With Disabilities, Seniors, People With Chronic Mental Illness, Substance Abusers and Children With Special Health Care Needs
gococcal outbreak in Cuba, New Mexico in 1995, the Cerro Grande fire of 1999, and the more recent fires in Ruidoso all required a large-scale health responses from public and private health organizations that included

- sheltering large numbers of people outside of their homes;
- providing these individuals with food, drink and basic health necessities;
- providing both primary and specialty health care to larger numbers of people than could be handled by existing health care facilities under “normal” circumstances, and
- identifying, locating and providing services to people with unique requirements such as individuals with mobility limitations or cognitive disabilities.

In recognition of this, the workgroup quickly adopted an “all-hazards” perspective on issues relating to the populations it was charged with representing. This perspective, which holds that planning for responses to a variety of public health crises with either natural or human causes, recognizes that prior work done by public agencies such as the Department of Health and private agencies such as the Red Cross can provide us with valuable lessons for future emergency preparedness efforts regardless of the cause.

The observations and recommendations included here incorporate this perspective. This perspective has been recognized by federal agencies focusing on emergency preparedness.

The Need To Build Community Capacity

Early discussions within the workgroup focused on centralized solutions to many of the issues described above. For example, there was much early discussion about the challenges of creating a centralized, voluntary registry of people in these populations to be used in the event of...
an emergency. As the workgroup considered these types of solutions, however, a new focus emerged that formed the basis of many of the findings and recommendations contained in this report. Response and mitigation to natural and man-made disasters as defined by past and current policy of federal agencies such as FEMA and the National Guard are classic examples of a “command and control”, top-down approach.

Such an approach, including evacuation planning, opening of public health service sites, provision of health care and voluntary or mandatory evacuations will, without question, be utilized in New Mexico should an emergency occur requiring a large-scale public health response. However, the unique challenges of identifying, locating and providing services to individuals who are members of these populations will best be overcome by adopting an approach that emphasizes assisting community-based groups and organizations to identify and assist individuals in these populations. These “naturally occurring 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, fraternal organizations, faith-based organizations, and affinity groups such as neighborhood associations.

This perspective also focuses attention on providing education and information to individuals who are members of these populations on how they can help prepare themselves for possible emergencies. As has been stressed by many individuals and other resources consulted by CDD staff in preparing this report, the level of preparedness among many American is low. In a
Harris Interactive Survey taken in December of 2001, 61% of Americans reported that they do not have home evacuation plans, 50% of employed have no plans to evacuate their workplaces, and 58% do not know whom to contact about community emergency plans.²

As will be discussed below, resources should be directed towards providing these community-based groups with technical assistance and other support to enhance their ability to assist their members with disabilities should an emergency requiring assistance occur. Resources should also be directed at providing educational and other materials to these groups about individual planning.

Avoid Duplicating the Wheel

While events since September 11, 2001 have focused the nation’s attention in a dramatic way on issues related to emergency preparedness, there is also a natural tendency on the part of many to assume that these are new issues. In fact, quite the opposite is true. Many public and private organizations have spent considerable time and resources devoted to addressing the unique needs and priorities of people with disabilities and members of other populations discussed in this report.

As plans are made to move from assessment to action in New Mexico, staff of public and private agencies addressing this issue should where possible use or adapt existing materials, rather than attempting to create them from scratch. To do so would not only be a waste of public resources, it would ignore the considerable knowledge and experience that organizations such as the Red Cross, Emergency Medical Services and FEMA have developed over time.

² Patricia Morrissey, Disaster Management for Individuals with Disabilities. Presentation made at the 2002 Southwest Conference on Disability, Albuquerque, October, 2003
resources, it would ignore the considerable knowledge and experience that organizations such as the Red Cross, Emergency Medical Services and FEMA have developed over time. It will also lead to quicker solutions than creating new sets of materials, training programs, etc.

### KEY RECOMMENDATIONS RELATED TO EMERGENCY PREPAREDNESS FOR PEOPLE WITH DISABILITIES, SENIORS, PEOPLE WHO ARE CHRONICALLY MENTALLY ILL, SUBSTANCE ABUSERS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Within these three key findings, a number of specific recommendations emerged based on the research questions posed by Shaening and Associates.

**Training (Question 11)**

Training is a key issue for staff and volunteers of Public Health Service Sites, disaster workers, medical providers, counselors, Disaster Mortuary Team members, transporters/drivers and others. All first responders, including firefighters, police, ambulance personnel and National Guardsmen and women, must be prepared to work with people with disabilities and members of the other populations discussed in this report. These individuals must have a clear definition of their individual role as well as a clear understanding of the disaster management process and the roles of other emergency personnel.

In addition, they must have adequate training in recognizing a physical or cognitive disability, a basic understanding of the various types of disabilities, and the physical and mental effects of those disabilities. For example, a first responder must be aware that alarming and dis-
ruptive behavior, anxiety, extreme emotional and physical distress, may be the direct result of an individual’s disability compounded by stress and/or lack of medication.

**Recommendation One:**

*Using and adapting existing materials, the Department of Health should develop a training program for first responders and other emergency preparedness personnel (including staff and volunteers of Public Health Service Sites) on the unique needs and priorities of individuals who are members of the populations discussed in this report. The training program should be developed in such a way that it can be incorporated into existing public safety training curricula or be delivered on a stand-alone basis.*

At a minimum, the training program should include as topics:

- Recognizing various physical and cognitive disabilities;

- Practical skills for interacting with individuals who are members of populations included in this report, including a special emphasis on communicating with people with cognitive disabilities such as autism; and

- Issues around lifting, transferring and transporting people with significant mobility limitations.

**Recommendation Two:**

*The training sessions should include as handouts an expanded series of “tip sheets” designed to be quick reference resources for first responders and other emergency preparedness personnel. These tip sheets should also be distributed to appropriate organizations whose members may not be attending training sessions.*

**Identifying and Locating People with Disabilities, Seniors, People Who Are Chronically Mentally Ill, Substance Abusers And Children With Special Health Care Needs**

While many individuals who are members of one of the populations identified in this report receive one or more services from a public or private agency, many do not. Even for those receiving services, the databases of the organizations from which they receive those services are not necessarily accessible quickly (e.g., nights and weekends) or structured for quick access. As discussed earlier, there is no central registry that can be used to identify individuals who might
need assistance. Even were such a registry to be created, significant problems remain. In addition to privacy considerations, the registry would not identify people who are not receiving services. However, these individuals are almost always members of one or more of the “naturally occurring networks” discussed earlier in this report.

Recommendation Three:

A brief educational and promotional program should be developed that can be presented to civic, faith-based, neighborhood and other community-based organizations around the state. The focus of the program should be on how these organizations can, if they wish, create a low-cost volunteer program to have members who wish to do so identify themselves as people in need of assistance in the event of an emergency.

The program should include tips on successfully operating such a program, how to avoid problems such as the distribution of private information, what information to collect (including sample forms), and tips on how to respond in the event of an emergency. At the conclusion of the program, an offer should be made to deliver the training sessions described earlier.

Membership On The Health Advisory Network: Disseminating Information to People with Disabilities, Seniors, People Who Are Chronically Mentally Ill, Substance Abusers And Children With Special Health Care Needs (Questions 1, 2 and 5)

The Health Advisory Network proposed by the Department of Health and Shaening Associates is a key component in the emergency preparedness planning. It will facilitate the dissemination of critical information during a variety of crisis situations. This communication process is even more vital to individuals who are members of the populations identified in this report, as they are historically more isolated and reticent to engage with entities, people and processes.
unfamiliar to them. The following is a list of agencies that were recommended for inclusion in the Health Advisory Network contact directory:

- New Mexico Developmental Disabilities Planning Council
- New Mexico State Agency on Aging
- New Mexico Commission for the Blind
- New Mexico Commission for Deaf and Hard of Hearing Persons
- New Vistas Independent Living Center
- New Mexico Department of Health Long Term Services Division
- New Mexico Home Health Association
- New Mexico Governor’s Committee on the Concerns of the Handicapped
- New Mexico Department of Vocational Rehabilitation
- New Mexico Disabled American Veterans
- New Mexico Department of Health Behavioral Health Services Division
- New Mexico Chapter of the National Alliance for the Mentally Ill
- New Mexico Association of Developmental Disabilities Community Providers
- New Mexico Association of Family Providers
- Information Center for New Mexicans with Developmental Disabilities/Baby Net
- Parents Reaching Out
- New Mexico Association of Retarded Citizens (ARC)
- New Mexico Children, Youth and Families Department
- University of New Mexico Medical School and Hospital
- Las Vegas Medical Center
Recommendation Four:

Information should be disseminated using a “phone tree” model. The agencies within the HAN should be responsible for notifying all the programs within their networks and these programs, in turn, would communicate with their clients or members on a local level.

This method of information dissemination would achieve two goals. One, it would facilitate efficient distribution of information throughout the state. Secondly, the messenger would be a local provider who has established recognition and trust with clients or members.

Issues in Communicating With People with Disabilities, Seniors, People Who Are Chronically Mentally Ill, Substance Abusers And Children With Special Health Care Needs (Questions 3, 4 and 5)

Accessible communication is an essential element of an effective emergency preparedness plan. Both interviews conducted for this report as well as the secondary sources reviewed emphasized the importance of incorporating multiple means of communication to meet the needs of individuals who are members of the populations included in this report.
Recommendation Five:

_The Department of Health should work closely with their Emergency Preparedness Consultant and others to ensure that to the extent possible, the communication-related needs and priorities of people with disabilities, seniors, people who are chronically mentally ill, substance abusers and children with special health care needs are met._

Specific recommendations include the following.

- Information should be communicated both orally and visually. All materials must be available in multiple formats, including, but not limited to, Braille, audio cassette, Large Print and email;

- Messages should also be communicated in American Sign Language;

- Educational materials to support individuals with disabilities, caregivers and other support persons and organizations must be prepared prior to a crisis situation;

- Materials should be used with the general media and with specific channels, such as Newsline for the Blind;

- Alternative channels of communication, such as Newsline for the Blind, Close Captioning, etc. should be identified;

- All materials should also be in appropriate Native languages;

- All materials should be developed at the appropriate reading and mental aptitude levels for the targeted audience, i.e. for individuals with developmental disabilities, chronic mental illness, seniors, etc.;

- Oral and visual Public Service Announcements should be developed to educate people and providers about how to help persons with disabilities and seniors during a crisis;

- Discussions should be initiated with New Mexico government agencies and non-profit entities that maintain various interpretive services to create a registry of available interpreters (sign, Native and other forms of communication). These interpreters would be located throughout the state and may be available to assist during a crisis situation at a PHSS or another pivotal location; and

- Discussions should be initiated with television news media to ensure that real time captioning is included for all breaking news.
The workgroup that has met regularly to consider issues relating to the populations discussed in this report should also be used to identify gaps in existing communication systems.

**Recommendation Six:**

*In order to develop and perfect this communication system, the Disabilities Work Group should conduct a table top simulation of a bioterrorist disaster, led by an experienced Emergency Manager and including critical service providers. Such an exercise would serve as a valuable source of “lessons learned” and identify gaps in existing communications systems related to people with disability.*

**Accommodations and Transportation (Questions 6, 7, 8 and 9)**

Public Health Service sites (PHHS) are an important part of the Department of Health’s plan to provide health-related services to residents of one or more areas of the state affected by a large-scale emergency. The PHHS would “…have the dual purpose of providing preventive services and/or identifying potential contagious illness to the general public in the event of a health emergency.” While the PHHS, if activated, would by definition be operating in an atmosphere of public anxiety or even panic, the need to provide accessible services at the PHHS to people with a wide range of physical or cognitive disabilities, including transporting or evacuating individuals to and from them, remains.

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Policy Issues in New Mexico For Emergency Preparedness for People With Disabilities, Seniors, People With Chronic Mental Illness, Substance Abusers and Children With Special Health Care Needs
Recommendation Seven

Transportation has been and continues to be an issue for people with disabilities and seniors due to the shortage of accessible vehicles. In response to this need, a registry should be created that identifies New Mexico government and non-profit entities throughout the state, including school districts, senior centers, independent living centers, vocational rehabilitation offices, etc., which may own or have access to these types of vehicles. Where possible, agreements with these agencies and organizations should be reached that would provide access to their services in the event of a large-scale emergency.

Once an individual arrives at a PHSS, the basic needs of individuals who are members of populations included in this report must be accommodated. These basic needs may include:

- Information in various formats as discussed earlier in this report;
- Specific dietary needs;
- Shelter including accessible housing, beds, toilets, showers, supplies for bowel and bladder maintenance, etc.;
- Medical needs including chemical sensitivities, vaccinations and interactions between medications, medical equipment and supplies (e.g., oxygen, ventilators, etc) and current medications; and
- The needs of service animals.

Recommendation Eight

If quarantining, observation and isolation is warranted, special considerations must be made to meet their basic needs under those strict conditions. In planning and establishing PHSS, it is recommended that a registry be created that includes New Mexico government agencies, non-profits and commercial medical providers and suppliers throughout the state. The registry should include medical suppliers, hospitals, home health agencies, senior centers, etc. that may sell or utilize items necessary to meet these basic needs. Where possible, agreements with these agencies and organizations should be reached that would provide access to their services in the event of a large-scale emergency.

Mass Fatalities (Question 10)

It is painful – although realistic - to consider that if a catastrophic event of sufficient magnitude occurs, there could well be a large number of fatalities, either in one catastrophic
event, or over a period of several weeks or months. Visual recognition, medical records, or DNA testing may be necessary to identify deceased individuals. When a senior or an individual with a disability is approached to assist with identification through one of these means, there are several things that must be considered:

- Persons with vision loss may need alternative methods of identification. For example, a photograph may be used or a friend or relative may be available to make a visual identification and to assist in the identification process.

- People with cognitive disabilities, chronic mental illness and seniors may also need a friend or family member to make the actual identification and to assist in the identification process.

- Consideration should be given in regard to the psychological and physical implications for the survivor who has lost this family member, friend or caregiver.

- Case management services should be available regarding arrangements for the remains of the deceased and the short and long-term implications of the death.

Once again, effective communication and physical accommodations should be provided.

CONCLUSION

In a speech at the 2002 Southwest Conference on Disability, Patricia Morrissey, Commissioner of the Administration on Developmental Disabilities of the federal Department of Health and Human Services, reinforced the idea discussed in the Introduction to this report that emergency preparedness planning is a good idea for all citizens – regardless of whether or not they have a disability and regardless of the source of the emergency. Effective planning for any type of disaster, including those caused by terrorist attacks, can and should take place on an individual as well as organizational level. Citizens, regardless of disability or health status, should be prepared to meet the challenges of a large-scale emergency.

This type of personal planning, while encouraged by the Red Cross and other organizations, is too infrequently used. It is the hope of the authors of this report that these recommen-
Deductions will be accepted and implemented in the second and subsequent years of the emergency preparedness planning process.
APPENDIX A: WORK GROUP PEOPLE WITH DISABILITIES, SENIORS, PEOPLE WHO ARE CHRONICALLY MENTALLY ILL, SUBSTANCE ABUSERS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS
Connie Amidon  
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Christina Rutland  
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Mary Ann Shaening/  
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APPENDIX B: RESEARCH QUESTIONS POSED BY SHAENING AND ASSOCIATES
Shaening and Associates generated the following eleven research questions to assess specific needs and issues regarding emergency preparedness.

1. Who are the people, programs, agencies or organizations who can respond on behalf of people with disabilities, seniors and people with chronic mental illness and substance abuse who should be part of the Health Advisory Network (HAN), the risk communication “must contact” list, and other contact directories?

2. How do you identify and locate people with disabilities, seniors and people with chronic mental illness and substance abuse? What resources (persons, programs, agencies, plans, etc.) currently exist?

3. How do you ensure an effective means of communication for all people with disabilities, seniors, and people with chronic mental illness and substance abuse? What resources (persons, programs, agencies, plans, etc.) currently exist?

4. What are the unique considerations, if any, in developing effective messages to communicate risk and provide information to people with disabilities, seniors and people with chronic mental illness and substance abuse, including providing information about the local Public Health Service Site (PHSS) (what it is, how to get there, when to go, etc.)? What resources (persons, programs, agencies, plans, etc.) currently exist?

5. What are the unique needs/accommodations, if any, regarding motivating people with disabilities, seniors, and people with chronic mental illness and substance abuse to go to their PHSS or to take other necessary actions or precautions? What resources (persons, programs, agencies, plans, etc.) currently exist?

6. What are the unique needs/accommodations, if any, regarding evacuating, quarantining, or isolating people with disabilities, seniors, and people with chronic mental illness and substance abuse? What resources (persons, programs, agencies, plans, etc.) currently exist?

7. What are the unique needs/accommodations, if any, regarding transporting people with disabilities, seniors, and people with chronic mental illness and substance abuse? What resources (persons, programs, agencies, plans, etc.) currently exist?

8. What are the unique needs/accommodations, if any, regarding vaccinating or treating people with disabilities, seniors, and people with chronic mental illness and substance abuse? What resources (persons, programs, agencies, plans, etc.) currently exist?

9. How do you ensure people with disabilities, seniors and people with chronic mental illness and substance abuse will report or seek help for unusual illness/symptoms? What are the unique needs/accommodations, if any, regarding informing people with disabili-
10. What are the special issues that need to be considered in terms of dealing with mass fatalities including activating a Disaster Mortuary Team (DMORT) when people with disabilities, seniors and people with chronic mental illness and substance abuse are involved? What resources (persons, programs, agencies, plans, etc.) currently exist?

11. What are the specific training needs, if any, for PHSS staff, disaster workers/emergency responders, hospital and health system staff, and others in terms of addressing the unique considerations of people with disabilities, seniors and people with chronic mental illness and substance abuse in the event of a bioterrorist incident? What resources (persons, programs, agencies, plans, etc.) currently exist?