



Emergency Preparedness: Addressing the Needs of People with Disabilities

National Consensus Conference



National Center for
Disaster Preparedness

Mailman School of Public Health
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Emergency Preparedness: Addressing the Needs of Persons with Disabilities

A National Consensus Conference

Executive Summary and Final Report

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TABLE OF CONTENTS

Introduction	3
Conference Structure	5
Accessibility at the Conference	6
Acknowledgements	7
Expert Consultants	7
Additional Speakers	9
Participants	10
NCDP Staff.....	14
Recommendations	15
1 Disaster Communications	16
2 Emergency Transportation.....	19
3 Decontamination, Isolation, and Quarantine	23
4 General and Medical Needs Sheltering	24
5 Disaster Drills.....	29
6 Community Preparedness	30
7 Individual Preparedness	31
8 Children with Special Health Care Needs	32
9 Continuity of Care	33
10 Strategic National Stockpile and Medications	34
11 Mental Health Needs	35
12 Federal Disaster Response Programs.....	36
13 Specialized Training for Emergency Planners and Responders.....	37
14 Research Priorities.....	39
Conclusions	41
Abbreviations	42
Appendix Assistive Communication Technologies	43
Reference Tables	47
Notes.....	50

INTRODUCTION

In July 2004, President Bush signed an Executive Order explicitly stating the policy of the United States in the area of emergency preparedness for people with disabilities.

Executive departments and agencies of the federal government were ordered to do the following:

- Consider the unique needs of agency employees with disabilities and of individuals with disabilities whom the agency serves in their emergency planning
- Encourage, including providing technical assistance, as appropriate, 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
- Facilitate cooperation among federal, state, local, and tribal governments and private organizations and individuals in the implementation of emergency preparedness plans as they address individuals with disabilities

The Executive Order built on The Americans with Disabilities Act (ADA), passed in 1990 “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities” (42 U.S.C. 12101[b][1]). Although the ADA does not address emergency preparedness directly, Titles II and III have clauses that are relevant to emergency preparedness.

Title II: Provides that no qualified individual with a disability shall be excluded from participation in or be denied the *benefits of the services, programs or activities of a public entity*.

Title III: No individual shall be discriminated against on the basis of a disability in the full and equal enjoyment of the *goods, services, facilities or accommodations of any place of public accommodation*.

“Public entity” is defined as state and local governments and certain transportation authorities. Thus, emergency services operated by a state or local government cannot discriminate against people with disabilities. Public accommodations are listed in the statute and include hotels, auditoriums, parks, professional offices of health care providers and gymnasiums (CRS, Report for Congress, “The Americans with Disabilities Act and Emergency Preparedness and Response” September 13, 2005). These structures could feasibly be utilized in times of natural or manmade disasters.

The ADA provides a legal framework for local and state government to account for the needs of people with disabilities in disaster planning: there must be equal access to emergency services. This general mandate was reinforced by the President’s Executive Order. The intent of equal preparedness is present, but the question remains: How do

emergency planners carry out this mandate? How can emergency responses be planned for a population with a wide range of physical, mental, and cognitive abilities?

Unfortunately, the literature is extremely limited and empirical evidence on best practices for addressing the needs of individuals with disabilities in disaster preparedness is sparse.

Hurricane Katrina provided unambiguous evidence of the critical and immediate need for specific and concrete guidelines on how to plan for and meet the needs of individuals with disabilities in times of disasters. This conference was originally planned for September 2005, before Hurricanes Katrina and Rita; however, it was delayed for three months because so many of the participants were involved in the disaster response in the Gulf region. These experiences also served to emphasize the need for planning guidelines.

The purpose of the conference and this consensus document is to provide specific, concrete recommendations on how communities, first responders and levels of government can incorporate the needs of persons with disabilities into emergency preparedness. *We sought to address the question:* What specifically do emergency planners and responders need to do to take into account the needs of individuals with disabilities in disaster planning and response?

Note that in this document, the term “disability” was defined as in the Americans with Disabilities Act (ADA): a) a physical or mental impairment that substantially limits one or more of the major life activities of an individual, b) a record of such an impairment, or c) being regarded as having such impairment.

In addition, instead of the phrase “individuals with special needs,” specific terms referring to the group of people being addressed have been used, for example, “people with hearing impairment,” “persons with vision impairment,” “people with mobility limitations,” etc. However, when addressing an issue that affects many such groups, the term “special needs” was used despite its limitations.

Conference Structure

For two days, nearly 70 experts from across the nation gathered for an unprecedented discussion of emergency preparedness and response guidelines to address the specific needs of individuals with disabilities. Participants included emergency planners, first responders, policy makers, and subject matter experts, including people with disabilities. The conference was unique in that people who would usually first meet under emergency situations had an opportunity to work together in a non-emergent situation.

Six months before the original conference date, subject experts approved the topics and the group leaders began developing the guidelines. The meeting was conducted according to the following format:

- 1) Presentations were given by experts on the subject areas to be addressed.
- 2) Breakout groups were formed for focused discussion on topics within each subject area.
- 3) The entire group met again to review each breakout group's conclusions and to develop a formal consensus recommendation.

The concept behind the format was to gather baseline information, followed by a small group discussion and then a large group discussion to reach conclusions. All sessions focused on presentation and review of the existing data for the relevant subject, followed by development of consensus recommendations and/or expert opinion and a research agenda to advance the current knowledge base.

Accessibility at the Conference

The planning for the conference required addressing the needs of person with disabilities who would be attending. As such the planning for the conference itself provided initial thoughts on issues which may arise when addressing person with disabilities. The following services were provided to ensure accessibility by all participants:

Communication Access Real-time Translation (CART): CART enables written text of all speeches to be projected in real time. This technology is helpful for individuals with hearing impairments and others who are visual (rather than auditory) learners. During the conference plenary sessions, text was projected onto two screens, one on each side of the speaker. During the smaller breakout sessions, CART writers sat next to individuals who had requested the service, with text provided on laptop computers.

American Sign Language (ASL): Interpreters provided ASL translation during plenary and breakout sessions, when requested.

Narrative description: Conference participants were able to listen to an on-site narrator's transmitted voice via headphones carrying the designated audio channel. The narrator described all visual information (e.g., graphics, videos, PowerPoint slides) presented.

Written documents in alternate format: The conference agenda was provided in Braille and in large print. Because the on-site conference materials were voluminous, transportation of all materials in Braille and large print would have been problematic. As an alternative, all materials were made available on CD before the conference, so that participants were able to download the information onto their computers for access via screen readers.

Accessible space: The meeting space was easily accessible to the outdoors, so that service animals could be taken outside on a regular basis. The rooms had wide hallways and an elevator lift that provided access to the hotel restaurant. Accessible rooms were available for all participants on request. The restrooms on the conference level were accessible by wheelchairs and scooters.

ACKNOWLEDGEMENTS

This document is the culmination of work of many individuals. We'd first like to thank our disability advisory board and group leaders who helped us identify and tackle the key issues in emergency preparedness for persons with disabilities. Much of this document is due to their expertise. Elizabeth Davis, Nathaniel Hupert and Alexis Silver were especially valuable teachers. We'd also like to thank the speakers who set the stage for the discussion and the participants who actively engaged in debate and brainstorming. We would also like to thank the Agency for Healthcare Research and Quality (AHRQ) and the Emergency Medical Services for Children (EMSC) Program of the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA) of the Department of Health and Human Services, for providing the financial support for the meeting. We appreciate the constant support and advice received from Sally Phillips, whose efforts made both the first and this second conference a reality. Accessible communication for the conference was provided by Marguerite Bardone, Communique InterActive Solutions, conference logistics were handled by the Bridge Group and the Watergate staff worked hard to assure that all of our meetings needs were met.

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Conference participants represented a cross-section of all those with expertise, responsibility, and authority to make decisions affecting preparedness for disaster and terrorist events. Participants included representatives of relevant professional organizations; representatives of multiple federal, state, and local government agencies involved with disaster and terrorism preparedness; experts in the fields of emergency medicine, disaster medicine, nursing, social work, mental health, and emergency management; and individuals with recognized national expertise in relevant subject areas.

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RECOMMENDATIONS

The specific recommendations can be found in the following sections listed below.

1. Disaster Communications
2. Emergency Transportation
3. Decontamination, Isolation and Quarantine
4. General and Medical Needs Sheltering
5. Disaster Drills
6. Community Preparedness
7. Individual Preparedness
8. Children with Special Health Care Needs
9. Continuity of Care
10. Strategic National Stockpile
11. Mental Health Needs
12. Federal Disaster Response Programs
13. Specialized Training for Emergency Planners and Responders
14. Research Priorities

DISASTER COMMUNICATIONS

Although the technological means of transmitting information during an event is important, disaster communications encompasses much more. Disaster communications can be defined as the ability to effectively move and share information, with an emphasis on facilitating emergency decision making and resource allocation to preserve life and property. An important part of this includes the exchange of information on risk and preparedness as well as on evacuation, sheltering, and recovery.

Public Emergency Communications

All public emergency communications should accommodate the needs of people who have disabilities of sensory impairments, and existing broadcast regulations should be enforced by the responsible agencies.

- 1.1 Incorporate auditory and visual alerts with appropriately detailed messages into automated alert radios.
- 1.2 Identify emergency exit doors by tactile letters and/or Braille lettering as well as by prominent letter display, and include a standardized localizing tone for visually impaired individuals. Mandate battery backups for these devices, just as for the visual signal.
- 1.3 Add full descriptive text messages to audible emergency community alerts in public places.
- 1.4 Develop local networks of emergency alert services, including Personal Emergency Response System (PERS) services (see Appendix), and outbound automated messaging systems for individuals with disabilities and anyone requiring assistance. Provide detailed descriptive messages for an emergency alert through these networks to visually impaired individuals.
- 1.5 Provide phones with Braille keyboards and one-button access to emergency services in the community.
- 1.6 Ensure public announcements broadcast over television regarding ongoing recovery efforts are communication accessible, e.g., are provided with captions, graphics or other visual display of information provided orally, and provided in such a way that is it not obstructed by other images.

Emergency Alerts

Methods of alerting include, but are not limited to, the following: captioned broadcasts on television, email alerts, cell phones with text messaging capability, alpha-numeric pagers, PDA, NOAA weather radios with visual and tactile alerts, text radios (such as Radio Data System), electronic message boards on highways and in other public places, alerts to Telecommunications Relay Services, Reverse 911[®] that is inclusive of and compatible with TTYs and accessible to individuals with hearing impairment, and written flyers that are brought door-to-door or posted in public places (see Appendix for brief descriptions of these technologies).

- 1.7 Messages sent to broadcasters for dissemination should include “boilerplate” statements indicating that the FCC requires all emergency information to be broadcast either with captions, graphics, or other visual display of information provided orally, and that it should not be obstructed on the screen by other images.
- 1.8 Emergency preparedness materials available to the public must be reexamined to offer recommendations for customized messages for people with special needs. This includes a reality testing of practices that are commonly recommended to realistically set the public’s expectation that people are better prepared and recognize that the best plan begins at the household level. These materials must also be made available in accessible formats.

Communications in Shelters

- 1.9 Place visual displays of audible announcements (e.g., electronic signs, open-captioned video, or handwritten white or blackboard displays) in a central location.
- 1.10 Include universal language signs and international symbols on picture boards. Make sign language interpreters, Video Remote Interpreting (VRI), CART, and hearing assistive technology (HAT) available. Mandate open-captioned display for any televised emergency information.
- 1.11 Make telecommunication options (e.g., videophones, Video Relay Services [VRS], TTYs, captioned telephones, amplified phones) available when telephones are provided.
- 1.12 Develop agreements between telecommunication organizations and the local community to facilitate accessibility in emergency situations, to assure availability of appropriate analog lines for TTY users and CART access in shelters.
- 1.13 Make the following available and easily accessible in all medical facilities, mass dispensing sites, and shelters: (see Table 1)

Table 1: Minimum Requirements for Communication in Shelters

All medical facilities, mass dispensing sites and shelters must have available and easily accessible:
Hearing Assistive Technology (HAT), written instruction on the operation of the technology and floor plans which detail where HAT is located
Instructions for staff on where to find sign language interpreters and VRI and what to do until the interpreter arrives.
Signage for consumers indicating where people who are deaf or hard of hearing will find interpreters, CART services, HAT, TTYs, amplified phones, visual display of announcements and/or other communication accommodations.
Videos with open captions and/or written instructions.
Pen and paper

Note: Descriptions of communication technology can be found on page 42.

Recovery Instructions

- 1.14 Provide written fact sheets on follow-up care for medical and mental health conditions.
- 1.15 Make available telephone hot lines accessible via TTY, detailed information on Web sites, and visual and audio information accessible on broadcast television stations.
- 1.16 Provide written copies of medical reports, including follow-up care and information on any needed medications, on discharge; include names and phone numbers of contact people if additional information is needed.

EMERGENCY TRANSPORTATION

- 2.1 Establish a voluntary mechanism in the community (in conjunction with individuals with disabilities, family members, and disability organizations) to identify before an emergency those individuals requiring special assistance for emergency transportation and to make that information available to emergency services providers. This includes a list of households with service animals.
- 2.2 Establish policy to ensure that every effort is made for individuals with disabilities to keep their assistive devices or service animals with them during pre-hospital care and transport (see Table 2 for situations of appropriate exclusion).
- 2.3 If evacuation or rescue efforts require separation of a person from his or her assistive device or service animal, include plans for return of the device or service animal.
- 2.4 Encourage communities to build guidelines and operate a tiered dispatch and emergency response system so that limited pre-hospital medical services (EMS) can be used responsibly during a disaster for those with acute medical needs. With a focus on pre-planning and communication, EMS should not constitute the primary means of evacuation of uninjured people during a disaster.
- 2.5 Develop work continuity assurances with community agencies (e.g., ambulettes, busses, and shuttles) who may be involved in the transportation of people with disabilities. Non-emergency vehicles that can accommodate and assist with evacuation of individuals with disabilities during a disaster are a valuable resource that can relieve some of the burden on the EMS system.
- 2.6 Waive license requirements for accessible vehicles during emergency and disaster situations.

Bus Transportation

In an analysis of transportation issues after Hurricanes Katrina and Rita, the Department of Transportation (DOT) in cooperation with the Department of Homeland Security (DHS) suggested signing agreements with out-of-state bus companies to ensure that the state has additional buses available to supplement resources already procured at the state and local level.

- 2.7 State officials should select bus companies that are not already contracted to provide emergency transportation for neighboring states, so that in a multi-state disaster, the same buses are not contracted to multiple localities.

GIS Technology

In addition, the DOT/DHS recommended optimal use of GIS technology, which can be used to collect and provide information about open and closed shelters to responders, government officials, and the public throughout the state.

- 2.8 GIS technology should be used to obtain information about locations of shelters, logistics areas, and command posts. This type of program is unique in that it provides for one-site storage and dissemination of emergency management and law-enforcement data to the state and county Emergency Operations Commanders, responders in the field who can share this information with the public via message boards and other communications channels, as well as via a public Web site. This allows staff at all levels to make decisions based on the same data and the public to be kept informed of the evacuation process, including danger areas and evacuation zones and routes.

Note: The DOT/DHS full Report to Congress can be accessed at www.fhwa.dot.gov/reports/hurricanevacuation/.

Service Animals

A service animal is defined as any guide dog, hearing signal dog, or other animal individually trained to do work or perform tasks for the benefit of an individual with a disability including, but not limited to, guiding individuals with impaired vision, alerting individuals with impaired hearing to intruders or sounds, providing protection or rescue work, pulling a wheelchair, or retrieving medicine and medical supplies.

- 2.9 Do not separate a person from his or her service animal for emergency transport except under the following criteria for exclusion of a service animal from a shelter, medical facility, or emergency vehicle:
 - The animal is a direct threat to the emergency workers' or shelter's ability to provide services to others.
 - The animal demonstrates aggressive behavior and cannot be controlled by its handler.
 - The animal does not meet the definition of a service animal.

Table 2: Criteria for Exclusion of Service Animals

Under the following conditions, service animals can be excluded from a shelter, medical facility or emergency vehicle:
If the animal is a direct threat to the emergency workers' or shelter's ability to provide services to others.
If the animal demonstrates aggressive behavior and can not be controlled by its handler
If the animal does not meet the definition of a service animal

Note: Service animal means any guide dog, hearing signal dog or other animal individually trained to do work or perform tasks for the benefit of an individual with a disability including, but not limited to guiding individuals with impaired vision, alerting individuals with impaired hearing to intruders or sounds, providing minimal protection or rescue work, pulling a wheelchair or retrieving medicine and medical supplies.

Addressing Needs of Individuals with Hearing Impairments

- 2.10 Require emergency response vehicles, including medical vans, ambulances, and aero medical transport, to have tools to communicate with people who have a hearing loss, including the following:
- Medical forms that include information regarding the communication mode and functional needs of the individual along with other pertinent medical information.
 - HAT, particularly in light of the possibility that individuals' personal assistive devices may have been lost or damaged during the emergency.
 - Pen and paper

Addressing Needs of Individuals with Mobility Impairments

- 2.11 Require all new multi-story buildings to install stair-descent devices, including but not limited to, evacuation chairs. Enforcement mechanisms should exist to ensure compliance with evacuation codes and regulations.

Evacuation of Group Homes and Psychiatric Facilities

2.12 Include the following functions in evacuation plans:

- Track the transfer of residents of group homes and psychiatric facilities to a relocation site.
- Facilitate ongoing contact between people with psychiatric disabilities and their family members and caregivers.
- Facilitate the eventual return of evacuees to their homes.
- Ensure that sites that receive evacuees are equipped to meet the needs of people with psychiatric disabilities. This includes sufficient medications and durable medical equipment to meet these individuals' needs.
- Prevent the inappropriate institutionalization of evacuees with psychiatric disabilities.

DECONTAMINATION, ISOLATION AND QUARANTINE

- 3.1 View fixed “pop-up” decontamination facilities in locations such as hospitals as an extension of the hospital facility and design, and mandate them to comply with ADA standards.
- 3.2 Establish protocols and procedures, along with maintenance of the necessary equipment to allow the decontamination of individuals who rely on durable medical equipment. Require manufacturers of medical equipment (including, but not limited to ventilators, oxygen administration systems, prosthetic devices, walkers/canes/crutches, wheelchairs, catheters, ostomy equipment, hearing aids, etc) to provide information on decontamination procedures.
- 3.3 Decontaminate service animals by going through a decontamination corridor/tent/trailer or other mass decontamination process *with* their owner/handler using the same process whenever possible. Consideration should be given to decontaminating the service animal in an area or corridor where people are not being decontaminated at the same time in case the service animal has an unexpected reaction to the process.
- 3.4 Provide decontamination instructions in audible, text, and picture formats to accommodate individuals with vision, hearing or cognitive impairments, and language barriers.
- 3.5 Identify the functional needs of individuals, particularly those with sensory, cognitive or language barriers, prior to entering decontamination facilities to ensure that proper accommodations or assistance will be provided to those individuals.
- 3.6 Consider the feasibility of shelter-in-place as an additional option for certain individuals with disabilities who have the appropriate care facilities and equipment at their residence. Make arrangements for health professionals to visit regularly and assess any quarantined, isolated, or sheltered individuals who are sheltered-in-place.
- 3.7 Ensure that isolation and quarantine locations are ADA compliant. ADA rules for accessibility can be accessed at www.access-board.gov/ADA-ABA/summary.htm.
- 3.8 Make accommodations for service animals in facilities designated as potential isolation/quarantine facilities.

GENERAL AND MEDICAL NEEDS SHELTERING

The term **general shelters** refers to shelters that have been established and identified before an emergency or disaster. They are commonly run by the American Red Cross and typically are equipped to handle mass sheltering, feeding and care but do not have a defined medical capability.

The term **medical needs shelter** refers to a physical location that is properly staffed, supplied, and managed to meet nonemergent care needs, at a level above first aid but below a hospital, just before, during, and immediately after an emergency or disaster.

- 4.1 Ensure that all shelters that have been identified before an emergency or disaster meet minimal accessibility standards.
- 4.2 Determine the functional level of individuals with special medical needs to ensure that they are as safe and informed in the shelter as the general public. Consider the following types of questions:
 - Can you hear the public address system and fire alarm?
 - Can you hear well enough to converse on a telephone?
 - Do you need a sign language interpreter?
 - Do you need written instructions?
 - Can you hear and understand spoken English?
- 4.3 Keep service animals and owners together using the guidelines in this document. Allow individuals who rely on adaptive technology to bring it to shelter and emergency facilities, unless it cannot be decontaminated. Adopt policy to ensure that environmental modifications are made to assist individuals with sight, hearing, and mobility impairments, and to provide adequate back-up options if a person is separated from his or her adaptive technology or service animal during evacuation or decontamination.
- 4.4 Resolve prescription overstock or personal medical supply in a uniform way at the federal level as a pre-shelter issue.
- 4.5 Develop universal minimal operational tasks in medical needs shelters for the following:
 - Skilled medical and paraprofessional staff

- Staffing ratios
 - Management/oversight
 - Safety and security
 - Medical equipment and supplies
 - Medication
 - Codes of conduct guidelines
 - Appropriate uninterrupted utilities (e.g., water, sewage, generators, climate control)
 - Physical and programmatic requirements of the ADA
 - Hearing Assistive Technology (HAT) and batteries for same.
 - Minimal intake and tracking capability for shelter clients
 - Connectivity/communication to the EOC or command structure
 - Maintenance of individuals and their support network as a unit
- 4.6 Ensure that congregate care facilities (e.g., skilled residential health care facilities, group supervised living, etc) plan, before an emergency or disaster, for continued and appropriate care of their population within their own network and industry, without relying on or expecting to use shelter operations for individuals residing independently in the community.
- 4.7 Provide for large generators and refueling arrangements for special needs shelters to ensure power for medical equipment and essential climate control systems.
- 4.8 Designate state departments of health as the key operational and oversight entity in medical needs shelters.
- 4.9 Designate local health departments to implement and manage the medical and public health aspects of local shelter operations in conjunction with local emergency management. Train local public health personnel in both public health management sheltering issues and mass care shelter management (as provided by the American Red Cross).
- 4.10 Partnerships between local public health, offices of emergency management and the American Red Cross should be used to facilitate the ability to provide both general

shelters and medical needs shelters. This can be done through either separate facilities or co-location of medical needs facility directed by local public health within a general shelter. Local public health departments may partner with other entities they deem appropriate and/or necessary.

- 4.11 Ensure that public health officials have a management role to oversee and implement a continuum of care spectrum for both general and medical needs shelter operations. Integrate the local community in planning efforts, with minimal criteria for training to be defined by each state. Having a medical model in place allows routine medical management needs (e.g., dialysis, psychotropic drug administration, insulin injections, etc) to continue.
- 4.12 Ensure that management of hotel or apartment complexes used as shelters are aware that individuals with disabilities have the right to be accompanied by their service animal during disaster response and evacuations.

Accommodating Medication Needs in Community Medical Needs Shelters

- 4.11 Accommodate, directly or through contracted pharmacies, the regular medication needs that enable disable and special needs populations to remain independent.
- 4.12 Include arrangements for the following routine medication needs:
 - Separate refrigeration storage for medication
 - Special medicine containers designed for those with sensory impairments or limited dexterity
 - Pre-set insulin syringes with caps/covers
 - Color coded medicine containers
 - Multi-day pre-pour containers

Accommodating Durable Medical Equipment (DME) Needs in Community Shelters

- 4.13 Provide for some on-hand DME supplies commonly needed both in the home and for independence outside the home by individuals who have sensory or mobility impairments:
 - Assistive devices (e.g., regular and quad canes, walkers, safety rollers, crutches)
 - Folding white canes

- Manual wheelchairs and rolling chairs
- Portable ramps
- Shower chairs
- Bathtub seats
- Large-handled eating utensils
- Flexible straws
- Two-handled drinking mugs
- Oxygen, portable oxygen tanks, oxygen regulators, oxygen tubing
- Drainage bags for catheters
- Standard ostomy supplies and dressings
- Bedpans, urinals, emesis basins
- Simple support surfaces (e.g., egg-crate pads), lambs wool pads
- Basic diabetic supplies
- Reading glasses in the higher diopter (200 – 400) range
- Adult and pediatric incontinence supplies and pads
- Leashes and collars for service animals

Table 3: Accommodating Medication Needs in Shelters

Community medical needs shelter planners need to accommodate the regular medication needs that enable disabled and special need population to remain independent directly or through contracted pharmacies
Separate refrigeration storage for medication
Special medicine containers designed for the sensory impaired and those with poor dexterity
Pre-set insulin syringe with caps/covers Color coded medicine containers
Multi-day pre-pour container

Table 4: DME Supplies Commonly Needed in the Home

Community emergency shelter planning needs to provide some stock on-hand for the emergency DME supplies commonly needed in the home of those disabled or impaired by mobility and sensory impairment, and those required for independence outside the home
Assistive devices like regular and quad canes, walkers, safety rollers and Crutches Folding White Canes Manual Wheelchair and Rolling chairs
Portable Ramp Shower Chair Bathtub seats
Large Handled Eating Utensils Flexible Straws Two Handled Drinking Mug Leash And Collar For Service Animal Oxygen, Portable oxygen tanks, Oxygen regulators, Oxygen tubing Drainage bags for catheters Standard ostomy supplies and dressings, and Incontinence pads Bedpans, urinal, Emesis basin Hearing Assistive Technology (HAT) and batteries for same Simple support surfaces (e.g. Egg-crate Pad), Lambs wool pads Basic diabetic supplies Adult and pediatric incontinence supplies

DISASTER DRILLS

Disasters affect communities as a whole. Unfortunately, disaster drills typically include only non-disabled adults as participants; as a result, response systems are not being appropriately challenged and evaluated. Participants in disaster drills should reflect the population of the community.

- 5.1 Run drills and exercises in the community, with at least 5% of participants being disabled (adults and children). If the community's disabled population is greater than 5%, increase the percentage of disabled participants.
- 5.2 Incorporate any required equipment, assistive devices, or service animals used by people with disabilities in drills or exercises, because these can pose challenges during disaster response.
- 5.3 Set specific, measurable goals for meeting the needs of individuals with disabilities when planning emergency drills and exercises.
- 5.4 Include a well-developed mental health component in all disaster drills and exercises.
- 5.5 Include disability experts and individuals with disabilities in the planning of disaster drills and exercises. Actively recruit individuals who are deaf-blind, deaf, hard of hearing, late deafened, and oral deaf to test available communication techniques and communication equipment and to troubleshoot any unforeseen problems.
- 5.6 Include individuals with disabilities, not only as disaster victims, but also as observers or data controllers to effectively evaluate drills and exercises.
- 5.7 Ensure that locations of disaster drills and exercises are compliant with ADA rules for accessibility (can be accessed at <http://www.access-board.gov/ADA-ABA/summary.htm>).
- 5.8 Include as a required component of all after action reports (AAR) a disabilities section to assess the incorporation of the needs of person with disabilities in the drill

COMMUNITY PREPAREDNESS

- 6.1 Create a special needs oversight position at federal, state and local levels to assure that emergency planning issues at the federal, state, and local levels address the needs of special populations. This office would have the vested responsibility, authority, and resources for providing overall leadership guidance and coordination of all emergency preparedness, disaster relief, and recovery operations on behalf of special populations which includes disabled, aging and pediatric populations.
- 6.2 Create an oversight task force as part of federal, state and local emergency planning agencies that includes emergency managers and other emergency-related professionals, as well as qualified disability leaders and recognized subject matter experts in the field of emergency preparedness, for people with disabilities.
- 6.3 Incorporate the inclusion of special needs issues into grant application processes at federal, state, and local funding levels. Ensure that deliverables include the unique emergency need of disabled and aging populations.
- 6.4 Require that all after action reports (AAR) at the federal, state and local level includes a disabilities section to assess the incorporation of the needs of person with disabilities in the event and to identify areas for improvement.

Role of People with Disabilities in the Planning Process

- 6.4 Foster partnering of emergency management with community resources, including recruitment of individuals who have sensory or mobility impairments, in the planning and evaluation processes. For example, if a shelter location is being assessed for wheelchair accessibility, a person with mobility impairment who uses a wheelchair should be involved in the evaluation of the property.
- 6.5 Include disability subject matter experts or representatives from state agencies that serve people with disabilities in each state emergency operation center.
- 6.6 Actively recruit professionals in the field of disabilities for the citizen corps, CERT, and MRC teams.

INDIVIDUAL PREPAREDNESS

- 7.1 Encourage all individuals with sensory impairments or other disability to have in the home a device tailored to specific needs that can receive accessible emergency warning information. If the device runs on electricity, it should have a battery back-up.
- 7.2 Use Web-based and wireless technologies to promote community emergency alert networks. Examples of community alert communications systems currently include the following:
- Outbound automated telephone calls
 - Automated pager alert systems
 - Wireless radio alerts systems
 - Simple text messaging alert devices
 - All-hazards alert radio (weather radio)
 - GPS-enabled electronic devices to identify residences of and track disabled individuals
- 7.3 Encourage individuals with disabilities to assemble personal disaster kits, including a list of any special equipment (and instructions for use) that need to remain with them if evacuated. Include a list of all medications currently being taken, dosage, prescribing physician, any special equipment (including instructions for use) needed to take the medications, and any medication storage requirements (e.g., refrigeration). For those with complex medical histories, including a summary of the medical record may be prudent.
- 7.4 Create checklists, within organizations that deal with specific disabilities, which are specific to their population. Examples include the following:
- Braille-labeled medicine containers
 - Insulin pens, special syringes for individuals with visual impairments
 - Diabetes glucometers with extra battery and test strips
 - Talking pill containers for individuals with visual impairments

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Families with children who have special health care needs will have additional considerations. Pediatricians and other health care providers should advise families of children with special health care needs on the following activities:

- 8.1 Notify utility companies to provide emergency support during a disaster. Help create contingency plans if the utility company is not able to provide an alternative power source in the event of power loss.
- 8.2 Maintain medications and equipment in case of supply disruptions during emergencies.
- 8.3 Know how to obtain additional medications and equipment during a disaster or emergency.
- 8.4 Train family members to assume the role of in-home health care providers who may not be available during a disaster.
- 8.5 Keep up-to-date emergency information to provide health care workers with the patient's medical information in case the regular care provider is not available.
- 8.6 Create a 72-hour or longer emergency preparedness kit.

CONTINUITY OF CARE

- 9.1 Develop systems that provide rapid dissemination of medical information related to the medical history and health care needs of vulnerable populations.
- 9.2 When an area is declared a disaster area, allow anyone living in zip code(s) of areas declared disaster areas to use their government (e.g., Medicaid) or nongovernmental health insurance in other areas without penalty.
- 9.3 Require both private and public health care insurers to develop a reimbursement and approval mechanism to allow stockpiling of certain essential medical needs. Medicare and Medicaid Services (CMS) and federal insurance regulation must allow reimbursement for replacement assistive technology in times of disasters.
- 9.4 Develop a universal, accessible (according to the ADA definition of accessible communication) approach to notify power companies to provide emergency power options to individuals whose medical equipment require a power source.
- 9.5 Fund, through the Department of Homeland Security and the Department of Health and Human Services, the creation of redundant community educational resources to ensure continuity of care to the entire population; include available care providers, accessible pharmaceuticals, durable medical equipment, alternative and accessible housing and transportation, as well as information on reimbursement.
- 9.6 Create a mechanism, including a point of contact between available resources and the potential consumers, at the county or equivalent level to ensure that resources are kept up to date. Feed information from this mechanism into a national database to coordinate resources, while co-existing with current point-of-entry systems. This resource must reach out to groups within disabled communities that are not regularly represented at emergency preparedness planning meetings and conferences.
- 9.7 Support development, at the federal level, of universal data standards for emerging medical identification systems (e.g., Medic Alert bracelets, smart cards, chips, IDs).
- 9.8 Assess HIPAA regulations for appropriateness during and after disaster, with the possibility that some aspects of HIPAA may be waived during a declared disaster or emergency to care for the public most efficiently.
- 9.9 All regulatory bodies, in conjunction with providers and other Federal, State, and local entities, should identify regulatory barriers to emergency response and collaboratively agree upon appropriate solutions to issues regarding, but not limited to scope of practice, supervision requirements, travel restrictions, plans of care and documentation requirements.

STRATEGIC NATIONAL STOCKPILE

- 10.1 Include durable medical goods and technology equipment to be used during times of emergencies in the Strategic National Stockpile. For example, the amount of DME required in the SNS should be figured the same way as the medications, based on the needs of the general population.
- 10.2 Include psychiatrists on committees advising on the composition of Strategic National Stockpile to provide guidance on the inclusion of psychiatric medications.

MENTAL HEALTH NEEDS

- 11.1 Set mental health needs standards and guidelines for federal agencies that state and local governments can follow.
- 11.2 Require funding and government programs to incorporate the disability community into the actual development of the disaster mental health program to ensure outreach methods are accurate and services are appropriate.
- 11.3 Integrate mental health guidelines for people with disabilities in disasters into government programs, recognizing that people with disabilities may have additional unique issues. Adopt such guidelines at the state and local levels. Include specialists in disability issues and mental health specialists with expertise in disability issues in the assessment of mental health needs during a disaster of individuals with disabilities.
- 11.4 Include provision of support services for crisis counselors and administrators in all programs.
- 11.5 Assure that children's mental health needs are addressed separately from adult mental health needs and are based on the unique mental health needs of children.
- 11.6 Develop and mandate programs to assist mental health relief workers and administrators to better cope with their own feelings of the disaster, secondary trauma (as a result of the work), compassion fatigue, and stress associated with initiating a program under such difficult, emotionally charged, and constrained circumstances.
- 11.7 Develop relations with all organizations, including faith-based, that work with and support the disability community before disasters and in preparedness and mitigation.

FEDERAL DISASTER RESPONSE PROGRAMS

- 12.1 Include a component for people with disabilities in any created crisis-counseling programs in a federally declared disaster.
- 12.2 Ensure accessibility and reasonable accommodations within all crisis-counseling programs.
- 12.3 Make interpreters, transliterators, and/or CART captioners readily available for meetings and counseling sessions, without solely depending on disability agencies that may be providing disaster mental health services. In other words, all agencies should be able to readily access interpreters or other forms of communication access as needed.
- 12.4 Require that all federal after action reports (AAR) include a disabilities section to assess the incorporation of the needs of person with disabilities in the event and to identify areas for improvement.

SPECIALIZED TRAINING: EMERGENCY PLANNERS & RESPONDERS

Clinical Providers

- 13.1 Provide specific training to medical providers who normally perform triage during a mass care incident or disaster on assessing individuals with disabilities using common rapid triage tools.
- 13.2 Include specific objectives in educational curricula that focus on assessing disabled and impaired individuals, including medical and clinical considerations in managing these patients.

Mental Health Practitioners

- 13.3 Recruit mental health practitioners who are experienced in working with individuals who are deaf or hard of hearing and who are skilled in communication techniques for Red Cross, CERT, or other emergency preparedness training. Those practitioners should receive identification and priority travel to medical facilities, mass dispensing sites, or shelters to deliver services as needed.
- 13.4 Provide mental health volunteers with specialized training in early psychosocial intervention before an event.

Shelter Managers and Staff

- 13.5 Provide training for shelter managers and staff about the disabled and special needs population with regards to DME, technology, and medication that needs to be in place in community shelters. FEMA has developed a comprehensive training course, "Emergency Planning and Special Needs Populations," designed for emergency planners that provides an excellent framework for training content.
- 13.6 Provide training for emergency personnel in decontamination processes that result in removal and/or disposal of critical adaptive technology (e.g., cochlear implant processors, hearing aids, personal assistive communication devices). Ensure that emergency personnel are aware that removal or disposal of these items could create a situation in which it is difficult or impossible for individuals with hearing impairments to understand and respond properly to instructions.
- 13.7 Provide training for emergency services personnel, medical staff, volunteers, mental health counselors, and others staffing medical facilities, mass dispensing sites, and/or shelters in communication modes and techniques of communicating with

people who have a hearing impairment. Include alternative ways of communicating in an emergency, such as using available assistive listening devices, pen and paper, gestures or basic tactile communication, as well as how to find an interpreter and HAT in an emergency.

- 13.8 Develop a tool kit for emergency planners with resources that facilitate the integration of considerations for individuals with disabilities. Include information on current best practices for emergency communication, set-up of shelters, recovery efforts, working with service animals, etc.
- 13.9 Mandate training of first responders and emergency managers in effective communication methods (Braille, large print, sighted reader, CCTV, accessible signage, etc), auxiliary aides and devices (canes, human guide, service animals, etc), and effective practices for service delivery.
- 13.10 Facilitate training by an online course developed by the Department of Homeland Security. Encourage the development of practical EMS education that includes training on responding to individuals with disabilities in the initial and ongoing certification for all levels of responders.

People with Disabilities and Caretakers

- 13.11 Enlist people with disabilities to participate both as trained team members and instructors in Community Emergency Response Teams (CERT).
- 13.12 Train interpreters, children of deaf adults, and community members who are deaf in emergency response.

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

CONCLUSIONS

This conference represented a major step forward in the preparedness for disaster and terrorist events, and resulted in a set of recommendations and guidelines to initially address the specific needs of individuals with disabilities as members of a community affected by disaster.

The development of these recommendations and guidelines are only the first step in improving disaster, terrorism and public health emergency preparedness. The next step is to ensure that these recommendations reach the individuals with the authority to make decisions regarding their adoption and to develop an agenda. This will be accomplished by sending the information to the many federal agencies with responsibility for disaster and terrorism preparedness, (i.e., FEMA, Department of Homeland Security, Department of Education, and Department of Health and Human Services, which includes the CDC, HRSA, Maternal and Child Health Bureau, Agency for Healthcare Research and Quality, SAMHSA, FDA, and the Office of Emergency Preparedness).

Keeping in mind that all disasters are local emergencies first, this information should also be distributed to the state offices of emergency management, state departments of health, and state departments of EMS. These agencies will be encouraged and assisted in implementing these recommendations and guidelines and directed to forward the information to their counterparts in local government.

Finally, the information will also be sent to congressional leaders who oversee the agencies that are responsible for preparedness and who can pass legislation to enable implementation of these recommendations and guidelines. As with much progress and research, this agenda will require strong funding and initiative at the federal level to be successful.

ABBREVIATIONS

ADA	Americans with Disabilities Act (1990)
AHRQ	Agency for Healthcare Research and Quality
ARC	American Red Cross
CART	Communication Access Real-time Translation
CDC	Centers for Disease Control and Prevention
CERT	Community Emergency Response Team
CCTV	Closed Circuit Television
CMS	Centers for Medicare and Medicaid
CSHCN	Children with Special Health Care Needs
DHS	Department of Homeland Security
DMAT(s)	Disaster Medical Assistance Team(s)
DME	Durable medical equipment
EMS	Emergency medical services
EMSC	Emergency Medical Services for Children
FCC	Federal Communications Commission
FDA	Food and Drug Administration
FEMA	Federal Emergency Management Agency
HAT	Hearing Assisted Technology
HRSA	Health Resources Services Administration
HIPPA	Health Insurance Portability and Accountability Act
MCHB	Maternal and Child Health Bureau
NCI	Neurocognitive impairment
NIH	National Institutes of Health
NDMS	National Disaster Medical System
MRC	Medical Reserve Corps
PERS	Personal Emergency Response System
TTY	Text telephone or teletypewriter
VRI	Video Remote Interpreting
VRS	Video Relay Services

APPENDIX: Assistive Technologies

Personal Emergency Response System (PERS)

PERS is an electronic device that enables an individual to summon help in an emergency (also called a Medical Emergency Response System). A PERS has three components: a small radio transmitter (a help button carried or worn by the user), a console connected to the user's telephone, and an emergency response center that monitors calls. When emergency help (medical, fire, or police) is needed, the PERS user presses the transmitter's help button. It sends a radio signal to the console. The console automatically dials one or more pre-selected emergency telephone numbers. Most systems can dial out even if the phone is in use or off the hook. (This is called "seizing the line.") Most PERS are programmed to telephone an emergency response center.

Source: American Association of Retired Persons

REVERSE 911[®]

REVERSE 911[®] is a communications system that uses a patented combination of database and GIS mapping technologies to deliver outbound notifications.

Assistive Technology for Hearing Impaired

Communication Access Real-time Translation (CART)

CART is a service that facilitates communication between people who use speech to express themselves and people unable to fully understand spoken language due to significant hearing loss.

A CART reporter types phonetic short-hand outlines onto the keyboard of a 24-key stenograph machine connected to a computer. The shorthand outlines are sent from the stenotype machine to the computer, equipped with a shorthand dictionary and a special software program that translates the outlines, with less than a one-second delay, into English text. The text is then displayed on a computer monitor. Additional technology such as display panels and overhead projectors allows the text to be read by many people at the same time. This is the same technology and service used to provide real-time captioning for live television programs such as news and sports events.

CART allows a person with hearing impairment to read the verbatim proceedings of a meeting or class in "real-time" and thus become an active participant. The information entered by the reporter can also be saved on a disk and printed out for use as notes or a record of meeting activities. The Americans with Disabilities Act specifically

recognized CART as an assistive technology that affords “effective communication access.”

Hearing Assistive Technology (HAT)

HAT refers to any technology that makes sound accessible to people with hearing impairment. The process of making sound accessible is accomplished through amplification of sound or using other senses to convey meaning (such as lights and vibrations). For example, alert sounds, such as doorbells, telephone rings, smoke detectors, and pagers, can be made accessible through flashing lights.

Tele-Typewriter (TTY)/Telecommunication Device for the Deaf (TDD)

TTYs (also called Telecommunication Devices for the Deaf (TDD) and text telephones) are terminals used for two-way text conversation over a telephone line. The TTY looks like a small typewriter with a display screen. It takes a typewritten message and transforms each letter of the message into tones that are sent to a second TTY via a telephone line. The receiving TTY then converts the tones back into letters visible on the TTY display screen. They are used by people who are deaf, hard of hearing or speech impaired for telephone conversation. These devices allow individuals with hearing or speech impairments to communicate directly via telephone with another person who is also using this device because the conversation is typed, not spoken. The devices come in many forms, including computer software programs. Most are completely portable, but some are located in a fixed position such as public pay phones. Some TTY/TDDs have especially large print displays to assist people with visual impairment, and others are capable of generating paper print-outs.

Video Remote Interpreting (VRI)

Video Remote Interpreting (VRI) uses videoconferencing equipment to provide sign language interpreting services. Videoconferencing equipment is set up in the room where the deaf and hearing person are located. An interpreter is at the call center. This interpreter uses a head set to hear what the hearing person says. The interpreter signs to a camera everything the hearing person speaks. The deaf person can see the interpreter on a monitor. When the deaf person replies, the interpreter sees and speaks the interpretation. VRI is especially useful in rural areas where there may be a lack of qualified interpreters.

Assistive Technology for Visually Impaired

Closed Circuit Television (CCTV)

CCTVs are specially designed to enlarge printed material for people who have low vision and can no longer comfortably use glasses or special lenses to read regular size

print. A video camera focuses on the printed page, and the print is then enlarged and displayed on a monitor. Through the use of a CCTV, an individual can change the level of magnification and the contrast, maneuver around the whole screen, or focus on select areas.

Narrative Description

Narrative or oral description is verbal description by a sighted person of actions, settings, and other visual stimuli for the benefit of people with visual impairments. A descriptive narrator speaks into a microphone contained within a facemask that retains the narrator's voice and excludes outside noise. The narrator's voice is then transmitted on a designated audio channel, much like the secondary audio channel (SAP) used for foreign languages on television programs. The descriptive narration audience receives the narrator's transmitted voice via headphones carrying the designated audio channel. On-site live descriptive narration "paints" with words, actions and visual information, such as graphics, videos, and PowerPoint presentations. Additionally, before and during breaks within a live event, the descriptive narrator reveals the layout of the event using a clock as a point of reference.

Screen Readers

Screen Reader is the commonly used name for Voice Output Technology. Screen readers are used by those with visual disabilities to replace the visual display traditionally viewed on a monitor. Hardware and software produce synthesized voice output for text displayed on the computer screen, as well as for keystrokes entered on the keyboard.

Note: Screen readers cannot translate PDF files; consequently, emergency preparedness documents in PDF format should also be available as Word documents.

Additional Methods of Communication

American Sign Language (ASL)

ASL is a complete, complex language that uses signs made with the hands and other movements, including facial expressions and postures of the body. It is the first language of many deaf North Americans, and one of several communication options available to deaf people. ASL is said to be the fourth most commonly used language in the United States (National Institute on Deafness and Other Communication Disorders (NIDCD), one of the National Institutes of Health).

Tactile Communication for Deaf-Blind

There are several methods of tactile signing including the following:

- Tactile Fingerspelling, also called Deafblind Alphabet: Every word is spelled out using a manual alphabet. Letters are produced onto the palm of the receiver's hand. Other simple signs like a tap for "yes" or a rubbing motion for "no" may be included.
- Hands on Signing: The receiver's hands are placed lightly on the back of the hands of the signer to read the signs through touch and movement. The sign language used in hand-over-hand signing is often a slightly modified version of the local Deaf Sign Language
- Tracking: The receiver holds the wrists of the signer to keep signs within the field of vision and to gain information from the signer's movements. This is sometimes used when the receiver has a limited field of vision.

REFERENCE TABLES

Table 1: Minimum Requirements for Communication in Shelters

All medical facilities, mass dispensing sites and shelters must have available and easily accessible:
Hearing Assistive Technology (HAT), written instruction on the operation of the technology and floor plans which detail where HAT is located
Instructions for staff on where to find sign language interpreters and VRI and what to do until the interpreter arrives.
Signage for consumers indicating where people who are deaf or hard of hearing will find interpreters, CART services, HAT, TTYs, amplified phones, visual display of announcements and/or other communication accommodations.
Videos with open captions and/or written instructions.
Pen and paper

Note: Descriptions of communication technology can be found on page 42.

Table 2: Criteria for Exclusion of Service Animals

Under the following conditions, service animals can be excluded from a shelter, medical facility or emergency vehicle:
If the animal is a direct threat to the emergency workers' or shelter's ability to provide services to others.
If the animal demonstrates aggressive behavior and can not be controlled by its handler
If the animal does not meet the definition of a service animal

Note: Service animal means any guide dog, hearing signal dog or other animal individually trained to do work or perform tasks for the benefit of an individual with a disability including, but not limited to guiding individuals with impaired vision, alerting individuals with impaired hearing to intruders or sounds, providing minimal protection or rescue work, pulling a wheelchair or retrieving medicine and medical supplies.

Table 3: Accommodating Medication Needs in Shelters

Community medical needs shelter planners need to accommodate the regular medication needs that enable disabled and special need population to remain independent directly or through contracted pharmacies
Separate refrigeration storage for medication
Special medicine containers designed for the sensory impaired and those with poor dexterity
Pre-set insulin syringe with caps/covers Color coded medicine containers
Multi-day pre-pour container

Table 4: DME Supplies Commonly Needed in the Home

Community emergency shelter planning needs to provide some stock on-hand for the emergency DME supplies commonly needed in the home of those disabled or impaired by mobility and sensory impairment, and those required for independence outside the home

Assistive devices like regular and quad canes, walkers, safety rollers and Crutches
Folding White Canes
Manual Wheelchair and Rolling chairs

Portable Ramp
Shower Chair
Bathtub seats

Large Handled Eating Utensils
Flexible Straws
Two Handled Drinking Mug
Leash And Collar For Service Animal
Oxygen, Portable oxygen tanks, Oxygen regulators, Oxygen tubing
Drainage bags for catheters
Standard ostomy supplies and dressings, and Incontinence pads
Bedpans, urinal, Emesis basin
Hearing Assistive Technology (HAT) and batteries for same
Simple support surfaces (e.g. Egg-crate Pad), Lambs wool pads
Basic diabetic supplies
Adult and pediatric incontinence supplies

NOTES