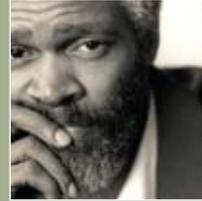


WE CAN DO

BETTER



LESSONS LEARNED *for* PROTECTING
OLDER PERSONS IN DISASTERS

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WE CAN DO BETTER: LESSONS LEARNED FOR PROTECTING OLDER PERSONS IN DISASTERS

By MARY JO GIBSON *With* MICHELE HAYUNGA

The AARP Public Policy Institute, formed in 1985, is part of the Policy and Strategy Group at AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of importance to mid-life and older Americans. This publication represents part of that effort.

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ACKNOWLEDGMENTS

Many individuals have made significant contributions to this report. First, we wish to thank Michele Hayunga, who reported the proceedings of the AARP conference held on December 1, 2005. That conference was spearheaded by Dalmer Hoskins, managing director of policy at AARP.

Others who played key roles in organizing the conference were Elizabeth Clemmer, associate director of AARP's Public Policy Institute (PPI), Lisa Stand and Molly Long of Office of Policy Integration (OPI), and many members of the PPI Independent Living and Long-Term Care Team, especially Andrew Kochera and Sheel Pandya. Shirley Ross and Tyaisha Williams of PPI and Gwen Craig of the OPI provided logistical support. Critical guidance in organizing the conference was also provided by Hilary Styron of the National Organization on Disability. Julie Cohn, AARP regional director, and Bentley Lipscomb, AARP Florida state director, chaired panels, and Lucy Theilheimer, director of AARP Strategic Planning, led the stimulating and lively participant discussions that occurred throughout the day. Last but far from least, we thank Dr. Georges Benjamin, the keynote speaker and the executive director of the American Public Health Association, the 12 conference panelists from diverse organizations, and more than 100 participants who shared their expertise and resources.

Ari Houser of AARP's PPI played a central role in developing the three questions used in the Harris Interactive survey of persons age 50 and older, which was conducted in November, 2005, under the leadership of Diana Gravitch. Shelly-Ann Sinclair of PPI provided valuable editorial assistance.

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MARY JO GIBSON

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FOREWORD

The searing images of older persons affected by hurricanes Katrina and Rita in the Gulf Coast region in September 2005 sparked the writing of this report and the conference upon which it is based. Along with the millions of other Americans watching the news during that month and even as we go to press, we at AARP are convinced that our nation can surely do better in protecting older persons in disasters.

In search of lessons to help prevent what happened in the Gulf Coast from ever happening again, John Rother asked the Public Policy Institute to bring together a diverse group of national leaders and state and local representatives “who have been there.” This report condenses the key lessons learned from that intense day of discussions in December 2005. In addition, Mary Jo Gibson of AARP’s Public Policy Institute integrated diverse sources from an extensive literature review to identify the special vulnerabilities of older persons during disasters *and* to provide concrete examples of promising practices and helpful resources.

We hope that this report and its recommendations help to spark action at federal, state, and local levels of government to better protect older persons and persons with disabilities during disasters. We also hope that it helps to further dialogue and partnerships among key networks that have so much to learn from one another: the aging community, the disability community, and the emergency preparedness and disaster relief communities.

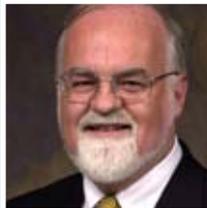
ELIZABETH CLEMMER

Associate Director, AARP Public Policy Institute

I.

EXECUTIVE SUMMARY

The information in this report is provided as a public service in an effort to offer a range of suggestions and practical resources helpful to diverse audiences. The information and opinions presented are entirely the responsibility of the public and private entities or individuals being cited. This information may not be interpreted as an endorsement in any way by AARP.



“We must do as much as we can to make sure what happened in the aftermath of the hurricanes does not happen again.”

JOHN ROTHER

INTRODUCTION

An estimated 1,330 people, many of whom were elderly, were killed as a result of Hurricane Katrina. The vast majority of fatalities were in the New Orleans metropolitan area, with substantial numbers in Mississippi as well. In Louisiana, roughly 71 percent of the victims were older than age 60, and 47 percent of those were over age 75. Most of these victims died in their homes and communities; at least 68—some of whom were allegedly abandoned by their caretakers—were found in nursing homes. As of February 17, 2006, 2,096 people from the Gulf Coast were still reported missing.¹ For the older people who survived, the emergency response problems often resulted in inappropriate displacements, deterioration in health and functioning, or other harms, even though these are more difficult to quantify.

This report and the conference on which it is based were sparked by those events and signal AARP's commitment to better protecting older persons in disasters.

Older persons are likely to be disproportionately vulnerable during disasters because they are more likely to have chronic illnesses; functional limitations; and sensory, physical, and cognitive disabilities than are those of younger ages. In addition, they often take multiple medications, rely on formal or informal caregivers for assistance, and, especially at advanced ages, experience general “frailty.” Other factors that increase older persons' vulnerability in emergencies and disasters include living alone and in isolated rural areas.

On December 1, 2005, AARP convened a diverse group of government officials at federal, state, and local levels; emergency preparedness and response experts; relief organizations; and aging and disability advocates to identify lessons learned and share promising practices in protecting older persons in disasters. The goal of the conference was to bring the right stakeholders together to explore workable strategies for the future to better protect older persons in both the community and nursing homes. All of the panelists and most of the participants were “people who have been there.”

PURPOSE AND METHODS

This report presents highlights from the AARP conference, an extensive literature review, and data from a short survey of persons ages 50 and older conducted by Harris Interactive on behalf of AARP in November 2005. The intent of the report is to provide suggestions and links to practical tools and resources that will be helpful to policy makers at federal, state, and local levels; nongovernmental organizations; and older persons, family caregivers, and persons with disabilities. While the vulnerabilities of older persons in disasters overlap with those of other vulnerable populations, including younger persons with disabilities, older persons also face special health and other risks with advancing age.

The report addresses the following issues as they relate to older persons in the community and in nursing homes: (1) planning and communications; (2) identifying who will need help and what

kind of help, including registries, tracking, and medications; and (3) evacuating older persons, including transportation and “special needs” shelters.

These topics span two phases of disaster events—preparedness and response. The recovery phase of disasters, while critically important and currently under public scrutiny in the aftermath of hurricanes Katrina and Rita in the Gulf Coast, is beyond the scope of this report.

CONFERENCE HIGHLIGHTS AND OTHER LESSONS LEARNED

Planning and Communications

Older persons and persons with disabilities, whose needs may overlap, face special risks during disasters. Government emergency planning documents or processes at any level—federal, state, or local—rarely mention the needs of vulnerable older persons.

Among the recommendations made at the conference and in the literature are:

- Establish clear lines of authority among federal, local, and state governments as well as with private sector entities, including nursing homes, with regard to emergency management, especially evacuations of older persons.
- Engage in integrated/coordinated planning that begins at the neighborhood/facility and community levels but reaches to the state, regional, or even national level. Develop strong relationships and partnerships before disaster strikes.
- Provide public information on emergency preparedness to older persons and persons with disabilities that is appropriate to their needs and in accessible formats. As part of these focused education efforts, include information about the need to evacuate if an order to evacuate is given and what can happen if one does not do so.
- Explore the psychological as well as other barriers to heeding orders to evacuate, and ways to overcome them.
- Educate older persons and others to have emergency supplies ready to “shelter in place” for three to six days without power or being able to go out for food, water, or medicines, and to make a personal plan to meet their “special needs,” such as temporary back-up power for home dialysis.
- Train emergency management personnel in the needs of older persons and train aging network personnel in emergency management procedures.
- Practice plans regularly and include older persons and persons with disabilities in emergency drills and training exercises.
- Make better use of aging and disability experts in planning for and responding to disasters, including making better use of “aging network” resources and expertise.
- Ensure that the federal Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities also addresses the needs of vulnerable older persons who do not have disabilities.

- Create a team that mirrors the management structure of the federal National Response Plan to support the needs of older persons and persons with disabilities. One component of this team would be a permanent, designated liaison who would report directly to the principal federal officer (PFO).
- Provide more funding to the U.S. Administration on Aging (AoA) to develop and implement its emergency management responsibilities on behalf of older persons.
- Use a combination of methods for public emergency notifications in alternative formats, such as both audible and visual cues to reach populations with sensory and cognitive disabilities, and develop close working relationships with the media to publicize the availability of hotlines in alternative formats.
- Have at least three backup communication plans and test at least one of them regularly.

Identifying Who Needs Help and What Kind of Help

A key finding from the Harris Interactive survey is that about **13 million persons age 50 or older in the U.S. say they will need help to evacuate, and about half of these individuals will require help from someone outside of their household.** This proportion increases with advancing age.

Among the recommendations made at the conference and in the literature:

- Make identifying, registering, and tracking older persons who cannot evacuate on their own a high priority in local communities.
- Have aging services staff work with clients to develop individualized emergency plans and coordinate this work with local emergency management personnel and those responsible for “special needs” registries.
- Encourage voluntary use of “special needs” registries.
- Pay special attention to the needs of persons with dementia and take advantage of special programs, such as the Alzheimer’s Association Safe Return Program.
- Use special tools being developed to quickly assess the needs of frail older adults who have been evacuated to settings in the community.
- When preparing for disasters in nursing homes, ensure that residents and their medical information, including medications, can be identified during and after evacuation.
- Move toward a national electronic health record that protects individual privacy, learning from experiences of the U.S. Department of Veterans Affairs, which has a consolidated records system that uses bar codes and captures medical history, medications, and the like.
- In the interim, encourage individuals to write down their medications, including dosage, allergies, and conditions, on an index card and keep it with them at all times.
- Encourage consumers to take advantage of their local pharmacy’s computer tracking system by filling out a medication profile that lists all current medications, and to take a waterproof bag with their current medications, even if the bottle is empty, if they have to evacuate.
- Invest in better technology to track individuals during emergencies, such as using “smartcard” chips, while protecting individuals’ privacy and confidentiality.

Evacuating Older Persons: How and to Where?

The lack of specific evacuation plans for older persons in the community and in nursing homes is a major problem. Among the key practical issues are how to transport older persons and persons with disabilities safely and provide accessible shelters that are appropriately equipped and staffed to meet essential needs.

Among the recommendations made at the conference and in the literature:

- Plan at the community level to provide accessible transportation for persons with mobility limitations or low vision or for others unable to transport themselves.
- Provide a notification hotline or other mechanism to alert hospitals, nursing homes, and other residential facilities to begin early evacuations, and contact previously identified older persons and persons with disabilities in the community who will take longer to evacuate.
- Identify older persons and persons with disabilities who will need emergency transportation.
- Include plans for transporting emergency supplies and appropriate labeling of medications when evacuating nursing home residents.
- Coordinate plans with transportation vendors for nursing homes residents with other facilities and community groups to avoid having too many providers relying upon too few vendors.
- Plan for transportation for long-term care facility staff as well as truck rentals to get water, food, and medical supplies to facilities.
- Require long-term care facilities, under federal and state licensing standards, to have well-developed, feasible, and practiced emergency plans for residents that are on file with the state; these plans should include evacuating residents, transporting medical records and properly labeled medications and supplies, and providing for care outside the facility.
- Plan for evacuating the families of long-term care facility staff and providing for their care.
- Adopt “special needs” shelter legislation at the state level that provides for appropriate registration, transportation, staffing, and discharge policies. In addition, “special needs” shelter policies should provide for coordination with community-based aging and disability organizations.
- Address barriers to the accessibility of public shelters by persons with disabilities, and the credentialing of health personnel so they can gain access to shelters and other evacuation sites.
- Provide for a sufficient number of shelters that have backup generators to power life-sustaining medical devices.

CONCLUSIONS

One overarching lesson can be drawn from the conference, Harris Interactive survey results, and literature review:

Integrating the needs of vulnerable older persons into existing emergency planning efforts at federal, state, and local levels is a pressing need. These plans encompass all phases of preparedness and response, including plans for evacuation and recovery. Simply adding the words, “older adults,” in planning documents to a list of other vulnerable populations whose needs should be addressed is a necessary first step, but it is far from sufficient.

In addition, over the course of the conference, five key challenges emerged. These issues pertain not only to older persons but also to vulnerable populations of all ages.

- The first challenge is clarifying the roles of the many different entities with responsibility in emergency management, including federal, state, and local governments. Important deliberations are needed about “who should do what and when.” Such discussions must also take into account the growing role of nonprofit organizations and corporate partners.
- There is also a tremendous need for public education around emergency preparedness. More must be done to reach older persons; persons with disabilities; non-English speakers; and those living in rural settings or institutions or alone in the community.
- The third issue is the need for better coordination and communication. Part of the solution is to build relationships before a disaster strikes and to develop better mechanisms to promote integrated planning.
- Another opportunity for improvement lies in identification and tracking—of both people and health information—which will require policy changes and a shift in public attitudes. Such changes will need to include appropriate data security safeguards.
- The fifth issue is appropriately defining and addressing the “special needs” of vulnerable populations. While there is much debate around roles and responsibilities, everyone agrees that planning for vulnerable populations can no longer be an afterthought.

“Probably the greatest challenge moving forward will be to keep emergency preparedness for older persons and persons with disabilities high on the public agenda,” observed Dalmer Hoskins, AARP’s managing director of policy, in concluding remarks at the conference. “It is a much bigger job than any single organization can undertake, and it touches every sector of our society. The question is how to work together.”

II.

INTRODUCTION

Hurricanes in the Gulf Coast region; tornadoes in Missouri; floods in Tennessee; blizzards in Maine; wildfires in Texas, California, and Arizona—natural disasters affect many parts of the country each year. In addition, concerns about potential terrorist attacks continue. In each emergency, and in every phase of each emergency, vulnerable older adults face challenges that are different from those of their younger counterparts.



“We are gathered here
to make sure history
doesn’t repeat itself.”

BILL NOVELLI

It has often been said that disasters reveal underlying weaknesses in how a country operates. The catastrophic hurricanes that plagued the Gulf Coast in 2005 brought to light severe shortcomings in the way America plans for the evacuation, sheltering, and safe return of some of its most vulnerable citizens. This report and the conference on which it is based were sparked by those events and signals AARP's concern about the need to better protect older persons in disasters.

On December 1, 2005, AARP convened a diverse group of government officials at federal, state, and local levels; emergency preparedness and response experts; relief organizations; and aging and disability advocates to identify lessons learned and share promising practices. The goal of the conference was to bring the right stakeholders together to explore workable strategies for the future to better protect older persons in both the community and nursing homes.

A WAKE-UP CALL

An estimated 1,330 people, many of whom were elderly, were killed as a result of Hurricane Katrina. The vast majority of fatalities were in the New Orleans metropolitan area, with substantial numbers in Mississippi as well. In Louisiana, roughly 71 percent of the victims were older than 60, and 47 percent of those were over 77. Most of these victims died in their homes and communities; at least 68—some of whom were allegedly abandoned by their caretakers—were found in nursing homes. As of February 17, 2006, 2,096 people from the Gulf Coast were still reported missing.² For the older persons who survived, the emergency response problems often resulted in inappropriate displacement, deterioration in health and functioning, or other harms, even though these are more difficult to quantify.³

Opening the AARP conference, AARP CEO William D. Novelli said, “We are gathered here today to make sure history doesn’t repeat itself.”

“These catastrophic events have taught us we have to pay greater attention to evacuating, identifying, and ensuring the safe return of the thousands of frail older adults living on their own or in care facilities,” said Bill Novelli. “Much of the suffering and loss was undoubtedly preventable, and it must not be allowed to happen again.”

“These catastrophic events have taught us we have to pay greater attention to evacuating, identifying, and ensuring the safe return of the thousands of frail older adults living on their own or in care facilities.”

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Mr. Novelli pointed out that older Americans and persons with disabilities face several unique challenges in disasters. Many have limited mobility, cope with chronic illnesses, and depend on medications for survival. Those whose homes were destroyed not only lost a place to live, but their largest retirement security as well. Others suffered tremendously because they were evacuated too late, couldn’t access needed resources, or simply slipped through the cracks.

While it was the tragedies that garnered the most headlines, he said, there were also notable successes. In many instances, care facilities successfully evacuated patients, saving thousands of lives. Neighborhood buddy programs and specialized shelters proved effective in some cases as well, raising several important questions:

- Why did emergency plans work in some communities, while ending in tragedy elsewhere?
- Who should ultimately be responsible for ensuring proper evacuation?
- Can community-based, voluntary efforts make a significant difference to the survival rates of older people?

Mr. Novelli emphasized that the goal should not be to assign blame, but rather to develop workable plans that will prevent vulnerable members of a community from being the most likely to suffer. He added that older adults live in a variety of settings, including nursing homes, assisted living facilities, and their own homes, and disaster-planning efforts must take all of those circumstances into account.

Legislation already requires hospitals and nursing homes to have emergency plans, Mr. Novelli noted, but some of those plans proved virtually inoperable when tested. In many other instances, however, care facilities successfully evacuated patients, saving the lives of thousands of older people.

“The recent tragedies are reminders that disasters imperil us all, but there are especially serious threats to older Americans and people with disabilities,” he said. “Let’s act with resolve now to minimize the needless loss of life when the next disaster strikes.”

IT’S ALL ABOUT RELATIONSHIPS

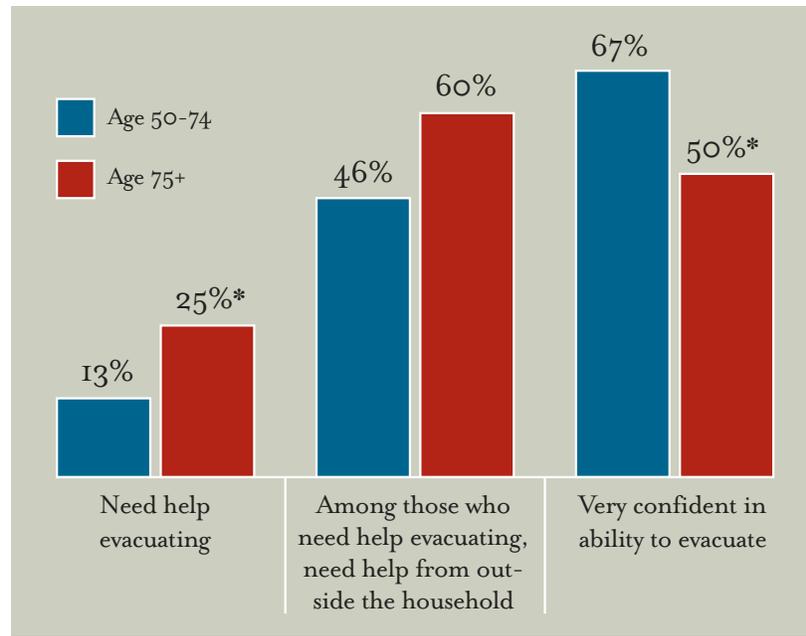
“There is perhaps no area where relationships are more critical than in disaster planning and response, and these relationships must be built before disasters strike,” said John Rother, AARP director of policy and strategy, in opening remarks at the conference. He emphasized that a key purpose of the conference was to bring together the right stakeholders to begin the conversation.

Mr. Rother underscored his appreciation for the groundbreaking efforts of leaders from the disability community, many of whom were present at the conference, in placing emergency preparedness issues for persons with disabilities on the national agenda.

“There is perhaps no area where relationships are more critical than in disaster planning and response, and these relationships must be built before disasters strike.”

JOHN ROTHER

HELP NEEDED EVACUATING IN EVENT OF NATURAL DISASTER, BY AGE, 2005



Source: Harris Interactive® on behalf of AARP, nationwide telephone survey of 1,648 U.S. adults age 50 or older, November 10-20, 2005.

*Difference from 50-74 is statistically significant at 5%.

By the Numbers

AARP also worked with Harris Interactive to survey people age 50 and older about their self-perceived ability to evacuate their homes in a natural disaster, reported Mr. Rother. (See the Appendix for the full survey results.) A key finding is that about **13 million persons age 50 or older in the U.S. say they will need help to evacuate, and about half of these individuals will require help from someone outside of their household.** This proportion increases with advancing age.

Highlights from the findings include:

- About 15 percent of Americans age 50 or older say *they would not be able to evacuate from their homes without assistance* in the event of a natural disaster; of that 15 percent, half would require help from someone outside the household.
- As a whole, Americans age 50 or older are very confident in their ability to evacuate their homes in the event of a natural disaster: 81 percent of Americans age 50 or older are “confident” or “very confident” in their ability to evacuate; however, 14 percent are only “somewhat confident,” and 3 percent are “not at all confident.”

- Those who are age 75 or older more frequently said they would need help evacuating (25 percent versus 13 percent of persons age 50–74). They are also less confident in their ability to evacuate than are their younger counterparts.
- Women, minorities, people living alone, and persons with lower incomes or less education are more likely to need help evacuating and are less confident in their ability to evacuate.

“The recent tragedies are reminders that disasters imperil us all, but there are especially serious threats to older Americans and people with disabilities.”

BILL NOVELLI

Although the AARP/Harris Interactive survey did not ask respondents if they had a disability, the National Organization on Disability was able to provide telling data from earlier polls. In a 2004 survey, it found that only 39 percent of persons with disabilities have made plans to evacuate from their homes if needed, and only 44 percent say they know whom to contact about emergency plans in their community.

“We have a lot of work to do,” Mr. Rother observed, adding, “there are vulnerable older Americans and people with disabilities who are often not confident of their ability to evacuate and not sure where to turn for help. We must do as much as we can to make sure what happened in the aftermath of the hurricanes does not happen again.”

STRUCTURE OF REPORT AND METHODS

This report presents highlights from the AARP conference, an extensive literature review, and the results of the Harris Interactive survey conducted for AARP. The intent is to provide suggestions and links to practical tools and resources that will be helpful to policymakers at federal, state, and local levels; nongovernmental organizations; and older persons, family caregivers, and persons with disabilities.

We first present the special risks faced by older persons in disasters, followed by a brief description of the nation’s emergency management system, especially as it relates to older persons.

We then focus on the key topics discussed at the conference: (A) planning and communications; (B) registries, tracking systems, medical records, and medications; and (C) evacuating older persons, including transportation and sheltering.

Within each major section, we present (1) a brief overview of the topic and some of the main questions to be addressed; (2) highlights of panelist remarks and audience discussion during the AARP conference; and (3) other lessons learned and promising practices drawn from a review of the literature and from information provided by participants and panelists at the conference.

The topics we address in this report span two phases of disaster events—preparedness and response. (See Glossary of Preparedness Terms in the Appendix for definitions of these and other terms.) The recovery phase of disasters, while critically important and currently being scrutinized in the aftermath of hurricanes Katrina and Rita in the Gulf Coast, is beyond the scope of this report.

III.

SPECIAL RISKS FACED BY OLDER PERSONS IN DISASTERS

Older persons and persons with disabilities tend to face different risks in disasters from those faced by persons in the general adult population. While there is a large volume of literature on disasters, relatively little of it focuses on older persons at any disaster stage—preparedness, response, and recovery. Fortunately, considerable literature related to the needs of persons with disabilities in disasters is also available, and much of it is directly pertinent to issues affecting many older persons because rates of disability increase with age.



“Older persons and
persons with disabilities
must be more than just
an afterthought.”

HILARY STYRON

Health and functional status are key factors in the ability of persons of any age to respond to disasters. Older persons are likely to be disproportionately vulnerable because they are more likely to have chronic illnesses; functional limitations; and sensory, physical, and cognitive disabilities than are younger persons. In addition, especially at advanced ages, some older persons experience general “frailty,” which itself can result in disability.

Older persons, of course, are as heterogeneous as other age groups. In fact, differences among individuals are more likely to increase, rather than decrease, as they age.⁴ While we focus in this report on the special risks they face, many older persons report “excellent” or “very good” health status⁵ and a desire to remain actively engaged in their communities.⁶ Many older persons are underused resources in preparing for and responding to disasters. For example, their experience and judgment, which increase with age, are important attributes when responding to crises. Thus, in addition to needing better protections for older persons in disasters, better use should be made of their talents and skills; for example, in identifying the most vulnerable in their neighborhoods, taking on direct disaster relief roles, and helping to manage and coordinate services in shelters.⁷

MEDICAL CONDITIONS AND FUNCTIONAL DISABILITIES MAKE OLDER PERSONS MORE VULNERABLE

Many older persons:

- Have chronic illnesses. The great majority of Medicare beneficiaries age 65 and older experience two or more chronic conditions at the same time.⁹ For example, the prevalence of arthritis increases with age, often making it difficult to move quickly when leaving homes or workplaces or to stand in line for lengthy periods. Sleeping on cold, hard, damp surfaces or getting up from low cots or mattresses on the floor can exacerbate chronic health problems. Chronic illnesses can increase the risk of pneumonia 40-150 times.¹⁰
- Have altered levels of immune function and increased risk of infectious diseases.¹¹
- Take prescription medicines. Fifty-one percent of persons age 65 and older take three or more prescription drugs per month.¹² Changes in medications can result in a host of serious consequences, ranging from confusion to falling to dangerous changes in blood pressure. Many older persons, and persons of any age with multiple chronic conditions, have complicated, individualized medication regimens that cannot be interrupted without serious, possibly fatal, complications.
- Are “frail.” Medical researchers and others now recognize that frailty is a syndrome that is distinct from both the normal aging process and disability. Key characteristics of frailty include unintentional weight loss, muscle weakness, slow walking speed, exhaustion, and low physical activity. It is estimated that about 20 percent of persons age 80 or older are frail, aside from any acute and chronic conditions they may have.¹³

- Have difficulties with physical functioning, such as being able to walk two or three blocks or reach up over one's head. In 2002, 31 percent of women 65 and older reported being unable to perform at least one of five physical activities.¹⁴
- Use some type of assistive equipment, such as canes, wheelchairs, walkers, or medical equipment, such as oxygen.
- Have sensory impairments. Close to half of men age 65 and older and nearly one-third of women reported trouble hearing in 2002. In addition, vision difficulties affect 18 percent of the older population.¹⁵
- Have memory impairments, especially at advanced ages. Fifteen percent of men and 11 percent of women age 65 and older experienced moderate or severe memory impairment in 2002; at age 85, about one-third of both men and women experience moderate or severe memory impairment.¹⁶ Persons with cognitive impairments may need help in understanding the severity of the risk and in making timely decisions.
- Have distinct mental health needs; for example, the rate of suicide deaths is much higher for older white men than for any other age group, including teenagers.¹⁷
- Experience hypothermia or hyperthermia.¹⁸

Almost three-quarters (73 percent) of Hurricane Katrina-related deaths in the New Orleans area were among persons age 60 and over, although they comprised only 15 percent of the population in New Orleans.⁸

SOCIODEMOGRAPHIC CHARACTERISTICS MAKE OLDER PERSONS MORE VULNERABLE

Compared with the general adult population, older persons are more likely to:

- Have lower literacy levels than the general adult population¹⁹, which can present difficulties in understanding directions and can complicate or slow communications.
- Not speak English if they are immigrants age 65 and older.²⁰
- Live alone. As age increases and widowhood rates rise, the percentage of the population living alone increases steeply. Half of persons age 85 or older lived alone in 2002.²¹
- Live in rural areas, especially persons age 75 or older. Persons living in remote rural areas may experience prolonged isolation after flooding or other disasters.
- Not be able to drive, which makes evacuation more difficult.
- Rely on informal caregivers, such as family and friends, for assistance with tasks of daily living. More than 90 percent of persons 65 and older with disabilities who receive assistance receive informal care; nearly two-thirds rely solely on informal caregivers.²²

PSYCHOSOCIAL CHARACTERISTICS MAKE OLDER PERSONS MORE VULNERABLE

Many older persons:

- Are reluctant to accept any public assistance; for example, because of the perceived stigma and the belief that if they accept assistance, someone else who may need it more will have to go without it.²³
- Fear losing independence or being institutionalized, which may affect their behavior.²⁴
- Experience “transfer trauma” that can result in illness or even death after being moved from nursing homes. Also, some older persons may regard the need to rebuild homes and life patterns, or undertake complex procedures for applying for aid, as too formidable, leading to inaction and potential depression.²⁵
- Experience multiple losses (e.g., spouse, friends, home, income, physical abilities), whose cumulative effect can heighten the risk of illness or death and make recovery more difficult.²⁶
- Are “invisible” to relief workers or emergency personnel. The following observations, based on international research by the world’s largest global relief organization focused on older persons, HelpAge International,²⁷ highlight the problem in many countries.
 - Relief organizations often fail to see or understand the needs and contributions of older people during disasters. Research identified an almost universal lack of consultation.
 - “Older people fight a losing battle in the competition for resources. In the chaos of emergencies, older people are physically less able to struggle for food or to travel far to find what they need. Many spoke of using valuable energy to reach central relief points only to arrive too late and find little or nothing left...”
- Are targeted by con artists and fraudulent contractors who financially exploit victims during a disaster.²⁸

IV.

THE EMERGENCY MANAGEMENT SYSTEM AND OLDER AMERICANS

To find ways to better protect older persons and persons with disabilities in disasters, one needs to understand the complex structure of the nation's emergency management system. Federal emergency management involves federal agencies, state and local governments, tribal organizations, voluntary organizations, the private sector—including nursing homes and hospitals, and individuals and families.



“In addition to having well-thought-out plans, leaders must be prepared to improvise in a disaster.”

CAPT. HENRY LOPEZ

The roles and responsibilities of many of these entities are currently under scrutiny by the Executive Branch, congressional committees, federal agencies, many state governments, and others. Since the AARP conference was held, several reports by congressional and federal entities have identified serious problems in the nation's emergency management system **that pertain specifically to older persons**. These problems include, for example, the lack of specific evacuation plans for older persons in the community at state and local levels. In addition, while state and local governments can order evacuations, nursing homes and hospitals may be exempt from these orders. Administrators at these facilities often are responsible for deciding whether to evacuate patients or to “shelter in place” during a disaster.²⁹

THE FEDERAL LEVEL

The Department Homeland Security (DHS) has administered many, but not all, of the federal emergency management policies since it was established in 2003, following the terrorist attacks of September 11, 2001. The Federal Emergency Management Agency (FEMA), which now is part of DHS, is the federal agency that establishes the guidelines and grants for state and local emergency management. The components of comprehensive emergency management with which FEMA is charged by statute include mitigation, planning, response, and recovery.³⁰

FEMA relies on a system known as the National Response Plan (NRP), which is the framework for how the federal government assists in managing emergencies of national significance.³¹ The NRP integrates “federal domestic prevention, preparedness, response and recovery plans into one ‘all discipline, all-hazard’ plan.”³² This plan provides guidelines, identifies agency roles and responsibilities, and creates structure and common language for emergency management for first response.³³

The NRP was released by former DHS Secretary Tom Ridge in January 2005. This document establishes the framework within which multiple federal agencies and voluntary agencies, such as the American Red Cross, operate when a catastrophe occurs.

The Stafford Act authorizes the President to issue major disaster declarations authorizing federal agencies to provide assistance to states overwhelmed by disasters. The presidential declaration identifies specific areas, by county, that have suffered the greatest impact.

When the President declares a national disaster, many federal agencies and departments are involved in emergency responses. The Administration on Aging (AoA), part of the Department of Health and Human Services, is one such entity that is especially relevant to older persons. The Older Americans Act (OAA) enables the AoA to reimburse state units on aging and Title VI tribal organizations for additional expenses incurred in the aftermath of a disaster; these funds may be used for such services as outreach, counseling, extra meals and food, in-home clean up, emergency transportation, and medications.³⁴

Federal officials used another federal system, the National Disaster Medical System (NDMS), to help evacuate patients from hospitals during Hurricane Katrina—the first time the system has been used to evacuate such a large number of patients. The NDMS, which is responsible for coordinating the federal medical response in the event of a declared disaster, is a partnership among the departments of Defense, Health and Human Services, Homeland Security, and Veteran’s Affairs.³⁵ In 2002, Congress transferred NDMS from HHS to DHS, which is responsible for the program’s activation, administration, and funding.³⁶ NDMS can assist hospitals with patient evacuations and has agreements with nonfederal hospitals to receive evacuated patients; however, it does not have agreements with nursing homes and “was not set up nor is it currently configured to provide assistance evacuating nursing homes.”³⁷

Disasters are usually grouped in the following categories:⁴⁴

- Natural: hurricanes, tornados, earthquakes, wildfires, floods, snow/ice storms, volcanic
- Man-made: large fires, transportation accidents, hazardous materials, terrorist attacks, weapons of mass destruction (WMD), civil unrest
- Technological: utilities, information technology (IT) failures
- Public health emergency: infectious diseases, such as epidemics; heat emergencies

STATE LEVEL

It is the responsibility of the governor to ask that the President issue disaster declarations for the state. Each state has an Office of Emergency Management and an emergency management plan, including evacuation plans. Governors are charged with issuing the order to evacuate and implementing the state’s emergency plans. State units on aging also have an important role in delivering assistance and resources to seniors during federal disasters and emergencies.

LOCAL LEVEL

Local offices of emergency management also have emergency response plans. Local and state governments can order evacuations of the population, or segments of it, during emergencies.

Local emergency personnel include the local office of emergency management, fire department, law enforcement, and medical personnel, often known as “first responders.” In addition, the “aging network,” local Area Agencies on Aging (AAAs) and aging service providers have staff expertise and programs that can be a crucial source of assistance in disasters, including (1) information and referral services; (2) nutrition programs; (3) in-home services programs for homebound elders who may require evacuation; (4) senior centers, some of which have capacity to provide food and/or shelter during a disaster; transportation services; and a volunteer network.³⁸

Nongovernmental relief agencies (such as the American Red Cross and the Salvation Army) are often at disaster sites to assist with feeding, sheltering, and other activities immediately after a disaster.

PRIVATE SECTOR: HOSPITALS AND NURSING HOMES

To receive Medicare and Medicaid funding, nursing homes and hospitals are required to maintain emergency plans.³⁹ They are also required by federal law to (1) have evacuation plans in the event of a disaster; (2) review evacuation procedures periodically with staff; (3) train new employees in emergency procedures; and (4) hold unannounced drills using those procedures. State law may or may not require other types of facilities, such as assisted living facilities, to have a comprehensive plan in place.⁴⁰

Hospitals and nursing homes also are required to have such emergency plans to receive accreditation from the Joint Commission on the Accreditation of Healthcare Organizations, as are assisted living facilities. (The Joint Commission is a not-for-profit accrediting organization that sets and regulates quality standards for a number of health care organizations in the United States.) However, relatively few nursing homes and assisted living facilities have sought accreditation by the Joint Commission.⁴¹

While state and local governments can order evacuations, both hospitals and nursing homes may be exempt from these orders.⁴² Consequently, administrators at these facilities often have responsibility for deciding whether to evacuate patients or to “shelter in place” during a disaster.⁴³

V.

PRINCIPLES FOR PREPAREDNESS

Dr. Georges Benjamin, executive director of the American Public Health Association, gave the keynote address at the conference.

“The middle of a disaster is not the time to begin exchanging business cards,” joked Georges Benjamin, M.D., executive director of the American Public Health Association. He began his luncheon address by suggesting several areas to focus on to improve emergency preparedness.



“It’s essential to develop
working relationships
with stakeholders before
a disaster strikes.”

DR. GEORGES BENJAMIN

“The first step is to know who is in your household and what their needs are going to be,” Dr. Benjamin said. He urged people to be prepared to “shelter in place” for at least 72 hours. Likewise, community associations should think through how they will be able to provide care for vulnerable persons who may need assistance.

It’s essential to develop working relationships with stakeholders before a disaster strikes, Dr. Benjamin emphasized. He encouraged individuals to become engaged in developing plans for themselves, their families, their workplace, and their community.

Dr. Benjamin stressed that it’s best to build on existing systems that will be familiar during a crisis. New components should be added primarily to serve as backup.

Two areas requiring special attention are communications and logistical support. “You need to have a Plan B, and a Plan C, and Plan D, but you should practice Plan A,” Dr. Benjamin said. “Plan A needs to be understood and predictable. That way, when something goes wrong, you have a base of reference.”

To improve responders’ ability to treat patients, Dr. Benjamin called for the creation of a national electronic health record system. In the meantime, he suggested people write their medications, allergies, and conditions on the back of a business card and keep that card with them at all times.

“We have to practice our plans and then share and evaluate what we do.”

DR. GEORGES
BENJAMIN

Tracking is another area in which technology could be used. “Bar codes are inexpensive and flexible, and with the Internet we ought to be able to find better ways to track ourselves,” Dr. Benjamin said. “The technology exists, but we have to decide to invest in a system.”

Perhaps one of the most important principles is to turn lessons learned into lessons applied. “We have to practice our plans and then share and evaluate what we do,”

Dr. Benjamin said. “Too often, we spend millions of dollars on drills, and then put the information on the shelf.”

PLANNING FOR A PANDEMIC

The push to improve disaster planning has gained even more momentum in the face of a potential flu pandemic. The concerns are well founded, considering 36,000 Americans die every year from the regular flu—and many others die of pneumonia—even though effective vaccines exist.

Dr. Benjamin explained that a pandemic flu results when a virus with a new genetic structure, from which people have no immunity, spreads quickly from person to person. This occurred in the United States in 1918, causing widespread death and a major interruption of society.

H5N1, the bird virus causing concern today, is lethal to both humans and birds, but, thus far, it hasn't been easy for people to catch. "The 60 individuals who died were all people who handled the birds," Dr. Benjamin said. "But we are concerned that this virus—or one like it—could mutate and become a worldwide infection that could be easily spread."

Dr. Benjamin noted there have been vast improvements in medicine since 1918, but he acknowledged that significant challenges remain. "We know a lot about this virus and can watch it transform, yet we don't have an effective vaccine at this point," he said. "There are antiviral agents, but the one company that makes them doesn't have the production capacity necessary."

"We're in the early days of planning for pandemic flu," Dr. Benjamin said. "Many states have plans, but it's very important for communities to become engaged in the process and talk to their local and state health officials."

Dr. Benjamin outlined three possible scenarios should the pandemic flu strike: (1) where there is an adequate supply of an effective vaccine and antiviral agents that can be efficiently distributed; (2) where there is a limited supply requiring a public discourse on priorities; and (3) where no remedies exist, and the nation must cope with many of its systems interrupted for an extended period.

One key challenge will be how to address the millions of Americans who don't have health insurance, particularly since many of them are caregivers. "We need to look at the distribution system now, prioritize groups that serve vulnerable populations, and make sure the people who take care of

HHS recently issued a new tool to help medical offices and clinics prepare for a potential influenza pandemic. While the checklist was designed with a pandemic influenza in mind, it could be helpful in other types of emergencies.

Recommendations include:

- Incorporating pandemic influenza preparedness into emergency management planning;
- Having a plan for surveillance and detection of pandemic influenza in the population served;
- Having a communication plan identifying key public health contacts; the organization's point person for external communication and health care entities and that person's points of contact;
- Providing education and training to ensure that all personnel understand the implications of and control measures for pandemic influenza;
- Developing a plan for triage and management of patients during a pandemic;
- Developing an infection control plan; and
- Developing a vaccine and antiviral plan.

Copies of the "Medical Offices and Clinics Pandemics Influenza Planning Checklist," along with a "Pandemic Planning Update" and other planning information and checklists, including one for individuals, are available at www.pandemicflu.gov.

us don't end up spreading disease," Dr. Benjamin said. "The middle of a disaster is not the time to try to decide on priorities."

DISCUSSION FOLLOWING DR. BENJAMIN'S REMARKS

Comments during the question-and-answer period focused on how the lessons from Hurricane Katrina could be applied to preparing for a terrorist attack or a nuclear or biological disaster.

Perhaps the biggest realization is how difficult it is to move half a million people, Dr. Benjamin acknowledged. There is much discussion about how to get therapeutic interventions into an affected area and possibly to allow citizens to keep preventive agents, such as iodine tablets, in their homes.

With respect to a mass evacuation, Dr. Benjamin suggested that a combination of sheltering in place and a staged release of people from the affected area would be needed. He also reiterated the need to embrace technology to create a better system for tracking individuals.

Hilary Styron of the National Organization on Disability shared information about a biometric smartcard chip, developed by one of her software vendors, that is part of an identification badge. The badges can be used to locate individuals in a building during an emergency and even distinguish someone who has voluntarily identified him or herself as having a "special need." "The capacity to track does exist," she said, "but we need to get past the confidentiality issue, and I'm not sure how it's going to happen or how long it will take."

VI.

LESSONS LEARNED AND PROMISING PRACTICES FOR PROTECTING OLDER PERSONS IN DISASTERS

In this section, we focus on the key topics discussed at the conference:

(A) planning and communications; (B) registries, tracking systems, medical records, and medications; and (C) evacuations of older persons, especially transportation and sheltering issues.

Within each of these topic areas, we present (1) a brief overview and some of the main questions to be addressed; (2) highlights of panelist remarks and audience discussion during the AARP conference; and (3) other promising practices and lessons learned from review of the literature and from information provided by participants and panelists at the conference.



“Planning is great,
but you have to carry
out the plan.”

WILLIAM LOKEY

IMPROVING PLANNING AND COMMUNICATIONS

The need to improve planning to protect older persons in disasters is underscored in a recent report by the U.S. Senate Committee on Health, Education, Labor and Pensions, which concluded, “many state and local governments do not have detailed evacuation plans for the elderly, and the federal government has no clear outlined responsibility for evacuating the elderly, unless a disaster is declared by the President upon request by a state governor.”⁴⁵

Among the questions explored at the AARP conference were:

- How can responses at the federal, state, and local levels be better coordinated with respect to meeting the needs of older persons; for example, are plans sufficiently detailed to identify who is in charge?
- How can the needs of older persons be integrated into existing plans at the federal, state, and local levels?
- How can first responders be trained in understanding the needs of vulnerable older adults and persons with disabilities?

In addition to the need for better planning, emergency communication procedures “make or break” effective management of an emergency. These procedures include the exchange of essential, timely information among agencies and others responsible for directing staff and resources as well as making emergency information available to the public through warning systems and media reports. Effective direct communications with older persons by first responders and others are also crucial. Among the issues are:

- How can all communication mechanisms, including television, radio, and telephones, which are the means by which most Americans are alerted to emergencies, be made accessible to older people and others with different types of disabilities?
- How can first responders, transportation providers, volunteers, and others be trained in communicating with people with hearing, speech, or visual disabilities?

Highlights from the AARP Conference

Roles and Responsibilities: A Federal Perspective

Emergency preparedness requires engagement at several levels, explained William Lokey, chief of FEMA’s Operations Branch Response Division and the federal coordinating officer in Louisiana during Hurricane Katrina. He outlined five layers of responsibility: the individual, the caregiver, local authorities, state agencies, and the federal government.

“Getting ready for disaster starts at home with the individual,” Mr. Lokey said. He stressed that individuals need to assess their situations and create a personal emergency preparedness plan. Likewise, caregivers, be they family or professional, must consider potential disasters and think through how they would be able to provide basic necessities.

Almost every local government entity has statutes requiring it to have an emergency plan, Mr. Lokey said. At the state level, agencies put forth preparedness requirements for organizations like hospitals and nursing homes, and the state outlines the governor's authority during a crisis.

With respect to the federal level, Mr. Lokey said that many agencies have a role in emergency preparedness; however, he stressed that "FEMA is not a federal 911. Federal assistance is, by law, supplemental, and it cannot take the place of other forms of assistance."

Mr. Lokey explained that, based on its authority under the Stafford Act, FEMA may only provide assistance when a governor requests it, and when the response needed is certified to be beyond the capabilities of the state. "We provide limited assistance to give people a safe, sanitary, and secure place to live," he said. "This includes grants, statutorily set at no more than \$5,200, to make emergency repairs to homes, and rental assistance for up to 18 months. We can also bring in commodities, such as food and water."

A policy debate is currently underway about whether the federal government's response capabilities should be expanded—and, if so—how such an expansion would be funded, Mr. Lokey said. "Hurricane Katrina went far beyond anything this nation has dealt with in the past, and the response wasn't as fast or robust as general expectation thought it should be."

Looking forward, Mr. Lokey offered four key themes for better preparedness:

- Educate the public to take care of themselves.
- Train first responders in the skills they need to respond to disasters that can be anticipated.
- Create a plan that outlines promises for what type of response the public can expect when disasters strike.
- Get acquainted ahead of time with the people who will need to work together when a disaster strikes.

Mr. Lokey closed by emphasizing, "Planning is great, but you have to carry out the plan." He called on the public to promote accountability by calling hospitals, nursing homes, and community leaders to ask what they have done to become prepared.

Partnerships and Planning: Lessons from Florida

"We need to change the way we plan from focusing on specific events to looking at broader processes and systems," said Judy Johnson, campus administrator of Covenant Village, sharing lessons learned during the hurricanes in Florida. She stressed the importance of thinking beyond the individual facility level, to the community, the region, or even the state.

A booklet, "Preparing for Disaster for People with Disabilities and other Special Needs," is available online from FEMA and the American Red Cross at www.redcross.org/images/pdfs/preparedness/A4497.pdf.

In planning for disasters, Ms. Johnson recommended assuming a worst-case scenario where all systems are interrupted, including water, fuel, power, and communications. “You need to think about the impact, not only on residents, but on staff as well,” she said. “How do they get to work, and how are they coping from a physical, economic, emotional, and structural standpoint?” Planning goals should address the need for more self-sufficiency, extended duration, and broader impact.

Ms. Johnson emphasized the value of developing strategic relationships, both locally and nationally, before a disaster strikes. As part of a multifacility organization, she was able to rely on her corporate headquarters in another part of the country to set up a hotline, access vital computer records, and send much needed cash. She called for integrated planning that would help all facilities have this type of backup available.

At the local level, it is essential to involve key vendors in emergency planning, Ms. Johnson explained. For example, if several local facilities contract with the same transportation company, will that vendor have the capacity to serve all of them during an area-wide evacuation?

For information on individual preparedness for persons with disabilities, go to www.nod.org/emergency/index.cfm.

One strategy that worked well in her facility during the hurricanes in Florida was its daily briefing for residents. “We had face-to-face contact with everyone in our community, which enabled us to give them information and assess who needed help.”

In closing, Ms. Johnson stressed the importance of ensuring that disaster planning efforts take into account preparation for the event, survival of the event, and post-event coping mechanisms. “How we respond in terms of creativity and compassion makes a huge difference in everyone’s ability to cope.”

Information and Service Delivery: Is It Needs-Appropriate?

“Many individuals with disabilities want to prepare for disasters, but they’re not finding information that is effective and appropriate to their needs,” said Hilary Styron, director of the National Organization on Disability’s (N.O.D.) Emergency Preparedness Initiative. She offered telling statistics from a 2004 survey her organization conducted of state and local emergency managers:

- Only 42 percent said “yes” when asked if they provide information to elderly or vulnerable populations on self-preparedness.
- Just 16 percent said they provide that information in an alternative format, such as Braille, large print, audio tapes, or in other languages.
- Of those 16 percent, the alternative format most commonly available was other languages.

Ms. Styron also shared observations from N.O.D.’s report on its Special Needs Assessment for Katrina Evacuees (SNAKE) project, which deployed field teams to capture a snapshot of service delivery to those with disabilities, seniors, and medically managed persons affected by the hurricane.

- A total of 85.7 percent of community-based groups surveyed that provide services to older people and those with disabilities did not know how to link with their emergency management system. Many thought they could get in touch with FEMA or their local emergency management office by calling 911.
- A total of 80 percent of shelters visited did not have access to TTY, and only 30 percent had a sign language interpreter.
- In many of the shelters, there were problems assessing whether a person had “special needs”, and no durable medical equipment stockpiles were on hand.

If plans are not tested before they are put into practice, they will not work. Exercises can range from discussions of specific scenarios to full-scale drills involving community members. Older persons should be included in these processes, and the needs of persons with mobility and other functional limitations should be addressed.⁴⁶

To better utilize aging and disability experts in planning for and responding to disasters, a key recommendation of the SNAKE report is to create a team that mirrors the management structure of the National Response Plan to support disability and senior issues. One component of this team would be a permanent, designated liaison who would report directly to the principal federal officer (PFO).

The report also suggests either creating a national stockpile of durable medical equipment or adding to the Centers for Disease Control and Prevention’s Strategic National Stockpile. Such action could ensure that supplies, such as wheelchairs, respirators, and augmentative communication devices, are readily available to communities in the event of a disaster.

Ms. Styron stressed that provisions for seniors and persons with disabilities must be more than just an afterthought. She highlighted the need to share local statistics about these populations with emergency managers, so they would have a better sense of who is in their jurisdiction before a disaster strikes.

Communication: Tools and Strategies

Responders need to have a better understanding of the challenges faced by older adults and persons with disabilities, echoed Michael Weston, director of Emergency Field Operations for the U.S. Administration on Aging. “When we’re looking at responding to the needs of seniors and persons with disabilities, there is no segment of the population that will be more labor intensive,” he said. “If that is not factored into plans, the dynamics of the job will be very difficult.”

Mr. Weston recounted an experience in Maryland following Hurricane Isabel, where, although only 12 percent of the population was over age 60, seniors represented about 40 percent of those who registered as in need through FEMA. To give staff more insight into how to serve this population, he conducted “Aging 101” training, which included making staff members try to complete the registration process with modifications that affected their vision, hearing, and motor skills.

Having appropriate educational materials before a disaster strikes is also key, said Mr. Weston. In Florida, he helped develop a hurricane preparedness guide geared toward older adults, which was later expanded to be an overall disaster preparedness guide. Mr. Weston also created a Special Needs Picture Board, which helps overcome communication barriers stemming from variations in language, culture, and cognitive abilities.

Mr. Weston noted that many older adults do not live in retirement communities or care facilities, but rather, rely on an informal network of community services to maintain their quality of life. He stressed that it is important to rebuild these connections when people are displaced. For example, in the case of using trailers as temporary housing, he recommended setting aside one out of every 50 trailers to serve as a community or senior center. “This could give us a head start in building a sense of community to help people get used to the ‘new normal.’”

Discussion Highlights: Planning and Communications

(See the Appendix for a fuller summary of discussion following this panel.)

- Organizations should become familiar with the National Response Plan (www.dhs.gov) as well as local and state plans. National Voluntary Organizations Active in Disaster (www.nvoad.org) is another example of a coordination mechanism already in existence. *(American Red Cross representative)*
- More emergency preparedness planning is needed at the community level. Engaging neighborhood leaders and block wardens is an effective way to keep vulnerable persons from slipping through the cracks. *(Ms. Styron, National Organization on Disability)*
- Local emergency managers often do not seem interested in working with home care agencies. A larger-scale plan for coordination is necessary. *(National Association for Home Care representative)*
- It’s essential to practice inclusive management. Rather than planning for persons with disabilities, agencies and organizations should ask them what their needs are. *(Maryland Department of Disabilities representative)*
- It’s time to transition from problem identification to effective action. The framework already exists for integrated and coordinated response, but the challenge is to demand accountability from all levels of government and ensure there are resources in place so plans can be carried out. *(International Association of Fire Chiefs representative)*

Other Promising Practices and Lessons Learned

Planning

At the Federal Level

- An Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities was established by Executive Order in July 2004 to address the needs of persons with disabilities and provide guidance for federal agencies. *This council, however, is not charged with addressing the needs of vulnerable older persons without disabilities.*

The council comprises senior leadership from 23 federal departments and agencies, ranging from the Department of Homeland Security (DHS) to the Federal Communications Commission (FCC) and the Department of Transportation (DOT). Its work is done in eight subcommittees addressing issues such as accessible communication systems, accessible transportation systems, and health-related concerns. For more information about the council, go to www.dhs.gov/disabilitypreparedness.

- The recent White House report, “The Federal Response to Hurricane Katrina: Lessons Learned,” recommended that DHS require state and local governments to develop, implement, and test emergency evacuation plans: “These plans should address establishing first-aid stations, tracking and coordinating movements of evacuees, evacuating pets, unaccompanied minors, the elderly, and evacuating people who lack the means to leave voluntarily.”⁴⁷
- The U.S. Senate Committee on Health, Education, Labor and Pensions recently investigated the 2005 Gulf Coast hurricanes and found a general, nationwide absence of disaster evacuation plans for persons age 65 or older. Its report, released February 16, 2005, called on federal and state officials to develop a coordinated emergency response plan that is proactive rather than reactive to keep older persons safe, including:
 - developing a coordinated response for the evacuation of the elderly;
 - creating a tracking system to locate and identify elderly victims during a disaster; and
 - establishing a clear delineation of responsibility during times of disaster at the federal, state, local, and institutional level with regard to evacuation of the elderly.⁴⁸
- The 2005 White House Conference on Aging included the following recommendation as one of its 50 top-ranked priorities (ranked #26⁴⁹): “Encourage the Development of a Coordinated Federal, State, and Local Emergency Response Plan for Seniors in the Event of Public Health Emergencies or Disasters.” The recommendation calls upon HHS, AoA, and the Office of the

The AoA is developing an important new resource that will encourage members of the aging network to become proactive partners in emergency response systems. Its draft *Emergency Assistance Guide*, a comprehensive set of technical assistance materials, is designed to help the aging network and others prepare and plan for management of major emergencies or disaster events. This document, which includes many practical tools, will be available at www.aoa.gov in the near future. The Guide makes specific recommendations to AAAs and aging service providers for procedures to include in a comprehensive planning process, including:

- Preparedness, including developing phone trees; educating staff and community agencies, including training events; and developing a list of older persons who may be at risk
- Emergency response, including communication procedures and immediate response to those affected
- Evacuation or sheltering procedures, including use of congregate dining sites

Assistant Secretary for Health and Emergency Preparedness to work with state and local governments so that emergency preparedness and disaster planning is unique to the needs of seniors and is coordinated at the federal, state, and local level.

To help older adults prepare for emergencies, AoA has recently released *Just in Case: Emergency Readiness for Older Adults and Caregivers*, (available on the AoA website: www.aoa.gov/PROF/aoaprogram/caregiver/overview/Just_in_Case030706_links.pdf or at www.aginginstride.org/emergencyprep/default.htm). This document consists of a checklist of steps older adults and their caregivers can take and the items they should gather to help them prepare for emergencies.

- The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families. In its recent (2005) report, *Saving Lives: Including People with Disabilities in Emergency Planning*, also available in alternative formats at www.ncd.gov, NCD recommends the following:
 - DHS should establish a Disability Access Advisory Group, in addition to the Interagency Coordinating Council on Emergency Preparedness, made up of qualified persons with disabilities and others with disability-specific disaster experience who meet regularly with senior officials to discuss issues and challenges.
 - The DHS Directorate of Emergency Preparedness and Response should integrate information on persons with disabilities into general preparedness materials. It also should inform readers and information users on how to access more customized materials.
 - The DHS Office of Civil Rights and Civil Liberties should issue guidance for state and local emergency planning departments regularly to reinforce their legal obligation to comply with the Americans with Disabilities Act (ADA) and sections 504 and 508 of the Rehabilitation Act in planning for, operating, and managing programs and services such as Citizen Corps, shelters, and other disaster services.
 - The FCC should develop stronger enforcement mechanisms to ensure that video programming distributors, including broadcasters, cable operators, and satellite television services, comply with their obligation to make emergency information accessible to people with hearing impairments.

At State and Local Levels

- Palm Beach, Florida, has detailed recommendations for developing a disaster plan for older adults based on interviews with key local and state experts and other research. The report, by the Center of Aging of Florida International University, concludes that such planning requires coordinated action among local organizations or by local organizations working collaboratively with state, federal, or other agencies that serve elders who are and who are not receiving services through the “system.” Agencies involved include: (1) the “aging services network”—specifically the AAAs, lead agencies, and aging service providers; (2) county officials, such as the Office of Emergency Management, police, and fire rescue; (3) state officials, such as the Department of Elder Affairs, Department of Health, and Agency for Health Care Administration; and federal officials, such as FEMA, HHS, and Centers for Disease Control and Prevention (CDC). The

report makes specific recommendations for allocating roles and responsibilities among agencies and organizations, evacuation, sheltering, provision of social and health care service after a disaster, and housing/relocation.⁵⁰

- Linn County, Iowa, which is home to a number of retirees, uses a geographic information system (GIS) program to put every nursing home and assisted living and congregate care facility in the county on an emergency management map. People who live at home and need help, and who register, are also put on the map, which is part of the county's broader plan for "special needs" residents, a model cited by the National Association of Counties.⁵¹
- Following the attacks on the World Trade Center, the Greater New York Hospital Association spearheaded a regional planning effort that brought together representatives of local, state, and federal agencies and providers representing hospitals and other services to ensure preparedness, including preparedness for "special needs" populations. The framework of this Emergency Preparedness Coordinating Council in place in the New York region can be applied in almost any area of the country, but "some party or entity must be the champion for the process." It does not matter whether it is someone from provider or human services or public health or emergency management agencies. In addition, the lead entity cannot lose sight of the "fact that preparedness is continual, and it must be collaborative."⁵²
- Also after September 11, 2001, five associations in New Jersey created an informal partnership, including the state hospital association, two state associations representing nursing facilities, the state primary care association (federally qualified health centers), and the home care association. They meet monthly to discuss and plan for disaster preparedness and to share resources. They also are collaborating on a unique disaster communications center, a Healthcare Emergency Communications Center, implemented with state grant funds.⁵³

Some older persons and persons with disabilities were left trapped for days near the disaster areas after the September 11 attacks. The International Longevity Center in New York City conducted interviews with representatives from emergency organizations, such as FEMA, and a wide range of organizations serving older persons to identify the critical issues in emergency preparedness for these vulnerable groups. Here are some of the recommendations that came out of those interviews:

- Create a system to identify community service providers and permit them to enter a disaster area to provide assistance and information to older and disabled people.
- Develop a comprehensive citywide plan, including a city map highlighting neighborhoods with a high concentration of older people as well as more detailed neighborhood maps. In addition, a comprehensive database of frail older people with contact information could be derived from client lists of service providers and census data and through voluntary reporting—use tenant and neighborhood organizations to identify those otherwise not identified.
- Disseminate information on public services and emergency planning several times a year.⁵⁴

- The Area Agency on Aging (AAA) of Southwest Florida seems to have learned more than its share of lessons after the area it serves bore the brunt of four successive hurricanes in a little over a month in 2004. According to Leigh Wade, its director,⁵⁷ the AAA had a disaster plan, was able to provide early warning of Hurricane Charley's arrival by calling older adults in its locale, and then responded to their needs by working side by side with other local, state, and federal agencies. Wade, however, points to wide variation by region and county in the degree of AAA involvement in coordinating disaster relief efforts as well as other barriers. She calls for removing barriers that prevent full participation by AAAs "on the ground," including obtaining adequate resources to permit active participation in emergency planning and response. For example, AAAs need better communications and technology to respond during emergencies, including multiple forms of communications, such as satellite phones, wireless Internet access, and systems that are compatible with equipment used by other local response agencies.

While the AAAs are often uniquely positioned to coordinate with other agencies in community-based services that older adults need, AoA has limited disaster funds, and the timing of FEMA funds to local providers can be delayed, according to Wade.

In Nursing Homes

The responsibility for both nursing home and hospital evacuations often falls to facility administrators, who indicate that facility plans are designed primarily to shelter in place and evacuation is typically a last resort, according to a preliminary evaluation by the Government Accountability Office (GAO).⁵⁸ Among nursing home administrators' considerations are the adequacy of resources for sheltering in place, risks to patients of evacuation, availability of transportation and a receiving facility to accept residents for a potentially lengthy period, and destruction of facility and community infrastructures.

It's Not Just a Good Idea: It's the Law.

Making local government emergency preparedness and response programs accessible to persons with disabilities is a critical part of the role of local government in protecting its citizenry from harm. Making these programs accessible is also required by the Americans with Disabilities Act of 1990.⁵⁵

On December 28, 2004, a landmark settlement in Montgomery County, Maryland, reinforced what disability advocates have been saying for years regarding the ADA and emergency evacuation planning. The lawsuit involved a nationwide retail store, a Maryland shopping mall, and a customer, Katie Savage, with multiple disabilities who used a scooter to travel independently. She became trapped in a shopping mall during an emergency evacuation. Under the ruling, Judge Debelius, of the Circuit Court of Montgomery County, found that "The ADA requires places of public accommodation to consider the needs of persons with disabilities in developing emergency evacuation plans."⁵⁶

- The Florida Association of Homes for the Aging (FAHA) has prepared “Blueprint for a Hurricane-Preparedness Plan for Nursing Homes and Assisted Living Facilities,” which lists specific recommendations for facility evacuation, logistics, communications, staffing, and patient care. FAHA also posts or disseminates a housing disaster evacuation preparation list for residents.

Tools:

“Questions Consumers Should Ask” is a fact sheet about emergency preparedness for residents and families in long-term care facilities prepared by the National Citizens’ Coalition for Nursing Home Reform (NCCNHR). This site also has a fact sheet for nursing home residents and their families affected by Hurricane Katrina: <http://nursinghomeaction.org>.

Communications

“Communication is the lifeline of emergency management... Fortunately, most emergency communication can be undertaken at minimal cost,” says the N.O.D. *Guide on Special Needs of People with Disabilities*.⁵⁹

- The FCC has launched outreach efforts to ensure that Telecommunications Relay Services (TRS) are a designated priority for service restoration in case of emergency or disaster.⁶⁰ TRS is a nationwide telecommunications system for persons with hearing and speech disabilities. When persons with these disabilities use a TTY, a type of machine with a keyboard and viewing screen to help in communicating over the phone, a relay operator or communications assistant can transmit and translate the call through the TRS transmission service.
- A **combination** of communication methods is often more effective and can reach more people than one method alone, such as using both audible and visual cues, according to the *ADA Guide for Local Governments* on making emergency programs more accessible to persons with disabilities.⁶¹ This guide also makes the following recommendations:
 - If the electric power supply is affected, telephone calls, auto-dialed TTY (teletypewriter) messages, text messaging, emails, and door-to-door contact with preregistered persons may be necessary.
 - Using open captioning on local TV stations in addition to incorporating other innovative uses of technology should be considered, as should such lower-tech

Examples of communication tools for first responders and other caregivers:⁶²

- Wired telephones, including pay phones
- Wireless telephones
- Pagers
- Computers/Internet
- Blackberry
- Ham radios (amateur radios), which can be more effective than other forms of communication because they can transmit voice messages as well as Morse code when there is difficulty transmitting audible messages

options as dispatching qualified sign language interpreters to assist in broadcasting emergency information provided to the media.

In addition, the media need to publicize the availability of hotlines and other tools in accessible formats, for example, TTY/TTD numbers, and to repeat the most essential emergency information frequently in a simple format for persons with cognitive impairments.

Other recommendations for making emergency information accessible to persons with disabilities include:⁶³

- Providing public information materials in alternate formats, including audiotape, electronic, and written materials in large type or braille.
- Captioning public service announcements (open or closed) for people who are deaf or hard of hearing.
- Coordinating with the disability community in planning trainings and alternate formats for materials.
- Ensuring that offices of emergency management (OEMs) and other government agencies have functioning Telecommunications Device for the Deaf (TDD aka TTY) as well as a public email address. These numbers and addresses should be published in all public information materials and websites.

Another tool: A “Reverse 911” system to alert residents during emergencies can have multiple uses, ranging from alerting residents to evacuations due to wildfires or other natural disasters; to power outages; to helping to find a missing person. For example, in Santa Barbara, California, the automated system software can call hundreds of homes an hour. A dispatcher can target a specific geographic area or a group of people, such as neighborhood watch leaders. Recently, a missing 85-year-old woman was found by a neighbor who was spurred by the 911 call to look around his property. Local officials say the system is a welcome addition to their tools for emergency notification, and while so far no one has complained about the automated calls, they caution that the system should not be overused.⁶⁴

IDENTIFYING WHO WILL NEED HELP AND WHAT KIND OF HELP: REGISTRIES, TRACKING, AND MEDICATIONS

In the aftermath of the recent Gulf Coast hurricanes, some of the most difficult challenges involved locating persons who urgently needed help, many of whom were older and had disabilities, and determining what types of health and rehabilitative services and other supports they needed.

Treatment of persons with chronic disease has “traditionally not been recognized as a public health or medical priority” when natural disasters strike. However, according to medical personnel interviewed in hurricane-affected areas, a leading concern was urgent treatment for people with diabetes, cardiovascular disease, hypertension, and kidney disease. Catastrophic disruptions in the medical infrastructure, including pharmacies, and severely compromised or nonexistent

access to medical care and medications were among the major problems,⁶⁵ raising such questions as:

- How can we identify older persons and others who will need help before an emergency?
- How can we communicate up-to-date medical information to first responders and others who need it?
- How can we ensure access to sufficient quantities of medications?
- How can we track evacuees who need special help?

Highlights from the AARP Conference

On the Frontlines: Lessons from Florida

“When you’re in a desperate situation, with no electricity and resources, you become the mother of invention,” said Janegale Boyd, president and CEO of the Florida Association of Homes for the Aging. She shared several successes and lessons learned over the last 15 months in Florida, which experienced eight hurricanes during that period.

Ms. Boyd praised Florida’s state agencies for reaching out to aging services associations in their planning and response efforts. “Our staff actually goes in and works the Emergency Operation Center desk,” she said. “I was in Palm Beach during Hurricane Wilma, and all assisted living, nursing home, and HUD [Department of Housing and Urban Development] housing issues came directly to the phone I was working.”

One challenge she experienced, however, was that state and local emergency operations centers do not share a common system for tracking emergency calls for assistance. Emergency requests for medications, evacuation, and the like are called into each County Emergency Operation Center, but the tracking communication systems are not linked and are not compatible with the state tracking system. Thus valuable time is spent calling, faxing, or emailing the status or request that needs bumping up to the state.

To better prepare for disasters, Ms. Boyd urged all case managers who work with older adults to develop a disaster plan for each of their clients. If seniors don’t have somewhere to go during a disaster, they need to be placed on the “special needs” shelter registry, which is maintained by the state Department of Health.

Convincing older adults to evacuate can often be a challenge, Ms. Boyd acknowledged. She suggested reminding those who wish to remain that they are not only putting their own lives at risk, but the lives of those who have to come rescue them as well.

From a policy standpoint, Ms. Boyd called for a notification hotline that would allow health care and elder care facilities to begin evacuations before the general public. “It costs \$100,000 per day to evacuate a facility, and our business interruption insurance will not kick in until the county has

declared an evacuation,” she explained. “There needs to be a prioritization for health care facilities to be notified, so they can begin evacuating before everyone else is on the road.”

Ms. Boyd also pointed to the need for improved tracking and delivery of essential supplies. She noted that most seniors cannot access transportation to “comfort stations,” nor are they able to wait in line for several hours. In the aftermath of the hurricanes, her association rented trucks to speed water, food, and medical supplies to FAHA’s members.

Similarly, cities and counties must develop backup plans for essentials like fuel delivery, since most local suppliers will be rendered inoperable. A plan is needed to get fuel to essential health care personnel and help personnel cut through red tape. One potential solution is a national identification card for essential health care personnel.

Communication is another major challenge. Ms. Boyd recommended that state agencies develop a private, central database of alternative contact numbers for aging services administrators. Her association is also looking into providing all of its members with satellite phones to ensure they can still communicate if cell phone towers are damaged.

One of the most pressing issues resulting from the hurricanes was seniors in need of medication, Ms. Boyd said. In 2004, 14,000 people ended up in emergency rooms because of medication and oxygen needs, and that number increased by 11,000, reaching 25,000 in 2005. “We need our national payers to work on a plan that will allow for dispensing of at least a two week supply and emergency refills,” she said, adding that dialysis is a serious concern as well.

Tracking evacuees is another large-scale problem. Ms. Boyd urges aging services providers to use wristbands on all of their residents; however, ideally, she would prefer to see a centralized tracking system that goes beyond individual nursing homes and health care facilities.

The issue of medical records also requires national attention, Ms. Boyd stressed. “We need to establish national standards for accessibility and integrated computer access,” she said. “HIPAA [Health Insurance Portability and Accountability Act] and privacy rules will make it tough to do, but if we look at the big picture, health care workers have a hard time treating people effectively if they don’t have the information and tools they need.”

A “Safe Return” and Other Concerns for People with Alzheimer’s Disease

“First responders must have at least a basic understanding of Alzheimer’s disease, because they’re going to encounter persons who have it,” said Scott Gardner, West Region field director for the Alzheimer’s Association. He cited statistics that 10 percent of people over age 65 currently have Alzheimer’s disease or a related disorder, which equates to about 4.5 million Americans.

“Alzheimer’s disease affects much more than memory,” Mr. Gardner said. “It affects a person’s language and his or her ability to speak coherently. Folks are often disoriented, not only to place and time, but even as to whom they are.”

Tool: A fact sheet on disaster preparedness for families caring for someone with dementia, available from the Alzheimer’s Association, includes advice on advance preparations and what to do if people with dementia and their caregivers are uprooted or displaced to other environments. For more information, go to www.alz.org.

People with Alzheimer’s disease are particularly vulnerable because they often are unable to advocate for their wishes and needs, Mr. Gardner explained. In addition, their difficult behaviors are likely to be exacerbated during a disaster, because they may lack regular medications and a familiar environment.

Mr. Gardner called for trained professionals in “special needs” shelters and other evacuee locations, who could help equip staff and volunteers to better meet this population’s needs. Medication is particularly problematic, since many people with Alzheimer’s disease may be on medication not only to treat those symptoms but also for other conditions such as diabetes and heart disease.

With respect to tracking individuals with Alzheimer’s disease, Mr. Gardner shared information about the Alzheimer’s Association *Safe Return*[®] program, which currently serves more than 140,000 older adults. If an enrollee is missing, one phone call activates a community support network to help reunite the lost person with caregivers. For more information, go to www.alz.org/safereturn.

Safe Return faxes the person’s information and photograph to local law enforcement. When the person is found, a citizen or law official calls the 800-number on the bracelet or other identification product, and Safe Return notifies listed contacts. Mr. Gardner noted that the Alzheimer’s Association is currently exploring the possibility of using GPS technology as part of this program.

A “SWiFT” Response in Houston

When evacuees from New Orleans began arriving at the Houston Astrodome, it quickly became evident that there were many frail seniors who did not have anyone to advocate for them, explained Aye Khaine, who runs the Services to the Alone and Frail Elderly (SAFE) program for older adults through Catholic Charities of the Archdiocese of Galveston-Houston. Khaine and other members of the Care for Elders Partnership, such as Harris County Hospital District, Baylor College of Medicine, Sheltering Arms, Harris County Services, and others, quickly joined together to develop the SWiFT (Seniors Without Families) Screening Tool.

The purpose of the SWiFT tool was to help frail seniors find a more suitable environment than the Astrodome, Khaine said. The screening tool allowed health professionals, such as licensed social workers and nurses, and volunteers to assess a person’s needs by asking about his or her medical conditions, medications, activities of daily living capabilities, cognitive abilities, and major needs.

Based on that assessment, seniors needing assistance could be separated into three priority levels. Those considered to be a health or mental health priority were referred to appropriate professionals; those who had case management needs were directed to local agencies; and those who simply needed to be linked with family or friends were referred to a volunteer.

One challenge the SWiFT screeners experienced was how to track people and follow up with them after the initial screening, Khaine said. Once this issue came to light, screeners were asked to mark each person's approximate location on a map of the Astrodome attached to the SWiFT tool, but this did not mean that they were able to locate them again. Finding seniors again after the initial screening was a difficult task, said Khaine, adding that "this is an area we need to address in future planning for disaster shelters."

In addition to assisting evacuees in the Astrodome, Khaine worked with her staff to prepare the SAFE clients for Hurricane Rita. The staff conducted a disaster plan assessment for each client. Questions included whether clients had a support system and emergency plan, what "special needs" they had, and which items and information they were prepared to take with them.

"Part of our annual assessment is to determine whether each of our clients has an emergency plan," she said. "If someone doesn't, we work with the emergency management center to make sure they have the information needed to provide assistance."

Integration and Coordination: The VA Model

"You don't prepare for a disaster—you overprepare for a disaster," said Chris Cahill, from the Veterans Administration in New Orleans. "Leadership is key, and in order to be prepared, you have to have leaders who believe a disaster could actually occur."

Mr. Cahill offered an overview of the VA's structure, which is organized into 23 Veterans Integrated Service Networks (VISNs) that provide regional coordination. All of the components within a VISN share resources, computer systems, and disaster plans. There are even VISN-wide drills, where people are hired to fly to different facilities.

With respect to patient identification and tracking, the VA has a consolidated records system, Mr. Cahill explained. The system uses bar codes, so providers can instantly access a patient's medical history, medication records, and any "special needs" information.

Developing such a system doesn't have to be a drain on resources—even for small, independent providers, Mr. Cahill stressed. For example, two nursing homes that provide mutual aid during an evacuation also might join together in purchasing new technology to ensure that their systems are compatible. Another suggestion is for independent facilities to use large, chain pharmacies, which would be able to pull up a person's medication records anywhere in the country. Mr. Cahill urged larger corporations to integrate all of the members within their systems. In the long term, he hopes the country will move toward a national registry of electronic health records.

In terms of staffing during a disaster, Mr. Cahill emphasized the importance of having the right team in place. Rather than forcing employees to work, the VA in New Orleans asked for volunteers, and more than half of the staff responded. “The ones who volunteer are going to work harder, be more focused, and take better care of patients,” he said. “When you develop your disaster team, make sure it’s a team of people who really want to help others.”

Discussion Highlights: Registries, Medications, and Tracking

(See Appendix for a fuller summary of the discussion following this panel.)

- Registries should be created, so nonprofits and aging-services providers can identify people who would likely need help in the event of an evacuation. *(AARP representative from Mississippi)*
- Registries will not be a catchall. In many cases, people with cognitive disabilities have not been formally diagnosed or will not self-identify. *(Mr. Gardner, Alzheimer’s Association)*
- The American Red Cross has also experienced challenges with people not wanting to self-identify. The organization would like to collaborate with disability advocates to develop better messaging. *(American Red Cross representative)*
- It’s important to fund emergency preparedness research that will identify and test best practices. *(Steven Tingus, director of the National Institute on Disability and Rehabilitation Research)*
- Many older adults living in the community planned on staying home during the hurricane in Houston, because they did not view it as a “big deal.” One community-based service provider assessed which clients had personal support networks and reported those who did not to the city for assistance. *(Catholic Charities representative from Houston)*
- Emergency managers should reach out to the medical community in preparation for disasters. In the aftermath of the hurricanes, many doctors were willing to volunteer, but their efforts were hampered by a lack of communication and a lot of red tape. The American Medical Association is currently exploring the possibility of a national volunteer registry and is seeking ways to address issues surrounding liability, credentialing, and verification. The organization also offers courses through its National Disaster Life Support Program (www.ama-assn.org) to prepare health care professionals and emergency response personnel for mass casualty events. *(American Medical Association trustee)*
- In the aftermath of Katrina, even when nurse volunteers had appropriate education and credentials, many were not allowed to provide care at Red Cross shelters because of “red tape.” *(American Nurses Association representative)*
- Credentialing in times of disaster is a key issue that will likely require congressional action. *(Mr. Lipscomb)*

Other Promising Practices and Lessons Learned

Registries and Other Tools for Identifying Individuals Who Will Need Help

- In Georgia, all Area Agencies on Aging have county, city, regional, and state emergency preparedness plans, coordinated with first responders, local emergency medical services (EMS), law enforcement, and county officials. AAA staff identify at-risk older adults and persons with disabilities who need assistance to evacuate or need medical assistance, have no family caregiver available, receive services through AAAs; client lists are updated quarterly and shared with EMS and first responders; and care managers keep client lists at home to activate telephone trees. Those who do not receive AAA services or other public services are encouraged to register with EMS or law enforcement.⁶⁶
- Florida law requires each local emergency management agency to maintain a registry of persons with disabilities and other “special needs” populations, including frail elderly and persons with “special needs,” such as dialysis and wound care.
- In Monroe County, Florida, all individuals are eligible if they are age 60 or older, frail, medically needy, and/or disabled and are not in a residential facility program. Everyone who is eligible must complete an application form as well as HIPAA Disclosure of Information and HIPAA Privacy Act forms before they are placed on the registry. All clients are contacted when a hurricane is threatening the county and are given instructions about evacuations in different categories of storms (hurricane categories 1–5). Those who have requested transportation (on the application) are contacted in advance and given an appropriate time to be picked up. Monroe County provides specific information on what to bring to the shelter. It also permits pets to accompany clients to shelter provided that pet-friendly sheltering is available. The pets also must be pre-registered, which includes sending in a copy of vaccinations. For more information, go to www.monroecounty-fl.gov/Pages/MonroeCoFL_Social/specialneeds.
- In Duval County, Florida, persons with “special needs” are either self-identified through a registration form mailed with their utility bill, usually in late spring, or through identification by public and private sector agencies, home care agencies, and physicians. Persons who have been identified are then evaluated by health department nurses to determine their appropriate shelter placement in the event of evacuation. A searchable database includes extensive information about each person in the registry; for example, demographics, physicians, pharmacy, home health agency, emergency contact persons in and out of town, permission to search the home, medications, disabilities, special medical needs, transportation requirements, residence in a surge zone, and the like. The database allows the Duval County Health Department, long before the projected arrival of gale force winds, to determine the number of people needing hospital or “special needs” shelter placement as well as those with specific transportation requirements, such as ambulance, wheelchair van, car, or bus.⁶⁷
- New York: The state of New York recently requested all home care and related agencies to undertake specific activities for emergency preparedness, which include:⁶⁸
 - collecting emergency current contact information for all staff and all community partners, including emergency management and medical services and law enforcement; and

- maintaining a current patient roster that will facilitate rapid identification and location of patients at risk; at a minimum the roster should contain
 - patient name, address, and telephone number;
 - patient classification level (high, moderate, or low priority);
 - identification of patients dependent on electricity to sustain life;
 - emergency contact telephone numbers of family/caregivers; and
 - other information that may be critical to first responders.
- **Tool:** A checklist to help organizations that provide home health services prepare for responding to pandemic influenza has been developed by the HHS and the CDC. For more information, go to www.pandemicflu.gov/plan/pdf/HealthCareChecklist.pdf.
- A range of tools—both low- and high-tech—is being developed to identify vulnerable older people and others who will need help during disasters. These include “individualized emergency preparedness plans” and “special needs” registries. Methods of identifying those most likely to be in need include (1) lists maintained by utility companies of persons on life-support equipment; (2) motor vehicle departments’ handicapped permit registrations; and (3) records of Meals-on-Wheels programs serving the homebound.⁶⁹
- Individualized emergency preparedness plans (IEPPs) could be effective tools for providing up-to-date health information to appropriate agencies. Such plans should contain information about diagnosis, level of function, and medications, and should be fully integrated into electronic health records (consistent with HIPAA privacy requirements).⁷⁰
- Aging service providers can develop individualized preparedness plans with clients, including evaluating the safety of their home and its location and their ability to function without the aid of others and without utilities. “When a home is judged to be at risk or the elder person is unable to function without electricity or other people for up to two weeks, that individual should be counseled to evacuate. These persons should register with the local “special needs” registry, indicating where they will be upon evacuation.”⁷¹
- The National Organization on Disability suggests developing a community “special needs registry,” on which individuals who meet specific criteria can *voluntarily* list themselves so that emergency personnel are aware of their presence. Such registries can have many purposes, from facilitating outreach and training to alerting individuals about impending emergencies to assisting in evacuation and recovery efforts. Some of the important issues to be addressed in developing such registries are:⁷²
 - What are the criteria for inclusion in the registry, and who will review applications?
 - What resources, such as funding and staff, are available to maintain the registry so that it is up to date? (If it isn’t up to date, it can be worse than useless because scarce resources could be diverted.)
 - How will registrants’ privacy and confidentiality be protected?
 - How will the existence of the registry be publicized?

Medications

- In the wake of Hurricane Katrina and many evacuees' loss of both their medications and their paper medical records, an online service was developed to help these individuals work with their health professionals to gain access to their own electronic prescription records, including specific dosages. With the assistance of federal, state, and local governments, Katrina Health is operated by the Markle Foundation, several private businesses, participating chain pharmacies, and national organizations of physicians and other health professionals. This secure site permits physicians and pharmacists to access basic medication histories to treat Katrina evacuees. Accurate medication histories are viewed as key building blocks of electronic medical records. The Katrina experience underscored the value of electronic data and the advantages of being able to secure them anytime, anywhere. For further information, go to www.KatrinaHealth.org.
- A Joint Commission white paper recommends ensuring a 48- to 72-hour stand-alone capability for all hospitals through appropriate stockpiling of necessary medications and supplies. In addition, community emergency plans should identify potential “surge” supply sources for pharmaceuticals and medical and special nutritional supplies, such as ventilators, which would also help prevent multiple organizations relying on the same supplier.⁷³

CDC's Strategic National Stockpile (SNS) has large quantities of medicine and medical supplies to protect the American public if there is a public health emergency (terrorist attack, flu outbreak, or earthquake) severe enough to cause local supplies to run out. For example, between August 30 and September 16, 2005, SNS sent more than \$38 million worth of medical supplies in response to Hurricane Katrina. Once federal and local authorities agree that the SNS is needed, medicines are delivered to any state in the United States within 12 hours. Each state has plans to receive and distribute SNS medicine and medical supplies to local communities as quickly as possible.

Training information for CDC's state and local partners in using SNS resources is available at www.bt.cdc.gov/training.

EVACUATING OLDER PERSONS IN THE COMMUNITY AND NURSING HOMES: TRANSPORTATION AND SHELTERING

In a New Orleans nursing home, 35 residents drowned when they were not evacuated before Hurricane Katrina hit, and 23 older persons from an assisted living facility in Houston were killed while being evacuated before Hurricane Rita when their bus burst into flames.⁷⁴

- The decision to evacuate frail older persons and persons with disabilities poses complicated safety issues in diverse settings, ranging from large residential settings such as senior housing, assisted living facilities, and nursing homes, to commercial office buildings, to people in their own homes in the community.

- In the community, individuals with different types of disabilities face a variety of challenges in evacuating, depending on the nature of the emergency.
- Nursing homes are required to maintain emergency plans to receive Medicare and Medicaid funding. However, most such plans pertain to “sheltering in place” rather than evacuating. In addition, the review process for nursing home evacuation plans may lack specific standards, and plans may not be well coordinated with other community emergency management efforts. In addition, while state and local governments can order evacuations, hospitals and nursing homes may be exempt.
- “Special needs” shelters, sometimes known as “medical needs shelters,” provide a location to house individuals who typically have physical or mental conditions that require limited medical/nursing oversight.⁷⁵ Specific definitions vary from state to state. In Florida, people with the following needs are included:
 - minor health/medical conditions that require observation, assessment, and maintenance;
 - contagious health conditions that require observation, assessment, and maintenance;
 - chronic conditions that require assistance with activities of daily living;
 - regular medications and/or vital sign readings among those who cannot manage these activities without regular assistance.⁷⁶

Among the issues discussed at the AARP conference:

- Will public transportation systems, including mass transit systems, be accessible in emergencies? What other forms of transportation will be available if the vehicles with lifts, etc., are in use elsewhere? How can special equipment (such as wheelchairs, ventilators) and guide animals be transported?
- How can evacuation plans in nursing homes be improved?
- What role can “special needs” shelters play in protecting persons with special health needs? Who should be in charge of these shelters to ensure that they are properly equipped and staffed, are accessible to persons with disabilities, provide appropriate care, and discharge individuals with good follow-up plans to appropriate settings?

Highlights from the AARP Conference

A Coordinated Transportation Plan: Bridging the Gaps

“The events of 9/11 served as a catalyst for our department, in terms of reviewing emergency plans and developing new ones,” said Natalie Jones Best, emergency transportation coordinator for Washington DC’s Transportation Department. “Our main focus is to make sure we fully use the transportation network to ensure vehicles are able to move from an incident area, and that our first responders have the road capacity to move resources into the city.”

Ms. Best highlighted her department’s “Transportation Tips During an Emergency Incident” brochure, which includes information about how to evacuate, shelter in place, and develop

emergency plans and “go kits.” The brochure is available in several languages and in large print and braille and on audio cassette. “Any message we’re trying to get out to the public needs to be done in a number of ways, recognizing the diversity in the city,” she said.

One challenge for the District of Columbia is that the cause of a mass evacuation would mostly likely be a terrorist attack with little or no warning. This reality makes it particularly important to consider the needs of special populations, such as seniors, students, or persons with disabilities, who are less likely to have their own transportation, Ms. Best said.

Tools: The District of Columbia’s brochure, “Transportation Tips During an Emergency Incident” is available at www.ddot.dc.gov.

To identify these populations, the department has increased coordination with several key partners. For example, the District Department of Transportation (DDOT) is identifying how it can use the database of the transportation service contracted with by the city Office on Aging as well as the Washington Metropolitan Area Transit Authority’s paratransit service. In addition, using census data, DDOT has a better sense of the ward locations of the 35 to 40 percent of households that do not have vehicles. Working with the D.C. Emergency Management Agency, the department hopes that some type of residential registry will be developed to better identify individuals and their needs.

Ms. Best’s department does not provide transportation for nursing homes, but it does coordinate with them and seeks to bridge any gaps in their plans. “We do not have the resources in D.C. to be able to evacuate every person in every single nursing home,” Ms. Best acknowledged. “That’s why it’s so critical that we understand each nursing home’s plan.”

Ms. Best also stressed the need to develop personal plans for those who are not in nursing homes that includes identifying people and resources needed should people need to shelter in place for a significant time or to evacuate.

The term, “special needs populations,” is used frequently in emergency preparedness literature and can encompass people as diverse as persons with disabilities, minority groups, children, older persons, and those who do not speak English. Disability expert June Isaacson Kailes points out that these populations could include more than 50 percent of the country’s residents and is so broad it is almost meaningless. She argues for more precise use of language, such as “medical needs shelters” to differentiate the actual needs.⁷⁷

Serving Evacuees: A View from the Ground

“We have to plan for the reality of a disaster, and that is what I’m here to share with you today,” said Captain Henry Lopez, of the Health Resources Services Administration. As team leader for the San Antonio metropolitan area in the aftermath of the hurricanes, he saw firsthand the challenges of serving thousands of unexpected evacuees.

Capt. Lopez’s mission was to ensure that evacuees were placed in suitable housing and received appropriate health care. One of the key challenges was trying to reconstruct patients’ medical histories and medication needs, particularly for those who did not speak English.

The mission expanded dramatically when Hurricane Rita threatened Texas. Over 16,000 people were evacuated into San Antonio overnight and began showing up at the shelters, Capt. Lopez explained. During this time, a decision was made to evacuate hospitals and nursing homes.

Capt. Lopez recounted a 3 a.m. phone call, when he learned that six buses with 320 “special needs” residents had arrived unexpectedly to a public shelter in a high school gym. Working with local agencies, his team scrambled to provide assistance and gather the necessary resources and medical supplies. For a description of Capt. Lopez’s experiences, go to www.hrsa.gov/katrina/updatehrsaIOII.htm.

At another shelter in a local Air Force base, 20 buses pulled up carrying people with “special needs,” and Capt. Lopez was told that others were being flown in. In one case, 15 nursing home residents arrived with only one caregiver. He said these experiences reinforced the notion that, in addition to having well-thought-out plans, leaders must be prepared to improvise in a disaster.

The American Red Cross: Roles and Responsibilities

“Americans cannot be prepared by any federal, state or local government, nor by any community-based or faith-based organization, public association or private company,” opened Keith Robertory, manager of Community Disaster Education for the American Red Cross. “Just as each disaster is an intensely personal event, it’s critical that each person ultimately accept responsibility for his or her own preparedness.

“Every individual needs to assess their own capabilities, make their own plans, and determine what assistance they need,” Mr. Robertory stressed. He indicated that the role of other entities should be to encourage people to do this planning and provide support where it is needed. Mr. Robertory cautioned against “talking down” to older adults or persons with disabilities, adding that they will be more invested in disaster plans they have created themselves.

“We do not have the resources in D.C. to be able to evacuate every person in every single nursing home. That’s why it’s so critical that we understand each nursing home’s plan.”

NATALIE JONES BEST

Mr. Robertory also outlined the capabilities of the American Red Cross, particularly with respect to shelters. “Ideally, people in Red Cross shelters are able to care for themselves and be self-sufficient in a shelter setting,” he said. “Shelter clients may be accompanied by caregivers, and we’re expecting people to be able to maintain their daily way of living themselves—or have someone there to help.”

Mr. Robertory stressed that the Red Cross cannot operate a facility during a disaster that would require licensure during non-disaster times. He said it is the responsibility of the local public health agency to ensure care and sheltering of populations with special medical needs.

While the definition of “special needs” varies by state, Mr. Robertory generally viewed the term as describing people needing assistance with activities of daily living, continuous health support, life support, significant nursing care, custodial care, or post-operative skilled care. “Special needs” are not special diets; artificial limbs; visual, speech, or hearing impairments; or individuals who use wheelchairs and can transfer themselves,” he noted.

Red Cross shelters can serve as alternative locations for a medical or special care facility if certain criteria are met, Mr. Robertory added. There must be a space separate from the general shelter population, and the staff of the evacuated facility must be present to provide care.

Mr. Robertory’s comments sparked a strong reaction from Ms. Styron of the National Organization on Disability. She argued that, in the reality of a disaster, the Red Cross will become a shelter of default for people with “special needs,” and it must be better prepared to assist them. Mr. Robertory responded that the Red Cross is open to ideas and is willing to work with groups representing aging and disability populations.

Picking up the Pieces

In the aftermath of the hurricanes, many older adults are struggling with depression without needed support. “We really haven’t addressed the mental health aspect yet,” said Linda Sadden, Louisiana’s Long-Term Care ombudsman. “A lot of people who walked when they left the state are now in nursing homes.”

Ms. Sadden voiced concerns about the trauma many seniors experienced when being transferred from facilities. “I’m very distressed that we still don’t know the difference between the good homes and the bad homes, in terms of planning,” she said. “How many residents were killed because they evacuated after the storm instead of before?”

In Houston, for example, one nursing home housing evacuees has already reported 20 deaths. “We have to do a better job of figuring out what people can withstand,” Ms. Sadden stressed. “How far can you transport them? I’m not sure we know the answer yet as to whether we should have mandatory evacuations for individuals.”

Ms. Sadden emphasized that federal tax dollars would be very important to rebuilding the affected areas and helping older adults pick up the pieces. She also called for more research into best practices of evacuations as well as lessons learned.

“Katrina changed everything for a very long time,” Ms. Sadden closed. “We’re not going to get over this quickly.”

Discussion Highlights: Evacuation

(See Appendix for a fuller summary of discussion following this panel.)

As the discussion turned to sheltering, there was a lively exchange about how prepared public shelters should be to accommodate persons with disabilities. The debate was sparked by a National Organization on Disability report highlighting accessibility issues that arose in the aftermath of hurricanes Katrina and Rita. Disability advocates called for more inclusive planning and urged the American Red Cross and emergency managers to explore best practices and training opportunities.

- Many public American Red Cross shelters were not equipped adequately for persons with disabilities during the hurricanes. Families should not be split up because one member has a “special need,” particularly since organizations are not permitted to use federal dollars in a discriminatory way. There are effective training programs and good practices that the Red Cross could use, but the organization is not using them to best effect. *(National Council on Disability representative)*
- The American Red Cross has a responsibility to treat all individuals with respect and to be in compliance with the Americans with Disabilities Act. It is currently conducting internal training to make people more aware of these issues; however, it should be noted that the Red Cross does not have the licensure to meet the needs of individuals who require care in an institutionalized setting. *(Keith Robertory, American Red Cross)*
- The American Red Cross provides a valuable service. It is the responsibility of local governments to care for people with “special needs,” such as nursing home residents. *(Montgomery County, Maryland, Homeland Security representative)*
- Regardless of the way a shelter is defined, the reality is that people with “special needs” will show up to a public shelter. Thus, the American Red Cross needs to be prepared to assist these individuals until they can be moved somewhere else. *(Bentley Lipscomb, AARP Florida state director)*

“Regardless of the way a shelter is defined, the reality is that people with ‘special needs’ will show up to a public shelter. Thus, the American Red Cross needs to be prepared to assist these individuals until they can be moved somewhere else.”

BENTLEY LIPSCOMB

Discussion then turned to how to get assistance for people living in the community who are not capable of developing their own emergency plans.

- The D.C. Emergency Management Agency is developing a “cluster plan” concept. Through this approach, community members come together to discuss issues such as shelters and evacuation routes, and conduct “neighbor-to-neighbor” planning for people who might need extra assistance. (*Natalie Jones Best, DDOT*)

Other Promising Practices and Lessons Learned

Transportation

Both public and private transportation may be disrupted due to overcrowding, because of blocked streets and sidewalks, or because transportation systems are not functioning at all. In addition, the transportation options available to older persons and others with disabilities may not be accessible.

- The U.S. Department of Transportation has launched a website that includes information to help ensure safe and secure transportation for persons with disabilities in the event of a disaster or emergency. Advice on emergency preparedness, transportation accessibility, and evacuation methods for certain modes of transportation, such as rail and transit systems, is provided, in situations ranging from evacuations of mass transit systems to being trapped in a car during a blizzard or hurricane. The site also includes information for transportation providers on how to respond to the unique needs of persons with disabilities during an emergency. For further information, go to www.dotcr.ost.dot.gov/asp/emergencyprep.asp.
- The Federal Interagency Coordinating Council on Access and Mobility (CCAM) and the Federal Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC) are partnering to evaluate and provide examples of best practices and systems for planning and implementing emergency preparedness transportation policies and programs for individuals with disabilities, older adults, and others who may need assistance.

For more information, visit the subcommittee’s website, www.emergencyprep.dot.gov. For more information about the ICC, visit www.dhs.gov/disabilitypreparedness/icc.

- The DOT has also prepared internal guidelines for emergency preparedness for persons with disabilities, which have been made available to all DOT personnel and contracting officers. For more information, go to www.dotcr.ost.dot.gov/documents/dotpart/pwd_guidelines.htm.
- Area Agencies on Aging (AAAs) can be a transportation resource during emergencies. AAAs have extensive experience in working with community transportation providers, and they can play key roles in disasters in organizing accessible and safe transportation for older adults and others with health and mobility limitations. For example, senior vans, some of which have wheelchair lifts, are available in many areas. Some local aging agencies also engage volunteer drivers who may serve as resources for evacuation and transportation following the disaster.⁷⁸
- Local communities can plan to help ensure that persons with disabilities can evacuate the physical area in a variety of conditions and with or without assistance. They can also identify accessi-

ble modes of transportation that may be available to help evacuate persons with disabilities during an emergency. For instance, during floods some communities have used lift-equipped school or transit buses to evacuate people in wheelchairs.⁷⁹

Other Evacuation Issues

In addition to transportation problems, older persons and other individuals with disabilities face a variety of challenges in evacuating, depending on the nature of the emergency. For example, people with a mobility disability may need assistance leaving a building that has no working elevator. Individuals who are blind or who have limited vision may no longer be able to use traditional orientation and navigation methods independently. An individual who is deaf may be trapped somewhere and unable to communicate with anyone because the only available communication device relies on voice.⁸⁰

- **Tool:** A recent publication of the Department of Education’s National Institute on Disability and Rehabilitation Research gives wide-ranging recommendations on emergency evacuation of people with physical disabilities from buildings. They include those for building design, codes, and construction; emergency management and first responders; and for using and improving evacuation equipment and mobility devices.⁸¹

Sheltering

“Special Needs” Shelters

The rapidly changing realities of a disaster pose major challenges in sheltering older persons and persons with disabilities. Here are examples of some of the ways states and communities can address these challenges:

- In Florida, a Special Needs Shelter Interagency Committee works to ensure a standardized, comprehensive county and regional approach to “special needs” sheltering, while addressing key areas such as transportation, registration, staffing, operations, and discharge planning. Committee members include AARP Florida in addition to state agencies, other nonprofit organizations, and emergency management agencies.
- In Duval County, Florida:⁸²
 - An “Adopt-A-Shelter” program was developed in which each hospital in the city has assumed responsibility for staffing, medical supplies, and support of a “special needs” shelter in the event of an emergency evacuation. This ensures that these shelters are not only fully staffed during the event but also have reserve personnel and are fully stocked with resources.
 - A contract with a medical supply company identifies all resources required to support a “special needs” shelter and requires them to keep an inventory available at all times and to deliver these supplies to each shelter before they open. In addition, if post-event plans require shelters to be relocated, the company is expected to transport the supplies between venues.

- A Medical Reserve Corps that includes 500 physicians, nurses, respiratory therapists, etc., has been established, trained, and prepared to support the health department and hospitals.
- Ham operators are present in all shelters to ensure continuity of communications with the Emergency Operations Center and the city and county government.
- An 800 MHz radio system connects public health with the shelters and hospitals to ensure communication links with the health system, for which the health department is accountable.

Lessons from the Association of State and Territorial Health Officials

According to the Association of State and Territorial Health Officials (ASTHO), some important lessons emerged from the experiences of Florida and Alabama that can be used in the future when preparing for disasters that require sheltering of “special needs” populations. For the complete statement and other ASTHO resources, go to www.astho.org; what follows is a summary of that information.⁸³

- In Florida, health department staff preregistered and identified individuals to be placed in “special needs” shelters well before the hurricanes. Each county health department was responsible for defining “special needs” individuals in its communities, working in conjunction with the local hospitals, local nursing homes, emergency responders, and members of the community. In Alabama, plans called for “special needs” patients to be sheltered in schools in the Mobile area and in hospitals in the rest of the state.
- Despite pre-event preparations, states faced several challenges due to the back-to-back hurricanes, including receiving more patients than those previously identified, damage to the shelters themselves, and major strains on the state’s health care system and pool of human resources. To sustain recovery and mitigation efforts, Florida turned to neighboring states’ public health experts for infrastructure support.
- Built-in flexibility allowed the states to overcome some of these challenges. In Florida, officials decided to shelter advanced life support teams in “special needs” shelters, allowing them to assist in the care of individuals as they awaited deployment the following day. Alabama hospitals and nursing homes agreed to shelter patients who were unable to travel to other shelters, and public health staff rose to the task of caring for these individuals.
- In the aftermath of the storms, several key lessons emerged in regard to sheltering “special needs” populations:
 - Define “special needs” communities.
 - Conduct pre-event planning with community partners.
 - Coordinate with agencies caring for patients with “special needs.”
 - Incorporate “special needs” populations in emergency management plans and exercise those plans.
 - Prepare educational materials.

- Identify available resources to support the shelter.
- Design plans to allow for maximum flexibility.

Additional Online Public Health Resources: Florida State Department of Health Public Health Nursing Disaster Resource Guide, www.doh.state.fl.us/phnursing/sns/disasterguide.html

Public Shelters and Persons with Disabilities

- The ADA guide for local governments on preparedness for persons with disabilities identifies a number of problems faced by persons with disabilities who need to use temporary shelters and lists action steps to help solve these problems.⁸⁴
- Problems: Many shelters are not accessible to persons with disabilities. Individuals using a wheelchair or scooter have often made their way, with some difficulty, to the shelter, only to find no accessible entrance, toilet, or shelter area. In addition, many shelter staff and volunteers know little about the needs of persons with disabilities. Many shelters have a “no pets” policy, and some mistakenly apply this policy to exclude service animals, such as guide dogs for people who are blind, hearing dogs for people who are deaf, or dogs that pull wheelchairs or retrieve dropped items. In addition, persons with disabilities and others who require medications that need constant refrigeration, such as certain types of insulin, may find no refrigerators or ice-packed coolers, and people who rely on electricity to function may find no generator or other electricity source.

Examples of Action Steps in the *ADA Guide for Local Governments*:

- Survey your community’s shelters for barriers to determine access for persons with disabilities. Until all of your emergency shelters have accessible parking, exterior routes, entrances, interior routes to the shelter area, and toilet rooms serving the shelter area, identify and publicize widely to the public, including persons with disabilities and the organizations that serve them, the locations of the most accessible emergency shelters.
- Adopt procedures to ensure that persons with disabilities who use service animals are not separated from those animals when sheltering during an emergency, even if pets are normally prohibited in shelters.
- Ensure that a reasonable number of emergency shelters have backup generators and a way to keep medications refrigerated (such as a refrigerator or a cooler with ice). These shelters should be available on a priority basis to people whose disabilities require access to electricity and refrigeration, for example, for using life-sustaining medical devices, providing power to motorized wheelchairs, and preserving certain medications, such as insulin, that require refrigeration. The public should be notified routinely about the location of these shelters.
- Adopt procedures to provide accessible communication for people who are deaf or hard of hearing and for those with severe speech disabilities. Train staff in the basic procedures for providing accessible communication, including exchanging notes or posting written announcements to go with spoken announcements. Train staff to read printed information, upon request, to persons who are blind or who have low vision.

- Physicians from the American College of Physicians have reported a lack of general health information written at an appropriate reading level that explains the importance of hand washing, not sharing medicine, and other important health issues. To overcome some of the challenges facing people living in shelters, the ACP Foundation, working with health literacy experts and physicians, created a one-page handout for volunteers to use with shelter residents. “HEALTH TiPS for Healthy Shelter Living” is written at a third-grade reading level and is available in English and Spanish (see <http://foundation.acponline.org/shelertips.htm>).

VII.

CONCLUDING REMARKS LOOKING AHEAD: NEXT STEPS

“Disasters reveal underlying weaknesses in the way we run our country,” said Dalmer Hoskins, AARP’s managing director of policy. He outlined five key areas that might serve as a basis for further dialogue; these issues pertain not only to older persons but also to vulnerable populations of all ages.



“There is a tremendous
need for public education
about emergency preparedness.”

DALMER HOSKINS

Mr. Hoskins began by calling for wider participation to *rethink and clarify roles* of the many different stakeholders. “We have several layers of government, but there are important deliberations that need to take place about who does what when,” he said. He added that such discussions must take advantage of the resources of for-profit entities such as Wal-Mart and CVS.

There is also a tremendous need for *public education* about emergency preparedness, Mr. Hoskins asserted. A key challenge is determining who will lead these efforts.

The third issue that emerged is the need for *better integrated planning*, as evidenced by the breakdowns that occurred in areas such as fuel delivery, food supply, and communication. “One thing that worked well was when people knew each other, but can we rely on that solely?” Mr. Hoskins asked. “There must be a better mechanism—a more systematic way of doing business—that relies on integrated planning.”

Another opportunity for progress lies in *identification and tracking*—of both people and health information, which will require policy changes and a shift in public attitudes. Such changes will need to include appropriate data security safeguards. “We know the technology exists,” Mr. Hoskins said, pointing to the successful implementation of electronic health records throughout Europe. “There are real sensitivities here about confidentiality, but this is an area that has to be high on the agenda for future discussions.”

The final issue that arose is the need to *define and address “special needs”* appropriately. “We have a real problem communicating with each other about “special needs,” but we have to start talking about it,” Mr. Hoskins acknowledged. “This is a particularly important issue for AARP. It’s about discrimination, it’s about sensitivity, and it’s about being aware of your fellow man.”

“We’re going to have to work together to keep this issue on the agenda and on the radar screen”

DALMER HOSKINS

Mr. Hoskins closed by calling for more success stories and continued dialogue among stakeholders. “We’re going to have to work together to keep this issue on the agenda and on the radar screen,” he said. “It’s a much bigger job than any single organization can undertake, and it touches every sector of our society. The question is how to work together.”

VIII.

APPENDIX



“We need actionable plans—and they must be well executed.”

LUCY THEILHEIMER

CONFERENCE AGENDA

An Invitational Conference

We Can Do Better: Promising Practices for Protecting Older Persons in Disasters

Thursday, December 1, 2005

AARP Brickfield Center

601 E Street, NW

Washington, DC 20049

E-mail: DoingBetter@aarp.org

- 8:00 a.m.–8:30 a.m. **Registration & Continental Breakfast**
- 8:30 a.m.–8:35 a.m. **Welcome**
William D. Novelli, Chief Executive Officer, AARP
- 8:35 a.m.–8:50 a.m. **Opening Remarks**
John Rother, Director, Policy and Strategy, AARP
- 8:50 a.m.–10:45 a.m. **First Panel—Planning and Communications**
How Can Disaster Planning for Older Persons in the Community and Nursing Homes Be Improved?
- Topics:**
Roles and responsibilities of key actors/coordination
Partnerships
Communication mechanisms
Drilling and training
- Moderator:** John Rother, Director, Policy and Strategy, AARP
- Panelists:**
Judy Johnson, Campus Administrator, Covenant Village, Plantation, Florida
William Lokey, Chief, Operations Branch, Response Division, FEMA
Hilary Styron, Director, Emergency Preparedness Initiative, National Organization on Disability
Michael Weston, Director of Emergency Field Operations, U.S. Administration on Aging
- 10:45 a.m.–11:00 a.m. **Break**
- 11:00 a.m.–12:30 p.m. **Second Panel—Identifying Who Will Need Help and What Kind of Help**
Registries, Tracking, IDs, and Medications: Older Persons in the Community and Nursing Homes
- Topics:**
Identifying people who need help with evacuation (e.g., registries)
Tracking these individuals post-disaster

Keeping track of medical records
Identifying and providing medications

Moderator: Julie Cohn, Regional Director, AARP

Panelists:

Janegale Boyd, President and CEO, Florida Association of Homes for the Aging

Chris Cahill, Veterans Administration, New Orleans

Scott Gardner, West Region Field Director, Alzheimer's Association

Aye Khaine, Catholic Charities of the Archdiocese of Galveston-

Houston, Services to the Alone and Frail Elderly (SAFE) Program
(Care For Elders Partner)

12:30 p.m.–1:30 p.m.

Luncheon

Introduction of Speaker

Tom Nelson, Chief Operating Officer, AARP

Speaker Address

Georges Benjamin, MD, FACP, Executive Director, American Public Health Association

1:30 p.m.–3:00 p.m.

Third Panel—Evacuating Older Persons in the Community and Nursing Homes: How and To Where?

Topics:

Special needs shelters

Transportation

Moderator: Bentley Lipscomb, AARP Florida State Director

Panelists:

Natalie Jones Best, Emergency Transportation Coordinator, District of Columbia Transportation Department

Capt. Henry Lopez, Director, Bureau of Health Profession's Division of Health Careers Diversity and Development, Health Resources and Services Administration, HHS

Keith Robertory, Manager of Community Disaster Education, American Red Cross

Linda Sadden, Louisiana State Long Term Care Ombudsman

3:00 p.m.–3:15 p.m.

Break

3:15 p.m.–4:15 p.m.

Summing Up: Where We Are and Where We Need to Go

Dalmer Hoskins, Managing Director of Policy, AARP

4:15 p.m.

Adjourn

DISCUSSION AT THE AARP CONFERENCE

Improving Planning and Communications

Lucy Theilheimer, AARP’s director of strategic planning, summarized the session, saying, “We need actionable plans to deal with the before, during, and after of an event—and they must be well executed.” She then opened the floor for discussion.

- Public expectations regarding the federal government’s response are very different from what is written in the Stafford Act. Could other federal agencies play a greater role in response, and should the states do more to build up their own capabilities? (*Congressional Research Service employee*)
- There has been an effort in Florida to address previously unfunded mandates. For example, the state provided funding to have a coordinator employed within each responding agency or group. In addition, legislation from 1993 created a pool of money through counties’ offices of emergency management that nonprofits can apply for to engage in disaster planning. (*Michael Weston, U.S. Administration on Aging*)

Participants also discussed successes and lessons learned:

- It’s important to ensure that essential personnel have access to the fuel they need to get to work. In Florida, the secretary of the Agency of Health Care Administration stepped in, by request, and put together five fueling stations in remote parts of the affected county, so essential workers could obtain 10 gallons of gas. The program worked well; however, there were some problems with local law enforcement as to whether employees such as housekeepers and cooks qualified as “essential.” (*Judy Johnson, Covenant Village*)
- A product, called the Evaculed, proved very helpful in evacuating residents from buildings that didn’t have elevators. (*Elder care provider from New Orleans*)
- In the aftermath of the hurricanes, churches often served as the first responders. In many cases, they were paramount in contacting vulnerable persons, convincing them to evacuate, and providing them with food, water, and other assistance. (*AARP representative from Mississippi*)
- When developing preparedness education materials, organizations should include information reminding people to take their medications with them when evacuating. (*American Nurses Association representative*)

Another key topic was how to ensure plans are actionable:

- It’s important to think beyond the individual facility level to area-wide planning. Better coordination is needed to ensure that multiple care providers are not all relying on the same vendors and backup support. (*Florida Association of Homes for the Aging representative*)
- Personal preparedness is essential. In terms of messaging, people are more receptive to planning for common adverse events, such as home fires or brief power outages, which seem tangible. In addition, rather than giving people a long list of emergency supplies to pack, encourage them to conduct a personal needs assessment. (*Maryland Department of Disabilities representative*)
- Organizations should engage their own employees and constituents in personal preparedness planning. (*Department of Homeland Security representative*)

- Many older adults living in the community planned on staying home during the hurricane in Houston, because they did not view it as a “big deal.” One community-based service provider assessed which clients had personal support networks and reported those who did not to the city for assistance. (*Catholic Charities representative from Houston*)
- Many older adults feel they are ready “if it’s their time to go.” One strategy is to remind them that if it is not “quite” their time; they could be in for several weeks of misery while waiting for help. (*Michael Weston*)
- More emergency preparedness planning is needed at the community level. Engaging neighborhood leaders and block wardens is an effective way to keep vulnerable persons from slipping through the cracks. (*Hilary Styron, National Organization on Disability*)
- Older people are not homogeneous in their attitudes, and it is important to craft multiple messages and communication tools that speak to those differences. For example, some New Orleans residents did not evacuate because they lacked the means, while others were unwilling to leave the homes they had worked for all of their lives. (*AARP representative from Louisiana*)
- Many transportation resources were available, but no one was “pulling the trigger.” (*Public Transportation Department representative from Louisville, KY*)
- It is important to establish relationships with nontraditional partners. These relationships must be in place at the local level before disasters strike. (*International Association of Fire Chiefs president*)
- Emergency managers should reach out to the medical community in preparing for disasters. In the aftermath of the hurricanes, many doctors were willing to volunteer, but their efforts were hampered by a lack of communication and red tape. The American Medical Association is currently exploring the possibility of a national volunteer registry and is seeking ways to address issues surrounding liability, credentialing, and verification. The organization also offers courses through its National Disaster Life Support Program (www.ama-assn.org) to prepare health care professionals and emergency response personnel for mass casualty events. (*American Medical Association trustee*)
- There is a strong need for unity of command and control. Eighty percent of response capabilities come from nongovernmental entities, and government agencies must do more to coordinate with these potential partners. (*American Medical Association representative*)
- Washington, DC, has developed a Medical Reserve Corps (www.cncs.dc.gov), which trains volunteer health professionals—many of whom are retirees—to serve in their communities during large-scale emergencies. (*DC Department of Health representative*)
- The next National Hurricane Conference (www.hurricanemeeting.com) will include a training block for county-level emergency managers on how to better receive and direct assistance. (*Michael Weston*)

The final topic of discussion focused on specific ways to promote coordination and integration in planning:

- Volunteers, health professionals, and faith-based groups should preregister with their county emergency management offices. (*Representative from Montgomery County, MD*)

- A “disaster board” composed of liaisons from nongovernmental organizations could be created to provide updates on each organization’s capabilities and better coordinate response. (*American Medical Association trustee*)
- The Metropolitan Washington Council of Governments (www.mwcog.org) is an example of this type of coordination already in existence. The council is an organization composed of 19 local governments surrounding the nation’s capital, plus area members of the Maryland and Virginia legislatures, the U.S. Senate, and the U.S. House of Representatives. (*Hilary Styron*)
- Organizations should become familiar with the National Response Plan (www.dhs.gov) as well as local and state plans. National Voluntary Organizations Active in Disaster (www.nvoad.org) is another example of a coordination mechanism already in existence. (*American Red Cross representative*)
- Local emergency managers often do not seem interested in working with home care agencies. There is a need for a larger-scale plan for coordination. (*National Association for Home Care representative*)

Identifying Who Will Need Help and What Kind of Help: Registries, Medications, and Tracking

Before posing specific questions to participants, Ms. Theilheimer opened the floor for general comments.

- It’s important to fund emergency preparedness research that will identify and test best practices. It is hoped that the conference will result in actionable items that can be developed further through a task force or alliance. (*Dr. Steven Tingus, director of the National Institute on Disability and Rehabilitation Research*)
- One success has been KatrinaHealth.org, a secure, online service developed to give authorized health professionals and pharmacies access to evacuees’ medication and dosage information. The information on the site was compiled and made accessible by a broad group of private companies, public agencies, and national organizations, including medical software companies; pharmacy benefit managers; chain pharmacies; local, state, and federal agencies; and a national foundation. (*American Medical Association representative*)
- Too often the concerns of persons with disabilities are overlooked or swept aside in emergency situations. Organizations should review the recommendations in “Saving Lives: Including People with Disabilities in Emergency Planning,” available on www.ncd.gov. (*National Council on Disability representative*)

Comments during the discussion focused primarily on how to identify and reach individuals who are not part of a formal care system.

- Registries should be created, so nonprofits and aging-services providers can identify people who would likely need help in the event of an evacuation. (*AARP representative from Mississippi*)
- Creating a “special needs” registry is a very labor-intensive project. In addition, such a registry might make participants more vulnerable to scams. (*Michael Weston, U.S. Administration on Aging*)

- Many individuals don't self-identify as having "special needs," and even those who do may not wish to give out their information. A multidisciplinary approach is needed. (*Maryland Department of Disabilities representative*)
- There also should be registries of available affordable housing and long-term care, and possibly one for health care professionals who are willing to volunteer. In the aftermath of the hurricanes, the American Association of Homes and Services for the Aging partnered with National Church Residences to set up a national database of affordable housing for displaced persons. (*Janegale Boyd, Florida Association of Homes for the Aging*)
- Seniors are not homogenous. The best way to keep people from slipping through the cracks is to focus on grassroots outreach through community channels. (*AARP representative from Louisiana*)
- Registries will not be a catchall. In many cases, people with cognitive disabilities have not been formally diagnosed or will not self-identify. (*Scott Gardner, Alzheimer's Association*)
- The American Red Cross has also experienced challenges with people not wanting to self-identify. The organization would like to collaborate with disability advocates to develop better messaging. (*American Red Cross representative*)
- A major lack of communication and coordination surrounded the evacuation of long-term care residents from New Orleans. In many cases, evacuees were brought to facilities in other states, but the original facility wasn't informed of the new location. There were also instances where FEMA evacuated residents, but refused to take along their medical records. (*American Health Care Association representative*)
- Organizations should remind their constituents not to "self-dispatch," but rather to coordinate response efforts through state and local emergency operations centers. (*International Association of Fire Chiefs representative*)
- One way to ensure that seniors and persons with disabilities are not an afterthought is to focus on the grants on which agencies and organizations rely for emergency preparedness planning. For example, as a result of advocacy efforts, one grant application now includes two questions about addressing "special needs" populations and coordinating with "special needs" providers and facilities. (*Hilary Styron, National Organization on Disability*)

Evacuation and Sheltering

Discussion

- Many public American Red Cross shelters were not adequately equipped during the hurricanes for persons with disabilities. Families should not be split up because one member has a "special need," particularly since organizations are not permitted to use federal dollars in a discriminatory way. There are effective training programs and good practices that the Red Cross could use, but the organization is not using them to best effect. (*National Council on Disability representative*)
- The American Red Cross has a responsibility to treat all individuals with respect and to be in compliance with the Americans with Disabilities Act. It is currently conducting internal training to make people more aware of these issues; however, it should be noted that the Red Cross does

not have the licensure to meet the needs of individuals who require care in an institutionalized setting. (*Keith Robertory, American Red Cross*)

- The American Red Cross provides a valuable service. It is the responsibility of local governments to care for people with “special needs”, such as nursing home residents. (*Montgomery County, Maryland, Homeland Security representative*)
- Regardless of the way a shelter is defined, the reality is that people with “special needs” will show up to a public shelter. Thus, the American Red Cross needs to be prepared to assist these individuals until they can be moved somewhere else. (*Bentley Lipscomb, AARP Florida state director*)

Discussion then turned to how to get assistance for people living in the community who are not capable of developing their own emergency plans.

- The D.C. Emergency Management Agency is implementing a “cluster plan” concept. Through this approach, community members come together to discuss issues, such as shelters and evacuation routes, and to conduct “neighbor-to-neighbor” planning for people who might need extra assistance. (*Natalie Jones Best, DDOT*)
- Aging networks and disability networks in cities and parishes throughout the country can assist individuals on a grassroots basis. (*Linda Sadden, Louisiana State Long Term Care ombudsman*)
- With respect to identifying individuals, partnerships with the private sector should be explored. For example, in some cases, a utility worker might be more familiar with a “shut-in” than the person’s neighbors would be. (*Scott Gardner, Alzheimer’s Association*)

As Ms. Theilheimer resumed facilitating the general discussion, a number of issues were raised.

- The National Organization on Disability recently created a task force to bring disability advocates and emergency management leaders together to address many of the issues raised at this forum. In addition, several best practices are available on the organization’s website (www.nod.org), as well as the website of the Department of Homeland Security, Office of Civil Rights and Civil Liberties. (*Hilary Styron, National Organization on Disability*)
- There is a need to be more inclusive in planning, so fewer people have to be considered “special needs.” For example, why weren’t the trailers that FEMA brought in built using universal design principles? (*AARP representative from Louisiana*)
- Disability advocates are often left out of disaster and response planning. There are good models and best practices, but they are not being used. (*American Association of People with Disabilities representative*)
- Even with the best-laid plans, unexpected issues will arise, and teamwork is essential to an effective response. (*Capt. Henry Lopez, Health Resources and Services Administration, HHS*)
- Who makes the call to evacuate, and what happens if a facility chooses not to? (*Government Accountability Office representative*)
- The laws vary by state, but in Florida the decision is made by the Department of Emergency Management. Once the decision has been made, evacuation becomes mandatory. Several issues right now surround “special needs” shelters, such as who constitutes medical personnel, and they should be clarified in the upcoming legislative session. (*Bentley Lipscomb*)

- Private and corporate funders could play an important role in the planning process, but they need to know more about the needs of vulnerable populations. (*Disability Funders Network representative*)
- In the aftermath of Katrina, even when nurse volunteers had appropriate education and credentials, many were not allowed to provide care at Red Cross shelters because of “red tape.” (*American Nurses Association representative*)
- Credentialing in times of disaster will likely require congressional action. (*Bentley Lipscomb*)
- When the federal government exists in local communities, it should use its resources to support those communities during a disaster. For example, if the military is removing planes from a base before a hurricane, it should use those planes to help evacuate citizens. (*AARP representative from Mississippi*)
- Why weren’t the rail lines used in the evacuation plans surrounding Hurricane Katrina? It’s important for leaders to include transit authorities in future planning. (*Public transit authority representative from Kentucky*)
- The District of Columbia is working with the Council of Governments to involve rail systems like Amtrak and VRE (Virginia Railway Express) in its planning. (*Natalie Jones Best*)
- The U.S. Fire Administration has a national credentialing system designed to ensure that fire and emergency services responders have the appropriate training to provide certain levels of service. In addition, the American Public Works Association is in the process of developing a national, mutual aid plan for public works agencies. Other organizations could model both of these concepts. (*International Association of Fire Chiefs president*)
- It’s essential to practice inclusive management. Rather than planning for persons with disabilities, agencies and organizations should ask them what their needs are. (*Maryland Department of Disabilities representative*)
- It’s time to transition from problem identification to effective action. The framework already exists for an integrated and coordinated response, but the challenge is to demand accountability from all levels of government and ensure that resources are in place so plans can be carried out. (*International Association of Fire Chiefs representative*)

Where We Are and Where We Need to Go

In the final session, participants worked in teams to summarize key themes and brainstorm next steps. A number of ideas came out of those discussions:

- A taskforce could be formed to identify other stakeholders, such as law enforcement associations, who should be involved in future meetings.
- Subcommittees could be formed to identify specific strategies for key issues, such as the need for more public education; better integrated planning; a clear command and control structure; and improved identification and tracking systems.
- A clearinghouse could be developed to better capture and coordinate groups’ efforts surrounding emergency planning and response.
- A spokesperson could be chosen to represent vulnerable populations.

- Legislation could be proposed to support integrated planning.
- A “navigator” for the system could be developed, possibly in the form of a hotline. Similarly, a graphic education tool could be created to help explain the command and control structure for disaster response.
- A long-term strategy could be developed to address the mental health needs of victims of the hurricanes and future disasters.
- Local governments could be encouraged to better utilize national resources (i.e., military bases) in their area.
- Inclusiveness must be emphasized in all efforts, from public education on emergency preparedness, to disaster response in terms of evacuation and sheltering.

BIOGRAPHIES OF PANELISTS

JANEGALE BOYD, president and CEO, Florida Association of Homes for the Aging, is a businesswoman, registered nurse, and former two-term member of the Florida legislature. She earned her nursing degree from Tallahassee Community College. Before entering private enterprise, she served in Tallahassee area hospitals as head nurse in both cardiac and intensive care units and taught as a critical care instructor. Since 1985, Ms. Boyd has developed and administered three successful health care businesses.

SCOTT A. GARDNER, West Region field director, Alzheimer’s Association, became executive director of the Alzheimer’s Association’s Phoenix Chapter in February 1993 and joined the national office in September 2003. In his current role, Mr. Gardner works closely with 14 Alzheimer’s Association chapters on organizational development, including strategic and operational planning, fund development and business development.

AYE KHAINE, LMSW, RMT, program supervisor, Catholic Charities of Galveston-Houston, oversees Services to the Alone and Frail Elderly (SAFE), AIDS Ministry, and Serenity House programs. Ms. Khaine has also been involved with the Katrina Relief Effort and the Medical Clinic in the Astro/Reliant Arena in Houston and has contributed to the formation and implementation of Geriatric Social Services command center and Seniors Without Families Tool (SWiFT) by working closely and collaboratively with many advocates for the elders, including partners of Care for Elders.

WILLIAM M. LOKEY, operations branch chief, Response Division of Federal Emergency Management Agency (FEMA), has worked on a variety of assignments since joining FEMA in 1999, including hurricanes Floyd, Isabelle, and Ivan; the Nisqually Earthquake; and two weeks at “Ground Zero” at the WTC in New York as part of FEMA’s Forward Coordinating Team. Recently, he served as federal coordinating officer (FCO) in Louisiana during Hurricane Katrina. He also has served as FCO for 17 declared disasters in New Hampshire, Alaska, Idaho, Washington, Missouri, Indiana, American Samoa, Maryland, Guam, Saipan, and Oregon.

HILARY STYRON, director, Emergency Preparedness Initiative, National Organization on Disability, has extensive experience in all-hazards emergency management, emergency management and long-range strategic planning. Her work in planning spans the country, as she helps develop standard operating procedures, performance measures, protocols and implementation and administration of programs related to emergency preparedness, especially for persons with disabilities.

MICHAEL WESTON, disaster consultant, who has played diverse roles in programs for the aging, created and directed numerous community-based initiatives, and is the former and founding director of Disaster Planning and Operations for Florida's Department of Elder Affairs. Recognized as one of the nation's foremost experts on "special needs" populations, he currently serves as a consultant to the U.S. Administration on Aging, and in that capacity has been tasked by the Department of Homeland Security as the federal coordinating officer over many recent disasters.

JUDY JOHNSON, campus administrator, Covenant Village of Florida (CVOF), has been at the campus for more than six years. Covenant Village, a Continuing Care Retirement Community (CCRC) located in Plantation, Florida, is part of Covenant Retirement Communities, a faith-based, not-for-profit organization headquartered in Chicago. Ms. Johnson's initial education and early professional experiences were in acute care nursing, and, after several additional years in health care consulting, she moved to working in senior living facilities.

CHRIS CAHILL, director of emergency management, Veterans Administration, New Orleans, has been with the VA for nine years. He has a bachelor's degree in nursing from Our Lady of the Holy Cross in New Orleans, and a master's in hospital system management from Loyola University in New Orleans. His emergency management experience includes expertise in response to bioterrorism and contaminating events, and he frequently trains first responders.

NATALIE JONES BEST, emergency preparedness and risk manager, District of Columbia Department of Transportation (DDOT), is responsible for managing the transportation emergency responses coordinated under the District of Columbia Emergency Response Plan (DRP) and overseeing all aspects of DDOT's Emergency Program. During her tenure with DDOT, she also served as a transportation specialist with DDOT's Office of Mass Transit (OMT), working on such issues as light rail development and transit planning, as well as overseeing OMT's Federal Grant Program.

KEITH ROBERTORY, manager of Community Disaster Education, American Red Cross, is responsible for making the public more prepared for disasters and other emergencies. He and his peers develop accurate, timely, and appropriate Red Cross preparedness recommendations by bringing together subject matter experts and scientifically based research to craft messages using communication concepts. Mr. Robertory has been with the Red Cross since 1997.

LINDA A. SADDEN, Louisiana State Long-Term Care ombudsman, is responsible for administering the Louisiana Ombudsman Program, a statewide, federally mandated program to protect and promote the rights of residents of long-term care facilities. Before assuming her current position, Ms. Sadden worked with a not-for-profit agency dedicated to research in social welfare policy issues and spent two years as a VISTA volunteer, working with refugee resettlement.

CAPTAIN HENRY LOPEZ JR., LCSW, MSW, director, Division of Health Careers Diversity & Development, Bureau of Health Professions, Health Resources Services Administration of the U.S. Public Health Service, oversees a \$3 billion portfolio and is responsible for the Campus-Based, Diversity Programs, and Heal Education Assistance Loan (HEAL) programs. These programs seek to increase the number of underrepresented minority and disadvantaged students and faculty in the health professions workforce. He received the Health and Human Services Secretary's Award for Heroism and Volunteerism as first responder to the September 11th tragedy, in both Pennsylvania and New York City.

OLDER PERSONS AND EVACUATION: WHO NEEDS HELP? A SURVEY OF AMERICANS AGE 50 OR OLDER

Most U.S. adults age 50 or older say they would be able to evacuate from their homes without assistance in the event of a natural disaster. However, for those who say they cannot, half will require help from someone outside their household.

- Fifteen percent of adults age 50 or older say they would need assistance from another person to evacuate from their home in the event of a natural disaster such as a hurricane, earthquake, or wildfire.
- Adults age 75 or older are more likely to say they require assistance evacuating from their homes than those age 50 to 74 (25 percent vs. 13 percent).
- Fifty percent of adults age 50 and older who are unable to evacuate their homes without assistance say that they need help from someone outside the household.

As a whole, the majority of U.S. adults age 50 or older are confident in their ability to evacuate their homes in the event of a natural disaster. However, adults age 75 or older and those who need help to evacuate are less confident.

- Sixty-four percent of adults age 50 or older are “very confident” in their ability to evacuate; 17 percent are “confident”; 14 percent are “somewhat confident”; and only 3 percent are “not at all confident.”
- Persons age 75 or older are less likely to be “very confident” in their ability to evacuate than those age 50 to 74 (50 percent age 75+ vs. 67 percent age 50–64 and 65 percent age 65–74).
- Persons age 50 or older who say they are unable to evacuate without assistance are much less likely than those who don't need help to be “very confident” in their ability to evacuate (34 percent vs. 70 percent) and much more likely to be “not at all confident” (12 percent vs. 1 percent).

Women, minorities, people living alone, and persons with lower incomes or less education are more likely to say they need help evacuating and are less confident in their ability to evacuate than are their counterparts.

- Among persons age 50 or older, women (19 percent vs. 10 percent men), and African Americans and Hispanics (22 percent for each group vs. 13 percent of whites) are more likely to say they would need help evacuating.
- Persons living alone (21 percent vs. 13 percent of those who have two or more members in their household) and persons who did not finish high school (26 percent vs. 14 percent who graduated from high school or went to college) are more likely to say they would need help evacuating.
- There appears to be a correlation between income level and the proportion of adults age 50 and over who need assistance: 30 percent of adults with household income less than \$25,000/year, compared with 13 percent of people with incomes of \$25,000–75,000/year, and 5 percent of people with incomes greater than \$75,000/year.
- Among persons age 50 or older, women (77 percent vs. 86 percent men), African Americans (72 percent* vs. 83 percent of whites), and persons with household incomes less than \$25,000/year (72 percent vs. 83 percent with an income of \$25,000/year or more) are less likely to say they are “confident” or “very confident” in their ability to evacuate.
- College graduates (85 percent vs. 80 percent for those who did not graduate from college) and people living in two-person households (85 percent vs. 77 percent of households with one person or three or more people) are more likely to say they are “confident” or “very confident” in their ability to evacuate.

About the Survey: Harris Interactive® conducted the telephone survey on behalf of AARP, November 10–20, 2005, among a nationwide cross-section of 1,648 U.S. adults age 50 and over. Figures for age, sex, race, and region were weighted where necessary to align them with their actual proportions in the population. In theory, with a probability sample of this size, one can say with 95 percent certainty that the results have a sampling error of plus or minus 2.4 percentage points. Sampling error for the subgroups based on gender, age, race/ethnicity, education, income, and number of household members is higher and varies.

**Caution should be used in drawing conclusions from this particular data point because this result is based on a sample of fewer than 100 respondents.*

GLOSSARY OF EMERGENCY PREPAREDNESS TERMS

Unless otherwise indicated, all definitions are adapted from the glossary of key terms in *Individuals with Disabilities in Emergency Preparedness, Annual Report July 2005*, Department of Homeland Security

Disaster—An occurrence of a natural catastrophe, technological accident, or human-caused event that has resulted in severe property damage, deaths, and/or multiple injuries. As used in the Robert T. Stafford Disaster Relief and Emergency Assistance Act, a “major disaster” is “any natural catastrophe . . . or, regardless of cause, any fire, flood or explosion, in any part of the United

States, which in the determination of the President causes damage of sufficient severity and magnitude to warrant major disaster assistance under [the] Act to supplement the efforts and available resources of States, local governments, and disaster relief organizations in alleviating the damage, loss, hardship, or suffering caused thereby.”

Evacuation—Organized, phased, and supervised dispersal of civilians from dangerous or potentially dangerous areas, and their reception and care in safe areas. (Source: *Draft AoA Emergency Assistance Guide*, forthcoming)

Mitigation—Activities designed to reduce or eliminate risks to persons or property or to lessen the actual or potential effects or consequences of an incident. Mitigation measures may be implemented before, during, or after an incident.

Preparedness—The existence of plans, procedures, policies, training, and equipment necessary at the federal, state and local level to maximize the ability to prevent, respond to, and recover from major events.

Prevention—Activities undertaken by the first responder community during the early stages of an incident to reduce the likelihood or consequences of threatened or actual terrorist attacks. (Source: Homeland Security Presidential Directive 8, December 2003)

Recovery—The development, coordination, and execution of service- and site-restoration plans for impacted communities and the reconstitution of government operations and services through individual, private sector, nongovernmental, public assistance programs that identify needs and define resources; provide housing and promote restoration; address long-term care and treatment of affected persons; implement additional measures for community restoration; incorporate mitigation measures and techniques, as feasible; evaluate the incident to identify lessons learned; and develop initiatives to mitigate the effects of future incidents.

Response—Activities that address the short-term, direct effects of an incident. Response includes immediate actions to save lives, protect property, and meet basic human needs. Response also includes execution of emergency operations plans and of mitigation activities to limit the loss of life, personal injury, property damage, and other unfavorable outcomes. As indicated by the situation, response activities include applying intelligence and other information to lessen the effects or consequences of an incident; increased security operations; continuing investigations into the nature and source of the threat; ongoing public health and agricultural surveillance and testing processes; immunizations, isolation, or quarantine; and specific law enforcement operations aimed at preempting, interdicting or disrupting illegal activity, and apprehending actual perpetrators, and bringing them to justice. (Source: National Incident Management System, March 2004)

SELECTED RESOURCES

Older Persons, Family Caregivers, and Persons with Disabilities

“Protecting the Home Front” by Barbara Basler, *AARP Bulletin*, May 2003
www.aarp.org/bulletin/yourlife/a2003-06-26-protecting.html

“Are You Prepared?” by The Home Depot and AARP, also available in Spanish
www.aarp.org/homedepot

“Just in Case: Emergency Readiness for Older Adults and Caregivers”, April 2006
www.aoa.gov/PROF/aoaprogram/caregiver/overview/Just_in_Case030706_links.pdf

“Prepare Yourself: Disaster Readiness Tips for People with Disabilities by the National Organization on Disability”; the N.O.D. also has specific tip sheets for people with mobility, sensory, and developmental/cognitive disabilities. www.nod.org

“Hurricane Preparedness for People with Disabilities” by the Federal Emergency Management Agency www.fema.gov/news/newsrelease.fema?id=24487

“Disaster Preparedness from the Alzheimer’s Association,” a fact sheet for families and friends of persons with dementia, also available in Spanish.
www.alz.org/Resources/FactSheets/FSdisaster.pdf

“Keep It with You: Personal Medical Information Form” by the Centers for Disease Control and Prevention; the form can be folded and placed in a plastic bag for safekeeping.
www.bt.cdc.gov/disasters/hurricanes/katrina/kiwy.asp

For nursing home residents and their families, “Emergency Preparedness: Questions Consumers Should Ask” by the National Citizens’ Coalition for Nursing Home Reform.
www.nursinghomeaction.org/public/245_1268_12002.cfm

A fact sheet for consumers affected by Hurricane Katrina is also available at this site.
www.nccnhr.org/uploads/EmergencyPreparedness.pdf

Many state and local governments have materials available on their websites—for example:

“Ready NY” website, www.nyc.gov/html/oem/html/readynewyork/home.html

State hurricane disaster materials at <http://elderaffairs.state.fl.us>

Governments and the Private Sector

(see additional links throughout this report)

“Saving Lives: Including People with Disabilities in Emergency Planning” by the National Council on Disability. This report provides an overview of steps the federal government should

take to improve emergency preparedness and disaster relief.

www.ncd.gov/newsroom/publications/2005/saving_lives.htm

“ADA Guide for Local Governments: Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities” by the U.S. Department of Justice.

www.usdoj.gov/crt/ada/emergencyprep.htm

The Association of State and Territorial Health Officials has helpful resources on disaster preparedness. www.astho.org

“Standing Together: An Emergency Planning Guide for America’s Communities” by the Joint Commission on the Accreditation of Healthcare Organizations. This guide is designed to assist rural communities in emergency planning.

www.jointcommission.org/PublicPolicy/ep_guide.htm

A checklist to help organizations that provide home health services prepare for responding to pandemic influenza has been developed by the Department of Health and Human Services and the Centers for Disease Control and Prevention. www.pandemicflu.gov/plan/pdf/healthcarechecklist.pdf

ENDNOTES

¹ As cited in The White House. (2006, February 23). *The federal response to Hurricane Katrina: Lessons learned*. Washington, DC: The White House, p. 8.

² Ibid.

³ Among residents of New Orleans affected by Hurricane Katrina, more than 52 percent of households interviewed post-Katrina had a household member who had been ill since Katrina struck. Also, almost 50 percent of adults exhibited levels of emotional distress indicating a need for mental health services, possibly including medications; Centers for Disease Control and Prevention. (2006, January 20). *Morbidity and Mortality Weekly Report*, 55(2).

⁴ Max B. Rothman, Burton D. Dunlop, Laura R. Seff, & Vukosava Pekovic. (2005, September). *Disaster planning for older adults in Palm Beach County*. North Miami, FL.: Quantum Foundation by the Center on Aging, Stempel School of Public Health, Florida International University.

⁵ In 2002, almost 47 percent of persons age 50+ reported excellent or very good health status; AARP. (2005). *The State of 50+ America*. Washington, DC: AARP, p. 22.

⁶ For instance, AARP’s *Beyond 50.05* study showed that there is a very high level of organizational membership among midlife and older Americans, with four in five persons age 50+ reporting membership in organizations of various kinds; AARP. (2005, May). *Beyond 50.05, A report to the nation on livable communities: Creating environments for successful aging*. Washington, DC: AARP, p. 7.

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¹¹ Ibid.

¹² National Center for Health Statistics. (2005). Health, United States, 2005. Hyattsville, MD: NCHS, p. 9. Retrieved March 2006 from <http://www.cdc.gov/nchs/hus.htm>. Data are from 1999 to 2002.

¹³ Jennifer Fisher Wilson. (2004, September). Frailty—and its dangerous effects—might be preventable. *Annals of Internal Medicine*, 141(6), 489–492.

¹⁴ Federal Interagency Forum on Aging-Related Statistics. (2004, November). *Older Americans 2004: Key indicators of well being*. Washington, DC: U.S. Government Printing Office, p. 29.

¹⁵ Ibid., p. 25.

¹⁶ Ibid., p. 26.

¹⁷ The suicide rate for white males age 85 and older is the highest rate of any age or ethnicity, at 53.9 deaths per 100,000 population in 2002; National Center for Health Statistics, op. cit., Table 46.

¹⁸ National Institute on Aging Fact Sheets on Hypothermia and Hyperthermia. Retrieved March 11, 2006 from <http://www.nia.nih.gov>.

¹⁹ Joyce Dubow. (2004, June). Adequate literacy and health literacy: Prerequisites for informed health care decision making. AARP Public Policy Institute Issue Brief # 70.

²⁰ AARP PPI analysis of U.S. Census Bureau. (2004). American Community Survey.

²¹ AARP PPI analysis of U.S. Census Bureau. (2002). American Community Survey.

²² Brenda Spillman & Kirsten Black. (2005, November). Staying the course: Trends in family caregiving. AARP Public Policy Institute Issue Paper #2005-17.

²³ Rothman et al., *op. cit.*, p. 18.

²⁴ Marie E. Cowart. (1993). *Disaster planning for older persons*. Tallahassee, Fl.: Pepper Institute on Aging and Public Policy, Florida State University.

²⁵ William Oriol. Washington, D.C. Psychosocial issues for older adults in disasters. DHHS Publication ESDRB. SMA 99-3323. Substance Abuse and Mental Health Agency, Center for Mental Health Services.

²⁶ Leigh Wade, executive director, Area Agency on Aging of Southwest Florida, Inc. Testimony before the U.S. Senate Special Committee on Aging. (2005, October 5). Preparing early, acting quickly, meeting the needs of older Americans during disaster.

²⁷ HelpAge International, *op. cit.*

²⁸ Sharon Hermanson & Kristin Moag. (1999, January). Home improvement contractors fact sheet. Washington, DC: AARP Public Policy Institute.

²⁹ U.S. Senate Committee on Health, Education, Labor, and Pensions. (2006, February 16). Chairman's report on elder evacuation during the 2005 Gulf Coast hurricane disasters; see also Government Accountability Office. (2006, February 16). Disaster preparedness: Preliminary observations on the evacuation of hospitals and nursing homes. GAO-06-443R. Washington, DC: GAO.

³⁰ Keith Bea, Congressional Research Service. Testimony before the U.S. Senate Special Committee on Aging. (2005, October 5). Preparing early, acting quickly, meeting the needs of older Americans during disaster.

³¹ Government Accountability Office, *op. cit.*, p. 10

³² Bea, *op. cit.*, p. 9.

³³ Elizabeth Davis & Jennifer Mincin. (June 26, 2005). *Nobody left behind, incorporating "special needs" population into emergency planning and exercises*. Topeka, KS: RTC on Independent Living, University of Kansas.

³⁴ Pursuant to the provisions of the Older Americans Act (OAA), each year the Administration on Aging (AoA) sets aside an amount equal to 2 percent of the total amount appropriated for Title IV, Training, Research, and Discretionary Projects & Programs for disaster assistance. Eligible applicants for funding are State Agencies on Aging and Title VI-funded Tribal Organizations in Presidentially declared disaster areas. In the past several years, AoA has used its set-aside funds for disaster events, including hurricanes, earthquakes, floods, fires, and ice storms. The amount available each year varies, but averages approximately \$500,000-\$800,000. AoA also provided Florida with \$134,040 and Alabama with \$100,000 in additional funding for relief following the 2004 hurricanes, and provided Louisiana with

\$425,000, Mississippi with \$250,282, and Texas with \$325,000 in additional funding for relief following the 2005 hurricanes.

In addition to Older Americans Act funds, following the San Francisco earthquake in 1994, the North Carolina hurricanes in 1995, the 9/11 terrorist events, and the four major hurricanes in 2004, the U.S. Congress appropriated supplemental funding to the state agencies affected by these events. This included \$2.4 million for Alabama, \$19.7 million for Florida, and \$.2 million for Puerto Rico (personal communication with AoA, March 20, 2006).

³⁵ Government Accountability Office, op. cit., p. 13.

³⁶ Government Accountability Office, op. cit., p.12; <http://ndms.fema.gov>.

³⁷ Government Accountability Office, op. cit., pp. 2, 21.

³⁸ Administration on Aging. (2006, February). Emergency assistance guide (draft).

³⁹ Government Accountability Office, op. cit.

⁴⁰ National Citizens' Coalition for Nursing Home Reform (NCCHNR). (2005, September). *Emergency preparedness: Questions consumers should ask*. Washington, D.C. NCCNHR.

⁴¹ The Joint Commission currently has 1349 accredited nursing care facilities. Market penetration is 8.3%. The Joint Commission closed its assisted living program effective January 2006. It will continue to support assisted living customers through 2008 when the last certificate expires. "Long-Term Care and Assisted Living PTAC Program Update," hand-out provided at Long-Term Care Assisted Living PTAC meeting, Chicago, Illinois, March 7.

⁴² Government Accountability Office, op. cit., pp. 1, 16.

⁴³ Government Accountability Office, op. cit., p. 2.

⁴⁴ Administration on Aging, *Emergency assistance guide* (draft) op. cit.

⁴⁵ U.S. Senate Committee on Health, Education, Labor, and Pensions, op. cit.

⁴⁶ Administration on Aging, op. cit., p.31

⁴⁷ The White House, op. cit., p. 100.

⁴⁸ U.S. Senate Committee on Health, Education, Labor, and Pensions, op. cit., p. 15.

⁴⁹ Retrieved March 13, 2006 from www.whcoa.gov/about/resolutions/WCHoA_2005_Rank.pdf

⁵⁰ Rothman et al., op. cit. pp.3-4.

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⁵² Susan Waltman, Greater New York Hospital Association. (2005, October 5). Testimony before the U.S. Senate Special Committee on Aging. Preparing early, acting quickly, meeting the needs of older Americans during disaster, pp. 11-12.

⁵³ Carol J. Kientz. (2004, September). Model of preparedness: State associations partner for relief response. *Caring*, Vol. 23, No. 9, pp. 11-13.

⁵⁴ Nora O'Brien. (2003, January-February). Emergency preparedness for older people. International Longevity Center Issue Brief. New York, New York: International Longevity Center.

⁵⁵ U.S. Department of Justice, Civil Rights Division. *An ADA guide for local governments: Making community emergency preparedness and response programs accessible for people with disabilities*. Retrieved October 28, 2005 from www.usdoj.gov/crt/ada/emergencyprep.htm

⁵⁶ Washington Lawyers' Committee for Civil Rights & Urban Affairs, 2005, as cited in Davis & Mincin, op. cit. Retrieved October 28, 2005 from ww.nobodyleftbehind2.org

⁵⁷ Wade, op. cit., p.2.

⁵⁸ Government Accountability Office, op. cit., p. 16.

⁵⁹ National Organization on Disability, Emergency Preparedness Initiative. *Guide on the "special needs" of people with disabilities for emergency managers, planners & responders* (revised). Retrieved February 15, 2006 from www.nod.org

⁶⁰ Federal Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (2005, July), Individuals with disabilities in emergency preparedness. Executive Order 13477, annual report. Washington, D.C.: Department of Homeland Security.

⁶¹ U.S. Department of Justice, Civil Rights Division, op. cit.

⁶² Administration on Aging, op. cit.

⁶³ National Organization on Disability, op. cit., pp. 18-19.

⁶⁴ Hildy Medina, Santa Barbara News Press, Monday, January 16, 2006

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⁶⁸ Waltman, op. cit., p. 12.

⁶⁹ Bea, op. cit., p. 11.

⁷⁰ Federal Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities. (2005, July) op. cit., p. 24.

⁷¹ B. Ciarella, Cynthia J. Mueller & MaryAnne Tosh. (2004, September). Disaster preparedness and home care: Is there a connection? *Caring*, 19–20.

⁷² National Organization on Disability, op. cit., p. 17.

⁷³ Joint Commission on Accreditation of Healthcare Organizations. (2005, September 1). *Standing together: An emergency planning guide for America's communities*. Oakbrook Terrace, IL: JCAHO, p. 51.

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⁷⁵ Association of State and Territorial Health Officials. *Special needs shelters are key component of the public health response to the 2004 hurricanes*. Retrieved February 10, 2006 from www.astho.org

⁷⁶ AARP Florida Fact Sheet

⁷⁷ June Isaacson Kailes. Disaster services and “special needs”: Term of art or meaningless term? Topeka, KS: Research and Training Center on Independent Living, University of Kansas. Retrieved November 28, 2005 from www.nobodyleftbehind2.org

⁷⁸ Administration on Aging, op. cit., p. 23.

⁷⁹ U.S. Department of Justice, op. cit.

⁸⁰ U.S. Department of Justice, op. cit.

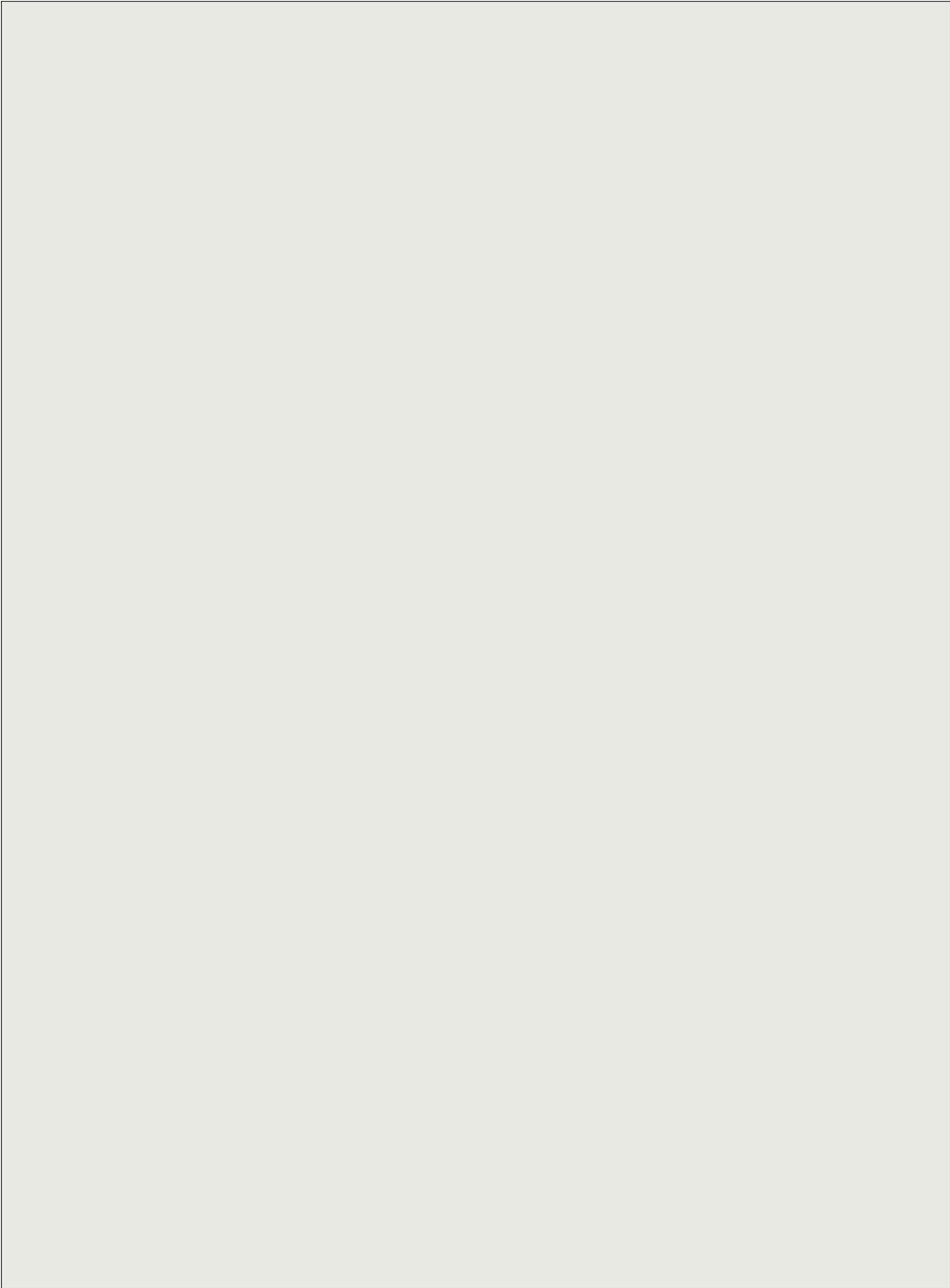
⁸¹ U.S. Department of Education, Interagency Committee on Disability Research. (2005). Emergency evacuation of people with physical disabilities from buildings: 2004. Conference proceedings. Washington, DC 2005. Order online at www.icdr.ius/pubs/EP_Summary.pdf.

⁸² Goldhagen, op. cit., pp. 5–8.

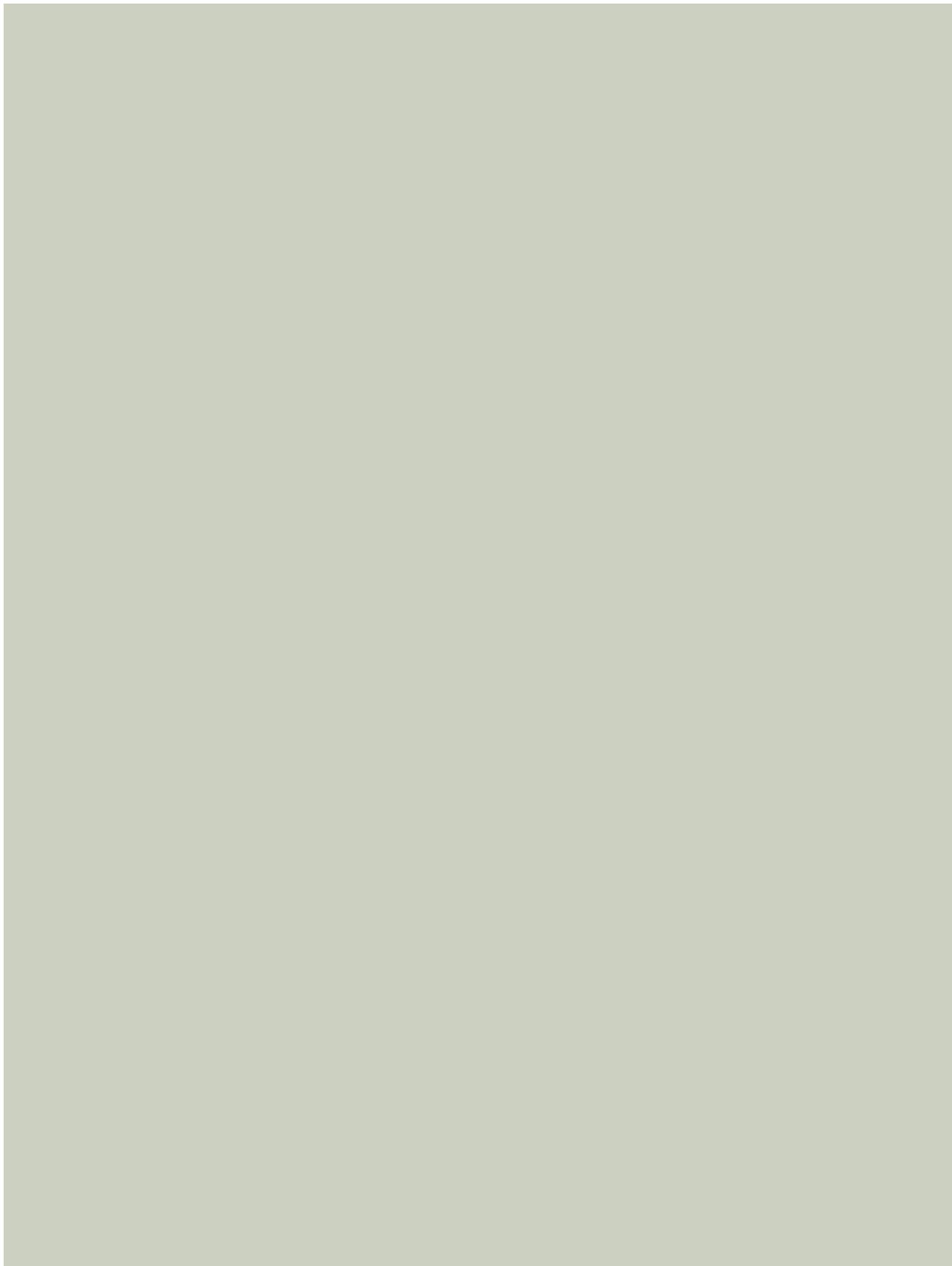
⁸³ Association of State and Territorial Health Officials, op. cit.

⁸⁴ U.S. Department of Justice, op. cit.

NOTES



AARP is a nonprofit, nonpartisan membership organization that helps people 50+ have independence, choice and control in ways that are beneficial and affordable to them and society as a whole. We produce *AARP The Magazine*, published bimonthly; *AARP Bulletin*, our monthly newspaper; *AARP Segunda Juventud*, our bimonthly magazine in Spanish and English; *NRTA Live & Learn*, our quarterly newsletter for 50+ educators; and our website, AARP.org. AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.





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