

WE CAN DO

BETTER



LESSONS LEARNED *for* PROTECTING
OLDER PERSONS IN DISASTERS

REPORT *and* CONFERENCE SUMMARY

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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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WE CAN DO BETTER

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.

It has often been said that disasters reveal underlying weaknesses in how a country operates. 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 surely can do better in protecting older persons in disasters.

On December 1, 2005, AARP convened a diverse group of more than 100 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.

This summary 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. It addresses three major topics as they relate to older persons: (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.

For practical tools and examples of promising practices that should be helpful to policy makers at federal, state, and local levels; nongovernmental organizations; and older persons, family caregivers, and persons with disabilities, please see the full report at www.aarp.org/better.

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. 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 harder to quantify.

To frame the day's discussion in December, AARP CEO William D. Novelli said, "These catastrophic events have taught us we have to pay greater attention to evacuating, identifying and ensuring

the safe return of thousands of frail older adults living on their own or in care facilities." Mr. Novelli emphasized that the goal should not be to assign blame, but rather to develop workable plans that will prevent the most vulnerable members of a community from being the most likely to suffer.

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

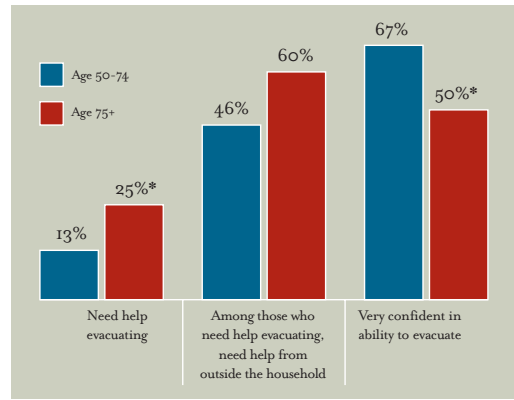
AARP Director of Policy and Strategy John Rother emphasized that a key purpose of the conference, which signals AARP's concern about finding ways to better protect older persons in disasters, was to bring the right stakeholders together.

AARP 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.

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.

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.

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%.

KEYNOTE: PRINCIPLES OF PREPAREDNESS

Tom Nelson, AARP's COO, introduced the keynote speaker, Georges Benjamin, M.D., executive director of the American Public Health Association, who suggested several areas of focus to improve emergency preparedness. For

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GEORGES BENJAMIN

example, Dr. Benjamin urged individuals to be prepared to “shelter in place” for at least 72 hours, and to become engaged in developing plans for themselves, their families, their workplace, and their community. He also encouraged community organizations to plan how to care for their

most vulnerable clients. “It is essential to develop working relationships with stakeholders before a disaster strikes,” Dr. Benjamin emphasized.

Dr. Benjamin stressed that it's best to build on existing systems that will be familiar during a crisis. 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.”

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 make a list of their medications, allergies, and conditions and keep it with them at all times.

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.

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, Dr. Benjamin explained. “But we are concerned that this virus—or one like it—could mutate and become a worldwide infection that could be easily spread.”

“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 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.”

PLANNING AND COMMUNICATIONS

To identify ways to improve planning and communications during emergencies, AARP’s John Rother moderated a panel including William Lokey, chief of FEMA’s Operations Branch Response Division and the federal coordinating officer in Louisiana during Hurricane Katrina; Hilary Styron, director of the National Organization on Disability’s (N.O.D.) Emergency Preparedness Initiative; Judy Johnson, campus administrator of Covenant Village, Plantation Village; and Michael Weston, disaster consultant, and the former and founding director of Disaster Planning and Operations for Florida’s Department of Elder Affairs.

Emergency preparedness requires engagement at several levels, explained William Lokey. He outlined five layers of responsibility: the individual, the caregiver, local authorities, state agencies, and the federal government.

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WILLIAM LOKEY

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.

“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

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HILARY STYRON

Styron. She offered telling statistics from a 2004 survey the N.O.D. conducted of state and local emergency managers. For example, only 42 percent said “yes” when asked if they provide information to elderly or vulnerable populations on self-preparedness.

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.
- In many of the shelters, there were problems assessing whether a person had special needs, and no durable medical equipment stockpiles were on hand.

“We need to change the way we plan from focusing on specific events to looking at broader processes and systems,” said Judy Johnson, who shared lessons learned as administrator of a continuing care community during the hurricanes in Florida. She stressed the importance of thinking beyond the individual facil-

ity level, to the community, the region, or even the state.

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?”

Michael 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 IOI” training, which included making staff members try to complete the registration process with modifications that affected their vision, hearing, and motor skills.

Among the recommendations made at the conference and in the literature related to planning and communications:

- 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.

Special Risks Faced by Older Persons

Government emergency planning documents or processes at any level—federal, state, or local—rarely mention the needs of vulnerable older persons. Yet older persons face special health and other risks with advancing age. For example, 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.
- take multiple medications, rely on formal or informal caregivers for assistance, and, especially at advanced ages, experience general “frailty.”
- live alone, often in isolated rural areas.

- 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*.
- 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.

IDENTIFYING WHO NEEDS HELP AND WHAT KIND OF HELP

The second panel, moderated by Julie Cohn, AARP regional director, featured discussion of the difficult challenges involved in locating persons who urgently need help, many of whom are older and have disabilities, and determining what types of health and rehabilitative services and other supports they need in the aftermath of disasters. The panel included Janegale Boyd, president and CEO of the Florida Association of Homes for the Aging; Scott Gardner, of the Alzheimer’s Association; Chris Cahill of the Veterans Administration in New Orleans; and Aye Khaine, of the Services to the Alone and Frail Elderly (SAFE) Program of Catholic Charities of the Archdiocese of Galveston-Houston.

“When you’re in a desperate situation, with no electricity and resources, you become the mother of invention.”

JANEGALE BOYD

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

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 Florida Department of Health.

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. "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."

One of the most pressing problems resulting from the hurricanes was lack of medications, which led to many seniors ending up in emergency rooms. "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.

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Scott Gardner underscored that "First responders must have at least a basic understanding of Alzheimer's disease, because they're going to encounter persons who have it." 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."

Chris 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.

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

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CHRIS CAHILL

purchasing new technology to ensure that their systems are compatible.

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.

Khaine, along with other members of the Care for Elder Partnership, quickly joined together to develop the SWiFT (Seniors Without Family) screening tool. The tool allowed health professionals, such as licensed social workers and nurses, and volunteers to assess needs by asking about evacuees’ 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 and referred to appropriate sources of help.

Among the recommendations made at the conference and in the literature related to identifying who needs help and what type of help:

- 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 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.
- 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?

Bentley Lipscomb, AARP's Florida state director, moderated the final panel, which focused on the lack of specific evacuation plans for older persons in the community and in nursing homes. 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. The panelists were Natalie Jones Best, emergency transportation coordinator for Washington DC's Transportation Department; Captain Henry Lopez of the DHSS Health Services Resources Administration; Keith Roberatory of the American Red Cross; and Linda Sadden, Louisiana state long-term care ombudsman.

"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. "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."

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NATALIE JONES BEST

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 people with disabilities, who are less likely to have their own transportation, Ms. Best said.

Capt. Henry Lopez, team leader for the San Antonio metropolitan area in the aftermath of the hurricanes, saw firsthand the challenges of serving thousands of unexpected evacuees. His 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, 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. He 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. Based on his experiences, Capt. Lopez observed, leaders must be prepared to improvise in a disaster, as well as having well-thought-out plans.

Keith 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.

In the aftermath of the hurricanes, many older adults are struggling with depression without needed support, said Linda Sadden. “We really haven’t addressed the mental health aspect yet.”

Ms. Sadden voiced concerns about the trauma many seniors experienced when being transferred from facilities. In Houston, for example, one nursing home housing evacuees had already reported 20 deaths. “I’m not sure we know the answer yet as to whether we should have mandatory evacuations for individuals.”

Among the recommendations made at the conference and in the literature on evacuating older persons in both community settings and nursing homes:

- Plan at the community level to provide *accessible transportation* for persons with mobility limitations or low vision or for others unable to transport themselves.

- 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.
- 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.

CONCLUSIONS

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

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 to vulnerable populations of all ages. The challenges are to:

- Clarify 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.
- Provide 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.

- Improve coordination and communication. Part of the solution is to build relationships before a disaster strikes and to develop better mechanisms to promote integrated planning.
- Improve 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.
- Appropriately define and address 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.”



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

BILL NOVELLI

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