Nobody Left Behind

Report on Exemplary and Best Practices in Disaster Preparedness and Emergency Response For People with Disabilities°

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Introduction

The Nobody Left Behind (NLB): Disaster Preparedness for Persons with Mobility Impairments research study determined the readiness of emergency management sites across the United States to assist persons with mobility impairments during disasters. This research was under the direction of Glen W. White, Principle Investigator, and Michael H. Fox, Co-Investigator, at the University of Kansas, Research and Training Center on Independent Living (RTC/IL). Thirty randomly selected sites that had experienced a Federal Emergency Management Agency (FEMA) declared disaster during 1998-2003 were the focus of the research. Emergency managers at each site were surveyed by telephone and their local emergency plans were reviewed. Experts in disaster preparedness and response and/or people with disabilities assisted in the project as advisors.

One component of the NLB project was to identify exemplary polices, practices, and programs in emergency management designed to assist persons with mobility limitations. The identified exemplary situations are the basis of this white paper. With the support of policy makers in emergency management and disabilities, these practices can serve as catalysts for change, which may be emulated by other counties, cities, parishes, or boroughs.

Results

Exemplary Emergency Management Practices

Interviews with the emergency managers helped determine whether guidelines were in local emergency plans to assist persons with mobility impairments.[1] Six sites out of 30 self identified that their local emergency management plan included such guidelines. Among these 6 sites, there was a 50/50 split between urban and rural locations. Two of these 6 sites included a nuclear facility plant in their jurisdiction which indicates additional responsibilities as well as financial resources to address these responsibilities.

What distinguishes these six sites as exceptional compared to the other sites in the study is the cumulative effect of policies and practices that they employed. Thus, these sites took a comprehensive approach to addressing the needs of persons with disabilities, including mobility impairments.

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[1] Fox, M.H., White, G.W., Rooney, C., & Rowland, J. (spring, 2007). Disaster preparedness and response for persons with mobility impairments: Results from the University of Kansas Nobody Left Behind project. *Journal of Disability Policy Studies,* 17 (4) 196-205.

Table 1 illustrates the six emergency management practices that the sites identified to assist persons with disabilities, including mobility impairments. These management practices included having guidelines and the inclusion of the disability community in planning. Each of the sites had at least three out of six emergency management practices, making for a more extensive approach to assisting persons with disabilities than the other sites.

Table 1

*Emergency Management Practices Including the Needs of Persons
with Mobility Impairments and the Corresponding Number and
Percentage of the Six Exemplary Sites with these Practices*

Emergency Management Practices	Number of the 6 Sites with Practice
Guidelines to assist persons with mobility impairments.	6
Surveillance identification of persons with mobility impairments.	5
Consumer outreach for persons with mobility impairments.	1
Customer service delivery in transportation, sheltering, problem solving, etc. as related to the needs of persons with mobility impairments.	5
Education and training about the disability community and their needs in disaster preparedness and response.	3
Inclusion of persons with disabilities in the local planning process, and/or in training drills of responders.	6

Specific consumer services delivery included:

1. Administering and maintaining a surveillance system, usually a self-identified registry system of persons needing assistance during a disaster or emergency;

2. Identifying accessible transportation vehicles and guidelines to evacuate persons with disabilities needing assistance;

3. Establishing a so called special medical needs shelter; and

4. Conducting training and exercises on evacuation of persons with disabilities.

Among the sites that did not consider their plan as having guidelines to assist persons with mobility impairments, several also administered registries, identified accessible transportation, evacuated persons with disabilities, established shelters, or

conducted training and/or exercises on evacuation of persons with disabilities.[2] Yet, the norm was to have a few policies aimed at addressing one specific disability and issue. For example, it was common to have policies on communication or warning alternatives for the hearing impaired. However, the remaining assistance needs of persons with disabilities, including persons with mobility impairments, were missing from the plans or practices.

Inclusion of Persons with Disabilities

The figures on Table 1 on page 4 show that only half of the exemplary sites reported having training in assistance needs of persons with disabilities. These findings support previous NLB recommendations on the need for better educated emergency management personnel regarding disabilities and disaster management.[3]

It is a must that active representation across disabilities be included at the planning table, not just service providers or advocates for the elderly. Persons with disabilities have much to contribute to emergency management efforts, as shown by the preparedness tip sheets developed for and by persons with mobility impairments in Attachments 1 and 2. From personal experiences, these

> *"Today there is more emphasis on animals in a disaster than disabilities. I hate to say it."*
>
> **Emergency Manager, NLB Study**

preparedness tips were formulated from responses to an online survey conducted by the NLB project. Inclusion of persons with disabilities in emergency management can lead to more effective preparedness for individuals and the community.

A resource to assist managers in this area is a white paper commissioned by the NLB study called, "*Why and How to Include People with Disabilities in Your Emergency Planning Process," by June I. Kailes.* This paper can be found on the www.nobodyleftbehind2.org website under findings.

Offices and organizations that could help get emergency managers in touch with qualified persons with disabilities to serve on planning committees are Governor's Offices on Disabilities, the Statewide Independent Living Council (SILC), and local or regional centers for independent living (CILs). Resource directories for the SILC and CILs by state can be found on http://www.ilru.org/html/publications/directory/index.html.

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[2] Staff. (2005, August). *Analysis of local emergency management plans to determine whether the needs of persons with mobility limitations are being met.* Lawrence, KS: The Research and Training Center on Independent Living, University of Kansas.

[3] Staff. (2005). *Nobody Left Behind: Objective three, focus area: Assurance and policy development recommendations.* Lawrence, KS: The Research and Training Center on Independent Living, University of Kansas.

Emerging Best Practices

The 30 sites randomly selected for the NLB project and other sites, as recommended by advisors and consultants, were investigated by the researchers with an eye for exemplary policies, practices, or programs to assist persons with mobility impairments. Four such cases were identified. Two exemplary practices were from sites that had also self-identified in the NLB study as having guidelines in their local plans to assist persons with mobility impairments. The researchers termed these exemplary policies, practices, and programs as "emerging best practices."

The emerging best practices are in: 1) comprehensive planning for persons with disabilities in the local emergency management plan 2) comprehensive planning tool using surveillance and consumer education; and 3) day to day surveillance and consumer education outreach.

Comprehensive planning in local emergency management plans. The optimal approach to comprehensive planning is an extensive set of guidelines in the local emergency plan to address the needs of persons with disabilities. One site did just this by creating an "Appendix on Persons with Disabilities" to the Annex on Direction and Control in their local emergency management plan. Attachment 3 of this report is that Appendix with slight modifications in formatting and to remove the identity of the site. Attachment 4 is the corresponding self-registry form for persons with disabilities.

The provisions of the Appendix take a multi-disability approach (sensory, physical, and emotional/mental), set minimum training and reception care requirements, seek inclusion of persons with disabilities, and place responsibilities on persons with disabilities and other responders in participation with preparedness and the plan. Attachment 4 is the self registry form that corresponds with the first directive that persons with disabilities make their needs known and prepare themselves for potential emergencies. The Appendix on Persons with Disabilities can be used as a model with minor adjustments to fit many local systems. It is an excellent starting point to bridge gaps in assistance measures for persons with disabilities, while providing for more knowledgeable and confident emergency management teams to address these needs.

Another component of this Appendix is it utilizing persons with disabilities in the training exercise. For those managers considering providing training and exercises that include persons with disabilities an excellent resource is: *Incorporating Special Needs Populations into Emergency Planning and Exercises"* by E. Davis and J. Mincin (2005, June). This paper can be found on www.noodyleftbehind2.org under findings.

Comprehensive planning tool using surveillance and consumer education. During the NLB study, it was discovered that one site was utilizing a best practice, field-developed, surveillance and consumer education model. It brings the health field and emergency management together to map the assistance needs of a community to best design non-medical and medical assistance. This planning tool relies on consumer education and participation. Survey questionnaires are included in the consumer

education packet or online at a website. The questionnaires allow for the intake of assistance information such as physical location, medical needs, medication, mobility, and medical history. The consumer packets are distributed by mail, Meals on Wheels, Area Agencies on Aging, and home health agencies in this Texas model.   Recently, distribution has occurred through churches utilizing the Faith-Based nursing program (Parish Nurses). Using the provided database software to map the various types of assistance needs and locations, planners can determine the placement of shelters, staffing, and medical equipment and supplies.

Patti Moss, RN, MSN, at the Lamar University Department of Nursing created this tool for local adoption and it is called "The Disaster Preparedness Planning for the Special Needs Population." (See Attachment 5 for website to obtain the database software, special needs assessment survey, survey questionnaires, and consumer education packet.) Existing shelters developed through this model were tested under the conditions of Florida hurricanes and Hurricane Rita. This tool is being used by several emergency managers in Texas, Louisiana, and Florida. In 2006, the State of Texas went live with a modified version of this database model, through the 2-1-1 program, in order to establish the State of Texas Registry.

Day-to-day consumer and surveillance outreach. One site in the NLB study stood out with its "accumulative effect of several policies and practices" aimed at meeting the needs of specific individuals with disabilities. Good management, a workable self-identifying registry, consumer education, and adequate resources were a part of the success of this operation as well.   The emergency manager took the consumer and surveillance outreach program designed for the part of the county that encompassed a 10 mile radius of the nuclear power plant and expanded it to cover the entire county. The end result translated into excellence in meeting the individual assistance needs of persons with various disabilities across this rural county.

Some 20 years ago, the emergency management and nuclear industry used a calendar as a means to provide the public with safety and evacuation routes in case of a nuclear power or other emergency. This site has found that changing the theme of the calendar with local attractions, photos or other points of interest each year on the calendar has kept the attention of the public. It has become the best tool to have safety

> *"One thing that ... would be valuable with jurisdictions ... an educational program for persons with disabilities that would prompt them to contact the local dispatch center to apply pertinent information in the [dispatch] system."*
> **Emergency Manager, NLB Study**

information readily available to the public. Along with the calendar, each household in the county gets a postage paid registration card. This card is to be filled out if anyone in the household requires assistance during disasters. Knowing these individual needs and residencies helped the emergency manager create an environment to meet those needs. For example, when the emergency management office was relocating, it built in

the capacity to serve as a special medical needs shelter and the entrance and bathrooms of the building were made accessible.

The emergency manager also has built upon small community scale of knowing one another and responding. For example, volunteers have been recruited from the county road and bridge staff to go to the homes of persons in the rural countryside who need assistance with evacuation or to receive warnings.

The office also has adequate staffing and financial support due to the tax revenue generated from the local nuclear power plant. Otherwise, the staff for an office that size would have been a part-time manager rather than three full-time staff persons. The nuclear power plant money pays for the calendars, inserts, and mailings, The county pays for the registry, and this information is shared with 911. One staff person maintains the registry and interagency exchange of information.

Required Resources for Guidelines

The emergency managers in the NLB study who did not include people with disabilities in their local emergency management plan said to create such guidelines, such as the Appendix on Person with Disabilities (Attachment 3), requires one or more additional resources.[4] Table 2 illustrates the resources identified by the emergency managers as needed to develop guidelines to assist persons with disabilities. A majority required additional funding while other resources included trained personnel, a mandate, and additional public education efforts.

Table 2

Resources Needed to Develop Guidelines in Local Emergency Management Plans on the Needs of Persons with Disabilities and the Percentage of these Managers Needing Specific Resources

Resources Needed to Develop Guidelines	Percentage of Managers Needing Resource to Develop Guidelines
Financial Resources	67%
Knowledgeable and Trained Personnel	33%
A FEMA, State, or County Mandate	25%
Greater Public Education Efforts	17%

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[4] Michael Fox presented PowerPoint, "County Level Disaster Preparedness and Response for Person with Mobility Impairments: Results from the University of Kansas Nobody Left Behind Study" by Michael H. Fox, Sc.D., Glen W. White, Ph.D., Catherine Rooney, M.A., and Jennifer Rowland, Ph.D., P.T., at the Centers For Diseases Control and Prevention, Public Health Preparedness Conference, Atlanta GA, 2/22-24/05. This can be found at www.nobodyleftbehind2.org under PowerPoint Presentations.

Discussion

Summary

More attention is required in local emergency management systems to effectively address the needs of persons with mobility impairments and other disabilities. An emerging best practice is to create an extensive approach to addressing the needs of persons with disabilities by developing an Appendix on Persons with Disabilities in the local emergency management plan (see Attachment 3 for Appendix example). Another emerging best practice is a workable database design for mapping local and state consumer medical and non-medical assistance needs for the planning of special medical needs shelters. (See Attachment 5 for this model.) Other factors that contributed to best practices included proactive management, effective consumer education, and adequate resources. Each of the exemplary and best practices scenarios can be used as models and, with minor adjustments, fit many local systems. Their scopes can also be expanded to address other gaps in services or policies. Regardless of which direction an emergency management offices takes, it is important to encourage the inclusion of persons with disabilities. A majority of the emergency managers without guidelines stated they required additional funding, trained personnel, a mandate, and additional public education efforts.

Policy changes are also needed to get emergency management and response personnel educated in disability sensitivity and specific disability related needs that encompass the broad spectrum of disabilities (sensory, physical and emotional/ cognitive). Prevention saves lives, so additional emphasis and resources need to go towards distribution of existing disability related preparedness information to the disability community as well as the creation of new materials.

The infrastructure of local emergency management offices needs to be strengthened. This may include the resources for emergency managers to receive and offer training dealing with persons with disabilities

> *"It would be helpful if FEMA incorporated more training in dealing with people with mobility impairments."*
> **Emergency Manager, NLB Study**

and their emergency management needs, create surveillance resources for identification of persons with disabilities, offer outreach materials for preparedness for persons with disabilities, and seek their input into the emergency management process.

Previous NLB research findings indicated there is limited attention by emergency managers on taking courses regarding persons with disabilities. This may be in part due to past policy decisions, particularly within FEMA, to focus the original required training and operational structure of emergency planning and response on the needs of the general population. Thus, learning about and planning for the needs of the so called "special needs populations," which includes persons with disabilities, becomes optional. Given this mind set, it is evident from the interviews of the emergency managers that the managers are interested and committed to providing quality services to all

constituents in their service areas. It is recommended that persons with disabilities be taken out of the category of special needs populations. By doing this, persons with disabilities would automatically be included in the overall training components for emergency management. However, additional continuing training options should be encouraged and promoted by policy makers as no one course to date is a true model training program.

Another resource on the topic of appropriate terminology in the field is from a white paper commission by the NLB project: *Disaster Services and "Special Needs": Term of Art or Meaningless Term?"* by June I. Kailes. This paper can be found on www.noodyleftbehind2.org under findings.

Limitations

For the purposes of developing a full scale resource guide, the size of the NLB sample was too small to obtain more than a few examples of exemplary and emerging best practices. Another approach designed specifically to collect and systematically review possible best practices is recommended. In addition, very few local emergency management plans were submitted to the researchers for review since the documents were frequently revised, security reasons, and because of the hassle of reproducing the document. Thus, the researchers had to rely on the self identification from the managers about having guidelines to meet persons with mobility impairments. It became evident during the interviews that some type of checklist on possible policies and practices constituting assisting persons with mobility impairments would be helpful. Without this list, emergency managers had to decide on their own what constitutes addressing needs. So, what one manager thought was not a specific policy or practice another might have thought it was such as special medical needs shelters.

Conclusion

The media coverage of the plight of the disabled, elderly, and poor from the aftermath of Hurricane Katrina in New Orleans is making policy makers' examine the system that failed. Attention is now being given to the assistance required of special needs populations which currently encompasses disabilities. The time is right to re-examine the mind set of the past and to address shortcoming in the field as a whole.

Who best can direct the changes other then emergency managers with exemplary practices. Taking research and placing it into practice is the next challenge to advance practices in the field. As the saying goes "An ounce of prevention is worth a pound of cure." Each of the emerging best practices presented in this white paper are a separate ounce of prevention. They can be modified to meet specific local needs and be implemented with support from policy makers in emergency management and disabilities community.

Do's and Don'ts Checklists for Individual Disaster Preparedness
for and by Persons with Mobility Impairments

Exemplary and Best Practices
Inclusion of Persons with Disabilities

Do's and Don'ts Checklists for Community Disaster Preparedness Involvement
for and by Persons with Mobility Impairments

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Attachment 3
Exemplary and Best Practices
Comprehensive Planning in Local Emergency
Management Plan

Appendix on Persons with Disabilities

Annex-Direction and Control

I. The following considerations must be addressed in order to integrate matters relating to persons with disabilities into all planning and procedural activities.

A. Identification

1. Active participation by persons with disabilities in the identification process is required in order to provide effective assistance.

2. Persons with disabilities must take responsibility for registering with emergency response agencies, making their needs known, and preparing themselves for potential emergencies to the maximum extent possible within their means.

B. Systems to provide alert or warning include, but are not limited to:

1. Open-captioned television.

2. Commercial radio Emergency Alert System (EAS).

3. Media Alert through Department of Public Safety.

4. Telecommunication devices for hearing/speech impaired persons (TT).

5. Standard warning systems such as sirens, klaxons, and public address loudspeaker systems.

6. House-to-house notification by law enforcement, fire, or other emergency response personnel.

7. Neighborhood watch/assistance programs.

8. Basic emergency sign language for persons who are deaf or hearing-impaired.

C. Training and exercises involving evacuation of persons with disabilities should emphasize:

1. How to address and relate to persons with disabilities.

2. How to guide persons with visual impairments.

3. Emergency sign language and finger spelling.

4. How to handle mentally impaired individuals in an emergency.

5. The use of specialized mobility equipment.

6. Moving individuals who use a breathing apparatus or other life-sustaining equipment.

7. How to move/transfer the bedridden and frail elderly.

8. Safe handling procedures for individuals who use a wheelchair or other assistive device.

9. The importance of taking medications and other items along with the evacuee.

10. Characteristics of an emergency call from persons with disabilities.

11. How to rescue persons with disabilities from para-transit vans and buses.

D. Reception and care centers for use by persons with disabilities must be identified as such.

The unique requirements of such facilities include:

1. Ramp entrances/exits.

2. Accessible rest rooms with 60" x 60" or larger stalls.

3. Refrigeration for medications.

4. Emergency electric generator for respiratory and other equipment.

5. Oxygen availability.

6. Facilities for accommodating service animals for persons with disabilities.

E. Specific Tasks

1. County Department of Emergency Management

a. Assist agencies without emergency plans to develop such plans.

b. Conduct or participate in seminars or workshops for staffs of agencies that serve persons with disabilities to provide information relating to emergency response alerts, warnings, sheltering, evacuation procedures, and other related matters.

c. Install a TT device for speech/hearing impaired persons in the EOC and train the staff in its use.

2. Sheriff's Office

   a. Participate in emergency preparedness planning, as required, for agencies representing or providing services to persons with disabilities.

   b. Assist in the notification, warning, and evacuation of persons with disabilities.

   c. Communicate with hearing impaired individuals at the Sheriff's communications center.

3. American Red Cross Chapter

   a. Identify and designate reception and care facilities capable of accommodating persons with disabilities.

   b. Provide emergency vehicles and drivers to transport disabled evacuees to reception and care centers.

4. Persons with Disabilities

   a. Be aware of individual warning, evacuation, and sheltering needs.

   b. Register with the local emergency services organization if special warning procedures, evacuation assistance, and/or special shelter facilities are needed (See Appendix 2 of this report).

   c. Maintain stocks of supplies, equipment, and medications which may be required for a minimum of three days in a shelter.

   d. Be aware of county warning procedures, evacuation plans, and shelter.

Attachment 4

Example of Self-Registry Form that
Corresponds with Attachment 3

Completion of this form is voluntary.

The information requested on this form is needed to assist emergency response agencies and their personnel in the event of an emergency to locate, warn and, if necessary, evacuate persons with disabilities.

The information will be held in strict confidence and will be disclosed only to authorized members of the *(name of the city or town goes here)* emergency response organization as described in the *(name of the city or town goes here)* Emergency Operations Plan.

When the form is completed, mail it to the *(name of the city or town goes here)* or phone *(name of the city or town phone number goes here)* and a member of the *(city or town)* emergency response organization will pick it up at your residence.

Name _____ Phone _____

Address _____ Date of Birth _____

Preferred/Required Form of Notification:

_____ Telephone   _____ Flashing Light or Other Visual Method

_____ In Person   _____ Tell Neighbor/Relative Listed Below

_____ Written   _____ TT

Relative/Friend who can provide assistance:_____

Address _____ Phone _____

Family Physician _____ Phone _____

Type of Disability _____

Attachment 5
Exemplary and Best Practices
Comprehensive Planning Tool uses Surveillance
and Consumer Education

"The Disaster Preparedness Planning for
the Special Needs Population"

This planning and educational tool is provided by Patti Moss, Lamar University, Department of Nursing and retired Sgt. Robert Smith, police department and emergency management. It can be found at www.disaster-research.us and the website contains:

1. Database software (also available on CD).

2. Special needs assessment survey.

3.   Survey questionnaires.

     a. Non-medical for database registry.

    b. Special needs evacuation form to gather planning information.

 4. Consumer education packet.

 5. PowerPoint on background and use of the tool.