“I have Juvenile Rheumatoid Arthritis and use a wheelchair. We had a bomb threat at work. Everyone evacuated, but I was still left on the 3rd floor by the stairwell for the firefighters to come get me. But, no one came. Finally, I just struggled and I used pure fear to get myself down the stairs and outside. It was scary...”

Glen W. White, Principal Investigator
Michael H. Fox, Co-Investigator

Catherine Rooney, Project Coordinator
Jennifer Rowland, Graduate Research Assistant

Research and Training Center on
Independent Living
The University of Kansas

Funded by Centers for Disease Control and Prevention through the Association for Prevention Teaching and Research TS, #0840
Abstract: “A common theme emerging from 9/11 is there are virtually no empirical data on the safe and efficient evacuation of persons with disabilities in disaster planning. The media heightened our awareness of this problem from the reports of many individuals with disabilities trapped in the World Trade Center Towers during the 9/11 disaster. While such acts of terrorism are rare, other catastrophic events, such as floods, tornados, hurricanes and fires, are more frequently experienced across this nation and can lead to tragic results. Disaster preparedness is facing many new challenges with the advent of terrorism and the changes to the environment and our demographics. For instance, more and more older Americans and persons with disabilities are in the workplace and community due to new laws, such as Americans with Disabilities Act (ADA) and the New Freedom Initiative (NFI). Typically, disaster preparedness and emergency response systems are designed for non-disabled persons, using typical escape or rescue procedures, such as walking or running, that are not appropriate for assisting persons with mobility impairments. Nor have many of these plans specifically addressed the transition needs back to pre-disaster conditions that are required for persons with mobility impairments.”

The Nobody Left Behind (NLB): Disaster Preparedness for Persons with Mobility Impairments research project is an empirical research study that explored the unchartered area of disability-related disaster and emergency response practices at local emergency management agencies. This project sought to determine whether disaster plans and emergency response systems include the health, safety, and survival needs for persons with mobility impairments. Other goals were to identify the morbidity and mortality of persons with mobility impairments in these disasters; assess whether post-disaster changes addressed the needs of persons with mobility impairments; and identify any best practice examples that meet the needs of persons with mobility impairments in hopes of preventing injuries and saving lives. The Centers for Disease Control (CDC) funded this three-year project through the Association for Prevention Teaching and Research (TS#0840).

Researchers. The Research and Training Center on Independent Living at University of Kansas research team consists of Glen White, principal investigator; Michael Fox, co-investigator, and Catherine “Cat” Rooney, project coordinator. Additional assistance was provided by Jennifer Rowland, Monika Suchowierska, and Jennifer L’Heureux, graduate research assistants; Nicole Denney, Chiaki Gonda, Jonathan Andrews, and Efe Ekpere, student research assistants.

Methods. The map below illustrates the disaster site sample that was randomly selected. There are at least two disasters (e.g., flooding, hurricanes, various types of


storms, a tornado, wildfires, winds, avalanches, an earthquake, and the 9/11 terrorist attacks) in each of the 10 Federal Emergency Management Agency (FEMA) regions.

Specifically, through telephone surveys and reviews of local emergency management plans, the researchers examined whether local emergency management plans, guidelines, and procedures addressed the needs of persons with mobility impairments.

The project’s online consumer survey, administered from the study’s website, captured personal descriptions about the circumstances that people with mobility impairments face during a disaster. This survey explored what was deemed helpful for survival, difficulties experienced during and after the disaster, lessons learned, and future directions for emergency management from the consumer perspective. For example, said one survey participant: “I have juvenile rheumatoid arthritis and use a wheelchair. We had a bomb threat at work, which was very scary. Everyone evacuated, but I was still left on the 3rd floor by the stairwell for the firefighters to come get me. But, no one came. Finally, I just struggled and I used pure fear to get myself down the stairs and
outside. It was scary just to realize that there are not really any procedures in place to help someone like me in an emergency.”

**Results and Significant Findings.** According to the *Nobody Left Behind* research survey of emergency managers, 43% of the emergency managers interviewed had some idea of the possible number of persons with mobility impairments within their jurisdictions. Twenty-seven percent of the emergency managers reported using Census figures or self-reported registries as a way of identifying this population for planning purposes. Out of the 17 sites that did not have an approximate number for the persons with mobility impairments in their community, 59% of the emergency managers stated that knowing the approximate number of persons with mobility impairments would be helpful. However, several managers noted their frustration with volunteer self-registry systems, since frequently a small percentage of the actual people needing assistance register.

Other findings included:

- A majority of the emergency managers are not trained in special needs populations, which includes persons with mobility impairments.

- There was little to no representation of persons with mobility impairments at the planning or revision stages of the emergency plan.

- A majority of the emergency managers did not know how many persons with mobility impairments live within their jurisdiction.

- Only 21% of the emergency managers are planning to develop guidelines for assisting persons with disabilities.

Overall conclusions from the empirical findings of NLB study suggest that emergency managers would benefit from taking educational courses, having reliable surveillance tools, and developing specific guidelines aimed at addressing emergency management needs of persons with disabilities.

Another component of the research is the consumer survey on persons with mobility impairments that survived a disaster or emergency. Based on the qualitative findings of the study, beneficial steps for the disability community include persons with disabilities developing individual and disability specific preparedness plans and getting involved in local level disaster planning.

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Some of the comments from survey participants who were persons with mobility impairments who had survived a catastrophic event that describe the issue of being “left behind” in preparedness and response included:

- “The able-bodied community MUST get the message that it is critical to think through and develop a plan to evacuate people with disabilities.” (From: New York City)

- “It is really difficult to get the utility company to understand power is a need if disabled.” (From: Knoxville, TN during severe storms)

- “We had to move out of our house for several weeks to have it repaired. All the places that people referred us to were not accessible to me in my scooter.” (From: Los Angeles, CA during an earthquake)

- “I ambulate with forearm crutches and my leg stamina is limited. As a social service provider in NYC, I am in tall buildings often and [while in] one in particular they had an evacuation drill. There were no plans or equipment to assist me. They told me to ignore the drill. I felt very vulnerable because I attend regular work meetings in this building.” (From: New York City)

- “After a hurricane, I did not use the shelters, because they were not wheelchair accessible and had no provisions for my service dog.” (From: Miami, FL)

Tables 1 through 4 describe the three primary focus areas (objectives and research questions) of the study, summarize findings, and provide recommendations to address the identified problem areas in accordance with cited Briefing Papers.
### Objective One

To determine whether counties that have experienced a natural or man-made disaster between 1998 and 2003 have systems in place for disaster preparedness and emergency response for residents with mobility impairment.

### Research Questions

1. Have FEMA-declared natural or man-made disasters facilitated changes for persons with mobility impairments? If so, how.
2. Have the disaster preparedness and emergency response planning process included community stakeholders representing people with disabilities? If so, what has been their involvement and outcomes?

### Conclusions/Problem Areas:

- Disasters can have an adverse impact on persons with mobility impairments.
- Changes had been made at only a few sites in the study to guidelines and procedures in the local plans to address the needs of persons with disabilities.
- Overall, the lessons being learned from declared disasters regarding persons with disabilities are not being reflected in the emergency plans or procedures.
- Local emergency management **does not** have systems in place for disaster preparedness and emergency response for their residents with mobility impairments.
- There is little to no representation of community stakeholders representing people with mobility impairments in disaster preparedness and emergency response planning processes.

### Recommendations:

- Homeland Security and state level emergency management offices develop minimum criteria that require emergency managers to review the effectiveness of their emergency management plans in meeting the needs of persons with disabilities.
- Develop a model training curriculum to train persons with disabilities to develop their own individual preparedness plans.
- Create a model training curriculum to assist persons with disabilities to serve on committees to assist in the development of guidelines, procedures, and other protocols in community emergency management’s efforts.
- Local and state chapters and centers representing persons with disabilities and independent living develop resource listings for local emergency managers to draw upon to assist with increasing the involvement of persons with disabilities in emergency management planning and rescue efforts.

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5 Staff. (2005). Nobody Left Behind: Objective One, focus area: County programs, policy, and practice. Lawrence, KS: The Research and Training Center on Independent Living, University of Kansas.
### Objective Two

To evaluate surveillance systems at the county level that can identify morbidity and mortality frequency and prevalence for persons with mobility impairments exposed to a disaster.

### Research Questions

1. Are counties able to assess prevalence of persons with mobility impairments who reside and work in their jurisdictions and are at risk of disaster exposure?
2. Among counties that have surveillance systems in place, what are the prevalence rates of disaster exposure for persons with mobility impairments, and what factors influence rates?

### Conclusions/Problem Areas:

- Overall, reliable surveillance tools are often lacking in emergency management to assess prevalence of persons with mobility impairments in local jurisdictions.
- Prevalence rates of persons with mobility impairments at risk in a disaster are unable to be drawn due to the inadequacies of current surveillance systems.
- Surveillance systems to calculate prevalence figures to project service delivery needs, and in some locales, to identify specific individual disaster-related service needs are required to meet operational objectives in county level emergency management plans.
- Existing surveillance systems need to be enhanced and new systems developed to improve the ability of emergency managers to identify prevalence and assess the needs of persons with mobility impairments and other disabilities.

### Recommendations:

Fund and conduct research that:

- Brings scientists from both the fields of disability research and emergency management research, along with persons with disabilities, to address surveillance issues.
- Assesses current registry and other surveillance systems that identify prevalence and individual disaster-related assistance needs of persons with disabilities.
- Identifies protective and risk factors that affect the participation of persons with disabilities in self-identifying registries or other surveillance systems. Based on findings, strengthen existing surveillance systems and create educational programs to increase participation in community surveillance systems.
- Develops surveillance tools for use by emergency manager, such as GIS mapping. Incorporates into existing data collection systems methods for collecting additional disability data useful for emergency management purposes, such as the state health departments’ Behavioral Risk Factor Surveillance System (BRFSS).
- Builds upon the successful components of best practice models, such as “The Disaster Preparedness Planning for the Special [Medical] Needs Population” program from Lamar University’s School of Nursing to create surveillance tools and methods.

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### Table 3

Objective Three – Policy Questions to Address the Identified Problems Areas in *Education and Training* and Corresponding Recommendations.\(^7\)

<table>
<thead>
<tr>
<th>Objective Three</th>
</tr>
</thead>
<tbody>
<tr>
<td>To recommend modifications to county disaster coordinating agencies to address the health, safety, and survival needs of persons with mobility impairments.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Question</th>
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</thead>
<tbody>
<tr>
<td>1. What steps can be taken to increase participation in education and training of emergency managers, first responders, and others?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Integrate the G-197 and the newly developing IS-197 into the career track for emergency managers, including, but not limited to, adding test questions on the national examination.</td>
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<tr>
<td>● Take the category of people with disabilities out of the definition of “special needs” population and develop targeted information on people with disabilities into the basic course.</td>
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<tr>
<td>● Do away with the “special needs” category altogether, and incorporate into the basic training the disaster-related information necessary to serve the entire population.</td>
</tr>
<tr>
<td>● Develop within the two week residency course a component on persons with disabilities and get it introduced into the Fire Academy’s career track.</td>
</tr>
<tr>
<td>● Incorporate people with disabilities into the actual training scenarios for first responders.</td>
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<tr>
<td>● Integrate emergency management systems with healthcare providers and other community service providers, such as Visiting Nurses, home health agencies, Area Agencies on Aging, in relationship to planning and response for people with disabilities.</td>
</tr>
<tr>
<td>● Create fact sheets for landlords, emergency services planners, and first responders on how to assist people with mobility impairments.</td>
</tr>
<tr>
<td>● Develop an educational program for direct care staff, such as personal care attendants, home health aids, and nurses, to act as intermediaries for disaster planning and response and their clients.</td>
</tr>
<tr>
<td>● Train organizations representing persons with disabilities and persons with disabilities to actively participate in their own emergency preparedness, and advocate for change at the personal and systems level.</td>
</tr>
<tr>
<td>● Teach consumers with disabilities to be more proactive and prepared for disasters and emergencies.</td>
</tr>
</tbody>
</table>

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\(^7\) Staff. (2005). *Nobody Left Behind: Objective Three, Part 1 focus area: Assurance and policy development recommendations.* Lawrence, KS: The Research and Training Center on Independent Living, University of Kansas.
Table 4

Objective Three – Policy Question to *Address Increasing Participation of Persons with Mobility Impairments in Individual and Community Preparedness* and Corresponding Recommendations.\(^8\)

<table>
<thead>
<tr>
<th>Objective Three</th>
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<tbody>
<tr>
<td>To recommend modifications to county disaster coordinating agencies to address the health, safety, and survival needs of persons with mobility impairments.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What steps can be taken to increase the role of people with mobility impairments in the planning stages on the local, state, and federal levels?</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organizations and government entities and individuals in the fields of Homeland Security, emergency management, first response, disabilities, education and health care are advised to:</td>
</tr>
<tr>
<td>● Stimulate interest in emergency preparedness among people with disabilities.</td>
</tr>
<tr>
<td>● Teach people with disabilities how to access information about emergency planning and preparedness and how to provide information to others that assist them in individual and community planning efforts.</td>
</tr>
<tr>
<td>● Teach people with disabilities to be proactive with emergency management systems and local health providers.</td>
</tr>
<tr>
<td>● Utilize educational information to make a shift in attitudes of people with disabilities about stigmas for not self-identifying with registries.</td>
</tr>
<tr>
<td>● Utilize community-based organizations to get information to people with disabilities and to organizations that serve people with disabilities.</td>
</tr>
<tr>
<td>● Encourage the Department of Justice to issue a statement on their Americans with Disabilities Act website regarding ways to reach people with disabilities to encourage self-identification in planning and communication guidelines.</td>
</tr>
<tr>
<td>● Encourage Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs) and other organizations that serve and work with people with disabilities to have a statement to encourage consumers to participate in self-identification and individual emergency planning.</td>
</tr>
<tr>
<td>● Encourage Local Emergency Planning Centers (LEPC) to include people with disabilities in interactions with their local emergency providers.</td>
</tr>
<tr>
<td>● Build interaction between the LEPC, CILs, SILCs, and other community-based organizations.</td>
</tr>
</tbody>
</table>

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\(^8\) 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.
The researchers also reported on emerging best practices in the field of emergency management among the 30 research sites. In summary, the best practice to comprehensive planning is to develop an extensive set of guidelines in the local emergency plan to address the needs of persons with disabilities. Thus, it is recommended that a template, Appendix on Persons with Disabilities, be created for adoption by emergency managers. In addition, emergency management plans should, at a minimum, address the guidelines for Americans with Disabilities Act (ADA) pertaining to emergency management as recommended by the Department of Justice.

It is also recommended that infrastructure of local emergency management operations across the country be maintained and extended to be able to make appropriate changes to accommodate people with disabilities in their services, assure accessibility in shelters, develop special needs shelters, and develop appropriate surveillance measures. The research found that additional resources are needed to develop these guidelines including additional trained staff, a federal or state mandate, and consumer educational materials.

**Evaluation Methods and Outcomes.** The 2007 Project Evaluation Report details the evaluation methods and outcomes of the project. This report noted that “throughout the course of the NLB research project, the principal investigator and the other research team members reviewed the progress of the research with pre-project measurements (project objectives and promised deliverables). The advisor-consultant team did the same at annual meetings or at scheduled conference calls. These formal and informal reviews looked at specific tasks to accomplish and any foreseen or unforeseen problem areas that could surface or did surface. Performance reviews were also conducted periodically among the principal investigator, project coordinator, and the financial officer in conjunction with the projected timeline, budget, and planned expenditures. Quarterly reports to the Association of Prevention, Teaching and Research and CDC’s project manager also served as a performance measure. When major problems appeared regarding meeting the expectations outlined in the grant or the timeline, it was reported to the CDC project manager either by telephone or in the quarterly report.

After the research was conducted and the reports finalized a peer evaluation form was sent by email to more than 2,000 persons in the emergency management, disaster relief, research, disability, and health fields. Twenty-nine individuals responded to the request to evaluate the research project. Table 5, on the following page, illustrates that the research was viewed as contributing to gaps in knowledge and contributing to the field of emergency management and response for persons with disabilities. An emergency manager who participated in the study said, “The final reports are excellent and we have already begun to incorporate some of them into our programs here and … into a workshop.” A person from the disability-disaster research field wrote, “The most useful recommendations from our project, based on our experience, are to focus on

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local emergency planning, evaluate consumers experience to improve planning and response, and the inclusion of persons with disabilities in all aspects of planning, training and community preparedness.” Another response from a health department director who is responsible for state-level Homeland Security’s bioterrorism programs wrote, “This is very helpful information that should be widely shared with emergency managers, local health departments, and hospitals to assist them in their special populations planning efforts.” Emergency managers found the best practice report, case histories, journal articles, and links to references on the website most helpful. One person in the disability field wrote, “The study emphasized to a great extent what many of us already knew, that local emergency managers are not well versed in developing emergency plans for people with disabilities. I appreciate the recommendations which I will disseminate to appropriate personnel.” Another person wrote, “I would like more products that offer real-life examples of how to offer emergency evacuation for people with disabilities.”

Table 5


<table>
<thead>
<tr>
<th>Evaluation Criteria</th>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>No Opinion</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
<th>No Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>The research addresses gaps in knowledge base</td>
<td>17 59</td>
<td>11 38</td>
<td>0 0</td>
<td>1 3</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>The research increased my understanding in this field</td>
<td>13 45</td>
<td>11 38</td>
<td>2 7</td>
<td>7 2</td>
<td>1 3</td>
<td>0 0</td>
</tr>
<tr>
<td>I found the research to be relevant and useful</td>
<td>18 62</td>
<td>7 24</td>
<td>4 14</td>
<td>0 0</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>This research contributed to the field of emergency management and response for persons with disabilities</td>
<td>19 66</td>
<td>6 21</td>
<td>3 10</td>
<td>1 3</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>The project’s website contains Useful information and/or resources</td>
<td>14 48</td>
<td>11 38</td>
<td>1 3</td>
<td>0 0</td>
<td>0 0</td>
<td>3 10</td>
</tr>
</tbody>
</table>
Challenges to the Project. The biggest challenge was getting a hold of these very busy emergency managers. It took, on the average, 10 calls to get a person at the intermediate to small emergency management offices as they did not return our messages or did not have staff available throughout the day to handle calls. The project was delayed several months while attempting to initially speak to the emergency managers to set up interviews. Then it was delayed because 20 additional sites had to be contacted in order to replace 8 sites who declined to be interviewed out of the 30 originally selected. In addition, researchers planned to review a majority of the local emergency management plans of each site. However, collection of plans proved difficult, since the plan is a “living document,” subject to constant revisions.

Dissemination Mechanisms. The dissemination mechanisms for the project included mass emailing to more than 2,000 persons in the emergency management, disaster relief, research, disability, and health fields, the official website of the project, (www.nobodyleftbehind2.org), and through 22 PowerPoint and poster presentations given by the principal investigator, co-investigator, and other research staff of NLB at 14 national and 6 state level conferences and professional meetings over the course of the 3-year grant period and extensions. Additional presentations were given at a town hall meeting at the researchers’ home city following a tornado touching down in a neighborhood and at two working meetings of the National Consortium on Disaster Preparedness and Emergency Response for People with Disabilities.

Products Resulting from Research. The following are the products of the project according to the topic areas of the grant.

Peer Review Journal Papers:


Objective One Focus Area: County Programs, Policy and Practice:

● Staff. (2005). *Nobody Left Behind: Objective One, focus area: County programs, policy, and practice*. Lawrence, KS: The Research and Training Center on Independent Living, University of Kansas.


Objective 2 Focus Area: Surveillance:


Objective 3: Focus Area: Assurance and Policy Development Recommendations:


● 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.

● Davis, E. & Mincin, J. (2005, June). Incorporating special needs populations into emergency planning and exercises." [A white paper commissioned by the research project and posted on the website].

● Kailes, J.I. (2005, August). Why and how to include people with disabilities in your emergency planning process? [A white paper commissioned by the research project and posted on the website].

● Kailes, J. I. (2005, February). Disaster services and “Special Needs”: Term of art or meaningless term?” [A white paper commissioned by the research project and posted on the website].

● Staff. (2005, July). Executive summary of the second working meeting on disaster preparation and emergency response for people with disabilities. University of Kansas Research and Training on Independent Living, American Association on Health and Disability, and University of New Mexico Center for Development and Disability, Kansas City, Missouri.
Additional Products- Lessons Learned from Persons with Disabilities:

- Developed and administered an online consumer survey to be taken by persons with mobility impairments who survived a disaster or emergency.


Potential for Future Research. The NLB research project could be expanded through future research grants to:

- Develop a best-practice Appendix on Persons with Disabilities to be included in local emergency management plans that clearly describe how to prepare people with disabilities for emergencies and how to get them out of harm’s way in the event of a catastrophic event. Further, the Appendix will describe how to incorporate people with disabilities and their knowledge and experience into the overall process of emergency management.

- Train the emergency managers interviewed in the original NLB study with new training guidelines and then conduct a follow-up evaluation to determine what gets integrated into the operations.

- Train persons with disabilities and their caregivers on how to be prepared through developing an evacuation plan and procedures to get out of harms way.

- Train organizations representing persons with disabilities on conducting workshops to foster interest in and develop confidence of persons with disabilities to serve as advisors on at local, state and national committees, taskforces, etc. for community and individual preparedness needs of persons with disabilities among the primary disability categories.

- Analyze the operational process of emergency management from a functional viewpoint, especially in addressing the needs of people with disabilities. Link the identified needs from this to a plan for technical assistance.