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**Assessing the Impact of
Hurricane Katrina
on Persons with Disabilities**

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■ About the Report

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Executive Summary

■ The Research Project

The report by the U.S. House of Representatives Select Bipartisan Committee to Investigate the Preparation for and Response to Hurricane Katrina, ***A Failure of Initiative: The Final Report of the Select Bipartisan Committee to Investigate the Preparation for and Response to Hurricane Katrina***¹ documents 90 specific failures at all levels of government in planning and responding to Hurricane Katrina and the other storms of 2005 in the Gulf Coast. Despite its comprehensiveness, this report pays inadequate attention to the unique challenges associated with ensuring that the needs and priorities of persons with a wide range of physical and cognitive disabilities are met before, during, and after a disaster.

Building on prior work of investigators from the University of Kansas and the University of New Mexico, the National Institute on Disability and Rehabilitation Research (NIDRR) sought to address this gap by funding a research project to identify major barriers faced during Hurricane Katrina by centers for independent living (CILs) and emergency managers in responding to the needs of people with disabilities. Through a combination of surveys, focus groups, and interviews in six research sites in the Gulf Coast states, investigators gathered information on the experiences of respondents and developed recommendations for future policy, planning, and practice to address identified gaps.

■ Key Findings

The research revealed that there were significant gaps in three key areas:

- pre-disaster planning by CILs, individuals with disabilities, and local emergency management agencies;
- pre- and post-disaster communication and information sharing within CILs, between CILs and consumers, and between local emergency management agencies; and
- pre- and post-disaster coordination between CILs and other disability agencies, local and regional emergency management organizations, and community supports.

¹ <http://katrina.house.gov/>

■ Recommendations

In developing recommendations based on these research findings, researchers avoided initiatives that would require massive new resources or significant revisions to existing policy or law. Instead, we focus on recommendations:

- targeted at the local level;
- that can be implemented with relatively modest investments;
- that in many cases can be implemented using existing materials and products developed by disability and emergency management agencies across the country; and
- are firmly within the assumptions of current emergency management planning and policy that “all response is local.”

Nine recommendations, each explained in detail in the body of the report, are offered.

- One:** An initiative should be developed that places statewide independent living councils (SILCs) in a leadership role in the process of bringing together disability organizations and emergency management organizations in the states.
- Two:** Disability organizations, including CILs and SILCs, should initiate planning for campaigns targeted at local and state emergency managers to separate people with disabilities from other persons with so called “special needs.”
- Three:** Staff and consumers of CILs should implement systematic training and education that will result in increased numbers of people with disabilities who have personal disaster plans.
- Four:** An education and training curriculum should be developed around effective organizational disaster response and recovery plans for CILs across the country. This should include content-specific elements of an organizational disaster plan, materials that can be used by the leadership and staff of CILs and ongoing technical assistance to CILs for developing and implementing these plans.
- Five:** Evidence-based research findings that are user-friendly should be made available to assist CILs, other community-based organizations, and interested people with disabilities to help them understand how existing emergency planning and response systems operate around the country.

- Six:** State emergency management officials should be encouraged to designate one or more disability contacts at the city and county level as first responders/relief providers for inclusion in emergency operations centers when a disaster strikes.
- Seven:** Community wide efforts should be put in place that identify persons with disabilities in need of additional services in a disaster, and should be developed to link these persons to services required to either evacuate or “shelter in place.”
- Eight:** Community wide efforts need to be put in place that can identify functional supports, including accessible transportation, durable medical equipment, alternative communication systems (screen readers, sign language interpreters, personal assistive services, etc.), and accessible shelters for persons with disabilities in a disaster. Systems need to be developed to link these goods and services to individuals in need of them during evacuation and in shelters.
- Nine:** Investments need to be made at the community level to provide back-up community supports for persons with disabilities in disaster affected areas whose abilities to function independently are dependent upon maintaining access to social and medical services.

Introduction

■ Background

On February 12, 2006, the U.S. House of Representatives Select Bipartisan Committee to Investigate the Preparation for and Response to Hurricane Katrina released a comprehensive report detailing failures and performance gaps in the planning for and response to the single most costly natural disaster in our nation's history. ***A Failure of Initiative: The Final Report of the Select Bipartisan Committee to Investigate the Preparation for and Response to Hurricane Katrina*** documents 90 specific failures in response at all levels of government.

Despite its comprehensiveness, one shortcoming of the report is that it does not pay sufficient attention to the challenges associated with ensuring that the needs and priorities of people with a wide range of physical and cognitive disabilities were met before, during, and after the disaster. This group represents a large portion of the population of the United States. The Centers for Disease Control and Prevention (CDC) estimates that over 50 million people in the United States have some form of disability. In a recent report, the CDC estimated that nearly a half-million people with disabilities lived in the counties and parishes affected by the storm in the states that are the sites for this research (see Table One). Finally, the 2000 Census reports that over one million families in Alabama, Mississippi and Louisiana contained at least one person with a disability.²

While some mention is made in the report of the responsibilities of local government to accommodate "special needs populations" as a component of an overall evacuation strategy, the report largely ignored an important and far wider range of issues related to people with disabilities during the disaster.

■ Research Questions

Building on prior work of investigators from the University of Kansas and the University of New Mexico in disaster preparation and emergency response for people with disabilities, the National Institute on Disability and Rehabilitation Research (NIDRR)³ sought to fill this void in our understanding through research which sought to answer six key questions:

² United States Bureau of the Census: Disability and American Families: 2000

³ In October 2005, leadership at OSERS and NIDRR had indicated interest in assessment of the roles CILs played in assisting people with disabilities living in affected coastal regions during Hurricane Katrina. Drawing upon work from the earlier Nobody Left Behind research project, Dr. Glen White of The Research and Training Center on Independent Living at the University of Kansas submitted a supplemental proposal to NIDRR to investigate hurricane related activities affecting people with disabilities before, during, and following Hurricane Katrina. Dr. White's supplemental proposal was awarded in December 2005. Collaborators on the proposal were Dr. Michael Fox from the Kansas University Medical Center and Dr. Anthony Cahill of the University of New Mexico.

Table One

Numbers Of People with Disabilities Five Years and Older Residing in Coastal Counties or Parishes Affected by Hurricane Katrina⁴

State	County/Parish	Disabled Population Over Five Years Of Age
ALABAMA		
	Mobile	86,863
MISSISSIPPI		
	Hancock	10,776
	Harrison	40,495
	Jackson	25,379
LOUISIANA		
	Jefferson	88,512
	Orleans	102,106
	Plaquemines	4,565
	St. Bernard	14,545
	St. Charles	7,554
	St. James	3,796
	St. John Baptist	6,690
	St. Tammany	30,8115
	Tangipahoa	20,675
	Washington	11,013

⁴ Centers for Disease Control, United States Department of Health and Human Services: Hurricanes - Special Populations: People With Disabilities. 2006
<http://www.cdc.gov/ncbddd/hurricanes/disabilities.htm>

■ Six Key Research Questions of the Katrina Project

- What were the major barriers faced by people with disabilities and staff of Centers for Independent Living (CILs) who work with them in planning for and responding to the disaster?
- What were the major barriers and gaps that CIL personnel experienced in three areas: (a) locating and assisting people with disabilities; (b) meeting their independent living needs including medication and durable medical equipment, accessible housing and transportation, and accommodating caregivers and service animals; and (c) providing for assistive technologies?



Lower Ninth Ward of New Orleans, LA
G. White, photographer

- What were the major barriers for staff of local emergency management agencies in identifying and locating people with disabilities before and during the disaster, including identifying their functional and health care needs?
- What were the major barriers and gaps that emergency personnel faced in evacuating people with disabilities?
- What were the major barriers and gaps faced by emergency management personnel in providing services to people with disabilities during and after the disaster, including providing medication and durable medical equipment, accommodating caregivers and service animals, and providing for assistive technologies?
- What types of resources, including planning, training, information, equipment, and facilities did people with disabilities, staff of CILs, and local emergency management personnel identify as being potentially most useful to them in the event of future large-scale emergencies?

The ultimate goal of this research project is to provide a series of recommendations at the policy and program levels that can be used by emergency management agencies, CILs, and the public that will result in improvements to services provided to people with disabilities in future disasters.

This report builds upon the CDC/ATPM funded ***Nobody Left Behind*** (NLB) project at the University of Kansas.⁵ Major findings from that research were used to inform survey and interview questions used in this project. Key findings of the prior NLB project included:

- Poor participation of persons with disabilities and agencies that work with them in the disaster management process;
- Inadequate training of emergency managers and first responders in understanding the unique needs of persons with disabilities in a disaster;



Accessible FEMA Trailer, New Orleans, LA metro area
G. White, photographer

- Insufficient emphasis on detailed county level surveillance that would help emergency managers and other disaster planners understand the range of mobility needs among persons at risk in their jurisdictions in the event of an imminent evacuation; and
- Inadequate information about specific people with disabilities and their needs located in their service areas, both those in institutions as well as individuals living in the community.⁶

■ **Methods**

Site Selection

Centers for independent living were identified in parts of Alabama, Mississippi, and Louisiana affected by Katrina. Contacts were made to coordinate site visits and identify key informants for surveying and interviewing CIL employees and consumers. Local emergency management personnel were then identified in corresponding counties or service areas.

⁵ www.nobodyleftbehind2.org

⁶ A detailed description of findings from the *Nobody Left Behind* research will be part of the forthcoming *Journal of Disability Policy Studies* special issue on Disaster Preparation and Emergency Response for People with Disabilities, to be published April 2007.

Background Demographic and Other Data Collection

Background data were compiled for counties and parishes that were in the sample.

Survey Instruments⁷

Investigators developed two written survey instruments: one for a representative of each CIL, either the executive director or a delegate, and a representative of the local emergency management agency in the corresponding geographic area (see Appendix A for the informed consent form used for both CIL staff and emergency managers; Appendix B for the CIL interview instrument; and Appendix C for the survey instrument for emergency managers). Initial drafts of the surveys were developed by the research team and were then pilot-tested with CIL and emergency management staff in Kansas and New Mexico. The surveys were available in both paper and electronic form, and other accessible formats as needed.

Interviews and Focus Groups

After completion of the initial surveys, site visits for individual and telephone interviews as well as focus groups were administered at many of the research sites to gather more in-depth information with CIL staff, people with disabilities, and emergency management personnel.⁸ Drs. White and Fox conducted a site visit to Mississippi in February, 2006 and a second trip in March to Louisiana, while Dr. Cahill and Ms. Rooney conducted a site visit to Alabama in April, 2006. (See Appendix D for a copy of the focus group and interview script).

Fifty-six individuals associated with CILs participated in the research. Six CIL directors or key CIL staff completed surveys in Mississippi, Louisiana, and Alabama. Additional on-site focus groups were convened using semi-structured interviews with 22 CIL personnel and 18 consumers. Ten more persons with disabilities, subsequently identified by CIL directors, were interviewed during the site visits or by telephone. After all site visits, recordings of interviews and focus groups were transcribed and analyzed for emerging themes using standard qualitative analytic techniques.

Relocation Center Interviews

An additional nine persons with disabilities who stayed in relocation centers and later resettled in New Orleans were interviewed along with staff of agencies that

⁷ Both survey and focus group instruments received approval from the University of Kansas Internal Review Board (HSCL #15573). Informed consent was received in writing or over the phone for each individual who was interviewed, participated in a focus group or completed a survey in the three states. Contractual agreements were made in which compensation was provided for respondent's time in participating in the research.

⁸ Focus groups and interviews were tape recorded for later transcription and analysis.

participated in the provision of services to people with disabilities in relocation centers in New Mexico.

Review of Statewide Independent Living Council's Plans

Contacts were identified for the 51 statewide independent living councils (SILCs), which includes the 50 states and District of Columbia, through the Independent Living Research Utilization (ILRU) Directory of Centers and SILCs websites.⁹ Each was contacted to obtain information on any material in their State Plans or annual report related to disaster preparedness or emergency response. Forty SILCs participated in this survey for a 78% response rate.

■ Conclusion

Together, 65 individuals associated with CILs and 6 emergency managers in corresponding service areas participated in the research through surveys, focus groups, and interviews across multiple settings in the three Gulf States. They, along with the review of SILC policies, represent a comprehensive and robust source of information to draw conclusions and make appropriate recommendations for future policy and practice regarding people with disabilities in disaster preparation and emergency response.

Findings

■ The Impact of Hurricane Katrina

Despite the long history of hurricanes in the Gulf States, Hurricane Katrina and the other storms of 2005 were an anomaly - far more severe than anything that had occurred before in terms of both severity and breadth. The recent history of hurricanes on the Gulf Coast were on a much smaller scale, and after a few days of inconvenience, individuals, including people with disabilities, resumed their daily lives. The force of Katrina pushed human and material resources to extreme limits. It had a severe disruptive impact on entire communities, including people with and without disabilities as well as political, social, and legal systems.

“About 6:15, I went and got the paper... I later heard gurgling water... I made it to the wheelchair... Then, I went down under the water three times. I called 911 on the cell phone and the operator told me to get up as high as I could get. But I told her, I said ‘Miss, I can’t get me any higher’....”

⁹ <http://www.ilru.org/html/publications/directory/index.html>

The research sites in the Gulf States were well equipped in terms of counties served by CILs (see Figure One). Emergency shelters and designated transportation providers were populated throughout the area, as were emergency management agencies at the county level. However, the infrastructure that supports communities of all sizes throughout the Gulf States was not significantly coordinated to maximize evacuation of residents with disabilities.¹⁰ Interviews and focus groups with people with disabilities in the affected areas revealed an unprecedented pattern of disruption and loss.



Abandoned Power Chair, New Orleans
G. White, photographer

Every person interviewed for this report lost their residence and household belongings, while over half lost items that significantly affected their independence for weeks or even months after the storm. These included such things as vehicles, durable medical equipment, or accessible housing. Many also lost the family or social networks that sustained them. Reactions of respondents understandably ranged from fear and disbelief, to shock, grief, anger, and considerable depression. For example, a respondent from New Orleans area stated,

“I get depressed and wished I would have just gone ahead [and stayed] and drowned. When you look around and you don’t have anything you used to have, it’s hard. You can’t get back the memories.”

A unique consequence of Hurricane Katrina is the significant amount of time that persons with disabilities displaced by the disaster stayed with extended families, and the corresponding physical, emotional, and financial stress this placed on them and their families. Many of the focus group interviewees among CIL staff and consumers evacuated to relatives’ homes. While some stayed only a few nights before moving on to shelters or other temporary housing, many stayed with families for weeks and even months while attempting to rebuild their lives.

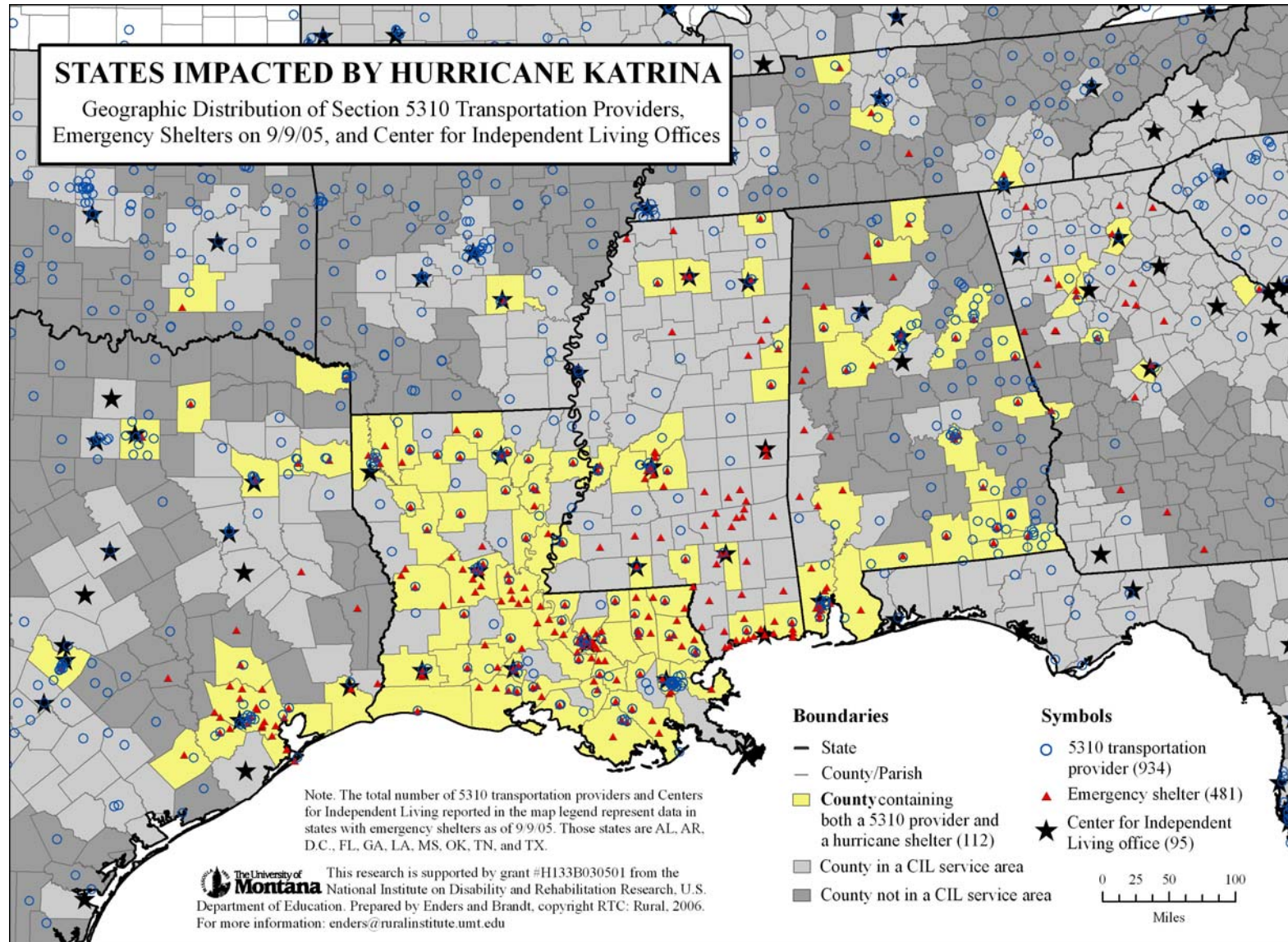
All of the CILs interviewed reported that damage to their facilities and equipment during the storms hampered their efforts to respond to consumers and others who

“We stayed because it never had been that bad before. Never thought the water would rise like that. It caught us off guard. We were pretty much going by the seat of our pants....”

Respondent from Mississippi

¹⁰ Enders, A. & Brandt, Z. (2007, April). Using Geographic Information Systems (GIS) technology to improve management and disaster response for people with disabilities. [special edition] *Journal of Disability Policy Studies*.

Figure One
Geographic Distribution of CIL Offices, Emergency Shelters and Designated Transportation Providers in States Affected by Hurricane Katrina



requested assistance. The ability of CILs to function internally also was significantly disrupted, including an inability to process payrolls, recover files on computers, pay vendors, and maintain other essential services.

What were the causes of this unprecedented upheaval in the lives of people with disabilities in the Gulf States? One cause, of course, is the unanticipated severity of the storm. However, the research on which this report is based revealed significant gaps in three key areas: pre-disaster planning, pre- and post-disaster communication and information, and pre- and post-disaster coordination.

■ Gaps in Pre-Disaster Planning

Governments at all levels have increasingly stressed the need for individuals with and without disabilities to prepare personal plans that will allow them to maximize their self-sufficiency in the first critical hours and days after a disaster occurs. In the case of people with disabilities interviewed for this report, the impact of the storm was heightened by the fact that few developed personal preparedness plans beforehand. Some of the people interviewed prepared by getting basic supplies, evacuating early or attempting to get to a shelter before the storm. However, most chose to stay based on their experience from past storms that the impact would be manageable. This belief had major consequences for those interviewed.

CILs were also caught unprepared. Responses from the CIL directors surveyed revealed that little pre-disaster planning took place in the CILs. There was also little interaction between the CILs and emergency management personnel before the hurricane (see Tables Two and Three). While four of six CILs that were interviewed did have a plan in place to protect data stored on computers, most planning in other areas, including equipment, vehicles, supplies, and staffing, was either incomplete or non-existent. (see Table Two).

- Four of the six CILs did not have anyone on staff with disaster preparedness training and five did not have a plan or procedures to provide services in the event of a disaster. The one CIL that did report having procedures in place also reported that they were not written down.
- While three CILs reported having a formal or informal relationship with local emergency managers before the storm, none had a formal plan in place with the local emergency management agency.¹¹

¹¹ CILs in Alabama reported discussing special needs shelters with local emergency managers before the storms, but these informal conversations stopped short of developing concrete, viable plans that could be incorporated into existing local and state plans and procedures.

- Only one third of the CILs interviewed reported having any training in emergency or disaster preparedness and response. Only one of the six CILs interviewed stated that they had any procedures in place in the event of a disaster.
- Most CILs that were interviewed reported having little written in terms of personal disaster planning for people with disabilities, saying instead that they expected consumers to have taken the initiative to develop a personal plan. None reported having an emergency inventory or “to go” list. Only one of the seven CILs stated that they had disaster-related information for consumers.

Most CILs interviewed reported having little written in terms of a personal disaster plan for consumers should a severe hurricane occur. Only one of the six CILs stated that they had disaster related information for people with disabilities.

In the same way, local emergency managers reported that they had little contact with disability organizations before the storm.

- Five of the six reported no contact between their offices and disability organizations before the storm. (See Table Three). The one that did report contact was not with disability organizations, but with the human service agency and public transit agencies.
- While five of the six reported having a plan in place that included people with disabilities, one was limited to bed-bound patients needing medical care. Another was in fact referring to the mass care and special needs shelter plans that were in place and a third was referring to the parish emergency operation plan in place.
- Of the five that reported having a plan in place that included people with disabilities, only two stated that disability organizations had been involved in the preparation of the plan.

Table Two

Summary of Pre-Disaster Planning At Centers for Independent Living ¹²

Survey Question	Research Site					
	1	2	3	4	5	6
Did anyone at your CIL have disaster preparedness training?	No	No	No	Yes, basic	Yes, limited	No
Before Katrina, did your CIL have a plan to provide services in the event of a disaster?	No	No	No	Yes	No	No
For those without a plan, did CIL staff or consumers put together an information plan of action when Katrina was approaching?	No	No	No	N/A	No	No
Did your CIL have an informal or formal relationship with emergency managers or first-responders before Katrina?	No	Yes	No	No	Yes	Yes
Was there any type of formal plan in place with local emergency managers before Katrina?	No	No	No	No	No	No
Before Katrina, did you have any off-site storage or back-up facilities for records that are needed to manage the center?	Yes, off site	Yes	Yes	No	Yes	No

¹² Responses of Directors of Independent Living Centers to survey questions regarding pre-disaster planning

Table Three

Summary of Disability-Related Pre-Disaster Planning By Local Emergency Management Personnel

Survey Question	Research Site					
	1	2	3	4	5	6
Were you contacted by people with disabilities or disability groups before as the hurricane approached?	No	No	No	No	Yes - by public agencies (DHS, public transit)	No
What did they want?	N/A	N/A	N/A	N/A	Information & offered housing	N/A
Before the hurricane, did your office have a plan in place to assist people with disabilities?	Yes - limited to bed-bound patients	Yes	No specific plan - relied on mass care and special needs sheltering plans	Yes - Parish EO Plan	Yes	No
Were disability organizations involved in preparing these plans?	No	Yes	No	No - prepared by medical personnel	Yes	N/A

■ Gaps in Pre- and Post-Disaster Information Sharing and Communication

Information

Interviews with CIL staff, consumers and emergency managers revealed a lack of information sharing at several levels. While CILs are a potentially invaluable source of information for the emergency management community on the characteristics and needs of people with disabilities in their service areas, their resources were largely untapped before, during, and after the storm. Only one county-level emergency management office reported knowing the location of individuals with disabilities in his service area. Yet, even this information was incomplete since it was based on service records maintained by agencies including the human service agency and public transit agencies rather than on-going communication with the local CIL or other disability organizations. By definition, administrative data sets are an incomplete source of information, since they only contain information about individuals receiving services from some public agency.

While CILs are a potentially invaluable source of information to the emergency management community on people with disabilities, they were a source that remained largely untapped before and during the preparation and response phases of the storms. However, all emergency management agencies interviewed reported that they would like to engage the disability community in future planning.

Further, no emergency management office interviewed maintained or had access to lists maintained by CILs or other disability organizations about individuals with disabilities. Emergency management offices had little or no communication with CILs, which effectively limited any access to available resources that could have been used for evacuation and sheltering of people with disabilities, including accessible vehicles, durable medical equipment and other resources (see Table Four). On-going contacts with CILs and other disability organizations could have yielded valuable information on the population of people with disabilities for that particular county or parish. All six emergency management agencies interviewed reported that they would like to engage the disability community, including CILs, in future planning.

Most pre-disaster communication on disability-related issues reported by emergency managers was usually with other government agencies including public transit agencies, human service agencies and other organizations searching for information on such things as available housing or supplies. In interviews, however, CIL staff repeatedly raised the fact that they were unable to obtain information about where shelters were opening, how to get consumers there, or what types of people with disabilities should not be sent to mass-care shelters.

Table Four
Summary of Responses of Emergency Managers on Information About People With Disabilities

Survey Question	Research Site					
	1	2	3	4	5	6
Did your office have information on the following:						
- Where people with disabilities were located?	Yes	Yes		Some	Yes	No
- What type of disabilities they had?	Yes (bed-bound only)	Yes		Some	yes	No
Special services needed (medication, equipment, transportation, etc.)	After event only	After event only	No	No	Yes	No
Where did this information come from?	Public health nurse; ambulance service; citizen calls	Department of Human Services, disability advocacy organization, hospitals			Department of Human Services, Public Health Service, public transit agencies	N/A
How useful was this information?	Very	Not needed		Very	N/A	N/A

■ Communication Within CILs

Before Katrina, most CILs were communicating face-to-face or via phone or e-mail. Communication of all kinds was disrupted for significant periods of time during and after the storm. In Mississippi, the main CIL office in Jackson tried to establish communication with the four southern satellite offices located in various sections of the state. However, communications were significantly disrupted, with some cell phones working in Jackson, yet having very limited connections with the satellite offices.

In New Orleans, CIL staff reported that voice communication was not available following the storm. Communications were lost in Baton Rouge for 26 days and cellular coverage was available two months after that. CIL staff members were thrilled when internal communication was re-established, but many staff expressed frustration at not being able to re-establish contact with consumers for long periods of time. CILs in Mississippi tried to contact consumers via phone, through personal contacts, and by radio and television in two areas. CIL staff in the New Orleans area worked with government agencies to determine if people with disabilities were relocated to nursing homes or other secondary or temporary shelters. However, most CILs reported having only vague knowledge several months following Katrina about how many consumers were still in their service areas, since they may have been in shelters and then moved to another location.

CILs reported that communication with other agencies after the storm was both unreliable and inconsistent due to failures of technology, including land and cell phone systems and a lack of pre-disaster communication that would have laid the groundwork for post-disaster communication and action.

Communication Between CILs and Other Organizations

All CIL executive directors and staff interviewed or who responded to surveys reported that establishing communication with other agencies, including emergency management agencies, was difficult or impossible for long periods of time after the storms. For example, during the post-evacuation stage in Mississippi, the main CIL office staff unsuccessfully tried to establish contact with a variety of public and private agencies, including advocacy agencies, rehabilitation and welfare departments, federal and local emergency management agencies, and human service agencies.

“FEMA did not know about us. The Red Cross didn’t know about us. So, when we were coming in to [talk about disaster planning], they said ‘Oh, no, we don’t need you guys.’ Yet a month later they did need us.”

Respondent from Alabama

Communication with other agencies and organizations after the storm was both unreliable and inconsistent. In part, this was due to the disruption of technology-based communication systems, including both land and cell phone systems. Efforts to identify or assist people with disabilities by both emergency management agencies and CILs

were significantly hampered by the breakdown of technological infrastructure during and after the storm.

While four of six CILs said that it was within their mission to locate and assist consumers during emergencies, the breakdown in technology hampered their efforts to do so. CILs incorrectly assumed that land and cell phones would be available to communicate with each other and with consumers, yet acknowledged after the fact that they were unable to do so. In the same vein, one emergency management agency reported that they relied on individuals calling “911”, but also reported that telephone service was not available for several days after the storm struck.

Communication failures were also due in part to the absence of effective pre-disaster communication, information sharing and planning by CILs and emergency management agencies. One of the key elements of emergency management planning is that it must be done well before an event. Once the emergency response system has been activated and put in place, it is difficult to introduce new, ad-hoc plans. Given the disorganized and fractured nature of the overall response to Katrina by public agencies at the local, state, and federal levels that has been documented in numerous reports, it is not surprising that communication at the organizational and personal levels was a significant challenge for CILs.

“The frustrating thing...was that we couldn’t communicate with each other. We didn’t know what was going on with people with disabilities”.

Respondent from Mississippi

The New Orleans CIL reported that much of the communications they received were actually from out-of-state organizations, including the National Council on Independent Living, the Association of Programs for Rural Independent Living, the National Spinal Cord Injury Association, the National Organization on Disability, the Rehabilitation Services Administration, the United Spinal Association in New York, and other CILs in the US.

These external calls and contacts resulted in tangible support in the form of money, volunteers, durable medical equipment, and clothing. A CIL in Alabama reported communicating with other Alabama CILs, United Cerebral Palsy Association of Mobile, and Volunteers of America. Each of these organizations also was contacted with offers of assistance by the Independent Living Research Utilization organization in Houston following Katrina. The overwhelming response to the question “What type of resources would be most helpful to better serve people they serve in an emergency or disaster?” was the need for better communication and networking at all levels.

■ Gaps in Pre- and Post-Disaster Coordination

Activities by CILs After the Storm

Despite the significant disruptions to CILs caused by these gaps in planning, information, and communication, the CILs interviewed for this project still played a significant role in locating and assisting consumers after the storm. Four of six CILs

reported providing services in the days and weeks after the storm, and reported providing services to between 200 and 2,000 people with disabilities. In the days and weeks following the storm, CILs:

- Contacted existing consumers to assess their immediate needs, including searching door-to-door and searching shelters to locate people with disabilities;
- Tried to ensure that persons with disabilities had the medical equipment and supplies they needed to be as independent as possible while staying in a shelter;
- Provided peer support, and assisted people with disabilities to obtain basic supplies including water, food, ice, and clothing;
- Replaced or loaned durable medical equipment lost in the storm such as wheelchairs, walkers, etc.;
- Assisted consumers in contacting emergency response and other public agencies including FEMA, the Red Cross, the Social Security Administration and motor vehicle agencies to obtain replacement Social Security cards, licenses, and ID cards; and
- Assisted consumers in obtaining services including food stamps, medication, medical services, equipment, personal assistance services, and toilet and grooming supplies.

Relationships with Responding Organizations

The active role that CILs played is consistent with their mission in the communities and regions they serve. However, since the disaster planning and linkages with emergency managers discussed above were almost non-existent, this placed CIL staff in difficult positions. Without adequate training they were often denied access to shelters and remained outside the formal communication loops established by the emergency management community, and were significantly hampered in their ability to provide effective assistance.

“Six weeks after the storm, the Red Cross director informed me in a meeting that it was not their responsibility to help people with disabilities. That was FEMA’s responsibility....”



CIL directors discussed the disconnect that existed between the CILs and emergency management agencies after the storm. There was a strong feeling that staff of many of these agencies did not understand the importance of serving people with disabilities affected by Katrina or were either uninterested or unaware of the expertise that CILs possessed and the services

“The Red Cross told me they didn’t get the grant to help people with disabilities.”

Interview Respondents

they were able and willing to provide in the response and recovery phases of the disaster.

Alternatively, some CILs believed that they were “dumped on” by emergency services agencies after the storm. One CIL reported being overwhelmed with telephone calls after the local emergency management agency began giving out their 800 number whenever a person reported they had a disability. The majority of calls were outside the knowledge and scope of the CIL, including how to get roof repairs, electricity turned on, and other issues. One CIL staff reported that a caller was referred by an emergency management agency worker who told a person with a disability that the CIL could get her a new van.

A particular source of concern on the part of CIL staff interviewed was the perceived refusal by the Red Cross to work with them, other disability organizations, and people with disabilities themselves. These concerns included:

- not allowing CIL staff to enter the shelters to identify or assist people with disabilities;
- not allowing service animals into shelters; and
- turning away people with obvious disabilities from entering the mass care shelters.

Evacuation

CILs that were part of this project reported that between 150 to over 4,000 people with disabilities were evacuated before or relocated after the storm. However, many others did not evacuate beforehand. According to a study of Houston shelter evacuees, the first and second major reasons for not evacuating prior to Katrina were people thinking that the storm was not going to be as powerful as it was and not having a car or way to evacuate.¹³ Interviews with CIL staff and people with disabilities who did not evacuate prior to Katrina confirmed that based on previous storms, they also did not think the storm was going to be as destructive as it was.



Abandoned Downtown After Katrina in Bayou Le Batre, AL
C. Rooney, photographer

CIL staff and consumers reported two additional factors that were barriers to successful evacuation – accessible transportation combined with a place to go for

¹³ Kaiser Family Foundation (2005, September). *Survey of hurricane Katrina evacuees* [Electronic version]. Retrieved June 27, 2006 from <http://www.kff.org/newsmedia/upload/7401.pdf>

safety. For example, several people with disabilities reported not evacuating because they did not own a car, did not have money for public transportation, or were unaware of transportation options to shelters. A CIL client's wife describes the sentiments of those interviewed:

“Without the money, there is nothing you can do and if you don't even have a car to get out of the storm, there is no where to go and I think that's the biggest problem. [So, we] resigned ourselves to the safest building that we could be in by sticking it out.”

This same couple said they were unaware until after the storm that emergency management agencies offered transportation services to local shelters. In two locations, emergency management offices offered rides to shelters during Katrina, but no one took them up on the offer. Given the lack of pre-disaster communication discussed earlier, this is not surprising. A number of people interviewed who evacuated in another person's vehicle and left their vehicle behind found the vehicle destroyed when they returned. This loss of personal transportation often contributed to feelings of losing independence and increased the difficulty in recovering from the storm.

“A friend called and asked if I wanted to go with him to evacuate. I said no because most motels and hotels are not wheelchair accessible. I would have to crawl on the floor to get into and out of the bathtub and to get back into my chair just to get dressed.”

Respondent from New Orleans

Temporary and Permanent Accessible Housing

Successful evacuation depended not only on the availability of transportation, including accessible transportation, but on appropriate housing being available. The complexity of finding accessible accommodations - whether in a public shelter, a hotel, or a private home of a family member or friend - is significant. Most interviewees reported that in many cases, they could not find - or in the case of mass care shelters, were refused entry into - accessible accommodations. Without accessible accommodations, the safety, health, and independence of persons with disabilities were severely compromised.

Many CIL staff and consumers reported difficulty even when they evacuated to family or friends' homes. A number of people with mobility limitations reported leaving the home after one or two nights because the home was not accessible, including being able to use the bathroom or transfer in and out of a bed.

Interviewees reported the same experiences with hotels and shelters. One person reported sleeping in his van while looking for accessible housing in Baton Rouge, while another reported being relocated from a non-accessible relative's home to non-accessible temporary housing in a hotel. A subsequent life-threatening pressure sore that required two surgeries caused this person to be transferred for eight months between a nursing home and a hospital because there were no accessible

accommodations for her to return to during the recovery stages. She did not qualify for a FEMA accessible trailer because her elderly mother received one, and only one person per household can get a trailer. Since she had lived in an RV parked on her mother's property, it was considered one household.

Restoring the “Civic Fabric” of Services Used by People with Disabilities

The unprecedented destruction wreaked by Hurricane Katrina and succeeding storms significantly disrupted the network of services provided by social, medical, and civic institutions for the majority of residents of the affected areas, whether with or without a disability. Together, these institutions and the services they provide - whether they be medical services, accessible transportation services, or services provided by social networks such as faith-based, disability advocacy, or civic groups - constitute the “civic fabric” which supports the ability of people with disabilities to function independently and maintain their quality of life.

Many persons with disabilities require personal services that allow them to respond or react to disasters in similar ways as persons without disabilities. These might include: social networks, in which individuals take responsibility for others in their midst in need of help; transportation networks, in which accessible vans or buses are widely available to all who need them; or specialized medical networks, in which extended services provide personal care or use of medical devices such as wheelchairs, ventilators, or glucose monitoring equipment.

The length of time that it took to restore these networks - many are still not fully functioning or functioning at all over a year after the storms - has had a disproportionate impact on people with disabilities in the affected areas of the Gulf States. This deficit was illustrated through several examples below provided by people with disabilities interviewed over the course of this project, as well as a brief supplemental interview conducted with a sample of New Orleans residents with disabilities one year after the storm (See Appendix E for a summary of these interviews).

- A resident of St. Bernard Parish whose wife had a disability refused to move into the accessible FEMA trailer placed in the yard of their destroyed home because the community lacked sufficient medical, social, and civic services to prevent his wife from being subjected to significant health risk.
- The daughter of a resident of Biloxi risked drowning in their home in order to retrieve a hearing aid, knowing that her mother would find it virtually impossible to replace one in the aftermath of the storm and loss of services.
- A resident of New Orleans could not move to Texas to stay with relatives after the storm for fear of losing Medicaid services, yet was unable to move back into his former neighborhood because it lacked food, reliable utilities, and medical services.

- Another resident of the Lower Ninth Ward was unable to evacuate her home once flooding became serious because her power chair no longer worked and there was no means of transportation that she could access – such as swimming or wading to a rescue boat – which her neighbors were able to do. She, as were many others, were simply left behind.

Recommendations

■ Introduction

How can the gaps identified in pre- and post-disaster planning, communication and information, and coordination be filled? In the years since 2001, significant attention has been given to improvements in planning, policy, and services for people with disabilities. Numerous organizations in the public, private, and non-profit sectors have examined the impact of disasters on people with disabilities and developed innovative programs, services, and revisions to existing policies that have the potential to mitigate the impact of future disasters on people with disabilities.

Work that has been done nationally in planning, communication and information sharing, and coordination provide a rich and useful source for changes in policies and programs targeted at improving services to people with disabilities. ...

Staff of both the CILs and emergency management offices interviewed for this project all reported a strong interest in learning from the mistakes that occurred during the storms of 2005.

The work that has been done nationally in planning, communication and information sharing, and coordination provide a rich and useful source for changes in policies and programs targeted at individuals with disabilities, CILs themselves, and local emergency management organizations. The recommendations offered here, while targeted at the people and organizations in the areas of the Gulf Coast states affected by Hurricane Katrina, are applicable to other parts of the country and other types of disasters as well. This is consistent with current emergency management policy at the federal levels, which uses an “all hazards” approach.

We have focused on recommendations that could be implemented with relatively modest investments at the local and state levels.

In developing recommendations, we have avoided initiatives that would require massive new resources or significant revisions to existing policy or law at the federal or state levels. While significant additional resources at all levels of government directed towards disability issues, as well as revisions to numerous existing statutes to include disability issues, are warranted in many cases, the hard, cold fact is that they are unlikely to be available. Instead, we have focused on recommendations that could be implemented at the local, regional, or state levels with relatively modest investments by

statewide independent living councils (SILCs) or within individual CILs and local emergency management agencies. However, we also recognize that many of them will require the investment of the scarcest resource available: time on the part of already over-burdened staff of CILs and local emergency management agencies.

“CIL staff and emergency managers must find ways to plan for unforeseen events, not prepare for the last known event.”

National Plan Review

■ **Pre-Disaster Planning: Increasing Leadership and Strategic Vision to Reduce the Impact of Disasters on People with Disabilities**

CIL directors and staff, as well as local emergency managers interviewed across the Gulf States, clearly have sufficient leadership skills and strategic vision for day-to-day management and oversight of activities and resources that people with disabilities need to live independently in their communities. However, the sheer size and destructive power of Katrina overwhelmed the leadership skills of most CIL personnel and emergency managers - not surprising since the leadership of the federal, state, and local governments were also in disarray following the catastrophic consequences of the storm.

One of the hallmarks of good leadership is strategic planning for the future. One conclusion of the recently published review of state disaster plans by the Department of Homeland Security and the federal Department of Transportation was that most plans “...cannot...manage catastrophic events” and “...are scaled to familiar events”.¹⁴ Individuals with disabilities, CIL staff, and emergency managers must find ways to plan for unforeseen events, not prepare for the last known event. Greater attention should be given to strategic planning to reduce or avoid the barriers and concerns encountered by CIL staff and consumers as well as emergency managers. Key stakeholders in each community should engage in strategic planning with specific attention to the needs of citizens with disabilities before, during, and following disasters.

Increase the Role of Statewide Independent Living Councils

Statewide independent living councils (SILCs) can play an important role in this strategic planning effort. They are a natural vehicle for planning, in that they are able to work with and provide information, technical assistance and other resources to CILs within their states. From the 78% response rate received by the SILCs surveyed for this report, there is an increased interest in including disaster preparedness and emergency response into statewide plans. There is a precedence of SILCs in Arizona, California, and Michigan taking leadership roles in disaster and emergency response activities.

¹⁴ Nationwide Plan Review: Phase 2 Report. U.S. Department of Homeland Security In cooperation with the U.S. Department of Transportation. Washington, 2006.

Recommendation One

Develop an initiative that places SILCs in a leadership role in a process of bringing together disability organizations including CILs, as well as state and local emergency planners, to develop mechanisms to increase information sharing, coordination, and the development of disaster preparation and emergency response plans that incorporate people with disabilities.

There are a number of ways this may be accomplished. These include:

- Forming planning committees consisting of state and local police, fire, emergency management and relief organizations, health agency, and representative disability organizations to assure adequate preparedness for persons with disabilities;
- Sending SILC representatives to agencies that are responsible for making statewide policies on disaster preparedness and response, such as the Community Emergency Response Team or State Emergency Management Agency to initiate contacts and begin the process of incorporating disability into those plans;
- Sending a representative to local and state-level Emergency Operations Centers (OEC) when they are activated to serve as a point of contact and resource for the population with disabilities;
- Serving as a catalyst to encourage CILs at a local level to work with local level emergency planning authorities.

Defining the Needs of People with Disabilities

In the official world of emergency management, people with disabilities are included in the much larger group of “vulnerable populations.” This group, however, is so inclusive as to be operationally meaningless.¹⁵ It includes not only people with disabilities but seniors, prisoners, pregnant women, homeless individuals, border populations, undocumented illegal immigrants, people with chronic mental illness, chronic substance abusers, and people with immuno-depressed conditions, among others. If something is everything, it is effectively nothing. In order to develop effective plans for people with disabilities, they must be identified and treated as one distinct population within the larger array of “vulnerable populations.”

¹⁵ Kailes, J. (2005). Disaster Services and “Special Needs:” Term of Art or Meaningless Term? A white paper commissioned by the Nobody Left Behind research project, www.nobodyleftbehind2.org/findings/index.shtml

Recommendation Two

Disability organizations including CILs and SILCs should initiate campaigns toward local and state emergency managers to separate the needs of people with disabilities from other “vulnerable populations.”

Even within the larger disability community, there is little homogeneity. The needs of individuals with Down Syndrome, for example, are significantly different in many ways from individuals who are paralyzed. However, identifying people with disabilities as a group distinct from other “vulnerable populations” will help to focus on plans, programs, and services for this heterogeneous group.¹⁶

Personal Disaster Planning for People with Disabilities

Recommendation Three

Staff and consumers of CILs should implement systematic training and education that will result in increased numbers of people with disabilities who have developed personal disaster plans.

In the years before and since September, 2001, many useful guides to personal disaster planning for people with disabilities have been developed, including guides by the American Red Cross¹⁷, state emergency management agencies,¹⁸ universities¹⁹ and disability organizations such as the National Organization on Disability and AARP.²⁰ Thus, the need is not to develop new materials, but to design and implement an initiative that will result in more Americans with disabilities being better prepared to maximize their health, security, and independence when a disaster occurs. Every individual with a disability interviewed for this project would have benefited from such a personal disaster plan.

¹⁶ For example, the New Mexico Task Force on Targeted Populations and Emergency Preparedness chartered by the State Office of Emergency Management has four workgroups: disability; wards of the state (incarcerated individuals and foster children); chronic mental illness; and other targeted populations (health children under the age of legal consent not with their parents or guardians, health seniors and pregnant women).

¹⁷ American Red Cross, Disaster Preparedness for People With Disabilities. <http://www.redcross.org/search/search.asp>

¹⁸ Pennsylvania Department of Health, Special Populations Emergency Preparedness Planning. <http://www.dsf.health.state.pa.us/health/cwp/view.asp?a=171&q=233957>; **California Department of Rehabilitation, Disaster Preparedness for Persons with Disabilities: Improving California's Response.** <http://www.ilru.org/html/training/webcasts/handouts/2003/08-27-PB/resources.htm#disaster>

¹⁹ Center for Unconventional Security Studies, University of California at Irvine, Emergency Preparedness Guidelines. http://www.cusa.uci.edu/emergency_preparedness.htm

²⁰ National Organization on Disability and AARP, Preparing Makes Sense for People With Disabilities and Older Americans. <http://www.nod.org/index.cfm?fuseaction=page.viewPage&pageID=1430&nodeID=1&FeatureID=1620&redirected=1&CFID=10223977&CFTOKEN=21130441>

The curricular design of this education and training program is relatively simple and could take many forms. It could be a one-to-two hour training program taught by CIL staff to their consumers. It could also be made available in alternate formats, including web-based and other electronic formats. As discussed above, there is an ample supply of materials targeted at individuals with disabilities, their families and caregivers that can form the basis of this program. What is needed is a systematic initiative that would give CIL staff in the Gulf States and nationally the tools they need - including a pre-designed training curriculum - to assist their consumers in increasing their levels of personal preparedness.

This “train the trainer” program would provide CIL staff with a curriculum to use with participants, tips and techniques on effective training, and content-specific information about what makes up a personal disaster plan. It could also include copies of guides such as those discussed above for distribution to participants. An important part of the program would be tips on how to engage in effective follow-up with participants to ensure that they have completed their plans.

CILs are an ideal centerpiece for this initiative. They have close ties with the communities they serve. They have credibility with the people they serve, and would not be viewed as an “outside” entity by participants. They have a clear understanding of the characteristics and needs of people with disabilities in their communities. Further, CIL staff in the Gulf States has a clear view of the consequences of not having personal disaster plans in place.

CILs are an ideal centerpiece for increasing the numbers of people with disabilities that have developed personal disaster plans.

This initiative is not limited to CILs in the areas affected by Hurricane Katrina, however. Disaster planning on the federal and state levels now uses an “all hazards” approach that emphasizes the common elements of personal disaster planning regardless of the nature of the emergency. Such a curriculum and a “train-the-trainer” education and training program, if implemented on a national basis, has the potential to significantly improve the health and safety of people with disabilities when another disaster occurs.

Organizational Disaster Planning for CILs

One key lesson learned from this research project was that the CILs did not have adequate organizational disaster plans in place before the storms struck. Organizations, like individuals, need plans in place to protect important assets (people, confidential information, supplies, and equipment) when a disaster occurs as well as plans to restore services as quickly as possible. These plans need to incorporate an understanding that many CIL staff has families who also will require their attention. As with information and materials on personal disaster planning, numerous models of and guides to organizational disaster planning exist, including those developed by

government and emergency management agencies.²¹ The “missing link” in assisting CILs to become better prepared on an organizational level is to provide the training and technical assistance needed to understand the elements of an organizational disaster plan and how to implement it.

Matching the needs of persons with disabilities with existing resources is hindered by lack of communication between local emergency management and organizations, such as CILs that serve or advocate for persons with disabilities.

Recommendation Four

An education and training curriculum should be developed around effective organizational disaster response and recovery plans for CILs across the country. This should include content-specific elements of an organizational disaster plan, materials that can be used by the leadership and staff of CILs and ongoing technical assistance to CILs for developing and implementing these plans.

CILs are necessary sentinels that could provide effective assistance to individuals with disabilities in the event of a natural or man-made disaster. Based on the research on which this report is based, it is clear that they urgently need assistance in developing plans that will allow them as organizations to resume the effective delivery of services and resources to people with disabilities. CILs may well need additional financial resources to help bring this recommendation to reality.

■ Pre- and Post-Disaster Communication and Information

Effective communication and information sharing between the disability community and local and regional emergency management systems is essential for planning, action, and mitigation to help people with disabilities to have the best possible outcomes in the event of a catastrophic event. As has been documented in this report, too little of either took place both before and after Hurricane Katrina hit the Gulf Coast. If a silver lining to the storm is to be found among the devastation, it is that the hurricane exposed the weaknesses within existing communication systems and the consequences of insufficient communication.

It is vitally important that there is on-going dialogue among CILs, statewide independent living councils and their counterparts with statewide emergency planning

²¹ Occupational Safety and Health Administration, **How to Plan for Workplace Emergencies and Evacuations.** <http://www.ilru.org/html/training/webcasts/handouts/2003/08-27-PB/resources.htm#disaster>; American Red Cross, **Preparing Your Business for the Unthinkable.** <http://www.ilru.org/html/training/webcasts/handouts/2003/08-27-PB/resources.htm#disaster>; **Howard County Agency Disaster Preparedness Plan.** [\http://www.cern.us/ht/d/sp/a/GetDocumentAction/i/634?PHPSESSID=de488a551769c0f75f21859930d76e8c#search=%22Volunteer%20Center%20Serving%20Howard%20County%20Agency%20Disaster%20Preparedness%20Plan%22;

services, county/parish emergency planners, and national agencies and organizations such as FEMA and American Red Cross. This dialogue and planning can help ensure that service provision for people with disabilities affected by disasters is more timely and relevant for their needs. It can also help avoid needless misdirection of people to services for which they do not qualify or that may be inappropriate for their needs.

Education and Training for CILs on Public Emergency Response and Recovery Plans and Procedures

Preparation, response, recovery, and mitigation from natural or man-made disasters do not take place in a vacuum. While this may sound like a statement of the obvious, a key finding of the research on which this report is based was the lack of knowledge on the part of both staff of CILs and emergency management agencies about each. One striking lesson learned is the extent to which CIL staff were unaware of the formal plans under which disaster planning, response, and recovery take place at the local, regional, state, and federal levels. These organizations, including local emergency management agencies with which CILs should work, adhere to a comprehensive set of policies, procedures, and guidelines that govern what occurs when a disaster happens. At the federal level, emergency planning and response is governed by a “Target Capability List” (TCL) that includes mandatory outcomes, procedures, and benchmarks with which state and local emergency management agencies must comply and report their progress.²²

In the same manner, state and local emergency management agencies develop their own plans based on the TCL that they will implement when a disaster occurs. While these agencies have a reasonable amount of flexibility to develop plans that meet unique local characteristics and resources, they are also meant to be implemented in a fairly rigid way once a disaster occurs. In summary, disability organizations and individuals who wish to influence these plans must do so armed with the knowledge of not only what those plans are, but the parameters and constraints within which those plans are developed and revised. Three recommendations are offered that will increase the level of communication and information sharing at the local level.

²² The target capability list (TCL) was developed in response to a presidential order (*National Preparedness* (HSPD-8) which calls for a National Preparedness Goal that establishes measurable priorities, targets, and a common approach to developing needed capabilities. The Goal utilizes a “capabilities-based planning approach to identify target levels of capabilities that Federal, State, local, and tribal entities must achieve in order to respond to natural or man-made disasters. http://www.ojp.usdoj.gov/odp/docs/Target_Capabilities_List_041405.pdf#search=%22target%20capability%20list%22

Recommendation Five

Evidence-based research findings that are user-friendly must be made available to assist CILs, other community-based organizations and interested people with disabilities to help them understand how existing emergency planning and response systems from around the country operate.

Knowledge of the current system of plans, policies and procedures developed by local emergency management agencies as well as the system of state and federal planning within which they operate is an absolute prerequisite to fully integrating the needs and priorities of people with disabilities in those plans. Such a training session that focuses on providing disability organizations with a “lay” understanding of the legal, policy and planning process that local emergency managers must follow will serve to streamline the process of integration, as disability organizations including CILs understand the policy, planning and resource context within which local emergency management agencies operate.

Response and Recovery Plans and Procedures

Further, that integration will take the form of adaptations to existing local emergency plans. Once a disaster has occurred, these plans will be used by numerous agencies much as a “playbook” is used in sporting events. Once a disaster has occurred, there is little room for major adaptation of these plans. Local emergency managers and other public agencies including health and public safety agencies will be fully occupied implementing the plans in place. To be effective, inclusion of disability issues and concerns must happen BEFORE an emergency occurs. A prerequisite to that inclusion must be an active engagement by disability organizations to better understand legal, policy and resource constraints faced by local emergency managers. Working with county and state emergency management planners, SILC Congress members should consider developing a template for these workshops targeted at SILC directors so that they can replicate them in their own states with CILs and other identified disability organizations.

Recommendation Six

Encourage state emergency management officials to designate one or more disability contacts at the city and county level as primary contacts for inclusion in Emergency Operations Centers when they are activated.

Emergency Operations Centers (EOCs) are at the center of planning, response and recovery for disasters of any type. Activated either before a disaster is anticipated or immediately after a disaster strikes, they are the command centers for the distribution of human and other resources as well as the collection of information about what is happening. They exist at different levels of government, depending on the system of political jurisdiction in place, population density, and resources. At the local levels, they can be small, even makeshift rooms with desks and telephone lines, while in

communities with more resources and at the state level they are frequently more sophisticated command and control centers.

Regardless of their sophistication, a designated contact for disability present at EOCs would be a valuable channel for communication between the emergency management and disability communities. Directors or key staff of CILs would make ideal candidates for such a position. They typically have extensive knowledge of people with disabilities in their communities - whether consumers or not - as well as resources that could improve the services offered to people with disabilities. This individual could also serve as a disability “ombudsman” to identify and mitigate problems regarding disability issues at an early stage.

■ **Pre- and Post-Disaster Coordination**

The new target capability on “Functional and Medical Support Sheltering” currently being developed by the Departments of Homeland Security and Health and Human Services has as its primary outcome “The population requiring support accommodated in general shelters is maximized by meeting individual functional and medical support needs; those needs that cannot be met to allow general sheltering are met in functional and medical support shelter accommodations to maintain the health and safety of such individuals.” Once a disaster occurs, it is too late to initiate systems that will provide the information necessary to meet this outcome. Whether an individual is transported to a mass care or function needs shelter, these systems include a plan for identifying:

- people with disabilities and the assistance they need,
- resources that might be useful in evacuating people with disabilities or providing services to them such as durable medical equipment, medicine, and personal assistance services; and
- accessible locations which provide accommodations necessary to support people with disabilities.

These things must be done before-the-fact. Information on these three things must be maintained, kept up to date, and be available for the people that need them - first responders - on an immediate basis.

Community-Based Registries of People Needing Assistance

There has been much debate and discussion both among the emergency management and disability communities of the need for registries that contain useful information concerning the location of individuals with disabilities and information about their disability, including any medications or durable medical equipment used, service or companion animals, and other information that would be useful to first responders for

evacuation and for shelter personnel. Numerous community-based efforts around the country have begun the process of putting such registries into place.²³

Recommendation Seven

Community-wide efforts need to be put in place that identify persons with disabilities in need of additional services in a disaster, and systems need to be developed to link these persons to services required to either evacuate or secure existing shelter.

Existing disability registries have several common elements. They are rooted at the community level, avoiding large-scale, centralized data sources that are difficult to manipulate and disseminate and require extensive support to maintain. They are organized either by local emergency management agencies with the support of local disability organizations, or vice versa. In either case, they are available on an immediate basis to first responders in the event of a disaster. They collect only information necessary for use by first responders in the response phase of the disaster, thus avoiding “information overload” as well as avoiding some of the concerns voiced by people with disabilities about privacy.

Community-Based Registries of Resources for People with Disabilities

Knowing the locations of individuals with disabilities who choose to self-disclose their location would be of great help to first responders and staff of mass care and functional needs shelters. Of equal help would be information about local resources that could be used to transport and/or assist people with disabilities in the evacuation and response phases of a disaster. Enders and Brandt discuss how the modern technology of geographic information systems and mapping can be used to specifically coordinate resources to enhance disaster preparation and response for people with disabilities.²⁴

²³ There are numerous “promising practice” community-based registries that can be used as a model for such efforts. These include Monroe County, Florida (<http://www.monroecounty-fl.gov/Pages/emergency>); Pasquotank and Camden Counties, North Carolina (<http://www.co.pasquotank.nc.us/departments/Emergency%20Management/specialneedsForm.htm>); Rowlett, Texas (<http://www.co.pasquotank.nc.us/departments/Emergency%20Management/specialneedsForm.htm>); Santa Clarita, California (<http://www.santa-clarita.com/cityhall/cmo/press/release.asp?ID=692>); and Colonie, New York (http://www.colonie.org/emp/Special_Needs.asp). These are only a few of the many examples that can be used to initiate this recommendation.

²⁴ Enders, A. and Brandt, Z. (2007, April). Using Geographic information systems (GIS) technology to improve emergency management and disaster response for people with disabilities. [special edition] *Journal of Disability Policy Studies*.

Recommendation Eight

Community-wide efforts need to be put in place that can identify functional supports, including accessible transportation, durable medical equipment, alternative communication systems (screen readers, sign language interpreters, etc.) and accessible shelters for persons in a disaster. Systems need to be developed to link these persons to services required to either evacuate or secure shelter.

As with registries of individuals requiring assistance, these resource registries need to be initiated and maintained on a local level with the active cooperation and engagement of both the emergency management and disability communities. Having a registry available that is unknown to first responders is structurally the same as not having a registry at all. The information will be unused and the individuals in need of assistance will not receive it. This registry also needs to identify accessible transportation options and evacuation sites needed for early evacuation of persons with disabilities who are dependent on public transportation.

Having a registry available that is unknown to first responders at the local level is the same as not having a registry at all - the information will be unused and people in need of assistance will not receive it.

Geographic information systems can also be used to link individuals with disabilities to needed transportation and shelters. For this report, we found that several SILCs, including the California and Michigan SILCs have already taken the initiative and have compiled and routinely revise disability-related resource information such as listings of disability related agencies and service providers to use after disasters. The California SILC even has gathered, cleaned and stored in strategic locations in the state supplies and equipment not used in the Katrina recovery effort that will be available for future disasters.

Review of Accessibility of Secondary or Temporary Shelters for People with Disabilities

A core goal of this report is to assuring that social, medical and civic services are extended in a systematic way to all individuals, regardless of their ability to walk or run, hear, see, or cognitively function. This requires embracing the concept of universality in design and inclusiveness in operations at the local, state and federal levels. The process for identifying and assessing potential mass care shelters (and in some cases, “special needs” shelters) is well-established through the official emergency management system. However, experience in the Gulf States affected by Katrina, as well as other disasters, has shown that many individuals with disabilities either relocated themselves or were relocated to other locations outside the official system of shelters.

Recommendation Nine

Investments need to be made at the community level to provide back-up community supports for persons with disabilities in disaster affected areas whose abilities to function independently are dependent upon maintaining access to social and medical services.

Many persons with disabilities require personal services that allow them to respond or react to disasters in similar ways as persons without disabilities. These modifications may be social networks, in which individuals take responsibility for others in their midst of need for help; transportation networks, in which accessible vans or buses are widely available to all in need of them; or specialized medical networks, in which extended services provide personal care or use of medical devices such as wheelchairs, ventilators, or glucose monitoring equipment. Efforts need to be made by CILs in conjunction with community agencies to provide back-up services that allow persons with disabilities to resettle or maintain earlier levels of independence through continued social services.

Conclusion

Good leaders learn from history in order to avoid repeating the mistakes of the past. Despite the attention which has been devoted in the national press to the inadequacy of the preparation for and response to Hurricane Katrina, it must also be kept in mind that this storm and those which followed were unprecedented in modern memory, both in severity and breadth. The findings of this research project are consistent with other research and assessment projects being undertaken by public agencies at the federal, state, and local levels; by disability advocacy organizations across the country; and by other University-based studies.

A centerpiece of current emergency management planning is that “all response is local.” This does not mean that higher units of government including state and federal agencies are irrelevant or do not play major roles in planning mandates as well as responses to future disasters. Rather, it means that those at the local level, whether they are first responders, emergency management agencies, or disability organizations including CILs, are the first line in our collective ability to successfully plan for and respond to a disaster. Depending on the scope of the disaster, assistance from state and federal agencies will arrive at some point after the disaster. Hurricane Katrina and the storms which followed were an anomaly in their fury and breadth. They revealed serious shortcomings at all levels of the public and non-profit sectors. However, over time, systems that represent the “civic fabric” of our communities will be restored and where necessary, reinvented.

The recommendations contained in this report do not focus on that longer-term recovery process. Rather, they are targeted at specific initiatives that disability organizations including CILs, emergency managers and people with disabilities themselves can implement in order to better prepare themselves and the communities of which they are a part to meet and increase the resilience of their communities when confronted by a disaster. As discussed throughout the **Recommendations** section of the report, numerous models exist in each area as discussed in the report which can be used as is or adapted to the unique characteristics of local communities.

A catalyst is needed that drives the transfer of existing knowledge to new locales and contexts. In part, this means serving as a clearinghouse of information. However, it also means that one or more organizations must take the initiative to provide organization and direction to this effort. CILs, SILCs, and the SILC Congress are all well-placed to provide leadership in making this a reality.

■ Appendices

Appendix A: Informed Consent

Appendix B: Survey of Centers for Independent Living (CIL) Managers and Key Personnel

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Appendix E: First Anniversary of Katrina: Life in New Orleans for Persons With Disabilities

Appendix A

INFORMED CONSENT

In-Person and by Phone Survey of Centers for Independent Living Managers, County or Community Emergency Managers, and Consumers with Disabilities

The University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time without affecting opportunities for participation in other projects offered by the University of Kansas.

This study is being conducted by the Research & Training Center on Independent Living at the University of Kansas and is being supported by a grant from the National Institution on Disability Rehabilitation Research (NIDRR). The purpose of this study is to assess the impact of recent hurricanes, particularly Hurricane Katrina, on persons with disabilities. Directors or key staff of centers for independent living (CILs) and county or local emergency managers are being asked to participate from the southern Gulf states most affected by recent hurricane activity and from other states that sheltered evacuees from these hurricanes. During this study, you will be asked questions about topics related to the role that the CILs played in evacuation, shelter and recover, and the experience of emergency managers in working with people with disabilities through these three phases of disaster management. There will be three broad areas of questions: 1) assessing abilities of counties and/or CILs to provide assistance to persons with disabilities; 2) identifying barriers and successes in providing services; 3) understanding potential best practices that appeared successful in these hurricane experiences that could be shared with other agencies throughout the country to assist persons with disabilities for future disasters. Consumers with disabilities who directly or indirectly experienced the effects of one or more recent Gulf hurricanes may also be asked about what was helpful or harmful to them during these events.

All questions will be asked in person or over the phone and will be tape recorded for future transcription and analysis. For purposes of confidentiality, your name will not be associated in any way with the research findings. However, the reports and other public documents will reflect information on location of CILs, emergency management offices, or consumers by state, county, city, or parish. Permission granted to use and disclose the information obtained in the survey remains in effect indefinitely. By signing this form you give permission for the use and disclosure of the information for purposes of this study at any time in the future. Do not hesitate to ask any question about the study before, during, or after the research is complete. The Principle Investigators for the projects are Drs. Glen White and Michael Fox, from the Research and Training Center on Independent Living at the University of Kansas. They can be reached at 785 864-4095.

A \$30 participation incentive and mileage, if needed, to get to the interview site will be provided to those who participate in the study, pending their ability to receive this money.

Please sign this consent with full knowledge of the nature and purpose of the procedures. Your assistance is much appreciated and should be beneficial in guiding future development and dissemination of practices and education programs, policies and strategies for CILs and

Emergency Managers to meet the needs and priorities of people with disabilities before, during and after major disasters. If you have any concerns or questions about your rights as a research participant you may contact the University of Kansas' Human Subjects Committee—Lawrence (HSC-L) at (785) 864-7429, Youngberg Hall, or by e-mail to David Hann at dhann@ku.edu.

Participant's Name and Official Job Title (Please print)

Date

Participant's Signature

Date

With my signature I acknowledge that I have received a copy of the consent form to keep and that I am at least 18 years old.

Appendix B

SURVEY OF CENTERS FOR INDEPENDENT LIVING (CIL) MANAGERS AND KEY PERSONNEL

Date:

Interviewee's Name: _____

Interviewer's Initials: _____

Introduction

Hi. I am (name) from the University of (name) and we are scheduled for an interview at this time. I will begin by turning the tape recorder on. Have you reviewed the informed consent statement (see attachment)? Do you have any questions about the informed consent statement? The information we receive from you will only be used for the purposed identified in our research protocol, namely to better understand the impact of Katrina on Centers for Independent Living, referred to as CILs, and on persons with disabilities. You may request a copy of the transcript of our interview if you like. You are free to stop the survey at anytime. May we begin now?

From the following information, can you provide the missing information and verify the accuracy of the stated information below:

Information acquired from secondary sources and verified by the interviewee.

CIL Name:

Location:

Contact person and title:

Address:

Phone numbers:

E-Mail:

Website:

Previously identified as *Nobody Left Behind* disaster site:

Main office:

If main office, name and location of other offices:

Identify primary service area:

At what location how many are served:

How long in operation?

Number of employees:

Most recent annual budget:

Do you receive federal funding?

Number of persons with disabilities who live in county/parish or primary service area:

Range of services provided to consumers:

Background Information (pre-Katrina)

I a. Prior to Katrina, how successful would you say that the CIL has been in meeting the core service area needs of consumers in the past? **Please specify reason.**

- Very successful ____
- Moderately successful ____
- Somewhat successful ____
- Not too successful ____
- Don't Know ____
- Not Applicable ____

I b. Prior to Katrina, did you have any off-site storage or back-up facilities for any of your records, files, or other related items that you need to manage the center?

- Yes ____
- No ____
- Don't Know ____

I c. Prior to Katrina, to your knowledge, did anyone at your CIL have any training in emergency or disaster preparedness and response?

Yes ____ **If yes, how many staff members had training? Please specify, _____**
If yes, what kind of training?

- University of Minnesota, Columbia University or similar online course, specify _____
- Training/course offered by the state (SEMA) ____
- Training/course offered locally, please specify _____
- _____
- G197 Federal Emergency Management Agency (FEMA) Course ____
- Other, please specify _____

- No ____
- Don't Know ____

Baseline/Shelter/Recovery (Planning)

1. Prior to Katrina, did your CIL have a plan in place to provide services in the event of a disaster?

Yes ____
If yes, was it a written plan? Yes ____ No ____
If yes, can we get a copy? Yes ____ No ____

- If yes, were the services to cover just for**
- Facility, including staff and consumers? ____
 - Large consumer groups and others regardless of where they were when the disaster occurred? ____
 - Both facility and large group of consumers and others regardless of where they were when the disaster occurred? ____
 - Don't Know ____

No ____

If no, did CIL staff or consumers put together an informal plan of action when Katrina was approaching?

Don't Know ____

2. If you had a formal, written plan in place before Katrina, what were the primary role(s) the CIL had hoped to play in the event of an emergency outlined in the plan?

Possible choices (**Check all the apply**)

- Assure accommodations and access for durable medical equipment? ____
- Notify persons who are blind and/or deaf? ____
- Identify accessible egress? ____
- Secure accessible transportation? ____
- Secure and maintain personal assistance? ____
- Assure accommodate service animals? ____
- Facilitate use of assistive technologies? ____
- Assist in getting help from FEMA, Red Cross, or other disaster management agencies? ____
- Other, please specify _____

3. Did your CIL help consumers prepare an inventory, checklist or "to-go list" of likely needs in a disaster?

Yes ____

If yes, where were the items to be kept? _____

If yes, were consumers able to use the information when Katrina was approaching or after it arrived?

Yes ____

No ____

Don't Know ____

If yes, was there a form developed?

Yes ____

If yes, could you share it with us? Yes ____ No ____

No ____

Don't Know ____

If yes, What were the major barriers to putting this information to use? _____

4. If any type of disaster plan for consumers was in place at the time of Katrina, how helpful was it in the following ways?

No plan in place ____

If plan was in place,

- Did the plan work as conceived? _____
- What parts worked? _____
- What parts didn't work? _____
- Among parts that didn't work, what were major barriers or gaps that created problems?
- What would (will) your CIL do differently in the future to address those gaps?

5. Other than by a written plan, please describe how else your CIL prepared for Katrina.

6. Was it within the mission of your CIL to locate and assist consumers during the emergencies?

Yes ___
If yes, please specify why? _____

_____ **If yes, specify the forms of assistance?** _____

No ___
If no, why not? _____

Don't Know ___

7. How did your CIL communicate to employees and consumers **immediately before and during** Katrina? (**Check all that apply**)

Phone? ___

E-mail? ___

Personal contact? ___

Central location meeting? ___

Radio/television? ___

Other? Please specify: _____

Didn't communicate ___

Don't Know ___

8. Did your CIL have any types of formal or informal relationship with local emergency managers or responders (specify City or County/Parish Emergency Manager, EMS, police, ambulance, etc.) **before** Katrina?

Yes ___

If yes, what did that relationship consist of? (Check all that apply)

- Providing information about people with disabilities ___

- Serving as resources for services to people with disabilities

___ - Other, please specify: _____

No ___

Don't Know ___

9. Was there any type of formal plan or agreement in place with local (city or county/parish) emergency managers before Katrina?

Yes ___

If yes, what did it contain? _____

No ___

Don't Know ___

10. Did you have any types of formal or informal communication with local emergency managers or responders (specify City or County/Parish Emergency Manager, EMS, police, ambulance, etc.) **at the time** of Katrina?

Yes ___

If yes, what did that relationship consist of? **(Check all that apply)**

- Providing information about people with disabilities ____
- Serving as resources for services to people with disabilities

- Other, please specify: _____

No ____

Don't Know ____

11. Did you have any types of formal or informal relationship with other CILs or similar organizations that may have been part of a regional network of independent living centers **before** Katrina?

Yes ____

If yes, what did that relationship consist of? **(Check all that apply)**

- Providing information about people with disabilities ____
- Serving as resources for services to people with disabilities ____
- Other, please specify: _____

No ____

Don't Know ____

12. Did you have any types of formal or informal communication with other CILs or similar organizations that may have been part of a regional network of independent living centers **at the time** of Katrina?

Yes ____

If yes, what did that relationship consist of? **(Check all that apply)**

- Providing information about people with disabilities ____
- Serving as resources for services to people with disabilities

- Other, please specify: _____

No ____

Don't Know ____

13. Did you have any types of formal or informal relationship with local, county or state disability advocacy organizations (i.e., Area Agencies on Aging, agencies representing persons with different types of disabilities, etc.) **before** Katrina?

Yes ____

If yes, what did that relationship consist of? **(Check all that apply)**

- Providing information about people with disabilities ____
- Serving as resources for services to people with disabilities ____
- Other, please specify: _____

No ____

Don't Know ____

14. Did you have any types of formal or informal communication with local, county or state disability advocacy organizations (i.e., Area Agencies on Aging, agencies representing persons with different types of disabilities, etc.) **at the time** of Katrina?

Yes ____

If yes, what did that relationship consist of? **(Check all that apply)**

- Providing information about people with disabilities ____
- Serving as resources for services to people with disabilities ____
- Other, please specify: _____

No ____
 Don't Know ____

Shelter and Recovery (one week and beyond Katrina)

15. How did you try to locate consumers affiliated with your CIL **before and during** Katrina whom you were unable to communicate with? **(Check all that apply)**

- Phone? ____
- E-mail? ____
- Personal contact? ____
- Central location meeting? ____
- Radio/television? ____
- Other? ____
- Didn't communicate ____
- Don't Know ____

16. How many persons with disabilities from your county/parish or primary service area - both consumers usually served by your CIL and others - do you estimate **had to either temporarily or permanently relocate in the aftermath** of Katrina? _____

17. How many persons with disabilities – both consumers usually served by your CIL and others - do you estimate your CIL **was in either direct or indirect contact within the month following** Katrina?

18. Did you retain contact with consumers **after their evacuation** from the county/parish?

- Yes ____
- If yes, approximately how many persons?** _____
- If yes, how? (Check all that apply)**
- Phone? ____
 - E-mail? ____
 - Personal contact? ____
 - Central location meeting? ____
 - Radio/television? ____
 - Other? Please specify: _____

No ____

If no, why not? _____

Don't Know ____

19. Did you continue to provide any services **after the evacuation** of the county/parish?

- Yes ____
- If yes, which services and how?** _____
- No ____
- Don't Know ____

20. Did you have any contact or work with any types of shelters after Katrina?

Yes ___
If yes, how many shelters did you work with? _____
 - what did you work with them on? _____

 - what type of shelter(s) were they? **(Check all that apply)**
 - Shelter(s) servicing the general population ___
 - Shelter(s) serving medical needs ___
 - Other, please specify: _____
 - Estimate the number of persons with disabilities your CIL served in these shelter(s) _____

No ___
If no, why not? _____
 Don't Know ___

21. Did you interact in any way with emergency managers or county/parish, state or federal officials in the post-evacuation stage?

Yes ___
If yes, what was the nature of that interaction? _____
 No ___
If no, why not? _____
 Don't Know ___

22. Where there other people or organizations that were critical for you to communicate with during the post-evacuation stage?

Yes ___
If yes, whom? _____
 No ___
 Don't Know ___

23. What do you feel were the most significant hardships your CIL faced during **the shelter and recovery phase** of Katrina?

24. What do you feel were the most significant accomplishments your CIL achieved **during the shelter and recovery phase** of Katrina?

Lessons Learned

25. Based on your experience with Katrina, how could CILs more effectively meet the needs and priorities of people with disabilities in emergency situations that arise in the future?

26. What type of resources would be most helpful to better serve consumers in an emergency or disaster?

27. What type of training or education would be beneficial to both CIL staff and consumers to prepare for large-scale disasters of this type in the future?

28. What role do you feel CILs can play in county/parish or statewide emergency management and disaster response in the future?

29. Do you feel that CILs and emergency management agencies could work better in future disasters?

Yes ____

If yes, how? (Check all that apply)

- Greater participation of persons with disabilities in the planning process? ____
- Improved communication? ____
- Shared registries or other information? ____
- Other? _____

No ____

If no, why not? _____

Don't Know ____

30. Did CIL employees have to take on different tasks and roles after the disaster(s)?

Yes ____

If yes, who kept working and what new roles did they have to take on? ____

If yes, who no longer worked, and what were the reasons? _____

No, they kept the same tasks and roles ____

Don't Know ____

31. Will Katrina significantly affect the way in which your CIL does business now?

Yes ____

If yes, how? _____

No ____

Don't Know ____

32. Do you anticipate any financial impact from Katrina?

Yes ____

If yes, how great an impact do you estimate it will have and in what areas?

No ____

Don't Know ____

33. How do you anticipate Katrina will influence how many consumers you serve in the coming year? (**Check one response**)

- Consumer volume increase? ____
- Consumer volume decrease? ____
- Consumer volume approximately stays the same? ____
- Don't Know ____

34. Are there any success stories you would like to share with us?

35. Were there any needs that could **not** be addressed that you would like to share with us?

36. Any other thoughts or comments?

37. Any other CIL administrators in the state you feel we should be in touch with?

This concludes our interview. Thank You!

Appendix C

INTERVIEW INSTRUMENT FOR EMERGENCY MANAGERS

SECONDARY INFORMATION TO BE GATHERED BEFORE INTERVIEW

1. NAME OF ORGANIZATION
 2. ORGANIZATIONAL CHART 9POSITION WITHIN COUNTY/PARISH GOVERNMENT
 3. NUMBER OF FTE'S
 - 3A. TYPES OF STAFF FTE'S
 4. TOTAL ANNUAL BUDGET
 5. CATCHMENT AREA
-

Date:

Interviewee's Name:

INTRODUCTION

Hi. I am (name) from the University of (name) and we are scheduled for an interview at this time. I will begin by turning the tape recorder on. Have you reviewed the informed consent statement (see attachment)? Do you have any questions about the informed consent statement? The information we receive from you will only be used for the purposed identified in our research protocol, namely to better understand how you and your agency dealt with people with disabilities. You may request a copy of the transcript of our interview if you like. You are free to stop the interview at anytime. May we begin now?

**SECTION ONE
PRE-DISASTER INFORMATION AND PLANNING**

Before we talk about what happened once the hurricane hit [County/Parish] County/Parish, I'd like to spend a few minutes talking about what kind of information you had available to you about people with disabilities in [County/Parish] County/Parish.

1. Before the hurricane, how much information did [you] [your office] have about people with various types of disabilities in your County/Parish in the following areas?

NO YES

↓

1A. Did [you] [your office] have information on:

- *Where people with disabilities were located in the County/Parish?*
- *What types of disabilities they had?*
Probe for types of disabilities:
 - *People with mobility limitations*
 - *People who are deaf or hard of hearing*
 - *People who are blind or visually impaired*
 - *People with cognitive disabilities*
 - *People who are mentally ill*
 - *People with chemical sensitivities*
- *What kinds of special services they would need in the event of a disaster such as the hurricane, such as medication, equipment (e.g., oxygen), transportation, evacuation etc.?*

1B: Where did this information come from?

Probe For:

- *source: (e.g., census, disability organization(s) (specify which ones), other; was it generated locally, from state sources or federal sources?*
- *what type of information and which disabilities*
- *Frequency of update*
- *Form (e.g., hard copies, maps/GPS, lists, etc.)*

1C. In general, how useful did you find this information just before, during and after the hurricane?

Probe for specific instances of useful/not useful among different information sources if more than one available.

↓

2. Before the hurricane, did [you] [your office] have any plans in place to assist people with disabilities in the event of a disaster such as the hurricane?

NO

YES

2A. Were these plans written?

2B. What did these plans include?

[Ask for copies of the plan(s) for later analysis]

2C. For which disabilities?

[Use disability types from question 1A]

2D. Do you know how they were developed?

* Could you tell me a little about the process that was used to develop these plans?

* Were disability organizations or people with disabilities involved in preparing these plans? In what ways?

3. Before the hurricane hit [County/Parish] County/Parish, had [you] [you or other staff in your office] received any formal training in how to assist people with disabilities?

NO

YES

3A. Do you recall what training you received?

- G197 FEMA Course
- University of Minnesota or Columbia University on-line course
- Training/course offered by the state
- Training/course offered locally
- Other: _____

3B. In general, how useful would you say the training you took was in preparing you to assist people with disabilities?

Probe for specific instances of useful/not useful in different courses if more than one taken.

4. As word came that the hurricane was approaching [County/Parish] County/Parish, were you contacted by any people with disabilities or groups or organizations representing people with disabilities for assistance?

NO

YES

4A. Who contacted you (group name/individual)?
Probe for level of contact - local, regional, state, national

4B. What did they want?
Probe for:

- Offering help - what kind?
- Offering information - what kind?

→ *Was the offer helpful? How and why?*

- Wanting Assistance - what kind?
- Wanting information - what kind?

→ *Were you able to provide the assistance/information?*

5. As word came that the hurricane was approaching [County/Parish] County/Parish, did [you] [your office] contact any groups or organizations representing people with disabilities?

NO

YES

5A. What group or organization did you contact?
Probe for level of contact - local, regional, state, national

5B. What did you contact them for?

6. Before we switch topics to what happened when the hurricane hit [County/Parish] County/Parish, is there anything else you'd like to tell me about your interactions with people with disabilities or disability organizations before the hurricane?

SECTION TWO

EVENT AND IMMEDIATE POST-EVENT

Next, I'd like to talk about the experiences [you] [people in your office] had with people with disabilities just before the hurricane hit and afterwards.

7. Did [you] [your office] assist people with disabilities immediately before the hurricane (e.g., evacuating people or getting them to shelters) and after the hurricane had past?

NO

YES

7A. What types of persons with disabilities or organizations that serve people with disabilities did you work with?

7B. What types of assistance did [you] [your office] provide?

Probe: did assistance vary by disability? Use disability types from question 1A.

1A.

7C. Looking back on your experiences assisting people with disabilities, what would you say were the major challenges [you] [your office] faced in providing them with assistance?

Probe: did barriers vary by disability and/or type of assistance provided?

Probe: explore the following: identification/locating; identifying/meeting health care needs; medications & durable medical equipment; accommodating caregivers and service animals; assistive technologies

7D. Did [you] [staff of your office] interact with people with disabilities in emergency shelters or evacuation areas?

No

Yes

7Da. Could you tell me a little about what the most difficult challenges were in assisting people with disabilities in the shelters?

Probe: did barriers vary by disability and/or type of assistance provide? Use disability types from question 1A.

Probe: explore the following: identification/locating; identifying/meeting health care needs; medications & durable medical equipment; accommodating caregivers and service animals; assistive technologies.

To finish up this interview, I'd like to talk with you a little about what types of things you think might be most useful to you in [County/Parish] County/Parish if a disaster like the hurricane strikes again.

8. Based on your experience in the hurricane, how could emergency managers and offices like yours more effectively assist people with disabilities in future emergencies? Are there specific suggestions or ideas that you can think of that would help improve services for people with disabilities in future emergencies, and help address some of the issues we've discussed in this interview?

No Yes DK/NS

Probe for relative priority of the following along with specifics of each and examples of how it would be useful:

- *greater participation by people with disabilities in the planning process*
- *communications*
- *shared registries or other information*
- ***role of public health***

9. What types of resources would you say emergency managers and offices like yours need the most to more effectively assist people with disabilities in future emergencies?

Probe for relative priority of the following along with specifics of each and examples of how it would be useful:

- *Training*
- *information*
- *equipment and facilities*
- *personnel*
- *technology*
- *funding*

10. Is there anything we haven't covered here about assisting people with disabilities during the hurricane that you'd like to bring up?

Appendix D

FOCUS GROUP SCRIPT FOR INDIVIDUAL EXPERIENCES

A lot of our work at the University of Kansas over the past few years has focused on identifying the unique challenges that people with disabilities have when faced with natural or man-made disasters. While nearly everyone agrees on the importance of disaster planning that includes all persons affected by some catastrophic event, we've found very few practices that can assure the safe evacuation, shelter and recovery for peoples with mobility disabilities.

1. Could each of you describe how you prepared for Katrina?
2. How would you have prepared for this type of hurricane differently?
3. Describe how were you able to evacuate?
4. What has life been like for you since you've been forced to relocate?
 - Health and medical
 - Housing
 - Finances
 - Transportation
 - Work or school
 - Family and other relationships
 - Spiritual
5. What do you see happening now and in the immediate future?
6. What should have been done differently by local, state, regional or federal agencies to have helped persons with disabilities?
7. What do you think needs to happen in order for changes to take place?

Appendix E

First Anniversary of Katrina: Life in New Orleans for Persons with Disabilities Executive Summary

Elisabeth Gleckler, DrPH, CHES

As the first year anniversary of Hurricane Katrina approached, the investigators from the NIDRR sponsored Katrina Project commissioned Dr. Gleckler to conduct a detailed investigation on impact of the hurricane on people with disabilities in New Orleans. Nine people with physical disabilities who evacuated from Katrina agreed to in-depth, semi-structured interviews. The interviews lasted between 20 minutes and one hour. All of them were audio taped, transcribed and analyzed for trends and underlying constructs. Interviewees were a convenience sample, consisting of eight males and one female; six were white and three African-American with ages from 17 to mid 60s. The disabilities were all physical and ranged from diabetes, HIV and neuropathy to high level quadriplegia or advanced osteogenesis imperfecta.

Gaps in Pre-Disaster Planning

None of the interviewees thought that Katrina was going to be particularly devastating. All expected a three-day evacuation, and prepared their medical and personal kits for no more than three days. Most evacuated the Saturday before landfall, with only two exceptions. One person stayed because he thought his high rise apartment was safe, which was true until the levees broke. The other stayed to protect his house from possible post-storm looters. Neither anticipated the flooding that occurred. One was well-stocked and prepared, the other ended up on the streets in front of the New Orleans Convention Center without money or supplies. ***Whether they stayed or left, the people in this sample weighed their options on their experiences of previous evacuations. No public entity had ever taken the effort to devise a public campaign to address the civic intent to evacuate.***

Gaps in Pre- and Post-Disaster Coordination

People moved between two and six times before settling down during the preceding twelve months. Most were staying in temporary housing having physical barriers that made daily lives more difficult. In some cases it was simply the irritation of losing some floor space in the house. In other cases, ***the barriers directly influenced the interviewee's health - in one case, with long-term effects.***

One commonly expressed concern was the loss of personal relationships. Sometimes people moved away to other cities permanently. People were separated by the evacuation and had to make choices about which friend or family members would stay

together. Sometimes one family member returned while others stayed in other parts of the country. The losses were compelling and deeply regretted by the interviewees. Keeping their jobs and having to report to work with co-workers was helpful for feeling a sense of stability.

Having some kind of an advocate, and more specifically a family network, was one of the most important factors for having a less onerous evacuation and smoother eventual return. There was consensus that first family and then friends were vital to surviving the evacuations. Trying to rebuild without friends or family seemed impossible to most interviewees. ***“I don’t know what I would have done without my family,”*** was a common sentiment, voiced in different ways throughout the interviews.

All interviewees noted an emotional price of the evacuation and return to New Orleans. There was a consensus that stress and emotional trauma had made some impact on their health. For some, losing control of their nutrition caused weight gain, which upset precarious physical balances. ***The interviewees noted that their costs were greater for evacuation and return than for persons without disabilities.*** The materials and equipment they lost were going to be more expensive to replace including adapted personal and household items.

Another common theme was that ***people with disabilities have to face multiple vulnerabilities in a disaster.*** One interviewee could not be housed with a lot of other people to protect against infection after his transplant operation so he stayed in his flooded house and evaded “capture” by bands of rescuers until he was sure he would be sent somewhere safe that had fewer people gathered. Several people had problems getting medications. Another interviewee was affected by cold weather and ended up in an evacuation site that contributed to a flare up of arthritis. Several were people with disabilities taking care of people with more profound disabilities. If any of these people had not had a disability, they would have still faced daily challenges. Their disability was directly linked to greater problems in evacuation, housing and health.

Gaps in Pre-Disaster Information Sharing and Communication

Several people said that ***they learned how to plan for evacuations by doing them.*** A couple noted that they regretted one or more of their decisions. ***No one mentioned that they had training or guidance on what to do*** from any educational resource. The complex vulnerabilities of persons with disabilities could be served by communicating the experiences of other disabled people in a well-organized strategic communications public education format.

For interviewees, having to ***re-educate people to understand and accept their disability*** was an additional burden. The frustration was not only with the general public, but moving from accustomed medical providers meant that the interviewees had to deal with some re-education of the new medical staff, too. Both took a toll, but more dangerous were the medical staff misunderstandings of the needs of the evacuees. Other administrative offices often dealt with the interviewees based on erroneous stereotypes.

One student and three parents talked about ***how difficult it was to get school systems to respond to their children***. This was for both disabled and non-disabled children. In particular, for the disabled student, she talked about how she had to prove her cognitive status to be placed in classes in which she had routinely enrolled back in her original school. The special case of disabled students getting into schools is an issue that should be addressed in school policies regarding disasters and evacuations. Disabled parents of able-bodied children also talked about coping with the school system and how difficult it was.

Other Lessons Learned and Discussion Points

1. ***More than the one month support for Medicaid drugs are vital to maintain health is needed.*** A drug program for disasters needs to be developed.
2. ***Interviewees expressed discomfort at having to interact with a public unaccustomed to dealing with them, a medical system ignorant of their issues, and physical environments hostile to physical disabilities.*** In one case, while being transported to the hospital for observation, the emergency medical staff could not identify the disability.
3. ***During evacuation, all interviewees encountered new physical environments that were not designed for people in wheelchairs or for people with limited movement.*** There are estimates in the popular press of as many as 150,000 houses that will need to be demolished in New Orleans. One goal, suggested by one of the interviewees, was that all public buildings and all new buildings be wheelchair accessible. Several people thought that any evacuation sites should have some part of the facility that is designed for wheelchairs.
4. ***The special case of disabled students getting into schools is an issue that should be addressed in school policies regarding disasters and evacuations.*** Disabled parents of non-disabled children also talked about coping with the school system and how difficult it was. Schools should have a plan for how to share credits. Student records should be honored in different school systems. Eventual transfer of credit needs to be established and recognized before the next event. Educators need training in disability. Many do not understand the difference between physical, emotional and cognitive disabilities.
5. ***Living in New Orleans was like living in the past.*** It was a city that operated at a different speed. There were few “big-box” franchise stores in Orleans parish. It was a city of mom-and-pop stores. The music was a throwback to less production and based on older styles. People sought out old diners, family businesses and treasured generational links. People did a lot of things together as if were a pre-television or pre-home entertainment center. ***Nearly all the interviewees noted a loss of their social lives with regret.*** One specifically noted that New Orleans is now operating on the time pressures of a modern city dweller yet without the infrastructure to do so. The

interviewee continued to say that people have adjusted to time pressures by reducing their time with friends and family – a direct hit on one of the defining characteristics of New Orleans that might not have quite the same resonance in a different city more accustomed to fast-paced anonymous city life.