

Assessing the Impact of Hurricane Katrina on Persons with Disabilities

Interim Report

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Background

On February 12th, 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" ¹ documents 90 specific failures in response at all levels of government.



*Damaged home in the Lower 9th Ward, New Orleans, LA
(© Glen W. White, 2006)*

One shortcoming of the report is that it pays inadequate attention to the unique challenges associated with accommodating the needs and priorities of persons with a wide range of physical and cognitive disabilities. This group represents a large proportion of the population. The Centers for Disease Control estimates that over 50 million people in the United States have some form of disability. In the three states that are the sites for this research, Mississippi, Alabama and Louisiana, the 2000 census reported that over one million families in the three states combined contained at least one person with a disability.² While some mention is made 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 range of issues related to people with disabilities.

This research project responds to the clear need to document all aspects of the experiences of persons with disabilities and agencies working with them in the preparation, evacuation, shelter, and recovery process. Building on the work of investigators from the University of Kansas and University of New Mexico in disaster management with people with mobility limitations, the National Institute on Disability and Rehabilitation Research (NIDRR) sought to fill this void in our national understanding through research which seeks to document the experiences of the staff and consumers of centers for independent living (CILs) in the Gulf Coast following Katrina and the other recent devastating hurricanes. The ultimate goal of the project is to provide a series of recommendations at the policy and program levels that can be used by public agencies to improve the services provided to people with disabilities in future emergencies.

¹ <http://katrina.house.gov/>

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

This current work builds upon the CDC/ATPM funded Nobody Left Behind project at the University of Kansas.³ Major findings from that project were used to form the survey and interview questions used in this research project, and included:

- Poor participation of persons with disabilities 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.
- Insufficient emphasis on detailed county-level surveillance that would help emergency managers and other disaster planners understand the range of mobility among persons at risk in their jurisdictions in the event of an imminent evacuation.
- Emergency personnel and service providers do not have sufficient information or resources to effectively meet the needs of people with disabilities in emergency situations.⁴

Interest in the effect Hurricane Katrina had on persons with disabilities goes back to October 2005, when NIDRR and Assistant Secretary of Education John Hager asked that the roles CILs played in assisting people with disabilities living in affected coastal regions during the storm be assessed. NIDRR Director Steven Tingus, who was aware of the Nobody Left Behind research project, invited Dr. Glen White of the Research and Training Center on Independent Living at the University of Kansas to submit a proposal to investigate hurricane related activities affecting consumers before, during, and following Hurricane Katrina. Collaborating with Dr. Michael Fox from the Kansas University Medical Center and Dr. Anthony Cahill, professor and disability researcher at the University of New Mexico School of Medicine, a proposal was submitted that month and awarded in December 2005.

This project is very timely since little research exists concerning CIL and emergency manager planning and preparedness for catastrophic events and their abilities to provide emergency service information and relief.

Scope of Work

This research project, “Assessing the Impact of Hurricane Katrina on Persons with Disabilities”, has two primary tasks.

- 1. Identify barriers and gaps that centers for independent living personnel have experienced concerning people with disabilities in the affected areas and relocation centers.*

³ www.nobodyleftbehind2.org

⁴ A more 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 in Spring 2007.

Activities for this task include:

- Identifying major barriers faced by CIL personnel in locating and assisting people with disabilities.
 - Further understanding independent living needs among CIL consumers.
 - Identifying resources, including training, information, equipment, and facilities that CIL personnel state as being most useful to them in the event of future large-scale emergencies.
2. *Identify barriers and gaps that emergency personnel have experienced concerning people with disabilities in the affected areas and relocation centers.*

Activities for this task include:

- Identifying major barriers faced by emergency management personnel in locating and assisting people with disabilities.
- Further understanding the role and planning Emergency Managers had in addressing consumer needs.
- Identifying resources, including training, information, equipment, and facilities that emergency management personnel state as being most useful to them in the event of future large-scale emergencies.

Research Activities Completed To Date

In the four months since the contract was awarded, project staff at the Universities of Kansas and New Mexico have made significant progress in completing the tasks described above, including the following:

- Contractual commitments with all research team members were completed.
- Contractual agreements with independent living center (CIL) staff and consumers in the three states that are research sites who would participate in research were identified and completed.
- Approval from the University of Kansas Internal Review Board (protection of human subjects) for survey and focus group data collection was received.
- Background data collection for counties and parishes that would be part of the sample was completed.



(© Glen W. White, 2006)

- Survey tools for CIL staff, consumers and emergency management personnel (See Appendices A and B) were created, pilot-tested, and revised.
- Drs. White and Fox conducted a site visit to Mississippi on February 2-4, 2006 to survey CIL director(s), conduct a focus group with consumers and IL staff, and conduct individual consumer interviews.
- Drs. White and Fox conducted a site visit to Louisiana on March 23-25, 2006 to survey CIL director(s), conduct a focus group with consumers and IL staff, and conduct individual consumer interviews.
- Dr. Cahill and Ms. Rooney conducted a site visit to Alabama on April 2-4, 2006 to survey CIL director(s), conduct a focus group with consumers and a focus group with IL staff, conduct individual consumer interviews and conduct interviews with local emergency management staff.
- Transcriptions of the focus groups conducted in Mississippi and Alabama have been completed; transcriptions are near completion from New Orleans meetings.
- Transcriptions for all but one individual consumer interviews have been completed.



*Accessible FEMA Trailer located outside of flood-damaged home in Arabi (New Orleans Metro Area)
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Interim Findings

Task One

Researchers conducted on-site visits with CIL staff and focus groups with selected CIL staff and consumers to learn more about disaster preparation and emergency response issues they faced before, during, and following Hurricane Katrina. In addition to these meetings, researchers conducted on-site visits to land and buildings directly affected by Katrina. Responses from CIL directors interviewed revealed that little pre-disaster planning took place in the CILs, and that there was little interaction between the CILs and emergency management personnel before the hurricane (see Table 1).

Table 1

Summary of Centers for Independent Living (CILs) Director Responses to Questions on Planning for the Disaster – Mississippi (MS), Louisiana (LA) and Alabama (AL). March 2006

Centers for Independent Living	MS #1	MS #2	MS #3	LA	AL #1	AL #2
<i>Survey Question</i>						
Anyone with disaster preparedness training at your CIL?	No	No	No	Yes, basic	Yes, very limited	No
Before Katrina, did your CIL have a plan to provide services in the event of a disaster?	No	No	No	Yes, procedures were in place	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, had procedures in place	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

* When asked to describe how else the CIL staff prepared for Katrina, *other than a written plan*, the responses were:

- “We were basically caught unprepared.”
- “We had no idea of what was coming. Had we known we would have prepared.”

- “Our CIL attempted to prepare for Katrina by determining what staff and consumers could expect in regards to communication about the status of the center and when it would reopen.”

Further, most CILs interviewed played a significant role in assisting people with disabilities at shelters during and after the hurricane and played an active role in providing services after evacuations had been ordered (see Table 2). The roles they played were varied and included locating clients with disabilities and assessing their needs, providing immediate assistance in securing medicine, food, or durable medical equipment, and working with emergency management personnel to acquire accessible housing for people with mobility limitations (see Table 3).

Table 2

Summary of Centers for Independent Living (CIL) Director Responses to Questions on Activities During and After Katrina – Mississippi (MS), Louisiana (LA) and Alabama (AL): March 2006

Centers for Independent Living	MS #1	MS #2	MS #3	LA	AL #1	AL #2
<i>Survey Question</i>						
Did your CIL have an informal or formal relationship with emergency managers or first-responders at the time of Katrina?	No	No	Yes	No	No	No
Did you continue to provide any services after the evacuation of the county/parish?	Don't know	Yes	Yes	Yes	Yes	N/A-no evacuation
Did you have any contact or work with any types of shelters after Katrina ? If so, how many?	Yes, 20	Yes, 4	Don't Know	Yes	Yes, 7	Yes, 3
How many people with disabilities from your county had to relocate following Katrina ?	Thousands	Don't Know	About 50%	Estimate 4,000	150+	0
How many consumers did your CIL have contact with in the first month after Katrina ?	2,000	Don't Know	95%	250+	200+	10

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, often denied access to shelters and outside the formal communication loops established by the emergency management community, they were significantly hampered in their ability to provide effective assistance.

Table 3 describes some of the activities that CIL staff reported resuming immediately after Katrina hit and the levees broke. This information was based on semi-structured personal interviews with CIL directors and staff members from Louisiana, Mississippi, and Alabama. The table shows that CIL staff members were extremely busy multi-tasking to help consumers cope with their losses after Katrina. The responses in many cases were extraordinary and speak to the commitment of CIL staff members of these counties and parishes.

Table 3

Summary of Centers for Independent Living (CIL) Directors on CIL Responses Immediately After Hurricane Katrina Hit and Subsided. Mississippi (MS), Louisiana (LA) and Alabama (AL): February-March 2006.

Centers For Independent Living Responses
MS #1: Ensured that persons with disabilities had the medical equipment they needed to be as independent as possible while staying in a shelter, provided peer support, previous consumers had what they needed including water, food, ice, and clothing. Assisted consumers with applying for available aid and services through local Red Cross and FEMA.
MS #2: Contacted consumers to assess their immediate needs and found ways to meet those needs that included delivering food and water to lending someone a wheelchair.
MS #3: Replaced or loaned equipment that was lost in the storm, such as wheelchairs, walkers, etc.
LA: Provided assistance directly related to the need of the disaster, such as obtain Social Security numbers for food stamps and other services, replaced abandoned or damaged equipment, called family members, helped persons with disabilities contact FEMA, found doctors, housing and transportation, and provided skills training on how to access things, etc.
AL #1: Went door to door to check on our consumers and then to shelters to locate consumers and other persons with disabilities. Assisted with obtaining medication, medical services, equipment, toilet and grooming supplies, provided food, water, and ice, transportation, helped get replacement copies of licenses and other documents, mail, etc.
AL #2: Assisted consumers with basic supplies of food, water, grooming, and toilet supplies, shower chairs, education, medical attention, transportation, etc. Located accessible housing, medical equipment, PAS, and connection to other services in the community.

The next section contains some additional questions asked of CIL directors in the semi-structured interviews and are offered as emerging findings with much more analysis required. Many of these were anecdotal responses with staff, at times very emotional since the enormity of the disaster and its consequences were still so fresh in their minds even six months after it occurred.

Additional questions:

Q: Did CIL employees have to take on different tasks and roles after the disaster?

- “Yes. Everyone did everything, whatever was needed that might include shelter work, equipment and supplies delivery, coordination of water and ice deliveries, search for lost persons, etc.”
- “Yes. We had to find housing, go to shelters, and make announcements on the radio about our services.”

Q. What were the most significant hardships your CIL faced during the shelter and recovery phase?

- Miscommunication from government employees (primarily FEMA) and shelter workers
- Lack of communication and shelters being non-functional.
- No plan in place to assist consumers, so difficult to develop in the middle of the disaster of this magnitude.

Q. What were your CIL’s most significant accomplishments during the shelter and recovery phase?

- Finding consumers and getting necessary equipment to them.
- Continuing to provide services.
- Getting into shelters and working directly with people in crisis. Assisting emergency managers in developing plans for people with disabilities.
- As long as we were doing the work, we saw that things were getting done.

Q. Can you report any success stories?

- Mississippi: “The generosity of the disability community was incredible! The pulling together of some agencies that historically don’t work very well together was remarkable. Many consumers who have relocated to the state have successfully found community supports they need with assistance from CIL staff.”
- Louisiana: “The huge amount of support we received from the CIL community and other supporters.”
- Alabama: “Nothing to report at this time.” The staff person taking the survey felt helpless amidst people losing everything, having such a large land mass to cover without the support to do so, and then dealing with limiting factors within the community, such as public transportation, etc.



*Power Chair abandoned in Lower 9th Ward home,
New Orleans, Louisiana (© Glen W. White, 2006)*

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

- Contacts with individuals who can get things done at the highest levels in state and federal government, as they are crucial resources when time can mean the difference between life, death, or serious injury.
- Reliable and better communication among all parties involved in disaster preparedness and relief services.
- Improved networking with local, state, and federal agencies to facilitate preparation for and recovery from a disaster.
- A way to provide basic needs with food, water, generators and gas, transportation, housing, medicine.

The next section contains promised deliverables that we are in the process of completing. These are continually being reviewed for action and completion during our weekly project meetings with the Katrina research staff members.

Remaining Activities to Be Completed

- Conduct interviews with relocation shelter directors to document experiences of persons with disabilities.
- Conduct interviews with emergency managers in Louisiana and Mississippi to document their preparation and experiences in dealing with persons with disabilities.
- Analyze focus group transcriptions for common themes.
- Analyze interview transcripts of consumers who experienced Katrina for common themes and cross-cutting issues.
- Share work with advisors and key stakeholders to receive their input and understanding of issues.
- Use findings and input from advisors and key stakeholders to develop a set of recommendations.
- Complete final report for presentation to NIDRR.

Finally, this report contains three appendices:

- Appendix A contains a copy of the *Survey of Centers for Independent Living (CIL) Managers and Key Personnel* that has been administered to CIL staff members in the affected Katrina states of Mississippi, Alabama, and Louisiana (also included is the IRB-required consent form).
- Appendix B contains the survey instrument for emergency managers.
- Appendix C includes a paper copy of the PowerPoint presentation by Dr. Glen White and colleagues entitled, "Nobody Left Behind: Disaster preparation and emergency response issues affecting people with disabilities in the Gulf region." This was presented at the Sixth International Conference on Occupational Stress and Health, Miami, FL in early March 2006. This conference was co-hosted by NIOSH, NIDRR, APA and this presentation was made as a result of a request by Dr. Constance Pledger to inform this audience about what NIDRR and the Department of Education are doing concerning people with disabilities affected by Hurricane Katrina.

Appendix A

Survey of Centers for Independent Living (CIL) Managers and Key Personnel 1/04/06

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!

We can be reached as follows:

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Attachment

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 for Emergency Managers

ASSESSING THE IMPACT OF HURRICANE KATRINA ON PERSONS WITH DISABILITIES

INITIAL INTERVIEW INSTRUMENT FOR EMERGENCY MANAGERS

SECTION ONE

PRE-DISASTER INFORMATION AND PLANNING

Before we talk about what happened once the hurricane hit [County name] County, 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 name] County.

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

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

- *Where people with disabilities were located in the county?*
- *What types of disabilities they had?(may have to list – this is a confusing question to many people)*
- *What kinds of special services they would need in the event of a disaster such as the hurricane, such as medication, equipment, transportation, etc.?*

1B: Where did this information come from?

Probe For:

- *source: (e.g., census, disability organization(s) (specify which ones), other)*
- *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. Where these plans written anywhere? If so, where?

2B. What did these plans include?

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

2C. For which disabilities?

2D. Do you know how they were developed?

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

3. Before the hurricane hit [County name] County, 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?

F197 FEMA Course
G197IS On-line 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? (suggest Likert type scale here)

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

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.

6. 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

6A. What types of persons with disabilities or organizations that serve persons with disabilities did you work with?

6B. What types of assistance did [you] [your office] provide?

Probe: did assistance vary by disability?

6C. 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 provide?

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

6D. Did [you] [staff of your office] interact with people with disabilities in emergency shelters or evacuation areas?

No

Yes

6Da. 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?

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

SECTION TWO

LESSONS LEARNED

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 name] County if a disaster like the hurricane strikes again.

7. Based on your experience in the hurricane, how could emergency managers like you and emergency management offices like yours more effectively assist people with disabilities in future emergencies?

8. What types of resources would you say emergency managers like you 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*

9. Do you think that more interaction between emergency managers like you and offices like yours and local disability organizations would be useful in preparing to assist people with disabilities in future emergencies?

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*

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 C

**Handout copy of the PowerPoint presentation given by
Dr. Glen W. White at the Miami Conference sponsored by
NIDRR/NIOSH/APA in early March 2006.**