

A STORM OF CARING: TENNESSEE'S DISABILITY COMMUNITY RESPONDS TO HURRICANE KATRINA

By Melissa Fortson

The damage done by Hurricane Katrina and its storm surge, including the flooding of New Orleans, made it the costliest and most destructive natural disaster in this country's history. While the disaster significantly affected each of the estimated million-plus evacuees, Katrina evacuees with disabilities faced additional challenges. In the rush to evacuate, people with disabilities were often forced to leave behind wheelchairs, walkers, and other equipment. Those seeking shelter in Tennessee faced separation from their homes, caregivers, healthcare, and other supports. However, the Tennessee disability community moved quickly to address these needs, ensuring that evacuees received the supports they needed to continue to live independently. The accounts of five service providers—and the people they helped—demonstrate the strength and unity of the disability community's response in Tennessee.

Memphis's Boling Center for Developmental Disabilities (BCDD), a University Center for Excellence in Developmental Disabilities (UCEDD) administered by the University of Tennessee Health Science Center, compiled an extensive collection of hurricane-related resources. These resources, available on the BCDD Website, included information about local shelter, healthcare, and aging services, as well as links to local media outlets and relief organizations. "Tips for First Responders," an 11-page field guide on how to best assist persons with disabilities, was also made available via the Boling Center site. The provision of these resources exemplifies the Center's mission of supporting children and adults with developmental disabilities and their families.

Down the road from Memphis, a unique partnership led to an "unforgettable" experience for evacuees in Jackson. Katrina Aid & Relief for Evacuees (K.A.R.E.), a local disaster group

assisting FEMA and the American Red Cross, was introduced to the Jackson Center for Independent Living (JCIL) by the director of the local Red Cross chapter. K.A.R.E. needed an office from which to assist evacuees. JCIL agreed to provide office space, and K.A.R.E. referred individuals with disabilities to JCIL.

JCIL's first referral involved a person who uses a wheelchair who needed transportation to a healthcare facility. JCIL arranged for the evacuee's transportation and also provided the following: a toilet seat extension for a person recovering from hip replacement, a telephone alert strobe light for an evacuee with hearing loss, a walker, and a set of forearm crutches. The agency also referred an evacuee with post-polio syndrome to a physician who was able to assist him in obtaining a power wheelchair, an item he had not been able to obtain in Louisiana. "We were fortunate enough to be able to provide assistance to all those referred to us," said Phillip Merrell, JCIL's Coordinator for Independent Living. "Thanks to the efforts of K.A.R.E., the Red Cross, Jackson Transit Authority, and JCIL, some of the evacuees will never forget Jackson, Tennessee."

It's safe to say that 120 people (and one dog) will never forget Tennessee, either. On Thursday, September 1st, the Division of Mental Retardation Services (DMRS) learned that 80 staff and 40 service recipients of two Louisiana agencies serving persons with mental retardation had fled New Orleans and were staying at Fall Creek Falls State Park while looking for a home. Quickly, DMRS went into action, exploring options for offering assistance and dispatching an intake team to the park that afternoon. It was decided that Clover Bottom Developmental Center was the best place for the agencies, Crossroads of Louisiana, Inc. and Hood Management Group, and the people they were serving.

After preparations were complete, the Louisiana evacuees arrived at Clover Bottom on Tuesday, September 6th. The DMRS guests are housed in several buildings, with the gymnasium available for day programs. While the plan calls for the Louisiana agencies to remain self-sufficient, DMRS staff is providing assistance, including arrangements for transportation and relief staffing. "This is a difficult time for our guests, having left home, not knowing the status of their lives there," said DMRS Deputy Commissioner Stephen H. Norris in a prepared statement. "Everyone at DMRS will work together, ramping up our efforts to make this the best possible experience for them." DMRS will likely serve as hosts into 2006.

Some evacuees had difficulty finding resources in the wake of Hurricane Katrina. In the days after the storm, Tennessee Disability Pathfinder, a statewide, bilingual information and referral service for the disability community, received calls from evacuees seeking information and access to services. "Evacuees contacted us needing services such as specialized equipment, especially wheelchairs, adult day care, and special education services," said Carole Moore-Slater, Pathfinder director. To assist evacuees, their families, and service providers, Pathfinder created a Web-based collection of resources in the areas of emergency management, education, employment, financial assistance, healthcare, insurance, long-term care, shelter, Social Security, transportation, and more. The hurricane resources page enabled the Pathfinder staff to organize the vast amounts of information they were receiving in a way that was accessible to themselves, professionals, and families.

The Memphis Emergency Management Agency and The Tennessean agreed; emergency management officials listed Pathfinder as a resource in their daily briefings and the

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The unemployment rate for individuals with disabilities in 1990 (when the ADA was passed) was approximately 70%. Fifteen years later, the unemployment rate still hovers around that same amount. Transition-aged youth with disabilities represent the greatest hope this nation has for reducing that figure and Congress appears cognizant of that hope.

The Social Security Administration also offers work incentives for transition-aged youth. The Student Earned Income Exclusion enables a student receiving SSI to "try out" working while they are in school without the concern of losing benefits. The Plan for Achieving Self Support allows a young person to set aside income or resources to be used to achieve specific work goals, even including owning his or her own business. For more information on SSA work incentives, contact a Benefits Specialist at 1-888-839-5333.

Finally, parents must be prepared for everything that may occur when their child turns age 18. If your child is receiving SSI or SSDI, for example, they will undergo a redetermination process at age 18 that could affect their future eligibility. At the same time, your child may become eligible for the Ticket to Work and Self-Sufficiency Program through the Social Security Administration. Additionally, in Tennessee, there is currently no mechanism for a parent to be allowed to participate in IEP meetings for their children over 18. Under the IDEIA, all rights formerly associated with the parent will transfer to the child, even though the child may stay in special education until the year in which they turn 22. Most school systems recognize that parents are an important part

of the IEP for this age group, and nothing prohibits them from inviting the parents, but technically the student can decide that the parent should not be a part of the IEP team and their wish will prevail. Like it or not, your child becomes an adult under the law at age 18, regardless of their physical or mental disability, judgment, or even maturity level. They can decide to quit school, hop on a bus to California and join a Polka band. Absent a Conservatorship, of course, and except for your "influence" over them, there is nothing you can do to stop them.

Parents can, however, influence the IEP process, and therefore their child's future, by becoming actively involved in their child's future planning, long before age 18. Make sure the focus remains on all the skills, services, activities, living arrangements, jobs and even recreational activities that your child will need or hope to experience post-school. Make sure your child is able to advocate for themselves to their maximum ability, since you will not always be around to advocate for them. If another agency will be picking up where the school system left off, DO NOT WAIT until your child exits school to find out everything you can about those services. Do the work now for your child's future. As The Dalai Lama says, "Happiness is not something ready made. It comes from your own actions." The actions you are willing to take now can ensure your child's future happiness.

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Nashville-area newspaper included Pathfinder in an article spotlighting local efforts to assist hurricane evacuees. Tennessee Disability Pathfinder is a program of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy Center for Research on Human Development, a University Center for Excellence in Developmental Disabilities (UCEDD).

Deana Claiborne, executive director of United Cerebral Palsy of Middle Tennessee (UCP), notes that within 24 hours of the evacuation of New Orleans, she made contact with the New Orleans UCP affiliate and initiated help for people evacuating to Tennessee. "The first evacuees included one direct support professional and a lady with Down syndrome

who was in her care. We provided emergency financial assistance and information about housing, employment options, and resources in the Middle Tennessee area," said Ms. Claiborne. In addition to providing durable medical equipment to evacuees in Tennessee, the affiliate also partnered with the Middle Tennessee Medical Reserve Corps to send a truckload of equipment to the hurricane ravaged areas. Along with United Cerebral Palsy of the Mid-South, the chapter established a payroll deduction plan to allow its employees to voluntarily deduct a portion of their paycheck to help cover payroll costs of the sister affiliate in New Orleans. In a letter to her fellow UCP Affiliate Executives, Ms. Claiborne wrote: "100% of our employees have opted in to help—and we all feel good about doing

this because we know the best way to help people with disabilities in crisis is to keep trained and knowledgeable professionals in the field for the long haul." Through these efforts, UCP continued to advance the independence, productivity and full citizenship of people with disabilities, even in the face of natural disaster.

Tennessee's disability community has mobilized to assist with the response to Hurricane Katrina. When confronted with natural disaster, the people of Tennessee rose to the challenge, making the long recovery process just a bit easier for the evacuees with disabilities who crossed their paths.

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