

Connecting Autism Families with Emergency Support

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In August 2005, Hurricane Katrina created serious public health problems in the coastal communities of Louisiana, Mississippi, and Alabama by destroying or degrading the capacity of many communities to deliver critical social services. Among the people adversely affected by the hurricane were more than 50,000 families with a member who has autism. People with autism can have great difficulty adjusting to change. The disruption of daily routines can cause severe anxiety and stress not only for the people with autism but also for their families and caregivers. During the evacuation from Hurricane Katrina, for example, many autism families were asked to leave public shelters because of the disruptive behaviors of their children. These families were in desperate need of services that local, state, or federal agencies could not provide at the time. In response, autism support groups mobilized to help.

Autism challenge

Autism is one of the fastest-growing and most prevalent childhood developmental disorders in the United States, affecting as many as one in every 166 births. Autism is a neurological disorder that interferes with normal development in language, intuitive thought, social interac-

tion, and the ability to connect with surroundings. Approximately half of all children with autism are unable to communicate their needs using spoken words. Most are unable to accommodate changes in their daily routines. Associated problems can include hyperactivity, self-injurious behavior, sleeplessness, eating disorders, and gastrointestinal problems. Order and consistently administered therapeutic interventions are important for the child and the family's well-being.

Relief initiative

To help autism families deal with the after-effects of Katrina, a consortium of leading national autism organizations, coordinated through the Center for Health Policy at Boise State University (BSU), formed an emergency relief and recovery initiative in September 2005, called AutismCares (www.autismcares.org). The initiative began in order to raise funds and provide immediate help by leveraging the existing network of autism support groups. The consortium includes a number of support organizations: Autism Speaks, Cure Autism Now, First Signs, TalkAutism, Southwest Autism Research and Resource Center, Unlocking Autism, The Help Group, and Princeton Autism Technology.

The services provided by the AutismCares initiative was made possible by the support received from volunteers living in the affected coastal regions and by the volunteers at BSU who contacted displaced families using the Internet and telephone. Key to locating displaced families was the sharing of contact information, family names, and known addresses contained in the files of the autism support group membership lists.

To date, AutismCares has raised more than \$140,000 for the relief program. Additionally, in-kind donation offers were received from more than 700 people from across the country. Christmas Day 2005 marked the 100th day of operations. By that time, 126 autism families had been helped directly through financial support and in-kind donations that included clothing, beds, personal hygiene articles, kitchen utensils, and autism-appropriate toys for children. Hundreds more were helped through referrals to local and state support services. Furthermore, more than \$30,000 was provided for direct housing rental support, and 46 new beds were purchased and delivered



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Dr. James Ball, Vice President of Autism Services at the Sawtelle Learning Center in Montclair, New Jersey, evaluates by videophone a child with autism spectrum disorder. The child is from a family displaced by Hurricane Katrina.

to 14 autism families. AutismCares also assisted families affected by hurricanes Rita and Wilma.

The effectiveness of the AutismCares relief initiative came from the organization's ability to quickly help with temporary relocation support, mobilizing specialty assistance teams in the Gulf region who could reach the families personally, and providing autism-conscious supplies to the affected families and to the professionals caring for them. Providing families with pre-paid Wal-Mart purchase cards, for example, helped them meet their immediate nutritional and household requirements.

Hurricane Katrina victim Linda Davis, who temporarily relocated to Texas with her daughter and autistic son, said about the program, "AutismCares really helped my family. We were living in our car because we were asked to leave the hotel when my son continuously made high-pitched screams, which is common when he gets upset. AutismCares

took advantage of this offer and pre-registered before evacuating for Hurricanes Rita and Wilma. All of these families were subsequently contacted to determine the level of immediate and longer-term assistance needed. AutismCares provided the families with resources available through autism communities in nearby locations. By March 2006, more than 320 families had registered with the AutismCares database, which will serve as a platform for future emergency response activities.

Organizational structure

The hurricane disasters revealed that autism community support groups were able to respond quickly and effectively in helping families with their special needs after the damage caused by the hurricanes. The relief efforts were effective in part because of the family-focused approach in delivering assistance and the simplicity of the organizational structure.

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paid for us to get an apartment, replaced the battery in our car, and made sure I had what I needed to take care of my kids until we could return home. I could not have done it without them."

Concurrent projects

To help displaced autism families during the Christmas holidays, AutismCares conducted the "Holiday Help a Child" program, assisting 211 autistic children and their siblings by posting their stories and wish lists on the AutismCares Web site. Each child was matched with a generous donor who provided items specific to the child's needs and wants.

AutismCares collaborates with The Help Group, which provides affected autism families access to trained therapists and grief counselors 24 hours a day, seven days a week through a toll-free telephone number.

AutismCares also facilitated the first Telehealth evaluation for an evacuated Katrina family to expedite a formal evaluation of a child's autism condition and produce a legal document enabling an out-of-state school to admit the child. The child's related health records had been lost during the storm.

Planning for future emergencies

To keep up with the changing needs of displaced families, AutismCares is using a short questionnaire to measure and assess on-going family issues related to housing, employment, and their children's needs. The telephone survey allows the identification of changes over time and delineates potential priorities in future relief efforts. The information will be shared with the autism support organizations and will provide a basis for helping the autism community better prepare for future emergencies.

After Hurricane Katrina hit the Gulf region, AutismCares encouraged families affected by autism to register with the organization's database. More than 200 families

BSU was able to provide financial oversight and transparency, thus establishing public credibility and confidence for donors who needed to know that their funds were disbursed appropriately. The legal account for AutismCares is housed within the Boise State University Foundation, and the Center for Health Policy provides fiscal oversight.

The Gulf Coast experience with Hurricane Katrina revealed important vulnerabilities in our special needs populations. Numerous families with autism had difficulty responding to this public health emergency. Many of their needs could not be met by the local, state, or federal relief agencies. However, the spontaneous and focused volunteer actions by autism support groups helped their members during the time of crisis. This experience illustrates the potential effectiveness of grassroots activism during and after a natural disaster. We believe that the AutismCares initiative may serve as a model for helping future special needs populations during a public health emergency. ■

Authors

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Resources

Autism Speaks. www.autismspeaks.org. Information about autism and advocacy.

Cure Autism Now. www.cureautismnow.org. Information about autism and research.

TalkAutism. www.talkautism.org. How the autism community shares knowledge information, and assistance.