

# Disaster Resilience and People with Functional Needs

Sophia Jan, M.D., M.S.H.P., and Nicole Lurie, M.D., M.S.P.H.

When Hurricane Sandy pummeled the northeast and mid-Atlantic states in October, uprooting trees and causing massive flooding, at least three large hospitals were forced to evacuate after emergency generators failed. Governors of 10 states declared emergencies and requested federal aid. As in the super derecho that swept through the Midwest and mid-Atlantic 4 months earlier, millions of residents were left without power.

One alarming consequence of these storms was their effect on residents with functional needs — those who are dependent on home nursing, personal care attendants, or electric medical technologies. Some residents depend on the electrical grid for refrigerating critical medications or for powering lifesaving medical equipment. Many residents, particularly those requiring ongoing respiratory care, streamed into emergency rooms to receive respiratory treatments, refill oxygen tanks, or recharge batteries. Some residents whose medical needs had not escalated but who needed to recharge medical equipment were turned away from shelters whose operators believed their needs could not be met in a general shelter.

Through initiatives launched under the Affordable Care Act, our health care system will increasingly enable the 54.4 million Americans with functional needs to remain in their homes and social environments.<sup>1</sup> Experts in disaster preparedness highlight the need to build community disaster resilience and reduce long-term vulnerability.<sup>2</sup> They also empha-

size that having strong systems in place for day-to-day use is essential for dealing with emergency situations.<sup>3</sup> With or without a major emergency, the ability of people with functional needs to remain in their community setting depends on a stable electrical grid and a resilient system of service agencies, such as home health and hospice care agencies, personal care assistants, and suppliers of medical equipment. Numerous reports highlight the vulnerability of our physical and social infrastructure<sup>4,5</sup>; some key policies can help to strengthen them.

The first strategy for building community resilience for people with functional needs is to continue to support the development of health information systems. For example, in 2011, using incentive payments authorized under the Health Information Technology for Economic and Clinical Health (HITECH) Act, St. John's Regional Medical Center in Joplin, Missouri, converted to electronic health records. Three weeks later, a tornado severely damaged the hospital and forced it to evacuate. Yet dispersed patients continued to obtain prescriptions and receive scheduled treatments because their electronic health records remained accessible.

Residents with functional needs also have frequent engagement with nursing homes, independent living facilities, home health agencies, and suppliers of durable medical equipment, many of which continue to rely on paper medical records and forms. Supporting the development of interoperable electronic records for use

among these agencies will not only allow them to obtain critical information in the event of a power outage, but also enhance routine coordination of care for people with functional needs.

Like smart phones and tablets, which have revolutionized the way people with disabilities communicate, new technologies can also substantially enhance quality of life for residents with functional needs, and they can be lifesaving in the event of a disaster, particularly for residents who cannot easily be moved. Through “innovation challenges” — which can leverage open innovation and the public's broad knowledge to solve a defined problem — public and private organizations can support the development of technologies that contribute to resilience. Such technologies might include alternative power sources (e.g., manual cranks or batteries powered by human waste) for critical medical equipment, safer home generators, and signaling devices enabled by global positioning systems, which can let medical-equipment suppliers or emergency responders know when critical medical supplies or battery backups are running low.

Supporting the development of technologies that enhance social connectedness, which has been shown to improve survival during disasters, can also contribute to community resilience. One such effort is the Lifeline Facebook Application Challenge, sponsored by the Office of the Assistant Secretary for Preparedness and Response of the Department of Health and Human Services, which leverages social media by

asking friends to check in on each other and provide assistance in the event of a disaster, formalizing these roles and responsibilities through a Facebook app.

Another way federal, state, and local municipalities can build community resilience is to invite residents with functional needs to participate in the process of emergency preparedness and response planning and to view such residents as community assets rather than vulnerable populations or liabilities. San Francisco, for example, regularly partners with its Centers for Independent Living on planning for emergencies. The centers were created by people with disabilities and normally provide information and referral services, peer counseling, and training in skills for independent living. The city also integrated a position for a disability services coordinator into the structure of its Incident Command System, a tool for the command, control, and coordination of emergency response used by nearly all disaster-response agencies. The coordinator's role is to assess whether residents' functional needs are being met and to draw on the expertise and resources of the city's large Human Services Agency and its multiple community partners through activation of memorandums of understanding.

Central to building community resilience is the development of strong partnerships between government and nongovernmental organizations for planning, response, and recovery. Many states have established partnerships between emergency management teams and businesses to improve situational awareness and resource sharing. California has passed legislation requiring the

inclusion of private businesses in governmental disaster planning and has signed memorandums of understanding with organizations such as the California Grocers Association, the California Utilities Emergency Association, and Walmart to provide critical supplies and infrastructure during an emergency. The American Red Cross of New England partners with Unutil, a regional provider of natural gas and electricity, to issue joint messages about safety and preparedness. Such partnerships could be expanded to include providers of services for people with functional needs. By sharing data, states could use these partnerships to share and jointly maintain registries of people with functional needs, in order to help in setting priorities for emergency response and power-restoration efforts. Such data sharing may not only enhance the ability of emergency managers to provide critical supplies and services during emergencies, but also help to improve more routine coordination of the multiple services for these residents.

Finally, there are policies that states and the federal government could implement to promote community resilience with regard to people with functional needs. For example, government could promote more widespread adoption of both business-continuity plans for critical agencies and data sharing among agencies and emergency management and utility companies by including related provisions in both federal grant guidelines and publicly reported quality measures. States could use their licensure and certification processes to promote more widespread adoption of reliable emergency power sources by dialysis centers and acute and

long-term care facilities. Maintenance of emergency generators and related equipment could also be included as part of public-reporting and quality measures for hospitals and nursing homes. Some states have such requirements now — Maryland and Texas, for instance, require that dialysis centers have access to an emergency generator.

As more and more people with functional needs remain in their homes and other noninstitutional settings, the strategic development of technologies and policies that decrease our dependence on traditional power sources and enhance information sharing and inclusionary planning will help improve community resilience.

The views expressed in this article are those of the authors and do not necessarily represent those of the Department of Health and Human Services.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

From the Robert Wood Johnson Foundation Clinical Scholars Program, Departments of Medicine and Pediatrics, Perelman School of Medicine; and the Leonard Davis Institute of Health Economics, University of Pennsylvania; and PolicyLab, Children's Hospital of Philadelphia — all in Philadelphia (S.J.); and the Office of the Assistant Secretary for Preparedness and Response, Department of Health and Human Services, Washington, DC (N.L.).

1. Affordable Care Act supports community living. HealthCare.gov, 2012 (<http://www.healthcare.gov/law/resources/reports/community-living-09112012a.html>).
2. Chandra A, Acosta J, Stern S, et al. Building community resilience to disasters: a way forward to enhance national health security. Santa Monica, CA: RAND, 2011.
3. Schoch-Spana M, Courtney B, Franco C, Norwood A, Nuzzo JB. Community resilience roundtable on the implementation of Homeland Security Presidential Directive 21 (HSPD-21). *Biosecur Bioterror* 2008;6:269-78.
4. Rendall MS. Household structure and social vulnerability: lessons from Hurricane Katrina. Santa Monica, CA: RAND, 2011.
5. Chandra A, Acosta JD. Disaster recovery also involves human recovery. *JAMA* 2010; 304:1608-9.

DOI: 10.1056/NEJMp1213492

Copyright © 2012 Massachusetts Medical Society.