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On Linkages

EMERGENCY PREPAREDNESS FOR VULNERABLE POPULATIONS: PEOPLE WITH SPECIAL HEALTH-CARE NEEDS

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Hurricanes Katrina and Rita not only exposed major gaps in emergency preparedness planning, but they also highlighted social, physical, and economic inequities among population groups. Of note, many vulnerable people were stranded while awaiting evacuation assistance, were refused shelter by unprepared organizations, or experienced difficulties in accessing emergency services because of preexisting health conditions or vulnerabilities.[1–5] While the public health community has since attempted to address such gaps as part of equity in preparedness, few have integrated the perspective and experience of local service providers to investigate the needs of these populations and create a unified framework for addressing the challenges involved.[6]

Complicating the issue are the terms “at-risk individuals,” “vulnerable populations,” and “special-needs populations;” these are often used interchangeably to characterize groups whose needs are not fully addressed by traditional health and social-service providers. These groups often include people who are elderly or young, have limited or no English proficiency, experience geographic or cultural isolation, or suffer from addiction.[7] One broad definition identifies vulnerable populations as:

> Any individual, group, or community whose circumstances create barriers to obtaining or understanding information, or the ability to react as the general population. . . . Circumstances that may create barriers include, but are not limited to age; physical, mental, emotional, or cognitive status; culture; ethnicity; religion; language; citizenship; geography; or socioeconomic status.[8]

Of particular concern, however, are the more than 23 million U.S. residents (roughly 12% of the total population aged 16 to 64 years) with special health-care needs (SHCN) due to disability.[9] This population deserves special attention. In Boston, Massachusetts, alone, for instance, 47,230 residents are affected by at least one of the following disabilities: physical (26,405), sensory (11,211), mental (19,586), self-care (7,535), and “going outside home”—people who report physical, mental, or emotional difficulty leaving the home to shop or visit the doctor (12,128).[9] Furthermore, the group is diverse and fluid because there is an 80% chance that any person will experience a temporary or permanent disability at some point in their lives.[10]

INTEGRATING COMMUNITY-BASED ORGANIZATIONS INTO PREPAREDNESS PLANNING FOR PEOPLE WITH SHCN

When addressing preparedness for people with SHCN, community-based organizations (CBOs) are underutilized resources. They traditionally have a special commitment to locate and reach such at-risk individuals to provide human services while accommodating language, cultural, and accessibility needs.[11] They offer day-to-day services and often have earned the trust of the people they serve. Hence, they can also help to provide an accurate barometer of post-disaster needs[11] and mobilize community and local resources in crisis situations.

Objective

To advance planning and protection for vulnerable populations with SHCN during emergencies in Boston, we leveraged the convening authority of an academic center and leading city and state agencies to sponsor "Equity in Preparedness: A Collaborative Symposium for Populations with Special Health-Care Needs in Boston" in December 2006. Key partners, including the Harvard School of Public Health Center for Public Health Preparedness (HSPH-CPHP), the Boston Public Health Commission, the Massachusetts League of Community Health Centers, and the Massachusetts Department of Public Health, collaborated to integrate the perspectives and experiences of CBOs with emergency management officials and public health planners. This symposium culminated in the development of a conceptual framework designed to facilitate future planning.

METHODS

The symposium planning committee recruited participants from professional directories of more than 800 relevant CBOs in the metropolitan Boston area,[12] including long-term care facilities, group homes, visiting nurses associations, community health centers, nonprofits, and social service agencies. The committee also considered local leaders in emergency management and response, public safety, public health, health-care communities, and academia, ultimately extending invitations to 130 people.

A total of 110 people attended, representing more than 66 organizations. A sample list of organizations/agencies represented at the symposium is provided in Figure 1.

The symposium agenda included morning and afternoon sessions:

1. Morning session: Morning plenary sessions reviewed the status of current efforts at the federal, state, and local levels. Presenters shared recent survey data documenting populations who were disproportionately affected by Hurricane Katrina, identified impediments to preparedness planning, and summarized state and city approaches to vulnerable populations and public health emergencies. A detailed after-action report on the morning's presentations and discussions is available on the HSPH-CPHP website.[13]
2. Afternoon sessions: The audience of 110 attendees was divided into the following eight focus groups to address issues of specific subpopulations with SHCN: those with behavioral health issues, the deaf and hard of hearing, the homebound, the homeless, people requiring long-term care, the mobility-impaired, those with substance abuse issues, and the visually impaired. Each group was charged with two goals: (*1*) identifying issues and barriers surrounding emergency planning and (*2*) making practical community and policy recommendations that could enhance emergency planning and preparedness efforts.

Trained facilitators conducted the groups, and note-takers recorded discussions. Following agreement between the facilitators and note-takers on the content of the records, the data were coded and a thematic analysis was performed to identify emergent themes and capture key content areas. Potential discrepancies in the findings were resolved by conducting face-to-face follow-up interviews with discussion group members or facilitators. Content analysis from the eight focus groups identified specific issues and barriers that were organized into a conceptual framework for emergency response.

RESULTS

The conceptual framework

Of the issue areas identified across the eight groups, three common themes included risk communication, evacuation procedures, and continuity of services. Identified barriers for addressing these issues included difficulty in identifying vulnerable groups; lack of coordination among emergency medical services, public health, CBOs, and community leaders; and lack of

Figure 1. Sample list of organizations/agencies represented at the Equity in Preparedness symposium in Boston, 2006

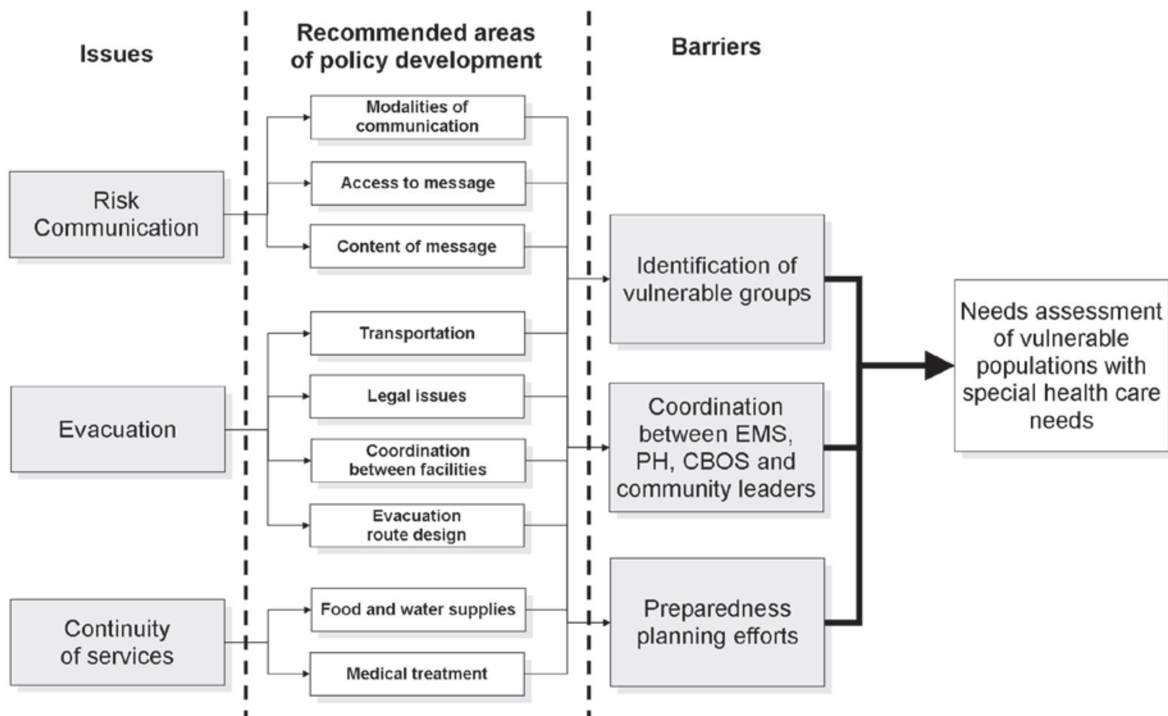
Special health-care needs community-based organizations	*Emergency preparedness and planning agencies and organizations*	*State and local health agencies*
Access Umbrella (disabled populations)	Collaborating Agencies Responding to Disasters	Boston Public Health Commission
Boston Health Care for the Homeless	Northeast Emergency Medical Services	Massachusetts Department of Public Health
Boston Senior Home Care	Visiting Nurses Association	
Deaf-Blind Contact Center	American Red Cross of Mass Bay	
Disability Policy Consortium	DelValle Institute for Emergency Preparedness	
Hearing Loss Association of Greater Boston	Massachusetts League of Community Health Centers	
Victory Programs (substance abuse populations)		

emergency planning. Identified issues, barriers, and areas for policy development are presented in Figure 2. Finally, participants developed several action items to address these concerns.

Issues

Risk communication. Participants noted not only the importance of risk communication before, during, and after an emergency, but also the significance of tailor-

Figure 2. Issues, barriers, and policy development areas in emergency planning for populations with special health-care needs



EMS = emergency medical services

PH = public health

CBO = community-based organization

ing messages to specific populations through a diverse range of communication modalities. Many specific suggestions were offered. For example, materials need to be in large print or in Braille for the visually impaired, or closed-captioned for the hearing-impaired. Citywide or community-wide broadcast announcements may be unlikely to reach those who are hard of hearing or deaf. Printed flyers are likely to be ineffective for the visually impaired. The limited public interaction of homebound individuals could result in a delay in receiving an evacuation message. On the other hand, the homeless might be difficult to reach due to their constant mobility and lack of access to media sources, such as television and radio.

CBO representatives also underlined the importance of improving the content of risk-communication messages. For example, several group members stressed the importance of universal design, which is the principle that the environments and communication tools should be designed in such a way that they are accessible and useful to as many people as possible (i.e., the systematic use of pictograms and images in emergency preparedness materials to reach multiple populations). Furthermore, participants noted that communication efforts among practitioners may be greatly improved by designing and implementing products that are accessible by all service agencies.

Evacuation procedures and shelter and care sites. The decisions surrounding evacuation, including the means to evacuate, pose particular risks of further displacement for those with SHCN. In addition to providing access to transportation, agencies should coordinate closely with facilities receiving the evacuated. Participants noted that the burden of displacement falls not just on evacuees, but also their family members. Many providers expressed fear that relocation would cause many of their clients to become lost. Further complicating matters, sharing and/or obtaining private client information with receiving parties raises much confusion about the legal issues related to the Health Insurance Portability and Accountability Act, the federal law protecting patient privacy of personal health information.[14] Two avenues for improvement would be to identify and publicize appropriate, accessible shelters and evacuation routes ahead of time, and to provide advanced education and communication training to those staff assigned to supporting relocation efforts.

Finally, participants noted that everyday evacuation routes and transportation services often do not accommodate the varying navigation abilities of those with SHCN. For example, many evacuation routes require the use of stairs, which are inaccessible for people with limited mobility. Similarly, vehicles used to transport people with disabilities are often not equipped to allow for the transport of specialized equipment, such as mobility aids.

Continuity of services. Focus group participants expressed concern about how to continue to provide basic necessities such as food, water, and medicine during an emergency. The possible collapse of the social-service infrastructure in an emergency raises fundamental questions of responsibility: i.e., which agency would be responsible for caring for individuals who rely on electrical medical devices during a power outage? Participants suggested that CBOs devote resources to individual preparedness efforts such as kits that include lists of needed medications, food allergies, and emergency contact information. Participants also suggested that CBOs train potential volunteers to assist in sharing and/or obtaining private client information with receiving parties during evacuations to ensure that important client information is not lost. For example, organizations could utilize "File-of-Life cards," available from Boston Emergency Medical Services, which are identification badges that include information such as name, medical condition, allergies, and emergency contact information.

Focus group participants recommended that government agencies, in partnership with the public health community, consider developing surveillance tools for vulnerable populations, including pregnant women and people with disabilities.

Barriers and action items. Barriers applicable across all SHCN groups included (*1*) an inability to clearly identify and locate vulnerable populations during an emergency, (*2*) a lack of regular consultation by emergency management and public health officials regarding needs assessments, and (*3*) a lack of integration of information from CBOs into broader, citywide emergency planning.

Suggested action items included the recommendation that CBOs, emergency management, and public health agencies work together to (*1*) conduct a comprehensive needs assessment that documents community vulnerabilities; (*2*) develop and implement education and training opportunities, such as tabletop exercises and drills, that involve representatives from public safety, local public health, health care, CBOs, and service providers; (*3*) foster cooperative working relationships on multiple levels, not just in emergency preparedness; and (*4*) develop continuity-of-operations plans that prepare staff in advance for the challenges of disaster mitigation and recovery with other community agencies.

Perceived value of the symposium. Representatives from 37 organizations completed a satisfaction survey at the close of the symposium. In all, 89% reported that the symposium helped them to identify available resources and agencies that support preparedness planning for vulnerable populations, 89% were able to identify action steps to enhance their agency planning efforts, 86% reported the symposium better enabled them to define at-risk populations in their community, 78% reported that the event helped them to identify best-practice strategies regarding preparedness planning, and 66% reported that they acquired instruments to better locate populations at risk in their community.

A year after the symposium, five organizations contacted us to report that thanks to the knowledge acquired during the symposium, they had all developed an emergency preparedness plan for their own organization and increased networking and communication with the state and local emergency preparedness and response community. Each of the five had also undertaken specific emergency preparedness initiatives that included (*1*) written protocols for staff and patients, (*2*) drills/exercises, (*3*) to-do lists for emergency preparedness personnel and patients, and (*4*) updated contact information lists and emergency resources. A few agencies reported that since their participation in the symposium, their managerial staff had been asked to review and update the continuity-of-operations plans annually.

DISCUSSION

To our knowledge, our article is one of the first to address preparedness planning for vulnerable populations by focusing explicitly on those with SHCN. Additionally, our experience uniquely integrates CBOs in planning so that they can help support first aid, health education, mental health, and mobile care following a disaster.[11] Results show that a number of participants, initially unclear about what their potential roles would be for preparedness, were subsequently able to identify resources, take action steps, and begin the process of translating plans into action.

The Equity in Preparedness symposium also contributed to the growing, but still embryonic, national dialogue through the development of a framework that builds upon a function-based approach[10] addressing medical, communication, supervision, and transportation needs. Specifically, with respect to people with SHCN, the framework underscores that the goal remains to maintain functional independence and may be useful in planning policy steps.

To date, the limited peer-reviewed literature on vulnerable populations in preparedness has focused primarily on groups such as ethnic minority populations, people with chronic diseases, or families with infants.[1,6,15] The Association of Schools of Public Health, in conjunction with the Centers for Disease Control and Prevention, convened a national network of Centers to join a Collaboration Group, Preparedness Education for Vulnerable Populations, whose work produced two documents designed to enhance the ability of public health and emergency management practitioners to define, locate, and reach vulnerable populations effectively and protect them in the event of an emergency.[16]

Limitations

There were some limitations to our approach. First, the agencies involved in the symposium represented only a sample of those associated with SHCN. Second, the symposium focused only on those agencies servicing populations within the greater Boston metropolitan area. Future planning efforts should broaden the range of relevant CBOs and service organizations and determine how these themes apply to other parts of the country. Third, we focused our efforts on only one group of those considered to be "vulnerable" populations.

CONCLUSION

Our experience represents one step toward addressing preparedness issues through a citywide, collaborative approach.[17] Further strengthening of the preparedness network through such collaborations could lead to effective organizational policies to protect our most vulnerable populations.

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