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Assessment of State- and Territorial-Level Preparedness Capacity for Serving Deaf and Hard-of-Hearing Populations in Disasters

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ABSTRACT

Objectives. Substantial evidence exists that emergency preparedness and response efforts are not effectively reaching populations with functional and access needs, especially barriers related to literacy, language, culture, or disabilities. More than 36 million Americans are Deaf or hard of hearing (Deaf/HH). These groups experienced higher risks of injury, death, and property loss in recent disasters than the general public. We conducted a participatory research study to examine national recommendations on preparedness communication for the Deaf/HH.

Methods. We assessed whether previous recommendations regarding the Deaf/HH have been incorporated into state- and territorial-level emergency operations plans (EOPs), interviewed state- and territorial-level preparedness directors about capacity to serve the Deaf/HH, and proposed strategies to benefit Deaf/HH populations during emergencies. We analyzed 55 EOPs and 50 key informant (KI) interviews with state directors.

Results. Fifty-five percent of EOPs mentioned vulnerable populations; however, only 31% specifically mentioned Deaf/HH populations in their plan. Study findings indicated significant relationships among the following factors: a state-level Kl's familiarity with communication issues for the Deaf/HH, making relay calls (i.e., calls to services to relay communication between Deaf and hearing people), and whether the Kl's department provides trainings about serving Deaf/HH populations in emergencies. We found significant associations between a state's percentage of Deaf/HH individuals and a Kl's familiarity with Deaf/HH communication issues and provision by government of any disability services to Deaf/HH populations in emergencies. Further, we found significant relationships between Kls attending training on serving the Deaf/HH and familiarity with Deaf/HH communication issues, including how to make relay calls.

Conclusion. This study provides new knowledge that can help emergency agencies improve their preparedness training, planning, and capacity to serve Deaf/HH populations in emergencies.

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An estimated 36 million Americans are Deaf or hard of hearing (Deaf/HH),¹ a group neglected in national planning for emergency communications. A 2004 landmark report from the Deaf and Hard of Hearing Consumer Advocacy Network gave a failing grade to U.S. public warning and emergency communications systems for the Deaf/HH in the wake of 9/11.²

During emergencies, individuals who are Deaf/HH are often left out of timely alerts or responses due to lack of communication access. Deaf/HH people are often the last group to receive emergency information.² To decrease disparities in emergency/disaster outcomes, it is critical that this group receives alerts at the same time as the general population. State agencies are typically charged with planning for the needs of diverse populations. Reports from 2004–2006 showed evidence that few agencies had engaged in planning for Deaf population needs.^{2,3} This study used a combination of methods to understand whether states had made any subsequent progress in their planning for Deaf/HH needs.

BACKGROUND

Substantial evidence exists that all-hazards emergency preparedness and response efforts are not effectively reaching populations with functional and access needs, especially those who have barriers related to literacy, language, or disabilities.^{2,4-6} Ninety million Americans have low literacy, and more than 36 million are Deaf/ HH).^{1,7} State (and Washington, D.C. [DC]) populations range from a low of about 2% to a high of about 6% Deaf or hearing-impaired people, according to the 2010 U.S. Census items on hearing.⁸ This percentage may include people who became deaf later in life ("late deafened"). Despite the resilience and adaptability of Deaf/HH individuals, these groups experienced higher risks of injury, death, and property loss in recent disasters, 2,5,9-11 including 9/11, Hurricane Katrina, and the 2007 Southern California wildfires. 10 These disparities illustrate the devastating effect of inequalities in our society.

The functional and access needs of individuals who are deaf, deaf-blind, hard of hearing, or late-deafened (referred to collectively as Deaf/HH in this article) are frequently given little or no attention in policies and regulations pertaining to communication for emergency preparedness, response, and recovery. All levels of organization (national, state, and local) play vital roles in ensuring effective communication for Deaf/HH populations by creating effective policies and regulations and continually monitoring them.

The objectives of this study were to examine

readiness for serving Deaf/HH populations and assess whether earlier Department of Homeland Security (DHS) recommendations³ for vulnerable populations (including Deaf/HH) were incorporated into state and territorial emergency operations plans (EOPs). We also wanted to understand if trainings were being implemented and why certain states might be doing a better job than others to incorporate training and planning for serving Deaf/HH populations.

METHODS

Researchers at the University of California, Berkeley (UCB), interviewed key informants (KIs) from state and territorial emergency management or public health agencies to assess the inclusion of emergency preparedness information and the capacity for serving Deaf/HH populations. We also collected basic EOPs from states and territories. An integral part of our study was engagement and partnership with the Deaf/HH community. Following the principles of communitybased participatory research (CBPR),12 we convened a National Advisory Board (NAB) of leaders from the Deaf/HH community to advise the academic team on instruments, protocols, recruitment, report review, and dissemination of findings. The NAB members were initially skeptical that issues of preparedness for Deaf/ HH populations could be understood by those from an academic "hearing" community. We were able to establish credibility in the Deaf community and successfully engage our board members by involving staff with American Sign Language (ASL) skills, a consultant with expertise in the Deaf community, and a Deaf graduate student, and by creating a strong relationship with our community partner, the Deaf Counseling, Advocacy and Referral Agency (DCARA). Through the NAB, UCB researchers/staff worked closely with the Deaf/ HH community leaders and the Deaf/HH-serving organizations they represented nationwide to ensure the relevance of our research activities and findings for the Deaf/HH community.

DCARA is a San Francisco Bay Area community-based organization that is recognized locally and nationally for its services and work in the Deaf/HH community. DCARA provides its clients and communities with advocacy, independent-living skills training, resources, employment, and peer counseling. DCARA also provides the hearing community with information about the Deaf/HH community and about working and living with people who are deaf, deaf-blind, late-deafened, and hard of hearing. It also collaborates with other agencies to ensure that their services are accessible to the populations that DCARA serves. DCARA's

participation in the project was a deeply important factor to build community trust in UCB's research team and lend credibility to the project within the Deaf/HH community. This partnership helped UCB researchers and staff better understand the needs of community-based, grassroots organizations and the Deaf/HH populations they serve.

We paid careful attention to the provision of full communication access (FCA) in the study. This FCA included providing ASL interpreters, close-vision interpreters, and communication access real-time captioning services for all activities that included Deaf/HH individuals. Individuals were consulted about their communication preferences, and accommodations were made based on their preferences. We faced many challenges in conducting CBPR given the staff-intensive logistical and financial requirements of convening meetings with FCA.

Sample

EOP sample. We contacted all 50 states, DC, and eight U.S. territories from 2009 to 2010. We obtained 55 basic EOPs from the 59 entities (93.2% response rate). We requested the most recent EOP but found that not every EOP had been revised within the 12 months preceding our analysis. Approximately 15 of the 55 basic EOPs (27.3%) were more than five years old but were reported by the state or territory as the most recent version. We analyzed content with a list of keyword search terms applied uniformly across all the EOPs, including the keywords "deaf," "hard of hearing," "people with disabilities," and "ASL interpreter." Keywords were counted and surrounding text was further reviewed to make sure that each word fit our search criteria (i.e., the word was referenced in the context of training, planning for, responding to, or recovering from a disaster/emergency). We analyzed all 55 basic EOPs and a limited number of EOP annexes (seven). While annexes (i.e., appendices to EOPs) are specified by topic and required for most states, only 37 states provided one or more annexes that were specific to topics of interest, such as risk communication.

KI interview sample. We recruited KIs from the same state/territorial agencies that provided the EOPs. In some cases, our initial contact referred us to another agency official who became our designated KI. From the 59 entities that we initially contacted, 50 KI telephone interviews were completed (84.7% response rate). KI interviews included both closed- and openended questions on KI position and organizational demographics, familiarity with Deaf/HH communication issues, emergency communication barriers and

facilitators for people who are Deaf/HH, presence or absence of emergency communication planning and services for the Deaf/HH, anticipated revisions or additions to EOP information on the Deaf/HH, partnerships with Deaf/HH organizations, and model state programs for the Deaf/HH.

Census data and state descriptors. We used data from the 2000 Census on the percentage of each state or territory's population that was reported as Deaf (i.e., Census 2000 item: Does this person have any of the following long-lasting conditions: blindness, deafness, or a severe vision or hearing impairment?). We also assessed whether a state had a state-level Commission for the Deaf. These commissions are tasked with a wide range of responsibilities, including legislative enforcement, advocacy, education, and promotion of Americans with Disabilities Act rights to equal access and accessible communication for the Deaf/HH community. We hypothesized that state-level Commissions for the Deaf might promote preparedness services to meet the needs of deaf residents.

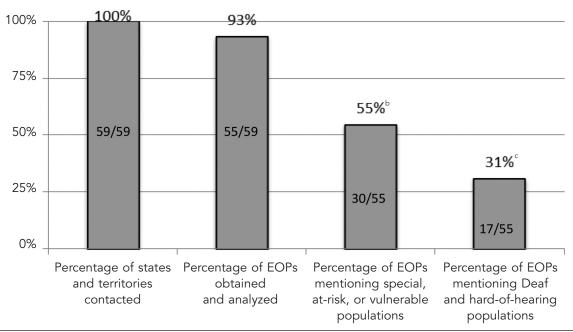
Analytic methods. We used mixed methods to analyze EOP and KI data. For EOP data, we conducted content analysis. For KI data, we entered closed-ended responses in Microsoft® Excel and conducted univariate and bivariate analyses using measures of association (Chi-square, Kruskal-Wallis, or Mann-Whitney). We considered p<0.05 to be significant. We categorized openended responses using Excel and a coding template. We examined relationships among state-level deaf/HH demographics (based on the 2000 U.S. Census¹³), EOP content items, and KI interview items. For example, we examined whether agency personnel were trained on serving the Deaf population, whether agency personnel were knowledgeable and familiar with specific skills staff needed to serve the Deaf/HH population, whether a state included a specific preparedness or response plan for the Deaf/HH in its basic EOP, and whether a state had a Commission for the Deaf.

RESULTS

EOP analysis results using the list of search terms

Fifty-five percent of EOPs mentioned vulnerable populations; however, only 31% specifically mentioned Deaf/HH populations in their plan (Figure). There was a significant positive association between whether or not an EOP mentioned people with disabilities and whether or not an EOP specifically mentioned Deaf/HH populations (p=0.03). We found a significant positive association between whether or not "disabilities" were defined in the EOP and whether an EOP

Figure. Analysis of state and territory emergency operations plans in 59 U.S. states and territories, 2004-2009



^aA total of 59 U.S. states and territories were contacted, and 55 EOPs were obtained and analyzed.

EOP = emergency operations plan

Deaf/HH = Deaf and hard of hearing

specifically mentioned provision of ASL interpreter services (p=0.01). Only 3.6% (2/55) of the EOPs mentioned disabilities and 5.5% (3/55) of the EOPs mentioned ASL interpretation. We found a significant positive association between whether or not an EOP mentioned Deaf/HH populations and whether a state EOP mentioned the needs of the following populations, which are also often categorized as vulnerable: seniors (p<0.001), limited English proficiency speakers (p<0.001), and other special or at-risk populations (p < 0.001) (data not shown).

KI interview analysis results

A KI's familiarity with communication issues for Deaf/ HH populations was significantly positively associated with the KI's familiarity with making relay calls (p<0.001). Relay services use an operator to connect calls between hearing people using voice phones and Deaf people using videophones or teletypewriters (known as TTYs). A KI's familiarity with communication issues for Deaf/HH populations was also significantly positively associated with whether the KI's department

provides any training about serving Deaf/HH people during disasters (p < 0.05) (Table 1). We also examined the association between the KI's familiarity with Deaf/ HH populations and the state or territorial demographics (in this case, the percentage of the population that is Deaf/HH). We found a significant association between a state's percentage of the population that is Deaf/HH and the KI's familiarity with communication issues for Deaf/HH populations (p=0.033), as well as between percentage of the state population that is Deaf/HH and whether governments provide any important disability services to Deaf/HH individuals in emergencies (p=0.003) (Table 2).

In addition, we noted a significant association between the presence of a state Commission for the Deaf and whether or not the KI anticipated adding new information on preparedness communication for the Deaf/HH to his/her EOP (p=0.034) (Table 2). This finding supports a hypothesis that state-level Commissions for the Deaf may have an important role to play in advocating for the needs of Deaf residents.

Further, we found a significant association between

^bOf the 30 EOPs that mentioned special populations, 16 of them also mentioned Deaf/HH populations (not mutually exclusive).

^{&#}x27;This percentage is comparable with no state EOP rating "sufficient" on preparing for the needs of special populations in the 2006 Department of Homeland Security Nationwide Plan Review.

a state's percentage of the population that is Deaf/HH and whether or not local governments provide disability services to vulnerable populations other than the Deaf/HH during emergencies (p=0.008) (Table 2). This finding supports a belief that increased attention to the needs of one population in state planning may benefit individuals from different vulnerable populations.

DISCUSSION

We compared results from our current research with earlier reports that documented low preparedness for serving Deaf/HH populations in disasters. This study contributes new knowledge about state and territory EOPs, demonstrating improvement since the 2006 U.S. DHS Nationwide Plan. That earlier report found that no states were sufficiently prepared to serve vulnerable populations (which might include populations such as children and seniors), while only 5% of state plans were rated as "sufficient" vis á vis action "being taken to fully address requirements for populations with special needs, particularly persons with disabilities." For instance, in the 2006 DHS report, only one state plan noted that translators must be available at

shelters, and no state plans specifically addressed ASL interpretation. A rating of "not sufficient" meant that no plan components and capabilities (either formal or informal) were in place at the time of the 2006 DHS review that complied with applicable federal guidance. In other words, the plan would not meet requirements for serving a specific population during a catastrophic incident.³

Our 2010 EOP analysis and KI interview findings, especially those about specific trainings, suggest that increasing attention is being paid to preparedness capacity for serving vulnerable populations at state and territorial levels. Fifty-five percent of the EOPs mentioned special, at-risk, or vulnerable populations. However, only 31% of the EOPs in our study contained specific information on serving Deaf/HH populations. The association seen between state/territorial demographics and KI's level of training indicates that some states and territories are better prepared; for example, those with larger Deaf/HH populations may be more attuned to serving the needs of this population. However, it also suggests that incorporating training content is an important step toward familiarizing state workers with the needs of Deaf/HH communities. Standardized

Table 1. Results of key informant interviews regarding issues of communication for people who are Deaf/HH: 59 U.S. states and territories, 2009–2010

Торіс	Familiarity with communication issues for Deaf/HH Percent (N)	Familiarity with relay phone calls ^a Percent (N)
Familiarity with relay phone calls ^a		
Not familiar	35.4 (17) ^b	NA
A little familiar	14.6 (7) ^b	NA
Somewhat familiar	14.6 (7) ^b	NA
Familiar	20.8 (10) ^b	NA
Very familiar	14.6 (7) ^b	NA
Department training on how to serve Deaf/HH populations in an emergency		
Yes	52.0 (26) ^b	54.2 (26)
No	48.0 (24) ^b	45.8 (22)
KI attendance at other trainings on how to serve Deaf/HH populations in an emergency		
Yes	67.3 (33) ^b	68.0 (32)
No	32.7 (16) ^b	32.0 (15)
Are trainings ^c recurring or not recurring?		
Consistent recurring training	50.0 (15)	48.3 (14)
Non-consistent recurring training	50.0 (15)	51.7 (15)

^aRelay services use an operator to connect calls between hearing people using voice phones and Deaf people using video phones, Internet-based text relay services, or teletypewriters (TTYs).

Deaf/HH = Deaf and hard of hearing

NA = not applicable

KI = key informant

^bStatistically significant at p<0.05

^cTrainings refer to both department training and any other training.

Table 2. State preparedness key informant interview responses to a survey assessing services provided to those with disabilities: U.S., 49 states, 2009–2010

Question	Proportion ^a of state population that is Deaf/HH Percent (p-value)	Proportion ^a of state population that has a disability Percent (p-value)	State has a Commission for the Deaf Percent ^b (p-value)
On a scale of 1–5, with 1 being not at all familiar and 5 being very familiar, how familiar would you say you are with communication issues faced by Deaf/HH populations? (n=50)	2–6 (0.033)°	9–21 (0.064)	34 (0.37)
Do local governments in your state provide any disability services to Deaf/HH populations for emergency preparedness or during emergencies or disasters? (n=48)	2–6 (0.003) ^d	9–21 (0.047) ^c	27 (0.523)
Do local governments in your state provide any disability services to other vulnerable populations for emergency preparedness or during emergencies? (n=49)	2–6 (0.008) ^d	9–21 (0.099)°	27 (0.762)
Does your state anticipate adding any new information on preparedness communications for the Deaf/HH to the emergency operations plan? $(n=49)$	2–6 (0.842)	9–21 (0.968)	27 (0.034) ^c
Has your state sought advice or input from any of your partnering organizations regarding information for the Deaf/HH? $(n=38)$	2–6 (0.048)°	9–21 (0.042) ^c	32 (0.201)

^aState population information varied among the 49 states that participated. Proportion of state population that is Deaf/HH varied from 2% to 6%. Proportion of state population that has a disability varied from 9% to 21%. Data culled from 2000 U.S. Census: Census Bureau (US). Census 2000 [cited 2008 May 6]. Available from: URL: http://www.census.gov/main/www/cen2000.html

Deaf/HH = Deaf and hard of hearing

training could help fill this gap. 14 KIs reported that training is available to state and territorial emergency management and public health personnel. Our findings suggest that training specific to serving Deaf/HH populations in disasters is needed for most state- and territorial-level planners and possibly for many first responders.

Although our study showed improvements in state/territorial planning compared with the 2006 review, recent reports illustrate continuing gaps in communication access and a continuing lack of understanding of the needs of Deaf/HH populations during local disasters. A 2008 California Wildfires After-Action Report¹⁵ gives examples of gaps and barriers in current response systems and how the lack of accessible communication during that emergency impacted the well-being of individuals who need accessible communication. In 2008, the Federal Communications Commission also upheld a fine against a San Diego, California, television station for failure to provide adequate visual warning to hearing-impaired viewers during the San Diego wildfires in October 2003.¹⁶ These types of

failures in capacity and communication continue to have a negative impact on the resilience of Deaf/HH communities. They also suggest that state/territorial emergency preparedness planning needs to translate into direct and specific local action.

Strengths and limitations

Strengths of the study included gathering the maximum number of basic EOPs (after our intensive follow-up efforts, only one state and three territories failed to provide an EOP). Similarly, we had a very good response rate (84.7%) to our KI survey with state- and territorial-level emergency management or public health preparedness officials. We also collected and examined a number of EOP annexes but found no significant content related to Deaf/HH populations in any of those examined.

Another major strength of this study was that stakeholders in the Deaf/HH community were active participants in advising on the study design and interpreting the results. Deaf community leaders brought unique expertise and experiences in the use of advanced

^bPercentage is calculated based on the number of state preparedness interviewees who were from states with a state Commission for the Deaf.

^cStatistically significant at p<0.05

dStatistically significant at p<0.01

technological tools for facilitating emergency communication with the Deaf community, such as relay services, videophones, and e911. Deaf communities have very different styles of cultural discourse, including the use of ASL as a visual language. As a consequence, Deaf stakeholder input was essential in this project. It was particularly important in understanding and addressing the technological and cultural complexity of the communication needs of Deaf/HH populations. It also helped researchers and staff to understand the need for specific first-responder training and other training that is culturally and functionally relevant to serve this population. Through partnerships and CBPR methods, we were able to develop assessments of access and inclusion that reflected the perspectives and practices of the Deaf community. This enrichment to the research process also yielded important new partnerships and models for collaboration with Deaf/ HH communities.

The study was also subject to several limitations. One barrier to success in research activities included recruitment issues and mistrust from some state- and territorial-level employees who worried about comparing unfavorably with other states. To build trust, KIs were given assurance that all responses would be confidential and would only be reported in aggregate.

Another limitation was that we included only 50 states, DC, and the eight territories recognized by the Centers for Disease Control and Prevention (CDC) (i.e., those with whom CDC has a cooperative agreement). Accordingly, the sample size limited analytic methods to descriptive statistics and bivariate associations that can help generate hypotheses but do not allow for more sophisticated inferential statistical analyses. Our funding also limited the number of KIs we could conduct. We drew about half of the KIs from emergency management entities and half from public health agency personnel charged with preparedness activities. We would have preferred to interview people from each type of agency in every state and territory as well as people from various organizational levels to gather more detailed findings.

CONCLUSIONS

Further research is needed about emergency preparedness for Deaf/HH populations. As noted previously, findings related to state- and territorial-level organizations do not necessarily generalize to local emergency preparedness agencies. For example, the 2006 DHS analysis included interviews with city- and state-level individuals and found that local capacity to serve vulnerable populations was also low (4%).³ Our study

provides updated information about capacity, training, and planning at state levels.

Preparedness research should include the involvement of Deaf/HH participants to examine not only the needs of this population, but also their capacity and resilience during emergency situations. This approach would draw on the unique abilities of Deaf/HH communities, including their rapid uptake of new technologies (e.g., texting, smartphones, and video communications). Better adoption of those technologies might help all populations, particularly low-literacy populations that require more communication options.

Our research study identified critical preparedness gaps in planning for Deaf/HH Americans by stateand territorial-level agencies that write EOPs and/or in state- and territorial-level emergency preparedness training. While the results of this assessment indicate that some of the recommendations in the 2006 DHS report have since been incorporated, planning for the needs of the Deaf/HH community is still far from adequate. Our project's participatory approach used a NAB as a routine part of the research process and developed tools to guide future research on the design of trainings and the development of better communication strategies. For example, we engaged Deaf individuals and ASL interpreters in the development and implementation of new trainings, and we supported the work of states and counties to include important communication considerations about ASL and captioning as they update their EOPs. This project provides another example of the value of CBPR, a vital approach for increasing the reach, effectiveness, and relevance of preparedness and emergency response research.

Three groups can potentially benefit from the findings of this research: (1) state- and territorial-level emergency management or public health personnel can benefit from training to address the identified gaps in readiness to serve Deaf/HH populations; (2) Deaf/HH communities may gain by contributing to training and by participating in preparedness activities, thus improving the cultural competence of state personnel, the effectiveness of EOPs and emergency services, and the resilience in the population itself; and (3) the general population may gain from better planning for vulnerable populations and improved communication capacity during disasters for all community residents.

All protocols were reviewed by the Institutional Review Board at the University of California, Berkeley, (Office for Protection of Human Subjects) and found to be exempt.

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