

Preparing for and Responding to Pandemic Influenza: Implications for People With Disabilities

State, local, tribal, and territorial emergency managers and public health officials must address the specific needs of people with disabilities in their pandemic influenza plans. Evidence from Hurricane Katrina indicated that this population was disproportionately affected by the storm and aftermath.

People with disabilities, particularly those who require personal assistance and those who reside in congregate care facilities, may be at increased risk during an influenza pandemic because of disrupted care or the introduction of the virus by their caregivers. Emergency and public health planners must ensure that personal assistance agencies and congregate care operators make provisions for backup staffing and that those who provide critical care are given adequate antiviral drugs and vaccines as they become available. (*Am J Public Health*. 2009; 99:S294–S300. doi:10.2105/AJPH.2009.162677)

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PRIOR TO¹⁻⁴ AND SINCE^{5,6} THE events of September 11, 2001, the disability and emergency preparedness communities have demonstrated increasing awareness that the specific needs of people with disabilities are inadequately addressed by emergency planning and response systems. In 2005, concerns further increased during and in the aftermath of Hurricanes Katrina and Rita. People with disabilities experienced inadequate evacuation and shelter, disrupted services, separation from family members and caregivers, and death as a result of poor planning, inadequate risk communication (i.e., instructions on preparing for an emergency, what steps to take should one occur, etc.), and slow response.⁷⁻¹¹ After Hurricane Katrina, more than 38% of the shelter residents in Houston, Texas, who had not evacuated New Orleans, Louisiana, before the storm reported that they stayed because they or someone they were caring for was physically unable to leave.¹¹

Beyond the threat presented to the general population, pandemic influenza poses a substantial risk to people with disability because of (1) a lack of epidemiological data on which to base preparedness plans and evaluate responses; (2) a lack of detailed emergency preparedness plans at all governmental levels with regard to people with disabilities; (3) disability-related factors that increase risk for exposure, complications, and death from pandemic influenza; (4) inaccessibility of risk

communication; and (5) ethical issues surrounding priority vaccination and treatments that affect the disability community.

We identify the potential needs of persons with disabilities during an influenza pandemic. For each of the challenges, we discuss the status of pandemic influenza planning and present recommendations. We also discuss legislation and regulatory guidelines that promote accessibility of government and private sector services and facilities for people with disabilities.

PEOPLE WITH DISABILITIES

The World Health Organization (WHO) defines disability as

an umbrella term for impairments, activity limitations, and participation restrictions; it denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal).^{12(p213)}

Disability can result from congenital or developmental conditions, injury, or chronic disease, and it can be manifested in limitations in cognition, mobility, vision, hearing, self-direction, activities of daily living (e.g., bathing, grooming, feeding), or independent activities of daily living (e.g., using a telephone, managing money). Disability ranges from mild to severe and can be associated with a need for partial or total assistance with the performance of personal care activities such as

bathing, dining, and toileting. The functional impact of disability can be mitigated through environmental accommodations (e.g., curb cuts, ramps, elevators) and supports or the elimination of environmental barriers.

Disability prevalence varies depending on the survey used, questions asked, and ages covered. Estimates from the 2002 Survey of Income and Program Participation place the figure at 51.2 million, or 18.1% of the of the US noninstitutionalized population (Table 1).¹³ A substantial proportion of survey participants comprising the noninstitutionalized population of the United States reported that they had a severe disability (11.5%) or needed assistance with bathing, dressing, eating, or toileting (3.8%). Consistent with these estimates, the 2006 American Community Survey indicated that 3.0% of the US noninstitutionalized population aged 5 years and older—that is, nearly 8.3 million people—have a self-care disability.¹⁴

The prevalence of disability varies by race/ethnicity,¹⁵ age, gender, income, education,¹³ and location.¹⁶ Disability is more prevalent among African Americans and Native Americans and less prevalent among Asian/Pacific Islanders and Hispanics than among Whites.¹⁵ The proportion of people who live below the poverty level is almost twice as high among people with disabilities (21.5%) as among people without disabilities (11.3%).¹⁷

TABLE 1—Prevalence of Disability and the Need of Assistance, by Age: United States, 2002

Age Group, y	Total Estimated Population	Estimated Population With Any Disability (%)	Estimated Population With Severe Disability (%)	Estimated Population Needing Assistance (%)
All ages	282 831	51 235 (18.1)	32 532 (11.5)	10 746 (3.8)
< 15	60 605	5 111 (8.4)	2 044 (3.4)	179 (0.3)
15-24	39 453	4 128 (10.5)	1 911 (4.8)	479 (1.2)
25-44	82 914	9 230 (11.1)	6 023 (7.3)	1 659 (2.0)
45-54	39 740	7 705 (19.4)	5 021 (12.6)	1 506 (3.8)
55-64	26 377	7 415 (28.1)	5 090 (19.3)	1 421 (5.4)
65-74	17 956	7 617 (42.4)	4 954 (27.6)	1 779 (9.9)
≥ 75	15 786	10 029 (63.5)	7 489 (47.4)	3 723 (23.6)

Note. Population estimates are in thousands.
Source. Adapted from Steinmetz.¹³

In an emergency event such as pandemic influenza, environmental factors would include support services that must be continued to prevent or mitigate disease and to prevent mortality. We do not address specific health conditions that may be associated with disability, such as diabetes, or the potential drug interactions of antiviral medications and vaccines with treatments for conditions underlying the disability.

PANDEMIC INFLUENZA AND PEOPLE WITH DISABILITIES

There are little if any population-based data on the experiences of people with disabilities during emergency situations;⁷ in addition, there are sparse data on the impact of seasonal influenza¹⁸ and no data on the impact of previous influenza pandemics on this population.^{19,20} Public health infectious disease—tracking and surveillance systems such as the Emerging Infections Program, the Pediatric Influenza Associated Mortality System, the National Immunization Survey, the New Vaccine Surveillance Network, and state and territorial epidemiologists’ reports do not identify

people with disabilities in any systematic fashion. Without the capacity to identify people with disabilities in emergency management surveillance systems, these populations may be overlooked when interventions are planned and evaluated.

Although a higher percentage of people with disabilities (36.5%) report getting annual immunizations for seasonal influenza than do people without disabilities (32.2%),^{21,22} nearly two thirds of this population does not receive these immunizations. Low vaccination rates against seasonal influenza may result from personal beliefs and misconceptions, a lack of serious concern about influenza, or a lack of influenza prevention programs in schools, colleges, workplaces, community-based organizations, and primary care settings. The data indicate that like the general public, people with disabilities are ill prepared for a seasonal influenza pandemic.

Inadequacy of Preparedness Planning

In addition to the inability of surveillance systems to determine the impact of emergencies on people with disabilities, planning

and response systems are deficient in other areas related to disability. The US Department of Homeland Security (DHS), in concert with the US Department of Transportation, conducted a review of emergency plans across the nation and found major fragmentation, inconsistencies, and critical gaps regarding populations with disabilities.²³ Few plans or guidelines provide details about how emergency planners can meet the needs of people with disabilities before, during, and after an emergency. Current plans tend to delegate critical responsibilities regarding disability to third parties or make scattered references to people with disabilities. These plans lack consistency of approach, depth, or evidence of safeguards and effective implementation. Additionally, most jurisdictions significantly underestimate the amount of advance planning and coordination that is required to effectively address the integration and accommodation of individuals with disabilities.

Increased Risk for Exposure and Service Disruption

To assess potential increased risk for exposure, complications,

and death as a result of an influenza pandemic, we examined factors that may increase risk of both seasonal and pandemic influenza. These risks are greatest among persons with severe disabilities who may rely routinely on assistance from others to perform basic activities of daily living and who may depend on support services for health and safety. Many of these individuals reside in institutional settings such as nursing homes or receive support services in their homes. Such persons would face substantial difficulties were these support services disrupted during an influenza pandemic.

Persons with disabilities who reside in congregate care facilities or group quarters may be at particular risk. The 2006 American Community Survey estimated that approximately 2.5 million people with disabilities live in institutional group quarters²⁴ and that approximately 97% of the more than 1.8 million individuals who reside in skilled or primary nursing facilities have a disability²⁵ (Table 2). The close proximity in which these individuals live increases the possibility of transmission of infection. Persons living in congregate care settings often rely on the assistance of staff for assistance with tasks of daily living. According to the Research and Training Center on Community Living at the University of Minnesota, in 2006, 173 large public facilities²⁸ served 38 305 individuals with intellectual or developmental disabilities.²⁹ More than half (59.8%) of these individuals required assistance in dressing, 52.2% needed assistance or supervision in dining, 53.7% could not communicate basic needs orally, and 52.7% required assistance or supervision in toileting. In 2006, direct patient care in these

TABLE 2—Number of People Residing in Group Quarters That Include People With Disabilities: United States

Type of Facility	No. of Residents
Nursing homes	
All residents	1 835 000 ^a
Residents with disability	1 785 000 ^a
Hospitals, residential schools for people with disabilities	234 000 ^b
Residential centers for emotionally disturbed children	13 000 ^c
Community-based congregate care settings for people with intellectual or developmental disabilities (no. of facilities = 57 188)	285 954 ^c
Residential facilities for individuals with intellectual or developmental disabilities (no. of facilities = 173)	38 305 ^d
Total (approximate)	2 400 000

Note. Except for “nursing homes, all residents,” all of the data are for people who have a disability.

^aData are from the US Census Bureau.²⁵

^bData are from the US Decennial Census.²⁶

^cData are from Alba et al.²⁷

^dData are from Alba et al.²⁸

facilities was provided by 414 physicians, 6599 nurses, and 45 861 direct support personnel.

In addition to large public residential facilities, small congregate care facilities such as group homes operated by state and nongovernmental agencies also house many people with intellectual and developmental disabilities. In 2006, an estimated 158 843 such facilities nationwide served 424 462 individuals.²⁷ (These estimates do not include individuals in community congregate care settings who have psychiatric disorders or are enrolled in residential services related to drug and alcohol problems.) During an influenza pandemic, individuals who provide needed support services may become ill and unable to work, be disinclined to come to work,^{30,31} or be vectors for infection. Gershon et al.³² noted that, in addition to the reluctance of some home health care workers to work in situations that could potentially expose them to infectious diseases such as pandemic

influenza and severe acute respiratory syndrome (SARS), a number of related professional groups expressed doubts about self-perceived competency and knowledge of emergency preparedness generally.

According to the 2000 US Census, nearly 29% of American families include at least one person with a disability.³³ Most individuals with intellectual and developmental disabilities live at home and receive assistance from family members. Assistive care is often provided in a supplemental manner or entirely under provisions of the US Medicaid Home and Community-Based Services program; in 2003, this program provided services to more than 2.5 million individuals in their homes.³⁴ Family caregivers for the 8.3 million people needing assistance with self-care¹⁷ are not currently identified as essential health workers who have priority for antiviral medication or vaccine.³⁵ Without access to antiviral medications and pandemic influenza

immunization, caregivers may be at increased risk for infection, which would reduce or eliminate their ability to provide care and increase the risk of infection among their care recipients. Despite risk of exposure to infection, caregivers and dependents of people with disabilities may typically feel they cannot or do not want to be separated from their care recipients during a disaster.²³ Planning for essential services for people with disabilities will be important because of the potential for disruption when and if caregivers cannot provide assistance or care for their family members.

In the event of pandemic influenza, the barriers to adequate preventive services that people with disabilities and their caregivers face under normal circumstances could further increase the risk of illness and adverse outcomes. These barriers include social isolation,³⁶ lower education and employment, and lower income.^{13,37} Inadequate knowledge and finances may be important barriers to obtaining prophylaxis (i.e., antiviral drugs and vaccines) for influenza. Independent transportation is also an important challenge for people with disabilities: 14% have no household vehicle, compared with 5.2% of the population without a disability (T. Sternberg, MSc, written communication, December 11, 2007).

INACCESSIBLE RISK COMMUNICATION

A major planning objective of pandemic influenza preparedness is to ensure an adequate system for risk communication, mobilization of communication resources and response, and disaster management.^{35,38–41} Risk communications during emergency events have been reported to be

inaccessible to people with disabilities. The Report on Special Needs Assessment for Katrina Evacuees, compiled after Hurricane Katrina, indicated that such communications in shelters were particularly lacking for individuals who were deaf or hard of hearing; more than 70% did not have access to American Sign Language translators, 80% did not have access to devices enabling individuals with hearing loss to communicate via telephone, and 60% did not have closed-captioned television.⁹ Although mass shelters and special needs shelters are not likely to be a response option during an influenza pandemic as they run counter to the social distancing practices (i.e., keeping people apart to avoid contagion) likely to be recommended,⁴² the findings related to sheltering following Hurricane Katrina highlight the importance of addressing the risk communication needs of various groups of people with disabilities. These needs relate to (1) receiving information about an outbreak of pandemic influenza, (2) planning for adequate supplies if social distancing is implemented, and (3) anticipating and arranging contingency plans for continuity of supports and services that may be disrupted by paid and unpaid caregivers' being ill or otherwise unable to work.

Evaluations of emergency operation plans have found that many do not adequately address the communication needs of people with disabilities.⁴³ Commonly used risk communication approaches that rely on auditory or visual messages may not be accessible to people who have hearing or vision loss, and message content may be difficult to understand for people with cognitive limitations or low literacy.^{44,45} Telephone messaging should be

augmented with text message notifications that are useful to individuals with hearing loss or deafness. Individuals with poor vision or blindness will require information in auditory formats or alternatives to standard print communications, such as large print and Braille. Accessible Web pages should use large, high-contrast fonts, little color, few illustrations, and file formats that can be read by screen readers.

The National Work Group on Literacy and Health noted in 1998 that 40 million to 44 million people in the United States do not understand materials that require only basic reading skills and recommended that materials should be written at the fifth-grade reading level and supplemented by nonwritten materials to be understood by populations with low-literacy.⁴⁴ In addition, nongovernmental social networks play a part in reaching community-based people with disabilities. Faith-based and community-based organizations may be useful partners in helping to communicate with people with disabilities during a pandemic or other emergency. Several of these groups assist congregations in welcoming people with disabilities. The Interfaith Disability Connection Web site provides various resources offered by denominations and faith groups.⁴⁶

REGULATIONS THAT ADDRESS THE NEEDS OF DISABLED PERSONS

Wide-ranging national legislation⁴⁷ since 1934 has promoted the elimination of barriers to communication,⁴⁸ housing,⁴⁹ and the built environment⁵⁰ and increased social participation through employment,⁵¹ education,⁵²

and protection against discrimination.⁵³ In addition, in response to the perceived impact of emergency events on people with disabilities, a growing number of health policy guidelines and legislative initiatives address the need to include vulnerable or at-risk populations in planning and response phases before, during, and after a disastrous event. In particular, the 2004 Individuals With Disabilities in Emergency Preparedness Executive Order 13347 established an interagency coordination committee to

ensure that the Federal Government appropriately supports safety and security for individuals with disabilities in situations involving disasters.⁵⁴

In an emergency event such as pandemic influenza, environmental factors would include support services that must be continued to prevent or mitigate disease and prevent mortality. More recently, the 2007 Pandemic and All Hazards Preparedness Act (PAHPA)⁵⁵ established Section 2814 of the Public Health Service Act, which requires the secretary of the US Department of Health and Human Services (HHS) to consider the needs of at-risk individuals in managing several preparedness programs, including the Strategic National Stockpile and preparedness grants to state departments. People with disabilities are not specifically cited as an at-risk population in the PAHPA; however, the HHS secretary has authority to include them under provisions of the legislation.

PRIORITY GROUPS, TRIAGE, AND ETHICAL ISSUES

Vaccines and antiviral drugs are the 2 most important medical

interventions for reducing morbidity and mortality during a pandemic, but they are and will be in short supply. Identification of the specific influenza strain resulting in a pandemic and preparation of a vaccine could take at least 6 months.⁵⁶ Allocation of antiviral drugs, such as oseltamivir, and of mechanical ventilators during an initial outbreak and vaccines following an initial outbreak pose important policy and ethical issues.

Various approaches to setting priorities for scarce resources in the event of an influenza pandemic have been proposed that would affect people older than 85 years and some populations with disabilities, including people with severe cognitive impairment, advanced and untreatable neuromuscular disease, and severe chronic disease.^{57,58} The WHO recommends that countries with sufficient resources invest in a stockpile of antiviral drugs for domestic use, particularly at the start of a pandemic, when mass vaccination is not an option and priority groups such as frontline workers need to be protected.⁵⁹ Guidance from HHS and DHS provides a framework for pandemic influenza planners at various governmental levels to allocate antiviral drugs and vaccines.^{41,60} This allocation process is intended ultimately to vaccinate everyone in the United States, but it gives priority to children and persons critical to the pandemic response and to the care of those infected—essential community service providers and those whose occupations put them at increased risk of infection.⁶¹ These guidelines reflect ethical considerations of fairness, equity, and reciprocity (i.e., putting a priority on the protection of individuals whose jobs relate to protecting the

public good and put them at increased risk for infection).

According to *Guidance on Allocating and Targeting Pandemic Influenza Vaccine*, drafted by the HHS in conjunction with DHS, the US government is taking steps to minimize the need to make vaccine allocation decisions by supporting efforts to increase domestic capacity for influenza vaccine production.⁶¹ Even so, according to the WHO, access to antiviral drugs and vaccines remains a major problem because of limited manufacturing capacity; fewer than 10 countries have domestic vaccine companies engaged in work on a pandemic vaccine. Regardless of vaccine production capability, a prioritization plan will have to be implemented at least in the short term, because the vaccine for the specific type of influenza that causes a pandemic cannot be produced until the pandemic occurs.⁵⁶

RECOMMENDATIONS AND RESOURCES

Numerous recommendations and guidelines have been put forward for emergency and public health planners, but they have not specified steps to include people with disabilities in their planning. Such action is needed, particularly at the local level, to ensure that service providers and administrators of congregate care facilities, for example, have contingency plans for staffing and continuity of supervision and services in the event of an influenza pandemic.

Following are recommendations to strengthen pandemic influenza planning and response that will reduce the risks posed to populations with disabilities. Table 3 provides links to Web sites with disability-related services (which

TABLE 3—State-Based Disability-Related Services and Information Resources

State Resource	Web Site
State and local independent living centers	http://www.wnyilp.org/database/directory.php http://www.ilru.org/html/publications/directory/index.html
Developmental disabilities planning councils	http://www.acf.hhs.gov/programs/add/states/ddcs.html
Developmental disabilities service directors	http://www.nasddd.org/MemberAgencies/index.shtml
State vocational rehabilitation directors	http://www.rehabnetwork.org/directors_contact.htm
State Medicaid waiver offices	http://www.pascenter.org/state_based_stats/index.php (click on "Contact Info and Descriptions for Medicaid Waivers")
State agencies that provide or support personal assistance services	http://www.pascenter.org (click on "Agencies Related to PAS" under State Background & Contact Information for Resources & Agencies Related to PAS and select relevant state)
State aging service agencies	http://www.nasua.org/about_nasua/sua_links.html
State agencies for individuals who are blind	http://www.ncsab.org/ncsab_directory.htm
State associations and agencies for individuals with hearing loss	http://www.nad.org/sadirectory http://clerccenter.gallaudet.edu/InfoToGo/501-2007.doc
National Organization on Disability interactive map of disability and emergency preparedness resources	http://www.nod.org/EPIResources/interactive_map.html
Disability Resource Center information on H1N1	http://disabilitypreparedness.gov
State-specific Medicaid waiver contact information	http://www.pascenter.org/state_based_stats/index.php (under "State Program Data")

can be of use in implementing these recommendations) and state-based resources for people with disabilities.

- Indicators of disability status are needed in all public health surveillance systems to assess the impact of public health threats and events on populations with disabilities so that effectiveness of planning and response can be assessed.

Healthy People 2010 emphasizes the need to include the means of identifying people with disabilities in public health surveillance activities.⁶²

- People with disabilities, their advocates, and service providers such as home health care agencies should be included in planning for pandemic influenza to inform emergency planners of the need for and resources to ensure adequate provisions for effective risk communication (including alternative messaging for people with hearing and vision loss and cognitive

limitations) and continuity of treatment and care.

- Personal assistance and home health service providers at the local level should be contacted by public health planners to ensure that contingency plans exist for continuity of these essential services should field staff become ill, need to care for their family members, or fail to report to work in the event of pandemic influenza.
- Surveillance is needed to identify people with disabilities in all emergency planning, including that conducted with regard to pandemic influenza. Questions that identify people with disabilities should be included routinely in all data collection related to pandemic influenza and preparedness activities.
- People with disabilities, their advocates, and caregivers should be involved in developing and evaluating the adequacy of planning and response.

- People with disabilities, their advocates, and caregivers should be involved in pandemic influenza planning drills and exercises.
- Specific contingency plans need to be developed to ensure continued staffing for in-home and personal assistance services and congregate care supervision and care.
- Specific guidance should be developed and disseminated to states, territories, localities, and tribes concerning the needs of people with disabilities and the importance of uninterrupted support and service.
- Alternative, accessible communications need to be developed for people with disabilities, particularly populations with deafness or hearing loss, low-literate individuals, people with cognitive limitations, and other hard-to-reach populations.
- Faith-based and community-based organizations may be useful partners in helping to communicate with people with

disabilities during a pandemic or other emergency, as several of these groups assist their congregations in welcoming people with disabilities.

- National pandemic influenza program managers need to continue to evaluate and provide detailed feedback to state, territorial, local, and tribal emergency planners on performance with regard to their preparations for all at-risk populations.

In summary, people with disabilities, particularly those who reside in congregate residential facilities such as nursing homes and those who rely on provision of services in their homes, may be at increased risk during an influenza pandemic. Increased risk may result from closely proximate living arrangements and staffing disruptions that could interfere with the delivery of essential services. Health communications need to be provided in alternative formats to address the informational needs of individuals

with limited vision, hearing, and cognition. Public health planning for pandemic influenza needs to include the involvement of people with disabilities to ensure that plans adequately anticipate and address these needs to minimize preventable exposure, communicate risks effectively, and ensure continuity of essential services. ■

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Contributors

V.A. Campbell developed the concept and organization of the essay, supervised its overall preparation, and did most of the writing. J.A. Gilyard provided critical comment and participated in the writing and editing of the essay. L. Sinclair managed the references, participated in the writing, and provided material on policy implications of pandemic influenza planning. T. Sternberg was responsible for identifying data and conducting analyses for population estimates. J.I. Kailes provided critical comment from a disability advocacy perspective and participated in the writing and editing of the essay.

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