Report of the Interagency Workgroup on Pandemic Influenza and At-Risk Individuals

Prepared by the Interagency Workgroup on Pandemic Influenza and At-Risk Individuals of the Federal Interagency Committee on Pandemic Influenza Health Care Steering Committee Workgroup

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I. PURPOSE AND SCOPE

This report is an introduction to planning for at-risk individuals during pandemic influenza. Limited explicit information is available to prepare emergency planners, public health agencies, and human services providers for the impact that pandemic influenza will have on the medical, behavioral health, and human services networks that provide needed functional support for at-risk individuals.

Using the functional definition of at-risk (special needs) individuals in the National Response Framework (NRF); at-risk individuals may constitute as much as 62% of the U.S. population. Historically, these individuals have not been well integrated into the emergency planning process and their needs and concerns have only recently begun to be more comprehensively addressed in State and local emergency planning.

The U.S. Department of Health and Human Services (HHS) Interagency Workgroup on At-Risk Individuals and Pandemic Influenza was tasked to make recommendations for integrating the needs and concerns of at-risk individuals into pandemic influenza emergency planning. This report presents these recommendations. It is intended as a resource for service providers and emergency planners.

The report serves as an introduction to planning for at-risk individuals during pandemic influenza. It begins with a review of the needs and concerns of at-risk individuals, moves to key concepts and planning assumptions, and provides specific recommendations and resources for integration of at-risk individual needs into Federal, State, and local pandemic influenza response plans.
II. INTRODUCTION AND BACKGROUND

In June 2007, the Federal Interagency Committee on Pandemic Influenza Health Care Steering Committee and the Workgroup updating the HHS Pandemic Influenza Plan requested that the Office of the Assistant Secretary for Preparedness and Response (ASPR) Office for At-Risk Individuals, Behavioral Health, and Human Services Coordination (ABC) provide recommendations for future efforts to include the needs and concerns of at-risk individuals in pandemic influenza planning. To develop recommendations, ABC convened an Interagency Workgroup on Pandemic Influenza and At-Risk Individuals (referenced hereafter as the Workgroup). Federal agency invitees included Department of Homeland Security (DHS) Federal Emergency Management Agency (FEMA), US Department of Veterans Affairs (VA), and HHS Operating and Staff Divisions responsible for programs, policy recommendations, or research regarding at-risk individuals. This report presents the Workgroup’s recommendations.

To inform their recommendations, the Workgroup identified best practices and on-going efforts to include at-risk individuals in pandemic influenza planning. The Workgroup also recognized that knowledge and experience with at-risk individuals and pandemic influenza was available from the perspectives of subject matter experts and stakeholders such as State, local, and non-governmental planners; at-risk advocacy organization representatives; and professionals in disciplines that address at-risk population needs. In order to benefit from the valuable perspectives of these experts and stakeholders, listening sessions were conducted to gather feedback and additional information.

A. Defining At-Risk Individuals

HHS has developed a working definition of at-risk individuals that is function-based and designed to be harmonious with the DHS NRF definition of special needs and the Pandemic and All-Hazards Preparedness Act (PAHPA). This HHS working definition is as follows:

Before, during, and after an incident, at-risk individuals may have additional needs in one or more of the following functional areas:

• Maintaining Independence
• Communication
• Transportation
• Supervision
• Medical Care

In addition to those individuals specifically recognized as at-risk in PAHPA (i.e., children, senior citizens, and pregnant women), individuals who may need additional response assistance should include those who have disabilities, live in institutionalized settings, are from diverse cultures, have limited English proficiency or are non-English speaking, are transportation disadvantaged, have chronic medical disorders, and have pharmacological dependency.

This approach to defining at-risk individuals establishes a flexible framework that addresses a broad set of common function-based needs irrespective of specific diagnoses, statuses, or
labels (e.g., those with HIV, children, the elderly, etc.). These functional needs of at-risk individuals are ones that may exist across segments of the population. Specifically:

- **Maintaining Independence:** Individuals in need of support that enables them to be independent in daily activities may lose this support during the course of an emergency or a disaster situation.

- **Communication:** Individuals who have limitations that interfere with the receipt of and response to information will need such information provided in methods they can understand and use.

- **Transportation:** Individuals who cannot drive due to the presence of a disability or who do not have adequate transportation will require transportation support for successful evacuation.

- **Supervision:** Before, during, and after an emergency or a disaster, individuals may lose the support of caregivers, family, or friends and be unable to cope in a new environment. Individuals who may require supervision to make decisions affecting their welfare include unaccompanied children as well as people with dementia, Alzheimer’s, severe cognitive limitations, or psychiatric conditions.

- **Medical Care:** Individuals who require the support of trained medical professionals. These individuals may be separated from support systems used to manage medical care.

In simple terms, at-risk individuals are those who have—in addition to their medical needs—other needs that may interfere with their ability to access or receive medical care.

**B. Historical Overview of Pandemics of the 20th Century**

The history of pandemic in the 20th century illustrates how the rapid spread, significant mortality, and subsequent waves of illness of a pandemic cause far greater damage and human suffering than typical, more limited occurrences of influenza. Twentieth century influenza pandemics span 1918 to 1968 (the date of the last significant incident of influenza pandemic). It is important to note that Great Pandemic which occurred in 1918-1919 was not the only influenza pandemic of the twentieth century. Influenza returned in a pandemic form in 1957-1958 and, again, in 1968-1969. These two later pandemics were much less severe than the 1918-1919 pandemic. Estimated deaths within the United States for these two later pandemics were 70,000 excess deaths (1958) and 33,000 excess deaths (1968). At-risks group, in general, should be expected to be more susceptible to pandemic influenza, may have functional barriers to receiving timely and effective treatment, and are likely to suffer disproportionately from the impact of an influenza pandemic.

**1918: Spanish Flu**

The Spanish Influenza pandemic is the catastrophe against which all modern pandemics are measured. It is estimated that approximately 20 to 40 percent of the worldwide population became ill and that over 50 million people died. Many people died from this very quickly and survivors of the first few days often died of complications from the influenza (such as

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1 Adapted from http://www.pandemicflu.gov/general/historicaloverview.html and http://1918.pandemicflu.gov/the_pandemic/04.htm
pneumonia) caused by bacteria. Mortality rates were high among healthy adults in addition to groups typically more vulnerable to influenza (e.g. young children and the elderly). The attack rate and mortality was highest among adults 20 to 50 years old. The severity of this virus has not been seen again.

**1957: Asian Flu**

In February 1957, the Asian influenza pandemic was first identified in the Far East. In preparation, vaccine production began in late May 1957, and health officials increased surveillance for influenza. Unlike the virus that caused the 1918 pandemic, the 1957 pandemic virus was quickly identified, due to advances in scientific technology. A vaccine was available in limited supply by August 1957. Infection rates were highest among school children, young adults, and pregnant women, including influenza-and pneumonia-related deaths. During January and February 1958, there was another wave of illness among the elderly. This is an example of the potential “second wave” of infections that can develop during a pandemic. Although the Asian influenza pandemic was not as devastating as the Spanish influenza, about 69,800 people in the U.S. died.

**1968: Hong Kong Flu**

In early 1968, the Hong Kong influenza pandemic was first detected in Hong Kong. The first cases in the U.S. were detected as early as September of that year, but illness did not become widespread in the U.S. until December. The same virus returned in 1970 and 1972. The number of deaths for this pandemic was 33,800, making it the mildest pandemic in the 20th century. A significant number of deaths occurred among the elderly. There could be several reasons why fewer people in the U.S. died due to this virus. First, the Hong Kong influenza virus was similar in some ways to the Asian influenza virus that circulated between 1957 and 1968. Earlier infections by the Asian influenza virus might have provided some immunity against the Hong Kong influenza virus. Second, this pandemic did not gain momentum until near the school holidays in December. Since children were at home and did not infect one another at school, the rate of influenza illness among schoolchildren and their families declined. Third, improved medical care and antibiotics that are more effective for secondary bacterial infections were available for those who became ill.

This brief history of influenza pandemics is also a history of public health preparedness. The spread of the influenza, the number of people infected, and the number of deaths has decreased with each episode in relationship to the increase in preparedness planning. Building on lessons learned from the disease (surveillance, tracking, containment, and the rapid development of vaccines), cross-cutting coordination, and advanced planning can quickly move mainstream citizens toward recovery and resilience. Those same lessons learned can be applied to efficiently assist at-risk individuals during an influenza pandemic.

**C. Overview of the Phases of Pandemic Influenza**

The following chart is taken from the World Health Organization (WHO) and depicts the six phases of pandemic influenza, which are categorized further into three periods: inter-pandemic, pandemic alert, and pandemic. This chart shows the overarching public health goals that correspond with each phase. In the discussion of pandemic influenza and at-risk
individuals in this report, we will reference risks and planning actions in accordance with each of the three pandemic periods.

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<tr>
<th>NEW PHASES</th>
<th>OVERARCHING PUBLIC HEALTH GOALS</th>
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<tr>
<td><strong>Interpandemic period</strong></td>
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<td><strong>Phase 1.</strong> No new influenza virus subtypes have been detected in humans. An influenza virus subtype that has caused human infection may be present in animals. If present in animals, the risk of human infection or disease is considered to be low.</td>
<td>Strengthen influenza pandemic preparedness at the global, regional, national and subnational levels.</td>
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<td><strong>Phase 2.</strong> No new influenza virus subtypes have been detected in humans. However, a circulating animal influenza virus subtype poses a substantial risk of human disease.</td>
<td>Minimize the risk of transmission to humans; detect and report such transmission rapidly if it occurs.</td>
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<td><strong>Pandemic alert period</strong></td>
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<td><strong>Phase 3.</strong> Human infection(s) with a new subtype, but no human-to-human spread, or at most rare instances of spread to a close contact.</td>
<td>Ensure rapid characterization of the new virus subtype and early detection, notification and response to additional cases.</td>
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<td><strong>Phase 4.</strong> Small cluster(s) with limited human-to-human transmission but spread is highly localized, suggesting that the virus is not well adapted to humans.</td>
<td>Contain the new virus within limited foci or delay spread to gain time to implement preparedness measures, including vaccine development.</td>
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<tr>
<td><strong>Phase 5.</strong> Larger cluster(s) but human-to-human spread still localized, suggesting that the virus is becoming increasingly better adapted to humans, but may not yet be fully transmissible (substantial pandemic risk).</td>
<td>Maximize efforts to contain or delay spread, to possibly avert a pandemic, and to gain time to implement pandemic response measures.</td>
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<tr>
<td><strong>Pandemic period</strong></td>
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<tr>
<td><strong>Phase 6.</strong> Pandemic: increased and sustained transmission in general population.</td>
<td>Minimize the impact of the pandemic.</td>
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D. Human Impact of Pandemic Influenza

Descriptions of social and economic interruptions, alternative public health clinics, and the general activities involved in social distancing related to non-pharmaceutical interventions in an influenza pandemic abound. The considerations that have received less attention are those describing the human impact, which may be heightened for at-risk populations:

- The effects of disaster and emergencies can place a great deal of stress on the coping skills of even the healthiest people—survivors, family members of victims, emergency responders, community leaders, and public officials.
- In a large-scale public health emergency, both the emergency and the response process itself can foster confusion, destabilizing both survivors and responders.

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• The medical stability, survival, and dignity of people with pre-existing illnesses and disabilities may be jeopardized when emergency conditions disrupt their patterns of care.

• The fear that can take place in some emergencies can create isolation and dismantle the sense of community that is essential to mental health and resiliency.

• The level of skill; sensitivity; respect; and disability, cultural, and linguistic competence with which public information about the crisis is conveyed can have a significant effect on the impact of the situation on the cohesiveness of the community.

• A number of factors play a significant role in mitigating the effects of disasters and other public health threats and emergencies, including:
  o Planning, preparedness, and response efforts designed to promote community resiliency and unity;
  o Normalization of disaster-related stress reactions and the presentation of programs and services in non-labeling, non-stigmatizing terms;
  o Disaster mental health intervention models such as the Crisis Counseling Assistance and Training Program (CCP) model supported by FEMA and SAMHSA and Psychological First Aid; and
  o Well planned and coordinated responses to the special needs of individuals with mental health or substance abuse disorders, disabilities (including visual and hearing impairment), age-related challenges, and language or cultural barriers.

From the perspective of Federal, State, and local agencies serving the public, the following features of an influenza pandemic emergency require special attention:

• The potential for a wider geographic area to be affected compared with the more localized operational disruptions that occur with hurricanes, earthquakes, and fire.

• The potential for greater periods of disruption, since influenza pandemics are generally of longer duration and can come in waves, rising and declining until they are contained.

• The potential unavailability of a significant proportion of the workforce and related human resource issues.

• The need for interagency planning and coordination among agencies not usually involved with emergency planning for natural disasters.

• The need to develop alternative strategies (e.g. social distancing approaches) to minimize direct staff contact with the public to carry out medical and social service day-to-day operations.

E. Critical Domains for At-Risk Individuals during Pandemic Influenza

Through resource review and special listening sessions with at-risk stakeholders, the Workgroup identified four domains critical to pandemic influenza planning and response for at-risk individuals. These domains—Outreach and Communication, Health Care Service
Delivery, Human Services Delivery, and Resources and Training—are also essential elements in general population planning and response, but take on even greater importance in relation to the distinct needs of at-risk individuals.

**Outreach and Communication**
Comprehensive public communications are essential before, during, and after pandemic influenza to ensure that people understand the situation and safety directives, as well how to access services. At-risk individuals may have limitations that interfere with the receipt of and response to information and will need information provided in ways that they can understand and use. For example, such individuals may not understand how to obtain assistance because of hearing, vision, speech, cognitive limitations or limited proficiency in the English language.

Information from responses to past disasters, such as the 2003 California wildfires and Hurricane Katrina in 2005, highlight the importance of including targeted outreach and communications mechanisms for at-risk populations in readiness plans. During these disasters a substantial number of at-risk individuals did not receive appropriate communications and warnings which may have contributed to increased injuries and deaths.

**Health Care Service Delivery**
In the event of an influenza pandemic, at-risk populations may experience different and additional barriers to accessing the health care system than will the general public. These populations often have limited access to the health care system in ordinary times. In a mass casualty event, such as an influenza pandemic, their ability to obtain necessary health care will most likely be further compromised. Additionally, at-risk populations may experience the effects of an influenza pandemic more severely than the general public due to vulnerable health status or limited ability to adhere to infection control practices.

Planning for pandemic influenza often occurs within State and local public health agencies as well as the formal health care network. At-risk populations may be disenfranchised from their communities and may not have strong ties to the formal health care system due to access constraints. For these reasons, issues pertaining to at-risk populations are often overlooked during pandemic influenza planning, thereby weakening the potential for effectiveness of plans due to unforeseen implications. Oversight or exclusion of the needs of at-risk populations is also an issue of overall public health preparedness as these populations account for a significant proportion of the nation’s populace.

**Human Services Delivery**
Pandemic influenza threatens to disrupt the essential services that human services organizations provide on a daily basis. Human services promote the economic and social well-being of families, children, individuals, and communities. These services function as a safety-net for people and communities with limited personal or economic resources through providing immediate, short term, and primary assistance. Human services support people who are likely to suffer disproportionately from the impact of an influenza pandemic. If an influenza pandemic curtails the delivery of home-based and community services to these
individuals—they will be at serious risk of adverse health consequences or hospitalization, regardless of whether they contract the influenza or not.

**Resources and Training**

All citizens need a basic level of training to respond in an emergency and a sound community infrastructure to support these efforts. The general population, professionals and responders, caregivers, and at-risk individuals themselves all require training so that they know how to react and utilize the resources available to them during an emergency. Individual preparedness coupled with the ability of public and private sector organizations to work together to establish a firm community preparedness and response strategy is the best defense against an influenza pandemic.

These are only several of the unique issues that at-risk individuals will face during pandemic influenza. The next section of this document will describe the methodology that was used to develop this paper and will elaborate on the issues that matured into the four major topic areas and findings of this report: Outreach and Communication, Health Care Services Delivery, Human Services Delivery, and Resources and Training.
F. The Listening Sessions

A special Workgroup session and two listening sessions were conducted to gather feedback and additional information from at-risk stakeholders and subject matter experts. To contextualize the discussion it was assumed that in the event of pandemic influenza, schools and medical and social day care facilities will close, homecare services will be more limited, and hospitals will become overwhelmed. Furthermore, many State and local emergency preparedness pandemic influenza plans have already been developed but will need to be reviewed for inclusion of at-risk populations.

**Listening Session Objectives**

- Identify what work is being done in the area of pandemic influenza planning for at-risk populations.
- Identify the key issues related to providing continuing medical and social services in a pandemic influenza event.
- Identify the most critical challenges and barriers in pandemic influenza planning for at-risk individuals
- Determine the guiding principles (e.g., to reach at-risk populations to prepare for an event, levels of medical and social service care).
- Discuss the key information gaps (what further work needs to be done) and specific needs (required tools, resources, action plans) associated with identified issues.
- Provide suggestions about the relative roles of different levels of government (State, local and Federal) and the private sector.
- Suggest future actions (e.g., where do we go from here, next steps).

**Issues for Consideration**

- What do planners need to know to develop a plan that addresses outreach and public messaging for at-risk populations?
- When thinking of all the different aspects of emergency planning, what factors are the most important in addressing the concerns of at-risk populations in a pandemic influenza plan?
- Based on your experience, which of the issues above are highest priorities in emergency planning?

**Summary of Listening Sessions**

The Workgroup session and the two listening sessions identified similar key considerations, outreach and communication approaches, and public messaging practices. Three important themes emerged from deliberations in all three groups. First, outreach and communication with isolated at-risk individuals and groups—conveyed by trusted leaders of these constituencies—is essential to meet at-risk group needs and concerns and ensure they are represented at planning tables. Second, public messaging, in formats and languages understood by at-risk individuals is critical to the success of the emergency response. And third, all-hazards planning should include mechanisms to educate all citizens in personal emergency preparedness to strengthen individual and community resiliency.
1. Outreach and Communication
   • Use trusted leaders within at-risk groups to convey important messages to at-risk groups and to represent their constituencies at planning forums.
   • Direct at-risk individuals and groups to effective resources, such as PandemicFlu.gov, to provide education on all levels (Federal, State, local, family, individual) of preparedness.
   • In addition to at-risk leaders, include community service providers and at-risk individuals themselves in planning efforts.

2. Public Messaging
   • Phrase messages in a manner that reflects the culture being addressed.
   • Always use alternate and redundant methods of communication.
   • Ensure that visual communication methods look like the population addressed.
   • Emphasize the role of the radio over print media or the internet.

3. All-hazards Planning
   • Prepare people at the local level for emergencies to minimize panic.
   • Share State and local plans that have effective at-risk group content to promote best practices.
   • Address the needs of children during pandemic influenza, but also their role in prevention and progression of the pandemic.
   • Take an all-hazards approach to planning.
   • Disseminate plans and information to often-isolated at-risk populations, as well as the public.

Other Key Findings and Comments from the Listening Sessions
The listening sessions produced many additional insightful comments and recommendations for improvements. Some highlights are listed below.
   • Service animals should remain with the person in shelters and during evacuation, and persons with disability should ensure they have a disaster supply kit of animal food and supplies as well as items for their own use.
   • Many at-risk individuals are also in poverty and will not be able to buy needed emergency supplies.
   • Local emergency managers must be trained about the needs and locations of at-risk individuals in their communities; likewise stakeholders and leaders in the at-risk community must be educated about emergency preparedness and response.
   • Health Insurance Portability and Accountability Act (HIPAA) regulations regarding sharing of information in emergency need to be clarified to care providers and emergency managers.
   • Voluntary lists of at-risk individuals can be a useful tool to quickly locate these individuals and plan services; however, it must be understood that not all at-risk persons will be on these lists.
Recovery efforts for at-risk individuals should focus on restoring daily functioning.

In some States tourists should also be considered at risk as they have functional deficits regarding transportation and housing.

As at-risk populations are not a homogenous group a variety of partners should be included in the planning and response stage including disability advocacy and service provider organizations; State and local mental health, substance abuse, and social service agencies; trusted leaders of at-risk communities; faith-based and volunteer groups; nursing homes, elder services providers, and elder living complexes; schools and school nurses; home health providers; Head Start; Meals on Wheels; cultural groups and media outlets.

Develop communication material relevant to specific at-risk populations that includes their specific medical situation.

Ensure materials are developed in multiple formats, in multiple languages, and employ multiple and accessible distribution mechanisms.

Tirelessly communicate the urgent need for personal and community preparedness to at-risk members of the public, and the need for participation in planning with local emergency managers to at-risk stakeholders and provider organizations.

In all communications use clear, simple language and ensure that any images of people represent the communities being communicated with.

Develop special outreach activities targeting schools and other organizations that provide services for children.

Don’t forget that incarcerated individuals may also be at-risk during emergency and include corrections officials and secure treatment programs for addictions in planning and outreach.

G. Resource Identification and Review

To reflect the current status of practices and materials regarding pandemic influenza and at-risk individuals, ASPR ABC staff conducted a resource review according to the following categories: 1) at-risk individuals and pandemic influenza, 2) emergency planning with persons at-risk, and 3) State pandemic influenza plans that included the needs and concerns of at-risk individuals. As expected, few resources touched on all three subjects.

Most resources were focused on personal emergency preparedness for at-risk individuals. Often the source was an advocacy group for disabled persons. This is not unusual as areas of the country that have experienced emergencies such as wildfires, hurricanes, flooding, and earthquakes have embarked on educational campaigns for both at-risk individuals and emergency planners for over 15 years. However, only recently have some of those recommendations become integrated into plans as emergency planning objectives. Advocacy groups have distributed information, including on the Internet, for planners that recommend adjustments in planning assumptions and, more generally, what to expect when first responders interact with at-risk individuals.

Today there is more of a concerted effort to prepare at-risk individuals to adapt recommendations for supplies for personal preparedness and to take charge of tailoring response and rescue efforts to their specific functional needs. Disability advocates emphasize
stocking a different level of survival gear for the first 3 to 10 days (for example, a flashlight to signal with and also use as a hammer to make a loud noise or a whistle to lead first responders to their location). In addition, guidance has been developed aimed at first responders and emergency managers to direct them how to best work with at-risk individuals (for example, how to properly carry someone in a wheelchair and the best way to guide someone who is blind).

Another significant group of resources targeted at-risk individuals’ personal and social behaviors to protect their health during a pandemic influenza event. State and local public health departments have produced clear, simple, and short brochures that are more easily understood by at-risk individuals. Service providers and advocacy groups have also developed written material, established Web site links, and have initiated pandemic influenza health trainings for their constituents. Written pandemic influenza information has been created in a wide range of languages that are available on the Internet. The Centers for Disease Control and Prevention (CDC) has produced closed captioned safety and health videos.

Despite improvements, at-risk individuals are still often left out of mainstream public and community information networks. Often the oversight is not deliberate, at-risk individuals simply may not be part of the everyday experience of the developers of these communication systems. To fill this gap, disability and at-risk individuals often must try to create their own network of communications that includes trusted community leaders, advocacy groups, and service providers. Connecting these valuable informal communications networks with mainstream emergency communications systems would undoubtedly yield greater integration and consistency in the response to pandemic influenza and other disasters.

State pandemic influenza plans that included the needs and concerns of at-risk individuals were the most limited resource category. When State influenza plans did include reference to at-risk issues, the approach was quite variable. Some plans simply identified the existence of at-risk individuals, some designate a State agency to be responsible for ensuring continuity of services to these individuals, while others assign very distinct responsibilities to health or social service divisions.
III. MAJOR FINDINGS: OUTREACH AND COMMUNICATION

Introduction to Major Findings Section Domains

Major findings are discussed below using the following four critical preparedness and response domains for at-risk individuals during pandemic influenza: Outreach and Communication, Health Care Service Delivery, Human Services Delivery, and Resources and Training. Subsections in each domain section vary according to the specific needs of each domain.

A. Outreach and Communication

Overview of Significant Issues

At-risk populations include Limited English Proficiency individuals (LEP), individuals who are deaf, hard of hearing, blind, or otherwise limited in vision, and individuals who are from diverse cultures. Communicating with such individuals requires special resources, such as interpreters for persons who are deaf or hard of hearing, interpreters for persons who have LEP, alternate formatting, and additional outreach strategies.

Significant communication issues for at-risk populations include:
- Persons with disabilities may not have access to written or oral information, depending on the disability;
- Persons with LEP may not be able to understand information in English;
- Persons with LEP may speak a wide range of languages;
- Persons with disabilities, LEP, and persons from diverse cultures may obtain important information about pandemic influenza from nontraditional sources, such as advocacy and community groups and alternative media, and trust and rely less on the government and other media typical for reaching the general population; and
- Persons with disabilities may require additional information to prepare for pandemic influenza and additional services and resources in the event of pandemic influenza resulting in the need to adapt message content for these individuals and groups.

BEST PRACTICE

The 2007 California wildfires in San Diego County presented an opportunity to demonstrate and test improvements in preparedness and response within the disability community. The statutorily mandated FEMA Disability Coordinator is in place and was on site in California; a disability advocate is under contract with the State of California; and the Mayor of San Diego has a Disability Coordinator on staff. The disability community and emergency planners were connected, a relationship that was cultivated during the emergency preparedness conference in June 2006 in Washington, DC, jointly sponsored by HHS/DHS. During the wildfires, the disability community coordinated regular conference calls that included the FEMA Disability Coordinator, the Independent Living Center, and the Protection & Advocacy Agency. Representatives visited shelters to assess needs and accessibility and were able to quickly identify needs such as wheel chairs, oxygen tanks, foam toilet seats, etc. As a result of this coordination, communication was effective, needs were identified and addressed, and no “horror stories” regarding at-risk individuals were reported in the mass media. The key factor was the connection that was made between the disability community and the emergency planners and responders pre-event and the coordination across these groups during response and recovery.
Directions for Planners

1. Planning assumptions related to outreach and communication for at-risk individuals:

   - Risk groups for severe and fatal reactions cannot be predicted with certainty but are likely to include at-risk individuals such as infants, the elderly, pregnant women, persons with chronic medical conditions, and LEP persons.
   - At-risk individuals are less likely to receive and/or respond to important communications regarding pandemic influenza and less likely to communicate effectively with emergency response officials. This may leave them more vulnerable and more likely to contract or spread the virus. They may also miss or fail to follow some community mitigation strategies, such as staying at home when ill, if they do not understand the rationale for such action.

Cross-cutting issues in at-risk population communication

Communications plans must include guidelines and steps to make communications available in a variety of languages and formats for various at-risk populations, including LEP persons and persons with disabilities. Communication delivery mechanisms must be adapted to reach at-risk populations as well.

In the early phase of an influenza pandemic, interventions may include social distancing, such as staying home when sick and avoiding large crowds, prolonged school closings, and planning for alternative work schedules. Communications planning must take into account how to reach all populations, especially those identified as at-risk, with these messages.

Further issues may arise due to the diversity of the communities involved. Planners should conduct a needs assessment and accommodate communications strategies based on the size of the communities involved and their differences, such as urban and rural populations.

Local planners will have to consider many crosscutting issues and assess barriers to develop the best possible communications plan. Although still in draft form, CDC has developed such a planning guidance, the Public Health Workbook to Define, Locate and Reach Special, Vulnerable, and At-Risk Populations in an Emergency which may be found on the Web at http://www.bt.cdc.gov/workbook/.

2. Issues in planning dependent on pandemic phase:

   Interpandemic period

   In the interpandemic period, planners should communicate the possibility of an influenza pandemic to at-risk populations. They must ensure that a plan is in place should the event move to the next phase. Individuals may be more aware of and better able to understand the risk of pandemic influenza during this period. Because of this, the interpandemic period should be used as an opportunity to work with community-based organizations and non-governmental organizations in building a collaborative effort for communication with at-risk populations.
**Pandemic alert period**
During the pandemic alert period, planners should continue communication with at-risk populations. Advance preparations should be emphasized and the threat level of a pandemic influenza should be communicated. Advance preparations before an event allow for a greater availability of resources to serve at-risk populations, including communication resources, transportation and delivery assistance, medical care, and social services.

**Pandemic period**
In the event of pandemic influenza, it is likely that resources will be in a higher demand and it may be more difficult for at-risk populations to access services they may need, such as interpretation, delivery of medications to their homes, or transportation to medical appointments. The circumstances of affected persons will not be normal during or in the period after an influenza pandemic. Communications should draw attention to this, and outreach to at-risk individuals should emphasize planning for alternative ways to meet their basic needs until the situation has stabilized. Emergency communications plans should include mechanisms to orient at-risk individuals to changes and disruptions that may occur in systems of care as an outcome of pandemic influenza.

3. **Issues in planning that may arise as the severity of the event increases**
Depending on the severity of the event, communication with at-risk populations may be necessary over an extended period of time, and the information content may also change over time. Communication through various media outlets, government agencies, and at-risk service providers should assist individuals to prepare contingencies and identify back-up service delivery systems for an extended period of time without their established treatments, social services, or therapy. It will be especially important for at-risk populations to receive information on alternate ways of obtaining needed services during a prolonged influenza pandemic event.

4. **Issues in planning dependent on audience**
Communication with—and materials for—emergency response, social service, and health providers of all types should be available to assist these providers in reaching out to and communicating with at-risk populations. These materials should help providers understand the characteristics of, service networks available for, and special needs of the various at-risk populations.

**Gaps, Barriers, and Emerging Solutions**
1. **Gaps and barriers to planning for outreach and communication for at-risk individuals.**
   The most important gaps and barriers include:
   - Identification and location of the various at-risk populations.
   - Assessment of the communication needs of the at-risk populations.
   - Distrust and/or fear of government among some groups, such as immigrant and refugee populations.
• Expense of certain communications resources, such as interpreter services, captioning, and translation of written materials.
• Timeliness in providing effective communication services.
• Limited availability of resources, such as qualified interpreters for persons who are deaf or hard of hearing, and interpreters in multiple languages for LEP persons.

2. Emerging Solutions

Communications plans should consider these barriers in advance and identify additional resources in the case of emergencies. For example, planners can seek advance agreements for interpretation and other services, arrange for the use of multiple-language phone lines or community language banks, or develop quick information cards for LEP persons and others.

HHS has launched a national influenza pandemic preparedness campaign, entitled Take the Lead, Working Together to Prepare Now to encourage people to actively engage in personal preparedness (available on the Web at http://www.pandemicflu.gov/takethelead/). The campaign engages and partners with influential leaders from the business, faith-based, civic, and health care sectors in selected pilot communities across the country, and will provide information, tools, and support to help people take steps to prepare.

Local planners should work to encourage the general public to get to know their neighbors, especially those identified as at-risk, and be prepared to assist them in an emergency. Assistance could mean making sure people with disabilities receive communication before, during, and after an influenza pandemic. The concept is as simple as “neighbors helping neighbors,” and this process can be strengthened by using existing resources such as the Take the Lead campaign previously mentioned.

Use of accessible pre-pandemic information developed by the Federal government and other entities can also provide a helpful resource to State, Territorial, Tribal, and local agencies as they carry out their own preparedness activities. It will be important for Federal, State, local, and Tribal entities to ensure that accessible information is available and that critical groups, including first responders, have access to this information. For the best outcomes, local planners should plan to tailor pre-developed messages to meet the specific needs of their communities.

An additional area of importance is determining the best way to document the locations and contact information of at-risk individuals prior to an emergency. An emerging solution to this issue may be creating a voluntary registration network among local organizations that already work with and serve those at-risk populations. The goal of such a network is to allow those with disabilities and other at-risk individuals to self-register for a notification list. In the case of an emergency, planners will know where such individuals are living and who they can contact. Many personal and health information privacy concerns will be avoided by self-registration.
Finally, additional solutions for assisting with communications with at-risk populations are continually emerging. For example, technology and new media are changing the communications landscape. Having tailored messages delivered by Podcast or a Really-Simple-Syndication (RSS) feed to an individual’s computer could be very beneficial in communicating with diverse populations. Technology also exists that allows for personalized emergency alert systems. One such example includes wiring that allows the bed of a blind person to shake when the local emergency alarm is sounded or a light to flash in the home of a deaf person. These technologies have not been implemented on a wide scale and the role they may play in emergency preparedness still needs to be addressed. Plans should be updated to include new recommendations to overcoming the communications barriers as new technologies and solutions emerge.

### BEST PRACTICE

1. **Outreach**
   - The American Red Cross (ARC) recommends that disaster planning include efforts to expand outreach to at-risk populations through community groups, schools, churches, and local agencies that know and have experience working with these individuals. ARC encourages such organizations to help individuals develop family or individual preparation plans and teach them where to look for information in case of an emergency.
   - The North American Mission Board (coordinating board for Southern Baptist Churches) suggests that its churches develop contingency plans to care for dependent populations, including those in resident care facilities such as homeless shelters and assisted living facilities. The Board has encouraged churches to include dependent populations in the planning stages. It also recommends that churches develop a fiscal plan for such events so that communication and care will be possible and so that they may offer financial aid to at-risk populations in need.

2. **Planning**
   - ARC and FEMA released a brochure entitled, *Preparing for Disaster for People with Disabilities and other Special Needs*. This has been widely distributed at conferences, briefings, and to ARC associates in local communities. It offers practical advice in helping an individual make a plan for a possible emergency.
   - The National Governors Association recommends that State officials identify the most vulnerable populations and sectors as the first step in the planning stages for a State emergency and develop responses that consider these populations/sectors’ unique needs.

3. **Public Messaging**
   - WHO promotes targeted outreach and advance education to at-risk populations. For example, in its Partnership for Maternal, Newborn, and Child Health, WHO develops targeted, culturally appropriate messages in various formats and languages, and partners with local organizations that work with women-at-risk.
   - The Fairfax, Virginia County Department of Health mailed a booklet on seasonal and pandemic influenza preparedness to every household that had a listed mailing address. The brochure provided a number to call to request the booklet in an additional language or format.
III. MAJOR FINDINGS: HEALTH CARE SERVICE DELIVERY

B. Health Care Service Delivery

Overview of Significant Issues

Current pandemic influenza surveillance efforts are highly concentrated in the formal health care system—in hospitals and outpatient clinics. At-risk populations often experience barriers to accessing the health care system and consequently there are limitations to detecting the presence of pandemic influenza among these groups. Therefore, populations with special needs in the functional areas of maintaining independence, communication, transportation, supervision, and medical care warrant special attention in the pandemic influenza planning process. Planners should be mindful of the following issues:

Maintaining Independence
- Disabilities, institutionalization, severe chronic disease, and age may all impact one’s ability to maintain independence.
- These individuals are often reliant on others to obtain access to health care information and services.
- Individuals who are homebound, in particular, may have limited access to traditional health care venues and require home health services.

Communication
- Individuals with functional communication challenges may have limited English language proficiency, be of diverse cultures, or have sensory disabilities.
- These populations are much more likely to have low health literacy and some individuals may not trust their providers or the institutions which the providers represent.
- All of these factors impact interpersonal interactions between providers and patients, potentially leading to health outcome disparities.
- Individuals with functional communication needs are more likely to be isolated from the community and less able to access local resources.

Transportation
- Indicators for functional transportation deficits including homelessness, geographic isolation, economic disadvantage, disability, and visitor/tourist status.
- These individuals may be restricted to health care facilities in areas close to their dwellings and have a limited ability to obtain resources if travel is required to utilize those resources.
- This population also has fewer opportunities for follow-up care.
- Many individuals with transportation needs rely on the mail system to obtain necessary medication and equipment, and this infrastructure may be compromised during an influenza pandemic.
**Supervision**
- Individuals with functional needs in supervision may be institutionalized (for example, in a nursing home, residential, or correctional facility); may have physical, cognitive, mental, or sensory disabilities; or may be children.
- These populations often must rely on others to make health care decisions and to provide access to health care services.

**Medical Care**
- Many populations will have functional medical care needs during an influenza pandemic, including those with severe chronic disease and immuno-deficiencies; the homeless; those who are economically disadvantaged; pregnant women; the elderly; children; those with disabilities; individuals from diverse cultures; and migrant workers.
- Some of these populations may encounter barriers to accessing health care, including lack of health insurance.
- They may be less likely to receive preventive and primary care, and may lack formal linkages with the health care system, relying on emergency and urgent care departments to meet primary care needs.
- Mistrust of large institutions and cultural beliefs on health and medicine may further discourage routine utilization of the medical system and the likelihood of appropriate care in the event of a pandemic influenza.
- Individuals with certain health conditions may command high resource utilization in terms of professional services and clinic appointments, pharmaceuticals, and specialized diets.

**Directions for Planners**

**Planning for Health Care Delivery for At-Risk Individuals**
General assumptions regarding planning for and responding to pandemic influenza may not account for differences among at-risk populations. Specifically, planners should devote special attention to the areas of surveillance, isolation as a mitigating practice, health care utilization, and distribution of a vaccine or anti-viral medication.

Local departments of public health should reach out to home health agencies and community-based agencies that have greater access to populations with the five identified functional needs. These agencies should be included in the surveillance process.

Hospitals and other health care institutions may plan to isolate individuals with a novel strain of influenza and limit visitation to these individuals as a means of preventing further spread of the virus. Some individuals have supervision and independence needs for which isolation may present difficulties such as safety risks. A health care workforce that is already thinly stretched may not be able to adequately supervise young children and individuals with cognitive disabilities, in addition to providing needed medical care. They also may not be able to address the attendant care needs of a physically limited
population. Planners need to consider guidelines for allowing outside individuals to enter isolated areas to address these needs.

Pandemic influenza planning in hospitals and other health care facilities may focus on the capacity to accommodate the surge in demand for treatment as a result of an influenza pandemic. These institutions, in conjunction with local planning authorities, should also consider the ability to maintain services for populations with a high level of medical need, such as hemodialysis patients. Planning authorities should make decisions regarding which treatments are essential to maintain continuity of services and which may be postponed or monitored by telephone, or identified community resources and partners.

The surge in demand for care, in conjunction with health care personnel shortages, may require individuals to provide care for themselves and loved ones in situations where they typically would rely upon the health care system. At-risk populations may be less able to provide self-care or less likely to have adequate assistance from others.

Pandemic influenza planning literature outlines guidance for distribution of an influenza vaccine and anti-viral medications during the event of a pandemic. In the event a vaccine is available, it should be administered rapidly and may require a second dosage in following weeks. Administering a second dose of vaccination may be difficult for transient populations.

**Overview of Community Mitigation**

Primary strategies for State and local community mitigation focus on several measures other than vaccination and drug treatment that might be useful in reducing the harm resulting from an influenza pandemic. Community-level intervention strategies will require specific actions by individuals, families, voluntary and faith-based organizations, and the community as a whole.

The community strategy for pandemic influenza mitigation supports the goals of the Federal government-to limit the spread of a pandemic and to mitigate disease, suffering, and death. The overarching public health goal is to reduce morbidity and mortality. Non-pharmaceutical interventions for community mitigation may include social distancing measures, as well as voluntary home quarantine of all individuals with confirmed and suspected cases of influenza. Social distancing of children through dismissals from schools and of adults through cancellation of public events and alternative working situations may also be required. Finally, individual hygiene education is recommended and integral to mitigation of an influenza pandemic’s impact on a community. As for the general public, at-risk populations should follow common sense approaches to limit the spread of germs. These include washing hands frequently with soap and water, covering one’s nose and mouth with a tissue or sleeve when coughing or sneezing, putting used tissues in the waste basket, cleaning hands with soap or an alcohol-based cleanser after coughing or sneezing, and staying at home when ill.
The CDC suggest that primary strategies for combating influenza are vaccination (an up-to-date Flu/Pneumococcal vaccination), antiviral medications for treatment of infected individuals and prophylaxis of exposed individuals, social distancing, and implementation of infection control measures. As it is improbable that a significant number of individuals could be effectively vaccinated against an influenza strain resulting in a pandemic, the CDC guidance recommends a four step non-pharmaceutical intervention to include isolation and treatment with antiviral medications for all confirmed and suspected cases of pandemic influenza, followed by voluntary home quarantine of all members of households with confirmed and suspected influenza cases.

Isolation of a confirmed or suspected case of pandemic influenza will be particularly challenging for those with supervision and independence needs. These populations often require attendant care and may not be safely left alone. It may be particularly difficult to isolate those in institutional living situations, such as nursing homes, group homes, and the correctional system, as well as transitory populations such as migrant workers, the homeless, and tourists.

Isolation may also create difficulties for those with transportation issues. These individuals may be reliant on public forms of transportation—a socially dense environment—which may contribute to transmission of influenza. Public transportation services may lessen as workers become ill or fear contracting influenza. If isolation is enforced, transportation disadvantaged individuals may have severely limited access to basic necessities and health care follow-up.

Home quarantine of individuals in households with confirmed influenza cases may impact special needs populations differently than the general public. Those with a high need for medical care may not be able to access resources, such as pharmaceuticals, or maintain frequent appointments. Quarantine of individuals may be difficult in the large institutions often serving those with independence needs unless there are areas within the institutions designed to serve this purpose. The need for quarantine may be difficult to convey to those with communication limitations and mistrust of the medical community, and would be difficult to enforce among transient populations.

Social distancing is a fundamental strategy for community mitigation during a pandemic influenza event. However, as is true with the mitigation measure of isolation, the effects of social distancing may further disenfranchise populations with communication, independence, or transportation challenges. For example, for individuals with functional needs related to maintaining independence, social distancing may preclude their receipt of services necessary to remain safely in the community. Social distancing may be difficult for individuals in group living situations and the homeless who may spend nights in shelters.

Individual infection control is particularly important for those with a vulnerability to illness due to high need for medical services. Individual infection control also may pose a challenge for populations limited in maintaining independence if they cannot perform basic hygiene functions such as hand hygiene and cough etiquette and must rely on
Caregiver assistance for these tasks. Populations with supervision needs may require cuing to ensure infection control measures are followed.

In the event a vaccination is made available for the strain of the influenza virus creating the pandemic, populations with transportation needs and barriers to accessing the health care system, including limited language proficiency and lack of formal ties to the medical system, may be less likely to receive the vaccination. This may leave these populations unprotected and reduce the overall effectiveness of vaccine administration. Additionally, due to medical conditions, some populations may be contraindicated to receive vaccination.

1. Issues in planning dependent on pandemic phase

*Interpandemic period*

The interpandemic stage involves increased disease monitoring, emergency preparedness planning and public education programs, and coordination with international, Federal, State, regional, and local partners.

The planning phase before the spread of pandemic influenza is an optimal time to prepare to mitigate the adverse effects on at-risk populations. For those with communication challenges, establishing meaningful and trusting linkages with the health care system will be important for conveying health information in a culturally competent and easily understood manner. Individuals with supervision needs may be taught and drilled on emergency responses in the event of a pandemic to reduce their reliance on others for health care decision making.

Communities will need to address transportation-challenged populations to ensure individuals are still able to access needed resources in the case that social isolation is a necessary precaution. Patients and health care providers will need to establish plans for ensuring individuals have necessary medications and supplies to last through the first wave of the influenza pandemic, i.e. for three months, and to compensate for missed visits and procedures. Communities should determine effective mechanisms for mobilization and rapid deployment of resources to areas of great need in the event an influenza pandemic should occur. Plans should be made to address how the needs of individuals requiring daycare and attendant care will be met if staff at these services become ill or are otherwise no longer able to perform their duties.

Regional coordination should be established at the State and local levels. Public and private health facilities must have a common approach for functioning during a disaster to facilitate coordination of activities. For instance, nursing homes should have a rigorously tested plan for functioning during an emergency event and should coordinate with local hospitals to address surge capacity issues.

One additional consideration for planners is that although the prophylactic effect of antiviral drugs is equivalent to vaccination for interpandemic periods, the protection is less for newly emerged pandemic strains.
**Pandemic alert period**
The main action for this period is to send a clear message: “Stay healthy, stay informed.” During the pandemic alert period, the interventions described in the previous section on the interpandemic period should be continued. In addition, the health care system should actively work to ensure adequate medical supplies are available for at-risk populations and that there is a plan for targeting and distributing supplies to these populations. Preparedness activities also need to continue at the local level, such as in nursing homes, childcare centers, assisted living centers, schools, and homeless shelters. These organizations may begin to finalize logistics of deployment of resources and alternative operations in the event an influenza pandemic occurs.

**Pandemic period**
In the event of a widespread human to human transmission of pandemic influenza in multiple locations overseas, HHS, State health services, and local agencies will need to increase coordination with partners and instigate broader outreach efforts. These efforts should include previously identified agencies representing at-risk populations. In addition, all sectors dealing with at-risk populations should have daily communication with State or local health departments.

Full mobilization of health services and full implementation of emergency/contingency plans should take place. Nursing homes, hospitals, and clinics should practice efficient triage procedures for efficient use of health care resources, and all care settings should ensure attention and health care for persons in quarantine, particularly those with functional needs in independence and supervision. Emergency plans for additional staffing should be activated. Designated nursing staff should visit community locations to increase access to at-risk populations. Community leaders, faith organizations, and neighborhoods may have designated volunteers to serve fragile and sick individuals to ensure delivery of supplies, such as food and water, and provide attendant care. Home health care personnel should be trained to detect and identify new cases of pandemic influenza.

Hospitals, nursing homes, and other institutions serving at-risk populations should ensure implementation of infection control procedures to prevent nosocomial transmission.

States and local entities may stockpile antiviral medications for people in high-risk groups as determined by Federal recommendations (e.g., nursing home residents). Planners should be mindful that children are not small adults, and interventions should be tailored to their unique needs. Childcare centers and schools should apply social distancing, hygiene, and vaccination measures.

Each doctor’s office and pharmacy should have fact sheets available on-site on how to care for family members and loved ones with influenza, as well as instructions for how to use appropriate protective measures such as masks, gloves, and/or gowns while caring for a sick person. This guidance should also be available in previously identified areas that increase accessibility to at-risk populations.
Recovery
It is important to remember that the recovery stage may be an intermediate stage between recurring pandemic influenza waves. This is an important time to recuperate strengths and better prepare for an ensuing pandemic influenza wave. During this time, at-risk populations may be less likely to access medical services related to pandemic influenza such as follow-up medical visits and vaccinations, should a vaccine become available. Additionally, for those with high levels of medical need, important services may have been interrupted during the pandemic. Special attention will need to be paid to ensure patients receiving frequent medical services (such as dialysis) and those needing prescription medications experience continuity of these services to the best extent possible.

During the recovery period, State and local planning authorities should reach out to the health care system and at-risk communities to learn what aspects of the health care delivery system may need to be strengthened or modified should a second wave of the influenza pandemic occur.

2. Issues in planning that may arise as the severity of the event increases
Hospitals should develop guidance for a surge capacity in terms of preserving hospital space for acute patients. They should also educate the public about when to seek medical care for pandemic influenza and develop patient admission criteria. The hospitals should modify this guidance for at-risk populations to include variations for those who have immuno-deficiencies or chronic diseases that might be exacerbated by contracting influenza.

Gaps, Barriers, and Solutions
Current gaps and barriers to planning for health care services for at-risk individuals during pandemic influenza include breakdowns in the local “burden sharing” approach. Local entities, such as faith organizations, volunteer organizations, community leadership, and States need to clearly define their roles, authority, responsibilities, communications, logistics, and resources.

A centralized response is needed for both transportation and for the minimization of the burden on hospitals. Use of other available resources such as primary care providers and local community resources (e.g., churches and community clubs) should be explored, as well as managing individuals in the home setting.

There is a need to enhance data collection on comprehensive community assets and resources across the U.S. that could be used to support local care of at-risk populations. Active engagement of researchers and geographic information system (GIS) technology can provide detailed mapping of these resources for use by State and local health departments and their public health partners. Similarly, accurate data is needed to better estimate the magnitude of the burden and underlying vulnerabilities of at-risk populations in terms of disabilities, functional limitations, and population size.
Challenges exist in defining best practices in the setting of pandemic influenza for a variety of reasons. Randomized controlled trials of interventions for effective prevention and control of pandemic influenza do not exist to inform best practices. Antiviral medications, even if effective, may not be available for the entire population. Vaccines developed during the pandemic alert phase may not be available in time or in sufficient quantities to protect the entire population before the pandemic phase. Depending on the magnitude of the influenza pandemic, medical care may be limited by inadequate manpower, medical equipment, and trained frontline personnel to operate the equipment and deliver care. All of these limitations are likely to have adverse impact at-risk populations.

Several strategies, including both pharmacologic and non-pharmacologic interventions, based on the best available evidence for prevention, rapid early detection, evaluation, treatment, and control have been proposed for the different phases of an influenza pandemic. Application of these strategies must specifically take into account population sub-groups considered at-risk during an influenza pandemic. The key concepts in addressing at-risk population needs include the following, which should be addressed in all phases of an influenza pandemic:

- Provision of culturally- and linguistically-appropriate services for individuals with functional communication needs and those for whom English is not a first language.
- Identification of low health literacy as a major barrier to receiving optimal information and care, and use of graphics and appropriate grade-level language in all publications.
- Maintenance of a low threshold for early diagnosis, evaluation, and treatment in infants, children, the elderly, and persons with multiple underlying chronic diseases that may not present with typical signs and symptoms.
- Rapid and aggressive treatment of persons with multiple chronic diseases who are at high risk for complications including exacerbation of their underlying disease.
- Recognition that populations with functional transportation and other mobility needs, including those who are homeless or live in geographically isolated communities, are less able to access needed resources even when such resources are locally available.
- Recognition that persons in long-term institutionalized settings and those with significant supervision needs are at increased risk.
- Identification of the unique needs of persons living with disabilities and providing linkages with appropriate community resources.
- Recognition of the existence of lack of trust in traditional health care systems and government agencies among some individuals, especially in populations from diverse cultural backgrounds and religious beliefs.
- Recognition that low socioeconomic status, poverty, and lack of health insurance adversely impacts health care utilization.
- Recognition that provision of health care in non-hospital settings may provide unique advantages and important options for some at-risk populations.
C. Human Services Delivery

**Overview of Significant Issues**

Human services promote the economic and social well-being of families, children, individuals, and communities. These services function as a safety-net for people and communities with limited personal and/or economic resources. Human services agencies and local providers can be critical partners in planning and response regarding at-risk individuals during an influenza pandemic for two primary reasons:

1. Human services agencies have excellent connectivity with, and reach into, at-risk communities.
2. Human services agencies support people who are likely to suffer disproportionately from the impact of an influenza pandemic, illustrating the importance of continuity of human services.

If an influenza pandemic curtails the delivery of services to these individuals in their homes or in the community, they will be at serious risk of adverse health consequences or hospitalization whether they contract influenza or not. Therefore, it is essential that human services agencies put in place robust plans to ensure the continuity of services during the event of a pandemic influenza event. A consistent and coordinated human services response will not only help to reduce the initial impact of the influenza pandemic but will also speed recovery.

Programs provided by the human services delivery system typically cover a wide range of user groups and includes care provided in elder-care homes and childcare centers, as well as services such as adoption and foster care, and meals on wheels. During an influenza pandemic it is likely that there will be additional demand from groups not usually in need of services. This could include people whose medical conditions would normally lead to hospitalization, but who will need to remain in the community due to limited hospital beds and require additional non-medical human service supports. The disparate nature of human services means that planning for an influenza pandemic will arguably be more challenging in this sector than in many other sectors. Strong leadership, efficient internal organization and coordination, effective communication, and clear lines of accountability will be critical to meeting the unique challenges faced by human services agencies in preparing for and responding to pandemic influenza.

The uncertainty surrounding the timing and impact of pandemic influenza emphasizes one of the main challenges for planners and providers: contingency planning. An effective response needs to take account of this uncertainty and will require the cooperation of a wide range of organizations, as well as the active support of the public, to ensure the continuity of services. Advance planning is essential to establish and rehearse contingency arrangements to enable normal business to continue as much as possible. Contingency arrangements will need to be proportionate, resilient, and flexible enough to deal with a wide range of possibilities. To be effective, the delivery of human services will need to be developed on an integrated multi-agency basis and be supported by strong local leadership and coordination when implemented.
As pandemic influenza threatens to disrupt the essential services that human services organizations provide on a daily basis there are significant issues facing this sector, including:

- **The administration of entitlement programs.** Many people rely on these services for basic needs. Programs like Social Security and food stamps may suffer service disruptions due to an influenza pandemic, possibly due to staff illness or slowing of mail delivery services. Due to how programs are administered, waivers and other policy changes may need to be instituted to handle the flexible needs of an emergency situation.

- **Multiple types of human service organizations.** Human service organizations may be public, private, or non-profit. Private and non-profit groups may not necessarily have the same mandate to provide services in times of emergency because they may not be as strictly regulated by the government.

- **Extensive reach into communities.** Human service organizations are in a unique position to identify people who may be at increased risk of pandemic influenza and complications (e.g., medically fragile individuals). This information should be used in pre-event planning to ensure the best continuity of services possible during an event.

- **Mandate to protect the most vulnerable groups.** Some human service organizations focus on protection, such as child welfare or elder abuse. The timeliness of investigating cases and protecting vulnerable individuals may be highly disrupted by an influenza pandemic, putting some people at increased risk.

**Directions for Planners**

1. **Planning assumptions related to human services delivery for at-risk individuals**

   As assumptions regarding planning for and responding to pandemic influenza may not fully include the needs of at-risk individuals, continuity of operations planning may not address the continuity of direct services to these clients. Providers need to proactively plan to maintain support for at-risk individuals through continuation of critical services. Some at-risk individuals function best in a structured setting. Broader community mitigation strategies may disrupt needed routines and support. Contingency planning should take into account the need to maintain a normal level of support, not replace or substitute other supports during an emergency.

   At-risk individuals may not have the personal resources to initiate contact with emergency support services. All support networks—health, human service, economic, and social services providers—will need to take the initiative to locate and engage at-risk individuals. Some at-risk individuals with specific functional needs may not want or accept assistance from responders or community members. Often this attitude reflects a fear of interruption of familiar routines and habits. Asking at-risk individuals how they can best be assisted will provide valuable information that will help to maintain normal orientation and routine. The homeless, for example, may be suspicious of external service providers and need social support to take place in a familiar shelter setting.

   Planners can establish a list of key contacts for community-based human services and update the list at least quarterly. These contacts are the trusted sources of information and communication with at-risk individuals. They can serve as the “eyes and ears” of
emergency planners committed to integration of at-risk individuals. Meeting regularly with these key representatives will be an opportunity to learn about the barriers at-risk individuals will have to receiving routine support and emergency information. Similarly, shelter-in-place plans will need to include ways to check on the status of at-risk individuals and alert service providers to individuals who may need personal care and assistance. Linkages with community-based organizations will facilitate this critical activity. The inclusion of at-risk individuals and their representatives in After Action Reports and hot washes is also a useful ongoing preparedness activity that can inform the update of emergency plans.

The continuity of human services in emergency is vital to the long-term recovery of community infrastructures. Planners should consider a sustained, long-term commitment to providing human services as a way to restore the well being of the community and all of its residents.

2. Crosscutting planning issues

A serious concern in all phases of emergency planning for pandemic influenza is the unintended consequences of social distancing on at-risk individuals. Families not acquainted with caring for at-risk individuals who usually attend day support programs will be faced with additional challenges, even if no family members are ill. Individuals who rely on structure and routine in order to maintain their independence and functioning may become disoriented or have a sudden increase in behaviors that threaten their ability to remain in the community. Some at-risk individuals may appear non-compliant with recommendations for isolation and quarantine due to their reliance of routine for stability.

Pre-event training is needed for at-risk individuals, families, and providers to counter the unintended consequences of social distancing. Topics might include personal and human service program contingency planning, care for at-risk individuals at home, personal protection, and connecting with emergency response and other social services in time of pandemic.

Issues in planning dependent on pandemic phase

Interpandemic period

Training of human service providers to be able to educate at-risk individuals and their families concerning expectations during an emergency event and coping with social distancing activities should take place in the pre-event period. As the possibility of an influenza pandemic increases, additional attention will need to be placed on specialized communication and public messaging to reduce the fears of at-risk individuals, especially those with chronic medical conditions and behavioral health issues. Use trusted community sources to develop and deliver appropriate training materials and messages to ensure that information is communicated effectively. Emergency precaution messages should be developed in multiple languages and for hard of hearing individuals. The interpandemic period should also include activities to develop linkages and strengthen individual and community resilience.
**Pandemic alert period**
Public messages specifically for at-risk individuals will need to be reviewed and customized to reinforce the emergency and individual preparedness instructions specific to the incident. It is likely that reducing the fear of contamination and promoting compliance with community mitigation and public health requirements will be important communication issues at this time. Human service providers will need to begin instituting contingencies to ensure continuity of services to at-risk clients. At-risk individuals who are more difficult to identify and locate should receive additional attention and energy.

**Pandemic period**
On-going vigilance in observing and reporting on the status of at-risk individuals to emergency managers will be essential in this period. Consistent and active communication with emergency managers within the existing incident command system will allow for allocation of appropriate resources to at-risk individuals. At-risk individuals will have the same reactions to increased severity as the general population—fear, frustration with social distancing, and the depletion of personal resources. However, it is likely that at-risk individuals’ needs will be at the more extreme end of the continuum, given that they typically have fewer resources to begin with.

**Gaps, Barriers, and Solutions**
The gaps and barriers associated with the delivery of human services to at-risk individuals are rooted in a history of disenfranchisement of at-risk individuals and limited involvement of human services stakeholders in emergency planning. In addition, the differences in training and job roles between human services personnel and emergency managers can lead to a lack of understanding and common terminology. Without a common language or similar points-of-reference meaningful integration of needs of at-risk individuals into emergency plans becomes challenging. It takes a deliberate effort on the part of both professions to educate themselves and initiate planning relationships prior to the impact of a pandemic influenza event.

This can be accomplished by establishing connections between both professions. It is essential to establish pre-event contacts with local community/faith-based organizations as well as the State human service network. Including these stakeholders in continuous planning activities—both for pandemic influenza and all-hazards disasters—will establish solid networks with at-risk individuals and their representatives. Likewise, human service providers can enhance their value to emergency planning networks by learning the terminology of emergency management and serving as trusted sources of information regarding at-risk issues, resilience promotion, public health messaging.
Best Practice

1. Develop Business Continuity Planning and Partnerships

A number of businesses and community service providers are developing continuity of business plans designed to continue assistance to their clients when a potentially large proportion of their own staff and volunteers may be unable to work. Many of these plans identify three or four persons as potential alternates responsible for delivering services to clients.

Many jurisdictions and service providers are using existing databases to identify at-risk individuals, such as those on dialysis or who rely on home-delivered meals, and the locations of the services they regularly access. For example, some jurisdictions map their metropolitan area at-risk population facilities and use GIS to show the locations these facilities. Other localities use reverse 911 systems to identify those who are at-risk. Knowing who these individuals are and how to contact them during the periods of social distancing can help ensure that these individuals will receive the supports they need to keep them safely in their homes. Without such supports, many individuals who need assistance with activities of daily living may be at higher risk.

The key to the strategy of continuity planning is developing, in advance, partnerships across all levels of the public, private, non-profit, and faith-based communities. Having these partnerships in place better ensures that the roles, plans, and limits of each sector will be understood and coordinated, and that potential gaps will be addressed.

2. Develop Relevant and Accessible Communication Materials

Other best practice strategies have successfully made use of faith-based organizations and churches, recognizing that these groups are familiar with at-risk individuals and are trusted sources of information. The faith community should be included in the process at the earliest stages of planning and preparation. Some counties have trained lay people from different cultures in the community as trusted sources of information. They visit kitchens, schools, senior centers, and other locations that reach high-risk populations who may not regularly access mainstream outlets of critical information.

3. Promote and Support Personal Preparedness

At-risk individuals need the same basic information about personal preparedness as the general population, but they may need it in different formats and are more likely to need some assistance in preparing and executing their plans. Consequently, some jurisdictions, community organizations, area agencies on aging, and service providers are developing pilot programs with neighborhood associations to identify the characteristics of persons who may need assistance with daily living activities or who are receiving community-based services in their homes. These “know your neighbors” initiatives can be used to identify people with special needs. They are also targeting group homes and assessing their needs. Some programs have developed buddy systems and doorknob tags that identify at-risk individuals for community providers and emergency response personnel. Doing so ahead of time can help ensure that communities know where these individuals reside so that plans can be implemented for continuing life-supporting, home-, and community-based services when normal assistance may be disrupted due to illness or other consequences of an influenza pandemic.
D. Resources and Training

In preparation for this paper, a review of various resources for education and training was conducted and listening sessions with at-risk stakeholders were convened. Listening session feedback regarding resources and training is described below.

At the local level, participants recommended promoting participation in existing community preparedness efforts such as citizen emergency response training to teach citizens how to assist professional responders, improve their individual level of readiness, and improve their community response capacity. Participants indicated that a forum for local agencies to share information, coordinated at the State level, would be useful. In addition, participants sought State-identified resources to assist local agencies in addressing the needs of at-risk individuals.

Participants proposed a number of Federal initiatives, which covered a range of pandemic influenza preparedness and response issues. These included: providing a financial incentive to families who engage in pandemic influenza preparedness training; creating a pandemic influenza kit that would be delivered to every household during a pandemic; creating a tracking system to use when movement of people is required; coordinating with the United States Department of Agriculture to develop a system to ensure children receive meals when schools are closed; clarifying Health Insurance Portability and Accountability Act (HIPAA) rules during a disaster, creating a National Disaster Day to promote readiness; and linking information from existing State- and non-profit program websites into the HHS website to serve as a central “one-stop-shop” for information. Planning for issues that result from high mortality due to an influenza pandemic (e.g. surge capacity in morgues and funeral homes, displaced children due to death, and adhering to burial and religious practices on a large scale) were also addressed. In addition, planning considerations for pets to promote better evacuation compliance for their owners was discussed.

Participants articulated specific training needs and suggestions, including: developing a planning team for training the general public and at-risk populations; developing and broadly communicating a general awareness message related to pandemic influenza preparedness; developing simple reference materials to spread this message; and training lay care-givers of individuals at risk, as well as the individuals at risk themselves.
IV. RECOMMENDATIONS

A summary of the recommendations and potential action steps is presented below, organized according by Outreach and Communication; Health Care Service Delivery, Human Services Delivery, and Education and Training.

A. Outreach and Communication

Recommendations and potential action steps for outreach and communication with at-risk populations before, during, and after an influenza pandemic are presented below.

In outreach, it is critical to first clearly identify the local at-risk populations that will targeted for messaging and services. Planners should also promote the preparation of educational and training materials addressing at-risk individual needs related to pandemic influenza. Dissemination mechanisms should include health care institutions, State and local health agencies, agencies and providers the work with at-risk populations, and first responder organizations.

The following approaches are recommended to ensure integrated and effective public health communication and messaging for at-risk individuals:

- Use multiple vehicles for communicating with at-risk populations:
  - Non-governmental, faith-based, and community-based organizations;
  - Health care providers;
  - National, State, and local government agencies and institutions, including schools and human and social service agencies; and
  - National, local, and alternative media outlets.

- Develop communication plans:
  - Assess media outlets and needs;
  - Identify and collaborate with the existing emergency communications system within the jurisdiction;
  - Pre-identify contemporary pandemic influenza issues and questions individuals may ask;
  - Identify and provide risk communications training for trusted spokespersons of at-risk communities;
  - Create guidance for the development of written and other communication materials, messages, and strategies that can be used in the event of an influenza pandemic, offering suggestions for when and how to prepare, and distribute resources in various formats;
  - Create prescripted messaging that can be quickly adapted and disseminated in time of pandemic;
  - Develop and deliver messages in multiple languages, culturally appropriate text, and alternate formats and languages;
  - Create separate materials for separate audiences, such as medical professionals, and offer guidance on how to tailor services and planning for at-risk populations;
  - Create simple, basic, and clear materials;
  - Post and display messages using traditional approaches (fliers, handouts) in locations frequented by at-risk populations, such as bus and subway stops, post offices, banks,
o supermarkets, stores, check-cashing locations, movies, churches, free medical clinics, and social service agencies; and

o Use existing resources to distribute information. For example, add information in electricity or telephone bills to residences or contact local Medicaid or Social Security/Disability offices to add information to their mailings.

Careful planning is perquisite to effective outreach and communication. Planning considerations include the following:

• Include key stakeholders in the planning process:
  o At-risk individuals;
  o Community-based organizations and non-governmental organizations serving at-risk populations, including faith-based organizations;
  o National, State, and local emergency service providers, public health agencies, and health care organizations; and
  o Media and local communication outlets, including alternative media outlets that offer information in various languages and formats.

• Reference and utilize existing national resources in planning:
  o CDC “Public Health Workbook to Define, Locate, and Reach Special, Vulnerable, and At-Risk Populations in an Emergency (Draft)”, available on the Web at: http://www.bt.cdc.gov/workbook/;
  o The ARC and FEMA brochure “Preparing for Disaster for People with Disabilities and other Special Needs”, available on the Web at: http://www.redcross.org/services/disaster/0,1082,0_603_00.html; and
  o Main government Web sites addressing preparedness and pandemic influenza, for example: http://www.ready.gov and http://www.pandemicflu.gov/.

B. Health Care Service Delivery

Recommendations and potential action steps for health care service delivery to at-risk populations before, during, and after an influenza pandemic are presented below.

In order to ensure that resources are in place to meet the needs of at-risk individuals during the actual pandemic period, the following activities are recommended for the interpandemic period:

• Conduct surveillance to assess and determine best access to at-risk populations.
• Conduct surveillance to assess and characterize specific functional needs of at-risk populations and the magnitude or extent of their underlying vulnerabilities.
• Engage research groups to assist in identifying best methods for communicating issues and meeting the needs of at-risk populations.
• Identify community resources and partners who have special expertise in working with at-risk populations. In particular, partner with local organizations that are trusted by specific at-risk populations. Include community leaders and faith based organizations in this effort.
• Maximize the uptake of vaccination against seasonal influenza and community-acquired pneumonia in at-risk populations in accordance with established clinical guidelines.
• Provide health care facilities and frontline health care workers with model protocols for early detection and treatment of influenza among at-risk patients.
• Specifically include the care and management of at-risk populations in Federal, State, and local pandemic influenza exercises.

In order to ensure that resources are in place to meet the needs of at-risk individuals during the actual pandemic period, the following activities are recommended for the pandemic alert period:
• Identify and engage traditional public health partners and non-traditional community partners (e.g., transportation workers) in pandemic influenza containment exercises and drills with specific emphasis on at-risk populations.
• Work with clinical and public health partners and other stakeholders to assure that State-based plans for vaccine effectiveness, safety, distribution, and use specifically address at-risk populations.
• Assure that State-based plans for distribution and use of antiviral drugs during an influenza pandemic specifically address at-risk populations, especially persons in geographically isolated communities and those with functional transportation needs.
• Identify or develop and distribute reading-level appropriate, language-specific, and culturally-appropriate materials about vaccines and antivirals for use by States and other stakeholders.
• Establish procedures for delivering medical care, food, and services to persons in isolation or quarantine and those in geographically isolated communities. These efforts should take into account the special needs of children, persons with disabilities, and those with chronic diseases such as diabetes and heart disease.
• Maximize public understanding of the dangers of pandemic influenza and the benefits of community-wide disease control practices, including social-distancing measures that can prevent illness and death.

Once the pandemic period is underway, the following considerations and activities can help mitigate the adverse risks to at-risk individuals:
• Maintain high index of suspicion for infants, children, the elderly, and persons with multiple underlying chronic diseases that may not show with typical signs and symptoms.
• Recognize that in the elderly the presenting signs can include respiratory symptoms with or without fever, fever only, lassitude, or altered mental status.
• Persons at high risk of complications include pregnant women, all children under two years of age, adults aged 65 years and over, residents of nursing homes and other chronic-care facilities, persons of any age who have multiple chronic diseases, and persons with chronic cardiopulmonary, metabolic, and immunodeficiency disorders.
• Assure adherence to established ethical principles and guidelines in the distribution of limited life-saving medications, medical supplies, and interventions during an influenza pandemic when resources are limited.
C. Human Services Delivery

Recommendations and potential action steps for human service delivery for at-risk populations before, during, and after an influenza pandemic include:

- Engage in pre-event planning between the health, emergency management, at-risk, community, voluntary, and faith-based organizations to foster careful coordination, robust leadership, and effective multi-agency working relationships.
- Develop integrated health and human services delivery plans as many influenza sufferers will need to be cared for in a community setting.
- Engage State and local emergency management professionals to work with local providers to ensure they have robust business continuity plan in place.
- Periodically verify and rehearse contingency arrangements to ensure that they are in place and resilient and flexible enough to deal with a wide range of possibilities.
- Engage in regular exercises and drills with local and State based social services agencies and at-risk stakeholders to ensure that their plans will meet the needs of actual and potential services users.
- Partner with Federal, State, local, and Tribal agencies that administer emergency human services programs to coordinate benefits and services.

D. Resources and Training

Recommendations and potential action steps for resources and training for at-risk population stakeholders and emergency management partners before, during, and after an influenza pandemic include:

- Evaluate existing training programs and materials to assess the effectiveness of training methodologies and identify best practices for both the individual at risk and those who provide services to them.
- Use existing training mechanisms to engage at-risk individuals and local public, non-profit and private sector agencies in community pandemic influenza preparedness and response efforts.
- Create a single, possibly HHS Web-based resource for planners and service and care providers to address the unique issues of at-risk populations.
- Develop and disseminate specialized training to target the diverse functional needs of at-risk groups. Customize training for key audiences.
V. CONCLUSION

The National Response Framework’s function-based definition of special needs individuals encompasses a significant portion of the population. Nearly every person knows someone who would benefit from additional assistance to remain safe and healthy during an emergency; for example, people who have difficulty walking, who are not fluent in English, who benefit from supervision, who use a portable oxygen tank, or who rely on a para-transportation system to name just a few functionally-based needs.

Emergency management professionals use their expertise to prepare for, respond to, and recover from natural or man-made disasters, including public health emergencies such as an influenza pandemic. Federal, State, and local human services agencies, community and faith-based organizations, care-givers, advocates, and at-risk individuals themselves can be extremely valuable planning partners to identify the functional supports best suited to at-risk individuals in time of emergency.

Promising work in this regard, for pandemic influenza as well as natural or man-made disasters, is already underway. Many States and local jurisdictions are integrating at-risk individual needs into their plans and best practices have been identified. However, additional and detailed planning for pandemic influenza that is informed by the participation of at-risk group representatives and at-risk individuals themselves is still needed. It is hoped that the findings in this report will assist HHS and its partners to continue to advance the meaningful integration of the needs of at-risk individuals into pandemic influenza preparedness planning. Indeed, of all the recommendations discussed, it is the promotion of deliberate networks that unite emergency planners and at-risk stakeholders—at the Federal, State, local, and Tribal levels—that holds the most promise to ensure a robust, targeted, and effective response for at-risk individuals during a pandemic influenza event.
REFERENCES AND RESOURCES

ACIP Recommendations: Prevention and Control of Influenza. MMWR, July 13, 2007; 56(RR06):1-54


Mody L, Cinti S. *Pandemic influenza planning in nursing homes: are we prepared?* J Am Geriatr Soc. 2007 Sep;55(9):1431-7

National Association of Childcare Resource and Referral Agencies:


Rhode Island State:
- *ESF #18 Behavioral Health Services: Pandemic Influenza Annex*


Trust for America’s Health Pamphlets:

University of Albany Center for Public Health Preparedness
- On-line Course:
Satellite broadcasts:


Workshop:


APPENDIX A: WORKGROUP PARTICIPATING AGENCIES

Department of Homeland Security
Federal Emergency Management Administration

Department of Health and Human Services
Administration for Children and Families
   Administration for Developmental Disabilities
Administration on Aging
Centers for Disease Control and Prevention
Centers for Medicare & Medicaid Services
Office of the Secretary
   Immediate Office of the Secretary
   Office of Intergovernmental Affairs
   Office of the Assistant Secretary for Planning and Evaluation
   Office of the Assistant Secretary for Public Affairs
   Office of the Assistant Secretary for Preparedness and Response
      Office for At-Risk Individuals, Behavioral Health and, Human Services Coordination
      Office of Medicine, Science, and Public Health
   Office for Civil Rights
   Office on Disability
Substance Abuse and Mental Health Services Administration

Department of Veterans Affairs
Office of Public Health and Environmental Hazards
Office of Patient Care Services
   Geriatrics and Extended Care Services

Note: Indentations indicate sub-agency relationship
APPENDIX B: LISTENING SESSION PARTICIPATING ORGANIZATIONS

Allergy and Asthma Network/Mothers of Asthmatics
American Academy of Pediatrics
Department of Veterans Affairs/Office of Patient Care Services
Department of Health and Human Services /Office on Women’s Health
National Association of Childcare Resource and Referral Agencies
National Association of State Alcohol & Drug Abuse Dir, Inc
National Alliance for Hispanic Health
National Association of State Units on Aging
National Association of School Nurses
National Association of Social Workers
The George Washington University/National Center for Disaster Preparedness
The Joseph P. Kennedy Jr. Foundation
Trust for America’s Health
Association of State and Territorial Health Officials
Center for Bioterrorism and All-Hazards Preparedness/NSU College of Osteopathic Medicine
District of Columbia Mayor’s Office of Health Policy
Government of the District of Columbia/Health Emergency Preparedness and Response Administration
Indian Health Service
International City/County Management Association
Metropolitan Washington Council of Governments
Montgomery County DHHS
National Association of Counties
National Association of County & City Health Officials
National Conference of State Legislatures
National League of Cities
New Hampshire Department of Safety/Homeland Security & Emergency Management
Office of Counterterrorism Policy and Planning
Public Health Service, Region III
US Food and Drug Administration
Veterans Administration Medical Center