U.S. Department of Health and Human Services
Assistant Secretary for Preparedness and Response

Office for At-Risk Individuals, Behavioral Health, and Human Services Coordination (ABC)

LISTENING SESSION ON AT-RISK INDIVIDUALS IN PANDEMIC INFLUENZA AND OTHER SCENARIOS

After Action Report

Washington, DC
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1.0 Executive Summary

On August 14, 2009 the Office for At-Risk Individuals, Behavioral Health, and Human Services Coordination (ABC) in the Office of the Assistant Secretary for Preparedness and Response (ASPR) held a Listening Session on **"At-Risk Individuals in Pandemic Influenza and Other Scenarios."** The Listening Session was designed and conducted as a "facilitated discussion" to engage stakeholder participants in a robust open dialogue. The Listening Session brought together a diverse group of more than 35 experts and practitioners representing public health non-governmental organizations, health care providers and federal agencies involved in public health preparedness and planning, emergency response, and at-risk individuals. The group was brought together to engage and promote dialogue about the challenges and solutions needed to effectively address the needs of at-risk individuals during pandemic influenza and other emergencies in five main areas:

1) **Locating and identifying** at-risk individuals;
2) **Unique concerns** of at-risk individuals in accessing public health and medical services;
3) **Best Practices** in public health and medical service delivery for at-risk individuals;
4) **Successful program implementation** at the state, tribal and local level, and:
5) **Gaps and Barriers** to accessing public health and medical services for at-risk individuals.

Summary of Key Themes and Findings
Participants identified several overarching themes and critical areas that have implications for the Department of Health and Human Services (HHS) as the lead agency for Emergency Support Function (ESF) #8 public health and medical service capabilities under the National Response Framework (NRF) as it relates to at-risk individuals. Participants indicated priority areas where strategic planning and action can be focused to more fully integrate at-risk individuals into public health and emergency plans.

Key Themes
There were four overarching themes that resonated throughout the Listening Session, all of which had equal importance to the discussed topic areas. These themes represent the status of how well at-risk individuals are being served by public health and medical planning, coordination and services. They also represent areas that can impede public health services and can be improved through development and application of best practices. While there was interdependence and overlap of these themes throughout, communication and messaging were viewed as a high-priority in each discussion.

Communications, Messaging and Outreach
Providing accurate, appropriate and accessible information is critical for at-risk individuals to understanding personal preparedness, be knowledgeable about available services, and understand where they can obtain services. Ensuring information is developed and disseminated in multiple mediums, multi-lingual formats, alternative formats, is age-appropriate and user-friendly is crucial to developing emergency plans, warning and notification systems, evacuation protocols and coordinating services for at-risk individuals including transportation, sheltering and medical care.

Model Plans and Best Practices
Developing plans and processes using specific techniques and applications including state-of-the-art tracking technologies, simple preparedness toolkits and creative outreach programs that

are delivered effectively and reflect community consensus can help achieve excellence in public health and medical service outcomes. This in turn can assist federal, state and local entities in providing optimal public health and medical services for at-risk individuals.

Service Coordination and Surge Capacity
Federal, state and local policies and initiatives which represent public commitment to ensuring medical services for at-risk individuals operate with a systems approach. A system integrates its separate parts — leaders, departments, plans, budgets, rules, personnel — to work with a unified purpose, a single driving force. The system must assure that its varying activities share the common purpose and are effectively integrated and support sustainable near and long-term capacity-building efforts to serve at-risk individuals.

Integrating transportation needs of at-risk individuals that may require additional assistance into local planning is essential to facilitate safe, appropriate evacuation while providing full access to public health and medical services.

Federal Support and Community Collaboration
Preparedness, response and recovery begin at the local level where communities have collaboration between state and local emergency planners, local government, human services organizations and consumers to address public health, medical needs, and personal preparedness for at-risk individuals. Federal agencies support state governments and local communities by providing support as appropriate and requested.

<u>Key Findings</u>
The Listening Session revealed key findings that reflect issues, topics and ideas that were mentioned frequently throughout the discussion and demonstrate a level of importance for consideration and action. Many of these issues are consistent with what has been observed in other federal reports and are currently being addressed by HHS, the Department of Homeland Security (DHS) including the Federal Emergency Management Agency (FEMA), and other federal agencies with Emergency Support Function responsibilities. The Listening Session affirmed that continued federal focus and partnership with state and local entities will ensure improved access to public health and medical services for at-risk individuals.

ESF #8 Planning and Preparedness

- As with the general population, at-risk individuals are very diverse and have heterogeneous needs. In addition, people who may not have had functional needs prior to an event may develop needs as a result of a public health emergency.
- Data on at-risk individuals are very complex and need to be standardized and better integrated among federal, state, local and tribal entities. HHS recognizes that enhancing its current operations and database systems is critical to coordinate data collection and dissemination processes on at-risk individuals.
- There needs to be a culture of personal preparedness. At-risk individuals need to be integrated into medical planning and preparedness at the state and local level.
- Federal agencies cannot maintain resources and support when there is no official or continuous national disaster declaration.
- At-risk, public health and service organizations and agencies need to be integrated into public health planning discussions. Federal and state agencies should provide coordinated outreach to non-traditional disaster agencies, organizations and individuals from within these networks.

Locating At-Risk Individuals

- There needs to be better demographic data on individuals with special medical needs. Specifically more information is needed on those individuals in a community setting who are medically dependent on uninterrupted electricity for therapies, require continual or intermittent medical care/support from a health care professional, or are not self-sufficient with the loss of adequate support from caregivers. There are databases from aging, disability, specialty hospitals and state health organizations that can provide data resources on at-risk individuals including neighborhood data, client lists, patient rates and medical equipment customers.
- Communications and messaging need to be tailored and accessible, utilizing accessible formats and empowering language. Public health and emergency communications should provide information in various formats including sign language, written messaging, large-print displays and tactile maps. There should be designation of times and places of sign language and foreign language interpretation.
- Communication plans and public information campaigns must include the diverse nature of at-risk populations. Utilizing community health workers can facilitate better communication among the Latino community.
- Communication and coordination regarding at-risk individuals must be improved among Federal, state, tribal, and local agencies involved in public health and medical services. Federal agencies should work with the health and medical provider community at the state level.
- Registries and Geospatial Information Systems (GIS) tracking tools need to account for security, privacy, the Health Insurance Portability and Accountability Act (HIPAA) and protection of personal health data. Guidance should be developed for registries to safeguard personal information and to share information appropriately during use.

Understanding ESF #8 Needs for At-Risk Individuals

- Disasters begin as local events and all public health responses for at-risk individuals needs to be addressed at the local level. The federal government's role is to support state governments when requested. Communities know their citizens needs and know what works best to serve them. Federal agencies provide guidance and support for state and local communities ranging from public health information guidelines, public health practices, and prevention and wellness strategies to legal guidance on personal health information data use and exchange, public health volunteers, and medical transport and housing.
- There needs to be increased planning support at the local level with toolkits, planning templates, best practices, and models for special medical needs and public health planning for at-risk individuals. At-risk individuals should be aware of how to best prepare for any public health emergency to enable self-sufficiency and bolster their ability to take care of themselves. They could also serve as trainers to enhance preparedness and response efforts.
- There needs to be better interaction between federal agencies, specialty medical providers and local communities to understand functional needs. States need to share resources during a public health event to tailor their support systems to fit their community needs and provide targeted support.
- Utilizing existing federal systems to enhance data integration and coordination can significantly impact planning for at-risk individuals. ASPR is working to enhance its Electronic Medical Records (EMR) and the Joint Patient Tracking System (JTPS) to

increase the ability to obtain, track and integrate data on at-risk individuals with special medical needs to improve public health and medical service planning.

Best Practices in Public Health and Medical Services for At-Risk Individuals

- Utilizing the C-MIST (Communication, Medical Care, Independence, Supervision, and Transportation) function-based approach for at-risk individuals allows for comprehensive public health and medical planning based on understanding personal functional needs--in addition to medical needs--that may impede full access to medical services.
- Public/Private partnerships can be productive and they should be inclusive and sustained. It is important to ensure everyone who has a stake in public health, medical services and preparedness can participate. Utilizing diverse communications technologies such as teleconferences, video-conferencing, social networks can increase stakeholder participation.
- The use of social media is a way to centralize messaging for disenfranchised populations. Twitter, Facebook, and MySpace, along with service provider and public health organization chat rooms can be a resource for accessing and sharing information.
- Develop and disseminate best practices in general public health such as how to correctly wash hands, keeping lists of personal medications, bar coding medical equipment to reinforce messaging. Recognize that there are cultural and social issues with messaging.
- Training at the community and grassroots level is important such as Community Emergency Response Training (CERT) exercises and practicing medication distribution processes.
- Develop personal preparedness plans.

Gaps and Barriers for Public Health and Medical Services

- Medicaid waivers and reimbursements do not sufficiently fund or support the special medical needs of at-risk individuals for basic public health prevention and medical services. Community organizations need faster processing and sufficient funding of Medicaid waivers for transportation programs, Centers for Independent Living (CIL), preventative care and wellness/health education classes.
- Addressing public health and medical services for homeless individuals and others who are at-risk and may be considered "off-the-grid" and not in the mainstream of society.
- Misconceptions about people with disabilities impede access to health care services. There are social barriers to accessing health services for at-risk individuals due to pre-conceived attitudes or concerns that at-risk individuals do not have the same acute health issues as non-at-risk individuals. Public health worker education and outreach can facilitate better understanding of the health needs of at-risk individuals.
- There are insufficient resources to support medical services for at-risk individuals.
- There is insufficient funding for states, local agencies and service providers to support and develop innovations in public health and medical services for at-risk individuals. Specialty training of public health workers on how to identify the needs of at-risk individuals, along with the implementation of electronic health records, would allow for optimal and responsive health services for at-risk individuals. These types of programs require continued funding for local communities to maintain and expand public health and medical services for at-risk individuals.

This summary report documents the findings of the Listening Session where critical stakeholders where engaged in collaborative activities to advance national preparedness and planning

prioritization in public health and medical service provision for at-risk individuals. This report provides a brief overview of the Listening Session, outlines the goals and objectives of the event, captures key discussion points based on the five topical discussion questions and highlights participant feedback on major challenges, gaps, best practices, and solutions in public health and medical services for at-risk individuals.

The report also includes an overview of presentations by HHS staff to facilitate understanding of its role in ESF #8, including areas where HHS experiences challenges particularly regarding the collection of essential demographic data on at-risk individuals and communication of information between federal, state, local and tribal levels. Finally, a series of recommendations and actions are outlined to understand and build opportunities for HHS to successfully develop and implement public health and medical services for at-risk individuals.

2.0 Listening Session Background: Purpose, Goals and Objectives

In 2007, the Office of the Assistant Secretary for Preparedness and Response established the Office for at-Risk Individuals, Behavioral Health and Human Services Coordination, to ensure that at-risk individuals with special needs have full and equal access to public health and medical services. As defined by the National Response Framework (NRF) under Emergency Support Function (ESF) #8—Public Health and Medical Services, HHS is designated as the lead agency to coordinate federal public health and medical response assistance to support state, tribal and local resources in response to public health emergencies and incidents. A critical function is providing support for the medical needs of at-risk individuals, as they are defined within the Pandemic All-Hazards Preparedness Act (PAHPA) and the NRF, respectively, who may require additional support before, during and after a pandemic or other disaster incident.

ASPR's ABC has been engaged in several activities to carry out its responsibilities under ESF #8 and PAHPA to effectively integrate of the needs of at-risk individuals on all levels of emergency planning. These activities have included a report to Congress on the implementation of relevant provisions in PAHPA, leadership of an interagency subcommittee on health and emergency preparedness, conference presentations, a web cast on the Initial Intake and Assessment Tool, white papers, toolkits, education and training modules, research projects and messaging strategies to promote awareness, outreach and best practices on at-risk populations for public health, medical service and emergency management personnel. Critical to the activities is obtaining stakeholder input through various work groups, interagency councils and listening sessions to understand the work being done by local communities to assure full access to medical services for at-risk individuals.

The Listening Session engaged a diverse representation of key stakeholders in the field of public health and at-risk populations as well as HHS representatives to address issues for identifying and locating at-risk individuals, service gaps, lessons learned, best practices, model programs, and mapping a way forward to improve medical service delivery during a public health emergency. The Listening Session solicited input from a cross section of experts and practitioners from the at-risk, public health and medical communities to address the following goals and objectives:

- **Communicate the department's ESF #8 roles and responsibilities in emergency response and the challenges in medical service coordination for at-risk individuals.** Provide an understanding for key stakeholders in public health and at-risk individuals of

the official role HHS and ASPR play in carrying out ESF #8 and the impact for at-risk individuals.

- **Expand engagement with and among public health and at-risk stakeholders.** Engage in a face-to-face session with select public health stakeholders to listen and obtain a broad-based understanding of the needs and concerns of at-risk individuals as it relates to ESF #8 public health and medical services. Become familiar with the topic areas in medical emergency service delivery and understand the unique medical needs of at-risk individuals.
- **Facilitate dialogue on ESF #8 and Special Medical Needs.** Create meaningful dialogue and deliberation with stakeholders by discussing how to address critical issues, major challenges and opportunities as related to ESF #8 and individuals with special medical needs. Provide opportunities to help shape departmental public health emergency planning programs and policy concerning ESF #8 and special medical needs.
- **Solicit stakeholder input on specific issues and planning processes impacting public health and medical services for at-risk individuals.** Successfully connect, brief and integrate the public health and medical service preparedness stakeholders in order to solicit guidance on developing and sustaining medical services that improve public health and medical service coordination and delivery for at-risk individuals.

3.0 Listening Session Profile: Engaging Diverse Stakeholders

The Listening Session was designed as a stakeholder engagement event where participants heard from senior officials within HHS and ASPR and engaged in a facilitated, interactive dialogue to provide input on topical questions focusing on ESF #8 and at-risk individuals. Leaders from ASPR and ABC launched the day's discussion making presentations on the role and responsibilities of their respective offices, as they relate to ESF #8 and providing public health medical services based on individual functional capabilities as defined by HHS and ASPR for at-risk individuals. Following the overview presentations, agency leaders engaged in a dialogue with participants as to how their roles and functions incorporate and impact their capability to provide public health medical services for at-risk individuals.

Discussion participants included experts and practitioners representing public health non-governmental organizations, health care providers and federal agencies involved in public health preparedness, planning and emergency response. Senior level representatives from: DHS, FEMA, HHS and state agencies along with nongovernmental organizations concerned with aging, disability, mental health, nursing and a number of other fields were joined by at-risk individuals. Together the stakeholders engaged in an open dialogue about the challenges and solutions needed to effectively address the needs of at-risk individuals during emergencies.

3.1 Listening Session Scope and Methodology
The focus of the Listening Session was on pandemic influenza, however participants also considered other public health incident scenarios and how they differ in response and recovery processes including mass evacuation, shelter-in-place and social distancing. Stakeholders were provided with a set of five questions to help frame the discussion and provide context for the information HHS wanted to obtain. The following questions were provided to participants for the discussion:

1. What is being done at the state, tribal, and local levels to identify and locate people with functional needs, particularly those with special medical needs?

2. What unique concerns do at-risk individuals have regarding access to appropriate public health and medical services?

3. What plans and best practices are you aware of that address these concerns and facilitate the provision of healthcare services (routine or event-related to these individuals)?

4. How have these practices, plans or strategies been successfully implemented at the state, tribal and local level to meet the needs of at-risk individuals?

5. What additional gaps or barriers exist for receiving public health and medical services?

4.0 Discussion Review and Evaluation: Gaps, Lessons Learned and Best Practices

Identifying, Locating and Understanding At-Risk Individuals with Special Medical Needs
(Questions #1 and #2)

> 1.What is being done at the state, tribal, and local levels to identify and locate people with functional needs, particularly those with special medical needs?
>
> 2. What unique concerns do at-risk individuals have regarding access to appropriate public health and medical services?

Communications, Messaging and Outreach
- Throughout the Listening Session, the need for communication and partnerships with community stakeholders was a significant discussion topic. Notably, all participants stated the need for more effective and inclusive messaging, multi-cultural awareness, diversity and the appropriateness of existing efforts to educate, notify and create awareness around locating and tracking processes. It was also noted that the National Resource Center on Advancing Emergency Preparedness for Culturally Diverse Communities serves as a clearing house for information to eliminate disparities for culturally diverse communities.
- There was discussion around the level at which communications is typically focused, mainly at the fourth and sixth grade level of understanding. There was general agreement that there needs to be a consistent level of messaging. It was suggested that there may be a role for HHS to provide guidance on appropriate messaging to "disenfranchised" populations and at-risk individuals.
- Effective, consistent and appropriate messaging was viewed as key to promote personal preparedness for at-risk individuals and to not have to rely on others. A point was made that using precise language is key to messaging and outreach, particularly for those not mentioned under the Stafford Act such as those with mental health or substance abuse, and confidentiality issues
- Communications among culturally diverse populations was mentioned as important due to social and economic issues such immigration laws that may affect their willingness and ability to obtain health services. It is important to create culturally-relevant materials, utilizing different mechanisms of communication. It was cited that registries need to be developed with bi-lingual capabilities.
- There was significant discussion on communicating to the youth population, utilizing teenagers and young adults as messengers and tapping the social and education networks, such as the "MTV crowd."

- Effective communication ensures that at-risk individuals clearly understand what services are available, where they can obtain them and how they can physically access them. It was noted that there also needs to be messaging to caregivers and support workers.
- There was specific mention of the need to provide greater outreach to those in public housing, homeless and others who are considered to be isolated or "off-the-grid." A specific comment was made that there should be greater focus on looking beyond traditional community housing and how people are relocated.
- It was specifically noted that there needs to be better communication with specialty health providers such as children's hospitals, not only for planning and operating models but also as a resource for demographic data on specific populations and individuals who may be at-risk. During this discussion it was noted that the American Association of Pediatrics (AAP) offers resources and data on vital children's health issues such as Medicaid, injury and violence prevention, immunizations as well as other related children's health information.

Model Plans and Best Practices
- There was discussion on the concept of a registry and the value of a registry in helping with public preparedness, transportation during evacuation, informing planning, and developing demographic information. Registries have been successful for some states and localities, yet there is still a need for clear guidance in establishing registries.
- Several participants mentioned examples where states have developed toolkits and registries to help communities with locating at-risk individuals. In particular, there is a program in North Carolina where these toolkits are being used successfully. In Georgia, a project has been developed that links a registry of people with a registry of service providers.
- Virtual Alabama was mentioned as a program that uses a dynamic, three-dimensional database for first-responders to conduct visual mapping, location aware and data sharing capabilities.
- It was indicated that clarification is needed as to how the Health Insurance Portability and Accountability Act (HIPAA) applies in emergency situations, particularly with registry and personal medical information. HIPAA information should be integrated into public health messaging.
- Collaborating Agencies Responding to Disasters (CARD) headed by Anna Marie Jones in Oakland, California, was cited as a unique preparedness program that complements traditional disaster response agencies by providing safe, culturally appropriate emergency services programs designed for community groups and the low-income and special needs communities they serve with a special focus on personal preparedness.

Service Coordination and Surge Capacity
- Working with power companies and medical equipment companies is a way to obtain access to their customer lists as a way of knowing where to find at-risk individuals. Participants felt that communities may be able to locate at-risk individuals with special medical needs by zip code because some utility, power and telecommunications companies use zip codes to track customers with special medical needs who rely on electricity.
- Several people commented that non-profit organizations/service providers (for example those focusing on aging, women, or children) have comprehensive databases of their clients that could serve as tracking resources.

- There was some discussion about tracking and locating people who live in nursing homes and those who live in private homes. There was general agreement that there needs to be better data on at-risk individuals at the community and neighborhood level.
- Diverse populations use state and local level networks such as churches, community-based organizations (CBOs), and social networks to locate people because they know them and trust them. For example, HHS partners with national organizations such as the National Council of La Raza (NCLR) to identify and communicate with Latino populations.

Federal Support and Community Collaboration
- It was consistently acknowledged that all planning services are provided at the local level, with a need to increase planning support for local communities. Many mentioned toolkits, planning templates, best practices, and models for at-risk population planning, as well as public health, medical and local emergency planning personnel. The idea of supporting central messaging and training efforts at the "grassroots" level was discussed as a way to help ensure access to medical services.
- It was noted that infectious diseases are a threat to the general population, and especially for at-risk individuals.
- Several participants spoke about the need for organizations to reach out to communities to understand the functional needs of their at-risk individuals. For example, understanding how many older adults on dialysis need medical services and transportation services will ensure that these individuals obtain adequate healthcare services.
- It was recognized that at-risk individuals can be very self-sufficient and that the term "special needs" is not always how people self-identify themselves which impacts the ability of federal agencies and localities to understand "who needs what" during an emergency.

<u>Successful Federal, State and Local Model Plans and Best Practices in Public Health and Medical Services for At-Risk Individuals</u> (Questions #3 and #4)

> 3. What plans and best practices are you aware of that address these concerns and facilitate the provision of healthcare services (routine or event-related to these individuals)?
>
> 4. How have these practices, plans or strategies been successfully implemented at the state, tribal and local level to meet the needs of at-risk individuals?

Communications, Messaging and Outreach
- The majority of participants recognized that tapping into social media and social networks can be very effective. Reference was made to how monitoring social media, such as Twitter, during Hurricane Katrina, worked well to coordinate tactical, policy and milling of messaging with people on the ground as well as with federal partners. Social media and technology were viewed as a way to centralize messaging for disenfranchised populations, with the Centers for Disease Control and Prevention (CDC) using social media applications and non-traditional messaging technology, such as mobile phones, pre-paid phones, list-serves, email, and community voicemail, to reach the homeless and other populations.
- There were several outreach and education best practices mentioned related to target populations such as women and children. One such example included how the

Association of State and Territorial Health Organizations (ASTHO) President partnered with the superintendent of schools to send a letter home with students for parents from the state health official to provide information on H1N1. Another example is the National Association of County and City Health Officials (NACCHO) partnering with Seattle King County to facilitate their school meal program, school kits, and school-based vaccination clinics. They have been increasing community outreach through the Mobilizing for Action through Planning and Partnerships (MAPP).

- A point was made regarding outreach and planning for pregnant women to ensure effective staff training on delivery and birthing through online training courses as is currently being offered by the Minnesota Emergency Readiness Education Training (MERET) program. It was noted that H1N1 has been shown to affect pregnant women disproportionately requiring increased worker training and greater focus on unplanned out-of-hospital births.

Model Plans and Practices

- The need was identified to develop best practices in mental health services and to ensure primary care medical services are available in mental health facilities, in doing so they could be used to provide prevention and wellness information and services. It was noted that there has been a lack of information about H1N1 prevention provided in mental health centers to patients. Mental Health America (MHA) has been working to better integrate mental health clinics and primary care services.
- One program that was highlighted in the Listening Session was the National Association of County and City Health Officials (NACCHO), which engages in cooperative agreements with the Medical Reserve Corps (MRCs) to build capacity through the Health Occupation Students of America (HOSA) program. HOSA's mission is to engage students early on for careers in public health. NACCHO also operates a "toolbox" that includes Advanced Practices and Model Practices, which are submitted and approved by the CDC.
- Several participants mentioned the need to develop best practices in basic public health such as how to correctly wash hands and reinforce messaging around these practices, while recognizing the social issues associated with messaging these practices. Educating people to keep a simple list of medications and prescriptions with them was cited as a messaging best practice. Bar coding durable medical equipment was viewed as a "promising practice" to track personal medical devices and equipment to know where people's equipment is at all times.
- There was considerable discussion related to programs that serve the aging population. Several programs were referenced as models for senior emergency preparedness, wellness and education. The Palm Beach Area Agencies on Aging's (AAA) Help Alert "Door Hanger" program was one of these groups/programs. The "Door Hanger" program encouraged seniors to leave hangers on their doors during an emergency to signify they were safe. This easily replicable idea proved to be an effective communication tool for seniors to use, allowing others in the community and authorities to quickly assess where help was needed. Local and state agencies have been developing innovative Medicaid transportation programs such as the Sickness Prevention Achieved through Regional Collaboration (SPARC) in Atlanta, Georgia. The AAA has also been working with counties to identify senior populations through the use of "Just-in-Time" registries that are linked with Medicaid transportation programs. Several AAA groups are working with community vaccination programs to provide transportation services for seniors, as well as education and outreach about these and other public health programs. AAA has set up "one-stop" vaccination centers to provide inexpensive or free

vaccinations, health screenings and preventive services. In addition, the Administration on Aging (AoA) at HHS publishes a multi-lingual newsletter and utilizes electronic media to send educational materials to its stakeholder network. AARP in addition offers toolkits through the "Operation Emergency Prepare" and Help a Neighbor program.

- Easter Seals is another organization that was highlighted for its work with local communities to provide transportation during a public health emergency through Project ACTION-- Accessible Community Transportation In Our Nation (ACTION). Through a public-private partnership between the U.S. Department of Transportation's Federal Transit Administration and Easter Seals, Project ACTION promotes cooperation between the transportation industry and the disability community to increase mobility for people and ensure they can access healthcare and other community services.

Service Coordination and Surge Capacity

- It was noted that during the recent H1N1 outbreak, it was very effective for hospitals to use pre-printed prescription scripts for different ages to facilitate faster discharging processes, more streamlined distribution of prescriptions and expedite treatment. For example, Children's National Medical Center (CNMC) was able to maintain its operational capacity to surge due to proactive planning factors such as messaging to families and matrixing staff availability with patient volume and instituting a no "opt-out" policy for staff. The use of Disaster Preparedness Advisors was noted as good way to provide tailored messaging for physicians, parents and medical personnel.

- Public-private partnerships were noted to work extremely well when they are well-organized and sustained. They worked well during Katrina because people felt like they had a stake, providing the opportunity for everyone to "opt-in" to the conversation to make their voice heard. The use of communications technologies such as conference calls using www.conferencecall.com and web casts to capture real-time input and information facilitates greater involvement and participation of stakeholders.

- It was noted that the FAST (Functional Assistance Service Training) program in Santa Clara, California has been extremely effective as a result of including peers with similar functional needs, along with service providers in training sessions.

Federal Support and Community Collaboration

- The national standards outlined in the Culturally and Linguistically Appropriate Services (CLAS) were recognized as 14 basic standards for health care organizations to integrate into culturally sensitive documents for messaging to cultural communities, particularly in social media. The Office of Minority Health launched the web site www.thinkculturalhealth.org to provide emergency preparedness information, strategies, training resources and emergency manager toolkits to promote cultural competency in public health and preparedness.

Gaps and Barriers in Public Health and Medical Services for At-Risk Individuals (Question #5)

> 5. What additional gaps or barriers exist for receiving public health and medical services?

HHS ASPR Operations Input

Prior to participant discussion, an overview was provided on the ASPR Operations structure and the process by which HHS receives data on at-risk individuals. This data is used to help implement ESF #8 and in the presentation included a flow diagram of how ASPR Operations

obtains information from the local communities up through state public health organizations. A challenge for HHS is collecting data from local communities on the number of hospital beds that are occupied by at-risk individuals at any given time, either day-to-day or during an emergency. From a federal perspective it is very difficult to locate at-risk individuals with special medical needs who are not in an institutional setting. Obtaining this information is a major challenge and an area where there could be greater partnership between the local and state agencies to obtain more accurate data.

Participants wanted to know why non-profit organization are not able to link directly to HHS to share information and how sharing information aligns with the health information technology efforts under the President's stimulus plan. It was explained that there were challenges with the standardization of data and the ability to integrate data across the federal, state and local levels. HHS relies on the information it obtains from state public health agencies, this creates specific challenges and gaps around the nature and amount of data each agency shares. It was indicated that efforts are underway to improve HHS data applications. Two examples are electronic medical records (EMR) and the Joint Patient Tracking System (JTPS) being used to develop a National Patient Tracking System. The National Patient Tracking System would provide an opportunity to develop integrated, standardization of data across the at-risk community.

Participant Input

Communications, Messaging and Outreach
- There was concern regarding the perception by federal agencies that there is a lack of data-information sharing. The point was made that state health agencies act as a "filter" of information for federal agencies and are only able to provide as accurate data as they receive from the local level.
- It was recognized that one of the challenges in data collection is that at-risk individuals are not necessarily "patients" so they would not be included in a medical model of data collection.
- There was an overriding consensus among the participants that messaging and communications on public health and medical services must be more tailored for at-risk individuals. Communications materials need to be in accessible formats, including accessible language formats. Simultaneously, public health messages need to be reinforced when they are crucial and demand significant resources such as vaccine dissemination for H1N1.

Model Plans and Best Practices
- There was general agreement that community planning guides need to better integrate data sources with best practices. The FEMA *Comprehensive Preparedness Guide (CPG) 301: Special Needs Planning* and the National Council on Disability's latest report on emergency preparedness and people with disabilities, provide information and advice to assist all levels of government in its work to establish evidence-based policies, programs and practices across the lifecycle of disasters. This report provides examples of effective community efforts that have increased capabilities to train personnel on evacuation, transportation, and special medical functional needs for at-risk. The report also evaluates many emergency preparedness, disaster relief, and homeland security program efforts deployed in both the public and private sectors.

Service Coordination and Surge Capacity
- There was common agreement from federal and non-federal participants that there needs to be better standardization, integration and flow of data regarding the public health demographic and medical service needs of at-risk individuals.
- It was recognized that there needs to be better understanding of the exact public health and medical service resources required to meet the needs of at-risk individuals that are known through various federal, state and local information sources.
- Mitigation and recovery were identified as areas in emergency planning that needed greater attention to effectively address the special medical needs of at-risk individuals on both the state and local level.
- To ensure at-risk individuals receive medical services in a timely, coordinated manner, it was suggested that HHS improve the process for obtaining Medicaid waivers, increase the Medicaid reimbursement levels, and improve overall processing of these monies.

Federal Support and Community Collaboration
- There was significant mention of addressing public health and medical services for homeless populations and others who are at-risk and may be considered "off-the-grid" and not in the mainstream of society.
- There were comments regarding the provision and implementation of medical services and making sure that there is clear distinction as to who are the "well' and who are the "sick" It was acknowledged that at-risk individuals are not necessarily sick and do not always require ESF #8 services.

Lessons Learned and Remaining Gaps (Questions #4 and #5)

> 4. How have these practices, plans or strategies been successfully implemented at the state, tribal and local level to meet the needs of at-risk individuals?
>
> 5. What additional gaps or barriers exist for receiving public health and medical services?

The Listening Session conversation revealed that despite concerted efforts by federal, state and local governments and agencies to develop best practices, promising practices and planning models that specifically address public health and medical services for at-risk individuals, there remain particular areas of concern including communication, messaging, demographic data, education, training, transportation, human and financial resources and general community and personal preparedness planning. The following represent particular areas cited as gaps, on-going challenges, and lessons learned as they relate to each question area and ESF #8 planning efforts for at-risk individuals.

Communications, Messaging and Outreach
- Lack of understanding of the specific data that facilitate a declaration of a public health emergency, such as hospital bed availability and specialty hospital admissions, and providing lead disaster declaration agencies with accurate data regarding the specific ESF #8 functions that are available and can be deployed effectively during a disaster or public health incident.
- Ensuring agency capability and capacity to sustain a long-term public health event, such as a pandemic, without an official disaster declaration as directed under the Stafford Act.
- Anticipating what states want from federal agencies to support public health and medical services that address functional and medical needs—such as the need for medical

equipment to walk and appropriate communication what is happening and where to go for help.
- Understanding what mission assignments need to be developed and how best to delegate mission responsibilities.
- The ability to accurately collect, assimilate and disseminate the complex demographic data on at-risk individuals to those providing public health and medical services.
- Ensuring effective coordination of ESF #8 public health services with other agencies.
- Cultural competency is often not well-integrated into messaging and public health materials. There are gaps in utilizing effective modes of communications for translating messaging and communications for multi-lingual and multi-cultural populations.
- There needs to be better integration of messaging of public health information in mental health centers.

Model Plans and Best Practices
- The cost of GIS, mapping and other tracking technologies for at-risk individuals can be expensive and prohibitive for smaller communities.
- Maintaining credible and trusted sources for disseminating public health and preparedness information, using trusted networks such as community-based organizations, demographic-specific organizations, faith organizations, workplaces, professional groups, or personal social networks. Messaging is too often inaccessible and inconsistent.
- Registries are often perceived as not maintaining security, privacy, or protecting personal data. They also need to be more diverse and developed with bi-lingual capabilities.
- Ensure people understand the importance of having a personal preparedness plan and having the resource to be able to take care of themselves. Public health messages are not reinforced enough.
- Many local groups do not have a clear picture of where people are located. Communities need valuable resources, such as Census data, for understating the at-risk demographic, as well for developing public health communications.
- There are discrepancies in how to track and locate people who live in various situations, including those who live in nursing homes and those who live in private homes.

Service Coordination and Surge Capacity
- Federal support cannot and does not mandate what communities need or how they act during a public health emergency. There needs to be better understanding of what communities and providers need federal agencies/HHS to provide, such as data on medical equipment users or physical or personnel resources.
- School closures do not work during a pandemic or flu outbreak because kids are going to find ways to congregate.
- Data on H1N1 was lagging and often inconclusive and inconsistent or had many discrepancies.
- Public-private partnerships are not always inclusive with those who have a significant stake.
- There is a lack of coordination of transportation providers between agencies and the need for adequate resources to support coordination activities for senior citizens and older adults to locate and provide physical access to Special Needs shelters and temporary shelter facilities.
- Public health and medical services such as vaccinations for people living in rural areas can be delayed or denied due to Medicaid waiver and reimbursement processes.

- The use of color-coded mechanisms to identify specific populations was characterized as a "bad practice" because it does not effectively represent accurate definitions of populations or cultural meaning.
- There was mention made regarding medical supply chain issues during H1N1 related to the insufficient supply of N95 masks and the lack of access to flu drugs such as Tamiflu at community pharmacists.

Federal Support and Community Coordination
- Medical needs should be integrated with personal support needs. People who require healthcare services may also require communication, transportation or personal attendant services.
- Using trusted relationships to facilitate communication and planning is important especially for culturally-diverse populations.
- Public-private partnerships work extremely well when they are well-organized and sustained.
- Training at the community and grassroots level is important including CERT exercises and practicing medication distribution processes.
- Developing a support network of personal care is important for maintaining self-sufficiency and ensuring continued support.
- Consistently utilizing a function-based approach for at-risk individuals ensures emergency responders, service providers and medical personnel understand how best to coordinate personal support needs with public health and medical service needs.
- For Latino community, CDC 1-800 Help Lines need to incorporate terminology that at-risk individuals understand, with centralized messages and use of common language. During the H1N1 outbreak, messaging in New Zealand and Australia began as very general and then moved to using targeted messaging for very specific groups to be more effective at reaching diverse, at-risk individuals.

5.0 Key Findings
The following findings are based on the discussion. They are intended for HHS/ASPR, as well as for the participants themselves and the various government and non-government organizations they represent. The recommendations present core thoughts and ideas on program and planning solutions for public health and medical services for at-risk individuals.

- HHS and public health officials should continue to promote a "culture" of personal preparedness that encourages personal responsibility using simple, clear and achievable goals and expectations.

- HHS and at-risk individuals' stakeholders should promote the theme that "all preparedness is local" and support community-based approaches that provide best-practice models.

- To respond to the significant challenges presented by public health emergencies, HHS should fully engage all at-risk stakeholders and create collaborative relationships between all levels of government, public service organizations, and communities with a vested interest in and ability to offer support for at-risk individuals.

- HHS and public health officials should provide more regular opportunities for active and bi-directional HHS and stakeholder engagement and coordination through increased

participation in future ESF #8 conferences, workshops, trainings, listening sessions and other venues that encourage open dialogue, input and feedback on public health and medical services for at-risk individuals.

- HHS planning programs and best practices should incorporate a functional needs-based approach for at-risk individuals based on C-MIST (Communication, Medical Care, Independence, Supervision, and Transportation) to provide guidance, coordination, and resource management to ensure the needs of at-risk individuals are fully addressed in preparedness and response plans.

- HHS should implement performance measures that facilitate better integration of the needs of at-risk individuals into its programs.

- HHS and public health officials should ensure that cultural diversity is recognized and fully included and integrated into all public health and medical service planning activities.

- HHS should increase outreach to rural communities to ensure that at-risk individuals are included in all aspects of emergency preparedness.

- HHS should increase education and communication to at-risk individuals on HIPAA and how it applies during an emergency response.

- HHS should utilize standardized data sets for capturing more accurate community-level demographic information on at-risk individuals to enhance emergency response capabilities.

- HHS should promote the concept and development of medical homes for at-risk individuals to provide better access to public health and medical services.

- Public health and medical service planning should be funded for states and localities to ensure their social service agencies, public health departments, and non-profit organizations can maintain capacity for public health preparedness and response for at-risk individuals.

6.0 Conclusion

At-risk individuals with special medical needs encounter disproportionate challenges in accessing public health and medical services in the course of daily living due to; cost, transportation, unavailable and inappropriate services, lack of trained service providers, general misconceptions about at-risk individuals and how personal functional needs impact not only medical needs but ultimately, access to adequate medical services. During a pandemic influenza outbreak or other public health incident, these challenges are magnified for at-risk individuals and the agencies, organizations and medical facilities that provide them with regular public health and medical services. HHS and ASPR are committed to working with their national, state, local and community partners to fully understand and assist with providing optimal support for at-risk individuals in emergencies and disasters based on their functional needs that may impede access to adequate healthcare.

The Listening Session demonstrated the benefit of obtaining a robust cross-section of ideas, actions, and meaningful dialogue from a diverse representation across federal, non-profit service organizations, medical providers and at-risk stakeholder groups. It created a unique venue for collaborative engagement of key stakeholders from an extremely diverse range of organizations with an interest, expertise and functional responsibility in public health, emergency preparedness, medical service and at-risk individuals. The dialogue provided valuable insight on public health and medical planning from the rich interaction of ideas from organizations and individuals serving and representing seniors, people with disabilities, women, Latinos, medical specialties, state and local public health officials, independent living and mental health communities. The Listening Session identified guidance on developing and sustaining medical services with partners that have a critical stake in improving public health and medical service coordination and delivery for at-risk individuals.

Most importantly, participants were able to have an open exchange of ideas that provided opportunities to learn from each other and provided for greater collaboration among the organizations. The collaborative nature was also instrumental in building new partnerships among participant organizations and strengthening their own capacity to impact health care access and service.

The information learned from the session will contribute to HHS/ASPR planning and operations responsibilities under ESF #8 and promote increased collaboration and information-sharing to ensure all at-risk individuals have full and equal access to public health and medical services, including behavioral health.

Appendix A
Listening Session Facilitation Format and Proceedings

Listening Session Facilitation Format
The Listening Session was designed and conducted as a "facilitated discussion" to engage stakeholder participants in a robust, open dialogue utilizing the five pre-determined questions and topic areas developed by HHS to prompt specific participant response. There were two outside facilitators that moderated the group discussion to stimulate, clarify, and focus the major points of discussion as well as capture the key topical data and information points provided on ESF #8 and special medical needs as it relates to location of at-risk individuals, best practices, model programs, program implementation success, and gaps and barriers to public health and medical services.

Listening Session Proceedings
The Director of the Office for At-Risk Individuals, Behavioral Health, and Human Services Coordination provided opening remarks including a brief explanation of ASPR and ABC and their specific role in preparedness and response for at-risk individuals. The day's discussion was designed to focus on ESF #8, for which the Department has the lead responsibility as designated by the National Response Framework (NRF). The Listening Session served as both an opportunity for participants to hear what HHS is doing in terms of ESF #8 and public health medical services for at-risk individuals, and for HHS to learn from the participants what is working at the grassroots level, what are the challenges and how they can be improved for at-risk individuals. Participants introduced themselves, providing a brief explanation of their organization and what they hoped to gain from the session discussion.

HHS/ASPR Overview
To provide context around how HHS responsibilities under ESF #8 are delineated and carried out, a presentation was provided on "ASPR and Emergency Support Function (ESF) 8: Roles in Emergency Response Operations." Topics discussed included ASPR's mission and vision, core functions, responsibilities, and the interdependence of HHS emergency operations and ESF #8 response and command structure. Key challenges were outlined such as anticipating states needs, fully understanding the at-risk demographic, developing mission assignments, and coordinating efforts against the primary ESF missions of other federal agencies to ensure services are not duplicated.

C-MIST and Special Medical Needs
ABC provided a brief overview of the definition of at-risk individuals specific to HHS and its public health and medical service responsibilities under ESF #8 to facilitate understanding of the demographic for the Listening Session. Further, ABC also outlined the context in which the population is defined by the Pandemic and All-Hazards Preparedness Act (PAHPA), highlighting the difference between at-risk and special needs and how it relates to special medical needs. The speaker explained C-MIST – Communication, Medical Care, Independence, Supervision and Transportation – the core functional needs, in addition to any medical needs, that may impede an individual's ability to access medical care during a pandemic or other public health emergency. (**See Appendix B & C for At-Risk Individuals and Special Medical Needs Fact Sheets**)

Participant Discussion Structure
Prior to engaging in larger participant dialogue, a question was asked regarding the specific disaster model for H1N1 to be used for the Listening Session. For the purposes of the day's discussion, HHS officials explained that it would be helpful for participants to use a social

distancing model in which people would be discouraged from going to a congregate setting, citing the example of those people with any medical vulnerability who may be required to stay at home and discouraged from going to a public setting, particularly where people obtain medical care. HHS also indicated that people should not only think about H1N1 influenza, but evacuation and transportation issues in other scenarios as well. It was pointed out that the two are not mutually exclusive such as there could be an influenza outbreak that occurs concurrently with an event that requires evacuation such as a hurricane.

HHS is seeking planning and operating models to identify and locate individuals and that provide solutions for providing optimal access to medical services. The participants were asked to provide options for locating individuals and identifying the nature of their special medical needs. Additionally, it was indicated that HHS would like to know how to find people with specific conditions, such as neuro-muscular disease, asthma, or Chronic Obstructive Pulmonary Disease (COPD); People with these conditions are at higher risk of complications from H1N1 influenza.

At key points in the dialogue, a review of the discussion was provided to indicate that themes stated upfront of evacuation and transportation, best practices, surge capacity, and messaging and outreach were still important. There was particular attention and discussion among the group regarding communication, messaging and outreach to at-risk individuals, with a focus on the concern about getting basic public health information to at-risk individuals. It was recognized that it is important for HHS and ASPR to ensure that messaging and communications do not become barriers to accessing medical services.

To facilitate the day's closing discussion on gaps and barriers that remain in public health and medical services for at-risk individuals, ASPR staff provided a brief presentation on what they rely upon for information and how it impacts medical services operations and the existing challenges HHS encounters in implementing ESF #8 activities for these individuals.

Appendix B
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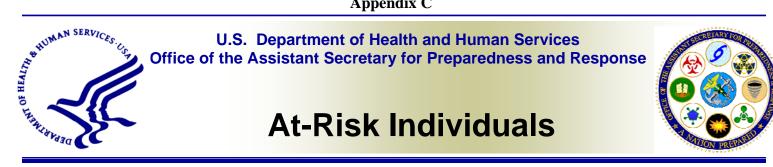Everett.Sedgwick@dhs.gov

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Appendix C

U.S. Department of Health and Human Services
Office of the Assistant Secretary for Preparedness and Response

At-Risk Individuals

The US Department of Health and Human Services (HHS) has developed the following definition of at-risk individuals:

> Before, during, and after an incident, members of at-risk populations may have additional needs in one or more of the following functional areas: communication, medical care, maintaining independence, supervision, and transportation. In addition to those individuals specifically recognized as at-risk in the Pandemic and All-Hazards Preparedness Act (i.e., children, senior citizens, and pregnant women), individuals who may need additional response assistance 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 HHS definition of *at-risk individuals* is designed to be compatible with the National Response Framework (NRF) definition of *special needs populations*. The difference between the illustrative list of at-risk individuals in the HHS definition and the NRF definition of special needs is that the NRF definition does not include pregnant women, those who have chronic medical disorders, or those who have pharmacological dependency. The HHS definition includes these three other groups because pregnant women are specifically designated as at-risk in the Pandemic and All-Hazards Preparedness Act and those who have chronic medical disorders or pharmacological dependency are two other populations that HHS has a specific mandate to serve.

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. They may have additional needs before, during, and after an incident in one or more of the following functional areas (C-MIST):

Communication – Individuals who have limitations that interfere with the receipt of and response to information will need that information provided in methods they can understand and use. They may not be able to hear verbal announcements, see directional signs, or understand how to get assistance due to hearing, vision, speech, cognitive, or intellectual limitations, and/or limited English proficiency.

Medical Care – Individuals who are not self-sufficient or who do not have adequate support from caregivers, family, or friends may need assistance with: managing unstable, terminal or contagious conditions that require observation and ongoing treatment; managing intravenous therapy, tube feeding, and vital signs; receiving dialysis, oxygen, and suction administration; managing wounds; and operating power-dependent equipment to sustain life. These individuals require the support of trained medical professionals.

Independence – Individuals requiring support to be independent in daily activities may lose this support during an emergency or a disaster. Such support may include consumable

medical supplies (diapers, formula, bandages, ostomy supplies, etc.), durable medical equipment (wheelchairs, walkers, scooters, etc.), service animals, and/or attendants or caregivers. Supplying needed support to these individuals will enable them to maintain their pre-disaster level of independence

Supervision – Before, during, and after an emergency individuals may lose the support of caregivers, family, or friends or may be unable to cope in a new environment (particularly if they have dementia, Alzheimer's disease, or psychiatric conditions such as schizophrenia or intense anxiety). If separated from their caregivers, young children may be unable to identify themselves; and when in danger, they may lack the cognitive ability to assess the situation and react appropriately.

Transportation – Individuals who cannot drive or who do not have a vehicle may require transportation support for successful evacuation. This support may include accessible vehicles (e.g., lift-equipped or vehicles suitable for transporting individuals who use oxygen) or information about how and where to access mass transportation during an evacuation.

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). At-risk individuals, along with their needs and concerns, must be addressed in all federal, territorial, tribal, state, and local emergency plans.
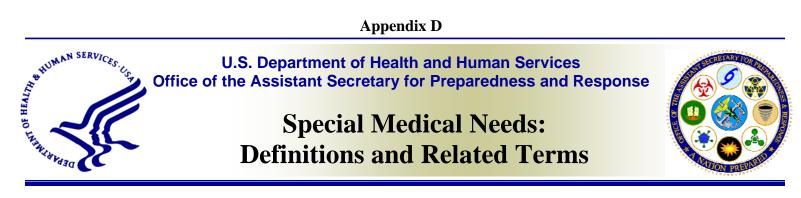
The following examples may assist with the understanding and identification of who may be considered at-risk.
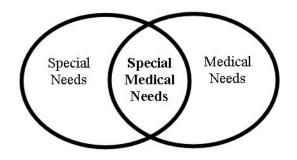
Example #1
An individual with HIV/AIDS who does not speak English and who contracts influenza could easily find herself in a precarious situation. In addition to treatment for influenza, her functional needs would be *medical care* (for the HIV/AIDS) and *communication* (her lack of English may keep her from hearing about where and how to access services). Without addressing those functional needs, she cannot receive adequate healthcare services.

Example #2
During an influenza pandemic, the health status of an individual who receives home dialysis treatment and who relies on a local para-transit system to attend medical appointments and food shopping could quickly become critical if 40% of the workforce is ill and transportation is suspended. In addition to treatment for influenza, his functional needs would be *medical care* (for dialysis) and *transportation*. Without addressing those functional needs, he cannot receive adequate healthcare services.

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Appendix D

U.S. Department of Health and Human Services
Office of the Assistant Secretary for Preparedness and Response

Special Medical Needs:
Definitions and Related Terms

Special medical needs populations are defined as those individuals, typically living in the community outside of a medical setting or environment, who need support to maintain an adequate level of health and independence during times of emergency. Included under this category are individuals who before, during, and after an emergency are medically dependent on uninterrupted electricity for therapies, require continual or intermittent medical care/support from a health care professional, or are not self-sufficient with the loss of adequate support from caregivers. The Venn diagram below may assist with the understanding of this population and its relationship to special needs and medical needs populations. Another way of understanding the relationship is to assume that special medical needs populations are a subset of special needs populations and medical needs populations, but not vice versa.

The National Response Framework (NRF) defines *special needs population* as populations whose members may have additional needs before, during, and after an incident in functional areas, including but not limited to: maintaining independence, communication, transportation, supervision, and medical care. Individuals in need of additional response assistance may include those who have disabilities; who live in institutionalized settings; who are elderly; who are children; who are from diverse cultures; who have limited English proficiency or are non-English speaking; or who are transportation disadvantaged.

Furthermore, HHS has developed the following definition of *at-risk individuals*: Before, during, and after an incident, members of at-risk populations may have additional needs in one or more of the following functional areas: communication, medical care, maintaining independence, supervision, and transportation. In addition to those individuals specifically recognized as at-risk in the Pandemic and All-Hazards Preparedness Act (i.e., children, senior citizens, and pregnant women), individuals who may need additional response assistance 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 HHS definition of at-risk individuals is designed to be compatible with the NRF definition of special needs populations. The difference between the illustrative list of at-risk individuals in the HHS definition and the NRF definition of special needs is that the NRF definition does not include pregnant women, those who have chronic

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medical disorders, or those who have pharmacological dependency. The HHS definition includes these three other groups because pregnant women are specifically designated as at-risk in the Pandemic and All-Hazards Preparedness Act and those who have chronic medical disorders or pharmacological dependency are two other populations that HHS has a specific mandate to serve.

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Appendix E
Examples of Promising Practices in Emergency Management
and Planning for At-Risk Individuals

Promising Practices
The following are examples of innovative and promising practices/programs geared toward addressing gaps in emergency management and planning for at at-risk individuals. These examples where taken from the National Council on Disability's (NCD) "Effective Emergency Management: Making Improvements for Communities and People with Disabilities" report.

Planning
The Kansas Association of Local Health Departments (2007) developed a Special Needs Assessment Tool Kit for pandemic influenza mapping and outreach. The tool kit provides detailed instructions on how to assess the needs of the elderly, people with disabilities, non-English-speaking people, and people living in congregate settings (homeless shelters, institutional settings, etc.). The tool kit also provides instruments for agency and household assessments.

The University of Kansas Research and Training Center on Independent Living created an online course to train hospital staff, health care workers, emergency personnel, and other workers to assist people with disabilities during disaster events. The online training is currently available to 22 states and the Medical Reserve Corps, including a version in large font. The course, "Ready, Willing, and Able" is eligible for continuing education credit by the Kansas Nurses Association and is available free at the Public Health Foundation's Train National website (other disability and emergency courses are also available on the site; see www.train.org).

What makes these initiatives examples of promising practices is that they:
- Are easily available over the Internet and free of charge.
- Offer clear instructions.
- Provide useful and practical tools (mapping, etiquette, communication, etc.).
- Are offered with the incentive of continuing education credit.
- Are available in alternative formats.
- Address a diverse set of potentially at-risk populations.
- Have content based on both research and practitioner knowledge.

Registries
Registries have emerged as a possible means to identify and conduct planning for citizens with needs for transportation, evacuation, and other kinds of assistance. In the spring of 2008 New Jersey's Office of Emergency Management launched a "Register Ready" effort to sign up people with disabilities who may need help during an evacuation or emergency. The registry is part of a multi-step education initiative that urges citizens to create a kit, develop a plan, and register if they anticipate needing assistance. According to New Jersey's Office of Emergency Management the registry holds information on 8,000 -10,000 individuals and will be state wide in 2010.

The following registry features reflect promising practices:
- Web-based registration.
- 2-1-1 telephone service support to register people who are unable to use web-based systems, along with free translation and TTY.

- Distribution of registration forms at emergency management offices, with the intent to expand to all 21 counties by 2010.
- Ads on billboards and in newspapers.

Response: Resources

OK WARN of Oklahoma's Office of Emergency Management (OEM) provides low or no-cost alternative warning messages through texts and pagers for people who are deaf or hard of hearing. The OEM worked with the National Weather Service to design and implement the service.

Using Community-Based Organizations

The San Mateo (California) Health Department is a good example of an organization that has a history of using organizations to conduct outreach during the response period. As part of the department's regular work it links seniors, people with cognitive or mobility disabilities, the homeless, undocumented immigrants, non- or limited-English-speaking people, and people living in rural areas with appropriate CBOs. After a survey of these special populations and a series of community forums, specific CBOs that served large service populations and had appropriate organizational capacity where selected to become community partners during the event of an emergency. One example of such a partner is Aging and Adult Services, which can reach thousands of clients through a phone tree system that can be activated during an emergency. The health department effort subsequently included training for CBOs, development of a communication system for use during an emergency, and a formal MOU (for a sample MOU, go to www.pandemicpractices.org/practices). The promising practices dimensions of this effort include:

- Using trusted and credible CBOs to disseminate information to at-risk populations.
- Using organizational-level links to distribute critical emergency information to at-risk populations.
- Providing training for the CBOs on pandemics, emergency planning, continuity of operations, and communications.
- Developing a formal MOU to clearly specify each organization's roles.

Transportation and Evacuation

Recent disasters have revealed issues with evacuating those with special needs. Many people with disabilities can evacuate with public transportation support, especially para-transit vehicles. After Hurricane Katrina, FEMA contracted with American Medical Response (AMR) to provide para-transit evacuation services for New Orleans and 12 other Louisiana parishes during the hurricane season of 2006. FEMA awarded an exclusive contract to AMR in 2007 to provide a variety of services to 21 states along the Gulf and Atlantic Coasts, with optional services to the West Coast and the central portion of the United States. Services include triage, treatment, transportation, hazard recognition, symptom surveillance and reporting, on-scene medical standby, transport of hospital patients, immunizations, shelter staffing, staffing of hospital emergency departments, and setup of mobile medical clinics. AMR was activated for Hurricane Dean in August 2007; it deployed 300 ground ambulances, 25 air ambulances, and enough vehicles to provide transportation for 3,500 passengers. Many people with disabilities can evacuate with public transportation support, especially para-transit vehicles. Involving para-transit assets is a promising practice because:

- Local para-transit systems have drivers who are already familiar with client needs and locations, and can be used as key assets in an emergency.

- It uses a pre-disaster agreement developed and implemented by FEMA and the General Services Administration (GSA), with a considerably larger and more diverse set of assets than most jurisdictions have.
- It uses a service that has expertise in both disabilities and disasters.

Appendix F
Listening Session Recommended Resources

Federal Resources

Department of Health and Human Services, "Know What to Do About the Flu,"
http://www.flu.gov/

Department of Health and Human Services, Administration on Aging (AoA), Emergency
Preparedness and Response, http://www.aoa.gov/AoARoot/Preparedness/index.aspx

Department of Health and Human Services, Assistant Secretary for Preparedness and Response
(ASPR), http://www.hhs.gov/aspr/
   • "Pandemic and All-Hazards Preparedness Act (PAHPA) Progress Report," November
     2007, http://www.hhs.gov/aspr/conference/pahpa/2007/pahpa-progress-report-
     102907.pdf
   • "Pandemic and All-Hazards Preparedness Act (PAHPA) Progress Report on the
     Implementation of Provisions Addressing At-Risk Individuals," August 2008,
     http://www.hhs.gov/aspr/opeo/documents/pahpa-at-risk-report.pdf

Department of Health and Human Services, Centers for Disease Control and Prevention (CDC),
http://www.cdc.gov/
   • Emergency Preparedness and Response: Clinician Outreach and Communication Activity
     (COCA), http://www.bt.cdc.gov/coca/
   • Social Media Campaigns, http://www.cdc.gov/SocialMedia/Campaigns/H1N1/

Department of Health and Human Services, Office of Minority Health, http://www.omhrc.gov/
   • Cultural Competency Curriculum for Disaster Preparedness and Disaster Response,
     https://cccdpcr.thinkculturalhealth.org/
   • National Standards on Culturally and Linguistically Appropriate Services (CLAS),
     http://www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=15

Department of Health and Human Services, Office for Civil Rights (OCR), Health Information
Privacy, "Disclosures for Emergency Preparedness - A Decision Tool,"
http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/emergency/decisiontoolintro.html

Department of Homeland Security, National Response Framework,
http://www.fema.gov/pdf/emergency/nrf/nrf-core.pdf

Department of Homeland Security, National Response Framework Resource Center,
http://www.fema.gov/emergency/nrf/

Federal Emergency Management Agency, Office of Civil Rights and Civil Liberties (CRCL),
"Comprehensive Preparedness Guide (CPG) 301: Special Needs Planning,
http://www.fema.gov/pdf/media/2008/301.pdf

National Council on Disability (NCD), "Effective Emergency Management: Making
Improvements for People with Disabilities and Communities," August 12, 2009.
http://www.ncd.gov/newsroom/publications/2009/NCD_EmergencyManagement_HTML/Effecti
veEmergencyManagement.html

S. 3678, Pandemic and All-Hazards Preparedness Act,
http://www.govtrack.us/congress/billtext.xpd?bill=s109-3678

Non-Federal Resources
The links provided here are for informational purposes only and HHS does not necessarily endorse the information contained on these websites.

Alabama Department of Homeland Security, "Virtual Alabama,"
http://www.dhs.alabama.gov/virtual_alabama/home.aspx

American Academy of Pediatrics (AAP), http://aap.org/
- Children and Disasters, http://www.aap.org/disasters/index.cfm
- Children's Health Topics: Disaster Preparedness,
  http://www.aap.org/healthtopics/disasters.cfm

American Association of Retired Persons (AARP), "Operation Emergency Prepare,"
http://www.aarp.org/makeadifference/volunteer/create_the_good/Operation_Emergency_Prepare
/
American Nursing Association, http://www.nursingworld.org/

Association of state and Territorial Health Officials (ASTHO), http://www.astho.org/
- At-Risk Populations Project (ARPP), http://www.astho.org/Programs/Infectious-Disease/At-Risk-Populations/
- "At-Risk Populations and Pandemic Influenza: Planning Guidance for state, Territorial, tribal, and Local Health Departments," June 2008,
  http://www.astho.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=402

Association of Women's Health, Obstetric and Neonatal Nurse (AWHONN), Online Learning Center,
http://www.awhonn.org/awhonn/content.do;jsessionid=2364FA1496C5B01DBC3C756119598C
C9?name=02_PracticeResources/2G5_OnlineLearningCenter.htm

California Department of Social Services, Functional Assessment Service Teams (FAST),
http://www.cdss.ca.gov/dis/PG1909.htm

Children's National Medical Center, http://www.childrensnational.org/

Collaborating Agencies Responding to Disasters (CARD), http://cardcanhelp.org/

EAD & Associates, LLC, "Resources," http://www.eadassociates.com/resources.html

Easter Seals, Project ACTION,
http://projectaction.easterseals.com/site/PageServer?pagename=ESPA_homepage

Mental Health America, http://www.mentalhealthamerica.net/

Minnesota Emergency Readiness Education Training (MERET) program,
http://www.nursing.umn.edu/meret/

National Alliance for Hispanic Health, http://www.hispanichealth.org/

National Association of Area Agencies on Aging (n4a), http://www.n4a.org/
- Annual and Topical Survey Reports[1], http://www.n4a.org/programs/annual-survey/
- National Center on Senior Transportation, http://www.n4a.org/programs/ncst/
- Sandy Markwood, Chief Executive Officer, National Association of Area Agencies on Aging, "Emergency Preparedness, Protecting Aging & Special Needs Populations." Testimony presented before the U.S. Senate Special Committee on Aging, June 24, 2009. http://www.n4a.org/pdf/Sen_Aging_Comm_EP_testimony_6.24.09.pdf

National Association of County and City Health Officials (NACCHO), http://www.naccho.org/
- Health Occupations Students of America, http://www.hosa.org/
- Mobilizing for Action through Partnerships and Planning (MAPP), http://www.naccho.org/topics/infrastructure/MAPP/index.cfm
- NACCHO's Toolbox of public health-related tools, http://www.naccho.org/toolbox/

National Association of Councils on Developmental Disabilities, http://www.nacdd.org/

National Association of State Alcohol Drug Abuse Directors, http://www.nasadad.org/

National Association of State Units on Aging, http://www.nasua.org/index.html

National Conference of State Legislatures (NCSL), http://www.ncsl.org/

National Council of La Raza (NCLR), http://www.nclr.org/

National Council on Independent Living, http://www.ncil.org/

National Disability Rights Network, http://www.napas.org/

National Resource Center on Advancing Emergency Preparedness for Culturally Diverse Communities, http://www.diversitypreparedness.org/

Sickness Prevention Achieved through Regional Collaboration (SPARC), Atlanta, GA, http://www.agingatlanta.com/agewise/documents/sparc_info_sheet.pdf

Trust for America's Health, http://healthyamericans.org/

University of Minnesota, Center for Infectious Disease Research and Policy (CIDRAP), "Promising Practices: Pandemic Preparedness Tools," http://www.cidrappractices.org/practices/article.do?page=home

Visiting Nurse Associations of America, http://vnaa.org

Washington State Department of Health, Perinatal Advisory Committee, http://www.doh.wa.gov/CFh/mch/PerinatalAdvCom.htm

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[1] The AAA Survey Report highlights the programs and services AAAs provide to assist older adults to remain in their homes and communities for as long as possible. . Over 80% of all AAAs responded to this survey. . The Emergency Readiness and Response report summarizes key findings from a short topical survey focused on the emergency planning and disaster relief activities of AAAs. . These reports illustrate the growth, innovation and adaptation of the Aging Services Network and their ability to address the needs of America's rapidly increasing aging population.