

Public Health Preparedness and Response for At-Risk Populations

Harnessing the Power of Health Information and Communication Technologies

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Table of Contents

Executive Summary	1
Protecting the Most Vulnerable Populations	1
Terms of Engagement	2
Improving Situational Awareness in Preparedness and Response.....	4
Legislative and Policy Framework to Improve Preparedness and Response	6
Public Health Preparedness and Health IT Innovation	11
Innovations in Communications Technology	15
Closing the Gaps in Public Health Preparedness	18
Conclusion	20
References	22
About the Authors	26
About Booz Allen	27
Principal Offices	Back Cover

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Executive Summary

People with disabilities and other vulnerable groups bear disproportionate risks during and after natural disasters and other public health emergencies. Low-income individuals and their families, seniors, language-locked communities (such as recent immigrants), and other “at-risk” groups also face similar risks during and after disasters. Already facing additional challenges on a daily basis and often lacking access to new communication technologies, these at-risk groups are often left out of disaster planning, experience gaps and delays in communication and coordination during the response phase, and need a longer time to recover compared to the mainstream.¹ Public health and disability organizations recognize this digital divide, and have taken many steps across the country to improve emergency planning and response for people in these at-risk groups.²

New opportunities for improvements have emerged since the passage of the American Recovery and Reinvestment Act (ARRA) in February 2009. ARRA includes funds to build the information and communications infrastructure through wireless and broadband technologies to enhance public health, safety, and security programs. It also includes nearly \$20 billion for developing electronic health records (EHRs) to promote health information exchange by consumers and providers. Combined with an emerging focus on “all-hazards” preparedness and response, this new environment offers fresh opportunities and resources to improve public health preparedness, response, and recovery for at-risk populations—including those who were at risk prior to an event and those who may become more vulnerable during or following an event.

Throughout this paper, we outline the preparedness challenges for people with disabilities and other at-risk groups, describe the information and communications technologies being used by healthcare providers and consumers, and give examples of innovative ways

state governments and local communities are using technology to reach those who are most at risk. We also recommend steps that consumers, healthcare providers, and government can take to harness information and communications technology and advocate for continued technology innovations to improve public health preparedness and response from an all-hazards perspective, including disease outbreaks, natural disasters, terrorist attacks, and for any potential threat.

Many consumers and advocates are encouraged by the investment in health and communications technology because it creates a level playing field with the rest of society, essentially mainstreaming those at risk and people with disabilities into the technology revolution.

Protecting the Most Vulnerable Populations

More than any other disaster in recent years, Hurricane Katrina brought the failures and flaws of our national emergency response system to light. Katrina was not only one of the worst natural disasters in the nation’s history, but a devastating failure of government and community infrastructure in protecting the most vulnerable members of the population in New Orleans and surrounding areas.³

Since Katrina, significant improvements have taken place in public health preparedness planning for vulnerable and at-risk populations as a result of national policies and directives that enable preparedness innovations, notably the Post-Katrina Emergency Response Act (PKEMRA).⁴ Improved collaboration, greater sharing of resources, more

Coordination is Key

As part of the Haiti earthquake response effort, social media and mobile phones have been used to coordinate relief efforts and provide online information about where resources could be found. An online volunteer network called Ushahidi created a map that showed where medical emergencies, food shortages, and other problems were located, based on information provided via text message, e-mail, and Twitter. Once telecommunications networks were re-established, a free telephone number for emergency information and appeals for help was set up and advertised by radio stations. Since many messages were in Creole, a group of volunteers at a CrisisCamp Haiti created a free Creole-to-English and English-to-Creole “app” for iPhones for use by the relief workers on the ground in Haiti.

Wilhelm, Ian. “Volunteer Technology Efforts Help Haiti.” *The Chronicle of Philanthropy*, January 26, 2010.⁵

consistent policies, and service integration among federal, state, and local agencies have reduced barriers to helping people during an emergency who have additional medical and functional needs. Communications technology has also had an impact. Consumer use of mobile phones has increased and the first sources of news during rescue and recovery efforts are often eyewitnesses using mobile phones to post information on Twitter and YouTube.⁶

Terms of Engagement

Many challenges remain in identifying and locating individuals during response and recovery phases, improving access to assistive communication and messaging, and ensuring adequate, real-time

information exchange among first responders. One of the major hurdles is to understand the diverse and unique special medical needs of undefined populations so that first responders and medical personnel can adequately triage and treat people in an emergency.

The definitions and determinants of the at-risk, vulnerable, and special needs populations continue to be a major subject of debate among public policy officials, federal agencies, advocacy groups, and local emergency planning departments. The terms “at-risk,” “vulnerable,” and “special needs” are used interchangeably by different federal and state agencies, and among communities and service organizations. This makes it difficult to find consistent guidance needed to effectively coordinate planning for these populations.⁷

The term “special needs” is widely used within disaster services and the emergency management field. It generally includes an extremely broad group of people, including people with physical disabilities, people with serious mental illness and psychological conditions, minority groups, non-English speakers, children, and the elderly. Other lists also add single working parents,

Functional Needs Can Delay Access to Medical Care

The Department of Health and Human Services’ (HHS) definition of at-risk individuals is compatible with the National Response Framework definition of a special needs population. Individuals with medical needs may also have needs in other functional areas before, during, and after a disaster: Communication, Medical Care, Independence, Supervision, and Transportation (C-MIST).

Office of the Assistant Secretary for Preparedness and Response, HHS, At-Risk Individuals Fact Sheet.

www.hhs.gov/aspr/oepo/abc/index.html

transportation-disadvantaged (people without vehicles), people with special dietary needs, people living in nursing homes and assisted living facilities, pregnant women, and people who are homeless.

Within each of these categories, local communities are challenged with understanding specifically who to include so they can target outreach efforts in proportion to the specific needs. Transportation-disadvantaged populations may be concentrated in urban (e.g., high-rise apartments, public housing, assisted living facilities) or rural areas (e.g., migrant farm community), each bringing a different set of challenges and potential solutions.

The lack of a nationally accepted, singular definition of “people with disabilities,” “special needs,” “at-risk” and “vulnerable populations” has caused much debate around who gets served by public health officials, first responders, and medical professionals during and after a disaster situation. In many respects, it represents the single greatest challenge when trying to plan effective emergency and public health service coordination for all citizens, and especially for populations with special needs.

While the interpretation of the term “special needs” varies among communities, some terms have legal implications and must be considered for preparedness planning.* For example:

- **Americans with Disabilities Act (ADA), 1990.**⁸

According to the ADA, persons with disabilities are a protected class. An individual is defined as someone with a disability if they:

- Have a physical or mental impairment that substantially limits a major life activity;
- Have a record of such an impairment; and/or
- Are regarded as having such an impairment.

- **US Health and Human Services (HHS), Pandemic and All-Hazards Preparedness Act (PAHPA), 2006 National Health Security Strategy (NHSS) of the United States of America, 2009.** According to

the PAHPA NHSS, the term “at-risk individuals” is applied to those individuals who “before, during, and after an incident...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.”⁹

- **Centers for Disease Control and Prevention (CDC), National Center for Birth Defects and Developmental Disabilities, 2004.** In a discussion of hurricane preparedness for people with disabilities, their families, and first responders, the following definition of “special populations” was provided: “groups whose needs are not fully addressed by traditional service providers or who feel they cannot comfortably or safely access and use the standard resources offered in disaster preparedness, relief, and recovery. They include, but are not limited to, those who are physically or mentally disabled (blind, deaf, hard-of-hearing, cognitive disorders, mobility limitations), limited or non-English speaking, geographically or culturally isolated, medically or chemically dependent, homeless, frail/elderly, and children.”¹⁰

In recent years, there has been a shift from a clinical definition based on individual conditions to a function-based approach using an established framework that encompasses a broad set of common needs irrespective of specific diagnoses, statuses, or labels (e.g., those with HIV, children, senior citizens). The functional definition of at-risk individuals established by the Federal Emergency Management Agency (FEMA) as outlined in the National Response

* It is important to differentiate between the ADA definition and agency definitions of “special needs” populations used by HHS, the Department of Homeland Security (DHS), and the CDC. Since the ADA is law, the definition of “people with disabilities” means that they are a protected class and can use the ADA as statutory authority for enforcement and lawsuits. Other agencies can offer definitions of special needs as guidance or for the purposes of that specific agency’s planning benefit, but often are not enforced or regulated in the same way that the ADA law is regulated and enforced.

Framework¹¹ is intended to become the standard for health preparedness, emergency planners and managers, and local public health departments. The framework is based on five distinct functional areas for individuals who have medical and other needs before, during and after a disaster: Communication, Medical Care, Independence, Supervision and Transportation (C-MIST).

The C-MIST definition provides a standard for agencies with Emergency Support Functions and other federal, state, and local entities with emergency responsibilities to more effectively meet the needs of people with disabilities. For HHS, the framework has been harmonized to be congruent with the Department of Homeland Security (DHS) National Response Framework and focuses on the ability to receive and access medical care, with an emphasis on pregnant women, those with chronic medical conditions

requiring medication, such as diabetes, and those with behavioral disorders.¹²

Characterizing at-risk populations by functional needs has improved the understanding of community demographics and the ability to locate those who might need help during an emergency, and it has improved service coordination in some communities. However, discrepancies remain in the ability of local governments to account for those who are outside the mainstream of a community, such as immigrants, language-locked communities, and homeless individuals. Compounding these challenges is that information exchange and data integration between federal, state, and local governments, first responders, service providers, and the public remains fragmented and incomplete. Information and communication technologies clearly can play a larger role in public health preparedness for at-risk and vulnerable populations.

Addressing Functional Needs for At-Risk Populations

“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 percent 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.”

"At-Risk Individuals," US Department of Health and Human Services, Assistant Secretary for Preparedness and Response
www.hhs.gov/aspr/oepo/abc/index.html

In December 2009, HHS released the Congressionally mandated National Health Security Strategy (NHSS), which is the nation's first comprehensive strategy focusing specifically on protecting the public's health prior to, during, and after an incident.¹³ NHSS provides a framework for a broad range of public- and private-sector stakeholders to coordinate their efforts to ensure timely and effective communications, interoperable information technologies, and effective risk communication with the public.

Improving Situational Awareness in Preparedness and Response

Effective and timely exchange of information among healthcare providers, state and local public health officials, and other health emergency response partners is essential to all-hazards emergency preparedness and response. It ensures that citizens understand the implications of an emergency situation, are prepared for the onset of an incident, will be able to evacuate, will be able to obtain emergency medical help, and will be able to access resources for recovery and reintegration back into the community.

Protecting and Providing for the Most Vulnerable Members of the Population

“In times of crisis, government plays a critical role in coordinating response and recovery efforts, especially in protecting and providing for the most vulnerable members of our population. The needs of children and other members of our communities with special access and functional needs cannot simply fall to secondary planning considerations, but must be one of the central focuses of our planning, response, and recovery.”

Craig Fugate, Administrator, Federal Emergency Management Agency, testimony before the Senate Subcommittee on Disaster Recovery, Committee on Homeland Security and Governmental Affairs, December 10, 2009

The National Council on Disability (NCD), an independent federal agency, reports that, “significantly more needs to be done to improve disaster response for people with disabilities.” In a 2009 report on improving emergency management for communities and people with disabilities, NCD noted that people with disabilities are “largely ignored in emergency planning and are rarely consulted when emergency management officials make disaster preparedness plans.” For example, inadequate communications and poor warning and alert systems can result in delayed and inadequate medical care and disruption to caregiver networks.¹⁴

While too few disaster response workers have been trained to deal effectively with people with disabilities, too few people with disabilities are adequately prepared to help save their own lives. Of the 54 million Americans with disabilities, approximately 6 out of 10 (61 percent) have not made plans

to quickly and safely evacuate their homes in an emergency, and nearly one-third (32 percent) report that plans have not been made to evacuate them from their workplace in case of a disaster. In 2005, nearly half (46 percent) of all people with disabilities did not know whom to contact about emergency plans for their community.¹⁵ According to the National Organization on Disability (NOD), almost nine out of ten (86 percent) community-based disability service providers did not know how to access their emergency management systems prior to Katrina.¹⁶

People with Disabilities Are Often Overlooked

“People with disabilities are “largely ignored in emergency planning and are rarely consulted when emergency management officials make disaster preparedness plans.”

National Council on Disability.
“Effective Emergency Management for
Communities and People with Disabilities—
In the Public Eye,” August 2009.¹⁷

As early as 1995, national experts were recommending accessible communications technology to improve disaster preparedness and planning efforts. A joint report by the Annenberg Washington Program of Northwestern University and the President’s Committee on Employment of People with Disabilities developed seven guiding principles for the disabilities and emergency preparedness communities to follow when developing disaster planning and response:

- Accessible disaster facilities and services;
- Accessible communications and assistance;
- Accessible and reliable rescue communications;

- Partnerships with the media;
- Partnerships with the disability community; and
- Disaster preparedness, education, and training.¹⁸

A little more than 10 years later, a White House report made several recommendations for ways to improve communications based on lessons learned after Katrina. The report recommended the development of a national communications strategy “that supports communications operability and interoperability” and a national crisis communication system that provides for connectivity among federal, state, and local officials. It also recommended an integrated public communications plan “to better inform, guide, and reassure the American public before, during, and after a catastrophe.”¹⁹ In September 2009, the Federal Communications Commission (FCC) released a readiness review indicating that the FCC is prepared to perform its mission in communications emergencies and will continue to work on improving emergency planning and response in the areas of education and training, outreach and collaboration, emergency operations and alerts, and network analysis.²⁰

Legislative and Policy Framework to Improve Preparedness and Response

Since 9/11, the anthrax attacks, and Hurricane Katrina, several new laws and directives specifically address the need for improved service coordination and information sharing among federal, state, and local entities. The most prominent legislative vehicle impacting emergency and disaster preparedness for people with disabilities and vulnerable populations has been the Post-Katrina Emergency Reform Act of (PKEMRA). The law amended the Robert T. Stafford Disaster Relief and Emergency Assistance Act with important disability provisions, including the appointment of a special needs advisor. Under PKEMRA, FEMA has an increased responsibility to ensure the welfare of special needs populations as the federal lead for disaster preparedness and response.

Take a Reality-based Approach

“Emergency preparedness for people with disabilities and activity limitations must integrate the users’ economic, physical, social, and communication realities.”

June Isaacson Kailes, Individual Emergency Preparedness for People with Disabilities, Their Families, and Support Networks, 2009.²¹

FEMA’s key responsibilities include promoting improved information exchange through accessible telephone and other telecommunications systems regarding emergency preparedness, evacuations, and disaster relief.²² For example, FEMA’s Office of National Continuity Programs has developed and is implementing an Integrated Public Alert and Warning System (IPAWS) to leverage newer communication technologies to improve the nation’s ability to provide warnings and alerts. PKEMRA includes provisions to improve disaster emergency communications and interoperability capabilities to ensure that people with disabilities and other special needs and at-risk populations are integrated into all emergency planning information originating with the federal government.

New opportunities for implementing communications infrastructure improvements are emerging since the passage of the American Recovery and Reinvestment Act (ARRA) in February 2009. ARRA includes the Health Information Technology for Economic and Clinical Health (HITECH) Act, an investment of nearly \$20 billion to help build the information and communications technology infrastructure and help transform the healthcare delivery system through electronic health records, health information exchange across providers, telehealth, and other technologies to improve provider access to medical records and consumer access to their own health information.

Greater awareness and understanding of how the nature of specific incidents and disaster situations affect special needs and at-risk populations is critical to making planning changes utilizing innovations in health information and communications technologies.

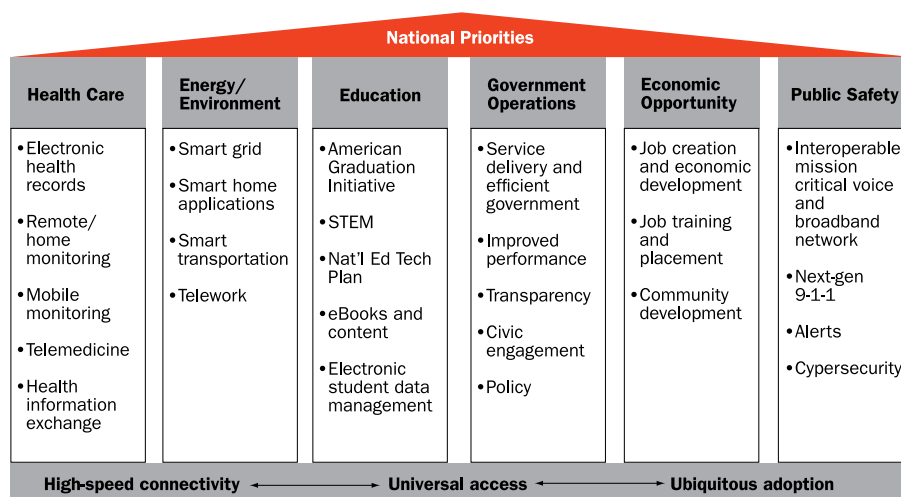
ARRA also includes specific provisions for advancing communications technologies such as wireless and broadband to improve public health, safety, and security programs for local communities. For example, it calls for the Federal Communications Commission (FCC) to develop a National Broadband Plan by February 2010 to ensure all people have access to broadband capability. A key goal of this plan is to ensure that technology preserves and protects the lives, property, and public safety of all citizens by making broadband technologies such as hand-held computers, video, and data wireless and mobile communications universally accessible and usable by first-responder personnel, public health officials, and citizens.

This new environment offers largely untapped resources for at-risk populations, including people with disabilities, low-income individuals and communities, and culturally distinct communities such as recent immigrants. For example, as the Haiti earthquake response has demonstrated, millions of people can benefit from the use of mobile phones and social media sites to communicate with family and friends during an emergency.

To fulfill the ARRA legislative mandate, the FCC is actively working to improve the use of personal communications technologies during an emergency, particularly for deaf and hard-of-hearing consumers. The FCC has issued new policies and launched outreach efforts to ensure that facilities that provide Telecommunications Relay Services for people with hearing and speech disabilities are designated priority for restoration of service in cases of emergency.²³

In addition, the FCC is collaborating with stakeholder groups such as the Rehabilitation Engineering and Research Center (RERC) at the Georgia Institute of Technology to determine what is needed to ensure that the next-generation, digitally based emergency

Exhibit 1 | Framework for a National Broadband Plan



Source: "Framework for a National Broadband Plan." www.fcc.gov/Daily_Releases/Daily_Business/2009/db0929/DOC-293742A1.pdf

alerts system affords full access to people with disabilities. Wireless and mobile phone technologies are increasingly being used to locate and track at-risk populations utilizing cell phones with Geo-spatial Systems (GPS).²⁴

The FCC has held a series of workshops with stakeholders to promote an open dialogue with people with disabilities, advocates for people with disabilities, service providers, assistive technology researchers, and other groups that have a stake in the future of broadband and its accessibility for people with disabilities. The discussions include ways to improve public safety and security in public health preparedness, including broadband capabilities for first responders, next-generation 9-1-1 networks, and telehealth and telemedicine networks.²⁵

Broadband technology can contribute to the overall safety of the public by vastly expanding the means by which all people, particularly those with disabilities and at-risk populations, receive emergency-related information, share personal health information, and obtain adequate public health and medical services. Broadband enables innovations in health care, public safety, and other national priorities that can vastly improve public health preparedness for at-risk populations.

Be Inclusive

“I firmly believe this National (Broadband) Plan must also include a principle of inclusion that would speak directly to the accessibility and usability of broadband for people with disabilities.”

Jenifer Simpson, American Association of People with Disabilities Testimony at FCC Field Hearing, November 6, 2009.²⁶

Risk Communication is an Ongoing Process

“Effective risk communication involves being able to reach all segments of the affected population, especially persons with limited English proficiency and persons with disabilities, in ways they trust and understand, and to receive information from the public through multiple channels.”

National Health Security Strategy, HHS, December 2009.²⁷

Emergencies require coordination of communications infrastructure and assets, as well as other national, state, and local resources. The guidance and protocols for communications and decision-making are set out in the National Incident Management System (NIMS) and the National Response Framework (NRF), which designates FEMA within DHS as the lead agency.²⁸

In addition to agency-specific directives and mandates, federal agency coordinating efforts and partnerships seek to facilitate cooperation among federal, state, local, and Tribal governments, private organizations, and individuals in the implementation of emergency preparedness plans as they relate to individuals with disabilities and at-risk populations. The framework as described on pages 9 and 10 of this paper summarizes key federal partnerships that affect emergency planning and preparedness efforts for at-risk and vulnerable populations, followed by a timeline of the key laws and executive orders that provide the framework for responsibilities.

Federal Framework of Responsibilities for At-Risk Populations in Emergencies

Federal Councils, Committees, and Task Forces

- **Department of Homeland Security Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities** was established to ensure that the federal government appropriately supports safety and security for individuals with disabilities in disaster situations. www.disabilitypreparedness.gov
- **Department of Homeland Security Federal Partnership for Interoperable Communications** addresses technical and operational activities for the federal wireless communications community. www.dhs.gov/files/committees/gc_1170097478666.shtm
- **National Security Telecommunications Advisory Committee** addresses the nation's critical national security and emergency preparedness challenges. www.ncs.gov/nstac/nstac.html
- **Department of Health and Human Service Interagency Public Health and Medical Preparedness Task Force** implements Homeland Security Presidential Directive (HSPD) 21, "Public Health and Medical Preparedness." www.hhs.gov/aspr/opsp/pahpa/highlights.html

Federal Laws

- **July 1990: The Americans with Disabilities Act (ADA).** Title II requires nondiscrimination in state and local government programs, services, and activities. These public entities cannot exclude individuals on the basis of disability and must make programs in existing facilities

accessible, including shelters. This includes private entities that are service providers, such as doctors' offices and nonprofit relief organizations. If a city contracts with the Red Cross or a private service provider, the city remains subject to Title II, and the other private entity would have independent Title III obligations. Title III requires that no individual shall be discriminated against on the basis of a disability in the full and equal enjoyment of the goods, services, facilities, or accommodations of any place of public accommodation. Title IV requires telephone companies to provide interstate and intrastate telecommunications relay services (TRS) 24 hours a day, 7 days a week at no extra cost to callers. TRS enables callers with hearing or speech disabilities to communicate by phone through a third-party operator called a communications assistant. Title IV also requires closed captioning of federally funded public service announcements (PSAs).

- **February 1996: Telecommunications Act of 1996, Sections 251 and 255, Access to Telecommunications Service, Telecommunications Equipment, and Customer Premises Equipment by Persons with Disabilities.** These provisions require manufacturers of telecommunications equipment and providers of telecommunications services to ensure that such equipment and services are accessible to persons with disabilities, if readily achievable.

Continued on next page

Federal Framework of Responsibilities for At-Risk Populations in Emergencies (Cont'd)

- **October 2006: The Department of Homeland Security Appropriations Act, 2007, and the Post-Katrina Emergency Management Reform Act (PKEMRA, P.L. 109-295).** Protects the United States against terrorism, secures the nation's borders, assists states and localities in dealing with natural disasters, and performs the other important functions of the Department of Homeland Security. The Act also strengthens the capabilities of the Federal Emergency Management Agency to prepare for and respond to emergencies requiring action by the federal government.
- **December 2006: The Pandemic and All-Hazards Preparedness Act (P.L. 109-417).** Establishes an Assistant Secretary for Preparedness (ASPR) within HHS and authorizes the Public Health Security and Bioterrorism Preparedness and Response Act of 2002 (P.L.107-188) to protect the public more effectively and efficiently by responding to public health emergencies with a clear line of authority from local to state to federal officials. Strategies address the public health and medical needs of "at-risk" individuals who have special needs during an emergency. Amends Section 2802 of the Public Health Service Act to provide statutory authority and requirements for the National Health Security Strategy (NHSS), released in December 2009.

Presidential Executive Orders

- **April 2004: Executive Order 13335. Incentives for the Use of Information Technology and Establishing the National Health Information Technology Coordinator.** Provides for the development and nationwide implementation of an interoperable health information technology infrastructure to improve the quality and efficiency of health care.
- **July 2004: Executive Order 13347. Individuals with Disabilities in Emergency Preparedness.** Intended to ensure that the US federal government appropriately supports safety and security for individuals with disabilities in situations involving disasters, including earthquakes, tornadoes, fires, floods, hurricanes, and acts of terrorism.
- **October 2007: Homeland Security Presidential Directive (HSPD) 21. National Strategy for Public Health and Medical Preparedness.** Addresses preparation for catastrophic events, whether natural or man-made, established biosurveillance capability, fostered countermeasure stockpiling, and formulated "a comprehensive plan for promoting community and public health and medical preparedness to aid state and local communities in building resilient communities."

Public Health Preparedness and Health IT Innovation

Closing the Adoption Gap

The nation's public health system has become much better positioned to respond to future emergencies because of federal investments to strengthen public health capacity and infrastructure, including communications systems and workforce training in information and communications technology.²⁹

There has been a clear shift in the perception of the public health role in emergency preparedness and national health security. Even though preparedness in public health began as a way to improve responses to bioterrorism after the anthrax attacks, the focus has broadened to include an all-hazards approach, including natural disasters and disease outbreaks.

As planning and preparedness efforts have progressed with the help of federal investment and local community innovation, additional attention is being paid to helping populations who may require extra assistance and care during an emergency. Local agencies and communities have improved coordination of emergency planning and response services for at-risk populations. Increased public health funding has allowed states and local communities to work in partnership with community-based organizations, the first-responder community, public health authorities, and consumer groups to build and test technology infrastructure and to be more innovative in the tools and systems they use to communicate with at-risk and special needs groups.

For example, OK-WARN—the Oklahoma Weather Alert Remote Notification program—provides low or no-cost alternative warning messages sent through e-mail, texts, and pagers to people who are deaf or hard-of-hearing. Developed in response to the 2003 Oklahoma tornadoes, OK-WARN is a customized database program that was designed in partnership with the Oklahoma Departments of Emergency Management and Rehabilitative Services, the National Weather Service, and other local service organizations. When the National Weather Service issues a weather

City of Oakland Adopts New Emergency Plan

In January 2010, the City of Oakland reached a settlement with Disability Rights Advocates over a 2007 class action lawsuit that asserted the city was not adequately prepared to assist the city's disabled residents in the event of an earthquake or fire. The city has agreed to adopt an emergency plan that includes 20 accessible emergency shelters that will accommodate people with mobility disabilities. Each emergency shelter will have a designated Shelter Functional Needs Coordinator who will be responsible for assisting people with disabilities. The city's emergency notification system will interface with various electronic and wireless devices used by people with hearing, mobility, and vision disabilities—in addition to traditional phone lines—and a GIS system has been created to help first responders identify the location of people who may need accessible transportation assistance and who have voluntarily registered for the service.

Rayburn, Kelly. "CityWise: Oakland settles lawsuit with disability rights group," *Oakland Tribune*, www.insidebayarea.com/news/ci_14242697, updated January 22, 2010

alert, the program automatically sends a message to all participating pagers, so notification is nearly instantaneous.³⁰

Another promising telecommunications program recognized by national and state public health organizations has been developed by the San Mateo, CA, Health Department to link 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 Community-Based Organizations (CBOs). Through this collaborative program, agencies serving targeted at-risk populations can reach thousands of clients through a phone tree system that can be activated during an emergency.³¹

These innovations clearly demonstrate ways that agencies can improve collaboration and better address the needs of at-risk populations. Greater awareness and understanding of the ways specific incidents and disaster situations affect special needs and at-risk populations is critical to making planning changes utilizing technological innovations in health and telecommunications.

Health IT Can Drive Patient-Centered Care

“Our goal, above all else, is to make care better for patients, and to make it patient-centered. Information policy and health IT policy should serve that goal.”

Dr. David Blumenthal, National Coordinator for Health Information Technology, “The HITECH Foundation for Information Exchange,” November 12, 2009.

Several provisions of the American Recovery and Reinvestment Act (ARRA) and the Health Information Technology for Economic and Clinical Health (HITECH) Act provide direct incentives for adoption of electronic health record systems. The ARRA provides over \$20 billion for the development and adoption of HIT, with approximately \$17 billion set aside for incentive payments through the Medicare and Medicaid programs to encourage providers and hospitals to implement interoperable EHR systems. Thus, the incentive structure builds on the policy goal of including individuals enrolled in public programs first to move the market toward a fully interoperable national health information network.³²

The HITECH Act provides incentives to create ways to exchange health information electronically within states and across a nationwide health information technology infrastructure.³³ A key premise of the law is that information should follow the patient and be available from anywhere at any time, making information technologies such as Personal Health Records (PHRs) and EHRs essential tools for ensuring accurate and timely information during a disaster or public health emergency.

Many consumers and advocates are encouraged by the investment in health and telecommunications technology because it creates a level playing field with the rest of society—essentially mainstreaming those at-risk and people with disabilities into the technology revolution. While they have concerns unique to them, they also have many of the same concerns as the general population, including usability of the technology and privacy of personal information.

Broadband Can Help to Improve Public Safety

“As the saying goes, ‘knowledge is power,’ and this is especially true in responding to crises. Broadband technology can contribute to the overall safety of the public by vastly expanding the means by which the public, including those with disabilities, can seek assistance and receive emergency-related information.”

David Furth, Deputy Chief, Public Safety and Homeland Security, FCC, Keynote Remarks, “Broadband Accessibility for People with Disabilities: Barriers, Opportunities and Policy Recommendations,” Wireless Emergency Communications Conference, Atlanta, GA, September 22, 2009.

The American Association of People with Disabilities (AAPD) Technology and Telecommunications Policy Initiative (TTPI) believes accessibility and usability of

health information technologies, such as PHRs, can empower people with disabilities and provide useful data exchange, as long as critical infrastructure, accessibility, usability, and affordability issues are addressed. Technologies for medical records need to be designed, developed, and customized so that persons with disabilities—including persons with vision, speech, and hearing disabilities—enjoy the same functionally equivalent access to and usability of their medical records as persons without disabilities.³⁴

At the same time that many people want access to personal health technology, there are concerns that technology applications maybe be technically structured in ways that disadvantage vulnerable populations. Many people, including at-risk individuals, may want the same access to personal health data as their neighbor via a Personal Digital Assistant (PDA), yet may be reluctant to provide personal health information via a larger community database that may be mismanaged and have improper security. Privacy protections, confidentiality and security measures are essential to protect personal health information and incentive systems to encourage providers to use EHRs and consumers to have PHRs.

Concerns About Privacy of Personal Health Information

The privacy issue poses one of the most significant challenges for public health officials and first responders whose fundamental duty in healthcare derives from the basic concept of “first do no harm.” In developing locating and tracking capabilities, designing and implementing emergency communications, accessing consumer health information, and sharing health information between emergency responders and health providers, it is vitally important to make sure that the right information reaches the right person at the right time. However, electronic systems need to be designed to protect information from breaches or unwarranted access while still ensuring the ability of consumers to maintain control and access of their health information.³⁵

In July 2006, HHS published a new Web-based interactive decision tool designed to assist emergency preparedness and recovery planners in determining how to access and use health information about persons with disabilities consistent with the HIPAA Privacy Rule.³⁶

The Privacy Rule addresses the use and disclosure of individuals’ health information and establishes an individual’s right to obtain and control access to this information. Specifically, the rule covers “protected health information,” defined as individually identifiable health information.³⁷

Incorporating health information technology into the mainstream of public health preparedness—be it within routine, everyday happenings or as part of a major disaster occurrence—can vastly improve coordination of care, thereby enhancing the quality and efficiency of care.

Consumers need to be aware of their rights and protections for sharing personal health information as defined under the Health Information Portability and Accountability Act (HIPAA). It is important for consumers, family members, or caregivers to thoroughly read and understand the privacy policies of a PHR vendor and the Internet-based service provider. It is important to be sure information provided in the PHR is fully protected and can only be retrieved by those who have been designated access by the owner (the consumer). It is also important to know where information goes if an account is closed for any reason. Consumers need to maintain “legal ownership” of their health information and ensure it is used properly in the right circumstances, by the right people.

The Privacy Rule factors heavily in the development of local registries and public health care services for at-risk and vulnerable populations. It is important

New Visions for Personal Health Records

Project HealthDesign, a \$5 million national program sponsored by the Robert Wood Johnson Foundation (RWJF), demonstrates how a new vision for personal health records can transform the way people engage in health care. Since September 2008, nine research teams from across the country have been working on innovative prototypes of personal health record (PHR) applications that provide a glimpse of the "next generation" of PHRs. The PHR applications represent the result of intensive research and design by multidisciplinary teams from some of the most prestigious institutions in the nation. The prototypes range from a medication management system to help children with cystic fibrosis manage their disease (housed in an age-appropriate form, like a stuffed animal or cell phone), to a sophisticated "conversational assistant," a computerized tool that helps people with congestive heart failure manage their health from home through a series of voice-activated questions and responses that they can quickly share with their medical providers.³⁸

to ensure these tools are appropriately designed to encourage at-risk and vulnerable populations to participate, as well as to improve public health preparedness.

Many of the early adopters of PHRs are individuals who live with chronic medical conditions or who are taking care of elderly parents.³⁹ However, adoption of PHRs is still quite low among the majority of the population and may be even lower for some specific cultural groups. For example, Latino and African-American participants in one focus group study generally distrusted the security of electronic records systems, said they wanted control over who has access to their

personal information, and preferred that a record be kept on a portable "smart card."⁴⁰

In 2003, a Sonoma County Health Department partnership with private health providers, software developers, and community health clinics launched MiVIA™ as a portable personal health record (PHR) for migrant and seasonal workers who spent part of the year in Sonoma County. Today MiVIA™ is an online PHR platform used by several thousand people across the country,⁴¹ including people who have no insurance, who have chronic medical conditions and/or who access care from many different providers or locations.⁴² The Web-based system is password-protected and individuals can choose who sees it, such as a new provider, but it is otherwise accessible only to the individual who "owns" the PHR.

Private technology companies are working in innovative partnerships with physicians and community hospitals to design smart PHRs that are designed specifically to provide personal health information necessary during a medical emergency. In March 2009, miCARD launched a proprietary medical information card and integrated online medical record consisting of a portable wallet card and integrated, online PHR. The wallet card provides emergency medical personnel a physical snapshot of a patient's vital medical information if needed in an emergency. The online PHR contains additional medical information, emergency contacts, physician information, advance directives, electrocardiogram results, lab tests, and current medications. All personal medical information is stored securely online and viewable at the miCARD Web site 24/7 by treating medical providers.⁴³

ARRA funds are providing greater opportunities for developing innovations in health information and communication technology that directly impact service delivery for at-risk populations. In addition, several federal partnerships support public-private initiatives that provide for innovative applications of information and communications technology. For example, the Indian Health Service (IHS) is developing a Personal

Health Record (PHR) for Native Americans and deploying its EHR to more than 200 sites across the country, including those in states eligible for Medicaid incentives.⁴⁴ The US Surgeon General's Office is collaborating with Microsoft HealthVault to expand access to a free, Web-based platform for recording and sharing family health history.⁴⁵

ARRA provides over \$20 billion for the development and adoption of HIT, with the largest allocation of funding—approximately \$17 billion—for incentive payments through the Medicare and Medicaid reimbursement systems to encourage providers and hospitals to implement EHR technology systems.

Last year, MedVirginia became the first regional health information organization to go live with the Nationwide Health Information Network. Using the NHIN CONNECT Gateway, the labor-intensive and often prolonged process of determining Social Security disability benefits using information from clinical records was reduced from 84 days to 25 days.⁴⁶

Other state collaborative efforts include the Carolina Homeless Information Network (CHIN), North Carolina's centralized, Balance of State Homeless Management Information System (BoS HMIS). They support a computerized data collection tool to aggregate client-level information, over time, on characteristics, service needs, and service utilization of individuals experiencing homelessness. They provide information exchange for a network of more than 100 service agencies to ensure critical human services needs are being met for homeless populations. In Bakersfield, California, a multidimensional, multidisciplinary community health center called Clinica Sierra Vista is developing Electronic and Personal Health Records for geographically dispersed, low-moderate-fixed income, ethnically diverse, frontier-rural-urban-migrant-homeless patient populations.⁴⁷

Innovations in Communications Technology

During public health emergencies, most people evacuate without any record of the medical treatments they have received, any data regarding medications, or their potential risk of psychological conditions. More than 1,000,000 paper-based medical records were destroyed during Hurricane Katrina. During the California Wildfires of 2008 and the outbreak of the H1N1 virus, first responders, medical personnel, service providers, and patients had to rely on the memory of family members, friends, and others to recall complex plans for medical care such as chemotherapy treatments, as well as day-to-day needs like medications, durable medical equipment, and personal assistance dogs and personal pets.

These communication and information sharing challenges represent a unique “digital divide” for at-risk individuals in public health preparedness and emergency management. They impede the ability of our public health preparedness and response system to effectively acquire, disseminate, and utilize consumer and other health information critical for locating, treating, and evacuating people during an emergency.

Social media such as Twitter, MySpace, and Facebook are also entering into national policy discussions as viable venues to communicate and disseminate public health information across the preparedness spectrum, from planning to response and on through to recovery.

Clearly, the ability to exchange medical information during a public health emergency or natural disaster will be essential to improve emergency response for everyone, and especially for those with disabilities, and chronic medical conditions, and/or other vulnerabilities. Incorporating electronic health information systems into the mainstream of health care delivery is the clearest route to improving public

Cultural Competency Is Essential in Risk Communication

A study of Web-based emergency preparedness information in Maryland found that the information was not culturally tailored for low-income minorities, and other studies have had similar findings. The National Consensus Panel on Emergency Preparedness and Cultural Diversity has made recommendations on effectively incorporating the needs of racially and ethnically diverse populations in all phases of emergency planning.

National Consensus Panel on Emergency Preparedness and Cultural Diversity.
www.diversitypreparedness.org/NCP/92/⁵⁰

health preparedness. Improving coordination of routine medical care will not only enhance the quality and efficiency of care but make it more likely that care in an emergency will also have the right information available to the right people at the right time.

Many routine daily activities—such as making doctor appointments, obtaining directions, and purchasing goods and services—already rely on existing telecommunication tools, particularly on mobile phones and personal digital assistants (PDAs).⁴⁸ With the new opportunities under ARRA, current health policy discussions focus on the “meaningful use” of health information technology tools such as PHRs, EHRs, and e-prescribing.⁴⁹ Communications policy discussions are emphasizing state-of-the-art, digital communications devices such as cell phones, pagers, and Wi-Fi. Together, these information and communication technologies are rapidly emerging as high-value mediums to send and receive data, text, voice, and video to improve routine health care as well as disaster response.

As the Haiti earthquake response has shown, social media such as Twitter and Facebook are

also demonstrating their value to communicate and disseminate medical and public health information across the preparedness spectrum—from planning to response and on through recovery.⁵¹ CDC and other federal agencies are using social media tools to augment existing alert and notification systems to issue emergency instructions and evacuation processes for employees.⁵² Information and communications technologies can vastly improve the ability of individuals—consumers, first responders, and medical personnel—to access, understand, and use health-related information and services to make appropriate health decisions during an emergency. These technologies are critical tools for public health and emergency response personnel to ensure everyone receives the right message, with the right care, at the right time.

Millions of people could benefit from the use of adaptive communications devices to communicate with family and friends during an emergency.

During any disaster, individuals who require additional resources due to physical mobility, communication skills, emotional or psychiatric conditions, or cognitive abilities may not be able to comply with public health and emergency response measures, such as evacuation, without some level of support and assistance. Yet, they are a population that already uses assistive technology in their daily lives to live independently in their communities to get around, open doors, drive, engage in dialogue, operate appliances and home hardware, among the myriad of daily functions everyone performs. Technological innovations that support improved personal preparedness and link individuals to more coordinated, integrated public health systems will enable better planning and care for at-risk populations.

Leveraging health information technologies is no longer simply essential to ensuring public health preparedness; it is inevitable, especially for at-risk and vulnerable populations.

Many states and communities have taken a proactive approach to developing innovative tools and practices by collaborating with public, private, and nonprofit

resources to address the unique needs of diverse populations. These technology-based innovations range from providing outreach and information, education and training, and personal preparedness to new applications for personal health record management. Many have been recognized and funded by national public health organizations and private foundations, through established accreditation and review standards, as promising or best practice models.⁵³

Health Technology Innovations: Select State Initiatives and Best Practice Models for At-Risk Populations

Kentucky Outreach and Information Network (KOIN)	The Kentucky Cabinet for Health and Family Services developed KOIN as a grassroots approach to communication via a partnership between government and community-based organizations to provide preparedness and emergency information to special needs populations. The volunteer network of community-based organization representatives become versed in emergency preparedness language and better acquainted with the locations of their populations. The messages from state health officials reach these hard-to-reach, vulnerable populations through the community network and mainstream and traditional media communication channels.
Emergency and Community Health Outreach (ECHO) Minnesota Collaborative	ECHO is a state-wide partnership between safety and public health agencies, nonprofit groups, and ethnic advisory organizations that strives to provide safety and health information to all residents of Minnesota. ECHO consists of all-hazards and pandemic influenza information that is distributed via fax, telephone, television, Internet, and e-mail in multiple languages. ECHO uses a combination of English-language and non-English language media, public television, informational telephone call-in lines, e-mail bulletins, the ECHO Web site, and its partners to reach at-risk, limited English-proficiency populations with emergency, public health, and safety messages.
North Carolina Division of Public Health "Be Ready!" Kiosks	"Be Ready!" kiosks are portable touch-screen computers designed to increase public interaction with preparedness information and stimulate ongoing household preparedness activities. Sharing the kiosks has been valuable in developing links between decentralized local health departments. The kiosks are usable at health fairs, conferences, clinics, and other locations.
Kansas Collaborative Special Needs Populations Assessment Toolkit and GIS Mapping Tool	The toolkit is a guide for developing a Web-based GIS system for tracking facilities that serve at-risk populations. It is connected to broader efforts at Kansas Association of Local Health Departments (KALHD) that use geographic information system (GIS) mapping to assist with the pandemic influenza response in identifying people in their community who will need assistance during evacuation or shelter-in-place.

Sources: Association of State and Territorial Health Organizations (ASTHO) At-Risk Populations Project site: www.astho.org/index.php?template=at_risk_population_project.html; and Center for Disease Research and Policy (CIDRAP), Project information on CIDRAP's Promising Practices site, with opportunity for public comment: www.pandemicpractices.org/practices/article.do?path=pubcom.html

Planning for People with Disabilities Can Also Help Others in the Community

“...Anyone at any time can acquire a disability, particularly during emergencies. Furthermore, the challenges faced by persons with disabilities, seniors, and residents of low-income households in disaster-threat situations often demonstrate considerable overlap. People with disabilities should not be viewed as one more special interest group that drains resources from the common pool. Planning for and accommodating this large group often means being better equipped to serve all people.”

John R. Vaughn, Chairperson, National Council on Disability, testimony before the House Subcommittee on Economic Development, Public Buildings, and Emergency Management, Transportation, and Infrastructure Committee, October 20, 2009.

Closing the Gaps in Public Health Preparedness

The effective adoption and use of health information and telecommunications technologies by the health preparedness community and at-risk consumers will help to close gaps and ensure there is no “digital divide” to impede emergency planning for at-risk and vulnerable populations. Facilitating electronic health information exchange and communications systems to work well for these populations requires a collective effort among consumers and families, health care providers, communities, and state and local governments. Each sector needs to be actively engaged and aware of what they can do to impact the adoption and use of new, next-generation technologies that can dramatically improve the safety, security, and well-being of at-risk and vulnerable populations during a public health emergency or disaster.

Understanding the public health and emergency management challenges and needs of at-risk and vulnerable populations—to include those who may have been vulnerable prior to the event and those who may become vulnerable after the event—is critical to the development and use of health information technologies to transform how communities plan, respond and, ultimately, save lives.

Federal agencies, state and local governments, public health preparedness officials, nonprofit and community-based organizations, along with the disability community and at-risk stakeholders' groups, need to coordinate actions and share valuable resources for developing and implementing innovative technology solutions to improve emergency preparedness and response. Interagency coordination and public-private collaborations have driven many of the policy and legislative changes currently in place and will drive future improvements in emergency planning for special needs, at-risk, and vulnerable populations.

Here are some steps that stakeholders can take:

Consumer Preparedness

- Create disaster contingency plans for evacuation and other protective measures including sheltering, medical care, and service animals. Follow the steps in federal, state, and local Web sites such as disabilitypreparedness.gov and ready.gov
- Subscribe to local government emergency warning systems through e-mail, mobile phone, and texting services
- Adopt an electronic Personal Health Record (PHR) to organize patient health history and document health conditions, medications, provider names and contact information, medical history, and special needs
- Encourage health care providers to adopt electronic health records (EHRs) so that more clinicians will be able to exchange electronic health information about medical history, medication history, allergies, and special needs in emergencies

- Establish personal support and readiness plans involving friends and family, co-workers, neighbors, providers, and others who can help in an emergency if necessary, since 70 percent of all rescues in major disasters are made by people who are in a personal support network rather than by professional responders⁵⁴

Health Care Provider Preparedness

- Adopt and use EHRs in clinical practice for all patients, especially for those with chronic medical conditions, disabilities, and/or other vulnerabilities
- Encourage patients to use PHRs
- Encourage patients with disabilities to join registries maintained by local health departments and first responders in case of evacuation or shelter-in-place
- Have an emergency preparedness plan for their own families and offices or clinics
- Be part of emergency planning in their communities—participate in drills and exercises sponsored by local health departments and funded by CDC or the Department of Homeland Security
- Consider volunteering for the local Medical Reserve Corps (MRC) (medicalreservecorps.gov) or their state's Emergency System for Advance Registration of Health Professionals (ESAR-VHP) program⁵⁵ to participate in emergency response

Local Government Preparedness Planning

- Include individuals from at-risk groups in local emergency planning
- Invest in help lines, mass phone alerting systems, as well as e-mail and mobile phone alerting systems (e.g., reverse 911) and conduct local campaigns to ensure that the public participates
- Maintain communications and contact information for community leaders who can assist in emergency response

- Maintain registries of individuals with disabilities and others with special needs who would be particularly at-risk during an emergency, including plans to shelter-in-place or evacuate
- Conduct training for first responders on how to work with at-risk and diverse groups
- Enhance accessibility features in local government buildings

State Government Preparedness Planning

- Ensure that information on emergency preparedness is available on state Web sites in various accessible formats (e.g., audio for visually impaired persons, video for hearing-impaired persons, multiple languages, and font sizes)
- Invest in new technologies—such as videophones, help lines, and mass phone alerts—and integrate them with traditional print, Internet, radio, and television outreach strategies
- Ensure that communications addressed to the general public include actionable information in multiple modes and languages on how to prepare for, protect against, respond to, or recover from risks
- Include individuals from at-risk groups in state-wide emergency planning
- Train emergency personnel in cultural competency
- Conduct training for emergency personnel on how to work with at-risk and diverse groups

Information is Power

“The new source of power is not money in the hands of a few, but information in the hands of many.”

John Naisbitt, Author, Megatrends 2000

Conclusion

The scope and magnitude of ARRA's investment in health IT and communications technologies presents an exciting opportunity to advance health care and health care IT across many sectors and among diverse populations. The stimulus funds provide opportunities to fundamentally alter the way we capture, store, use, and share health information, which will then enable improvements in efficiency, quality, and condition management to transform the health system during ongoing and emergency operations.

Leveraging health information technologies is no longer simply essential to ensuring public health preparedness; it is inevitable, especially for at-risk and vulnerable populations. Technological innovations are rapidly changing the way we communicate, exchange information, and provide health care during a public health incident. Health information and communication technologies have tremendous potential for improving

health preparedness for at-risk populations, and for recognizing the functionality, operability, and security and privacy concerns specific to at-risk populations—those who were at risk prior to an event, as well as those who become more vulnerable during or following the event.

Effective implementation of health information technology policies requires federal agencies to align their missions, work in partnership with state and local agencies, health care organizations, emergency planners and first responders, public health officials, community service providers and informed consumers, to achieve optimal access, functionality, security, and use. Coordinating the public health and emergency management missions and integrating the strengths of federal, state, and local agencies responsible for providing communications, situation tracking, and public health and medical services can vastly impact the safety and security for all.

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