Inclusive Emergency Planning... What Do Access and Functional Needs And Registries Have To Do With It?

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Approved by:
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Purpose
The Durham County Services for Access and Functional Emergencies (DCSAFE) committee was formed by the Durham County Public Health Department to collaborate with community stakeholders to identify access and functional needs populations within Durham County.

The mission of DCSAFE is to work to reduce injury and disease within the access and functional needs populations in Durham County through organized and interdisciplinary efforts. DCSAFE is currently mapping out their strategic plan and is interested in research around access and functional needs registries. The purpose of this paper is to assist the DCSAFE committee and the Durham County Health Department in identifying and documenting the current legislation, literature, examples and challenges in regards to establishing and implementing an access and functional needs registry.

Defining Terminology
When discussing the intersection of emergency management and access and functional needs inclusion, there are numerous terms used interchangeably to define the population discussed in this intersection. These terms include social vulnerability, at-risk, Intellectual and Developmental Disabilities (I/DD), special needs and access and functional needs.

Social vulnerability is defined as the “characteristics of a person or group in terms of their capacity to anticipate, cope with, resist and recover from the impact of a discrete and identifiable event in nature or society.” Previous research has demonstrated that populations with higher levels of social vulnerability are more likely to experience negative consequences to disasters. The term at-risk is interchangeable with socially vulnerable.

The functional abilities of people with Intellectual or Developmental Disabilities (I/DD) vary widely. The Federal definition of developmental disability is “a severe, chronic disability of an individual that is attributable to mental or physical impairment, or combination of mental of physical impairments, which is manifest before age 22. Specifically, I/DD results in substantial functional limitations in three or more of the following areas of life activity: self-care, receptive and expressive language, learning, mobility, self-
direction, capacity for independent living, economic self-sufficiency; and reflects the individual’s need for a combination and sequence of special, interdisciplinary or generic services, individualized supports, or other forms. North Carolina statute expands this definition to include traumatic brain injury acquired after age 22. The term I/DD is interchangeable with special needs.

Access and functional needs populations (commonly referred to as special needs populations or socially vulnerable populations) are populations whose members may have additional needs before, during and after an emergency in specific areas. These specific areas are defined by Kailes et al through the C-MIST framework: Communication, Medical needs, maintaining functional Independence, Supervision and Transportation. One can have an access and/or functional need with or without having a disability. Within each category of the C-MIST framework individuals in need of additional response assistance due to an access and functional need may include: those who live in institutionalized settings, older adults, children, children and adults with physical, mobility, sensory, intellectual, developmental, cognitive or mental health disabilities, those from diverse cultures, those who are transportation disadvantaged, people with chronic or temporary health conditions, women in late stages of pregnancy, people needing bariatric equipment, people with limited English proficiency (adults and children), low literacy or additional communication needs, people with very low incomes, people experiencing homelessness and others.

For the purpose of this paper, access and functional needs will be the terminology used because that is the terminology that North Carolina and Durham County alike have adopted. It is also important for this paper to define two additional terms that are found in the discussion of emergency management and access and functional needs inclusion, “whole community” and what constitutes as an emergency and a disaster.

The “whole community” approach to emergency management stems from systems thinking, which works to bring stakeholders from different facets (families, individuals, NGOs, etc.) to the planning
table instead of just the emergency management personnel. The incorporation of individuals with access and functional needs is vital towards inclusive planning for the “whole community” and therefore are a large part of the “whole community” approach. Additionally, the “whole community” approach is what links the C-MIST framework to emergency planning, which then works to facilitate more inclusive emergency operations plans. It is important to note that this approach serves to assist emergency managers in better preparing for whatever access and functional needs populations exist within the community, not to better prepare for direct assistance. To ensure that the needs of more than half of the US population (who have access and functional needs), it is imperative that emergency preparation include a plan for operationalizing support for the “whole community.”

An emergency is a sudden event that calls for immediate measures to minimize its adverse consequences. Emergencies take many forms from a 911 call to a national disaster. They can range in any combination of consequences stemming from the following:

- Personal: heart failure, injuries, seizures, kidney failure, anaphylactic shock, heat stroke, etc.
- Technological and man-made hazards: nuclear waste disposal spills, radiological, toxic substance, or hazardous materials incidents, utilities failures, pollution, epidemics, crashes, explosions, urban fires.
- Natural disasters: earthquakes, floods, hurricanes, tornadoes, tsunami, sea surges, freezes, blizzards of snow and ice, extreme cold, forest fires, drought and range infestation.
- Internal disturbances: civil disorders such as riots, demonstrations run amok, large-scale prison breaks, strikes leading to violence and acts of terrorism.
- Energy and material shortages: from strikes, price wars, labor problems and resource scarcity.
- Attack: nuclear, conventional, chemical, or biological warfare.
According to the North Carolina General Assembly’s legislative definition G.S. 166A-4(1), a disaster is “any occurrence or imminent threat of widespread severe damage, injury, or loss of life or property resulting from any natural or man-made accidental, military, or paramilitary cause.”

**Background**

Research has shown that a person’s vulnerability to an emergency or disaster is a social and community construct. In other words, the social and environmental factors that limit a person’s everyday ability or resiliency to cope with daily life also make them vulnerable to the effects of emergencies. Since previous research has demonstrated that access and functional needs populations are more likely to be adversely affected in emergencies, planning and implementation of mitigation strategies should incorporate these segments of the population to reduce the public health impact of emergencies.

Historically, access and functional needs populations have been marginalized by the emergency management community. According to the National Council on Disability, this can be attributed to the fact that these populations were generally placed into one large category, without consideration for the unique needs associated with each type of access and functional need. People with access and functional needs were not often consulted and included in the emergency planning arenas. This practice further alienated people with access and functional needs and therefore increased their vulnerability during emergencies and disasters.

But recently, the field of emergency management is shifting towards the “whole community” approach. These changes can be attributed to demographic trends, outcomes of previous disasters and recent court cases. All of these factors point towards a need for emergency managers to take an inclusive “whole community” approach. Understanding risk starts with examining the many places and points at which vulnerabilities intersect, then targeting those areas using good science and effective practices.

The United States’ (US) population is aging, growing increasingly diverse and shifting health care to the home. An estimated 13 million individuals age 50 or older in the US need evacuation assistance,
and for about half of them, such assistance is required from someone outside of their household.

Eighteen percent of the US population speak a language other than English at home, which means they require additional emergency communication assistance. More than 1.4 million people in the US receive home health care. Many of the individuals accounted for in these statistics are part of mainstream communities and function independently under normal situations. In an emergency situation, however, they may need assistance and are thus identified as access and functional needs populations. In order to appropriately assess the resources needed for “whole community” preparedness, requires that emergency managers measure, identify and factor demographic trends into their emergency plans. This will also assist them in creating collaborative relationships with the stakeholders who work with these various populations on a regular basis. Furthermore, the impacts from an emergency are expressed differentially across and within communities, emergency managers must be aware of the access and functional needs within their community to mitigate risk.

The goal of integrating emergency plans and strategies at every level is to ensure that the “whole community” will have warning and be aware of an impending emergency and therefore can take suggested actions to increase their personal preparedness and safety. Unfortunately, several recent catastrophic disasters have revealed major gaps in emergency plans. One stark example is Hurricane Katrina in 2005, which caused catastrophic damage to New Orleans and the Gulf Coast. Post-disaster evaluations have found that the emergency plans that would proactively account for and serve the more than 1,800 people who died during the storm and in subsequent floods were inadequate to say the least. Though agencies found it hard to determine exactly how many, a disproportionate number of Hurricane Katrina’s victims were people with access and functional needs. Statistics show that of the approximately 100,000 children and their families evacuated from the city of New Orleans, over one third of the children who remained displaced post Hurricane Katrina had at least one diagnosed chronic medical condition. Additionally, the American Association of Retired Persons (AARP) reported that 73 percent of Hurricane
Katrina-related deaths were among persons age 60 and over who had access and functional needs, although they comprised only 15 percent of the population in New Orleans.\textsuperscript{13,14}

One year after Super storm Sandy, a federal court decided that New York City did not take proper planning efforts toward protecting the “disabled” during the Super storm.\textsuperscript{15} The court found that the city specifically violated the Americans with Disabilities Act (ADA) by not adequately planning for and protecting the access and functional needs populations during that disaster.\textsuperscript{16} This was the first ruling of its kind.\textsuperscript{15} Following this, a coalition of disability rights advocates filed a federal class action lawsuit in the United States District Court for the District of Columbia. The lawsuit challenges the District of Columbia’s poor emergency planning for persons with access and functional needs.\textsuperscript{17} These recent court cases have reinforced the importance for including access and functional needs populations in emergency preparedness plans.

Because of these factors, North Carolina has convened a diverse committee at the state level to increase inclusiveness for access and functional needs populations in emergencies. The committee members range from individuals with access and functional needs to community leaders to administrators. Taking North Carolina’s lead, Durham County formed a similar committee of stakeholders to focus on the local county level.

**How Registries Are Involved?**

When it comes to access and functional needs populations both the Federal Emergency Management Agency (FEMA) and the Department of Health and Human Services (DHHS) recommend utilizing a registry for people with access and functional needs to voluntarily sign-up and provide the necessary information for local and state responders and emergency managers to properly prepare and assess the community needs in the case of an emergency.\textsuperscript{18,19} But, there are many concerns and barriers regarding the use of registries to identify access and functional needs populations. The DCSAFE
committee wants more information around the effectiveness of implementing a registry as a method to identify access and functional needs populations.

**Legislation, Regulations and Grants**

It is essential to consider at-risk individuals with access and functional needs to develop an inclusive plan for the “whole community.” In the past fifteen years the “whole community” approach to emergency planning has been mandated for inclusion in federal, state, territorial, tribal and local public health emergency plans by the Public Health Service (PHS) Act. Such plans must also meet applicable requirements of the Americans with Disabilities Act (ADA). A list of legislation that has been yielded by these mandates can be found in Appendix A.

Additionally, the federal government, in collaboration with its state, local, tribal and nongovernmental partners, is undertaking key initiatives to strengthen planning for the safety and security of individuals with access and functional needs. These collaborations include:

- “In June 2006, the U.S. Department of Homeland Security (DHS), in cooperation with the U.S. Department of Transportation, released the Nationwide Plan Review Phase 2 Report. Among other things, the report assessed the degree to which state and urban areas have integrated disability- and aging-related issues into their emergency operations plans (EOPs), and found that—substantial improvement is necessary to integrate people with disabilities in emergency planning and readiness. Moreover, during the plan review process, emergency managers were consistently requesting technical assistance to guide the identification and incorporation of individuals with disabilities and other special-needs populations into emergency planning.”

- Following the 2006 Post-Katrina Emergency Management Reform Act, FEMA issued its guidelines for accommodating individuals with disabilities in disasters and established the role of disability coordinator within FEMA management.

- In 2007, the Homeland Security Grants Program incorporated language that focuses on planning for special-needs populations.

- In 2008, the revised National Response Framework (NRF) and the National Incident Management System (NIMS) established considerations related to access and functional needs throughout the intergovernmental operational protocols.

- Numerous tools and guides around identifying socially vulnerable and access and functional needs populations have been developed for local, state, and tribal emergency managers to use in the making of EOPs that cover all populations within the community.

**North Carolina’s Initiative**

In recent years, emergency managers have started to reconsider established preparedness models and are updating emergency plans to focus on resources and services that benefit the “whole
community.” In 2014, North Carolina embarked upon a four-year program to identify, address and prioritize service gaps and action items needed to better serve people with access and functional needs.4 Referred to as the North Carolina Emergency Preparedness Initiative, this project represents the first comprehensive examination of “whole community” emergency preparedness since publication of the 2008 North Carolina Disability and Emergency Management (DEEM) Report.

The initiative is guided by the North Carolina Division of Emergency Management, the North Carolina Department of Public Safety and the North Carolina Council on Developmental Disabilities. It is made possible by a multi-year grant from the North Carolina Council on Developmental Disabilities (NCCDD).4 The initial meeting to launch the tiered program convened a large and diverse group of stakeholders including emergency management planners, first responders, state agencies, partner organizations, self-advocates and family members. Their collaborative goal is to increase emergency preparedness for persons with access and functional needs. In order to reach this goal, the committee is following the C-MIST framework.

“The Emergency Preparedness Initiative is being implemented to help people like Nessie Siler. Ms. Siler has been responsible for managing her independence for a long time. Walking difficulties limit her mobility so planning ahead for potential emergencies or other disruptions is an essential aspect of Siler’s daily routine. As a longtime resident of the hurricane-prone Outer Banks, personal preparedness has meant, among other things, having an emergency kit with adequate supplies for her household. It also means being aware of and connected with local responders who serve the “whole community”, as well as agencies that provide aid to address the unique functional needs of people within it.”4

Durham County’s Initiative

Durham County decided to form their own local committee, DCSAFE, utilizing local stakeholders to focus on an all hazard and “whole community” approach to emergency preparedness. Durham County intends to follow NC’s lead and utilize the North Carolina Emergency Preparedness Initiative and
Blueprint. This guide is a direct output of the DCSAFE committee. DCSAFE is currently mapping out their strategic plan and is interested in research around access and functional needs registries.

Registries

What is a Registry?
There are many kinds of registries. The type of registry that is being assessed in this paper is a voluntary database of individuals who meet the eligibility requirements for receiving additional emergency response services based on specific needs established by the territorial, tribal, state, or local jurisdiction. Registries can be a useful tool to help emergency planners strategically target and deploy resources, transportation assistance, and emergency services to access and functional needs populations.

Registries vary considerably in terms of how they are set up and used. Registry set ups range from a simple paper list of people who may need assistance during a response effort or it can be as detailed as an Internet-based database with multiple layers of information. Registries can include a wide range of potential registrants, from congregate care groups to individuals at home. There is not currently a national registry, but there are numerous state and county level registries across the nation. Because registries collect various information including geographic data, the use can be further enhanced when using mapping software and Geographic Information Systems (GIS).

Many counties in North Carolina utilize registries. Some started over 30 years ago and others are still in development. Many counties use registries because FEMA and the DHHS recommend access and functional needs registries as an effective method to identify those in need within each community. Similarly, many planning guides, including the Federal Emergency Management Agency's Comprehensive Preparedness Guide 301, Interim Emergency Management Planning Guide for Special Needs Populations, recommend that emergency managers use registries to aid in identifying and locating their community's access and functional needs populations.
After conducting a systematic literature review, empirical scientific work on this topic is limited. There is a major disconnect between scientific research and the recommendation to use a registry. Currently, there is no scientific evidence specifying the types of registries that exist and the conditions under which those lists operate best.

Examples of state and county level registries can be found in Appendix B.

Stories of Success and Failure of Registry Use

Because FEMA and the DHHS recommend using registries many states, counties, territories and jurisdictions have piloted registries. Therefore, there are many stories of success and failure. One story of success and one story of failure is highlighted below.

Success

“Beth Haner dialed 911 several years ago when her son was having uncontrollable seizures because of a rare form of epilepsy. Paramedics arrived within minutes. They ran upstairs to his bedroom and quickly treated him. One of the emergency workers told Mrs. Haner later that he had studied the boy’s condition for two years. "It made me feel good," she said. "What a relief that is." That the paramedic was familiar with the boy’s condition wasn’t luck. His family was the first to sign up for a special-needs registry at the Liberty Township Fire Department in southern Delaware County. Liberty Township’s registry, which began in 2005, has been expanded countywide. Delaware County now offers residents with disabilities or chronic health conditions more-personalized treatment during emergencies. A database lists the names and addresses of people who require special assistance. Registration is voluntary, and personal information is protected by medical privacy laws and shared only with emergency workers, said Capt. Bill Piwtorak of the Liberty Township Fire Department. Firefighters and paramedics had visited with the Haners long before their emergency to gather information about their son. "There’s always a heightened state of readiness when it comes to a child," Mrs. Haner said. "If you’re prepared ahead of time, you have better confidence of knowing it’s going to turn out right." ... In Delaware County, each registrant’s address is added to a computer-aided dispatching system, and an alert pops up when a 911 call is made from their home. The system allows emergency workers to tailor their response. "They’re learning about their community, and it’s more specific to what they’ll be exposed to," Piwtorak said. Twenty-seven Liberty Township residents are listed. About a dozen more county residents have been added since the registry went countywide in February. The service is designed for people of all ages, particularly those with physical or mental disabilities or chronic medical conditions. It’s also helpful for people with vision, hearing or speech impairments or who speak little or no English. The database also could be used during a flood, power outage or other large-scale disaster, said Brian Galligher, county Emergency Management Agency director. "Think about New Orleans and if they would’ve had something like this" before Hurricane Katrina hit, Galligher said. "Any EMA director in the state would love to have this." Delaware County’s registry is worth studying, said Mark Anthony, spokesman for the Franklin County Emergency Management Agency.”
**Failure**

“The development of various forms of registries that identify people with disabilities has received some support in recent years. However, the California wildfires in 2003 exposed several problems with registries that should receive consideration before expanding the use of this technique. First, the California State Independent Living Council (SILC) reported that individuals in charge of these registries were unable to access them because of power outages and lack of access to their work sites. Second, lists that had been distributed to local fire stations remained locked in cabinets, as everyone was out fighting the fire and no one was staffing the station. A related problem is that many registries are "static" and list only a home location, and the person may be at work, out shopping, or in another location. Because people with disabilities may not be able to evacuate, registries could be used to assist those left behind. However, as Dr. Margaret Nosek in 2008 noted after Hurricane Ike, "I had registered earlier with 211 as a person with a critical medical need, but found it impossible to get through to them after the storm.”

**Challenges and Recommendations**

The use of registries has been a hot topic of discussion among state and local emergency managers and within the access and functional needs community in North Carolina. Many counties and jurisdictions in North Carolina have developed registries and many others are considering the use of a registry. Therefore, it is important to explore and address the various concerns and challenges around the implementation of an emergency registry. These concerns and challenges include the following:

- Unrealistic expectations on first-responders capability in a disaster. May be perceived as a promise or guarantee by local government that the registrants will be provided for no matter what. Some people believe that entering their name and information into a registry means the government will automatically provide transportation or sheltering for them in the event of an emergency.
- Emergency managers tend to focus on the registrants first rather than looking at the “whole community”. This can be a concern because there are many barriers for access and functional needs populations to register and therefore the registry doesn’t reflect the “whole community”, only those who have the capacity to register.
- If a registry is designed based on individual residential information only, planning will have a major gap as disasters can occur at any time of the day. Many individuals register using their home address, but these people might be at school, work, or elsewhere during the day. Registries that seek to provide emergency services should include a question about the location of the registrant during daytime hours.
- There are Health Insurance Portability and Accountability Act (HIPAA) considerations that must be factored into the development and deployment of registries. More on this topic in the How to Collect Data section.
- Maintenance of information on the registry can be a challenge. Accuracy as to names, addresses, telephone numbers, and impairments is essential to being able to provide the assistance needed by each individual of the special needs population. The data are perishable, requiring constant aggressive maintenance, because a large percentage do not readily respond to update requests.
• The costs and resources necessary to keep the registry current should be factored into a jurisdiction’s decision about establishing such a system. It is recommended that appropriate funding should be provided to a designated agency to manage and update the registry at least once a year. This includes consideration of the scale and size of the registry which can be a major barrier. Is the registry only going to cover a sample of the population or is the registry going to be community wide? If community wide then what is defined as the community.

• Providing individuals on the registry emergency information is not enough. Jurisdictions should have a method for reaching everyone in the community before, or during, an emergency.

• Back-up power sources are needed to access the registry during a power outage. As demonstrated in the California State Independent Living Council report on the 2003 wildfires, access to the registry is an issue. Emergency responders in the wildfires were unable to access the lists to determine who might need evacuation assistance.21

• Registries do not include individuals who develop disabilities or health or mental health conditions as a result of the emergency itself.

• The willingness of individuals to self-identify as having a disability. Some individuals may not see themselves as having a disability, whereas their family members do.

• No clear standardization. No single agency appears to be the sole entity responsible for development of a registry. Across the nation, it appears that registry lists develop from a number of sources, including emergency management offices, 9-1-1 call centers, public health agencies, private contractors, and specific agency lists.

• To reach the potential registrants, significant measures may need to be taken that can require considerable staff time and funding. In an Alabama location with a potential for a chemical release, efforts to develop a special needs registry involved the state and local emergency management agencies, a privately contracted mailing firm, and a variety of social service and health agencies. Identifying and reaching out to those potentially in need of assistance took a great deal of time and money, involving scientifically based random sampling, saturation mailing, self-registration, targeted distribution, agency lists, and referrals.21

People may be reluctant to sign up for assistance, in part, because they do not want to disclose their personal data for the following reasons21:

• They fear their financial assets will be taken.
• They fear legal consequences, in the case of undocumented workers.
• They think the privacy of their medical information will not be protected, making them targets of crime and fraud.
• Their function-based or medical needs are new, temporary, or incurred as a result of the disaster.
• They do not believe they have a need for assistance.

To date, no empirical research exists on the value or effectiveness of registries. Reports suggest that registries can be expensive, hard to maintain, need to be well integrated among participating agencies and adequate access can be a problem. It is apparent that registries have many barriers and limitations and should not be used as a master tool for first responders.
Additional recommendations for maximizing the use of a registry is to be proactive in innovative approaches to collecting registry data. In addition to voluntary sign-up, there are numerous methods that can be utilized to collect data to populate registries. For example, collecting data from NGOs and advocacy groups who already work with access and functional needs populations. This approach is commonly referred to as a “list of lists” concept, when emergency managers compile a database of access and functional needs populations’ information from various lists. Note that these lists are shared securely under the Health Insurance Portability and Accountability Act (HIPPA) and de-identified to protect those on the lists. These lists will provide an estimate of the number of individuals residing in their communities, which will benefit planning for sufficient acquisition of resources. There may be duplication of numbers and some individuals who require assistance during an emergency will not use these service providers or agencies. Together these lists can provide raw numbers vital to understanding the magnitude of the community’s requirements.21

Another method is to create specific partnerships with various stakeholders in the community. For example, the American Red Cross of New England partners with Unitil, a regional provider of natural gas and electricity, to issue joint messages about safety and preparedness. Establishing these partnerships would allow them to share and jointly maintain registries of people with access and functional needs, in order to help in setting priorities for emergency response and power restoration efforts.24

Promising Practices
If a community already has a registry or an assessment of the community has been done and the need for a registry has been identified, then according to the grey literature, emergency managers and planners should consider how they will5,10,21,22,25:

- Use the registry. Will the registry be used as a targeted communication tool or as a tool for locating at-risk individuals before, during, and after an emergency incident? The intended use of
the registry will greatly impact the breadth and depth of the information that is collected and regularly updated.

- Educate the public, community and faith-based organizations, and potential registry candidates about the purpose, limitations, and potential uses of the registry. Particular attention should be given to both the value of participation and the circumstances under which registry information will be shared. The education message must also disclaim that participants may in fact not get anything from the registry. In other words, just because a participant registers doesn’t mean that they will get direct emergency support no matter what. Instead the value of participation is that emergency managers will be able to better prepare for whatever vulnerable populations exist within the community, not to better prepare for direct assistance. Participation in an access and functional needs registry does not take the place of personal preparedness. All registry participants should have a personal preparedness plan.

- Educate those at risk about the registry and make sure to mention that information is kept confidential, and discuss the value of participation.

- Launch regular public relations campaigns to update the registries and to gather new names and addresses.

- Secure funding for staff and costs related to developing and maintaining the registry. To be effective, a registry will need both initial and sustained funding.

- Recruit and enroll participants for the registry. Successful state and county registries have utilized a mixture of methods including having individuals sign up online, through the mail, over the phone using local 211 services, and in person at local government social service offices. It is also important to make registry documents and information available in multiple languages and formats (Braille, large print, etc.). Specify the type of person who should be eligible for inclusion in the registry and the number of people that a given jurisdiction can manage.
The following registry features show promise as best practices:\footnote{10}:

- Web-based registration.
- 2-1-1 telephone service support to register people who unable to use web-based systems, along with free translation and TTY.
- Distribution of registration forms at 10 county emergency management offices, with the intent to expand to 21 counties.
- Ads on billboards and in newspapers.

- Maintain and operate the registry. To be effective, registries should contain up to date contact/emergency contact information, as well as information on the location and functional needs of participants. Many state and county registries perform a yearly update (by phone, email, or mail) or require participants to re-register as a way of keeping participant information as current as possible. Individuals should register annually and should be periodically contacted to determine if they still require the registry’s services. Some communities have asked their Citizen Corps volunteers to help gather registry information by going door-to-door to the houses of individuals who identify themselves as having access and functional needs.

- Identify alternative ways to establish registries, given the costs and time that can be involved. Registries maintained by voluntary organizations or social service agencies may be an option. Client lists and phone trees may be another option. Using 2-1-1 call-in systems for specific evacuation requests during or after an emergency may be yet another option.

- Identify the full range of agencies and personnel (first responders, emergency managers, etc.) that will need access to the list in an emergency, and ensure that they will be able to obtain the list. Train those individuals on confidentiality issues related to the registry.

- Cross-check registries with available transportation inventories and map out how needs link to resources. Prioritize those at highest risk with regard to the local hazard.
• Involve those at risk and their advocates in creating a registry.

Below is a visual of things to consider for collecting data to identify access and functional needs populations, specifically when considering an emergency registry. This framework was based off of Kailes and Enders Flow Chart: Deciding to Use an Emergency Registry (2014) \(^2\) and incorporates the expanded recommendations found in this guide.
Things to Consider when Deciding to Use an Emergency Registry

When an organization is considering the implementation of an emergency registry to help identify access and functional needs populations here is a visual of questions to answer. This was adapted from Kailes and Enders Flow Chart: Deciding to Use an Emergency Registry (2014).

Data Collection at All Levels

Community
- Stakeholder Data
- In-Home Supportive Services
- Meals-on-Wheels
- Health Departments
- Utility Providers
- Congregate Settings
- Community Based Organizations
- Faith Based Organizations

National
- Census Data

State
- DSS
- DHS
- CMS
- Para-transit Providers and Durable Medical Goods Suppliers
- Bureau of Motor Vehicles (accessible parking permit holders)

Individual
- Registries

Determine the purpose of the registry.
How will the information be used?
How will it aid in the planning for and delivery of services?
Educate the public.
Secure funding.
Recruit and enroll participants for the registry.
Maintain and operate the registry.
Cross-check registry data.
Include those at risk and their advocates in creating a registry.
What about HIPAA?

For many individuals, there are major concerns over sharing private information and appearing dependent on public services. These concerns deter some people from registering. Because a standard for managing confidential information does not exist for registries, and because Health Insurance Portability and Accountability Act (HIPAA) regulations may prevent disclosures, sharing information among responding agencies can be problematic if the rules are not known.

HIPAA’s Privacy Rule controls the use and disclosure of protected health information held by “covered entities,” which are healthcare providers who conduct certain transactions electronically, healthcare clearinghouses and health plans. “The Privacy Rule permits covered entities to disclose information for public health and certain other purposes. Transportation and social service providers are not likely to be subject to the Privacy Rule and may be permitted to disclose the number of individuals they serve.”21 “The HIPAA Privacy Rule protects the privacy of patients’ health information (protected health information), but is balanced to ensure that appropriate uses and disclosures of the information still may be made when necessary to treat a patient, to protect the nation’s public health, and for other critical purposes.”26

The HIPAA Privacy Rule allows patient information to be shared to assist in disaster relief efforts, and to assist patients in receiving the care they need. According to the DHHS, providers and health plans covered by the HIPAA Privacy Rule can share patient information in all the following ways:

I. Treatment. Healthcare providers can share patient information as necessary to provide treatment.26 Treatment includes:

   a. Sharing information with other providers (including hospitals and clinics).

   b. Referring patients for treatment (including linking patients with available providers in areas where the patients have relocated). The patient does need to sign a release form for the provider to communicate with other available providers.
c. Coordinating patient care with others (such as emergency relief workers or others that can help in finding patients appropriate health services).

d. Providers can also share patient information to the extent necessary to seek payment for these healthcare services.

II. Notification. Healthcare providers can share patient information as necessary to identify, locate and notify family members, guardians, or anyone else responsible for the individual’s care of the individual’s location, general condition, or death.26

a. The healthcare provider should get verbal permission from individuals, when possible; but, if the individual is incapacitated or not available, providers may share information for these purposes if, in their professional judgment, doing so is in the patient’s best interest.

b. Thus, when necessary, the hospital may notify the police, the press, or the public at large to the extent necessary to help locate, identify, or otherwise notify family members and others as to the location and general condition of their loved ones.

c. In addition, when a healthcare provider is sharing information with disaster relief organizations that, like the American Red Cross, are authorized by law or by their charters to assist in disaster relief efforts, it is unnecessary to obtain a patient’s permission to share the information if doing so would interfere with the organization’s ability to respond to the emergency.

III. Imminent Danger. Providers can share patient information with anyone as necessary to prevent or lessen a serious and imminent threat to the health and safety of a person or the public—consistent with applicable law and the provider’s standards of ethical conduct.26

IV. Facility Directory. Healthcare facilities maintaining a directory of patients can tell people who call or ask about individuals whether the individual is at the facility, their location in the facility, and general condition. Of course, the HIPAA Privacy Rule does not apply to disclosures if they are not
made by entities covered by the Privacy Rule. Thus, for instance, the HIPAA Privacy Rule does not restrict the American Red Cross from sharing patient information.

It is imperative that the confidentiality of the registrant be strictly protected. State, Territorial, Tribal and Local officials are advised to consult with legal counsel regarding the applicability of HIPAA and State and Local laws and regulations that govern the confidentiality of information maintained in the registry.

For guidance on how personal health information may be shared for emergency preparedness planning, use the DHHS’s decision tool. This tool addresses when and how a covered entity may disclose the number of individuals it serves, as well as other data for planning purposes. See Appendix C for details.

Durham County Recommendation

Durham County currently has a registry implemented that serves to inform emergency management in regards to sheltering needs and availability for their access and functional needs populations (Link to Registry). The findings in this paper suggest that utilizing only a registry, although possibly useful, may not yield the most comprehensive and efficient effort when identifying access and functional needs populations within Durham County. It can also be expensive, time consuming and resource heavy. Instead, collecting these data at multiple levels utilizing systems of data that already exist may paint a more informed picture for emergency managers to use when developing “whole community” emergency plans.

In order to tackle the above recommendations this paper urges for DCSAFE to consider establishing a Community Outreach Information Network (COIN). COINs work to expand the community’s presence and involvement in emergency planning at every step of the way. The process to accomplish this mission is divided into three phases: define, locate and reach. Each phase includes specific activities to help DCSAFE create and maintain their own COIN: a grassroots network of people and trusted leaders
who can help with emergency planning and give information to access and functional needs populations
during an emergency.  

Community-based driven information dissemination is critical in disasters as people often turn to
those that they already know and trust. Therefore, it is imperative that Durham County utilize a tool such
as the COIN to strengthen partnerships among community stakeholders to be inclusive of the access and
functional needs community.

Additionally, Durham County should build on community resiliency, which is the sustained ability
of a community to withstand and recover from adversity. Resilient communities include healthy
individuals, families, and communities with access to health care, both physical and psychological, and
with the knowledge and resources to know what to do to care for themselves and others in both routine
and emergency situations. As mentioned throughout this paper personal preparedness is always the
priority.

Resilience is considered critical to mitigating vulnerabilities, meeting needs, maximizing
resources, reducing negative health outcomes and rapidly restoring community functioning after public
health emergencies. Using tools such as COIN will promote and develop strategies for building individual
and community resilience that are inclusive of both behavioral health and the access and functional
needs of at-risk individuals.
Alternatives to a Registry

Considering the lack of empirical data and research on the effectiveness of registries, this paper recommends the use of additional or alternative methods to identify access and functional needs populations in a community. It would particularly be ideal to collect data on access and functional needs populations within a community from as many sources as possible. Figure 1 portrays the layers of data that can be utilized to triangulate and quantify an estimated number of access and functional needs populations. This could be seen as a master registry, but it is more of a living database or “list of lists.” The data from the living database could then be used in GIS techniques, analyses, needs assessments and various other methods to assist the “whole community” approach by increasing inclusiveness in order to improve emergency mitigation and response efforts.

Figure 1 Data Collection at All Levels to Identify Access and Functional Needs Populations
In order to integrate access and functional needs populations to shift emergency planning to the “whole community” approach there are key elements that need to be put in place. These elements are highlighted in Figure 2.

There are currently numerous resources that can help an organization identify access and functional needs populations. See Appendix D for a matrix of resource guides.

Research Recommendations

Empirical research is very limited on this topic. Therefore, many federal, state, bi-lateral, multi-lateral and non-governmental organizations call for additional research around the effectiveness of using registries to reduce adverse public health outcomes in emergencies. There is currently one study under way. In collaboration with FEMA, Argonne National Laboratory is conducting a study on how the Alabama Chemical Stockpile Emergency Preparedness Program administered and maintained their registry over an extended period of time. This study uses data collected from surveys and questionnaires over a 10 year period, as well as a series of qualitative research interviews with key personnel involved in creating and maintaining the registry. It will be interesting to see the results and findings of this study.

Research recommendations from the emergency management community range from typologizing and identifying the range of registries currently in use to behavioral research around who does not register and why. One of the major requests is for research around the evidence-base of using registries. Also, comprehensive examination of registry elements such as costs and sustainability,
effectiveness successes and failures, geographic coverage, event specific and scale of event specific issues and the essentials of best practices would provide valuable information.  

Conclusion

Ultimately, emergency managers and public health preparedness professionals need to make sure that underlying health disparities and marginality do not get worsened or amplified by an emergency. As stated previously, understanding risk starts with examining the many places and points at which vulnerabilities intersect, then targeting those areas using good science and effective practices. The lack of empirical research on registries does not lend information on the effectiveness of their use.

Therefore, if a registry does not exist in a county then it might be more efficient, comprehensive and effective to collect data from numerous resources. It is important for emergency managers to collect access and functional needs population data from national, state, community and individual sources.

If a community already has or decides (after an assessment) to implement a registry, then they should consider forming a stakeholder committee similar to DCSAFE and evaluate who is not registering and collect data from other sources to triangulate the data and form a living database or “list of lists” that will better inform their “whole community” and all hazard emergency planning.
Appendices


- Executive Order 13347 – Individuals with Disabilities in Emergency Preparedness: In 2004, this order established the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC) to guide the work across governmental and nongovernmental sectors. Chaired by the Department of Homeland Security, the ICC helps to ensure that the federal government accounts for the safety and security of people with disabilities during disasters. Charges federal agencies to focus on individuals with disabilities when developing emergency preparedness plans.

- FEMA Office of Disability Integration and Coordination: In 2009, the President created and staffed the new position of Senior Advisor on Disability Issues within FEMA to report to the administrator. This senior staff position is responsible for addressing emergency management issues relating to the disability community and is intended to enhance preparedness efforts at the agency’s highest levels.

- Pandemic and All-Hazards Preparedness Act (PAHPA): In 2006, the PAHPA lead to the creation of the Office of the Assistant Secretary for Preparedness and Response (ASPR) to lead the nation in preventing, preparing for and responding to the adverse health effects of public health emergencies and disasters. ASPR focuses on preparedness planning and response; building federal emergency medical operational capabilities; countermeasures research, advance development, and procurement; and grants to strengthen the capabilities of hospitals and health care systems in public health emergencies. The office provides federal support, including medical professionals through ASPR’s National Disaster Medical System, to augment state and local capabilities during an emergency or disaster.

- The PHS Act, as amended by PAHPA (2006) and PAHPRA (2013), established a variety of requirements for addressing needs of at-risk individuals with access and functional needs in public health emergency preparedness and response.

- The Pets Evacuation and Transportation Standards Act of 2006: This act requires evacuation plans to take into account the needs of individuals with household pets and service animals, prior to, during, and after major disaster or emergency.

- Federal Communications Commission – Emergency Alert System Rules: In 2005, the Federal Communications Commission (FCC) expanded the Emergency Alert System (EAS) rules to require that an EAS provide access to people with disabilities by providing both visual and aural alerts. Under the rules, a visual EAS alert does not have to be an exact transcription of an audio alert, but must be “any method of visual presentation which results in a legible message conveying the essential emergency information.”

- Post-Katrina Emergency Management Reform Act (PKEMRA): This act aims to strengthen the Department of Homeland Security/FEMA’s ability to prevent, prepare for, protect against, respond to, and recover from disaster. The act also required that new leadership roles be created within DHS, including the position of National Disability Coordinator (NDC). The Act also includes provisions for the inclusion of people with disabilities in evacuation plans, accessible housing, and regional disability coordinators, among many other changes.

- Robert T. Stafford Disaster Relief and Emergency Assistance Act of 1988: This Act is an amended version of the Disaster Relief Act of 1974. The Act provides the statutory authority for FEMA to
coordinate most Federal disaster response activities. It also established a system through which financial and physical assistance can be obtained from FEMA following a presidential declared disaster.32

- **Americans with Disabilities Act (ADA):** A broad civil rights law that prohibits discrimination against people with disabilities. The ADA requires that people with disabilities have equal access to all government programs.33

- **ADA Amendments Act of 2008 (ADAAA):** This amendment act to the ADA broadens the scope of the definition of what it means to have a disability. These amendments make it easier for people with access and functional needs to seek protection under the law. The ADAAA also mandates that individuals with access and functional needs be included in all disaster plans developed for a community under Title II.33

- **Section 508 of the Rehabilitation Act of 1973:** Requires that when federal agencies develop, procure, maintain, or use electronic and information technology, federal employees with disabilities have access to and use of information and data that is comparable to the access and use by federal employees who are not individuals with disabilities, unless an undue burden would be imposed on the agency. Section 508 also requires that individuals with disabilities, who are members of the public seeking information or services from a federal agency, have access to and use of information and data that is comparable to that provided to the public who are not individuals with disabilities, unless an undue burden would be imposed on the agency.34

- **Americans with Disabilities Act Accessibility Guidelines (ADAAG):** Covers the scoping and technical requirements necessary to ensure that buildings and facilities are accessible. The scoping and technical requirements outlined in the ADAAG must be applied during the design, construction, and alteration of buildings and facilities covered by Title II and Title III of the ADA to the extent required by regulations issued by federal agencies such as the Department of Justice and the Department of Transportation.35
Appendix B: Examples of State and County Registries

**Fairfax County Special Needs Registry**

**Utah Special Needs Registry**


**AT A GLANCE – May I disclose protected health information for public health emergency preparedness purposes?**

*From the perspective of the source of the information*

**Disclosure to a Public Health Authority**

- **START**
  - Am I a covered entity? §160.102
    - **NO**
      - The Privacy Rule does not apply to non-HIPAA covered entities
    - **YES**
      - Is the intended recipient a public health authority (PHA)? §164.501
        - **YES**
          - Is the PHA authorized by law to collect or receive information for the purpose of preventing or controlling:
            - Disease
            - Injury
            - Disability
          - Including, for purposes of emergency preparedness? §164.512(d)(1)(i)
            - **YES**
              - Disclosures can be made without regard to the Privacy Rule
            - **NO**
              - The disclosure may NOT be made unless there is a signed authorization

**Disclosures related to treatment & public health**

- **Is the intended recipient an agency that seeks information for public health purposes?**
  - **NO**
  - **YES**
    - Is the intended recipient a health care provider that uses or discloses information for treatment purposes?
      - **NO**
      - **YES**
        - Is the disclosure by a provider and is the recipient another person or agency that would use or disclose information for treatment or certain health care operations?
          - **NO**
            - The disclosure may NOT be made unless there is a signed authorization
          - **YES**
            - You may make a disclosure subject to minimum necessary
              - §164.502(b), §164.514(d)

**Disclosure of a Limited Data Set**

- Are you disclosing only a limited data set (LDS)? §164.514(e)
  - **YES**
  - **NO**
    - Do you have a data use agreement with the recipient of the information? §164.514(e)
      - **YES**
      - You may make a disclosure subject to minimum necessary
        - §164.502(b), §164.514(d)
      - **NO**
      - Obtain individual authorization; unless the disclosure is otherwise permitted by another provision of the Privacy Rule §164.508
    - **NO**
      - The disclosure CAN be made
## Appendix D: Matrix of Resource Guides on Identifying Access and Functional Needs Populations

**Inclusion criteria for this matrix were as follows:** Resource has to be specifically focused on access and functional needs populations and all other relative terminology (i.e. special needs, social vulnerability, at-risk and intellectual or developmental disabilities); Resource must be accessible online; Resource must be a tool, guide or resource guide.

<table>
<thead>
<tr>
<th>Resource</th>
<th>Link</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Social Vulnerability Index (SVI)</td>
<td>Link</td>
<td>CDC/ATSDR's Social Vulnerability Index uses U.S. census variables at tract level to help local officials identify communities that may need support in preparing for hazards, or recovering from disaster.</td>
</tr>
<tr>
<td>Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters</td>
<td>Link</td>
<td>The purpose of this document is to provide planning guidance that can be incorporated into existing shelter plans to State emergency managers and shelter planners to meet access and functional needs in general population shelters. This document provides guidance to assist emergency managers and shelter planners in understanding the requirements related to sheltering children and adults with functional support needs in general population shelters. Functional Needs Support Services (FNSS) and the guidance provided are designed to assist in the planning and resourcing of sheltering operations whether government, NGO, faith- or private-based to meet the access and functional needs of children and adults.</td>
</tr>
<tr>
<td>Vulnerable and At-Risk Populations Resource Guide</td>
<td>Link</td>
<td>In Spring 2014, NC PERRC will release the updated and enhanced <em>Vulnerable and At-Risk Populations Resource Guide</em>. The new Guide will better assist state and local public health agencies, hospitals, and other agencies with identifying and planning needs related to at-risk and vulnerable populations to meet requirements for capability-based preparedness planning and response.</td>
</tr>
<tr>
<td>Guidance on Integrating People with Access and Functional Needs into Disaster Preparedness Planning for States and Local Governments</td>
<td>Link</td>
<td>This guidance will introduce and connect you to available resources and inclusive strategies for integrating the access and functional needs of at-risk individuals into emergency preparedness, response, and recovery planning at all jurisdictional levels.</td>
</tr>
<tr>
<td>Office of Disability Integration &amp; Coordination</td>
<td>Link</td>
<td>This page contains the mission of the Office of Disability Integration and Coordination (ODIC), resource links, a distribution list signup, news and more, and is intended for anyone looking for information and resources about emergency preparedness and disaster response, recovery, and mitigation that is inclusive of people with disabilities and others with access and functional needs.</td>
</tr>
<tr>
<td>Access and Functional Needs Emergency Registry Assessment Tool</td>
<td>Link</td>
<td>Registries continue to be recommended, and in some places, required. Until objective research is available, we have drafted criteria to help your jurisdiction evaluate if a registry will achieve the desired objectives, and to assist you in deciding where and when a registry could be effective.</td>
</tr>
<tr>
<td>At-risk Populations eTool</td>
<td>Link</td>
<td>The At-risk Populations eTool is a companion to the At-risk Populations Workbook. The purpose of this tool is to help you create a Community Outreach Information Network (COIN) to reach at-risk populations in an emergency.</td>
</tr>
</tbody>
</table>
References


