Emergency Registries
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This expanded discussion covers in greater detail some of emergency registry content and recommendations covered in the After Action Report **Getting it Wrong: An Indictment with a Blueprint for Getting It Right** (2018).

Considered are the challenges and shortcomings of existing emergency registries with examples from recent hurricanes in Texas and Florida, as well as other disasters. Recommendations focus on the need to look beyond emergency registries to the new, ubiquitous technologies that more easily connect people with disabilities and others with access and functional needs to the supports and assistance they need in their communities before, during, and after a significant emergency.

> As soon as Raymond Guzman, 35, learned Hurricane Harvey was headed toward the Texas Gulf Coast, he started calling for help.
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> The Victoria resident lived with his 63-year-old disabled mother in an aging trailer, where he worked as her full-time caretaker. Before the storm, Guzman registered with 211, a resource hotline, to be added to a list of Victoria residents who might need help evacuating.
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> But as the deadly storm barreled toward the coast, Guzman, who doesn't own a car, wasn't having luck getting help. He started frantically calling law enforcement and government officials to schedule a ride to safety - to no avail.
>
> "Please send someone to come get us," Guzman recalled saying.
>
> Help didn't come until more than a day after the storm passed, forcing Guzman and his elderly mother to hide in their mobile home as the hurricane ripped apart its walls and collapsed part of the ceiling.
>
> But that isn't supposed to happen.
>
> … Authorities say they usually start reaching out to vulnerable residents about 96 to 120 hours before a disaster strikes to ask whether they need help.
>
> But Hurricane Harvey created unexpected logistical challenges for emergency officials as the forecast changed from a strong tropical storm to a Category 4 hurricane within two days.
>
> "Obviously with Hurricane Harvey and the rapid intensification of it, that became a very unique situation for us," said Richard McBrayer, who oversees emergency operations for Victoria.

> Usually, when emergency planners call residents before a storm hits, it gives officials time to arrange transportation. That could mean picking them up at their homes or directing them to a bus stop, McBrayer said.
>
> But Hurricane Harvey's rapid intensification upset those plans. With little time left before the hurricane was expected to make landfall, emergency officials started a major "shelter-in-place" campaign, McBrayer said.
>
> According to county data, the number of people registered in the emergency program plunged from 1,250 in 2016 to 270 this year. Officials attribute the decline to the fact that some people may have moved in with family, passed away or left the area (Footnote 1).

Victoria's county population is about 90,000 and, according to the 2012-2016 *American Community Survey 5-Year Estimates*, there are approximately 13,500 people with disabilities in the county. A key question for Victoria County emergency managers is whether they need to plan for 270 people, or 1,250 people or 13,500 people?

Raymond Guzman's story as well as other issues discussed in this section represent many of the inherent problems with registries. These shortfalls include registrant expectations and responder capacity, integrity of the data, recognition of performance failures related to scale of events and no-warning and short warning events and lack of evidence-based research regarding registry effectiveness,

Registry use in emergency management

In this report registries refer primarily to government plans to collect information about people with disabilities. This information typically consists of a database of individuals who voluntarily sign up and meet a variety of eligibility requirements for receiving emergency response services based on a need. Registries vary in form. In theory they collect the names, locations, and contact information of people in a given area or jurisdiction who are likely to need emergency help. The intent of a registry is to provide a priority warning regarding pending emergencies, including the shut off of power or water service; evacuating people from a danger area; providing sheltering, checking on individuals' health and safety; and connecting people with other viable and available supports and resources.

This discussion provides additional information on the State of Texas Emergency Assistance Registry (STEAR) and its use in Hurricane Harvey and on Florida's Special Needs Shelter Program and its use in Hurricane Irma. STEAR focuses on practices, procedures, updates and recommendations for a free state registry to provide local emergency planners and responders with additional information on the needs of individuals in their communities. If STEAR was used in the 2017 Hurricane Harvey response, finding anyone able to report the result was elusive. The Florida's Special Needs Registry is tied to its Special Needs Shelter Program and was used in the 2017 Hurricane Irma.

From a voluntary registrant's perspective, any emergency registry is a tool for managing personal risk. From a responder's perspective, a registry is a tool for locating a person in danger and connecting them with needed resources. The fundamental dilemma in registry effectiveness is the relationship between registrant expectation and responder capacity. Timing, resources, scale, and type of warning all influence that relationship. The ambiguity of this catch-all "registry" term, can lead to oversimplification of complex concepts, encompassing and dependent on many elements, such as the nature and scale of the hazard, type of warning, promised assistance, prioritization, and methods of response.

It must always be assumed that a needs-oriented registry is incomplete and includes only a small percentage of the population who has potential needs. The University of Texas School of Public Health at Brownsville, for example, estimated that 350,000 people, about 1 in every 4 Rio Grande Valley residents require transportation assistance for evacuation, but only 11,000 have registered (Footnote 2).

In practice, needs-oriented registries have typically been unable to achieve well-intentioned objectives for two major reasons. First, the response capacity is not considered or calculated based on the size of potential events and presumes there are enough responders to act in the case of mid- to large-scale events when there are not. Second, the simple fact of knowing where people live doesn't tell you where they are at the time of the event, which wastes critical time and resources looking for people in the wrong places (Footnotes 3 and 4). Fixed location registries can mean wasted trips and wasted time for overstretched first responders. According to the *New York World*, 658 people in Suffolk County Long Island were on a registry maintained by the county's Office of Emergency Management. Before and after Hurricane Sandy hit, volunteers placed 4,000 calls to the people on the list and their emergency contacts. In all, responders only evacuated 130 people on the list from flood-prone areas (Footnote 5).

"Just because you, know where I live, doesn't mean you know where I am!"
June Kailes

Many people object to the inherent registry bias that most people with disabilities are easy to locate because they are "homebound." Registries negate the fact this diverse population, just like everyone else: works, volunteers, plays, prays, shops, eats and travels. As the author often says, "Just because you, know where I live, doesn't mean you know where I am!"

Many registries are developed using outdated technology and collect information using medical model biases about people with disabilities. Applying the social model, versus a medical model, of disability entails identifying, remedying, and retooling interventions

that reflect common stereotypes and beliefs about people with disabilities. Manifestations of medical model stereotypes include assuming that people with disabilities are sick, are “homebound” and need medical care, protection, supervision, and separate shelters.

The numbers indicate that in a large-scale emergency, despite planning, first responders and most communities do not have the capacity to respond to large events. For example, the 911, 211, 311 call centers and first responders are often overwhelmed and unable to handle the call volume. Although traditional emergency registries may work in small scale response events, e.g., a house fire, registry effectiveness is much more questionable in larger, catastrophic events.

In areas where large-scale emergencies seldom or rarely occur, significantly less time is typically spent on the details of emergency plans. The more often emergencies are experienced, the stronger the perception of risk and the more time is spent on planning. Recent memory is a great motivator for thinking through the effectiveness of registries and tends to counteract “magical thinking” that they are likely to be effective.

Clarifying Purpose and Expectations - Planning tool? Response tool?

Planning will continue to miss the mark when people with disabilities and others with access and functional needs are considered separately, instead of recognized as people who are a part of every segment of the general population. These are, in plain terms, the people that in an emergency will have difficulty seeing, reading, hearing, understanding, talking, thinking, remembering, walking, using stairs, hiding, running, jumping, etc. In larger scale emergencies, functional needs significantly increase as people lose access to their devices, equipment, supplies, medications and to the supports and customizations they rely on in their environments. Counting others who acquire injuries resulting from the impact of the disaster, this group can represent well over 50% the population.

The numbers of registered people will never be the same as the number of people with access and functional needs in any community. This discrepancy leads planners to be ill-prepared for reality, especially in larger scale events. Many people with disabilities will not sign up for registries because they worry about their privacy and fear being tagged as vulnerable. Others are concerned about their legal status or that of their family members, and/or fear losing independence. Some will question what happens to the many who do not register. Developing voluntary registries as the basis of planning for people with access and functional needs is, at best, an exercise in symbolic planning or “magical thinking”, rather than realistic and practical planning.

Symbolic Planning

Symbolic planning refers to guesses based on untried, undocumented, or unsuccessful practices. Symbolic plans lack specifics of who, what, where, when and how. A classic example is the April 20, 2010, gas leak and explosion on the Deepwater Horizon oil

drilling rig in the Gulf of Mexico. Although not related to registry issues, eleven people died because of the accident, and others were injured. The fire burned for 36 hours before the rig sank, and hydrocarbons leaked into the Gulf of Mexico before the well was closed and sealed. Ultimately, the company's emergency functions failed to seal the well after the initial explosions. As Lee Clark explained in his book Mission Improbable, there was a cleanup plan for spills in the sound, but this massive spill was unprecedented. The plan that had been developed and accepted as policy was based on little more than a patchwork of guesses, which is what typically happens with needs-based registries.

Planning with and for People with Access and Functional Needs

Planners who recognize the actual composition and characteristics of their communities would be more productive identifying the community profile demographics using tools such as the Social Vulnerability Index, which can point to location of clusters of people, such as retirement communities, public housing and assisted living complexes.

Because of the multi-disciplinary nature of the people and agencies involved with emergency management, there are different expectations and sometimes competing priorities for using a registry. It is essential to agree on expected outcomes, the protocols for achieving these outcomes; and how the registry integrates with other parts of the emergency management and services system. (At a minimum, this includes emergency managers, planners, and responders for different types and scales of events; public health; potential registrants; resource organizations and services, e.g., transportation.) The most important issue to clarify is whether and why to establish/maintain an access and functional needs registry. What are developers/sponsors trying to accomplish with the tool? Whose perspective is driving the system? For example, a registry viewed from a public health and emergency management planning perspective may look quite different and have a different emphasis, then a registry viewed from the registrants' and responders' perspective.

Operationally, an emergency registry is a response tool that provides a response safety net for the people registered. Responders will be using it to improve their response effectiveness. A voluntary registry, however, is not an effective "stand-alone" planning tool because not everyone that needs to be included in the planning process will ever register. Thus, no voluntary registry can provide complete data about demographic and geographic distribution patterns and any subsequent analyses that might rely on registry data would be inaccurate.

The first registry questions from a registrant's perspective are: *What am I registering FOR? What will it do for me? What can I expect?* It is surprising to find that public health and emergency management professionals have a strong reaction to the concept that a registry is operationally a response tool, and not a planning tool. They have difficulty addressing the question: *"Why would an individual register in a system that will be unable to provide assistance when emergency response is needed?"* (Footnote 6).

Personal emergency response systems (PERS) like LifeAlert and vehicle-based OnStar provide a useful comparison and benchmarks for other registries. These commercial systems provide “emergency response” to individuals who pay for the service and security provided by an on-call response system. They link an individual to the resources needed to respond to an individual emergency – e.g., falls in the home, car crashes. OnStar advertises that it will stay with you (by voice) until help arrives. The subscriber knows what to expect. They know that the PERS service personnel are not coming, but that someone will stay on the line with them until summoned help arrives. The subscriber is willing to pay a subscription fee to get assistance in contacting people who can help get responders to help them when assistance is needed. In a medium to large scale event, the call service would be able to tell them that assistance was not going to be available (e.g., the local jurisdiction’s call center was overloaded), and the subscriber would then know they were on their own. PERS systems are focused on response. They are not used for emergency planning.

Connecting Registrants and Responders

How the connections are made between the registrant and the responder is essential to making the system work. What is the interface with responders? How is that handshake made and sustained? Private commercial PERS have a business model for operating the emergency response communication. Personnel in the service centers are neither registrants nor responders, but make connections between the two, on a fee for service basis. Most government registries do not have this active bridging element. This essential element is missing in most registries.

Registry Disclaimers

Registries use disclaimers to address situations where a mismatch between registrant expectation/need and responder resources/timeframe may occur. But that leaves the individual not knowing what they can and cannot expect in any given emergency. Will the responders, the transportation, the assistance be there? And if so, when?

Despite the disclaimers that most registries require, there will still be expectations about registering providing priority for being rescued or evacuated and not being left behind.

The STEAR disclaimer states:

> “Does registration with STEAR guarantee I will be evacuated during an emergency event such as a hurricane? No, your information will be provided to participating local governments for their use in developing emergency management plans and to assist them in preparedness and response activities. Each local government uses the information in different ways and registering in the system does NOT guarantee that you will receive additional assistance during an event. Contact your local Emergency Management Coordinator to determine their level of participation in this program.” (Footnote 7)

Registries give people a false sense of security, even when they come with educational efforts and clear disclaimers. Registries can reinforce the phenomenon of “magical thinking.” This occurs because most people do not want to think about emergencies. Most people don’t pay attention to emergency details until they need to, just as people don’t pay attention to the details of health insurance, or using a fire extinguisher, or shutting off the water, or opening a power-dependent gate or garage door during a power outage. Many people also find it disturbing to think about large-scale, Katrina-like events. It is much easier to believe that the government will automatically be there to help.

People persist in the magical belief that signing up for a registry guarantees assistance. This misguided belief can diminish or even divert the energy people should devote to developing and strengthening their personal preparedness plans that should include thinking through and taking appropriate steps to establish and keep current personal support systems.

Failures

Disclaimers point to one of the major limitations of all registries. In a medium to large scale event, even the best commercial personal emergency response system is likely to fail. The person in need (or the PERS service center representative, or the staff at a human service agency) can make calls to the call center -- but if there are no response resources to deploy, there will be no response. The best the PERS service center can do, is stay on the phone with customers while they wait. Or if possible, help customers to activate another plan. Optimally, assistance in developing a personal emergency response plan would be included by default in the services any PERS systems offers.

Integrity and Accuracy of the Data

A registry is not effective as a planning tool for populations with access and functional needs. There is little likelihood that everyone, or even most individuals, that need to be included in the planning process will ever register, making analysis inaccurate.

Reports from California detail serious problems in keeping registries current as well easily and quickly retrieving the data and responding when needed. Individuals in charge of registries were unable to access the list because of power outages and lack of access to work sites. Lists provided to local fire stations list were irretrievable because they were locked in cabinets, and all firefighters were out fighting the fires.

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Costs

Maintaining registries is expensive and is typically not economically viable. In 2004, the Los Angeles County Office of Emergency Management "…conducted research on the costs of developing and implementing a voluntary registry. According to this research, a registry program in LA would require 14 full- time staff, including 10 analysts, two employees to do geographic information system (GIS) mapping, and two administrative assistants. The total cost was estimated at just under $1.4 million per year for the first three years of the program, with two-thirds of the funds going towards staff and the remaining one-third for technology."

State of Texas Emergency Assistance Registry (STEAR)

Texas has invested significant dollars, time and effort in the establishment of the State of Texas Emergency Assistance Registry (STEAR). STEAR "focuses on practices, procedures, updates and recommendations for a free state registry to provide local emergency planners and responders with additional information on the needs of individuals in their community (Footnote 8).

Once the data is entered, STEAR information is the responsibility of a data custodian at the local level (for rural counties, usually the custodian is appointed at the county level). The county or city has discretion regarding how they use the data. There are significant questions about the rigor applied to the critical effort of keeping data current and accurate given the short shelf-life and perishable nature of registry data. In STEAR, for example, there are several reported current vacant positions for the local data custodians (Footnote 9). Also, STEAR functions are decentralized. Emergency personnel at the county and city level do not have to use STEAR. There is no an overall reporting mechanism to evaluate the STEAR and there are no required procedures for using the information. There are reports that Harris County and the City of Corpus Christi used their STEAR data in response to Hurricane Harvey. In addition, there are unverified reports that STEAR information was used for search and rescue operations for Hurricane Ike and the 2016 Floods. However, searches for data regarding effectiveness and outcomes did not yield any publicly available information.

Comments from the City of Houston to Federal Communication Commission regarding response efforts related to the 2017 hurricane season provides some effectiveness and outcome information. These comments reflect the input of the Houston Emergency Center, the Houston Police Department, the Houston Fire Department, the Houston Information Technology Department, and the Mayor's Office for People with Disabilities.

> Texas uses the State of Texas Emergency Assistance Registry (STEAR). In theory, people with disabilities can register with STEAR so that they can receive assistance evacuating during a disaster. Many people with disabilities registered with STEAR and expected that they would receive assistance that emergency responders when their homes started flooding. They repeatedly called 911 and 211 and received no assistance. The State of Texas makes it clear that registering with STEAR does not guarantee assistance with evacuation, however, for Harvey, because broad evacuations were not ordered, only six individuals were actively contacted through the STEAR database. Many power-dependent people with disabilities received water in their homes and needed to be evacuated, despite the lack of an official evacuation order. States and localities are increasingly using databases/registries like this. The FCC should issue guidance on best communications practices for entities using a disaster response assistance registry for people with disabilities. Such guidance could assist in getting more people with disabilities more consistent, responsive interactions with emergency workers (Footnote 10).

A review of 11/14/17 and 5/11/17 STEAR Advisory Council minutes yielded no insight into response outcomes. A major emphasis of the minutes was analyzing the statistics and demographic characteristics of STEAR registrants. The November 2017 minutes contained this statement regarding STEAR data used during Hurricane Harvey.

> "Harris County Office of Emergency Management pulled information from B and C registrations and set up a call center to reach residence and inquire about emergency plans. They explained there was no evacuation order or transportation for residents; calls were for planning purposes only and conducted in a manner to avoid panic. Residence were glad to receive the calls. "Some roll over 9-1-1 calls were received. " (meaning unclear)

Florida's Special Needs Shelter Program

The Florida Division of Emergency Management, in coordination with each local emergency management agency in the state, developed a registry to allow residents with special needs to register with their local emergency management agency to receive assistance during a disaster (Footnote 11).

The Florida Division of Emergency Management, in coordination with each local emergency management agency in the state, developed a registry to allow residents with special needs to register with their local emergency management agency to receive

assistance during a disaster. The statewide registry provides first responders with valuable information to prepare for disasters or other emergencies (Footnote 12).

Concerns about this system were frequently raised by key informants (interviewed for After Action Report **Getting it Wrong: An Indictment with a Blueprint for Getting It Right**), stakeholders, Hotline callers, traditional and social media. Key informants voiced many serious concerns about the registry, especially as it related to sheltering. Concerns included lack of capacity to accept registrants into their special needs shelters as well as registrants who were turned away because of lack of space; refusal to admit registrants who were unable to bring a personal assistant with them and no capacity to admit people in need who did not pre-register.

Efficient and Effective Use of Technology as an Alternative to Voluntary Registries

The emergency sector's performance depends on resilience and flexibility to evolve as economic, learning, technology, legal and social landscapes change. In this world of shrinking budgets, scarce first responder resources must be used wisely. This includes prioritizing efficiencies that modernize how people signal for and receive help in real time, and harnessing technology through potential viable applications like social media, mobile devices, sensors and supply delivery via drones and services such as Uber, Lyft, Amazon, UPS and FEDEX (Footnote 13).

Pew Research Center reports that cell phones ownership in 2018 to be 95% of the US population and 77% of those people own smartphones (Footnote 14). In many disasters, landlines and cell towers remain operational or come back up quickly in a significant portion or outages. Technology is also finding new solutions for prolonged cell tower and internet outages by using internet via drones and high-altitude balloons that deliver temporary communication and internet connectivity.

Rapidly advancing technology plus a more technologically savvy population change the public's expectations and emergency management's response capacity. Technology can broaden and replace the traditional registry concept. For example, proprietary systems exist which fully integrate data provided by individuals into a local call center's 911 database. Instead of a registry's focus on people who are viewed as different, special, at risk, at home, or vulnerable, there are software systems such as Smart 911 that allow any community member to build a safety profile which provides responders with immediate access to information about their access and functional needs, chronic conditions, medications, service animals, vehicles, pets, and emergency contacts. When someone in a household calls 911, their data is displayed for the 911 call taker and can be used to inform the response to the specific location. These systems are also not home dependent. The phone numbers are registered, not the location. Technology can efficiently build into the response infrastructure responder friendly mechanisms that enhance connections with all community members (Footnote 15).

Commercial Registries

Personal Emergency Response Systems (PERS) (Footnote 16) are commercial registry systems that coordinate "emergency response" to individuals who pay for the service and security provided by an on-call response system. The vehicle-based systems like OnStar SOS (Footnote 17) and Sync 911Assist (Footnote 18) are also tied to mobile phone technology. Since 2010, the Personal emergency response systems (PERS) model has quickly evolved to a broad array of mobile-based platforms. People who "have fallen and can't get up" are no longer tethered to their homes.

Capturing the Power of Technology

The focus should be on how to capture the power of accelerating technology capabilities which can effectively and efficiently perform some of the many life-saving and life-sustaining tasks (search and rescue, evacuation, transportation, delivery of emergency supplies, restoration of communication arteries) that overwhelm first responders in catastrophic events.

Mobile devices include smartphones, tablets, virtual assistants (Alexa, Cortana, Echo, Siri, etc.) wearables like Fit bits, Apple watches, etc. These mobile devices and their apps offer exciting new possibilities. The many peer to peer (P2P) apps available and in development take advantage of social media software that captures the strengths of spontaneous community response. Peer-to-peer (P2P) is a decentralized communications model in which each party has the same capabilities and either party can initiate a communication session. Existing products and newer prototypes of technologies to achieve an "anywhere anytime" communication and location identification systems for assistance already exists (Footnote 19).

The preciseness of location services is quickly evolving in their ability pinpoint exact locations. The wasted time, calls, and trips problem could be dramatically reduced by optimizing these location services. There are "Check In," and "Find Me" apps," and sensor technologies that detect falls and other dangers. Global positioning system (GPS) enabled apps like "Follow Me" features allow users to choose contacts who can track their location in real-time. An "I'm Safe" or "Need Help" signal can be activated to let ones' designated lists of people know one is safe.

Some apps that activate a help signal that can be set to send a panic alert containing a link to one's GPS location. The alerts go to one's pre-selected emergency contacts via text message, and email, and if set up, posts to Facebook and Twitter. When "help" is activated, it automatically prompts the user to contact 911. Other apps offer one-button activation that calls everyone on a pre-designated list with a pre-programmed message.

People needing evacuation help could use the ride sharing economy's Uber or Lyft-like transportation applications, when accessibility is a built-in feature, such as "need a wheelchair accessible vehicle" or "need driver able to lift/put my mobility device into the trunk." Use of a signaling device could read the remaining battery power of a piece of life-sustaining requirement and signal designated organizations and responders with

global positioning system coordinates of the device once it fell below a given battery charge threshold (Footnote 20). Airbnb-like sharing economy model could be adapted for use in providing temporary housing.

Recommendations

Based on the documented experiences of the 2017/2018 disasters, as well as previous emergencies, this report concludes that most if not all, access and functional needs registries have common similar systemic problems. A registry plan may sound feasible, but it may not be able to achieve its well-intentioned objectives for two major reasons. First, the response capacity is not considered or calculated based on the size of potential events, and second, knowing where people live doesn't tell you where they are at the time of the event. The former presumes that there are enough responders available for mid- to large-scale events when there are not. The latter wastes critical resources and time as responders look for people in the wrong places, which helps neither the responder nor the evacuee.

The following recommendations to national, state and local entities are offered to improve disaster response and outcomes for people with disabilities and others with access and functional needs.

1. Government should use existing planning tools to collect data about people with disabilities and others with access and functional needs.

2. Emergency services should strengthen connections and planning with organizations who maintain current lists of the individuals they serve, such as accessible transportation providers, paratransit providers, Aging and Disability Resource Centers, Area Agencies on Aging, equipment vendors, assistive technology centers, developmental disability services, health plans, home health agencies, Meals on Wheels, mail order pharmacy services, personal assistance services (public and private), utility discount lists (power and water), independent living centers, early childhood, in-home, and school based special education services and many other existing sources of information that can guide whole community planning.

3. Government should not mandate or endorse emergency registries.

4. Government should use technology to improve how people with disabilities and others with access and functional needs signal for and get help.

5. Conduct evidence-based registry research that includes outcomes, costs, and stakeholder satisfaction measures.

Recommendation 1: Government should use existing planning tools to collect data about people with disabilities and others with access and functional needs.

Use effective planning tools to collect data regarding people with disabilities and others with access and functional need. Local governments often use registries as a planning tool. However, a registry is not effective as a planning tool. There is little likelihood that everyone, or even most individuals, that need to be included in the planning process will ever register, making analysis inaccurate.

> "A registry will not be effective if it is used as the primary planning tool for populations with access and functional needs. Believe it or not, many emergency planners look at registries, spreadsheets, lists, tables, and matrices as a sort of planning panacea. Neat columns and rows replete with filled-in data fields are de-facto substitutes for substantive information. All too often, tabular data is accepted without any real analysis on the part of plan reviewers. So long as the key words appear in the heading boxes and some degree of descriptive "stuff" in visible in the appropriate columns/rows, the "plan" passes muster." Philmont M. Taylor, commander of the Emergency Services Division of Los Alamos, New Mexico.

To collect data about the demographic and geographic distribution patterns in a jurisdiction for planning purposes, use readily available existing data. These information sources include program administrative data from government sources including the US Census, US Department of Health and Human Services emPOWER Tool, the Social Security Administration and community service agencies, and GIS (geographic information systems) tools.

Recommendation 2: Emergency services should strengthen connections and planning with organizations who maintain current lists of the individuals they serve, such as accessible transportation providers, paratransit providers, Aging and Disability Resource Centers, Area Agencies on Aging, equipment vendors, assistive technology centers, developmental disability services, health plans, home health agencies, Meals on Wheels, mail order pharmacy services, personal assistance services (public and private), utility discount lists (power and water), independent living centers, early childhood, in-home, and school based special education services and many other existing sources of information that can guide whole community planning.

Successful partnerships with the resources of government, community organizations and businesses are far more likely to yield favorable outcomes for disaster impacted communities than separate voluntary collection of perishable and inexact information.

> California emergency responders commenting on the use of registries stated: "The act of creating a registry does not increase response capacity, but focusing on integrating community stakeholders in response does."

It is important that government not limit its definition of community stakeholders and engagement only to those involved with Voluntary Agencies Active in Disasters (VOADs) or others who have as their mission emergency work. This leaves out many

organizations that do not have emergency work as part of their primary mission but play a critical role in supporting people with disabilities and others with access and functional needs.

Emergency services should strengthen connections and planning with organizations who maintain current lists of the people they support who would be disproportionally Impacted in disasters. Successful partnerships with the resources of government, community organizations and businesses can result in far more positive outcomes for disaster impacted communities than separate voluntary collection of perishable and inexact information.

How effectively government can partner with, and leverage, the resources of community organizations and businesses will determine the success of the response. For example, these organizations can help during large emergencies by pre-developing a “priority emergency contact list” that can be used for life-safety check-in systems to reach out, to those who, through a pre-discussion process with the people they support, have self-identified as having the greatest need for assistance. This list can include people who are geographically isolated; lack viable support networks such as relatives, friends, and neighbors; cannot use or understand or be reached by existing alert and notification systems; are transportation-dependent and who are unable, or least able, to get to commodity distribution points. Leveraging community resources also entails recognizing the critical force multiplier value and efficiencies of working with self-organizing communities. It means partnering with the next Cajun Navy response effort and the many other examples in the 2017/2018 disaster seasons of self-organizing responders.

During Hurricane Irma and Maria the paratransit agency on St. Thomas proactively and independently contacted all their riders to check on their safety and their needs of and offer any assistance they could. Their rider list is current, and they know well all their customers.

Life-safety wellness checks by organizations also apply to people who are sheltering in place in their homes and do not need life-saving search and rescue. These checks provide people, when needed, with essential items, such as water, food, medications, supplies, evacuation, and transportation for health care (such as dialysis), batteries, waste disposal, home health, and personal assistant services (Footnote 21).

An emerging government resource is the emPOWER tool maintained by Health and Human Services. This is a non-inclusive list of people who rely upon electricity-dependent medical equipment. This emPOWER provides information to local public health officials about the number of known Medicare beneficiaries in each impacted area who rely on 14 types of life-maintaining and assistive equipment. This equipment ranges from oxygen concentrators to electric wheelchairs, as well as data on the number of people who rely on dialysis, oxygen, and home health services (Footnote 22). (Note: it is imperative to recognize that there are many people on Medicare who won’t be included, as the equipment they are using was not paid for by Medicare.)

One critical caveat that must repeatedly be acknowledged is that these organizations will never reach all people with disabilities and others with access and functional needs. There are many who may need assistance who do not affiliate with, interact with or receive services from any of these organizations.

Recommendation 3: Government should not mandate or endorse emergency registries.

State and local government emergency planners should not mandate or endorse the use of emergency registries unless and until registries effectiveness outcome data merits this endorsement. Government codifying registries confines and delays adopting newer technology approaches.

Texas, Florida, and North Carolina among other states and some local governments have regulatory language mandating the creation of registries. For example, the 2009 session of the North Carolina General Assembly authorized North Carolina Emergency Management to develop a voluntary special needs registry for use by counties and municipalities (Footnote 23).

These regulations are sometimes followed and sometimes ignored. Key informants explained that legislators are reluctant to remove these regulations or allow them to sunset (expire) because whether based on reality or not, they fear that at some point the may get blamed for some preventable disaster-related deaths. Ironically an even stronger argument can be made regarding the liability of allowing these statutes to remain in place.

Recommendation 4: Government should use technology to improve how people with disabilities and others with access and functional needs signal for and get help.

Universal design specifications and features must be integrated into the device and app development process to insure ease of use of these emerging emergency innovations by diverse populations which include those with limited function related to dexterity, seeing, hearing, speaking, reading, understanding or remembering. If access and functional needs elements are not consistently integrated into this rapidly evolving technology, it will mean continual catch-up and retrofit. It may also lead to wasted time and money in expensive litigation and settlements.

Recommendation 5: Conduct evidence-based registry research that includes outcomes, costs, and stakeholder satisfaction measures.

The number of local jurisdictions (cities and counties) developing and using registries appears to be increasing. An online search for emergency management registries provides many links to registries focused primarily on “special needs populations.” Yet little is known about their effectiveness, and most of that is anecdotal. There has been

little objective discussion about when and where a registry is a useful tool for emergency response, at what scale a registry becomes inoperable, and perhaps even more dangerous when it provides a false sense of security and diverts the registrants from developing emergency plans.

Registries have diverse and complex elements which include funding, administration, focus, recruitment of potential users, enrollment, disclaimers, education efforts, data management (information collected, privacy, refreshing-maintenance, storage and retrieval), and response capacity. Research does not exist that comprehensively examines registry elements such as costs; sustainability; effectiveness (successes and failures), geographic, event specific and scale of event specific issues; and the essentials of promising practices for these efforts.

Social Media

How can stronger use of social media, Global Positioning Systems (GPS) and Google location services be strategically leveraged and integrated into response efforts?

> Angela Wrigglesworth has a form of muscular atrophy and uses an electric wheelchair. She and her fiancé had decided to get supplies and hunker down in their home near downtown Houston. “I’ve lived in Houston my entire life, so hurricanes weren’t foreign,” she says. “No one in our area was leaving. Even though we live in an area that floods, our house has never flooded.”
>
> The couple woke up early Sunday morning, August 19, to a river of water in front of their house. “We turned on the news and saw people up on their roofs getting rescued not far from us. That’s when we knew we needed to go,” she says. They tried to call 911 but could not get through. Other emergency management services told Wrigglesworth to get on her roof. Wrigglesworth took to social media to ask for help when water started seeping into her house later that morning.
>
> Her post went viral. A few hours later, a team of firefighters arrived, but they determined they could not transport her and her wheelchair safely. Later, three former Marines in a canoe paddled to her house, but there was too much risk that the canoe would tip over in the rushing water. “Being medically fragile, I was worried about being transported and transferred safely,” Wrigglesworth explains. “There were these moments of relief because we thought we were being rescued, but then these letdowns when we realized it wouldn’t work.”
>
> In all, it took six hours of trying before they were safely rescued. Two friends arrived with a snorkel Jeep that could drive into high waters and a 12-foot-long fishing boat that could accommodate her. Wrigglesworth’s wheelchair was damaged from the rain and her home is still being repaired from flood damage, but she considers herself lucky to have had so many people try to help (Footnote 24).

Compare different models

Compare different registry approaches and outcomes STEAR, PERS, SMART911 and the Florida Special Needs Registry.

How can the self-organizing community (s) be force multipliers and enhance efficiency for all?

Personal emergency response systems (PERS)

What can government learn and apply from commercial PERS registry systems? (For example, PERS saw the value of mobile systems early on to accommodate the issues of "where I live, doesn't tell you where I am."

What were the PERS systems experiences in connecting to 911 or other response resources during 2017/2018 disasters?

What role does PERS play in assisting their customers in developing emergency plans?

Closing Thoughts

To paraphrase a quote attributed to many people," If you always do what you always did, you always get what you always got. Is that enough?" The answer is no. Thinking in the future tense means better decisions, strategies and policies for today and better outcomes for tomorrow. It means embracing and using technology. It means finding the resources to make the technology ubiquitous, affordable, and universal. This work will entail weaving together traditional emergency services and volunteer models with the emerging P2P models.

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