

Readiness registries: improving the effectiveness of state access and functional needs registries

by

Kyle Jon Oneth

A REPORT

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Department of Landscape Architecture and Regional and Community Planning  
College of Architecture, Planning and Design

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Approved by:

Major Professor  
Dr. Susmita Rishi

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## **Abstract**

Populations with access and functional needs are a demographic group that requires specific planning and response considerations to ensure their safety during disasters. People with disabilities face greater exposure to physical hazards and are more likely to experience negative social, economic, political and psychological consequences when impacted by disasters (Wolkin, Patterson, Harris, Soler, Burrer, McGeehin and Greene, 2015). People with disabilities, therefore, are more socially vulnerable when compared to the rest of the population. This social vulnerability is further exacerbated by the higher rate of poverty and lower level of education experienced by people with disabilities. (American Psychological Association, 2019). A direct consequence of being more socially vulnerable is that people with disabilities reside in areas that are more frequently impacted by hazards correlated to lower housing costs (Hallegatte, Vogt-Schilb, Bangalore and Rozenberg, 2017). Further, on average people with disabilities have lower levels of personal preparedness than people without disabilities (Smith & Notaro, 2009).

As a response to the greater level of social vulnerability to disasters and a lack of adequate local and state emergency planning, the Americans with Disabilities Act (ADA) required that those with disabilities are incorporated into emergency plans (Federal Emergency Management, 2010). Collecting basic demographic and location information about people with disabilities is a necessary first step towards more comprehensive emergency planning for people with disabilities. Statewide access and functional needs registries are a government program aimed at collecting information about people with disabilities. The data collected through these registries is intended to be utilized for emergency planning and response services. The intent of a registry varies based upon state emergency management program capabilities, and data collected can be utilized for varied planning and response interventions such as the incorporation into

geographic information systems for analysis, situational awareness, priority warning, communication, decision making, evacuation, sheltering and connection of available support and resources.

Multiple states have developed access and functional needs registries including Texas, New Jersey, Florida, Utah, Pennsylvania, North Dakota, Rhode Island and Delaware. These registries all have similar concepts but often vary in form and function based upon particularities of statewide needs. Despite the benefits of the information gathered from access and functional needs registries, there are some inherent difficulties in implementation that can potentially impact the overall effectiveness and success of these programs. Some issues can include advertising the program, displaying the importance of voluntarily registering, making the process accessible, ensuring security and privacy of personal information, as well as utilizing the information for the intended purposes. Due to problems similar to ones mentioned above, the access and functional needs registry program in Kansas was discontinued a few years after development, and state initiatives were redirected towards other projects. The problems faced in Kansas with the implementation of the access and functional needs registry program need to be mitigated to improve the success of the program and ensure maximum effectiveness. Through an analysis of the Texas, Florida and New Jersey access and functional needs registries, the report gathers insight into their utilization, challenges faced and perspectives, that will help identify potential variables that could impact the program's effectiveness. Once identified, these inherent issues with access and functional needs registries can be mitigated so the effectiveness, success and benefits provided by these registries can be utilized for the integration into emergency plans and to help create an environment for an inclusive planning process involving some of the most vulnerable populations in the state of Kansas.

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## **Acronyms**

ADA - Americans with Disabilities Act

ESRI - Environmental Systems Research Institute

EPCRA - Emergency Planning and Right to Know Act

FEMA - Federal Emergency Management Agency

GIS - Geographic Information System

KDEM - Kansas Division of Emergency Management

STEAR - State of Texas Emergency Assistance Registry



# Executive Summary

## Access and Functional Needs Disaster Vulnerability

Populations with access and functional needs are a demographic population group that require specific planning and response considerations to ensure their safety during disasters. People with disabilities have a high level of social vulnerability when contrasted to people without disabilities. People with disabilities face greater exposure to physical hazards and are more likely to experience negative social, economic, political and psychological consequences when impacted by disasters (Wolkin, Patterson, Harris, Soler, Burrer, McGeehin and Greene, 2015).

On an average, people with disabilities are more vulnerable to disasters as a result of:

- Higher rate of poverty and a lower level of education (American Psychological Association, 2019).
- Residing in more hazardous areas (Hallegatte, Vogt-Schilb, Bangalore and Rozenberg, 2017).
- Lower levels of personal emergency preparedness (Smith & Notaro, 2009).

## Access and functional needs Registry

Due to the increased vulnerability to disasters, the Americans with Disabilities Act (ADA) requires that people with disabilities are included in emergency planning by local and state governments (Federal Emergency Management 2010). Access and functional needs registries can be utilized as a tool for identifying this population group and the data collected can be utilized for a variety of planning and response purposes such as incorporation into geographic information systems for analysis, situational awareness, alert notification, communication and decision making.

Although access and functional needs registries can provide many benefits, often these State programs have fallen short of their intended purposes. In Kansas, a registry established in 2010, was discontinued in 2013 due to issues with the registry database. In Texas, a similar program created in 2013, has faced harsh criticism in lieu of recent disasters because of under-utilization of the data collected. A new program in Florida was established by a state statute in 2015 and the New Jersey program in 2008 has remained linear and stagnant without much adjustment to reflect statewide changes including demographic and hazards.

Some common challenges with these programs include:

- Making registration accessible and inclusive for individuals with access and functional needs.
- Impediments in clarifying the importance of registration by education and advertisement.
- Confidentiality and security of personal information.
- Privacy concerns around usage of information collected by the community.
- Utilization of the collected information and data by agency.
- Transparency of the how information and data is being used.

## Analysis

The information and data obtained from registries can be valuable, especially when integrated into other systems for geospatial analysis and visualization. Although, there are certain problems that impact the effectiveness of access and functional registries. Such variables could include:

- **Accessible and Inclusive Registration Methods**  
If someone with access and functional needs doesn't have ready access to the registration method, then this could lead to a reduction in the number of people registering within a community. At the same time, the factors that might limit access are not universal amongst all communities within a state. Therefore, in order to be inclusive, it is optimal to have a wide variety of registering methods available to community members in all communities. One way that accessibility to registration can be increased is by incorporating the registering process with other systems frequently utilized by individuals with access and functional needs. This could include allowing service providers such as other state agencies, long term care facilities, home health, clinics, hospitals and pharmacies to register the information gathered from their internal intake processes and input the information into the access and functional needs registry. In essence such services become registration and data collection points for the registry.
- **Confidentiality and Integrity of Registry**  
In today's digital age, there are often concerns around providing information to the government in fear of misuse, not proper protection of sensitive information as well as a distrust of government institutions. These concerns translate into a distrust and misunderstanding on how registering will benefit community members, as well as a fear of data leaks and public exposure of private information (FEMA, 2011). States therefore must take the confidentiality and security of personal and medical information collected in a registry seriously. In order to maintain the integrity of the information within a registry database, there is need for regular maintenance and management of the database by trained professionals. These efforts will improve confidence in the data and make the information more holistic, accurate and actionable during an emergency.
- **Utilization by the Government**  
A realistic understanding of the purpose and application of the registry is an important step in establishing expectations with those with access and functional needs. After collection and maintenance, indication on how the registry is being utilized by the government is also important in establishing the importance of registration. Once there is an understanding of the registry's role within emergency planning and response, those registered can make an informed decision about their reliance on planned response and make appropriate planning arrangements. Transparency in establishing the intended purpose of the registry as well as active dialogue with the community would also build trust as well as lead to the betterment of the system.

- **Community Involvement**  
State access and functional needs registries need to be developed based upon capabilities of the government agencies and keeping in mind the needs of the local communities. The development of registries needs to be an inclusive process, incorporating stakeholders, community organizations and citizens related to and part of, the access and functional needs community. One major component of this process is community engagement and involvement. This interaction would assist in generating ideas and interest in program, further investing the access and functional needs community. Proper advertising could help increase awareness and encourage more individuals within the community to register, further increasing the effectiveness of a registry.

### Recommendations

There are systematic challenges with registries that can potentially reduce their effectiveness and success. Actively addressing these challenges can increase overall usage and ensure that the information collected is the most accurate and actionable. Further, registering in any access and functional needs registry is voluntary and therefore means that not all individuals with access and functional needs in a community will be within the registry. Therefore, any registry will always have incomplete information and if it is utilized as the only planning tool, the information will be inaccurate and not account for all individuals who need to be included in planning process. A registry's value can be enhanced when utilized in conjunction with supplementary tools to create a comprehensive planning system. Some tools that can improve the efficacy of any planned response using an access and functional needs registry are:

- **Improving personal, family and facility planning and preparedness**  
In addition to the utilization of planning and response tools by state and local governments, people with access and functional needs must take initiative and create a self-help network of family, friends and neighbors to assist them during emergencies and disasters (McGuire, Ford, and Okoro, 2007). As people with disabilities on average are significantly less prepared than people without disabilities for emergencies or disasters (Smith & Notaro, 2009) a campaign to increase this personal preparedness can increase the preparedness of those with disabilities.
- **Utilization of Established Planning Tools**  
To capture individuals who may not voluntarily register, existing planning tools and sources could be utilized complementary to a registry to account for these individuals.
- **Community Outreach**  
Outreach to community stakeholders to develop partnerships with organizations, agencies and others disability related groups can assist in efforts in identifying those at risk and help in increasing education and finding other local community solutions (Wolkin, et al., 2015). There should be a focus on strengthening relationships and developing partnerships with non-profit organizations that serve populations with access and functional needs. This could result in increased information sharing and developed partnerships that could assist in providing better emergency planning and response within the community.

- **Incorporation of Technology.**

The use of technology to support access and functional needs registries and enhance data gathered from registries could be another way to supplement information gathered from registries. Technology systems can be utilized to assist in gathering information, which could include gathering information from 911 systems, utilizing mobile devices and mobile applications. GIS can also be utilized, particularly in an online format, for increased information sharing, situational awareness and geospatial analysis for emergency planning and response.

## Chapter 1 - Introduction

Populations with access and functional needs<sup>1</sup> are a demographic group who may be impaired by a disability and can also include those who have needs that extend beyond the general population. (FEMA, 2010). People within this group face a high degree of social vulnerability, often experiencing higher rates of poverty and lower levels of education as a result of their disability (American Psychological Association, 2019). Further, people with access and functional needs are more likely to reside in lower income areas and may be at a greater risk to hazards, increasing the frequency at which they utilize and rely on emergency services (Hallegatte, Vogt-Schilb, Bangalore and Rozenberg, 2017). Further, people with disabilities have lower levels of personal preparedness when compared to people without disabilities (Smith & Notaro, 2009). As these factors together mean that people with access and functional needs rank high on the scale of social vulnerability.

As a result of a high social vulnerability and lack of adequate integration into emergency planning, the American with Disabilities Act (ADA) was established to expand upon and protect, the basic civil liberties to those with disabilities within the United States. Passed into law in 1990, the ADA prevents discrimination against people with disabilities. Further the ADA ensures that individuals with disabilities have the same access to and opportunities to utilize services, facilities and accommodations provided by state and local government, including emergency services (FEMA, 2010). In 2004, an executive order was established to ensure that the protection

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<sup>1</sup> The term access and functional needs is a commonly used, all-inclusive term within the field of emergency management. It is used to describe a demographic group that potentially needs additional assistance during an emergency due to a disability such as mental or physical impairments as well as those with limited mobility, injuries, or lack of communicative proficiency, etc. (Hazlett, 2009).

of services expanded to the services related to emergency management.<sup>2</sup> “In planning for emergencies such as hurricanes, tornadoes, fires or terrorist attacks, people with disabilities have functional and access needs to consider that require extra planning so that they can get the additional assistance or services required during an emergency” (Texas Governor’s Committee on People with Disabilities, 2019, p.36.). As established further by the American with Disabilities Amendments Act of 2008, there is also a “legal obligation to undertake advance planning and preparation to meet the disability-related needs of individuals who have disabilities, in which includes emergency management.” (Federal Emergency Management 2010, p. B-2.). Ultimately, those with access and functional needs or disabilities<sup>3</sup> have a right to have access to adequate emergency services and responders have an obligation to provide emergency services during disasters despite any potential additional challenges endured by the emergency management agency.

Individuals and facilities with access and functional needs considerations (i.e. hospitals, long term care facilities), often rely on assistance from local and state government to meet their needs during a disaster and emergency. This expectation of assistance can quickly overwhelm local resources and create life threatening rescue situations for responders. As a result, creating undue challenges for local emergency management, leading to ineffective planning and an inadequate response. Due to the complex response challenges to these populations, advanced planning is required before an emergency and disaster. In order to plan and respond adequately

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<sup>2</sup> Emergency management involves the planning, mitigation, prevention, preparedness, response and recovery to emergencies or disasters for incident stabilization, protection of life and the preservation of property (Federal Emergency Management Agency, 2010).

<sup>3</sup> Disabilities are a restriction or lack of the ability to perform an activity, due to an impairment, within the range considered normal for a human being and people with disabilities might require special assistance (World Health Organization, 1980).

to the needs of people with disabilities, local and state governments need to know where people with access and functional needs reside and what kind of needs, they have. First and foremost, therefore, planning agencies need data and information about people with access and functional needs. As a solution, access and functional needs registries have been utilized as a tool to collect information from individuals with access and functional needs within a community which is then subsequently actioned by state and local governments to try and plan, and provide adequate emergency services. These registries are a database of information that is voluntarily submitted by individuals with access and functional needs (FEMA, 2011). The intent of a registry varies based upon state emergency management program capabilities but can be utilized for many planning and response interventions. This includes the incorporation of the information into geographic information systems for analysis. Further, the information can be utilized for situational awareness, priority warning, communication, decision making, evacuation, sheltering and connection of available support and resources.

Despite usage by state and local governments, access and functional registries often fall short of their intended purposes. There are systematic challenges related to access and functional needs registry programs such as inadequate response from community, inadequate usage, costs and maintenance. When not mitigated, these challenges can undermine the effectiveness of the registry as a planning tool. Without proper utilization of the information, the registry will provide no benefit to the community during emergencies and remain as a collection of (useless) information. The Kansas registry program only lasted a few years until it was discontinued due to poor maintenance and upkeep. In Texas, the program is facing public criticism regarding the purpose of the registry program in the shadow of Hurricane Harvey.

The goal of this report is to determine the important elements of a well-designed and effective registry that addresses the needs of people with disabilities during a disaster or emergency. A strategy can then be developed with the view of incorporating these identified elements and mitigating identified systematic challenges. Then registries can be effectively actioned in conjunction with other tools during emergencies to better assist populations with access and functional needs. This report will primarily serve as a guide to mitigate systematic challenges when developing and maintaining a state access and functional needs registry. The report will also be an inquiry into the reintroduction of the state access and functional needs registry within Kansas



## **Chapter 2 - Background**

### **Demographics**

Being aware of people within a community who will require assistance, especially those older in age, can be critical for decision making and to provide the necessary assistance whilst being the most efficient with available resources (McGuire, Ford, and Okoro, 2007). Identifying the proportion and distribution of populations with disabilities within a community could also allow an enhanced understating of system limitations as well as utilizing resources for the greatest good to assist the greatest number of people when an emergency occurs (Hick and O’Laughlin, 2006).

Approximately, 13.1% of the population within the United States has a disability accounting for 42,630,000 people in 2018. This has risen since 2008 where only 12.7% or 38,560,000 individuals within the United States had a disability (Institute on Disability, 2019). Emergency management considerations for planning and response to those with disabilities are becoming even more critical considering shifting demographics within the United States. This includes the rising number of older generations within the United States. As of the 2017, there are estimated to be approximately 47,000,000 people in the age group of 65 or older in the United States (United States Census Bureau, 2017). The age group of 65 and older, grew by approximately 5,000,000 between 2000 and 2010. Since 2010, the group has grown by another 7,000,000 and accounts for 15% of the United States population (United States Census, 2017). Further, this age group is expected to continue to increase in population, and by 2030, there will be 72 million people aged 65 or older. Similarly, individuals aged 85 or older are one of the fastest growing age group in the United States. (Aldrich and Benson, 2008).

With better healthcare and the continued aging of the baby boomer generation, the population of older people in the United States is rising, and is resulting in a major shift in demographics (Aldrich and Benson, 2008). As people get older, they tend to develop more access and functional needs that require considerations such as arthritis, Alzheimer's, decreased sensory sensitivity, lower mobility, etc. "Certain characteristics of older adults may prevent them from adequately preparing for emergencies and may hinder their adaptability during disasters. In addition to chronic health conditions, older adults may have impaired physical mobility or cognitive ability, diminished sensory awareness, and social and economic limitations" (Aldrich and Benson, 2008, p.2.).

According to the American Community Survey (2013 - 2017) conducted by the United States Census Bureau, 12.7% of the noninstitutionalized population within Kansas has a disability.<sup>4</sup> This results in a total population of approximately 360,000 civilian noninstitutionalized individuals with a disability, and another 60,000 individuals residing within correctional institutions, juvenile facilities, skilled-nursing facilities and other long-term care living arrangements with limitations of mobility (United States Census Bureau, 2017). Additionally, there are approximately 425,000 people aged 65 or older, which accounts for 14.6% of the Kansas state population (United States Census Bureau, 2017).

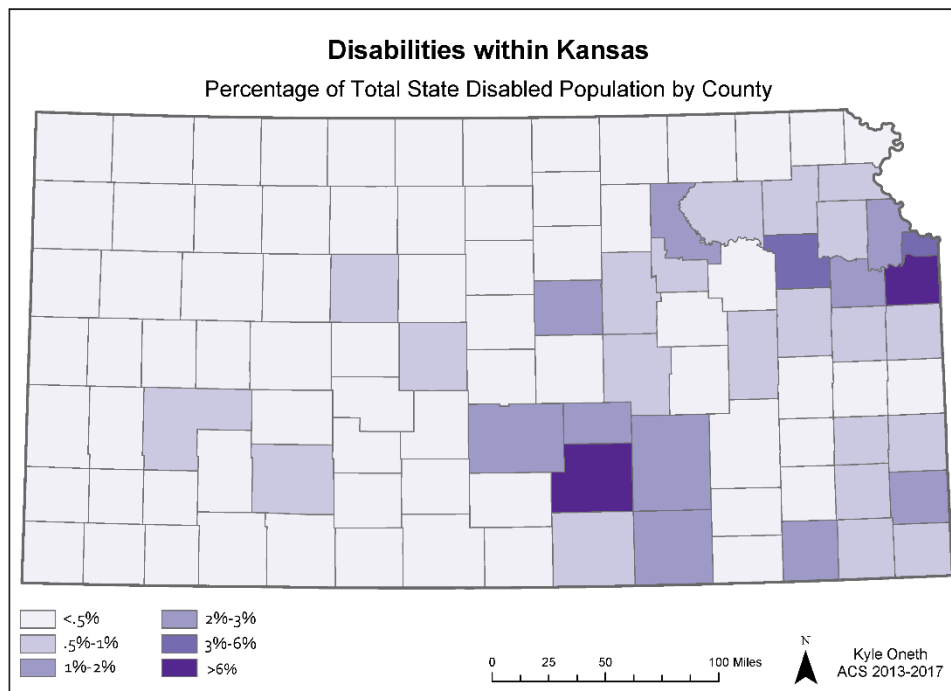
A majority of the people with a disability in Kansas, reside within largely populated metropolitan areas that have developed infrastructure, facilities, services and programs designed for these individuals. The counties in Kansas with non-institutionalized population of people with disabilities of over 10,000 are all part of metropolitan statistical areas, including Sedgwick

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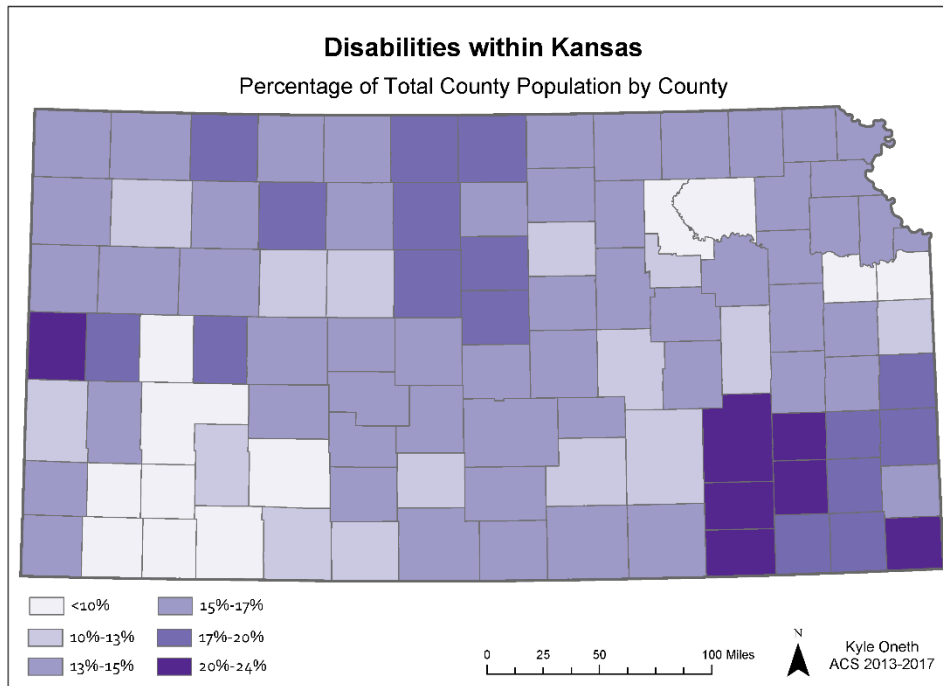
<sup>4</sup> The classification for a disability by the United States Census Bureau includes hearing, vision, cognitive, ambulatory, self-care and independent living difficulties (United Census Bureau, 2017).

(approximately 62,100 individuals), Johnson (52,400), Shawnee (24,700), Wyandotte (23,700), Douglas (12,700) and Leavenworth (10,600) (United States Census Bureau, 2017). Therefore, there is a large and densely concentrated population of individuals with access and functional needs that reside within urban areas in Kansas (see figure 1). This creates additional concerns for emergency management, particularly when there is an emergency or disaster that requires the specific planning considerations and response operations to the large and concentrated population with access and functional needs in metropolitan areas.

Despite the larger number of people with disabilities in urban metropolitan areas, there is a larger proportional number of individuals with disabilities as a percentage of the county population within rural areas (see figure 2). This phenomenon is particularly relevant in southeast Kansas, which accounts for eight out of the top ten counties by percentage of



**Figure 1:** Proportion of individuals with disabilities by percentage of total state population (United States Census Bureau, 2017).



**Figure 2:** Proportion of individuals with disabilities by percentage of total county population (United States Census Bureau, 2017).

individuals with disabilities (United States Census Bureau, 2017). This higher percentage of individuals with disabilities in rural counties are an additional concern for emergency management when contrasted to urbanized counties, as rural counties often lack the required resources, developed infrastructure, facilities, services and programs designed for these individuals that would be required for an effective response that urbanized areas may have.

Regardless of the differences in the demographic distribution of populations with disabilities between rural and urban areas of Kansas, the entire state of Kansas is experiencing similar problems when it comes to planning and responding to populations with access and functional needs during disasters. These common issues include identification of these populations within the community, spatial awareness on where these populations live and work and communication with these populations for education, preparedness or response. An access and functional needs registry may assist with these planning and responder efforts statewide.

## Vulnerabilities

Populations with disabilities are often on the lower end of the socioeconomic spectrum, experiencing higher rates of poverty and lower educational attainment, remaining overrepresented amongst America's poor and undereducated (American Psychological Association, 2019, p.3). Within local communities, particularly in urban areas where land is scarce, land and housing markets often push people who are lower on the socioeconomic spectrum, including people with disabilities, to settle in more hazardous areas (Hallegatte, Vogt-Schilb, Bangalore and Rozenberg, 2017). Lower income areas are more prone to be impacted by disasters such as flooding or are located near facilities and transportation networks that expose them to hazardous materials. This is often due to lower income areas having on average lower land and housing values, as a result of the increased risk of a disaster. Reduced housing prices make it possible for populations that are lower on the socioeconomic spectrum to have access to housing opportunities and services that would be out of reach if the risk of a hazard wasn't present (Hallegatte, et al., 2017).

This increased vulnerability is further compounded, as people with disabilities on average are significantly less prepared than person without disabilities for emergencies or disasters (Smith & Notaro, 2009). An individual with a disability is 1.22 times more likely to not be prepared for an emergency than someone without a disability. This includes them being less likely to have a 3-day supply of water, a working battery-operated radio/ flashlight and plan to evacuate an emergency situation (Smith & Notaro, 2009). As a result, people with disabilities having a high level of social vulnerability.<sup>5</sup> When contrasted to people without disabilities,

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<sup>5</sup> Social vulnerability is a term used to describe the social factors that increase an individual's exposure to disasters as well as limiting their capability to appropriately plan, prepare, mitigate, respond, and recover from the impacts of disasters (Wolkin, Patterson, Harris, Soler, Burrer, McGeehin and Greene, 2015).

people with disabilities, experience greater exposure to physical hazards and are more likely to experience the negative social, economic, political and psychological consequences when impacted by disasters (Wolkin, Patterson, Harris, Soler, Burrer, McGeehin and Greene, 2015). All of these factors together result people with disabilities having a larger reliance on emergency services, further increasing the importance of adequate planning by state and local government.

In this context of having a dense population of people with functional and access needs concentrated in particular parts of Kansas, incidents involving hazardous materials<sup>6</sup> will be devastating to communities in Kansas. These would be a much great hazard for populations with access and functional needs. An example of a devastating and plausible hazardous materials incident is the accidental leakage of chlorine gas during transportation. Due to the frequency of usage, chlorine is a common hazardous material that is transported via rail and highway transportation networks nationwide. Chlorine is a heavy toxic gas that attacks the respiratory system, eyes and skin in which is used extensively in industry and households alike (Mitchell, Edmonds, Cutter, Schmidlein, McCarn, Hoggson, and Duhe. 2005).

In January of 2005, 18 freight train cars derailed near Graniteville, South Carolina. The derailment led to the rupture of a rail tank car which was carrying 90 tons of chlorine. This resulted in a plume of chlorine gas over the city of Graniteville. This release of chlorine gas- which can be lethal with a few deep breaths- resulted in the deaths of 9 people. In all 1400 people were exposed, 550 people treated at hospitals and a total of 5,400 people were evacuated (Mitchell et al., 2005). This Graniteville incident confirms that a hazardous material release is a

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<sup>6</sup> Hazardous materials consist of any substance or material when exposed poses a risk to the health, safety, property and environment. “These substances and materials include explosives, radioactive materials, flammable liquids or solids, combustible liquids or solids, poisons, oxidizers, toxins, and corrosive materials.” (Federal Emergency Management Agency, 2010, page B-6).

very plausible and deadly incident that can impact entire communities. In particular, a hazardous material release needs focused attention in terms of logistics when planning for the evacuation of facilities that have individuals with access and functional needs.

Facilities with a high density of individuals with access and functional needs, such as nursing homes or hospitals, are a particular concern to emergency management. This is due to the increased complexity of planning and response when sheltering in place or evacuating, which would happen in the case of a hazardous materials incident such as a chlorine gas spill. These complexities increase further with logistical challenges such as supply shortages, facility damage, staff availability, transportation for staff and residents as well as unintended consequences such as resident mortality. These issues are largely due to the logistics and complexity of moving frail residents and all of their supportive equipment (Dosa, Grossman, Welte, and Mor, 2007) and are indicative of the need for thorough planning and a coordinated response.

Despite the large logistical challenges with sustaining individuals and facilities with access and functional needs, the Emergency Planning and Community Right-to-Know Act (EPCRA) requires local communities to plan for hazardous materials incidents and other incidents linked to hazardous materials.<sup>7</sup> Specifically, communities are required to plan for the impact of a hazardous material incidents on their community including those with access and functional needs. Many of the planning elements required by EPCRA can be supported with the use of information gained from an access and functional needs registry such as summary of

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<sup>7</sup> “The Emergency Planning and Community Right to Know Act (EPCRA) of 1986, also known as SARA title III, requires reporting and planning requirements for industry and government in the case of hazardous materials” (Federal Emergency Management Agency, 2019, p. 15). The Community Right-to-Know provisions assisted in increasing the public's knowledge and access to information on chemicals at individual facilities, their uses, and releases into the environment (Federal Emergency Management Agency, 2019).

individuals and facilities with access and functional needs within their communities including location and contact information.

An incident similar to the one in Graniteville involving chlorine is very plausible and could have a great impact on Kansas. Within Kansas, there are approximately 22,600 facilities that use, store and manufacture a variety of hazardous materials on site (KDEM, 2019). Along with the fixed facilities, hazardous materials are transported on transportation infrastructure systems frequently. The North American Emergency Response Guidebook of 2016 sets protective action distances, commonly utilized for evacuations, for multiple hazardous materials including chlorine.<sup>8</sup> The US Department of Transportation (2016) defines a worst-case protective action distance of 7 miles for a rail tank car incident and 4.3 miles for a highway tank truck or trailer incident for chlorine.<sup>9</sup> In other words, in the case of an incident where chlorine is involved, the maximum impacted area would be within 7 miles in the case of rail tank car and 4.3 miles in the case of a highway tank truck or trailer incidents (US Department of Transportation, 2016).

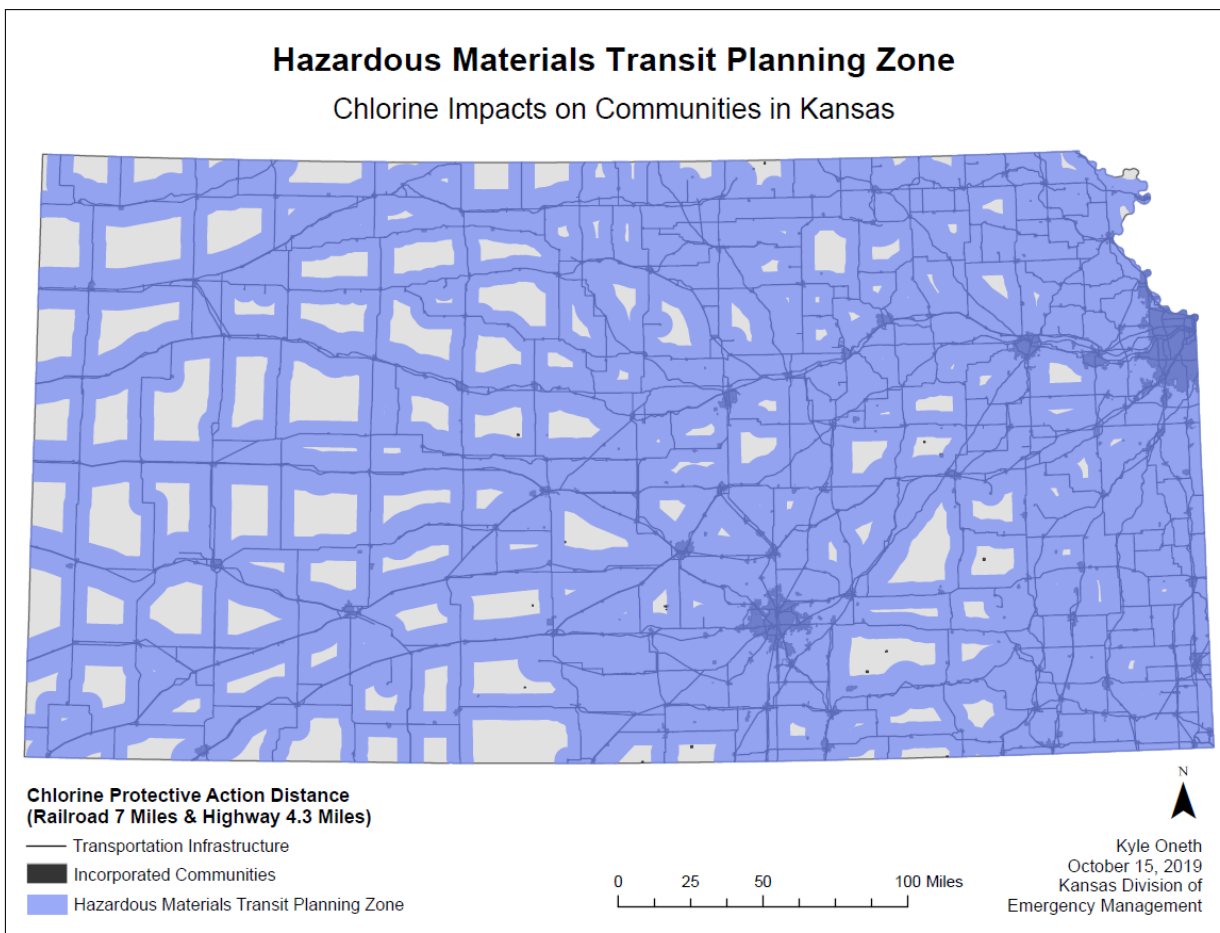
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<sup>8</sup> The Emergency Response Guidebook, developed by the US Department of Transportation, is utilized by emergency management and first responders during the initial phase of a transportation incident involving hazardous materials (US Department of Transportation, 2016).

<sup>9</sup> A worst-case scenario for an incident involving chlorine would be at night with low wind (less than 6 mph).



Chlorine is a severe hazardous material that frequently travels Kansas’s highways and railroads. An analysis of the impact of a potential release of chlorine around highways and railroads results in an 83.4% impact on all the land area of Kansas (see figure 3). Many cities in Kansas are near major transportation networks, resulting in 99.8% of incorporated communities in Kansas coming within the radii for a worst-case impact in the event of a chlorine incident. Majority (99.5%) of facilities with individuals with access and functional needs are within incorporated communities and could be impacted by a chlorine incident i.e. approximately 3,400 of Hospitals, Long-term care facilities, Correctional facilities and Schools (KDEM, 2019).



**Figure 3:** Chlorine Protective Action Distances within Kansas. (7 miles of off Railroads and 4.3 Miles of off Highways) (US Department of Transportation, 2016).

## Geographic Information Systems

Geographic Information Systems (GIS)<sup>10</sup> is a geospatial analytical tool that can be utilized at every stage of disaster including planning, mitigation, preparedness, response, and recovery (Johnson, 2000). With cooperation with other emergency management departments such as the first responders, emergency managers or public officials, GIS can be used to coordinate efforts between multiple disciplines for an effective response (Johnson and Davenhall, 2005). In particular, GIS can be used for community mapping and vulnerability analysis, when in relation to people with disabilities or access and functional needs, as it is important to integrate them within a community for a seamless analysis of the overall community.

GIS can be used to identify where people with disabilities are located, especially at higher densities, to focus disaster planning efforts and develop better plans. For example, after Hurricane Charley that swept across Florida in 2004, workers found that approximately 1/3rd of households had a person who was chronically ill older adult, and 9% of these households did not have access to a common prescription drugs (Aldrich and Benson, 2008). Local health care providers used information found by Geographic Information Systems to swiftly restore access to the drugs within the affected county (Aldrich and Benson, 2008). Using mapping software to locate people with disabilities can also be integrated with other systems, technology, and agencies in the event of an emergency (Fox, White, Rooney, & Rowland, 2007).

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<sup>10</sup> Geographic Information Systems (GIS) is a capability for gathering, managing, and analyzing data. The tool allows for the geospatial analysis of information and organization of data into visualizations to reveal greater insights into data, displaying visual correlation of data to help with decision making (Environmental Systems Research Institute, 2019).

Collective information sharing between agencies and organizations with inclusion of data can be crucial for creating plans and response during disasters. The challenges involved in coordinating an effective response to emergency events are compounded by the number and variety of organizations involved. The complexities emphasize the need to develop robust yet simple frameworks for sharing information and communication within and between organizations involved in planning, response and recovery activities. “A greater focus is needed on defining data and information-sharing requirements between organizations and how the characteristics of the organizations involved affected implementation.” (Dantas, Seville, and Gohil, 2007, page 27).

Adopting information sharing networks could improve emergency response efforts between different levels of government and organizations/ agencies within a region. These systems can also reduce the time and cost of emergency response activities due to increased efficiency if the conceptual framework was implemented through reduced response times, faster access to relevant information and therefore enhanced decision making (Dantas, Seville, and Gohil, 2007).

Collective information collection and sharing between agencies and organizations can be crucial for emergency planning and response when this data can provide insight such as spatial awareness of geographic location or contain attributes such as name, contact information, address, additional requirements, etc. Since the release of ArcGIS online in 2012- allowing the utilization of GIS in an online format- it has become easy to share and display data and information, and there has been an increased ability to share and visualize geospatial information (Environmental Systems Research Institute, 2012). For increased utilization of GIS, more data needs to be collected federally, regionally, and locally, pertaining to people with disabilities.

This geospatial and demographic data is crucial to developing plans, determining needs, addressing resources, advance response strategies and create solutions to local problems based upon local needs.

## **Access and Functional Needs Registries**

A report released by the US Department of Homeland Security identified that people with disabilities were not adequately integrated into emergency plans (Hoffman, 2009). To increase planning integration of the community of people with access and functional needs, the Department of Justice released guidance to local governments for the inclusion of ADA in emergency plans, encouraging the use of access and functional needs registration systems (Hoffman, 2009). There are two main components of any access and functional needs registry:

- (1) A database of information collected from individuals with access and functional needs,
- (2) The utilization of the information for emergency planning and response

Registries can provide local and state governments with a database of information voluntarily submitted by individuals with access and functional needs (FEMA, 2011). The information acquired from registration systems can be utilized for a variety of purposes including for identifying and locating individuals within a community to provide better emergency services such as improving integration into emergency planning, logistic resource allocation, response operations, emergency dispatch, evacuation assistance, warning, education, sheltering, alert notification and communication (FEMA, 2011). These programs are largely developed based upon the needs of the jurisdiction and vary widely in form and function whilst maintaining similar concepts and themes.

Registries can provide valuable information for disasters so the right amount emergency services can be provided to populations with access and functional needs within a community. Guidance by the Department of Justice, to local emergency management when planning for people with disabilities mentions the use of voluntary registries to collect the appropriate information and the importance for these systems to be confidential and have a process to be

maintained (US Department of Justice, 2008). The information obtained from voluntary registration systems can be utilized by local officials for communication, creation of complex plans and integration into GIS to visualize individuals, households and communities. This geospatial data can be used to understand the correlation between people with disabilities and hazards ultimately expediting the process of identifying vulnerable populations with access and functional needs and supporting resources to provide assistance to those in need (Parsons & Fulmer, 2007).

Despite the usefulness of registries, there has been some criticism regarding the administrative frameworks that undergird the program. Some flaws in the system include people with disabilities often do not sign up for these systems for multiple reasons including concerns about the privacy and confidentiality of data collected (Parsons & Fulmer, 2007). Further, lack of awareness, poor accessibility, low confidence in the government maintaining integrity of private information and transparency by utilizing the information in the methods as appropriately promised also play a role in the low number of individuals with disabilities registering from a given community (Renne, Sanchez & Litman, 2011). Lower usage by individuals with access and functional needs reduces the effectiveness of access and functional needs registries. This due to the lower quantity of accessible information that is representative of the local community for emergency planning and response to individuals with disabilities or access and functional needs. Poor utilization by the community within a voluntary system leaves planning gaps, as those who aren't registered cannot be accounted for when developing plans or their information can't be used for response.

The Federal Emergency Management Agency (FEMA), recognized the downfalls of these programs and established best practices based upon lessons learned for the use by state and

local emergency management agencies. This report identified a similar series of considerations and issues with registries, reaffirming certain themes including:

(FEMA, 2011)

- Inclusive planning process when developing access and functional needs registries.
- Ensuring the confidentiality of personal and private information on registry.
- Maintenance of information ensuring it's up to date and accurate.
- An established purpose of the system justifying the importance for registration.

Another issue with these access and functional needs registries are encouraging participation. Many people, including those with disabilities, may have a distrust of government institutions and are not willing to provide personal and medical information to government in fear of misuse, not proper protection of sensitive information or a misunderstanding on how registering will benefit them (FEMA, 2011).

Many of these issues are based in the voluntary nature of these types of programs and could be remedied by mandating the use of these registries by the access and functional needs community. Although, these programs must be voluntary for those with disabilities to protect their civil rights as established by the Americans with Disabilities Act, preventing discrimination of all services, programs and activities, on the basis of a disability, provided by state and local governments (Americans with Disabilities Act, 2016). The mandate for only individuals with disabilities to be identified and required to register with a state program would be discriminatory through subjugation to different treatment and an infringement on the rights and freedoms of any one with a disability.

Communication, advertising and proper messaging can play a large role in the success of these registries. Most importantly, the engagement with the community allowing for an open forum for questions and discussion is vital to building trust with the citizens, increasing usership and allowing for an inclusive planning process (FEMA, 2011).

The information gathered from these applications needs to be up to date, accurate and maintained regularly, often requiring the re-registration by people with disabilities yearly (Parsons & Fulmer, 2007). Yearly re-registration can assist in preventing outdated information within registries or to correct incorrectly entered (Wolkin, et al., 2015). Incorrect information will prevent facilitation of adequate emergency response and planning efforts and will make the registry less effective (FEMA, 2011).

This maintenance of the database with all the private information of people with disabilities whom registered to ensure accuracy and up to date information in which is often too large of a task for an emergency management agency to assume as it requires a large amount of manpower, time and resources (Renne, Sanchez and Litman, 2011). These systems are expensive to develop and maintain and may not be economically viable. The Los Angeles County Office of Emergency Management in 2004 researched the cost of the development and maintenance of a registry. Concluding the cost would be estimated at 1.4 million for the first three years of the program, two third going towards staff and one third towards technology (Kailes, 2018).

Another concern with registries by local and state governments is that these programs shift the responsibility of from individuals to emergency management when it comes to the preparedness and well-being of people with access and functional needs (Wolkin, et al., 2015). This gives a false sense of security and misleads populations with access and functional needs as there is the belief that emergency management, through use of the registry ,will protect them



from disasters, whereas in reality emergency management may not have the capability to meet the needs of those registered (Wolkin, et al., 2015).

People with access and functional needs are also not homebound due to a disability. Often, many people with access and functional needs live a normal life which includes having a job, leaving town to see family, vacationing, going shopping, etc. This means that access and functional needs registries can inform planners and responders where a person with an access and functional needs lives but that doesn't necessarily mean that the individual will be home at the time of an emergency event.

Finally, there are issues with displaying the importance of registration within these systems as there is often complacency in the community regarding disaster preparedness. Individuals with disabilities may believe that they will never be impacted by a disaster or that they will never need additional assistance during a disaster resulting in someone not registering (Wolkin, et al., 2015). Once a disaster is impending, a person with a disability may realize that they will need help and to secure assistance from emergency management will register last minute resulting in overwhelming the system. Defeating the purpose of an access and functional need registration system for planning efforts, resources allocation and identification of people with access and functional needs within the community.

## **Chapter 3 - Methodology**

Throughout the United States, there are multiple statewide access and functional needs registries in which include Texas, New Jersey, Florida, Utah, Pennsylvania, North Dakota, Rhode Island and Delaware. Additionally, there are also many dedicated county or city access and functional needs registration systems that assist local communities. Many of these programs are conceptually similar but often vary in purpose based upon required capabilities of the state and local governments. Variations in the form, function and administration of state access and functional need registries can be analyzed to understand the strategies used in the development of registry programs. Through case studies of state registry programs, the analysis will result in a greater understanding how to mitigate the systematic variables that impact the success and effectiveness of these programs.

Despite there being many applicable state access and functional needs registries, in which all may provide beneficial information, there are limiting constraints such as time, resources, and accessibility to information and internal documents for the purpose of completing an in-depth analysis. The primary purpose of case study analysis is to understand and mitigate potential systematic challenges when developing and maintaining registries. This means that active state registries will be analyzed to understand the methods that have been utilized to combat potential issues. Although, due to inquiring into the reintroduction of a registry in Kansas, the former discontinued program in Kansas will additionally be analyzed. For an enhanced perspective on the variables that impact the effectiveness, analysis of state access and functional need registries will include:

- Active state access and functional needs registries. Active programs will be the most applicable for understanding how these registries can be incorporated and utilized with modern emergency management practices.
- Large population with access and functional needs (greater than Kansas) to understand the greatest potential and capabilities of registries.
- States where evacuations are a common practice in order to gain an enhanced perspective on the utilization of access and functional needs registries for evacuations of population with access and functional needs due to risks of hazardous materials incidents requiring evacuation within Kansas. (Focused on states at risk of as hazard often requiring evacuation (i.e. Hurricanes)).
- States that vary in population density to understand the difference of perspectives and challenges when planning for populations with access and functional needs in urban vs rural areas.
- States that have access and functional needs registries that vary when their program were established. To understand differences in perspectives and challenges of older programs when compared to newer programs.

The analysis will result in a better understanding of voluntary registration applications, keys to success, and potential challenges. The analysis will document the variables that impact the success of these unique program when applied to other states. Most importantly, this report will serve as a basis for increasing emergency management initiatives within Kansas for improving emergency planning and response to populations with access and functional needs.

## Chapter 4 - Access and Functional Needs Registries

The programs chosen for analysis include the prior program in Kansas, the Kansas Vulnerable Needs Planning Systems as well as the three external programs, the State of Texas Emergency Assistance Registry, Florida Special Needs Registry and New Jersey Registry Ready.

### Kansas

The Kansas Vulnerable Needs Planning System was the former program in Kansas and can be most directly applied to the reintroduction of such as program within the state of Kansas. Understanding the history of the program, reasons for discontinuation, positives and negatives could provide useful for identifying the variables that impacted the success and effectiveness of the program. With access to internal documents, insight into the development, structure and discontinuation of the program will be the most applicable to reintroduction of an initiative in Kansas.

### Texas

The State of Texas Emergency Assistance Registry (STEAR) is an active statewide program that was established in 2013 (Texas Division of Emergency Management, 2019). Along with this program, other access and functional needs work in conjunction with STEAR which includes the *Governor's Committee on People with Disabilities* seeking to further opportunities for persons with disabilities to enjoy full and equal access to lives of independence, productivity, and self-determination throughout state of Texas. The committee recommends changes in disability policies and programs in the areas of accessibility, communication, education, emergency preparedness, health, housing, recreation, transportation, veterans and workforce (Office of the Texas Governor, 2019).

Texas is a large state consisting of 254 counties and 6 sub state emergency management regions (Texas Division of Emergency Management, 2019). Along with the large area, Texas has the second largest number of individuals with disabilities within the United States. The percentage of individuals with disabilities relative to the entire Texas population is 11.7%, accounting for approximately 3,150,000 individuals in 2016. Approximately 55 percent of Texans 75 and older had a disability (Texas Workforce Investment Council, 2016). As a result of the large number of individuals with disabilities, many programs have been developed and tailored to these populations with access and functional needs. These insights, challenges as well as lessons learned will be very beneficial for improving emergency management planning and response for individual with access and functional needs within Kansas.

Being nearby to Kansas, Texas shares similar hazards and geography as well as having a large range of population density with an average of 96 people per square mile (United States Census Bureau, 2017). Since Texas is located on the coast of Mexico, the costal portions of the state are at a risk of hurricanes, a severe incident often requiring evacuation of large areas in which can be insightful when evacuating facilities with access and functional needs from incidents involving hazardous materials. The state has experienced a total of 59 hurricanes between the years of 1851-2004 with 19 being considered major hurricanes (Blake, Rappaport, Jarrell and Landsea, 2005). Recent past incidents will provide useful information and lessons learned from the evacuation of facilities with access and functional needs including the most recent Hurricane Harvey in 2017. The program is relatively newer and has large and undefined purpose, seeking to fulfill general emergency planning and response capacities to populations with disabilities statewide.

This program will be beneficial to understanding the perspective on how a more recently developed and more generalized program can be utilized. This program is also more recently developed and as Texas is relatable to Kansas, can be an indicator on how effective and successful a program will be within Kansas.

### Florida

The Florida Access and functional needs Registry is the most recent demonstration of a voluntary registration program that was developed for evacuations in 2015 (Florida Statute 252.355, 2019). Florida has a mixture of urbanized and rural areas with an average population density of approximately 350 people per square mile (United States Census Bureau, 2017). Florida has a large amount of people with access and functional needs including 2,720,000 people or 13.4% of the state population (State of Florida Department of Health, 2018). This

Along with the large population of people with disabilities. There is also a large population of older generations including an additional 4,000,000 over the age of 65 residing in the state accounting for 19.4% of the state population (United States Census Bureau, 2017). Hurricanes are a common natural disaster and pose a great risk to the state of Florida. From 1851-2004, Florida has experienced 110 hurricanes and out of those 35 major hurricanes, the most out of all states (Blake, Rappaport, Jarrell and Landsea, 2005).

### New Jersey

The New Jersey Register Ready is a prominent program on the east coast that is currently active, statewide, developed, robust within the United States (New Jersey Office of Emergency Management, 2019). One of the longer standing access and functional needs registries, the program was established in 2008 (Fuentes, 2008). New Jersey is a smaller state that is surrounded by large metropolitan areas within the northeastern corridor. Due to the geographical

position between metropolitan areas, New Jersey has one of the highest population densities in the United States, at approximately 1,200 residents per square mile (PBS&J, 2001). New Jersey also has a sizable population of individuals with disabilities, 10.3% of New Jersey residents have a disability, accounting for approximately 911,000 individuals (Erickson, Lee, and von Schrader, 2016).

Apart of the New York Metropolitan area, there agency relies on the close relationships it has built with its partners across state lines. New Jersey faces a marginal risk of hurricanes, between the years of 1851-2004, the state experience 2 hurricanes (Blake, Rappaport, Jarrell and Landsea, 2005). With a large and dense population as well as being at a risk of coastal storms and hurricanes, evacuations of large and dense populations, including those involving populations with access and functional needs are a common practice. The benefits to the new Jersey register ready program will to gain perspectives on a long running and highly focused program can be utilized. The long sustainment of this program can be an indicator on how a program of this nature will need to be developed to remain relevant with changes of emergency management best practices and community demographics over time.

## **Kansas Vulnerable Needs Planning System**

The registry within Kansas was generated from the lessons learned from tremendous disasters in the later 2000s. In 2007-2008, a spring Tornado outbreak wiped out the town of Greensburg, one of the worst ice storms in Kansas history and widespread flooding in which inundated the Coffeyville refinery. In 2007, a registration system began development within Kansas, similar to other states within the United States (KDEM, 2012). This system, in which was unveiled in 2010, sought to successfully fill those planning and response gaps to populations with access and functional needs identified from lessons learned after recent disasters (KDEM, 2012).

The Kansas Vulnerable Needs Planning System initiative was an attempt to assist local and state emergency management in planning and response to populations with access and functional needs before, during and after emergencies (KDEM, 2010). This planning initiative was a free voluntary registration system through the self-identification of facilities and individuals with access and functional needs, also known at the time as vulnerable needs. The planning tool is not a guarantee of assistance, but it will confidentially collect and protect the information emergency coordinators need in the planning process to best utilize available resources. This program was developed in conjunction by the Kansas Division of Emergency Management, Kansas Emergency Management Association and the United Way (KDEM, 2010).

Information gathered by this program to assist individuals and facilities with access and functional needs included Name, Location, Age, Language, Gender, Type of Home, Number, Emergency Contact, Special Equipment Needs, Transportation Needs, Service Animal Needs, Health Issues/Limitations, Caregiver Requirements, Mobility Needs, Oxygen Dependability, Electricity Importance for Medical Equipment and Allergies (KDEM, 2010). This information



was gathered through an online website or could be inputted through a phone call to the United Way. The information was placed in a database that was developed and maintained by a private contractor (KDEM, 2010).

The Kansas Vulnerable Needs Planning System lasted until 2012 and its discontinuation can be attributed to multiple issues, oversights and inefficiencies over the life of the program. These variables made the program unactionable by state and local emergency management agencies in which lead to the decision to discontinue the registry. Although there is no documentation of the failure of the program and that a single variable ended the program, it is safe to speculate that a few factors could have help lead to its discontinuation. This could include the program was shared by multiple agencies, lack of utilization by the community, accessibility for registration, security and integration into GIS frameworks.

#### Shared Effort

This program was developed in conjunction with many parties including Kansas Division of Emergency Management, Kansas Emergency Management Association and the United Way with the software and database being contracted to a private company (KDEM, 2010). According to fiscal records provided by the Kansas Division of Emergency Management, the private contractor was tasked with developing the initial registration system including the website and database (KDEM, 2012). The United Way was then contracted to maintain the database along with validation services to ensure the accuracy of the database (KDEM, 2012).

The Kansas Division of Emergency Management relied on these partners for the development and maintenance of this program. This ultimately meant that the program's success was entirely dependent on these partnering stakeholders, agencies and contractors. Mismanagement or mistakes could be made by these partners and could result in a fatal blow

leading to the ultimate demise of the program. The reliance on these partners meant that the coordinating agency, the Kansas Division of Emergency Management, lost an element of control including the full management, ability for forward planning of potential issues, accountability and insight of mismanagement. Potential issues that could be devastating to the program wouldn't be identified or revealed and so that measures could be taken to prevent problems. Despite there being no documentation of, the role and mistake of these partners could have been a variable that lead to the demise of this program in Kansas.

### Lack of Utilization

Although there are no records of the total number of registries, the success of a voluntary registration planning system is dependent of the usage by the number individuals with access and functional needs registered within a community. Proper advertising could help increase awareness and encourage more individuals within the community to register. The Kansas Division of Emergency Management dedicated \$5,000 for the development, standardization and distribution of advertising materials across the state to county governments for advertisement (KDEM, 2012). A larger advertising budget could have dedicated to the program to ensure proper promotion this program to increase usage by individuals with access and functional needs. This advertising could have also been completed by the state who would had a particular stake in success of the program as well as a larger budget than many county governments, particularly rural jurisdictions.

Alternatively, it is unsure on how the information was used or actioned by emergency management as a result of this program. Other than a vague statement "A system allowing those with vulnerable needs the opportunity to provide information to emergency management to assist in planning before, during, and after emergencies", there is no clear evidence that this

information collected was utilized for any emergency management planning efforts (KDEM, 2010, p.1). This could in part, be a result of the loss of confidence in the access and functional needs registry due to the voluntary nature of the system, ultimately requiring other planning methods to account for the entire population with access and functional needs. There was no indication that this information could have been used for increased analysis, planning and response including the integration into GIS frameworks, extended ability for communication or alert notification procedure or increased spatial awareness for better decision making. This meant that the access and functional needs community wasn't fully aware on how inputting their information would increase state planning and response efforts, potentially resulting in an even lower of number voluntary registrations.

#### Registration Accessibility

The Kansas Vulnerable Needs Planning Systems also had limitation on the accessibility on registering methods. There were two methods to input your information, either by going to the website or calling in (KDEM, 2010). If you don't have frequent access to a computer or a phone providing limited accessibility to initially self-registering. When factoring in the requirement to re-registering on a yearly basis, to keep the collected information accurate, meant that there could be challenges with re-registering due to limited accessible from available registering methods, those already registered would likely forget to reregister, won't see the importance of re-registering yearly or dissuaded by the large number of attribute field that were required to be inputted on a yearly basis. The Kansas Division of Emergency Management didn't document their yearly registration numbers but I can imagine that there was a continued decline of the usage over the life of the program due to challenges with re-registering to keep the

information accurate. The decline in usage would decrease the effectiveness of the information provided by the database as there would be less usable information by KDEM.

### Security

Privacy and security of the information being collected by the state was an important variable to the public. Transparency by the state to ensure the public that the information was being used in its intended purposes and how it was being actioned during emergency incidents in the best interest for those who register. Despite concern, physical advertising record never went into depth on how the information was being actioned and the importance of registering other than “The information collected on the Website will not be available to the public – it will only be released to public safety agencies to improve their ability to effectively plan for the needs of vulnerable populations.” (KDEM, 2010, p.1).

Despite messaging that the information collected on the website would be available to the public, the reliance of a private contractor for the maintenance of private information could have potential privacy and security risks. Improving the communication by the state to the public on how the information was being used and actioned by emergency management, the importance for those with access and functional needs to register and ensuring the privacy as well as security of the information collected was crucial to maintaining registered individuals with access and functional needs.

### Integration into Geographic Information Systems

The information that was gathered would be particularly useful in conjunction with GIS mapping applications, as it would provide another method of the spatial understanding of the data. The Kansas Vulnerable Needs Planning System was developed in a time before geospatial breakthrough that included an online format of GIS that could be easily shared and displayed to

local emergency management for the data utilization. ArcGIS online, an online application of Environmental Systems Research Institute (ESRI) ArcGIS, was release in June 2012 at approximately the time that Kansas Vulnerable Needs Planning System was discontinued that offered an expanded ability to store, visualize, and share geospatial information (Environmental Systems Research Institute, 2012). Without this, this meant that this information gathered couldn't have been utilized to its full potential as the capabilities weren't quite developed and this program was before its time. The information collected from an access and functional needs registry could be incorporated in an ArcGIS online format to be easily shared with the local emergency management agencies across Kansas for their interaction and analysis of the data.

## **State of Texas Emergency Assistance Registry**

The State of Texas Emergency Assistance Registry (STEAR) is a free access and functional needs registry that began development after Hurricane Katrina and Rita. Originally known as the Transportation Assistance Registry, in 2013 the program was renamed to reflect efforts to focused more on gathering information about individuals with access and functional needs for all hazards (Fabian, 2019). The program prioritizes on the practices, procedures, updates and recommendations to provide local emergency planners and responders with information of the needs of individuals within their communities (Kailes, 2018).

The program collects name, address, phone number and language and requires information is re-register on a yearly basis (Fabian, 2019). The information can be registered online, through the phone, or on an electronic/ paper form. The information will then be provided to participating local governments for the use of developing emergency plans, preparedness, and response efforts (Fabian, 2019). This program does not guarantee that an individual who is registered will receive additional assistance during an emergency and identifies that there is no replacement for personal or family preparedness (Fabian, 2019).

The State of Texas Emergency Assistance Registry also is not required to be utilized across the state and a number of counties can elect to utilize the system further decreasing its value for statewide planning and response (Texas Division of Emergency Management, 2020). Within the local communities with the registry is also utilization the information in different ways, ultimately making very difficult for the Texas Division of Emergency Management to control (Texas Division of Emergency Management, 2020).

Despite the continuity of STEAR within the Texas Division of Emergency Management, the program has faced harsh criticism in lieu of recent disasters. After hurricane Harvey of 2017,

the public questioned the purpose, usefulness and importance of the program to assist those with access and functional needs in Houston. In the article, *After Harvey, questions remain about whether registry helped people with disabilities* by the Texas Tribune, it is “unclear how many people actually received help through the State of Texas Emergency Assistance Registry, or STEAR, during Harvey” (Evans, 2018, par.4). After the event, there were questions on how the system was being utilized and whether it was being used to its full potential.

The criticism stems from the purpose of the program and how the information is being utilized, in which the information provided by the program is used by the state and local governments for planning and preparedness and not to provide direct response services (Texas Division of Emergency Management, 2019). Along with the yearly re-registration requirement, many people with disability often don’t see the need or simply forget (Evans, 2018). This lowers usage by the community and ultimately decreases the effectiveness of the program further.

Even if the program was utilized for planning and response by the Texas Division of Emergency Management, the use of the information provided by the program wasn’t publicized and the concerns weren’t eased by knowing how the program helped, but even if the program use was not identified, it was identified that this program is no replacement to personal emergency plans, further bringing up questions on why resources are being directed towards the program. (Evans, 2018). “People with disabilities during natural disasters are vulnerable because of a lack of planning, consideration and engagement. The registry was “ineffective” as a rescue tool and recommended the money earmarked for STEAR be given to local disability organizations that have better strategies for helping the disabled community in a disaster.” (Evans, 2018, par.33).

Despite this, the Governor’s Committee on People with Disabilities independently identified that these issues influenced the effectiveness of the program and developed a report on

policy recommendations for Texas's 86th Legislative Session on the improvement of STEAR. These recommendations include creating a new position for a full-time disability coordinator, requiring all local emergency management jurisdictions to hire a data person to manage STEAR data and encouraging state health and human services agencies to discuss emergency preparedness and evacuation planning with people with disabilities (Texas Governor's Committee on People with Disabilities, 2019).

It is unclear on if these changes were implemented but it is obvious that there are flaws with the program and how the information is being utilized. If the community does not see the importance of voluntarily registering, it won't be a priority. The information gained from these applications will be practically useless and the program will be a waste of resources.



## **Florida Special Needs Registry**

The Florida Special Needs Registry is an active statewide access and functional needs registry that was established in 2015 to maintain a registry of people who would need assistance with evacuation (Florida Statute 252.355, 2019). In coordination with local governments, the registry heavily focuses on sheltering aspects during emergencies, connecting with the state Special Needs Shelter Program (Kailes, 2018). The registry collects a variety of information and requires all of its local jurisdictions to utilize the registry. There are multiple accessible ways to register including through online, phone, fax, and mail (Florida Division of Emergency Management, 2020). Florida Special Needs Registry collects information such as personal information including name, address, height, weight, age, and contact information, emergency contact information as well as any other contacts such as physician, pharmacy and care giver information (Florida Division of Emergency Management, 2020).

The state of Florida has taken the approach of establishing a state statute that required a statewide registry consisting of people with disabilities. This registry would be accessible to local emergency management agencies for the purposes of planning for evacuation including resource allocation and identifying shelter demand (Florida Statute 252.355, 2019). The registry is administered by the state although it was developed with coordination and support by local emergency management agencies.

This statute solves many inherent issues of access and functional needs registries, including outlining processes and responsibilities of the different components of the program. For example, the statute required the Florida Division of Emergency Management to maintain an electronic database of the registry while local emergency management agencies are required to input the information (Florida Statute 252.355, 2019). The statute also provides the opportunity

for people with disabilities to automatically register with the Florida Special Needs Registry through the intake process with service providers such as other state agencies, long term care facilities, home health, clinics, hospitals and pharmacies (Florida Statute 252.355, 2019). This allows those utilizing service providers the ability to automatically input the information they gathered into the access and functional needs registry on an annual basis, ensuring that there are as many individuals with access and functional needs utilizing the program as possible ultimately increasing the effectiveness of the program for planning and response purposes.

The statute also designates the Florida Division of Emergency Management as the authority in control of all advertising and outreach but service providers as well as local emergency management agencies are allowed to provide education about the registration process and disaster personal preparedness (Florida Statute 252.355, 2019). As a solution to the privacy, confidentiality and security of the access and functional needs registry, all the records, data, information, correspondence and communication connected to the registry is exempt from public disclosure (Florida Statute 252.355, 2019). This confidentiality of private information is further protected by another state statute that exempts all registry information from public records requests (Florida Statute 252.905, 2019).

During Hurricane Irma, a downfall of this programs is that people with access and functional needs who needed assistance didn't sign up for the registry in advance of the disaster in which resulted in a flood of registries, overwhelming the system (Salk, Henry, and Wadas 2019). You can mitigate this issue by advertising that pre-registering before an emergency will be essential for effective planning and response to there isn't much else you can do to enforce and ensure everyone will be registered before an emergency.

Florida recognizes the limitation that this program won't be a guarantee for assistance during emergencies but instead heavily utilizes the registry as a planning tool that can help create an environment that can assist in sustaining an individual's current level of health (Florida Division of Emergency Management, 2020). The registry is utilized for emergency planning for populations with access and functional needs, including the evacuation but also serves as a way to forecast the demand for shelters, supplies and staff to assist in the sheltering (Salk, Henry, and Wadas 2019).

## **New Jersey Register Ready**

The New Jersey Register Ready is a currently active access and functional needs registry that was unveiled in 2008 in preparation for upcoming hurricane seasons (Fuentes, 2008). The New Jersey Register ready program allows “NJ residents with disabilities or access and functional needs and their families, friends and associates an opportunity to provide information to emergency response agencies, so emergency responders can better plan to serve them in a disaster or other emergency.” (New Jersey Office of Emergency Management, 2019). Unlike Kansas and Texas but similar to Florida, this program is heavily focused on evacuations due to the large hazard of a hurricane.

The New Jersey register ready program is a designed to help emergency responder locate and evacuate people during disasters (New Jersey Office of Emergency Management, 2008). With nearly the sole purpose of this program being derived on evacuation during hurricanes, “New Jersey’s access and functional needs registry for disasters is designed to help those who may have difficulty during an evacuation because of physical or other limitations, or lack of transportation. Signing up with the New Jersey's access and functional needs Registry for Disasters program will help first responders make the best use of limited time and resources by planning to help those with limited options for evacuation during an emergency.” (Fuentes, 2008, par.3). The program focuses on strong privacy and confidentiality to protect personal information complying with all applicable privacy laws and statues.

The new Jersey Register ready program is a long-standing initiative by the New Jersey Office of Emergency Management. The program focuses highly on personal preparedness, as seen through the advertising brochure, by preparing a go bag, creating household plans and staying tuned to local news networks (New Jersey Office of Emergency Management, 2008).

The program allows the ability to register through a website, phone and paper form to the local emergency management agency (New Jersey Office of Emergency Management, 2008).

Despite the program's existence, there is no indication on how the information is being actioned other than the alert notification ability through registering. Registry provides ability for alert notification and procedure through SMS text and email (NJ Register Ready, 2019). The program is heavily focused on the evacuation aspect of emergency planning and response, noting to why you should register is based upon the notification when an evacuation order is established (NJ Register Ready, 2019). The only information gathered is directly related to the necessary information for an evacuation including name, address, email and phone number (NJ Register Ready, 2008). The New Jersey Register Ready program is highly focused to providing those who need additional assistance to evacuate due to hurricanes. This means that the scope of the program is highly limited and the information gathered is not being utilized to its fullest capabilities. Although, the program is a long-standing initiative and designed specifically for a single purpose whilst not over promising the capabilities.

## Chapter 5 - Analysis

According to the Nobody Left Behind study completed in 2007, a majority of the emergency managers did not know how many persons with mobility impairments live within their jurisdiction. Acknowledging that knowing the approximate number of persons with mobility impairments would be helpful for planning and response. However, there have been frustrations with volunteer self-registry systems across the nation, since frequently a small percentage of the actual people needing assistance register. (White, Fox, Rooney and Rowland, 2007).

The information obtained from registries can be valuable for planning and response, especially when integrated into other systems for geospatial analysis and visualization. Although, there are certain variables that could be problematic, ultimately impacting the effectiveness of access and functional registries. Such variables could include:

- A. Accessible Registration Methods
- B. Confidentiality and Integrity of a Registry
- C. Utilization by the Government
- D. Community Involvement

Despite this, there are creative mitigation strategies that could reduce their impact. State governments have taken different approaches to the development and maintenance of registries. These varying approaches in administration of registries can be insightful to understand how to develop a capable registry that meets the needs of community. When analyzing state access and functional needs registries, Florida's mitigation of these problems was the best when compared to Texas and New Jersey (table 5.1).

**Table 5.1 State Registry Effectiveness Matrix**

<b>State Registries</b>	<b>Accessible Registration Methods (A)</b>	<b>Confidentiality and Integrity of a Registry (B)</b>	<b>Utilization by Government (C)</b>	<b>Community Involvement (D)</b>
Texas	-	✓	-	-
Florida	✓	✓	✓	-
New Jersey	-	✓	✓	-

(A) Accessible Registration Methods

When analyzing accessible registration methods, Texas and New Jersey had two or three methods of registering in which included by phone, online or a physical form. If an individual with an access and functional needs doesn't have frequent access to these methods, this could result in limited accessibility. Ultimately, this could lower registration by the access and functional needs community and weaken the effectiveness of the registry.

Unlike the other states, Florida addressed the limited accessibility issue by incorporating the capability of seamlessly register an individual's information. Florida accomplished this by utilizing common existing systems that were frequently utilized by individuals with access and functional needs. This includes allowing the ability to automatically register into the program through service providers such as long-term care facilities, home health, clinics, hospitals and pharmacies. These service providers gather information from their internal intake processes which then could be automatically inputted into the Florida registry on a consistent basis.

(B) Confidentiality and Integrity of a Registry

Citizens may have a distrust with government institutions. The lack of confidence that personal information is being adequately protected and secured could dissuade people from voluntarily registering. Texas, Florida and New Jersey all focused on strong privacy and

confidentiality to protect personal information. This included disclaimers before registering and advertisements ensuring the protection of information.

#### (C) Utilization by the Government

Indication on how the information within registry will be utilized is important to reinforce the importance of registration and assist with developing expectations with the access and functional needs community. Once there is an understanding of the registry's role within emergency planning or response is clarified, those registered can reduce reliance and make appropriate planning arrangements. This transparency of displaying the intended purposes and dialogue with the community could alternatively build trust as well as lead to the betterment of the system.

Within Texas the utilization of the registry varied by local jurisdiction and citizens were often unaware on how the system benefited them. New Jersey and Florida determined statewide how registry information would be utilized rather than the local jurisdiction. In Florida the information is used to identify people would need assistance with evacuation. In New Jersey the information was established to help emergency responders locate and evacuate people during disasters, particularly after hurricanes.

Florida also established a state statute that requires all local jurisdictions to adopt a registry. This is unlike Texas and New Jersey where local jurisdictions can opt out of utilizing the program creating a patchwork of registry information across a state.

#### (D) Community Involvement

State access and functional needs registries need to be develop based upon capabilities of the government agencies but also need to consider the needs of the local communities. A line of communication needs to be established with stakeholders, organizations and citizens. In



particular, this community outreach needs to occur during the development of the system to ensure that the system will be adequate to meet the needs of the access and functional needs community. Additionally, this outreach can uncover other uses of the information within a registry. This could include how the information can be used in conjunction with other programs.

In Florida all local communities are required to utilize a registry and is utilized in conjunction with a sheltering program. In Texas, the program was developed with input from the Governors Committee on People with Disabilities although it isn't clear on how the registry is being incorporated into other programs. In New Jersey, its not clear how the community was involved and there was limited indication of the incorporation of registry information into other disability related programs. Overall, I believe more coordination with the access and functional needs community would be beneficial for the continued improvement of all registries.

## Chapter 6 - Recommendations

When developing a registry, there are systematic challenges with registries that can potentially reduce their effectiveness and success. As outlined from the analysis in the previous chapter, these elements can include:

- Accessible Registration Methods
- Confidentiality and Integrity of a Registry
- Utilization by the Government
- Community Involvement

If Kansas wanted to develop an effective registry, the mitigation of these variables would need to be prioritized. If these issues can be properly addressed, there could be an increase in overall usage and ensure that the information collected is the most accurate and actionable by the state and local government.

### Accessible Registration Methods

If the methods of registering aren't inclusive, accessible and simple, there could potentially limit the number of community members that register. As limitations of registering may not be universal amongst all communities within Kansas, having a wide variety of registering methods would be the most inclusive. These methods could include common archaic forms such as through the phone, online or a physical form. Additionally, there should be efforts to expand upon registration methods to new mediums such as social media or mobile applications. New registration methods could make the process more inclusionary as well as capturing information in an accessible and novel matter.

Streamlining the process for registration could also assist in mitigating potential registration issues. A method of increasing accessibility could include incorporating the

registering process with other common systems frequently utilized by individuals with access and functional needs. This could include allowing service providers such as other state agencies, long term care facilities, home health, clinics, hospitals and pharmacies to register the information gathered from their internal intake processes and input the information into the access and functional needs registry.

#### Confidentiality and Integrity of a Registry

Often there are concerns of providing information to the government in fear of misuse, not proper protection of sensitive information or a misunderstanding on how registering will benefit them (FEMA, 2011). There needs to be efforts by Kansas to protect of the confidentiality and security of the private personal and medical information within a registry. This requires that Kansas would need to ensure that precautionary measures are being taken to protect the information in advance. This includes establishing security measures of the database and planning for the continuity of the database in the event of failure or access by unauthorized users. Further, properly notifying the community that these precautionary measures to secure their personal information are in place.

Once the database is established, to heighten the integrity of the information within a registry database, there will need to be maintenance and management of the database. This will include validation of the data to ensure the accuracy of the information, increasing credibility. This process may require a large amount of manpower, time and resources (Renne, Sanchez and Litman, 2011). Despite increase costs, proper management of the database will improve the confidence in the data and make the information more actionable during an emergency.

### Utilization by the Government

Kansas needs to be transparent regarding the intended utilization of an access and functional needs registry. This will require communication with the community to understand the boundaries on how the information should be used. This could alternatively build trust and led to a better registry system. This information can be potentially used within GIS, allowing for improved geospatial analysis, visualization, information sharing and communication for better emergency planning and response operations. Additionally, incorporating this geospatial information into an online format can increase capabilities for mobile viewing and information sharing.

### Community Involvement

The development of registries needs to be an inclusive process, incorporating stakeholders, organizations and citizens within the access and functional needs community. This interaction could assist in generating ideas and interest in a program, further investing the access and functional needs community. This could involve generating awareness throughout the access and functional needs communities across Kansas.

To accomplish this, Kansas could conduct an advertising campaign to increase awareness and encourage more individuals within the community to register, further increasing the effectiveness. A larger advertising budget to utilize multiple mediums to would generate the most awareness. This advertising could be done in conjunction with agencies and organization who serve individuals with access and functional needs. Strategic advertising could be done in a matter to improve emergency preparedness education, distribute information about the registry and address concerns.

## **Additional Considerations**

Despite adequate mitigation of these variables, the voluntary nature of the registration program ensures that not all individuals with access and functional needs in a community will be within the registry. When a registry is utilized as the only planning tool, the information will be inaccurate and not account for most individuals who need to be included in planning process. A registry's value in Kansas can be enhanced when utilized in conjunction with supplementary tools to create a comprehensive planning system. Other planning methods that could complement an access and functional needs registry could include:

- Improving personal, family and facility planning and preparedness.
- Utilization of Established Planning Tools
- Community Outreach
- Incorporation of Technology

### Improve Personal, Family and Facility Planning and Preparedness

Despite the utilization of planning and response tool by state and local governments, people with access and functional needs requiring assistance during disasters must take initiative and create a self-help network of family, friends and neighbors to assist them during emergencies in a worst-case scenario (McGuire, Ford, and Okoro, 2007). The importance of preparedness is increased as people with disabilities on average are significantly less prepared than person without disabilities for emergencies or disasters (Smith & Notaro, 2009).

Consequently, state access and functional needs registries can be counterproductive as they may provide a false sense of security for individuals with access and functional needs. Often, there is a misconception that being on the registry will ensure the rescue of an individual who needs assistance whereas that may not be the case (Salk, Henry, and Wadas 2019).With this

false security provided by the government, individuals often rely on access and functional needs registries as their only emergency or evacuation plan, disregarding other personal preparedness emergency planning initiatives (FEMA, 2011).

A campaign to improve disaster planning at a local level and could reduce the resources required for response when an emergency occurs including less rescues, less injuries, etc. Encouraging and educating the development of personal or family preparedness plans for individuals with access and functional needs will be required to destroy misconceptions of these planning systems. This can include communication with disability-oriented non-profits that provide services to people with disabilities, targeting hospitals or long-term care facilities. Also coordinating with local officials, advertising best practices through television or social media awareness, ensure consistent message and conduct training for education on how to best prepare and plan.

#### Utilization of Established Planning Tools

To capture individuals who may not voluntarily register, existing planning tools and sources could be utilized complementary to a registry to account for these individuals. An example of an existing source could include disability information from US Census or American Community Survey. Other tools can be used in conjunction with these efforts such as utilizing the Center for Disease Control's social vulnerability index to assist in identifying areas within the community that may be more at risk from disasters (Wolkin, et al., 2015). There is available and applicable information that can be used in conjunction with a registry to supplement information.

### Community Outreach

Outreach to community stakeholders to develop partnerships with organizations, agencies and others disability related groups can assist in efforts in identifying those at risk, vulnerabilities, increasing education and finding other local community solutions (Wolkin, et al., 2015). This should focus on strengthening relationships and developing partnerships with non-profit organizations that serve populations with access and functional needs. This could result in increased information sharing and developed partnerships that could assist in providing better emergency planning and response within the community.

### Incorporation of Technology

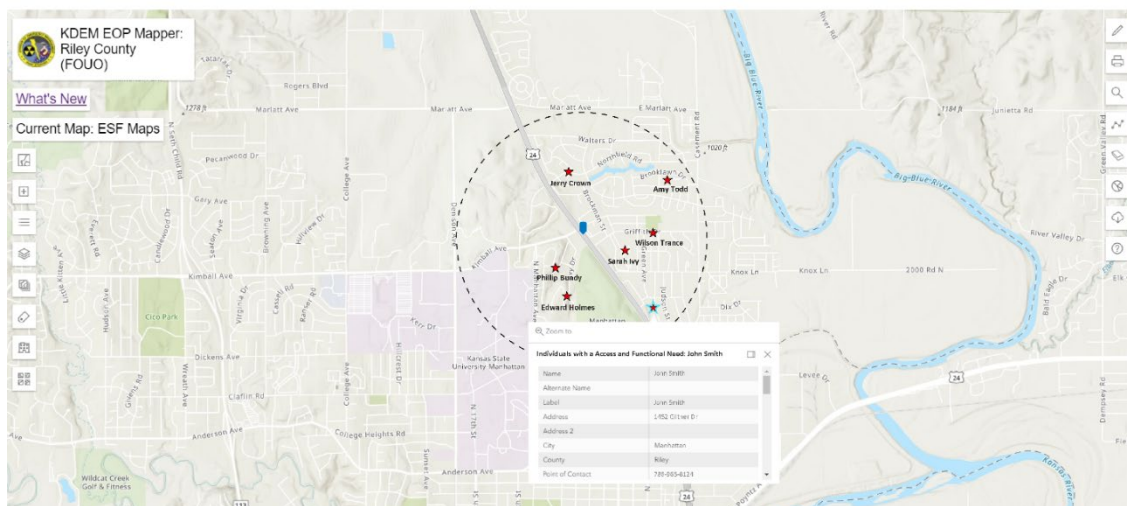
The use of technology to support access and functional needs registries and enhance data gathered from registries could be another option to supplement information gathered from registries. Technology systems can be utilized to assist in gathering information, in which could include gathering information from 911 systems, utilizing mobile devices and mobile applications. GIS can also be utilized, particularly in an online format, for increased information sharing, situational awareness and geospatial analysis for emergency planning and response.

An example on how GIS could be used during an emergency scenario could involve a tanker of chlorine being transported to a facility for disinfecting processes. The truck is stuck by another vehicle and the tank is punctured, releasing chlorine at a steady rate. Local emergency management is notified and when utilizing the emergency response guidebook. A protection action distance can be identified from the incident location and an advisory evacuation buffer around the origin of the crash can be instituted. When ordering a precautionary voluntary evacuation, alert notification procedures can be utilized to advise the community of the incident and for evacuation instructions. With multiple data elements as well as utilizing information

from an access and functional needs registry within an online geospatial application for state and local planning and response, local emergency management can identify hazards, vulnerable individuals and other facilities within the max potential protection action distance.

Attributes included with locational data could allow better alert and notification procedures that route directly to those with access and functional needs especially during an impending nearby hazard. Mapping these individuals could provide for the easy identification of those with access and functional needs with direct communication capabilities if assistance is needed dispatched to provide support. By using the data obtained from an access and functional need registry and incorporated with GIS, can increase efficiency and effectiveness of planning and response services to populations with access and functional needs.

With the ability to use the information gained from an access and functional needs registry in the form of geospatial data, the local emergency management agency could identify everyone with an access and functional need within the evacuation buffer. They may require additional notification or assistance with evacuation depending on the impairment. Within the mapping application, relevant attributes collected by the program would be made available for

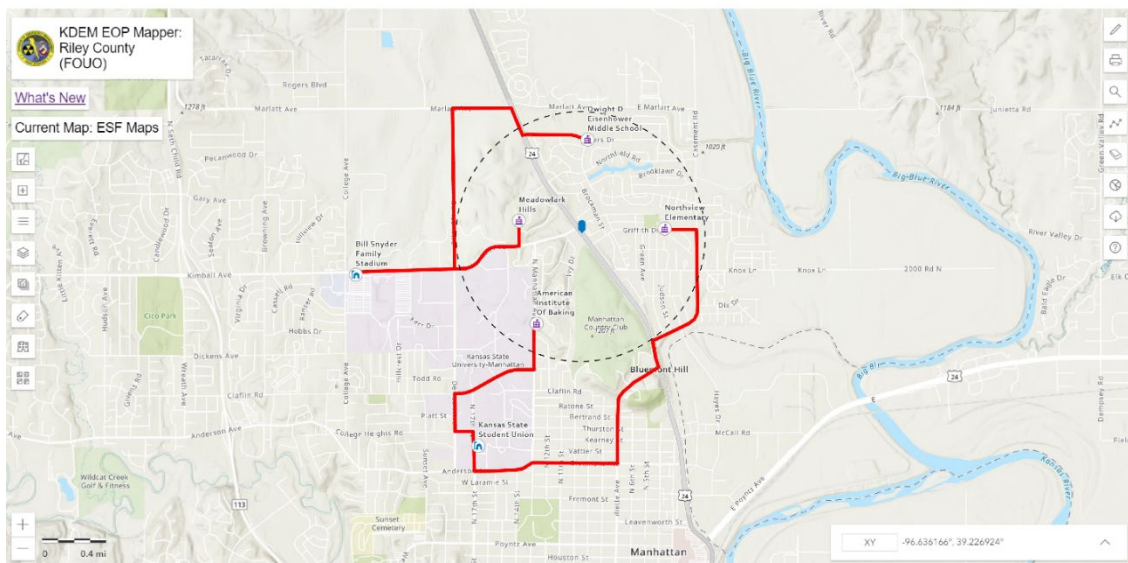


**Figure 4:** Proposed registry information within an online mapping application for identifying individuals impacted by a chlorine incident.



each registered individual including their address, contact information, access and or functional need (see figure 4). This information would allow for notification of evacuation and if additional assistance was needed, could be shared with first responders to provide the appropriate service. For individuals, everyone that is within that area can be identified and a direct line of communication can be established using attribute information correlated with that individual. Additional response services can be dispatched to provide additional assistance to ensure the safety of the individuals.

Another potential impact are facilities with access and functional needs within that evacuation buffer and would need to be advised of a hazard. Facilities could be easily identified, and spatial analyst tools and models can be developed for a greater understanding and decision making in the goal of incident stabilization (see figure 5). There are large logistical concerns with the evacuation of facilities with access and functional needs, so this identification would allow for early warning. Additional geospatial analysis could be provided to these facilities by allowing the information to be inputted directly into a model to find the safest and most efficient



**Figure 5:** Proposed model to assist with the evacuation of facilities with access and functional needs considerations from an access and functional needs registry.

way out of the facilities to a designated staging location. For example, an evacuation model can be incorporated to easily map out the best route of evacuation for all facilities within the buffer and be provided to the facility manager utilizing tools from the network analyst toolbox, to meet planning requirements established by EPCRA. The facility manager could be sent a map of the route of the most ideal route.

## Chapter 7 - Conclusion

In summary, people with disabilities or access and functional needs require complex planning and response to ensure that emergency services are adequately provided. On average, population with disabilities also have an increased vulnerability to disasters. Additionally, the Americans with Disabilities Act requires that adequate emergency services are provided to populations with disabilities. Access and functional needs registries are commonly used by multiple states to assist in emergency planning and response to these populations. Although, there are systematic challenges with registries that can potentially reduce their effectiveness and success.

Through analysis of the Kansas Vulnerable Needs Planning System, State of Texas Emergency Assistance Registry, Florida Special Needs Registry and the New Jersey Register Ready, variables were identified that could impact the success of the program. These variables accessibility of registration methods, confidentiality and integrity of registry, utilization by the government and community involvement. These potential challenges could be mitigated to improve the number individuals with access and functional needs and overall effectiveness of a registry.

The mitigation of these variables can increase overall usage and ensure that the information collected is the most accurate and actionable by the state and local government. Although, the voluntary nature of the registration program ensures that not all individuals with access and functional needs in a community will be within the registry. When a registry is utilized as the only planning tool, the information will be inaccurate and not account for most individuals who need to be included in planning process. A registry's value can be enhanced when utilized in conjunction with supplementary tools to create a comprehensive planning

system. Other planning that could complement an access and functional needs registry could include improving personal, family and facility planning and preparedness, utilization of established planning tools, community outreach and incorporation of technology.

Overall, if systematic challenges are mitigated then the effectiveness and success of registries can be improved. Access and functional needs registries can then be integrated within communities in conjunction with other planning tools to improve emergency planning and response.

### **Avenues for Future Development**

For future development, more evidence-based research is required to be conducted to understand the how registries can be utilized for emergency planning and response. This can include fully understanding how information from registries could be applied to reduce the impact of a disaster on populations with access and functional needs. As all communities are different, it will be important to understand the diverse and dynamic usage of registries and how they are applicable to the community. Analyzing the different usage can help communities utilize the information more efficiently and effectively.

Further, there is a need for quantitative analysis on how a registry impacts disaster planning and response within communities. This can include analyzing how the implementation of a registry within a community improved planning and response efforts. Statistics can be utilized to support the outcome that the registry can have on a community after a disaster. This will be used to support the relevance of registries within emergency planning and response.

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