

# State of Texas Emergency Assistance Registry (STEAR) Usage Among Emergency Managers in Texas

Crystal Goodwin<sup>1</sup>

[goodwin.crystal8@gmail.com](mailto:goodwin.crystal8@gmail.com)

Ronald L. Schumann III<sup>2</sup>

[ronald.schumann@unt.edu](mailto:ronald.schumann@unt.edu)

<sup>1</sup>Department of Emergency Management & Disaster Science, University of North Texas, 1155 Union Circle #310637, Denton, TX 76203

<sup>2</sup>Department of Emergency Management & Disaster Science, University of North Texas, 1155 Union Circle #310637, Denton, TX 76203

# Abstract

The State of Texas Emergency Assistance Registry (STEAR) is a state-run database designed to assist emergency managers working for city and county governments to prepare for the needs of citizens with disabilities or transportation needs. Disability or special needs registries similar to STEAR have been widely promoted within emergency management as an improvement for inclusive planning and response. However, little research on the use or effectiveness of these registries exists.

The study aims to fill the gap in disaster-related disability research by investigating current and potential uses for the STEAR data to better assist people with disabilities. Three focus groups were first conducted to learn how STEAR data may be used across two regions that face different hazards. Focus group results then informed the design of an internet survey. The internet survey asked local emergency managers from participating jurisdictions across the state about their knowledge, usage of, and programming based on STEAR data.

Results from the focus groups show that while local emergency managers possess a broad understanding of the information contained in the STEAR database, jurisdictions often encounter a lack of registration or personnel to dissect the data, which leads to a lack of programming using STEAR. Results from the survey show regional differences in jurisdictional knowledge of STEAR data and suggest an overall hesitancy to fully integrate STEAR data into emergency management programming.

## Keywords:

Social Vulnerability

Disability

Disaster Planning

Special Needs Registries

# Introduction

The State of Texas Emergency Assistance Registry (STEAR) is a state-run database designed to assist emergency managers working for city and county governments to prepare for the needs of citizens with disabilities or transportation needs. Disability or special needs registries like STEAR have been widely promoted within the emergency management field as tools for making disaster planning and response more inclusive. However, little research has been conducted on the effectiveness of these registries.

Research on people with disabilities in disasters began in earnest after Hurricane Katrina, in 2005, revealed the disproportionate impacts and lack of emergency planning for this community. After Hurricane Katrina, the Federal Emergency Management Agency (FEMA) took actions to close service gaps for individuals with disabilities. One such action was the signing of the *Post-Katrina Emergency Management Reform Act* in 2006 that mandated the integration of individuals with disabilities during the planning and response phase (Congress, 2006). Additionally, FEMA established a new Office of Disability Integration, added disability integration specialist positions in each FEMA region, acknowledged the importance of sociocultural sensitivity through their Building Cultures of Preparedness Report (FEMA, 2019), and declared promoting equity in emergency management as one of the organization's strategic goals.

To date, most research on disability in disasters has focused on barriers in sheltering, evacuation, or housing for people with functional and access needs during the post-disaster phases of response and recovery (e.g., Phillips and Stough, 2016). Few studies examine the preparedness phase as it relates to people with disabilities, and even fewer studies investigate emergency managers' use of data sources about residents with special needs. One of the few examples of research on this topic examined emergency managers' usage of special needs registries across three different locations within the United States, a Northern state, a more rural Midwest state, and an area in the mid-Atlantic region (Donny, 2013). They found that emergency managers in all three locations did use the registries to make decisions, however there was variation in most other aspects, including how often the registry data were used, the perceived accuracy of information, available training provided to use the registry, and what instances led to use of the data for decision making (Donny, 2013). Accordingly, the current study explores how local emergency managers in the state of Texas are using the STEAR database to better serve the disability community across all four phases of emergency management.

Five research questions guide the current study:

1. To what extent are local emergency managers comfortable using STEAR data?

2. To what extent are local emergency managers encouraging residents and organizations to register with STEAR?
3. How is STEAR information currently being used in local jurisdictions?
4. What are the barriers to using STEAR data?
5. How might STEAR be improved to make it more useful to local emergency managers?

To answer these questions, focus groups were first conducted with emergency managers from coastal and inland regions of Texas that face different hazards, and thus, may have unique uses for STEAR data. Focus group findings then informed the design of a state-wide internet survey that asked local emergency managers from participating jurisdictions about their knowledge, usage, and jurisdictional programming based on STEAR data.

The following sections provide background on previous research conducted about disability in disasters, followed by details about data collection and analysis methods used for this study. Results for each of the five research questions are presented and their implications for the field of emergency management are then discussed. This research on current and potential uses for a state-wide disability registry represents a necessary first step to increase the utility of emergency planning tools focused on people with disabilities. Ultimately, the findings of this study are intended to improve disaster outcomes for constituents with functional and access needs.

## Background

People with disabilities and their conditions have been defined and categorized differently throughout time. The American Disability Association (ADA) currently defines a disability as “a physical or mental impairment that substantially limits one or more of the major life activities of such individuals” (ADA National Network, 2023). Research on disabilities in disasters is relatively new, mainly beginning after Hurricane Katrina and focused on the failures of helping people with disabilities during that disaster (Stough, 2012). Of the current published research on disabilities in disasters, most studies focus on the response and recovery phases of emergency management detailing how people with disabilities can access aid after a disaster event.

Response-oriented research centers on either specific access barriers or on segments of the population who are perceived to be at higher risk due to age or (dis)ability. One example of the former type of research is the Report on Special Needs Assessment for Katrina Evacuees Project (SNAKE), which detailed the barriers that people with disabilities had in access and communication in shelters in Louisiana, Mississippi, and Texas (Phillips and Stough, 2016). Common examples of the latter type of research include studies on those over 65, on children, or on individuals with specific disabilities (e.g., intellectual disabilities, mobility disabilities, communication disabilities). From the research that has been done, those with disabilities are

known to struggle more with evacuation due to medical needs, transportation issues, and reliance on others in order to leave (Reynolds et al., 2013).

Recovery-oriented studies on individuals with disabilities often focus on why individuals with disabilities recover at a slower rate or have worse outcomes than the general public. This disparity is often cited because of difficulties gaining access to resources that are critical for disaster recovery, such as modified housing, specialized transportation, tailored health information, and other resources that require accommodation (Phillips and Stough, 2016). Overall, the field of disability research in emergency management is limited and concentrated primarily in disaster recovery after major events. To date, few studies have focused on mitigation and preparedness before a disaster (Phillips and Stough, 2016).

While there are few publications on preparedness or mitigation for individuals with disabilities, the publications that do exist often focus on the individual's preparedness level and less on governmental planning for individuals with disabilities. Studies found that the only institution that regularly keeps data on individuals with disabilities is FEMA. FEMA routinely collects information on the preparedness levels, habits, and beliefs of individuals with disabilities (Kruger, 2018). Research has found that preparedness levels among individuals with disabilities were more strongly correlated with their perceived risk to a threat rather than the type and extent of their disability (Marceron and Rohrbeck, 2018). Differences in individual preparedness levels have also been attributed to variations in reliance on assistance from neighbors and kin, reliance on governmental and community-based resources, or reliance on personal financial resources (Marceron and Rohrbeck, 2018). Research finds that people with disabilities often lack the funds to adequately prepare for disaster (Marceron and Rohrbeck, 2018). Individuals with disabilities have also reported the government should be doing more to help individuals with disabilities prepare for disasters (Elisala et al., 2020).

While STEAR is currently referred to as a resource for *individuals with disabilities*, the lexicon used within the emergency management field to describe this group has evolved considerably over the last two decades. The category of individuals targeted and encouraged to join these registries has variously been called *special needs*, *vulnerable populations*, *at-risk populations*, *individuals with functional and access needs*, and *disability populations*. Registries similar to STEAR are often called special needs registries, however, *special needs* is a broad definition that could encapsulate a majority of the United States' population. One study by Kailes and Enders (2007) shows that this definition could account for 51.44 percent of the population. "Special needs" has been frequently used in emergency management as a blanket term meant to include people with disabilities, individuals with serious mental illness, racial or ethnic minority groups, limited or non-native English speakers, children, and the elderly (Kailes and Enders, 2007). *Vulnerable populations* is another expansive moniker that includes "any individual, group, or community whose circumstances create barriers to obtaining or understanding information, or

the ability to react as the general population [would]... Circumstances that may create barriers include, but are not limited to age; physical, mental, emotional, or cognitive status; culture; ethnicity; religion; language; citizenship; geography; or socioeconomic status” (Nick et al., 2009). While this definition is similar to the definition of special needs, it adds a wider variety of marginalized groups and vastly expands the number of individuals considered. *At-risk populations* is a broad and ever-changing definition within emergency management; this population is often defined as individuals who have “concerns with communication, medical, independence, supervision, and transportation services” (Sheldrew, 2010). However, even this definition of *at-risk* varies between organizations. *Functional and access needs* is similar to *at-risk* groups but comprises a wider swath of “individuals who need assistance due to any condition (temporary or permanent) that limits their ability to act” (FEMA, 2021). The most precise definition used in emergency management to describe this population is *having a disability* or *disabled*. The definition of disability is “a person who has a physical or mental impairment that substantially limits one or more major life activities” (ADA National Network, 2023). These terms are so similar they are often used interchangeably by emergency management practitioners; however, it is important to recognize these differences because large groups may be inadvertently excluded during planning and response if an exceedingly narrow term is used. Similarly, registries can be highly restrictive or broad enough to include a majority of the population, all depending on the term that is used to describe them.

Special needs registries have become commonplace in recent years and are frequently viewed as a panacea for jurisdictions aiming to address the needs of constituents with disabilities during emergencies. However, serious questions have been raised about their effectiveness. First, the nature of most (if not all) of these registries is to rely on individuals to register themselves and disclose their personal medical information. This raises questions about registrant confidentiality, database security, and the accuracy and completeness of such information. Second, these registries often assume that individuals with disabilities are homebound and are not capable of leaving their documented address at all (Kailes, 2018). This assumption neglects the fact that most individuals with mobility disabilities often travel around their communities to perform regular errands. Third, special needs registries may create confusion among the public who may assume that registering guarantees them special services in time of disaster, even when a jurisdiction may not be able to provide the expected assistance (Kailes, 2018). Finally, Enders et al. (2022) point out that the number of registrants rarely come close to the number of individuals with disabilities within the same community. Given these crucial questions, the current study aims to understand how emergency managers use data from one specific special needs registry (STEAR) and how they confront these issues of data reliability, confidentiality, and uncertainty.

# Methods

## Research Design

The five research questions guiding the study explore several aspects related to the use of STEAR data by local emergency managers. These include emergency managers' levels of comfort/familiarity with the database, previous and current applications for the data by local jurisdictions, and the extent to which local jurisdictions encourage their residents and facilities serving people with disabilities to register with STEAR. Additionally, the last two questions elicit information from the perspective of local emergency managers on barriers to using the database and potential solutions that would facilitate greater use.

Since the student researcher and faculty advisor conducting this research had no previous experience using the STEAR database, systematically answering these research questions required an iterative research design with two phases of data collection: 1) focus groups with local emergency managers who had experience using STEAR, and 2) an internet survey of local emergency managers across the state of Texas. The focus groups represented a qualitative, exploratory method that informed the design of an internet survey for large scale, quantitative data collection. While the questions posed to participants in both focus groups and surveys were largely the same, the differing aims of the two phases of data collection (exploratory/qualitative and confirmatory/quantitative) required different sampling strategies, study areas, and analysis techniques. These are detailed below.

## Focus Groups

The researchers planned focus groups in two distinctive Texas regions: one inland and one coastal. These two environments represented a diverse set of hazards and communities to be evaluated. Participants for the focus groups were recruited through regional Council of Government (COG) organizations (Figure 1). After contacting the North Central Texas COG, a list of possible interested parties was given to the researchers who were then recruited through email. For individuals recruited from southeast and coastal areas, a call for participants was circulated within COG organizations and interested participants reached out to the researchers. The North Central Texas (inland) and South East Texas (coastal) COG regions were ultimately selected as study areas because of established connections to emergency management professionals in these regions. Professionals in each region helped publicize information about the study and assisted with recruitment for the focus groups. Verbal consent was obtained from all participants before each focus group began discussion.



Figure 1: Map showing regional Councils of Government (COGs) in Texas. Participants were recruited from the North Central Texas and South East Texas COG regions. Source: <https://comptroller.texas.gov/transparency/reports/expenditures-by-county/2007/cogs/cogmap.php>.

Seven participants were recruited to take part in three focus groups (two inland, one coastal). Each focus group was planned with 2-3 participants each. However, due to scheduling conflicts and extreme weather, not all were able to participate. In the end, five individuals (n=5) participated in the focus group portion of the research—three individuals from North Central Texas and two individuals from South East Texas. Two focus groups were conducted with North Central Texas participants: one of these focus groups included two individuals and the other focus group was conducted interview-style with a single participant. A third focus group was conducted with two participants in the South East (coastal) region of Texas. All participants were either current or former local emergency managers who had knowledge of or experience using the STEAR database. Focus groups were conducted virtually on Zoom in February and March of 2022. These conversations were recorded and later transcribed. Each focus group session lasted about 50 minutes.



Focus groups were conducted in a semi-structured style, meaning that although the researchers used a standard set of questions and probes, their exact wording and order may have differed slightly based on the natural flow of the conversation. A total of ten questions guided the focus group conversations (Appendix A). Questions posed in the focus groups closely followed the research questions but included additional questions about local residents' participation in STEAR. Deductive coding was used to identify a concourse of possible answers to each focus group question. The researchers then used each concourse to devise the set of multiple-choice answers that would be used for each survey question.

## Surveys

Survey questions (Appendix B) were devised at the same time as focus group questions and were intended to replicate the focus group questions as closely as possible with a larger sample using multiple choice format (i.e., a confirmatory, quantitative method). The survey was created using the online survey tool Qualtrics. Based on the focus group conversations, multiple choice answers were added to focus group questions, transforming them from open-ended to close-ended questions. Questions regarding barriers to using STEAR were removed from the survey because the focus group participants had difficulty in answering them. Instead of identifying barriers, focus group participants were more apt to suggest how STEAR might be improved. Thus, the internet survey preserved questions about potential improvements to STEAR.

In total, there were 25 questions in the internet survey including the question to obtain consent to participate. Prior to seeing survey questions, consent was obtained from all respondents through an electronic checkbox. The survey asked respondents to identify their county and jurisdiction, but no other identifying information was collected. The survey was created with logic to skip certain blocks of questions if the respondent answered they had not personally used STEAR or had no plans to use STEAR in the future. The survey ended if the respondent answered that their jurisdiction had never previously used STEAR data.

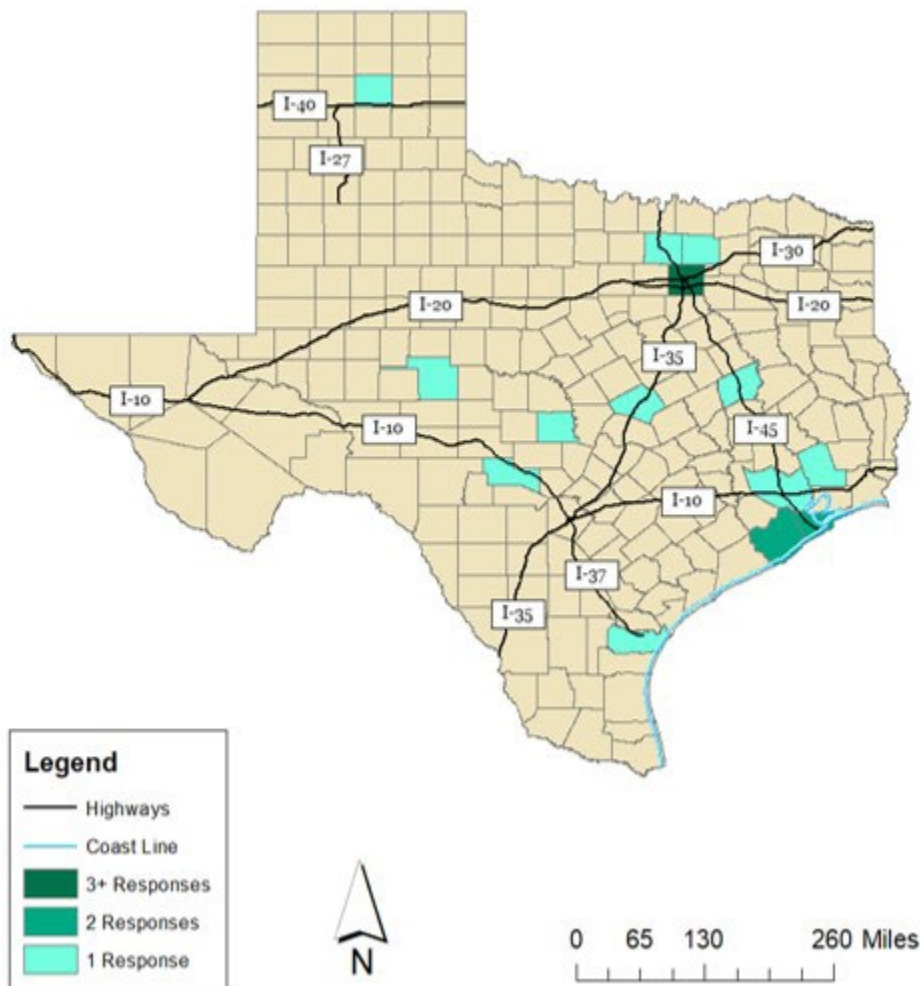
Given that STEAR is a database unique to Texas, the original intent of the study was to collect data from all local jurisdictions (i.e., cities/towns and counties) across the state. However, the researchers learned that two factors limited the reach of data collection: the nature of program participation and jurisdictional contact information. First, the STEAR database relies on voluntary participation by both jurisdictions and residents. Jurisdictions must register with the Texas Division of Emergency Management (TDEM) to gain access to data for their area. Likewise, residents hoping to receive services must register themselves and provide detailed information on their needs. At the time of this research, there were 180 jurisdictions that TDEM has listed as participating in STEAR (Figure 2).



The internet survey was successfully distributed to 153 jurisdictions who currently used STEAR data. The initial email containing the internet survey invitation was sent on March 13, 2022, and a reminder email was sent a week and a half later on March 23, 2022. The survey officially closed on March 25, 2022, meaning the survey was open for a total of 12 days.

The final response rate for the internet survey was 14.38 percent. Of the 153 possible jurisdictional participants, a total of 22 unique jurisdictions (a mix of cities, towns, and counties) responded. There was variation in the geographic distribution of the survey respondents across the eastern two-thirds of Texas. Higher concentrations of responses came from Dallas and Brazoria Counties. There were no respondents from west Texas and few from the panhandle region (Figure 3).

## Disability Data Survey Responses



*Figure 3: County level map showing locations of survey respondents across Texas. Highlighted counties indicate participation from any type of jurisdiction (city/town government or county government) within that county. Cities or towns that overlapped multiple counties were assigned to the county where most of their population lived.*

## Results

This section summarizes findings for each research question. Although the focus groups were used to inform the survey design, here we detail quantitative findings from the survey first and use focus group data to further contextualize them. Focus group findings derive from insights contributed by all five participants, while survey findings derive from subsets of respondents who opted to answer each question. Of the 22 survey respondents, 19 reported that their jurisdiction was actively using STEAR data. The remaining three respondents indicated that their jurisdiction either did not currently use STEAR or that they personally had no previous experience with STEAR, which automatically ended the survey. Hence, the maximum number of responses to any question was 19.

### RQ 1: Level of Comfort Using STEAR Data

This question focused on local emergency managers' general knowledge about the STEAR database, familiarity with the information provided through STEAR, and overall comfort using these data. Findings for this research question summarize respondents' answers to survey questions 7, 8, and 11 (Appendix B) and focus group participants' answers to question 1 (Appendix A).

#### Survey Results

Ninety percent of respondents (18 of 20) perceived their overall knowledge of the STEAR program to be either average or above average (Question 7). When respondents were asked about their knowledge of their own jurisdiction's STEAR data, 85 percent of respondents answered they had average or above average knowledge. However, when respondents were asked about their level of comfort in using the STEAR data available to them, respondents fell into a bimodal distribution (Figure 4). Two-thirds reported that they were somewhat comfortable or extremely comfortable and one-third reported that they were neutral or somewhat uncomfortable.

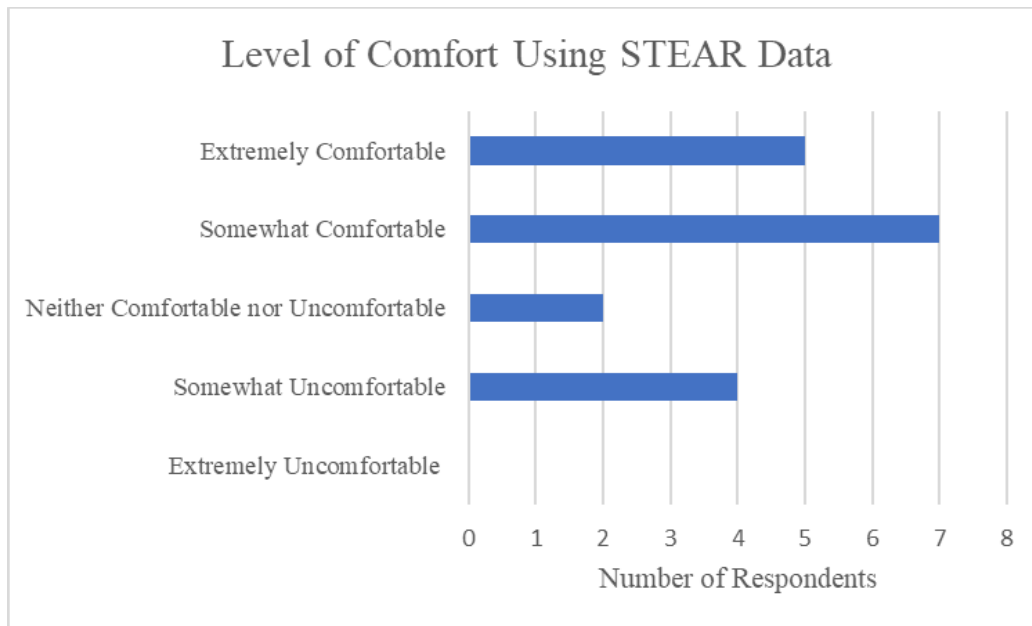


Figure 4: Results from survey question 11 regarding respondents' level of comfort using STEAR data.

## Focus Group Results

Focus group participants varied in their responses and comfort levels using STEAR data from their jurisdiction. Participants discussed three aspects that contributed to their comfort levels with STEAR: ability to access the dataset, knowledge of the variables contained in the dataset, and trust in the data. Participants were generally comfortable accessing the database, and their knowledge of what the dataset should contain added to this comfort level. However, most participants doubted the reliability and completeness of the STEAR data, especially when it came to individual needs. This resulted in most participants feeling uncomfortable using the data in an actionable way.

Several participants noted they were comfortable using their jurisdiction's STEAR data on congregate care and group living facilities (e.g., nursing homes, assisted living facilities, senior living apartments). Participants stated they often checked STEAR data to better understand the needs of their community and to estimate the number of individuals who might need assistance in these facilities.

## RQ 2: Promotion of STEAR Registration Among Residents and Organizations

This question focused on the extent to which local emergency managers are encouraging their residents and facilities to register with STEAR and the channels used to promote registration. Findings for this research question summarize survey respondents' answers to questions 16 and 17 (Appendix B) and focus group participants' answers to questions 6 and 7 (Appendix A).

## Survey Results

Survey respondents were given several options describing the channels through which they promoted STEAR registration to specialized facilities and to residents with disabilities who lived in their jurisdictions. These included using their own department's website, using social media, or sending emails to residents and facilities who had registered in the past. Because respondents had to choose only one answer, we offered two additional answer choices to indicate whether they used a combination of these channels or whether they used none of these channels.

Only six of the respondents opted to answer this question. Among those who answered, five of the six respondents indicated they did promote registering with the STEAR program. Social media was the most popular channel for promoting STEAR registration among constituents.

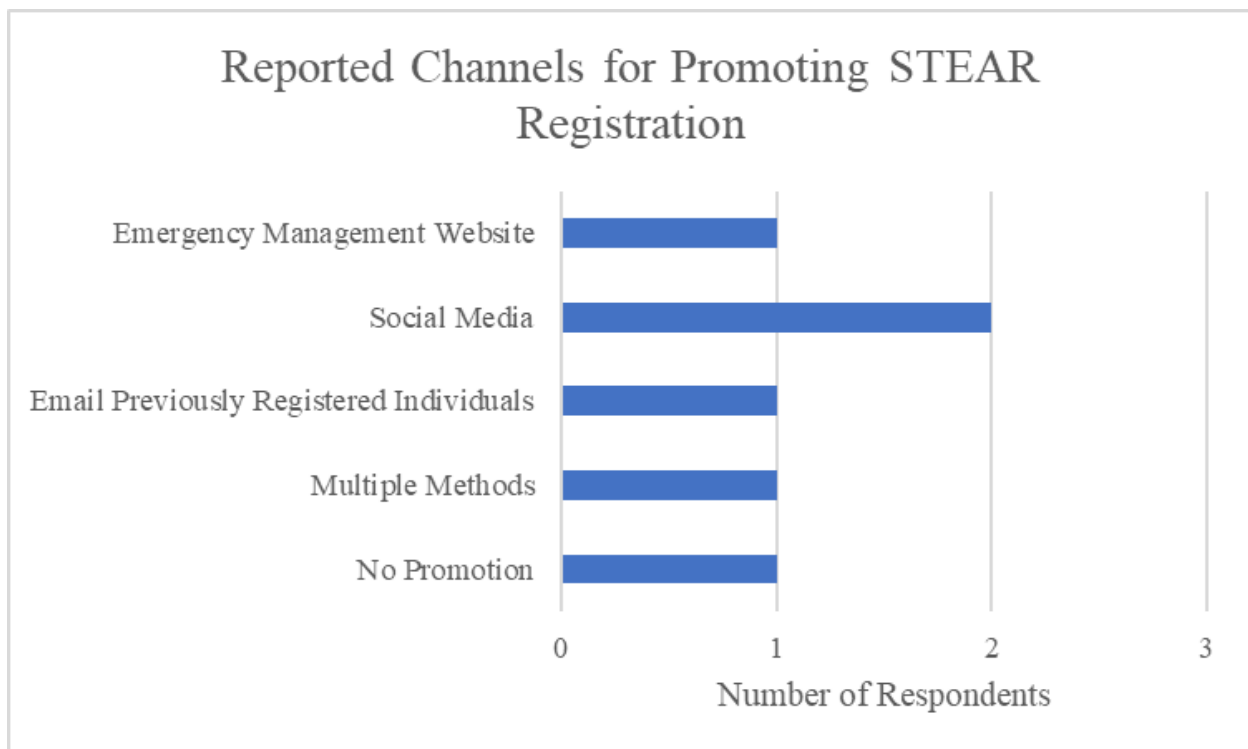


Figure 5: Results from survey question 17 regarding channels respondents used to encourage residents and facilities in their jurisdiction to register with STEAR.

## Focus Group Results

Focus group participants reported hesitancy in promoting the STEAR program to their residents based on the belief that registered residents would become reliant on government-assisted response instead of taking their own individual preparedness measures. Participants expressed worry that once residents registered, they would assume it guaranteed they would always receive

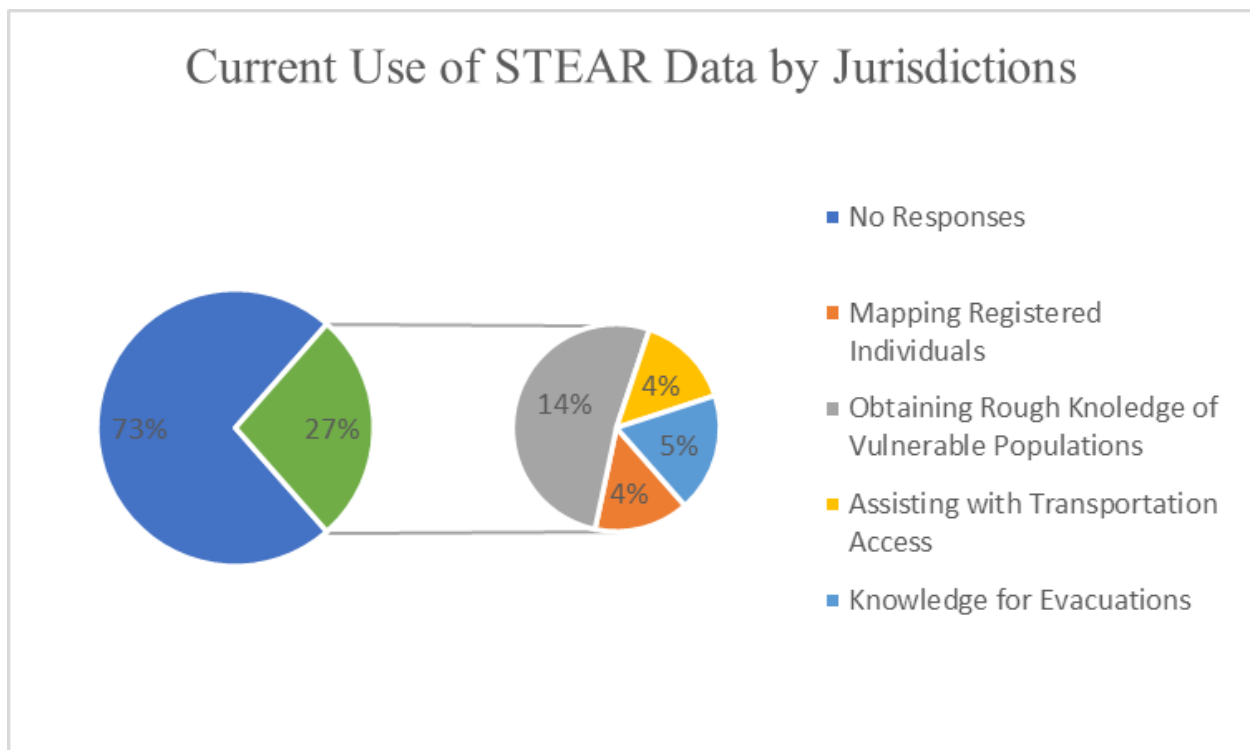
local response resources based on their recorded needs. Participants noted that they did not want their jurisdiction to be blamed if they were unable to deliver specialized services for any reason. Due to these factors, focus group participants noted there was little to no targeted outreach done for residents within their jurisdictions. Only one participant noted targeted outreach that was only done while performing visits to specialized care facilities within their jurisdiction.

### RQ 3: Current Uses of STEAR by Local Jurisdictions

This question focused on the ways in which local emergency managers are using data from STEAR to support their mission. Researchers were also interested to know the extent to which uses for disability data spanned the four phases of the emergency management cycle. Findings for this research question summarize survey respondents' answers to questions 13 and 14 (Appendix B) and focus group participants' answers to question 2 (Appendix A).

#### Survey Results

As with the previous question, only six of the survey respondents answered this question about projects in which they currently used STEAR data. Of the respondents who are currently using STEAR data, the most common use was to obtain rough knowledge of the jurisdiction's vulnerable populations and their needs.



*Figure 6: Results from survey question 14 about how respondents were currently using STEAR data to inform emergency management operations. Seventy-three percent of respondents skipped this question. The smaller pie chart shows responses among the 27% of respondents who answered this question.*

## Focus Group Results

Focus group participants discussed a variety of uses for STEAR data within their jurisdictions. We observed geographic variability in the types of projects that used STEAR data. In the coastal focus group, emergency managers from South East Texas often used the data for evacuation and transportation planning in floods and hurricanes. They equated STEAR data to a “snapshot” of the community, and they used it to estimate resource needs to respond to flood or hurricane scenarios. While emergency managers in North Central Texas also used STEAR data for transportation needs, the hazard of focus was different. Here they focused on identifying special medical needs of residents and assisting with transportation planning for hazardous chemical release scenarios near fixed facilities, major roads, or rail lines. Other emergency managers from North Central Texas used STEAR data to map both registered individuals and congregate care settings within their jurisdiction.

## RQ 4: Barriers to Using STEAR Data

This question focused on barriers that limited the use of either the STEAR database or STEAR data by local emergency managers (question 5, Appendix A). When conducting the focus groups, researchers found that participants were unable to identify specific barriers that inhibited their use of STEAR. Instead, participants offered suggestions on how STEAR could be improved to make it more user-friendly. Given the failure of this question when piloted with focus groups, it was removed from further consideration and not included in the internet survey. Potential improvements to STEAR are discussed next.

## RQ 5: Suggestions for Making STEAR More User-Friendly

This question asked about ways in which STEAR data or the STEAR database itself could be improved to facilitate ease of use by local emergency managers. Findings for this research question summarize survey respondents’ answers to question 24 (Appendix B) and focus group participants’ answers to questions 8 and 9 (Appendix A).

## Survey Results

Only six respondents continued to answer how they wished to see improvements; respondents desired three types of improvements. The most popular suggested improvement was the addition



of interactive data filtering capabilities to sort through the raw data prior to downloading it (4 of 6). In equal parts, respondents desired built-in mapping capabilities to visualize the locations of registered facilities (1 of 6) and residents and more detailed data on facilities themselves and the needs of residents within those facilities (1 of 6).

## Focus Group Results

Emergency managers identified three types of potential improvements to STEAR that were ultimately included as answer choices in the survey: 1) advanced data filtering options prior to data download, 2) a built-in GIS or mapping function within the database to visualize the location of facilities and special needs residents living outside of those facilities, and 3) more detailed information on facilities and the residents who live there.. Focus group participants indicated that STEAR data is given to jurisdictions in the form of an Excel spreadsheet. Emergency managers described this format as problematic because of the excessive time needed to clean the data to prepare it for use. Staffing was a related issue that emerged from this discussion. Given other priorities, either valuable staff time could not be expended on this menial task, or staff members simply lacked the proper training to perform these tasks efficiently within Excel. Participants suggested that STEAR data is best utilized when tied to geographical data to plan for residents where they are located. However, many jurisdictions do not have their own ability to create and design GIS based information. Finally, participants noted that while having information on facilities was widely desired, the information about facilities currently captured in STEAR lacked detail about the needs of individual residents.

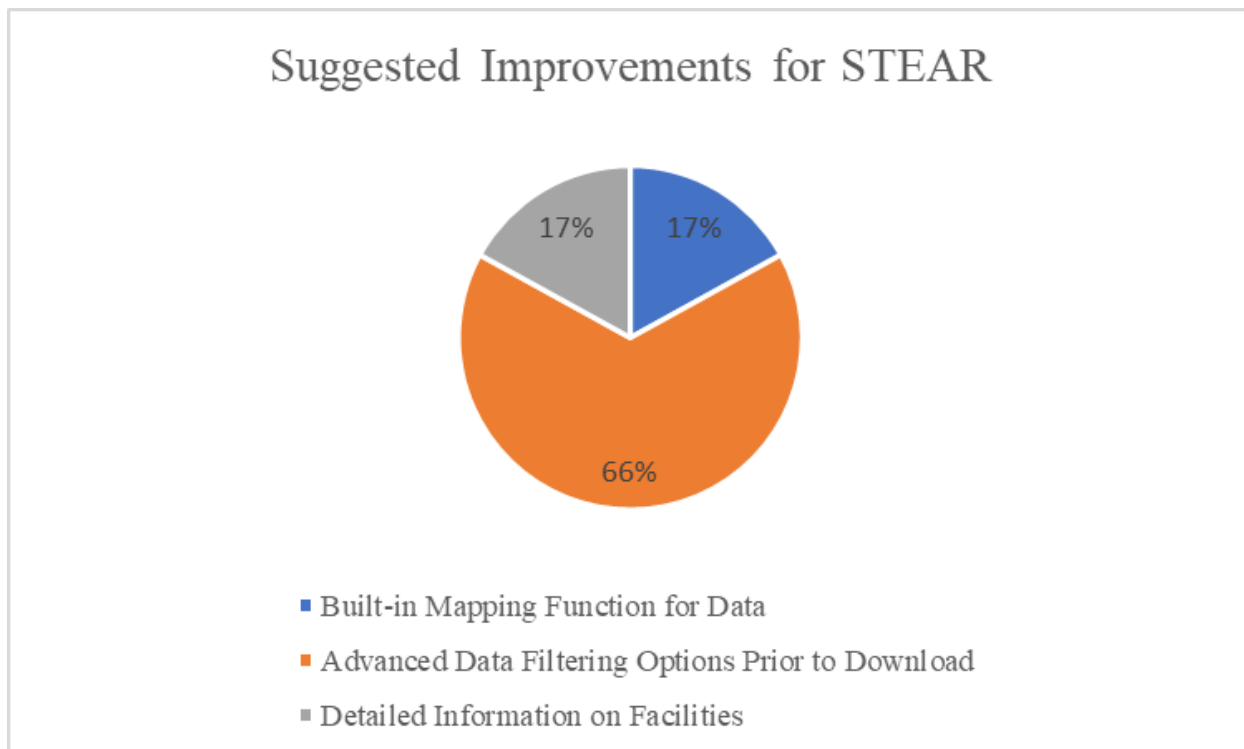


Figure 7: Results from survey question 24 that asked respondents how to improve the STEAR database.

## Conclusion

### Summary of Findings

Findings from the focus group conversations and internet survey results reveal important insights regarding uses of the STEAR disability registry and its effectiveness. First, STEAR seems to be a well-known program among local emergency managers in Texas, and most of these professionals report being fairly knowledgeable about and comfortable using the data. Second, despite knowing about and feeling comfortable using the data, STEAR remains a heavily underutilized dataset. The significant drop-off in responses observed during the internet survey when respondents were asked about actual uses or plans for STEAR data underscores this point. Third, specific improvements could be made to the STEAR interface, such as adding filtering and GIS mapping capabilities, to remove some of the barriers to its use. Along with these improvements, greater technical support from the state and greater openness to dialogue with users about ways for improving the database, including ensuring reliability and completeness, would also likely increase data utilization by local emergency managers.

Our findings from the focus groups further suggest that emergency managers may be hesitant to discuss their exact uses for STEAR because there is a lack of formal programs or projects currently underway that utilize STEAR data. Results from both the focus groups and survey show that emergency managers most often use the data to gain a rough idea of vulnerable populations and their locations but rarely go further to integrate the data into disaster exercises, mitigation planning, or other formal uses. To further utilize the STEAR data set, STEAR data could be incorporated into disaster preparedness exercises to ensure a wider cross-section of emergency managers gain knowledge of the dataset and become comfortable using it on the fly. To integrate STEAR on a state level, TDEM and the government may consider combining STEAR data with datasets that target individuals with access and functional needs. These might include tract level data from the American Community Survey on disability, household vehicle ownership, and language proficiency, or emPOWER data from the US Department of Health and Human Services, which maps residences of individuals who have energy dependent medical equipment. This would allow for a cross section of individuals who may need immediate assistance and have critical access or functional needs to be better represented.

## The Role of Culture

Findings from both the internet survey and focus groups allude to larger cultural issues that may complicate the design, operationalization, and usage of a statewide disability registry for Texas. Texas prides itself on a culture of rugged individualism, which has historically defined the state and continues to be highly valued among its people and institutions. In this culture, residents are expected to prepare and respond largely for themselves. The core value of self-sufficiency may limit the willingness of residents to offer their individual data to a state agency or to ask for or expect help from the government in an emergency. Likewise, local jurisdictions may be skeptical of mandates that come from higher levels of government and could curb their self-sufficiency.

At the state level, TDEM possesses an organizational culture that often acts in a top-down manner, meaning that most instruction for emergency management practices comes from the state level and is disseminated down to county and city level. We found an example of this in our focus group discussions. The North Texas region had previously developed and maintained a system similar to STEAR that focused on special needs populations and was tailored to the region's needs. When STEAR was being created and launched statewide, TDEM instructed the region to use the state system rather than incorporating the regionally developed system and the knowledge of its creators into the state system. Focus group respondents felt like their opinions and knowledge were not valued in the situation, and that top-down bureaucracy stifled an opportunity for bottom-up learning. The result was resentment and resistance to using the STEAR database within the region when it was first introduced.

Local emergency managers continue to lack trust in the reliability of current STEAR data. Beyond an awareness that residents may be reticent to contribute individual data, thus limiting accuracy, the lack of trust also stems from lack of transparency in data management. Focus group participants discussed their understanding that STEAR data statewide would be updated, and old records purged on an annual basis<sup>1</sup>; however, they observed that update timeframes varied for each jurisdiction on a seemingly random basis. This, in turn, led to questions about data reliability and contributed to both distrust and avoidance of the state level information that local jurisdictions were being instructed to use.

## Connections to Other Studies

While research on disability and special needs registries is minimal, this research aligns with many findings from previous studies. First, like other disability registries, STEAR is built on the assumption that individuals with disabilities never leave their home (Kailes, 2018). STEAR relies heavily on the notion that registrants will be singularly located at their reported address, thus perpetuating the false notion that all individuals with disabilities who may require assistance are confined to their homes. Second, as in other states and jurisdictions, emergency managers expressed concern that individual registration would create confusion as to whether registries guarantee registered individuals additional assistance during an emergency (Kailes, 2018). Many emergency managers throughout the study discussed their worry that registrants would expect additional assistance during disasters due to their participation in STEAR, which the jurisdiction may or may not be able to give, leading emergency managers to avoid promoting and speaking about STEAR with their citizens. Third, the completeness and reliability of the data appear questionable at best considering the number of registered individuals is far lower than the number of individuals who likely qualify for the registry (Kailes & Enders, 2007).

## Limitations

The current study is not without its limitations. The primary limitation of the study was a small sample size, which affected both portions of the study but was most problematic in the survey. Of the 153 jurisdictions that were invited to participate in the internet survey, only 22 responded. Further, not all 22 jurisdictions answered every question. The lack of responses was most pronounced in questions related to specific uses of the data or plans for data use. The recruitment method may have contributed to low participation. All of the dissemination of materials were made through cold calling and emailing done by the research team. Initially, it was believed that TDEM could assist with survey distribution among participating jurisdictions, however this

---

<sup>1</sup> Since the conclusion of this study the state has changed to a biennial update and purge of the STEAR database.

avenue for distribution was later not allowed. The limited time window for response to the internet survey (roughly two weeks with only one reminder email) could have also limited the response rate. Furthermore, both focus groups and the internet survey took place in early to mid-spring during peak winter/severe weather season in Texas. Several prospective focus group participants had to forgo participation to focus on response and recovery activities occurring in their jurisdictions.

A second limitation involved potential inconsistencies in survey answer choices. When the survey was first launched, there was a technological glitch where the first few internet survey respondents saw a different answer choice format than later respondents. This entailed multiple choice questions being shown as fill-in-the-blank format questions, thus creating a more burdensome survey experience. This glitch potentially affected up to four questions and may partially explain why some of the respondents skipped later questions in the survey.

Finally, it is important to note that this research was conducted in early 2022. Therefore, results may not reflect recent changes to STEAR based on revised current regulations, laws, or best practices of STEAR. The authors are aware of efforts already underway by TDEM to include filtering and GIS mapping capabilities to the STEAR interface that are highly desired by local emergency managers.

## Future Directions for Research and Practice

There are still many areas related to disabilities and disasters, and specifically emergency registries that warrant further exploration and improvement. Broadly speaking, there is a dearth of disability research on the preparedness and mitigation phases of disaster, since most previous studies have focused on response and recovery. Within the domain of special needs and databases, we see three potential lines of inquiry.

First, research should seek to document specific projects and programs that result from the use of local or state registry data. If systematically documented, a review of current programs could contribute to a comprehensive manual of best practices including focusing on other phases of emergency management outside of response. Further, such actions could promote cross-jurisdictional learning and support better services for constituents with access and functional needs.

Second, more research is needed to gauge the extent of knowledge on databases, GIS systems, and demographic data among local emergency management managers. This line of research might entail large surveys of emergency managers to inform both training protocols and emergency management education. Given both the aging population in the US and the likelihood

that residents will acquire one or more disabilities with age, the findings from this research agenda could inform education and training programs for future professionals in the field. Finally, there are open questions about the effectiveness of voluntary “special needs” registries, as currently designed, in supporting emergency planning and preparedness. This study found that jurisdictions tended to use registry data only for rough knowledge but did not use it to directly respond to their communities’ needs. We also learned that with STEAR much responsibility rests on individuals to register with no guarantees that they will receive what they need from responding agencies. Exploration of inclusive planning strategies or alternative means of estimating the extent of functional and access needs could lead to more tailored and responsive emergency services for residents with disabilities.

STEAR may be a well-intended program meant to address the needs of growing vulnerable populations, however, as currently conceived, it falls short of its goals. While the registry is evidence that the emergency management community is at least considering inclusion, one questions whether the presence of a registry merely obfuscates the critical need to actively engage with stakeholders from the disability community in planning for emergencies and disasters. Fortunately, STEAR and other state-level disability registries will continue to evolve as mandates and best practices change. This research team hopes that future disaster science research could be better integrated into this evolutionary process to inform the design of improved data repositories and preparedness programs that provide tailored services to residents with functional and access needs rather than hollow promises.

# References

- ADA National Network. (2023). *What is the definition of disability under the ADA? | ADA National Network*. Adata.org. <https://adata.org/faq/what-definition-disability-under-ada>
- Congress, U. S. (2006). The Post Katrina Emergency Management Reform Act of 2006. *Title VI, Public Law 109-295, 120 Sta. 1355 (2006)*.
- Donny, M. (2013). *Do Special Needs Registries Make a Difference to Emergency Managers in their Decision-making?* Virginia Commonwealth University Capstone Seminar for Homeland Security and Emergency Preparedness Graduate Program.
- Elisala, N., Turagabeci, A., Mohammadnezhad, M., & Mangum, T. (2020). Exploring persons with disabilities preparedness, perceptions and experiences of disasters in Tuvalu. *PLOS ONE*, 15(10), e0241180. <https://doi.org/10.1371/journal.pone.0241180>
- Enders, A., Kailes, J., Roth, M. (2022). Emergency Registries: A Misleading, Harmful & Non-inclusive Fix [Webinar]. <https://www.youtube.com/watch?v=mexNCwt1lw8>
- Federal Emergency Management Agency. (2019, January). *Building Cultures of Preparedness*. FEMA Training. [https://training.fema.gov/hiedu/docs/latest/2019\\_cultures\\_of\\_preparedness\\_report\\_10.22.18%20final.pdf](https://training.fema.gov/hiedu/docs/latest/2019_cultures_of_preparedness_report_10.22.18%20final.pdf)
- Federal Emergency Management Agency. (2021, January 11). *FEMA Reaches Out to People with Disabilities, Access and Functional Need | FEMA.gov*. [Www.fema.gov](http://www.fema.gov). <https://www.fema.gov/press-release/20210318/fema-reaches-out-people-disabilities-access-and-functional-need>
- Kailes, J. I. (2018). *Emergency Registries*. Published and distributed by June Isaacson Kailes, Disability Policy Consultant. <http://www.jik.com/pubs/EmergencyRegistries.pdf>

- Kailes, J. I., & Enders, A. (2007). Moving beyond “special needs” A function-based framework for emergency management and planning. *Journal of Disability Policy Studies, 17*(4), 230-237.
- Kruger, J., Hinton, C. F., Sinclair, L. B., & Silverman, B. (2018). Enhancing individual and community disaster preparedness: Individuals with disabilities and others with access and functional needs. *Disability and Health Journal, 11*(2), 170–173.  
<https://doi.org/10.1016/j.dhjo.2017.12.005>
- Marceron, J. E., & Rohrbeck, C. A. (2018). Disability and disasters: the role of self-efficacy in emergency preparedness. *Psychology, Health & Medicine, 24*(1), 83–93.  
<https://doi.org/10.1080/13548506.2018.1492730>
- Nick, G. A., Savoia, E., Elqura, L., Crowther, M. S., Cohen, B., Leary, M., Wright, T., Auerbach, J., & Koh, H. K. (2009). Emergency Preparedness for Vulnerable Populations: People with Special Health-care Needs. *Public Health Reports, 124*(2), 338–343.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2646456/>
- Reynolds, C. R., Vannest, K. J., & Janzen, E. F (Eds.). (2013). *Encyclopedia of Special Education*. Hoboken, NJ: John Wiley & Son Inc.
- Sheldrew, D. (2010). *Defining “At Risk” Populations*.  
<https://www.health.state.mn.us/communities/ep/afn/atriskdef.pdf>
- Stough, L. (2012). *Choosing agency in the midst of vulnerability: Using critical disability theory to examine a disaster narrative*. New York: Peter Lang.
- Stough, L., & Phillips, B. (2016). Populations with Functional or Access Needs. In K. Koenig, & C. Schultz, (Eds.), *Disaster Medicine: Comprehensive Principles and Practices* (2nd ed. pp. 137-162). Cambridge, NY: Cambridge University.



## Appendix A: Focus Group Questions

1. **How familiar** are each of you with the STEAR Dataset? How did you each **first learn about it**?
2. **Does your jurisdiction currently use the STEAR Dataset? If so, how do you use STEAR?**
  - If not, why don't you use STEAR?
  - Mandatory Probe: Think about all four phases of the emergency management cycle (mitigation, preparedness, response & recovery).
3. **Do any of your jurisdictions have current plans to use the dataset in the future? If so, how?**
4. For those who currently use STEAR, what **benefits** does this **dataset provide**?
  - Probe: Is there any information that you can only get through STEAR and nowhere else?
5. What are the **limitations** of the **STEAR dataset**?
  - Probe: Are there any barriers specific to your jurisdiction's planned uses of the dataset?
  - Probe: Do these relate to personnel, software, training, organization structure? Please explain.
6. Do your residents know about the STEAR program? And to what extent do you see residents participating?
7. **What, if anything, are you or your jurisdiction doing to promote registering with STEAR?**
8. **Thinking across all four phases of the EM cycle (mitigation, preparedness, response & recovery), what other uses for STEAR can you imagine?**
9. **If you could change anything about this dataset to make it more useful, what would it be? (e.g., types of data collected, method of aggregation, geographic specificity)**
10. Is there **anything else important to know** about STEAR usage that I have not asked about?

## Appendix B: Survey Questions

1. Research information and consent obtainment.
2. In what county are you located (for work)?

3. What is the name of your jurisdiction/organization?
4. Which best describes your jurisdiction/organization?
  - a. City government
  - b. County government
  - c. Regional body (e.g., Council of Governments, Regional Planning Authority)
  - d. Texas Department of Emergency Management
  - e. Other: Please specify
5. Where is emergency management housed within your jurisdiction/organization?
  - a. Standalone emergency management office
  - b. Not standalone: public safety/police
  - c. Not standalone: fire department
  - d. Not standalone: planning/public works
  - e. No emergency management office: county judge
  - f. No emergency management office: volunteer position
  - g. Other: Please specify
6. Which best describes the type(s) of work that you do in your position? Select all that apply:
  - a. Data Management
  - b. Public Education & Outreach
  - c. Grants Management
  - d. Response Planning
  - e. Mitigation Planning
  - f. Logistics
  - g. Other: Please specify
7. What is your level of knowledge about the STEAR program?
  - a. Far below average
  - b. Somewhat below average
  - c. Average
  - d. Somewhat above average
  - e. Far above average
8. How familiar are you with the STEAR data specific to your jurisdiction?
  - a. Far below average
  - b. Somewhat below average
  - c. Average
  - d. Somewhat above average
  - e. Far above average
9. Does your jurisdiction use STEAR data?
  - a. Yes
  - b. No
10. Did your jurisdiction previously use STEAR data?

- a. Yes
  - b. No
11. To what extent are you comfortable using your jurisdiction's STEAR data in practice?
- a. Extremely uncomfortable
  - b. Somewhat uncomfortable
  - c. Neither comfortable nor uncomfortable
  - d. Somewhat comfortable
  - e. Extremely comfortable
12. Are you the primary person in charge of using STEAR data in your jurisdiction/organization?
- a. Yes
  - b. No
13. In which phases of emergency management cycle are you currently using STEAR data?
- a. Preparedness
  - b. Mitigation
  - c. Response
  - d. Recovery
14. List your jurisdiction's current uses of STEAR data:
- a. Mapping registered individuals
  - b. Mapping registered facilities
  - c. Obtaining information about assisted living/nursing homes
  - d. Obtaining rough knowledge of vulnerable populations
  - e. Assisting with transportation access
  - f. Other
15. To what extent does your jurisdiction/organization encourage individuals to register with STEAR program?
- a. Far below average
  - b. Somewhat below average
  - c. Average
  - d. Somewhat above average
  - e. Far above average
16. Describe how you promote STEAR registration among residents in your jurisdiction:
- a. Emergency management website
  - b. Social media
  - c. Email previously registered individuals
  - d. Flyers
  - e. Other
17. Does your jurisdiction/organization plan to use STEAR in the future?
- a. Yes
  - b. No

18. Are there existing plans for using STEAR data that have not yet been implemented?
  - a. Yes
  - b. No
19. Describe your jurisdiction's/organization's existing plans to use STEAR data:
  - a. Mapping registered individuals
  - b. Mapping registered facilities
  - c. Obtaining information about assisted living/nursing homes
  - d. Obtaining rough knowledge of vulnerable populations
  - e. Assisting with transportation access
  - f. Other
20. For what future purposes or projects could you envision using STEAR data?
21. In what ways would you change the STEAR dataset to make it more user-friendly?
  - a. Built-in mapping function for data
  - b. Built-in search function for individual data categories
  - c. Pre-sorted categories for free response answers
  - d. Advanced data filtering options prior to download
  - e. Detailed information on facilities
  - f. Detailed information on primary language spoken
  - g. Detailed information on primary language spoken
  - h. Detailed information on cultural background
  - i. Other
22. Is there anything else about STEAR usage in your jurisdiction that you would like to share?