ORGANIZATIONAL NETWORKS AND

EMERGENCE DURING DISASTER PREPAREDNESS:

THE CASE OF AN EMERGENCY ASSISTANCE

REGISTRY

By

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ORGANIZATIONAL NETWORKS AND EMERGENCE

DURING DISASTER PREPAREDNESS: THE CASE OF

AN EMERGENCY ASSISTANCE REGISTRY

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Abstract: Natural, technological, and human-caused disasters affect minorities and
individuals with lower socioeconomic status more than people with non-minority, high
socioeconomic status. Age, disability, and health can compound disaster impact. These
factors could limit an individual's access to emergency services or contribute to a need
for functional assistance during disaster. Emergency planners must consider how
government and non-government organizations can provide the same disaster-related
services as those provided to the general population that meet the requirements of people
who have self-identified as having an access or functional need. Registries often are
recommended as the most useful, primary means of locating such individuals prior to,
during, or after disaster. However, scarce empirical or practice-based research supports
this recommendation as practitioners and researchers have not evaluated and assessed the
usefulness, effectiveness, or impact of emergency assistance registries. This study
considered how communities support registry operations and their effectiveness, and it
provided data to help establish a base for comparing registry operations in other
locations. Through an embedded, single-case study, this dissertation explored Calhoun
County, Alabama's experiences and perceptions with operating an emergency assistance
registry. It used qualitative methods for data collection and analysis regarding the registry
designed to support the Chemical Stockpile Emergency Preparedness Program (CSEPP).
Data from individual interviews, registry records, registry-related reports, and clarifying
conversations revealed how and why this emergency assistance registry operated in the
context of local risk. The analysis indicated that publicly presented purposes for the
registry had a more direct effect on registry design than did official purposes. Analysis
also revealed evidence of emergent phenomena as the network of organizations'
formation and interactions bridged gaps in service. Finally, the evidence suggested that
post-CSEPP registry operations were moving from a loosely coupled, emergent model
toward a command and control, dominant-theory model. Implications for future practice
include the need for (1) further research into list-of-list and service provider registration,
(2) recognizing the inherent contract caused by registry establishment, (3) emergency
managers aligning provided services with the hazards and associated risk registrants face,
and (4) tailoring providers' disaster-related service delivery to meet individual registrant
needs.

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CHAPTER I

PROBLEM DEFINITION AND RESEARCH QUESTIONS

Every community in the United States is at risk from natural (e.g., floods, tornadoes, earthquakes), technological (e.g., transportation-related hazardous materials releases, power failures), and deliberate, human-caused (e.g., acts of terrorism) hazards. National Weather Service (2012) data for 2011 indicated that weather-related disasters caused 1,096 deaths, 8,830 injuries, and nearly $24 billion in weather-related damages. Similarly, the Federal Emergency Management Agency [FEMA] (2012) reported 99 major disaster declarations, two emergency declarations, and 22 fire management assistance declarations during 2011. However, these numbers do not reflect the impact of social and demographic characteristics on the affected communities. Research reveals that disasters affect minorities and individuals with lower socioeconomic status more than people with non-minority, high socioeconomic status (Phillips, Metz, & Nieves,2006; Fothergill & Peek, 2004; Fothergill, Maestas, & Darlington, 1999). Factors

such as age, disability, and health can compound the impact of a disaster (Bethel,

Foreman, & Burke, 2011; Peek & Stough, 2010; Peek, 2008; Fernandez, Bynard, Lin,

Benson, & Barbera, 2002; Tierney, Petak, & Hahn, 1988). Any of these factors could

limit an individual's access to emergency services or contribute to a need for functional

(e.g., communication, medical, independence, supervision, or transportation) assistance

during a disaster. From the perspective of emergency planners, these individuals have

specific needs related to their functional capacities; that is, during a disaster they would

require government and non-government organizations to provide some service different

from what the general population would receive (e.g., a different style of cot at an

emergency shelter).

If, as Waugh (2000) suggested, providing disaster-related assistance and support

to individuals and families is "the quintessential governmental role," then making

emergency services accessible to people with disabilities and access or functional needs

is an essential part of that role (p. 3). In fact, the Americans with Disabilities Act of 1990

(the ADA) required state and local governments to ensure that people with disabilities[1]

have the same access to and receive the same benefits of services, programs, and

activities as people without disabilities. In its 2007 guidance to state and local

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[1] At the time of the ADA's passage, *disabled* was an accepted term for people identified as having physical or mental impairments. Similarly, *special needs population* was an acceptable characterization within the emergency management community. Neither term recognizes the diverse abilities and characteristics of people with disabilities. In the context of disaster management, these terms suggest the provision of separate or segregated services. Some people within the disability community find the terms *disabled* and *special needs* particularly abhorrent (Haller, Dorries, & Rahn, 2006; Kailes, 1985). As much as possible, this dissertation uses the people-first language found in FEMA's *Language Guidelines for Inclusive Emergency Preparedness, Response, Mitigation, and Recovery*: "people with disabilities or access or functional needs." Because this language choice may make some sentences longer or more difficult to comprehend, it will be altered, as needed, for clarity. Exceptions to this people-first language may occur when reporting the actual words used in a document or interview.

governments, the Department of Justice (DOJ) specifically noted that implementing the ADA includes making emergency services and programs accessible to the disability population. However, a nationwide review of emergency plans conducted by the Department of Homeland Security (DHS) (2006) indicated that few emergency operations plans acknowledge state or local government's legal obligations under the ADA. Recent court cases (e.g., Communities Actively Living Independent and Free, et al. vs. City of Los Angeles, et al., 2011; Shirley vs. City of Alexandria School Board, 2000;) and recently enacted state laws (e.g., Registry of Persons with Special Needs, Title XVII Florida Statutes § 252.355; Illinois Premise Alert Program (PAP) Act, 430 ILCS 132) have reinforced the need for emergency managers to take a variety of actions. First, they must include people with disabilities or access or functional needs in emergency preparedness plans. Second, they must ensure their notification and evacuation in the event of disaster. Finally, they must provide these people with transportation and shelter during a disaster.

In order to meet the ADA's requirements for same access to emergency services, governmental entities first must determine the number of people with disabilities or access or functional needs in their community. For more than 20 years, public policy and research coming from both the disaster and disability domains has recommended that governments use some form of *emergency assistance registry*[2] to pre-identify people with disabilities or access and functional needs within their communities. Shortly after

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[2] These registries have many names, with *special needs*, *special needs populations* being the most common. This dissertation uses the term *emergency assistance registry* as a way of including any registry, no matter the name, that enrolls people with disabilities or access or functional needs for providing additional support before, during, or after a disaster.

the ADA was enacted, special preparedness programs (e.g., FEMA's Radiological

Emergency Preparedness and Chemical Stockpile Emergency Preparedness programs)

and planning guidance (e.g., *Civil Preparedness Guide 1-8* and *State and Local Guide

101*) began calling for community emergency managers to identify and locate their

special needs populations and consider them when planning. Yet, it was not until after

the particularly devastating hurricane season of 2005 that the emergency management

community began paying real attention to the issue. Between 2006 and the present, the

U.S. DOJ, the U.S. Centers for Disease Control (CDC), FEMA, the AARP, the National

Council on Disability (NCD), and the National Organization on Disability (NOD)

published guidance or reports recommending the use of registries. During the same

period, Florida and Illinois passed laws requiring local jurisdictions within their states to

establish registries for "persons with special needs" (Registry of Persons with Special

Needs, Title XVII Florida Statutes § 252.355) or "persons with disabilities or special

needs or both" (Illinois Premise Alert Program (PAP) Act, 430 ILCS 132). The unstated

assumption that the recommendations and mandates make is that registries are somehow

helpful.

However, there is little empirical or practice-based research supporting that

assumption. Practitioners and researchers have yet to evaluate and assess the usefulness,

effectiveness, or impact of emergency assistance registries. In fact, throughout the same

20-year period, researchers and policy interest groups have challenged the usefulness of

registries, highlighting the limitations of self-identification, monetary and staff cost, and

responder access (NCD, 2005; Tierney et al, 1988). Some members of the disability

community do not support using registries simply because of this lack of research, as indicated by R. Devylder, Senior Advisor, Accessible Transportation, U.S. Department of Transportation (personal communication, 16 July 2012).

While using a registry may seem to be nothing more than a common sense approach to solving the identification and location problem, there is resistance to using registries among emergency managers. The most likely organizations to support registry development come from the emergency management and disability sectors. Yet, a NOD (2009) report indicated that 37% of emergency management agencies and 46% of disability organizations do not maintain emergency assistance registries. These statistics suggests that a conflict exists between intent and execution and between expectation and service delivery that can affect community preparedness.

Research Questions

Researchers know little about how particular factors influence registry design and operations, how a registry emerges and develops over time, and how organizations deliver services created in response to registry information. Unanswered questions regarding registries in the emergency management field include: Is developing and using a registry worthwhile if only a very small portion of the population will enroll? Other than registries, how else can a community achieve its goals related to providing same access to disaster services? What are the benefits and tradeoffs of the different ways to collect information? What is the inherent commitment that local governments are making with enrollees? Should assistance efforts be focused on response phase activities such as evacuation or sheltering rather than developing and using registries? Would disaster

service providers find a more valuable assistance path through preparedness and mitigation?

Answering these questions even partially requires in-depth research in a community that has a fully implemented registry and that has operated that registry for more than one or two years. Researchers can learn what worked and what did not work by analyzing that community's registry operation and exploring the intent behind their decisions and documenting their experiences. Additionally, researchers can benefit from a study to determine how registries can improve overall community preparedness. With that context in mind, three research questions for this study have emerged:

1. How and why do social and organizational factors influence community emergency management decisions regarding emergency assistance registry operations?

2. How and why do emergent networks and interorganizational interactions influence registry formation and delivery of registry-related services?

3. How do community organizations use registry information to inform their assistance efforts for enrollees? How does the community in question execute assistance efforts?

Using these research questions as a guide, this study addresses a significant research gap regarding how communities support registry operations and the effectiveness of registries. Furthermore, this study provides data that can help establish a base for comparing registry operations in other locations. Additionally, it may help practitioners identify problems and best practices when establishing such registries.

Defining Registry

One problem with developing a conceptual definition of a registry is the lack of

universal agreement on what constitutes a registry. Reporting on public health registries,

Brooke (1974) generally defined a registry as any "file of documents containing uniform

information about individual persons, collected in a systematic and comprehensive way,

in order to serve a predetermined purpose" (p. 2). In his review of medical registries,

Weddell (1973) suggested that a registry is the organization and process of supporting

and maintaining a register and that a single registry can support multiple registers.

Solomon, Henry, Hogan, van Amburg, and Taylor (1991) believed that registries differ

from other databases in that the information collected is directly associated with a

specific, identifiable person. Additionally, they indicated that registries usually collect

information on a specific topic and have limited scope. One principal objective for

registries is collecting information for the purpose of evaluating, planning, and providing

services (Weddell, 1973).

Using the registry characteristics outlined above as a guide, this research uses the

following conceptual definition for emergency assistance registries:

> An emergency assistance registry is a specified list or set of lists
>
> of identifiable individuals used by a community to plan for and
>
> provide emergency services to its enrollees. The indicators that a
>
> list functions as an emergency assistance registry exists include:
>
> (1) an organization responsible for coordinating or providing
>
> disaster services maintains the list and (2) the list's data elements

consisting of enrollee names, addresses, contact information, and

the enrollee responses to community-determined characteristics

used to define disability or access or functional need.

The registry may take the form of indexed card decks, spreadsheets, tables,

electronic databases, or complex geographic information systems.

Defining *People with Disabilities or Access or Functional Needs*

In order to establish an emergency assistance registry, a community must

conceptualize and then operationalize disability and access or functional needs. Such

definitions determine the type of information the community will collect. However,

community officials can become bewildered as they sort through the various and

seemingly conflicting definitions found in policy and guidance documents.

One potential definition for people with disabilities or access or functional needs

comes from the U.S. Census. Brault (2008) reported that the American Community

Survey defined disability as a sensory (i.e., blindness, deafness, or severe vision or

hearing impairment), physical (i.e., limits walking, climbing stairs, reaching, or carrying

objects), mental (i.e., problems learning, remembering, or concentrating), or self-care

(i.e., problems dressing, bathing, or getting around the inside of the home) limitation.

Other potential definition sources include those found in law and preparedness program

guidance. The ADA defined a disability as a physical or mental impairment that

substantially limits one or more of the major life activities of an individual. The DHS

National Incident Management System defined *special needs populations* as:

A population whose members may have additional needs before,

during, and after an incident in functional areas, including but

not limited to: maintaining independence, communication,

transportation, supervision, and medical care. Individuals in need

of additional response assistance may include those who have

disabilities; who live in institutionalized settings; who are

elderly; who are children; who are from diverse cultures, who

have limited English proficiency, or who are non-English-

speaking; or who are transportation disadvantaged. (DHS, 2008)

One problem with these definitions is that they do not reflect the language preferred by

people with disabilities to describe themselves. Van Willigen et al. (2002) summarized

how this language has evolved: handicapped → disabled → differently abled → people

with disabilities. Note that "special needs" is not included in their lexicon.

However, if two people have the same disability, their needs may be different.

Focusing on disability alone forces definitions that generalize each individual's level of

functionality and that ignore each person's unique abilities and characteristics. The

current thinking is to focus on access or functional issues that might drive need and

thereby would require one to consider individuals who need support because they have

non-disability-related limitations (Kailes & Enders, 2007). FEMA has adopted a *C-MIST*

model to define *access or functional needs* (Kailes & Enders, 2007; Parson & Fulmer,

2008). The C-MIST model—which stands for *communication, medical care,*

(maintaining) independence, supervision, and transportation—describes five areas for which individuals may require support during and following a disaster:

1. *Communication.* Individuals who have limitations that interfere with the receipt of and response to information may need to have that information provided in ways they can understand and use and from authorities they trust. They may not be able to hear verbal announcements, see directional signage, or understand how to get assistance because of hearing, vision, speech, cognitive, or intellectual limitations, and/or limited English proficiency.

2. *Medical Care.* Individuals who are not self-sufficient or who do not have adequate support from caregivers, family, or friends may need trained medical assistance with managing unstable, terminal, or contagious conditions; managing intravenous therapy, tube feeding, and vital signs; receiving dialysis, oxygen, and suction administration; managing wounds; and operating power-dependent equipment to sustain life.

3. *(Maintaining) Independence.* Individuals who rely on assistance in order to be independent in daily activities may lose this support during an emergency. This support may include supplies (e.g., diapers, catheters, ostomy materials), durable medical equipment (e.g., wheelchairs, walkers, scooters), and attendants or caregivers.

4. *Supervision.* Individuals who rely on caregivers, family, or friends in daily life may be unable to cope in a new environment, particularly if these individuals are children or have intellectual or psychiatric disabilities.

5. *Transportation.* Individuals who cannot drive or who do not have a vehicle
    may require transportation support for successful evacuation. This support
    may include accessible vehicles (e.g., vehicles equipped with lifts or
    otherwise suitable for transporting individuals who use oxygen) and mass
    transportation.

Influences of Demographics, Administration, and Purpose on
Emergency Assistance Registry Operations

Once a community commits to establishing an emergency assistance registry, it

must come to terms with what that means. The NCD (2009) suggested that geography,

demographics, perceived risks, requirements for updates and maintenance, and resource

allocation influence the form a community's registry takes. Demographics, administrative

processes, and the registry's accepted purpose seem to have the most influence on

registry operations (NOD, 2009; Delvyder, 2008).

The Influences of Demographics

National data illustrate the potential impact of demographics on a registry. The

2010 American Community Survey indicated that 11.9% (36.4 million people) of the

population had some form of sensory, physical, mental, or self-care disability (U.S.

Census, 2011). Others who might need assistance come from zero-vehicle households

(10.8 million), people who do not speak English (18% of the U.S. population), people

with special dietary needs, the homeless, and minority groups (Parsons & Fulmer, 2008;

Fox, White, Rooney, & Rowland, 2007; Kailes & Enders, 2007). Depending on the

definition of disability used, the size of the population with disabilities or access and

functional needs could be as high as 49.99% of the overall U.S. population (Kailes &

Enders, 2007). These numbers do not account for transient populations or for people with

temporary needs caused by accidents, illness, pregnancy, and the like. With such

diversity among people with disabilities or access and functional needs, it is clear that not

all require the same assistance nor do all have the same needs.

The Influences of Administrative Processes

　　Little empirical research exists that describes the mechanics of implementing an

emergency assistance registry. Only Metz, Hewett, Muzzarelli, and Tanzman (2002)

provided a detailed account of the process they used to establish an emergency assistance

registry for the Alabama Chemical Stockpile Emergency Preparedness Program (CSEPP)

community. Because participating in an emergency assistance registry must be voluntary

(DOJ, 2007), jurisdictions using such registries are faced with the challenge of how to

collect the necessary information to populate the database. The voluntary nature appears

to force them to use some form of survey, through either a return mail questionnaire or

on-line registration system (Hess & Gotham 2007; James et al. 2007; Metz et al. 2002).

However, some researchers have suggested taking a *list-of-lists* approach to registries.

Under this approach, a responsible agency maintains a list of the databases held by other

organizations that can provide needed information about a community's people with

disability or access or functional needs.

　　The National Council on Disability (2009) reported that registries vary in style

and content—ranging from paper lists consisting of names, addresses, and telephone

numbers to complex digitized databases. The type of information a community collects

influences registry style and content. Potential information covers a broad spectrum ranging from simple indications of a medical or disability condition through identifying support networks to identifying distance from nearby support facilities. Registries also require maintenance, which includes such actions as: adding newcomers; updating disability or functional need information; deleting registrants that have moved from the area, who are deceased, or who fail to reregister; and modifying data on registrants that have had a status change (e.g., new address within the jurisdiction, change in disability, change in the type of assistance needed) (NCD, 2009; Metz et al., 2002).

Running an emergency registry is an expensive proposition because of the indeterminate duration of registry operations and their community-wide focus. Communities also must manage the recurring expenses of data collection, editing, and processing as well as marketing, staffing, automation, and such.

The Influences of Purpose

The demographic and administrative influences provide communities a bureaucratic perspective of emergency assistance registries. That perspective leads communities to ask and answer questions about which guidance to follow, how to define special needs populations, and what mechanics to use to enroll individuals. However, it does not provide the perspective of how a registry affords access to disaster-related services. In other words, the bureaucratic perspective does not address questions of purpose.

One purpose for establishing an emergency assistance registry is compliance, or at least the appearance of compliance, with the mandates of law or regulation. In the mold

of what Clarke (1999) called *symbolic planning*, communities that establish registries solely for compliance may do so to indicate to their citizens that they are doing something about the special needs problem. Communities that appear to fit this category are those that place caveats in their registration marketing and registration material indicating that enrollment is not a promise of rescue or special assistance during a disaster. However, such statements do show recognition on the part of the community that some type of implied contract exists with the enrollee.

The alternative paradigm is to take a service-providing perspective to determine the registry's purpose. In his examination of medical registries, Weddell (1973) indicated that the least successful registers were those that attempted to address ill-defined needs. Solomon et al. (1991) suggested that a community could establish their registry's purpose by determining how they will use its information to make policy and administrative decisions, what action they will take based upon the information collected for the registry, and how the registry's information will facilitate the community's delivery of services.

Summary and Approach

In the wake of Hurricane Katrina in 2005, emergency management practitioners have faced renewed pressure to meet the requirements of laws or regulations that direct governments to provide people with disabilities or access or functional needs with the same access to disaster services as the rest of the population. To do so, practitioners grapple with how to identify and locate their communities' populations of people with disability or access and functional needs who may need assistance during and after a

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disaster. Research, policy guidance, and law tell them to use an emergency assistance registry to accomplish this task. However, many communities have balked at implementing these recommendations or mandates. Feedback from the disability community that questions the utility of having an emergency assistance registry just adds uncertainty to any decision about whether to use one.

This study explored how one local government used an emergency assistance registry to identify and locate people with disabilities and access or functional needs who may require assistance during and immediately after disasters or mass emergencies. More specifically, this research used an embedded, single-case study approach to examine how Calhoun County, Alabama approached operating such an emergency assistance registry in the context of community risk. To that end, the study examined the registry's influence on the county's emergency planning, training, and education processes. This study also examined the factors leading to community decisions regarding registry form, the type of data collected, and how to use the registry data to support disaster services.

This study adds to extant knowledge regarding the actual use of emergency assistance registries to identify people with disabilities and functional needs who may require additional assistance during disasters or mass emergencies. It fills identified research gaps by evaluating the process of implementing a registry during a ten-year period. The results of this study may be useful to develop process performance measures for establishing and maintaining emergency assistance registries. From a practice perspective, this research provides insights into registry development leading to identification of potential best practices for registry development. Finally, it provides

baseline information for future research into registry development and use in the emergency management field.

This dissertation takes the following approach to addressing the research questions. Chapter 2 provides a review of the literature addressing emergency assistance registries with a focus on: (1) insights from research on registries used in the medical and public heath domain, (2) the use of registries in the United States, methods of collecting information, (3) the role of geographic information systems, and (4) organizational roles and interaction in delivering services. Chapter 3 discusses the details of the methodological approach used in this study, including the case study approach, fieldwork, and qualitative analysis processes. Chapter 4 provides the study's findings and results in the context of the research questions. Finally, Chapter 5 presents conclusions and the practical and theoretical implications generated by the results. It also offers suggestions for future study.

CHAPTER II

LITERATURE REVIEW

At its core, this study is about emergency assistance registries although not the physical list or database. It attempted to answer questions pertaining to the factors that influence a community's decisions regarding registry use, how an organizational network supporting registry operations emerged, and how those organizations interacted. In order to answer those questions, one requires an in-depth understanding of the theoretical and practical contexts of registry operations. This literature review provides both. It also discusses the role of organizational interaction in service delivery. Because the use of emergency assistance registries is a relatively new and little studied phenomenon, the author identifies gaps, omissions, and issues shown in the existing research.

The Call for Emergency Assistance Registries

The disaster-related needs of people with disabilities or access or functional needs often are different from people without those characteristics (Bethel, Foreman, & Burke, 2011;

Peek & Stough, 2010; Peek, 2008; Fernandez, Bynard, Lin, Benson, & Barbera, 2002; Parr; 1987; Tierney, Petak, & Hahn, 1988). Under the ADA, government agencies are required to provide people with disabilities the same access to disasters services as the non-disabled population (U.S. Department of Justice [DOJ], 2007; Jones, 1991). In order to meet this requirement, communities must first determine the size, characteristics, and disaster-related needs of their population with disabilities or access or functional needs (National Council on Disabilities [NCD], 2009; Tierney, et al., 1988).

Following the recommendations of researchers and interest groups, many communities have established registries to identify and locate their citizens with disabilities or access or functional needs who might need assistance during a disaster. Using registries for collecting information about a specific population is not a new phenomenon. The medical and public health domains have used such registries for nearly a century. Weddell (1973) reported that Great Britain established one of the earliest medical registries—its Blind Registry—in 1917. However, the concept of using a registry to aid in disaster management is relatively new.

Disaster Research Recommendations for Registries

Parr (1987) suggested that communities pre-identify "disabled persons" so that they can receive the assistance they desire during disasters. He also emphasized that individuals "should be given a choice about whether to be included on an identification list of disabled persons" (p. 150). Similarly, Jones (1987) recommended "the establishment of a disabled persons register, kept by the fire department, to be called upon for information concerning location and particular requirements of certain

occupants in the event of fire" (p. 16). More recently, Van Willigen, Edwards, Edwards, and Hessee (2002) advocated for a "a voluntary system of registering people with 'special needs'…who might need assistance evacuating and to plan shelters to accommodate people who have needs which cannot be adequately accommodated in a regular shelter" (p. 105).

Others researchers have called for registries of the frail and elderly and their caregivers (Fernandez, Byard, Lin, Benson, & Barbera, 2002), for older adults with disabilities or medical or relocation needs (Rosenkoetter, Covan, Cobb, Bunting, & Weinrich, 2007), and of individuals needing evacuation assistance (Turner et al., 2010). Vogt Sorenson (2006) suggested that voluntary registries be used as a data source for locating disability (i.e., visual, hearing, or mobility impaired), transient, tourist, and vehicle-less populations. According to Rooney and White (2006), study respondents suggested that forming a registry with emergency responders would help persons with mobility impairments survive a disaster.

Interest Group and Government Recommendations for Using Registries

The research community is not alone in making recommendations for using emergency assistance registries to identify and locate people with disabilities and access or function needs. An AARP (2006) report cited registries as a promising tool for communities to identify people who need help. Specifically, the report recommended registries as a best practice for identifying the elderly who are "unable to function without electricity or other people for up to two weeks" (p. 47). Other organizations recommended that communities establish "contact registries" and registries that prioritize

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evacuation based on medical needs (Association of State and Territory Health Officials [ASTHO], 2007; North Carolina Disability and Elderly Emergency Management [NCDEEM], 2006). The National Organization on Disability (NOD) advised communities to consider using "special needs registries" that allow "people meeting specified criteria voluntarily [to] list themselves, making the local emergency authority aware of their presence" (Davis & Styron, 2009, p. 29).

From a government perspective, DOJ (2007) guidance regarding emergency management compliance with the ADA recommended that communities establish a "voluntary, confidential registry for persons with disabilities to request individualized notification, evacuation assistance, and transportation" (p. 9). In its guidance to state and local governments regarding identification of vulnerable older adults, the Centers for Disease Control and Prevention (CDC, 2012) suggested using registries to "identify *before an event occurs* those individuals who may need special attentions or help before, during or after an emergency" (p. 18). At least two states—Florida and Illinois—have mandated that their counties establish emergency assistance registries (Registry of Persons with Special Needs, Title XVII Florida Statutes § 252.355; Illinois Premise Alert Program (PAP) Act, 430 ILCS 132).

Concerns Expressed about Using Registries

Researchers and practitioners have expressed concerns about using emergency assistance registries. Chief among their concerns was the lack of basic research about such registries. State representatives at a U.S. Department of Health and Human Services conference on emergency management and disabilities identified the need for "research

on how well registries work, what the issues are that serve to barriers to success and what types of resources are needed to develop, implement, and sustain registries" (DHHS, 2006, p. 37). Similarly, the National Council on Disability (2009) calls for research that typologizes registries currently in use and that identifies means for developing registries. The concern seems to be that while many locations are using emergency assistance registries, little information exists on their usability and usefulness. In fact, throughout the same 20-year period, researchers and policy interest groups have challenged the usefulness of registries, highlighting the limitations of self-identification, high monetary and staff costs, and difficulties with responder access (Tierney et al, 1987; NCD, 2005).

Emergent Themes Regarding Emergency Assistance Registries

Several themes emerge from these recommendations and concerns. One theme regards the promotion of a specific process and policy intervention directed at providing disaster assistance for people with disabilities or access or functional needs. A second theme relates to setting expectations that emergency assistance registries should: (1) be a list of some type; (2) with voluntary enrollment; (3) focused on identifying the elderly and people with disabilities or medical conditions who have emergency transportation needs; (4) that official response agencies maintain and coordinate; and (5) that supports response phase activities (primarily evacuation). A third theme indicates that the medical and public health domains should provide the primary push for using emergency assistance registries (e.g., CDC, 2012; ASTHO, 2008; Rosenkoetter et al., 2007; Fernandez et al., 2002). One possible explanation for this rationale is the familiarity those domains have with registries in general. The fourth theme concerns research in that

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insufficient basic research is available into the administrative, logistical, and operational challenges practitioners face with registries.

The Medical and Public Health Perspective on Registries

As indicated earlier, medical and public health domains have used registries for at least 100 years (Solomon, Henry, Hogan, van Amburg, & Taylor, 1991; Weddell, 1973). The rapid proliferation of new disease and epidemiological registries in the 1970s and 1980s caused researchers from those domains to examine registry implementation (Solomon et al., 1991).

Weddell (1973) asserted that the most successful registries were those where "the data collected are accurate, restricted to the essentials, and meet a need that cannot be satisfied any other way" (p. 226). He recommended that registry operators collect data from as many sources as possible and that they check the data for duplication and completeness. He endorsed voluntary registry enrollment. Weddell also noted that managers should periodically evaluate whether their registry is meeting its objectives and close it when it does not.

Solomon et al. (1991) identified eight criteria for evaluating whether using a medical registry is defensible. Of those eight items, four may be applicable to assessing emergency assistance registries. First, the registry has to have a clear *purpose—* something that points to how an organization will use the collected information. To determine purpose, Solomon et al. recommended answering questions related to how the collected data might influence administration, policy, and delivery of services. Second, managers should determine whether there are other ways to achieve the same outcomes

by asking questions about the registry's *function, duration, and scope*. Third, managers should determine whether an *alternate source of information* could provide the desired information. The goal would be to avoid duplication of effort and to have data coming in from multiple sources. Finally, and probably most significant, managers must determine the *likelihood of obtaining start-up and long-term funding*. Like Weddell (1973), Solomon et al. (1991) recognized that cost is the foremost problem with establishing and maintaining a registry. They argued that registry budgets often are exhausted by data collection and processing actions.

Additionally, Solomon et al. (1991) proposed criteria for determining whether an existing registry is successful. First, a registry should have an implementation plan and a pilot phase that executes and refines the plan. Second, the registry should have document registry procedures, enrollment criteria, data collection and processing, and confidentiality processes. Third, the registry's processes must have quality control built-in to ensure data completeness and validity. Fourth, the registry's data elements should be few and well-defined.

Goldberg, Gelfand, and Levy (1980) provided some insights into typologizing registries. They reported that registries might be classified by their intended use. The first two registry types they identified concerned hospital populations. However, their third registry type, the *population-based registry,* appears to describe emergency assistance registries best. Goldberg et al. asserted that population-based registries collect detailed information about all cases in "a population of known size and composition" (p. 211). They indicated that population-based registries aid the planning for and delivery of

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services by providing data for calculating needs estimates (Goldberg et al., 1980).

These researchers all agree that the biggest issues associated with registry operations are high cost and data quality. However, Goldberg et al. (1980) identified other critical issues such as organization and staffing. They suggested that difficulties with developing cooperative agreements, problems with defining registry goals and objectives, and an inability to locate staff and funding sources are impediments to successful registry operations.

Of note are the parallels among the concerns expressed by disaster researchers and practitioners about registries and those identified by Weddell (1973), Solomon et al. (1991), and Goldberg, et al. (1980). For example, many reports (e.g., NCD, 2009; NOD, 2009; Devylder, 2008) have cited practitioner concerns about the purpose of emergency assistance registries and lack of staff and funds for conducting registry operations. Furthermore, the evaluation criteria developed by these researchers provide a framework for evaluating registry processes.

Defining the Target Population

If one agrees that emergency assistance registries fit Goldberg et al.'s (1980) concept of a population-based registry, then the starting point for building an emergency assistance registry is defining the population the registry serves. The literature offers insight into the difficulty of defining the population of people with disabilities or access or functional needs.

One definition available to communities comes from the U.S. Census. The 2000 census long-form and forms used by the American Community Survey defined disability

as having sensory, physical, mental, or self-care limitations (Brault, 2008). These categories and examples are similar to the C-MIST (i.e., communication, medical care, independence, supervision, and transportation) concept that FEMA currently supports (Parsons & Fulmer, 2008, Kailes & Enders, 2007). Metz et al. (2002) defined *special needs households* "as a residence having at least one person with physical or mental problems, transportation dependence, or a child who is home alone at times and requires…assistance to take specific protective actions" (p. 255).

Public law, policy, and preparedness program guidance are sources for other possible definitions. As indicated in Chapter 1, the ADA defined disability in terms of physical or mental impairment that substantially limited an individual's ability to accomplish major life activities. One CDC report recommended using such categories as economic disadvantage, language and literacy, medical issues and disability, isolation, and age to define the nature of people in *special, vulnerable, and at-risk* populations (CDC, 2012). The CSEP program used the term "special populations" to describe the disability and functional needs population. Using FEMA (2006) guidance, CSEPP defined that population as including:

> the sensory, mobility, or mentally-impaired; unattended children;
> children in preschool facilities; school students; hospital patients;
> nursing home residents; individuals in correctional facilities;
> individuals living at home with special equipment needs due to
> medical conditions; chronically ill persons particularly susceptible
> to agent exposure; people who do not own or have access to an

automobile; residents of private care or convalescent homes; and

people who do not speak English. (p. 39)

Post-Katrina investigative reports indicated that community response efforts had focused on two special needs groups: (1) those with medical conditions and (2) the elderly, infirm, and poor who needed evacuation assistance (U.S. House of Representatives 2006; U.S. Senate 2006). However, there appeared to be little agreement on the criteria for placing an individual in an appropriate category. The U.S. House of Representatives (2006) report stated that the State of Louisiana defined the highest category of special needs persons as "patients who are acutely ill and need to be admitted to a hospital as a patient during an emergency evacuation of the area" (p. 278). However, Jefferson Parish, LA classified the same group as "patients who do not yet need to be admitted, but whose condition will probably deteriorate during an evacuation" (U.S. House of Representatives, 2006, p. 278). The common denominator in both definitions is the view that special needs populations are *patients* who will need hospitalization at some point during or after an evacuation.

These definitions and perspectives reflect the evolution of disability as viewed within the disability policy domain and its influence on practitioners. Prior to 1970, disability policy focused on the medical and economic problems of people with disabilities (Jeon & Haider-Markel, 2001). The medical perspective of disability emphasizes a person's limitations based on physical functions. It treats disability as a diagnostic category. The policy outcomes resulting from this medical perspective foster both medical research and healthcare funding (Jeon & Haider-Markel, 2001). The

economic perspective views disability as a health-related inability to function in a work environment. Its policy initiatives tend to support overcoming barriers to work, allowing a person with disabilities to contribute to the economy. Policy solutions for the economic perspective typically focus on job training and income stabilization (Jeon & Haider-Markel, 2001).

As Jeon and Haider-Markel (2001) reported, disability policy approaches took on a more socioeconomic perspective in the 1970s. They noted that disability activists began to use the language of the civil rights and women's movements to frame disability issues. The disability groups presented two key arguments. First, they rejected the concept that people with disabilities need to adjust to the environment presented to them. Rather, they argued, society should adjust the environment to the needs of the disabled. Second, they asserted that disability is a body attribute, making it no different than gender or skin color (Jeon & Haider- Markel, 2001; Van Willigen et al., 2002).

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Use of Registries in the United States

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Use of registries as a tool for identifying U.S. special needs populations appears to be inconsistent at best. As indicated earlier, Florida law requires that all of its 43 counties have special needs registries. James, Hawkins, and Rowel (2007) reported that only five of the 23 counties and three municipalities in Maryland encourage their residents to participate in a registry through the use of emergency needs surveys. Metz et al. (2002) described the centralized special needs registry used by the six counties comprising the Alabama CSEPP community. In a study of how Regional Catastrophic Preparedness Grant Program locations integrate the disability population into their

emergency management systems, NOD (2009) reported that only 63% of emergency management maintained emergency assistance registries.

Little other empirical research exists regarding registry use; however, anecdotal evidence is plentiful. A report on special needs registries prepared by the Arizona Emergency Preparedness Oversight Committee (EPOC) Vulnerable Populations Workgroup (2008) highlighted registries used by five individual counties in Florida, New York, North Carolina, Texas, and Virginia and a statewide registry in Utah. Summaries for each location provided little information beyond the existence of a registry and data collection methods (e.g., paper form, Web-based). An internal survey conducted by the California Emergency Management Agency (Devylder, 2008) showed that of 45 responding counties, only 14 had special needs registries. FEMA's (2009) Fiscal Year 2008 Report to Congress on the CSEPP indicated that all 38 counties in nine states that participated in the program had special needs registries.

Most of the cited reports provided short summaries of emergency manager concerns about using registries. Locations that reported not using registries—especially the more populated urban areas—indicated such factors affecting their decision as cost, perceived ineffectiveness, low participation rates, lack of staff and funding, and having limited resources to support enrollees (NOD, 2009; Devylder, 2008; EPOC, 2008). Table 2.1 below summarizes other aspects of registry use as described in the research.

Registry Component	Research Findings
Target Population	• People with special needs • People needing evacuation assistance • Children home alone • People with medical needs

Registry Component	Research Findings
	• People with social (e.g., C-MIST) needs • Economic disadvantage • Language and literacy • Individuals who require access to electricity • The frail elderly
Registry Use	• Providing enrollees warning and other emergency information • Checking on enrollee status pre- and post-event • Providing evacuation or transportation assistance • Targeting preparedness efforts • Identifying enrollee locations for planning
Agency Responsible for Collecting and Maintaining the Registry	• Emergency Management Agency • Utilities (collecting information) • Fire Department • Paratransit Agency • Department of Health
Registration Methods	• Forms or cards (Return mail, email, or fax) • Online (Web-forms) • Telephone • Service provider registrations
Registry Information Storage	• Purpose designed GIS • Crisis information management systems (e.g., WebEOC) • Business software spreadsheets or databases (e.g., Microsoft Excel or Access) • Agency created databases • Card decks

Table 2.1. Registry components found in research literature

Existing research provides superficial descriptions regarding enrollment processes, how the collected information affects emergency programs, cost of program operation, and staffing needs. Only Metz et al. (2002) and Metz et al. (2005) provided any detail regarding registry implementation.

Implementing Special Needs Registries

Once a community decides to use a special needs registry, it must design and implement the processes for information collections and data maintenance. Scarce empirical research describes these processes. However, various reports and studies have attempted to classify registries by type and have made recommendations about how to collect and use registry information.

Types of Emergency Assistance Registries

The CDC (2012) report on identifying older adults for all-hazards emergencies identified three types of registries; *special needs, medical,* and *transportation*. It defined a special needs registry as a broad listing of *any* person "who might need help during an event" or a more limited listing of individuals with "specific types of physical or mental disability, impaired mobility, dependence on medicine or medical equipment, or limited cognitive function" (CDC, 2012, p.19). The CDC indicated that medical needs registries list only individuals with specific, identifiable medical needs such as oxygen support or dialysis. Finally, they defined a transportation registry as a list of individuals that "cannot evacuate a location before an event without help" (CDC, 2012, p.19). Similarly, the Transportation Research Board [TRB] (2011) identified *transportation; voluntary*, and *"exceptional circumstance" special medical needs* registries as its alternatives; the CDC calls a special needs registry "voluntary." Interestingly, in their reports on disability and emergency management, the NCD (2009) and the NOD (2009) made no such distinction when they discussed emergency assistance registries.

Other researchers have reported registry approaches that appear similar to the

function-based support paradigm suggested by Parsons and Fulmer (2008) and Kailes and

Enders (2007). For example, Metz et al. (2002) reported using an outcome-oriented

approach that focused on an individual's ability to take protective actions when

developing the Alabama CSEPP community. Fairfax County, VA (2007) took a similar

approach by establishing two registries, one for medical needs and a second for social

needs. Their medical needs registry focused on evacuation and sheltering and was

designed to identify individuals who cannot function independently in a general shelter or

evacuation center. Fairfax County's social registry was oriented toward identifying

service organizations that desire to provide emergency information to their members with

special needs.

Collecting Registry Information

Specific research regarding how registry information is collected is also scarce.

However, some common threads emerge from researchers that do make such

recommendations. The most common recommendation is that participation must be

voluntary (Parsons & Fulmer, 2008; Fox et al., 2007; Rodney & White, 2007; Van

Willigen et al., 2002). The second most prevalent recommendation is that information

collection effort should include advocacy, disability, and service organizations (Parsons

& Fulmer, 2008; Fox et al., 2007; Vogt Sorenson, 2006). Other common concerns

include the need for data confidentiality and questions about how to maintain and how

frequently to update the registry. For example, maintenance issues include adding

newcomers, deleting registrants that have moved from the area, and modifying data on

registrants who have had a status change (e.g., new address, change in disability, and change in the type of assistance needed) (NCD, 2009).

Because participating in a special needs registry must be voluntary (DOJ, 2007), jurisdictions using such registries are faced with the challenge of how to collect the necessary information to populate the database. The requirement for registries to be voluntary appears to force using a form of survey, through either a return mail questionnaire or on-line registration system (Hess &Gotham, 2007; James et al., 2007; Metz et al., 2002). A third option is the "list-of-list" approach, which involves coordinating and consolidating population information collected by various government and non-government service providers (Vogt Sorenson, 2006).

Return mail surveys. James et al. (2007) and the Arizona EPOC (2008) expressed that return mail survey is the most commonly used method to gather registry information. Metz et al. (2002) supported the findings of James et al. (2007) and the Arizona EPOC (2008), indicating that the primary means for identifying special needs populations in the Alabama CSEPP community prior to their registry efforts was a return mail post card that was included in an emergency management calendar. However, there are indications that on-line registration is becoming a more prevalent technique (NOD, 2009; Devylder, 2008; Fairfax County, 2008; James et al., 2007).

The method of presenting the registry survey to the public influences the amount of information that the registry owner can request. Metz et al. (2002) reported using both a self-registration form and longer survey questionnaire when initially enrolling individuals in the Alabama CSEPP registry. The self-registration form was a single-sided,

8½ by 11 inch document with specific fields for the respondent to provide personal (e.g., name, address, and telephone number) and family information, a checklist of possible physical and medical problems that indicated a need for assistance, and a small blank space to provide explanatory comments. The survey questionnaire was a multi-page document, consisting of four sections that took significant time to complete.

In comparison, the off-line version of the Fairfax County, VA medical needs registration form printed out to four 8½ x 11 inch pages. It asked detailed questions regarding gender, language, service animals and pets, transportation, caregivers, medical conditions, medical equipment use, and mobility and sensory impairments. It also asked respondents to identify who the county should contact to verify the survey content and who completed the form (Fairfax County, 2008).

Advantages and disadvantages of using return mail surveys. Using a return mail survey offers a number of advantages over other methods. First, return mail surveys can reach a larger and more geographically spread population simultaneously, negating the monetary and temporal costs of face-to-face or telephone interviews. Mail surveys also are very effective at reaching difficult-to-access respondents. Additionally, respondents are more willing to divulge private information because of the sense of relative anonymity provided by return mail surveys. Kanuk and Berensen (1975) reported that using mail surveys increases the validity of collected data because they remove interviewer bias and respondents have time to verify information from records or family members before returning the survey. Dillman (1991) suggested that organizations tend to use return mail surveys because of their perceived simplicity of execution.

Metz et al. (2002) found these advantages to hold true when using return mail surveys to gather initial information for the Alabama CSEPP community special needs registry. As part of their project, more than 44,000 return mail, self-registration forms were sent to households in a 250-300 square mile area covering two counties. They also reported a significantly higher rate of identifying children in self-care through the return mail survey than was obtained through interviews.

The major disadvantage to mail surveys is low return rate (Dillman, 1978; Kanuk & Berensen, 1975). Recommendations to improve response rates include: advanced notification, a cover letter, clear identification of survey sponsorship, and a stamped or franked return envelope. Clear indication of government sponsorship causes a significant increase in the rate of return. Use of a stamped return envelope increases response rates by 30%. Notifying respondents in advance about the survey increased return rates up to 20% (Dillman, 1991, Dillman, 1978; Kanuk & Berenson, 1975).
Dillman (1991) also reported that using colored stationary, graphic designs, and scheduled follow-up communications could positively influence survey rates of return.
Metz et al. (2005) reported using many of these techniques when conducting their registration project, yet they did not provide any sense of effectiveness of the measures. They did report that the number of individuals with special needs who registered by return mail survey increased almost threefold over previous attempts (i.e., 1750 versus 632).

Some researchers have expressed concern about the perishable nature of registry data. Parr (1987) suggested that such concerns are unfounded because disabled persons

do not move frequently. However, Metz et al. (2005) presented evidence to the contrary. During the period from 2001 to 2004, three registry survey mailings were conducted. While the total number of special needs registrants remained stable, the turnover rate averaged 38%, with a 51% turnover occurring between 2001 and 2002. These high turnover rates suggest that regular maintenance surveys are critical to an accurate registry. The Florida special needs registry statute offered a unique solution to the update problem by requiring electrical utilities to inform their customers upon start of service and annually thereafter that a special needs registry is available at their county emergency management agency (Registry of Persons with Special Needs, Title XVII Florida Statutes § 252.355).

On-line surveys. Cobanoglu, Warde, and Moreo (2001) compared mail, fax, and Web-based (on-line) surveys. They found that Web-based surveys offered lower costs to the respondent, a lower level of labor to execute, and a minimal cost to customize when compared with mail and fax surveys. Conversely, they found that set-up costs for on-line surveys were much higher. They also identified as an advantage an online survey's open-ended availability to respondents who had its Uniform Resource Locator (URL). However, Kwak and Radler (2002) reported that electronic (i.e., Web-based or email) surveys have an 8 to 37% lower rate of return than return-mail surveys.

One potential concern with using an on-line registry is how the major segments of the potential special needs population—the elderly and disabled—access and use the Internet. Katz, Rice, and Aspden (2001) reported that the percentage of people who are age 65 or older and who use the Internet is lower than their representation in the general

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population. Kiel (2005) asserted that while the population older than 65 is the fastest

growing segment of the U. S. population, their use of the Internet is the lowest of any age

group. Persons age 65 or older are less likely to own a computer (i.e., 25%) and are less

likely to use the Internet at any location. Only 25% of people with disabilities own

computers and only 10% use the Internet (Kaye, 2000). Kaye also contended that the

elderly are even less likely to use the Internet that the disabled. African Americans with

disabilities display even lower computer and Internet usage rates (Kaye, 2000). The

implication for communities using on-line registries is that their target audience is not

likely to access their registration form without the assistance of direct kin, fictive kin, or

other care providers.

Dillman, Tortora, and Bowker (1998) cited personal computer processing power,

monitor configurations, and Internet connection speeds as technical issues that can

influence a person's ability to respond to an on-line survey. They also indicated that how

an on-line survey's questions display on the monitor affects whether potential

respondents are able or willing to answer the questions accurately or respond to them at

all.

One distinct advantage of the on-line registry is the dynamic nature of its

supporting database. Yun and Trumbo (2000) suggested that an on-line survey can

provide statistical results and detailed responses to queries on a daily or hourly basis, and

in some instances, upon request.

Mixed-mode surveys. Dillman (1991) defined mixed-mode survey as a process

where one uses two or more survey methods to collect data for a single purpose. There is

evidence that locations maintaining special population registries are moving toward a mixed-mode approach. Data collectors typically use mixed-mode surveys to increase response rates, recognizing that respondents may be accessible by the use of one method and not another (Dillman, 1991). Cobanoglu et al. (2001) indicated that within respondent groups there are people who are reachable by one method (i.e., telephone, mail, electronic) rather than a combination of methods. However, they also indicated that employing more than one method typically yields a higher response rate.

Dillman and Christian (2005) reported on the drawbacks of mixed-mode surveys. They indicated that when respondents answer identically constructed and worded questions across survey modes, they often provide different answers. The researchers suggested that this *answer instability* is caused by the responders trying to make sense of the questions by drawing on the information the survey provides as clues and their perceived context of the survey. They surmised that any changes to a question between survey modes, no matter how small, could significantly affect how respondents answer the question. Metz et al. (2002) experienced this phenomena when collecting data for the Alabama CSEPP registry, indicating that respondents provided equivocal response (e.g., "so-so" or "maybe") on the survey form that allowed scaled answers to what were "yes" and "no" questions on the self-registration post card. Further complicating the mixed-mode concept, Dillman et al. (2009) suggested that providing respondents a choice of response modes does not improve the rate of return.

Lists from Advocacy, Disability, and Service Organizations. Registry efforts need to involve government and non-government advocacy, disability, and service

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organizations that support special needs populations (Parsons & Fulmer, 2008). The Florida special needs registry statute (2009) specifically required home health agencies, hospices, home care, and medical equipment providers to share their client lists with county emergency management agencies. The Alabama CSEPP community registry project obtained client lists from community, neighborhood, and religious organizations, schools, and medical facilities. The Alabama Department of Motor Vehicles provided lists of handicap tag users (Metz et al., 2002).

Confidentiality of Registry Data. Cho and LaRose (1999) reported that seven of ten survey respondents worry about privacy issues when completing on-line and return-mail surveys that ask for personal information. They defined information privacy as the desire to control the movement of personal information, particularly the release, use, retention, and disposal of that information.

Registry data fall into the category of personally identifiable information, or PII. The National Institute of Standards and Technology (NIST) (2009) defined PII as "information that can be used to distinguish or trace an individual's identity (ES-1). PII includes information such as name, address, telephone numbers, email addresses, personal characteristics, or other information that one can link to a specific individual. To protect PII, NIST recommended that organizations establish procedures that address security controls, individual consent, and data sharing. Sponsors of special needs registries must also be aware of state or local laws and regulations that guide the protection of PII.

Cho and LaRose (1999) suggested several solutions for maintaining information confidentiality when using on-line surveys, of which the following have the most promise for special needs registries:

1. Provide a separate consent form from one that is on the Web site, and when respondents submit a competed form, direct them to another Web site to complete the survey (p.429).

2. As part of the survey, identify the organization collecting the data, purpose of the registration, and data retention procedures (p. 429).

3. Provide contact information (an email address or telephone number) where a respondent can inquire about privacy concerns (p. 430).

4. Use credible domain names, such as ".edu" or ".gov" that clearly indicate the source of the registry effort and where the data will be sent and stored (p. 431).

5. Use encryption protocols when transmitting data (p. 431).

The Alabama CSEPP experience described earlier indicates that emergency managers can expect resistance from community organizations about sharing their client lists, many citing Health Insurance Portability and Accountability Act (HIPAA) privacy rules and other privacy acts. However, the HIPAA does allow disclosures made for national security purposes or in accordance with data use agreements (Hodge, Brown, & O'Connell, 2004). As indicated earlier, Florida law specifically requires the sharing of such information.

Geographic Information Systems (GIS) and Registries

The National Research Council (2007) indicated that demographic data such as special population information, by its nature, is spatial because individuals live within geopolitical boundaries and natural and built environments. Nash (2002) reported that geographic information systems (GIS) have the ability to integrate geographic and spatial information and non-geographic data. Morrow (1999) and Cutter, Mitchell, and Scott (2000) suggested that GIS can improve an emergency manager's understanding of the interaction of population with place and hazard. Cutter et al. (2000) suggested that special needs populations require additional consideration because of lead times required to take protective or other actions before and during emergencies. They asserted that by overlaying population clusters and hazard analysis information, emergency managers could better identify population segments at risk. Morrow (1999) and Cutter et al. (2000) agreed that involving neighborhood groups, disability organizations, and similar bodies in locating vulnerable populations is critical to determining appropriate mitigation and preparedness measures.

Once they have identified and located individuals with special needs, emergency managers need to match needs with available resources. GIS Mapping can pinpoint both where individuals and resources are located (Morrow, 1999). Similarly, GIS mapping provides the ability to integrate registry and resource databases. GIS mapping can help emergency managers understand the spatial interaction between the two. Spatial analysis using GIS may cause resources to be shifted closer to locations with higher densities of

individuals requiring assistance or assist in developing specific assistance plans (Enders & Brandt, 2007).

Tatsuki (2012) reported using GIS layering to build a *person in environment model of vulnerability* that followed the principles outlined by Cutter et al. (2000). Combining a hazard layer, a personal layer, and an environmental layer, they produced an overall vulnerability map that showed the vulnerability of *people with special needs in disaster* in relation to a tsunami hazard. The project's goal was to help service providers, community emergency response groups, and shelter operators produce better plans for supporting people with disabilities during disasters.

One example of a GIS-integrated registry is the Special Population Planner (SPP) used for the Alabama CSEPP registry project (Kuiper, Metz, & Miller, 2001). The SPP is composed of a database of special needs individuals and special facilities, a GIS map that indicates point locations for those persons and facilities, and a database integration tool. Built as an ArcView™ extension, SPP allows users to query and examine data, create and retrieve emergency plans for individual enrollees, and generate maps and reports (Kuiper et al., 2001). The map view enables event data (e.g., chemical plume isopleths, flood maps) to be overlaid on maps that indicate special population locations, evacuation routes, and other critical planning data. The current SPP architecture allows for direct interface with data received from on-line registration.

The Alabama CSEPP registry project faced one significant problem when geocoding respondent's address information into SPP. The registry team used Topographically Integrated Geographic Encoding and Referencing (TIGER) files to

locate an address within the SPP. However, Kuiper et al. (2001) reported that street

segments in the TIGER files often did not have street names or address ranges, had

incorrect street names, used inconsistent names for the same street, used alias street

names, and were spatially inaccurate. Compounding these issues, planners can only

determine accurate locations within the TIGER files through a process of interpolation

(Curry, Phillips, & Regan, 2004). Curry et al. indicated that "ground truthing" is required

to determine exactly where a specific address might actually be located on a given street.

Such errors suggest that emergency managers must use caution when using GIS as a basis

to make preparedness, response, recovery, or mitigation decisions for special needs

populations.

Organizational Networks and Registries

As reported earlier in this chapter, researchers (Parsons & Fulmer, 2008; Fox et

al., 2007; Vogt Sorenson, 2006) have recommended that communities use advocacy,

disability, and service organizations to collect registry information. These

recommendations suggest the use of an organizational network to accomplish the

registration task and, potentially, the delivery of registry-related services.

Kapucu (2006) observed that networks of "actors who necessarily rely on each

other" (p. 205) conduct emergency management operations. Provan and Milward (2001)

asserted that organizational networks are more effective at providing complex

community-based services than when individual organizations try to provide such

services on their own. Kapucu (2005) also indicated that organizational networks are

appropriate for addressing multi-faceted and complex problems—those that require

extensive collaboration among different types of organizations. He directed his comments

at the dynamic context of emergency response; however, his observations can apply to

preparedness activities such as operating an emergency assistance registry. For example,

the organization providing disaster services (i.e., evacuation support) is often different

from the organization primarily responsible for maintaining the registry (NOD, 2009).

When a community runs a registry using the list-of-lists approach, it must have a network

of private and public partners to provide the data (CDC, 2010; Vogt Sorensen, 2006).

Similarly, communities need to use a network of organization if they follow lessons

gleaned from public health registries to collect data from as many sources as possible.

Kapucu (2005) defined an organizational network as a voluntary grouping that

exchanges information or takes joint action and that organizes itself in such a way that its

members maintain their autonomy. O'Toole (1997) viewed networks as a "structure of

interdependence involving multiple organizations" (p. 45) where there is no formal

hierarchy or formal subordination. These definitions tend to focus on structure. However,

networks have a service delivery aspect to them. Thus, Provan and Milward (2001)

defined networks as "a collection of programs and services that span a broad range of

cooperating but legally autonomous organizations" (p. 417). Taken together, these

definitions provide clues for determining whether a community is using an organizational

network to operate its emergency assistance registry.

Organizational networks deliver more than problem-solving benefits to

communities where they operate. McQuaid (2010) reasoned that organizations

participating in a network benefit through sharing knowledge, expertise, and resources

that support improvement in delivering other services. Kapucu (2005) and Provan and Milward (2001) suggested that individuals and organizations form networks to undertake joint activities that meet needs of self-interest, legitimacy, and resource exchange. Young (2001) claimed that organizations often express self-interest in terms of *identity* (i.e., how members perceive, think, or feel about their organization) and *image* (i.e., how they think others view them). Identity and image help organizations determine whether there is a reason to affiliate with a network (Young, 2001) and help define the network's domain (Wiewel & Hunter, 1985). Provan & Milward (2001) suggested that organizations seek network membership to acquire legitimacy—status and acceptability that would take years for an individual organization to acquire on its own. An organizational network can also gain legitimization by effectively delivering services and invoking affiliations with its member organizations (Wiewel & Hunter, 1985). Closely related to legitimacy is the ability for network members to enhance client outcomes through resource exchange (Provan, Fish, & Sydow, 2007; Provan & Milward, 2001). Kapucu (2006) asserted that network partnerships are built around the exchange of knowledge and skills by leaders and staffs of member organization. Resource exchange also adds to the human capital and property available for an organization to carry out its role within the network (Katz & Gartner, 1988).

Network Governance

Governance is the process by which a network's member organizations maintain their relationships and how the network gains structure (Provan et al., 2007). Provan and Kenis (2007) reported that organizational networks need some form of governance to

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ensure that members engage in mutually supportive action and use resources efficiently and effectively. They identified three forms of network governance:

1. *Shared governance*, where every individual organization or a significant subset of member organizations in the network interacts with every other participating organization to manage network relationships. There is no separate governing entity.

2. *Lead organization governance*, where a single network member coordinates all network activities and decisions. An external authority may mandate what organization takes the lead role, or the lead organization may emerge from participating members due to efficiency or demonstrated effectiveness.

3. *Network administrative organization governance*, whereby outside mandate or network decision a separate administrative entity is created to govern the network's activities (Provan & Kenis, 2007).

Provan et al. (2007) asserted that the type of governance the network chooses directly influences the network's outcomes (e.g., effective service delivery or responsiveness to clients).

Emergence and Network Formation

Drabek and McEntire (2002) suggested that networks of organizations can emerge from disaster situations to resolve disaster-related demand placed on a community. Stallings and Quarantelli (1985) asserted that individual emergent groups could form during non-emergency times such as periods of disaster preparedness or mitigation. Therefore, it follows that an emergent network (a group of organizations) could form

during non-emergent times, as well. Emergent groups that form during the preparedness

phase tend to have four characteristics:

1. They focus on specific and unresolved disaster-related problems that have

   potential impact on the community,

2. Their members have an identifiable individual or personal stake in the

   problem's solution,

3. They recognize that the disaster-related problem exceeds a single

   organization's capability, and

4. The group is composed primarily of public organizations, with some private

   participation (Drabek & McEntire, 2003; Stallings & Quarantelli, 1985).

Note the similarities between network formation and group emergence. First, both focus

on solving a particular problem of common concern through shared effort and resources.

Second, both have a sense of identity or image (i.e., a personal, familial, or community

stake) that ties them to the problem the group is addressing. Finally, both groups form

because their individual members recognize an inability to accomplish their tasks or

achieve their goals on their own. Quarantelli (1984) identified other characteristics of

non-emergency phase emergent groups that are similar to characteristics of shared

governance in networks. First, such emergent groups tend to manage themselves through

informal meetings. Furthermore, Quarantelli suggested that only a core set of members

participate in regular formal meetings, similar to lead organization governance.

Dynes and Quarantelli (1968) established the basic typology for organization

emergence, often referred to as the *DRC Typology*. Keying on the relationship between

organizational role and structures during disasters, they identified four types of organized

behavior:

Type I.   *Established*, where an organization performs it regular tasks and

maintains it normal structure.

Type II.   *Expanding*, where an organization performs its regular tasks but

takes on a new structure.

Type III.   *Extending*, where an organization performs new tasks but maintains

its old structure.

Type IV.   *Emergent*, where an organization both performs new tasks and takes

on a new structure.

However, Stallings and Quarantelli (1985) noted that emergent groups that form during

non-emergency times, particularly those composed of public sector organizations, do not

go through full emergence. Drabek and McEntire (2003) identified six additional

categories of emergence outside of the DRC Typology, of which two appear to be

applicable to this study:

1. *Structural emergence*, where organizations maintain their previous functions

while developing a new structure, yet they cannot be classified as Type II due

to new network linkages.

2. *Interstitial emergence*, where a group forms between two or more other

groups to foster cooperation and manage resources.

Because organizational networks build new relationships to solve common problems

while allowing members to maintain their autonomy, they may take on characteristics of

structural emergence as they form. Similarly, use of shared governance or lead organization governance by a forming network may be an indicator of interstitial emergence.

Saunders and Kreps (1989) and Quarantelli (1984) suggested that emergent groups have a life span. Quarantelli (1984) argued that the longer non-emergency phase emergent groups exist, the more likely they are to turn toward organizing in a more formal structure, becoming *institutionalized*. Saunders and Kreps (1989) reported that emergent groups cease to exists (achieve *suspension*) when their needs are met, the lose access to key resources, or they are absorbed into other entities. They indicated that to maintain viability, emergent groups often move toward formal organization. Similarly, they suggested that an emergent network composed of existing entities was less likely to reach suspension (Saunders & Kreps, 1989).

Summary

This chapter has presented the existing literature regarding emergency assistance registries. As it demonstrates, there are few empirical studies that directly address registry use in the disaster domain and even fewer studies that consider the subject in any depth. Typically, the current research only recommends the use of registries, provides a count of who is or is not using them, and summarizes emergency managers' concerns about using registries. There is no evidence of studies that focus on how a registry operates in the context of actual community risk, the consequences of implementation decisions within that context, and registry operations during an extended period. This study is designed to develop such evidence by addressing research questions regarding community decision-

making about registries, how community organizations interact when operating a registry,

and how a community uses registry information to integrate enrollee needs into its

disaster management programs.

CHAPTER III

METHODOLOGY AND RESEARCH APPROACH

Disaster and disability policy advocates and researchers consistently recommend the use of emergency registries to identify and locate people with disabilities or access or functional needs who might need disaster assistance. Some state and local governments have even decided to make use of an emergency assistance registry mandatory. The implied outcome associated with these recommendations is that, somehow, using an emergency assistance registry works or is otherwise efficacious. One might assume—without research that supports this assumption positively or negatively—that such a registry will ensure equal access to the emergency services provided by a community.

With few exceptions, the existing research on registries comes from two types of studies. The first type regards disability-related disaster policy analyses that recommend registry use as part of their conclusions. These often focus on specific medical conditions

(e.g., mobility impairment and blindness). The second type regards larger, government-sponsored studies concerning emergency preparedness for people with disabilities that short, generalized sections on registry use. This study contributes to such studies by examining the under-researched aspect of how a registry operates in the context of actual community risk. This research explored one Alabama county's experiences and perceptions with operating an emergency assistance registry by conducting an embedded, single-case study (Yin, 2009); it used qualitative methods for data collection and analysis regarding the Calhoun County, AL emergency assistance registry. Focusing on the organizational and community aspects of registry operations, it addressed three primary research questions as provided in Chapter 1:

1. How and why do social and organizational factors influence community emergency management decisions regarding emergency assistance registry operations?

2. How and why do emergent networks and interorganizational interactions influence registry formation and delivery of registry-related services?

3. How do community organizations use registry information to inform their assistance efforts for enrollees? How does the community in question execute assistance efforts?

This chapter describes the methods used to conduct this study by discussing the following areas: (a) overview of the research design, (b) the data source, (c) types of data

and data collection methods, (d) data analysis and interpretation methods, (e) and trustworthiness and credibility issues.

<div align="center">**Research Design**</div>

Case Study Research

Yin (2009) reported that social science researchers commonly use case study as a research method. In their examination of research published in *Public Administration Review*, Perry and Kraemer (1986) stated that 37% of the journal's articles reporting on empirical research came from case studies. Platt (1992) traced the use of case studies in sociology back to the *Chicago School* in the 1930s. He also argued that case studies enable researchers to examine unexpected or unusual events like tornadoes. Because the fields of sociology and public administration are major contributors to disaster-related research, one often finds case studies used as a research strategy within their domain. Examples include Quarantelli' s (1982) examination of sheltering and housing after disaster, Birkland's (1997, 2002) studies of disaster policy formation, and Enarson's (1999) comparison of women's housing issues after Hurricane Andrew and the Red River Valley flood. Modeling behavior for future researchers, Khondker (2002) used the case study approach to describe methods for conducting disaster research in developing countries.

Researchers disagree about whether case study is a research method or a strategy. In their reviews of case study research, Gerring (2004), Platt (1992), and Perry and Kraemer (1986) regarded case study as a research method. However, Hesse-Biber and Leavy (2011) and Yin (2009) suggested that case study actually is a *research strategy*

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that can use qualitative, quantitative, or mixed methods. Most recent research and guidance about conducting research clearly have indicated that case study is a research strategy that employs primarily qualitative methods for data collection and analysis (Berg & Lune, 2012; Hesse-Biber & Leavy, 2011; Creswell, 2009). Expanding on this assertion, Hesse-Biber and Leavy (2011) noted that researchers tend to identify their case studies by the method (e.g., ethnography) used within the study. Lincoln and Guba (1985) asserted that the outcome of naturalistic inquiry is "a case report—a case study" (p. 189). Yin (2009) cited documents, archival records, interviews, direct observation, participant observation, and physical artifacts as appropriate sources of evidence when conducting case studies. These evidence sources are types of research methods recommended by Berg and Lune (2012), Corbin and Strauss (2008), and Lincoln and Guba (1985) for conducting qualitative research or naturalistic inquiry.

Defining the Case

No standard definition exists for either a case or a case study, and existing definitions overlap (Berg & Lune, 2012; Hesse-Biber & Leavy, 2011; Yin, 2009; Gerring, 2004; Platt 1992; Perry & Kraemer, 1986). For example, Johansson (2003) argued that a case should "be a complex functioning unit, be investigated in its natural context with a multitude of methods, and be contemporary" (p. 2). Yin (2009) defined a case study as "an empirical inquiry that investigates a contemporary phenomenon…within its real-life context" and that "relies on multiple sources of evidence…[that] converge in a triangulating fashion" (p.18). The common elements of these definitions (i.e., a measureable phenomenon, experienced by some unit of analysis

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in its natural context, occurring during a contemporary [not historical] period, and researchable through multiple methods) provide a case study's design factors.

Yin (2009) offered a four-fold typology to classify case study design based on the relationship between the number of units of analysis and the number of cases. His typology identified case studies using only one unit of analysis as *holistic* and studies using multiple units of analysis as *embedded*. Thus, Yin's four possible design types are: *Type 1*, or single-case, holistic; *Type 2*, or single case, embedded; *Type 3*, or multiple-case, holistic; and *Type 4*, or multiple cases, embedded (pp. 46-47).

The researcher chose a case study using a single-case, embedded design for this study. The case was the operation of an emergency assistance registry (i.e., the phenomenon) in support of Calhoun County, AL's hazard-focused disaster preparedness program (i.e., the context) between 2000 and 2011 (i.e., the contemporary period). The units of analysis were the individual organizations and the organizational network that participated in establishing and operating the registry. Information about organization and organizational network experiences and perceptions emerged from interviewing individuals within relevant groups. Information regarding outcomes of decisions, processes, and policies were gleaned from documents, archival records, and artifacts.

Data Sources

This study used existing data collected as part of another investigation that generally examined emergency assistance registries in the CSEP Program. The researcher participated as the principal investigator of that investigation, and he conducted the original investigation for a U.S. Department of Energy (DOE) national laboratory in

response to a federal interagency research request. The researcher obtained permission to incorporate design elements germane to this research in that investigation's methodology in anticipation of using its data for this study. Some program changes in the community of interest affected interviewee availability and the ability to obtain archival records. Such timing concerns therefore necessitated this study's data collection through the other investigation. To that end, the five-person research team, led by the author as primary researcher, collected this study's data between April 2011 and March 2012, coinciding with the closeout of the CSEP program in the study location.

The institutional review board (IRB) application for the original investigation included information regarding the use of its data for additional studies. Similarly, the informed consent form used for the original investigation indicated the potential use of a respondent's interview data for other academic studies. The Oklahoma State University IRB reviewed those materials and gave its approval to proceed with this study using the existing data set. Additionally, the researcher obtained permission from the DOE laboratory, the interagency sponsor, and officials in the study location to use the existing data for this study. The Oklahoma State University IRB approval is provided at Appendix A.

The data set consisted of three elements:

1. Digital recordings and transcripts of interviews conducted with representatives from community organizations that participated in the Alabama special needs population registry;

2. Episodic archival documents, electronic files, artifacts, and other items collected during the interviews and visits to the study location; and

3. Electronic copies of the Alabama Special Needs Registry enrollee and decrement databases for calendar years 2000 through 2010, with traceable personally identifiable information (PII) redacted.

Because the study has used an existing data set, this chapter's discussion of individual collection techniques reflects past decisions and methods used by the original investigation's research team. This researcher was a part of that decision-making process and subsequent investigation.

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The Study Location

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Geographic Location and Natural Hazards

The study's location was Calhoun County, AL, which is in the east central portion of the state. The City of Anniston—the county's commerce, political, and population center—is located approximately 50 miles east of Birmingham, AL and 100 miles west of Atlanta, GA. Geographically, Calhoun County lies predominately in the Ridge and Valley Province of the Appalachian Highlands. The Coosa River flows along its western boundary. The county encompasses a land area of 608 square miles and has a water area of four square miles.

The Calhoun County Hazard Mitigation Plan (2009) identified several natural hazards that county residents typically face; in order of highest to lowest frequency, they are: tornadoes, severe storms, flooding, severe winter storms, hurricanes, and drought. The mitigation plan did not address technological hazards. However, the county is at risk

for transportation-related, hazardous materials releases along the Interstate-20

transportation corridor and the rail lines that serve Anniston Army Depot and the City of

Anniston. Additionally, the H. Neely Henry Dam on the Coosa River presents a risk of

dam failure to the population living downriver.

Special Needs Surveys

This study's period of interest coincided with the conduct of two decennial

censuses (2000 and 2010), which offered insight into the disability status of Calhoun

County's population. For 2000, the U.S. Census Bureau reported Calhoun County's

disability population (i.e., age 5 years and older) at 25,861, or approximately 23% of the

non-institutional population[3] of 112,249. That census also indicated that 51% of the

county population age 65 or older reported at least one disability factor. The 2010

American Community Survey set the county's disability population at 21,295 or

approximately 18.1% of the non-institutional population of 117,641. This survey reported

that approximately 46% of the county's population age 65 or older had at least one

disability factor, such as a hearing or self-care difficulty. Both the 2000 Census and the

2010 American Community Survey indicated that slightly more women (i.e., 2000:

13,276; 2010: 10,736) than men (i.e., 2000: 12,585; 2010: 10,559) identified themselves

as having a disability factor.

When comparing these numbers, one should note that the 2000 Census included

specific questions regarding disability status. However, the 2010 Census did not include

disability questions because the data emerged from the less accurate American

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[3] Estimates of the civilian non-institutional population differ from the civilian population estimates in that they exclude persons residing in institutions. Such institutions consist primarily of nursing homes, prisons, jails, mental hospitals, and juvenile correctional facilities.

Community Survey, which used a sampling protocol rather than 100% enumeration and reported a margin of error of +/- 2.551%. The disability categories/factors used on their respective questionnaires also differed. The 2000 Census used categories of sensory, physical, mental, and self-care while the 2010 American Community Survey used hearing, vision, cognitive, ambulatory, self-care, and independent living difficulties. In both cases, the categories roughly equated to the C-MIST access and functional needs categories of communication, maintaining independence, and supervision. Table 3.1 summarizes the county's disability status as reported by the U.S. Census Bureau for 2000 and 2010.

Disability Status	2000[†]	2010
Total civilian non-institutional population	112,249	117,641
With a disability	25,861	21,295
Male	49,519	55,812
With a disability	12,585	10,559
Female	54,764	61,829
With a disability	13,276	10,736
Sensory condition	5,518	-
Physical condition	14,356	-
Mental condition	7,506	-
Self-care difficulty	4,098	-
Going outside the home (age 16 and older)	9,143	-
Hearing difficulty	-	5,901
Vision difficulty	-	5,377
Cognitive difficulty	-	9,288
Ambulatory difficulty	-	13,611
Self-care difficulty	-	6,208
Independent living difficulty (age 18 and older)	-	9,745

Table 3.1. Disability status for Calhoun County, AL. U.S. Census Bureau (2010, 2000).
[†]Data reported only for age 5 and older.

CSEPP Participation and Registry

The Department of Defense Authorization Act of 1986 (Public Law [PL] 99-145) directed the Department of the Defense (DOD) to destroy its stores of chemical warfare agents and munitions. One critical aspect of PL 99-145 was its mandate that the DOD provide maximum protection to the public in the unlikely event of an accident during storage or destruction. The DOD assigned the Department of the Army (DA) responsibility for meeting the demilitarization and maximum protection mandates because it was the owner of the chemical warfare agents. In an attempt to meet the maximum protect requirement, in partnership with FEMA, the DA established the CSEPP in 1989. This joint program focused on enhancing emergency response capabilities of communities that surrounded Army installations where chemical warfare agents were stored. From early 1989 until September 2011, Calhoun County participated in the CSEPP. During its 22-year participation in the CSEPP, Calhoun received approximately $159 million in grants to improve its level of emergency preparedness. The enhancements that Calhoun County received included a state-of-the-art emergency operations center, an interoperable communications system, a countywide outdoor warning system, and community preparedness and disaster education technical assistance.

The CSEPP used programmatic planning guidance to identify preferred preparedness and response enhancements to its participating communities. Among those recommendations was using special needs population registries to identify and locate people with disabilities. Seven of the eight CSEPP communities established such

registries, using some form of return mail, self-registration to enroll individuals. Only one

registry conducted annual updates and regularly used additional enrollment methods—the

Alabama Special Needs Population Registry. This CSEPP-supported registry operated

from April 2000 until the program ended in Alabama in September 2011. While the

registry maintained data from six counties, Calhoun County's central role in the Alabama

CSEP program made it the focus of the registry's operation. Of those counties

participating in the registry, Calhoun was the only one that is entirely within the hazard's

emergency planning zone (EPZ). An EPZ is an area defined by time/distance/risk

considerations where a community applies specific emergency response actions (FEMA,

1996).

Figure 3.1 shows that the areas identified as having the most risk (the "pink

zones") were located entirely within Calhoun County. The map in the upper left of this

figure depicts Calhoun County's location in Alabama. The main map shows enrollment

in the Alabama Special Needs Registry circa 2001. Each dot represents an individual

enrollment. The map in the lower left of Figure 3.1 depicts the county's CSEPP

emergency planning zones. The "pink zones" represent the areas most at risk; the greatest

concentration of registry enrollees is in those zones, which is of interest to the choice of

the CSEPP registry for this research.
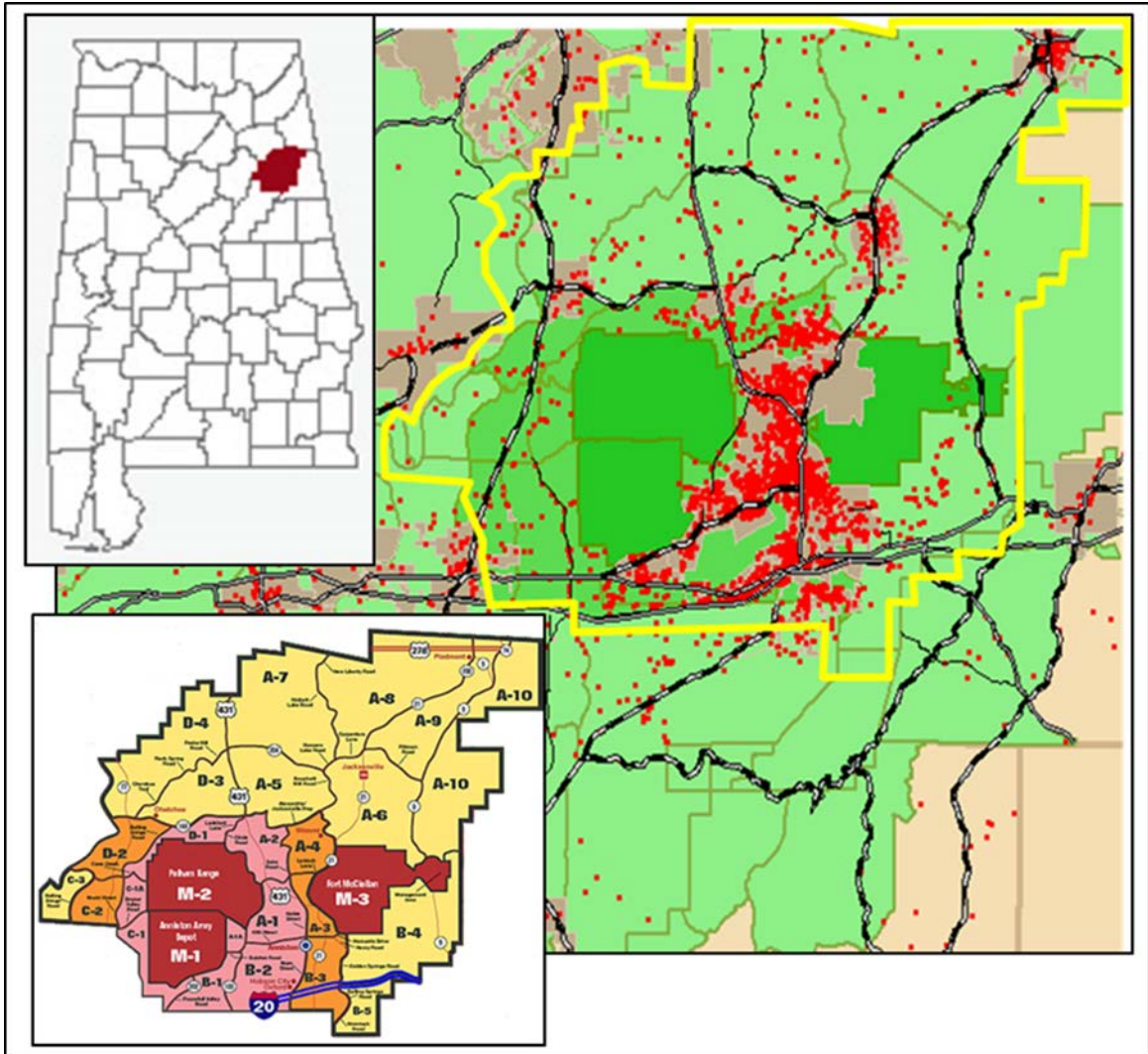
Figure 3.1. Calhoun County. (Source: Hewett, Metz, Kushma, 2002)

During the 11 years that the CSEPP registry functioned, it evolved from a single
organization operation to a contractor-managed, multi-organizational, network model.
Reinforcing its central role in the CSEPP registry, Calhoun County was the location from
which the network of government, private for-profit, and private not-for-profit
organizations operated. In early 2012, Calhoun County began the process of transferring
its registry to a 9-1-1 dispatch center-run model.

Calhoun County was an appropriate location for this study for a variety of

reasons. First, this county provided the natural setting for the operation of an emergency

assistance registry that had been in development and use since 2000. Second, this county

used both a single organization and an organizational network to run the registry, which

is of interest because it allows for comparison of two units of analysis. Additionally,

Calhoun County ran its registry for an extended period that encompassed multiple

programmatic and policy changes, leading to an ability to examine how such changes

influenced the registry's evolution. Finally, and of tremendous use to this research study,

this county documented its operations during that period through reports to stakeholders,

meeting minutes, training materials, and published procedures.

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Types of Data

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Interviews

   Interview strengths and weaknesses. Interviewing is a fundamental qualitative

research tool that explores social or political processes (Lofland, Snow, Anderson, &

Lofland, 2006; Rubin & Rubin, 2005; Gorden, 1992). It also is considered the most

critical data collection method when conducting a case study (Berg & Lune, 2012; Hesse-

Biber & Leavy, 2011; Yin, 2009). The foundation for qualitative interviewing is natural

human conversation. Gorden (1992) defined interviewing as "a conversation between two

people in which one person tries to direct the conversation to obtain information for some

specific purpose" (p. 2). Rubin and Rubin (2005) agreed and indicated that qualitative

interviews serve as extensions of normal conversations, where the research questions are

part of the give and take between the researcher and the interviewee. In qualitative

interviewing, the researcher targets specific people or groups, intentionally introduces the

topic, and coaxes details specifically related to the topic. When participating in normal conversation, one may listen intently to what the conversation partner is saying, showing interest to keep the talk flowing. During qualitative interviewing, the researcher listens both for what the interviewee says and does not say not about the topic, attempting to determine what is important about the topic from the interviewee's perspective (Rubin & Rubin, 2005; Gorden, 1992). Through the interview process, the researcher clarifies information or probes for more information, leading to a fuller understanding of the interviewee's perspective and experiences (Lofland et al., 2006; Rubin & Rubin, 2005; Gorden, 1992).

Even though researchers generally accept interviewing as a strong qualitative method, it does have limitations. First, interviewing requires skill on the part of each researcher. When conducting the interview, the researcher must be able to manage the interview, take notes, evaluate responses, and watch for non-verbal indicators while trying to listen carefully to the interviewee. Second, interviewees are not equally open, cooperative, communicative, or insightful. Finally, setting, researcher-respondent interactions, and other contextual attributes affect interview outcomes (Lofland et al., 2006; Rubin & Rubin, 2005; Gorden, 1992). Given the relative strengths and benefits as a research method for qualitative studies, the investigative team that initially collected data for a CSEPP-sponsored study of emergency assistance registries (as detailed earlier in this chapter) selected interviews as its primary tool.

For this study's data collection, the interview team modeled its interviewing after techniques described by Rubin and Rubin (2005) and Gorden (1992). The team attempted

to ameliorate setting and contextual limitations by conducting the interviews at a location

of the interviewee's choice and positioning during the interview. At any one time, only

two researchers from the five-person research team attended an interview, and only three

of the five operated as interviewers. Of these three, two were male and one was female.

Using this two-person interview-team structure allowed for one member to be the

primary interviewer and the other member to take notes and otherwise support the

interview; team members alternated roles. The primary researcher, who operated in the

dual roles of being part of the original investigation team and dissertation researcher,

participated in all interviews except one. All three interview team members were

experienced researchers, practiced in using interviewing for data collection.

      Selection process/sampling. When using quantitative methods, researchers prefer

a randomly selected (i.e., all members of the population of interest have an equal chance

of selection) sample. However, qualitative researchers typically use purposeful sampling

because they are interested in interacting with people who have firsthand experience and

knowledge of the phenomena being studied (Lofland et al., 2006; Rubin & Rubin, 2005).

Purposeful sampling allows researchers to select specifically insightful respondents that

can provide information about different parts of an event or issue with a goal of providing

a balanced and accurate picture of the entire phenomena (Rubin & Rubin, 2005; Killian,

2002; Quarantelli, 2002).

      A second method for identifying potential members for the study population is

snowball or *chain-referral* sampling. This method generates a sample population from

the field by asking interviewees whether they know of others who are familiar with the

phenomena being studied and who might agree to be interviewed (Lofland et al., 2006; Rubin & Rubin, 2005). Chain-referral sampling allows the researcher to build a complete picture of the phenomena under study by enlarging the sample and increasing the number of observation points (Lofland et al., 2006; Rubin & Rubin, 2005; Killian, 2002).

Because of its potential to ensure representation of certain types of organizations, the research team used purposeful sampling to identify initial interviewees from a pool of government and non-government individuals involved in Calhoun County, AL's registry activities regardless of their physical location. For example, the initial sample included representatives from three state government agencies without a physical presence in Calhoun County. The pool of potential initial interviewees emerged from a roster of organizations attending a registry meeting in December 2010. Purposeful sampling further allowed the research team to draw its initial interviewees from organizations that could provide different perspectives on registry operations. Thus, the initial sample list included 20 individuals drawn from the organization contracted to administer the registry, the Alabama and Calhoun county emergency management agencies, and both government and non-government service providers. However, only eight people in the sample agreed to participate. Chain-referral sampling led the research team to conduct four additional interviews, each representing a new organization. Eventually, the near universal referral to the individual primarily responsible for registry administration provided one indicator that the research team was achieving saturation, or the point where no new referrals would emerge.

The interview guide. Gorden (1992) indicated that the most critical aspect of

interviewing is planning the questions to ask interviewees. Rubin and Rubin (2005) recommended using an interview guide that outlines the main questions the researcher wants to ask and of whom to ask the questions. The interview guide also may include more focused questions, potential follow-up questions, or probes as sub-elements of the main questions. Lofland et al. (2006) recommended a process of writing down general questions about the subject; globally organizing those questions into clusters with some type of order (e.g., chronological); sorting those clusters into some logical sequence; and adding potential probing questions to specific questions. Rubin and Rubin (2005) suggested that the wordings of the main questions are not important as long as they lead to answers that shed light on the research question. A final recommended element is a fact sheet where the researcher can record information about the interview setting.

With the primary researcher, the research team used knowledge of the community, existing research, and the research questions to develop a set of open-ended questions that formed a draft interview guide. Three colleagues who understood interview methods and who had knowledge of disability preparedness research reviewed and commented on the draft. After assessing the feedback, the researcher prepared a second draft. The interview team met with a person from the study location to review question language for cultural appropriateness and comprehensibility. Subsequently, a final draft that incorporated recommendations from the local review was prepared. Finally, the primary researcher checked interview guide questions to ensure that the integrity of the research questions had been maintained during the editing process. Subsequently, the primary researcher submitted the final draft interview guide to the DOE national

laboratory's IRB for approval.

After conducting the first three interviews, the research team listened to the audio recordings to determine whether the questions were eliciting the desired types of responses and information. The research team made similar evaluations at the end of each interview phase. According to accepted practice (Lofland et al., 2006; Rubin & Rubin, 2005; Gorden, 1992), the research team modified the interview guide when needed. Similar to achieving saturation in sampling, the research team recognized saturation in response when it began receiving the same or very similar answers to questions regarding decision-making, chronology, and purpose. The final interview guide is provided in Appendix B.

Interview data collection. A team of two researchers, one of whom was this dissertation's author, conducted both telephone and face-to-face interviews in the study location between April 2011 and March 2012. The research team conducted the face-to-face interviews at the respondent's work location or other location designated by the interviewee. For example, they conducted one interview in the interviewee's home between work shifts at the individual's request. In order to eliminate potential gender bias when conducting the interview, the interview team always consisted of a male and female member. When more than one interview was conducted during any area visit, the two team members alternated roles after each interview.

The research team gained entrée through email and telephone contact, using attendee contact information found in an attendance roster from a December 2010 Calhoun County emergency assistance registry business meeting. When possible, initial

contact with a potential interviewee started with an email explaining the study and

requesting the individual's participation in the study. Again alternating responsibilities,

one member of the interview team made a follow-up telephone call within five days of

sending the email. The team member initiated contact through a cold phone call to the

potential interviewee when an email address was not available. The interview team

confirmed appointments through email or a call the day prior to a scheduled interview.

Immediately before conducting an interview, the interview team executed

informed consent protocols. The interviewer summarized the purpose of the visit and

then reviewed the informed consent form and process with the interviewee. For telephone

interviews, the interviewers faxed or emailed the informed consent form to the potential

interviewee. The interviewers provided instructions to fax or scan and email the signed

signature page when people elected to participate in the study. Each interviewee was

provided as much time as needed to read, ask questions about, and choose an option

regarding study participation. If the interviewee declined to sign the informed consent

form or elected not to participate in the study, the interviewers ended the session.

Telephone interviews did not start until the interviewers received the signed informed

consent form by fax or email.

The research team used semi-standardized qualitative interviews as its

questioning approach. A semi-standardized interview involves implementing a number of

predetermined questions and topics (Berg & Lune, 2012). When using this method,

researchers typically ask the main and follow-up questions in a systematic and consistent

order. This technique enables interviewers to digress from the guide, particularly when

using probing queries to gain additional information. Other characteristics of the semi-standardized interview include flexible wording and adjustment of language level during the interview and the addition or deletion of probes between interviews.

When conducting the interviews, the researcher designated as the lead questioner for that interview completed informed consent protocols and asked main, follow-up, and probing questions. The second interviewer took notes, tracked the interview guide, and asked follow-up and probing questions. All interviews were digital-audio recorded. At the completion of each interview, the team consolidated interview notes and conducted a post-interview review.

A professional transcriber made the initial transcription of interview digital audio files, producing verbatim transcriptions for review and correction by the interview team. The interview team compared each transcript against the associated digital audio file to ensure accuracy and veracity. Next, the interview team conducted member checks by providing interviewees a copy of their respective interview transcripts for review and correction (Lincoln & Guba, 1985). Finally, the research team collaboratively edited the transcript and saved the digital audio and text files on a computer system approved for storing personally identifiable information (PII).

Ethical issues. A researcher's first ethical concern with using qualitative interviewing is to ensure that the interviewees are not harmed (Lofland et al., 2006; Rubin & Rubin, 2005; Yow, 2005; Gorden, 1992). The primary researcher used IRB scrutiny and the informed consent process to help ameliorate this issue. However, the long period over which the interviews occurred placed an extra burden on him to

maintain confidentiality and respect throughout the entire project. The primary researcher made special efforts to avoid deceiving the interviewees, particularly about his identity, role, or deliverable benefits of the research.

A second concern centers on the practice of recording interviews. Using digital recorders is critical to accurate data collection and analysis. However, the researcher must show respondents that they own their words and thoughts and ask permission to record the interview (Lofland et al., 2006; Rubin & Rubin, 2005; Yow, 2005; Gorden, 1992). The interview team specifically requested that permission during the informed consent process. If the interviewee requested that the researcher turn the recorder off during the interview, the interviewer complied. During the interview process, only two interviewees requested a pause in recording. Interview transcripts indicate where those breaks in recording occurred.

Brace-Govan (2004) reported that unintentional coercion is possible when researchers use chain-referral to increase their sample size. She suggested that the coercion is caused by internal personal pressure not to say "no" or a perceived obligation to the person who made the referral. The primary researcher kept in mind that potential interviewees can feel undue pressure to participate in the study. Following Brace-Govan's advice, he consciously reduced follow-up contacts after interviewee-caused missed appointments or false starts.

The researcher has an ethical duty to represent correctly the interviewee's meaning through the transcripts and analysis (Yow, 2005). This study's transcription process, use of member-checking to validate transcripts and findings, and the detailed

coding process reduced the potential for misinterpretation although that potential cannot be mitigated fully.

Documents and Records

As indicated earlier in this chapter, one critical aspect of case study research is its need for multiple sources of evidence to triangulate data. Yin (2009) asserted that "documentary information is likely to be relevant to every case study topic" (p. 101). Similarly, Lincoln and Guba (1985) observed that "documents and records are singularly useful sources of information" (p. 276) when conducting naturalistic inquiry.

Lincoln and Guba (1985) argued that even though researchers use *documents* and *records* as interchangeable terms, the words describe two different concepts. They viewed a record as "any written or recorded material (movie, video tape, photograph, audio tape, etc.) prepared by an individual or organization for the purpose of *attesting to an event* or *providing an accounting*" (p. 277). It follows that their characterization of a document took an "everything else" perspective. Thus, they defined a document as "any written or recorded material *other than a record* that was not prepared specifically in response to a request from the [investigator]" (p .277). However, Yin (2009) contended that documents include administrative reports (e.g., programmatic reports, internal records), meeting minutes, and "other written reports of events" (p. 103). He categorized statistical data, numerical performance ratings, maps and charts, and survey data as *archival records*. Quarantelli (2002) noted that in its fieldwork, the Disaster Research Center (DRC) viewed documents as "anything of a physical nature that could be either

obtained or copied" (p. 116). Scanlon (2002) indicated that the use of documents (e.g.,

newspapers, archives, and official records) is accepted practice in disaster research.

Strengths and weaknesses. Lincoln and Guba (1985) claimed that the strengths

of documentary evidence include their availability, stability, unassailability, and

nonreactive nature. Yin (2009) suggested that documents are helpful in verifying details

(e.g., spelling of names and titles) from interviews, corroborating evidence from other

sources, and providing broad coverage (e.g., span of time, events, and settings). One

common complaint about documents and records involves the researcher not knowing the

individual and organizational biases that affected their choice of items to keep. A second

complaint is the potential denial of access to materials due to privacy, security, or other

concerns (Hesse-Biber & Leavy, 2011; Yin, 2009; Lincoln & Guba, 1985). However,

Berg and Lune (2012) argued that the strengths associated with using documentary

evidence outweigh its weaknesses because it provides information that other data

collection techniques cannot capture.

Documents and records collection. The research team collected documentary

evidence during each of its visits to the study area. The interview team asked each

interviewee whether they could provide any documents or records that pertained to their

organization's involvement in the registry. Most often, the local interviewees would not

provide documentary evidence, citing privacy (typically Health Insurance Portability and

Accountability Act, or HIPAA) provisions or the documents' proprietary nature.

Nonetheless, the research team collected an extensive and rich data set consisting of more

than 750 electronic files and approximately 100 hard-copy documents from the registry's

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administrative organization. The files included meeting records, managerial reports, training materials, marketing and public education materials, internal procedures, and plans. Additionally, the registry's controlling organization provided copies of actual registry data (with personally identifiable information redacted) for the period from 1999 (first collection under CSEPP, for use in 2000) through 2010 (the last collection under CSEPP).

Ethical issues. Webb et al. (1986) noted a possible ethical concern with using documentary evidence when reporting the study's results. They suggested that a reader could trace potentially embarrassing information back to an individual or organization if the researcher does not take care when reporting the study's findings. A final comprehensive member check, conducted by key individuals from the study location, can ameliorate this issue (Webb et al., 1986; Lincoln & Guba, 1985). This step will be taken upon completing this study.

Data Protection. The primary researcher has maintained all interview data and electronic documents and records on a computer approved by the U.S. Department of Energy for storing PII material (e.g., raw digital audio recordings and raw interview transcripts that include an interviewee's name, occupation, and organization). The storage system provided two levels of protection: (1) crypto key (login/password) access to the storage location and (2) crypto key access to individual digital audio recordings and transcripts. Only the primary researcher has had access to data containing PII. All hard copy items have been stored in an office setting in a locked file cabinet.

Data Analysis

Lincoln and Guba (1985) asserted that researchers should use a technique that allows for simultaneous collection and processing of observational notes, interviews, and accumulated documents and records when analyzing their data. They recommended using the *constant comparison* method associated with Glaser and Strauss's (1967) grounded theory approach to data analysis. The constant comparison technique involves three key factors. The first is to *explore* the data by reading and thinking about the collected information and preparing initial memos. The second is to *reduce* the data through coding and writing memos. The third factor is to *interpret* the outcomes of data reduction into research findings (Hesse-Biber & Leavy, 2011).

Codes and Memos

Codes. The goal of qualitative analysis is to transform interviews, field notes, and other collected data into findings that answer the central research questions. Data coding is essential to that transformative process. Data coding involves dividing information into categories by identifying themes and topics in the text (e.g., interview transcripts, documents) in which they reside. The actual codes are the tags or labels the researcher uses to identify those themes and topics (Corbin & Strauss, 2008; Lofland et al., 2006; Patton, 2002).

Coding occurs in an analysis often called the *constant comparison process*. The researcher processes data in a sorting and categorizing process consisting of *open* or *initial* coding, followed by *focused* or *axial* coding. Initial coding breaks down, condenses, and organizes the data into basic themes and categories. Focused coding elaborates, refines, and deepens initial codes by tying together data chunks and relating

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categories to each other (Lofland et al., 2006; Erlandson, Harris, Skipper, & Allen, 1993; Lincoln & Guba, 1985). Codes may be *cultural*, *connotative*, or *analytical*. Cultural (or "folk") codes are those derived by things already known and codified by the culture, usually conveyed in the language used and the behaviors reported in the data (Lofland et al., 2006; Bereska, 2003). Connotative codes are groups that the researcher sees as themes when conducting text-based (document) analyses (Bereska, 2003). Analytic codes are the theory generation-related codes that focus on concepts, process, and perspectives that come to the researcher's mind while inspecting the data (Lofland et al., 2006).

Memos. Writing memos, or *memoing*, is the process of recording of recording thoughts and ideas regarding codes, procedures, and theory. The memos become the written record of the analysis process (Corbin & Strauss, 2008; Lofland et al, 2006). Lofland et al. (2006) noted that researchers typically use three types of memos: *code, theoretical,* and *operational.* However, Corbin and Strauss (2008) offered a less structured concept. Concerned about researchers focusing more on fitting memos to the categories rather than on memo content, they suggested a descriptive paradigm and recommended that researchers use memos that describe the following process. First, researchers should use open exploration to sensitize themselves to data content. Then, they should identify and/or develop the properties and dimensions of concepts/categories. Another important step in the process involves the need to make comparisons and ask questions of the data. Corbin and Strauss also indicated that researchers should elaborate the paradigm in terms of the relationships among conditions, actions/interactions, and consequences. Finally, they recommended that researchers develop a story line (p.118).

For this study, the researcher used the memoing process recommend by Corbin and
Strauss because of its inherent flexibility.

Use of NVivo Qualitative Analysis Software

Many qualitative research methodologists (Berg & Lune, 2012; Hesse-Biber &
Leavy, 2011; Yin, 2009; Dean & Sharp, 2006) have recommended that researchers use a
computer assisted qualitative data analysis software (CAQDAS) package to facilitate
their data analysis. These methodologists suggested that CAQDAS packages help
organize and analyze literature reviews and assist with the coding, collating, analysis, and
reporting of both interview and archival records.

For this project, the primary researcher used NVivo (version 9) to assist with the
qualitative analysis process. Qualitative researchers developed this popular CAQDAS
package, and its use is well examined in the literature (Siccama & Penna, 2008; Wong,
2008; Dean & Sharp, 2006; Godau, 2004; Richards, 2004; Durian, 2002). NVivo
provides a critically useful tool that allows the researcher to interrogate a qualitative
study's validity and credibility through questioning interpretations and codes, scoping
data, and establishing saturation through modeling (Bazeley, 2008; Siccama & Penna,
2008). For this study, the researcher used NVivo primarily to store interview data,
conduct data queries, code data, and build coding hierarchies.

Analytic Procedures

For this study, the primary researcher used the following general procedure for
analyzing interview transcripts and documents. First, the researcher conducted a close
reading or review of the data in its entirety before coding. As suggested by de Wet and
Erasmus (2007), the researcher's goal was to gain an initial sense of what was in the data

and to become familiar enough with the data before coding to avoid only finding the most obvious themes and topics. Next, the researcher completed initial/open level coding by assigning unique labels to text passages and bringing together selected data and emerging themes. Then, he assigned analytical codes to link data segments to concepts and refined codes as analysis progressed. To complete the coding process, the researcher used focused/axial coding to identify emerging themes, explanations, concept clusters, and hierarchies of information that led to topic domains and taxonomies. Finally, he generated findings and drew conclusions.

The researcher coded interview transcripts in the order in which the interview team conducted them. Initial coding resulted in nearly 1000 coded references grouped into 126 themes such as *identity* and *value of registries*. The researcher used NVivo's query function to ensure code saturation. For example, a query using NVivo's broadest range of *similar* to explore the concept of *value* yielded nearly 700 potential references. After completing coding, the researcher identified theme clusters that led to developing taxonomies related to the research questions. Figure 3.2 provides a line and node diagram depicting one such taxonomy that resulted from this process and responded particularly to Research Question 2.
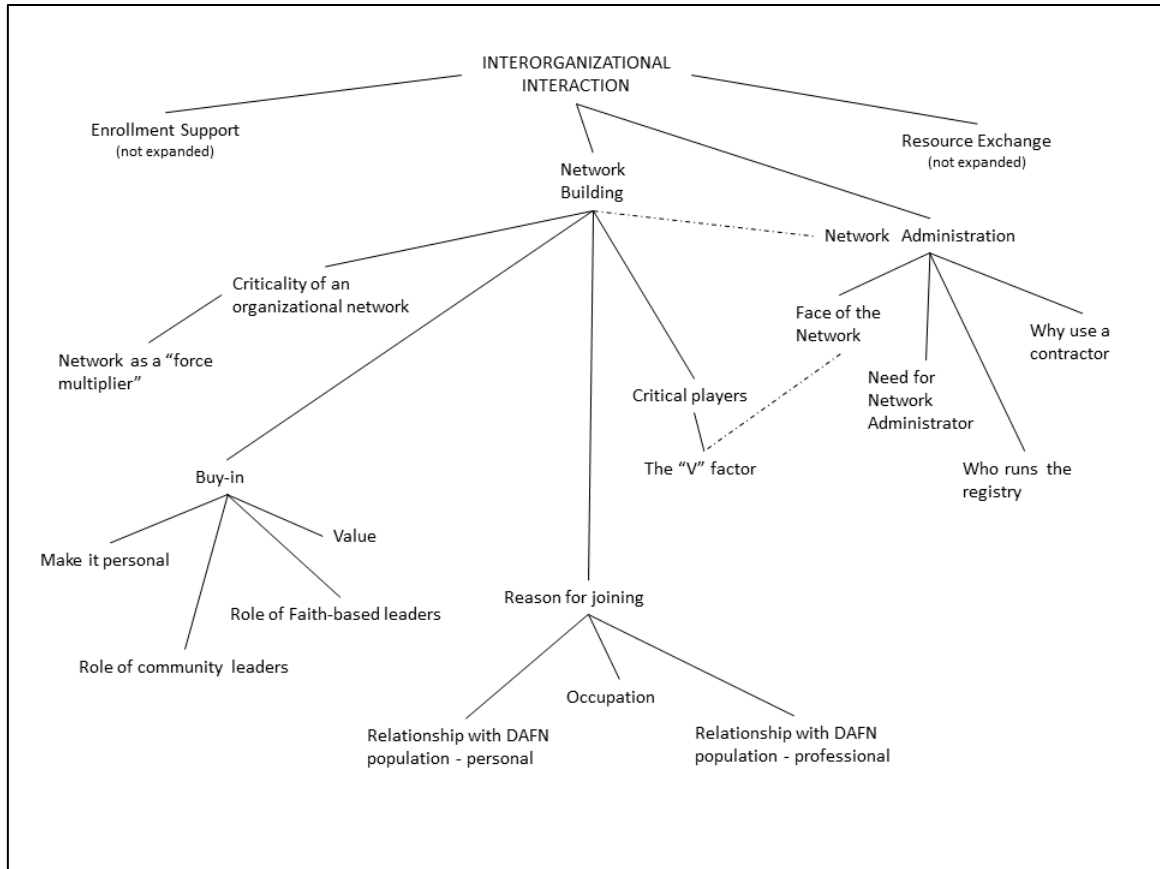
Figure 3.2. Line and node taxonomic diagram constructed for the network building relationship in the interorganizational interaction domain.

Trustworthiness of the Data

Lincoln and Guba (1985) argued that qualitative research must meet four criteria to achieve the same trustworthiness as quantitative research. First, researchers must show the *truth value* or *credibility* of their findings and interpretations. Second, researchers must provide sufficient descriptive detail that allows others to make judgments about the *transferability* of findings and interpretations to a new situation. Third, researchers need to show *dependability* by demonstrating that they have used consistent, stable, and predictable procedures to account for data instability and design induced change. Finally,

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researchers must be able to trace their findings and interpretations back through the data, providing *confirmability* of their conclusions.

Qualitative researchers generally accept nine strategies for establishing data trustworthiness (Erlandson et al., 1993; Lincoln & Guba, 1985). Not surprisingly, the majority of strategies focus on establishing data credibility, and they include:

- *Prolonged engagement*, whereby the researcher spends sufficient time in the study's contextual setting to be able to interpret in the same way as person who is part of the setting.

- *Persistent observation*, whereby the researcher obtains depth by consistently interpreting data in different ways, using a process of constant and tentative analysis.

- *Triangulation*, whereby the researcher collects information about events and relationships form different points of view and different sources. This process includes checking an individual's statements against documents and records associated with the event under study.

- *Referential adequacy materials*, whereby the researcher uses documents, photographs, and other materials to provide evidentiary support for and rich contextualization of analyses and interpretations.

- *Peer debriefing*, whereby the researcher uses professional colleagues to provide feedback and help refine analyses.

- *Member checks*, whereby the researcher is associated with individuals who participated in the study review data and study interpretations.

Strategies for achieving transferability include *thick description* and *purposive sampling* (Erlandson, 1993; Lincoln & Guba, 1985). The researcher's goal in using thick description is to provide a sufficiently detailed and precise representation of the context to allow others to judge whether it applies to their situation. Purposive sampling allows the researcher to select participants based on the insights relevant to the study that they might supply rather than trying to obtain a random sample that provides only aggregate qualities. Researchers obtain the qualities of dependability and confirmability for their studies through external reviews of their audit trail of memos, notes, and other documentation of the research process (Erlandson, 1993; Lincoln & Guba, 1985). Table 3.2 presents the approach the researcher used in this study to meet trustworthiness criteria.

Trustworthiness Criterion	Strategy	Approach Used in the Study
Credibility	Prolonged engagement	Multiple multi-day visits to the study location to collect data. More than 10 years of periodic contact with the community of interest.
	Persistent observation	Use of the constant comparative method for coding; use of NVivo software to allow for data querying.
	Triangulation	Use of interview data from multiple organizations located at different levels of government. Use of organizational records and other documents to verify interview data.
	Referential adequacy materials	Use of documentary and other evidence to build a complete and precise description of the context of registry operations in the study location.
	Peer debriefing	Conducted discussions with Dr. William Metz (Argonne National Laboratory), who was not associated with the study and who had knowledge regarding emergency assistance registries, disability policy, or organizational networks.

Trustworthiness Criterion	Strategy	Approach Used in the Study
	Member checks.	Member checks of the interview data were completed as part of the original CSEPP-related investigation. For this study, the researcher used key member checks of interpretations and findings and of the final report.
Transferability	Thick description	Through this study's findings (Chapter 4), the researcher provided a detailed description of the registry's operation in the context of community risk.
	Purposive sampling	The researcher selected study participants from multiple levels of government, multiple government and non- government agencies, and with different organizational perspectives who were involved in operating an emergency assistance registry is the study location.
Dependability	Audit trail	Dr. Brenda Phillips of the Department of Political Science at Oklahoma State University conducted the dependability and confirmability audit. Dr. Phillips has experience with naturalistic inquiry and familiarity with the study location and disability policy.
Confirmability		

Table 3.2. Trustworthiness strategies.

This study's trustworthiness was enhanced primarily through extensive use of credibility processes. First, the researcher had periodic interaction with Calhoun County's emergency management structure while conducting technical assistance visits for the CSEP program between 1996 and 2010. Additionally, the researcher made six multi-day visits to the study location while conducting interviews and collecting document data. The more than 750 electronic files and 100 hard-copy documents made it possible for the researcher to confirm respondents' recollections, verify chronology, and discern operational evolution. Peer debriefings with Dr. Metz, whose previously published

research regarding the Alabama CSEPP Special Needs Registry sparked this study, added to the credibility of findings related to Calhoun County's early registry activities.

Summary

This chapter described the methods used to conduct this study. It provided an overview of its case study approach. Additionally, it provided a detailed description of the study location, supplying context for the findings discussed in the next chapter. It also reviewed the types of data used in this study and their collection methods. This chapter discussed the qualitative data analysis and interpretation methods used to produce this study's findings. Finally, it summarized the steps taken to ensure the study's trustworthiness and credibility.

CHAPTER IV

RESULTS

This chapter reports on findings that emerged from analyzing the accounts of people who participated in operating the Alabama CSEPP Special Population Registry, agency documents, local reports, and informal conversations. Specifically, it addresses factors that influenced registry design and operations, interactions of the registry's organizational network, and delivery of services resulting from registry information. It presents and discusses the following six findings from the data analysis:

1. Multiple, overlapping purposes influenced registry design and implementation.

2. Improved awareness of enrollee locations in relation to hazard risk led to the emergence of a network of organizations that supported the registry and a change to preparedness-focused outcomes.

3. Using return mail self-registration was more effective than using a network of organizations to enroll individuals in the registry.

4. Identity, resource exchange, and legitimization defined the organizational network's interorganizational interaction.

5. Absent a formal governance mechanism, the network used a hybrid of lead organization, shared-governance to guide registry operations.

6. CSEPP closeout caused changes in registry purpose, administration, governance, and organizational interaction.

The Alabama CSEPP Special Needs Registry Operational Setting

While this study's focus was not on the physical registry that the Alabama CSEPP developed, understanding its operational environment helps to contextualize the qualitative findings. As indicated in Chapter 3, the Alabama CSEPP special needs registry operated from 2000 to 2010. Although the registry maintained data from six counties, Calhoun County's central role in the Alabama CSEP program made it the focus of the registry's operation and of this study. Figure 4.1 depicts the registry's enrollment data for the ten years of interest for this study. Data for years 2000 and 2001 came from the 24-month process of collecting and verifying the registry's initial data. The enrollment method changed in 2001 to return-mail self-registration and referral by a service-providing organization. Data from the 2010 database update was not available for this study. The remaining years (2002-2009) reflect data collected from an annual process of saturation mailing (i.e., mass mail to all residences and businesses) of return mail self-registration forms and subsequent verification (i.e., by mail and telephone

follow-up).
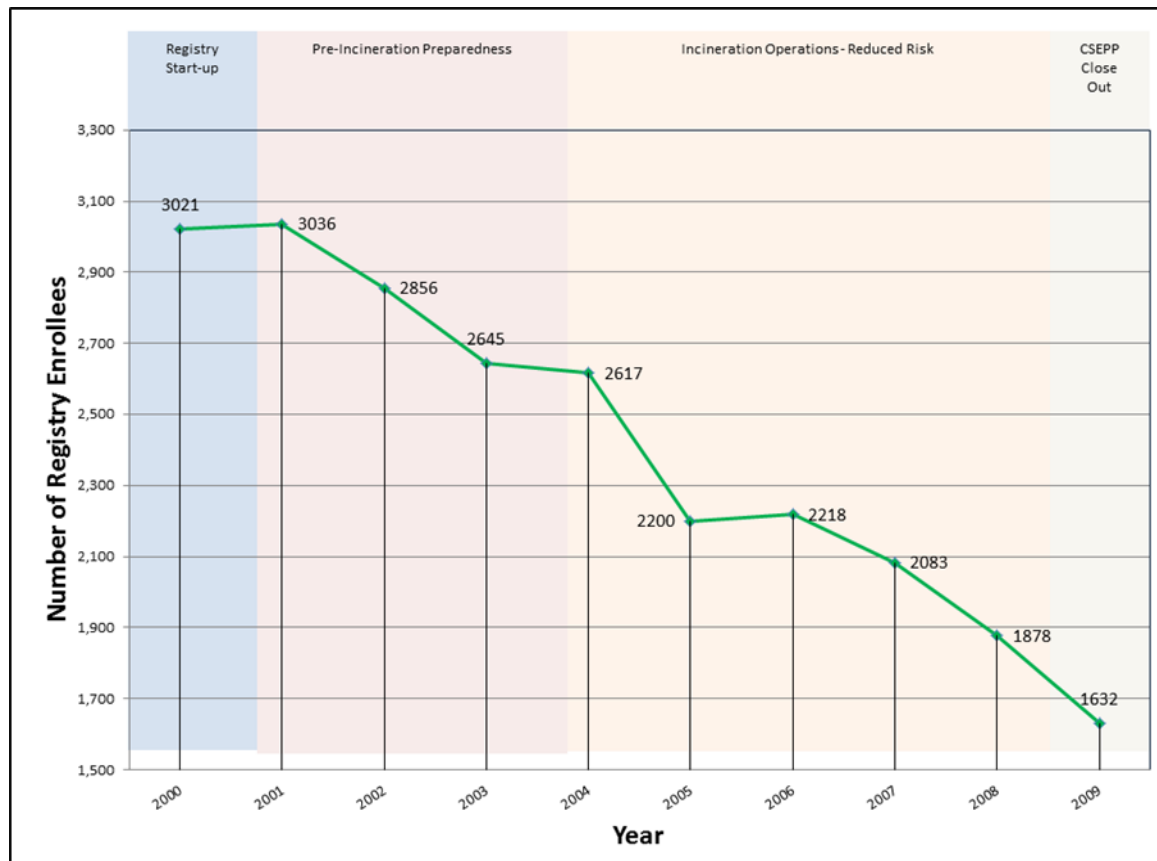
Figure 4.1. Calhoun County enrollees in the Alabama CSEPP Special Population Registry, 2000-2009, associated with registration phase. . Sources: Alabama CSEPP Special Population Registry Database (2000-2004) and end-of-year reports to the Alabama CSEPP Integrated Process Team (IPT) (2005-2009).

In addition to enrollment numbers, Figure 4.1 identifies four phases of registry operations: (1) registry start-up, (2) pre-incineration[4] preparedness, (3) incineration operations, and (4) CSEPP closeout. The registry phases are similar to phases associated with incineration operations. For example, the registry's pre-incineration preparedness phase ended when incineration operations started at the Anniston Chemical

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[4] Incineration was the method chosen by the U.S. Army and accepted by the State of Alabama to demilitarize, or destroy, the chemical weapons stored at Anniston Army Depot (AAD), which is located in Calhoun County, AL. The U.S. Army started incineration operations in August 2003 and completed them in September 2011.

Demilitarization Facility (ANCDF).

The registry's startup phase began in mid-1999 and ended in late 2000. Initial data collection and database creation occurred during this phase. A report to the Alabama Emergency Management Agency (AEMA) indicated that a team drawn from a nearby university, a U.S. Department of Energy national laboratory, the regional planning commission, and a mass mailing company collected the initial data. Their collection methods included household public safety surveys, surveys of formal community and informal neighborhood leaders, return-mail self-registration forms, and existing databases. A purpose-developed ArcGIS extension (Special Population Planner) stored registrants' demographic, problem indicator (e.g., can't walk), and location information (Lueschen & Wernette, 2001).

The registry's pre-incineration phase began with the 2001 registry update and ended with the beginning of demilitarization operations in August 2003. During this period, registry operations focused on updating and validating registry data, building an organizational network to support registration and provide services, and determining individual enrollees' specific needs. The incineration operations phase ran from August 2003 until mid-2008. From a hazard perspective, this period's main characteristic was the consistent reduction of overall community risk as the chemical weapons stockpile's destruction progressed although the admitted risk of an accident or other event remained until the stockpile was destroyed completely. Registry operations remained focused on updating and validating registry data and maintaining the organizational network that supported enrollment and provided services. The beginning of the final chemical

weapons incineration campaign[5] marked the start of the registry's final phase, CSEPP closeout. During this phase, registry strategies consisted of activities designed to transition registry activities to a more general risk/all hazards approach. The CSEPP closeout phase ended in 2011, with the end of incineration activities and the registry's transfer to Calhoun County's 9-1-1 Center from a private company that was under contract to AEMA to maintain the registry.

Of interest to this study's context is the almost linear decline (as shown in Figure 4.1) in enrollment throughout the registry's operation. Metz et al. (2002) reported that the decline in enrollment for 2000 and 2001 came from the validation and verification process used when establishing the registry. Because confidentiality agreements and regulations caused an inability to survey enrollees, one can only speculate about the causes of enrollment decline in the remaining years. Clarifying conversations with registry operators and county emergency managers indicated their belief that registrations declined because enrollees thought the county had met their needs or they felt less at risk as incineration operations progressed. Registry data seems to support this belief. Between 2004 and 2007, the peak years of incineration operations, 39.5% of individuals removed from the registry's database indicated that they no longer needed assistance. In comparison, the next closest category consisted of individuals identified as having died during the previous year, at 29.4 %. By 2008 and 2009, apparently only individuals who believed they still needed some type of assistance remained enrolled. Individuals who indicated that they no longer needed assistance comprised only 4.7% of registrants

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[5] ANCDF conducted incineration operations in phases called campaigns. Each campaign destroyed a specific chemical weapons configuration (e.g., rockets filled with non-persistent nerve agents). ANCDF's first campaigns destroyed weapons configurations causing the most risk to communities surrounding AAD.

removed from the registry. Registrants who had died during the previous year accounted for 68.0% of people who were disenrolled.[6]

The final piece to the operational context is how the number of enrollees fit into the county's general population and disability census. Using 2000 and end-of-year 2009 registry data, Table 4.1 compares the number of enrollees with general and disability population from the 2000 and 2010 censuses. The table uses end-of-year 2009 data for the enrolled population because the county did not make 2010 end-of-year data available for this study.

Census Year	General Population	Disability Population	Enrolled Population	Enrolled Population as a Percentage of General Population	Enrolled Population as a Percentage of Disability Population
2000[†]	112,249	25,861	3021	2.69	11.68
2010	117,641	21,295	1632	1.39	7.66

Table 4.1. The number of individuals enrolled in the Calhoun County emergency assistance registry as a subset of the general and disability populations in 2000 and 2010. (U.S. Census Bureau, 2010, 2000). [†]Data reported only for age 5 and older.

Findings

Finding 1: Multiple, overlapping purposes influenced registry design and implementation.

Finding 1 corresponds to Research Questions 1 because it addresses the influence of *purpose* on design and administration, which are organizational functions. Solomon et al. (1991) indicated that a clear statement of purpose—something that points to how a registry's owner will use its information—is essential to a registry's success. Their use of

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[6] The registry operator determined whether to remove an individual because of death by daily checking local newspaper obituaries and through follow-up telephone calls when a registrant did not return a registration form during annual updates.

clear purpose suggests the existence of some single objective for a registry. This study found evidence of multiple purposes associated with the Alabama Special Needs Registry: (1) the official programmatic purpose, (2) the publicly presented purpose, and (3) the purpose perceived by participating organizations. Additionally, there is evidence that policy decisions made by local officials had a greater impact on registry design than any specified or implied purpose.

The CSEPP is a national preparedness program that provides funds and technical support to communities surrounding chemical weapons storage locations. In order to receive the program's support, communities must follow the CSEPP's programmatic guidance. That programmatic guidance provided the official purpose for the Alabama CSEPP special needs registry. Rather than presenting a single, clear purpose statement, different guidance sections recommended the following:

A data storage method:

An automated database and register system must be developed to

(a) record…special needs individuals.

Inclusion criteria:

All special-needs individuals…in the IRZ will be identified….

These special populations include, but are not limited to, the

sensory, mobility or mentally impaired; unattended

children…individuals living at home with special equipment needs

due to medical conditions; chronically ill persons;…

An expected use for the registry information:

Each plan shall… Specify protective, transportation and care options for

the noninstitutionalized handicapped. This includes designating a relative,

friend, or neighbor responsible to contact and help the impaired at the time

of an emergency (FEMA, 1996).

Although stated in a fragmented way, all elements of Solomon et al.'s (1991) definition

of registry purpose are present in the data. The CSEPP guidance's official statements of

purpose also reflect the internal, administrative focus implied by Solomon et al.'s

definition of a registry's purpose.

Individuals involved in operating the Alabama CSEPP Special Needs Registry

alluded to the existence of another purpose—a publicly presented purpose that tells

potential enrollees what the registry does for them. When asked what they would tell

other communities is most important when starting a registry, this study's participants

provided answers that suggested that the publicly presented purpose is more important

than the official purpose statement:

My first question is what's the purpose [for the registry]? What's

the purpose? What are you telling these folks when you register

them?

If you are going to establish a registry and have not thought out

how you are going to use it, how you are going to maintain it, and

how you brought value back to the person who gave you the

information it is going to die on the vine…. It's like a person trying

to sell you a car. I have to give you value on this car. If I can't

establish a value here you are not going to give me the

information.

The official and publicly presented purposes overlapped in the cover letters and

forms use in the enrollment process. The first overlap occurred in the actual registration

form (see Appendix C for a copy of all registration forms). The initial self-registration

form used in 1999 did not include a purpose statement; however, every registration form

thereafter did include some indication of purpose. For example, the 2000-2001

registration form provided the following statement suggesting a planning-related purpose:

County emergency management agencies need to identify those

with special needs for planning purposes in case an accident occurs

at the Anniston Army Depot.

The registration form used from 2002 to 2004 followed the language found in the CSEPP

planning guidance more closely and continued to communicate a general planning-related

outcome.

County Emergency Management Agencies seek to identify those

needing help from outside their circle of family, neighbors,

relatives, and friends for planning purposes in case an accident

occurs at the Anniston Army Depot.

Eventually, the self-registration form used between 2005 and 2007 indicated the specific

assistance a registrant could expect:

Your county EMA, as part of its public protection strategy, would

like to identify persons who cannot prepare for or carry out

protective actions either on their own or with assistance from

nearby family, neighbors, or friends. If you qualify as a person

with special needs, your county EMA can provide you with special

emergency planning information, a tone alert radio, and protective

equipment.

Return mail self-registration packet cover letters also contained these themes. The

cover letter used during registry start-up indicated a general use for registry information,

suggested who should register, and alluded to providing some form of assistance:

Please look at the enclosed form. It gives you the chance to register

yourself or anyone in your family who might have a special need

for help if an accident or emergency would occur at the depot….

They [plans] are especially important for: people with handicaps or

health problems, people who do not have cars or other means of

transportation available to them, and children who are not being

supervised by an adult and who would need help in case of an

emergency…. We need to identify these people for planning

purposes…. The information you provide will be available for your

county's EMA to help make emergency plans. It will be used to

make you and your family members safer in case of an emergency.

Cover letters for 2002-2004 reflected changes in protection strategies[7] and offered more

information about the services that individuals might receive because of registering:

For planning purposes, your county's Emergency Management Agency

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[7] The original cover letter did not indicate a protection strategy.

(EMA) needs to learn which persons with special needs do not have

someone…who can be counted on *to help them leave the area*

(evacuate)…or *to create a shelter environment at home if advised to do so*

by their county EMA during an emergency…. Emergency preparedness

information is being provided to those who are registered to assist each

person and household to become more self-sufficient in the event of a

disaster.

Finally, the cover letters used for the 2005 through 2007 registrations used the

same purpose language as the registration forms:

If you or someone in your family qualifies as a person with special

needs, your county EMA can provide you with special emergency

planning information, a tone alert radio, and protective equipment.

The purposes described above specify officially expected actions (i.e., identify

special needs individuals) and set expectations (i.e., help in emergency planning).

However, perceived purposes also exist. Perceived purposes are interpretations made by

individuals participating in registry operations about how the community will use the

registry's information. For example, interviewees from service providing organizations

indicated objectives that differed from official and publicly presented purposes.

Well, I thought that what it would do, like, if there was a chemical

emergency, they would know the locations of people who would

not get out of their homes and someone would come assist those

people.

Well, of course the main thing we wanted it to accomplish was [to]

give us an opportunity to be able to help these people in case there

was an incident and make sure it was accurate and it would be the

best way possible to coordinate any rescue or recovery or just

response effort if anything happened in the process.

If we know these people are in the affected zone, then we can get

to them and take care of what's got to be taken care of or at least

get them the education if something happens when their health care

providers are not around, something they can do or their family can

do to help protect them for an extended length of time.

One factor that appears to influence these respondents' sense of the registry's

purpose is their identity (i.e., how they perceive, think, or feel about themselves) in

relation to response phase activities. The last two respondents indicated identities that

included altruistic behavior and bridging perceived gaps in service. Thus, a combination

of the respondents' identity, their belief about official policy, and their understanding of

how the registry functioned appeared to have influenced their perceptions of purpose.

They also seemed to tie elements of location, need (i.e., cannot get out of their homes),

and an expected response activity (i.e., rescue) together. Such interpretations may be in

conflict with official policy or with official information provided to potential registrants.

For example, every registration packet cover letter indicated in some fashion that the

county EMA "may not be able to respond to each request for assistance." However, some

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respondents' perceived purposes indicated a firm commitment to government-provided rescue.

Document examination revealed another influence on registry design not related to purpose—political positions taken by elected officials. During the registry start-up phase, elected officials made a policy decision that Calhoun County would use evacuation as its only protective action strategy. Thus, the self-registration form used in 1999 and 2000 did not ask questions about a registrant's ability to shelter in place. Similarly, the registry database included an element that indicated an inability to evacuate but did not have an element that indicated an inability to shelter in place.

Correspondence regarding self-registration form content shows tension between the registry's managers trying to meet requirements from official guidance by collecting sheltering information and the political position taken by elected officials:

> I am concerned about [a county commissioner's] directive to
> [name removed] to delete parts of two questions on the self-
> registration form and on the data verification forms planned for use
> in Calhoun County. The questions deal with the respondents'
> perceived ability to create a shelter without outside assistance….
> The rationale for this position that I can recall is the questions
> might mislead residents into believing that sheltering is an
> available home protective action when in fact it is not realistic in

Calhoun County at this time. Consequently, the self-registration

form distributed last year did not include such questions….

The official and publicly presented purposes remained virtually unchanged during

the registry's entire operational period. Thus, there were few changes to information

sought by the registration forms and to the registry's database elements. The first change

to the CSEPP-related registration form occurred in 2002, when officials added a question

regarding an enrollee's ability to shelter in place. The second major change to the

CSEPP-related form occurred in 2008, when the county sought more information about

what limited a registrant's ability to take protective actions. The registry operator made

two sets of changes to the database. The first occurred in 2002, when the registry operator

added a data element to indicate a registrant's ability to shelter in place (coinciding with

the change to the registration form). A change in the level of assistance the county

provided to enrollees because of a new hazard analysis caused the second database

revision. The database added new functional need elements to track whether enrollees

received protective equipment and whether an enrollee's caregiver had received training.

Finding 2: Improved awareness of enrollee locations in relation to hazard risk led to

the emergence of a network of organizations that supported the registry and a

change to preparedness-focused outcomes.

Finding 2 responds to Research Questions 1 and 2. However, it provides the most

information regarding Research Question 1 in that it provides evidence of the influences

of hazard and demographic information on registry operations.

During the registry's start-up phase, Calhoun County was just starting to gather

information about its disability and access or functional needs population while this evacuation-only policy was in effect. Therefore, its emergency managers were not aware of the number and location of people with disabilities or access or functional needs who might need assistance with evacuation. The evacuation-only policy and incomplete information appear to have led county emergency managers to a response-focused assistance strategy. As one emergency manager reported:

…honestly, early on, we were kind of thinking we could suit-up

first responders and get [the special needs population] out.

Another individual involved in day-to-day registry operations indicated that registrants reported a similar expectation:

[They thought] [t]hat someone is going to rescue them. You know

they feel like that, you know.

A registry operator reflected on the conundrum the evacuation policy caused:

The question is "can you shelter in place or can you evacuate?" If

they were on our registry from the beginning, they thought they

had a choice [between evacuation and sheltering in place]. But

after a while we realized that there wasn't a choice, that they

would have to shelter in place…. Of course, it wasn't our call. We

couldn't voice our opinion there, but personally, I always thought

why are we asking them [about evacuation] if they are going to

shelter in place anyway?

Thus, the county's apparent expectation for individuals with disabilities or access or

functional needs, whether they had registered or not, was to evacuate on their own; get

help from family, neighbors, or friends to evacuate; or wait on rescue.

That expectation was contradictory to an inherent assistance contract suggested by

the language used in registration materials. From Finding 1, it is apparent that registration

packet covers letters were informing potential enrollees that the county could not respond

to all assistance requests. The letters also indicated that the emergency management

agency would use registration information "to make emergency plans" for people "who

might have a special need for help if an accident or emergency would occur at the depot."

However, registration may not have ensured any difference in priority of assistance or

responder awareness of an enrollee's situation. One respondent with knowledge of early

registry operations recounted:

> Well, but from day one for several years, that registration data was
>
> never looked at. It was gathered; it sat there. There were no plans
>
> for these residents…

Toward the end of the registry start-up phase, Calhoun County reassessed the risk

from a chemical munitions accident to its citizens. One outcome from that reassessment

was the identification of an area of increased risk within the county, commonly called *the*

pink zones[8]. Calhoun County pink zones included the City of Anniston, the county's

population, business, and government center. An emergency manager described the

reassessment's impact:

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[8]Maps produced to depict the new risk analysis results indicated areas most at risk with pink shading. When briefed, the presenter would refer to data for "the pink zone." Emergency planners quickly adopted the term because of its ease of reference. The term found its way into the public lexicon through public education materials that reproduced the risk maps.

When we first ran the special population [planner software] and

pulled up that map, and it showed the number of people located in

the pink zone, I mean light bulbs started going off immediately and

we had a big problem. It was a huge problem. So, we knew we

needed to come up with something very unique for those people

close in and then take care of the people in the outlying area.

A large number of our special needs population was located in the

pink zone, the area that was most at risk…. They weren't really

spread out all across the CSEPP community; they were in the

worst area possible.

The new risk analysis led elected officials to reevaluate their position on

protective actions for Calhoun County. Consequently, they authorized expedient and

enhanced shelter-in-place as alternatives for protection in the pink zones. The release of

the new risk analysis coincided with the start of the registry's pre-incineration phase.

Thus, county emergency managers had to reevaluate how they were going to support

registry enrollees and provide services equivalent to those provided to the public at large.

The first step of that reevaluation was county officials recognizing the inherent contract

that the registry made between the county and the enrollees. An emergency planner

commented on that realization:

When we started getting [registration forms] in, it was kind of

interesting, because we had the conversation "ok we identified

those special needs people, what are we going to do with them?"

Because, now something is expected of us.

Comments from three respondents responsible for registry management demonstrated the shift to objectives often associated with preparedness:

It was very clear early on that we were not going to provide someone to go to every special needs house and help in an emergency so we had to come up with some other strategies to provide assistance and a lot of it included self-help and public information on how families and individuals could assist their special needs folks.

Of course, it was at that point where the equipment played a big role because they [registrants] all felt like they needed assistance in their home sheltering in place. But, from distributing the equipment, we went from that point to a training program for residents.

We addressed that issue by trying to make people self-reliant. From the go, we asked, "what can we do to help you help yourself?" Is it education? Is it we need to modify something? Is it that we just need to get a care provider next door or somewhere in the neighborhood to help you out?

Service strategies resulting from the reassessment included forming an organizational network to provide registrants preparedness assistance, modifying

shelter-in-place enhancements provided to pink zone residents to meet specific

registrant needs, and publishing the Alabama Caregivers Guide. An emergency

manager at the time of the hazard reevaluation and the registry operator described

how Calhoun County implemented its service strategies. First, they had a one-day

working group at the county EMA to which the "The FEMA CSEPP folks,

basically on a one day notice, came down. I believe, in fact I know that [a national

laboratory's] representatives were there. The contract personnel…. State

representatives were there and army representatives." During that day, the registry

operator stated, "we came up with a plan to offer protection to our special needs

population and it involved local, state, and federal agencies." After that point,

they needed to plan a database:

> We met with all these county agencies and we said, "What do we
>
> need to do? What do we need to produce here?" Then, of course,
>
> they voiced their opinions on whatever it was that was needed,
>
> whether it was transportation, whether it was Braille, whatever it
>
> was and that's how the county caregivers training program began.
>
> It was based on what they wanted, you know. Where we could, we
>
> took it back again to a local area.

Of special interest to this process, in Calhoun County, the group "had meetings in

our office and we actually brought in a person with special needs. We would let

them help design the program and these books and all." These strategies point

toward the exchange or resources that characterize the operation of an organization network.

To summarize, when registry operations began, county officials did not know where individuals with disabilities or access or functional needs were located in relation to hazard risk. A new hazard assessment and early analysis of registrant information caused county officials to recognize that they did not have the resources to meet the enrollees' response phase needs. This realization served as a call to action and caused the county to focus on individual preparedness to solve their capability shortfalls. As a result, a network organization formed that provided registry enrollees with preparedness and mitigation support.

The chain of events described above provides evidence that the network of organizations formed because of emergent phenomena. First, the new risk interpretation identified a specific and unresolved disaster-related problem that could impact the community. Second, the network's members had an identifiable individual or personal stake in the problem's solution (see Finding 4). Third, respondents from the county EMA clearly stated that the disaster-related problem exceeded their capabilities to resolve. Finally, the network was composed primarily of public organizations, with some private participation.

Finding 3: Using return mail self-registration was more effective than using a network of organizations to enroll individuals in the registry.

Finding 3 corresponds to Research Questions 1and 3. It provides information regarding both the influence of administrative processes on registry operations and interorganizational interactions.

Both research literature and public policy documents frequently recommend that communities should build their emergency assistance registries by using organizations that provide services to people with disabilities or access or functional needs to register their clients (Parsons & Fulmer, 2008; Fox et al., 2007; Vogt Sorenson, 2006). Calhoun County attempted to include a network of service providers in the registration effort from the CSEPP registry's inception. In their report on registration processes used during the start-up phase, Lueschen and Wernette (2001) noted low participation by community groups during the Alabama CSEPP registry project. Of the 39 community organizations contacted as part of the registry project, only seven organizations provided information on their special needs clients. Nine organizations refused to provide any information, most citing privacy concerns as the reason for not participating. The remaining 23 organizations simply did not respond, even after multiple requests. As a result, community organizations provided information for less than 3% of Alabama CSEPP registry enrollees.

During the pre-incineration phase, Calhoun County held a workshop for "agencies and organizations that serve and support people with special needs" (internal workshop summary, 2003). Workshop organizers invited 28 organizations; 16 organizations sent representative to the workshop. At the workshop, organizers asked the attendees to

complete a Special Needs Planning Agency Questionnaire that indicated their ability or willingness to help in any of five areas:

1. Providing technical assistance to design special needs shelter kits,

2. Help with the design of training and education for persons with special needs,

3. Help with the delivery of training and education for persons with special needs,

4. Help with outreach to persons with special needs, and

5. Help register persons with special needs.

Of the sixteen organizations that attended the workshop, only nine responded to the questionnaire. While all responding organizations indicated that they could provide outreach assistance, only five indicated that they could provide registration assistance. What is not clear is whether not participating in registration reflects an organization's interpretation of privacy laws and regulations or an unwillingness to take on another task. Some respondents mentioned HIPAA's privacy provisions for protected health information as the primary reason for not providing registration information:

> Well, these [potential registrants] are considered patients for public health so you fall into the HIPAA thing. So, I know that [the registry contractor] was allowed as much information to have as [it] could.

> One of the major problems we had [a contractor] look into was the HIPAA requirement and what we found out was that doctors cannot refer a patient directly to [the registry].

We had to be very careful in dealing with the home health care

agencies and some of the medical agencies. They could not

provide that information directly to us because of the laws and

HIPAA and some other things.

However, some officials believed that HIPAA requirements did not apply or that

organizations could overcome the requirements if they desired:

Well, we have to deal with HIPAA compliance, but through the

MOU, you can get away with that…. To me a great deal of it is

paranoia and a lot of concern and there probably is a little bit of

possessiveness in there too. A lot of people don't want to share,

they want to keep their own clients and make sure that they are the

point of contact and all those things…. But, as I've said a lot of

them use HIPAA as a way to get out of being cooperative. "I

would love to but HIPAA prevents this and this." Technically it

doesn't.

How we got around that is we had an Attorney General opinion

done and we had, [a contractor] researched it, and basically then

public health got involved and the CDC got involved. If they

individually voluntarily give you the information then you are not

subject to HIPAA.…

Liability and HIPAA. We researched it. HIPAA doesn't really

apply to what we are doing, gathering information. These people

are giving up information voluntarily as far as the registry is concerned

Member organizations from the registry network did support the enrollment process. Various agencies described their participation in registering their clients and interaction with the registry operator.

Yeah, I think we did it through our public transit, which isn't technically my department, but it's part of a plan we administer here in the city of Anniston for Calhoun County urban and rural program and through our senior center. After a period of time [the registry contractor] started making periodic visits to our senior centers and they took care of a lot of that and our center managers participated by targeting those homebound residents.

If I remember right the information was actually collected from the nurses and then turned in and that's how it was put into the registry.

I worked with [the registry contractor] getting like our residents names, the ones that would need special assistance, the ones that were disabled.

It [enrollee information from organizations] was put in the database and the agency…. What they did, they went back to the folks they were working with. The special needs individual, their

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clients, and encouraged them to fill out the special needs cards and

information and then they assisted them in sending them in….

Beginning with the workshop and continuing throughout the period examined by this study, the registry operator met with service-providing organizations to obtain their support. Registry operators described how they interacted with registry network organizations to increase enrollments through a variety of distribution methods designed to reach more people through their contact with a number of organizations:

But um, then we also started taking the same registration form and

putting it in [the county] transit program….We would place it in

organizations where they could give them out in their packets, in

meals on wheels, our salvation army, places where people came to

get help. Our Chamber of Commerce. We had these registration

forms in doctors' offices…. What we would do is we would mark

that form, the back of that form, it would say transit or East

Alabama Planning. That way when those forms came back, when

we were registering that resident, we would go in one extra step in

one of the [Special Population Planner] fields that says where was

this information gathered. It would come from transit. Does that

make sense to you?

Every respondent at some point mentioned that registrations came from the network of organizations, usually with a tone that suggested obtaining registrations was an important role. However, both the network organizations and the registry contractor

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seemed to have expended more energy to obtain registrants through the network than the

results would warrant. Even with the registry contractor making frequent contact and

providing service organizations with registration forms, year-to-year enrollments from

those organizations ranged from 34 to 97 individuals, averaging 59 per year. Table 4.2

presents the number of registrations recorded in the registry database as coming from

service organizations.

	2003	2004	2006	2007	2008	2009
Number of enrollees coded as coming from service organizations	97	96	50	37	42	34
Total enrollments from all sources	2645	2617	2218	2083	1878	1632
Percentage of total enrollments coming from service organizations	3.67	3.67	2.25	1.78	2.24	2.08

Table 4.2 Number of enrollees in the Calhoun County emergency assistance registry coded as being registered by service organizations. Data for 2005 is not available.

Nothing in in the data suggests why there were so few registrations from

supporting organizations. One possible explanation is that the public was accustomed to

the county's annual return mail self-registration campaign. Each year, the county

conducted a saturation mailing of registration forms to every business and residential

address. Weeks before that mailing occurred, the county ran newspaper ads and public

service announcements that informed citizens when the saturation mailing would take

place. Thus, registering through the return mail process became the norm, and

registrations from outside that process were the exception. Another possible explanation

for the low numbers could be poor record keeping; however, no evidence exists to that

effect. The registration forms made available to the researcher were marked as described by the registry contractor.

Finding 4: Identity, resource exchange, and legitimization defined the organizational network's interorganizational interaction.

Finding 4 responds to Research Questions 2 and 3 in that it provides evidence of network formation, emergence, and interorganizational interaction. However, it provides the most information regarding Research Question 2.

As discussed in Findings 2 and 3, Calhoun County used a network of organizations to conduct registry operations and deliver registry-related services. A former Calhoun County emergency management official attested to the need for using a network of organizations to support their emergency assistance registry:

> A network of organizations is critical. An individual organization
> could not accomplish what needed to be accomplished. So, a
> network of organizations.

The CSEPP planning guidance suggested that communities involve a number of organizations in their registry efforts.

> Planners have to work closely with welfare or social service
> agencies, religious, fraternal, sororal, and service organizations,
> and volunteer and nonprofit groups at the state, county, and
> community levels. Typical agencies are those dealing with the
> aging, day-care youth, exceptional children, the homeless or those

needing shelter, people with language or cultural differences, the

mentally or physically disabled, etc. (p. 8-23, DA & FEMA, 1996).

However, a need identified by the emergency management agency and a suggestion

found in unenforceable programmatic guidance does provide potential members the

motivation needed to join an organization network. Individuals and organizations form

networks to undertake joint activities that meet needs of self-interest, resource exchange,

and legitimacy (Kapucu, 2005; Provan & Milward, 2001). Interview data indicates that

these factors were present in the Calhoun County registry's network of organizations.

Young (2001) claimed that organizations often express self-interest in terms of

identity (how members perceive, think, or feel about their organization). Registry

managers appeared to define organizational identity as an organization *making it*

personal:

You have to make it personal. I think that that is why it worked for

us, because they made it personal.

They took it personal. They did and they still do even after twelve

years they still take it personal.

Respondents from organizations that joined the network expressed identity though use of

I and *we* statements that indicated a private or professional relationship with a person

with disabilities or access or functional needs:

I have parents that are still living and great aunts that are in their

90s…. Also, I have a friend who has a special needs son…

I have a special needs daughter and then my heart is with senior

citizens…

And, how we became involved initially with special needs

populations were in the aspect that if something should happen we

were a resource. We participate in training and activities with the

Calhoun county health department in that aspects and that's how

all of our initial contacts were made and how we were involved in

the [registry] project.

What we do is we put caregivers in the homes of seniors.

I drive a bus for Calhoun county special needs schools.

I am the founder of [name redacted], a non-profit organization

established to provide services to [a minority] community of

Calhoun County and surrounding areas.

Two items stand out in these comments. First, the respondents' personal and professional

ties to the disability or access or functional needs population shows a clearly identifiable

personal stake that is closely tied to emergent behavior. Second, indications of resources

that an organization could exchange (e.g., training translation services and caregiving)

were included in many of the identity statements. The potential for resource exchange

plays a role in both the emergence and forming of organizational networks.

Resource exchange provides member organizations access to skill sets or other

capacities that enhance their abilities to deliver services. The registry operator (a

contracted small business) received support from network organizations that extended its limited staff. The registry operator described the resource exchange in this way: "…they really became our eyes and our ears, because we couldn't be in all the communities all of the time." Typically, the resource exchange took the form of registration support; however, it also included special skills such as providing translation services:

> Sometimes, just an informal question and answer thing to make sure that we knew that someone had moved or passed away or whatever…. yeah, I think we did it [distributed forms] through our public transit…
>
> If I remember right, the information was actually collected from the nurses and then turned in and that's how it was put into the registry.
>
> So, we offered translation services… [to] reach out to people and be present during that activity to help them with the communication issue.

The resource exchange between the registry operator and network organizations had reciprocity. Respondents from member organizations reported that the registry operator provided them with training and public education materials and worked with them on providing protective equipment to their clients:

> …they were kind of the folks that helped deliver the equipment because our contract did not include delivering equipment. It included people coming to a site to pick up equipment. They

assisted with delivering equipment and determining kind of if the core of engineers needed to come in or if it was ok to leave that there.

After a period of time [the registry operator] started making periodic visits to our senior centers and they took care of a lot of that and our center managers participated by targeting those homebound residents.

Well, I didn't [help people figure out their personal emergency plans] per se…. That's where [the registry operator] came in. They trained [our clients], we sat down with them, we worked with them. They brought in the paper work and the literature. We sat down one on one with them wrote out their plans.

The registry operator offered a glimpse into how the resource exchange worked in regular practice. Note that the registry operator considered the resource exchange's biggest effect was as a service multiplier.

We started with the registry and we provided equipment and on a daily basis we always made sure the residents had everything that they needed. But then when you start working with say fifty agencies and those fifty agencies have a hundred residents that they deal with then that is that many more homes that we are touching. Whether it was just education material or whether that

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home needed a tone alert radio or whether it needed more training,

we were able to go back and provide that information.

Organizational networks gain legitimacy by effectively delivering services and invoking affiliations with other organizations (Wiewel & Hunter, 1985). The data do not enable determining the effectiveness of the services the registry network provided. The earlier discussion of resource exchange provides some indicators of invoking affiliation. One registry manager summarized the import of legitimization to the registry's success, using the term *buy-in* to describe the need to involve key groups for the registry to have value in the community:

You got to make sure it's a full partnership. The registry must be a

full partnership, and they must buy into the registry, and you must

have value given to them…. You must go out and get buy in from

all of those potential support agents. You have to get buy in from

the religious leaders. You have to get buy in from the city and the

political leaders. You have to get buy in from the first responders

and receivers…. They have to understand your registry and they

must agree to support it.

One respondent also expressed that their organization gained legitimacy that it would normally only be able to gain after years of effort by joining the network:

…when I tried to make the proposal to the EMA, nothing

happened. So, then I met [the registry contractor] and I knew that

[the registry contractor] had a relationship with [the EMA], so I

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had to attach to [the registry contractor].… For instance with [the

registry contractor], I knew that [it] was really and correctly related

to the people we needed to contact and was on top of the issue.

Finding 5: Absent a formal governance mechanism, the network used a hybrid of

lead organization and shared governance to guide registry operations.

Finding 5 responds to Research Questions 2 and 3. However, it provides the most

information regarding Research Question 2 in that it provides evidence of how the

organizational network governed its support of registry operations.

Finding 4 revealed the organizational network's strong commitment to

interorganizational cooperation. The network's resource exchanges and delivery of

services required more than informal cooperation and coordination. Recognizing that

need, one Calhoun County CSEPP coordinator explained that the governance mechanism

must be in place early in registry operations:

You also have to have an individual to head up once you get to the

point where you need to start establishing your database. You have

to have an individual or agency hired to kind of corral all of that

and keep it going.

Another respondent reflected upon the need for an individual or organization that not

only managed the registry's data but also coordinated the preparedness support:

Well, you break it down into registry/training, education, and all of

that. If you are going to do it all you have to have a person who is

dedicated to just that. If you are talking about just registry and then

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letting the other come from your planners, or your operations

managers, or your EMA people, then you might not need a full

time person. But, if you are going to make it a successful program,

then you need someone dedicated to it, I believe.

Similarly, a state-level emergency management official outlined the need for a dedicated

coordinator, suggesting that the registry's lead individual or organization could become

the registry's public face. That official expressed that trust, value to the community, and

actually doing registry work are critical characteristics for a lead individual or

organization:

So, that's one reason when we establish the registry that you have

to figure out when you get the five groups together who is going to

maintain it, who is going to be that spokesperson, that out front

leader… Whoever is going to have the most contact with the

potential [registrant] and has the best trust level should… be the

face.

Eventually, the government officials contracted with the company that provided

mail services during the registry start-up phase to run day-to-day registry operations.

Initially, the company coordinated collection of registry data, maintained the database,

and ensured that registry data were available to county emergency managers. During the

pre-incineration and incineration operations phases, the company added functions for

issuing shelter-in-place equipment, coordinating development of caregiver guides, and

supporting service providers with registry-related training.

The combination of the networks' style of interorganizational interaction (Finding 4) and the contracting of a company to run day-to-day registry activities suggests that the registry network used the lead organization typology as its governance mechanism. The study found evidence that two characteristics of lead organization governance were present in network operations. First, the organizational network shared a common purpose (i.e., registering clients, providing CSEPP-related preparedness services). Second, network members regularly interacted with each other. A third characteristic, coordinating the network's decision-making through a single organization was not present. However, member organizations attributed to the registry contractor decision-making and controlling power that it did not officially have:

> …every time [the company] said you all better get them things
>
> registered, you know, you better get them in (laughter).

> …if they didn't have [the company] on top of the project, I don't
>
> think the project would have been as successful as it was…

> I was contacted by [the company] and…went to a meeting about
>
> the special needs registry that the EMA was involved in…granted,
>
> [the company] was responsible for most of the work.

Although perceived as the lead organization, the contractor could not be responsive to member organization needs as would be expected of a network leader. The company had to work within the bounds of its contract and took its direction from the contracting agency, not network members. It is here that the lead organization typology did not fit the registry's actual governance mechanism. The network's interactions were

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more typical of shared-governance in that control of network activities occurred through formal meetings, informal contacts, and member collaboration:

> …I mean I talked to [the company] about it [the registry program] several times and [a company employee] and I are always bumping into each other at health fairs and things like that. We discuss it, and I looked at it. You know, [the company] asked me to look at some of the stuff they put together.
>
> We started meeting with the agencies that already had clientele and we were meeting with them on a regular basis…
>
> And, [the company] came up several times….

Finally, being the perceived lead organization and perceived face of the registry led to questions about the contracted registry operator's legitimate role. One respondent viewed the company as being "responsible for all of the work." Another indicated that the contracted company "was pushing for everything to happen." However, not all organizations shared that perspective. When asked about the local emergency management agency's role in running the registry, one county official expressed a mixture of resentment and relief about the perception that the registry operator was the network's lead organization:

> There was a lot of contention on the fact that the program was managed by a contractor who when you called their business line would answer the phone saying simply "EMA, how may we help you. " I think the fact that the special populations program

contractor did so much public relations work and the program was

such high visibility that some people literally did confuse the

special pops contractor with legitimate county EMA offices. But, it

was very, very nice when people would call and ask questions

about the program after having seen some of the promotion

materials or hearing about it, that we could simply refer them over

to the contractor to have their call processed and information

recorded…. but as far as our involvement, actually up until the

very end when we started wondering how we were going to

transition the program going forward, I would say very, very little

other than making referrals to the program to the contractor.

Lack of a formal governance structure did not appear to hinder organizational

interaction within the network. Findings 3 and 4 showed that organizations willingly

joined the network and exchanged services. In this case, the de facto use of a hybrid

shared-lead organization governance typology resulted in coordination and collaboration

that resulted in favorable client outcomes.

Finding 6: CSEPP closeout caused changes in registry purpose, administration,

governance, and organizational interaction.

Finding 6 corresponds to concerns related to Research Questions 1, 2, and 3. It

provides the most information regarding Research Question 1 in that it present evidence

of the influence of loss of key resources on registry operations.

During the registry's CSEPP closeout phase, Calhoun County began transitioning into

what respondents called "life without CSEPP." County officials and the registry's

network of organizations had to make decisions about the registry's operational future.

One respondent from the organizational network remarked about the change in situation:

> We go from a county that has a potential problem on our hands to a
>
> county that's just like the county next door. We have tornados, we
>
> have acts of God that nobody can control.

The change of situation caused some respondents to express concern about whether the

registry would exist after the CSEPP ended:

> I've … tried to get people to realize is, we cannot let this registry
>
> just go away…. I mean we've got to have funding for it, we've got
>
> to have someone to keep it up, because too much money and effort
>
> has been put into getting the registry, updating it, keeping it
>
> registered, keeping it up with the folks. We can't just 6 months
>
> from now decide, "You know what, we might, should have kept
>
> that special needs registry."

> I'd like to see it be able to continue because it is a need, to be able
>
> to know where the individuals are and make sure they're registered
>
> and know who's who and what's what.

> That it will end. I may be wrong, but I kind of think that it will
>
> end.

It is not surprising that these respondents were not aware that the county had decided to

continue operating the registry. They were participants in the first interviews, which

occurred during the time county officials were just beginning to develop the registry's future concept of operations. At that point, the county had not presented the concept to any organizations in the registry's network. However, the concerns expressed by these respondents showed the registry's value to both the organizational network and community.

The county did not formalize or publish the registry's new concept of operations during the period this study occurred. Therefore, the analysis that follows comes from an interview conducted with a county emergency manager responsible for developing the registry concept and an August 2011 draft of the county's *At Risk Populations Emergency Preparedness Action Plan* (hereafter, Action Plan). These two sets of evidence show both realized and potential effects on registry purpose, administration, governance, and organizational interaction.

The first hint of the registry's change in focus was its renaming. The county emergency manager suggested that the new name—the *At Risk Registry*—better indicated the population that the registry targets:

> Well, the special needs term has negative connotations. *At risk* seems to be the new phrase and it's more, it's easier to digest from the emergency management standpoint than functional needs because, to the layperson, the phrase functional needs is a pretty vague term. I think that risk implies more what we are trying to work with, which is literally folks that are at risk during emergencies and disasters more than the average citizen because of

their functional needs limitations.

The 2010 and 2011 self-registration forms reflected this change in philosophy. While the 2010 form continued to use the *special needs* language, the identification categories followed the C-MIST functional needs paradigm. The 2011 self-registration form completed the transition by indicating it was for the *At Risk Registry* and asking for *functional needs* information. Copies of the 2010 and 2011 forms are provided in Appendix C.

The county emergency manager also indicated that a combination of agency referrals and web registration would replace saturation mailing of self-registration forms as the primary means of collecting registry information. Framing the registration as a function of the service providers' existing assessment processes, the county emergency manager described the new procedure that moved from a systemic information collection effort to an episodic and less formal method.

> In the past, they did mass mailers every household in the county.
> We have a signed memorandum of understanding with home
> health care, the area agency on aging, folks like that, nonprofits
> who work with the elderly and the disabled so they will complete
> this registration form/functional needs assessment on all of their
> clients…. It's an assessment form. It becomes a registration form
> when, if the individual so chooses, he or she signs the liability
> waver release at the very bottom of the last page. It's a two page
> form that says "I agree for my information to be shared with local

fire, EMS, law enforcement, public health, whoever." If they

choose to sign that release then the form can be forwarded to the

9-1-1-EMA for inclusion in the registry.

The proposed memorandum of understanding (MOU) between the county EMA and

community-based organizations (CBOs) confirmed the process described by the county

emergency manager. The MOU also required CBOs to complete an assessment form for

each of their clients on an annual basis. Additionally, the former registry operator, who

was helping Calhoun County develop the new registry concept of operations, reported on

one other registration option:

What we are working towards is making a web-based registry

where you can go online and register. Anyone will be able to

register into this database.

What is not clear is why the county EMA chose these registration options. As indicated in

Finding 3, very few registrations came from service providing agencies, even though

most used essentially the same assessment or intake procedures as proposed in the

county's registry action plan. Similarly, web-based registration was available for the

CSEPP-related registry from 2007 until the program ended. The registry database

indicated and the registry operator verified that no web-based registrations occurred

between 2007 and 2010. Historically, saturation mailing of return mail self-registration

forms was the most effective choice for the registry.

The county's draft Action Plan revealed that the county 9-1-1 call center would

become the registry operator, signaling a change in purpose for the registry. Data from

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the CSEPP-related registry primarily guided county disaster preparedness and mitigation activities. Now, data from the At Risk Registry would be used primarily for everyday response by fire, police, or emergency medical services (EMS). The county emergency manager offered three observations regarding this change in focus, first noting that:

> [Fire, police, and EMS] need to be the fundamental drivers of the registry because they are the primary consumers of it.

Expanding on that thought, the county emergency manager summarized the role of fire, law enforcement, and EMS organizations in determining what information the registry will contain:

> [The county will] put some folks on [the At Risk Task Force] from the fire, and EMS and law enforcement communities and let them make those decisions [about what information the registry contains]…. The stop-gap measure that we put in place when we were merging the data over [was]…to go through them [registration forms] and look at them from the perspective of a 9-1-1 dispatcher who processes calls on a daily basis what is good information to have.

Finally, the strongest insight into the At Risk Registry's purpose came from this exchange between the interview team and the county emergency manager:

> Interviewer: Picking on two things you said earlier. One was the data. The only data really that should be in a special needs registry should be data that the emergency response community feels that it

needs in a disaster emergency rather than public health might need

or other people might think it would be nice to have in there.

Respondent: Absolutely.

What becomes clear through these comments is that the purpose of Calhoun County's registry is changing from disaster preparedness to daily response.

The draft Action Plan also indicates a change in governance. By establishing an *At Risk Task Force* (hereafter, Task Force), the plan imposes a formal, command and control-style governance system on the organizational network, replacing the CSEPP-related registry network's more loosely coupled, hybrid governance. The first indication of the change in governance is the requirement placed on the organizational network's members to sign an MOU with the county EMA:

Agencies choose to join the Task Force by signing an MOU with

the CCEMA. By signing the MOU, agencies agree to participate in

Task Force meetings, undertake training and preparedness

programs recommended by the Task Force, and assist with the

delivery of services related to the At Risk Registry.

A second indicator is an Action Plan requirement that personnel (including contractors and subcontractors) of CBOs participating in the Task Force are required to meet "voluntary compliance minimum competency standards."

The command and control-style governance also affects the free resource exchange characteristic of organizational networks. Where informal coordination under the CSEPP-related registry was the norm, the Task Force now "facilitates communication

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among CBOs and authorities….” Rather than network members obtaining mutual benefit from resource exchange, the Action Plan characterized transactions as being unidirectional, either information going to or through the registry operator. While emergency preparedness services were previously coordinated among the network's members, they now must use a standardized community resource list published by the EMA.

Interpretation of Findings

This study's findings indicate that Calhoun County's CSEPP-related registry had an emergent quality, dynamically created by human agency with an interactive organization network, impacted by multiple influences. Figure 4.2 depicts the registry operation described by the respondents. These findings correspond in an interesting way to Research Questions 1, 2, and 3. For example, the model depicts the influences of purpose, hazard, demographics, and administration on enrollment and the provision of registry-related services (Research Question 1). Furthermore, it depicts both the role of an organizational network in developing and providing services as well as the influences of identity and personal or professional stake in network formation (Research Questions 2 and 3).

The respondent's insights suggest that registry purpose, design, and implementation start with an official risk assessment. Local authorities then provided risk information to the population at large, along with differentiating inclusion criteria and a description of the registry and its purpose. Individuals had to interpret their risk, decide whether they meet registry inclusion criteria, and whether they would need additional
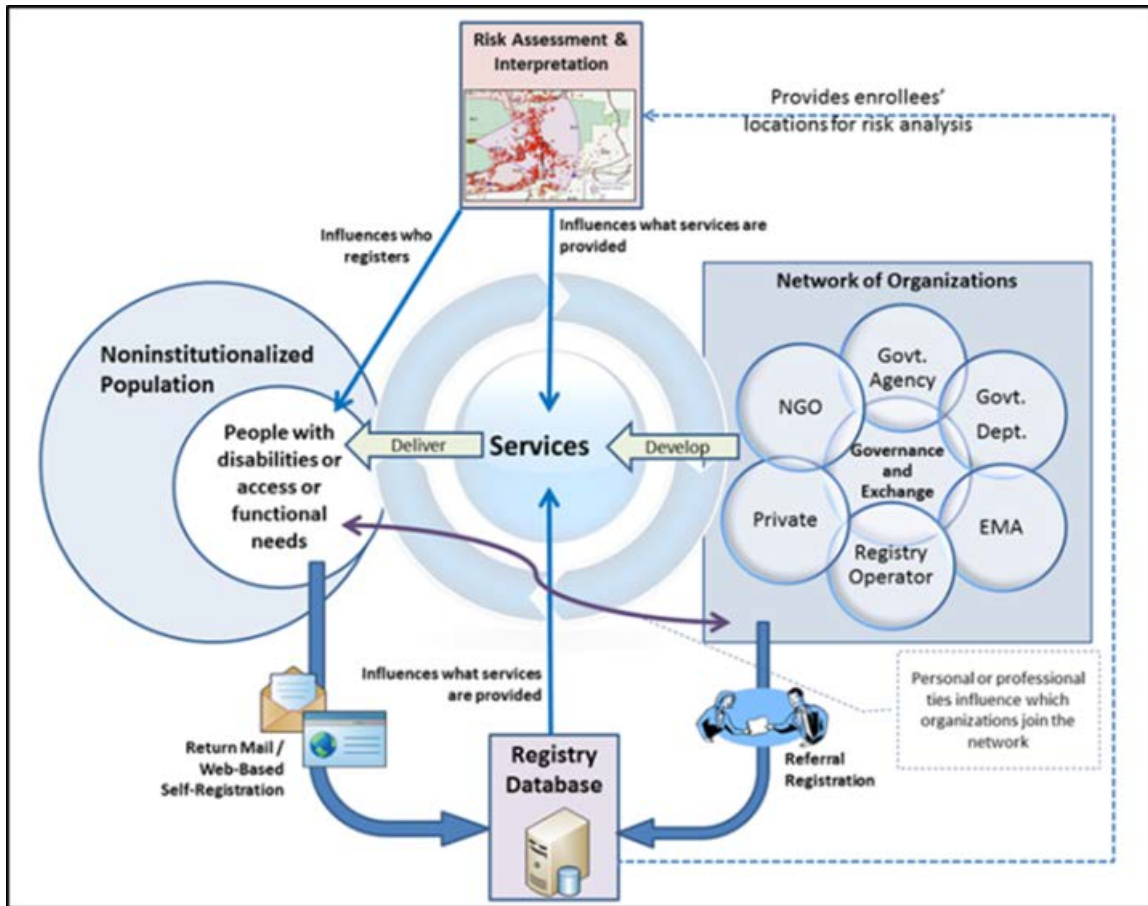
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Figure 4.2 Model of an emergency assistance registry operation

assistance to protect themselves from hazard effects. If they submit registration

information, their data are stored in the registry database. The registry data go to the

supporting network, whose organizations use it to guide how they develop and deliver

disaster-related services to registrants. The registry data also feed back into the ongoing

risk assessment process. Community organizations decide whether to join the network

based on a number of factors, including resource exchange and identity. Participating

organizations typically manifest identity through personal or professional ties to the

disability or access or functional needs population. Resource exchange within the

organizational network consists of informational transactions and service delivery

support. The organizational network determined how to tailor the services that its members provide to meet an individual registrant's unresolved needs by analyzing registry data and making direct contact with the enrollee. An individual must identify himself or herself to the registry, by either self-registration or referral from a service provider, to receive services from the network. By providing services, the network fulfills the inherent contract made between an individual registrant and emergency management officials by the act of registering. The types of services provided are not static. Influences include the risk assessment, registrant need, and the types of services provided to the population at large. During periodic registry update activities, registrants must evaluate whether network-provided assistance has met their needs or whether they need continued assistance. The registry database captures changes in registrant data and the cycle repeats.

Summary of Findings

This chapter presented six findings revealed by this study. It identified factors that influenced emergency assistance registry design and operations, interaction among members of the registry's organizational network, and delivery of registry-related services. Data from individual interviews, registry records, registry-related reports, and clarifying conversations revealed how and why an emergency assistance registry operated in Calhoun County, AL in the context of local risk. The analysis indicated that publicly presented purposes had a more direct effect on registry design than official purposes did. Analysis also revealed evidence of emergent phenomena as the network of organizations' formation and interactions bridged gaps in service. Finally, the evidence suggested that post-CSEPP registry operations were moving from a loosely coupled, emergent model

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toward a command and control, dominant theory model. Chapter 5 discusses the

conclusions drawn from this chapter's analysis. It also offers implications for theory,

practice, and future research resulting from this study.

CHAPTER V

CONCLUSIONS AND IMPLICATIONS

The purpose of this embedded, single-case study was to explore the approach

used in Calhoun County, AL for operating an emergency assistance registry for people

with disabilities or access or functional needs in the context of community risk.

Analyzing that community's registry operations helps determine which factors influenced

registry design and operations, how those influences translated into practice, and why.

Qualitative analysis of interview and document data revealed six findings related to (1)

registry purpose, (2) hazard interpretation and organizational emergence, (3)

effectiveness of different registration methods, (4) interorganizational interaction, (5)

organizational network governance, and (6) registry lifespan. Using the research

questions as a guide, this chapter discusses conclusions drawn from the findings

presented in Chapter 4 and their implications to theory and practice.

Conclusions

Conclusions Regarding the Influence of Purpose

The first finding from this study is that multiple purposes exist for a registry and

each affects the registry's design and implementation. The research literature from the public health domain indicated that a clear purpose is essential to a registry's success (Solomon et al., 1991; Weddell,1973). That research seemed to suggest that a registry's purpose is a singular entity that points to how the registry's owner will use its data. However, Calhoun County's experience indicates that at least three purposes may affect emergency assistance registries: (1) the purpose found in official guidance, (2) the purpose presented to the public, and (3) the purpose perceived by organization supporting the registry.

Calhoun County participated in the CSEPP and if it expected to receive funding and other support from that program, it had to follow programmatic guidance. One such requirement was operating a *special needs registry*. The CSEPP programmatic planning guidance recommended an information storage method (i.e., an electronic database), provided broad inclusion criteria (i.e., all special needs individuals in a planning zone), and indicated an expected outcome (i.e., planning). However, this official guidance had only a general impact on the Calhoun County registry's design and implementation. The official programmatic guidance left any specific determination of purpose beyond its general intention to the county. The county made its vision of purpose known through what it told the public about the registry.

Respondents indicated that the purpose presented to the public through registry enrollment material was more salient than the official purpose. They explained that the publicly presented purpose set outcome expectations for registrants and registry operators alike. Interestingly, this purpose evolved over the registry's life span. Initially, the

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publicly presented purpose was one of collecting information for official planning

purposes. Immediately after the county reassessed community risk and had initial

registration information, the publicly presented purpose was revised to include statements

about providing informational assistance that would lead to self-sufficiency during a

disaster. Toward the end of the CSEPP, public purpose statements indicated that the

County would use registry information to provide registrants with planning information

and protective equipment. Documentary evidence indicated that this publicly presented

purpose drove registration form design and the information county officials kept in the

registry database. Thus, this purpose type most closely fits Solomon et al.'s (1991) and

Weddell's (1973) theory that purpose influences registry design and administration, a

finding that somewhat supports registry-related literature from the public health domain,

the study showed that changes in purpose only caused minor changes in the registry's

physical design.

Some respondents identified a perceived purpose that they derived from their

interpretation of the official purpose and a local protective action policy. The study found

no indication of the perceived purpose directly affecting registry design. However, the

perceived purpose appeared to affect whether a community organization joined a network

that supported the registry and its beliefs about its role within that network.

Conclusions Regarding the Influence of Hazard and Demographics

The second finding indicated that knowing registrant locations in relation to

hazard risk areas actually defined the registry's purpose—to provide preparedness and

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mitigation assistance to its enrollees. That change of purpose also led to the emergence of a network of organizations to support the registry and provide registry-related services.

Respondents reported that the absence of any real knowledge about the numbers of individuals requiring assistance within the originally defined hazard area directed their support efforts toward rescue. Many reported a sense of dissonance caused by contradictions between approved support activities and observed reality. They wrestled with knowing that most registrants could not take protective actions without assistance and that the county had insufficient resources to provide for their rescue.

While initial registry enrollments were occurring, Calhoun County conducted a new hazard risk assessment. Using the GIS function in its purpose-developed registry software, the county was able to layer registrant locations over a map indicating risk areas. This layering methodology is similar to that suggested by Tatsuki (2012), Cutter et al. (2000), and Morrow (1999) in that it used digital geographic and spatial information combined with hazard information and population information to identify special needs populations with the purpose of determining appropriate mitigation and preparedness measures. Emergency managers and the registry operator alluded to the effect of combining a new risk assessment with the initial registration data. They reported an immediate understanding of the insufficiency of rescue and other response-oriented assistance. Thus, the respondents supported Morrow's (1999) and Cutter et al.'s (2000) assertion that by using geographic information systems emergency managers would better identify population segments at risk.

Respondents reported that the improved risk assessment and registrant location data moved assistance efforts toward providing preparedness and mitigation support to enrollees. They also reported that the change in assistance focus caused a network of organizations to form in order to provide the needed support. The evidence suggested that the network of organizations might have formed because of emergent phenomena. Respondents and registry documents suggested the presence of organizational characteristics that Drabek and McEntire (2003) and Stallings and Quarantelli (1985) indicated are necessary for forming preparedness phase emergent groups. Those characteristics included: (1) a specific and unresolved disaster-related problem that had potential impact on the community, (2) the network's members having an identifiable individual or personal stake in the problem's solution, (3) recognition that the disaster-related problem exceeded a single organization's capability, and (4) group composition primarily of public organizations, with some private participation.

Conclusions Regarding the Influence of Administration

The third finding was that return-mail self-registration was more effective at enrolling individuals than using the registry's organizational network. The use of advocacy, disability, and service organizations is an often-recommended method for collecting registry information (Parsons & Fulmer, 2008; Fox et al., 2007; Vogt Sorenson, 2006). This method includes using a *list-of-lists* approach, which involves obtaining and consolidating population information collected by various government and non-government service providers (Vogt Sorenson, 2006). Document evidence and respondent interviews showed unwillingness on the part of some organizations to provide

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registration support. They cited HIPAA privacy provisions most often as the reason for not taking on a registration role. Some organizations reported including registration as part of their client services. However, analysis of registry data revealed that registrations from the network of organizations never exceeded 3.67% of annual enrollments.

The evidence suggests that the reason for the low level of organizational registrations was that the public was accustomed to responding to the county's annual return mail, self-registration campaign. The return mail, self-registration campaign used all the techniques recommended in the research literature to increase response rates: advanced notification (i.e., a media campaign starting weeks before the annual registration started), cover letters that indicated sponsorship, and providing stamped return envelopes (Dillman, 1991, Dillman, 1978, Kanuk & Berensen, 1975).

Conclusions Regarding Organizational Interaction

The influence of organizational identity, resource exchange, and legitimization on network formation. The fourth finding confirmed expectations from research literature that identity, resource exchange, and legitimization would influence organizations to join the registry network (Provan & Milward, 2001; Young, 2001; Wiewel & Hunter, 1985). Respondents reported registry-related identity through statements indicating that personal or professional relationships existed with people with disabilities or access or function needs before joining the network. Disaster-related emergent behavior is also a function of an individual's personal stake or an organization's professional stake in the community (Stallings & Quarantelli, 1985). In this case, the personal or professional relationship with registrants and the personal or

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professional stake in the community are the same: caregiver (personal) or service provider (professional). Thus, *identity* appears to provide a point of overlap between emergent group and organizational network theories. Some respondents cited the benefits of resource exchange in the form of providing services to and receiving services from the registry operator as an enticement for network membership. Such resource exchange adds to the human capital and property available for an organization to carry out its role within the network (Katz & Gartner, 1988). The registry operator believed that the biggest benefit of resource exchange was its service multiplying effect. That is, by interacting with multiple service providing organizations, the registry operator believed there was more contact and impact with actual and potential enrollees. Member organizations expressed the ability to provide enhanced disaster preparedness-related services as the benefit they derived from network involvement. One respondent also expressed that their organization gained legitimacy—the ability to acquire resources and status that it would not usually have—by joining the network.

The influence of governance on interorganizational interaction. The fifth finding indicated that the organizational network governed its interaction with a hybrid lead organization, shared governance mechanism. Respondents firmly stated the need to have a single individual or organization to lead the network. While the network operated without a designated formal leader, it did have a *de facto* leader in the registry contractor. Documents and interviews showed that the network had some characteristics of lead organization governance (i.e., a common purpose and regular interaction), but it was lacking others (i.e., one organization making decisions for the network and it being

responsive to network needs). Rather than a formal decision-making and coordination structure, the study found the network used regularly scheduled meetings and informal contact to guide its activities. That style of interactions is more in keeping with a shared governance approach.

This hybrid approach to governance is an indicator of an organizational network formed through structural and interstitial emergence. Because its members are both expanding and extending their organizational functions while working within both an existing and new organizational structure, the registry's network takes on aspects of structural emergence (Drabek & McEntire, 2003). Similarly, there is evidence of interstitial emergence. First, the network members have overlapping resources across multiple fields (e.g., paratransit, home health care, and housing) without one resource having dominance (Morrill, 2002). Second, the network has placed itself between the EMA and the registrants to foster cooperation and manage registry-related services and resources (Drabek & McEntire, 2003). Therefore, the network's approach toward governance is the second indication of overlap between organizational network and organizational emergence theory. Both theories indicate that a new organization or network of organizations will form to voluntarily share information, undertake joint activities, and keep their autonomy intact (Kapucu, 2005; Provan & Milward, 2001).

Conclusions Regarding the Influence of CSEPP Closeout

The sixth finding detailed changes to emergency assistance registry operations in Calhoun County that resulted from CSEPP Closeout. The end of CSEPP saw the end of special funding to operate the county emergency assistance registry. Emergency

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managers recognized the registry's value and developed an action plan to keep the registry operating. However, the loss of funds caused many changes. First, the county 9-1-1 center began to operate the registry. County officials viewed this change not only as a cost savings measure, but also as a way to add registry value on a day-to-day basis to the response community (e.g., fire, law enforcement, EMS). In fact, documents and respondents' comments indicated that by this change the response community would have greater influence over the type of information collected by the registry. Additionally, draft action plans and respondent comments indicated that the registry's focus would change from providing primarily preparedness-oriented disaster-related services to primarily supporting day-to-day emergency calls. Furthermore, the draft action plan indicated a move toward a formal governance structure managed through memoranda of understanding and led by the 9-1-1 center. Thus, the changes removed any sense of organizational emergence. Saunders and Kreps (1989) indicated that such *suspension of process* often results from loss of resources such as occurred in Calhoun County with the end of the CSEP program. Another indicator of the end of emergence in the network of organizations was the network's absorption into a hierarchical structure outlined in the county's At Risk Registry Action Plan (Saunders & Kreps, 1989; Quarantelli, 1984).

Implications

The discussion that follows presents the implications developed from the findings and conclusions, potentially adding depth to the theoretical and practical knowledge base in emergency management. Hopefully, the context provided throughout this report makes

it possible for practitioners and researchers to determine how applicable these lessons are to their individual situation.

Implications for Theory

The findings from Chapter 4 provided two insights that warrant further theoretical development: (1) the points of overlap between organization network and emergent group formation and (2) organizational emergence during the preparedness phase. Both are discussed below.

Overlap between organization network and emergent group formation. Early in the study, it was evident that an organizational network formed to execute the delivery of registry-related services. Thus, it was natural to examine registry operations through factors that lead to an organization joining the network (i.e., common purpose, organizational identity, possibility of resource exchange), governance structures, and the like. The similarity between those factors and the characteristics that lead to the formation of an emergent group were unexpected.

The common goal (organizational network theory) of providing disaster-related preparedness and mitigation services to registrants was the unresolved disaster-related problem that affected the community (emergent group theory). Similarly, the realization that the ability to meet registrant needs exceeded the capability of any one organization (emergent group theory) dovetailed with the possibility of resource exchange within the network to enhance the ability of member organizations to provide services (organizational network theory). The hybrid governance used by the registry network provided evidence of structural and interstitial emergence. Because the research literature

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on emergency assistance registries often calls for using organizational networks to support registry activities, this theory convergence calls for further investigation. Of particular interest is whether there is evidence of emergence in networks formed in locations where legal mandates for establishing an emergency assistance registry and sharing of data between organizations exist (e.g., Florida and Illinois).

Emergence during the preparedness phase. Stallings and Quarantelli (1985) suggested that emergence does not occur during the response phase of a disaster alone. Their research discussed the formation of specific and general goal-oriented citizen groups during non-emergency phases. They also mentioned that public sector emergence may occur during emergency time. However, they provided no indication of public/private emergence occurring during non-emergency phases (i.e., preparedness or mitigation). This study offered evidence of that type of emergence. However, such emergence may be unique to the context of registry operations in Calhoun County, AL. This study indicates a need for further research to determine whether other organizational networks that provide non-emergency phase services (i.e., not necessarily related to emergency assistance registries) show evidence of emergence in their formation and operation.

Implications for Practice

Choosing a registration method. From the beginning of its registry operation, Calhoun County used multiple methods to enroll individuals in its emergency assistance registry. After the registry start-up phase, the county decided that its primary registration method would be an annual return mail, self-registration campaign. Service provider

referrals provided a secondary source of registrations. At the end of the CSEPP registry's lifespan, the county added the ability to enroll through a web-based registration application.

Researchers often advocate for building a registry database using lists of clients from service-providing organizations. Some communities reported using only web-based applications to enroll individuals into their registries. Evidence from this study does not support these choices as effective. Most organizations in Calhoun County's registry network reported an inability to share their client lists because of privacy laws and regulations. Others were willing to help their clients complete the registration form only as part of their intake or home care visits. As a result, registrations through service providers never exceeded 4% of total registry enrollments. Potentially reflecting research that indicates low computer usage rates among the elderly, minorities, and the disabled populations, the Calhoun County registry reported no web-based enrollments. Therefore, communities using service provider or web-based registration methods should consider the impact of low enrollment rates in their decision-making processes.

This study indicated the need for further research into list-of-list and service provider registration. Some locations (i.e., Florida) mandate that service-providers share their client information with county emergency management agencies that operate emergency assistance registries. As indicated earlier, other locations use only web-based registration methods. Broadening the understanding of how those choices affect registration rates would help practitioners make choices that are more appropriate for their communities.

Hazard, phase, and inherent contract. When the Calhoun County registry started, emergency managers based their decisions regarding service provision to registrants on a poor understanding of hazard risk. Typical of what current research indicates is the norm, the county chose to focus its efforts on response phase actions of evacuation support and rescue. Additionally, county registration material indicated that enrollment in the registry did not guarantee that identified needs would be met. The emergency managers' perceptions changed after they combined a detailed hazard assessment with registrant location information. First, they realized that when an individual enrolls in the registry, he or she has established an inherent contract with the county to have his or her identified needs addressed. Second, they grasped that providing equal access meant they had to arrange for registrants to receive the same preparedness items and other services provided to the general population, modified to meet the unique needs of individual registrants. Third, they determined that making registrants more self-sufficient during a disaster by providing preparedness and mitigation services was preferable to planning for evacuation and rescue.

Lessons. These two implications suggest several lessons for practitioners. First, whenever possible, communities should use multiple methods and sources for obtaining registry information. Return mail, self-registration and service provider referrals appear to be most effective. If possible, an individual or organization should be assigned responsibility for coordinating registry activities and maintain the registry database. Second, communities must recognize the inherent contract created by establishing a registry. Because the ADA applies to emergency services, if an individual identifies a

disaster-related need to an appropriate authority (e.g., the local EMA through the registry), that authority is responsible for ensuring the individual's need is met. Third, emergency managers should align the services provided to registrants with the hazards they face and their associated risk. Finally, providers need to tailor their disaster-related service delivery to meet individual registrant needs.

Concluding Remarks

The opening statement of this study noted pressures that emergency management practitioners face in a post-Hurricane Katrina environment. They have to understand and then meet requirements of laws or regulations that direct governments to provide people with disabilities or access or functional needs with the same access to disaster services as the rest of the population. They struggle with how to identify, locate, and provide appropriate services to their disability or access and functional needs population. Research, policy guidance, and law tell them to use an emergency assistance registry to accomplish this task. The research and guidance they see offers little help. They typically suggest using registries, provide a count of who is or is not using registries, and summarize concerns about registry use.

This study attempted to provide some insight into how purpose, hazard, demographics, and administration influence emergency assistance registry operations. Furthermore, it explored how organizations involved in running an emergency assistance registry interacted with each other to deliver services. From a theoretical standpoint, the study confirmed insights from the public health domain regarding the importance of purpose. It also identified a point of overlap in organizational network theory and

emergent group theory regarding how the network that supported the Calhoun County

registry formed. From a practical standpoint, the study offers a model of registry

operations that practitioners might find helpful when establishing or evaluating

emergency assistance registries.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL

Oklahoma State University Institutional Review Board

Date: Tuesday, June 19, 2012

IRB Application No   AS1274

Proposal Title: Emergency Assistance Registries in the Context of Disaster Preparedness

Reviewed and   Exempt
Processed as:

Status Recommended by Reviewer(s): Approved   Protocol Expires: 6/18/2013

Principal
Investigator(s):

Paul L. Hewett   Brenda Phillips
1301 Beaumont Court   214 Murray
Forest Hill, MD 21050   Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.
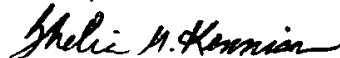
☐ The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval. Protocol modifications requiring approval may include changes to the title, PI, advisor, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Beth McTernan in 219 Cordell North (phone: 405-744-5700, beth.mcternan@okstate.edu).

Sincerely.

Shelia M. Kennison

Shelia Kennison, Chair
Institutional Review Board

APPENDIX B

INTERVIEW GUIDE

<u>Special Needs Populations Registry Interview Guide: Anniston Alabama</u>

Thank you for taking the time to take part in this research project for Argonne National Research. The purpose of this project is to conduct research and analysis of the Alabama Chemical Stockpile and Emergency Preparedness Program (CSEEP). The Alabama Emergency Management Agency (AEMA) and the six Alabama counties involved in CSEPP have undertaken an extensive program to protect the special-needs population within the surrounding Anniston area. Many planning guides recommend using registries to aid in identifying and locating individuals with disabilities or access and functional needs who may require additional assistance before, during, or immediately after a disaster or mass emergency. However, there is little empirical or practice-based research that validates those recommendations. We are very interested in your participation in this program and the experiences you and your organization had in identifying and registering those populations identified as "special needs" The term special needs is defined as those individuals with a variety of disabilities, access, or functional needs who may require additional assistance in the event of a chemical weapons incident.

The interview will last approximately 30-40 minutes. Your name and the name of your organization will be kept confidential.. You have the right to refuse to answer any question, and reserve the right to terminate your participation in this interview at any time. Choosing to do so will have no impact on your relationship with Argonne National Laboratories. Before we begin do you have any questions?

Respondent Information:
- What is your name and position?
- Please tell me about your professional experience related to your current position
    - How long have you worked there?
    - What tasks do you perform in your position?
    - Has your position changed over time?

We are interested in learning – in as much detail as possible about your organization. Can you talk to us about your organization and walk me through what your organization does on a typical day?
Probes:
- When was your organization founded?
- What are the functions of your organization?
- What are the goals and objectives of your organization?
- Tell me about the population that you provide for?
- What are the average age and demographic characteristics of individuals you provide for?
- What type of services do you provide?
- What type of material resources do you provide?
- How many employees does your organization have?

- How many volunteers does your organization have? What is the role of volunteers? How do they interact with employees and clients?

Can you please talk to us about the special population registry? Did you play a role in helping to identify, locate, and keep track of special needs populations?
Probes:
- What role (if any) did your organization play in identifying and locating special needs populations?
- What role did you personally play?
- How long were you and your organization involved in identifying and locating special needs populations? (Number of years / months)
- Prior to the Chemical Stockpile Emergency Preparedness Program, what role did your organization have in assisting special needs populations?
- Did the role of your organization change over time? If so, how. Please elaborate.
- What challenges (if any) did you face in attempting to identify, locate, and assist those populations in need? How did you overcome these challenges? Did new challenges develop over time? If so when and why?
- Were there challenges in assisting one type of special populations verse another?
    - Were different policies and plans put into place for persons with disabilities, persons without evacuation vehicles, unattended children, etc.):
    - Are there distinct needs for each type of special needs population identified?
- Did you or anyone within your organization have any caregiver training prior to working with this registry? If so, did caregiver training play a role in helping to implement the database?

We are interested in hearing about the process of implementing and maintaining the registry. Can you please go through this process in as much detail as possible?
Probes:
- Citizens were made aware of the special populations registry in a number of different ways. In your opinion, which methods worked well? Which methods need improvement?
    - phone calls (number of phone calls made, number of call backs)
    - internet
    - door to door
    - mass mailings
    - mailings attached to calendars
    - advertisements (newspapers)
    - word of mouth (from who?)
        - religious organizations
        - community leaders
        - nursing homes / assisted living facilities

- ○ booths set up at community functions
- - other

- Were there any limitations in contacting people? If so, what recommendations would you make for those methods of contact?
- In your opinion, what were people's reasons for volunteering their information for the registry?
- If people chose to remain on the registry over time, what reason did they give for doing so? Did their needs change over time?
- If people were removed from the registry, what was the reason behind this?
  - death
  - relocation out of the area
  - moving in with family members
  - moved into an assisted living facility
  - assistance no longer required
    - ○ no longer ill / disabled
    - ○ acquired access to transportation
    - ○ will receive assistance from family members
    - ○ other
  - issues of perceived safety (no longer perceive a threat
  - other (please specify)

- For those people who wished to remove themselves from the registry were attempts made to convince them to remain registered?
  - If so, what attempts?
  - If phone calls were made, how many? What arguments were given?
  - If no attempts were made, why not?
  - Were any attempts more successful than others?

- Were attempts made to follow up with these individuals in later years?
  - If so, were these attempts successful? What did they show?

- Did anyone who removed themselves from the registry, re-register themselves later on?
  - If so, how many?
  - What reasons were given?
  - How were these individuals kept track of (were they assigned their original registry number or given new ones)?

- Did the questions on the registry change over the years?
  - How often were changes made?
  - What questions were changed?
    - ○ Were the changes related more to wording or content?
  - What were the reasons for these changes?
  - What impact did these changes have (if any) on the number individuals registered?

- What long term issues did you have in maintaining the registry over time?

<u>Organizational Involvement</u>

Did any other organizations assist in helping to identify, locate, and keep track of special needs populations?

If so, what organizations?

- What role did these other organizations play?

- Had you or your organization worked with these organizations in the past?
    - Did you have any type of previous relationship with these organizations?

If not, were there other organizations that you believe would have been beneficial to work with?

Did any of these organizations have plans in place to assist at risk populations?
- What were these plans?
- If not, have plans been put into place to assist at risk populations since the creation of the database?
    - What are thse plans?
    - Who developed them?
    - Have they ever been tested in a training exercise or an actual event?

Has your relationship with these organizations changed since the implementation of the Chemical Stockpile Emergency Preparedness Program (if at all)?

Do you think relationships with these organizations will continue once the registry changes hands?

Have any emergency management exercises between organizations occurred? If so, please discuss these interactions (when, where, how often)

What worked well? Do you have any suggestions to improve organizational relationships?

Did you work with any caregiver networks on implementing the database? What role (if any) did care provider networks play in the registry process?

<u>Future Plans</u>

How will the registry be maintained?

What happens once the weapons stockpile is depleted?

Do you have plans to work with the 9-11 call service database on keeping track of special needs populations?

What will your role be?

Do you think plans and policies will change once there are no further threats from the chemical weapons stockpiles? What will these changes be?

Will plans previously put in place to assist special needs populations in the event of a chemical weapons incident still be used in the case of another event?

Are preparedness efforts designed to improve the ability of members of the disability community to take protective actions during a disaster event being put into place?
- If so, please elaborate on these efforts. What is being done?

In your opinion, what types of incidents do you view as being a threat to this area? What is being done to protect people from these threats?

Are there any lessons learned that you would like known so that they can be passed along to other special-needs registries through out the country?

Are there any other pieces of information that you think I should know?

Can you recommend anyone else to get in touch with regarding this topic?

Thank you for your time by serving as an interview subject. If we have any follow up questions, can we contact you at a future date? What would be the best way to reach you?

APPENDIX C

REGISTRATION FORMS

Please REGISTER each family and household member who has a special need in case an emergency occurs at the Anniston Army Depot and residents are requested to leave their homes or evacuate. If there is a second person that has special needs, you need to fill out only Question 1, 2, 3, and 8 on a second form and attach it to the first form.   PLEASE PRINT ALL RESPONSES.

SECTION A. Physical or Medical Problems:

1. Is there anybody in your household who is unable to leave in case of a chemical accident? *(D.11)*

Name of Person _____ Age _____

2. Why is this person unable to leave, what makes her/him unable?
(D.13a&b)   *(Please check all that apply)*

Can't see _____
Can't hear _____
Is confused _____
Mentally disabled _____
Can't walk _____
Can't move _____
Is confined to bed _____
Can't drive _____
Back problems _____
Physically unable _____
What else? _____

3. Can you and your family provide all the assistance this person needs to leave? *(D.15a)* Yes _____ No _____

SECTION B. Transportation Problems:

4. Do you have someone (neighbor, relative, or friend) who could help your family in case a car is not available? *(D.7a)* Yes _____ No _____

5. Are you certain that you or family might get a ride? *(D.7b)*
Yes _____ No _____

SECTION C: Children at Home:

6. Would there be times when children in your household are alone and in need of assistance to evacuate? *(D.9a)*
Yes _____ No _____

7. If yes, have arrangements been made for evacuating these children in case you are not at home? *(D.9b)*
Yes _____ No _____

SECTION D. Registration Information:

8. To be registered, we need your home address, mailing address (if different), and telephone number. Please print them below:

Street Address _____

Mailing Address (if different) _____

City _____ Zip Code _____

Phone Number _____

Date you completed form: _____

This information is being gathered under the authority of the State of Alabama for the purpose of planning an emergency response. The State of Alabama will protect your privacy and all private information that you provide here.

Figure C.1. Self-Registration Form: 1999

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This Self-Registration Form is being used to register each family member or household with a special need. County emergency management agencies need to identify those with special needs for planning purposes in case an accident occurs at the Anniston Army Depot.

PLEASE PRINT ALL RESPONSES.

SECTION A. Physical or Medical Problems:

1. Is there anybody in your household with physical or medical problems who is unable to leave in case of a chemical accident?
Yes _____ No _____

Print Name of Person with Physical or Medical Problem
_____ Age _____

2. Why is this person unable to leave, what makes her/him unable? (Please check all that apply)

Vision problem _____   Can't walk well _____
Hearing problem _____   Wheelchair _____
Heart problem _____   Physically unable _____
On oxygen _____   Can't move _____
Is confused _____   Is confined to bed _____
Mentally disabled _____ Back problems _____
Can't drive _____

What else? _____

3. Can you and your family provide all the assistance this person needs to leave? Yes _____ No _____

SECTION B. Transportation Problems:

4. Do you have someone (family, neighbor, relative, or friend) who could help your family in case a car is not available?
Yes _____ No _____

5. Are you certain that you or your family will get a ride?
Yes _____ No _____

9/27/00

SECTION C. Children at Home:

6. Would there be times when children in your household are alone and in need of assistance to evacuate?
Yes _____ No _____

7. If yes, have definite arrangements been made for evacuating these children in case you are not at home?
Yes _____ No _____

SECTION D. Household Registration Information:

8. To be registered, we need your name, home address, mailing address (if different), and telephone number. Please print them below:

Resident Name _____

Apartment/Lot Number _____ Street Number _____

Street Name _____

Mailing Address (if different) _____

City _____ Zip Code _____

County _____

Phone Number _____

Date you completed form: _____

This information is being gathered under the authority of the State of Alabama for the purpose of planning an emergency response. The State of Alabama will protect your privacy and all private information that you provide here.

Figure C.2. Self-Registration Form: 2000-2001

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SELF-REGISTRATION FORM

In the unlikely event of an accident at the Anniston Army Depot, your county Emergency Management Agency (EMA) may advise you to evacuate, shelter in place, or go inside and tune to your local Emergency Alert System radio or TV station. Your county EMA, as part of its public protection strategy, would like to identify persons who cannot prepare for or carry out protective actions either on their own or with assistance from nearby family, neighbors, or friends. If you qualify as a person with special needs, your county EMA can provide you with special emergency planning information, a tone alert radio, and protective equipment.

Instructions: Use one Self-Registration Form for each household member with special needs who requires assistance. If you feel this person can prepare for and respond to emergencies by him/herself or has nearby family, neighbors, or friends who can provide assistance, please do not register. If you need additional forms or have questions, please call (███) ███-████ or toll-free (███) ███-████. Text telephone users, please call (███)███-████.

1(a). Is there anyone in your household who lacks transportation or has physical, mental, or medical problems that make him/her unable to evacuate without help and does not have a Help Network of nearby family, neighbors, or friends

Yes (I need assistance.)   No (I do not need assistance.)
        Please circle response

1(b). Is there anyone in your household who has physical, mental, or medical problems that make him/her unable to shelter in place (following your county EMA's basic steps to shelter in place in a safe room) and does not have a Help Network of nearby family, neighbors, or friends who can assist in preparing a safe room and in sheltering in place?

Yes (I need assistance.)   No (I do not need assistance.)
        Please circle response

If the answer is YES to either question 1(a) or 1(b), please register this person.

2. Why is this person unable to evacuate or shelter in place?   (Please check all that apply.)

Severe vision problem ___		Heart problem ___
Severe hearing problem ___		Wheelchair ___
Cannot walk well ___		On oxygen ___
Physically disabled ___		Confined to bed ___
Mentally disabled ___		Easily confused ___
No vehicle available ___		Cannot drive ___

Other? (Please print.) _____

3. Are there times when children would be alone in your home without someone you trust available close by, whom you can count on to help the children in an emergency?
      Yes   No   (Please circle response.)

If you answer YES, please register your children below and provide the name of a parent or guardian for contact purposes.

To Register: Please provide the following information, including a contact for the person with special needs.   (PLEASE PRINT.)

Name _____ Age _____

Apt./Lot no _____ Street Number _____

Street Name _____

City _____ ZIP _____

County _____ Phone _____

Mailing address (if different) _____

City _____ ZIP _____

Parent or guardian or other contact person:

Name _____ Phone _____

This information is being gathered under the authority of the State of Alabama for the purpose of implementing public protection strategies for all types of hazards. The State of Alabama will protect your privacy and all private information that you provide here.

Figure C.3. Self-Registration Form: 2002-2007

SELF-REGISTRATION FORM

In the unlikely event of an accident at the Anniston Army Depot or other hazardous event, your county Emergency Management Agency (EMA) may advise you to evacuate, shelter in place or go inside and tune to your local Emergency Alert System radio or TV station. Your county EMA, as part of its public protection strategy, would like to identify people who cannot prepare for or carry out protective actions either on their own or with assistance from nearby family, neighbors or friends. If you qualify as a person with special needs, your county EMA can provide you with special emergency planning information.

Instructions: Use one Self-Registration Form for each household member with special needs who requires assistance. If you feel this person can prepare for and respond to emergencies by him/herself or has nearby family, neighbors or friends who can provide assistance, please do not register. If you need additional forms or have questions, please call ███████ or ███████ or email ███████████. Text telephone users can call ███████.

> This information is being gathered under the authority of the State of Alabama for the purpose of implementing public protection strategies for all types of hazards. All information contained in this form is confidential and exempt from disclosure and can be made only to other emergency response agencies.

1 (a). Is there anyone in your household who lacks transportation or has physical, mental or medical problems that make him/her unable to evacuate without help and he/she does not have a help network of nearby family, neighbors or friends?

   Yes (I need assistance.)   No (I do not need assistance)   *Please circle your response.*

1 (b). Is there anyone in your household who has physical, mental or medical problems that make him/her unable to shelter in place (following your county EMA's basic steps to shelter in place in a safe room) and he/she does not have a help network of nearby family, neighbors or friends who can assist in preparing a safe room and in sheltering in place?

   Yes (I need assistance.)   No (I do not need assistance)   *Please circle your response.*

2. Are there times when children would be alone in your home without someone you trust available close by, whom you can count on to help the children in an emergency?

   Yes   No   *Please circle your response.*

If the answer is YES to question 1(a), 1(b) or 2, please register this person.

To Register: Please provide the following information. (PLEASE PRINT.)

Name_____ Age _____

Apt./Lot No. _____ Street Number _____ Street Name _____

City _____ ZIP_____ County _____

Phone _____ Alternate Phone or Email Address_____

Mailing Address (if different)_____

City _____ ZIP_____

Please provide a contact person for the person with special needs. If you are registering a child, please provide contact information for a parent or guardian.

Name _____ Phone _____

Relationship to person with special needs _____

> *The Self-Registration Form is continued on the back of this page. Complete the entire form.*
> *Please answer the questions on the back page about the person with special needs.*

Figure C.4a. Self-Registration Form: 2008-2009, page 1.

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Continued from front page

Is your physical or medical condition temporary?   Yes   No
If you circled Yes, when do you expect your physical or medical condition to improve? _____

Do you have a **Severe Vision Problem**?   Yes   No
If so, what is your severe vision condition? (Please check all that apply.)
Blind ___ Legally Blind ___ Partially blind ___ Night blind ___ Other (please explain) _____

Do you have a **Severe Hearing Problem**?   Yes   No
If so, what is your severe hearing condition? (Please check all that apply.)
Deaf ___ Partially deaf ___ Use hearing aid ___ Other (please explain) _____

Do you have **Difficulty Walking**?   Yes   No
If so, do you use a walking aid? (Please check all that apply.)
Wheelchair ___ Walker ___ Cane ___ Brace ___ Crutches ___ Other (please explain) _____

Do you have **Severe Mobility Problems**?   Yes   No
If so, what are your severe mobility problems? (Please check all that apply.)
Confined to Bed ___ Paralyzed ___ Partially paralyzed ___ Quadriplegic ___ Paraplegic _____
Other _____

Do you have a **Mental or Cognitive Disability** or are you **Easily Confused**?   Yes   No
Please explain your condition. _____

Do you have **Difficulty Breathing**?   Yes   No
If so, what causes your difficulty in breathing? (Please check all that apply.)
Asthma ___ COPD ___ Emphysema ___ Other (please explain) _____
Do you use oxygen or medical equipment to assist your breathing?   Yes   No
If so, please explain. _____

Do you have **Difficulty Communicating**?   Yes   No
If so, what causes your difficulty in communicating? (Please check all that apply.)
Cannot speak ___ Does not understand English ___ Speech impairment ___ Other _____
If you do not understand English, what language do you understand?

_____

If you checked speech impairment or other, please explain.

_____

Do you have a **Heart Condition**?   Yes   No   Please explain. _____

Are you on **Dialysis**?   Yes   No

Are you **Diabetic**?   Yes   No

Do you have a **Physical Disability**?   Yes   No   Please explain. _____

Do you use **Medical Equipment** that requires electricity?   Yes   No
If so, do you have a back up power supply such as a generator?   Yes   No

Would you require **Special Transportation** such as an ambulance during an evacuation?   Yes   No
Please explain why. _____

Can you drive?   Yes   No   Do you have a vehicle?   Yes   No

Figure C.4b. Self-Registration Form: 2008-2009, page 2.

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CALHOUN COUNTY SPECIAL NEEDS REGISTRY

DISCLAIMER

The Calhoun County Special Needs Registry provides emergency responders in Calhoun County, Alabama with important information regarding individuals who may require special assistance during emergencies such as flooding, severe weather, extended power outages, or in the unlikely event of an accident at the Anniston Army Depot.

This program is voluntary and in no way ensures that the individual registering for this program will receive immediate or preferential treatment in an emergency. This program merely provides the emergency response community with information that is pertinent to developing an effective response. The Calhoun County Special Needs Registry in no way replaces the responsibility of individuals to have their own emergency plans.

INSTRUCTIONS

1. Please use blue or black ink to complete this form.
2. Complete one form for each household member with special needs who may require help in an emergency.
3. If you need additional forms or have any questions regarding this form, please call ▒▒▒▒▒▒ for assistance.
4. Text telephone (TTY) users can call ▒▒▒▒▒▒ or email ▒▒▒▒▒▒▒▒ for assistance.
5. **PLESE SIGN AND DATE THIS FORM IN BOX G (SEE BACK SIDE OF FORM)**

A. CONTACT INFORMATION

Last Name	First Name	MI	Date of Birth	Sex: ☐Male ☐Female
Street Address	City	ZIP	Primary Phone #	
Mailing Address (*If different from above*)	City	ZIP	Alternate Phone #	
Name of Subdivision, Mobile Home Park, Apartment Building, etc.		Primary Language Spoken		

B. SPECIAL NEEDS (*CHECK ALL THAT APPLY*)

Communication Needs

☐ I am deaf
☐ I am blind
☐ I have a speech impairment
☐ I have difficulty understanding verbal instructions
☐ I speak in sign language

Independence Needs

☐ I use a walker or cane
☐ I am in a wheelchair or use a scooter
☐ I have a mobility limitation (such as paralysis or amputation)
☐ I have a service animal
☐ I am a bariatric patient

Transportation Needs To evacuate, I require a:
☐ Car/truck/SUV
☐ Van with wheelchair lift
☐ Bus
☐ Ambulance or medical transport

Medical Care Needs

☐ I receive daily I.V. therapy or tube feeding
☐ I am on dialysis
☐ I am on oxygen or a ventilator
☐ I have life-sustaining medical equipment that needs electricity
☐ I require new medical supplies daily (ostomy, catheter, etc.)

Supervision Needs

☐ I need a caregiver with me at all times
☐ I have a severe psychiatric condition
☐ I get confused easily
☐ I have severe memory problems

Shelter-In-Place Assistance

☐ I have a disaster supply kit (food, water, etc. for up to 72 hours)
☐ I need assistance in sheltering in place
☐ I do not need assistance in sheltering in place

PLEASE COMPLETE BACK OF FORM ➡

Self-Registration Form   Version 2010 – Calhoun County, Alabama

Figure C.5a. Self-Registration Form: 2010, page 1.

C. EXPLANATION OF SPECIAL NEEDS

Please explain the special needs you indicated in Box B. If you like, you may also list important medications along with any other information you would like emergency responders to know. *If you need more space, use Box F, below.*

D. EMERGENCY CONTACTS

First Emergency Contact Person *(NOT YOURSELF – This may be a friend, neighbor, family member, etc.)*

Last Name	First Name	Relationship	Phone
			Cell Phone

Second Emergency Contact Person *(NOT YOURSELF – This may be a friend, neighbor, family member, etc.)*

Last Name	First Name	Relationship	Phone
			Cell Phone

E. MEDICAL PROVIDERS *(OPTIONAL)*

Physician Name	Phone
Pharmacy Name	Phone
Home Health Care Agency Name	Phone

F. ADDITIONAL COMMENTS

Please provide any additional information or comments here.

G. INFORMATION RELEASE AUTHORIZATION *(PLEASE SIGN AND DATE)*

This information is being gathered under the authority of the State of Alabama for the purpose of implementing public protection strategies for all types of hazards. By signing and submitting this form, I agree, or my legal guardian agrees, that my name and other information as reported on this form shall be added to the Calhoun County Special Needs Registry.

By submitting this form, I hereby grant the Calhoun County Emergency Management Agency and the Calhoun County 9-1-1 District authorization to use and share this information with emergency responders including but not limited to fire departments, law enforcement, emergency medical services, and local health care agencies in order to facilitate an effective emergency response. I also hereby grant emergency responders permission to enter my home during an emergency if deemed necessary to assure my safety and welfare.

PLEASE SIGN HERE   **PLEASE DATE HERE**

Signature of Registrant or Legal Guardian: _____ Date: _____

H. VOLUNTEERING AND TRAINING

☐ I would like to receive information on volunteering with local groups like the Community Emergency Response Team (CERT).
☐ I would like to receive additional information on how I can increase my emergency preparedness.

Self-Registration Form   Version 2010 – Calhoun County, Alabama

Figure C.5b. Self-Registration Form: 2010, page 2.

CALHOUN COUNTY AT RISK REGISTRY
FUNCTIONAL NEEDS ASSESSMENT/REGISTRATION FORM

DISCLAIMER

The Calhoun County At Risk Registry provides emergency responders in Calhoun County, Alabama with important information regarding individuals who may require special assistance during emergencies such as flooding, severe weather, extended power outages, or in the unlikely event of an accident at the Anniston Army Depot.

This program is voluntary and in no way ensures that the individual registering for this program will receive immediate or preferential treatment in an emergency. This program merely provides the emergency response community with information that is pertinent to developing an effective response. The Calhoun County At Risk Registry in no way replaces the responsibility of individuals to have their own emergency plans.

INSTRUCTIONS

1. Please use blue or black ink to complete this form.
2. Complete one form for each household member with functional needs who may require help in an emergency.
3. If you need additional forms or have any questions regarding this form, please call ▓▓▓ ▓▓▓-▓▓▓▓ for assistance.
4. Text telephone (TTY) users can call ▓▓▓ ▓▓▓-▓▓▓▓ or email ▓▓▓▓▓▓▓▓▓▓▓▓▓ for assistance.
5. **PLEASE SIGN AND DATE THIS FORM IN *BOX F* ON THE BACK SIDE TO PARTICIPATE IN THE REGISTRY.**

A. CONTACT INFORMATION

Last Name	First Name	MI	Date of Birth	Sex: ☐Male ☐Female
Street Address	City	ZIP	Primary Phone #	
Mailing Address (If different from above)	City	ZIP	Alternate Phone #	
Name of Subdivision, Mobile Home Park, Apartment Building, etc.		Primary Language Spoken		

B. FUNCTIONAL NEEDS (CHECK ALL THAT APPLY)

Communication Needs

☐ I am deaf
☐ I am blind
☐ I have a speech impairment
☐ I have difficulty understanding verbal instructions
☐ I speak in sign language

Independence Needs

☐ I use a walker or cane
☐ I am in a wheelchair or use a scooter
☐ I have a mobility limitation (such as paralysis or amputation)
☐ I have a service animal
☐ I am a bariatric patient

Transportation Needs To evacuate, I require a:

☐ Car/truck/SUV
☐ Van with wheelchair lift
☐ Bus
☐ Ambulance or medical transport

Medical Care Needs

☐ I receive daily I.V. therapy or tube feeding
☐ I am on dialysis
☐ I am on oxygen or a ventilator
☐ I have life-sustaining medical equipment that needs electricity
☐ I require new medical supplies daily (ostomy, catheter, etc.)

Supervision Needs

☐ I need a caregiver with me at all times
☐ I have a severe psychiatric condition
☐ I get confused easily
☐ I have severe memory problems

Shelter-In-Place Assistance

☐ I have a disaster supply kit (food, water, etc. for up to 72 hours)
☐ I need assistance in sheltering in place
☐ I do not need assistance in sheltering in place

PLEASE COMPLETE BACK OF FORM ➡

Functional Needs Assessment/Registration Form   Version 2011 – Calhoun County, Alabama

Figure C.6a. Registration Form: 2011, page 1.

C. EXPLANATION OF FUNCTIONAL NEEDS

Please explain the functional needs you indicated in Box B. If you like, you may also list important medications along with any other information you would like emergency responders to know.

D. EMERGENCY CONTACTS

First Emergency Contact Person *(NOT YOURSELF – This may be a friend, neighbor, family member, etc.)*

Last Name	First Name	Relationship	Phone
			Cell Phone

Second Emergency Contact Person *(NOT YOURSELF – This may be a friend, neighbor, family member, etc.)*

Last Name	First Name	Relationship	Phone
			Cell Phone

E. MEDICAL PROVIDERS *(OPTIONAL)*

Physician Name	Phone

Pharmacy Name	Phone

Home Health Care Agency Name	Phone

F. INFORMATION RELEASE AUTHORIZATION *(PLEASE SIGN TO PARTICIPATE IN REGISTRY)*

This information is being gathered by the Calhoun County Emergency Management Agency (CCEMA) for the purpose of implementing public protection strategies for all types of hazards. By signing and submitting this form, I agree, or my legal guardian agrees, that my name and other information as reported on this form shall be added to the Calhoun County At Risk Registry.

By submitting this form, I hereby grant CCEMA and the Calhoun County 9-1-1 District authorization to use and share this information with Community Based Organizations (both private and public) and emergency responders including but not limited to fire departments, law enforcement agencies, emergency medical services, and local health care agencies in order to facilitate an effective emergency response. I also hereby grant emergency responders permission to enter my residence during an emergency if deemed necessary to assure my safety and welfare.

I hereby understand that by signing this authorization I am agreeing to the release and transfer of my personal information herein by, between, and among CCEMA, Community Based Organizations, and emergency responders, including their employees and agents. I also recognize that if I no longer desire my personal information to be shared by, between, and among these agencies and organizations that I have the option of having my information removed from the At Risk Registry within sixty (60) days after receipt of my written request to CCEMA.

PLEASE SIGN HERE   **PLEASE DATE HERE**

Signature of Registrant or Legal Guardian: _____   Date:_____

*If signing as Legal Guardian, please print your name, address, telephone number, and relationship to registrant below:

_____

| Name | Address | Telephone | Relationship |

G. VOLUNTEERING AND TRAINING

☐ I would like to receive information on volunteering with local groups like the Community Emergency Response Team (CERT).
☐ I would like to receive additional information on how I can increase my emergency preparedness.

Functional Needs Assessment/Registration Form   Version 2011 – Calhoun County, Alabama

Figure C.6b. Registration Form: 2011, page 2.

VITA

Paul L. Hewett, Jr.

Candidate for the Degree of

Doctor of Philosophy

Thesis: ORGANIZATIONAL NETWORKS AND EMERGENCE DURING DISASTER PREPAREDNESS: THE CASE OF AN EMERGENCY ASSISTANCE REGISTRY

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Completed the requirements for the Doctor of Philosophy in Fire and Emergency Management Administration at Oklahoma State University, Stillwater, Oklahoma in May, 2013.

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Completed the requirements for the Bachelor of Arts in Political Science at Western Maryland College, Westminster, Maryland in 1977.

Experience:

Deputy Director, Center for Integrated Emergency Preparedness, Argonne National Laboratory, 2003 - present.

Adjunct Faculty, Emergency Management and Continuity Planning Program, University of Illinois-Chicago, 2006 – 2009

Emergency Systems Analyst, Social Science and Law Group, Argonne National Laboratory, 1994 – 2002

Special Assistant to the Director-Chemical Stockpile Emergency Preparedness Program, Maryland Emergency Management Agency, 1993-1994

Officer, U.S. Army, 1977-1992

Professional Memberships:

International Research Committee on Disasters