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School Disaster Needs for Students with Disabilities: Voices from the Field

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of

Education

By

Jill Maria Barnes

2013

ABSTRACT OF THE DISSERTATION

School Disaster Needs for Students with Disabilities: Voices from the Field

By

Jill Maria Barnes

Doctor of Education

University of California, Los Angeles, 2013

Professor David Paul Eisenman, Co-chair

Professor Patricia M. McDonough, Co-chair

The purpose of this dissertation was to identify aspects of disaster care for students with

disabilities that are of concern to representatives of various stakeholder groups. This

phenomenological research examined the experiences and expertise of 22 parents and

professionals who identified school-based disaster needs and recommendations for schools that

serve students with disabilities. The views of these parents and professionals were explored

through approaches to the theory of distributive justice. Interviews were conducted using a one-

on-one, semi-structured interview protocol with a variety of personnel from a large, urban,

southern California school district, district-level education offices, local government agencies, and parents. Schools were purposefully selected, and included two special education centers with student populations comprised entirely of students with multiple, severe disabilities, and one comprehensive, general education high school that included several special education classes and other students with disabilities.

Data were analyzed into five categories. Findings followed each of three research questions: disaster needs for schools serving students with disabilities, disaster recommendations for schools serving students with disabilities, and stakeholder alignment with approaches to distributive justice and disaster resource allocation. Two categories of emergent findings centered on the disaster experiences of participants, and participants' knowledge of school disaster preparedness. One intriguing finding showed that school staff exhibit collective resilience. This research will be used to inform future disaster planning for school districts and local governments.

The dissertation of Jill Maria Barnes is approved.

Eugene Tucker

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University of California, Los Angeles

2013

Dedication Page

This manuscript is dedicated to the teachers and other school staff members who care for students with disabilities, for being extraordinary people in ordinary and extraordinary circumstances. You are ALL heroes.

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Acknowledgements

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The Darkside, for Friday night hockey and beer

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Chapter 1: Introduction to the Study

My oldest son is in a wheelchair, and he was in middle school in the valley when we had the Northridge (CA) earthquake. You know, there were a lot of aftershocks after that quake, but they never evacuated him with the rest of the students. He was on the third floor and they just left him there! They said they didn't have a plan for him.

Debra Duardo, parent.

Disaster preparedness is an underserved need in America's schools. Specific disaster planning for students with disabilities is rare, and is an issue that lacks priority amidst dwindling resources (Ashby, 2007). This dissertation explores what is known about disaster care for students with disabilities among the intersecting, but rarely interconnecting, fields of community emergency management, education, and parenting. I interviewed staff members from local schools, school district education offices, local government agencies, and parents to identify school disaster needs and recommendations for students with disabilities. This research will be used to inform future disaster planning for school districts and local governments.

Background to the Problem

There are a great many definitions of the word disaster, and disasters are often divided into categories such as natural, technological, and human-induced. A disaster is commonly understood to occur in a situation where local resources are overwhelmed, requiring more resources than are immediately available (Rottman, Shoaf, & Dorian). These resources include tangibles such as equipment and supplies for disaster response, intangibles such as knowledge of appropriate techniques used during a disaster to save lives or extricate victims, and blends of both categories, such as personnel who have specialized training and skills. Money and time can also be considered resources in a disaster. How all of these resources are allocated during a

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disaster, and before a disaster to mitigate the effects of a disaster as well as prepare for one, are crucial issues for the emergency management community.

This dissertation is framed by the theory of distributive justice, which explores approaches to allocating resources among individuals with competing needs or claims (Roemer, 1996). As a disaster occurs when resources are overwhelmed, resource allocation is critical to disaster management. There are three approaches to distributive justice that are . Utilitarian principles operate on the concept of the greatest amount of good for the greatest number of people. A second approach to distributive justice is the principle of equal chances, which in a disaster might mean a first-come, first-served philosophy. The third approach maximizes the resources that go to the most disadvantaged, to avoid the worst outcome (generally death) being suffered by the least advantaged population. Children, especially children with disabilities, would be considered a disadvantaged population in a disaster.

Children are at an increased physical risk during disasters, and the 12 million children in the United States with special healthcare needs and disabilities (US Census data, 2007) are even more vulnerable (Murray, 2011; Dolan & Krug, 2006). While schools need to develop disaster preparedness plans for students with special healthcare needs and disabilities, little literature exists on which to base such plans. One survey conducted on school emergency preparedness found that, nationwide, almost one-quarter (22.1%) of school superintendents report that their district does not have an evacuation plan with provisions of any kind for children with special health care needs (Graham, Shirm, Liggin, Aitken & Dick, 2006). The percentage of schools lacking evacuation plans for students with health care needs is likely actually higher, as researchers suspect that responding superintendents may overstate their preparedness, and

superintendents whose districts are not prepared for emergencies may be less likely to have responded to the survey.

Schools cannot count on their communities being prepared, either. A survey funded by the U.S. Department of Homeland Security and conducted by the National Organization on Disability found that emergency managers in each state and in cities of "all sizes" reported that only 69% had incorporated the needs of people with disabilities into their emergency plans. Of that 69%, 59% did not have plans for the pediatric population (2004). A similar study focused on disaster preparedness in counties that had experienced a disaster and found that only 20% had guidelines for people with disabilities in place, and of the counties who did not have such guidelines, 66% had "… no intention of modifying their guidelines to accommodate the needs of persons with mobility impairments …" (Fox, Rooney, Rooney, & Rowland, 2007, p 201).

Lack of Solutions and Research

Currently, research offers no solutions or approaches to the lack of school disaster preparedness for students with disabilities and special healthcare needs. One article starkly noted that, "The common theme is not that [disaster medical] planning for children failed, but rather that planning for children did not exist" (Carley, Mackway-Jones, & Donnan, 1999). Where disaster plans do exist, the prevailing attitude seems to be "one size fits all" (Barile, Fitchen, Ferraro, & Judd, 2006; White, 2006; Rowland, White, Fox, & Rooney, 2007). Schools offer one generic disaster plan for an entire school community to serve everyone's needs, regardless of an individual's ability to act according to that plan or an individual's needs.

Available research on disaster and disabilities usually focuses on site evacuation and sheltering concerns (Dolan & Krugg; Van Willigen, Edwards, Edwards, & Hessee 2002; Kailes,

2006; White, 2006). However, an evacuation that involves relocating an entire community in a disaster is not a strategy often undertaken by schools (Brandon, unpublished thesis), and sheltering students at schools raises quite different concerns from community-based sheltering, as K-12 schools care for an entirely dependent population of minors.

Existing Approaches to the Problem

Including the disabled community and/or their advocates in the community disaster planning process is one new solution gaining ground to address meeting the disaster needs of people with disabilities (Kailes, 2006; Rowland et al 2007; White, 2006). The American Red Cross, the Federal Emergency Management Agency (FEMA), the Department of Homeland Security, the National Organization for the Disabled (NOD) and many other governmental or service entities stress that every person should have a personal disaster preparedness plan; this recommendation includes persons with disabilities. One approach for schools is to create an individualized school disaster plan for each attending child with disabilities (REMS Grant Meeting, 2011), as these minor children are in the care of the schools. However, school districts have no comprehensive model for creating such plans, nor have best practices been established. Nor are financial resources available to develop or implement such plans. A home-based Department of Homeland Security model for family disaster preparedness, ReadyKids, is currently being formally studied (Ramirez, in progress) for use by families of children with disabilities.

Purpose

Imagine being in a large, urban school district in California at one of the 18 schools for students with severe, multiple disabilities when a major earthquake strikes – you and the school

staff may need to care for those students for at least three days, with no outside help. Care will involve building evacuation, search and rescue, triage, feeding, personal care, behavior management, and shelter. Some of the students are non-verbal, some are capable of very little movement, and some use respirators – and for some students, all three conditions apply. As a school district Coordinator of Emergency Services, it's my responsibility to plan for an emergency like that, as well as many other possible disaster scenarios. We do not have specific disaster plans or procedures in place that adequately support our students with disabilities. Other school districts also do not have those plans developed in a way that truly meets the needs of their students.

The purpose of my research is to improve school disaster planning for students with disabilities. I conducted qualitative research that identified disaster care needs and recommendations for students with disabilities. I interviewed 22 staff members from schools, district and county-level education offices, local government agency representatives, and parents to identify the disaster needs of students with disabilities and the needs of their schools.

This study explored the perceptions of what is needed to provide school site disaster care for students with disabilities according to parents and educators, and local government agency representatives. Together, these groups make up the community of a student with disabilities. Each group has different responsibilities, resources, and specialized knowledge to contribute. Parent interviews add an important dimension to the study, as experts in the care of their own children with disabilities, and as non-professionals who experience and voice their concerns differently than people in a professional capacity. I will use the results of this research to inform

disaster planning design to help schools create comprehensive disaster plans that include students with disabilities.

I framed by research within the following research questions:

1. What are the perceived school site needs of students with disabilities in the event of a major disaster as identified by school and district-level education personnel, local government agency personnel and parents?

2. What recommendations about school disaster preparedness for students with disabilities do stakeholders suggest?

3. How do stakeholders align with the approaches to the theory of distributive justice?

   A. How do stakeholders describe their vision for resource allocation in a disaster?

Design

Although I oversee all disaster planning for the 1,100+ schools in a very large school district, I am not an expert in any type of disability, I am not in the field of special education, and I am not even currently assigned to a school site. I need the expert advice and practical field experience of parents, educators, disaster management personnel, and others who manage these children and their needs on a regular basis. This input is crucial to understanding the comprehensive disaster care needs of students with disabilities. Understanding these needs is in turn essential to creating disaster plans that address these needs. This study was a qualitative, phenomenological research project employing one-on-one, semi-structured interviews. Because there is no research to draw from, interviewing made the best fit for this study. I captured how

each stakeholder experienced differently the disaster needs of students with disabilities. Interviewing allowed me to create a holistic account of the multiple perspectives and factors on the disaster needs of students with disabilities. Qualitative studies, especially those employing interviewing methods, are well represented in disaster research, and have been found valuable for identifying the needs of underserved groups (Philips, 2002), one of which could be the students with disabilities who ultimately will benefit from this study. The small number of participants and the time spent in a deeply reflective and descriptive interview fit well with the phenomenological strategy of inquiry. The question set was used as a general guide to capture similarities and differences of experiences among participants, and allowed enough variation to account for the differing roles of the participants. The interviews and my analysis of them allowed me to understand the variety of these experiences and be able to identify patterns and themes among them. The interview data was triangulated among the different job titles and work sites of the participants. The Interview Protocol is included as Appendix B.

I also conducted document analysis in this study, looking for best practices and lessons learned. I analyzed research conducted in related fields, and sought guidance from other districts that have begun to explore the issues of disaster care for students with disabilities. I also kept a research journal of field notes and research tasks, which was used to create an audit trail that documents the research process.

Sample, Methods and Analysis

Target Population

The target population of this study was school district employees who had regular contact with students with disabilities, parents of students with disabilities, and district, city and county

agency representatives who provide emergency management services that supportedt the schools of students with disabilities. These groups were the essential stakeholders in this study, as each group had different responsibilities, resources, and specialized knowledge to contribute. School-level personnel knew school needs, and offered practical experiences in managing children with a range of disabilities. District-level school employees knew the management needs and concerns of the district, and made decisions and guided policy. Local government agency personnel saw how school needs fit into the larger needs of the community. Parents offered a personal and emotional perspective that kept the study concrete.

Public Engagement

The results of this research may improve disaster planning and emergency management in school districts and local governments, due to the greater understanding of the challenges and needs across stakeholder groups as well as those unique to a particular group of stakeholders. The knowledge gained by this project will also allow school district personnel to strengthen collaborative emergency management partnerships with city and county agencies, by focusing on the needs of the community (including schools in that community and the students with disabilities that those schools serve) and among stakeholder groups. This will allow better and more specific public messaging, more robust inter-agency coordination, and new community and agency training to be created and implemented.

I hope that this dissertation will provide the missing information that school districts need to be able to create comprehensive school disaster plans that address the needs of all students, including students with special health care needs and other disabilities.

School districts across the nation are looking for practical solutions to the issues surrounding assisting and caring for students with disabilities in a disaster. School district safety directors, county offices of education, and state departments of education all potentially benefit from this research. Special education teachers, the families of students with disabilities, the students, and the communities in which they live will all benefit from having specific disaster plans in place.

Chapter 2: Literature Review

Introduction

Community planning for disasters is essential, and schools, as part of their communities, need to create their own disaster plans specific to their population's unique needs, including the needs of their students with disabilities. This literature review opens with studies that identify the nature and scope of disasters and the problem of school planning for disasters. It then transitions to the literature on children in disasters, including how children are especially vulnerable, and ways in which disaster planning is, or should be, different for this population. Next, the literature review continues with studies of another population that is vulnerable to disasters, people with disabilities, and disaster planning efforts for them. The literature review concludes with the scant research available that addresses children with disabilities as a vulnerable population in a disaster and what possibilities exist for planning for their disaster needs.

Disasters

The word "disaster" has several different meanings, varying with context and scope. A disaster has sometimes been defined as a rare, unexpected incident of an unpredictable nature (Ramirez et al., 2009). This is one definition commonly in use, but it is only one of many disparate definitions. Sixty-three definitions for the word "disaster" are given in the appendix of emergency management-related terms and definitions for an introductory course in emergency management offered by the Federal Emergency Management Agency (FEMA) (2011). Among these definitions is that of disaster researcher Enrico Quarantelli, who asserts that "Disasters occur when the demands for action exceed the capabilities for response in a crisis situation" (as cited in FEMA, 2011, p. 20). Broad definitions such as those offered by Quarantelli and Ramirez

suit the purposes of this dissertation best, as what may be considered a disaster in a school may not rise to that level in the outside community, and may vary among schools as well. Participants in this study gave a wide variety of responses when asked to describe their disaster experiences, and many of those experiences would not be considered disasters if a narrower definition was used. Using a broad definition that works for school employees contextualizes the term. The term "emergency" also has multiple definitions, some of which overlap with definitions of "disaster." The two terms are used synonymously here.

Disasters occur any time that available resources have been overwhelmed. Communities are vulnerable to a wide array of disasters, some natural, some technological, some human-induced (Rottman, Shoaf, & Dorian, 2005). Each school disaster plan should be site-specific and take into consideration types of emergencies that are likely in the geographic area (Council on School Health, 2008). Some of these disasters arrive with advance notice and others strike without warning. Following the lead of community preparedness strategies, schools have been planning for natural disasters for years (Allanson, 1967), more recently for technological disasters, and most recently have begun to plan for terrorist attacks and school shootings. Preparing an all-hazards disaster plan is recommended for every school (FEMA 2006; US Department of Education Office of Safe and Drug-Free Schools 2008; Cole, Henry, Tyson, Fitzgerald & Hopkins, 2007) , as is the case for local, county, and state governments nationwide.

An all-hazards approach to disaster planning emphasizes addressing all of the hazards that threaten a jurisdiction in a single, comprehensive emergency plan instead of relying on multiple plans, each specific to a type of disaster (FEMA, 1996). Rottman, Shoaf, and Dorian (2005) define an all-hazards approach as a consistent set of core responses is developed that

incorporates all potential hazards. This approach simplifies response and eliminates the need for multiple, redundant plans (FEMA, 1996). The all-hazards approach allows a school to respond consistently and efficiently during an emergency (Rottman, Shoaf, & Dorian, 2005). The plan provides the foundation for any hazard-specific elements such as drop-cover-hold on procedures for an earthquake, which will supplement the basic plan (Rottman, Shoaf, & Dorian, 2005).

Planning for disasters is not a theoretical exercise undertaken by school administrators - emergency plans are activated at schools with some regularity. Since 2002, most school districts surveyed in California had experienced one or more emergencies or disasters (Kano & Bourque, 2006). In a survey of three Los Angeles County school districts, several different types of emergency situations commonly affected each school site. The most commonly reported incidents in frequency order were injuries among students or staff, student violence, animals or insects on campus, criminal activity in the neighborhood, strangers on campus, power failures, and gang activity (Kano, 2007). This is a wide variety of situations for which these schools would need response plans. Emergencies that had the greatest effect on schools were neighborhood criminal activity or strangers on campus, and school violence or shootings (Kano, 2007). Preparing for such emergencies with measures such as an all-hazards disaster plan can increase a school's ability to function during and following an emergency, no matter the type of emergency experienced (Kano & Bourque, 2006).

Natural disasters are statistically more likely and more destructive than human-induced hazards (Gheytanchi, 2007). Each type of weather event has its own specific set of guidelines for preparation and response, and is included in a school's set of disaster plans based on the geographic likelihood of such an occurrence. Weather-related emergencies can cover a wide

geographic area, and involve multiple infrastructure challenges. These challenges increase the likelihood of overwhelming local emergency response agencies, and increases response time to a school. Weather disasters make having contingency plans and a well-stocked emergency supply cache for long-term survival important on campus.

Most of the hurricane disaster planning for schools takes the form of mitigation and emergency evacuation procedures (Redlener et al., 2008). Because there is advance notice, hurricanes command a different type of emergency response than many other weather-related disasters. Hurricane Katrina, in August of 2005, became one of the deadliest storms in United States history, killing more than 1,000 people, and causing widespread injury and property damage (Gheytanchi et al., 2007) . Authorities reported more than 5,000 children missing after Katrina, and it took six months to reunify the last of these children with family (Gausche-Hill, 2009). Following Katrina, families and communities saw the need to prepare for disasters with greater urgency (Gheytanchi et al., 2007). Fortunately for schools, meteorologists can generally predict hurricanes some days prior to landfall, allowing school districts time to cancel school and take measures to mitigate hurricane damage.

By contrast, as an example of a natural disaster that strikes without warning, earthquakes present more obstacles and challenges for planners than hurricanes (Redlener et al., 2008). In addition to injuries caused directly by the earthquake from damaged buildings, students risk injury by airborne room contents, or injuries from other earthquake-associated hazards (Richie, 2003). In planning for an earthquake, a school must prepare for the possibility of aftershocks, and also for a variety of secondary disasters that are caused by the earthquake, such as fires, power outages, tsunamis, and/or chemical spills (Richie, 2003).

Human-induced disasters are another category of disaster, and these incidents may be accidental or malicious in origin FEMA, 1996). Surveyed Los Angeles County schools reported "terrorism or bioterrorism" as the type of emergency for which most schools are least prepared, but chemical-biological weapons, hazardous materials, and radiological releases are all examples of human-caused, environmental disasters for which schools ought to be prepared (Kano et al., 2007). The six different categories of chemicals most commonly used for chemical weapons each have their own set of symptoms and treatments, and children have more vulnerability to these chemicals than adults (American Academy of Pediatrics, 2006). Both of these concerns are reasons for including chemically-based incidents in a school emergency plan. If a chemical weapons threat at a school seems far-fetched, consider that with an all-hazards approach to emergency planning, a school would use the same response for an overturned truck carrying hazardous material, a chemical leak at a local factory near a school site, or a chemical weapon (FEMA, 2011). The adaptability of the plan is one advantage of creating an all-hazards disaster plan. Depending on the level of threat in a chemical situation, a school might shelter in place with doors and windows closed and heating and air conditioning turned off, or might evacuate the premises.

Another type of human-induced disaster is a mass shooting. Terrorism incidents and school shootings, such as the tragedies at schools in Jonesboro, Arkansas; Littleton, Colorado; Virginia Tech; Newtown, Connecticut and the school hostage terrorism crisis in Beslan, Russia, provided the impetus for many schools and their first responder agencies to create a plan for armed intruders on campus (Vossekuil, Fein, Reddy, Borum, & Modzeleski, 2002). These types of mass casualty events have unique needs, including a need to coordinate with local law enforcement and to provide for multiagency response (Graham et al., 2006). Prior to the Columbine shooting,

the law enforcement special weapons and tactics teams that responded to Colorado's Columbine High School had never devised a school-based scenario of their own as they believed that such a situation was "…too far-fetched to serve as a realistic training scenario" (State of Colorado, 2001, p. 102). Even after multiple mass shooting incidents occurred in a span of several years, a substantial number of schools still did not include an active shooter component of their emergency plan. Six years after the Columbine massacre and eight years after the Jonesboro school shooting killed five people and injured ten more in the state of Arkansas, 42.8% of schools surveyed in Arkansas still had no written plan for preventing or responding to a terrorist or mass-casualty incident (Graham et al., 2006). Schools cannot adequately protect against a threat for which they have no plan.

School Disaster Planning

There are no federal laws or oversight of school emergency plans. A U.S. Government Accountability Office study conducted in 2007 (Ashby) found that only 32 states have laws or policies requiring school districts to have emergency plans of any kind. There is no federal financial incentive for school districts to have disaster/emergency plans in place. Without funding or legal backing, adequate disaster planning at schools rarely happens, despite the need.

Where plans do exist, they, and the preparedness efforts that accompany them, are often inadequate. In 2006, a survey of school superintendents revealed that most (86.3%) reported having an emergency response plan, but fewer had plans in place that addressed preventing emergencies (57.2%). Almost a third of responding superintendents reported never conducting an emergency drill (30%) (Graham et al, 2006). A preparedness survey of California schools reported that 90% had evacuation plans and first aid supplies, about half (50%) had an

emergency alert system and food, and less than half had a sheltering plan, rescue equipment, or supplies for students with special needs (Kano et al, 2007).

Most K-12 schools in the United States prepare inadequately for disasters, even schools located in areas with known and persistent hazards (Cole, Henry, Tyson, Fitzgerald, & Hopkins, 2007; Graham, Shirm, Liggin, Aitken, & Dick, 2006; Kano, Ramirez, Ybarra, Frias, & Bourque, 2007; Redlener, Grant, Abramson, & Johnson 2008). Planning and preparing for a variety of emergency situations is a vital part of maintaining a safe, healthy school, but administrators often overlook these duties. A national survey found that 70% of school district officials "consider competing priorities to be a challenge to planning for emergencies" (Ashby, 2007), yet such plans and preparations are essential to protect students in emergencies. School staff members serve a completely dependent student population, whose needs may become magnified in a disaster. As Hurricane Katrina, the 2011 Tohoku earthquake and resulting tsunami in Japan, the events of 9-11 and other tragedies have shown, communities and the schools within them must have the ability to respond to natural disasters and human-induced hazards alike. As institutions with large numbers of a vulnerable population in their care, schools need to be especially mindful of disaster preparedness.

Federal agencies and researchers are aware that schools need to do more to properly plan for disasters. The findings of Graham et al's 2006 study highlight the need for schools to continue planning and preparation efforts, while Cole et al. state that, "Schools must dramatically increase their ability to develop plans," (2007, p. 2) as well as practice and implement the plans. Outside interests and educators themselves are also aware of this need. The American Academy of Pediatrics recommends that every school devise protocols unique to their location and population, "…rather than following a one-size-fits-all disaster plan that fails to take into

account [these considerations]"(Committee on Environmental Health and Committee on Infectious Diseases, 2006, p. 1273). The America Prepared Campaign reminds us of the obligations of public school officials with regard to terrorism preparedness, "During the school day, governments … are responsible for the safety of our children. Their work is not voluntary," (Phinney, 2004, p. 4). And an internal report on school administrators in the Los Angeles Unified School District found that school emergency management was the third most reported topic administrators were interested in, preceded only by teacher evaluation and budget (Patton, 2010).

School administrators are rarely safety experts, and need clear recommendations to guide them in creating practical school plans that meet the needs of their students (Ashby, 2007). Those recommendations need to be research-based best practices. The field of school disaster planning is under-researched. Kano and Bourque (2008, p. 49) and Borum et al. (2010, p. 34) both refer to the "paucity" of research in the field. Researchers ranging fields as diverse as sociology (Muschert, 2007) to public health (Ramirez, 2009) mention the need for more research in school disaster preparedness. Even the United States Department of Education Office of Safe and Drug-Free Schools (2008) cites the lack of research in school disaster preparation. Research yielding best practices will result in successful emergency planning at schools, which in turn will save lives and reduce injury severity in the next community emergency or disaster (Ramirez et al., 2009).

Children in Disasters

The need for adequate emergency management in schools is palpable, as schools protect an entirely dependent population of children; during an emergency, schools cannot simply close and send everyone home. Public schools are accountable for students in their *in loco parentis*

role; while a student is in the custody of a school, the school must take care to provide for students' care (Graham et al., 2006). During an emergency, schools are obligated to shelter, feed and otherwise care for students until each minor student is reunited with a custodial adult. In some disaster situations, it may take days before all students are collected from school by a parent.

Children face greater risk during disasters for a host of reasons. Typically, more than one-third of victims of a disaster or multi-casualty incident in an affected United States community are children (Gausche-Hill, 2009), and this proportion rises to half of all individuals affected by disaster worldwide (Dolan & Krug, 2006). Children have anatomic, physiologic, immunologic, developmental, cognitive and psychological differences from adults. Children are also vulnerable because of their dependence on others, the necessary decision-making support and the level of emotional support they need (Hoffman, 2009). In addition, children are also more vulnerable than adults to the direct consequences of a disaster, such as loss of family protection, hypothermia and coldness due to inadequate shelter, food shortages, and lack of potable water (Nakamura, 2005).

Disaster Medical Needs of Children

There are many challenges in treating children's injuries during and following a disaster, and these challenges dovetail with medical disaster response needs that adversely affect children. In a large-scale disaster, schools will need to react to the situation without waiting for emergency crews. School personnel will often be the first responders to events occurring on their own campus, as formal emergency crews are frequently unable to reach disaster scenes immediately (Auf der Heide, 2003), even though school personnel do not traditionally serve as first

responders (Kano, 2007). Local medical agencies can easily become overwhelmed when faced

with great numbers of pediatric patients, and can easily reach their surge capacity long before all

pediatric patients have been seen. A survey of US emergency medical systems agencies found

that only 13% of surveyed medical agencies such as hospitals and trauma centers had a

pediatric-specific mass-casualty plan of any kind (Shirm, 2007). On a national level, only two of

the 27 Disaster Medical Assistance Teams (DMATs) deployed to multi-casualty incidents and

disasters across the United States currently have pediatric response sub-teams in place (American

Academy of Pediatrics Committee on Environmental Health and Committee on Infectious

Diseases, 2006). No pediatric training is required of DMAT members, even though a study of

DMAT deployment to four recent natural disasters revealed that one-third of the patients seeking

treatment from the DMAT in those disasters were children (Gnauck et al, 2007).

Disaster care for children must be differentiated from that for adults; they cannot be

treated like "little adults." ((Dolan & Krug, 2006, p. 62). Many of children's special treatment

concerns are due to their smaller size and high metabolic rate. This causes them to develop

dehydration, fatigue, and malnutrition faster than adults (Dolan & Krug, 2006). In addition to

dehydration, a smaller volume of circulating blood can create other fluid loss, such as bleeding

or vomiting (Gausche-Hill, 2009).

The small size of children creates multiple challenges when they are injured. Multiple

traumas are common, as greater force is applied per unit of body area. Thinner skin, a greater

body surface area to volume ratio and lower fat levels make children more susceptible to changes

in temperature (both body and environmental); the lack of fat also leads to higher rates of blunt-

force trauma in children, as their solid organs are not as well cushioned. A child's more pliable

skeleton also leads to increased trauma injury rates. Children also suffer from greater systemic effects of toxins due to the ratio of body surface area to mass. Being shorter than adults on average, children are also closer to the ground where some toxins, such as chlorine and sarin gas, accumulate (Gausche-Hill, 2009).

Children's faster metabolic rate also makes them more susceptible to inhaled toxins; a greater concern given the recent possibility of children being targeted in a terrorist action (Gausche-Hill, 2009). Recent events such as 9-11, the Oklahoma City bombing, and the Beslan, Russia, school takeover by terrorists have shown that civilians and children can be specifically targeted by terrorists (Graham et al., 2006). This necessitates changes in disaster planning for biological, chemical or radiological weapons attacks. Prior response planning for these weapons was focused on military personnel as targets. Simply modifying practices intended for adult members of the military will not work as an approach to caring for children. Children are actually more likely to be exposed to these weapons and contaminated by them than adults because of their intake patterns, as the above information on children's smaller body size and higher metabolic rate shows (Committee on Environmental Health/Infectious Diseases, 2006).

There are other vulnerabilities and planning considerations specific to children for biological, chemical or radiological weapons, many of which have not yet been incorporated into disaster plans. Following exposure to one of these types of agents, children cannot be decontaminated in adult decontamination units, as children require high-volume, low-pressure heated water systems. Physical protections, such as gas masks for biological and chemical weapons, have proved to be risky for children. An unknown number of Israeli children reportedly suffocated after donning gas masks during Operation Desert Storm. Children also

need different post-exposure antidotes, antibiotics, or dosages than adults. The currently approved smallpox vaccine does not even list an approved age range in its literature, nor is the autoinjector for use with nerve agents approved for pediatric use. To address this need, the Strategic National Stockpile must include pediatric supplies, formulations and dosing schedules (Markenson & Redlener, 2004).

Children also have immature immune systems, and combined with their poorer hygiene habits, are more susceptible to infectious diseases (Dolan & Krug, 2006), as well as to biological weapons (Committee on Environmental Health/Infectious Diseases, 2006). Children experience more complications to illnesses and more severe reactions to vaccines, and have less natural protection against diseases as herd immunity is not fully developed (Gausche-Hill, 2009). Diseases prevalent in shelters established after the 1995 Hanshin Awaji, Japan, earthquake included diarrhea, respiratory infections, and measles, which children suffered at higher rates than adults (Nakamura, 2005). Similar diseases and rates are reported in Gnauck et al's DMAT deployment study (2007). A high rate of pediatric gastroenteritis was diagnosed in three out of four of the studied DMAT deployments. The authors theorized that this may have been due to damaged water and sewer infrastructure that led to a compromised water supply, which is not uncommon following a natural disaster.

Specific injuries, illnesses, and causes of death will vary based on the type of disaster experienced (Dolan & Krug, 2006; Nakamura, 2005). Although rates and severity of reactions may affect children differently than adults, the types of injuries are not significantly different between children and adults experiencing the same disaster (Dolan & Krug, 2006). For example, and in contrast to the chemical, biological, and radiological agent examples above, the Hanshin

Awaji earthquake revealed distinct cause of death patterns. Of the children under the age of 15

who died in that earthquake, 55.7% of them died of suffocation. An additional 15.3% died from

contusions (below the surface blunt-force trauma), and 12.3% were crushed to death (Nakamura,

2005). As Nakamura points out, disasters are repeated regularly (p. 383, 2005), which only

serves to add to the need for disaster planning.

Disaster Planning for Children

Despite the evidence that children are a vulnerable population in a disaster and at

increased risk for harm, disaster planning efforts specific to children appear to be rare outside of

school plans. In studying disasters that affected children, "The common theme is not that

planning for children failed, but rather that planning for children did not exist, " (Carley,

Mackway-Jones, and Donnan, 1999, p 406). Multiple studies researching the effects of disasters

on children cite the need for pediatric-specific disaster plans as a next step (Dolan & Krug, 2006;

Hoffman, 2009; Carley, Mackway-Jones, and Donnan, 1999; Markeson & Redlener, 2004;

Nakamura, 2005), as do the recommendations from a 2006 policy document from the American

Academy of Pediatrics' Committee on Environmental Health and Committee on Infectious

Diseases. Markeson and Redlener refer specifically to the lack of disaster and disaster planning

literature about children as "sparse" (p. 302), pointing out that existing studies in these areas

focus almost exclusively on adult needs. Further, where literature on children and disasters does

exist, it almost always addresses identifying and treating Posttraumatic Stress Disorder (PTSD)

in children. A MEDLINE database search going back 20 years using disaster-related keywords

found more than 4,000 results, but only 350 references concerned children. Of those child-

specific entries, 95% were about PTSD (Markeson & Redlener, 2004).

Gaps in disaster planning - for children, among other issues - were exposed following Hurricane Katrina in 2005. Hurricanes are preceded by several days of advance warnings, ideally giving government agencies and other entities time to prepare. Prior recent disasters such as the terrorist attacks of September 11th, 2001, the school bombing in Beslan, Russia in 2004, and the 2004 Indonesian tsunami that killed more than 50,000 children, provided recent disaster experiences and valuable lessons for emergency managers and government officials to draw from. Yet planning and response for Hurricane Katrina were fraught with errors and inefficiencies, many of which disproportionately affected children, even though school was not in session, and most children were home with family. Some hospitals experienced debilitating losses of power that necessitated hand-ventilating critically ill patients for days on end. Other hospitals endured inadequate amounts of food and supplies, and staff members resorted to intravenous hydration. Other hospitals reported security concerns such as sniper fire and looting. No arrangements were made by the government to evacuate pediatric patients from hospitals, and hospitals relied on their own networks and partnerships, resulting in a haphazard patchwork of fixed-wing aircraft and helicopter evacuation response (Murray, 2011).

Technology-dependent children and other children with special health-care needs at home experienced increased morbidity and mortality due to lack of back-up electricity. Local emergency medical services were largely unaware of technology-dependent children, children on oxygen, and children who had other special healthcare needs in their areas, and so did not provide adequate assistance to these children and their families. The experiences – and failures – in Hurricane Katrina response provide strong evidence that pediatric-specific disaster planning is essential (Murray, 2011).

Disabilities and Disasters

Children are not the only vulnerable population in a disaster. Another group of people who face added risk in disasters is people with disabilities (Usher-Pines, Hausman, Powell, DeMara, Heake, & Hagen, 2009), although this population has only recently been studied. A study of the 1995 Hanshin-Awaji earthquake refers to people with disabilities as a "… new probable risk factor…" for earthquakes (Osaki & Minawa, 2001, p. 156). This statement suggests that people with disabilities had not been looked at as a discrete population disproportionately affected by disasters such as earthquakes before this point. Studies published after the Osaki and Minawa article all mention how sparse the literature is on the disaster experiences of people with disabilities. One study states that the "academic literature is extremely limited," (Priestly & Hemingway, 2006), another refers to " little empirical data exist[ing]" (Fox, White, Rooney, & Rowland, 2007), and a third complains that, "The majority of literature available regarding emergency preparedness and people with disabilities" focus only on policies and are meant for the first responder community (Smith & Notaro, 2009). References to the lack of literature fall into one of two categories; studies that referred to "the disabled" as one group of people - as do the above-mentioned studies - and other studies that focus on a singular type of disability.

Referring to people with disabilities as "a population" is actually somewhat of a misnomer, as each category of disability can be considered a population in its own right. Many studies address only one type of disability. Studies variously refer to " mobility impairments" (Rowland, White, Fox & Rooney, 2007), "people limited to wheeled mobility" (McClure, Boninger, Oyster, Roach, Nagy, & Nemunaitis, 2011), "Physical disabilities," which included

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persons with any one of 36 diseases (Osaki & Minowa, 2001), "physically or mentally fragile persons" (Chou, Huang, Lee, Tsai, Chen & Chang, 2004), and "[individuals] with perceptual or cognitive disabilities" (Sullivan & Hakkinen, 2006).

The term "disabled," while fairly commonly used, can have a variety of meanings, as the uses included here illustrate. The Americans with Disabilities Act defines "disability" succinctly although broadly and non-specifically as "a physical or mental impairment that substantially limits one or more of the major life activities" (1992). Another frequently-used term is "special needs," but it is falling out of favor. June Kailes, a disability policy consultant and advocate, writes that labeling a person as special needs is "often used as first responder shortcut language," but that its meaning "is confusing and unclear" (2006, p. 20). Another study points out that the needs of the disabled are not special, as "Like all other people, disabled people need safety, shelter, and support during natural disasters" (Van Willigen, Edwards, Edwards, & Hessee, 2002, p. 98).

One term coming to prominence is "functional needs," which is the term that will primarily be used in this paper. The federal government defines a functional needs population as one "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" (National Response Framework Glossary). This definition lends itself to emergency management, as it allows planners and first responders to focus on what needs an individual has, regardless of diagnosis or symptoms. The term is in heavy usage by federal entities, especially the Federal Emergency Management Agency (FEMA), and the term has also been adopted in many state government emergency planning

documents, including those from California, Florida and New Hampshire. However, the "functional needs" designation is used to also refer to pregnant women, those who do not speak English, and older adults in addition to people with disabilities (CSTI, 2012). This dissertation primarily uses the term disability to avoid confusion on the part of the reader.

Disaster Planning for People with Disabilities

The need for disaster planning specifically for people with disabilities was one of the lessons learned from Hurricane Katrina in 2005. Although Katrina was not even the most powerful of storms in the Atlantic Basin that year, to date it is the most widespread and costly single-source natural disaster in United States history. The storm surge flooding of the city of New Orleans and its surrounding area resulted in extensive damage. More than a million residents were displaced from their homes, up to 5 million lost electrical power, and an estimated 1,300 people were killed (Priestly & Hemingway, 2006). Death and injury rates disproportionately affected populations with disabilities, many of whom had no transportation and thus no way to evacuate, and/or relied on electrical power for daily living. Storm warnings and evacuation notices were given in advance, but evacuations were incomplete or misguided, leaving many residents on their own (Sullivan & Hakkinen, 2006). Some institutions were as vulnerable as individuals – an entire hospital gathered its patients in the ground floor lobby ready to evacuate, after being told that "FEMA is coming" to facilitate the evacuation. FEMA never arrived, and many waiting patients and staff members died (Community Healthcare Planning and Response to Disasters, 2012).

Guidance documents since issued by many federal and state agencies have begun to address functional needs (FEMA, 2011; ready.gov, 2011; US Department of Education, 2008;

US Department of Homeland Security Chemical Stockpile Emergency Preparedness Program, 2006; State of California, 2008; State of New Hampshire 2010; State of Florida, 2011), although typically the guidance is exceedingly general (Priestly & Hemingway, 2006; Smith & Notaro, 2009; Wisner, 2002). Some research existed on the disaster experiences of people with disabilities before these planning documents became available (Van Willigen et al, 2002; Fox et al, 2007; Rowland et al, 2007; Shields, Boyce & McConnell, 2009), and other studies have looked at the personal preparedness rates of people with disabilities (Smith & Notaro, 2009; Uscher-Pines et al, 2009; Rooney & White, 2007; McClure et al, 2011). What is missing is research that evaluates the effectiveness of specific disaster planning for people with disabilities.

The need for research that evaluates the outcomes of disaster planning for disabilities is well documented, however. Preparedness strategies and best practices need to be established and tested (Rooney & White, 2007), and move beyond response procedures that apply to first responders (Rowland et al., 2007). Function-based definitions of disability and strategies to address them need to be incorporated into local disaster plans and tested (Uscher-Pines et al, 2009). This is more difficult to achieve in disaster research than many other fields, as disasters cannot be created for the purposes of testing a plan, and simulations do not readily replicate disaster conditions (Fox, et al, 2007). Validating a new design, such as a functional-needs approach to disaster planning, is a challenge, as actual disaster conditions can only be approximated (Sullivan & Hakkinen, 2006), and waiting for a disaster before researching to occur is not practical.

Creating guidance documents at macro levels of government is a reasonable first step towards disaster planning for people with disabilities, but does not necessarily translate into the

existence of such plans at the community level. A survey funded by the U.S. Department of

Homeland Security and conducted by the National Organization on Disability found that

emergency managers in each state and in cities of "all sizes" reported that only 69% had

incorporated the needs of people with disabilities into their emergency plans (2004). A similar

study focused on disaster preparedness in counties that had experienced a disaster and found that

only 20% had guidelines for people with disabilities in place, and of the counties who did not

have such guidelines, 66% had "… no intention of modifying their guidelines to accommodate

the needs of persons with mobility impairments "(Fox et al., 2007, p. 201). Counties in that

same study also had few best practices to offer in planning and operations concerning their

disabilities populations (Fox et al., 2007). This lack of transference from knowledge to practice

has been referred to as "Lessons learned, but not applied" (Kailes, 2006).

Children with Disabilities and Disasters

Parallel (though limited) tracks of disaster research have developed, studying two

separate populations at risk: children, and people with disabilities (Peek & Stough, 2010).

Knowing the population that is routinely cared for in schools, children with disabilities emerge

as a distinct population whose needs must be included in school disaster planning, and this

population represents a larger percentage of children than one might expect. Between 13% and

18% of all children under 18 years of age are identified as being a Child with Special Health

Care Needs (CSHCN),depending on the definition of CSHCN (American Academy of Pediatrics,

2010; Garrett, Grant, Madrid, Brito, Abramson, & Redlener, 2007; Van Dyck, McPherson,

Strickland, Nesseler, Blumberg, Cynamon, & Newacheck, 2002). As medical care becomes more

advanced, more of these children live at home rather than in a specialized care facility (Garrett et al., 2007), which means that more of them attend school.

The population of children with disabilities has begun to be mentioned in disaster literature, although rarely. A literature review searching for mention of this population found 51 articles on people with disabilities in disasters; only five of these articles addressed the disaster needs of children with disabilities (Murray, 2011). More research is called for by experts in the field. The most recent article in the field, from 2011 by John S. Murray, refers to a "paucity of published literature (p. 227)," "a significant gap in understanding (p. 227)," and states that "not enough scholarly work has been done (p. 228)" to address the disaster needs of CSHCN – and all within three columns of a 4-page article. Lori Peek and Laura Stough take a similar tone in their 2010 article. They state that "researchers have rarely considered how disability may contribute to the short-and long-term impacts of disaster on children (p. 1260)," observe that the" functional-needs approach has not yet been used (p. 1262)" in disaster research, and twice refer to the "dearth" of empirical studies on CSHCN and disasters (pp. 1262, 1267).

The term CSHCN has been used since at least the 1990's in the medical literature about this population, and the term is still in use, although its definition has been changed. The meaning has changed from one defined more by lists of conditions, which varied, to a focus on the consequences of the conditions, which are indicated by the child's functional needs (Van Dyck et al, 2002). One table used previously is included here (Foltin & Cooper, 2009):

Table 1: Medical Conditions Included as CSHCN

Airway/pulmonary
Asthma
Bronchopulmonary Dysplasia (BPD)
Cystic Fibrosis
Tracheomalacia
Tracheal Stenosis
Tracheal Atresia
Babies with Apparent Life Threatening Event
Apnea

Cardiovascular
Complex Congenital Cardiac Defects
Acyanotic Defects
Cyanotic Defects

Down syndrome/other congenital birth problems

Traumatically disabled children

Neurological
Epilepsy
Hydrocephalus
Mental Retardation
Spina Bifida
Cerebral Palsy

Hematological/oncological
Sickle Cell Disease
Cancer

Immunological
HIV and AIDS

Endocrinal

Musculoskeletal
Children with a history of meningitis
Birth Defects
Genetic Disorders
Osteogenesis Imperfecta (OI or "Brittle Bone Disease")

The current definition of CSHCN is based on a range of functional needs, including the "dependence upon prescription pharmaceuticals, a need for an increased level of care, the need for emotional or behavioral sciences, a limitation of activities, and a requirement for special therapies" (Garrett et al, 2007). The use of the term "disability" will be primarily used to maintain consistency within the paper and align with disaster management terminology.

Hurricane Katrina in 2005 brought visibility to the issues of children with disabilities and the support they require in disasters (Murray, 2011). Several concerns emerged from this disaster. Children with disabilities suffered disproportionately during the mass evacuations, and were often made to evacuate without assistive or life-sustaining medical equipment. These children also frequently require specialized medications, and their often-fragile state makes them vulnerable when separated from their regular health providers and specialists, known as their "medical home" (Garrett et al, 2007). These issues added to the difficulties experienced by children with disabilities during Katrina. Additionally, of fourth to twelfth graders surveyed in the region affected by Hurricane Katrina, one in five reported an injury to a family member, and 15% stated that a family member had died as a result of the hurricane or its aftermath (Osofski, Osofski & Harris, 2007). If a large disaster strikes during the school hours, children whose family members and caregivers are injured or killed may not be retrieved from school for quite some time, and schools must have disaster plans that prepare to care for children for days.

School disaster plans for children with disabilities are important for other reasons as well. These children are particularly dependent on their regular knowledgeable and skilled caretakers, including teachers and other school staff (Foltin & Cooper, 2009; Garrett et al, 2007; Murray, 2011), to manage the specialized care, complex treatments and diets, and technological

assistance that this population requires (Mace et al, 2010). Children are also dependent on the good decision-making of their caretakers (Garrett et al, 2007); in a disaster at school, those good decisions are in turn dependent upon having good plans and training in place. Additionally, as Dolan and Krug point out, children make up almost 30% of the population at large, but almost 100% of the population if a school is struck by a disaster (2006), making good disaster plans at schools even more important.

Creating comprehensive disaster plans for schools that meet the needs of all students will require some level of individual planning for students with disabilities. These children may need help with feeding and toileting, mobility, medications, medical treatments, and communication (Murray, 2011), as well as having a range of technological needs such as ventilators, tracheostomy tubes, catheters, defibrillators and shunts to name a few (Foltin & Cooper, 2009). Comprehension levels may also impede the ability of children with disabilities to appropriately respond in disaster situations (Peek & Stough, 2010). Addressing all of these needs in a school disaster plan takes a lot of resources, both human and material. And part of the definition of the word disaster is "… a situation in which your resources have been overwhelmed" (FEMA, 1996). How then, can a school justify the tremendous resources needed to accommodate the disaster needs of children with disabilities?

Approaches to Distributive Justice

Allocating limited resources and prioritizing needs is a part of managing every disaster. How those resources should be allocated is theorized in three distinct approaches to distributive justice. Utilitarian principles operate on the concept of the greatest amount of good for the greatest number of people. In this approach, actions and decisions are based on achieving the

maximum overall benefit (Smart & Williams, 1973). This is the principle that guides medical triage, and is predicated on directing treatment to those who are most likely to benefit from it (Moskop & Iverson, 2007). In triage protocols for multi-casualty incidents, a person whose heart is not beating is not given CPR, because CPR requires a continuous effort by at least one rescuer, and that rescuer would not be able to help anyone else. Instead, that person is tagged as "deceased" and the rescuer moves to the next victim (START, 2001). Individuals who require a disproportionate amount of resources might not be a priority. As federal guidance suggests, most emergencies are managed based on these principles (FEMA, 1996) When looking at managing care for a child with disabilities for example, this approach requires "unpalatable assumptions about the value of one life over another" (Hoffman, 2009, p. 1509).

A second approach to distributive justice is the principle of equal chances. In this approach, each individual is given an equal chance at survival, as one's life is of equal value to its owner (Taurek, 1977). In a disaster, this might mean that a first-come, first-served philosophy prevails over treatment regardless of need or severity, or where supplies are low, supplies might be handed out by lottery, a coin toss, or other randomized sequence (Winslow, 1982).

The final approach supports prioritizing the needs of people with disabilities and other vulnerable populations over the needs of others without enhanced levels of need. This theory is often stated as "the best outcome for the least well off" (Farber, 2007, p. 321). In this approach, maximum resources go to the most disadvantaged, to avoid the worst outcome (generally death) being suffered by the least advantaged population. This may be difficult to justify in terms of medical treatment, but is often used in education. For example, children who have learning difficulties get extra resources such as smaller class size or intensive instruction, and children

whose families cannot afford healthful food are given meals at school. Those resources are not available to everyone, because some families have greater resources and support networks of their own (such as the ability to pay for tutoring), and thus a lesser need for utilizing limited resources at the school site.

Chapter 3: Research Method

Introduction

This dissertation used a series of interviews to gather information about the school disaster needs of k-12 students with disabilities. The information will then be used by school districts to inform disaster preparedness for students with disabilities. Interview subjects included a mix of school-site and District-level educators, city and county government employees, and parents of students with disabilities. This study explored the views of these parents and professionals through the theories of distributive justice, guided by the following research questions:

Research Questions

1.   What are the perceived school site needs of students with disabilities in the event of a major disaster as identified by school, district-level education personnel, local government agency personnel and parents?

2.   What recommendations about school disaster planning for students with disabilities do stakeholders suggest?

3.   How do stakeholders align with the theories of distributive justice?

        A.   How do stakeholders describe their vision for resource allocation in a disaster?

Research Design

The qualitative design of this study appropriately employed interviews, document analysis, and field notes. This approach allowed interview participants to share in-depth experiences that informed their thoughts and ideas about the school disaster needs for students with disabilities, and focused on the inductive nature of that process. These characteristics are among those that define qualitative research (Merriam, 2009). The intended descriptive nature of the findings is also a qualitative measure (Merriam, 2009). In addition, as little research has been conducted about disaster planning for students with disabilities, this study was exploratory, which also calls for a qualitative approach (Creswell, 2009). Data collection and analysis were conducted simultaneously, with analysis of earlier interviews informing and refining the interview process for successive interviews. This reflexive process and the ongoing assessment of the process was ideal for a qualitative approach (Maxwell, 2005). Quantitative methods do not give the level of in-depth information necessary to provide schools and districts with disaster preparation guidelines, nor would they provide the practical insights of field experts; i.e. the educators who work on a daily basis with students who have disabilities. Qualitative studies in disaster research can "…empower and give voice to respondents" (Stallings, 2002, p. 203), which bolsters the confidence of interview subjects. Exploring the world of those who serve students with disabilities in some capacity best served this dissertation through qualitative means, as only qualitative methods allowed me to generate the detailed descriptions that gave context to the thoughts and ideas expressed in interviews.

Sample

Target Population

The target population of this study was school district employees who have regular contact with students with disabilities, parents of students with disabilities, and district, city and county agency representatives who provided services that support the schools of students with disabilities. Together, these groups made up the whole community of a student with disabilities. Each group had different responsibilities, resources, and specialized knowledge that helped serve the needs of these students.

Sampling Frame

The sampling frame for this project employed maximum variation sampling to include a variety of employees in the school district: two Special Education Center principals and one regular education principal, two Special Education Center classroom teachers and one regular education classroom teacher; three one-on-one Special Education aides to students, two at Special Education Centers and one at a regular education site; one itinerant Occupational Therapist; one itinerant Least Restricted Environment counselor; one member of district-level Student Nursing management staff; one member of district-level Special Education management staff; one Educational Service Center instructional superintendent; and one Office of General Counsel lawyer. I focused on the Special Education Center staff because investigating the most extreme needs will allow school district emergency managers to best create comprehensive disaster plans. The regular education site participants provided a contrasting point of view to those who work exclusively with a student population who has disabilities.

There were also a variety of non-district employees interviewed for this study, including one City of Los Angeles Emergency Management Department staff member; one City of Los Angeles Department on Disability staff member; one staff member from a county-funded, outside agency that provided services to students and their families, and one regional occupational center staff member. Three parents of special education students, one from each school, also participated in the study.

These job classifications were purposefully selected to be representative of the major stakeholder groups in the disaster needs of students with disabilities – those who manage students with disabilities, those who manage schools and the emergencies that happen there, and those who manage community emergencies and people with disabilities in the community. The roles listed in the preceding paragraph captured the range of a student's community. These representatives held diverse perspectives on school disaster planning for students with disabilities and how the theories of distributive justice applied to this issue. For these reasons, the above job classifications join parents as the most crucial stakeholders.

These stakeholders were selected as crucial for reasons as varied as the job classifications themselves. Parents of students with disabilities are an essential group, as no one is more intimately familiar with the needs of these children than their parents, or more vested in the well-being of these children. As primary caretakers and family members of students with disabilities, parents had already thought about how a disaster might affect their family. Parents provided a rich source of information and data about their children, as well as personal experiences to share. As these students are minors with severe disabilities that affect cognition and communication, including their parents as participants is close to giving voice to the students themselves.

School site personnel must be involved in any discussion of school disaster needs of students with disabilities. Including the principal was key, both as the leader of the school and as the person on campus with the best whole-site perspective. Classroom teachers of students with disabilities needed to be included, as they are charged with the care of these children on a daily basis. Another necessary perspective was that of educational aides, some of whom are assigned to students with disabilities on a one-on-one basis, and assist with care such as toileting and feeding. These paraprofessionals get to know students and their needs on a personal level, and provided valuable input about the practicalities of providing care during a disaster. Occupational therapists and physical therapists provided another facet of the disaster needs of students with disabilities, as they work on specific skills with students, and were familiar with assistive technology and equipment designed for these students. These therapists are assigned to multiple school sites, and travel among their assigned schools on a rotating basis. Because of their work with multiple disabilities and multiple sites, offered a broad and comparative perspective on the needs of students with disabilities and the resources available to meet some of the needs.

School district personnel assigned at the district management level covered different aspects of the disaster needs of students with disabilities, as they operate at a "macro" level and are familiar with a wide range of school situations. District-level personnel were also often familiar with available community resources, how to leverage those resources, and the limitations of community resources. Having the perspective of a member of district-level Special Education management staff helped ensure that the breadth of disabilities in the district was represented. A member of management from District Nursing similarly provided the breadth of the medical and special health-care needs of the students, and what it takes to serve those needs. Including an Instructional Superintendent provided the perspective of how disaster needs fit into

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the larger context of school district needs. The legal perspective from the Office of General Counsel provided recommended and discouraged courses of action, and existing legal challenges for students with disabilities and the school district that serves them.

A school district and the community it serves may operate independently during times of normal operations, but those roles and expectations may change during times of disaster. As greater contact, cooperation and resource-sharing are expected between these two entities during disasters, it made sense to create space for city and county community partners in this study. The City of Los Angeles has an Emergency Management Department, whose members plan for a variety of emergency situations and guide the city's emergency response actions, including management strategies for community members with disabilities. A staff member from this department provided context for how the school's disaster plans fit with the plans for the city. The City also has a Department on Disability, that provided insight into issues and challenges in emergency planning for and response to people with disabilities, including challenges that may not be apparent during the school day. The Department on Disability also accesses a network of resources that may be beneficial to school disaster planning. one staff member from a county-funded, outside agency that provided services to students and their families, and one regional occupational center staff member. The Los Angeles County Regional Occupational Center also provided valuable input, as they interact with a multitude of service providers, and serve many adults with disabilities. A final perspective on the school disaster needs for students with disabilities came from a county-funded disability service provider located on a school campus, and worked with students and families, but is not considered a part of the school. These varied perspectives and experiences combined to provide a comprehensive picture of the disaster needs of schools for their students with disabilities. Each of these groups had an interest and a role in

the welfare of these children, and together family, school, and local government defined a child's community.

Selection Procedures

In the school district used for the study, there is a wide network of district-level coordinators and directors who oversee and manage the operational aspect of education, separate from a similar structure that operates the instructional piece. These mid and upper-level managers maintain close contact with individual schools and with local agencies in their areas of expertise. Working with recommendations from these coordinators and directors as well as my own contacts, I selected district and local government employees who expressed prior concern about the disaster needs of students with disabilities, and who hold one of the stakeholder positions identified in this study. I tried to maximize the diverse perspectives and experiences within and among job classifications, and selected schools in different geographical areas of the district that reported to different units. I used snowball sampling to fill the required number of participants for each job classification. Special Education Center principals were identified in a similar manner, with principal recommendations and snowball sampling used to fill the numbers of required school-based participants. School site participants worked at the schools of the selected principals, and were selected in equal proportions from the schools of the three principals. I obtained permission from the school principal of all participants who work at a school site before interviewing.

This study used purposefully-selected school sites, including two of the 18 Special Education Centers that each exclusively serve hundreds of children with multiple severe disabilities. This "extreme case" provided the "crucial test" of theory (Maxwell, 2005); if the

information from these interviews can help create disaster plans to serve the children of these "centers," the same plans could be used successfully for students with a lesser degree of specialized need. Purposefully selecting sites also provided a data-rich environment, as many neighborhood schools might only have a handful of students with disabilities, and a narrower cross-section of types of needs. Including multiple sites increased the diversity of needs represented and prevented creating a study that was too narrowly focused on a particular site's set of needs with lessons that may not apply elsewhere. Special education centers also gave me access to a staff with a wealth of experience, through both volume and severity of student needs. This knowledge base was crucial to the success of the study, as I collected a broad range of experiences and ideas.

Selection

I informed participants that participation in the study was completely voluntary, their information kept confidential, and their identity protected. Participants were provided with a study information sheet (Appendix A). I reminded participants that my role in the district was advisory to the schools, not supervisory, and that there was no possible harm to their career for choosing to participate or not participate.

Timeline

Initial contact with potential interviewees was made between November and January, and interviews were conducted between December 2012 and January 2013. Each interview was intended to take about an hour, and ran between 46 minutes and 77 minutes. Data analysis began concurrently with the interviews, and concluded at the end of March, 2013.

Research Methods

Site Access

To gain access to school sites in my capacity as researcher, I obtained approval from the school district's Committee for External Research Review (CERR), housed in the Research Unit of the Office of Data and Accountability. I also obtained permission from the University of California Los Angeles (UCLA) Institutional Review Board, in the Office of Human Research Protection Program.

Participants

I reminded district-employed study participants that my district position was advisory to the schools, not supervisory, and that the intent of this work was to help schools become better prepared for disasters. I shared with staff members my family's history with disabilities, as well as my school-based background to ease the potential discomfort of speaking about the issues raised in the interviews. Many educators are concerned about adequately caring for their students following a disaster, but have not had the time to devote to the extensive planning that it would take to create a comprehensive plan, nor are they comfortable tackling an area such as disaster management that they perceive to be outside their sphere of expertise.

Project

Data Collection Methods

This was a qualitative, phenomenological research project employing one-on-one, semi-structured interviews. Because there was no research to draw from, interviewing was the best fit for this exploratory study. I wanted to capture how each stakeholder experienced the disaster

needs of students with disabilities. Interviewing allowed me to create a holistic account of the

multiple perspectives and factors on the disaster needs of students with disabilities. Qualitative

studies, especially those employing interviewing methods, are well represented in disaster

research, and have been found valuable for identifying the needs of underserved groups (Philips,

2002), such as the students with disabilities who ultimately will benefit from this study. The

small number of participants and the time spent in a deeply reflective and descriptive interview

fit well with a phenomenological strategy of inquiry. The interview question set was used as a

general guide to capture similarities and differences of experiences among participants, but

allowed enough variation to account for the differing roles of the participants. The term

"disaster" was not defined for participants, who were thus able to include incidents they

personally deemed "disasters," regardless of whether or not an incident rose to the level of

overwhelming community resources. The interviews and my analyses of them provided me with

an understanding of the variety of these experiences and I was able to identify patterns and

themes among them. The interview data was triangulated among the different job titles and work

sites of the participants. The semi-structured Interview Protocol is included as Appendix B.

I also conducted document analysis in this study, looking for best practices and lessons

learned. I analyzed research conducted in related fields, and sought guidance from other districts

that have begun to explore the issues of disaster care for students with disabilities. I also kept a

research journal of field notes and research tasks. This research journal created an audit trail that

documented the research process. Rudimentary disaster plans developed by other school districts

for students with disabilities were also reviewed. Interviews were recorded and transcribed, and

supported and triangulated each other and the other collection methods.

Data Analysis Methods

As I began to code the interviews, I realized that the statements fit best by first separating data into sections by research question. The "needs" and "recommendations" sections were then sub-divided into strands focused on plans and preparations, supplies and equipment, response actions, staff, and parents, and then were treated chronologically . The "distributive justice" data were sub-divided into each of the three approaches, other approaches, and undecided. Categorizing the data in this way made it easier to later sequence the story of school preparedness for students with disabilities.

I employed inductive data analysis, using grounded theory, for the categories of data that I had not anticipated. New, unanticipated categories included a category of the actual disaster experiences of the participants, and a category for what participants know about current disaster preparedness at schools. A third emergent category centered on the collective resilience of school staff. These categories arose from open coding and the analysis of significant statements from the interviews. Data analysis began simultaneously with data collection, beginning after the conclusion of the first few interviews, guided ultimately by whether or not the results were consistent with the data collected. The literature review also informed the data analysis.

I embedded several reliability procedures into the data analysis process. I incorporated member checks of selected participants to ensure that information gathered from interviews was accurate. I also maintained a codebook and checked it periodically to guard against a drift in definitions of the codes as I analyzed later data. I also cross-checked codes with another person for inter-coder agreement, and conducted peer debriefing to review and ask questions about the study to make sure that it has meaning to others and not just myself. I also looked for data that

support alternative explanations. This helped to guard against seeing my own interpretation of the data as the only possible interpretation. Finally, when writing up my findings, I emphasized details in descriptions of the participants' experiences that would enable readers to better assess what may be transferable to their own situation.

Legal and Ethical Principles

My research project complied with existing legal and ethical codes. I followed all LAUSD regulations, UCLA guidelines, the Federal Policy for Human Subjects (34 CFR Part 97), the Family Education Rights and Privacy Act (FERPA: CFR Part 99), and guidance from the American Psychological Association's (1992) Ethical Principles of Psychologists and Code of Conduct. I provided a study information sheet to all potential participants (Appendix A). I provided all research participants with a consent form (Appendix C), and obtained a signed and dated written consent form before beginning each interview. Participants received a copy of their signed consent form. The consent form ensured confidentiality of the information obtained in connection with this study. Interviews each took place in a location with privacy of the participant's choosing, behind closed doors. Confidentiality was maintained by changing any descriptive or demographic information that might identify the participant or the participant's affiliated school, and identifying participants by category only, and not by name. Data is stored in a password-protected computer that is stored in a fire-proof safe when not in use, and only accessible to me. Data will be securely destroyed after the dissertation has been approved and filed.

This study was of minimal risk to participants, and completely voluntary. I was not in a supervisory position over anyone in the school district, and the decision to participate in the

study or not did not cause harm to the participant's career. No students or student data were involved in this study. I received permission to conduct this study from the school district Committee for External Research Review, and notified the district of UCLA Institutional Review Board approval before I began any research activities.

Ensuring Credibility

There are a number of ways that I ensured the credibility of this dissertation. Although I was the only researcher conducting the interviews, I maintained systematic data analysis by using standardized interview protocols. This technique addressed both internal and external credibility issues, as it worked as a check against my own biases about the site, as well as providing evidence for my conclusions. Others will be better able to judge whether or not my results can be generalized with standardized protocols, and the technique allows for others to conduct future research at different types of sites and with different sample populations. I recorded, transcribed, and thoroughly documented all meetings and kept my own field notes. This will helped the study maintain objectivity, and acted as a check against reactivity.

Transferability

Participants' perceptions and experiences will assist disaster researchers identify the benefits and barriers that exist as they create comprehensive school disaster plans that include students with functional needs. Reporting individual experiences and their context will also help future researchers create research projects that address the barriers uncovered in this study (Creswell, 2009). Detailed descriptions of the disaster needs, recommendations and experiences of participants, will also help practitioners such as school principals and emergency managers evaluate the findings in their own settings (Merriam, 2009).

Anticipated Benefits of Research

The results of this research may improve disaster planning and emergency management at school sites and for school districts. A greater understanding of the challenges and needs across stakeholder groups as well as those unique to a particular group of stakeholders will allow for better community disaster planning as well. Through the exploration of the theories of distributive justice, this research will also bring to light the reasoning that guides emergency management decision-making in schools and communities. The knowledge gained through this dissertation will also allow school district personnel to strengthen collaborative emergency management partnerships with city and county agencies, by focusing on the needs of the whole community (including schools in that community and the students with disabilities that those schools serve) and among stakeholder groups. This will allow better and more specific public messaging, more robust inter-agency coordination, and new community and agency training to be created and implemented.

Findings will be presented orally to selected school district staff during a staff meeting. A PowerPoint presentation and a report of findings will be made available to district employees. Findings will also be embedded into future trainings and presentations on school emergency preparedness in this district. The report of findings as well as the PowerPoint presentation will be made available online to all district employees through the district's emergency preparedness and training website. A link to the findings and PowerPoint will be distributed to all interested research participants via district email.

Burden on Research Subjects

Fifteen school district employees were interviewed. Participant job classifications will consist of: Three Special Education Center principals; three Special Education Center classroom teachers; three one-on-one Special Education Center aides to students; one itinerant occupational therapist; one itinerant Least Restricted Environment specialist; one member of district-level Student Nursing management staff; one member of district-level Special Education management staff; one Instructional Superintendent; and one Office of General Counsel lawyer.

Seven other (non-district) people were interviewed; three parents of District special education students; one City of Los Angeles Emergency Management Department staff member; one City of Los Angeles Department on Disability staff member; one staff member from a county-funded, outside agency that provided services to students and their families; and one regional occupational center staff member.

Each of the 22 research project participants was contacted three times between November 2012 and February 2013 (via phone or email) – once to secure participation in the research project, once to arrange the time and place of the interview at the convenience of the participant, and once for the hour-long interview. Selected participants were contacted again to conduct a member check. The total participation time for each participant was no more than 1.5 hours. Twenty-two interviews representing a wide range of stakeholder groups were necessary to ensure that all relevant stakeholder groups were represented in the project. The three contacts plus a possible fourth contact for a member check totaled no more than 1.5 hours. This amount of time was sufficient to obtain consent, arrange and conduct an in-depth interview on the topic, and

provide a member check without being intrusive. Research participants each received a $30.00

Target gift card in appreciation for their time upon completion of their one-hour interview.

Summary

Creating comprehensive school disaster plans that include the needs of students with

disabilities is a process that has not been undertaken before in a systematic way by schools.

Using special education centers that serve students of all ages with multiple, severe needs

provide purposefully-selected sites with data-rich environments and knowledgeable staff.

Methods undertaken in this study include interviews and document reviews. These methods and

the careful collection and analysis of the results will together provide informed answers to the

research questions for this study, and will yield the information necessary to create

comprehensive, practical planning information to help schools create disaster plans that include

students with disabilities.

Chapter 4: Findings

Overview

Specific school disaster planning for students with disabilities is rare, and studies documenting those needs are rarer still, as documented in chapter 2. This dissertation examined the experiences and expertise of 22 parents and professionals who identified the school-based disaster needs of students with disabilities, and offered recommendations to address those needs. Interviews were conducted with a variety of personnel from local schools, district-level education offices, local government agencies, and parents. Among the interviewed were personnel from three schools in a large, urban southern California school district. Two of the schools were Special Education Centers, serving students with multiple, severe disabilities, and one large general education high school. The principal, a special education teacher, a classroom paraprofessional, and a parent were interviewed from each school. High-level district employees, including a staff member from Special Education, District Nursing, the Office of General Counsel, and an Instructional Superintendent, were also interviewed. The remaining four interviewees came from the city's Emergency Management Department, the city's Department on Disability, a county Regional Occupational Center, and a county-funded disability service provider. This research will be used to inform future disaster planning for school districts and local governments.

The purpose of this research was to identify aspects of disaster care for students with disabilities that are of concern to representatives of various stakeholder groups, guided by the following research questions:

1.   What are the perceived school site needs of students with disabilities in the event of a major disaster as identified by school and district-level education personnel, local government agency personnel and parents?

2.   What recommendations about school disaster preparedness for students with disabilities do stakeholders suggest?

3.   How do stakeholders align with the approaches to the theory of distributive justice?

      A.   How do stakeholders describe their vision for resource allocation in a disaster?

Findings for the Disaster Experiences of Participants

The thoughts and opinions expressed during the interviews were palpably informed by each individual's experience with disasters and other emergency situations. Only three respondents reported that they had never experienced a disaster personally or professionally. The experiences described by the remaining participants varied as widely as the participants themselves, partially because the nature of a disaster was not pre-defined for respondents. Respondents detailed incidents of weather, violent acts, and personal tragedies.   Although some respondents were raised in Southern California, others described situations unfolding in other areas of the United States, as well as in Canada, Mexico, and Japan.

Of the 22 people interviewed for this research, 15 respondents mentioned 30 disaster incidents that affected them personally. Perhaps not surprisingly for Southern California, a full half of the self-defined disaster incidents were earthquakes. Seven of these incidents referenced the local 1994 Northridge earthquake, the last moderate quake to strike the area. The effects on respondents of the Northridge earthquake included a few whose homes were damaged, one who

lost water service for several weeks, one whose family was evacuated due to possible damage to a nearby dam, one who was unable to get to work due to damage to roads and the place of work, and one whose apartment was "red-tagged" as uninhabitable. Other earthquakes, such as the Sylmar, California earthquake in 1971, the 1985 Mexico City earthquake in which one respondent lost her family home, and an earthquake in Japan were also mentioned.

Tornadoes were the next most-cited disaster personally experienced, mentioned in four separate interviews. During one of these tornadoes, while the interviewee was stranded in her car, the tornado passed overhead and then moved on to destroy her brother's business. In another tornado, the family trailer of the interviewee was flung through the window of a church. Other weather-related disasters mentioned were blizzards and storms.

Disasters caused by humans were also mentioned by several respondents. These incidents included car crashes, an apartment fire, and the civil unrest experienced in Los Angeles surrounding the outcome of the 1992 Rodney King police brutality trial. Some of the incidents in this category were experienced on an extremely personal scale, such as the participant who performed CPR on his mother, the participant who spoke of having a gun aimed at her head during her drive home from work, and the participant who witnessed a suicide attempt by his father.

Sixteen of the 22 interviewees reported current or past work experience at a school, and half of them spoke about disasters that occurred at school. The eight respondents who reported both work experience and disaster experience at a school mentioned 22 discrete school-based disaster incidents, indicating a rich variety of school-based incidents. No parents or non-school district employees mentioned actual disaster experiences at schools. All three of the current

principals as well as three former principals were among those who had experienced what they described as disasters at school. One principal recounted six separate incidents, five of which involved violence. The breadth and depth of these disaster experiences indicates that disasters are not just theoretical in southern California schools.

Lockdowns were the most frequently-cited type of disaster experience at schools, numbering five occurrences. These five lockdowns came from three participants, and included two intruders on campus, two shootings in the area surrounding the school, and one instance about which the respondent did not elaborate. An additional incident was noted in two interviews, involving a person with apparent mental illness who wandered onto campus and created a disturbance, but was not defined as a lockdown in either interview. Six other violent incidents were also not characterized by respondents as lockdowns. These incidents included three stabbings; one by a student with a machete on campus, one unspecified, and one where an adolescent who had been stabbed multiple times was thrown out of a passing car onto the sidewalk next to the school at dismissal time. Other violent incidents included an attempted dating violence assault on a student by a non-student gang member, an assault on a school employee by a student with a mental illness that had not been disclosed to school personnel, and an after-school shooting that left two gang members dead in the alley next to a school.

Other incidents that were described by school employees as disasters included a trash can fire, a bomb threat, a threatening phone call that resulted in a SWAT-team search of the school, an irate, gang-affiliated parent on campus who was suspected to be carrying a gun, a shelter-in-place, and a bee swarm. One unusual situation involved a busload of students who witnessed a classmate get hit by a truck. Another unusual occurrence involved the 1997 North Hollywood

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bank robbery shootout, regarded as one of the longest and bloodiest events in U.S. police history. Several busloads of elementary school children were re-routed to a nearby high school, and cared for by high school staff members who initially had no information about the children. The elementary students remained at the high school for hours, until all parents had been contacted and picked up their children.

Table 2: Representative Quotations about the Disaster Experiences of Respondents:

Northridge Earthquake, 1994 (personal)

- What I learned in that quake is that I had absolutely no clue about being prepared. I think I went outside with a mesh shopping bag from Tijuana, a bathrobe, my hair looked like the Bride of Frankenstein. I had two mismatched shoes and my keys and my wallet. And that was it. That was my level of preparedness.
- I just remember thinking, "Wow! All that I've learned, and I can't even move," you know? And it was shaking so hard, I couldn't even get out of bed. I couldn't even move. And I don't know how much was just actual emotional freezing on my part, or could I physically not get up because of the shaking? A lot of broken glass from various things falling over and breaking like that. So it was not pleasant, not pleasant.
- They thought the Hansen Dam was going to burst; we were in the line of the flood channel. We actually did get evacuated with that particular earthquake. That impacted me because I was actually relocated to an aunt's house in L.A. until they gave the all-clear that we can return home.

Other Personal Disasters

- Of course, the civil unrest in 1992 that I got to witness right at my back door, as looters were coming through. And that was a little unnerving.
- I've seen several of my dogs get run over by cars, but I don't know. You know, my sister Marjorie ran over one in a lederhosen dress while she was on her way to Mr. Dunderback's Bavarian Restaurant to work while I was in my yellow denim leisure suit for picture day. And she left the dog with me to bleed and die, gasping for air.
- I was driving toward my brother's business, and I had never seen a tornado. The skies darkened and it got very ugly out. I pulled my car over under an overpass, just like other cars, because we thought it was a hailstorm or something coming. It sounded like a freight train. And it destroyed my brother's business. Everybody kind of huddled inside away from doors and windows and things. And they were fine. The roof was lifted off it. Contents were all thrown around everywhere. The building had to be torn down.

- o One day we get a call that there is a kid with a machete in the quad. And we go running out there, and sure enough, we see a kid with a big – what's called a hog-sticker. I don't know if you know what that looks like, but it looks like a giant bowie knife. It's not like your typical machete, it actually comes to a point. And that machete had been in the hands of a judge that morning who gave it to the kid's parents who gave it back to him, who then comes here and stabs somebody with it.
- o At [name of school] one year, we had a bee swarm just show, appear from nowhere from the sidewalk at dismissal time.
- o Another time, leaving an after-school program, as we're about to leave, we got locked down because there was a shooting going on. And so we had to gather up all the parents already starting to leave and hustle them back into the buildings and make sure everything was safe before we could let them out. After having a few incidents, we did things to make it safe for kids, but we really reconsidered where they were and the safety for the families coming. The safety in the neighborhood made these kinds of programs no longer really all that viable.

Findings for Knowledge of School Disaster Preparedness and School Disaster Preparedness

Specific to Students with Disabilities

Many of the school disasters reported by participants involved students with disabilities, and some incidents occurred on Special Education Center campuses. Experience during actual emergency incidents, training and campus preparedness efforts, as well as participants' experiences as students and/or parents themselves each helped to provide a base level of knowledge about school disaster preparedness in general, and as it applies to students with disabilities. Although some participants later contributed some knowledge of school preparedness efforts, when initially asked how schools are prepared for emergencies and disasters, half of the participants responded that they did not know. This was especially striking, considering their participation in this research. This group included all of the parents, two school staff members, three district employees who do not currently work at a school site, and all four of the non-district people in this study, including one non-district person working at a school.

When asked, "Do you know anything about what's in [the emergency plan]?" one teacher replied, "Can you explain what the plan is?" One of the non-district participants stated that what she knows about school disaster preparedness is what is reported in the local newspaper. The non-district person working at a school site confessed, "I know we have a plan, but I honestly haven't read it. So I couldn't tell you more than that." The respondent from the city's emergency management department posited that he does not know exactly how prepared the schools are, adding that he "guesses" that the schools are as prepared as the general community.

These statements belie the disaster preparedness plans, training, supplies, and teams that schools do have in place, and about which the majority of participants were able to elaborate. Twelve participants mentioned in some detail the disaster plans in place at the school or district level, with 10 of those respondents articulating that the plans are robust. Interviewees mentioned several different facets of school disaster plans, and evacuation was described by 16 respondents, the most-frequently occurring specific facet of existing disaster plans. Responses about evacuation were articulated about students in general as well as students with disabilities, notably students in wheelchairs. Responses were fairly consistent and knowledgeable across interviews regardless of work site or job title; school employees know how to evacuate buildings in an emergency and know where to go once they get out of the building.

Training was another category of school disaster preparedness mentioned by respondents. Generalized references to emergency drills were mentioned by 12 of the 22 people interviewed for this study, most of them not working at school sites. Almost all of the responses categorized as training that mentioned a specific type of drill or training were from participants working at schools. Earthquake drills were mentioned by six respondents, including all three principals. Fire

drills, shelter-in-place drills, lockdown drills, and triage training were each mentioned in a few interviews.

Equipment and supplies that are kept at schools for disasters were brought up by 16 respondents. Each school in this district has a shipping container of emergency supplies, usually referred to as a "bin," that is kept outdoors at each site. This container was mentioned by 10 study participants. The knowledge of what this bin contains and the level of detail describing the contents varied widely among participants. Three participants only noted that they had a bin, and eight others rattled off a fairly comprehensive list of contents. Similarly, classroom disaster supplies were reported in 11 interviews, almost all school-site people, including all classroom teachers and aides. Many schools stock their classrooms with a bucket or backpack containing emergency supplies for the class. Personal kits or supplies brought in by students, medical supplies and medication, shelter supplies such as tarps, and communication equipment also each received several mentions. Despite a three-day emergency supply of water in 55-gallon barrels at each school, food and water was only mentioned by three respondents, all from the same school.

Disaster teams and the emergency responsibilities of specific school personnel was addressed in 18 of the 22 interviews. The duties of various school disaster teams were recounted in 13 interviews, including all respondents from one school site. Details about the duties of a specific team were mentioned in several interviews, with the first aid/triage team receiving five mentions, the most for any specific team. While recounting the duties of the first aid team, one special education center principal realized that she had far more medical personnel on staff than she had thought. That campus includes students categorized as "medically fragile," and often these students are required to be accompanied to school by a Licensed Vocational Nurse (LVN).

Adding these LVN's to the two full-time Registered Nurses at that campus makes a total of 14

nurses at that school. The principal expressed relief that she had that much medical coverage on

hand.

Table 3: Representative Quotations about Knowledge of School Disaster Preparedness:

Unknown

- o I'm assuming there's a plan in place.
- o You know, I don't know what the school sites have; I don't know what's in all those bins.
- o Unfortunately, I don't know if I can comment on the adequacy of our plans.
- o I'm not sure exactly what they have on hand.
- o I'm operating on the assumption that there are supplies on hand.

On Site

- o We have the water. We have canopy tops, and the big buckets that can be used with the portable toilets.
- o The silver blankets. There's something magical in it. They say it really works. It becomes as small as a flip phone when you fold it.
- o They know where the cots, the blankets, the diapers, the water, the food, the emergency trach tubes are.
- o Then in the bin, there's everything from axes to break open doors, crow bars to pry things off of people with.
- o Everybody's got a backpack … I have some snacks, diapers, wipes, gloves, the face masks, flashlight, batteries, pen, my little list. I think I've got a couple of little toys or little things in there.
- o So the bins open, they are stocked immaculately; unbelievably well-stocked bins.

Emergency Plans

- o At least we know in the beginning – this is what you do.
- o Well, I believe the plan calls for evacuating the students to a safer location.
- o They do have an escape plan. They have a place where every kid can go and if anything starts crashing down, they have an open field for them all to evacuate and be clear because they do have a place where they can all line up and be free from any falling trees, falling buildings.
- o We are prepared, we get the kids out rather quickly. Sometimes it's kind of difficult, maybe we're understaffed or something. We get our kids out and then maybe go and help another classroom, but we all come together and we get it done.
- o We have lists: Is everybody here? Who's not accounted for? And then the safety team goes to work.

- They take roll, make sure all the students are there, they account for everybody, and then they turn in all their rosters to the principal or whoever is in charge.
- The front office has everyone check in out front, and we immediately lock all the gates. And the request gate is over here, in this area. And then down here, close to the tunnel, is the reunion gate. And we will have back-up, but two members from the main office will go and man those with walkie-talkies.
- We got to get out. We got to make sure the building's still okay. Kids got to be accounted for.

Examples

Students attend school with a wide range of disabilities that are managed on site every day. Some students have needs far greater than many people realize, and these needs impact these children in their everyday lives as well as during a disaster. One principal of a special education center described her medically-fragile students like this:

> They are in wheelchairs. They are unable to move on their own. They are unable to breathe. Some of them are on breathing mechanisms. They have trachs. They have truly no movement on their part. They have to be moved, fed through g[astric]-tubes, special diets. And usually they're on medication for serious seizure spells, so all of those things are involved in one little body … they will not protect themselves. They will not put up a hand. They're truly under our supervision, and we need to help them in all ways.

At another special education center, a mother described her 14-year old son in this way:

> He is like a baby. He has to be fed like a baby, he has to be carried: I change his diaper. He is non-verbal also. He does recognize me, but it is like a 6-months old baby. He is so dependent. I smash his food. He does not have the g-tube – he is able to swallow. He is not able to manipulate [a motorized wheelchair]. They have to have some type of cognitive ability in order to be able to move it; we have to push him. He is able to pull things with his left hand, and he can drink with a sippy cup. He has really low vision. When he sees you with something I know that he wants it, because his eyes are so intense … it's just like his eyes are speaking to you. And I am grateful [for him], I'm honestly going to say I'm grateful, but it's hard.

It is for children like these, as well as children who have fewer or simpler requirements, that participants in this study articulated disaster needs and recommendations.

Findings for the Perceived School Site Needs of Students with Disabilities in the Event of a

Major Disaster as Identified by Respondents

Disaster Preparedness Needs

Every one of the seven respondents who specified a need for disaster planning worked or

is now working at a school site. The planning needs that were mentioned reflected this focus on

the school site, as opposed to district-wide concerns. Concerns included a perceived lack of

follow-up on the annual disaster plans that are submitted online. While acknowledging that the

plans are important, one district-level participant indicated that it was likely that schools that

experienced challenges completing some tasks probably experienced the same level of challenge

with many tasks. One respondent expressed that, "A school is *supposed* to have a disaster plan,

correct. Whether they've taken the time to ensure that they've incorporated students with

disabilities, that we do not know." This perspective was confirmed by a participant working in a

district-level special education position, who stated, "We do not look at their school [safety]

plans," and later elaborated, "[Disaster planning is] not something that you think about a lot. You

always think somebody else is taking care of it, that it's something that's being done." The idea

that someone else bears responsibility for making sure that disaster preparation occurs for

students with disabilities was echoed in a few other interviews.

Training was mentioned in six interviews as a necessary component of managing the

disaster needs of students with disabilities. Training was valued as the best method for testing

disaster plans, although interviewees also acknowledged the differences between disaster drills

and response to an actual disaster. Six respondents (not the same six who mentioned the value of

drills) made similar statements noting that drill conditions can be far different than disaster

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conditions and reaction to actual disaster conditions is an unknown factor. Fires, crumbled

walls, collapsed ceilings, injuries, and panic were each cited as factors that differentiate disaster

drills from actual disasters. The untested is the unknown, and simulations cannot always

accurately mimic disaster conditions. No participants indicated that drills were unimportant or

unnecessary.

Differences between the preparedness training levels of personnel at special education

centers and general education campuses and the respective challenges at both types of sites were

brought up in nine interviews. In addition to the severity level of student need being different,

general education campuses are often larger, and do not offer the same ratio of adults to students.

Several interviewees perceived that special education center staff members were better prepared

for disasters than general education staff members. More students with increasingly serious

disabilities are being placed on general education campuses because of the Least Restrictive

Environment requirements. Those students lose the benefits of a specialized setting with a

greater numbers of skilled adults. This fact may broaden the effects of a disaster to a wider range

of schools, and as one respondent opined, "In a true emergency, there's going to be a lot of kids

who die. I mean, having a student in a wheelchair just duck and put its hands over its head … I

mean, what can happen, realistically?"

Disaster Equipment and Supply Needs

There are many supplies and much equipment needed to respond appropriately to a

disaster at school, especially for students with disabilities. Several respondents rattled off a list of

basic emergency supplies, one invoking Maslow's hierarchy of basic needs as a means of

prioritizing the stocking of supplies. Supplies can be broken into categories, each serving a

particular disaster need. Within these categories, interviewees discussed an array of supplies and equipment needed at school to adequately serve students with disabilities.

All of the 11 respondents who mentioned a disaster shelter need have direct experience with students with disabilities. Several mentioned shelter in general, listing tarps, canopies, and tents as means to protect children from exposure to the elements. Five of the respondents went on to explain that some children with disabilities are unable to regulate their body temperature and unable to tolerate being in the sun. These conditions are especially a concern in the sunny, earthquake-prone southern California area of this study. Following an earthquake, district protocol calls for students to be evacuated outside until buildings have been inspected and declared safe to re-enter. One district-level participant explained, "Many of our students who are medically fragile cannot be sitting out on the playground in the sun for hours. How do you provide the shade and coverage from the elements for the kids? How do you keep the kids cool who are the ones who even have to ride on an air-conditioned bus?" This concern reaches beyond medically fragile students, and beyond special education campuses. A teacher on a general education campus described a student of hers whose cancer treatments left him with sun sensitivity as well as severe environmental allergies.

In addition to shelter concerns, toileting and diapering was expressed as a need by 10 respondents, including the need to have an area with privacy to manage diapering assistance. Although principals at both special education and general education campuses stated that this was a need that did not impact general education sites, diapering is not exclusive to special education centers. Two of the aides and all three teachers addressed this need, and affirmed that it applied to their own students at both types of schools. In addition to having an area to manage

diapering, keeping diapers, wipes and gloves in the emergency supply bin, and providing for storage and disposal of human waste products were all noted as part of disaster diapering needs.

Generators are another piece of necessary equipment needed to manage the health and well-being of students with disabilities. An increasing variety of students are technologically dependent (Dolan & Krug, 2006); for some of these dependencies, non-electric backup systems are easier to provide than for others. Ventilators, oxygen, suctioning equipment and feeding pumps were all mentioned by the six contributors to this area as equipment requiring power. One participant pointed out that the battery life on some of this life-sustaining equipment does not last much beyond the end of a normal school day, so generators may need to be used to re-charge equipment relatively early in disaster response. Available manual backup equipment was also advised to be stored in the emergency bin.

Food supplies were mentioned as a disaster need by 10 respondents, both as a general need and specifically to address certain needs of children with disabilities. Food as a general disaster supply was brought up by seven school site interviewees, six of whom were associated with special education centers. Respondents remarked that they were unsure what food supplies were stored on campus, or were concerned that food amounts at schools would not be adequate to serve long-term feeding needs spanning several days. One principal expressed, "We probably need to have more food in there. Holy guacamole, if I'm here for seven days and we're stocked for three days, I do not want my kids starving! In a campus with medically fragile kids, it really is a concern."

Respondents also described feeding issues with specific children. Some students have medically necessary prescribed diets. Some children can eat foods that would typically be stored

for emergency use, but are required to have foods chopped, finely chopped, blended or pureed. Other students can tolerate only liquids, or thickened liquids. Still others can take nothing by mouth and are fed through gastric tubes (g-tubes) that bypass a body's swallowing mechanism. Formula – and there are several types addressing different needs – and feeding supplies such as tubing, battery-operated blenders, and sippy cups need to be stored with the school's other disaster supplies. One participant described an emergency drill in which she participated, where they practiced evacuating students by school bus from her site to another school. The drill lasted for two or three hours, and students were given a snack and water at the receiving school site. The snack was a hard granola bar that many of her students could not eat, and water was passed out in cups, which many of her students could not use. There were no provisions made for students who required alternate feeding and drinking methods.

Access to emergency supplies, and a school's ability to truly stock all that is needed, concerned six study respondents, who raised issues such as having supplies in a readily accessible area. Not everything may be kept in the disaster bin, as some supplies may be used on a daily basis, and the expectation is that in an emergency, those same supplies will continue to be used. A few respondents questioned whether schools really have the specific supplies and equipment needed to take care of children with highly-specific needs. Some students require a substantial amount of equipment, and one respondent acknowledged the volume of equipment required, and stated disbelief that schools could actually stock a large enough supply to be self-sustaining. She also wondered about the district's ability to ascertain needs early enough during a disaster response to get supplies out to schools on an as-needed basis.

One final supply need of particular concern to participants in this study was medication and other medical needs, which was reported by 18 participants. Several respondents expressed that medication is the "number one" or "most important" need, as well as one of the most difficult ones to address. Medication issues that were described include problems with stocking extra doses of medication, knowing what medications students take outside of school hours, expiration of stored medications and keeping track of expiration dates. Evacuating medications in emergencies was also mentioned, especially for schools that do not have a nurse or the nurse is not on campus when an emergency evacuation takes place. Even running out of the applesauce that is used to get some students to take their medications was mentioned as a potential issue. One teacher in a special education class on a general education campus reflected that in her class of eight students, some have medication for ADHD, one takes medication for Tourette Syndrome, and another student is in remission from cancer and has an EpiPen for severe allergies.

A few medications were singled out by respondents as particularly of concern. Insulin was mentioned in three interviews, as diabetes is both fairly common and can be serious if insulin is not available. One respondent described one middle school she used to serve that had 15 insulin-dependent diabetics, and she wondered how many extra doses were stored at school for emergency needs. Diastat, a prescription rectal gel administered to stop acute seizure activity that happens despite regular seizure medication, is another specific medication that was mentioned by multiple respondents. One respondent estimated that 75% of the students have some type of seizure at the special education facility where she works. The seizures can be quite serious, and Diastat is not always kept on hand for each student. She made the point that, "If they

do not have their medicines and there's no nurse to do the Diastat if they are in prolonged

seizure, we're going to medically be in big trouble at that point." Another interviewee stated,

> If a child went into a seizure, and we did not have Diastat, we couldn't stop it. I'm not sure, but they could die. And it's a conversation we have with the parents. They are aware of that… I really think that medication would be a very difficult [issue] for us.

Medical needs not related to medication were also noted in several interviews. Medical

protocols such as suctioning and catheterization happen daily on school campuses, and disaster

concerns include creating a private area for managing those needs as well as guarding against the

risk of infection. There are also concerns about medical conditions that have not been disclosed

to the school that are usually managed outside of school hours. One parent mentioned that she

knows of several children with disabilities who only sleep a few hours each night. She also

mentioned that her son's condition is incredibly rare – one of seven in the world. One of the

interviewees who provides support to school sites mentioned another student she knows who is

one of five children surviving with her condition. Rare or unknown conditions can become

concerns during a disaster that impacts the school, as it is unlikely that many staff members

would have the knowledge or experience to manage complications if they arose.

Response Action Needs

One of the most pressing disaster needs that 18 contributors identified was building

evacuation, especially for students who use wheelchairs. Students who cannot walk down stairs

or walk with difficulty and are located above the first story in a school must have a way to exit

the building that does not involve using the elevator. Students who use power wheelchairs are of

particular concern, as the wheelchair alone can weigh upwards of 100 pounds and cannot easily

be carried. Respondents also mentioned that students themselves may weigh 200 pounds or more, which makes evacuation more difficult. Getting slow-moving students out rapidly enough for safety was also mentioned as a concern, as was evacuating students when they are out of their chairs to participate in a movement program or for other reasons. Having an adequate number of adults available to help students evacuate was also a concern noted by several respondents.

All three of the schools represented in this study have an autism-specific program and 10 of the 12 interviewees associated with school sites, including each of the parents, mentioned that students with autism demonstrate specific needs that will need to be managed during a disaster. "Freak outs," "meltdowns," and "runners" were all terms used to describe the agitated reactions to a disaster by students with autism. Respondents commonly cited the disruption in routine and sensitivity to sensory input as reasons for behavioral changes. One parent spoke of it as, "They already live in discomfort with themselves, but to see all of the disaster around them and now they have to react … it messes them up completely." The reactions caused by the disaster were described as depending on the individual student. Specific behaviors mentioned included screaming, crying, biting, hitting, throwing objects, tantrums, and running. Running was described as a behavior that could be seen in the classroom, during evacuation, or while outside after the evacuation. Sensory input sensitivities were described in relation to sound, texture of clothing and foods, and not having access to their own belongings. One teacher had experienced a minor earthquake while teaching students with autism. He described their reactions as,

> The ground shaking was very scary [for them]. Some of them dropping to the floor and just crying [and others] just kind of running around the room. They had no idea where to go. And whenever we were trying to get them in line and go out, they were resistant to it. They had just become very disoriented.

Non-verbal students were also mentioned as a concern in a disaster. Non-verbal students cannot communicate that they are injured, how they are feeling, or what happened to them. It can also be difficult to determine if they are alert and oriented, which is usually assessed through questioning someone. Some respondents also pointed out that non-verbal students cannot call out to a search and rescue team if they are buried in rubble or if something is on top of them and a non-verbal student could easily be left behind by a search team. One parent struggled to maintain composure when she realized the implications of this situation. "So if something happens and he gets trapped, he's not going to be able to say, 'I'm here.' Right. So wow! It's just … oh! It's just stopped my mind thinking about that."

An additional category of disaster need is students whose disabilities are not apparent. Invisible disabilities can include communication disorders, autism, and many physical disabilities. Students may not be cared for by their usual teachers and others, due to staff injuries or disaster duties, which may exacerbate the effects of the disaster on these children. Appropriate care may be delayed for students in many circumstances whose disabilities are not apparent.

Parent Needs

Parents were indicated as a need and an area of concern in a disaster by 18 of 22 respondents, including all three teachers and two of three parents. Most frequently mentioned among responses was the agitated state in which parents will arrive to collect their children post-disaster. One parent predicted, "I think the problem's going to come from outside - us, the parents. We'll want to come inside [the school] and just grab the kids … It's what we do; we panic, we run around." The other parent actually began crying when speaking about her 15-year-old, saying, "As a mom, 'Where's my baby? Somebody out there better save my baby, please

save my baby!" School personnel spoke about prior experiences when discussing parental behavior. They mentioned incidents in which parents became angry, climbed over gates, and even were restrained during emergencies. They indicated understanding the frustrations that parents experience during emergencies, stemming from the confusion and chaos of the scene, anxiety when not knowing the condition of their child, not understanding the school's procedures or the reasoning behind them, and receiving inadequate information. One school employee described the resulting situation as flooding the gates where hysterical parents will pick up students, creating a crowd control situation, a scene that another employee described as parents "bum-rushing us."

One of the issues compounding parental anxiety is the need for communication during a disaster. Respondents mentioned challenges such as phone lines being down, contact numbers not being updated, and the potential for social media to get information out ahead of official communication. One district-level participant spoke of the expectation of immediate communication outstripping the district's ability to provide accurate, approved communication. Translation issues and other language barriers were also mentioned as factors that complicate disaster communication. One aide even mentioned sign language as a barrier to communication with students in a sign language-based program for deaf and hard of hearing students. This issue was unique because some of the parents were unable to communicate with their child because they did not know sign language and relied on school staff for translation. As the aide pointed out, in a disaster it will be difficult for these students to indicate to their parents their emotional state or delayed injuries.

Transportation is another identified need that parents will have following a disaster. Thirteen interviewees specified two different types of disaster transportation difficulties that impact parents. One difficulty is that parents may just be unable to reach the school because of infrastructure damage to the area, such as bridges being down and routes being compromised, especially as students and their families can be spread across a wide geographic area. Several interviewees did emphasize that even with these challenges, parents will try their hardest to get to the school to collect their children. An additional challenge is that many parents in this district do not drive or do not own cars, with one school-based employee estimating that 50% of parents at her school do not have their own means of transportation. Some parents of students with power wheelchairs rely exclusively on the school bus to transport their child. If these families do not live within walking distance of the school, these students may not be reunited with their families for quite some time. One parent elaborated several possibilities for picking up her child including asking family members for assistance, borrowing a neighbor's car or running to the school, but then said that the school was kind of far from her house, and laughingly confessed that she had never thought about transportation problems.

Staff Needs

Disaster needs regarding school staff members were addressed by 19 respondents to this study, most mentioning the staff's ability to manage student behaviors. Eight respondents used the term "panic" to describe not only the primary reaction to disaster by students, but also a reaction by staff members. Many respondents mentioned the necessity of having staff members that can maintain a calm demeanor during a disaster and be an influence and example for others. Imbuing a disaster situation with calm was cited as desirable for all students, both those with and

without disabilities. Several respondents did mention that some students with disabilities seem to react to the anxiety of others, making a calm demeanor even more important for those populations.

Having enough staff members to cover all of the disaster duties was the other staff need prevalent among interview responses, with eight respondents mentioning staff coverage. This issue was raised by all three teachers and school or district supervisory personnel. One respondent referred to this need as being the "what if?" scenario. Concerns raised here ranged from not having a good second in command and not having back-ups for key response positions if primary responders are unavailable or injured during the disaster, to the changing ratio of adults to students if adults leave the disaster scene, and the impact of substitutes who are unfamiliar with particular students. Responses on this issue were all variations on a theme, expressed most succinctly by the respondent who simply stated, "That's my biggest concern. Will we have enough people to cover?"

Table 4: Representative Quotations about Disaster Needs:

Planning

- o We also hope we have prepared the school [when we move a student with disabilities]. But you don't keep going back every month, every year, whatever. It's not something you think about a lot. You always think somebody else is taking care of it, that it's something that's been done.
- o Are they practicing? Are they meeting? Are they connecting? Your plan is as good as you practice. It's your response.
- o I think that's why the plans are important, because you go back to that common sense agenda, and then you act quickly and you give orders, or you have your staff, and they give an order.

Student Dependency

- o If there are obstacles along the way because things have fallen and are blocking our path, it might be more difficult to get kids that are in wheelchairs out, because there's not going to be a way out.

- It's finding the alternate [exit routes]. Other children can crawl over something. Other children can go through; if you have to go through a smaller space, you can. You cannot do that in a wheelchair, and you cannot do that in a walker.
- Some of those students are very large. And if they're out of their chairs at the time [of the emergency], it does take them more time. Hopefully we shall have enough assistance to work with those classrooms, but it does take them more time to get out of the building.
- At home [a student who uses a wheelchair] had an instance where his mom left the water boiling, and the water started evaporating, and he started smelling the burning of the pot. But he said he was in his room and he smelled it and he didn't do anything, he just laid there. Then he said he started seeing the smoke, and he just still stayed there.
- If you have students who are non-verbal, they cannot tell you if they've been hurt unless you see bruises and blood. They're not going to be able to tell you what happened to them or where they hurt more, or that they're in pain. Somebody comes by and says, "Anybody here?" shines a light – they can't communicate to you that they're on the other side of the wall. So you might miss them.

Supplies

- Are you telling me that the schools are going to do it out of their own allotment [of funds]?!?
- So do we have extra? I mean, that really means: do we have the supplies that they specifically need and not just some generic kit?
- Kids with disabilities, they need to have all sorts of things that relate to their devices, their system technology, batteries, power supplies, back-up generators in order to supply all the equipment.
- He always carries three diapers, and we have extras in the office. But now that you mention it, I'm thinking maybe we have to go back in that box, and I'm going to put some diapers and catheters in there.
- We may well have students who still have toileting issues way past the toddler years, so assistance is needed and it may not always be available. We have students with rare medical conditions where they need medical protocols and equipment in order to discharge their waste, so how is that going to happen on the field?
- Typically you have a tent, you have a screen, you have some privacy, but there are kids who get catheterized. Their diagnosis isn't terminal, they can function, but they have medical protocols that happen every two or three hours. Because the biggest thing with those kids are infections.
- How do you fill [oxygen]? Where do you get it? Stuff like that I really don't know. How long does it last, their oxygen? They have them here during the day, but I don't know during the night how much oxygen they need.
- Big time issues in medication. Absolutely, yes. Running out of it.
- If they are on medication, that's a big one. They came to school thinking the medications they need are enough, thinking that they would be able to get them again when they go home.

- o And the families can't get more medication. Their insurance won't allow that. So that's a fine line that we do walk, and a challenge that we see.
- o What if the office manager happens to be at lunch when an earthquake happens? Who has access to the medication? Are you going to have a kid in a stressful situation have an asthma attack, and no access to an inhaler? You know, that's a really dangerous situation.
- o At least 75% of the kids in that last building have some type of seizure. If they are in it too long, we at one point used to have the paramedics coming at least once a week for somebody who had a seizure or who stopped breathing.

Staff Availability

- o What if one of the assistants is off on their break, and that's when something happens? Chances are, they're at lunch. Have you thought about what you will do? Just in case something happens today, who is going to cover? So who else on campus have those kids built up a relationship with, so there's somebody else on campus that has relationships with them?
- o My biggest concern is who makes it out, because if certain people don't make it out, it will be more difficult for the others to organize those issues, to solve those issues. There will be people who don't make it out, and that is what worries me. There's not much we can do to make up for a nurse, because their knowledge is not duplicatable so much. That's an absolute need.

Parents

- o I think we'd probably have some problems with parents, like climbing over the gates, or you know, trying to get in.
- o With violent acts nearby the school, parents of course get very concerned. Some of them want to storm in, and we've had to restrain people from going in. "I just want my child," all that good stuff.
- o Keeping them in order is going to be very difficult. Within 10 to 15 minutes, we're going to start getting very flooded at both gates. It won't matter which one is supposed to be which. That would be crowd control for that.
- o I'm hoping that trust factor is there, and they know that we will keep their child safe for however long we have to keep them safe. And that we're committed to safety. With that being said, they will be frantic.

Findings for Recommendations about School Disaster Preparedness for Students with

Disabilities

Recommendations about Disaster Preparedness

Respondents interviewed for this study offered numerous recommendations to address

school disaster needs for students with disabilities. Recommendations did not necessarily

correlate with the distinct disaster needs identified in the same interviews and written about

above, but can be classified into the same larger categories as those used for the disaster needs. A

total of nine respondents offered general preparedness recommendations that stressed the

importance of being robustly prepared for disasters with plans, training, experience, and proper

equipment. A member of the city's Emergency Management department pointed out that, "If

everyone prepares for the earthquake, at least you have a starting point for any of the

catastrophes that may befall us here."

Disaster plans were mentioned as an important preparedness component by 10

respondents, as was having plans flexible enough to be consistent among school sites and across

different student populations while adequately serving the individual needs of each site and its

students. As one classroom aide explained, "It would be the same plan, but a little different

because they're your students. Every school should have the same plan and then they would use

that plan to accommodate themselves at that site where they are." This idea is applied to students

with disabilities as well as those without. One teacher at a special education center declared,

"Looking at those as special needs is not really the way we look at it. It's just *our* needs. It's

been a while since I've been on a general ed. campus but there shouldn't be things that we're

doing that they do not." One respondent was of the opinion that standardized emergency plans

would help create uniformity among schools managed differently by different administrators. School disaster plans were expressed as a crucial step to being prepared for disasters.

Individual disaster plans for students with disabilities was also offered as a possible recommendation. Although only suggested by five respondents, the idea is included here by virtue of its utility. One contributor, who provides legal counsel to the school district, stated that taking reasonable actions during a disaster and having an emergency plan that factors in some individual needs can even be seen as reducing liability. Individual plans were not envisioned by respondents as a separate plan from the school disaster plan, but more as a supplement to the school plan, including only the procedures that would differ from those for the general populace. Making the plan available through an online planning tool and having the plans available centrally were suggested as ways to make the plan more accessible to school personnel. Individual plans were also suggested as a means to engage families in a conversation about their child's care at school, although individual plans were not suggested by any respondents who worked at schools.

Training was recommended by 13 study respondents, more than any other idea categorized as preparedness. The need for general emergency training for school staff was recognized by several respondents, who offered a variety of training methods. Suggested methods included sending trainers to schools, training by video, online training, in-services, and training students. Making emergency training mandatory was also suggested. In addition, a diverse group of respondents weighed in on specifically training school staff to manage students with disabilities in emergencies. A district-level, special education department management person explained, "The abilities of people to know how to handle students [with disabilities]

needs to be expanded to a far larger circle. Everyone on campus, in other words, needs to know, not just one or two people." A classroom special education aide elaborated,

> There should be more training for teachers, and maybe training on how to approach and recognize kids that have special needs. Because what if the kid is for some reason in P.E. and he has a regular P.E. class? And he does not have an assistant. The teacher needs to know how to deal with that kid. A lot of times because they're special, [other staff members] do not want to deal with them; they do not want to have anything to do with them. But I think there should be more awareness in the whole school of our kids and who they are, and you know, they're not that different.

An itinerant professional supporting several schools added, "Because you're going to be called on in a disaster to help anybody."

Emergency drills, which are required of every school in this district, were recommended as a learning tool in half of the interviews. Drilling was mentioned as a method of reinforcing disaster protocol for staff and students, particularly for students with disabilities. Some students with cognitive disabilities benefit from repetition, and during a disaster, drills can provide a point of reference in what might otherwise be seen as an unfamiliar and scary situation. One principal experienced multiple false alarms when a new fire alarm system was installed. He initially cringed each time the local fire station responded so promptly to the alarm activations, but realized that the alarms provided crucial opportunities for students to interact with the first responders. Unplanned emergency drills were also valued by other respondents, who recommended surprise drills and drills at challenging times of day, such as lunch. Having more frequent, extensive drills that test a school's organization, include scenarios, and require disaster response teams to practice was also suggested. Integrating students with disabilities fully into disaster drills was one more suggestion. One respondent mentioned that students with disabilities are not always included in a school's emergency drills, and that students and staff need practice

to become comfortable with specialized evacuation techniques. She pointed out that for students with disabilities during emergency drills, "They're not even people, because some of the time it's a time-based requirement … what good is knowing how fast you can get the fast kids out?"

A final disaster preparedness recommendation is to create some sort of database that a school can use to determine what equipment is needed on site, as well as what resources a school already possesses. The database was suggested by several participants, but each envisioned the database functioning in different ways, and serving different needs. Using a database of disaster equipment and supplies for students with disabilities would inform schools of their disaster needs, and the database could be monitored at the district level to ensure that appropriate resources reached the schools. Another suggested application of the database is to list the location of specialized disaster equipment. Specialized equipment and supplies could be moved from school to school as students changed schools and the needs of the students changed. Other district computer systems could be integrated into the database, to create a more comprehensive list. The database could be used to create a baseline expectation of preparedness for each school.

Recommendations about Disaster Supplies and Equipment

In terms of sheer numbers, interviewees had the most recommendations about the supplies and equipment that need to be at schools to adequately manage the disaster needs of students with disabilities. All respondents had contributions to this category, and only one had just a single contribution. Other respondents offered between two and seven suggestions for recommended disaster supplies and equipment.

Seven respondents, all but one current school employees, mentioned classroom disaster supplies. In this district, classroom disaster supplies are often kept in a special bucket or

backpack, which was where most respondents suggested classroom disaster supplies be kept. The buckets are commonly outfitted with a toilet seat lid, and double as a portable toilet that can be set up in the classroom during lockdowns. Some suggested supplies in the bucket included diapers and food, with one teacher recommending that food be kept particularly for students with allergies, so that those students will not have to rely on standard emergency food supplies, which may not be safe for them to consume. Medical supplies were mentioned in multiple interviews, as were toys or other items to keep students entertained during emergency situations. A blanket was also a suggested item. Having each teacher stock their disaster backpack or bucket for the individual needs of each student was another idea.

Generators were suggested by five interviewees, both for generalized site electricity needs and to power equipment for students with disabilities who are dependent on technology. Ventilators, oxygen, and suction machines were all brought up as equipment for which it would be vital to have a generator on campus. One teacher emphasized the importance of power for this equipment; "If you're putting children on [a general education campus] that have any kind of need for a power supply, you've got to have the generator. I do not care what your other priorities are. That is essential."

Unique supply recommendations to assist students with disabilities were made by 20 of the 22 respondents. In all, 36 items that did not fit into other supply categories were recommended. These recommendations also included two items that a respondent did not wish to see at schools: guns and classroom surveillance cameras. Some of the unique ideas included taping a key to the disaster bin inside selected classroom supply buckets, sippy cups, soothers (stuffed animals, soft blankets, etc.), shade umbrellas, and calming vests for students with autism

who become upset by changes in routine. One nursing staff member suggested keeping a log book of student I.D. pictures with the medical emergency supplies. These pictures can be used to identify children, or match them to the appropriate prescription medications.

Medication and medical recommendations were made by 12 participants. This included four recommendations for additional health professionals such as nurses and health-care aides. Extra trained medical personnel were seen as important for ensuring post-disaster health. A supervisory member of district nursing staff stated, "We have 500 nurses. They're your soldiers. They can respond." The need to have adequate numbers of health care assistants, who are assigned to specific students with special health care needs, was later emphasized in that same interview; "We need to make sure of the health care assistants who are with the students … We have 8,000 special-needs assistants in the district; We have nearly 85,000 special-needs students district wide."

Consumable medical supplies such as extra catheters and tracheostomy tubes, and durable medical equipment such as extra wheelchairs and walkers, were also proposed as useful to keep on hand. Medication was mentioned by eight participants, all of whom recommended keeping extra doses of student prescription medication at school. Along with medication, one respondent suggested keeping a supply of applesauce in the disaster supplies, for students who need to take their medications crushed up and mixed into a soft food. To address the issue of obtaining extra doses of student medication, one respondent from the Office of General Counsel recommended sending home a letter of request for the medication. This will alert families to the need for extra medication at school for disaster use. Some families may be prompted to send in

the extra doses, and for those that do not, the letter actually can help protect the staff from liability.

Recommendations about Response Actions

Recommendations regarding response actions taken at schools in times of disaster were offered by 19 of the study participants, including all but one respondent directly associated with school sites. Recommendations for evacuating students with disabilities received the most suggestions, coming from 10 people who most directly manage the needs of students with disabilities; all three teachers, classroom aides, parents, specialized itinerant support staff, and nursing. Not using the elevator during drills to evacuate students who use wheelchairs was recommended, so that school staff can practice stair evacuation techniques. Two respondents strongly suggested assigning students who use wheelchairs to classrooms only on the ground level, "… because those methods of getting a chair safely downstairs take time. And time is not always the thing you have." "Rifton chairs," a brand of sturdy, wooden, wheeled chairs that are stable, low to the ground, and offer additional support were mentioned as a means to quickly evacuate students during a disaster for students out of their wheelchairs.

Techniques for assisting students with disabilities during evacuation included training mobile students to hold on to the wheelchair of a classmate to help keep the class together, and giving students specific directions during evacuation. One respondent pointed out that giving directions during evacuation to students who are deaf requires the teacher to walk backwards at the head of the class so that students can see the directions – necessary for those students using sign language, for those who read lips, and for those with cochlear implants and hearing aids. Disaster conditions make walking backwards hazardous, and stairs provide an additional

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challenge, so having those classrooms on the ground floor was recommended. This recommendation was also made for students who are blind or who may become disoriented by a disaster. Providing separate evacuation routes to students with disabilities, and making other staff and students aware of the alternate route, were suggested to reduce crowding and speed evacuation.

Recommendations to manage panic and keep students calm were proposed by nine respondents, most of which related to the demeanor of the staff. One parent described a child's thought process as, "I'm looking at you; you're the leader, you're the adult, you're the grown-up, what should I do?" Students taking behavioral cues from the adults around them during a disaster was mentioned by six respondents, and training teachers in disaster response was one recommendation to lessen panic on the part of adults. Speaking firmly with a sense of confidence and being organized were recommendations to alleviate the concern that an adult might not usually be seen as a leader. One respondent with school site work experience stated, "We know we have children watching, so we try to model better behavior for it." Reassuring students, explaining the disaster to them and keeping to normal routines as much as possible were recommended as strategies to keep students calm. One principal advised, "There are three things you have to do in every single situation, three things: stay calm, stay calm, and stay calm."

Specific recommendations for students with autism were offered by five respondents, all school-based, representing parent, teacher, aide, and principal roles. Creating a space in the disaster assembly area where students can get "alone time" was one recommendation to combat over-stimulation. Techniques to accept the changes in routine that may be necessary in a disaster, and can be so difficult for students with autism, were also suggested. Acknowledging the change

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in routine and reassuring the child that the changes would be minimal and that the situation would be okay despite the changes was one recommendation. Also mentioned was having an adult work with the child to imagine the child's regular routine and experience it through the visualization. Having a distraction available to counteract fixation, such as an alternate activity or a video, was another idea. Using a visual such as a communication board was recommended to help with comprehension and reduce repetitive questioning. Creating a task analysis sheet for emergency procedures was also suggested to help children with autism transition in emergencies, so that they could review procedures and stay calm. Training teachers in applied behavioral analysis and positive behavioral support and then applying those principles to disaster situations was also recommended.

Recommendations about Parents

Recommendations about parent interactions with the school in and about disasters were made by several respondents. Getting information to parents in advance was mentioned by seven contributors, including two parents and representation from all three school sites. One suggestion offered by several respondents was to inform parents about the school's disaster plan and supplies. Suggested methods varied, and included a letter home, a parent meeting, or a newsletter. Making sure that parents know that their children will be cared for in a disaster, and offering parents a way to participate in disaster drills was also recommended. Giving parents precise details about the disaster reunification process and the locations of the request gate and the reunion gate was also suggested.

Having parents make a personal disaster kit for their child and send the kit to school was recommended by four respondents and strongly objected to by one parent. A plastic zipper bag

or backpack with supplies to meet the child's particular needs including medication, and a stuffed animal or other toy was suggested. One parent recommended that a picture of the family be part of the individual kit. The family picture might not only bring comfort to the student, but could be used to identify family members who may come to the school without identification. to pick up the child following a disaster.

One parent admitted that she had not brought in a personal disaster kit for her child, even though asked by the principal to provide one. She stated that she provided extra doses of his anti-seizure medication in the backpack that traveled to school with her son daily and felt that was adequate. She thought that she would be better able to keep track of the expiration dates on the medication because she saw that backpack on a daily basis. She did not want the nurses to have the additional responsibility for disaster medications, which she thought might be overwhelming. She stated that she thought that it was "too much" to expect parents to provide the kits and keep up with the disaster medication expiration dates in a separate kit, saying, "There are so many things I have to do with my kids for sure on a daily basis. And no. I do not think I will be able to [provide a kit]." She has four children between the ages of eight and 13, attending three different schools. Two of the children have disabilities. She further remarked, "Honestly, I never brought in anything because I thought, 'No, if there is a disaster, I will come and get my son."

Recommendations about School Staff

Respondents who have worked at schools acknowledge the enormity of caring for students with disabilities and eight of these talked of greatly valuing experience in themselves and their co-workers. "There are these moments as principal when I just think, 'Holy shit, this is a lot of responsibility!" exclaimed one participant, who later expressed gratitude toward the

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former principal for the well-trained staff he inherited. Another respondent, a former principal, described how she was guided by common sense in place of experience when managing an emergency early in her career. One respondent spoke of the comfort level that people learn when they know what they are supposed to do, and what actions are expected of them. Four respondents stated the worth in knowing the students and their needs well, and how that familiarity would benefit students during a disaster.

Few respondents spoke of staff members leaving the school site or failing to respond to work if a disaster struck during non-school hours. Of the four who mentioned that scenario, two were the newest employees of the district in the study, one mentioned that possibility as a part of the normal range of human responses, and the other respondent predicted that only half of school employees would or could perform their disaster duties. That respondent, not an employee of the school district, recommended that schools account for this high level of non-response into their disaster plans.

Other study respondents spoke of their school staff as a team or a family and expected that there might be difficulties in a disaster, and that they would be able to overcome those obstacles. Gaining that team/family feeling and the trust inspired by it was recommended by seven respondents as integral to a cohesive disaster response. One classroom aide explained that:

> Basically I feel that we're here because we know that we're needed, even before the disaster. So that's going to be amplified after the disaster and we know that these students cannot take care of themselves, so we're going to be needed to do that. Even though we might not want to be here, we're going to do what we need to do in the situation to get it under control and to take care of the students or whoever - the adults or whoever needs assistance. So we're strong, we're good at that.

Confidence in the abilities of their co-workers or school employees in general was declared by 17 study respondents, including eight of the nine employees working at school sites. Many respondents spoke of confidence in particular individuals, such as the nurse or principal, or teams such as the search and rescue team. One participant referred to specific staff members when listing disaster resources of the school. Five participants, at least one from each of the three school sites, mentioned their site as well-trained and able to respond well to disasters. For some respondents, the trust in co-workers was borne of close working relationships established over many years. Two respondents expressed that the special education centers were trained and disaster-ready, but doubted that the same was true for general education campuses. Seven other respondents, including all school sites in this study, reported that their particular school site would respond well to a disaster. One principal stated, "I think we would make it through just about any disaster. Well, except for maybe a nuclear explosion that may happen very close." Several interviewees with experience at multiple sites stated that all schools in this district were well prepared for disasters. Drilling, policy from the district, and planning were all cited as components that contributed to district-level disaster preparedness.

Table 5: Representative Quotations about Disaster Recommendations:

Plans and planning

- The principals that I know who have actually been through any kind of disaster, they obviously make it a priority. I think there's a comfort level for us as adults when we know what we're supposed to do, where we're supposed to go, what actions we need to take, all of that good stuff.
- I just realize more and more, how much preparation is really involved in this job. But I do feel so fortunate to have come to a school where the former principal was so uber-organized, and the staff is so well-trained. Now I realize that can easily cease to be the case if we don't continue the practices that have been in place here.
- Many of those teachers that have been through something make it a priority, and help the kid make the transition. If my cognitive functioning would be severely impacted by any kind of change, let alone a scary one, then I'm going to need to

practice what I'm supposed to do more often than once or twice a year. I've seen some of our Special Day Class teachers do that, because especially if it's an emotionally disturbed class or an autism class, we want to make sure there's a routine to the non-routine to the extent that's possible.

- o [Students] can think back and go, 'Okay, we did this before,' so it's not a new thing, and it's not something scary. Just so they have a reference, because if I have any kind of schedule change, it's always, "NOOOOOOO!" I just feel if I just let them know this is what's going on and they get it, then I feel that would reduce a lot of stress on their part.
- o I think we need to look at how all those general education campuses do, now that they are getting all the students who are in wheelchairs and in walkers, and are visually impaired, who are deaf, or who are non-verbal or have very poor language skills.
- o It's been a while since I've been in a gen. ed. campus, but there shouldn't be things that we're doing that they don't. Looking at those as special needs is not really the way we look at it. It's just our needs.
- o It should be the same plan, but a little different because they're your students. Every school should have the same written plan, and then they would use that plan to accommodate themselves at that site where they are.
- o I think it's very important to communicate your needs to everyone on campus. We have staff meetings that's almost like a conversation regarding the incident back east [Sandy Hook school shooting]. Where do you feel the need? What do you see around the campus that is a concern to you? How can we brainstorm and make it better?

Response

- o I think in an emergency you have to really act really quick on your feet, and that's why we have these plans.
- o So you've just got to really pick up what's going on and take the initiative and do what needs to be done.
- o Your teams may be devastated, in which we have to regroup at the command center and re-form. And then form other teams and start looking for people and doing the best we can.
- o What it is, we're a team. I am not your boss. The truth is our mission: all students graduate, proficiently prepared. Our mission happens in the classroom.
- o There would be more mistakes as we lose our veterans, as we lose these people who will step up, who we know have a history of stepping up. And we get new people who are not as dedicated, who are here as a stepping stone. You are going to see less and less of those willing to step up, or even knowing they have a duty to step up. They are going to actually have to be taught.

Findings for how Stakeholders Align with the Approaches to the Theory of Distributive Justice and how they Describe their Vision for Resource Allocation in a Disaster

Decision-making about how disaster resources should be allocated by a school district is part of the preparedness and response process. In the current educational climate, resources are not abundant, and all needs cannot be filled for every school site. Allocating resources and prioritizing needs can be addressed through distributive justice theory, and utilizing one of three approaches to it. Participants responded with both philosophical and practical applications of the approaches to distributive justice. When presented with the three options, only two study participants even mentioned the approach of advocating an equal chance at survival that operates on a first-come, first-served basis. Those two participants rejected that approach.

Triage Approach to Distributive Justice

The triage approach, based on the concept of doing the greatest amount of good for the greatest number of people, was addressed in nine interviews. Opinions about the triage approach varied widely among respondents, and only two of these respondents were school site employees. One teacher working at a special education center said, "That would be an argument against not giving special ed. centers their resources because they're like, 'Well, those kids cannot get themselves out of that rubble anyway. So let's not dig them out.' I could see that. I do not like that logic." Another respondent mentioned that some students are terminally ill and that the triage philosophy could be a factor in making resource decisions. A respondent who is a member of the district's legal team felt that the triage approach might help avoid litigation, and added that that was, "outside of any ethical consideration." She added that some unique needs would still need to be prioritized to minimize the chance of litigation. Three respondents

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acknowledged that triage works well in medical, multi-casualty incidents, but one later stated that students with disabilities change the dynamics of the situation. Of the remaining three respondents who addressed the triage approach, one stated that triage would be a "close second" choice, one picked triage as the best approach in the erroneous belief that in triage the resources would go to those with the greatest need, and the remaining individual stated definitively that the triage approach would work best for resource allocation. Four of the respondents who mentioned the triage approach as working in at least some conditions stated a preference later in the interview for the approach advocating for the best outcome for the least well-off.

Best Outcome for Least Well-off Approach to Distributive Justice

The remaining approach to distributive justice is not often used in disaster management, and prioritizes the needs of people with disabilities and other vulnerable populations over the needs of others without enhanced levels of need. Of the 22 participants in this study, 18 declared the best outcome for the least well-off approach as the best one to use when allocating disaster resources in a school district. This option was preferred across all segments of the study population: employees at both special education centers and at general education campuses, district support staff and district-level management, and non-district personnel. One principal cited liability as a reason for selecting the best outcome approach.

Most respondents simply seemed to see this approach as the right thing to do, with one respondent explaining that, "It's sort of a measure of a society of what you do for the ones that need you most." Among the responses by school-site employees, one stated, "It still baffles me that we haven't figured out that separate but equal does not really create equal. And that is true with regard to supplies, too." One special education center aide elaborated, "They lump us [all

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together] as students and they do not seem to remember that these students are different and they need to be treated differently and the equipment we need should be a little different or maybe a little more .… If they just sat down and thought about their needs and not just [one type of] students, that's where we get left behind." A teacher at the same site added, "It seems like able-bodied people can help themselves. Our kids just cannot help themselves at all, so we have *some* responsibility to keep them safe."

One parent of a special education center student with multiple disabilities prefaced her comments by stating that it wasn't just about the needs of her child, as she also had a child at the general education elementary school down the street. She explained,

> In a severe case, if something happens really bad, I think survival is the main thing. So if other than food for this school, they need medication or oxygen tanks, stuff like that, I think they should have it. Because other kids, if they run fast enough, they're going to get out. [Students at this school] do not have this ability to communicate. They do not have the ability to run outside if something happens .… For special-needs schools it's different because you have all these things that you need, and really I think they should think about it – how is it going to affect the kid? You do not have it, the answer is he's going to die.

Other Distributive Justice Options Proposed

Selecting an approach to resource allocation was a difficult decision for many respondents. Ten respondents struggled with the options, eight of these respondents managing the needs of students with disabilities on a daily basis as a parent or in their job. These respondents voiced that the question was difficult, and that there might not be one correct answer. One principal retorted, "I do not think if you'd ask most administrators that they could say which of those three theories the district would have you pick." Another principal called it a "horrible question." Some respondents expressed that the decision would be situationally

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dependent, could not be the same from one school site to the next, or that the approaches should be blended. One teacher attempted to think through the decision out loud, stopping and starting sentences multiple times, inserting new thoughts or backtracking halfway through the expression of an idea. Her final, and most definitive, statement on the topic was, "But yeah, as far as who gets what – that's hard. I'm glad I do not have that job because it's hard."

Some respondents thought that baseline assessment of disaster needs could play a part in resource allocation decisions. These seven respondents indicated that school needs could be prioritized based on their self-assessments, and in this way, the district could allocate resources. One respondent suggested that resources could be allocated tiered to factors in the assessment. A respondent from the city's emergency management department offered an instant prioritization matrix that quantifies the severity of multiple incidents, and suggested that this could be customized to be school-district specific and implemented during disaster response. He expressed that this might help make resource allocation more objective, stating, "And the thing with the schools, I am sure that every school administrator would think that their school is the most critical."

In fact, no school site respondent mentioned that their school was the most critical. Sharing resources was proposed by five interviewees, including staff from each school, two of those respondents being principals. Interviewees from each school proposed that in a disaster, they could share their resources with other schools. No respondent mentioned taking resources from another school. A special education center teacher reflected, "I think we should take what we need and not be greedy, because we're resourceful people. We can always figure things out, you know." An aide at a different center stated, "I know we have a school right across the street.

So maybe they might have a little bit of something and we have a little more. They're able to come over and partake and share with us or whatever. That'll be awesome…. If we're all here for the kids, you know, we should help each other out." One principal from a special education center remarked that a disaster, "Would be [more traumatizing] on a general ed. campus. Those children would know that something is wrong, know that mom cannot get in, cannot get over there, and it could be very, very traumatic for them….I really think that they would probably need more help." A principal at a general education campus declared:

> We will not need a whole bunch of stuff. At a school where they haven't thought about these things, or haven't done the drills or haven't taken the inventories and stuff like that – well, if we care … we'll go, 'Okay, you need this and we've got it over here.' Bam! There it goes. And if you have a bunch of trucks, we can truck things, and we can even bicycle things if we have to. We can walk it to them. Like if I have a bunch of stuff and [the school down the street] does not, I'll just walk it down there. You know what I mean? Because we care. Because we care.

Some study respondents rejected the idea that resources would have to be prioritized at all, instead taking the position that disaster resources are necessities, and as such, must be fully funded and provided to schools. Half of the eight respondents with this view were school-based employees, and stated their views emphatically, as did this principal conducting a hypothetical conversation with the government during his interview:

> So what kind of crap is this? You are trying to shove it down our throats that we do not have the resources; that we should have to sit here and talk about making decisions about where the resources should go in the allegedly greatest country in the world. We're supposedly the greatest nation in the world, right? Why would we even have to ask that question? It is ridiculous. There should be plenty of resources for everybody. And there are, actually. We just do not give it.

A teacher simply stated, "It's my particular feeling that the first and absolute thing that we have to put as priority – and I do not accept 'not enough to go around' – is the safety of the students."

In addition to school staff, some district-level management staff members also proposed that necessary disaster resources could and should be funded fully.

Analogies were offered to illustrate the position that the school district could fund all necessary disaster resources. One analogy was that for disaster resources at school and throughout education, schools have been asked to provide Mercedes service, but have been given a go-cart to drive, and that go-cart is being driven as fast as possible, sometimes even on two wheels to attempt to deliver what is expected. The other analogy acknowledged that the school district in this study was large, but that large institutions can create standardization, and this could be applied to disaster resources in the district. "Big Mac in Spain tastes a lot like Big Mac in Kansas, I suppose, so it's do-able." Respondents ultimately had the interests of the children at heart; "It's for the kids," was a common refrain through and among the interviews.

Table 6: Representative Quotations for Distributive Justice

Triage Approach

- o I think realistically, the triage model is going to be the one that's going to function the best. Yes, I think that's how it's probably going to end up. Part of the reason why is because, in a disaster, you're working with people.
- o In mass casualties, that's what you have to do. People are going to be left behind. People are, unfortunately, going to die, because you can't take the time on one person. So I'm good with that mentality on a mass casualty.
- o I think it's really going to depend on the moment that people in control are going to have to make sometimes some split-second decisions. And like any kind of disaster, we learned from 9/11 you are going to put your priorities on someone who you think is going to survive.
- o I would probably go for the greatest good for the greatest number and then make those exceptions where they arise for the high-priority students. But also keeping in mind, well, we're stocked for three days. We may need to do a little turning bread into – what was Jesus' miracle in the Passover celebration?
- o So getting the item out by triage [approach]? I'm sorry, I throw that one out as an option.
- o Well, I never did like the triage, so I just don't like that style, I really don't.

Best Outcome for Least Well-off Approach

- So doing things in an equitable fashion is not really appropriate either. I know people will say, "Well, that's not fair." Well, life isn't fair. Not everybody is starting out at the same level of needs. Where the need is greatest is where the effort should be put first.
- I'm not saying that all kids are not equally of value - I'm not valuing kids. I'm just saying that some people need more, need you more, than others.
- You have these people's lives in your hands. I think it should be where the people first with the higher need, you should put their need first. 'Okay, who has the most need?'
- We still have Special Ed. Centers, where an entire center is the severe population. They're going to need more resources than say a gen. ed. elementary school that doesn't have any health-related special-needs kids. But we know where these schools are, we know what the population is, so we just have to figure it out.
- I mean, honestly, sometimes you just have to go with severe. They really, really need it. They really do need it.

Indecision

- How? That's a hard one. In terms of resource allocation, knowing that there's never enough to go around, how do we allocate our resources as a district for emergency planning? That's the million-dollar question.
- Yeah, wait. I don't even know how – there's so many factors that – yeah, who will get these services? I feel like I don't have an answer for that.
- Ooh, that's a tough one, Jill.
- I don't know. I mean, I have in my – I have only ten. I don't know.
- Right (sighs). Well, I think it should be – it's a hard decision.
- And thinking about the admonition to always think about what a reasonable person in this situation would do. Am I, as the principal, going to face the civil suit if parents say, "You neglected my child or our children in an emergency, because you prioritized these other children's needs above mine." And so, I don't think you can forget about that entirely.
- It's a hard question. I would – you know, I don't know. Yeah, our population is smaller; we're not a big school. Because you can't say, well, we're going to help these kids, but there's a large high school; those kids are going to need stuff, too. So that's hard. I'm sort of torn because – and then again, those kids can help themselves and our kids can't, so you would – I don't know, it's a hard question. Oh gosh, I don't know … Yeah, that's a hard question. I don't know what the answer is. I know, and I really – I don't know, because there's really no right answer.

Fully Fund Disaster Resources

- Couldn't we take care of everybody? Would there not be a better strategy? We could do it easily.
- It doesn't make sense, because the government is telling us we take care of [students in a disaster], we have money. We can do this, and this is what we do.

- o What it boils down to is the safety of the kids and making sure that they're okay, that they would be able to survive or have a good chance of survival if anything should happen. I think that all the kids should be serviced and have at least a fighting chance if something were to happen.

Chapter 5: Discussion

Introduction

The purpose of my research is to help school districts, schools, and individual school-based personnel prepare to adequately care for students with disabilities in a disaster. I conducted qualitative research to identify disaster care needs and recommendations within a distributive justice framework for students with disabilities. I interviewed 22 parents and employees of schools, the school district, and local government agencies to identify the disaster needs and recommendations for schools who serve students with disabilities.

This study explored what is known about disaster care for students with disabilities through the perspectives of parents, and people who work in community emergency management, education, and disability services. Each group has different responsibilities, resources, and specialized knowledge about students with disabilities and their disaster needs. Using this research, I can help schools create comprehensive disaster plans, complete with resources that meet the needs of students with disabilities.

In this chapter, I provide an overview of the study's findings and discuss their significance. Then I discuss the limitations of this research. I follow with recommendations for practice, policy, and future research. I conclude with a reflection on the study participants and the relationship of this study to concurrent disaster events.

Overview of Findings

The thoughts and opinions expressed during the interviews were palpably informed by the individual's experiences with disasters and other emergency situations. The term "disaster"

was not defined for participants, instead using the experiences that participants described to contextually frame what constitutes a disaster on a school site. Allowing participants to define disaster for themselves broadened the definition to be inclusive of incidents that impact a school, legitimizing the context and valuing school-based stakeholders. Only three of the 22 respondents reported that they had never experienced a disaster, personally or professionally. The experiences described by the remaining participants varied as widely as the participants themselves. Respondents detailed incidents of weather, violent acts, and personal tragedies.   Although some respondents were raised in Southern California, others described situations unfolding in other areas of the United States, as well as in Canada, Mexico, and Japan.

Many of the school disasters described by participants involved students with disabilities, and some incidents occurred on Special Education Center campuses. Experience during actual emergency incidents, training and campus preparedness efforts, as well as participants' experiences as students and/or parents themselves each helped to provide a base level of knowledge about school disaster preparedness in general, and as it applies to students with disabilities. Respondents elaborated the disaster preparedness plans, training, supplies, and teams that schools do have in place.

Every one of the seven respondents who specified a disaster need about planning worked or is now working at a school site. There are many supplies and much equipment needed to respond appropriately to a disaster at school, especially for students with disabilities. Supplies can be broken into categories, each serving a particular disaster need. One of the most pressing disaster needs that 18 contributors identified was building evacuation, especially for students who use wheelchairs. Parents were indicated as a need and an area of concern in a disaster by 18

of 22 respondents, including all three teachers and two of three parents. Disaster needs regarding school staff members were addressed by 19 contributors to this study, most concerning the staff's ability to manage student behaviors.

Respondents interviewed for this study offered numerous thoughtful and creative recommendations to address school disaster needs for students with disabilities. In terms of sheer numbers, interviewees had the most recommendations about the supplies and equipment that need to be at schools to adequately manage the disaster needs of students with disabilities. All respondents had contributions to this category. Recommendations regarding response actions taken at schools in times of disaster were offered by 19 of the study participants, including all but one respondent directly associated with school sites. Recommendations about parent interactions with the school in and about disasters were made by 12 respondents. Respondents who have worked at schools acknowledge the enormity of caring for students with disabilities and eight of these talked of greatly valuing experience in themselves and their co-workers. Respondents also stressed the importance of school staff working well together, and described their experiences on campus as being part of a team or family.

How disaster resources should be allocated by a school district is part of the preparedness and response process. In the current educational climate, resources are not abundant, and all needs cannot be filled for every school site. Allocating resources and prioritizing needs can be addressed through distributive justice theory, and utilizing one of three approaches to it. When presented with the three options, only two study participants even mentioned the approach advocating an equal chance at survival that operates on a first-come, first-served basis. Those two participants rejected the equal chances approach. The triage approach, based on the concept

of doing the greatest amount of good for the greatest number of people, was addressed in nine interviews. Of the 22 participants in this study, 18 declared the best outcome for the least well-off approach as the best one to use when allocating disaster resources in a school district. This option was preferred across all segments of the study population.

Responses about resource allocation and distributive justice reflected respondents' individual interpretation of disasters that affect schools and the resources needed for them. Responses included resources needed during the response phase of a disaster, as well as resources that could be pre-staged to mitigate or prepare for disasters. Selecting an approach to resource allocation was a difficult decision for many respondents. In fact, sharing resources was proposed by five interviewees, including staff from each school, two of those respondents being principals. Some study respondents rejected the idea that resources would have to be prioritized at all, instead taking the position that disaster resources are necessities, and as such, must be fully funded and provided to schools.

Conclusions about Findings

Collective Resilience

Most striking about the findings from this research was what it revealed about the participants and the school communities to which they belong. School-based employees and those with substantial prior schoolsite work history spoke of the confidence they placed in their co-workers, and the teamwork that would enable them to weather a disaster well. I was unsure what to make of these statements, and at first wondered whether they were indicative of a tendency to overstate one's disaster preparedness, or perhaps denial about the severity and difficulties encountered in a disaster. As more of a practitioner myself than a researcher, I was

unfamiliar with the growing body of literature on collective resilience in disasters. Community resilience can be defined as the process that links adaptive capacities after a disturbance, such as a disaster (Norris, Stevens, Pfefferbaum, Wyche, & Pfefferbaum, 2008). A school can certainly be considered a community, using either the typical definition of geographic boundaries and shared fate (Norris et al., 2008), or the definition of persons who work in a given area (Wells, Tang, Lizaola, Jones, Brown, Stayton, Williams, Chandra, Eisenman, Fogleman, & Plough, 2013). My interviewees offered up multiple statements in interviews that spoke to the disaster resiliency of their school staff. These statements included those in the Chapter Four section on Recommendations about School Staff, responses regarding distributive justice, and were also embedded in responses to most of the interview questions ranging across all three research questions. The sense of being a team or family was recognized and stressed as important by school members, which is an example of social capital, one of Norris et al.'s four key resources of a community that adapts well to adversity (2008). Even though they were never asked explicitly about the effect of school culture on disaster readiness, participants cited having a staff that functioned as a family or worked as a team as an important reason for their successful disaster preparedness. While school staff serve a vulnerable population comprised of students with disabilities, the staff of a school is not necessarily a vulnerable population itself.

School personnel, past and present, seem to understand that in a large-scale emergency, schools may be on their own for several days, embodying the "bottom up" approach to disaster preparedness and response that helps sustain community resilience (Wells et al., 2013). Few participants mentioned first responders coming to their site following an earthquake, and all seemed to be well versed in the substantial response actions expected from school staff members following a disaster. We promote this concept in the district as "YOYO 7: You're on Your Own

for Seven Days," and this expectation has a contributory effect on the collective resiliency of a school staff. Feeling that it's "us against the world," or at least "us without the world" may increase the trust among colleagues that several respondents mentioned, and adds to community competence, another key resource for community resilience (Norris et al., 2008). One piece of building resilience is also the recommendation that more staff members be trained and ready to manage the disaster needs of students with disabilities, which is a message that helps build resilience as it emphasizes helping a vulnerable population (The National Academies, 2012). Employees at both the general education campus and special education centers spoke of the necessity of everyone on campus having greater general familiarity with the needs of students with disabilities, as well as specific recommendations for training all school staff on evacuation needs and behavior support. Staff members who recognize the collective resilience of their site may be more insistent that everyone be cross-trained, knowing that, as one interviewee stated, "You're going to be called on in a disaster to help anybody."

School staff members often went beyond efficacy to altruism, offering to share resources with schools less prepared than they envisioned their own school to be, as discussed in the findings for the concept of distributive justice. They also exhibited a willingness to perform their disaster duties, and stay on campus indefinitely following a disaster, as required by California state law. Of school site employees, only two thought that some of their co-workers might leave, and these were the two newest employees in the study. This willingness to stay may provide further evidence of collective resiliency, and provides further evidence of community competence (Norris et al., 2008) in stark contrast to the member of the city's Emergency Management department, who predicted that only half of school employees would perform their disaster duties. A district-level nursing manager even offered all of the district's 500 nurses to

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the collective good of the school district, remarking that, "They're your soldiers. They can respond."

The sense of acting as a cohesive team and with a sense of trust may relate to prior disaster experience together on school campuses, as described in the Chapter Four findings section about the disaster experiences of participants. Each of the three schools in the study has been affected by multiple emergency incidents that staff described as disasters, and these types of shared experiences help a school staff bond and increase their resiliency as they learn from previous shared experiences and use them to mitigate against future events (The National Academies, 2012). The sole school staff member who did not mention trusting coworkers or valuing familial relationships at school is one of the two newest employees in this study. She has had less time to bond with coworkers, and fewer shared experiences, and her perspective of their collective resilience may be impacted by this lack of shared experiences. Additionally, as stated in chapter 4, some special education center staff expressed the belief that their schools are more prepared for disasters than general education campuses. This could reflect their generally smaller student numbers than general education campuses, the greater numbers of medical emergencies experienced on their campuses due to students with significant medical challenges, or tighter bonds among staff members. Any – or all - of these factors could also contribute to the sense of community resilience experienced by school staff by establishing the supportive social context to withstand and recover from disasters (Plough, Fielding, Chandra, Williams, Eisenman, Wells, Law, Fogleman, & Magana, 2013). Some of the more personal disasters experienced by participants outside of the school realm, such as the respondent who witnessed a suicide attempt by his father, also contribute to the personal resiliency of the participants, and this might then have a contributory effect on a school's collective resiliency.

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The concept of disaster collective resilience touches the educational world when considering the research on prevention and mitigation of school shootings. A key recommendation for prevention of school shootings is the necessity for a positive school climate. Studies by the Federal Bureau of Investigations (O'Toole, 2000), and the United States Secret Service in conjunction with the United States Department of Education (Vossekuil, Fein, Reddy, Borum, & Modzeleski, 2002) found that prior to a school shooting, others, most frequently fellow students, knew the shooter's intentions, but did not tell adults at school. In the Bethel, Alaska, school shooting in 1997, 26 students knew the shooter's intentions, some bringing cameras to school to document the attack, and many gathering beforehand on the balcony overlooking the area of the shootings. Not a single student shared information with staff at the school before the attack (FBI, 2013). A positive school climate, characterized by a positive, caring culture, a responsive administration, a feeling of connectedness, and physical safety (Cole et al., 2007), works to establish trust on a school site, and break the code of silence that keeps students from reporting threats of violence (Borum et al., 2010). Positive school climate has been studied and promoted in educational circles for quite some time, and is an essential component of a well-functioning school for students and staff. The effects of a positive school climate may, in turn, positively affect a school's collective resilience to disasters.

Database

On a pragmatic level, one issue for which respondents posed solutions that crossed multiple research questions and multiple findings categories was establishing a database of equipment for the disaster needs of students with disabilities. Seemingly simple, this idea surfaced in five different interviews when discussing recommendations. The idea was proposed

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by both classroom aides at the two special education centers, and three district-level management positions, an unusual stratification pattern not replicated in other findings. Each respondent envisioned the database functioning a bit differently, and for different reasons, several of which converged on the outcome of being able to share resources as necessary, before or during a disaster. A common database could help bridge the cost of some of this specialized equipment, the size of the district, integration with other existing systems and databases, and the autonomy with which schools in this district conduct their daily operations.

The nexus of the database idea emerged again in the discussion of the approaches to distributive justice. Participants were loath to pick one approach, knowing that if resources were scarce, selecting one approach would leave some students without the specialized resources that some students with disabilities require in a disaster. Instead, many participants tried to create their own approach, many times incorporating a version of a self-assessment of needs linked to a database. Seven respondents posed a variation on this idea, five of them different than the participants who proposed a resource database in the discussion of disaster recommendations. Related ideas that could incorporate a database of resources, including a hazard assessment and a prioritization matrix, brought the total suggestions for this area to 11 respondents. This expanded group included parents and non-district respondents in addition to the district-level management personnel and classroom aides in the prior sub-group.

Interestingly, the idea of a database circles back to collective resiliency and altruism, as several respondents envisioned the database as a way to make equipment available to other schools. The database became a conceptual means to further share resources that school personnel envisioned themselves utilizing in a disaster. Once again, this vision was contradictory

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to what the city emergency management department representative anticipated, who assumed that each school principal would claim that their own school had the most critical need. His vision of school needs did not include perspectives such as the aide who expressed the common sentiment, "If we're all here for the kids, we should help each other out."

Limitations

This study had several limitations. As it is the first piece of research in the field of school disaster preparedness for students with disabilities, it was intended to provide a "first look" at some of the issues. As such, it was not designed to comprehensively address the issues raised by this research. It was a small, exploratory study, consisting of interviews of 22 disparate individuals. The study included three school sites at which four individuals were associated per site: three employees and one parent. School-based participants shared a professional category with only two other people in the study, and each of the 10 non-school participants was the single participant in their job classification. This research does not provide enough depth or breadth to make any definitive statements about the disaster needs and recommendations for students with disabilities. This research does, however, begin the discussion as intended.

Participants in this study gave many thoughtful answers that were detailed and informative. However, they were asked about needs and recommendations for students with disabilities in a disaster – a disaster which they may not have experienced in the company of these students, if they had experienced a disaster at all. These participants were not interviewed after experiencing a disaster. In fact, while many participants reported having experienced disasters, and some participants even told stories of disasters at school, no participant specifically cited an actual disaster when stating disaster needs or recommendations for their students. This

kept participants' statements conjectural, as statements appeared to be based on everyday need, or assumptions about disaster needs. As disaster conditions cannot be simulated well, and waiting for a disaster to affect students at school could delay research in this field, exploring what people know in advance of a disaster is reasonable.

Another potential limitation of this study was that selection of schools and participants was not random. Selection went beyond that of a "convenience sample," and was actually purposeful. In many cases, a participant was selected for this research based on prior contact with my office for assistance with the disaster needs of students with disabilities. In other cases, participants were drawn from previously established professional relationships in the field. This ensured a study population that was both vested in the outcome of the research, and one that may exhibit a higher level of disaster preparedness than the general population. Participants made rich contributions to the data, but did not represent the variance of responses that might have been possible if the study had randomized participation.

Given that I am the coordinator in the Office of Emergency Services for this school district and conducted these interviews myself, one might question whether school-based respondents were honest when speaking to me. My position in the district is advisory and not supervisory, and I do not conduct audits or inspections as part of my work. Participants seemed to understand that I was genuinely interested in understanding the issues in managing the disaster needs of students with disabilities, and working to improve conditions at schools. I detected response bias in a section of one interview, with a participant whose position carries political overtones. That participant discussed distributive justice and resource allocation quite circumspectly, not going deeper with the issue than politically expedient. I did not detect

instances of participants trying to overstate their preparedness for these students, nor did I notice exaggerations of need in expectation that I might provide more resources to them.

The findings of this study may have been different in other school districts with different disaster plans, different expectations of the level and duration of care of students, and in different geographical areas, all of which could affect specific findings and their transferability to other school districts. This study was conducted in earthquake-prone, sunny southern California, an area that does not experience winter weather, or hurricanes. Tornadoes are also quite infrequent, though common in many other areas of the country. Sheltering-in-place for weather rarely happens in southern California. This district's disaster plan, while an all-hazards plan, is skewed towards earthquake response. Earthquake response includes preparing schools to be self-sufficient for a number of days, as first responders may be overwhelmed, have other priorities, or be challenged by infrastructure damage that makes response difficult.

The self-sufficiency of schools is reinforced by the State of California's government code 3100 which declares all public employees, including school district employees, Disaster Service Workers. As Disaster Service Workers, in a declared or proclaimed disaster, employees must stay at work and may be tasked with jobs outside their normal duties. The Disaster Service Worker provision may be a factor in the district's expectation that school staff care for students for a number of days in a disaster, which may vary from the amount of time that schools in other areas are expected to care for students. Earthquake plans in this area also usually assume that schools may take refuge outdoors, contrary to what schools in other parts of the country may do in response to disaster, as weather is not usually a primary concern, and building damage from an initial quake or aftershocks is a known and persistent danger. This study also did not address the

disaster needs and concerns for moving students off-campus and the transportation challenges that action poses, as due to the nature of the disasters experienced, taking refuge in an off-campus location is rarely the response action taken.

Whether this study could be replicated and produce the same findings is also a concern. Certainly the same research questions, methodology, and interview protocols could be used in future studies, but findings could vary widely. Issues concerning other school districts with different disaster plans, different expectations of the level and duration of care of students, and in different geographical areas are all factors that affect the ability to replicate the study. The small sample size of this study also makes it less likely to effectively replicate the findings, as each participant is much more likely to offer unique responses with a sample of this size.

A final limitation of this study is that I was not an impartial researcher, coming in as an outsider. Rather, I was – and remain – heavily vested in the outcome of this study, and will use the findings to inform my future work in the district. My role in the research and in the district makes me uniquely suited to speak authoritatively about the school disaster needs of students with disabilities, and address some of the issues raised in the study. My experiential knowledge is not necessarily a bias to be eliminated, but can provide insights and validity checks. This insider's perspective can be seen as both helpful and necessary, and does not need to be eliminated, or silenced as a voice.

Recommendations

Recommendations for Practice

Someone needs to advocate for the disaster needs of students with disabilities at every school site, so that these needs can be proactively addressed and become a part of the school's overall disaster plan. This duty should not be envisioned as the person who provides the support to students with disabilities during a disaster, but rather as the person who ensures that the support is in place. These supports should include the full breadth of disaster needs as mentioned in this dissertation, and include enough depth to ensure that appropriate support is available no matter what impact the disaster has on the school community. Adequate information gathering to understand a student's needs, training staff members to be able to respond to identified needs and recognize unidentified ones, inclusive disaster planning, ensuring that adequate disaster supplies and equipment are in place, accounting for students during a disaster, providing care following a disaster, and reunifying students and parents are all necessary pieces that contribute to the well-being of students with disabilities in disasters.

Parents and other guardians and family members need to be a part of every school's disaster planning process for students with disabilities. Planning should also involve the student with the disability wherever practicable. Parents are a good source of information about their children. Parents can provide essential medical information, including medication that is taken outside of school hours, which is important in an extended disaster. Parents may also be able to provide extra doses of medication, as well as supplies and personal items that may help a student be more comfortable in a disaster. Parents of children with disabilities also know how their child's habits and behaviors differ during the after-school hours, at night, and on weekends from

during the school day. Parents can also provide tips for managing their children's needs. Schools need to have productive, deep conversations with parents of students with disabilities about how their child's needs can be met in a disaster. Parents usually know their children better than anyone else does, and schools need to embrace this resource.

Establishing, maintaining, and strengthening a positive school climate is crucial to many aspects of a highly-functional school, and acts to strengthen a school's ability to cope with a disaster. Developing a positive school climate affects all four phases of emergency management. Aspects of school climate such as positive relationship-building and sense of belonging are important to staff and students alike, and help schools create and build on the connections that lead to collective resiliency. Schools need to actively cultivate the culture they wish to grow, and a school's vision of a positive school climate is dependent on a multitude of factors. Each school's plan and path to positive school climate is unique, and should be explicitly planned.

School disaster readiness for students with disabilities needs to happen at several integrated levels to be both comprehensive and effective. Disaster issues that impact students with disabilities should be integrated at the personal, classroom, school, and district levels. The personal level includes ensuring that any disaster needs of a student with disabilities that are greater than or different from the needs of other students are known, documented, and accommodated, perhaps with an individual disaster plan. Integrating disaster needs at the classroom level supports individual needs and includes providing information and training to adults in the classroom about the student's disaster needs, and managing those needs for a variety of disaster responses, such as lockdowns, sheltering in place, building evacuation, and outdoor safe assembly areas. School-level integration of disaster needs of students with disabilities

supports classroom needs and involves coordinating the necessary awareness, planning, training, and resources to manage these needs site-wide. Integrating the disaster needs of students with disabilities at a district level supports school needs and includes creating policy that provides all necessary resources to schools, classrooms, and individual students.

Schools and districts must discuss disaster resource prioritization and allocation, and the philosophy they use to guide decision-making. These discussions may be difficult, as people often do not want to make these difficult and uncomfortable decisions. The resulting decisions will at least then be fully informed. Honest dialogue about how disaster resources will be allocated, and whose needs may not be served adequately, may lead to creative solutions that serve more needs more fully. Some of these discussions may even lead to disaster resources being fully supported and funded.

Recommendations for Policy

All schools should have disaster plans that support the needs of their students with disabilities, and these plans need to provide comprehensive disaster care. School districts should provide the policy and framework for disaster plans for students with disabilities. All classrooms should have copies of the disaster plans for students with disabilities in their classrooms, and know the location of any special resources for their students. All classroom personnel should be trained to provide disaster assistance to their students with disabilities. All students should be familiar with their disaster plan, as age and developmentally appropriate.

Mandates must be passed that allow parents to provide several days' worth of critical medication to their child's school for use in a disaster. This medication needs to be provided at no extra cost to families, so that financial constraints do not prevent a parent from providing

essential emergency medication to a school. Medication should be provided in a blister pack for greater shelf-life and stability. The blister pack can have the prescription label affixed directly to it, to provide easy identification of the proper medications, dosage, and instructions for each child. Expiration dates should be prominently displayed, and the label can be marked to indicate that this medication is provided for the use of the school. Making emergency medications available for disaster use at schools will save lives.

Recommendations for Research

That more research needs to be conducted in the nascent field of school disaster needs for students with disabilities hardly needs to be stated. Understanding the connected fields and disaster needs of schools, people with disabilities, and children will help us understand the disaster needs of students with disabilities at school. These related fields all need more research, and contributions will make a difference in both the pragmatic world of the practitioner, and the more conceptual world of the academic. Researching what works and publishing results will allow both worlds to advance by providing the evidence necessary to spark change.

The most thought-provoking research may be exploring collective resilience at schools, and how this resilience impacts an individual school and its disaster preparedness and response. Studies need to first be conducted to confirm that collective disaster resilience exists at some school sites. I can only envision subsequent studies as a series of questions, each an area of research: What makes a school resilient? Can we grow this resilience? How can resilience be taught, or transferred among people and schools? What effect does this resilience have on school culture? How connected is resilience and positive school culture? What is the interaction between a school's resilience and the community it serves? What effect does the staff's resilience

have on the students' resilience? How large of an influence can collective resilience exert? Can an entire district be collectively resilient? Are schools that experience trauma (serious illness/injury/death within school community, or violence) more resilient? Does the level of collective resilience vary if a campus experiences trauma directly versus indirect effects? Research that explores the collective resilience of a school has the potential to impact daily interactions, as well as disaster actions.

Conclusion

This dissertation is bookended by disasters affecting children at school. Yesterday, the Moore, Oklahoma, tornado killed seven children in their elementary school. As I sit here typing out the final words to this last chapter, that tornado has just been upgraded to an EF 5, with wind speeds clocked at 210 mph. I began the interviews for this research just after the Sandy Hook school shooting, in which twenty children lost their lives at school. In both tragedies, reports surfaced of teachers using their own bodies as shields to protect students. In both disasters, school personnel did everything possible, and in some cases impossible, to protect their students from harm. Of course they did – we take care of students every day at school. It's just that in a disaster, we take care of different needs.

Disaster planning for schools is not theoretical. I have never met a group of people who individually and collectively impressed me as much as the participants in this research. The earnestness of parents, forthrightness of principals, measured reason of district-level employees, ingenuity of classroom aides, resolve of teachers, and generosity of non-district participants all contributed to this study and the lives of children with disabilities.

Our children are in good hands.

List of Appendices

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Appendix B: Interview Protocol

Appendix C: Consent to Participate in Research

University of California, Los Angeles
Study Information Sheet

School Disaster Planning for Students with Disabilities

Jill Barnes, Doctoral Candidate in education and Dr. Pat McDonough in the Graduate School of Education and Information Studies, together with Dr. David Eisenman in the School of Public Health at the University of California, Los Angeles (UCLA) are conducting a study.

You were selected as a possible participant in this UCLA research study because of your interest in the disaster needs of students with disabilities. Your participation in this research is voluntary, and your identity will be kept confidential.

Why is this study being done?

The purpose of this study is to explore what is known about disaster care for students with disabilities among the intersecting, but rarely interconnecting, fields of community emergency management, education, disability services, and parenting. The results of this research may improve disaster planning and emergency management at Los Angeles Unified School District (LAUSD) school sites. This research will provide LAUSD schools with information to create comprehensive disaster plans that include students with disabilities.

What will happen if I take part in this research study?

If you volunteer to participate in this study, the researcher will ask you to do the following:

> Participate in an audiotaped interview for an hour about your experiences in emergency management, education, disability service management, or parenting and how your professional or parenting experiences relate to disaster care at schools that have students with disabilities.

How long will I be in the research study?

Participation will take a total of about 60 minutes for the interview, and another possible 30 minutes to review and make any necessary changes to a transcript of your interview.

Are there any potential risks or discomforts that I can expect from this study?

There are no anticipated risks or benefits.

Are there any potential benefits if I participate?

You will not benefit directly from your participation in the research.

The results of this research may benefit K-12 students with disabilities, by providing schools with information to create more comprehensive disaster plans, which may improve the survival chances of students with disabilities in a disaster.

Will I be paid for participating?

You will receive a $30.00 Target gift card for participating in the interview

Will information about me and my participation be kept confidential?

Any information that is obtained in connection with this study and that can identify you will remain confidential. It will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of coding. Only the research team will have access to the data, and the data will be secured in a locked, fireproof safe.

What are my rights if I take part in this study?

You can choose whether to be in the study or not, and you may withdraw your consent at any time.

Whatever decision you make, there will be no penalty to you, and no loss of benefits to which you were otherwise entitled.

You may refuse to answer any questions that you do not want to answer and still remain in the study.

Who do I contact if I have questions about this study?

The research team:

If you have any questions, comments or concerns about the research, you can talk to one of the researchers. Please contact:

Jill Barnes
Doctoral Student - Educational Leadership Program (Ed.D) University of California Los Angeles
Graduate School of Education & Information Studies
310-880-9006
Jill.barnes@lausd.net

Dr. Pat McDonough
Professor, Higher Education and Organizational Change
Vice-Chair, Department of Education
Co-Director, Educational Leadership Program
University of California Los Angeles,
Graduate School of Education & Information Studies
310-206-2120
mcdonough@gseis.ucla.edu

Date:

Location:

Participant:

Signed confidentiality form completed?   Yes / No

Introduction: Thank you for agreeing to participate in this interview. I'm here to learn about what we can do to better prepare schools to care for students with disabilities following an earthquake. I'd like to hear about your experiences in your role as _____. I want to assure you that your name or anything else that could identify you personally will not be used in this research. Is it okay if we record this conversation? Thank you; let's get started.

One of the reasons that this topic is important to me is because of my own family and our experiences … (describes father with twin brother born blind who still live independently; mother with brain damage at 42 that caused physical, communication, and cognitive disabilities; sister with kinder-aged son who has cerebral palsy) and my professional experiences in education/fire/police.

Warm up: Tell me a little about your experiences here in this job.

> (Parents: Tell me a little about your child)

Key Questions:

Imagine that your school (or a school you know) has just experienced a significant earthquake. Describe for me what you would see people doing.

> Anything else?

> What about (drop-cover-hold on, search and rescue, first aid, parents, emotional upset)

Now imagine that it has been 2 or 3 days since the earthquake, and many students still remain at school. What would you see people doing now?

> How are things different than right after the quake?

> Anything else?

What is your biggest concern about students with disabilities in a disaster, say a pretty big earthquake?

What other concerns do you have?

I noticed that you didn't mention (medication, shelter, transportation, communication, medical protocols, etc.), what are your thoughts on that disaster issue at school?

I noticed that you also didn't talk about (medication, shelter, transportation, communication, medical protocols, etc.), what are your thoughts on that?

What challenges do schools face in preparing for disasters?

What strengths do schools have in preparing for disasters?

What would be useful for schools (or your school) to better prepare to care for students with disabilities after an earthquake?

    Can you think of anything else that might be useful?

Do you think individual disaster plans for students with disabilities would be useful? Why?

    What should such a plan include?

    How would plans like these help schools?

    Who should make the decisions about the contents of each plan?

    How would the school manage the plans (make sure they are implemented)?

Are there other strategies that might be good for schools? Like what?

    How would that help schools?

Thinking about everything it takes to be prepared for a disaster at school, the money, the time, the employees, and the equipment, how do you think schools should decide how much is used to prepare for a disaster?

    (If necessary, prompt with:

    Divide everything equally so that each school has the same amount?

    Divide things to be able to do the greatest amount of good for the greatest number of students, including students who do not have disabilities?

    Give the most resources to those who need the most?

    How would those decisions be different from school to school?

    How is your answer different if we are talking about preparing specifically to care for students with disabilities?

CONSENT TO PARTICIPATE IN RESEARCH

School Disaster Planning for Students with Disabilities

Jill Barnes, Doctoral Candidate from the Educational Leadership Program (Ed.D) in the Graduate School of Education and Information Studies at the University of California, Los Angeles (UCLA) is conducting a research study.

You were selected as a possible participant in this UCLA research study because of your interest in the disaster needs of schools that serve students with disabilities. Your participation in this research is voluntary, and your identity will be kept confidential.

Why is this study being done?

This study will explore what is known about disaster care for students with disabilities among the intersecting, but rarely interconnecting, fields of community emergency management, education, disability services, and parenting. The results of this research may improve disaster planning and emergency management at Los Angeles Unified School District (LAUSD) school sites. This research may provide LAUSD schools with information to create comprehensive disaster plans that include students with disabilities.

What will happen if I take part in this research study?

If you volunteer to participate in this study, the researcher will ask you to do the following:

> You will participate in an audiotaped interview for an hour about your experiences in emergency management, education, disability care management, or as a parent and how your experiences relate to disaster care for students with disabilities.

1. The interviews will take place at location of your choosing, outside your working hours.
2. After the interview has been transcribed, you may receive a copy to review and to make any changes as needed.
3. Once all of the interviews have been conducted, I will email a link to the report and PowerPoint of the findings to all interested research participants. Your identity will be kept confidential, and findings will be reported in aggregate.

How long will I be in the research study?

You will only be asked to participate in one 60-minute, audiotaped interview. However, you may be asked to review and make any necessary changes to a transcript of your interview.

Participation will take a total of about *60 minutes.* If transcript review is needed, an extra half hour will be asked by the end of February.

Are there any potential risks or discomforts that I can expect from this study?

There are no anticipated risks or discomforts.

Will I be paid for participating?

You will receive a $30.00 Target gift card in appreciation for your time.

Will information about me and my participation be kept confidential?

Any information that is obtained in connection with this study and that can identify you will remain confidential. It will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of secure coding procedure that uses a pseudonym instead of your name to identify data. The list that links the pseudonyms to the participant names will be kept in a locked, fireproof safe with limited access by authorized personnel only. You have the right to review, edit, or delete the audio files of your interview in whole or in part.

What are my rights if I take part in this study?

You may withdraw your consent at any time and discontinue participation at any time.
You can choose whether to be in the study or not. If you agree to participate you may withdraw your consent at any time. Whatever decision you make, there will be no penalty to you, and no loss of benefits to which you were otherwise entitled. You may refuse to answer any questions that you do not want to answer and still remain in the study.

Who do I contact if I have questions about this study?

If you have any questions, comments or concerns about the research, you can talk to one of the researchers.

Please contact:
Jill Barnes
Doctoral Student - Educational Leadership Program (Ed.D) University of California, Los Angeles Graduate School of Education & Information Studies 310-880-9006
Jill.barnes@lausd.net

Dr. Pat McDonough
Professor & Co-Director, Educational Leadership Program University of California, Los Angeles
Graduate School of Education & information Studies
310-206-2120
mcdonough@gseis.ucla.edu

If you have questions about your rights while taking part in this study, or you have concerns or suggestions and you want to talk to someone other than the researchers about the study, please call the OHRPP at (310) 825-7122 or write to:

UCLA Office of the Human Research Protection Program
11000 Kinross Avenue, Suite 211, Box 951694
Los Angeles, CA 90095-1694

You will be given a copy of this information to keep for your records.
SIGNATURE OF PARTICIPANT

_____
Name of Participant

_____   _____
Signature of Participant   Date

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