IDENTIFYING AND ACCOMMODATING HIGH-RISK, **HIGH-VULNERABILITY POPULATIONS IN DISASTERS**

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LEARNING OBJECTIVES

When this chapter is completed, readers will be able to:

- 1. Define and apply the concept of high-risk, high-vulnerability populations to disaster contexts.
- 2. Identify the social populations most at risk when disaster strikes and offer an intersectional analysis that explains how overlapping population characteristics may increase or decrease the vulnerability of an individual in a disaster.
- 3. Understand how stakeholder involvement is essential throughout all phases of a disaster to identify and validate gaps, solutions, and unresolved issues regarding vulnerability.
- 4. Identify varying systemic levels where medical intervention can reduce disaster vulnerability.

KEY MESSAGES

High-risk, high-vulnerability populations refer to groups who have the greatest probability of being exposed to disaster and who have the least capacity to anticipate, cope with, resist, or recover from

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This fourth edition chapter updates and expands the chapter in the previous editions. The current authors wish to acknowledge the contributions of three authors from the earlier chapter editions: Jane Kushma with Jacksonville State University, Jennifer Mincin with SUNY Empire State College, and Alan Clive, who was formerly with FEMA and has since passed away after a long and noble fight against cancer.

the event, including: the poor, racial and ethnic minorities, immigrants and non-native speakers, women, children, the elderly, and persons with disabilities. Here, such individuals are viewed as possibly having particular medical issues.

- By using a systems approach, it is possible to think beyond traditional medical models and influence the social, economic, and policy structures that induce vulnerability.
- Anticipatory planning and preparedness actions are key drivers to successful response and recovery outcomes. Such actions do not necessarily require significant effort or expense, and can be integrated with routine activities.
- Awareness of possibilities for action is enhanced when individuals understand and personalize the risks they face in their community.

CHAPTER OVERVIEW

Some populations are more vulnerable and at higher risk from disasters than other populations. This chapter will help you identify high-risk, high-vulnerability populations and understand their potentially unique needs in a disaster context. Employing an ecosystems approach across the life cycle of a disaster, you will explore potential strategies to reduce vulnerability, provide necessary assistance or accommodation, and build the capacity of individuals, families, caregivers, agencies, and organizations, and the community. Case studies, tips, and tools are included to help you apply what you learn.

DEFINING AND UNDERSTANDING VULNERABILITY

Disasters in the United States and around the globe have caused widespread loss of life, destruction of built and natural environments, significant economic damage, and prolonged suffering and hardship among survivors. Photographs of flooded communities submerged under murky waters, of historic structures turned to rubble in earthquakes, and of homes and businesses flattened during tornadoes can leave the impression that disasters are "equal opportunity events." Decades of social science research, however, provide substantial evidence to the contrary. Consider the following:

- In 1987, a tornado destroyed nearly half of Saragosa, TX. Home to about 400 people, virtually all of the families in this small west Texas town were of Mexican descent and the majority spoke only Spanish. Yet, the residents received no culturally appropriate official warnings and messages that were disseminated through the Spanish-language media that members of the community typically used were poorly translated (Aguirre, 1988). After failing to take shelter, 30 people ultimately died and 120 sustained injuries (Tierney, Lindell, & Perry, 2001).
 - The 1988 Armenian earthquake killed perhaps as many as 25,000 people. About two-thirds of the total deaths were

children and adolescents who were in classrooms in inadequately designed schools at the time of the quake (Miller, Kraus, Tatevosyan, & Kamechenko, 1993).

- In the 3 years following the 1995 Great Hanshin (Kobe) earthquake in Japan, the proportion of low-income elderly men and women living alone in temporary governmental housing increased substantially. The elders who were most socially isolated suffered from the highest rates of sickness and depression and were at elevated risk for suicide and increased rates of alcoholism and suicide (Kako & Ikeda, 2009; Otani, 2010). In response, a nursing college volunteered in the "kasetu" used for elderly survivors. There, they encountered isolated seniors with increased rates of alcohol and suicide. Out of concern for increased deaths (called "kodokushi" or death alone and unnoticed), they moved residents into "kasetu" on the grounds of the nursing college (Kako & Ikeda, 2009).
- Among the approximately 1,300 persons who perished in New Orleans in Hurricane Katrina in 2005, 67% were at least 65 years old. Prior to the storm, this group represented just 12% of the population (Sharkey, 2007). In Orleans parish, the mortality rate among Black adults was 1.7 to 4 times higher than among White adults (Brunkard, Namulanda, & Ratard, 2008).
- Superstorm Sandy, which struck the East Coast in 2012, highlighted that Black and Latino populations disproportionately reside in the census tracts within three miles of the storm surge zone. In addition to seeing a direct and disproportionate impact on people of color, public and subsidized housing residents were also disproportionately affected. In Connecticut and New Jersey, roughly half of the public housing and subsidized housing units within storm-affected census tracts were "highly impacted" by storm surge or other storm damage (Haas Institute, 2016).

In this chapter, we use the term "high-risk, high-vulnerability populations" to refer to the people with a higher probability of being exposed to disaster who also face barriers to anticipate, cope with, resist, or recover from the event (also see Fordham, Lovekamp, Thomas, & Phillips, 2014; Mileti, 1999; Wisner, Blaikie, Cannon, & Davis, 2004). What can the previous examples and the myriad other cases that are now part of the ever-growing disaster research literature teach us about human vulnerability to disasters?

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First, some groups in society are more prone than others to damage, loss, and suffering in the context of differing hazards (Wisner et al., 2004). The poor, racial and ethnic minorities, immigrants and non-native speakers, women, children, the elderly, and persons with disabilities are among those most at risk to the adverse impacts of disaster (see Phillips, Thomas, Fothergill, & Blinn-Pike, 2010). Although these groups differ in many ways, they often lack access to vital economic and social resources, have limited autonomy and power, and have low levels of social capital (Barnshaw & Trainor, 2007; Morrow, 1999). They also, for various sociohistorical and economic reasons, tend to live and work in the most hazardous regions and in the lowest-quality buildings, thus further exposing them to risks of morbidity and mortality associated with natural hazards (Cutter, Bryan, & Shirley, 2003; Sutley, van de Lindt, & Peek, 2017a, 2017b).

Second, the aforementioned demographic characteristics socioeconomic status, race, gender, age, disability—intersect in complex and dynamic ways that may increase or decrease the vulnerability of any given member of a social group (Phillips & Morrow, 2007). For example, although African Americans experienced higher mortality rates than Whites in Hurricane Katrina, not all African Americans were equally at risk. Race interacted with age, gender, and evacuation status, resulting in Black men over 75 years of age who did not leave the city before the hurricane landfall being significantly overrepresented among the dead in Orleans parish (Brunkard et al., 2008; Sharkey, 2007).

Third, over the past decade, there has been some movement away from simple taxonomies or checklists of "vulnerable groups" to a concern with what Wisner et al. (2004, p. 15) refer to as "vulnerable situations." This approach emphasizes vital temporal and geographical dimensions to examining vulnerability and the social contexts and circumstances in which people live (also see Fothergill & Peek, 2015). The thousands of children who died in the Armenian earthquake may not have lost their lives had the disaster not happened during the school day. Extensive loss of life among women and children from the 2004 Indian Ocean tsunami occurred as they waited on the shore to process fish brought home by their husbands who survived the event at sea. In one Indian school for children with disabilities, nearly all perished. This approach also reminds us that people may become more or less vulnerable depending on their age and stage of development, or due to injuries, pregnancy, or other temporary health conditions (Peek, 2013).

Fourth, when trying to understand why disasters happen and who is affected most, it is crucial to recognize that it is not only "natural" hazards that cause them (Wisner et al., 2004). Disasters are the product of social, political, and economic environments that structure the lives and life chances of different groups of people.

Models for Understanding Vulnerability

When considering high-risk, high-vulnerability populations, two schools of thought, or models, are used to frame the discussion that follows. Note that these models—medical and functional—are derived from a disability-focused approach but can be applied to other high-risk, high-vulnerability groups. To be most effective, however, a balanced use of both methodologies will likely have the most benefit when preventing harm or minimizing the consequences of disasters.

Medical Model

This model is derived from disease, trauma, or health conditions that disrupt what is considered to be "normal" functionalityphysically, mentally, or socially. It has implications for public health programming and policy development as it places emphasis on treatments and interventions that manage, reduce, or prevent the debilitation, disease, or condition. But in the realm of high-risk, high-vulnerability planning or response to a disaster, the model is limiting because it does not fully consider the social, cultural, and economic roots of vulnerability nor does it adequately account for capability, ability, and self-direction during disaster. The medical model has been critiqued as ignoring sociopolitical dimensions that marginalize people with medical or disability conditions and overlooking the potential capacity of populations if barriers to full participation and independence are removed (Tierney, Petak, & Hahn, 1988).

Functional Model

The functional model, also called the "social model," moves the focus from categorizing deficits at an individual level, such as found in the medical model, to understanding the vulnerability in the context of the built, social, and political environment. The core principle in the functional model is how it places the onus on society and not on the individual to intervene and make systemic changes that will benefit all people, especially those with support needs in the areas of communication, health, functional independence, support and safety, and transportation. In the realm of disaster, this approach attempts to enable individuals the same opportunities to access services or to take self-determined actions during disaster. So within the disaster life cycle (preparedness, response, recovery, and mitigation), while it is imperative that all individuals take on a responsibility to plan to the best of their abilities, it is equally important that professionals and the overall response system become and remain fully inclusive and sufficiently flexible to actively address barriers, collaborate with stakeholders, and utilize resources effectively.

Currently, the Federal Emergency Management Agency's (FEMA's) "whole community" philosophy is promulgated on the functional model just outlined. As such, FEMA suggests that planning for everyone ensures the exclusion of no one. This means knowing one's community demographics as intimately as possible, beyond a surface level of statistical and census information. Working with direct service providers and others in the community serves as the firm foundation of an effective and stand-alone emergency management program or one within a healthcare organization. For example, this could include activities such as:

- Working with durable medical supply vendors to map higher levels of oxygen delivery to homes
- Partnering with public utilities to identify electrically dependent customers

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- Working with immigrant advocacy groups to determine non-native language usages and the best ways to reach people with information
- Supporting domestic violence program organizations to identify security and safety concerns for women and children not easily reached
- Collaborating with local health departments and community clinics to take into account higher area reliance on emergency rooms for standard health needs as an indicator of economic conditions

Using a whole community approach in all phases of emergency management helps to reduce vulnerability and lessen the impact of disasters.

Application

In the medical profession, the medical model represents a common approach as health conditions denote pathology and lead professionals to identify appropriate interventions and treatments. The functional model expands and transforms the medical approach allowing for additional analysis of social systems, providing the opportunity to work more closely with community members, and recognizing that not all health conditions are isolated but instead interwoven with the economic, social, political, racial realities of people's lives. Thus, an appreciation and application of both models are necessary to be most effective.

To demonstrate the need to understand a wider social context, consider that one 87-year-old person may be completely capable of self-sustaining actions in a disaster once provided the appropriate information on which to act, while another person of the same age may have multiple health or medical conditions preventing self-care. The latter may be economically capable of compensating for the physical conditions by utilizing private care support services. So age is not a singular fact; nor is health; nor is economics.

To demonstrate the need for interventions that are more inclusive, consider that another 87-year-old person is deaf or hard of hearing and critical instructions are transmitted in spoken English only via loudspeaker, causing a barrier to understanding, being able to take action and engage in self-protection. If that same person receives printed information, sign language interpretation, or by other alternative ways, then he or she is more likely to take action that results in self-protection. Similarly, imagine the challenges faced by a person with limited English proficiency. Again, providing information in multiple languages and formats will result in a higher likelihood that persons at risk will be empowered to take appropriate action desired because they received the necessary information and messaging.

When acting in the midst of a disaster or within the following short-term recovery period, using a functional rather than a purely medical model can also improve the triage process. Once past the acute medical need, a functional model will enable nurses and others to anticipate resources needed to further facilitate recovery and help prevent adverse outcomes. For instance, after being evacuated from an area, priority should then be put on reuniting a medically healthy individual with his or her service provider (e.g., a home health aide or family member) to facilitate self-reliance, independence, and help more quickly move the person out of the disaster system. Consider also a situation when a culturally competent nurse can quickly identify that a woman will require a female provider due to religious beliefs, expediting her care while meeting her cultural and religious requirements. Such practices acknowledge that once individual abilities and needs are recognized, barriers to medical care and self-protection can be overcome, providing greater access to care by more people. In short, the functional model promotes efficacy in patient assessment and efficiency in provision of care.

Understanding Vulnerability Systematically as a Basis for Intervention

By understanding vulnerability systematically, it is also possible to identify points of intervention. One such approach considers the "ecosystem" that comprises various levels from the individual to the broader society (Brofenbrenner, 1979; Garbarino, 1992). At each ecosystem level, numerous conditions can be identified that increase or decrease the vulnerability of people, households, neighborhoods, communities, and even societies. The value of using the ecosystem framework for understanding vulnerability is clear: it explains why some people suffer disproportionately in disaster while, importantly, suggesting pathways toward action within each systemic level. Moreover, this framework highlights the complex, dynamic, and interactive nature of vulnerability in both pre- and postdisaster contexts. As such, this section provides an overview of each level of the ecosystem coupled with relevant examples. The chapter's concluding section draws upon the ecosystem approach to offer intervention strategies.

The first level of the ecosystem, the microlevel, includes individuals, households, and families. Here, vulnerability may result from interaction between an individual's unique personality, disposition, and physical and psychological status, and the practices, resources, and circumstances of the family situation and the household in which the person lives. As a consequence of the interaction between these variables, people experience different types of risk and degrees of exposure based on various conditions. Social isolation represents one such condition; it can cause people to miss disaster warnings or influence the potential for an individual to experience malnutrition and depression (Norris, Friedman, & Watson, 2002; Norris et al., 2002). Central to microlevel vulnerability, then, is the understanding that social networks represent a critical resource to reducing exposure. In short, when individuals have people around them who care about them, they are more likely to hear a warning and be able to take protective action. Social networks, though, may be compromised by income levels, advanced age, disability, and medical conditions. Surviving on entitlement checks, such as social security or supplemental security income, means a wait at the end of the month until funds arrive. Limited income reduces capacity to afford ready kit items including extra medications, gasoline for evacuation, or funds to survive away from home. During response and especially during recovery, people also compete for limited resources (Comfort et al., 1999; Peacock & Ragsdale, 1997; Poulshock & Cohen, 1975). The microlevel also considers exposure levels, which have historically been

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higher among low-income, minority, and elderly populations, who are more likely to live in or near floodplains in less hazardresistant and older housing not built to current hazard codes. By focusing on the microlevel, healthcare providers can increase awareness and supply critical information or resources to reduce the impact, assist with the response, and facilitate the recovery of high-risk populations.

In the second, meso-level tier, organizations operate to reduce the impact of disasters. Traditionally, such organizations include emergency management agencies and, increasingly, healthcare providers. Pandemics represent one such interorganizational concern with efforts being made recently to establish accessible points of distribution for countermeasures. But a wider array of partners is possible at the meso-level. Consider the places and ways in which healthcare organizations can distribute information at healthcare offices, outreach clinics, and home health agencies (Phillips, 2010). Such efforts can be leveraged by partnering with advocacy and community-based organizations (CBOs). In this regard, consider the potential to influence people's daily lives through their immediate environment, from laundromats, senior centers and schools, to grocery stores, pharmacies, barbershops, beauty salons, churches, and other places of worship. For their part, meso-level organizations can also amass resources to distribute across inequitable access points experienced by households marginalized economically by medical, disability, and aging-associated costs.

The more abstract exo-level focuses on policy. Until Hurricane Katrina, many efforts in the United States to enact policies specific to people with disabilities and medical concerns largely failed to garner widespread attention. Post-Katrina, much has happened. The simple existence of a postdisaster housing plan for the FEMA, which includes the needs for disability advocacy and representation in housing planning, serves as one such example. Indeed, legislation in 2011 created FEMA's Office on Disability Integration and Coordination (ODIC). Under that Office, FEMA has developed a cadre of 285 disability integration experts including advisors, American sign language interpreters, and certified deaf interpreters, along with an integration specialist in each FEMA region to coordinate organizational and systemic change in this area. The Federal Highway Administration (2009) represents another example of a step forward with the publication of its guidance document detailing effective evacuation practices for medically fragile populations. In 2016, the U.S. Departments of Justice, Health and Human Services (HHS), Housing and Urban Development, Homeland Security, and Transportation jointly issued guidance to state and local governments engaged in emergency management activities regarding complying with nondiscrimination and civil rights laws. This guidance is further evidence of exo-level activity and the advancement in this area as it pertains to meeting the needs of high-risk, high-vulnerability people and populations in disasters.

The *macro-level* encompasses historical, cultural, and geographical factors that influence social vulnerability. Historic patterns of racism and legally enforced segregation have marginalized some populations into risky areas, including floodplains and areas requiring relocation due to climate change (Bronan & Pollock, 2017; Cutter, 2006). The historic communities of Princeville, North Carolina (first town incorporated in the United States by African Americans) and the Lower Ninth Ward of New Orleans (over 95% African American pre-Katrina) both sustained catastrophic damage from hurricane-related floods. In Princeville, segregation on the floodplain side of the river meant that the predominantly older population, with a majority being African American and female, sustained heavy damage in 1999 and again in 2016 in Hurricane Matthew. In New Orleans, the Lower Ninth Ward also suffered some of the highest water damage with only one-fourth of its predominantly older and African American population back at the 5-year anniversary of the storm in 2010. A legacy of political marginalization in the community created the macro-level context for the higher loss of life and reduced rate of return (Phillips, Stukes, & Jenkins, 2011).

The potential impact of a systematic, successful intervention strategy across all these aforementioned levels can be considerable. The challenge lies in individual and collective willingness to address vulnerabilities and undertake specific interventions. Toward that end, the healthcare sector plays a significant role in each level and can offer considerable human capital that can be leveraged to reduce vulnerability. With a focus exclusively on patients, without concern for organizational intervention, policy attention, and cultural-level change, we will not see change in human vulnerabilities.

USING AN EQUITY AND EMPOWERMENT LENS

When implementing the ecosystem model of vulnerability, using an Equity and Empowerment Lens can assist in understanding how decisions, policies, procedures, and strategies can impact high-risk, high-vulnerability populations and individuals. Adapted by the Multnomah County, Oregon Mass Shelter Access and Functional Needs Task Force, the Equity and Empowerment Lens can be useful to nurses in many applications and settings. As is done through a camera, a lens helps bring ideas into focus or widen perspectives to see things not seen before.

Equity establishes an expectation to *provide the resources everyone needs to be successful* and differs from equality, which is *treating everyone the same*. While both equity and equality are strategies to promote fairness, equality works only if everyone has the same needs and starts from the same place.

Achieving equity in emergencies and disasters requires practitioners to engage more fully in evaluating and understanding the unique needs of high-risk, high-vulnerability community members. The Equity and Empowerment Lens asks users to consider four domains—People, Place, Process, and Power. Within each domain, a series of questions help the user consider who is affected by the decision; what benefits and burdens could yield; and what actions could mitigate and minimize potential burdens. The full version of the Equity and Empowerment Lens tool and guidance can be found at multco .us/diversity-equity/equity-and-empowerment-lens.

Within this framework, the *People* domain refers to individuals, groups, communities, or populations. When evaluating the People domain, consider which communities are impacted by the decision, policy, or plan under consideration. Ask who wins and who loses.

The *Place* domain refers to the physical space and also the social relationships and meaning attached to a physical location that give it context and value. Practitioners should consider the pros and cons and associated impacts of Place and its context within community.

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EQUALITY VERSUS EQUITY



In the first image, it is assumed that everyone will benefit from the same supports. They are being treated equally.



In the second image, individuals are given different supports to make it possible for them to have equal access to the game. They are being treated equitably.



In the third image, all three can see the game without any supports or accommodations because the cause of the inequity was addressed. The systemic barrier has been removed.

FIGURE 7.1 Equality versus equity.

Sources: Panels A and B reproduced with permission from Craig Froehle, PhD. Panel C, Office of Diversity and Equality, Multnomah County, Washington.

The Process domain encompasses the policies, plans, and decision-making structures. Process questions consider methods to engage and build relationships to create a more inclusive, respectful, and aware process. In Process, how is as important as what and why.

Lastly, the Power domain addresses who is making decisions and who is impacted by those decisions. Similar to process-related questioning, when working through the Power domain, consider methods to engage and build inclusive and respectful relationships. Again, how is as important as what and why questions within this domain. When thinking about Power, consider how the issue under consideration shifts power dynamics to better integrate voices and priorities of underrepresented individuals or communities.

THE LIFE CYCLE OF DISASTERS

Any disaster, whether natural or man-made, can be viewed as having a *life cycle* with certain distinct stages (Mileti, 1999), including: acting to improve readiness to respond (preparedness); taking immediate actions after a disaster has occurred to protect life, property, and the environment (response); restoring functions and dealing with the aftermath of the disaster to return to a predisaster state or an improved state (recovery); and engaging in efforts to lessen the effects of a disaster (mitigation).

While the life cycle stages of disaster are distinct, and are described in this section as such, the process is not linear. Actions within phases can and do overlap and influence outcomes within phases.

This section provides suggestions for addressing and integrating within each stage of a disaster the needs of high-risk, high-vulnerability populations. Examining each stage, consider the following:

- How does this information apply to particular specialties of nursing practice?
- How can professional expertise and experience working with high-risk, high-vulnerability patients link into the disaster planning arena?
- What steps can be taken at a particular healthcare setting to improve integration of emergency-related needs of high-risk, high-vulnerability populations in each phase?
- How can nurses, as trusted members of a community, leverage their professional role to enhance disaster resiliency in the community? How can nurses serve as change agents to inspire and empower patients, coworkers, and partners to take necessary steps to increase their own resiliency?

Preparedness

Preparedness involves planning and getting ready for disasters by individuals, families, organizations, businesses, and communities. The state of preparedness includes the following contexts: recognizing the specific hazards that pose a threat,

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understanding the associated risks and potential impacts, and identifying suitable strategies and actions to take to be ready to respond should a disaster occur. Planning, personal preparedness, training, and exercises are vital to all strategies and actions involved.

Hospitals and healthcare systems must be prepared for emergencies (McGlown & Robinson, 2011). The Hospital Preparedness Program (HPP), funded by the Assistant Secretary for Preparedness and Response (ASPR) for the U.S. HHS, supports states, territories, and municipalities to improve surge capacity and enhance community and hospital preparedness for public health emergencies. "From Hospitals to Healthcare Coalitions: Transforming Health Preparedness and Response in Our Communities," is the program's first comprehensive report, identifying the advances states have made in preparing hospitals for all types of disasters. According to a May 2011 report, a majority of U.S. hospitals meet all-hazards preparedness measures (HHS, 2011).

Additionally, in 2006, the Centers for Medicare and Medicaid Services (CMS) issued guidance to assist nursing homes and long-term care facilities in complying with Federal requirements regarding emergency preparedness and response. In 2012, the HHS issued a report evaluating progress made by nursing homes and long-term care facilities in achieving emergency preparedness and response requirements since the issuance of the guidance. The report found that though most facilities had written emergency plans and training that complied with Federal requirements, significant gaps persisted (HHS, 2012). For example, nursing homes face challenges with unreliable transportation contracts, lack of collaboration with local emergency management, and concerns about what to do with residents who developed health problems during an emergency.

In November 2016, the CMS issued a final rule "Emergency Preparedness for Medicare and Medicaid Providers and Suppliers." The rule establishes a national emergency preparedness requirement to ensure adequate planning for both natural and man-made disasters and coordination with Federal, state, tribal, regional, and local emergency preparedness systems. Nurses can anticipate engaging in emergency preparedness activities such as developing emergency plans and participating in training and testing as a result of the CMS emergency preparedness rule.

Personal Preparedness

Nurses can encourage individuals and families to take steps toward greater preparedness. In many communities across the United States, organizations have found ways to integrate personal preparedness education and training into their everyday programs. For example, as part of the formal discharge process, nurses can walk patients through emergency-related considerations to help them prepare for emergencies. In some cases, individuals and families will return home with capabilities and limitations that may differ from what they know. These individuals will have to make changes in terms of everyday life and in disaster planning. Some home healthcare agencies have added personal preparedness as part of their assessment and often educate their patients, consumers, or families during home visits. Posing questions such as: What transportation arrangements have you made if you need to leave your home? and What equipment and supplies do you need to have with you ready to take in an emergency? can help individuals start to formulate a plan. Nurses can also lend expertise to the development of personal preparedness materials and training to ensure that information is provided in multiple modalities, that critical information and resources are included, and that information is delivered in a way that makes it accessible and understandable. Something as simple as including a disaster preparedness checklist in annual reviews or distributing materials in multiple, accessible media can enhance awareness and spur personal change (Phillips, 2009; see Case Study 7.1). Using the Equity and Empowerment Lens as a foundation for these conversations can help nurses ensure consideration of the whole person including the social, economic, racial, and community realities that may influence their personal preparedness. And in some cases, it can be a great service for nurses and others who are supporting this preparedness effort to remind individuals to include their service animals and their well-being in all disaster planning as well.

It is also necessary that agencies inform clients how the agency will operate in an emergency in order to sustain services. Such information will help clients to create more realistic plans for a disaster and to identify alternate ways to receive assistance.

Personal preparedness is also key for nurses and healthcare providers as first-line responders. Ensuring that health professionals and their families are disaster ready stabilizes and sustains services to high-risk, high-vulnerability populations within a community. Personal preparedness should include identifying alternate routes and means of transportation to work, planning emergency caregiving (e.g., for children or elderly family members) with neighbors or friends, and having emergency supplies stocked at home.

Organizational Planning and Preparedness

Individual governmental agencies, not-for-profit organizations, faith-based organizations, schools, and businesses that work directly with high-risk, high-vulnerability populations need business continuity plans as well. Thus, healthcare providers should create plans to sustain services postdisaster. Planning teams should include staff from different programs and levels, facility managers, patients/clients, clinical staff, social workers, partners, vendors, and other critical community-based partners. Encouraging a wide and deep set of groups to work together will lend expertise and validate the process, so that plans they generate capture appropriate strategies, problem areas, or gaps, and result in more informed, creative, and realistic solutions.

• *Emergency Plans*: The emergency plans of an agency explain the role and actions of the organization in responding to the specific needs of that agency in a disaster, as well as the role that the agency will play in a community-wide response to a disaster. The following are some examples of emergency-related planning issues that pose challenges to planners and questions that should be answered in the planning process.

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- Notification: How will patients/clients/students be notified during an emergency? Will the agency be making home visits/phone calls to check in on people? What kinds of alternate communication methods will be utilized to ensure that patients/families/caregivers can receive and understand information and follow instructions?
- Evacuation: How will patients/clients/students evacuate who have mobility disabilities and are unable to use the stairs? Will specialized evacuation equipment be purchased? What kind of vehicles will be needed to evacuate people and relocate to another location? What kind of facility will be safe to evacuate patients/ clients/students based on their medical and functional needs? Will staff accompany people to an evacuation site? Will a service animal be accompanying the individual as well?
- *Continuity of Operations Plans (COOPs)*: A COOP works in tandem with emergency plans and specifically addresses how the entity will continue to carry out critical functions during an emergency or other disruption. For agencies that provide critical medical services to individuals such as dialysis, cancer treatments, physical or occupational therapy, or methadone, the ability to continue services with little or no disruption will directly impact the patient's/client's resiliency to disaster.
 - Essential Functions: What functions of the agency are critical? What functions provide critical care/assistance to individuals/families? How will these be staffed and carried out during different types of emergencies?
 - Staffing: How will staff be notified of the situation? What kind of responsibility do they have to the agency versus their own family? Where are they located and how can they communicate with the agency, where should they report, and so forth?

Organizations and individuals serving vulnerable populations have historically been left out of the planning efforts making it very difficult to join or coordinate during response to a disaster. In a report written just a few weeks after Hurricane Katrina hit the Gulf Coast, 87.5% of CBOs interviewed said that they did not know how to link with the emergency management system (National Organization on Disability [NOD], 2005). This can have devastating impacts on the populations that CBOs serve during nondisaster times. When organizational planning is inclusive, CBOs can be brought to the table and have a fuller opportunity to offer many valuable resources and community connections that may be needed during response.

Training and Exercises

Training and exercises are part of every emergency management planning process in that they prepare professionals and the public to test plans and to identify gaps, alternate strategies, and need for improvement. One important initiative, the National Nurse Emergency Preparedness Initiative (NNEPI), has recognized the role that nurses play in emergency preparedness. Their "Nurses on the Front Line" is a highly interactive, web-based course developed to provide emergency preparedness training for nurses working in a wide variety of settings. (To learn more about this initiative and the course, visit https://nnepi.gwnursing .org/). As demonstrated in this course, nurses are often part of training and exercise activities, and can advocate for and integrate issues pertaining to high-risk, high-vulnerability populations. Some ways that this can be done include:

Training

- Include awareness curricula in training for staff to deepen understanding of working with diverse and at-risk populations. Include specific information about emergency-related issues.
- Conduct cross-training with emergency management agencies to deepen knowledge of emergency management structure and in particular how that sector integrates high-risk and high-vulnerability populations.
- Conduct cross-training with agencies and organizations that work directly with high-risk, high-vulnerability populations to better understand ways of serving members of those groups, as well as identifying resources and expertise that may be needed.
- Invite people with expertise in high-risk, high-vulnerability populations to help develop training materials and integrate the issues into existing training curricula.
- Train staff on particular roles in an emergency and how to specifically advocate for and address emergency-related needs of high-risk, high-vulnerability populations in their care.
- Be sure that space where training is held, instruction/ presentation, and materials are available in accessible formats. Ensure that accommodations allow greater access and participation. Provide childcare and hold meetings at times when large segments of the target population will actually be available.

Exercises

- Involve staff from varying levels of practice, settings, and expertise within the agency to participate in planning exercises as they bring valuable perspectives to the process.
- At the exercise development phase, integrate issues that will test the capacity to address the needs of high-risk, high-vulnerability populations; include these as part of the plan objectives and identify evaluation markers in order to assess this aspect of the exercise.
- Utilize individuals who make up diverse populations to actually "play" and test the system as that will allow for more authenticity and reality-based outcomes.
- The Los Angeles County of Emergency Management Drills and Exercises Guidance for Inclusive Emergency Planning provides strategies, resources, and guidance, including training vignettes, regarding establishing and executing a collaborative, inclusive exercise design and execution process that better addresses the needs of high-risk, high-vulnerability populations (available at lacoa.org/ PDF/IEP%20Drill_and_Exercise_Guide_08202014.pdf).

Response

The response phase of the disaster life cycle encompasses the period during and immediately after a disaster occurs. FEMA defines response as the immediate actions to save lives, protect

Veenema, T. G. (Ed.). (2018). Disaster nursing and emergency preparedness, fourth edition. ProQuest Ebook Central http://ebookcentral.proquest.com Created from johnjay-ebooks on 2021-01-14 09:05:39. property and the environment, and meet basic human needs. Response also includes the execution of emergency plans and actions to support short-term recovery (FEMA, 2008).

Collaboration

Response to a disaster also requires collaboration among governmental and public partners that make up the response network. In terms of addressing high-risk, high-vulnerability populations, those working in the health sector will necessarily coordinate response within their sector, but must also work closely with other key partners, including:

- Governmental agencies encompassing emergency response, transportation, housing, environmental protection, public works, public assistance, and disability and senior services, among others;
- Private and public sector agencies including congregate care facilities, utility companies, CBOs, faith-based organizations, and businesses, among others.

Because of their exposure through the healthcare sector, nurses have a distinct understanding of the diversity of the community and the impact that disasters can have during the response phase. As nurses are dispersed throughout the community in many different kinds of health and caregiving settings, hospitals, public health departments, schools, or other entities, there is a reach and relationship with diverse communities that can come only from working directly with that community. Utilizing these opportunities to help identify resources—possibly not planned for or known to the formal response system—will be invaluable during an actual response. Understanding existing communication protocols and systems also will allow nurses to bring their unique skills and understanding of diverse populations to the response arena.

By working on an interdisciplinary or integrated planning committee, nurses can share their experience and advocate for their patients. The result? A more complete and enriched plan with emergency tactics, strategies, and plans that more effectively and efficiently meets the needs of the whole community. Such integrated planning committees, often organized out of local emergency management agencies or healthcare coalitions, are often looking for diverse membership, including nurses. By reaching out to their local emergency management agency, nurses can provide valuable insights for planning around highrisk, high-vulnerability populations.

Response Activities

This section highlights a few key response activities to demonstrate ways that nurses can better work with, support, and advocate for high-risk, high-vulnerability populations in their care and within their communities during the response phase. Actual activities will vary based on several factors, including area of practice, disaster roles and responsibilities, personal experience, and access to resources, among others.

 Notification and Communication: There is no one-size-fits-all solution to communicating with patients and their families and other potentially vulnerable populations during a disaster. Instead, using a multiple modality approach that overcomes different barriers is more likely to reach more people at a time when it is critical. The particulars will differ depending on the setting (hospital, outpatient, inpatient, at-home, residential) and should be tailored to and appropriate for addressing the needs of those involved. The following are some suggestions to consider:

- Use sign language interpreters on-site or remotely via the web.
- Use language interpreters, included through remote access or through a language bank.
- Create internal communications systems that are customized to patient and staff needs.
- Integrate augmentative and alternate communication systems ranging from options that are low-tech (e.g., pointing board with symbols, pictures, and words) or conversely, high-tech communications devices (e.g., a voice output communication aid [VOCA]).
- Ensure that alarm and notification systems provide notifications in multiple ways such as aural, visual, vibrating, through notification systems (i.e., texts), and so forth.
- Utilize different forms of technology to communicate to a wider variety of age groups—television; landline emergency alerts; cell phones; email; texting; and social media.
- Match staff communication skills (e.g., proficiency in a language) with needs.
- *Temporary Healthcare or Shelter Sites*: During the response phase it is possible that alternate care and shelter sites are opened. Steps can be taken to ensure that sites accommodate different needs through coordination with the agency coordinating the operations, the facility manager(s) and on-site staff, agencies working within the site, and external organizations or businesses that can provide resources. Nurses can help to advocate for and identify accommodation needs. The following are some ways to account for diverse needs.
 - Ensure that sites meet physical and programmatic accessibility standards. The U.S. Department of Justice (DOJ) offers a shelter checklist based on accessibility standards (DOJ, 2007).
 - Systematically identify needs of individuals with the individual/caregiver/family (e.g., during intake or triage) and put a standard operating procedure in place for meeting accommodation requests.
 - Find ways to offer space that is separate from the main congregate space such as quiet rooms; supervised children's areas; supervised areas for persons with dementia, Alzheimer's disease; gender-specific areas; breastfeeding areas; examination or counseling areas that are private; and so forth.
 - Develop ways to refrigerate medications and/or specialized food.
 - Locate power supplies for those using oxygen machines, power wheelchairs, or other electrically dependent durable medical equipment. This may include alternate locations (e.g., fire stations) where people can regenerate equipment.

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- Have durable medical equipment on hand such as canes, wheelchairs, walkers, medical/specialty cots.
- Identify organizations and other suppliers with supply and equipment resources (e.g., medical supply stores, assistive technology organizations, generator supply companies).
- Establish memorandum of understandings (MOUs) with skilled staffing (nurses, social workers, physical and occupational therapists, psychologists, personal care assistants, sexual assault counselors, et al.) that can provide expertise and support operations at the site.
- Utilize multiple modalities to communicate with those at site.
- Decontamination: Undergoing decontamination operations can challenge high-risk, high-vulnerability populations. There are specific steps that can be taken to mitigate risk, injury, and/or trauma that can all cause deteriorating conditions and limit independence. The following are examples of ways to mitigate the impact:
 - Identify strategies for decontaminating and/or replacing durable medical equipment, consumable medical supplies, and/or augmentative communication equipment and reconnecting them with owners.
 - Systematically identify needs (with the individual, caregiver, and/or family) and put a standard operating procedure in place for addressing these needs.
 - Practice strategies for decontaminating service animals and/or pets and reconnecting them with owners.
 - Utilize multiple modalities to communicate with those at the site.
 - Establish ways to respect privacy and/or safety concerns of the individual.
 - Offer gender-specific decontamination operations.
 - Craft strategies to address medication needs.
 - Work with caregivers to help support their children through the process.

Although it is critical for nurses to anticipate the needs of patients/clients, it is equally critical for nurses to listen carefully to patients and fully grasp their specific needs. This can be extremely challenging in a high-pressure emergency response environment, where needs are great and may be life-threatening and when there is a shortage or depletion of resources. As such, plan in advance. However, if such planning has not been done or only in a limited way, then ensure that there is flexibility, openness, and communication with those in need to find solutions to help mitigate physical and psychological injury or loss of life.

Recovery

Ideally, recovery in the disaster cycle is characterized by actions that help to restore functioning at predisaster levels, often described as a return to a sense of "normalcy." In practice, however, this rarely occurs, since disasters can forever alter conditions, and another term, "new normal," is often employed (Phillips, 2015a, 2015b). Recovery activities begin once the immediate danger has passed, when lifesaving and life-preserving activities begin to wind down, and when emergency needs have been met. Recovery activities that occur in the short term include restoring utilities, removing debris, and providing temporary housing. Long-term recovery efforts involve repairing and rebuilding damaged infrastructure, restoring routines and mental health functioning, and redeveloping communities. In some cases, communities may attempt to "build back better" and improve quality of life and sustainability. Greensburg, Kansas, for example, decided to build back as a "green" town with all buildings reconstructed to meet LEED-platinum standards after a devastating tornado leveled 95% of its structures. Such efforts should consider how to enhance life for high-risk, high-vulnerability populations.

One of the most important lessons of disaster recovery is that investing some time thinking about recovery *before the disaster strikes* pays tremendous dividends in a disaster's aftermath. Although it is still relatively rare for communities to engage in predisaster "recovery planning," anticipating demands, organizing resources, and determining a basic recovery strategy can lead to greater efficiency, adaptability, and reduced vulnerability. Such foresight is useful for individuals and families as well as organizations and communities.

High-risk, high-vulnerability populations often experience complex recovery-related issues that can overlap and have compounding effects that influence access to recovery assistance and the actual ability to recover. Postdisaster needs will often extend longer into the recovery period and require additional and specialized assets to resolve. Some of the common needs to facilitate recovery include:

- Access to one or more necessary health-related services such as monitoring, daily or regular interventions/treatments, physical/occupational therapies, psychological treatment and counseling
- Access to appropriate housing (e.g., accessible housing or supervised settings) that allow for maximum independence and safety
- Need for resources that are not often identified in recovery programs such as assistive devices, technologies, or other specialized equipment (lifts, ramps, etc.; see Box 7.1)
- Availability of childcare and/or adult daycare services, which free up time allowing for caregivers to identify recovery assistance, find jobs, secure housing, and so forth
- Access to schools and transportation to schools that allow children to return to a sense of routine and normalcy while parents can return to work
- Access to public transportation and to accessible transportation for transportation-dependent populations and persons with disabilities
- Access to recovery information in different languages but also targeting information to hard-to-reach groups such as socially/culturally isolated populations
- Mental health services to support predisaster and postdisaster psychiatric issues
- Access to necessary prescribed medicine to manage predisaster health conditions so as to avoid diminished health status

Given the vast diversity of populations, there are many different barriers that might prevent someone from accessing these aforementioned needed services or resources, including: lack of information about recovery agencies in general and about providing assistance to high-risk, high-vulnerability populations

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BOX 7.1 Assistive Technology

In recovery, access to assistive technologies can be critical for some in resuming independence, self-reliance, and functionality. Often in the chaos of disaster, assistive technology (AT) can be destroyed, damaged, or lost, or the disaster itself causing the need for AT not used before, results in greater vulnerability and trauma for the person experiencing the loss of functionality. For health professionals and emergency management, linking to programs as described below can help facilitate connecting someone with necessary AT.

Under the Assistive Technology Act, the Rehabilitation Services Administration—a component of the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS)—funds a statewide AT program in each of the 50 states and six territories, and the majority of these programs support AT device reuse activities.

For many people with disabilities, AT is an essential support to daily living. A person may depend on a wheelchair, walker, special computer keyboard, speech-generating device, or other AT device at home, at school, or at work. AT is a broad descriptor for anything from low-tech (e.g., a transfer board on which a person can slide from a wheelchair into the backseat of a car) to high-tech equipment (e.g., speech reader software) and constantly emerging new technologies including wireless and wearable technologies (Bennett, Phillips, & Davis, 2017).

Reuse of AT is emerging as one of the ways to make AT more available. To the extent that AT reuse is practiced today, it is generally done through device exchange programs, device recycling programs, or device refurbishment programs. Hundreds of organizations around the country, large and small, are involved in AT reuse. From state agencies to nonprofits, to hospitals, to churches, there are AT reuse programs in all parts of the country that meet all kinds of needs.

Until recently, there was weak coordination or networking of and among these programs to ensure an efficient and effective system for getting used AT into the hands of those who need it. However, with the realization of the important role AT can play, especially during the recovery phase in disaster, this is changing. The reality is that with proper identification of immediate need for access to AT postdisaster and a proper match to available AT, those affected by disaster can more quickly regain independence. It must be noted, however, that even if AT is provided for someone in the immediate aftermath of a disaster, this might still only be a "quick fix" requiring proper evaluation, fitting, customization, and so on for a more permanent solution.

There are three levels to viewing AT and disaster recovery. The first is at the individual level. If people who use AT on a regular basis actually incorporated their AT into the predisaster planning, then the recovery process is greatly improved. This can be as simple as keeping a record of equipment make, model, and funding program, for example, along with other important documents in the event that their AT is damaged, destroyed, or lost during a disaster.

The second is at the nexus of care level and here is one place nurses can play a role. It means that those in contact with people who use AT can advise of the importance of taking those necessary preparedness steps but also as professionals learning how to identify ways to utilize AT in unconventional ways during a disaster until appropriate solutions can be put back in place. This might mean learning how to switch a power chair into manual use mode, or realizing that with Velcro attached to utensils, a person can independently feed him or herself, or that a picture communication board or chart using pictorials can assist in communication until power-sourced technology can be restored. Any care professional can become involved at this level including certified rehabilitation counselors, AT professionals, speech language pathologists, occupational therapists, physical therapists, and the like. In fact, many of these professionals actually have added disaster preparedness to their code of ethics and/or responsibilities. Nurses often find themselves engaged across these lines of care providers and are well positioned to tie all the skills together to benefit a disaster survivor.

The third level is a systems network level. This is where nurses and other emergency professionals should reach out to the local AT network to find matches of AT in the existing reuse programs that can be redirected for needed matches during the first phases of recovery postdisaster. It is the AT network that is best suited to help with those matches but also to logistically coordinate the quality review before materials are brought in to be sure they will not cause further harm and are appropriate for immediate reuse. Because AT reuse is already a supported mission of the AT system, it is a perfect example of bringing assets to the recovery table that may not have been thought of as disaster specific under usual circumstances.

in particular; providers impacted by the disaster who are no longer available to offer services; lack of professional services and expertise in the area; no list available to identify alternate providers in new temporary or permanent communities; lack of health insurance access; lack of information in different languages or pertaining specifically to the needs of different groups; and no transportation or access to recovery centers, schools, childcare providers, and so forth.

With increased awareness of likely needs and barriers, nurses can help advocate during the recovery planning process and during an actual recovery to ensure the inclusion of populations that might otherwise go with little or no support postdisaster. Nurses can also start to craft interim solutions such as clustered care or a single intake process for multiple uses to reduce the physical and emotional impact to high-risk, high-vulnerability disaster survivors.

Recovery Programs

In the United States, recovery from disaster is predominantly based on a model dependent on individual insurance. In addition to homeowners' and renters' insurance, assistance for individuals affected by a disaster has historically come from public and private aid. Many community groups and organizations mobilize to provide assistance when disaster strikes. Sometimes communities will receive a Federal disaster declaration making Federal disaster assistance available to help with individual and family recovery.

The Robert T. Stafford Disaster Relief and Emergency Assistance Act authorizes the president to issue major disaster or emergency declarations in response to catastrophes that overwhelm local and state governments. Such declarations result in the distribution of a wide range of Federal aid to individuals and families, certain nonprofit organizations, and public agencies. Congress appropriates money to the Disaster Relief Fund for disaster assistance authorized by the Stafford Act, which is administered by FEMA within the Department of Homeland Security (DHS).

Federal disaster assistance may be offered in the form of cash payments or other direct assistance to individuals, families, and businesses in an area whose property has been damaged or destroyed and whose losses are not covered by insurance. This assistance is meant to help with critical expenses that cannot be covered in other ways. The assistance is not intended to restore damaged property to its condition before the disaster. While some housing assistance funds are available through the FEMA Individuals and Households Program, most disaster assistance from the Federal government is in the form of loans administered by the Small Business Administration (SBA). That said, many high-risk, high-vulnerability individuals will not qualify as they fail to meet loan criteria such as home ownership.

Grants may also unintentionally leave high-risk, high-vulnerability individuals at a disadvantage. The additional costs needed to make a home functional may not fall within the financial range of a grant such as installing a ramp, lower kitchen counters, or accessible bathroom configurations. Such basic necessities are often not calculated into funds guidelines, as was the case post-Katrina Road Home program (Browne, 2015). To meet such needs, voluntary organizations and faith-based groups often form community-based, long-term recovery committees as a way to address unmet needs. Nurses may be in a position to identify gaps in service delivery and call these to the attention of appropriate service providers and/or such newly formed committees.

Usually, unmet needs are addressed through a case management process in the long-term recovery committee, another area where nurses can exert influence. The purpose of case management is to help plan, coordinate, monitor, secure, and advocate on behalf of patients or clients. Case management in a disaster must take into account the unique practice environment in the aftermath of disasters that can involve difficult environmental conditions presenting additional challenges for patients, caregivers, and providers. Such conditions might include infrastructure losses, disruption of operations, communication challenges, and so forth. In addition, an influx of services and resources sent to the disaster area can pose additional access and coordination challenges. People who have experienced a disaster need to think through their daily experience, consider how their needs may have changed, and determine how to move forward, often in collaboration with service providers. The Post Disaster Personal Assessment Tool (Appendix 7.1) can be used with individuals/ families to identify recovery needs including housing, medical services, education, social services, among others.

In a study of the largest disaster case management effort in U.S. history following Hurricane Katrina, Stough, Sharp, Decker, and Wilker (2010) found that the disaster recovery process is typically more complex and lengthy for persons with disabilities. In addition, they noted that recovery requires negotiation of a service system that is often ill-prepared for disability-related needs. In particular, they identified accessible housing and transportation as barriers to recovery (Kelman & Stough, 2015; Phillips, 2015a, 2015b). Factors that supported recovery included case manager individual effort and advocacy skill, agency collaboration, and client motivation and persistence. They concluded that disaster recovery is enhanced by case managers who have disability expertise, including knowledge about the needs of individuals with disabilities and services to help. By application, this lesson can be applied to other high-risk, high-vulnerability populations.

Mitigation

Mitigation is widely regarded as the "single best step that can be taken to safeguard human wellbeing" (National Council on Disabilities (NCD), 2009). FEMA (2008) defines mitigation as:

Activities providing a critical foundation in the effort to reduce the loss of life and property from natural and/or manmade disasters by avoiding or lessening the impact of a disaster and providing value to the public by creating safer communities. Mitigation seeks to fix the cycle of disaster damage, reconstruction, and repeated damage. These activities or actions, in most cases, will have a long-term sustained effect. p. 50)

Mitigation may entail structural and nonstructural measures that are taken to reduce risk, increase resiliency, and have a long-term impact on community well-being. Structural mitigation includes measures taken to alter the built environment in an effort to reduce risk and become more resilient to disasters. Nonstructural mitigation includes many different types of activities or measures that are just as critical to reducing risk as structural changes. The following are some examples of mitigation measures that can reduce the impact of disasters on high-risk, high-vulnerability populations.

- *Structural mitigation examples:*
 - Harden existing facilities and build new structures—hospitals, clinics, residential care facilities-to withstand likely hazards such as tornadoes, hurricanes, or flooding. This may prevent damage resulting in injury/death and/ or the need for evacuation.
 - Identify facilities that may support response and recovery . operations (e.g., a shelter or recovery assistance site) and identify ways to harden and stock these sites.
- Nonstructural mitigation. examples:
 - Protect critical supplies and keep them in safe areas. For example, in areas likely to experience earthquakes, tie and secure cabinets, containers, and shelves. Identify suppliers who can quickly restock supplies, identify supplies that will be difficult to replace, and identify strategies for keeping these in an off-site cache if possible.

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- Install alarm systems that will immediately alert someone of a potentially hazardous condition—such systems may detect smoke, fire, carbon monoxide, or a radiological occurrence, for example.
- Create redundancies to ensure that medical records and other critical documentation is backed-up at an off-site location. Keep records in safe positions; rather than keeping them in a basement that is likely to flood, move them to a higher floor.
- Create a redundant system for internal communications as well as communicating with external sources.
- Purchase and maintain appropriate insurance that is specific to protecting against hazards. FEMA offers flood insurance for flood damage to properties, residences, and buildings through the National Flood Insurance Program (NFIP).
- Educate staff and patients/clients on mitigation measures that are important for them to take.

According to FEMA, every dollar spent on mitigation saves society an average of four dollars. FEMA offers the Mitigation Best Practices Portfolio on its website with several examples of local and state mitigation efforts (FEMA, 2011).

Although the value of mitigation is widely acknowledged, there are still gaps in terms of implementation, guidance, and information on mitigation best practices, particularly in regard to high-risk, high-vulnerability populations. For example, as of September 30, 2015, only 117 of the 566 Indian tribes recognized by the U.S. government had FEMA-approved disaster mitigation plans. This means that more than three-quarters of all tribes are ineligible to apply for FEMA grants and cannot receive Federal funding for disaster mitigation projects (Carter & Peek, 2016). In 2009, the NCD conducted research to evaluate how well disability issues have been integrated into emergency management research and practice. In terms of mitigation, NCD (2009) reported that:

It is clear that research has failed to address the question of mitigation for people with disabilities in any meaningful manner. Scant evidence exists in practitioner materials either. (p. 193)

When implementing mitigation measures, it is best to integrate issues pertaining to high-risk, high-vulnerability populations at the hazard vulnerability assessment and initial planning levels. The following are some considerations to take into account when involved in mitigation measures. First, utilize a universal design approach when taking mitigation measures that require alteration or purchase of physical space, equipment, or products. The concept of universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design to ensure greater accessibility and usage (Livable for a Lifetime, n.d.). The universal design approach is important because several factors may act as barriers preventing individuals and families from taking mitigation measures such as:

- Lack of time, education, or understanding to implement measures
- Lack of funds to act on mitigation measures such as purchasing insurance, shuttering windows, making structural changes

to homes, building a safe room, and buying and stockpiling extra supplies of food, medications, and other goods

- Having limited or no physical capacity to carry out the measures without assistance
- Living in substandard rental housing that is in a constant state of disrepair, but the owner refuses to act on behalf of the tenant

Second, to develop sustainable mitigation programs that effectively support high-risk, high-vulnerability populations, as with the other phases already noted above, it is critical to involve key stakeholders in the community who can represent the diversity of interests of this population. This kind of collaboration is absolutely necessary to validate working assumptions, identify barriers, create meaningful and sustainable measures and solutions that meet the needs of diverse communities, and to help educate constituents.

Third, mitigation measures can benefit schools, hospitals, shelters, clinics, and other service sites, and congregate care facilities, reducing impact to facilities as well as patients/clients. These types of facilities, which provide services to some of the most at-risk populations, will help to minimize the physical and emotional toll of disasters and allow for continuity of services that are so necessary to a community after a disaster.

Guiding Principles

Nurses can help to reduce the risk and increase the resiliency of individuals and families who are considered high-risk, high-vulnerability populations. The following principles are meant to guide nurses when working toward a more inclusive approach to emergency programs in all phases of disaster.

- Professional Continuing Education: Continually learn about ways to improve the integration of high-risk, high-vulnerability populations in emergency management programs during all phases of disaster. Provide training for staff and clients on emergency preparedness as well as opportunities for cross-training with partner organizations and agencies on emergency plans and procedures.
- Involvement: Build sustainable relationships with individuals and organizations that represent high-risk, high-vulnerability populations. Collaborate to identify and validate needs, solutions, and resources to lessen the impact of disasters on individuals, families, and communities.
- *Assessment*: Establish informal and formal assessments to measure the integration of high-risk, high-vulnerability populations in emergency programs.
- Flexibility: Programs and plans must be flexible to allow for improvement and change toward a greater outcome in serving high-risk, high-vulnerability populations in all phases of disaster.
- Building Capacity: Create plans, build resources, train staff and clients, and exercise plans to build capacity of individuals, families, and communities. For those visiting nurses or others providing in-home service delivery, this can be an extremely beneficial way to ensure directed awareness and planning takes place to mitigate further risks for certain persons.

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- Coordination: Coordinate resources, information, and plans across organizations, governmental agencies, and health systems to maximize resources and more effectively meet the needs of individuals, staff, organizations, and communities in all phases of disasters.
- Collaboration: Apply the nursing perspective and skills knowledge in a related position not necessarily as a practicing nurse. This could be by establishing a rotation into a local emergency management office as a planner.
- Anticipation: When functioning on scene during a disaster, articulate anticipated near future impacts for your charge even if not part of the immediate medical response. Nurses can make a difference for disaster survivors by treating them for the immediate medical condition but not ignoring the secondary conditions of lost housing to return to or the missing community support systems, for instance.
- Agents of Change: Nurses know their community. They cross over many specialty skills areas to touch people directly. Nurses are in a position to be advocates on scene and during recovery for the holistic approach to those impacted by disaster because they are trusted agents to the individual as well as part of the care services team.

Conditions Fostering Change

It has only been over the past one to two decades that planning work to address unique disaster-related impacts on high-risk, high-vulnerability groups has become a central focus, and thus these groups remain underserved in many aspects of emergency management. During the Obama Administration, FEMA and the U.S. DOJ shifted their paradigm when it comes to whole community planning, as already discussed. And while there is a great deal of emerging data internationally about gender impact in disaster and climate change and aging, for instance, in the United States the shifts have been most notably influenced by the disability rights focus of the functional model.

But certain conditions have encouraged great preparedness for these populations. In the wake of the 9/11 attacks, FEMA gathered information about the response to what was then categorized as the "special needs population" and codified this in a focused after-action report (AAR) ordered by the Federal coordinating officer (Mackert & Davis, 2002). That was the first time a full AAR was dedicated completely to this issue at the Federal level. This was paired with a Congressional Subcommittee on Aging hearing of the same focus held in New York City. While enlightening, the more time that passed since the events of 9/11, the dimmer the attention on these concerns had become. It was not until the tragic loss of life among the elderly at Saint Rita's Nursing Home and real-time images of frail elderly in hospital gowns and socks lying in the streets in the hours, days, and weeks post-Katrina that the attention was focused again on the most vulnerable in our society. Following Katrina, legislation led to the creation of a position of national disability coordinator in DHS; the National Advisory Council (NAC) was established and had representation of several specific stakeholder groups on it; among other actions. This built on some of the post-9/11 changes such as the creation of an Interagency Coordinating Committee (ICC) as articulated in Executive Order 13347 signed by then President George W. Bush but the depth and breadth of the attention and subsequent actions lasted longer and was much more public. It was during the work done on the ICC that the DOJ took on the task of drafting its Americans with Disabilities Act (ADA) Best Practices Tool Kit for state and local governments outlining their obligations under the ADA. As applied to the practice of emergency management countrywide, of particular focus is Chapter 7, Emergency Management Under Title II.

More recently, evidence of a stronger attention at least in part on certain groups sometimes classified as high-risk, highvulnerability has emerged in the legal arena. The ADA was signed into law by President Bush in 1990 and was reenacted in 2008. The ADA was a culmination of many years of rightsbased movement for people with disabilities and the broader reaching piece of civil rights legislation since the famed Civil Rights Act in 1964. It is under the provisions of Title II and Title III that most of the issues pertaining to emergency management, provision of emergency services, and thus by extension much of the work done by the nursing profession are covered and the DOJ maintains the authority to enforce the ADA. The DOJ is now routinely including language about equitable application of emergency response for people with disabilities into all its Project Civic Access settlements with local jurisdictions and agencies.

In addition to DOJ settlements, there has been an increase in the number of legal challenges to disaster planning efforts in an endeavor to make them more inclusive of and responsive to the needs of people with disabilities. In these class actions in California, New York City, and Washington, DC among others, the plaintiffs represent a group of persons who assert the claim that the government for the city or county in which they reside has not taken their specific needs into account in the planning doctrines and thus they will be unequally impacted when the disaster response system and responders directly cannot address their needs. The outcomes of the current actions are mixed at this time. Whether changes and forward movement in the places involved in litigation are a result of terms of a settlement between parties or a result of actions ordered by a court, there still remains no common approach across the nation. Because these actions are litigated and/or negotiated to address specific concerns in particular places and account for resources, allocations, and conditions in that place alone, it has not always been possible for others to simply replicate the results with success. While the resulting advances are embraced by the community, its advocates, and even the governments involved, it remains to be seen how this may change planning in other areas and for other high-risk, high-vulnerability populations over time and geography in a consistent way.

Under the Obama administration, the role and responsibilities of the NDC were subsumed into the then-newly created ODIC established by former FEMA Administrator Craig Fugate. ODIC is now in a position to spearhead many changes and improvements in the way the disaster services community applies its efforts for people impacted by emergencies, including also the development of new regional integration specialists across the country in all 10 FEMA regions and also the issuance of guidance for response activities such as sheltering operations. It is in the fully integrated shelter provision that nurses and other health professionals will see newly crafted roles.

We see via the abbreviated chronology above the progress toward a "whole community" approach to planning and response.

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The nursing profession and its individual practitioners would be well advised to watch this trend to anticipate and get ahead of the ball when it comes to their disaster-related roles and responsibilities as they pertain to all parts of the community they serve. And with every change in administration, watch for ways to identify opportunities to continue the work regardless of direct project funding priorities and/or policy shifts.

EXAMPLES ORGANIZED AROUND THE ECOSYSTEM MODEL

The ultimate goal of an ecosystemic framework is to inculcate change at various systemic levels (see Figure 7.2) and across various time points in the disaster life cycle. In this section, we offer case examples where the micro-, meso-, and exo-levels can be influenced by medical providers, particularly nursing professionals, to reduce vulnerability. Beyond impacting the human condition by reducing injuries and deaths, an ecosystemic approach can reduce patient inflow during a disaster by mitigating harm before it occurs.

Microlevel Example: Personal Preparedness

At the microlevel, the emphasis is on building capacity of those at highest risk. By encouraging personal, household, and familial preparedness, those at risk can stand more ready to take protective actions (shelter in place, evacuation), assist themselves and others, move through response time periods, and recover expeditiously. Though many materials and tools exist for personal-level preparedness, medical providers can participate in personal readiness efforts by educating patients and the broader public on preparedness issues. The summer of 2011 serves as a good example. In the heart of the United States, a heat dome built and stayed in place causing temperatures to soar and remain in place for a record number of days. Those at highest risk included senior citizens, people who were homeless, and those who had to earn their livelihood outside, particularly low-income workers. Programs initiated to reduce risks included educational efforts to raise awareness of the potential for heat-related illnesses. Emergency managers, elder



FIGURE 7.2 Change and the ecosystem model.

care providers, first responders, and the media all collaborated to alert the public through traditional and social media and encourage them to check on those at risk. Cooling centers opened for seniors and individuals who were homeless with some communities providing transportation.

Hurricanes Katrina and Rita also generated new attention to those at risk and in need of medical care. Late evacuations meant that people died in assisted living facilities for Katrina. Heavier than expected evacuation for Rita led indirectly to a nursing home bus catching on fire and causing the deaths of nearly 30 residents. More recently, 18 nursing home residents and a caregiver died when an EF5 tornado destroyed over one-third of Joplin, Missouri in the spring of 2011. At the microlevel, these case examples suggest the minimum action steps:

- Educate those at risk in medical care situations about local hazards and appropriate responses. Home healthcare agencies can reach out to those living at home. Medical providers supporting congregate populations can do the same with residents and their families. Experience demonstrates that having one's family around during a disaster event can reduce exposure and mortality. By educating people about area shelters and their ability to meet medical needs, it may be possible to spur evacuation among those with the greatest medical needs (Fernandez, Byard, Lin, Benson, & Barbera, 2002).
- Encourage personal preparedness to the greatest extent possible. Efforts can vary from keeping a Vial for Life on hand (Public Health Agency of Canada, 2008) to a fully developed preparedness kit consistent with federally recommended standards so that individuals can survive on their own for a time (www.ready.gov, also available in languages other than English).
- Identify a means to secure area hazard information and recommendations. In Oklahoma, OK-Warn offers low-cost messaging for people who are hard of hearing or deaf.
- Create a personal plan to evacuate or respond as directed. This means embedding patients in a medical provider and/ or social network to assist them. The City of New Orleans, in the aftermath of Katrina, has moved toward such a community-based effort specifically for seniors.

Meso-Level Example: Safe Centers in Alabama

After Hurricane Katrina in 2005, the Alabama Department of Senior Services in partnership with the U.S. Administration on Aging, Alabama Emergency Management Agency, Alabama Department of Economic and Community Affairs, and the City of Guin introduced and began to implement the concept of Safe Centers within the State of Alabama. The Safe Center concept combines a senior center that is used daily and known by the community with a Safe Center that will provide a place of respite for seniors in the event of a disaster.

The first Safe Center was completed in 2008, and as of April 2014, Alabama had created a total of 41 Safe Centers/rooms across the state; some are full freestanding structures while others are smaller scale or even a safe room within a facility. Some of the features of the Safe Center include the following:

- Generator power and extra wall outlets can be used to operate light medical equipment such as portable oxygen machines.
- Designated area(s) for seniors in the early stages of Alzheimer's or dementia are available. Each Safe Center has a satellite telephone to ensure communication after storms and other natural disasters.
- Safe Centers are designed according to FEMA standards to withstand hurricane and tornado force winds, floods, and other hazardous conditions in the geographic area.
- All have similar architecture and the same light blue roof color. If a senior from south Alabama is visiting family in north Alabama, he or she can look for the blue roof and know the Safe Center is there to serve after a disaster. This feature also makes it easier for first responders to identify and locate centers.
- Caches of appropriate supplies and shelf-stable meals are rotated on a regular basis.
- Full showering and laundry facilities are available in the event seniors need to stay for an extended period of time.
- Teams of trained volunteers are on call to support staff at the Safe Center in the event of an emergency.

This is a best practice because it:

- Can potentially save lives and lessen the impact of a disaster
- Is a wise use of public resources as it serves the dual purpose of a place for daily senior activities and a hardened facility with disaster protection features
- Allows local municipalities an opportunity to maximize resources under tornado warnings
- Is a replicable practice that goes beyond the state of Alabama and beyond senior centers
- Is a place of comfort and safety for seniors within high-risk communities

The centers have already been tested through real events:

One of our centers used their Safe Room this spring when the tornado sirens went off while attendees were there. Some were exercising, some playing cards, etc., but when the siren went off everyone made it to the Safe Room in 30 seconds. The seniors were glad they were protected at the center. (Collins, Coman, & Black, 2011)

Exo-Level Example: FEMA Trailers and Housing Policy

Policy change in the field of emergency management tends to develop in response to issues and concerns that result after disaster. Lawsuits also change policy. This was the situation following Hurricanes Katrina and Rita in 2005, when a class action discrimination lawsuit (*Brou v. FEMA*) was filed against FEMA and the DHS because of a shortage of accessible FEMA trailers (e.g., trailers with wheelchair ramps, maneuvering room, accessible bathrooms and kitchens). The settlement involved FEMA establishing a call-in process to request accessible trailers and as a result, FEMA provided over 1,000 new accessible trailers and modified over 200 other trailers.

This lawsuit not only set new policy in terms of the Katrina/ Rita recovery, but also influenced part of the development of FEMA's National Disaster Housing Strategy (released in 2009). Through the added pressure from advocates and other Federal partners such as the NCD, the integration of disability issues continues to be addressed in new disaster housing policy and guidance documents. In 2009, the NCD published the report, "Effective Emergency Management: Making Improvements for Communities and People with Disabilities." In this report, the NCD recommends that the outcomes of the lawsuit not be lost. Part of the housing policy development integrates disability organizations, advocates, and people with disability in identifying temporary housing options; empowers these groups to participate in FEMA housing efforts and have a role during disaster activations; establishes a hotline for case management for temporary and permanent housing assistance; encourages expertise within the case management system working with people with disabilities; and allows for postevent evaluations as a result of this policy change.

The NCD report itself offers a good example of how organizations can influence and change policy. In addition to producing this report, the NCD testified to Congress on the findings and recommendations to ensure a broader and ongoing awareness.

Macro-Level Example: Muslim Americans – Targeting and Tolerance after 9/11

Following 9/11, Muslim Americans experienced the most severe wave of backlash violence in their collective history. Civil rights organizations recorded thousands of incidents of anti-Islamic harassment, hate crimes, and vandalism in the months after the terrorist attacks. Federal officials surveilled and raided mosques and froze the assets of several major Islamic charities. Muslim, Arab, and South Asian men were arrested and deported, often without their family members' knowledge of their whereabouts (for a complete discussion of the backlash, see Peek, 2011).

The targeting of vulnerable racial and ethnic minorities during times of national emergency has long been an unfortunate feature of U.S. life. Thus, it is not surprising that many commentators drew parallels between the post-9/11 treatment of Muslim Americans and the experiences of Japanese Americans who were interred during World War II. Both groups, already marginalized, were quickly stereotyped as the "enemy" and subsequently experienced severe violations of their civil rights.

But there are also many differences between the Japanese American and Muslim American experiences. The internment of 120,000 persons of Japanese descent—two-thirds of whom were U.S. citizens—without trial or hearings represents one of the most egregious deprivations of liberty in our national history. The violations that Muslim Americans experienced, while extreme, were on a different scale. The fact that millions of Muslim Americans were not rounded up, stripped of their possessions and property, and imprisoned indefinitely speaks to the *macro-level, systemic changes* that have occurred in the decades since World War II. More currently, a proposed travel ban on Muslim-dominant countries has generated heated debate.

These changes in the social and political climate in the United States—and in particular the strengthening of minority rights—have resulted from, among other things, grassroots advocacy work, the

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civil rights movement, and many Federal-level policy changes such as the passage of the 1964 Civil Rights Act. These micro-, exo-, and meso-level changes and many others help account for why Muslim Americans, and advocates who worked on their behalf, were able to find a voice after 9/11 and to issue calls for tolerance. At the same time, the ongoing discrimination and prejudice that Muslims continue to face speaks to the often slow and unsteady process of macro-level change (Peek & Meyer, 2016).

SUMMARY

The term "high-risk, high-vulnerability populations" refers to people with a higher probability of being exposed to disaster and who also face challenges in anticipating, coping with, resisting, or recovering from disaster. Vulnerability is a complex phenomenon that is influenced by many social, economic, cultural, and other characteristics. Both the traditional medical model and more recent functional model offer approaches for understanding and addressing vulnerability in a disaster. In addition, understanding vulnerability systematically using an ecosystem framework allows for more precise identification of points of intervention at the micro-, meso-, exo-, and macro-levels. The disaster life cycle is another useful concept for exploring vulnerability and structuring activities related to the routine disaster phases of mitigation, preparedness, response, and recovery. Contemporary collaborative approaches such as FEMA's whole community philosophy emphasize inclusive planning, broad stakeholder engagement, and community resilience as critical factors for success. Healthcare organizations and nursing professionals are key actors in a whole community approach to reducing vulnerability to disaster, particularly for high-risk populations.

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CASE STUDY 7.1

Parish Nurse as Evacuation Advisor

Joanne C. Langan, Associate Professor, Saint Louis University School of Nursing

HOME EVACUATION: TO GO OR NOT TO GO IN HURRICANE KATRINA

Mr. and Mrs. Harrison survived Hurricane Camille which made landfall on the Gulf Coast of the United States during the 1969 hurricane season as a Category 5 hurricane. It moved through the area quickly and dropped only moderate amounts of precipitation in most areas.

Nearly 35 years later, Mr. and Mrs. Harrison are still living on the Gulf Coast of Mississippi. Mr. Harrison is 82 years old and in relatively good health and still drives. Mrs. Harrison is 80 years old and has dementia and is 6 months post-cerebrovascular accident (CVA). They live in a close-knit subdivision but their two daughters live in northern Mississippi. They have two small dogs. A parish nurse visits them once each month.

It is late August and they have heard of an impending storm, Katrina, that "might be a big one." Mr. Harrison

states, "We survived Camille. There is no way we are leaving this time." Mrs. Harrison has slurred speech and difficult mobility. She tells him that she is afraid to stay in the house during the storm.

- 1. You are the parish nurse. What would you advise this couple?
- 2. What are some of the community resources that you might share with them?
- **3**. How would you assure them that a shelter is a safe, temporary solution?
- 4. What should they take with them to the shelter, should they decide to evacuate?
- 5. If they decide to shelter in place, what are the minimal supplies that they must have readily available?
- 6. What would you advise them to do with their small dogs if they decide to shelter in place, or if they decide to go to a shelter?

CASE STUDY 7.2

Older Adults in Disaster: 2017 Northern California Wildfires

In disaster after disaster we see that people with disabilities and others with access and functional needs, including older adults, bear a disproportionate burden. Older adults are far more likely than other people to become sick, injured, or die as a result of a disaster, regardless of the type of event (United Nations Department of Economic and Social Affairs, 2011). It is not their age that inherently makes them especially vulnerable, but instead physical conditions such as mobility limitation and hearing loss and social features such as isolation and poverty that cause excess morbidity and mortality (Adams, Kaufman, Van Hattum, & Mood, 2011).

This reality was terribly illustrated in the 2017 Northern California wildfires. Of the 43 people known to have died, the average age was 79 years (Nix, 2017). Reports indicate that most were found inside their homes, unable to escape the fast-moving flames. At least two individuals were wheelchair users and two others were reported by their families to be confined to their beds.

Older adults in nursing home or other care settings also show an elevated vulnerability, even though they are under the care of others including staff with medical training. An estimated 215 people died in hospitals and nursing homes in Louisiana following Hurricane Katrina in 2005, most of them older adults (Brunkard, Namulanda, & Ratard, 2008). Following Hurricane Irma in 2017, 12 people died in a rehabilitation center that had lost power and was unable to keep patients cool (Frisaro, 2017).

In working with older adults, nurses should be cognizant of their elevated disaster risk and, when possible, engage them in conversation regarding personal protection, practical preparedness, and social preparedness. Additionally, nurses should be cognizant of the physical and social vulnerabilities that older adults face in disaster and work to assist their older adult patients in staying healthy and safe before, during, and after any disaster.

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CASE STUDY 7.3

Vulnerable Elderly and Vulnerable Infrastructure: The Case of Hurricane Irma and the Rehabilitation Center at Hollywood Hills 2017

Hurricane Irma, which hit South Florida in September 2017, was an exceptional storm in terms of its size, its duration, the geographic area affected, and the damage it wrought. Florida's governor declared a state of emergency on September 4; over the ensuing days, as the hurricane picked up strength and the forecasts and warnings became dire, mayors across the state began to declare mandatory evacuation orders. In the end, hundreds of thousands of Floridians took to the highways, making it the largest evacuation in the state's history.

Some Floridians, however, did not evacuate because the risk the evacuation posed was perhaps higher than staying in place. Among those who remained to ride out the storm included over 140 patients at the Rehabilitation Center at Hollywood Hills. In the end, 8 elderly patients perished in that nursing home facility, and an additional 3 died after being evacuated to a nearby hospital.

What happened at Hollywood Hills serves as yet another cautionary tale for the high costs that the most vulnerable pay when infrastructure fails. In this case, a transformer box was knocked out that led to the failure of the air conditioning in the facility. When the backup generator failed to power up that air conditioning, the heat in the facility rose to excruciating levels, with some of the patients who perished having recorded body temperatures ranging from 107° to 109°F.

It is true that as people age their bodily systems that are designed to ward off the damaging effects of heat break down. The consequences often include higher susceptibility to dehydration, heat exhaustion, respiratory conditions, and cardiac arrest. But the story of the deaths at Hollywood Hills are not just about the physical vulnerability of people. The real story is about the physical vulnerability of infrastructure that is meant to serve humanity and the failure to pass strict regulations.

In this case, the nursing home facility had an emergency preparedness plan, and they had a backup generator. But due to lax regulations, the generator was not powerful enough to keep the air conditioning on. The plan was not robust enough to ensure that there were adequate medical personnel on site to care for such a high number of vulnerable elderly. And the local and state response was not rapid enough to save the lives of the most vulnerable among us. Now, criminal charges are pending against the facility, which has a long history of safety violations, and its owner, a medical doctor who has previously been charged with fraud.

This case should serve not just as a cautionary tale, but as a catalyst to prioritize facilities and critical infrastructure that serves the most vulnerable among us. Nurses are at the front line and even under such circumstances should consider inserting themselves into the facility disaster planning efforts; demand periodic review of such plans; help identify areas for improvement; and continue to advocate for their patients by being involved.

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Appendix 7.1

The Post-Disaster Personal Assessment Tool

The following tool can be used by a nurse, caseworker, and others who are assisting survivors with recovery. Staff would go through the form together. This tool takes into account important health, social, educational, and other critical areas for a person who is in the recovery process, and helps to prioritize areas that need to be addressed to begin recovery.

Consider what's important to you about where you live ...

After a disaster occurs, this tool will help you consider the things that are the most important to you about where you live. Once you have completed this assessment, you can compare this list to what is available, or what is likely to be available soon in your neighborhood. After completing this form, the results can also inform you and your case manager as you make informed and safe decisions about temporary housing options or long-term relocation decisions that meet your most important needs.

This "snapshot" should give you a better idea of what weight to give certain factors when considering your housing options. You may add to this list anything else you consider important and still use this tool to help you get a better picture.

SELF-ASSESSMENT

Indicate in the spaces below:

- 1. Independent
- 2. Needs some assistance
- 3. Needs full assistance

Walking	Cooking
Climbing stairs	Bathing
Vision	Housekeeping
Shopping	Others (specify here):

EVERYDAY ACTIVITIES

Rank each item below by how important the service is to you:

- 1. (Not important)
- 2. (Somewhat important)
- 3. (Very important)

Services

- ____ Grocery store within walking distance
- _____ Other goods and retail within walking distance
- _____ Pharmacy within walking distance
- _____ Bank within walking distance

Schools

____Day Care ____Elementary School ____College level _____ Pre-K _____Middle School _____Specialty School (e.g., trade school, school for the blind) _____High school

Accessible public

____ House of worship

Friends/family

Library

Healthcare

- _____ Hospital with emergency care
- _____Access to primary doctor, clinic, etc.
- _____ Access to medical specialist, support (cardiologist, radiology center, etc.)
- ____ Dialysis center

Appendix 7.1 (continued)

Support/Care Services

Home-based care agency (nurses, home attendants, physical therapy, etc.)

- Meals (congregate or delivered programs)
- ____ Senior center

Housing Options

- ___ Rental availability
- Fully accessible unit/location
- _____ Elevator building
- Proximity to public transportation system
- _____ Assistive living community

After ranking the importance of the items just listed, circle the items that you know are in your community. Then consider:

- How many "very important" items are circled? Will they be available in your neighborhood soon?
- . Do you have enough support and are you safe if you do not have some of the "very important" items that you need in your neighborhood?

___ Housing stock for purchase

____ On-site parking

____ Doorman building

- Do you need more information about your neighborhood before you can make a decision?
- Do you need to talk to a case manager about this before you make a decision?

Any other notes:

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Appendix 7.2

Think Before You Speak or Write: Polite Communication

The words one chooses to use when referring to people with disabilities in oral and written communication often carry either a positive or a negative connotation. Therefore, adopting the following suggestions will help others know that you respect people with disabilities and may also encourage people to think and act more appropriately toward others.

PUT PEOPLE FIRST

The person should always come first. An individual has abilities as well as disabilities. Focusing on the person emphasizes the status we share, rather than conditions we presently do not. Thus, say "the person who has a disability," rather than "the disabled person." Similarly, it is better to refer to "people with disabilities" than to "the disabled" or "the handicapped."

EMPHASIZE ACTION

People with disabilities, even severe ones, can be quite active. Thus it is better to say "President Franklin Roosevelt used a wheelchair and occasionally walked using braces and crutches" rather than "he was confined to a wheelchair," or "the wheelchair-bound president," or "the president was in a wheelchair."

DO NOT SENSATIONALIZE, PITY, OR CHARACTERIZE

Avoid words like "afflicted," "crippled," "handicapped," and "victim" when referring to a person with a disability. Also, remember that people are more than their disabilities. Instead of saying that "President Roosevelt suffered from asthma," "Helen Keller was handicapped by blindness," "Peter Stuyvesant was an amputee," or "Moses was afflicted with a speech impairment," do say "Einstein had a learning disability," "Napoleon had epilepsy," "Alexander Graham Bell was hard of hearing," or "Marlee Matlin is an actress who is deaf."

AVOID INAPPROPRIATE WORDS

Words have enormous power in shaping how we view the world and how we view one another. As such, it is very important that we work together to use currently acceptable language out of respect and care for those with whom we work, serve, and encounter on a day-to-day basis.

When it comes to the current state of the disability field—like many other areas of research and practice—acceptable terminology is often changing to fit with our times. "Handicapped," for instance, has gone the way of "invalid" and "crippled" and is no longer viewed as an appropriate term to refer to a person with a disability. "Differently abled" and "physically challenged" are fad phrases which have not gained general acceptance among people with disabilities and, in fact, offend many. "Special" when used to refer to people with disabilities, is a rather backhanded compliment—everyone is special in some way—and use of that term as an alternative to "different" is as inappropriate as using the latter term. Words like "wheelchair person" simply should not be used. People without current disabilities, when referred to in contrast to people with disabilities should be referred to as "people without disabilities" rather than as "able bodied" or "normal" since a person with a disability may be more "abled" than others with respect to pertinent activities. Of course, in some contexts, when quoting from an old statute or referring to a particular entity by name, use of some words which otherwise should be avoided may be necessary. For example, the Federal Rehabilitation Act uses the term "handicapped" and schools have "Committees on Special Education" (an improvement over the former "Committees on the Handicapped"). At the time when some organizations were formed and laws were written, few people had yet considered the important role of inclusive language in encouraging inclusion.

POINTS TO KEEP IN MIND

- Physical disability does not imply a mental disability or childishness.
- Different means of communication do not mean low intellectual ability.
- Disabilities can occur to anyone at anytime in life.
- Some disabilities can be temporary or episodic.
- Don't be afraid to encounter someone with a disability.

NOTE ON LANGUAGE REFERRING TO THE "ELDERLY"

There are several terms used to refer to the "elderly" that are used interchangeably, depending on the agency or organization. Common terms include "seniors," "elderly," "the aging," and "older persons." Often the title used in the name of the agency or organization will indicate the appropriate term to use while working with that entity (e.g., the Administration on Aging uses the "aging" primarily in speech and written materials).

By choosing words which convey a positive image of our colleagues, clients, and friends, we begin to break down often unconscious attitudinal barriers to their integration and meaningful participation in society.

Source: Adapted from Leeds, M.H. (1990). Rights and responsibilities-People with disabilities in employment and public accommodations. New York, NY: Mark H. Leeds, Esq.

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