

Evacuation and Sheltering of People with Medical Dependencies – Knowledge Gaps and Barriers to National Preparedness

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ABSTRACT

Emergency plans are mandated by a number of federal regulations, often with conflicting definitions, to incorporate people with medical dependencies. However targeted planning for this segment is presently hampered by substantial knowledge deficits defining this population and the potential resource requirements in a disaster. These gaps prevent the development of evidence-based best practices for locating, communicating with, transporting, sheltering, and ensuring the safe recovery of those with medical dependencies. The authors discuss the knowledge gaps in preparing for this population and propose solutions to fill these gaps in order to facilitate enhanced preparedness for people with medical dependencies.

INTRODUCTION

Federal regulations such as the Americans with Disabilities Act of 1970, the Rehabilitation Act of 1973, and Post-Katrina Emergency Management Reform Act of 2006 stipulate the general principle that children and adults with disabilities and functional needs must be able to access the same programs and services as everyone else. This essentially mandates that emergency plans must develop and incorporate strategies for locating, communicating with, transporting, and sheltering those with needs beyond the general population when disaster strikes.

Incorporating this and other “whole of community” concepts is a fundamental aspect of the emergency manager’s role in the community.¹ However the broad, evolving, and often conflicting guidance on the extent to which the community can be understood based on functional limitations can cause confusion and slow down planning efforts as

the legal requirements and implications are understood. This is especially problematic for responding to members of the community who are normally self-sufficient, but have medical conditions stressed into greater severity due to the impact from a disaster. This heterogeneous group raises special preparedness challenges, as its members’ wellbeing demand specialized equipment or medical supplies not only to prevent deterioration of their health, but in many cases also to sustain life. Evidence suggests that many of those who may have the greatest need for such support pay insufficient attention to personal preparedness.² The scarcity of knowledge with regards to the composition and size of this group prevents proper preparation and could lead to inefficiencies in disaster response; limited acute-care transport assets being tied up for non-essential transport when what was really needed was just a wheelchair, or evacuees who are used to functioning independently in daily life being directed to hospital emergency departments because of shelters lacking the necessary generator capacity and power outlets to charge their essential medical equipment. Factors such as these could explain observations pointing to a disproportionate fatality rate among those with medical dependencies.³

We originally sought to comprehensively review the underlying evidence for recommendations aimed towards people with medical dependencies, including aspects such as communication, transport, sheltering and recovery. However, during the course of this process we concluded that to create an efficient research agenda to plug current knowledge gaps, it is imperative to understand this subset of the “access and functional needs” population better. Therefore, we focused this piece on the key questions of how to identify this segment and how to estimate what critical resources are needed. We believe that strategies for

delivering tailored information, using appropriate transportation resources or ensuring that shelters have the requisite features and supplies, will be more efficiently improved once answers to the above questions have been found.

METHODS

The following discussion is based on subject matter expert and responder interviews conducted as part of various planning and training programs developed by the Yale New Haven Center for Emergency Preparedness and Disaster Response (YNH-CEPDR), which has highlighted challenges in developing a community response to support people with medical dependencies. Through a review of the literature and the preparedness guidance of United States agencies, we have attempted to identify some of the critical knowledge gaps in applying the scope and intent of national level doctrine into improved response paradigms to support people with medical dependencies at the community level.

We conducted a literature review using online medical databases (Medline, Cinahl, Cochrane and Scopus) and internet-based search engines (Google Scholar) to retrieve published information related to people with medical dependencies in mass evacuations and disasters. The following search words were used in various combinations: “medical dependencies,” “vulnerable populations,” “at risk populations,” “special needs,” “special healthcare needs,” “disaster,” “evacuation,” “emergency,” and “preparedness.” This was supplemented with a review of reference lists in articles deemed relevant, as well as post-event reports from Hurricanes Katrina and Rita, the 2004 Hurricane season in Florida, as well as hurricanes in Texas and Louisiana such as Gustav and Ike. A number of articles from international sources were assessed for relevancy, but were not included due to doubts about their applicability to US conditions. Relevant information was also provided in interviews or personal conversations with various subject matter experts (listed in Acknowledgements).

WHAT ARE “MEDICAL DEPENDENCIES”?

Although there is a recognized need to better address the inadequacies in preparedness planning for members of the population who can be expected to require assistance beyond what is provided to the average citizen, there is an ostensible lack of consensus with regards to the terminology. Guidelines and recommendations use a wide variety of terms, and as a consequence, many recommendations target overlapping, but slightly different groups.⁴

The use of broad definitions for planning purposes has the potential to result in imprecise preparation and poorly targeted measures. For example, the general term “special needs population” is used in the National Response Framework (NRF) to designate all individuals “who may have additional needs before, during, and after an incident.” Official guidelines operationalize the definition to include, but not be limited to, those who are elderly, children, institutionalized, have limited or no English proficiency, or lack transportation. As pointed out by others, this term may in its widest sense encompass more than half the United States population.⁵

As stated above, we seek to focus this text on those classified as having a “medical dependency,” who we have defined more formally as:

Individuals who rely on specialized equipment, medications, or caregivers in order to sustain life, minimize deterioration in health status, and/or retain some degree of personal independence in performing activities of daily living.

This segment of the population is more or less universally included in the terms often used for emergency planning (e.g., “at-risk,” “vulnerable,” “access and functional needs,” or “special needs”), but the above definition subsets these broader terms to apply to people who require mobility or other functional aids, medications, or portable medical equipment, or rely on a caregiver for maintenance of their health.

However, despite being featured in most planning guides and recommendations, the targeted group is complex to delineate, as the

degree of medical dependency is dependent on baseline resilience and time. An individual with type I diabetes mellitus may require minimal support from the community in everyday life, but would decidedly qualify in terms of the above definition if access to medications was blocked in the aftermath of a disaster. Similarly, loss of electrical power beyond battery life on specialized equipment in an area could rapidly alter the composition of population with medical dependencies. The extent and urgency of medical dependency thus have a substantial temporal factor, and a functional definition with tiered categories defined by time may be appropriate. However, due to the scarcity of knowledge on the dynamics of vulnerability among people with medical dependency during disasters, we limit ourselves to note this aspect without attempting to partition the above definition with regards to time.

IDENTIFYING AND LOCATING THE POPULATION WITH MEDICAL DEPENDENCIES

To ensure compliance with federal regulations aimed at providing universal access to services and shelters, emergency planners need either knowledge or reasonable estimates informing them of the size and composition of the people with access and functional needs. FEMA guiding documents such as *Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters* emphasize that identification and planning for this population segment cannot wait until disaster occurs, and need to be planned well in advance.⁶

Considerable uncertainty exists with regards to the size of the People with Medical Dependencies (PMD) population, regardless of the exact definition used. Data from the US Census Bureau (American Community Survey) indicate that roughly 12 percent of the population falls into one of six disability categories (hearing, vision, cognitive, ambulatory, self-care, or independent living difficulty), although this proportion rises to about 37 percent when looking at those over sixty-five years.⁷ Ambulatory difficulties were found to constitute the biggest single

disability category, constituting 24 percent of the elderly. Similar estimates have been found for the sixty-five years and older population using the CDC's Behavioral Risk Factor Surveillance System survey, which estimated about 32 percent of the population in 2003-04 to have a disability and 17 percent to be in need of specialized equipment.⁸ Other methods have concluded with even higher estimates for the general population. A study of St. Louis County, which is fairly representative to US demographics as a whole, found medical dependencies to account for 18 percent of the population, and personal communication with six subject-matter experts yielded estimates in the range of 15-20 percent of the total seeking shelters.⁹

FEMA lists the Center for Personal Assistance Services as a resource for disability statistics when anticipating and planning shelter capacity.¹⁰ However, as there is no accepted best practice for emergency planners for estimating and identifying people with medical dependencies, we will review some of the suggested methods to accomplish this. For all of these methods, there is unfortunately limited, if any, peer-reviewed literature on their effectiveness in identifying and locating people with medical dependencies in mass emergencies. Some potential resources that have been suggested to fill this knowledge gap include surveys, registries, community-based organization engagement, and even door-to-door registrations.

SURVEYS

When developing plans to include the needs of evacuating and sheltering-in-place people with medical dependencies, FEMA suggests using survey data on disabilities for estimating resource needs.¹¹ The advantages of such an approach are that underlying data is generated at regular intervals with considerable attention to methodological aspects of sampling, the surveys in question have national coverage, and it is readily available for state or local planners over the internet.

However, for practical planning purposes the use of surveys have several obvious limitations. Granularity is often limited to the

state level, and there may be considerable regional and local variation within a state. National surveys often employ dialing to household landline phones as their interview method, a method that excludes those who use cell phones exclusively or are without a permanent residence. Surveyors may also not be prepared to communicate using Teletypewriter and Telecommunications for the Deaf Device (TTY/TTD) technology, missing a critical cohort of the population. Since data is linked to permanent residences, rates may be inaccurate for local areas that experience substantial seasonal fluctuations. For planning purposes, disability statistics within these surveys is often built around a set of few and fairly general questions, and as a consequence do not identify specific medical support requirements.

REGISTRIES

Several local jurisdictions have established dedicated registries of people with medical dependencies in their community, and this has been suggested as a means to locate those who have special medical needs in the aftermath of disasters.¹² In the event of an incident requiring evacuations, such registries may provide an easily accessible list identifying individuals in need of additional support. However, such registries have not been universally established across the nation, and even if they were, there are numerous caveats with this approach. Established registries typically rely on voluntary sign-up at the initiative of those with additional assistance needs, and as a consequence, coverage is likely to depend heavily on how the registry is marketed towards people with medical dependencies. Limited published experience indicate that such registries may only capture a fraction of the true population.¹³ Low coverage rates represent a problem if emergency planners or responders start viewing those on the registry as the only ones in need of assistance, and inappropriately narrow their attention and efforts solely towards the registrants. Registrants also may perceive participation as a promise of evacuation services that may be beyond the planning and capacity of the jurisdiction. Registries of this kind inherently

deal with protected health information, and it is highly uncertain to what extent planners have incorporated routines to ensure compliance with the legal framework for such data.¹⁴ Maintaining registries with information that is up to date is generally labor-intensive and costly, and the absence of plans and budgets to do so will quickly cause information to be outdated and unreliable.¹⁵

One special strategy for creating and maintaining registries has been employed in Texas, a state frequently affected by hurricanes. Several counties have implemented a policy where the community's Fire Chief organizes a task force to go from door to door in order to identify individuals who may require additional assistance during a mass emergency.¹⁶ This is typically done at the start of hurricane season, and the chief elected official or county judge subsequently validates the numbers. Such an approach is likely to counter problems such as a varying population, people with medical dependencies relocating, and undocumented residents who would otherwise not self-report. However, the method employed by Texas may be considered too resource-intensive by officials in areas where the need to evacuate is less frequent.

ESTIMATING RESOURCE NEEDS

Despite advance planning by the authorities and personal preparedness for the community, a disaster will almost certainly result in people with medical dependencies in need of durable medical equipment and medications or other consumable medical supplies. Emergency plans must estimate what resources will be needed, and establish a process in advance to locate, purchase and store necessary supplies, in order to ensure that they are available during and after a disaster.

However, for the individual emergency planner, who typically lacks logistics training or expertise, it can be challenging to convert rates of disability and functional needs into adequate estimates of resource needs. Beyond some suggested lists from FEMA of possible medications and equipment one might need, with no quantification of the number of these items needed, the official

guidance on resource planning for people with a medical dependency is virtually nonexistent. In addition, these lists provide no evidence base for their composition, and evaluations on how well the suggested selections cover the needs in real disasters have not been published.¹⁷

BASELINE RESILIENCE

Improving self-sufficiency and increasing community resilience has become a fundamental concept in disaster preparedness for the general population. For people with medical dependencies, personal preparedness may reasonably be one of the most effective strategies to improve resilience during a shelter-in-place or evacuation event. If a substantial share of this population have spare medical supplies and backup power supply for vital equipment capable of sustaining them for some days, the strain on emergency efforts would be reduced and the probability of survival greatly increase in the event that caregivers, delivery people, or emergency responders were unable to reach them due to the disaster.

Unfortunately, knowledge on the level of baseline resilience for this population is inadequate. Emergency planners have limited data on what proportion of the population with medical dependencies can be expected to be independent in terms of medical supplies for seventy-two hours, an often used recommendation for self-sufficiency in the general population, for notice or no notice events. The limited number of studies we identified which looked at disaster preparedness among dialysis patients, wheelchair patients, families with special care children, diabetics, and other populations with medical dependencies, all pointed towards an insufficient level of preparation, regardless of other demographic and socioeconomic predictors.¹⁸ In addition, the implications of medical dependency are temporal; a ventilator may have sufficient backup power to safely endure a short outage, but the urgency of restoring electricity to such life-saving equipment rapidly increases with time. Unfortunately, little is known of the vulnerability dynamics of a community with regards to disruption in power or the

supply of critical medications. There is also scarce data on the extent of people with medical dependencies and their ability to prepare by storing up food, water, and other necessities for shelter-in-place during a notice event, the lack of which could compound their baseline illness.¹⁹

ALTERED COMPOSITION AFTER VOLUNTARY EVACUATION

There are indications suggesting that the composition of the remaining population may change markedly after an evacuation event, and that those remaining afterwards the evacuation are disproportionately vulnerable to the effects of a disaster.²⁰ However, the evidence is currently limited and methodologically lacking. There is a need for better understanding of which factors determine willingness to evacuate, and with regards to people with medical dependencies, the factors that may impede their ability to comply with evacuation orders or recommendations.

STRATEGIES FOR IMPROVEMENT

The growing interest to incorporate strategies and capabilities aimed at people with medical dependencies in emergency preparedness is decidedly welcome. However, it should be evident from our review of official suggestions that current evidence is woefully inadequate to identify and test best practices in the field. We also contend that evaluation of existing strategies for communicating with, transporting, and sheltering this population during mass emergencies will be ineffective unless a better picture is formed of those with medical dependencies, where to find them, and what type of assistance they can be expected to require. In order to develop planning recommendations backed by empirical evidence, there is a patent need to fund research into emergency preparedness. Based on our review of the published literature, we conclude that the knowledge gap may be most effectively plugged if efforts are focused on exploring what strategies work at identifying people with medical dependencies in the community and ascertaining precisely what assistance it will

be necessary to provide. When the target population and their baseline level of resilience is established it will be possible to revisit more specific questions such as how to ensure enough appropriate transportation assets, what shelter modifications are necessary, and which level of care generalized shelters should be prepared to handle.

EVALUATION OF EXISTING STRATEGIES FOR IDENTIFYING THE POPULATION WITH MEDICAL DEPENDENCIES

Based on our review of the available literature, we believe the current official suggestion in *Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters* of using survey data is highly unlikely on its own to yield good results in terms of practical planning.²¹ Available surveys on disability may provide some indication of rates on a national and state level, but the granularity is insufficient both at the level of geography and in terms of medical needs. However, these surveys duly demonstrate that the problem is sizeable enough to justify more intense research effort into what produces better plans, and ultimately, better response during disasters.

In order to gain a better evidence-base for identifying persons with medical dependencies in the community, we suggest that a fact-finding effort should be made to map what practices are currently being used in areas where disasters frequently occur. Jurisdictions with prior experience in organizing mass evacuations are more likely to have developed approaches to the problem at a local level, and practical know-how present among officials, planners, and responders in such communities should be systematized for evaluation.

Attention should also be devoted to evaluate the use of registries, as this is an approach already adopted by many jurisdictions. However, such registries can be expected to be highly diverse in coverage, content, and maintenance. It is therefore important that research efforts try to estimate what fraction of the total community population with medical dependencies are captured, using either local surveys or a

method like door-to-door registration, and that policies for recruitment of individuals and regularly updating the information is well described. These studies would provide a basis for evaluating whether registries are worthwhile and if so, help elucidate what practices are needed to make them useful and efficient. Good knowledge of how comprehensive registries are would also make it possible to conduct retrospective inquiries post-disaster to determine how the composition of the population with medical dependencies changes in response to governmental alerts of impending mass emergencies such as hurricanes.

IMPROVED ESTIMATION OF RESOURCE NEEDS

Although the information on baseline resilience is scarce, a handful of publications clearly suggest that the level of preparedness among persons and households with medical dependencies are vastly inadequate.²² Increasing the level of self-sufficiency in terms of supplies within this population is likely to yield substantial benefits in terms of their resilience. Consequently, research into the effectiveness of different practices and communication strategies that jurisdictions can employ to help people with medical dependency become aware of the need for personal preparedness should be a priority. Thus, surveys to assess community resilience should plan to repeat the same survey in order to test the effectiveness of interventions to improve preparedness among this population.

There is also a discernible need to better understand how the population with medical dependencies translates into actual resource needs, both for planning and post-disaster response. Efforts should be made to establish a system of good resource tracking in a few “learning” communities where mass evacuations happen with some frequency and door-to-door registrations are practiced, in order to allow for retrospective assessment of what resources are being used. This could provide an evidence-base for recommendation on what durable equipment and consumable medical supplies are critical for local preparedness; however, due to the

inherent hectic work environment mass emergencies represents, plans for data collection must be laid prior to the event.

Another approach that may help resource planning in areas where disasters are less frequent is research into mathematical modeling of the relationship between persons with medical dependencies and resource use. Such a model could be based on baseline supply-side inputs that are routinely generated, such as pharmacy sales within a community. Over time, predictions from the model could be matched with real-life experience on actual resource use, and the results could be used to refine the model. Although the construction of a robust model would take sustained effort over time, the outcome could be an invaluable tool for use by emergency planners.

CONCLUSIONS

Emergency plans are mandated by a number of federal regulations, often with conflicting definitions, to incorporate people with medical dependencies. However targeted planning for this segment is presently hampered by substantial knowledge deficits in defining this population and the potential resource requirements in a disaster. These gaps prevent the development of evidence-based best practices for locating, communicating with, transporting, sheltering and ensuring the safe recovery of those with medical dependencies.

To facilitate adequate integration of those with medical dependencies into the emergency response, we believe it is critical to align working definitions of people with medical dependencies as well as prioritize knowledge on the size, composition and baseline resilience of this population, and we suggest doing this through a systematic assessment of existing strategies for identifying and locating those with medical dependencies in jurisdictions that frequently respond to natural hazards. Once a better understanding of these aspects has been

achieved, it can be used to evaluate strategies on how to increase personal preparedness and establish a better link between the target population and resource requirements. We believe that efforts aimed at developing evidence-based best practices in these fundamental areas will be an important first step towards addressing wider preparedness issues for persons with medical dependencies, leading to more effective national policies and recommendations for local emergency planners working to protect our most vulnerable populations.

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²² See note 2.



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