

The Semantics of Disability in the Context of Emergency Preparedness and Response

Lex Frieden^{1*}, Chiehwen Ed Hsu¹, PhD, MPH, Kim Dunn¹, MD, PhD, Ning Shang¹, Richard Petty², MBA

¹University of Texas Health Science Center at Houston, School of Health Information Sciences; ²TIRR Memorial Hermann, Houston, Texas *lfrieden@bcm.tmc.edu

Introduction

The National Response Framework (NRF) crafted by Congress to authorize preparation and response to disasters in the U.S. acknowledges the importance of addressing the unique attributes of "special needs populations" (SNP) when preparing for and responding to disasters. Now the SNP is defined as "Populations whose members may have additional needs before, during, and after an incident in functional areas." But in practice, SNP seems to have lost its functional value, and is often misinterpreted. So it is difficult for disaster preparedness officials and emergency responders to analyze carefully specific needs of the various subsets of the population included in the current definition.

Significance of defining SNP: By using a more refined, segmented approach to addressing the diverse needs of subpopulations included in the NRF's definition of SNPs, authorities could also plan, train, and operationalize response matters pertaining to the various groups analytically and effectively.

Objective

We aim to clarify understanding and improve communications related to that subset of the SNP population who are people with disabilities* by proposing more descriptive and functionally useful terms.

**In addition to people with disabilities, other sub populations are included in SNP, but not considered in this research*

Methods

- Discuss the semantics pertinent to the segment of the NRF's SNP who are people with disabilities, and elaborate on various terms.
- Provide critique on the most frequently used terms pertaining to disability community and explain how these terms are used in emergency context.

Key Terms Defined

Disability: The state of being limited (due to a chronic mental or physical health condition) in the type or amount of activities

- NHIS disability measures: activity limitation in major activity, work limitation, and need for personal assistance with ADLs
- Americans with Disabilities Act: have a physical or mental impairment that substantially limits one or more major life activities

- Most frequently used and widely accepted descriptor of people with physical or mental impairments
- To meet the disaster related needs of each segment of the population of people with disabilities, emergency preparedness practitioners must carefully analyze the population

Chronic Health Condition: A general term that encompasses both chronic illness and chronic impairment.

- The term is not clear that the reference is particularly useful in the context of emergency preparedness and response.
- Virtually all people with chronic health conditions would also fit the definition of disability.

Frail Elderly: Older adults or aged individuals who are lacking in general strength and are unusually susceptible to disease

- Aging advocates and older people with disabilities dislike the term "frail elderly," because it is often used as a general descriptor of older persons, most of whom are neither weak nor prone to sickness
- People who are regarded by health and social service professionals as "frail" also, most likely, fit the definition of "disabled."

Medical Special Needs: A person with medical special needs is someone who:

- Needs assistance during evacuations and sheltering because of physical or mental disabilities, is a minor under the age of 18 *and/or*
- Requires the level of care and resources beyond the basic first aid level of care that is available in shelters for the general population

Unacceptable: most people with disabilities do not regard their needs as "special," and large portion of them do not regard themselves as having medical needs at all

Classification of Medical Special Needs: The classification of people with medical special needs according to levels of functional needs proposed by the Texas Hurricane Evacuation and Mass Care Plan (2007)

- Even if the classification is a functional planning and operations tool, it provides no clear means to differentiate people according to their level of self-care or independence
- The Texas classification system of functional levels of need by people with disabilities has promise, but further work is needed to make it most useful

Medical Special Needs Shelter: A shelter which provides, to the extent possible under emergency conditions, an environment in which the current level of health of persons with special needs can be sustained within the capabilities of available resources

- It is not a hospital, a nursing home/restorative care center nor a hotel

Results

- Use a much more functional approach to referencing, planning for, and responding to the unique needs of the so called "special needs population"
- Break down the catchall definition into parts, and address those parts individually
- Resolve the concern of people with disabilities about the association between disability and "special needs."

Discussion

- By refining and elaborating SNP and its semantic and contextual bases, disaster preparedness practitioners can address the unique needs of various subpopulations
- Working with people with disabilities and other responsible community groups can facilitate disaster preparedness practitioners in their areas

References

- <http://www.fema.gov/emergency/nrf/glossary.htm>
- Moving Beyond "Special Needs": A Function Based Framework for Emergency Management and Planning, Kailes and Enders, May, 2006
- The National Health Interview Survey [NHIS]
- The National Medical Expenditures Survey (NMES)
- Texas Hurricane Evacuation and Mass Care Plan, Texas Governor's Office, Division of Emergency Management, June 5, 2007)
- Texas Governor's Office, Division of Emergency Management, June 5, 2007