Disaster Services and “Special Needs”: Term of Art or Meaningless Term?

By June Isaacson Kailes, Disability Policy Consultant
Associate Director, Center for Disability Issues and the Health Professions
Western University of Health Sciences, Pomona, California
www.cdihp.org | www.jik.com

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Special Needs Populations

- Why Spend Time on This, It's Only a Term?

Who Are People with Disabilities and Other Activity Limitations?

- There Are No "The Disabled" and No "One Size Fits All"
- Defining Disability Broadly
- Disability Should Not Be Viewed as a "You Have" or "You Don't Have" a Disability
- Definitions That Leave No One Behind

Accommodating People with Disabilities Often Translates into Being Better Equipped To Serve All

- People With Disabilities and Activity Limitations Are Part of Every Segment of the Population

Nothing About Us Without Us

- Selecting Acceptable, Respectful and Precise Terms

References

About the Author

Distribution

About the Sponsoring Organization

Special Needs Populations

The term "special needs" is widely used within the disaster services and the emergency management world. It generally refers to an extremely broad group of people with disabilities, people with serious mental illness, minority groups, the non-English speaking, children, and the elderly (Centers for Disease Control and Prevention undated). These groups represent a large and complex variety of concerns and challenges. Many of these groups have little in common beyond the fact that they are often left out of programs, services and emergency planning (Kailes 2000).

It is time to include people with disabilities in emergency services as contributors and collaborators, not just as people viewed as victims to be rescued users.

Given the definition, it is conceivable that "special needs" could cover more than 50% of the nation's population rendering the term rather meaningless. Continuing to use "special needs" does a disservice to every group included. This term combines a huge number of heterogeneous groups. Many question the usefulness of such a term. Repeated pleas, over the years, from disability advocates to replace "special needs," with more respectful, precise, segmented, and discrete groupings, continue to be ignored.

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Why Spend Time on This, It's Only A Term?

Some argue "why spend time on this, it's only a term?" Words can empower, encourage, confuse, discriminate, patronize, denigrate, inflame, start wars, and bring about peace. Words can elicit love and manifest hate, and words can paint vivid and long lasting pictures. Words affect thoughts, thoughts affect beliefs, beliefs affect feelings, feelings affect behavior, and behavior affects the world! Public attitudes about disability are usually much more disabling than an

actual disability. Attitudinal barriers are the most difficult barriers to break through. The challenge is to change attitudes using legislation, regulation, enforcement, integration, education, relationships and LANGUAGE (Kailes 1990).

In addition to the issues of respectful language, it would be beneficial for emergency managers to scrap the umbrella term "special needs" and replace it with terms that refer to specific situations of people who might need warning or evacuation, sheltering and other services. Managers would have a more accurate idea of the needs they will be faced with, and how to meet those needs. For example:

- "Medical needs shelter" is a more useful term than "special needs shelter." This terminology points to the specific reason that some people need enhanced shelter services. Most people with disabilities and activity limitations do not require a medical shelter. Combining the majority who don't with the few who do need medical services, compounds the problem for disaster service providers. There is a danger that it may seem so large that it is unmanageable, leading to doing nothing. In some disaster situations. the terminology triggered great confusion causing people with disabilities to be sent to a "special needs shelter" only to be told they were at the wrong shelter, as they had no medical needs.

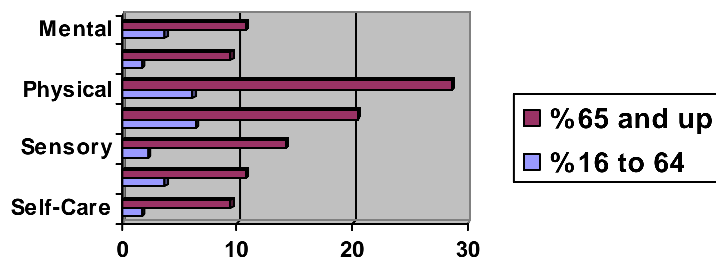
- People who do not speak English need shelter and other disaster services provided by people who speak their language or have interpreters present. They do not need special medical services because of their language, and there is no reason to combine them with people who do. On the other hand, if a non-English speaking person does need medical services, offering these services can be problematic in the absence of effective communication.

- Emergency managers need to anticipate how many people there are in their jurisdictions that have significant memory and understanding limitations. For example, people with cognitive limitations who do not have families or people to assist them cannot be placed in an open emergency shelter. There needs to be a plan for where they will be housed, and for experienced personnel to assist them, if they need to be evacuated.

- The only thing that seniors have in common with each other is age. Some climb mountains or run marathons in their 90s, most do not. Only older people who have disabilities need to be considered as part of the population. The sub-group of the older people who have specific medical needs should be identified as such. Just grouping them with all older elderly people will not meet their needs. Actually many older people serve as volunteers and can be an asset in a disaster, not as part of a group with specific needs.

Who Are People with Disabilities and Other Activity Limitations?

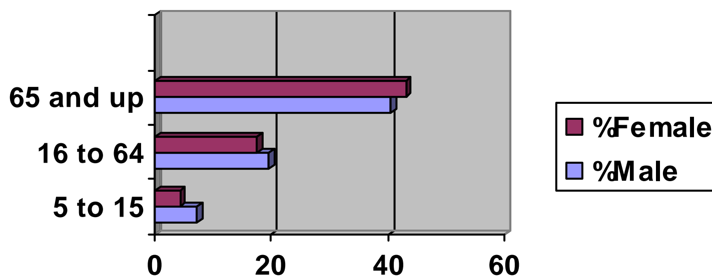
% of U.S. Noninstitutionalized Population With Disabilities by Age and Disability Type



By identifying who are people who have disabilities and other activity limitations, one can better understand the enormity of one subset of the so-called “special needs” group. These charts using data obtained in the 2000 U.S. Census illustrate that individuals with disabilities make up a sizable portion of the general population within the United States. According to the U.S. Census of 2000, they

represent 19.3 percent of the 257.2 million people who were aged 5 and older in the civilian noninstitutionalized population, or nearly one person in five.

As the population ages, people with disabilities rise in proportion to demographic changes. Medical and technology advances continue to keep more people with disabilities, chronic conditions, and activity limitations alive, healthy and functioning independently. Planning for inclusiveness is the agenda which makes the most sense (National Council on Disability 2000).



There Are No "The Disabled" and No "One Size Fits All."

Disability should not be thought of as a condition that affects the "special" or "unfortunate few." Disability is a common characteristic and occurrence within the human experience. There are no "the disabled," and there is no "one size fits all." People with disabilities have the same range of personality traits, interests, and desires as everyone else. People with disabilities are a part of the world's diversity. (Kailes 2002)

Most generalizations based on particular types of disabilities have numerous exceptions. Two individuals with the same type of functional limitations man have very different abilities and needs. Like everyone, people with disabilities and activity limitations deal with life with different histories, resources and attitudes. (Kaplan 1992)

Defining Disability Broadly

In disaster management activities, it is important to think about disability broadly. Traditional narrow definitions of disability are not appropriate. Disability is not limited to wheelchair users and people who are blind or deaf. Individuals with disabilities include those with one or more activity limitations such as a reduced or inability to see, walk, speak, hear, learn, remember, manipulate or reach controls, and/or respond quickly. Some disabilities are quite visible, while others may be hidden such as heart disease, emotional or psychiatric conditions, arthritis, significant allergies, asthma, multiple chemical sensitivities, respiratory conditions, and some visual, hearing and cognitive disabilities.

Longer life expectancies and decreasing death rates from heart disease substantially prolong longevity and increase the numbers of people living with chronic, nonfatal, but disabling conditions (Reis 2003).

People with disabilities and activity limitations include those who have:

- Conditions which interfere with walking or using stairs (joint pain, mobility device user – wheelchair, canes, crutches, walker)
- Reduced stamina, fatigue or tire easily (due to a variety of temporary or permanent conditions)
- Respiratory conditions (due to heart disease, asthma, emphysema, or other symptoms triggered by stress, exertion, or exposure to small amounts of dust or smoke, etc.)
- Emotional, cognitive, thinking, or learning difficulties
- Vision loss
- Hearing loss
- Temporary limitations resulting from, but not limited to:
  - Surgery
  - Accidents and injuries (sprains, broken bones)
  - Pregnancy (Kailes 2002)

Disability Should Not Be Viewed As a "You Have" or "You Don't Have" a Disability

> Medical and technology advances continue to keep more people with disabilities, chronic conditions, and activity limitations alive, healthy and functioning independently. Planning for inclusiveness is the agenda that makes the most sense.
> (National Council on Disability 2000)

The concept that people either have a disability or do not have a disability perpetuates misperceptions about the nature of disability and activity limitations. Do not view disability as a "you have" or "you don't have" a disability. Activity limitations exist along a continuum of severity and duration (partial to total, temporary to permanent) that affect almost everyone at some point in their lives.

> Anyone can convert at any moment to having a disability particularly during emergencies.

Definitions That Leave No One Behind

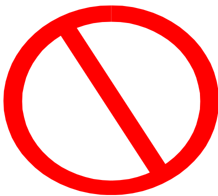
By adopting a broad definition, no one is left behind, and the imperative is clear that everyone address the broad spectrum of disability and activity limitation issues. (Reis 2004) If planning does not embrace the value that everyone should survive, they will not!

Accommodating People With Disabilities Often Translates Into Being Better Equipped to Serve All

The approach to include people with disabilities should not be viewed as one more "special interest" group that drains resources from the common goal. Preparing to accommodate people with disabilities often translates into being better equipped to serve all people. Anyone can convert at any moment to having a disability particularly during

emergencies. Disasters and terrorism instantly contribute to many more people acquiring new disabilities. Following such an event – the numbers of people with disabilities escalate. “All Americans live in the antechamber of disability brought on by these disasters; anyone can join the disability community in a moment, as was so dramatically demonstrated on September 11th (National Organization on Disability 2002).” “Special is us.”

People with Disabilities and Activity Limitations Are Part of Every Segment of the Population



People with disabilities and activity limitations are very diverse and should not be sidelined or compartmentalized into a “special needs” box. "Special" implies differentness and apartness. Among disability advocates "special" is the label often used for segregated programs. (Woodward 1991) Programs and services continue to miss the mark when people with disabilities are seen and served as people with “special needs” instead of people who are a part of every segment of the general population.

Individuals with disabilities live in the country, and the cities, go to school and work at home and in high-rise buildings. Most people with disabilities and activity limitations are integrated into and are actively involved in society.

All discussions and interventions to improve programs and services for people with disabilities should use a broad definition of "disability" that encompasses people:

- Of all ages, from infancy to old age
- With full range of learning, understanding, emotional, hearing, visual and physical abilities.

People with disabilities and people who are aging will soon constitute the majority of the population. Most people, if they live long enough, will age into disability. As time alters our bodies, activity and functional limitations become natural occurrences. There is an 80% chance that all people will experience a temporary or permanent disability at some point in their lives. (Kailes 2002)

Incorporate issues specific to including people with disabilities and activity limitations into the fabric and the culture of emergency services, so that the issues are not viewed as “special” “sidebar” or “in addition to,” but part of the daily radar screen of business as usual.

Nothing About Us Without Us

“Special needs” is a term that comes from outside of the disability communities. A significant element in the struggle for basic human rights is acknowledging and honoring what people call themselves. For example, "Negro" became "Black" and is now "African-American." "Indian" became "Native American," "ladies" and "girls" became "women," and “crippled” became "handicapped" and is now "disabled."

Avoiding negative attitudes and stereotypes means neutralizing disability-specific terms. Disability-specific language should be precise, objective, and neutral to avoid reinforcing negative values, biases and stereotypes. Language goes hand-in-hand with social change, both shaping it and reflecting it. (Kailes 1990)

“Special needs” reflects the old paradigm “a lot about us without us.” It is time to include people with disabilities in emergency services as contributors and collaborators, not just as people viewed as victims to be rescued. It is time to revise methods and embrace the approach “nothing about us without us!”

Selecting Acceptable, Respectful, and Precise Terms

It's time to honor the plea of people with disabilities, retire "special needs." Update the concept in order to infuse meaning. Segment the diverse groups that are currently lumped together in this term. Work with the disability community and other groups currently tossed together in "special needs" to select acceptable, respectful and precise terminology.

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About the Author

June Isaacson Kailes, Associate Director, Center for Disability Issues and the Health Professions Western University of Health Sciences, Pomona, California, is well known for her national and international work in disaster preparedness for people with disabilities. Her publications include *Living and Lasting on Shaky Ground: An Earthquake Preparedness Guide for People with Disabilities*, distributed by California Office of Emergency Safety *and Creating a Disaster: Resistant Infrastructure for People at Risk Including People with Disabilities* used and published in several countries. Inspired by 9/11 and influenced by her past work in disaster preparedness, she authored *Emergency Evacuation Preparedness: Taking Responsibility for Your Safety: A Guide for People with Disabilities and Other Activity Limitations.* Material from this guide has been incorporated into several government and private sector evacuation plans as well as used by emergency management personnel.

About the Sponsoring Organization

Nobody Left Behind: Disaster Preparedness for Persons with Mobility Limitations is a three-year research study funded by a grant to the Research and Training Center on Independent Living at the University of Kansas, from the Centers for Disease Control and Prevention through the Association of Teachers of Preventive Medicine, TS#-0840. The goal of the research is to learn whether local emergency management planning and response systems are addressing the needs of people with mobility impairments. Best practice models are also being explored in hopes of preventing injuries, saving lives, and assuring that …. Nobody is Left Behind. Dr. Glen W. White is the principal investigator and Dr. Michael Fox is the co-investigator. For information www.nobodyleftbehind2.org or contact the project coordinator at 785-864-3791 or 785-864-0706 (TDD), 785-864-5062 (Fax)

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