

# **Moving Beyond “Special Needs”: A Function Based Framework for Emergency Management and Planning**

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## **Abstract:**

Disaster preparation and emergency response processes, procedures and systems can be made more effective for people with disabilities, as well as for the population as a whole. An essential element of building appropriate levels of capacity is to move beyond use of the "special needs" category, which makes up more than 50% of the population. This paper suggests development of a more accurate and flexible framework based on essential functional needs: maintaining functional independence, communication, supervision, medical, and transportation. It also suggests new approaches to leadership, service delivery and training.

**Key words:** communication access, disaster and emergency services, independent living, maintaining functional independence, medical needs, people with functional limitations, people with disabilities, special needs, team building, and transportation.

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## 1. Introduction

The “special needs” population is often viewed as a homogeneous group. This practice, although understandable, is dangerous given this group’s significant size. Lumping groups together and using an ambiguous special needs label translates into vague planning, which results in response failures. The 2005 U.S. Gulf states’ experiences reinforce and underscore the necessity of disaggregating this diverse group and devising a more effective and sophisticated framework in order to meet health, safety and survival needs.

A function based framework allows emergency managers to define, locate, reach and plan comprehensively for managing resources and individuals’ specific functional needs of people. It helps avoid planning that relies on diagnostic labels and definitions of disability used primarily for programmatic eligibility – categories which are often not helpful in preparing for, responding to and recovering from an emergency.

## 2. Demographics

### 2.1 Who Are People with Special Needs?

The term “special needs” is widely used within disaster services and the emergency management field. It generally includes an extremely broad group of people, including people with disabilities, people with serious mental illness, minority groups, non-English speakers, children, and the elderly (Centers for Disease Control and Prevention, 2004). Other lists also add single working parents, people without vehicles, people with special dietary needs (FEMA 2004), pregnant women, prisoners, people who are homeless, etc. While there appears to be little consensus on exactly who should be included in the special needs category, our data show that these groups represent a large and complex variety of concerns and challenges for disaster planning and response. 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; National Council on Disability, 2005).

The first author frequently claims that the special needs category may include almost half the population; therefore we did a demographic analysis to determine the actual size of this category. For consistency, decennial Census 2000 data were used. The total of the most typical groups of special

needs populations - people with disabilities, including people with serious mental illness; people who do not speak English or do not speak English well; children, age 15 and under, and people 65 years old and over - was almost 141 million people, 49.99% of the population. Table 1 shows the categories used, with age ranges for each. Everyone age 15 and under, and age 65 and older, was included. Since people with disabilities were included in the 15 and under, and 65 and older age categories, only the population 16-64 was included in the disability category. This was necessary to avoid over counting when an individual, such as a 70 year old person with a disability, was in more than one category. Census data were not available for 16 and 17 year olds who do not speak English or do not speak English well, so we were only able to include people age 18-64 in this category. Those age 65 and over would already be included in the elderly age category.

Table 1 . Emergency Management “Special Needs” Groups: Percentage of the US Population

<b>Population category</b>	<b>Total</b>	<b>% of U.S. total population (281,421,906)</b>
Children, age 15 and under	64,272,779	22.84
Elderly, age 65 and over	34,991,753	12.43
Speak English “not well”, age 18-64	5,703,904	2.03
Speak English “not at all”, age 18-64	2,575,154	0.92
Noninstitutionalized population with a disability, age 16-64	33,153,211	11.78
<b>Total special needs population</b>	<b>140,696,801</b>	<b>49.99</b>
Data Source. U.S. Census Bureau, Census 2000 Summary File 1: table P2, total population; table PCT12, total population sex by age. Summary File 3: table P19, age by language spoken at home by ability to speak english for the population 5 years; over and table P42, sex by age by disability status for the civilian noninstitutionalized population age 5 years and over.		

In addition to the typical special needs group, including the entire institutionalized population, about 4 million people (Census 2000, Summary File 1, Table PCT16) brings the percentage of the population in the special needs category to 51.44%. People live in institutionalized group quarters because there is a perceived ongoing need for medical care and/or supervision. The residents of nursing homes, “hospitals/wards, hospices, and schools for the handicapped”, correctional institutions, state prisons, halfway houses, etc. have medical or supervision needs that will continue in an emergency. We

did not include the almost quarter million individuals who live in group homes, because in the 2000 Census, they were counted in noninstitutionalized group quarters, and already included in the Census tables for people with disabilities.

Minority groups are included in some lists of special needs populations. The United States continues to grow in racial, ethnic and diversity. California, Hawaii, New Mexico, and Texas are ‘majority-minority’ states, in which a majority of the population differs from the national majority population. Arizona, Georgia, Maryland, Mississippi, and New York have minority populations of 40 percent. (U. S. Census Bureau 2005). The 2000 Census reports over 70 million minority individuals if the white alone population is subtracted from the total population. Since minorities were included in the age categories 15 years and under, and 65 and older, only the population age 16-64 should be counted here. Further adjusting for minority group individuals who do not speak English and are counted in the language category, leaves 35 to 40 million minority group individuals in the 16-64 year old category.

Other groups with function based needs that may not be captured in this analysis include people who are morbidly obese, pregnant women, people on kidney dialysis, and people living in zero vehicle households:

- *Obesity*. People with morbid obesity can present a range of challenges in emergency management, from adequate rescue transportation modes to beds and chairs that will support them. The American Obesity Association reports approximately 9 million adult Americans as morbidly obese, defined as having a Body Mass Index (BMI) of 40 or more. (American Obesity Association, n.d.) The prevalence of morbid obesity in 2003-2004 was 2.8% in men and 6.9% in women. (Ogden, et al. 2006).

- *Pregnancy*. The American Pregnancy Association (n.d.) reports there are approximately 6 million pregnancies every year in the United States. Pregnant women may have no needs beyond the need to avoid exposure to toxins, or may be about to give birth and need medical assistance.

- *Kidney Dialysis*. The United States Renal Data System at the National Institutes of Health (2003) reports that in 2001, there were 287,494 U.S. residents receiving kidney dialysis.

- *Zero vehicle households*. The 2000 Census (Summary File 3, Table H44) reports that 10.8 million U.S. households, out of about 110 million total occupied households, did not have a vehicle. About 1.1

million of these households are in rural areas; the remainder are urban. (Note: these are household numbers, and cannot be directly added to the data on individuals). While lack of a vehicle is generally considered a poverty issue related to lack of personal resources, Table A shows that some cities, such as New York and Washington D.C., have high rates of zero vehicle households which may not be solely related to poverty. These cities typically have good public transit systems. In Manhattan, 77% of the households did not have a vehicle in 2000, while 56% households in the five New York City boroughs combined had no vehicles. In each location, renter occupied households have higher rates of being carless than owner occupied households. Even in Los Angeles, an area known for its reliance on personal vehicles, 20% of renter occupied households do not have a vehicle. Loss of all or part of the transportation system can in and of itself be an emergency situation, but is compounded by natural disasters, technological acts or acts of terrorism such as 9-11.

Table A. Zero Vehicle Households\*

City/County	Occupied housing units: Total	Percent of carless households	Owner occupied housing units: No vehicle available	Renter occupied housing units: No vehicle available
Manhattan (New York county)	738,644	77%	60%	82%
District of Columbia	248,338	37%	17%	50%
New Orleans (city)	188,251	27%	12%	41%
Los Angeles (county)	3,133,774	13%	5%	20%
Data source: U.S. Census Bureau, Census 2000 Summary File 3, table H44				

\* Table A is not part of the original paper.

Given this demographic data, it is clear that special needs can cover much more than 50% of the nation's population, rendering the term meaningless. Some methods of calculating the totals approach 70% of the population, even when figuring in the overlap among categories. Continuing to use special needs does a disservice to every group included and greatly weakens the chances of planning for specific needs and providing an effective, comprehensive response.

Unfortunately, there is no single term that can be substituted for special needs. Over the years, disability, cultural, and linguistic advocates have repeatedly pleaded to replace special needs with more precise, segmented, and discrete groupings, but have been largely ignored.

This is not simply a linguistic issue. Naming this functionally diverse group using a single term is equivalent to trying to describe over half of the United States population. The large number of heterogeneous groups it represents is too large and too diverse for the use of any single designation.

## **2.1 Who Are People with Disabilities?**

Disability is not a condition that affects the “special” or “unfortunate few.” Individuals with disabilities make up a sizable portion of the general population within the United States. According to the U.S. Census (Waldrop and Stern, 2003) they represent 19.3 percent of the 257.2 million people aged 5 and older in the civilian, noninstitutionalized population, or nearly one person in five. Disability is a common characteristic and occurrence within the human experience. People with disabilities have the same range of personality traits, interests, and desires as everyone else. People with functional limitations are a part of the world’s diversity (Kailes, 2002).

While people with disabilities will compose a major segment of any special needs population, as a group they are very heterogeneous. It is important to understand the range of function based needs within the population with a disability. This approach leads to a common framework which is function based and designed to improve resource management in any type of incident.

Census 2000 asked disability questions related to sensory, physical, and mental functioning; the capacity for self care; and difficulty going outside the home alone. Figure 1 and Table 2 show the numbers of people who reported within each of these categories, separated into age categories that correspond to Table 1: age 5 -15 years, age 16-64, and age 65 and over. The question about going outside the home alone was not asked for individuals below age 16. There is overlap among these

categories, because one individual may have reported more than one characteristic. While there were about 49 million people with a disability, about 89 million separate conditions are reported.

Figure 1. Civilian, Noninstitutionalized Population by Age and Disability Type

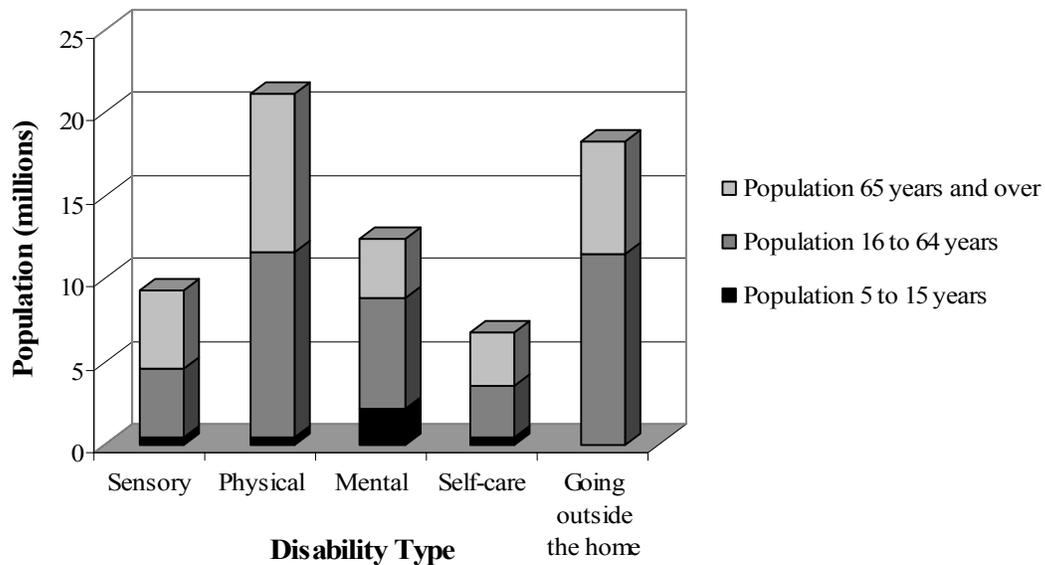


Table 2. Civilian, Noninstitutionalized Population by Age and Disability Type

Population age	Sensory	Physical	Mental	Self-care	Going outside the home	Total
5 to 15 years	442,894	455,461	2,078,502	419,018	*	3,395,875
16 to 64 years	4,123,902	11,150,365	6,764,439	3,149,875	11,414,508	57,890,659
65 years and over	4,738,479	9,545,680	3,592,912	3,183,840	6,795,517	27,856,428
Total	9,305,275	21,151,506	12,435,853	6,752,733	18,210,025	89,142,962

Data source: U.S. Census Bureau, Census 2000 Summary File 3, table P41. All numbers are based on the civilian noninstitutionalized population. \* The U.S. Census does not collect going outside the home disability data for people age 5 to 15 years.

## 2.2 Defining Functional Limitations Broadly

There are more than 50 definitions of disability in federal laws and regulations. Most of them are used to determine eligibility for programs such as Social Security Disability Insurance. Other definitions, such as the one in the Americans with Disabilities Act, are used to establish civil rights and protections. Narrow eligibility criteria are meaningless in the face of preparing for, responding to and recovering from a disaster. These criteria may help determine access to, and distribution of, resources in the more long term recovery stages. However, the closer to the time of the incident, the more need there is to focus on function based needs.

In disaster management activities, it is important to think broadly about disability. 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 limitations are quite visible, while others such as heart disease, emotional or psychiatric conditions, arthritis, significant allergies, asthma, multiple chemical sensitivities, respiratory conditions, and some visual, hearing and cognitive disabilities may be less readily apparent.

Not all people who experience functional limitations consider themselves to have a disability. Some disabilities are little more than diagnostic categories, and say little about how the person actually functions. Generalizations based on particular types of disabilities have numerous exceptions. Two individuals with the same type of functional limitation may have very different abilities and needs. Like everyone, people with disabilities and functional limitations have different histories, resources and attitudes. (Kaplan 1992)

All discussions and interventions to improve emergency management services for people with disabilities should use a broad definition of "disability" that encompasses people of all ages, from infancy to old age, within the full range of learning, understanding, and emotional, hearing, visual and physical abilities.

People with disabilities and functional limitations include those who have:

- Conditions which interfere with walking or using stairs, e.g. joint pain, paralysis, use of a mobility device such as a wheelchair, canes, crutches, walker
- Reduced stamina, or easily fatigued, due to a variety of temporary or permanent conditions
- Respiratory conditions due to heart disease, asthma, emphysema, 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, etc.

The concept that people either have a disability or do not have a disability perpetuates misperceptions about the nature of disability and functional limitations. 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.

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). As the population ages, people with disabilities and functional limitations rise in proportion to demographic changes. Medical and technological advances continue to keep more people with disabilities, chronic conditions, and functional limitations alive, healthy and functioning independently. Planning for inclusiveness in emergency services is simply more efficient (National Council on Disability 2000). Inclusive planning enables incident managers to have a common framework available for people with similar function based needs. What they call themselves, how they have been labeled or diagnosed, or which programs they are eligible for is irrelevant.

If planning does not embrace the value that everyone should have the chance to survive, few will (National Council on Disability, 2005). By adopting a broad function based approach, no one is left behind. Everyone involved, from planners to first responders, needs to address the broad spectrum of disability and functional limitation issues. (Reis 2004)

### *2.3.1 People with Functional 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 difference and isolation. Among disability advocates special is the label often used for segregated programs (Woodward, 1991). Programs and services continue to miss the mark when people are seen and served as people having special needs instead of people who are a part of every segment of the general population.

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

If they live long enough, most people will age into disability. As time alters our bodies, activity and functional limitations are 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). More than 40 percent of noninstitutionalized people age 65 and over have a disability.

However, it is important to recognize the largest number of individuals with disabilities – 33 million people – are in the 16-64 working age population. Although the employment rate of people with disabilities is lower than that of people without disabilities, people with disabilities are both employees and employers. Emergency planning needs to include planning for people with disabilities in the workplace as well as in residential settings. Figure 2 and Table 3 show the prevalence disability by age.

Figure 2. Prevalence of Disability by Age

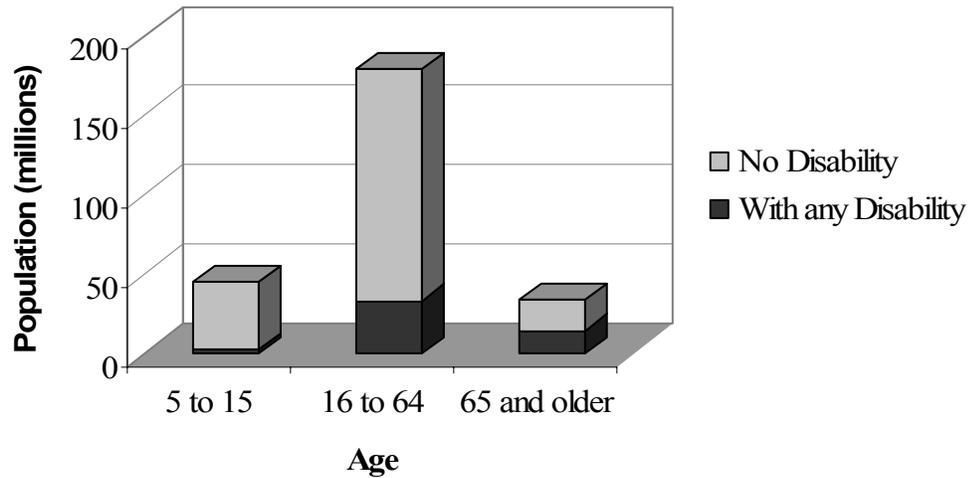


Table 3. Prevalence of Disability by Age

Population age	Total	% of age category
5 years and over	257,167,527	100.0
With any disability	49,746,248	19.3
5 to 15 years	45,133,667	100.0
With any disability	2,614,919	5.8
16 to 64 years	178,687,234	100.0
With any disability	33,153,211	18.6
65 years and over	33,346,626	100.0
With any disability	13,978,118	41.9
Data source. U.S. Census Bureau, Census 2000 Summary File 3: table P42, civilian noninstitutionalized population 5 years and over.		

### **3. Better Equipped to Serve All: Using a Function Based Approach**

People with disabilities should not be viewed as one more special interest group that drains resources from the common pool. Accommodating this large group often translates into being better equipped to serve all people. Anyone, at any moment, can incur a disability, particularly during emergencies. “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 11<sup>th</sup> .” (National Organization on Disability 2002). Disasters and terrorism instantly create many more people with new disabilities and functional limitations. Following such an event, the numbers of people with disabilities, and functional limitation and loss escalate. In addition, emergencies can intensify an individual’s vulnerabilities. For example, loss of mobility equipment may render independent wheelchair users totally mobility dependent. Some older people will experience transfer trauma and significant confusion that affects their ability to function independently.

Effective planning and incident response which includes people with a wide range of function based needs should be woven into the fabric and the culture of emergency management and disaster planning. As long as disability and other special needs groups are viewed as unique or special, the system’s existing inefficiencies will continue. The following common framework incorporates function based issues as routine elements in effective emergency planning and response.

#### **3.1. A Function Based Framework for Emergency Management and Planning**

This article proposes a flexible framework, built on five essential function based needs: medical, communication, supervision, maintaining functional independence, and transportation. The intent is reduce negative consequences and improve readiness in all planning, preparedness, response, recovery, and mitigation activities. Addressing functional limitations includes both people who identify as having a disability, and the larger range of people who do not identify as having a disability, but do have limitation in hearing, seeing, walking, learning, language, and understanding.

This framework may need future refinement, but for now consider these five areas of essential

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functional needs:

3.1.1. *Medical needs*: includes individuals who are not self-sufficient, or do not have or have lost adequate support from family or friends and need assistance with:

- activities of daily living such as bathing, feeding, going to the toilet, dressing, and grooming;
- managing unstable, chronic, terminal or contagious health conditions that require observation, and ongoing treatment;
- managing medications, intravenous (IV) therapy, tube feeding and/or regular vital signs readings;
- dialysis, oxygen, and suction administration;
- managing wounds, catheters or ostomies; and
- operating power-dependent equipment to sustain life.

People with visible disabilities tend to be automatically, but often mistakenly, placed in this category. A more specific function oriented determination of medical needs, discussed below, needs to be incorporated into training on disaster management of medical needs

3.1.2. *Communication needs*: Most people who have limitations that interfere with the receipt of, and effective response to information are self-sufficient, but need information provided in methods that they can understand and use. This is a very large and diverse population of those who will not hear, see or understand, in addition to those who cannot hear, see or understand. They may not be able to: hear verbal announcements, see directional signage to assistance services, or understand how to get food, water and other assistance because of a hearing, understanding, cognitive or intellectual limitations. They include people who:

- are ethnically diverse,
- have limited or no ability to speak, read or understand English,
- have reduced or no ability to speak, see, and hear, and
- have limitations in learning and understanding.

Effectively meeting communication needs can include, for example:

- posting content of oral announcements in a specified public area so that people who are deaf, hard of hearing or out of hearing range can go there to get or read the announcements.

- designating a specific time of the day and place where foreign language and sign language interpreters will be available to communicate information.
- employing trusted community based organizations who can effectively communicate with the communities they serve.

3.1.3. *Supervision needs*: Support for individuals who do not have or have lost adequate support from family or friends must be determined on a case-by-case basis. For example, after an emergency some people with mental illness may be able to function well with healthy responses and coping skills while others with serious and persistent mental illness may need a protected and supervised setting (U.S. Department of Health And Human Services 1996).

People with supervision needs can include:

- people who decompensate because of transfer trauma, trauma stressors that exceed their ability to cope, or lack of ability to function in a foreign environment;
- people with conditions such as dementia, Alzheimer’s and psychiatric conditions such as depression, schizophrenia, and intense anxiety;
- people who function adequately in a familiar environment, but become disoriented and lack the ability to function in an unfamiliar environment;
- prisoners; and
- unaccompanied children.

3.1.4. *Maintaining functional independence needs*: At risk individuals who are identified early, screened and whose functional independence needs are addressed within the first 48 hours can avoid costly deterioration of their health and functional mobility. Early disaster response intervention services offered through competent organizations that are familiar with functional limitation allow people to maintain their health and independence, and manage in mass shelters. Effectively meeting these needs prevents secondary conditions and institutionalization, and reduces the use of scarce, expensive and intensive emergency medical services.

Maintaining functional independence can include:

- medical stabilization – replacing essential medications (blood pressure, seizure, diabetes,

psychotropic, etc), and

- functional mobility restoration – replacing lost or damaged durable medical equipment (wheelchairs, walkers, scooters, canes, crutches, etc) and essential consumable supplies (catheters, ostomy supplies, padding, dressings, sterile gloves, etc.), and assistance with orientation for those with visual limitation.

3.1.5. *Transportation needs*: Emergency response requires mobility. Many people cannot drive due to disabilities, age, addictions, legal restrictions, etc. (Littman 2005). As noted in the demographic analysis, 10.8 million U.S. households do not have a vehicle. This includes people who are old, poor, and people who need wheelchair accessible transportation. Many non-drivers and people from zero vehicle households can function independently once evacuated to safety.

Transportation is a well established component of emergency response plans, and merits detailed focus beyond the limited scope of this paper. However, the lack of details regarding transportation dependent people may be caused because “decisionmakers are unfamiliar with and insensitive to their needs” (Littman 2005, p.12). Emergency action plans need to routinely specify exactly who will do what and when to address the logistical and function based needs of people with a wide range and different combinations of physical, economic, and social challenges.

#### **4. Improving Readiness Involves Leadership, Service Delivery, Expertise, and Training**

Although government plays a major role in disaster planning and response, traditional government emergency agencies are not equipped to respond to the essential services needed by people with a variety of functional needs. The 2005 Gulf state events confirm what has been recognized for decades - traditional response and recovery systems are often not successful at meeting many human needs (National Council on Disability 2005, National Organization on Disability 2001).

Typically, disaster preparedness and emergency response systems are designed for people for whom escape or rescue involves walking, running, driving, seeing, hearing and quickly responding to

directions. Emergency management systems need help with the very specific and sometimes complex needs of people with functional needs. Well-intentioned emergency medical and public service personnel cannot adequately address complex functional independence, physical, communication, supervision, and transportation needs because they lack knowledge of available services, the values and goals of independent living and self-determination, human and civil rights laws and protections, and cultural and linguistic issues.

Functional Needs Service Coordinators (FNSCs) could serve as “point people,” vested with the responsibility, authority, and means for providing leadership, guidance, and coordination and resource management of emergency preparedness, disaster relief and recovery operations for people with functional needs. These positions should be within the emergency service agency at the senior executive level of government (federal, state and local). The FNSC’s qualifications should at a minimum include in-depth understanding and proven community based experience:

- in the implementation of values and goals of independent living and self-determination;
- human and civil rights policies, procedures, and implementation practice; and
- in providing for people’s complex function based needs.

These FNSCs would lead and coordinate activities that:

- ensure that programs and services are accessible to, accommodate and are inclusive of people with essential functional limitations;
- employ the often overlooked abilities of some people with functional needs and activity limitations to provide specific types of human services as interpreters, ham radio operators, shelter managers;
- document, disseminate, promote and support the use of good practices;
- use community based organizations (CBOs), and develop partnerships with experts who are closely connected to and trusted by the communities they serve;
- recruit, encourage and provide sustained funding incentives that allow CBOs to integrate disaster work into their mission;
- fund, orient, mobilize and deploy teams of CBOs to coordinate disaster planning, preparedness, response, recovery and mitigation services and integrate them with existing emergency systems,

in a way that is immediate, flexible, and collaborative;

- establish mutual aid agreements that integrate the strengths and skills of CBOs into the emergency service plans and strategies of local government;
- integrate function based issues, into all emergency management courses, so the subject is not considered special;
- integrate and evaluate function based scenarios, goals and objectives in all drills, exercises and after action evaluations.

Functional Needs Service Coordinators would be required to have the skills and the resources to build teams of qualified subject matter experts who are knowledgeable in emergency management, and who would also:

- be present in shelters, temporary housing and other assistance centers;
- add intake screening questions that identify, triage, and track needs so people can maintain their functional independence by receiving appropriate “just in time” assistance, referrals, and long-term solutions.
- work side by side and quickly orient shelter personnel and emergency managers, to the essential functional needs of populations and to the resources available (National Organization on Disability 2005)
- train shelter emergency personnel to distinguish between people who only need assistance in maintaining their health, medical stability and mobility, and those whose medical and supervision needs cannot be met in a mass shelter because they are not self-sufficient or do not have adequate support from family or friends.
- train shelter emergency personnel to make “quick access fixes” such as installing temporary ramps and designating a specific time of the day and place where interpreters will be available to communicate information.

## **5. Conclusion**

It is critically important to move beyond using the category special needs, to using a more effective, accurate and flexible framework. A common framework built on essential functional needs is the crucial element needed to:

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- build appropriate levels of capacity for disaster preparation, emergency response processes, procedures and systems;
- adopt appropriate guidelines and protocols for resource management;
- strengthen service delivery and training;
- improve response successes;
- prevent secondary conditions and reduce institutionalization and the use of scare, expensive and intensive emergency medical services and the use of “downstream” services;
- allow disaster services to integrate the value that everyone should have the chance to survive; and
- translating lessons documented into lessons applied.

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