

Be Real, Specific and Current: Emergency Preparedness Information for People with Disabilities and Others with Access and Functional Needs

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General emergency preparedness information is important for everyone. Emergency preparedness information for the general population is not always equally applicable for people with disabilities. These materials can be more inclusive when they contain information that focuses on specific functional needs. This document offers a checklist, examples, and resources to help make emergency preparedness information more inclusive.

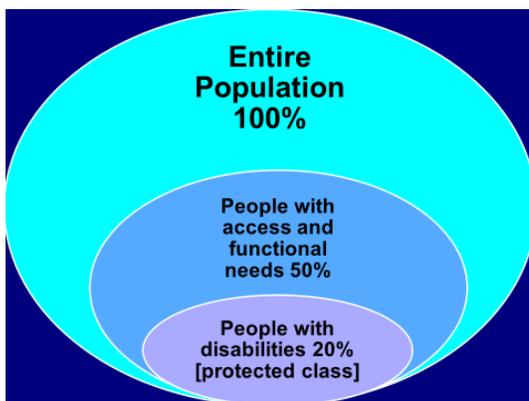
**Checklist for producing useful, relevant, real, specific and current:
emergency preparedness info for people with disabilities
and others with access and functional needs**

Emergency preparedness materials should:	Yes	No	Follow up
1. Be developed in partnership (of, with and by) people who live with disabilities and others with access and functional needs.			
2. Include content that is useful and specific to people with limitations in hearing, vision, mobility, speech, and cognition (thinking, understanding, learning, remembering).			
3. Describe disability in accurate and respectful ways. Use neutral terms that avoid offensive words which reflect negative attitudes and stereotypes.			
4. Focus on no cost and low cost preparedness in addition to costly activities. Recognize that not all people can afford to buy emergency supplies and equipment.			
5. Be available in accessible and usable formats and give users information on how to get these materials in other formats such as large print, audio, disks, or Braille.			
6. Use resources that are clearly described and annotated with specific links to more resources.			

Who are people with disabilities and others with access and functional needs?

People with disabilities and others with access and functional needs represent a large diverse group. In addition to people with disabilities being a protected class under the Americans with Disabilities Act. People who need tailored information include a diverse and large slice of the population includes people who experience limitations in behavior, walking, balancing, climbing, seeing, reading, hearing, speaking, understanding, and remembering as well as those who experience chemical sensitivities. What is important is to address needs based on these functions not diagnoses, chronic conditions or medical labels. Many of these functional needs are under recognized and undercounted in various population counts and data. There are many more people who experience disabilities and functional needs than the commonly referred to “one in five individuals.” This segment of people is estimated to be up to 50% of the population. In emergencies functional needs can increase significantly when people do not have access to their devices, equipment, supplies, aids and access changes in their everyday environments. This lack of access can contribute to decreased independence.

This article refers to this large part of the population interchangeably as either people with disabilities or people with functional needs.



People with disabilities need quality emergency preparedness information. Advice that is real, specific and useful. These materials must also recognize and address the diversity of disability by customizing relevant preparedness information as “One size does not fit all.”

1. Materials developed in partnership (of, with and by) people who live with disabilities and others with access and functional needs.

Incorporating user perspectives, the “lived disability experience,” strengthens preparedness information. Attending to details is a needed survival skill when living with functional needs. This detail can be missing when materials are produced “for and about” instead “of, with and by,” people with disabilities and others with access and functional needs. This is why it is important to include people who can not only represent their own experiences, but can also understand and think through and communicate issues using disability, access, functional needs and universal design filters. Often these are individuals who are active in national, state or local disability-related organizations. When users are not involved in the development of material, the information can be vague, incomplete, offensive, impractical and naïve.

2. Include content that is useful and specific to people with limitations in hearing, vision, mobility, speech, and cognition (thinking, understanding, learning, remembering).

Example:

“Whistle to signal for help.”[5]

Weakness:

Some people have disabilities that make whistling impossible.

Stronger:

Attend to the diversity of disability by suggesting the use of many kinds of noise makers such as keys, etc.

Resources: F, H



Example:

“...if you can-not “stop, drop, & roll” during a fire, you should “pull, aim, squeeze, and sweep.” [2]

Weakness:

This is a humorous, extreme, and unrealistic suggestion.

Stronger:

- Learn how and if you are able to use a fire extinguisher. If you cannot operate one, it is important to know how to use one so you can instruct others in an emergency.
- Test your abilities to do specific emergency actions to determine what you can do independently and what you will need help with (using a fire extinguisher, activating a

fire alarm, shutting off gas and water, evacuating buildings where you spend your time (home, school, job, church, etc.)

Resources: F, H

Example:

During an earthquake drop, cover and hold

Weakness:

People with mobility limitations may not be able to drop, cover, and hold on (take cover under tables and desks), common advice regarding how to respond immediately to an earthquake. [1]

Stronger:

Include that if you are unable to drop and cover and hold, cover your head and neck with your arms or a pillow until the shaking stops.”

Resources: B

Example:

Contact Your Local Emergency Information Management Office: Some local emergency management offices maintain registries of people with disabilities so you can be located and assisted quickly in a disaster.

Weakness:

- Asking people to contact a vaguely named department sets them up for a time consuming and frustrating experience. This assumes people who can answer the question.
- Registries often set up false expectations and security that the promised response with actually happen.

Stronger:

- Some local emergency management offices maintain registries for people with disabilities.
- Some registries are only used to collect planning information; others may be used to offer assistance in emergencies. If you add your name and information to a registry, be sure you understand what you can expect.
- Be aware that a registry is NEVER a substitute for personal preparedness. Even if the registry is linked to first responders, assistance may not be available for hours or days in a disaster.
- Emphasize importance of establishing a support team and the importance of not relying only on government for assistance.
- Most people believe that they will be helped by firefighters, police officers and paramedics in a large emergency. The truth is 70 percent of the time, in big emergencies, your PA, friends, coworkers, neighbors and other people do the “first responding.” It is important to make sure these folks are aware of your specific needs in the case of an emergency. These people are known as your support team.
- A support team typically is made up of people willing to help each other in an emergency. They include your PAs and others at places where you spend time, like your home, workplace, or school. If you create a large team, you are more likely to get help when you need it.

Resources: C, E, F, G, I, K

Example:

“Arrange for more than one person from your personal support network to check on you in an emergency, so there is at least one back-up if the primary person you rely on cannot.” [4]

Weakness:

This plan may not be good enough. Do not depend on any one or even two people. Buddy systems (choosing and training one or two people to assist you in an emergency) have weaknesses. These buddies may not be available or able to respond quickly in an emergency. [6]

Stronger:

Create support teams where everyone is included and trained. That way everyone can help! When you include many people, you create bigger teams.

Resource: C, E, F, I

Example:

“Plan in advance for shelter alternatives that will work for both you and your animals;”[5]

Weakness:

What does this mean? What exactly should be done? What is realistic?

Stronger:

Plan where to go if you are told to evacuate. (e.g., shelter, a friend’s house). Confirm places to stay at varying distances and directions from your home. The closest places may not be usable because of the emergency (e.g., 10 miles away, neighboring city or state). [6]

Resources: A, C, F

Example:

Consider getting a medical alert system that will allow you to call for help if you are immobilized in an emergency. Most alert systems require a working phone line, so have a back-up plan, such as a cell phone or pager, if the regular landlines are disrupted.

Weakness:

In a large scale emergency these personal emergency response systems will not work. Land line phones, cell phones and pagers may also not work.

Stronger:

- Suggest alternatives in addition to phones. For example, have members of your support team agree to check in on you.
- Include in your plan how to communicate with your personal assistants (PAs) and support team at home, at work, etc., via: landline phone, cell phone, email, social media, text message or other devices (two-way radio, ham radio, personal emergency call response system, etc.

Resources: C, E, K

Example:

“Include copies of important documents in your emergency supply kits such as family records, medical records, wills, deeds, social security number, charge and bank accounts information, and tax records. It is best to keep these documents in a waterproof container.”[5]

Weakness:

This tip needs to be specific regarding what is really needed and why and what is realistic to carry.

Stronger:

Important documents include:

- Identification: copies of driver's license/passport (for family members, as well)
- Personal and property insurance
- Passwords
- Banking and credit card information (consider signing up for Direct Deposit and electronic banking)
- Pet's veterinary medical records and pictures for emergency identification if you are separated.

Options for storing your important documents such as personal and financial records include:

- Create a password-protected area in “the Cloud” allowing you access from any internet connected mobile device anytime and anywhere.
- Store information on a secure password protected flash drive. A flash drive can be kept on a key ring.
- Store information in a folder in your email program and on your computer.

Resources: K

Example:

“Since September 11th, many people with disabilities have expressed reluctance to depend on areas of refuge, wanting to evacuate with everyone else. This may not always be possible, so learn the location of your building’s designated refuge areas.” [7]

Weakness:

People want better advice. They do not want their concerns dismissed.

Stronger:

- Do not assume you have been included in emergency plans. If you rely on an employer or the building manager to make sure things are in place, it may or may not happen.
- Check out the emergency plans where you spend your time. Are the needs of people who cannot use steps, run, hear, see, and understand, included in the plan?
- Seek out the people responsible for the emergency plans and discuss if, where and how the plan may need to be strengthened to include you and others with functional needs.
-
- To plan for a safe evacuation, be part of the discussion that creates the procedures and selects equipment that work best for you and your abilities.

Resources: C**Example:**

If you are electric-dependent, be sure to register with your local utility company.” “Let your personal care attendant know you have registered, and with whom.

Weakness:

This tip incorrectly assumes that all communities have plans and registries that actually work.

Stronger:

If you rely on electricity and battery dependent assistive technology and medical devices create a plan for alternative sources of power.

Resources: I**Example:**

If you do not own a vehicle or drive, find out in advance what your community’s plans for evacuating those without private transportation.

Weakness:

This tip assumes there is a community plan.

Stronger:

- Be sure to ask if your support team can provide you with transportation. Ensure that they have room for you in their vehicle in addition to themselves and their family. Check that their vehicles are accessible to you and your equipment.
- Contact local transportation providers to ask if they are able to help you in an emergency. Do they keep a list of those who will need help with transportation? Make sure that this is not your only plan! A back up plan is critical.

Resources: A**Example:**

Show friends how to operate your wheelchair so they can move you if necessary. Make sure your friends know the size of your wheelchair in case it has to be transported.

Weakness:

There are a variety of manual and power wheelchairs. Some cannot be easily moved.

Stronger:

Plan for how your devices can be moved. Have your support teams think through and plan for different situations:

- Know what the evacuation procedures are
- If you spend time above or below the ground floor of multi-story buildings.
 - Are evacuation devices available?
 - If yes, where are they located?
 - If no, could they be purchased? If no, what is the plan?
- Can you transfer in and out of evacuation devices independently, or with assistance?
 - Are floor wardens (designated emergency leaders) and others trained with you on how to use these evacuation devices?
- Can you give quick instructions regarding how safely to transport you if you need to be carried, carried with or without your wheelchair?
 - Include in these instructions areas of caution and vulnerability regarding how to safely transfer you from your wheelchair.
- If you want to be lifted in while staying in your wheelchair make sure this is realistic (How much does your chair weigh with you in it).

- Determine if the places where you spend time have “evacuation elevators.” If yes, know where they are located and if no, plan for other ways to evacuate. [6]

Resources: C

Example:

Base your plan on your lowest anticipated level of functioning.

Weakness:

It is unclear what this means.

Stronger:

Base your plan on your worst, most limited days. That is, those days that you have the most difficulty with activities that involve mobility, seeing, hearing, understanding, and getting around.

Example:

“Unless you have other severe disabilities, you should have little difficulty as a person with a mobility disability staying in a public shelter for a short time. People with more serious needs might have to use the nearest “special needs” shelter, where medical issues can receive appropriate attention.”[7]

Weakness:

Advice regarding using a special needs shelter creates false expectations. Special needs shelters are not available in most areas. They are not needed by most people with disabilities and others with access and functional needs who can be accommodated in a general population shelter. [9]

Stronger:

Most people with disabilities and others with access and functional needs do not have acute medical needs and can be accommodated in general population shelters

Example:

The term “mobility disabilities” refers primarily to persons who have little or no use of their legs or arms. They generally use wheelchairs, scooters, walkers, canes, and other devices as aids to movement.[7]

Weakness:

This definition is not accurate and too limiting. Many people with mobility disabilities can walk and use their arms with and without devices.

Stronger:

People with mobility disabilities include people who have walking and / or moving limitations. They may or may not use wheelchairs, scooters, walkers, canes, and other devices as aids to movement.

3. Describe disability in accurate and respectful ways. Use neutral terms to avoid offensive words which reflect negative attitudes and stereotypes:

Example:

If you are confined to a wheelchair

Weakness:

Use of outdated, condescending and offensive, language. ‘Confined to a wheelchair’ perpetuates negative attitudes and false stereotypes.

Preferred:

“If you are a wheelchair user”

Update language: replace confined to a wheelchair with wheelchair user

People are not bound to wheelchairs. "Wheelchair bound" or "confined to a wheelchair" conveys a stereotype that sets people with disabilities apart from others and portrays people who use wheelchairs as devalued, impotent, slow and passive. People use wheelchairs to increase their mobility, similar to the way people use cars. Many people who use wheelchairs can walk but choose to use a wheelchair or a scooter because of limited endurance, decreased balance, or slow walking speed. Often, ability, productivity, independence, ease and speed of movement are increased by wheelchair use. For many, a wheelchair means increased mobility and freedom, it does not mean imprisonment! People who use wheelchairs can transfer to cars and chairs. Thus, they are neither confined nor bound to their wheelchairs. [3]

Example:

"Persons who have *suffered a stroke*"[8]

Weakness:

Negative disability language

Stronger:

People who have had strokes.

Resources: J**Example:**

"If you require handicap accessible transportation be sure your..."[5]

Weakness:

Use of outdated language.

Stronger:

If you require wheelchair accessible transportation ...

Resources: J

4. Focus on no cost and low cost preparedness in addition to costly activities. Recognize that that not all people can afford to buy emergency supplies and equipment.

Example:

Preparedness information which focuses only on the costly collecting new supplies for kits

Weakness:

This focus leaves out people who cannot afford to buy supplies and equipment because they have little or no extra funds. Many materials lack information on collecting emergency supplies for people with little or no income. [9]

Stronger:

These tips take some time to do, but they do not include any cost. These no cost preparedness activities include: identifying your support teams and evacuation plans, collecting emergency health information and emergency documents.

Resources: C, F

5. Be available in accessible and usable formats and give users information on how to get these materials in other formats such as large print, audio, disks, or Braille.

Example:

Small font, dense paragraph style

Weakness:

- Lacks
- mention of availability of alternative formats.
- Dense information using paragraph format and 8 point font is difficult for many to see, use and understand.[9]

Stronger:

- Use at least 14 -18-point font, or make content easily available in large print upon request
- Give users information on how to get materials in needed formats: "This material is available on request in accessible and usable formats (large print, disks, audio, Braille).

Weakness:

Words and terms commonly used by emergency professionals are often not understood by the public. Avoid words, unless clearly defined, such as resilient, mitigation, assets, support annex personal hygiene, modes of transportation, and cognitive or intellectual disability.

Stronger:

- Use plain and simple language and easy to recognize pictures, improves understanding. Be more inclusive of diverse cultural groups and users who may not read or speak English well or at all.
- Many people who do read, read well, see, and / or understand print. To reach more people use of easy-to-understand pictures, with or without the addition of text.
- Supply checklist in pictures and choice of 5 languages
<http://www.sf72.org/supplies#tab-personal>

Example:

Distribute emergency preparedness information for people with disabilities to disability specific organizations.

Weakness:

Do not assume that people with disabilities get information only from disability specific service organizations. Many people do not get support from these organizations, do not know about them, or do not identify as a person with disability or having functional needs.



Stronger:

Information must be easy to get. Emergency preparedness Information must be easily available, through the same means that other general preparedness materials are distributed. Integrate information into standard emergency preparedness information and / or within that information refer people to more specific disability-related information.

6. Use resources that are clearly described and annotated with specific links to more resources.

Example: Visit the websites listed below to obtain additional information:

www.fema.gov

www.ncd.gov National Council on Disability

www.aapd.com American Association for People with Disabilities

www.afb.org American Foundation for the Blind

www.nad.org National Association of the Deaf

www.easter-seals.org Easter Seals [4]

Weakness:

These are big web sites with lots of information that does not relate to emergency preparedness.

Stronger:

Direct users where to look and what to look. For example:

<http://emergency.cdc.gov/disasters/floods/>

<http://m.fema.gov/flood>

<http://www.ready.gov/floods>

<http://www.redcross.org/prepare/disaster/flood>

<http://sfwater.org/stormprep>

<http://pge.com/en/safety/preparedness/index.page>

See: [Preparing Makes Sense for People with Disabilities, Others with Access and Functional Needs and the Whole Community.](#)

Summary

When promoting or producing Emergency Preparedness Information material remember to ensure that the content:

- is developed in partnership (of, with and by) people who live with disabilities and others with access and functional needs
- includes information that is useful and specific to people with limitations in hearing, vision, mobility, speech, and cognition (thinking, understanding, learning, and remembering)
- describes disability in accurate and respectful ways and uses neutral terms that avoid offensive words reflecting negative attitudes and stereotypes
- focuses on no cost and low cost preparedness in addition to costly activities
- recognizes that some people cannot afford to buy emergency supplies and equipment

- is available in accessible and usable formats, and provides information to find material in other formats such as large print, audio, disks, or Braille
- uses resources that are clearly described and annotated with specific links to more resources.

Resources:

- A. [Be Ready to Go: Evacuation Transportation Planning Tips for People with Access and Functional Needs.](#) June Kailes [2010]
- B. [Earthquake Preparedness Guide for People with Disabilities and Others with Access And Functional Needs](#) [2014] Earthquake County Alliance
- C. [Emergency Evacuation Preparedness: Taking Responsibility For Your Safety, A Guide For People with Disabilities and Other Activity Limitations](#)
June Kailes [2002], contents include:
- create, review and practice plans
 - gather emergency health information
 - evaluate your need to identify as someone who will need help during an evacuation
 - practice the skill of giving quick information on how to best assist you
 - establish personal support networks
 - conduct an ability self-assessment
 - know your emergency evacuation options
- D. [Emergency Health Information](#) June Kailes [2011 Edition 2], [in PDF](#), [Microsoft Word](#). contents include:
- create your emergency health information (includes forms)
 - storing copies in key places
- E. [Emergency Preparedness for Personal Assistant Services \(PAS\) Users, Edition 2.0, 2016](#)
contains tips specific to individuals who use personal assistants, attendants or caregivers. Planning elements include a checklist, support teams, communication, evacuating and sheltering, supplies and resources that provide more ‘how to’ details. [WORD](#)

Emergency Preparedness Webinar for PAS Users: [Transcript](#), [Slides](#) Personal Assistance Center for Personal Assistance Services 8/23/13. Highlights tips relevant to individuals who use personal assistants, attendants. Planning elements include support teams, communication, evacuating and sheltering, supplies and resources that provide additional ‘how to’ details on these areas. Input from online surveys and research with PAS users with real world experience living through an emergency are also be woven into this webinar.

F. [Emergency Preparedness: Taking Responsibility For Your Safety - Tips for People with Activity Limitations and Disabilities](#)

Written by June Kailes for Los Angeles County Emergency Survival Program [2006], in: PDF, Microsoft Word [1](#) & [2](#), content includes:

- Know why preparing is key
- conduct an ability self-assessment
- establish a support team
- create emergency plans
- collect disability-specific supplies for emergency kits / go kits and check lists
- make an out-of-state contact list (includes form)

G. [Emergency Registries for People with Access and Functional Needs](#), [2014].

- What is a Registry?
- Emergency Registry Assessment Tool
- Flowchart: Deciding to Use an Access and Functional Needs Emergency Registry
- Stakeholder Opinions of Registries
- Registry Websites
- Papers, Presentations, Webinars, Resources

H. [Emergency Supplies Kits for People with Disabilities and Activity Limitations, 2010, Edition 2.0, 2016](#) Checklist suggests emergency kit contents including no cost supplies, that you can tailor to your needs and abilities. Kits to consider for different places and situations: keep it with you, grab and go, home, bedside and car. Specific suggestions are made for hearing, speech and communication and vision issues as well as for wheelchair and scooter users, service animal owners and people with allergies, chemical sensitivities and breathing conditions. [WORD](#)

I. [Emergency Power Planning for People Who Use Electricity and Battery Dependent Assistive Technology and Medical Devices](#) Edition 2, 2009 A checklist for planning emergency power for people who use electricity and battery-dependent devices such as breathing machines (respirators, ventilators), power wheelchairs and scooters, and oxygen, suction or home dialysis equipment. Some of this equipment is essential to maintaining independence while other equipment is vital to keep someone alive! Also contains information on establishing support teams, mastering the skill of giving quick information on how best to assist a person and how and advice from users.

J. [Language is More Than a Trivial Concern!](#) [2010] Sensitizes people to appropriate terminology to use when speaking with, writing about or referring to people with disabilities. Challenges readers to be aware of the importance of using disability-neutral terms. Details preferred language and gives reasons for the disability community's preferences.

K. [Tips for Emergency Use of Mobile Devices](#) – [Edition 2, 2015] Cell phones, smart phones and other mobile wireless devices like tablets are a big part of our lives. We rarely leave home without them and we often store important information on them. In a small or large emergency these devices can be a communication life line. Provides details regarding preparing your device to quickly get and give emergency information which includes a checklist, emergency contacts and documents, alerts, texting, apps, bookmarks of important mobile sites, “no service” backup plans, skill drills and other resources.

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7. National Organization on Disability, *Disaster Readiness Tips for People with Mobility Disabilities*, 2004.
9. National Organization on Disability, et al., *Disaster Readiness Tips for People with Developmental or Cognitive Disabilities*, 2004.



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