



**Emergency Preparedness
Workbook for Older Adults
and Older Adults Living with
Disabilities, Facilitator Handbook**



Disability will
affect every person
in some way during
their lifetime.

Introduction

In the United States, over 25% of people have a disability and this number is significantly higher for people who are aging. Therefore, disability accessibility and inclusion are critical to everything we do. Understanding disability accessibility and inclusion includes understanding systemic bias and core perspectives of disability.

Which model or perspective of disability best describes you or your agency?

- **Medical model.** People with disabilities have something wrong with them that should be fixed/cured if possible (the people need to be fixed).
- **Charity model.** People with disabilities have something wrong with them, need our help, and helping them is the right thing to do (the people need charitable help).
- **Social/Independent Living Philosophy model.** People with disabilities experience barriers because we have not created environments that are accessible and inclusive (the environment needs to be fixed).
- **Rights/Independent Living Philosophy model.** People with disabilities have the same rights as everyone and systems must prioritize the rights of everyone (the system needs transformation).

Engaging with people with disabilities on emergency preparedness requires us to embrace an Independent Living Philosophy model. We can do this by applying the principles of inclusion to our interactions.

These principles can be summarized as:



Principle #1

Each person has the right to equal access to all available programs and services.



Principle #2

Include physical accessibility, programmatic modifications and effective communication.



Principle #3

Inclusion must be integrated into the programs and not separate, there cannot be an additional charge, and a 'one size fits all' strategy is insufficient.



Principle #4

Equal and equitable experiences depend on the ability to exercise self-determination.





We need to plan with people

and not for people

if we want to create plans that work.

Based on these principles, an easy way to think about disability inclusion in emergency and disaster planning is that people are the experts in their own needs and solutions to get those needs met. Their expertise needs to be applied to emergency planning and preparedness.

When it comes to emergency preparedness planning for older adults living with disabilities, planning efforts should embrace a strengths-based perspective centering the needs and priorities of those who are aging with disabilities. This workbook is designed to introduce human service and aging professionals to person centered planning guidelines and to take an asset-based perspective towards preparedness when working with older adults and older adults with disabilities.

To start, this can be accomplished by leading with the following:

- Focusing on the strengths, resources and knowledge of older adults and older adults living with disabilities;
- Adhering to the person-centered and person-directed principles of inclusion (explained later in the handbook);
- Ensuring that decision-making and preparedness planning are accessible and achievable; and
- Providing a self-paced, flexible structured tool for use before-during-and after a disaster event.



Background and Context

Emergency Preparedness Planning Requires Helping People to Overcome Their Resistance to Emergency Planning

Some of this resistance comes from not seeing emergency planning as a priority - either because individuals don't think that a disaster will ever happen to them, or because individuals are too focused on immediate stressors to prioritize planning for hypothetical future events. Another reason that individuals may avoid or resist emergency preparedness planning is the negative emotions that can be associated with the process. Thinking about hypothetical emergencies might cause individuals to experience fear, anxiety, or helplessness. Especially for people with disabilities who have mobility, communication, and/or care needs that could be interrupted by a disaster, thinking about facing emergencies and worst-case scenarios can be distressing. Financial stress may also arise related to preparing emergency kits.



Developing and updating emergency

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available or aware of their role.

When conversations about disaster planning are rooted in the “what if” perspective, the premise behind preparedness is fear – fear of the event, fear of the unknown, fear of the impact. People may not know where to begin to address such a large challenge and often stop in their preparedness. This is especially true for people with disabilities and other marginalized groups such as older adults due to the realities of existing health inequities and limited resources faced on a daily basis.

Shifting the rationale and language from ‘what if’ to preparedness as a part of what people do every day creates a thought framework based on current activities, accomplishments, capabilities and actions. This approach naturally leads people to think about their unique needs and how these needs are being met on a daily basis; resulting in empowered and ‘asset-based’ thinking.

Developing and updating emergency preparedness plans can be complicated when individuals have support persons who are vital to their care who may not be available in an emergency or who may not be aware of their role in that individual’s plan. Emergency preparedness plans are also much less useful when they are not regularly reviewed and updated to account for changes.



Developing emergency preparedness plans may also be challenging for older adults living with communication or cognitive disabilities. Organizations who assist the aging population and people with disabilities also cite capacity issues due to lack of funding and staffing shortages. Small budgets make it difficult to provide emergency supplies and planning services to clients and staffing shortages make it difficult to ensure that clients are getting the support and time they need in creating and updating their plans. Lack of inter-agency cooperation can also be a barrier for supporting emergency preparedness planning. Many organizations who serve the aging population have limited access to emergency planning committees and first responders in local communities, so they've had few opportunities to collaborate on inclusive emergency preparedness efforts.

Table 1
Disaster Preparedness for People with Disabilities

Is Not	Is
A one-time activity	A way of thinking every day
Completing a checklist	Unique to each person and their needs
Expensive	Managing limited resources
Something that someone can do for you	Something each person is capable of doing with or without assistance

Recognizing Ageism and Ableism When Speaking to Adults with Disabilities

Disabilities Can Sometimes Make People Very Uncomfortable



Due to the inaccessibility of many areas of our society, many people don't see visibly disabled people very often in their everyday lives. The result is unintentional or implicit bias. People may have low expectations of a person's ability to contribute to a task, or to society, or may assume that they need assistance and help without being asked. They may assume that all people with disabilities are the same, change their behavior in the presence of people with disabilities, or prefer to not work with someone with disabilities. These are all examples of implicit bias.

Bias can appear on the surface as positive or negative attitudes and behaviors. For example, saying someone is brave, inspirational, or heroic, because they are overcoming or enduring their disability may sound like positive statements, but they are actually rooted in ableism and are as inappropriate as negative stereotypes that assume people are sad about their disability, have less productive lives, are more sensitive, or don't want you to notice their disability.



People with disabilities

know their disability

is not only part of their daily living,

but part of who they are.

It can also be tempting to treat a person with extra attention or be overly polite to try and demonstrate that you are ignoring their disability or to avoid eye contact to avoid the appearance of staring. Please keep in mind: a disabled person knows they have a disability. They live with their disability every day. Trying to pretend it doesn't exist will make everyone uneasy.

If you experience discomfort when engaging with someone with a disability, the best strategy is to:

- Remind yourself that your discomfort is your problem. It is not anyone else's responsibility to make you comfortable with someone else's body or brain. An honest self-check and self-reminder can help you help yourself.
- Ask for help. People with disabilities know they have a disability. Their disability is a part of their daily living and a part of who they are. If you are uneasy, they already know. Asking the person about the best way to communicate and interact will show that it is important to you to be respectful of who they are and what they need.

Language Matters

Language Both Determines and Reflects Our Beliefs and Values

Therefore, what we say and the words we use are important. People with disabilities are a person first. Their disability is one aspect of what makes them unique. The driving principle to direct language choice is following 'person directed' or 'personal choice' decision-making. Respecting that there is diversity within the disability community, the language choices of the person and their method of self-identification supports their leadership. Always refer to people in the same way that they refer to themselves. There are some words and language choices that should be avoided since they reflect a bias perspective of disabilities.

Table 2

Word and Language Choices to Avoid

User	Avoid
Person first language: person with a disability; Identity first language: disabled person	Old stereotypes (handicapped, cripple, victim, invalid, special)
Person who uses a wheelchair	Confined to..., wheelchair-bound
Person without a disability	Normal (indicating able-bodied people are 'normal' and disabilities are abnormal)
Person who is hard of hearing; deaf; Deaf; or has a hearing loss	Deaf and dumb; deaf/mute
Has _____ (e.g., arthritis, epilepsy, a visual disability)	Victim of _____ suffering from _____ afflicted with (<i>name the disability</i>)
Person with a learning disability	Slow, special, differently-abled, retarded
Person with a mental health disability	Crazy, mentally ill, psychotic, depressed

Accessibility and Inclusion

Addressing disability accessibility and inclusion can be divided into three overarching areas: physical accessibility, program inclusion and modifications, and effective and accessible communication. These all play a role in equitable disaster preparedness and resilience.



Physical Accessibility

When planning with people who have disabilities, planning considerations may include:

- ☐ Accessible transportation that can accommodate their equipment and that they can get in and out of and accessible pathways.
- ☐ Building entrances, parking lots, external and internal pathways, rooms, and areas that are free from obstructions or barriers.
- ☐ Buildings that have accessible restrooms, counter heights, equipment, and furnishings.
- ☐ Internal environments that are free from pollutants, excessive fragrances, strobe type lighting, and poor acoustics.
- ☐ Emergency exits with stairwells, heavy doors, or exit signage that relies on vision.



Programmatic Inclusion

When planning with people who have disabilities, planning considerations may include:

- ☐ Accessibility and availability of forms, materials and information.
- ☐ Lack of knowledge of responders, volunteers and personnel (a strong plan would not assume that responding personnel will know how to provide appropriate assistance).
- ☐ Lack of knowledge of disability rights in disasters. It is a common misperception that laws, rights, and responsibilities change in a disaster, they do not.
- ☐ Inflexible practices and procedures that are based on implicit bias or founded in a medical or charity model of disability.
- ☐ Response practices may be overtly exclusionary, such as shelter mask requirements that prohibit people who are Deaf from reading lips, or shelter-in-place requirements that prohibit personal assistants from providing aid that keeps a person from being institutionalized.
- ☐ Alerts and warnings that are only distributed electronically and through smart devices.
- ☐ Mental and behavioral health disabilities can frequently be misinterpreted as public safety concerns in a disaster.



Effective Communication

When planning with people who have disabilities, planning considerations include:

- ☐ Accessibility and availability of forms, materials and information.
- ☐ Busy open spaces, background noises and fast paced interactions like are common in a disaster response can make communication impossible for many people.
- ☐ Websites, messaging and technology-based communication should be accessible to a screen reader.
- ☐ Messaging should always be provided in multiple formats that best meet the persons needs
- ☐ Information must be accessible, meaningful, and useful to the person.
- ☐ Many people may need communication to be slowed down to give them a chance to both give and receive information.

Assisting People with Disabilities

There are practical ways that you can demonstrate disability inclusion, create an equitable collaboration with people with disabilities and to generate engagement in shared preparedness goals. Listed below are a few overarching recommendations and tips for assisting people with disabilities in emergency and disaster planning:

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- Introduce yourself and speak directly to the person, not to an interpreter or others.
- Respect personal space and property.
- Sit/stand at eye level. This will support eye contact, lip reading and keep the person from having to bend their neck to communicate.
- Durable medical equipment (such as wheelchairs, walkers, canes, oxygen, and service animals) ALWAYS stay with the person.
- Be patient and know your own limitations. Take time to allow the person be comfortable and don't pretend to know, hear, or understand something that you do not.
- Be aware of your surroundings, hazards, noise, distractions, etc. If something is distracting to you, it may be a significant barrier to someone else.
- Offer alternatives for how, when, and where to meet and communicate.
- Don't assume you know someone's needs. Not everyone with the same disability has the same needs. And not everyone with the same needs benefits from the same support.
- Follow their example using the language they want to use.
- ASK if you don't understand, if you don't know, and before helping.



Considerations for Assisting People with Mobility and Physical Disabilities

- ❑ People with mobility disabilities may use assistive equipment or no equipment at all. Not all physical disabilities are mobility disabilities. Some people may have difficulty moving or using certain parts of their body, grasping, lifting, turning or exerting pressure on an object.
- ❑ If a person uses a wheelchair, sit so that you are at the same eye level. Or if necessary, stand at a slight distance so the person doesn't have to strain their neck to make eye contact.
- ❑ Do not touch the person's body regardless of what you think they can or cannot do.
- ❑ Always ask the person what type of help they need.
- ❑ Do not touch the person's assistive devices (wheelchair, cane, walker, etc.). Treat the assistive devices as if they are a part of the person's body.
- ❑ Make eye contact and do not stare at any atypical body parts.



Considerations for Assisting People with Speech Disabilities

- ☐ People may have speech and language disabilities that impact their ability to speak clearly, at a pace or flow that you are used to, or in a way that you understand.
- ☐ If you have difficulty understanding someone, let them know.
- ☐ Be prepared to take extra time and be patient.
- ☐ Don't finish someone's sentences.
- ☐ Face the person with the disability and speak directly to them. Use a normal voice and don't shout.
- ☐ Be prepared to use their devices such as communication/letter boards, electronic communication devices, picture books, pencil and paper or others items that they have.



Considerations for Assisting People with Blind and Low Vision Disabilities

- ❑ Some people may have low or limited sight but needs magnification or be able to see light and dark. People may have a wide variety of vision disabilities.
- ❑ Identify yourself when you arrive so the person knows you are there, when you first speak if the person does not know you by your voice and when you are leaving.
- ❑ Do not assume that the person does not know their way and needs your assistance.
- ❑ If the person asks you to guide them, position yourself on the far side from a cane or dog where your elbow is easily within reach and allow them to take your elbow.
- ❑ Describe the setting as you walk, including potential obstacles so that they can learn the environment and how to navigate it independently (use a 360 degree view).
- ❑ Never touch, grab, push, pull or touch the person, their device, or their dog.
- ❑ Speak as you normally would using a normal voice and volume.



Considerations for Assisting People Who Are Deaf or Have Hard of Hearing Disabilities

- ❑ First, get their attention so they know you want to communicate with them.
- ❑ Always face them and speak directly to them; don't hide your face or your mouth. Some people read lips and your expressions are a part of your communication.
- ❑ Face the light source to maximize your visibility.
- ❑ If someone is using an interpreter, face and speak to the person, not the interpreter.
- ❑ Speak clearly, naturally, and at a consistent pace; don't shout or use exaggerated mouth movements.
- ❑ You can communicate with gestures and/or writing. Keep a pen and scratch paper nearby.
- ❑ Be aware of background noise that could impact a person's ability to hear, understand, or filter different sources of sound.
- ❑ Be sensitive to older people who may be hard-of-hearing and reluctant to say so.
- ❑ If they do not understand you, try to rephrase and repeat your message.



Considerations for Assisting People with Cognitive Disabilities

- ❑ Some people may need additional information, time, or explanation, be patient.
- ❑ Offer quiet spaces if you see that the person may be having trouble focusing on the conversation, is distracted, or is uncomfortable with the environment.
- ❑ Do not assume that no response or unexpected responses means that the person is non-compliant, isn't paying attention, or is non-responsive.
- ❑ Speak calmly, clearly, naturally, and at a consistent pace.
- ❑ Do not touch or "get in someone's space" without their permission.
- ❑ Have paper and pencil available as an optional way to communicate.
- ❑ Use plain language and sentences with a clear meaning and message.



Note:

A person is not required to disclose their disability or demonstrate the animal's trained work or tasks. They must only provide enough information to distinguish it from a pet or other assistance animal.

Considerations for Assisting People With Service Animals

Federal Guidelines

- ❑ Under the Americans with Disabilities Act service animals can be a dog or miniature horse. Service animals must be treated like a part of the person and cannot be separated from the person. A person and their service animal have the right to go wherever the public is allowed to go.
- ❑ Under federal law, service animals do not need to be registered, wear any identifying patches, or cards.
- ❑ Under federal law a person can be asked the following questions to determine if an animal is a service animal and protected by law.

These questions are:

- Is the service animal required because of a disability?
 - What work or task has the animal been trained to perform?
- ❑ Do not touch or engage with a service animal, remember they are part of the person and should be treated as such.
 - ❑ The status of a service animal does not change in disasters and people who use a service animal should plan with their service animal in mind.



Considerations for Assisting People with Service Animals [Continued]

State of Michigan

- ❑ The State of Michigan follows the same definition as the ADA. The State has a free voluntary service animal identification program. This does not entitle a person and their animal to any benefits but can assist to ease their experiences.
- ❑ Assistance Animals are not service animals and are not protected by the ADA. They are recognized by the Fair Housing Act for places where a person lives. An assistance animal works, provides assistance, and performs tasks for the benefit of a person with a disability or provides emotional support that alleviates one of more identified symptoms or effects of a person's disability.
- ❑ Assistance animals may or may not be allowed into shelters in disasters. People who have an assistance animal should plan for alternate shelter options in the event that their animal is not permitted. This would be particularly relevant for warming and cooling shelters which are not intended for temporary residence.
- ❑ Assistance animals, emotional support animals and pets are not protected by the ADA or Michigan law in the same way as a service animal.

The Think-Plan-Do Approach

To assist in executing person-directed planning, this workbook is intended to follow a problem-solving strategy of Think-Plan-Do for each part of the exercise. You can help the individual to apply this strategy as a method for them to identify and implement their own solutions to each aspect of preparedness.



Pausing to **THINK** first about their needs and how they are met each day will help many people to organize their thoughts, to not feel pressured to act immediately, and to identify their resources and supports (their assets). Thinking answers the question ‘what’ needs to be done.

After thinking about their needs, people can problem solve, identify a solution, and make a **PLAN** on how they intend to meet their needs in a disaster. Planning helps to answer the question of ‘how’ they will act. Inclusion must be integrated into the programs and not separate, there cannot be an additional charge, and a ‘one size fits all’ strategy is insufficient.

There may be multiple things to **DO** that need to be accomplished. Creating timelines and priorities can help people take action to accomplish their tasks. Taking multiple action steps can answer the question of ‘when’ things will happen and make large tasks manageable.



Emergency Preparedness as a Routine

The Workbook Is Divided into Three Sections Which Roughly Correspond to the Disaster Life-Cycle

The majority of the time will be spent in section one but it is good to emphasize the importance of sections two and three as they will help the person prepare for the event of an emergency. Their work in section two can easily be integrated into existing routines along with changing smoke alarms or hearing aid batteries, regularly scheduled medical visits, or seasonal events. Like all other aspects of the preparedness plan, this will be determined by what works for the individual person.



This document can be viewed

as a living document that

will change over time

with the needs and desires

of the individual person.

This workbook is designed to help providers and people to collaboratively identify the needs and resources of each individual. When it is complete, the workbook will be a guide and resource for the individual that they can use for reference and as a tool to get, stay and be ready. Completion of the workbook may take multiple sessions and once complete, should be revisited on a periodic basis during meetings. The provider or support person plays an important role in assisting the person to create a preparedness plan, communications plan and kit that meets their individual needs and reflects their individual priorities. Some individuals may wish to have this workbook in electronic form while others may prefer written form (including large print, Braille, or in their first language). It can be viewed as a living document that will change over time with the needs and desires of the individual person.

If someone prefers to use a printed copy, please recommend that the workbook is filled out in pencil so that they can easily go back and make any necessary changes as needed.

The Routine in the Workbook

Assisting people to become prepared requires knowledge and application in disability and aging, inclusion and accessibility, and emergency and disaster preparedness. This handbook and accompanying person centered emergency preparedness workbook aims to provide the basic knowledge and skills necessary to assist people in their efforts to make, maintain, and use their emergency plans and kits.



Section One (Getting Ready). Identifies the needs that a person might have, the resources that they will need to shelter in place or to evacuate, things they will need to do, and the people they will need to include in their plan. When completing Section one, use the prompts and examples provided to help them think about their answers and what will work for them. You can then help them make a plan about when they decide they are going to do their preparedness action and follow up to help with any difficulties they may have experienced.



Section Two (Staying Ready). Focuses on how the person can integrate preparedness into their life and to make sure that their thinking, planning, and resources remain current. It is important to emphasize that being prepared isn't something that is done once and remains useful weeks, months or years later when a disaster happens. Section two will give you the tools to help them think about what needs to be done to the plan and kit to keep it useful, plan when to do updates or changes, and how they are going to do the modifications. Revisiting their emergency plan on a regular basis encourages people to focus on what they can do rather than what might happen to them. It also helps to empower the individual person with the knowledge that they can impact their health, safety, and independence.



Section Three (Being Informed). Provides the person the opportunity to prepare for what might happen in a disaster. The more information each person has about what to expect, the greater their ability to stay calm, advocate for their health, safety and independence, and effectively communicate their needs, desires and rights. Section three encourages people to think about how they may need to use their plans and resources in an emergency. Understand that they need to plan to share important information in overwhelming circumstances, what they can expect others to do for them, and what they will need to do for themselves.



Additional Resources

Informational Videos

Introduction to Disability and Health Equity

Barriers to Health for People with Disabilities

Accessible Information

Accessible Facilities

Program Accommodations

Workbooks

Disability Competency

Understanding Systemic Bias

Planning for Accessible Meetings

Building Meaningful Relationships with Disability Partners

Facilitating Effective Workgroups

Facility Accessibility Quick-Check Tool

Inclusive and Accessible Places of Service

Note:

The resources listed on this page are available at the [World Institute on Disability website](https://bit.ly/43K6CrN) (URL: <https://bit.ly/43K6CrN>).