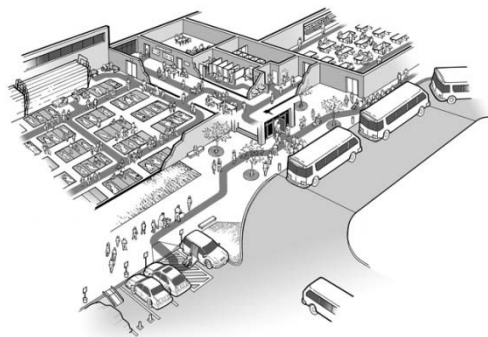# Serving People with Functional and Access Needs in Shelters

Welcome to the Shelter Worker online course about serving people with functional and access needs in shelters. First, let me thank you for your commitment to work in a shelter and assist those who are dealing with the stresses of a recent disaster or emergency. The duties you will engage in are fundamental to helping communities recover and makes a positive impact to the lives of those affected, including the most vulnerable – people with disabilities.

We truly believe this course will empower you with valuable knowledge that will improve the care of all residents in a general population shelter. This course can and will be a model to the nation for how successful shelter workers can be given the proper tools to embrace the needs of people with disabilities – with compassion, using people first language and focusing on their abilities rather than their disabilities.

The personal assistive services (PAS) you may provide as a shelter worker may be the resident's first contact with a shelter. The assistance you provide will be the first stepping stone in reassuring residents that you are trained, willing, and able to help with their various needs.

The course you are about to complete is designed to ensure you have the knowledge about people with disabilities and the people skills necessary to serve all residents. This innovative approach will ensure you can succeed and provide the highest level of service to all residents. We are confident that when you complete this course and become a fully trained shelter worker, you will be an asset in many ways to your community.

1.1.0 Introduction to the Serving People with Functional and Access Needs in Shelters (FANS) Course

There are many types of natural and human caused disasters that will bring residents to a shelter.

Natural Disasters:	Human Caused Disasters:
• Tornadoes • Hurricanes • Fires • Flooding and Mud Slides • Earthquakes • Ice Storms • Volcanoes	• Bio-terrorism • Chemical-terrorism • Nuclear-terrorism • Toxic waste spills • Fires • Petroleum/chemical spills

When an emergency or disaster hits an area, it can cause short- or long-term shelter needs. Short-term needs are typically less than a week, and long-term needs can last for months.

As a shelter worker (this collective term is used to include volunteers and paid workers and everything in these modules will not always apply to all these workers), you will be directly involved with people who may be stressed, frustrated and/or confused. In many cases, your shelter will be the last resort. In addition, some of the adults and children will have functional and access needs. People with these needs have different ability levels. These people may:

- use manual or motorized wheelchairs, crutches, canes or walkers
- be blind or have vision impairments
- be deaf or hard of hearing
- have emotional (mental) or intellectual impairments
- have medical conditions such as allergies, epilepsy or asthma
- have difficulty communicating in English
- be frail
- have a number of other conditions or combinations of conditions needing assistance

Official definition: The Americans with Disabilities Act defines a **disability**, with respect to an individual, as a physical or mental impairment that substantially limits one or more of the major life activities such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working[1.1].

Another source defines a disability as an impairment caused by an accident, trauma, genetics, or disease which may limit a person's mobility, hearing, vision, speech or mental function[1.2].

limitation.[1.3] So whether you are working in a public, school, or faith-based shelter, the chance of having people with disabilities in your shelter is relatively high.

When people with disabilities or other functional and access needs seek shelter, it is important to work with them individually to assess their needs and to determine the best way to meet those needs. Many individuals find mass care shelter arrangements difficult, since they are separated from their personal items and familiar surroundings. This can be more difficult, and often frustrating, for an individual with a disability who, as a result of a disaster or emergency, has been cut off from people and equipment that they rely on for assistance.

This course will identify four categories of people:

- People with physical disabilities
- People with sensory disabilities
- People with mental or psychological illnesses
- People with intellectual disabilities

Some of these disabilities may be visible, while others are not. For example, most of the people in this photograph have one or more disabilities. You will learn about most of them in subsequent modules.

1.2.0 Objectives

The overall course objective is not intended to make you an expert on people with disabilities; instead it is intended to make you aware and more sensitive to recognizing, communicating with, and serving their functional and access needs.

Upon completion of this module, you will be able to:

1. Understand what a disability is and what types of disabilities there are.
2. List different laws and guidelines which protect people with disabilities against discrimination.
3. Understand what a service animal is and does.

1.3.0 Laws that Protect People with Disabilities

Before we teach you about serving people with disabilities, it is important for you to understand a couple of legal aspects that apply when you help others in a general population shelter.

1.3.1. Laws that Apply to People with Disabilities

The Americans with Disabilities Act of 1990 and Amendments through 2010 (ADA), the Rehabilitation Act of 1973 (RA), the Fair Housing Act (FHA), as well as state counterparts, provide some hallmarks of equal opportunity for people with disabilities, which include:
- General policies must not discriminate on the basis of disability, even in emergency circumstances.
- Shelters must integrate people with disabilities in the most integrated setting appropriate to the needs of the person, which in most cases are the same setting people without disabilities enjoy.
- Shelters must provide auxiliary aids and services to ensure effective communication, with primary consideration of the aid or service given to the person with a disability.
- Shelters must remove eligibility criteria, discriminatory administrative methods, paternalistic safety requirements, and surcharges which discriminate against people with disabilities.
- Shelter planners must choose accessible sites for the location of general population shelters, the construction of architecturally compliant mass care shelters and elements, and required physical modifications to ensure program accessibility in existing facilities.[1.4]

An Example of a State Law – Florida Civil Rights Act of 1992
"The general purposes of the Florida Civil Rights Act of 1992 are to secure for all individuals within the state freedom from discrimination because of race, color, religion, sex, national origin, age, disability, or marital status and thereby to protect their interest in personal dignity…."

1.3.2. Laws that Specifically Apply to Shelters

Two other laws, The Stafford Act and Post-Katrina Emergency Management Reform Act (PKEMRA), mandate integration and equal opportunity for people with disabilities in general population shelters. To comply with these laws, those involved in management and shelter planning should understand the concepts of accessibility and nondiscrimination and how they apply in emergencies or disasters. The following are key nondiscrimination concepts applicable under federal laws, and examples of how these concepts apply to all phases of shelter assistance.

a. Self-Determination – People with disabilities are the most knowledgeable about their own needs.

b. No "One-Size-Fits-All" – People with disabilities do not all require the same assistance and do not all have the same needs.
   • Many different types of disabilities affect people in different ways. Preparations should be made for people with a variety of functional needs, including people who use mobility aids, require medication or portable durable medical equipment (DME), use service animals, need information in alternate formats, or rely on a caregiver.

c. Equal Opportunity – People with disabilities must have the same opportunities to benefit from programs, services, and activities as people without disabilities.
   • Recovery services and programs should be designed to provide equivalent choices for people with disabilities as they do for people without disabilities. This includes choices relating to short-term housing or other short- and long-term disaster support services.

d. Inclusion – People with disabilities have the right to participate in and receive the benefits of programs, services, and activities provided by governments, private businesses, and nonprofit organizations.
   • Inclusion of people with various types of disabilities in planning, training, and evaluation of programs and services will ensure that all people are given appropriate consideration during emergencies.

e. Integration – Programs, services, and activities typically must be provided in an integrated setting.
   • The provision of services such as sheltering, information intake for disaster services and short-term housing in integrated settings keeps people connected to their support system and caregivers and avoids the need for separate facilities.

f. Facility Access – Programs, services, and activities must be provided at locations that all people can access, including people with disabilities.
   • People with disabilities should be able to enter and use facilities and access the programs, services, and activities that are provided.

g. Equal Program and Services Access – People with disabilities must be able to access and benefit from programs, services, and activities equal to the general population.
   • Equal access applies to preparedness, notification of emergencies, evacuation, transportation, communication, shelter, distribution of supplies, food, first aid, medical care, housing, and application for and distribution of benefits.

h. Effective Communication – People with disabilities must be given information that is comparable in content and detail to that given to people without disabilities. It must also be accessible, understandable, and timely.
   • Auxiliary aids and services may be needed to ensure effective communication. These resources may include pen and paper; sign language interpreters through on-site or video; and interpretation aids for people who are deaf, deaf-blind, hard of hearing, or

who are speech impaired. People who are blind, deaf-blind, have low vision, or have cognitive disabilities may need large-print information or people to assist with reading and filling out forms.

i. Program Modifications – People with disabilities must have equal access to programs and services, which may entail modifications to rules, policies, practices, and procedures.

- Shelter workers may need to change the way questions are asked, provide reader assistance to complete forms, or provide assistance in a more accessible location.

j. No Charge – People with disabilities may not be charged to cover the costs of measures necessary to ensure equal access and nondiscriminatory treatment.

- Examples of accommodations provided without charge to the individual may include: ramps; cots that meet their disability-related needs; visual alarms; grab bars; additional storage space for medical equipment; lowered counters or shelves; Braille and raised letter signage; sign language interpreters; message boards; assistance in completing forms or documents in Braille, and large-print or audio recording.[1.5]

1.4.0 FEMA 2010 *Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters*

Although this FEMA guidance is not a law, its purpose is to provide federal guidance that can be incorporated into existing shelter plans and allow emergency managers and shelter operators to understand the **requirements** for serving children and adults with functional support needs in all types of general population shelters.

> Official definition: **Functional Needs Support Services** (FNSS) enable individuals to maintain their independence in a general population shelter. They include:
> - Reasonable modifications to policies, practices, and procedures to provide:
> - Durable medical equipment (DME)
> - Consumable medical supplies (CMS)
> - Personal assistance services (PAS), and
> - Other goods and services as needed

Children and adults requiring FNSS may have physical, sensory, mental, or intellectual disabilities affecting their ability to function independently without assistance. Others who may benefit from FNSS include women in late stages of pregnancy, elders, and people needing bariatric (obesity) treatment.[1.6]

1.5.0 Service Animals

Paragraph "b" in section 1.3.0 above talks about service animals. Although many shelters do not allow residents or workers to bring their pets or other animals inside, shelters must allow people

with disabilities to be accompanied by their service animals. Service animals are not pets and are therefore not subject to restrictions applied to pets or other animals.

Most people are familiar with dogs that guide people who are blind or have low vision, but there are many other functions that service animals perform for people with a variety of disabilities. Examples include:

- alerting people who are deaf or hard of hearing to the presence of people or sounds;
- providing non-violent protection;
- pulling wheelchairs;
- alerting individuals to the presence of allergens;
- carrying or retrieving items for people with mobility disabilities or limited use of arms or hands;
- assisting people with disabilities to maintain their balance or stability;
- alerting people to, and protecting them during, medical events such as seizures; and
- working or performing tasks for individuals with psychiatric, neurologic, or intellectual disabilities, such as
  - waking up a person with depression
  - assisting a person with Alzheimer's in way-finding
  - retrieving misplaced objects for persons with traumatic brain injury
  - protecting a person with autism from self-injury
  - orienting an individual with schizophrenia to his or her environment

The following discussion about service animals comes from the 2010 ADA Amendment.

According to the Final Rule to Amend the Department of Justice's Regulation Implementing Title II of the ADA *which became effective March 15, 2011,* a **service animal** means any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability, including a physical, sensory, psychiatric, intellectual, or mental illness. Other species of animals, whether wild or domestic, trained or untrained, are not service animals for the purposes of this definition.

One other animal (miniature horses) can be used as a service animal and is discussed later in this section.

The work or tasks performed by a service animal must be directly related to the owner's disability. The crime deterrent effects of an animal's presence and the provision of emotional support, well-being, comfort, or companionship do not constitute work or tasks for the purposes of this definition. The ADA furthers states:

- (a) *General*. A public shelter shall modify its policies, practices, or procedures to permit the use of a service animal by an individual with a disability.

- (b) *Exceptions.* A public shelter may ask an individual with a disability to remove a service animal from the premises if –
  - o (1) The animal is out of control and the animal's handler/owner does not take effective action to control it; or
  - o (2) The animal is not housebroken.
- (c) *If an animal is properly excluded.* If a public shelter properly excludes a service animal, it shall give the individual with a disability the opportunity to participate in the service, program, or activity without having the service animal on the premises.
- (d) *Animal under handler/owner's control.* A service animal shall be under the control of its handler/owner. A service animal shall have a harness, leash, or other tether, unless either the handler/owner is unable because of a disability to use a harness, leash, or other tether, or the use of a harness, leash, or other tether would interfere with the service animal's safe, effective performance of work or tasks, in which case the service animal must be otherwise under the handler/owner's control (e.g., voice control, signals, or other effective means). There are also no limitations on the size or breed of dogs that can be used as service animals.
- (e) *Care or supervision.* A public shelter is not responsible for the care or supervision of a service animal.
- (f) *Inquiries*. <u>A public shelter shall not ask about the nature or extent of a person's disability</u>, **but may make two inquiries** to determine whether an animal qualifies as a service animal. A public shelter may ask:
    1) Is the animal required because of a disability?
    2) What work or task has the animal been trained to perform?
  - Generally, a public shelter may not make these inquiries about a service animal when it is readily apparent that an animal is trained to do work or perform tasks for an individual with a disability (e.g., the dog is observed guiding an individual who is blind or has low vision, pulling a person's wheelchair, or providing assistance with stability or balance to an individual with an observable mobility disability).
  - A public shelter shall not require documentation, such as proof that the animal has been certified, trained, or licensed as a service animal.
- (g) *Access to areas of a public shelter.* Individuals with disabilities shall be permitted to be accompanied by their service animals in all areas of a public shelter's facilities where members of the public, participants in services, programs or activities, or invitees, as relevant, are allowed to go, including bathrooms, areas where food is served, and almost all areas where medical care is provided. **If someone is allergic to a service animal, the person without the disability should be moved to another room or area. Finally, DO NOT separate the owner from the service animal.**
- (h) *Surcharges.* A public shelter shall not ask or require an individual with a disability to pay a surcharge, even if people accompanied by pets are required to pay fees, or to comply with other requirements generally not applicable to people without pets. If a public shelter normally charges individuals for the damage they cause, an individual with a disability may be charged for damage caused by his or her service animal.

- (i) **Miniature horses** *(Paragraphs c - h above also apply to miniature horses).*
    - o (1) *Reasonable modifications.* A public shelter shall make reasonable modifications in policies, practices, or procedures to permit the use of a miniature horse by an individual with a disability if the miniature horse has been individually trained to do work or perform tasks for the benefit of the individual with a disability.
    - o (2) *Assessment factors.* In determining whether reasonable modifications in policies, practices, or procedures can be made to allow a miniature horse into a specific facility, a public shelter shall consider—
        - (i) The type, size, and weight of the miniature horse and whether the facility can accommodate these features;
        - (ii) Whether the handler/owner has sufficient control of the miniature horse;
        - (iii) Whether the miniature horse is housebroken; and
        - (iv) Whether the miniature horse's presence in a specific facility compromises legitimate safety requirements that are necessary for safe operation.[1.7]

1.6.0 General Shelter Areas

According to the FEMA 2010 *Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters*, shelters should have access to the following areas.

Shelters need accessible:
- Entrances
- Routes to all services/activity areas
- Routes within toilet rooms
- Passenger drop-off and pick-up areas
- Parking
- Sidewalks and walkways
- Shelter entrances, hallways, and corridors
- Check-in/information areas
- Sleeping areas
- Restrooms, showers, and toilet stalls, including portable toilets
- Public telephones
- Drinking fountains
- Eating areas
- Medical health/first aid areas and
- Recreation areas

Refer to the diagram below for a high level visual representation of a typical shelter setup.[1.8]
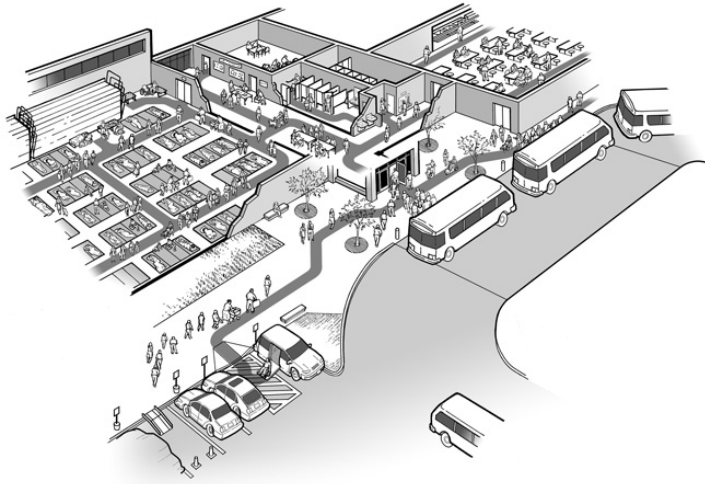
1.7.0 Communicating with and Serving People with Disabilities

As a shelter worker, you will be working with all types of people with disabilities. As mentioned earlier, some of these people will have obvious disabilities, and some will have disabilities that are not obvious. It will be important that as a worker you treat all residents the same.

Here are some general tips for communicating with people with disabilities:

- When introduced to a person with a disability, it is appropriate to offer to shake hands. People with limited hand use or who wear an artificial limb can usually shake hands. (Shaking hands with the left hand is also an acceptable greeting.)
- If you offer assistance, wait until the offer is accepted. Then listen to or ask for instructions.
- Treat adults as adults. Address people who have disabilities by their first names only when extending the same familiarity to all others.
- Relax. Don't be embarrassed if you happen to use common expressions such as "See you later," or "Did you hear about that?" that seem to relate to a person's disability.
- Do not be afraid to ask questions when you are unsure of what to do.[1.9]

Specifically, remember the following five steps when serving all individuals:

1. Ask the person how you can help, and listen – listening is most important!
2. Look directly at the person you are speaking to – eye contact shows you care.
3. Speak in short, direct sentences – a lot of details add to confusion.
4. Allow time for the person to respond – it can take up to 10 seconds to respond.
5. And, be patient – a kind word goes a long way.

1.8.0 Advice from Shelter Managers

When this course was being developed, a survey was sent to experienced shelter managers all across the U.S. asking for their advice about what shelter workers need to know about working with people with disabilities. Each module will add an "Advice Section" from the forty-five managers who responded to the survey that applies to the module-specific disability type.

1.9.0 Helping Reduce Shelter Residents' Stress

In 2006 the American Red Cross began offering a *Psychological First Aid: (PFA) Helping Others in Times of Stress* course. The twelve principles of its PFA program are:

1. Making a connection
2. Helping people be safe
3. Being kind, calm, and compassionate
4. Meeting people's basic needs
5. Listening
6. Giving realistic assurance
7. Encouraging good coping
8. Helping people connect
9. Giving accurate and timely information
10. Making a referral to a Disaster Mental Health worker
11. Ending the conversation
12. Taking care of yourself

These principles allow all workers to focus their "awareness, attitudes, and actions" to support all residents. If you have taken the PFA course, many of the skills from that course may give this course more context and grounding.[1.10]

1.10.0 Summary

This introductory module provided you with a lot of information about serving people with functional and access needs. People with disabilities are protected from discrimination by several laws such as the American Disabilities Act of 1990 (ADA), the Rehabilitation Act of 1973 (RA), the Fair Housing Act (FHA), The Stafford Act, Post-Katrina Emergency Management Reform Act (PKEMRA), and state-specific laws that protect civil rights. There is also federal guidance provided in the FEMA 2010 *Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters*. The module covered what constitutes a service animal and how disabilities are not always obvious as well as five basic steps to follow when helping all people in a shelter. Finally, this module showed what a shelter should contain and areas where you might help as a worker. The next four modules will tell you about four disability types:

- Physical Disabilities
- Sensory Disabilities
- Mental Illnesses
- Intellectual Disabilities

These four modules will also help you learn how to recognize, communicate with, and help people with these disabilities. Once you finish a module, you will be tested on your grasp of the knowledge presented in each module. Once you finish the course, you will be tested over all the information covered in this course.

End Notes Module 1

[1.1] *The Americans with Disabilities Act*, Retrieved 12/10/2010 from: http://www.ada.gov/qasrvc.htm

[1.2] The Georgia Council on Developmental Disabilities Website. Retrieved 12/10/2010 from: http://www.gcdd.org/press-room/people-first-guidelines/

[1.3] U.S. Census Bureau Newsroom. Retrieved 12/10/2010 from http://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb08-ff11.html .

[1.4] *The ADA Title II Technical Assistance Manual.* Retrieved 12/10/2010 from http://www.ada.gov/taman2.html

[1.5] *Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters*, Retrieved 12/10/2010 from: http://www.fema.gov/pdf/about/odic/fnss_guidance.pdf

[1.6] *Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters*, Retrieved 12/10/2010 from: http://www.fema.gov/pdf/about/odic/fnss_guidance.pdf

[1.7] *Part 35 Nondiscrimination on the Basis of Disability in State and Local Government Services (as amended by the final rule published on September 15, 2010).* Retrieved on 12/10/2010 from *http://www.ada.gov/regs2010/titleII_2010/titleII_2010_regulations.htm*

[1.8] *Americans with Disabilities Act, ADA Checklist for Emergency Shelters.* Retrieved on 12/10/2010 from http://www.ada.gov/pcatoolkit/chap7shelterchk.htm

[1.9] *People First. Communicating with and About People with Disabilities.* Retrieved on 12/10/2010 from http://www.health.state.ny.us/publications/0951.pdf

[1.10] Taken from the July 2006 American Red Cross Presentation, *Psychological First Aid: Helping Others in Time of Stress* on 12/10/2010.

2.1.0 Introduction to the Physical Disabilities Module

As a shelter worker, you may be directly involved with people who have physical disabilities. When people with disabilities seek shelter, it is important to work with them individually to assess their needs and to determine the best way to meet those needs. Many individuals find mass care shelter arrangements difficult, since they are separated from their personal items and familiar surroundings. This can be more difficult, and often frustrating, for an individual with a physical disability who, as a result of a disaster or emergency, has been cut off from people and equipment that shelter residents rely on for assistance.

The Americans with Disabilities Act, [2.1] other laws, and the efforts of shelter operators (specifically the American Red Cross) and emergency managers have also been working to make shelters more accessible, especially in hurricane states. Where progress is still needed is in communication and interaction with people with physical disabilities. Individuals are sometimes concerned that they will say the wrong thing, so they say nothing at all—thus further segregating people with impairments. [2.2]

As a foundation for our discussion, **physical disabilities** are a group of conditions that impact the manner in which the individual interacts with or performs in his or her physical environment. Physical disabilities may be the result of any number of disabling conditions, which may either limit or completely eliminate the use of a person's lower and/or upper limbs. Conditions may be evidenced by either lack of coordination, weakness, poor circulation, or paralysis. [2.3]

It may be helpful to separate physical disabilities into those that are visible and those that are unnoticeable. The visible conditions may be the result of amputations or neuromuscular disorders affecting the individual and resulting from disease, work, or accident injuries. The less obvious physical disabilities that may not be readily discernible include diabetes, multiple sclerosis, rheumatoid arthritis, cerebral palsy, and a group of conditions that fall under the umbrella of Chronic Obstructive Pulmonary Disease (COPD).

Activities of Daily Living (ADL) refer to activities of bathing, dressing, eating, and getting around the home. Remember, some people with physical disabilities can do all of these activities by themselves.

Please remember that a ***disability*** is an impairment that limits a person's ability to walk, talk, see, hear, or reason: a ***handicap*** is an imposed barrier that restricts a person. People with disabilities are handicapped by society's mistaken beliefs about their disabilities. It is up to everyone to help make sure disabilities are seen as challenges and not burdens.

2.2.0 Objectives

Upon completion of this module, you will be able to:

1. Increase awareness of common health conditions that can cause physical disabilities.
2. Differentiate between types of physical disabilities.
3. Increase awareness of disabling factors, hazards, barriers, conditions, attitudes, and challenges that exist for people with physical disabilities.
4. Explain the key factors that you should be aware of in assisting those individuals with physical disabilities during their residence in the shelter.
5. Enable course participants to identify and develop useful solutions or strategies in assisting residents of the shelter so that:

    i. They complete the registration process with the least amount of difficulty, their safety and health needs are met, and they have ready access to shelter facilities.
    ii. They have a positive attitude about the workers who assist them.
    iii. Formal and informal Personal Assistance Services (PAS) provided by workers will enable children and adults to maintain their usual level of independence in a general population shelter. [2.4]

2.3.0 Recognizing Residents with Physical Disabilities

The term physical disability as it relates to citizens can cover a great number of disabilities or conditions in this broad category. People may become paraplegics or quadriplegics through disease or accidents. Physical disabilities could also be due to a person having been born with a condition that severely limits movement of both legs and arms.

2.3.1 Groupings of Physical Disabilities

The next four subsections will provide information on the different groups of diseases that can cause a physical disability.

2.3.1.1 Mobility Impairments[2.3]

The most common mobility impairments include:
- **Cerebral palsy (CP),** a disorder usually occurring before or after birth that relates to bad coordination and involuntary movements of the muscles; [2.5]
- **Spina bifida**, a birth defect that involves the incomplete development of the spinal cord or its coverings. The term comes from Latin and literally means "split" or "open" spine; [2.6]
- **Amputations**, in which an arm or leg is removed because of an injury or disease;
- **Spinal cord injuries (SCIs),** many individuals who use wheelchairs resulting from SCIs have a series of other health impairments; [2.7] and
- **Diseases** that attack the muscular or nervous system.

2.3.1.2 Neuromuscular Impairments

Neuromuscular impairments are physical disabilities that are a major challenge. The following are some of the common neuromuscular diseases:

- **Multiple sclerosis (MS)** - a disorder of the nervous system that attacks the brain and spinal cord and causes deterioration of the nerve tissue. MS is usually associated with paralysis, muscle spasms, disorders of speech, and tremors of the hand. [2.8]
- **Amyotrophic lateral sclerosis (ALS, also referred to as Lou Gehrig's disease**) - the disorder causes muscle weakness and atrophy throughout the body caused by degeneration of the upper and lower motor neurons. Unable to function, the muscles of the entire body weaken and atrophy until death. [2.9]
- **Polio** - a disease that kills nerve tissue in the spinal cord, which causes a high fever and paralysis of different muscles. [2.10]
- **Parkinson's disease** - a progressive disorder of the nervous system that affects movement. It develops gradually, often starting with a barely noticeable tremor in just one hand. While tremors may be the most well-known sign of Parkinson's disease, the disorder also commonly causes a slowing or freezing of movement. [2.11]
- M**uscular dystrophy (MD) -** a disease that is inherited, incurable, and often life-threatening and that affects the limbs and trunk muscles. The worst type causes the person to waddle or have a swaying gait. A person with MD may walk on his or her toes and have difficulty getting up from the floor. [2.12]

These impairments have a progressive/degenerative component, which implies that the condition will worsen over time regardless of the treatment.

2.3.1.3 Respiratory Impairments

The major respiratory impairments that are listed under Chronic Obstructive Pulmonary Disease (COPD) include asthma, chronic bronchitis, and emphysema. [2.13]   One of the most common diseases is exercise-induced asthma (EIA). For example, residents with EIA may exhibit none of the impairments when they leave the sleeping area but as they walk to the restroom or cafeteria may have a full blown EIA attack. There is also a hereditary respiratory impairment known as cystic fibrosis.

2.3.1.4 Aging-Related Impairments

The fastest-growing segment of the population in the United States is in persons over the age of sixty-five. As the population grows older, the number of impairments associated with aging will likely increase. Some of these disorders include Parkinson's disease, stroke, Alzheimer's disease, arthritis, fibromyalgia, and osteoporosis.

2.3.1.5 Three Types of Paralysis[2.14]

Paraplegia –the paralysis of the lower extremities and part or all of the trunk muscles. Usually there is a loss of sensation in paralyzed limbs and other effects such as muscle spasms, pain, and loss of bowel and bladder control.

Quadriplegia –paralysis is caused by damage to the spinal cord. This will cause impairment to the hands and arms in addition to the effects of paraplegia.

Hemiplegic – a paralysis of one side of the body as a result of a stroke or traumatic brain injury that should not be confused with paraplegia or quadriplegia. With quadriplegia and paraplegia, the brain is not affected. With hemiplegic, there may be an impairment of intellect, personality, speech, or senses in addition to the paralysis.

2.4.3 Mandatory Services for People with Physical Disabilities

As you learned in the last module, The Stafford Act[2.15] and Post-Katrina Emergency Management Reform Act (PKEMRA)[2.16], along with federal civil rights laws, mandate integration and equal opportunity for people with physical disabilities in general population shelters. The U.S. Department of Justice has provided guidance to state and local governments advising that people with physical disabilities should be housed in these shelters even if they are not accompanied by their personal care provider(s).

The above paragraph is important for you to understand because during emergencies or disasters, many personal care providers evacuate or shelter with their own families instead of staying with their residents. Shelter workers may be called upon to provide support services in general population shelters to accommodate people with physical disabilities who are not medically fragile but need some assistance with ADL unless doing so would impose an undue financial and administrative burden. Depending on the services required, such assistance may be best provided by trained workers.

2.4.3.1 Personal Assistance Services (PAS) in General Population Shelters

Every day, Americans provide extraordinary levels of assistance to individuals of all ages and situations. Formal and informal Personal Assistance Services (PAS) are provided in virtually every community to children and adults with physical disabilities who have functional and access needs to maintain their independence and fully participate in all aspects of home and community life. The FEMA 2010 *Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters*[2.17] discussed in Module One was created to ensure that children and adults with disabilities are appropriately accommodated and PAS are provided in general population shelters.

Personal Assistance Services (PAS) are formal and informal services provided by friends, family members, **and workers** that enable children and adults to maintain their usual level of independence in a general population shelter. These services (when necessary) may include, but are not limited to, assisting with:
- Basic personal care:
  - Grooming and eating
  - Bathing and toileting
  - Dressing and undressing

- o Walking and transferring
- o Maintaining health and safety
- Activities of daily living:
  - o Taking medications
  - o Communicating and accessing programs/services

2.5.0 Communicating with Residents with Physical Disabilities[2.18]

Positive language empowers. When writing or speaking about people with physical disabilities, it is important to put the person first. Group designations such as "crippled," "gimp," or "the handicapped" are inappropriate because they do not reflect the individuality, equality, or dignity of people with physical disabilities. Further, words like "normal" imply that the person with a physical disability is not normal, whereas "person without a disability" is descriptive but not negative. The accompanying chart shows examples of positive and negative phrases. When writing or speaking about people with disabilities, it is important to put 'people' first.

Affirmative Phrases	Negative Phrases
person with a disability	the disabled; handicapped
person who has multiple sclerosis	afflicted by MS
person with cerebral palsy	CP victim
person who uses a wheelchair	confined or restricted to a wheelchair
person with a mobility disability, daily activity limitations	crippled; lame; deformed
person who has muscular dystrophy	stricken by MD

Tips for Communicating with Individuals with Physical Disabilities:

- If possible, put yourself at the wheelchair user's eye level
- Do not lean on a wheelchair or any other assistive device
- Never patronize people who use wheelchairs by patting them on the head or shoulder
- Do not assume the individual wants to be pushed – ask first
- Offer assistance if the individual appears to be having difficulty opening a door

Remember:

- Relax
- Treat the individual with dignity, respect, and courtesy
- Listen to the individual, and do not assume he or she needs your help
- Always ask first, and do not do anything without permission

2.6.0 Assisting Residents with Physical Disabilities at the Registration Area and Intake Form Completion Process[2.17]

As a shelter worker, it may be necessary for you to assist a resident who is mobility impaired in the initial registration process. If you must complete or assist in this process, it may be necessary to move away from the main registration area to another area that does not have as many distractions. Then complete the registration process in a timely manner.

Remember, individuals are not required to provide information about their impairment or functional or access needs, but the opportunity to provide that information must be given. As a worker you should include specific strategies for complying with the legal mandate that people with disabilities must be able to access the same programs and services as the general population. An individual request for an accommodation, based on a physical disability, should be provided even if not requested during the registration or initial intake form process.

2.6.1 The Intake Form Completion Process Considerations

Remember to use the communication skills presented in Section Five above as you collect and record the information about the shelter resident with whom you are working. Remember there is no "One-Size-Fits-All" – people do not all require the same assistance and do not all have the same needs. As a worker you may want to familiarize yourself with the forms being used to register and collect detailed information about shelter residents. An example of an American Red Cross and U.S. Department of Health and Human Services *Initial Intake and Assessment Tool* is shown in Figures 1 & 2 below. This form is used to obtain information about all families or single individuals (if by themselves) once they are settled in the shelter.

INITIAL INTAKE AND ASSESSMENT TOOL - AMERICAN RED CROSS - U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Date/Time: _____ Shelter Name/City/State: _____ DRO Name/#: _____

Family Last Name: _____

Primary language spoken in home: _____ Does the family need language assistance/interpreter?: _____

Names/ages/genders of all family members present: _____

If alone and under 18, location of next of kin/parent/guardian: _____ _____ If unknown, notify shelter manager & interviewer initial here: _____

Home Address: _____

Client Contact Number: _____ Interviewer Name (print name): _____

INITIAL INTAKE	Circle	Actions to be taken	Include ONLY name of affected family member
1. Do you need assistance hearing me?	YES / NO	If Yes, consult with Disaster Health Services (HS).	
2. Will you need assistance with understanding or answering these questions?	YES / NO	If Yes, notify shelter manager and refer to HS.	
3. Do you have a medical or health concern or need **right now**?	YES / NO	If Yes, stop interview and refer to HS immediately. **If life threatening, call 911.**	
4. Observation for the Interviewer: Does the client appear to be overwhelmed, disoriented, agitated, or a threat to self or others?	YES/ NO	**If life threatening, call 911.** If yes, or unsure, refer immediately to HS or Disaster Mental Health (DMH).	
5. Do you need medicine, equipment or electricity to operate medical equipment or other items for daily living?	YES / NO	If Yes, refer to HS.	
6. Do you normally need a caregiver, personal assistant, or service animal?	YES / NO	If Yes, ask next question. If No, skip next question.	
7. Is your caregiver, personal assistant, or service animal inaccessible?	YES / NO	If Yes, circle which one and refer to HS.	
8. Do you have any severe environmental, food, or medication allergies?	YES / NO	If Yes, refer to HS.	
9. Question to Interviewer: Would this person benefit from a more detailed health or mental health assessment?	YES / NO	If Yes, refer to HS or DMH.	*If client is uncertain or unsure of answer to any question, refer to HS or DMH for more in-depth evaluation.
(STOP) **STOP HERE!** (STOP)	REFER to:	HS Yes ☐ No ☐ DMH Yes ☐ No ☐	Interviewer Initial ____

DISASTER HEALTH SERVICES/DISASTER MENTAL HEALTH ASSESSMENT FOLLOW-UP

ASSISTANCE AND SUPPORT INFORMATION	Circle	Actions to be taken	Comments
Have you been hospitalized or under the care of a physician in the past month?	YES / NO	If Yes, list reason.	
Do you have a condition that requires any special medical equipment/supplies? (Epi-pen, diabetes supplies, respirator, oxygen, dialysis, ostomy supplies, etc.)	YES / NO	If Yes, list potential sources if available.	
Are you presently receiving any benefits (Medicare/Medicaid) or do you have other health insurance coverage?	YES / NO	If Yes, list type and benefit number(s) if available.	
MEDICATIONS	Circle	Actions to be taken	Comments
Do you take any medication(s) regularly?	YES / NO	If No, skip to the questions regarding hearing.	
When did you last take your medication?		Date/Time.	
When are you due for your next dose?		Date/Time.	
Do you have the medications with you?	YES / NO	If No, identify medications and process for replacement.	

INITIAL INTAKE AND ASSESSMENT TOOL - AMERICAN RED CROSS - U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES			
HEARING	Circle	Actions to be taken	Comments
Do you use a hearing aid and do you have it with you?	YES / NO	If Yes to either, ask the next two questions. If No, skip next two questions.	
Is the hearing aid working?	YES / NO	If No, identify potential resources for replacement.	
Do you need a battery?	YES / NO	If Yes, identify potential resources for replacement.	
Do you need a sign language interpreter?	YES / NO	If Yes, identify potential resources in conjunction with shelter manager.	
How do you best communicate with others?		Sign language? Lip read? Use a TTY? Other (explain).	
VISION/SIGHT	Circle	Actions to be taken	Comments
Do you wear prescription glasses and do you have them with you?	YES / NO	If Yes to either, ask next question. If No, skip the next question.	
Do you have difficulty seeing, even with glasses?	YES / NO	If No, skip the remaining Vision/Sight questions and go to Activities of Daily Living section.	
Do you use a white cane?	YES / NO	If Yes, ask next question. If No, skip the next question.	
Do you have your white cane with you?	YES / NO	If No, identify potential resources for replacement.	
Do you need assistance getting around, even with your white cane?	YES / NO	If Yes, collaborate with HS and shelter manager.	
ACTIVITIES OF DAILY LIVING	Circle	Ask all questions in category.	Comments
Do you need help getting dressed, bathing, eating, toileting?	YES / NO	If Yes, specify and explain.	
Do you have a family member, friend or caregiver with you to help with these activities?	YES / NO	If No, consult shelter manager to determine if general population shelter is appropriate.	
Do you need help moving around or getting in and out of bed?	YES / NO	If Yes, explain.	
Do you rely on a mobility device such as a cane, walker, wheelchair or transfer board?	YES / NO	If No, skip the next question. If Yes, list.	
Do you have the mobility device/equipment with you?	YES / NO	If No, identify potential resources for replacement.	
NUTRITION	Circle	Actions to be taken	Comments
Do you wear dentures and do you have them with you?	YES / NO	If needed, identify potential resources for replacement.	
Are you on any special diet?	YES / NO	If Yes, list special diet and notify feeding staff.	
Do you have any allergies to food?	YES / NO	If Yes, list allergies and notify feeding staff.	
IMPORTANT! HS/DMH INTERVIEWER EVALUATION			
Question to Interviewer: Has the person been able to express his/her needs and make choices?	YES / NO	If No or uncertain, consult with HS, DMH and shelter manager.	
Question to Interviewer: Can this shelter provide the assistance and support needed?	YES / NO	If No, collaborate with HS and shelter manager on alternative sheltering options.	
NAME OF PERSON COLLECTING INFORMATION:	HS/ DMH Signature:		Date:

2.7.0 Assisting Residents with Physical Disabilities at the Sleeping Area[2.17]

Placement of residents with physical disabilities in the sleeping areas needs to reflect planning to address the access issues associated with mobility devices. Cots and other furniture items should be placed in such a way that routes are accessible to people who use wheelchairs, crutches, or walkers.

When available, cots for these residents need to meet the requirements listed below.

A universal/accessible cot that meets the following recommended criteria:
- Height: 17"-19" without the mattress
- Width: minimum 27"
- Weight capacity: 350+ pounds
- Flexible head and feet position
- Rails, if any, must be positioned or moveable in such a way as to allow for wheelchair access

2.8.0 Assisting Residents with Physical Disabilities at the Eating Area

PAS in the eating area will depend on the severity and type of physical disability. Typical functions include ensuring that there are spaces at tables reserved for those using a wheelchair or other mobility devices, transporting food to tables, and assisting with eating. Remember to offer assistance, but do not insist or be offended if your offer is not accepted.

2.9.0 Assisting Mobility-Impaired Residents at the Recreation Area

Access to the recreation area is important because the disaster or emergency may confine people from going outside. The recreation area may vary from a few tables set up for puzzles or games to a gymnasium with basketball goals, a music system, or a TV and video player. This area will be used for children to expend their energy by running and playing indoors. People with physical disabilities should have full access to the area and may not need any special services or assistance in this area.

2.10.0 Advice from Shelter Managers

According to the forty-five shelter managers who completed the survey, the most common disabilities encountered in a shelter will be people with physical disabilities. When asked which disability needs were challenging for workers, they responded that the needs of people with physical disabilities were sometimes challenging, but not the most challenging. When asked what area in the shelter was the most challenging for people with physical disabilities, they stated the sleeping area. Finally, when asked to provide extra information for workers who assist people with physical disabilities, they provided the following:

- Most residents will work with you if you take their needs seriously.
- Treat their accessory (wheelchair, canes, or walkers) as part of them.
- Treat them like everyone else; see their abilities first.
- Realize they have feelings and are stressed like everyone else.
- Allow them to do as much as possible by themselves.
- Do not treat them like children with your mannerisms or speech.
- Ask them what they need and listen to their answer – do not assume.
- Let them know what to expect (what is the routine) while in the shelter.
- Do not assume they need the mobility device always; you may see them walking without it.
- A physical disability does not mean a mental illness; however, a person in a wheelchair may also have another disability type.
- Ask the resident if he or she needs PAS with daily activities.
- Use them as workers if they ask to help and if you need workers.
- Be compassionate and patient.

2.11.0 Summary

Shelter residents with physical disabilities are people first and have abilities and then disabilities. Offer assistance, but do not insist or be offended if your offer is not accepted. Those with daily activity limitation impairments may require PAS for daily activities that we take for granted. Etiquette considered appropriate when interacting with people with disabilities is based primarily on dignity, respect, and courtesy.

End Notes Module 2

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[2.4] Executive Order 13347—*Individuals with Disabilities in Emergency Preparedness*, Retrieved 12/10/2010 from: http://edocket.access.gpo.gov/2004/pdf/04-17150.pdf

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3.1.0 Introduction to the People with Sensory Disabilities Module

Some of the people you will help when working in a shelter will be people with sensory disabilities. Sensory disabilities are often what are known as "invisible disabilities". That means that you may not be able to easily tell if a person has a disability. There are three main types of sensory disabilities that you may encounter: hearing, visual and deaf-blind. There are also some other sensory disabilities that you may encounter that are less common but are still things of which you should be aware. It is important that you know that disabilities are not all-inclusive. There can be many degrees to which a person may have a disability and many ways in which they may overcome it. This module will help you gain an understanding of what you can do to best facilitate a person with a sensory disability.

3.2.0 Objectives

1. Understand how to recognize a person with a sensory disability.
2. Understand how sensory disabilities vary.
3. Learn how to communicate with people with sensory disabilities.
4. Learn how to assist a person with a sensory disability in all aspects of the shelter.

3.3.0 Hearing Disabilities[3.1]

As of 2008 there were more than thirty-five million people in the U.S. who have some degree of hearing loss[3.1], which encompasses 11.3% of the population. There are many degrees of hearing loss, from having slight troubles hearing a quiet conversation to full loss of hearing. There also is a difference between hard of hearing and being deaf. Hard of hearing can range from a near total loss of hearing to minor hearing loss.[3.2] Deaf is used to refer to a person whose sense of hearing is nonfunctioning for the purposes of communication and whose primary means of communication is visual[3.2]. Persons who strongly identify themselves with a Deaf culture and communicate primarily in sign language may refer to themselves as Deaf with a capital "D". [3.2]

Hearing loss can be affected in the following ways. A person can lose the ability to hear loudness or the loss of a specific frequency. There are three main types of hearing loss. They are Conductive, Sensorineural and Mixed hearing loss. [3.3]

- **Conductive hearing loss**[3.4]– caused by disease or obstructions to the outer or middle ear. It typically results in hearing at a reduced sound level. It is often treated medically or with surgery.
- **Sensorineural hearing loss**[3.5] – caused when there is damage to the inner ear or to the nerve pathways to the brain. Some of the causes are illness, aging, hereditary, or a head

injury. It often affects a person's ability to hear certain frequencies. It may be corrected surgically with bone-anchored hearing aids (BAHA) or cochlear implants. It may be treated with hearing aids to amplify and augment whatever sounds a person is still able to hear, or, it may not be treated at all. Understand that nothing completely restores a person's hearing to normal…it is not like seeing 20-20 with the right pair of glasses. Hearing loss often affects a person's ability to hear certain frequencies more than others. That means that even with a hearing aid, a person will still be unable to hear certain things. Sensorineural hearing loss is the most common form of permanent hearing loss. Sometimes the loss of hearing due to the nerve connection is known as central hearing loss.

- **Mixed hearing loss**[3.6] – This is the term to use when a person has both conductive and sensorineural hearing loss.

Hearing loss does not always affect a person's ability to speak. Please keep in mind that hearing loss in general, and whether or not the person with hearing loss speaks, does not necessarily indicate the intelligence level. However, you may need to have a person repeat himself to fully understand what he is saying.

A person who is deaf or hard of hearing may or may not identify him- or herself as such when you first meet them. If they do not, you may be able to recognize people with hearing loss by some of the equipment they use. They may have a hearing aid or a cochlear implant, both of which you will read about in the next section. However, they may not have any devices. You may be able to identify someone with hearing loss if they keep having you repeat a question or seem to be answering questions incorrectly. Also an individual asking you to repeatedly speak louder or clearer is another indication that a person may have a hearing disability.

3.3.1 Ways to Help the Deaf and Hard of Hearing Communicate

People who are deaf or hard of hearing may use services or devices to help them communicate.

3.3.1.1 How People who are Deaf or Hard of Hearing Communicate

There are many services people with hearing loss have to help improve their ability to communicate. Here are some of the ways they may use.

Sign language[3.7] **:** A complex language which uses the hands to represent words or letters. There are hundreds of kinds of sign language. The most commonly used sign language in the U.S. is American Sign Language, also known as ASL. ASL is not a direct word-for-word translation of English. It is a visual and symbolic language that is actually closer in resemblance to French in its sentence structure and grammar than it is to English. All persons who are deaf do not use sign language to communicate. Approximately 10% of persons with hearing loss do use sign language as their primary language.

You may be fortunate enough to have an ASL picture board of signs commonly used in the sheltering environment. If you do, you can point to pictorial representations of the signs to attempt to communicate briefly with the person, i.e. ask if they are hungry, or sick or injured, etc.

Lip Reading[3.8] **(also known as speech-reading):** While some people who are deaf can read lips to some extent, it is not nearly as effective as commonly believed. It is considered rude (and illegal) to insist that a person who needs sign language to communicate to lip read instead. Only about 30% to 40% of the English language is conveyed through the lips and even the best lip reader will catch less than 30% of what is being said. Lip readers will often have to make educated guesses to understand what is being said in context. When you encounter a person who is lip reading, make sure to speak normally. Do not try to exaggerate the enunciation of your words; this will not help, and, in fact, it will make it harder to understand you.   Also, if necessary, you will want to keep your facial hair trimmed away from the lips and avoid shadows on your face.

And finally, if all else fails, you can try writing short and concise notes. Just be aware that the reading comprehension of people whose first language is sign language may be reduced. However, you may encounter a great many people with hearing loss whose first language is English and not sign language. Approximately 90% of persons with hearing loss fall into this category. These people will NOT be able to understand sign language and will require text translations of anything they need to know.

Persons who are deaf or hard of hearing AND whose primary language is English may request CART, which stands for Communication Access Real-time Translation. CART is the underlying technology behind closed and open captioning. As the name implies, it is an instantaneous translation of the spoken English word to the written English word. Now that we have covered services used by people with hearing disabilities, let us look at technologies used by them.

3.3.1.2 Devices Used to Help People who are Deaf or Hard of Hearing

There are many technologies people with hearing loss use to help improve their hearing. They are commonly known as Assistive Services and Technology. A legal term you may often hear is Auxiliary Aids and Services. They refer to the same thing. Persons with hearing loss may use multiple services and technologies to help facilitate their listening.   Here is a list of some of the services and technology they may use.

- **Hearing aids**[3.9]**:** Devices worn in or behind the wearer's ear. They help amplify and modulate sound. Just because someone has a hearing aid does not mean they will have perfect hearing. You may still need to repeat yourself at times. Hearing aids are more common in people with lower levels of hearing loss. As shown in the pictures, the hearing aid can be inside or behind the ear.

Two types of hearing aids
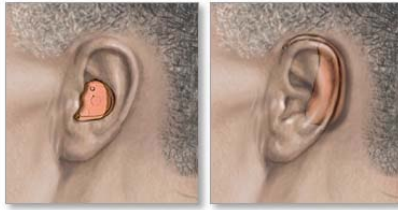
* **Cochlear Implants**[3.10]**:** Cochlear implants are often used by people with more severe sensorineural hearing loss who are unable to be benefitted by conventional hearing aids. Different from hearing aids, these are devices that convert analog sound waves into digital and electrical signals that then directly stimulate the cochlea and auditory nerve inside a person's head. They consist of two parts, an external processor attached to a person's head by way of a magnetic plate embedded beneath a person's scalp and a surgically implanted internal processor inserted through the mastoid bone into the inner ear.

* **Telecoil**[3.11] **(T-coil):** Telecoils are most often used in conjunction with hearing aids and cochlear implants. The T-coils are electromagnetic coils inserted into hearing aids and cochlear implants that receive electromagnetic signals directly from a sound source. To the wearer of hearing aids and cochlear implants that have t-coils, it sounds like the sound is being transmitted directly into their ears from the sound source.

Not all hearing aids are equipped with t-coils. Approximately 60% of the hearing aids currently being purchased are large enough to have room for a t-coil. Those that have t-coils enable their users to connect directly with the electromagnetic signals found in t-coil compatible telephones, assistive listening devices such as pocket talkers and personal FM systems, and a whole host of other technologies. There are portable assistive listening systems that can be worn around the neck, called neck loops, and they work in conjunction with the t-coils in hearing aids and cochlear implants. They can be plugged into devices such as telephones to boost the clarity and volume of the signal.

- There are also some electromagnetic systems that are integrated into the architecture of buildings, often in the floor. These systems are known as hearing loop systems[3.12]. They are becoming a more common occurrence where large groups are known to gather, such as in auditoriums, school cafeterias, or gyms, which are places where shelters may be located. A person inside the loop switches on their t-coil and their hearing aid or cochlear implant instantly picks up the sound directly from the building's sound system. You will be able to identify a building where a hearing loop system is installed by this sign.

- Pocket talkers are personal amplification devices a person can use to amplify a conversation they are attempting to hear one on one with a single speaker close up. Depending on the type of headset selected (headphones or neck loop); they can be used by persons with or without hearing aids.
- Personal FM systems are more powerful personal amplification systems that can accommodate speakers at greater distances, such as around a table or in a classroom. Depending on the type of headset selected (headphones or neck loop); they can be used by persons with or without hearing aids.

- **Teletypewriter (TTY) or telecommunication device for the deaf (TDD)**[3.13]**:** A TTY or TDD is an electronic device for text communicating over a telephone line, used when one or more of the parties has hearing or speaking difficulties. The typical TTY is a device about the size of a typewriter or laptop computer with a QWERTY keyboard and small screen that displays the text of the live conversation. In addition, TTYs commonly have a small spool of paper for printing the conversation. There are also capabilities that enable people who can hear but cannot speak, or people who cannot hear but are able to speak to use the telephone.

3.3.2 "Deaf" versus "deaf"[3.2]

While two people who have the same level of hearing loss may be both considered deaf, they may not see each other in the same light. There is a big difference between big "D" Deaf and little "d" deaf. Little "d" deaf is the loss of hearing, while big "D" Deaf is who you are. They often do not consider themselves as disabled at all. In fact, many will refuse receiving assisted listening devices or cochlear implants. Deaf is a total culture similar to being a nationality, though they will often still identify themselves by their native nationality. An example would be a Deaf person born in the U.S. may consider themselves a Deaf American. They often speak only using sign language. In some cases they may not be able to communicate with you via written English because there is a big difference between English and ASL. If there is no one to act as a signer, you can try communicating by using mime, other hand gestures or point to pictures on a message board to try to convey your point.

3.4.0 Assisting the Deaf and Hard of Hearing in the Shelter

3.4.1 Registration and Intake Form Completion

This will likely be your first contact with all the people coming to your shelter, which means it will also be your first contact with a person with a sensory disability. This will also be when you will have to use your communication skills the most. Most of the time you can use your common sense to help assist people. Here are some things you can do to make it easier for you.

- Speak clearly, slowly, and directly to the person with the disability.
- Maintain eye contact with the person you are talking to even if an interpreter is present.
- Use hand and facial gestures to help bring about the point for what you are saying.
- Only speak louder if the person you are talking to asks you to. Speaking louder sometimes makes it actually harder for a person with an assisted listening device to hear you because it distorts things.
- Do not feel bad about repeating yourself if asked. However, if you must repeat yourself, try to repeat word-for-word what you are saying. If two repeated attempts fail to gain comprehension, try rephrasing the question or comment in a different way. Short sentences of five-six words usually work best.
- Try to find a quieter location to talk to the person, if necessary. Sometimes background noise can be distracting and make it harder to communicate.
- Try to find someone who can act as a sign language interpreter for you.
- If you cannot find someone to sign, you may try passing notes back and forth.
- You may be able to have the person read the intake forms with you and point to the answers that apply to them.

- Have a Shelter Message Board for communicating major items to all residents.

Be aware that the limited English proficiency of a person who communicates in sign language may make the shelter intake form too difficult for them to comprehend. This in no way reflects on their intelligence level or mental status. It simply reflects their limited English proficiency and they may require extra help to understand the questions on the form.

3.4.2 Sleeping and Living Areas

The sleeping and living areas are where you will have the most prolonged contact with the shelter residents. Many of the same skills you use in the Registration and Intake Form area remain valid for this area. However, some additional skills you may need are as follows:

- If you need to get the attention of someone not facing you, tap him or her gently on the shoulder or arm, and if possible flick the lights.
- If possible it is a good idea to provide a person with a sensory disability with a flashlight. In the event of a power loss, this will help them find their way around and will also assist in lip and sign reading.
- Try to find places that are away from excessive background noise to talk with an individual.
- If there is a loop system in place, set up cots inside the loop and designate them for people with deaf and hearing disabilities.

3.4.3 Dining Areas

Again you can use the same skills you have previously learned to assist you in the dining areas. Here are some other specific skills that you can use. Again, most of these are common sense.

- Have the person gesture to what foods he or she may want.
- If you are eating at the same time, make sure you do not talk to them with your mouth full.

Remember that no matter what happens, it is best to stay calm and have patience. With a little bit of creativity you will find a way to communicate.

3.4.4 Recreation Area

A person with a hearing disability can still enjoy most recreational activities. If the recreation area has a TV, make sure the closed caption feature is turned on.

# 3.5.0 People with Visual Impairments

3.5.1 Visual Acuity[3.14]

Visual acuity is the way a person's vision is measured. It is determined by having a person read the smallest letters on a chart at a distance of twenty feet. An example of a person who has 20/60 vision is a person who can read the smallest letters from twenty feet away that another person could read at sixty feet away.

3.5.2 Visual Impairment and Blindness[3.15]

As with hearing loss, there are also many degrees of vision loss. They can range from someone who needs the assistance of glasses when reading to one who has a total blindness.

There are various types of visual impairments; they are as follows:

- **Partially sighted:** Is the overall term used to describe those who are not totally blind but still have some impairment even with corrective lenses.
- **Low vision:** Is a severe visual impairment. A person with low vision may be unable to read a newspaper from a short distance even with the assistance of corrective lenses. However, it does not always involve having a problem seeing from distances, but can also have to do with a person's viewing angle (also known as visual field). The average visual field is 180°, and a person with low vision could have a visual field as small as 20°. Below is a basic example of the degree to which a person's visual field may be affected. It should be noted that the impairment of the visual field may not be from the center of the eye. An individual may only have 20° of vision on the peripheral and have a complete blackout in the middle of his or her vision.
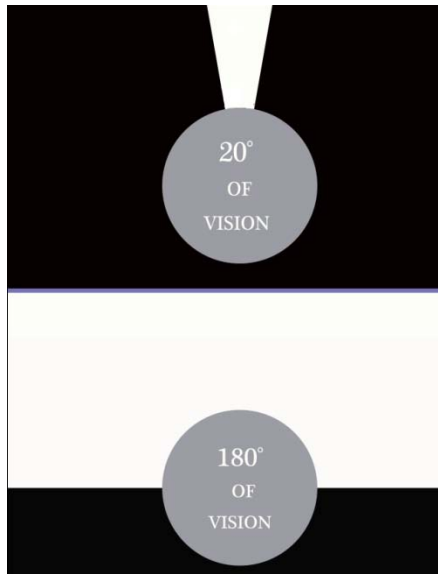
- **Legally Blind:** A person with a visual acuity of greater than 20/200 and a visual field smaller than 20° when using corrective lenses.
- **Total Blindess:** A person who has a 20/400 visual accuity or worse when using corrective lenses or someone with less than 10° visual field. Often it is a total loss of vision. Nearly 10% of people who are legally blind have total blindess.

Visual imparment can be caused by many things. The most common causes of blindess are cataracts, glaucoma, or macular degeneration. It can also be caused by injury, genetic defects, or poision. Injury is the leading casue of monocular blindess (loss of vision in one eye) in people under the age of thirty.

As with a person who is deaf or hard of hearing, people with a visual imparment may inform you of it when you first meet them. However, if they do not, there are some things you can look for. They may be wearing dark glasses, carrying a white cane, or both. A white cane with a red stripe is the internationl symbol of the blind. A visually impaired person who is unsure of where he or she is may be standing in one spot and not moving for an extended periof of time.

3.5.3 Accessories Used by People with Visual Disabilities

People who are visually impaired have many options when it comes to being able to get around. Many people's vision can be corrected using glasses or contact lenses. However, when those are not enough to assist a person's vision, he or she may use one of the devices below to assist in getting around. A visually impaired person may use more than one device. Sometimes he or she will use none.

- **White Cane:** There are many models of the white cane; however, the most common is called the long cane. It is white with a red stripe on the bottom. Most often the cane extends from the user's chest to the floor. Sometimes they will be collapsible.
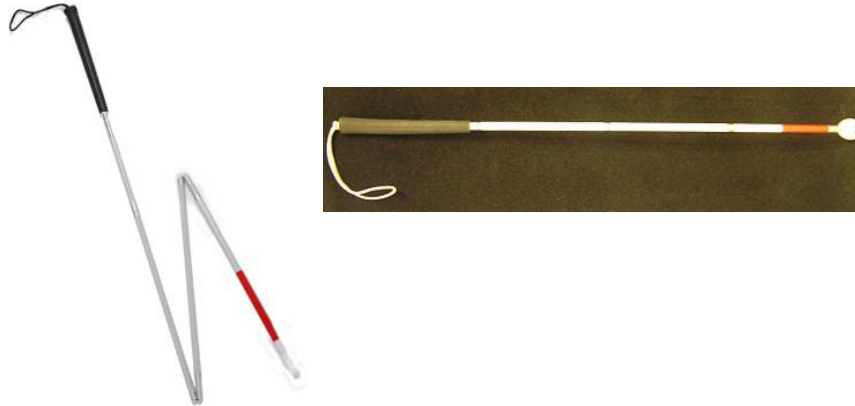
The white cane can also be used as a symbol of a person who is blind. There is a model of cane that is used primarily as an identification device. It is often shorter and much lighter than a long cane. The identification cane often is not used for mobility assistance.

- **Guide Dogs**[3.16]**:** A service animal that is specially trained and used by the visually impaired to help facilitate getting around. A guide dog assists its handler/owner by getting him or her somewhere safely. The dog does not necessarily know where it is going, but it does know which obstacles are in the way and how to avoid them.

- **Echolocation**[3.17]**:** A visually impaired person may use sound to help him or her move around. People may make a sound by tapping their cane, stomping their foot, or most often making a clicking sound with their mouth. They will then listen to how the sound reflects back to them and will know how to navigate. It is very similar to how bats fly and submarines navigate the seas by sonar. Echolocation is not very common, but its use is growing.

With permission, a visually impaired person may also be led by another person. <u>It is considered rude to take a person by the hand or arm and lead them around without permission.</u> If you must guide a person out of danger, have them place a hand on your shoulder or arm.

3.5.4 Reading

Visually impaired people have many options when it comes to being able to read when glasses or contact lenses are not enough. As with getting around, they will often use more than one device in order to assist their reading abilities.

- **Braille**[3.18]**:** A system of six raised dots in two columns of three dots each. A trained user will run his or her finger over a line of dots in order to read what is written on the page. You may be surprised to know that Braille is not as common as you may suspect. Approximately 10% of blind adults use Braille as their main form of reading.
- **Text-to-Speech:** Also known as talking books or reading machines. There are many ways a person could get audio versions of written materials. There are also machines that can scan the words written on paper or a screen and then translate them into digital spoken words. Sometimes the words that are converted from text-to-speech are not pronounced properly and will require some clarification.
- **Magnification:** There are many ways an image or piece of text can be magnified so that a visually impaired person can read it. In the past it was done using cameras to project a high contrast image with greatly enlarged text onto a screen. Now it is done using computers to scan documents and enlarge the type, making it easier to read. The same thing is done in large-print information.

3.6.0 Assisting People with a Visual Disability

3.6.1 Registration and Intake Form Completion

As with the deaf and hard of hearing, this will likely be your first contact with all the people coming to your shelter, which means it will also be your first contact with a person with a visual disability. This will also be when you may have to use your communication skills the most. Most of the time you can use your common sense to assist people. Here are some things you can do to make it easier for them.

- If you have Braille registration sheets and shelter rules, you can use them.
- You may also be able to use large-print documents.
- If either of those is unavailable, you or a caregiver can read the information to the person while the shelter worker completes the form.
- If they do not have a cane or guide dog you can have them place a hand on your shoulder or arm and guide them around. Explain where you are going as you walk and alert them to any obstacles that are in the way.

3.6.2 Sleeping and Living Area

- Again, make sure you introduce yourself and those in the surrounding area.
- It is best to locate the cot of a person with a visual disability in the corner of the sleeping space. This will allow them to have a wall as a reference to judge the distance of the cot from the corner.
- When you first show them to their cot, also show them all the routes to the areas where they may need to go such as the bathroom, dining, and recreation areas.

3.6.3 Dining Area

- Introduce yourself when the resident comes through the line.
- Describe to the person what foods are available.
- When you serve the food, place the foods in a certain location on the tray and/or plate, and inform the resident of the locations of the food on the plate.
- If need be, guide the resident to a seat and place the person's hand on the back of the chair or tell him or her when they have arrived at the table if it is lunch room/bench seating.
- Do not forget to introduce them to others at the table.

3.6.4 Recreation Area

- There are games that people with a visual disability can play. If possible, have them available so these residents can enjoy their stay as much as possible. Music and TV may help calm them as well.

3.7.0 People with a Deaf-Blind Disability[3.19]

There are approximate seventy to one hundred thousand (about .4% of the U.S. population) deaf-blind individuals in the U.S. Their vision and hearing loss may be partial or total; it does not matter. If the vision and hearing loss interferes with major activities of daily life, the term deaf-blind is appropriate. Persons who are deaf-blind will use many of the same assists that people who are blind use and that people who are deaf or hard of hearing use. They may have hearing aids or cochlear implants and may use a cane or service animal to move around. They also may use large-print text or magnifiers to read items. When interacting, you will use many of the skills you used with people who are deaf or hard of hearing as well as people with visual impairment. However, there are some notable exceptions.

- Some people who are deaf-blind use a different form of sign language called tactile signing. Much like sign language, which uses hands to make representations of letters or words, tactile signing does the same. There are a couple of types of tactile signing that are in use in the U.S.[3.20]:

- o **Hand-over-hand:** The recipient's hands are placed on the back of the speaker's hands, and the motion and signs are felt by the reader. This form of tactile signing is often used in those who lose hearing first then vision later.
- o **Tracking:** Sometimes used with a person who has a limited field of vision. In this, the receiver holds the wrist of the signer so they can keep the hands in their field of vision.
- o **Tactile Finger spelling:** In this, every word is spelled out using a manual alphabet. Like hand-over-hand signing, the recipient will place his or her hand on the back of the signer. There is another subset of tactile finger spelling called the two-handed finger spelling or the Deaf-Blind Alphabet. In this, the signer will hold the wrist of the receiver's non-dominant hand and then make individual letters using symbols.
- In case of an emergency or accident you can make the "X" symbol on the back shoulder of a person who is deaf-blind. This is an indication that you are there to assist them in an emergency and will take them to safety.

Most of the time when a person who is deaf-blind arrives at your shelter, he or she will have someone there to assist.

3.8.0 People with Other Sensory Disabilities

There are many other forms of sensory disabilities. Most are not very common, but it would be good for you to know some of them in case you encounter them.

- **Face blindness:** Also known as Prosopagnosia happens when the ability to recognize faces is impaired. It was first thought that face blindness was only caused from brain damage; however, it is now believed to have a hereditary form that can affect up to 2.5% of the population to some degree. It is usually a minor condition, and people who have it learn to get around it by using other contexts to recognize people by using hair, clothes, physical mannerisms or people's voices as identifiers. However, in these instances a radical changing of hairstyle can make someone seem to be a different person. The best way to assist someone with face blindness is to wear a name tag. If you are interested in taking a face blindness test, write this website down, and take the test later: http://www.faceblind.org/facetests/index.php.
- **Color blindness:** The inability to distinguish between some colors that others may be able to clearly see. Usually color blindness is considered a minor disability. People with color blindness will often tell you they are color blind if they feel it is relevant to their current situation. The best way you can assist someone with color blindness is to identify things in other ways than using color.

- **Anosmia/ageusia:** Smell/taste disabilities. Both are pretty rare and something you may not encounter. Only if you are in a place where there is a gas leak may you need to assist someone with anosmia.

3.9.0 Advice from Shelter Managers

According to the forty-five shelter managers surveyed, they rarely had to address the needs of people with sensory disabilities in a shelter. When asked what area in the shelter was the most challenging for people with sensory disabilities, they stated the sleeping and eating area. Finally, when asked to provide information for workers who will assist people with sensory disabilities, they provided the following:

- Most residents will work with you if you take their needs seriously.
- Treat their accessory (service animals, canes, hearing aids) as part of them, and do not touch them without permission.
- Treat them like everyone else – use people first language and focus on abilities.
- If they have a service animal, do not distract it or try to pet it without permission.
- Deaf and blind does not mean dumb.
- Often their other senses are heightened, such as smell or hearing (for blind).
- Realize they have feelings, and their stress levels may be higher than others'.
- Allow them to do as much as possible by themselves; some are very independent.
- Do not treat them like children with your mannerisms or speech.
- Ask them what they need and listen to their answer – do not assume.
- Let them know what to expect (what is the routine) while in the shelter.
- Do not assume they need the accessory all the time; you may see them without it
- A sensory disability does not mean a mental illness.
- Are they with a caregiver or by themselves in the shelter?
- Do they need PAS with daily activities?
- Be compassionate and patient.
- Learn basic sign language for **thirsty** (the index finger draws a line down the throat to indicate that the throat is dry), **toilet** (the T hand sign—thumb between the index and middle finger—is shaken), **follow me** (one hand follows the other), **help** (one hand lifts the other hand up to represent the concept of assisting or helping.), **yes** (the right fist makes the "S" letter – [thumb under the fingers]and raise and lowers the fist by bending it at the wrist, and **no** (using the right hand first two fingers to firmly close them against the thumb – also shaking the head in a negative manner).

3.10.0 Summary

You should now have the skills to identify, communicate with, and assist a person with a sensory disability. It is important to remember that not all types of sensory disabilities are the same. Like everyone else, they are unique individuals with different skills and abilities. Most of the people you encounter will be comfortable with who they are and familiar with their abilities. Chances are, if you do encounter a person with sensory disabilities, he or she will have the life experiences to help you communicate. Just remember that with a little patience and a bit of creativity you should have no problem in communicating and helping, if requested.

End Notes Module 3

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4.1.0 Introduction to the Mental Illness Module

As a shelter worker, you may be directly involved with people with mental illness. Thus, it is important for you to have a general understanding of the various kinds of mental illness and how to interact and communicate effectively with individuals who are mentally ill.

4.2.0 Objectives

Upon completion of this module, you will be able to:
1. Recognize shelter residents with mental illness.
2. Explain the intake/registration processes for people with mental illness.
3. Identify the correct communicational etiquette for people with mental illness.
4. Assist people with mental illness in a knowledgeable and professional manner.

4.3.0 Recognizing Residents with Mental Illness

Mental health issues are common in the United States. However, serious mental illness (SMI) appears much less frequently in the population. Serious mental illness refers to a group of brain disorders that can profoundly disrupt a person's ability to think, feel, and relate to others and their environment. Often this results in an inability to cope with the ordinary demands of life. Symptoms and severity vary as every individual is unique.[4.1]

4.3.1 Basic Elements of Mental Illness[4.1]

There is a certain combination of basic elements that one may observe when interacting with an individual who has a mental illness. This person may exhibit only one of the following traits, or a combination of them. Each individual stands alone, and is not to be determined as having a "mental illness" solely by portraying one or a few traits. The information is to be used as a tool for helping you assess and recognize a person who may have a diagnosed mental illness. If a resident **self identifies** themselves as a person with a mental illness, you may suggest they meet with a Disaster Health Services person or a Disaster Mental Health team member. The basic elements are broken down into:

• Behavior
• Mood or Emotions
• Thought Processes
• Communication Disorders

Any one or combination of the following traits of each element may be observed in a person with a mental illness:

Sample Behaviors:
• Hyperactivity
• inactivity
• deterioration in personal hygiene
• noticeable and rapid weight loss
• drug/alcohol abuse
• forgetfulness
• loss of valuable possessions
• staring
• strange posturing
• unusual sensitivity to noise, light and clothing
• social withdrawal

Sample Mood or Emotions:
• Depression
• unrelated to events or circumstances
• loss of interest in once pleasurable activities
• expressions of hopelessness
• excessive fatigue and sleepiness or inability to sleep
• pessimism
• perceiving the world as dead
• thinking or talking about suicide

Sample Thought Processes:
• Inability to concentrate or cope with minor problems
• irrational statements
• peculiar use of words or language structure
• excessive fears or suspiciousness
• delusions (false beliefs)
• hallucinations (false perceptions-seeing, hearing, smelling or feeling things that aren't really there)

Sample Communication Disorders:
• Hostility from someone who is usually passive and compliant
• indifference
• inability to cry
• excessive crying
• inability to express joy
• inappropriate laughter

4.3.2 Categories of Mental Illness[4.2]

There are over 300 different mental or psychiatric disorders. Some common mental illnesses include obsessive-compulsive disorder (OCD), phobias, depression, bipolar, schizophrenia, autism, Asperger's syndrome, and attention-deficit/hyperactivity disorder (ADD or ADHD). They are categorized according to their main features. Rather than try to understand the various diagnoses of mental illnesses, it's most important to understand that people with mental illnesses may exhibit any of the various behaviors listed above. No matter what the specific illness is that a person deals with, all persons with mental illnesses need to be treated with respect and dignity, just as you would treat any other shelter resident.

4.3.3 Medications for Minimizing the Effects

Many people with mental illnesses take medications to minimize the effects of the mental illness. Because they are consumers of mental health services, they may refer to themselves as "**consumers**". It is important for you to determine for residents who self-declare themselves as a consumer:
  • did they bring their medications to the shelter?
  • how long will their medication supply last?
  • what are any side effects from taking the medications?
  • what are symptoms from not taking the medications?

4.4.0 Communicating with Residents with Mental Illnesses[4.3]

While each disorder may present its own means of complicating normal communication, a general set of principles may be followed and applied to individuals with any mental illness to prevent insensitivity, and enhance your objective to welcome shelter residents and provide them with peace of mind and assistance, as needed. People with mental illnesses may at times have difficulty coping with the tasks and interactions of daily life. Their disorder may interfere with their ability to feel, think or relate to others. The majority of people with mental illnesses are <u>not</u> violent. One of the main obstacles they face is the attitudes that people have about them. Because in many ways it is a hidden illness, chances are you will not even realize that the person has a mental illness at first.

4.4.1 General Communication Guidelines for Those with Serious Mental Illness:

By following these guidelines when communicating with an individual who has a severe mental illness, or anyone for that matter, you can help ensure their satisfaction and cooperation:
• Treat each person as an individual. Ask yourself what will make him/her most comfortable and respect their needs to the maximum extent possible.

• Think before you speak. Don't make assumptions; respond graciously to requests. Put the person first.
• Speak in a normal and consistent tone to all parties involved in the conversation. Do not switch tones for the person(s) you are directly speaking to. For example, do not speak slowly and in a soft tone to a shelter resident with a disability, then immediately switch to a faster and more direct tone to someone in the general population or fellow worker.
• Try to keep the pressure of the situation to a minimum. Stress can affect the person's ability to function more so than those without mental illnesses.
• In a crisis, stay calm and be supportive as you would with anyone. Ask how you can help, and find out if there is a support person who can be sent for.
• Ask before you help and be sensitive about physical contact.
• Verbalize your actions. Before asking someone to perform a task or before you involve yourself with someone else in a task, provide a detailed explanation of what you will do first. Ask for their permission and receive their consent before the activity.

4.4.2 Communicative Variations

In tandem with the above guidelines, there are several communicative variations which you will want to expect and be cognizant of before and during your conversations.

Eye Contact:
During dialogue, eye contact may be reduced or non-existent. Don't let this detract from your ability to make eye contact, but also don't be put-off by a lack of reciprocation. If you sense you are making excessive eye contact (as evidenced by your assessment of their relative level of comfort), look at something else nearby and be sure to give them an occasional smile and/or nod of agreement to remind them that you are having a non-hostile conversation.

Variable Degrees of Social Interaction:
Among people with mental illnesses, you will encounter variable degrees of social interaction. At times, they may not be fully aware of what they're saying to you, or the purpose of why they're speaking aloud. These occasional verbalizations will not always require direct feedback or a response from you. Allow them time to talk it out and respond only as needed.

Direct/Literal Communication:
Some may choose to comment in very literal and seemingly insulting terms. For example, if you weigh more than a fellow worker, they may plainly comment that you are much larger than the person standing next to you. They are making an observation of an object within their environment (you and your colleague) and lack a social filter. You may feel self-conscious about such matters, but do not mistake these replies as a personal attack.

Routines and Deviations from Routines:
A set routine is very important to some. If they do not recognize you as part of their routine and your presence then becomes a significant portion of their day, the result may manifest in a lack of cooperation or social interaction. Your best defenses in this situation is to always introduce yourself, verbalize all your actions beforehand, and always remember to ask for confirmation that they understand and/or accept your request. A sibling, guardian, family member or significant other may be able to assist in your introduction and communication to ease the shelter

resident's stress from this break in their routine. If cooperation is not feasible, do not push the matter further.

Volume of Voice:
When engaged in conversation, some residents may become frustrated or excitable when trying to form words together or ask something. As a result, they may not monitor the volume of their voice. Do not directly tell residents that *they* are talking too loud, but rather tell them that your ears are sensitive and ask if they can please talk a little softer. Explain that it's okay and that we all sometimes talk in a higher volume when we're frustrated or excited.

Also, people who have mental illnesses have symptoms and characteristics that require adaptations in the way you communicate to increase your chances of being understood. The follow table shows common symptoms of mental illness and corresponding adaptations. Realize that in times of stress such as the situation which brought the person to the shelter, these symptoms and characteristics may become enhanced, so it is especially important that workers be trained in how to respond appropriately.

Symptom or Characteristic	Appropriate Response or Action
Confusion about what is real	Be simple and straightforward
Difficulty in concentrating	Be brief, repeat
Over-stimulation	Limit input; don't force discussion; create a "quiet area" in the shelter
Poor judgment	Don't expect rational discussion
Preoccupation with internal world	Get attention first
Agitation	Recognize agitation and allow the person an exit
Fluctuating emotions	Don't take words or actions personally
Little empathy for others	Recognize as a symptom
Fluctuating plans	Stick to one plan
Withdrawal	Initiate conversation
Belief in delusions	Don't argue
Fear	Stay calm
Insecurity	Be sincere, caring and accepting
Low self-esteem	Stay positive and respectful

Adapted from Rothman, J.C. (2003). *Social Work Practice Across Disability*. 1 NY: Allyn and Bacon.

4.5.0 Assisting Residents at the Registration Area and Intake Form Completion Process

4.5.1 The Registration Process Considerations

When your shelter residents arrive to register, they will be making their first contact with you directly after the event that brought them to you. At this time, these individuals may be more emotionally unstable. Your presence should radiate the very sense of calm that they may be lacking at that time. Understand that some may choose not to speak with you at all. Alternatively, they may be very literal and express whatever's freshest in their mind. If they approach you and say something unexpected, treat them with respect, listen and point them in the right direction for the registration process. Be cautious and don't take any belongings away from them at this sensitive time. If the object is something you must take away from them for security purposes, tell them what you're doing, why you're doing it and (if appropriate) that they will get the item back after exiting the shelter. It may be necessary to escort them to a quiet area to gain their initial information before showing them to the rest of the shelter.

4.5.2 The Intake Form Completion Process Considerations

When communicating with anyone involved in a crisis, it's important to take into consideration the psychological elements of the surroundings to reduce stress on the resident. When asking a resident questions, during the intake form completion process, do not sit directly across from the resident. Sit at a 90 degree angle so that it's more comfortable for the interviewee. Sitting directly across the table from someone with a pen and paper can be interpreted as a hostile interrogation, regardless of your demeanor, and may reduce cooperation.

Give a copy of the form to those residents requesting one. This will allow them to read over the form with you and gives them something to hold onto or make their own. Very carefully explain the entire process to them and, if necessary, read each question individually for their response. Get confirmation that they understand and that their response is valid. Their confirmations can be verbal or non-verbal. If a familiar person is there to assist the person with a mental illness, they may be able to help you understand and interpret responses. The person with a mental illness may also prefer the familiar person to read them the questions directly and field responses. Alternatively, they can also introduce you as the person who will be asking questions so they feel more comfortable with you in the room.

4.6.0 Assisting Residents at the Sleeping Area

As you lead the person with severe mental illness to the sleeping area, prepare them for what they'll see and what will happen when you enter this new space. Provide as many details as possible and be specific in your description. Explain the necessity of a shared space and the need to be respectful of others, as you would explain to any other resident.

Familiarize them with the layout of the building so they know where the exits and restrooms are located. Depending upon the structure of the building, you may wish to keep people with mental illnesses towards the perimeter of the sleeping area, so that they have landmarks, lighting and easy access to their beds. Some people with severe mental illnesses may have poor hygiene. When appropriate or deemed necessary, provide a gentle reminder and ask them if they've taken

care of or need assistance taking care of those issues. If someone should become disturbed during the night and act startled or scared, help calm them down by reminding them where they are and why they are there. Use your best judgment to help determine if they need anything more, apart from basic comforting. Seek medical assistance if they become severely disturbed or agitated as a result of the interruption of their sleeping ritual. Some people may require a noise to fall asleep. For this reason, sleeping in a noisy area may actually enable them to get to sleep easier – ask the resident or her/his caregiver before assuming this is true.

4.7.0 Assisting Residents at the Eating Area

When entering the cafeteria, begin by explaining step-by-step what they need to do to obtain food. Make sure they know where to go and ask if they require any assistance. Remember to seek either verbal or non-verbal confirmation before assuming they are okay with your instructions.

Keep in mind that some mental illnesses directly affect motor skills and social decencies. Some residents may eat messily. They may have food on their face; they may burp, fart or make noises while eating. Do not draw negative attention to them by scolding or laughing. Instead, display the behavior you would expect of them. Children with autism will often mimic your actions. For example, if an autistic child has a messy face while eating and you wipe your face, they may wipe their face too.

4.8.0 Assisting Residents at the Recreation Area

When assisting people with a mental illness in the recreation area, keep in mind that they may not know what it is they want to do. They may also just be wondering or exploring the new area. Prompt them by asking if there's something specific they need or want to do.

4.9.0 Advice from Shelter Managers

According to the 45 shelter managers surveyed, people with mental illnesses are common in a shelter. They stated that helping the needs of residents with severe mental illnesses can present some of the most difficult challenges in a shelter. When asked what area in the shelter was the most difficult for people with mental illnesses, they stated the sleeping and eating areas. Finally, when asked to provide information for workers who work with residents with mental illnesses, they provided the following:
• Most residents will work with you if you are sincere and take their needs seriously
• Don't assume they are not listening because you get no verbal or visual feedback. Ask if they understand.
• If they are confused, don't give multiple commands – ask or state one thing at a time.
• Be empathetic – show that you have heard them and care about what they have told you.

• If the person is delusional, don't argue with them or try to "talk them out of it." Just let them know you are there to help them.
• Try to avoid interrupting a person who might be disoriented or rambling – just let them know you will try to help them if they desire.
• Don't talk down to them, yell or shout.
• Have a forward leaning body position – this shows interest and concern.
• Make sure they take their medications and if possible, know their medication schedule
• A calm monotone soft voice will help calm them – do not challenge them or raise your voice – Be reassuring.
• A person's mood can change dramatically because of stress – they may need a quiet area
• If they have a service animal, do not distract or try to pet it without receiving permission
• Realize they have feelings and may be more stressed than others
• Do not treat them like children with your mannerisms or speech
• Ask them what they need and listen to their answer – don't assume
• Let them know what to expect (what is the routine) while in the shelter
• Are they with a caregiver or by themselves in the shelter?
• Be compassionate, respectful, and patient

4.10.0 Summary

In summary, many of the topics that have been addressed in this module are inherent and common sense. We simply lose awareness of following these social standards and take them for granted in our daily communications. Stereotypes and the media shine a negative light on the comprehension and communication skills of people with mental illnesses. By recognizing the basic elements of mental disorders, following the general communication guidelines and understanding the possible variations in your conversation, you can equip yourself with the tools to approach and communicate with people who have mental illnesses; using etiquette and a newfound understanding of their illness.

End Notes Module 4

4.1 *Family Guide on Mental Illness*, Tallahassee: National Alliance on Mental Illness-Florida.

4.2 *Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.).* Washington, DC: American Psychiatric Association. (2000). DSM-IV-TR.

4.3 *Disability Etiquette: Tips on Interacting With People With Disabilities.* Jackson Heights: United Spinal Association.

5.1.0 Introduction to the Intellectual Disability Module

As a shelter worker, you will be directly involved with people who learn differently or socialize differently. Society calls some of these people intellectually disabled.

Before we get started, it is important for you to understand the official definition of people with intellectual disabilities. An intellectual disability is a decreased ability to think and learn. The diagnosis is based on intelligence quotient (IQ) tests and a person's ability to learn academic and social skills.[5.1]

5.2.0 Objectives

Upon completion of this module, you will be able to:

1.   Identify people with intellectual disabilities.
2.   Explain the best way to communicate with people with intellectual disabilities.
3.   Identify different ways to help people with intellectual disabilities.
4.   Recognize that some people may act the same as people with intellectual disabilities and not have a disability.

5.3.0 Intellectual Disabilities

Intellectual disabilities can range from mild to severe. People who have intellectual disabilities may have a hard time with:

- Learning, especially complex tasks
- Language
- Memory, attention deficits, mood swings, and frustration
- Self-care (in cases of severe intellectual disability)

Many people with Down syndrome (formerly called mental retardation) are also born with possible heart, intestine, ear, or breathing problems. These health conditions often lead to other problems, such as airway (respiratory) infections or hearing loss.

Besides Down syndrome, there are three types of developmental disorders:

- **Autism**[5.2]: As mentioned in the previous module, adults and children with autism have problems with social interaction and communication. They also have a limited range of activities and interests. Many with autism (nearly 75%) also have some degree of intellectual disability. You have already learned about autism in the module on people with mental illness.

- **Childhood disintegrative disorder**[5.2]: Children with this rare condition begin their development normally in all areas, physical and mental. At some point, usually between two and ten years of age, a child with this illness loses many of the skills he or she has developed. In addition to the loss of social and language skills, a child with disintegrative disorder may lose control of other functions, including bowel and bladder control.
- **Rett syndrome**[5.2]: Children and adults with this very rare disorder have the symptoms associated with a developmental disorder and also suffer problems with physical development. They generally suffer the loss of many motor or movement skills—such as walking and use of their hands—and develop poor coordination. This condition has been linked to a defect on the X chromosome, so it almost always affects girls.

There are also several types of learning disabilities:

- **Dyslexia**[5.3]**:** These individuals may have difficulty distinguishing words or letters on signs/documents or remembering their right from their left.
- **Stuttering or stammering**[5.4]**:** These individuals may have difficulty communicating because their speech is broken by repetitions (li-li-like this), prolongations (llllllike this), or abnormal stoppages (no sound) of sounds and syllables. There may also be unusual facial and body movements associated with the effort to speak. Stuttering is most likely caused by genetics, neurophysiology (which means processing speech and language occurs in different areas of the brain than those who do not stutter) and family dynamics where there are high expectations or a fast-paced life.
- **Hyperactivity**[5.5]**:** These individuals may have difficulty staying in one place and may not stay with a task for any length of time.
- **Hypoactivity**[5.6]**:** The individuals will act slowly and will be difficult to motivate.
- **Memory disorder**[5.7]**:** The individuals may have either auditory or visual short-term memory. They may have difficulty answering questions about material they just heard or saw.
- **Over-attention:** These individuals may stare for long periods of time at one object.
- **Perceptual difficulties:** The individuals have poor sensory perception, even though their sensory organs are functioning correctly. Information coming in audibly, visually, or tactually may be garbled, and the person may hear or see letters or words out of order or cannot differentiate between two textures. People with this disability may have difficulty following instructions, locating a specific object in a group of objects, or feeling differences, for example between polished marble and volcanic rock.

Next, another cause of intellectual disabilities is **Traumatic Brain Injury**[5.8] (TBI). In the U.S., more than 5.3 million people live with disabilities caused by TBI. The four main causes of TBI are car accidents, gunshot wounds, explosions (common among the military), and falls. Other causes include poisoning (lead, carbon monoxide or drugs), hypoxia (lack of oxygen, which occurs during drowning), tumors, strokes, and infections. Unfortunately, there is no cure for TBI.

TBI is either mild or severe. Mild TBI results in cognitive problems such as headaches, difficulty thinking, memory and decision-making problems, attention deficits, mood swings and

frustration. Severe TBI results in limited functions of arms or legs, abnormal speech, loss of thinking abilities and emotional problems. It is possible that you could have both types in your shelter. Hopefully, the severe TBI individual would have a family member or caregiver with him or her.

Finally, many elderly people have limited thinking abilities due to dementia or cognitive decline, Alzheimer's (the most common kind of dementia), and disorientation. Dementia is a loss of mental skills that affects your daily life. It can cause problems with memory and how well a person can think and plan. Usually dementia gets worse over time. How long this takes is different for each person. Some people stay the same for years. Others lose skills quickly. The chances of having dementia rise as a person gets older. But this does not mean that everyone will get it. People rarely have dementia before age 60. But, after age 85, up to half of all adults will have it.

Dementia[5.9] is caused by damage to or changes in the brain from strokes, tumors, or head injuries. After Alzheimer's disease, strokes are the most common cause of dementia.

Alzheimer's[5.10] disease is a progressive condition that damages areas of the brain involved in memory, intelligence, judgment, language, orientation and behavior. It is the most common form of mental decline, or dementia, in older adults.

Alzheimer's disease always gets worse over time, but the course of the disease varies from person to person. While some people lose the ability to do daily activities very early on, others may still be able to function relatively well.

Over time, Alzheimer's disease causes severe mental and functional problems and eventually results in death. There is no cure for Alzheimer's disease. However, much can be done, including medicines and behavioral modifications, to maintain the person's quality of life and to help the person stay active. Many people with Alzheimer's disease receive home care.

5.4.0 Recognizing Residents with Intellectual Disabilities

Although as a shelter worker you may be working primarily with residents without disabilities, occasionally you will be assisting residents with intellectual disabilities.

Remember the picture from Module One; click on the pictures in the course to learn more about people with intellectual disabilities.

5.5.0 Communicating with Residents with Intellectual Disabilities

Positive language empowers. When writing or speaking about people with intellectual disabilities, it is important to put the person first. Group designations such as "crazies", "retards", or "the dumb" are inappropriate because they do not reflect the individuality, equality or dignity of people with intellectual disabilities. Further, words like "normal person" imply that the person with an intellectual disability is not normal, whereas "person without a disability" is descriptive but not negative. The accompanying chart shows examples of positive and negative phrases. When writing or speaking about people with disabilities, it is important to put 'people' first.

Affirmative Phrases	Negative Phrases
Person with a disability	The disabled; handicapped
Person with Down syndrome	Mentally retarded or Retard
Person who stutters or stammers	Stupid or slow talker
Person with dyslexia	Slow or stupid
Person with a TBI	Dumb or spaced-out

5.6.0 Assisting Residents at the Registration Area and Intake Form Completion Process

This area may be a challenge for some people with intellectual disabilities. Besides the stress of the disaster, there will be a fear of the unknown, and the new environment may be hard to grasp or overwhelming. Individuals with intellectual disabilities may not be able to answer questions on a form or have difficulty responding to questions or instructions.

Use short, simple sentences, be patient, and ask questions to make sure you are understood. Don't complete sentences for individuals unless they ask for help. Don't pretend you understand what a person is saying just to be polite. Ask them to repeat if you don't understand. For people with a severe stutter, ask them if "singing the answers" will help because singing uses a different part of the brain than speaking. Another idea may be to provide them a pen and paper and ask them to write out what they are trying to say.

5.7.0 Assisting Residents at the Sleeping Area

This area may cause challenges for people with intellectual disabilities because the noise may overstimulate them and cause them to have difficulty falling asleep. They may be unable to remain quiet themselves and make it difficult for others to fall asleep. If there is room for a separate sleeping area, then some of these people may benefit from sleeping in an area with noise, such as with heavy snorers. As mentioned many times before, there is no "one size fits

all," and people with intellectual disabilities will cover the spectrum of needs in the sleeping area.

5.8.0 Assisting Residents at the Eating Area

This area should not present any problems unless someone needs PAS to help with carrying a tray or feeding an individual. Typically, a friend, family member, or caregiver will assist individuals with these needs.

5.9.0 Assisting Residents at the Recreation Area

This area will be very popular with some people with intellectual disabilities because it will hopefully remind them of home. Others may avoid it entirely because the activity is over stimulating. Some adults or older children with Down syndrome may enjoy watching movies and playing games with people younger than they are. This is an area they may be used in to help with different activities—they love to help.

5.10.0 Advice from Shelter Managers

According to the forty-five shelter managers surveyed, people with intellectual disabilities are not very common in a shelter. The shelter managers did not have any challenges meeting the needs of people with intellectual disabilities. When asked what area in the shelter was the most challenging for people with intellectual disabilities, they stated the sleeping area. Finally, when asked to provide information for people who work with people with intellectual disabilities, they provided the following:

- Most residents will work with you if you take their needs seriously.
- Do not assume they are not listening because you get no verbal or visual feedback. Ask if they understand.
- Make sure they take their medications, and you know their schedule.
- A calm, monotone, soft voice will help calm them.
- A person's mood can change dramatically because of stress – they may need a quiet area.
- If they have a service animal, do not distract or try to pet it without receiving permission.
- Realize they have feelings and are stressed like everyone else.
- Do not treat them like children with your mannerisms or speech.
- Ask them what they need, and listen to their answer – don't assume.
- Let them know what to expect (what is the routine) while in the shelter.
- Are they with a caregiver or by themselves in the shelter?
- Realize they are unaware of personal space comforts some times.
- Be compassionate, respectful, and patient – to them, they have needs, not disabilities!

5.11.0 Summary

In summary, many of the topics that have been addressed in this module are inherent and common sense. We simply lose awareness of following these social standards and take them for granted in our daily communications.

Stereotypes and the media shine a negative light on the comprehension and communication skills of the intellectually disabled.

By recognizing the basic elements of intellectual disabilities, following the general communication guidelines and understanding the possible variations in your conversation, you can equip yourself with the tools to approach and communicate with people with intellectual disabilities with etiquette and a newfound understanding of their disability.

End Notes Module 5

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    http://www.webmd.com/brain/autism/development-disorder

5.3 A definition of Dyslexia; Retrieved 6/15/2011 from:
    http://www.mayoclinic.com/health/dyslexia/DS00224

5.4 A definition of Stuttering or stammering; Retrieved 6/15/2011 from:
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5.5 A definition of Hyperactivity; Retrieved 6/15/2011 from:
    http://namimi.org/adhd?gclid=CIWkz8G5uKkCFape7AodMTSD9A

5.6 A definition of Hypoactivity; Retrieved 6/15/2011 from: http://www.healthguideinfo.com/causes-of-add-adhd/p83457/

5.7 A definition of Memory Disorder; Retrieved 6/15/2011 from: http://www.memorydisorder.net/

5.8 A definition of Traumatic Brain Injury; Retrieved 6/15/2011 from:
    http://www.nlm.nih.gov/medlineplus/traumaticbraininjury.html

5.9 A definition of Dementia; Retrieved 6/15/2011 from:
    http://www.nlm.nih.gov/medlineplus/dementia.html

5.10 A definition of Alzheimer's; Retrieved 6/15/2011 from: http://vsearch.nlm.nih.gov/vivisimo/cgi-bin/query-meta?v%3Aproject=medlineplus&query=Alzheimer%27s&x=23&y=17

6.1.0 Final Assessment

You have reached the final activity for the training program. This final Module is a 10 question examination. The test you are about to take is required to become an emergency shelter volunteer. Remember to select the most correct answer to each question. At the end of the examination you should click the "Check My Answers" button to have your examination scored. Unlike the other Knowledge Checks you will not be able to go back and find the correct answer once the examination has been scored. Instead, you will receive the number of questions that you answered correctly, and your score. Once your examination has been scored and you pass, you can print the Certificate of Training.

If you are ready, begin the examination.

General Course References

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2. Emergency Planning for Special Needs Communities DVD by FEMA, June 6, 2008
3. Florida Division of Emergency Management "Special Needs", July 2009
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6. NAMI Florida Family Guide on Mental Illness, 2007
7. American Red Cross (ARC) Shelter Operations Workbook, 1996
8. Volunteer Florida, SERT, and FLDOH Accommodating Persons with Disabilities in Shelters Manual, 2008
9. ARC Serving People with Disabilities Following a Disaster Manual, July 2006
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13. Americans with Disabilities Act of 1990 and as Amended with 2010 Standards
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15. Interview with Judith Barrett from Ability 1st in Tallahassee, FL about all disabilities
16. Interview with Beth Boyd and Karen Hagan from ARC, Tallahassee, FL
17. Information gained during the Florida Coordinating Council for the Deaf and Hard of Hearing meeting in Tampa, FL on November 4, 2010
18. Interview with Valerie Stafford-Mallis from Bradenton, FL about sensory disabilities
19. The University of Kansas training program, "Ready, Willing & Able Internet Course"
20. The New Zealand Psychological Society, Life After Earthquakes" paper
21. Internet sources such as WebMD, National Council on Disabilities and the California State Parks
22. An 11 question survey was developed and distributed to emergency shelter managers across the U.S. by Ms. Beth Boyd. The results of the survey were included in the course.

Acknowledgements