



Outdoors for All Foundation

Volunteer Manual

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Disability Awareness

Every person, regardless of gender, age, sexual orientation, race, religion, creed, or ability, deserves to be treated with dignity and respect. Thank you for treating Outdoors for All participants, volunteers and staff the way you would like to be treated: with respect.

A person is a person first, not a condition or a feature. Any reference to a person's appearance, features, religion, age, gender, ability, etc, is appropriate only when the reference is pertinent to the conversation. A person with a disability may have some challenges that cause them to talk, walk, think or look differently from others. Most people with disabilities learn to accommodate for their differences and live the same type of life as anyone else; just as others have learned to accommodate for their left or right handedness, or wearing glasses or contacts.

To be more effective when working with your participants, you should be knowledgeable about the disability or disabilities that your participants may have. The more knowledge that you have about various disabilities, the better you will be able to assess each participant's individual needs.

Disability Information

This disability information is provided so that you can make informed decisions when working with Outdoors for All participants. The information presented here describes some *typical* characteristics of the different types of disabilities we may see as Outdoors for All volunteers.

Be aware that there is no such thing as a *typical* person. Please use the information here to understand the general nature of a person's disability, and as a guideline for assessing potential issues that may impact the participant's performance.

Categorizing Disabilities

Disabilities are either congenital or onset later in life. A *congenital* disability is one that the person is born with, such as spina bifida or Down syndrome. People with a congenital disability only know what it's like to function with their current level of ability. An *onset* disability is one that a person acquires later in life, due to a traumatic injury or a disease after birth. Examples include multiple sclerosis (MS) or spinal cord injuries.

There are two primary types of disabilities: diseases and conditions. A *disease* is progressive and generally gets worse, resulting in an increasingly affected condition. Examples include diabetes, multiple sclerosis (MS), and muscular dystrophy. A *condition* is a fixed state of ability, which generally does not get worse. Examples include spinal cord injuries, cerebral palsy and intellectual disability. A person may benefit from therapy, but there are no existing means to cure a condition. Some disabilities may begin as a disease, such as cancer or polio, but become conditions when the progress of the disease is arrested.

We also discuss disabilities in reference to their physical, cognitive and/or sensory nature:

Physical Disability— A condition or disease that interferes with mobility or physical movement. Onset can be at birth or later in life, due to an accident or the onset of a disease. Examples include amputation, cerebral palsy, stroke, multiple sclerosis (MS), post-polio syndrome, spina bifida, spinal cord injury, head/brain injury. The following terms can help describe a physical disability:

Paresis— Partial loss of function.

Plegia— Complete loss of function.

Hemi— Affecting one side of the body (i.e. right leg and right arm).

Para— Affecting the lower extremities.

Quad—Affecting all four limbs.

Cognitive Disability—A wide group of conditions that involve cognitive delays as a result of damage to the brain. Cognitive disabilities are specifically classified as developmental disabilities if the condition appears during the first 18 years of life, with an indefinite duration. Cognitive disabilities can be caused by congenital abnormalities, trauma, disease and/or deprivation, and the origin can be organic (related to disease) or non-organic (caused by injury or trauma). Examples include autism, learning disabilities, Down syndrome, attention deficit disorder (ADD), intellectual disabilities, head/brain injury and stroke.

Sensory Impairment—A group of conditions or diseases that affects a person’s ability to see, hear, smell, touch, taste, and understand spatial awareness. Examples include visual impairments (some vision), blindness (no vision), hearing impairments (some hearing), and deafness (total loss of hearing). Sensory Impairments are also common among people with Autism Spectrum Disorder, or other Pervasive Developmental Disorders- Not Otherwise Specified (PDD-NOS). When coupled with these types of disorders, Sensory Impairment most commonly presents as affecting touch, taste, and spatial awareness.

Disability Specific Information

Amputation

An amputation is a condition involving the removal of a limb or portion of the body. A person may have an amputation for one of several reasons: amputation can result from injury (e.g., trauma or burns), disease (e.g., cancer or diabetes) or congenital limb loss (limb deficiency due to a developmental defect, often during pregnancy).

Amputations are characterized by the location of the amputation. Disarticulation refers to the removal of a limb at the joint.

Hip Disarticulation—Removal of the entire leg at the hip.

Above-Knee (AK)—Above the knee and below the hip.

Below-Knee (BK)—Below the knee and above the ankle. Leaves a functional knee.

Above-Elbow (AE)—Between the elbow and the shoulder.

Below-Elbow (BE)—Between the elbow and the wrist. Leaves a functional elbow.

Shoulder Disarticulation—Removal of the entire arm at the shoulder joint.

Unilateral Amputation—Multiple amputations on the same side, for example, BK and BE.

Bilateral Amputation—Multiple amputations equal on both sides, for example, double BK.

Considerations: Since amputees typically wear prosthetics, the type of prosthesis depends on the type of amputation. When working with your participant, make sure that the residual limb is protected from injury and the elements. Be aware that people who normally walk with prosthetics may have difficulty adjusting to participation in sports without their prosthesis. Watch for muscle fatigue.

Assess the participant to discover relevant information, such as when the injury occurred and whether there are any secondary conditions. Because a portion of the body is missing, balance issues may impact the participant’s performance.

Equipment: If you or the participant have a difficult time getting their prosthetic foot into a ski or snowboard boot, consider using a plastic bag over the prosthetic foot to help it slide into the liner more easily. Depending on how an amputation or prosthetic affects the participant’s balance, consider using poles or outriggers for stability. Make equipment adjustments to ensure that the participant is able to hold a flat ski with his or her prosthetic.

Cerebral Palsy

Cerebral Palsy (CP) is a condition that affects a person's movement and posture. The condition is the result of brain damage (typically, a lack of oxygen) that occurs prior to, during, or just after birth. CP manifests in a variety of different ways, usually physical, and may include speech and/or cognitive impairment. The area and the degree of damage to the brain determines the individual's level of ability.

Typical characteristics of an individual with CP may include paralysis, weakness or the inability to coordinate motor function. Other aspects of CP may include abnormal muscle tone, a delay in normal development and/or abnormal reflex activity. Some people with cerebral palsy have difficulty with hearing, vision or speaking (dysarthria). CP is generally not associated with learning disabilities or intellectual disabilities. Individuals with CP may also experience seizures and abnormal sensation of the limbs, such as hypersensitivity or diminished sensitivity.

Considerations: If the person is non-verbal, ask the participant how he or she communicates. Ask the person to demonstrate how he or she says yes and no. If balance is an issue, the individual may need equipment adaptations or modifications to assist with balance and stability. In addition, many people with CP are unable to relax their limbs (due to muscle spasticity). Increased muscle spasticity can make falling more painful and potentially dangerous, so take extra care to avoid falls.

Equipment: If a participant has difficulty with their ski tips crossing or scissoring, consider using tip connectors or a ski bra. ***Do not allow participants to ski backwards while using tip connectors!** If a participant has difficulty with balance on turn initiation, consider using outriggers. Remember to introduce equipment adaptations, such as tip connectors, with a short or long-term plan to phase them out of your lesson! Ideally, this equipment is a stepping stone that allows a participant to gain ownership of a certain movement or skill without assistance. Depending on a participant's individual diagnosis, he or she may use a bi-ski or mono-ski.

Intellectual Disability (ID)

An intellectual disability limits a person's ability to learn at an expected level; it also affects a person's functional skills within their home environments. Intellectual disability can be caused by injury, disease or development of the brain before or after birth. Intellectual disabilities were formerly known as "mental retardation," which is no longer an acceptable term (although you may continue to see this term used on some of our participant's Personal Information Forms).

Considerations: Use clear instructions, and break a task down into one component at a time. Work with the individual or caregiver to figure out how he or she learns best.

Equipment: If a participant has difficulty with their ski tips crossing or scissoring, consider using tip connectors or a ski bra. ***Do not allow participants to ski backwards while using tip connectors!** Remember to introduce equipment adaptations, such as tip connectors, with a short or long-term plan to phase them out of your lesson! Ideally, this equipment is a stepping stone that allows a participant to gain ownership of a certain movement or skill without assistance.

Down Syndrome

Down syndrome is a genetic disorder caused by an extra chromosome. Individuals with Down syndrome often experience cognitive delays, although the effects are typically mild to moderate. These cognitive delays may include characteristics such as poor judgment, a short attention span, impulsive behavior (including an inability to comprehend danger), and delayed language and/or speech development. Individuals with Down syndrome also may experience decreased or poor muscle tone, as well as excessive joint flexibility.

Considerations: Use clear instructions, and break a task down into one component at a time. Work with the individual or caregiver to figure out how he or she learns best. Be aware of impulsive or stubborn behavior, and watch for signs of fatigue. Many people with Down Syndrome learn best through memory, so repetitive movements may work best for teaching.

Equipment: If a participant has difficulty with their ski tips crossing or scissoring, consider using tip connectors or a ski bra. ***Do not allow participants to ski backwards while using tip connectors!** If a participant has difficulty with coordination or following directions, consider using stand-up tethers to help build muscle memory. Remember to introduce equipment adaptations, such as tip connectors, with a short or long-term plan to phase them out of your lesson! Ideally, this equipment is a stepping stone that allows a participant to gain ownership of a certain movement or skill without assistance.

Attention Deficit Disorder (ADD) / Attention Deficit Hyperactivity Disorder (ADHD)

Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder is a neurological syndrome that is usually hereditary. ADD is characterized by distractibility, short attention span, impulsiveness, hyperactivity, and restlessness that interfere with everyday function. ADHD is ADD combined with excessive activity and energy.

Considerations: Keep the individual engaged and focused by staying active! Individuals with ADD/ADHD often have a hard time sitting still to listen as you explain something. Make your lesson interactive, and encourage the person to learn by doing.

Autism Spectrum Disorders (ASD)

Autism spectrum disorders are a group of neurological disorders characterized by communicational and behavioral impairments. Common characteristics of autism include repetitive mannerisms and limited patterns of behavior, including obsessive resistance to change. Many individuals with autism have trouble understanding social cues and feel uncomfortable in social situations; this can include awkward or repetitive conversation, discomfort with touch, and inappropriate behavior.

ASD can be associated with intellectual disability, difficulties in motor coordination and attention. Some persons with ASD excel in visual skills, music, math and art.

Considerations: Use a calm, even tone of voice and give clear, succinct and direct instructions. Give the person ample time to respond before repeating instructions. Provide visual cues when possible (e.g., a thumbs up when the participant is doing well; pointing in the direction you want the participant to go). Avoid idioms and sarcasm when speaking, as many individuals with ASD take things literally. Having a schedule for the day and sticking to it also works well. Many people with ASD learn best through memory, so repetitive movements may work best for teaching.

If the individual becomes frustrated, or has a “melt-down,” give him or her space and time to calm down. If the person becomes physically aggressive, keep yourself and others safe – stay out of the way. And do not feed into attention seeking behavior. Please work with your Lead Volunteer or the Program Manager to address any behavioral concerns.

Equipment: If a participant has difficulty with their ski tips crossing or scissoring, consider using tip connectors or a ski bra. ***Do not allow participants to ski backwards while using tip connectors!** If a participant has difficulty with coordination or following directions, consider using stand-up tethers to help build muscle memory. Remember to introduce equipment adaptations, such as tip connectors, with a short or long-term plan to phase them out of your lesson! Ideally, this equipment is a stepping stone that allows a participant to gain ownership of a certain movement or skill without assistance.

Brain Injury

Brain injury can be caused by a variety of factors. Symptoms are determined by the section of the brain that is injured, and can vary greatly. Effects of a brain injury can be physical, cognitive, social, and/or emotional. Damage on one side of the brain tends to affect the opposite side of the body, and the degree of impairment depends on the portion of the brain that is injured. People with brain injuries often have a predisposition to seizures.

The Brain

- Frontal Lobes—Thinking, speaking, basic movement, emotions, behavior, personality, judgment
- Parietal Lobes—Sense of touch, sense of pain, spatial perception
- Temporal Lobes—Hearing, memory
- Occipital Lobes—Vision

The two most common types of brain injury are:

Stroke/Cerebral Vascular Accident (CVA)— A stroke, or CVA, is a temporary loss of blood (and therefore oxygen) to the brain. Strokes are either *ischemic* (blockage of a blood vessel) or *hemorrhagic* (eruption/dissolution of a blood vessel).

Traumatic Brain Injury (TBI)—A traumatic brain injury is caused by non-organic events such as injury or trauma.

Common characteristics of brain injury include partial loss (hemiplegia) or complete loss (hemiparesis) of function or control of one side of the body. People with this condition often have balance issues and/or possible vision loss. Other common characteristics include lack of balance or coordination, limited agility and cognitive difficulties (including memory deficits, limited attention span and/or lack of judgment).

Considerations: Individuals with an acquired brain injury are often frustrated by what they can't, or can no longer, do. Be considerate, and support the person to accomplish his or her goals. Set realistic expectations, within a realistic time frame. If memory loss is of concern, write down important information or loop-in the individual's caregiver into your conversation. Be aware of their judgment in relation to safety awareness on the hill as that may have been affected as well.

Equipment: Depending on the participant's diagnosis, choose equipment that will support his or her individual needs. If a participant has difficulty with their ski tips crossing or scissoring, consider using tip connectors or a ski bra. ***Do not allow participants to ski backwards while using tip connectors!** If a participant has difficulty with coordination or following directions, consider using stand-up tethers to help build muscle memory. Remember to introduce equipment adaptations, such as tip connectors, with a short or long-term plan to phase them out of your lesson! Ideally, this equipment is a stepping stone that allows a participant to gain ownership of a certain movement or skill without assistance.

Seizure Disorder (Epilepsy)

Epilepsy is a disorder of the central nervous system marked by unusual electric activity in the brain that causes seizures. Seizures are sudden, brief changes in how the brain work: this causes partial or complete, brief or prolonged, lapses in consciousness. Epilepsy is a physical condition manifested by focal point, petit mal, or grand mal seizures. In many cases, there is no known cause of epilepsy.

Seizures usually last a short time (a few seconds), and can be either convulsive or non-convulsive. The most common types of seizures are:

- **Tonic-Clonic** (formerly Grand Mal seizure): The most dramatic type of seizure, characterized by loss of consciousness, rigidity, jerking of the extremities and falling. When a Tonic-Clonic seizure occurs, move the person to a quiet area or place the person in a comfortable position. Try to position the person on his or her side. Do not place anything between the person's teeth. Be comforting after the seizure.
- **Absence seizure** (formerly Petit Mal seizure): Characterized by a brief lapse of unconsciousness or awareness. Usually lasts only a few seconds, and may appear as a blank stare. As with other types of seizures, mental processes cease during an absence seizure. Other symptoms may include muscle twitching, rolling or blinking eyes, or visual fixation on one object. The person may not even be aware that a seizure is taking place.
- **Myoclonic seizure:** Rapid, brief jerks of arms or legs however the person usually still has awareness
- **Atonic seizure (drop attack):** Seizure that produces an abrupt loss of muscle tone

Considerations: Seizures can be brought on by a variety of factors, including fatigue, cold, stress or problems with medications. If possible, it's important to know any potential triggers for your participant's seizures. When a person has a seizure, keep calm and make sure that the person doesn't hurt themselves when they lose consciousness. Do not attempt to restrain a person while they're having a seizure. Make the person as comfortable as possible. After regaining consciousness, an individual may feel confused, disoriented and sleepy. During seizures many people lose continence. Make sure to be polite and discreet if someone needs to clean up or change clothes. Be sure to allow an individual to rest after a seizure.

Equipment: Please know the Outdoors for All seizure policy, and use a seizure retention strap when appropriate. When in doubt, talk to your Lead Volunteer or Program Manager!

Deaf or Hard of Hearing

A hearing loss occurs when one or more parts of the ear or brain that are needed to process sounds become diseased or damaged, resulting in partial or total loss of hearing. Hearing loss can be caused by injury to the ear or brain. Damage to the middle ear can often be off-set by the use of a hearing aid. Damage to the inner ear or the brain is often more severe, and hearing aids may not be beneficial. Some people with hearing loss associated with the inner ear may also have balance issues. Speech impairments are a common secondary condition.

When talking about someone with hearing loss, it is more appropriate and respectful to use the term "hard of hearing" in lieu of "hearing impaired". "Hearing impairment" can imply that something is not as it should be, and ought to be fixed if possible.

Considerations: People with hearing loss may communicate in a variety of ways. Some methods of communication include reading lips, sign language or finger spelling. People with hearing loss often rely on facial expressions and body language to understand the conversation. Be sure to speak clearly and face the person when speaking. Do not over-enunciate words.

Equipment: Use high-visibility guide vests to help your participant to see you, and to help identify your lesson on the slopes.

Visual Impairment

The most common causes of visual impairment in the United States are diabetes, myopic degeneration and glaucoma. Legal blindness is defined as corrected visual acuity of 20/200 or less. This means that at a distance of 20 feet, a person who is legally blind can see what a person with 20/20 vision can see at 200 feet. More than 90% of persons who are legally blind have some residual eyesight. Many can perceive light and can sense motion.

Considerations: When working with a person with a visual impairment, communication and guiding are two very important concerns. Speak to the participant so that he or she is aware of where you are. Use a normal voice and tone. Take the time to determine the level of sight the person has and ask how long the person has had the visual

impairment. A person who has recently lost sight may have more balance issues or nausea. Determine whether the person has other secondary conditions, such as a brain injury.

When guiding, always ask the participant how he or she prefers to be guided. Be consistent and use clear communication. Remember, you are the person's eyes in an unknown environment.

Equipment: Use high-visibility guide vests to help your participant to see you (if they have any vision), and to help identify your lesson on the slopes. Consider using a bamboo pole to support kinesthetic learners. Use a two-way headset for better communication at higher speeds – this is particularly important for intermediate to advanced participants with little to no vision.

Post-Traumatic Stress (PTS)

Post-traumatic stress (PTS) is a mental health condition that is triggered by either direct or indirect exposure to a traumatic experience. Symptoms may include flashbacks, nightmares and severe anxiety, as well as uncontrollable thoughts about the event. Although often referred to as post-traumatic stress *disorder* (PTSD), it's important to understand that PTS is a *normal* response to an *abnormal* set of circumstances, and is therefore not a *disorder*.

Some common symptoms of PTS are psychophysical and emotional numbing/detachment, hyperarousal (irritability or constant alert for danger) and acting or feeling as if the event is recurring (flashbacks). Visual cues include irritable behavior or anger outbursts, trouble with concentration, hypervigilance (constantly "on guard") and an exaggerated startle response.

Considerations: As with any of our participants, ask before touching an individual with PTS. Avoid possible triggers, if possible – these might include crowds or loud and unexpected noises (such as avalanche explosives). If the participant has a flash back or an anxiety attack, give them space to remove themselves from the activity. Make sure that they're safe, then check-in after a few minutes. Don't hover, and when appropriate, ask how you can help them feel more comfortable.

Spinal Cord Injury (SCI)

A spinal cord injury is a severe injury or disease to the spinal cord that causes partial or complete loss of sensation and loss of voluntary movement below the level of the injury. The injury is often caused by a broken bone of the vertebrae or a dislocation of the vertebrae. Typically, the higher up the injury occurs along the spinal cord, the greater the loss of function.

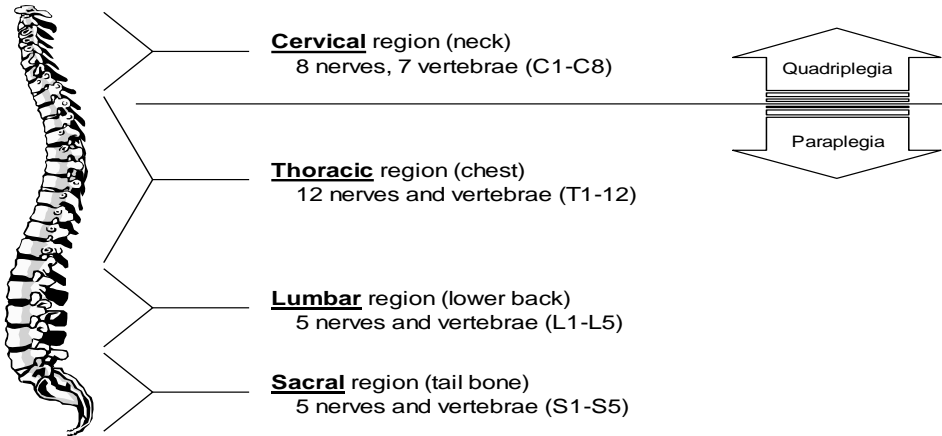
The Spinal Cord

The spinal cord is an extension of the brain and is composed of nerve cells and fibers. The spinal cord connects the brain to the nerves that control the body's muscles, skin and organs—it is the vehicle through which the brain communicates with the body.

Muscle movement begins in the brain as electrical impulses descend through the lateral and anterior parts of the spinal cord, through the spinal nerves and out to the muscles. When this motor pathway is injured, the result is a person's inability to move those muscles below the level of injury.

Sensation occurs when impulses travel from the skin or organs through the spinal nerves, up the spinal cord to the brain. When this sensory pathway is injured, the result is a loss of sensation below the level of injury.

The spinal cord is protected by the backbone, composed of bony structures known as vertebrae. The spinal cord is located in a canal that runs through the center of the vertebrae. There are four major sections of the spinal column.



Spinal cord injuries can be caused by disease (tumors, spina bifida) or by traumatic injury, and they are categorized by the area of the spine where the injury occurs. For example, an injury to the third vertebrae of the thoracic segment is known as T3 injury. Different areas of the spine are associated with specific functionality. Generally speaking, the higher the injury occurs along the spine, the greater the impact on person's functionality.

There are two common classifications of spinal cord injuries, determined by the level of impact:

Paraplegia— Injury of the lower spine (thoracic, lumbar or sacral) with partial or complete paralysis of the lower body, without involving the arms, shoulders, neck or head.

- L4 and below — Paralysis/paresis includes the lower legs, typically from the knees and below. Most people with a sacral or lower lumbar injury can walk with bracing and crutches.
- L1 through L3 — Paralysis/paresis now includes the lower extremities, including hip flexors, quadriceps and below. Many people with this level of injury can walk with bracing and crutches.
- T12 through T9 — Paralysis/paresis includes lower extremities and abdominal muscles. Trunk balance may be compromised. Most people with this level injury use a wheelchair. Upper body strength is not impacted by the injury.
- T8 through T2 — Paralysis/paresis now includes upper chest muscles and below. Trunk balance is compromised, which can impact dynamic balance. People with T8 and above almost always use wheelchairs that require additional support.

Quadriplegia— Injury of the upper spine (cervical, T1 and above) with partial or complete paralysis of the body involving both arms and legs. This level of injury may also involve shoulders, neck, head and respiration.

- T1 through C8 — Paralysis/paresis now includes intrinsic hand muscles. A person with a T1 injury and above is considered a quadriplegic (depending on the completeness of the injury) because all four extremities are now involved. At this level, the ability to hold things with the fingers is impacted.
- C7 through C5 — Paralysis/paresis now includes the fingers, hands and arms. Many people with this level of injury use powered wheelchairs because they lack the arm muscles necessary to propel a manual chair.
- C4 and up — Paralysis/paresis now includes the neck. People with this level of injury generally have movement limited to the head and neck. People with injury at this level often require devices to assist with breathing.

Potential Considerations Associated with Spinal Cord Injury

- **Autonomic Dysreflexia:** Autonomic dysreflexia can be a life-threatening condition. Autonomic dysreflexia is a hypertensive (high blood pressure) crisis that can occur in people with a SCI above T6 level. Symptoms

include sweating, gooseflesh, pounding headache and increased spasticity. It is caused by the body's inability to sense and react to specific stimuli, including such things as bladder distention from a kinked indwelling catheter or full leg bag, catheter irritation, skin pressure sores or spasticity from a stretched muscle.

If autonomic dysreflexia occurs and is not managed correctly and immediately, it could lead to a stroke, coma or even death. Many individuals who could be prone to this condition are aware of the symptoms. Should symptoms occur, sit the person upright and loosen any straps to relieve excessive pressure on the skin. Help the participant check the urinary catheter or leg bag for kinks or plugs. Check for spasticity and relieve the muscle by decreasing the stretch on the spastic muscle.

- **Skin Sores/Pressure Sores:** Sores can develop in areas of insensitive skin, especially in areas of bony prominence such as ankles, knees, hips, sacrum, and ischium. Pressure sores are a very serious condition. Avoid prolonged pressure on the skin by performing weight shifts often. Be aware of improper positioning and check for pressure and pinching. Use adequate padding on bony areas.
- **Thermoregulation:** Many people with an injury of T8 or above are prone to impairments of internal temperature control. It is important to make sure that the individual is dressed appropriately, so that they do not become too cold or overheat.
- **Bladder functioning:** Be aware that many people with SCI have a tube (catheter) inserted into their bladder to deal with bladder control. The catheter connects to a plastic bag that attaches to the leg. People with SCIs are trained to deal with this issue. When working with a participant with an SCI, make sure adaptive equipment does not interfere with the leg bag and that the leg bag is placed in a position that will not cause pressure sores.

Other considerations: Many people with SCI use wheelchairs for mobility. Remember that just because the person is in a wheelchair, it does not mean there is anything wrong with the person's brain or hearing. A wheelchair provides a mechanism for moving around and becomes part of the person's "personal space." Never move, lean on, or touch a person's chair without permission. Always ask a person in a wheelchair how you can help before doing so.

Equipment: Depending on the participant's level of injury, consider using outriggers, the slider, a bi-ski or a mono-ski to support his or her individual needs. Be conscious of how equipment is fit, and use padding to avoid skin irritation or pressure sores. Consider using some type of grip assist for outriggers, if needed.

Spina Bifida

Spina bifida is a birth defect of the spinal column and spinal cord. In this congenital condition, the spinal column fails to fully develop and close around the spinal cord, causing partial or complete paralysis below the level of injury. Individuals with spina bifida also may experience a disruption in the flow of cerebrospinal fluid (CSF), which nourishes and cushions the brain and spinal cord. This disruption often results in a buildup of fluid and pressure in the head. A *shunt* may be used to relieve excess pressure in the brain. A shunt is typically located under the skin running from the base of the skull, down the side of the neck and across the chest, where the CSF is reabsorbed by the body. An individual with a shunt may not be able to ski with a helmet.

The symptoms of spina bifida are similar to a spinal cord injury at the level of the spinal cord exposure. The extent of an individual's impairment depends on the level of the exposure. Most instances of spina bifida occur in the lower spine, but it can occur at any level. The lower the level of exposure, the more lower-extremity function the person will have. In some cases, the person may be able to walk with bracing.

Considerations: Take special care to provide appropriate padding for the location of the spinal column defect. If necessary, place a donut-shaped pad around the tender area to provide protection. Individuals may also have a curvature of the spine, impacting the person's center of mass and resulting in balance issues.

People with spina bifida are often prone to skin problems caused by poor circulation. Make sure to take protective measures to avoid pressure sores, frostbite, excessive heat or cold, etc. Many people with spina bifida have extreme allergic reactions to latex. Duct tape, ace bandages and coban (vet wrap) frequently contain latex.

Equipment: Depending on the participant's diagnosis, consider using outriggers, the slider, a bi-ski or a mono-ski to support his or her individual needs. Be conscious of how equipment is fit, and use padding to avoid skin irritation or pressure sores.

Multiple Sclerosis (MS)

Multiple Sclerosis is a progressive disease of the central nervous system in which the body's nerve fibers become scarred (sclerosed). The myelin sheath (insulation surrounding the nerves) allows messages from the brain and spinal cord to be sent throughout the body. Individuals with MS lose sections of myelin sheath along different portions of the nervous system, which in turn blocks the electrical impulses of the nerves. The scarring and deterioration of the myelin sheath can take place anywhere throughout the nervous system. Because MS can strike anywhere in the nervous system, the symptoms can vary widely, even with the same person.

MS is unique in its cycle of remissions, seeming to come and go over time. Symptoms can vary from day to day, and no two people have the same symptoms. MS is characterized by muscle weakness, chronic fatigue, balance problems, heat intolerance, and sometimes visual and cognitive impairments. Some people experience paralysis or weakness in their extremities, mood swings (lability) and slurred speech. Many people with MS have an unsteady gait and shaky movements of the limbs (ataxia).

Considerations: When working with a person with MS, watch for evidence of fatigue. Provide assistance as needed, and avoid unnecessary exertion. As symptoms can vary, it's important to have a continuing dialogue with the individual about his or her needs from day to day.

Equipment: Depending on the participant's diagnosis, consider using outriggers, the slider, a bi-ski or a mono-ski to support his or her individual needs. A participant may choose to use both stand and sit equipment during the course of one day, depending on his or her level of fatigue.

Muscular Dystrophy (MD)

Muscular Dystrophy includes a group of hereditary disorders that are characterized by the progressive and irreversible wasting of muscle tissue. MD may include weakness of both voluntary and skeletal muscles, which control movement. The degeneration of the muscle tissue originates within the muscle tissue itself (compared to MS where muscle atrophy is the result of neurological defects).

Most types of MD appear by early adulthood, and are more common in males than females. The most common type of MD is Myotonic MD, which has a very slow progression and affects the central nervous system, eyes, heart, and endocrine glands. Duchenne MD, the second most common type, affects children (usually boys) and is often fatal (usually in the 20s).

The various types of MD have different symptoms; however, all typically experience a progressive loss of muscle tone. The muscles first affected are usually the pelvic girdle and upper legs, then the shoulder girdle and arms. People with MD may walk with the aid of crutches or a cane, although eventually most require a wheelchair.

Considerations: Because of the lack of muscle tone, the person's joints may be more susceptible to injury. Strength, endurance and balance may be issues impacting performance. When working with a person with MD, watch for evidence of fatigue. Provide assistance as needed, and avoid unnecessary exertion.

Equipment: Depending on the participant's diagnosis, consider using outriggers, the slider, a bi-ski or a mono-ski to support his or her individual needs. A stand participant with low muscle tone may benefit from the use of a tip connector or ski bra. ***Do not allow participants to ski backwards while using tip connectors!** Remember to introduce equipment adaptations, such as tip connectors, with a short or long-term plan to phase them out of

your lesson! Ideally, this equipment is a stepping stone that allows a participant to gain ownership of a certain movement or skill without assistance.

Working with People with Disabilities

Language

Language can be inappropriate, negative and demeaning. If information about a disability is pertinent, then use language such as "person with a mobility impairment" or "person who uses a wheelchair." Notice how we choose to put the *person* first, and then any information about his or her disability.

Old Terminology	Acceptable Terminology
Handicapped	Person with a disability or person who is disabled.
Afflicted/Stricken-With	Person who has _____.
Victim	Person who has survived _____.
Crippled	Person with a mobility impairment. Person who uses _____.
Retarded/Retard	Person with a developmental disability.
Lunatic/Nuts/Crazy	Person with a mental illness.
Deaf and Dumb	Person who is deaf and mute.
Normal	Person without a disability. Able-bodied.

Enable Ability

Appreciate what people *can* do. The difficulties a person faces often stem more from society's attitudes and barriers than from the effects of their impairment. Focus on *ability*, and use the participant's strengths to compensate or adapt.

Respect the person's right to indicate the kind of help he or she wants. Give assistance, if asked; if the need seems obvious, offer assistance before helping. Do not give unwanted assistance and never insist. Usually a simple statement such as, "*let me know how I may help,*" opens up communication without making either party feel awkward or dependent. When someone does indicate desire for assistance, ask *how* you may help. For example:

Ask a person with a visual impairment to show you how he or she wants to be guided.

Ask a person using a wheelchair to tell you how you could assist with their transfer.

A person with a visual impairment can usually hear without difficulty, so you need not yell. An adult with an intellectual disability is not a child, so you may speak to him or her as you would any of your adult friends. A person using a wheelchair does so because his or her legs do not allow bipedal mobility, not because he or she cannot understand, hear, or see. People in wheelchairs are not confined; rather, wheelchairs liberate by allowing mobility. The wheelchair is part of his or her personal space, so do not lean on the person's "legs" without permission.

When working with a participant in an activity, always allow the person to experience as much *independence* as possible. Do not assume our participants cannot do something simply because of a disability.

Conversing

If it comes up naturally, or if you need to know something specific, feel free to ask about the participant's disability. Let the participant, or his/her significant others, guide you. Be respectful and sensitive, and focus your questions on information that is pertinent to the activity. For example, ask "Can you describe your vision to me?" instead of "How did you lose your eyesight?"

Speak directly to a person with disability, even if they have an interpreter, companion or attendant. Explore your mutual interests and conversational topics just as you would with any new acquaintance. People with disabilities have much more to discuss than their impairments!

Common societal expressions are acceptable, for example, "Did you see that movie?" or "Let's take a walk." People with disabilities do not usually desire different treatment. Along that line, they also do not want someone to be condescending. Talk to people with disabilities just as you would to anyone their age.

People who have visual impairments use other senses to take in environmental information. Ask him/her if s/he would like you to describe the scenery, explain who else is around, or if s/he would like to hold or touch an object you are explaining. When directing him/her from a distance, use directions or your voice. For example, say "*Come over this way toward my voice*" or "*Just a little to the right.*" If you do use your voice as a guide, remember to keep talking.

Be patient with those who have difficulty speaking. Do not finish sentences or answer for participants. When you do not understand something said, ask them to repeat themselves. Try repeating what you thought you understood. They will tell you whether you are correct and repeat what you did not understand. Do this as often and as much as you need. Ask him/her to rephrase if you feel you cannot understand a word or sentence.

If the person cannot verbally communicate, it does not mean that they don't have other ways of communicating. Ask a parent or guardian how they communicate at home. They could use Picture Exchange Communication System (PECS- pictures to display feelings/tasks/needs), To-Do/Done Boards, First/Then boards and/or many more.

Before leaving their parent and guardian make sure you at least know how they communicate “yes” and “no”, and then you can use yes/no questions to communicate, while learning their unique communication system.

Slow your rate and speak calmly without yelling or exaggeration to a person with a hearing impairment. Be sure they can see your face and use gestures or other methods of communication. Ask him/her to show you commonly used gestures so you may use them also.

It is OK to say no to a person with a disability, just as you might to anyone else. You are welcome to set your comfort limits that do not interfere with others' rights. For example, if a person with a disability invades your personal space, you can tell them not to. With some people, you may have to be repetitive.

People with disabilities are not necessarily special, inspirational or courageous. They are people, making the best of their situations — just like you. They usually do not want to be patronized or put on a pedestal — just like you. They just want to be accepted, supported, encouraged, praised, and loved — just like you.

Treat a person with a disability as you would anyone you know.
Treat them as you would want to be treated by others.

Participant Evaluation

The participant, with assistance from you and the participant's significant others, determines his/her strengths and participation considerations. You, with input from the participant as to his/her goals, develop a plan to assist him/her to participate using his/her strengths and adapting, as needed, for areas of consideration. **In all cases, strive for minimum adaptation to achieve maximum participation and fun.** Use the following method to assist you in this process:

- Obtain and read the individual’s Participant Information Form (PIF) through Outdoors for All. Contact the participant, and/or significant others, before the activity for specific questions and/or information. **This is a great time to ask about his/her goals for the activity.**
- Observe the participant interacting with you and others, moving around, putting on equipment, during lessons, etc. Your observations will assist you greatly in determining how to best work with your participant. Continue to ask him/her about his/her goals as they may change.
- Let the participant guide you. Most individuals will offer reliable information and know their compensations. Exceptions may be those with cognitive or behavioral impairments; you may need to confirm information with significant others.
- Perform simple tests and ask questions with the participant. Examples are testing for basic muscle strength (offer your hand for a handshake), and asking questions to determine understanding of complex information or memory (ask what they remember about their lessons last season). If in doubt, ask your Lead Volunteer or Program Manager for assistance.
- Talk with significant others, if needed. Significant others may include family, friends or staff. They can confirm and add information.
- Talk with volunteers who know the participant. Read previous progress reports.
- Talk with Lead Volunteers. They can direct you to resources and advise you on tips, adaptive equipment and teaching methods. Ask them for any assistance you need. Their job is to help you to do your job!

Behavior Management Suggestions

All behaviors happen for a reason – although, sometime, that reason can be difficult to determine. Determining the *why*, or the *function*, for any behavior is an important step towards positive behavior management. Most behaviors occur for one of four reasons:

- *Escape or Avoidance:* An individual might engage in self-injurious or challenging behavior to avoid a certain situation, task or person.

- *Social Attention*: An individual might engage in behavior that draws attention to them – they want someone to look at them, talk to them, laugh at them, or even scold them. They may act out to receive “bad” attention, instead of no attention at all.
- *Tangibles or Activities*: An individual might scream and cry until they get a specific item, or are allowed to engage in a specific activity.
- *Automatic or Sensory Stimulation*: An individual might engage in a self-stimulating behavior that either results in a pleasing sensation or relieves a displeasing sensation (ex: pain). In either case, this type of behavior does not rely on an external factors.

The following suggestions may be helpful when working with someone to manage difficult or inappropriate behavior. When in doubt, please work with your Lead Volunteer or Program Manager for support!

- You are the role model – model positive and appropriate behaviors. Reinforce positive behaviors, and ignore undesired attention-seeking behaviors.
- Be clear, concrete and concise about your expectations to the individual, and determine his/her expectations of you.
- Offer choices and/or use a visual schedule. Cue transitions.
- Redirect the individual to alternative, positive behaviors that have the same *function*. For example, an individual could tap the keys on a piano, instead of tapping the table.
- Be compassionate. Give ample encouragement to participate and behave appropriately. All encouragement should be age-appropriate and respectful.
- Identify an individual’s successes, and encourage appropriate self-praise.
- Be consistent.

Medications

Many of our participants will be taking a variety of medications. Many medications have potential physical and/or cognitive side effects that you should know about. Be sure to consult your participant's Personal Information Form to determine if their medications have side effects that may impact the student's performance.

Not every person experiences side effects in the same way. When possible, consult the participant or participant's caretaker for more information about whether the participant has side effects that may impact performance.

During the evaluation of your participant, find out about the participant’s medication schedule. You might need to remind your participant to take their medication, but NEVER administer medication to a student!

Additional Resources

The field of adaptive snow sports is constantly evolving. For more information about disability awareness and/or adaptive equipment and instruction, please take some time to peruse the following resources.

- Outdoors for All's online training library provides links to a variety of different resources for Alpine, Nordic and Snowboard Instructors: www.outdoorsforall.org/get-involved/training/
- PSIA-NW is the local, divisional resource for information about clinics, exams and continuing education: www.psia-nw.org
- The PSIA-AASI national website contains additional information about the growing field of adaptive skiing and snowboarding: www.thesnowpros.org

Kayaking

National Overseeing Organization- [American Canoe Association](#)

Kayaking Instructor Manual- [American Canoe Association](#)

International Governing Body- [International Canoe Federation](#)

Paralympic Kayaking/Canoeing- [U.S. Paralympics](#)

Rock Climbing

ADAPTIVE CLIMBING MANUAL- [PARADOX SPORTS ADAPTIVE CLIMBING MANUAL](#)

NATIONAL GOVERNING BODY- [USA CLIMBING](#)

INTERNATIONAL GOVERNING BODY- [INTERNATIONAL FEDERATION OF SPORT CLIMBING](#)