

ADAPTIVE OUTDOOR EDUCATION CENTER

VOLUNTEER MANUAL



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WELCOME TO THE ADAPTIVE OUTDOOR EDUCATION CENTER

"Your Adaptive Gateway to the Outdoors!"

Thank you for choosing to volunteer with the Adaptive Outdoor Education (AOEC)! The AOEC is a part of the Albiston Foundation, a two-fold nonprofit including the AOEC and the Aphasia Center of Maine. Our mission is to enhance the quality of life for all people with disabilities through adaptive outdoor recreation and education. We couldn't achieve this without help from people like you! Thank you and we look forward to building a wonderful relationship.

Volunteer Manual

This manual may be lengthy but it is packed full of useful information to ensure safety and FUN for you as the volunteer and the participants you will be working with.

Adaptive Recreation Programs

The AOEC has developed many wonderful programs in adaptive outdoor recreation and this is just the beginning! Our programs currently include:

- Biking
- Fishing
- Water Sports Camp
- Rocking Climbing (indoor and outdoor)
- Skiing
- Snowshoeing
- Hiking
- Sailing

A majority of our participants come from Maine, though we often have folks coming from throughout New England as well! Our programs are designed to serve all ages and all types of disabilities, including cognitive, physical, developmental, and sensory impairments.

Please visit our website for additional information about our programs and to learn about our fully accessible lodging!

www.adaptiveoutdooreducationcenter.org

Volunteer Roles and Responsibilities

Roles will vary depending on activity.

Regardless of your volunteer role, your primary responsibility as an AOEC volunteer is to provide support to all AOEC participants. This includes creating a safe, fun, and positive learning experience for both you and the participant!

For a complete list of current volunteer opportunities, please visit our website:

www.adaptiveoutdooreducationcenter.org

Volunteer Benefits - Lodging

The AOEC will provide free accommodations at the Center during your time volunteering. You will, however, need to bring linens (twin sized or a sleeping bag) and a pillow.

Volunteer Benefits - Ski Pass Privileges

Horizons Ski program volunteers will receive a lift ticket for every two days they volunteer, good for any day. As a volunteer for the ski program, you will also receive a day pass for the days you are volunteering and will have time before and after lessons to ski!

Volunteer Training

Volunteer training is determined by your volunteer role and tenure as a volunteer. AOEC staff will be in contact about required trainings.

Cancellations

The AOEC occasionally cancels programs due to weather. We will be in contact via phone if this is the case. We will also post cancellations on our Facebook page.

RISK MANAGEMENT

There are certain risks and dangers inherent in any activity, and the field of adaptive sports involve its own specialized set of risks. The goal of the following safety policies, guidelines and procedures is to identify the risks that we face and to develop methods by which these risks may be reasonably controlled to provide a safe and fun learning environment.

The following material provides an overview of the major points of risk management within the AOEC's programs. This is not an exhaustive list; rather, this offers a baseline from which each individual volunteer should operate.

Volunteer Guidelines

Please adhere to the following:

- Absolutely no use of alcohol, marijuana or illegal drugs before or while you are volunteering for the AOEC. This includes during lunch, if you are volunteering all day. Violation of this policy will lead to termination of your position and/or other disciplinary action.
- No smoking during AOEC activities or at AOEC buildings or facilities.
- Be prepared! Keep your body in shape, get plenty of sleep, take precautions when driving to programs, keep your equipment safe, stay warm, and eat to keep your energy up.
- Have knowledge of all terrain and select terrain appropriate for your student.
- Be knowledgeable of weather conditions and how they affect an activity. Plan accordingly.
- Act professionally at all times while representing AOEC.
- In the case of an unexpected absence, call AOEC as soon as possible!
- AOEC does not arrange carpools. Volunteers assume full responsibility for transportation to and from events, unless they are traveling in the AOEC van. If helpful, we recommend that you set up a carpool group with other volunteers in your program.
- AOEC staff is not responsible for any lost/stolen personal items.
- AOEC does not provide medical insurance for our volunteers.

Participant Guidelines

- Before working with any participant, review his or her questionnaire. If you notice anything that concerns you, please notify staff immediately. Please be respectful of the information on a person's questionnaire and do not discuss any 'issues' with other participants or volunteers.

- Ensure that participants are dressed and protected from existing weather conditions. Never take participants into adverse weather with inadequate clothing or equipment.
- During an outdoor program, check participants for cold or numbness in the extremities, signs of heat loss, and his/her comfort level. If you are concerned, bring the participant indoors. Reversely, check in with participants in hot weather during summer activities and ensure you and the participant are drinking adequate amounts of water.
- During climbing sessions please be aware of skin and abrasions, length of time in a harness and impact injuries.
- Do not administer any medication, prescription or non-prescription, to any participant.
- Due to various participant dietary restrictions and food allergies, do not provide food or meals to a participant, unless it is food that they have brought with them. If a participant forgets his or her lunch or lunch-money, please notify staff.
- Ask permission from your participant before touching them. Although many activities necessarily include physical contact (such as transfers), you should still ask for permission.
- If a participant informs you that he or she is being mistreated or harassed during any AOEC activity, report the incident to staff.

Confidentiality

In the course of your volunteer activities with AOEC, you may have access to participant information, including medical information, as well as other proprietary information and data. You are expected to not disclose this information outside of the AOEC at any time during, or subsequent to, your volunteer activities.

Equipment Guidelines

The AOEC uses a wide variety of equipment during programs. To keep our equipment organized and in good working condition, please remember to:

- Check all equipment before, during and after an activity. Any deficiency that affects the operational safety of the participant's equipment must be reported to staff and the equipment should be taken out of service.

Ski Binding Adjustment

Ski binding adjustment is an important aspect of AOEC risk management. Instructors may not make any adjustments to a participant's ski bindings. If your participant is having issues with his or her personal equipment, or with equipment rented from Sugarloaf, please refer him or her to the ski shop. *AOEC staff and volunteers, regardless of his or her training, may not make adjustment to a participant's personal ski equipment, or equipment that is rented from another organization.*

Helmets

AOEC's helmet policy requires *participants, volunteers, and any participating family and caregivers* to wear helmets when actively participating in Downhill Skiing, Downhill Snowboarding, Biking, Climbing, and any other activity when directed by AOEC staff and released parties. The selection and use of an appropriate helmet is the sole responsibility of the user. AOEC will not be liable for any injury or damages resulting from failure to use a helmet or incorrect use or selection of a helmet.

WARNING: Outdoor activities are inherently dangerous and use of a helmet is no guarantee of safety and the activities requiring the use of a helmet may expose the participant to forces that exceed the limits of protection provided by a helmet.

INCIDENT PROCEDURE GUIDELINES

Any incident related to AOEC must be reported to staff in a quick, accurate, and responsible manner. Please adhere to the following guidelines if you witness or experience an incident while volunteering for AOEC.

1. Get Help

Send one or more competent persons to get help. Have them note the exact location of the injured person so that they know where to send help.

2. Protect the Accident Site

3. Protect the Injured Person

Do not move the injured person except when it is necessary to protect them. Stay calm. Talk to the injured person; tell them what is happening. Obtain witness' names, addresses and phone numbers.

4. Do Not Discuss the Incident

Do not discuss the incident with anyone other than AOEC staff and medical professionals. Do not give an opinion, place blame, or admit guilt – just state the facts.

5. Fill Out an Incident Report Form

Fill out an Incident Report Form with AOEC staff. Please review the blank Incident Report Form at the end of this section. No matter how small the incident may be, it's important for staff to know about it.

When filling out an Incident Report Form:

- Use legible writing.
- Use complete sentences.
- Be objective.
- Get the names and witness statements from all those who saw the incident.
- Complete the form as soon as possible after the incident, preferably within 24 hours.
- Do not leave any blank lines. Do not abbreviate. Instead of "N/A", write "does not apply".

REMEMBER, the Incident Report Form may be the only thing you have to refer to five years after the incident. Make it accurate, succinct, and complete.

6. Follow-Up

An AOEC staff member will follow up with the person once they've been treated. Follow up with staff to check on the status of your participant after their injury.

PLEASE REMEMBER: When in doubt, seek advice from AOEC staff.

If you have any questions concerning any of the above policies, please contact AOEC.

INCIDENT REPORT FORM

Use back if more space is needed.

(Be complete – write legibly – no blank lines – do not abbreviate.)

Activity	Date: _____ Time: _____ Activity: _____ General Location: _____
Injured Party	Name: _____ <input type="checkbox"/> Participant <input type="checkbox"/> Volunteer
Location Description	Exact Location: _____ Description of Area (Be Detailed): _____ _____
Injury	What was the person doing when injury occurred? _____ _____ _____ Description of Injury: _____ _____ Injured party's description of incident ("exact words"): _____ _____
First Aid	1 st Responder Name: _____ First Aid: _____ 2 nd Responder Name: _____ First Aid: _____ Professional medical service rendered? <input type="checkbox"/> Yes <input type="checkbox"/> No Did injured party return to activity? <input type="checkbox"/> Yes <input type="checkbox"/> No Explain: _____ _____
Witnesses	Name: _____ Phone: _____ Address: _____ Name: _____ Phone: _____ Address: _____ Name: _____ Phone: _____ Address: _____
Volunteer Information	Volunteer Name: _____ Phone: _____ Signature: _____ Supervisor's Name: _____ Phone: _____ Signature: _____
Follow-Up (Completed by Staff)	
Incident # _____ Date _____ Staff Name _____ Title _____	
Spoke to whom (name and relationship): _____	
What was said: _____ _____ _____	

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 AOEC 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.

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 AOEC participants. The information presented here describes some typical characteristics of the different types of disabilities we may see as AOEC volunteers.

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.

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.

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.

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.

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 behavior, and watch for signs of fatigue.

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.

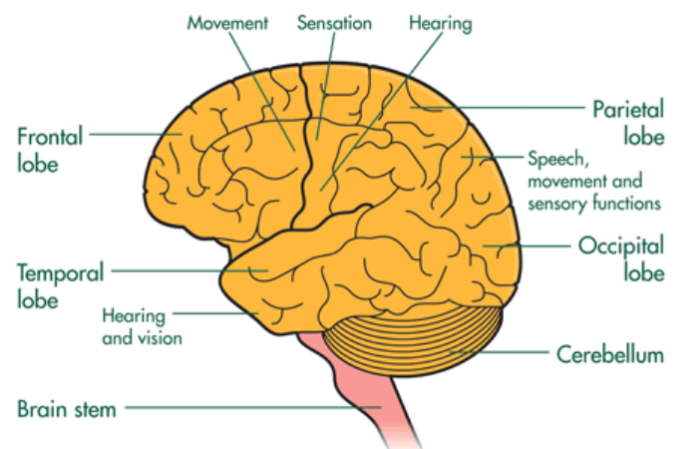
Considerations: Use a calm, even tone of voice and give clear, succinct and direct instructions. Give the person ample time to respond before repeating instructions. Provide visual cues when possible (e.g., a thumbs up when the participant is doing well; pointing in the direction you want the participant to go). Avoid idioms and sarcasm when speaking, as many individuals with ASD take things literally. 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. Please work with staff to address any behavioral concerns.

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). Some people who have had a stroke have difficulty with vision, oral-motor movements during speaking (dysarthria) and feeding (dysphagia) and may be at risk for aspiration.

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. If the person is non-verbal, ask the participant or caregiver how he or she communicates. Ask the person to demonstrate how he or she says yes and no.

Aphasia

Aphasia is a language disorder caused by damage in a specific area of the brain that controls language expression and comprehension. In short, Aphasia is loss of language. Not intellect. A person with Aphasia may have trouble speaking (may not be able to speak at all), struggle to find an appropriate term or word, or use inappropriate words in conversation. Some people with Aphasia cannot read, write, or speak at all.

Considerations: Individuals with Aphasia can often be frustrated by their lack of ability to communicate or come up with the correct words to convey what they're trying to say. Speak slowly and in clear sentences. Sometimes it is best to ask yes or no questions.

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 works: 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:

- **Grand Mal Seizure:** The most dramatic type of seizure, characterized by loss of consciousness, rigidity, jerking of the extremities and falling. When a grand mal 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.
- **Petit Mal Seizure:** During a petit mal seizure, unconsciousness lasts only a few seconds, and may appear as a blank stare. As with other types of seizures, mental processes cease during a petit mal seizure. Other symptoms may include muscle twitching, rolling or blinking eyes, or visual fixation on one object.
- **Psychomotor and/or Focal Motor Seizures:** These types of seizures are less frequent and less severe. In some cases, the person may not be aware that a seizure is taking place. Symptoms include confusion, staggering, performing purposeless movements, and making unintelligible sounds. The person should rest after these types of seizure.

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 by supporting their head. 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.

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.

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.

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.

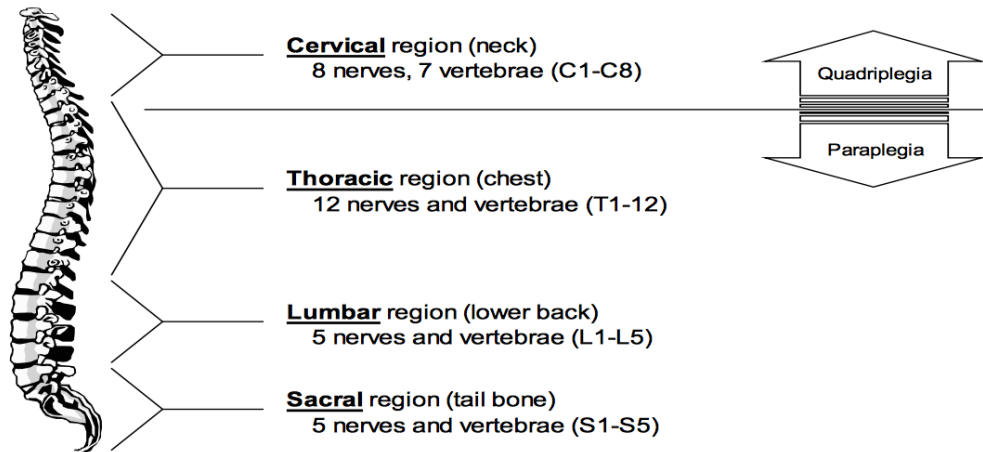
The Spinal Cord

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.

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.

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.

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.

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.

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.
- 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.
- 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!

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 staff 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.

THANK YOU FOR VOLUNTEERING WITH THE ADAPTIVE OUTDOOR EDUCATION CENTER!

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