



Train the Trainer Clinic

Tools and strategies to become better educated at understanding the diagnoses, and more effective at managing the behaviors of athletes with disabilities

Sunday, April 25, 2021
by Marcy Pelkey, OT and Meg Denton, OT
GMAS BOD members
www.greenmtnadaptive.org

Green Mountain Adaptive Sports

Ski and Ride

Paddle Sports

Rock Climbing

Aquatics

Educational Clinics



Stowe, Vermont

GreenMtnAdaptive.com

Marcy Pelkey

Occupational Therapist

Lamoille South Unified Union

20 years of experience

GMAS Board member



Meg Denton

Occupational Therapist

Independent Contractor

30 plus years of experience

GMAS Board member



Goals for this clinic - Informed coaching

- Educate coaches and instructors about common diagnoses.
- Provide tools and strategies for coaches to implement during their coaching sessions.
- Become more successful at communicating and coaching disabled athletes of all ages.
- Inform coaches of current best practices when working with athletes with disabilities.

Focus on Abilities and Celebrate Differences

- Having a diagnosis doesn't define the individual.
- Clearly identify yourself.
- Speak directly to the person/athlete.
- Don't make assumptions: offer help and wait for it to be accepted .
- Listen or wait for directions on how to help instead of doing what you think is needed.
- Don't patronize.
- Do not touch their equipment or touch them without asking.
- Get down to their level or step back so they don't have to look up at you.
- Don't worry about getting it right or wrong just focus on showing every human being respect and value.

Diagnoses Reviewed Today

- Cerebral Palsy (CP)
- Down Syndrome
- Autism
- Vision Loss
- Hearing Loss
- Traumatic Brain Injury (TBI)
- Spinal Cord Injuries (SCI)
- Amyotrophic lateral sclerosis (ALS)
- Multiple Sclerosis (MS)
- Muscular Dystrophy

Cerebral Palsy - CP

CP is caused by damage that occurs to the immature brain as it develops, most often before or during birth. Movement and muscle tone or posture are often affected.



Cerebral Palsy - What you might see

- Spasticity (tightness in the limbs)
- Difficulty with balance and stability
- Difficulty with fine motor skills
- Difficulty speaking (slow and hard to understand)
- Swallow may be affected
- Eye movements may be unbalanced
- Wide variety of abilities
- Quickness to fatigue

CP - High Muscle Tone

A person with high muscle tone may appear to be tight or resisting movement.



CP - Low Muscle Tone

A person might have difficulty maintaining an upright posture. It takes more energy for a person with low muscle tone to hold themselves stable and upright and move their limbs away from their bodies.



Down Syndrome

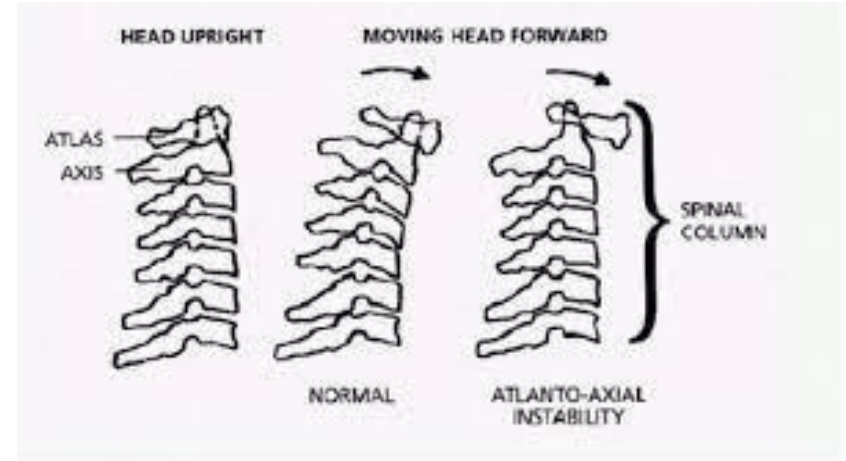
A genetic disorder caused when abnormal cell division results in extra genetic material from chromosome 21.

Causes a distinct facial appearance, intellectual disability, developmental delays, and may be associated with thyroid or heart disease.



Downs Syndrome - Spinal Problems

- Misalignment of the top two vertebrae in the neck (atlantoaxial instability).
- Risk of serious injury to the spinal cord from overextension of the neck.
- Family/student should be forthcoming with this information. It can be stabilized with surgery.



Down Syndrome (continued)

- **Heart defects:** About half the children with Down syndrome are born with some type of congenital heart defect. These heart problems can be life-threatening and may require surgery in early infancy. Often times the heart rate will be slow to respond to increases in activity. (They may have a pacemaker.)
- **Other problems:** Laxity of the joints and low muscle tone, endocrine problems, dental problems, seizures, ear infections, and hearing and vision problems.

Autism / Autism Spectrum Disorder (ASD)

Refers to a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication.

According to the Centers for Disease Control, [autism affects an estimated 1 in 54 children](#) in the United States today.

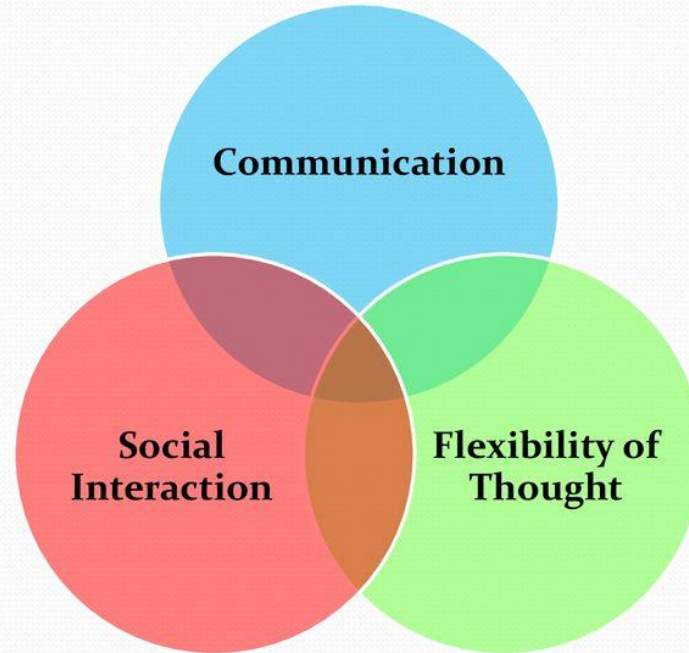


“If you’ve met one person with autism, you have met one person with autism.”

Stephen Shore – Author and adult on the Spectrum

Core Features of Autism

challenges in these three areas



Autism - Various Interventions That May Help

- Social Stories
- Visual Support
- Visual Intervention
- Video Modeling

Social Stories

This a great way to teach children with special needs a variety of skills and behaviors, as well as outline special events and social situations. Basically, it is a story that teaches about a specific topic, event, or social skill.

Read more about social stories [here](#).

Examples of a social story:

- [Social story about going skiing](#)
- [Pool social story](#)

Visual Supports and Visual Schedules



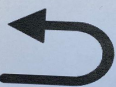

A **visual support** refers to using a picture or other visual item to communicate with a child who has difficulty understanding or using language. Visual supports can be photographs, drawings, objects, written words, or lists. Research has shown that visual supports work well as a way to communicate.

A **visual schedule** is helpful for breaking down a task that has multiple steps to ensure the teaching and compliance of those steps. It is also helpful in decreasing anxiety and rigidity surrounding transitions by communicating when certain activities will occur throughout the day or part of the day.

Examples of Visual Supports

First	Then
	
listen	swim

- 
snow suit
- 
SKI BOOTS
- 
ski mask
- 
Ski Helmet
- 
mittens
- 
ski goggles

- 
Chair lift
- 
ski
- 
turn
- 
follow

Video Modeling

VM is a very popular and effective tool to use for teaching a variety of skills to students on the spectrum.



Vision Loss

There are many reasons that someone may have a vision loss. Similar to deafness, vision loss is a spectrum and most individuals with vision loss have some vision.

Central Vision Loss: Loss of detailed vision

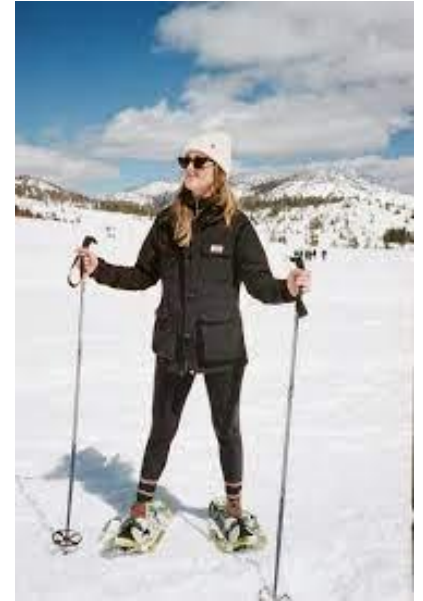
Peripheral Vision Loss: Loss of side vision

Cortical Vision Loss: Results from trauma to the brain where vision is processed. Most often seen in children who have had a stroke, traumatic brain injury, or prematurity.

Vision Loss: Strategies



This is Joe speaking.
I am going to talk you
through how to turn.



Hearing Loss

Can occur in one or both ears and can range from a mild loss to a profound loss. There are numerous reasons why a person could lose their hearing. Most common with children is either a congenital hearing loss, meaning the child was born with a loss or a hearing loss from chronic ear infections.

Mild Hearing Loss: Can basically hear everything that is said but slightly less clear. Doesn't do as well with background noise.

Moderate Hearing Loss: Will most likely have some sort of amplification such as hearing aids or a bone conduction hearing device. Background noise is an issue.

Severe Hearing Loss: Will likely have amplification or may have a cochlear implant.

Profound Hearing Loss: Has very little hearing. May use American Sign Language

Amyotrophic Lateral Sclerosis (ALS)

Multiple Sclerosis (MS)

- **ALS** is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord.
- **MS** is a disease in which the immune system eats away at the protective covering of nerves. In MS, resulting nerve damage disrupts communication between the brain and the body. Multiple sclerosis causes many different symptoms, including vision loss, pain, fatigue, and impaired coordination.
- The symptoms, severity, and duration can vary from person to person. Some people may be symptom free most of their lives, while others can have severe chronic symptoms that never go away.
- Physical /Occupational therapy and medications that suppress the immune system can help with symptoms and slow disease progression.

ALS/MS

Can affect the person's ability:

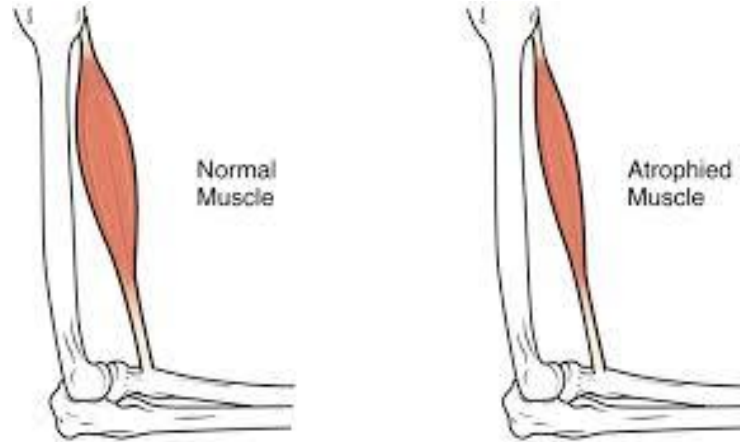
- to talk, swallow and control fluids
- to walk
- to use their arms
- may have poor trunk control and need more support with chest harnesses or lateral supports
- may use an augmentative communication device or an app on their Ipad or phone to communicate.
- May fatigue quickly.

Muscular Dystrophy

- In muscular dystrophies, abnormal genes (mutations) lead to muscle degeneration. Most forms begin in childhood.
- Damaged muscles become progressively weaker. Most people who have the condition eventually need a wheelchair. Other symptoms include trouble breathing or swallowing.
- Medications, therapy, breathing aids, or surgery may help maintain function, but life span is often shortened.

Muscular Dystrophy

- Muscle weakness
- Difficulty walking
- Frequent falling
- Difficulty getting up from a lying or sitting position
- Limited movement at certain joints (called contracture)
- Heart problems
- Problems with breathing and swallowing
- Muscle pain or stiffness



Traumatic Brain Injury - TBI

TBI is anything caused by an outside force, usually a violent blow to the head. It often occurs as a result of a severe sports injury or car accident.

- **In mild cases**, immediate or delayed symptoms may include confusion, blurry vision, and concentration difficulty. Infants may cry persistently or be irritable.
- **In more severe cases**, brain swelling, coma, seizures, brain damage can occur.
- **Treatment** may involve rest, medication, and surgery. Sometimes patients have to learn how to do basic skills like walking, talking, bathing, eating, etc.
- Some patients may require wearing of foot or hand splints after a TBI.

Spinal Cord Injuries

Can be divided into two types of injury:

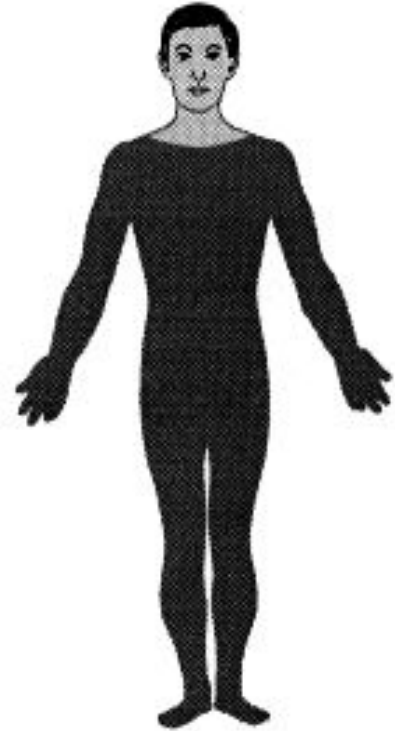
- A **complete spinal cord injury** causes permanent damage to the area of the spinal cord that is affected. Paraplegia or tetraplegia/quadriplegia are results of complete spinal cord injuries.
- An **incomplete spinal cord injury** refers to partial damage to the spinal cord.
- The ability to move and the amount of feeling depends on the area of the spine injured and the severity of the injury.
- Outcomes are based on a patient's health and medical history.

Spinal Cord Injuries - Causes

According to the **National Spinal Cord Injury Statistical Center (NSCISC)**, vehicle crashes are currently the leading cause of injury, followed by falls, acts of violence (primarily gunshot wounds), and sports/recreation activities.

Tetraplegia - Quadriplegia

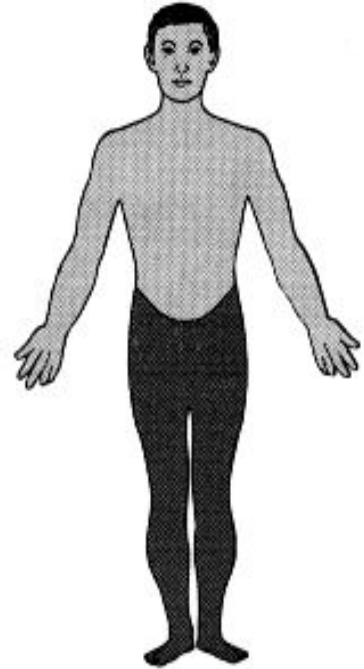
- Tetraplegia (sometimes referred to as quadriplegia) is a term used to describe the inability to voluntarily move the upper and lower parts of the body.
- The areas of impaired mobility usually include the fingers, hands, arms, chest, legs, feet and toes and may or may not include the head, neck, and shoulders.



A person with a complete C4 level of injury is paralyzed from the shoulders down.

Paraplegia

- A person with a complete T12 level of injury is paralyzed from the waist down.
- A term used to describe the inability to voluntarily move the lower parts of the body.
- The areas of impaired mobility and sensation usually include the toes, feet, legs, and may or may not include the abdomen.



General Thoughts on Positioning

When thinking about positioning an athlete there are some key points to consider.

- The athlete needs to have a stable base of support proximally in order to have mobility distally (core strength). The trunk needs to be stable.
- Look at the pelvic positioning (is it level, is it back far enough, are thighs supported?)
- Look at the trunk. Does the athlete need lateral supports? Chest straps?
- Can they balance in the ski? Or kayak? Chair? Do they feel balanced?

Positioning (continued)

- Is the back of the chair, bucket up high enough? Is it needed to support the upper body? If it's too high it could restrict movement.
- What does the head control look like? Does the athlete need additional support to keep the head stable? Maybe a cervical collar to support the neck?

USUALLY THE BEST SPECIAL SEAT IS ONE THAT PROVIDES THE LEAST AMOUNT OF SUPPORT NEEDED TO HELP THE CHILD DO THE MOST FOR HERSELF



For a child whose body stiffens like this.



don't do this.



when all that is needed is this.



Case Study 1 - Bobby

- 15 y.o. student with CP, Cortical Visual Impairment (CVI)
- Higher Muscle Tone in his legs and arms, tight hamstrings
- Non-ambulatory uses power chair
- Uses Mountain Man Bi-ski, ski instructors use tethers and bucket him
- Difficulty initiating turns, distinguishing right/left, hanging onto bar and maintaining good head position so he can look up and anticipate what was coming.

Bi-Ski



Case Study 1 Bobby - Adaptations

- Padded the back of the bucket and the sides of hips and thighs to provide a more stable base.
- Added an upper body strap around his chest to help him feel more stable and provide additional support after a trial without it left him feeling like he was going to fall out.
- We tried taping mittens to hand bar but as his muscle tone increased he would pull out of the mittens, and it restricted his ability to initiate turns.
- Added red tape to one side for instructor to say “Turn Red” (right), “Turn Black” (left) to solve right/left discrimination confusion.

Case Study 1 Bobby - Adaptations (continued)

- Suggested that biski be held in upright position not tilted while instructor wrapped tethers and attached outriggers as to not initiate reflexes.
- Added soft cervical/neck collar to provide additional neck support when going over bumps and whale backs.
- Added built up hard surface at base of feet so feet would rest fully on footplate.
- At top of chairlift, stretched arms and upper body so he could better initiate turns.
- At school during OT/PT, we added daily use of sitting on therapy ball to help initiate weight shift from pelvis and lying on ball to open up upper body.

Behavior

What types of behaviors do you see?

- Crying
- Not following directions
- Shutting down
- Asking lots of questions
- Joking around
- Feeling embarrassed
- Using the bathroom a lot (anxiety)

We should ask ourselves what is this behavior telling us?

What is the function of the behavior?

- Escape
- Avoidance
- Attention Seeking
- Sensory stimulation
- Control

Tips that can help manage behaviors

- Establish a relationship (trust is key)
- Try to give choices if you can
- Provide reassurance and reward good behavior
- Can you ignore some behaviors?
- Establish a routine that predictable (especially helpful for people on the Autism Spectrum)
- Have clear expectations
- Less talking is better
- Ask if they need help, don't assume they do


Case Study 2 Annie

- Is a 10 year old girl with autism.
- She lives at home with her parents and younger sister.
- Gets easily overwhelmed with loud noises.
- Can be loud at times.
- Scripts movies and TV shows but not much functional speech.
- Has a speech generating device but needs help to use it.
- Has some sensory issues with touch and knowing where her body is in space.
- Flaps hands and twirls hands when excited.

Case Study 2 - Annie (continued)

- Annie was not making many gains in her swim lessons according to her coach.
- She had difficulty following directions.
- She got very loud and appeared frustrated when asked to go under water, or get her face wet.
- She only wanted to stay in the shallow end near the stairs and would not venture away from them without getting upset.
- She would get out of the pool and run away after 15-20 minutes.

Case Study 2 - Annie - Adaptations

- We asked the coach if we could attend a session with the athlete.
- Her coach chose 2-3 goals to focus on.
- We made a list/schedule of the tasks Annie would be required to do in the lesson.
- We added more structure by using icons with the tasks broken down.
- **First** 10 bobs or jumps  **Then** blow bubbles 4 times.
- We made a social story.
- We had her watch a video before going into her lesson.
- Created a token board where she earned tokens.

Periodic review - Feedback after lessons

- It's very important to ask the athlete for their opinion.
- Did that feel more supportive? What worked? What didn't? Did you feel a difference when your coach asked you to_____?
- Collaborate with the coach, athlete, family and other team members (PT, OT, SLP, Special educators).
- Revisit goals and progress.
- Celebrate successes.



We are here for you!

GMAS has therapists, special educators and coaches on staff that can help you problems solve. Reach out if you have any questions, need assistance in coming up with a plan to help you athlete meet their goals, or just want to brainstorm with another person.

Please feel free to [contact us](#), and we will connect you with the right person. You are not in this alone.

Things to think about:

- [GMAS Application/Information](#)
- Various consent forms
- Hipaa/Ferpa
- Release of Information to communicate with therapists, doctors, etc.

Resources

- [Spinal Cord Injury Rehabilitation Center](#)
- [SCI Fact Sheets - Spinal Cord Injury Model System](#)
- [Video modeling: What it is and why use it?](#)
- [Visual Supports and Autism](#)

And that's a...wrap!



- **Survey:** Thank you for taking a minute to answer our [short survey](#). Your input will help us with future educational clinics.
- **Recording:** Can be viewed [here](#).
- **Slide deck:** You can review the PPT deck and share with peers with peers. Thank you for using it responsibly.
- **Speakers:** A huge thank you to Marcy Pelkey and Meg Denton for their time, expertise, and energy in creating, and presenting this clinic.