

Your Role As Caring Professionals

This guidebook is merely meant to make you aware of various aspects of a disability that may effect your camper or client's leisure or recreation experience. It is our hope that the information provided here will allow you to better serve the population you are working with. Almost any activity can be modified to accommodate the individual you are working with as well as promote your goals for participation in leisure and recreation. For example, just because a child is in a wheelchair, does not mean they cannot use their upper body to dance while you push them in their chair. Just because a child may not understand the rules of the game, does not mean he or she can not feel included by feeling and manipulating the objects that are being used. Don't let the fear of a child not participating in the typical manner be a barrier to their inclusion.

Try and remember that all individuals with disabilities are people first and that their disability is only one aspect that makes up who they are. You won't meet a single person who can be summed up by anything written in this handbook. Learn about their personality and their interests, while being sensitive to the unique needs a disability may present. Most of all be fun, caring, and engaging!

Kabuki Syndrome

Prevalence: 1 in 32,000

Cause: 70% of cases have a known genetic abnormality that effects the activation of certain proteins necessary for normal human development. In approximately 30% of cases, this genetic marker is not found and the cause of disorder is unknown

Characteristics: It is characterized by distinctive facial features including arched eyebrows; long eyelashes; long openings of the eyelids, and often times protruding earlobes. Individuals with Kabuki Syndrome generally have an intellectual disability that ranges from moderate to severe. Many people with Kabuki Syndrome are also prone to seizures, weak muscle tone, poor hip and knee joints, and visual impairments (in particular depth perception and tracking movement). Individuals with Kabuki Syndrome are also prone to frequent ear infections and early hearing loss.

Recreation participation:

- Be mindful during physical activity of weaker muscle tone and joint issues. During an obstacle course, for example, encourage them to take their time and support them during any activity that involves one leg balancing
- Be mindful of potential auditory and visual impairments. For example, be careful while playing catch because the individual may have difficulty tracking the movement of the ball. Try throwing with a softer object and avoid throwing right at the face. You could also modify by playing catch at a closer distance or with an inflatable ball that moves slower.
- If non-verbal, frequent ear infections may be a point of irritation that they may struggle to convey

Rett Syndrome

Prevalence: 1 in 10,000 females (occurs almost exclusively in females)

Cause: Rett Syndrome is a genetic disorder linked to the X-Chromosome. The gene affected is believed to play an important role in brain function and development. Although it is a genetic disorder, more than 99 percent of individuals with Rett Syndrome have no other history of the disorder within their family.

Characteristics: In most cases, the child experiences their first 6-18 months with normal development before deterioration of certain functions begin. Individuals with Rett Syndrome are prone to seizures, scoliosis, and often have sleeping difficulties. There are often deficits in learning, language, communication, and coordination. A common characteristic for people with Rett Syndrome, is hand flapping or clapping, a feature that is often associated with autism.

Recreation participation:

- Be mindful of spinal coordination by providing support during activities that require balance
- Try modifying hand-eye coordination activities such as baseball, tennis, badminton etc. by using a slower moving inflatable ball or allowing them to hit a ball off of a stationary object like a tee.
- Due to sleeping difficulties, individual may benefit from times of rest as needed.

Prader-Willi Syndrome

Prevalence: estimates have ranged from 1:8,000 to 1:25,000 with the most likely figure being 1:15,000.

Cause: Genetic abnormality that is carried on the 15th chromosome. In 75% of cases it is caused by a non-inherited deletion of the 15th chromosome contributed on the father's side.

Characteristics: Most distinctive feature of Prader-Willi Syndrome includes a strong and insatiable appetite believed to be caused by hypothalamic dysfunction (under production of the thalamus). Few behavioral issues are common at a young age but appear during adolescence and early adulthood in the form of difficulties with transitions and sudden changes. Motor milestones are often delayed slightly and there may exist minor difficulties in strength, coordination, balance, or endurance. Average IQ for an individual with Prader-Willi is 70 which barely pushes into the minor intellectual disability range (although IQ variation occurs between 40-105)

Recreation participation:

- Weight management is a huge concern for individuals with Prader-Willi. Food intake should be monitored and participation in physical activities should be strongly encouraged
- Proficiency in visual processing is often reported. Therefore individuals with Prader Willi syndrome are often skilled at jigsaw puzzles and may express an interest in similar activities
- Do not assume that because an individual has Prader-Willi Syndrome that they do or do not have an intellectual disability. As you would interact with anyone you first meet, give them the opportunity to demonstrate their cognitive abilities before you make any assumptions.

Williams Syndrome

Prevalence: 1 in 10,000 world-wide

Cause: Williams syndrome is caused by the spontaneous deletion of 26-28 genes on chromosome #7 at the time of conception and is said to occur equally in men and women.

Characteristics: Certain common facial characteristics are associated with Williams Syndrome that include puffiness around the eyes, a wide mouth, and small up-turned nose. These features generally become more prominent with age. Individuals with Williams Syndrome generally are known to be more sociable than average and a strong interest/affinity for music. Intellectual and learning disabilities are associated with this disorder as well as being predisposed to cardiovascular disease. Spatial reasoning, abstract concepts, and numbers can also be a point of difficulty with this population

Recreation participation:

- Individuals with Williams Syndrome often times are strongly attracted to music. Try engaging them in musical activities or use music to teach concepts/give instructions.
- Individuals with Williams Syndrome may have a strong sensitivity to certain sounds and pitches which can be painful such as whistling sounds or dinging of a microwave. Specifics depend on the individual
- Individuals are very social but can often be overly sociable and lack boundaries. Attempt to teach appropriate social behavior
- Encourage participation in activities that promote cardiovascular health such as fitness and free gym, but always check with information sheets and nurses to make sure the parents has not set any restrictions on physical activity

Down Syndrome

Prevalence: 1 in 700 born in the US

Cause: A genetic disorder caused from a partial or complete extra chromosome on chromosome 21. This is why this disorder is also known as trisomy-21.

Characteristics: Down Syndrome is always coupled with some degree of intellectual and learning disability though the severity generally ranges from mild to moderate. There are also common physical characteristics such as shorter stature, almond shaped eyes, low muscle tone, and smaller oral cavity which can interfere with speech. Individuals with Down Syndrome often have hyper-flexibility and decreased muscle tone, especially in their necks. Individuals with Down Syndrome are at a higher risk for heart conditions, hearing impairments, and often develop cataracts at an earlier age. Thyroid disease is prevalent in this population (around 12%). Thyroid disease often results in weight gain or heart conditions.

Recreation participation:

- Individuals with Down Syndrome often have weaker muscle tone in their necks and therefore you should be cautious of activities that place unnecessary strain or force on the neck such as gymnastics or attempting to break dance (happens more often than you might think)
- Because individuals with Down Syndrome are at a higher risk for obesity, encourage physical participation such as sports and play and healthy eating habits
- Down Syndrome itself provides very few unique limitations to leisure and an individual with Down Syndrome should be able to fully participate in most leisure activities such as sports, music, and arts and crafts.

Cerebral Palsy

Prevalence: CDC places prevalence in US ranging from 2-4 individuals out of 1,000

Cause: Cerebral Palsy (CP) is an umbrella term that describes a wide range of neurological disorders that occur at or around birth. CP is non-progressive and non-genetic.

Characteristics: Common characteristics include involuntary movement or muscles, muscle stiffness, jerky movements, and scissored gait or inability to walk. Cerebral Palsy possesses a wide range of cognitive abilities and IQ scores. In some cases, an individual's intelligence is completely unaffected by CP.

Recreation participation:

- Be mindful that not all individuals with CP have an intellectual disability. Speak to them according to chronological age level
- Muscle stiffness and difficulties with coordination can effect their participation in physical activities but do your best to engage them as much as possible. Stretching benefits are currently being studied but it has not yet been proven whether or not this assists with long term stiffness or muscle coordination. In my personal experience, I find individuals with cerebral palsy enjoy opportunities to get out of their wheelchair or stroller (if used) and enjoy that freedom if applicable
- Utilize hand over hand assistance if needed because fine motor skills are often a point of difficulty

Autism Spectrum Disorder (ASD)

Prevalence: CDC predicts that 1 in 88 eight year old children will be diagnosed with some form of autism spectrum disorder

Cause: ASD is used to describe a wide range of neurodevelopmental disorders with common characteristics. The cause of ASD is unknown but much research suggests there may be a genetic link

Characteristics: The term “autism” is only used to describe the most severe end of the ASD spectrum. ASD also includes Asperger Syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). The most distinctive feature of ASD is impaired social interaction. Many individuals will be unresponsive to others and hesitant to respond to their name and avoid eye contact. Echolalia (automatic repetition of sounds or noises made by another) is a common symptom for individuals with autism. Individuals with ASD often times do not understand social cues or abstract concepts. Many children with ASD engage in repetitive movements such as rocking, hand flapping, self abusive behavior, biting, or yelping. Individuals with ASD often have sensory sensitivities and will have fascinations with some sensations and strong aversions to others (such as loud noises or certain textures). Children with autism are also significantly more likely to be left-handed when compared to the general population.

Recreation participation:

- “If you’ve met one child with autism, then you’ve met ONE child with autism”. This is an expression often spoken about this population and is meant to emphasize the wide ranging differences in individual personalities and symptoms of the disorder
- Many individuals with ASD will experience a strong fixation on certain topics or items. Often times you can use this to your advantage to encourage participation in an activity by incorporating that person’s individual interests
- The main barrier to recreation and leisure that this disorder presents is social in nature. Try and promote healthy socialization and increased participation. For example, if an individual with ASD enjoys playing with alone, try asking them to share or show an object of interest with another client or camper. You can also encourage them to cheer on teammates during team activities
- Be mindful of individual sensory characteristics of your camper or client. If an individual is sensitive to loud noises, avoid loud situations or wear noise canceling headphones.
- Approximately 62% of children with autism are left handed. Take notice of what hand they prefer during activities

Fragile X Syndrome

Prevalence: Males range: 1 in 3,600-4,000 Females range: 1 in 4,000-6,000

Cause: A genetic disorder caused by changes in the *fmr1* gene on the X chromosome, which plays a role in healthy brain development. Symptoms are generally more severe in men than in women.

Characteristics:

In Males: Cognitive effects range from moderate learning disabilities to severe intellectual disabilities. Common physical characteristics may include a long face, large ears, and soft skin. There is a high comorbidity rate associated with behavioral disorders such as ADHD, Autism Spectrum Disorder, and Anxiety Disorder.

In Females: Same characteristics as in men but often much more mild. Lower incidence of certain behavioral disorders compared to men with the disorder but are prone to emotional and anxiety disorders

Recreation participation:

- Often have flat feet or high arching feet and may need corrective shoes during physical activity
- Individuals (more commonly in males) with fragile X are more likely to display aggressive behavior. Competitive games or sports can be frustrating and lead to aggression. Try focusing on enjoying an activity for the fun of it instead of winning and losing. Also try providing healthy energy releasing activities such as swim time, outside time, and fitness

ADHD

Prevalence: 3-7% of school aged children are reported to have ADHD. Studies suggest it is more common in males than in females

Cause: Cause of Attention Deficit Hyper-Activity Disorder is unknown, but research suggests there may be a genetic link

Characteristics: There is no longer a distinction between ADD and ADHD. Instead there are 3 subcategories of ADHD: Predominately inattentive, predominately impulsive/hyper-activity, and combined which presents both symptoms. This is a neurobehavioral disorder that results in the following symptoms:

- difficulty paying attention
- difficulty taking turns
- impulsive behavior
- forgetful
- difficulties in socialization

Recreation participation:

- Try and promote an environment that will allow a person with ADHD to pay attention during instructions. For example, explaining the rules of an activity before handing out supplies that may prove distracting.
- Try and remove distractions from a room where activities are going on
- Attempt to work on turn-taking and discouraging impulsive behavior
- Try and provide opportunities and proper channels for the participant to expel their excess energy freely such as encouraging running during free gym and outside time. If the child is consistently attempting to run down the halls, find a fun and appropriate way to move down the hall that still expels that energy. An example would be marching in which you call out a marching beat (that way you can control the pace without seeming overly strict in the child's eyes).

Apraxia of Speech

Prevalence: There are currently no sound estimates as to the true prevalence of this disorder and much more research is needed. Developmental ataxia is believed to effect more boys than girls.

Cause: There are two types that are distinguished by cause: acquired apraxia of speech and developmental apraxia of speech.

- a) Acquired Apraxia is caused by damage to the brain of areas that are responsible for speaking and results in loss or impairment of speech abilities.
- b) Developmental Apraxia occurs in children and is present at birth. Cause is unknown but recent research suggests genetics may play a factor.

Characteristics: Individuals with apraxia show difficulty organizing sounds and syllables in the formation of words. Speech ability often varies from day to day. A child may say a word correctly one day but then be unable to repeat it correctly. Children with developmental apraxia often times are better able to understand language than to speak it. It is believed to be a neurological disorder and not a factor of muscle weakness or paralysis, nor is it believed to be a disorder in hearing or comprehension.

Recreation participation:

- Complex words are harder to say than shorter words. Try prompting the use of shorter words
- Just because a child with apraxia cannot repeat back certain words, does not mean they do not understand what you are saying (this is honestly good advice to keep in mind for working with anyone with any disability)
- If you do not understand what was said by a person, do not pretend to understand. It is not rude to ask someone to repeat themselves (also true for any disability)
- For words of frequent use, you can try encouraging informal sign language of the word. For example, if a camper or client loves basketball, but struggles with the word, you can act out shooting a ball every time the word is used.

Epilepsy or Seizure Disorder

Prevalence: approximately 3 percent of individuals in the US will receive a seizure disorder diagnosis, although nearly 10 percent of Americans will experience a seizure in their lifetime

Cause: Epilepsy or a seizure disorder can be caused by almost any condition that effects the brain such as infection, injury, genetic disorder, complications during childbirth, etc. In most cases the cause is unknown.

Characteristics: Epilepsy, or seizure disorder, is a neurological condition characterized by chronic seizures. A seizure is caused by abnormal electrical activity in the brain and can present itself in many different ways: sudden involuntary contractions of muscle groups, lapses of awareness that will appear like the individual is staring or “zoning-out”, sudden loss of muscle tone that may cause a person’s head to drop or body to collapse, but the most common type of seizure is called a grand mal seizure. In a grand mal seizure an individual will experience intense muscle stiffness followed by convulsions and jerking of limbs.

Recreation participation:

- Episodes occur naturally and end naturally. If an individual is experiencing a seizure the most important thing to remember is to protect their head to insure they do not harm their head if they collapse. If they are convulsing, you may want to place a jacket or towel under their head to prevent head injury and quickly send someone to get a nurse
- Note the time of the start of a seizure. An individual may become very sleepy after an episode or need time to recover.
- Find out what triggers a seizure in the individual you are working with and avoid those triggers. Triggers can include flashing lights, illness, weather changes, or other sensory stimuli.
- If an individual is prone to seizures, be particularly vigilant during activities swimming times and provide extra assistance or one on one attention if needed.

Intellectual Disability

Prevalence: An intellectual disability is categorized as being 2 standard deviations below standard intelligence. Therefor in the United States there are said to be 2.2% of the population

Cause: Intellectual disability is a generic term used to describe any significant limitation in cognitive or adaptive functioning and therefor there is not one accepted cause. Often times the cause is unknown.

Characteristics: Diagnostic criteria for intellectual disability ranges depending on IQ level (though these cut offs are somewhat arbitrary and vary based on your source)

Mild: 55-70: May find social subtleties difficult to understand or follow. May or may not be able to read and write. Can achieve a significant level of independence given proper support channels

Moderate: 40-55: Slightly greater difficulties understand social interactions than the mild group. Likely needs assistance in organizing or planning trips as well as handling money. Usually understands schedules and is able to make decisions independently and may develop personal care and hygiene independence.

Severe: 25-40: Usually recognizes familiar people and forms strong relationships with key figures in their life. Likely has little or no speech and will rely heavily on gestures to communicate. Requires help in personal care tasks, communicating, and activity participation

Profound: below 25: Similar prognosis as with severe intellectual disability

Recreation participation:

- Ability and modifications for intellectual disability will vary greatly from person to person. Tailor the activity to the individual.
- Simplified instructions or additional time may be needed for an individual with an intellectual disability. For example, you may want to use short phrases when explaining directions or allot an hour for a 30-45 minute activity
- Even though an individual may be diagnosed with a certain level of intellectual disability, diagnosis of ID can be very difficult and confounded due to deficits in communication, attention span, or motivation. For example, do not assume someone diagnosed with severe intellectual disabilities does not understand speech just because of their diagnosis

Developmental Delay

Prevalence: CDC reports that between 2006-2008 that 1 in 6 children had a developmental disability, though this is not exactly the same as developmental delay, because developmental delay is not necessarily a lifelong condition and can be treated with early intervention. There are currently no reliable studies on the prevalence of delay

Cause: There is not one accepted cause of developmental delay. Often times the cause is unknown.

Characteristics: Developmental delay is a generic term that simply means a failure to meet certain physical, intellectual, or communicative milestones typically met by a particular age. When referring to intellectual delay, it varies from intellectual disability in that the child is too young to definitively diagnose or tests were inconclusive

Recreation participation:

- Considerations for recreation participation are going to depend entirely on the individual and the type of developmental delay
- For physical developmental delay, individual may need support during games that require balance or hand over hand assistance if there are deficits in fine motor skills
- For Intellectual Developmental Delay, refer to intellectual disability page
- Depending on the type of communicative developmental delay, camper or client may need additional time to verbalize. It is important that you allow the individual to finish their sentences and not “jump in”. They may also need to utilize formal or informal sign language as well as have words or phrases repeated

Oppositional Defiant Disorder

Prevalence: Because this is merely a spectrum of otherwise typical behavior, the prevalence of this disorder is hard to pin-point. Current estimates range from 1-16% of children in the US

Cause: Unknown

Characteristics: ODD is characterized by excessive or extreme arguing with parents and others, frequent temper tantrums, easily hurt feelings, frequently questions or breaks rules, and other defiant behavior. All of these behaviors can be seen in children of comparable age groups, but ODD is distinguished by excessive prevalence of these behaviors that is damaging or interfering with the child's ability to perform at home, in school, or create and maintain healthy social interactions

Recreation participation:

- May have difficulty working cooperatively in team games. Try encouraging turn taking and appropriate social behaviors. Also make sure to give praise when he or she displays such positive behaviors
- Because children with ODD often engage in power struggles and can get upset more easily than others, encourage and administer time outs as a way to calm the child down. Try and emphasize that it is a tool for managing our moods and not just a punishment by saying things like, "We're going to take a break for 5 minutes in this chair" After the time-out, you can talk about better conflict resolution skills or anger coping skills
- Try encouraging the child to recognize when he or she is getting upset and provide an option for them to help cope with that stress such as going for a walk, giving themselves a time out, or squeezing a ball. Give praise when they choose utilize healthy coping skills or recognize their feelings

Traumatic Brain Injury

Prevalence: The CDC recently published that at least 1.4 million people sustain a TBI. Of these, about 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from an ED.

Cause: BIAA defines TBI as “an alteration in brain function caused by an external force”. It distinguishes itself from other disorders in that it occurs some time after birth. TBI is generally divided into two main categories: A penetrating force and non-penetrating force. A penetrating force pierces the skull such as with a bullet, and the resulting brain injury is usually more localized. A non-penetrating force does not penetrate the skull and examples include shaken-baby syndrome, car accident, falls, or blunt forces to the head.

Characteristics: Symptoms will vary depending on what region of the brain has been affected by the injury. Traumatic Brain Injury is a life-long disease that does not go away. Impairments can include physical, communication, intelligence, hearing, vision, and changes in emotions. Individual may experience seizures, headaches, exhaustion, confusion, memory loss, or a decreased ability to pick up on social queues such as waiting their turn to talk.

Recreation participation:

- Considerations are going to vary drastically depending on the area of the brain affected
- Take extra precautions during any activity that could potentially cause harm to the head such as trampolines or contact sports
- Use visual reminders such as a picture schedule to decrease potential confusion or memory loss
- A frequently reported increased activity after traumatic brain injury is television watching. Try and encourage participation in more engaging activities such as sports, arts and crafts, or music.

Fetal Alcohol Syndrome

Prevalence: CDC states their best estimate for occurrence lies around 0.2-2.0 cases per 1,000 live births.

Cause: Fetal Alcohol Syndrome (FAS) is classified as a spectrum of birth defects that are caused by a mother who drinks alcohol during pregnancy. In 2005, the Surgeon General's office updated their position on alcohol consumption during pregnancy to advise women to completely abstain from drinking alcohol. This replaced their 1980s release that suggested small amounts of alcohol consumption were safe during pregnancy.

Characteristics: Most incidents of FAS have both physical and cognitive impairments (in particular changes in central nervous system functioning). A person with FAS may have learning disabilities, decreased memory skills, or intellectual disabilities. Children with FAS are at a higher risk of developing ADHD as a secondary diagnosis and commonly have motor functioning delays such as executive command skills (ability for the brain to tell muscles to move). There are also physical features commonly associated with FAS: low birth weight, small head size, or smooth ridge between their nose and upper lip.

Recreation participation:

- When giving instruction for physical activity, individuals with FAS may need additional time to execute the command.
- Activities that require a quick physical responses may need to be modified to slow down for individuals with FAS. For example, try playing catch with a inflatable beach ball instead of a tennis ball. During a game like Duck, Duck, Goose, you can try telling an individual with FAS ahead of time that they will be chosen so that they can get ready to stand up and chase.
- Try encouraging and practicing memory skills. Try working with the individual playing memory games such as Fun Match or picture games
- Due to learning and intellectual disabilities, provide simple instructions and additional time to complete activities or challenges

Multiple Sclerosis

Prevalence: About 1 in 750 individuals in the US will develop MS. Majority develop MS between 20-50 but it can occur in children and adolescents. More likely to occur in females than in males

Cause: Multiple Sclerosis is an immune-mediated disease of the central nervous system where the myelin sheath around nerve fibers is compromised. Why the disease develops is still not known. It is believed that development is a combination of genetic and environmental factors.

Characteristics: While severity ranges, individuals with MS generally experience a wide array of symptoms involving the central nervous system. According to the National MS Society, around half of individuals with MS will experience disfunction in cognition. This includes problem-solving skills, learning ability, memory, loss of vision and attentional focus. Individuals with MS often experience numbness, loss of balance, pain, abnormal walking gait, and loss of bladder control.

Recreation participation:

- Because fatigue is one of the most common symptoms of MS, provide opportunities for rest during and following physical activity
- Due to loss of touch sensation, individuals with MS may enjoy certain sensory-focused activities such as running their feet or hands through sand or other materials
- Be mindful and provide additional support during activities that require balance such as riding a bike or obstacle courses
- Because loss of vision is often one of the first symptoms reported by individuals with MS, signs with writing or type may need to be enlarged or bolded. Activities involving hand-eye coordination such as catching a ball may need to be slowed down or modified
- Depression and anxiety are very common with individuals living with MS. This makes participation in recreation and leisure especially important. Always provide a warm, supportive environment

Chiari Malformation

Prevalence: Approximately 1 in 1000 is currently the most accurate estimate. Many individuals with CM show no symptoms until a later age and therefore often goes undiagnosed

Cause: CM is caused by structural differences in the brain and spinal cord that places pressure on the cerebellum and brain stem. This pressure adversely affects development and inhibits the free flow of cerebral spinal fluid. These structural differences can be caused by genetic predispositions, nutrition factors, infection, or other environmental factors

Characteristics: The cerebellum is the portion of the brain largely responsible for balance and motor function. Resulting symptoms include issues with balance, hand-eye coordination, fuzzy vision, neck pain, muscle weakness, vertigo, and reports of ringing in the ears

Recreation participation:

- Be mindful of challenges with balance and provide additional support such as riding a scooter or bike
- Try and modify games involving hand-eye coordination. Some examples include hitting a ball off of a tee instead of throwing it or using an inflatable ball to play catch instead of a tennis ball
- Due to decreased hand-eye coordination, arts and crafts activities that require controlled motions may prove difficult. Try modifying arts and crafts activities that is flexible to uncontrolled motions such as finger painting or splash art

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