

Play Like a Champion Today Educational Initiative

Intellectual Disability and Down Syndrome



Helping Athletes with Intellectual Disability and Down Syndrome

What is intellectual disability?

**The term intellectual disability has replaced the formerly used term mental retardation.*

- Intellectual disability (ID) is a disorder with onset during the developmental period that involves intellectual and adaptive functioning deficits in conceptual, social, and practical domains.
- Level of severity is based on adaptive functioning, or amount of support required in daily life (not IQ scores).
- Severity Levels of ID:
 - Mild
 - Moderate
 - Severe
 - Profound

What is Down Syndrome?

- Down syndrome (DS) is a form of intellectual disability associated with a genetic syndrome.
- DS is associated with physical characteristics such as a flat face, slanted eyes, a short neck, small ears and mouth, low muscle tone, and loose joints.
- Most cases of DS result from trisomy 21, meaning that each cell in the body has an extra copy (three instead of two) of chromosome 21.

Prevalence:

- ID has a general population prevalence of about 1%. Prevalence rates vary by age. Rates for severe ID are approximately 6 per 1,000.
- DS is present in approximately 1 in 800 newborns. About 5,300 babies with DS are born in the United States each year, and an estimated 250,000 people in this country have the condition.
- Males are more likely than females to be diagnosed with mild and severe forms of ID.
- ID occurs in all races and cultures.

Athletes with ID and DS are unique and require different management of athletic participation and athletic injuries.

Things to know about ID/DS...

- People with ID display higher body mass index and obesity rates than typically developed individuals of the same age.
- About half of children with DS have heart defects at birth and require early treatment. Many also have impaired immune systems and are prone to respiratory infections. Heart and blood vessel abnormalities can limit the capacity for exercise and sport participation among those with DS.
- Unstable joints, poor muscle strength, and weak ligaments increase the risk of spinal problems and neck injury in those with DS. Those with DS can be especially vulnerable to dislocation of the first two neck bones (atlantoaxial dislocation). Approximately 10-30% of children with DS have atlantoaxial instability and may risk spinal cord compression if they play sports.
- Foot problems are more common in people who have Down syndrome than in the general population, likely due to loose ligaments.
- People with Down syndrome consume about half the amount of oxygen as compared to what an individual without Down syndrome consumes. This can cause oxygen intake rates to seem like those of a much older individual – sometimes the equivalent of twice the chronological age of the individual with DS, impacting his or her response to physical exertion.
 - Keeping drills brief, offering frequent breaks, limiting repetitions and implementing substitutions regularly (as feasible) may help to accommodate for this.
 - It is important to incorporate strength and cardiovascular conditioning into the sport regimen for this population. These activities have less physiologic stress and can also help with fulfillment of activities in daily life.
- Children and adults who have DS may not be able to tell you or the doctor if they don't feel well or are in pain. Instead, their behavior may change. Or they may stop doing things that they used to do. These may be signs of a medical problem. Talk to the doctor if you notice that an athlete with DS behaves in a new way. Also be alert for signs of depression, anxiety, or other mental or behavioral health problems.

Studies show that the average involvement in physical activities among those with an Intellectual Disability is far lower than the recommended daily amount of physical activity. Cognitive deficits seem to contribute to a lack of motivation to maintain athletic involvement or a designated exercise regimen for sufficient periods of time.

Suggestions for coaching athletes with ID/DS:

*Look for the GROW model within these tips!

Promote Self-Determination

- Self Determination is a concept involving high aspirations for the self, perseverance in the face of obstacles, and the ability to view various options for action, & learn from failures.

- Self-determined behavior is made with conscious choice – intentional and self-initiated.
- According to sport research, self-determination (vs. other forms of determination) occurs in a social context.
- Challenges can serve as opportunities OR threats to one’s self-determination. As a coach, try to help your athletes conceptualize them as opportunities. Challenging circumstances, also known as “causal events,” can propel one to set and achieve goals important to him or her.

Participation in Goal Setting and Planning

- Help athletes respond to challenges by developing a goal generation process to identify and prioritize necessary actions.
- Help athletes identify and define goals clearly and specifically.
- Establish learning objectives or tasks to master in order to accomplish the goal(s).
- Specify the actions needed to develop specific skills and achieve the desired outcome. The plan can always be modified along the way.
- Adjust teaching tactics according to athletes’ output – be flexible!
- Expose athletes to conditions they may encounter during competition:
 - Try practicing under high-stress circumstances (e.g., close score; championship at stake)
 - Allows athletes to stretch their emotional “muscles” as well as push their physical limits
- Focus on enhancing one’s capacity for self-direction and self-regulation and making environmental adjustments to increase this capacity:
 1. Promote **ownership**- active involvement in problem solving and decision making.
 - You may need to teach new skills to enable more effective problem solving & decision making skills.
 - Encourage athlete involvement in practice planning and development of team strategies to reinforce these skills.
 - Explore and test various solutions to problems as proposed by the athletes. Discuss the consequences.
 2. Engage Athletes (youth and adults) in self-directed learning and self-management strategies.
 - These can enable greater independence in tasks across multiple domains
 - e.g., antecedent cue regulation strategies, self-instruction, self-monitoring, self-evaluation, self-reinforcement
 - You may implement some of these by asking athletes how they think they did; modeling positive self-talk and praise; verbalizing/narrating actions and instructions and asking them to do the same.
 - Use visual aid to monitor progress. You can have athletes keep it updated themselves.

One study showed that athletes with DS scored higher than those with other types of ID on self-determined types of motivation.

Examine athletes’ incentives for sport participation

“Sport motivation in persons with ID is based on a combination of extrinsic (e.g., winning ribbons and medals) and intrinsic (e.g., having fun, being fairly skilled, and spending time with friends) incentives” (Hutzler, Oz, & Barak, 2013).

According to the Goal Perspective Theory (GPT), sport motivation is driven by:

1. Task Orientation: desire to master the demands of a particular task and improve one's ability or competence
 2. Ego Orientation: motivation is driven by the desire to perform well or better than others
 - Male athletes are reported to have a higher ego orientation than female athletes.
- A study which examined a group of athletes with ID who participated in the Special Olympics showed that these athletes scored significantly higher on Task Orientation as compared to a group of "typically developed" (TD) individuals. Those with DS had significantly higher Ego Orientation, Internal Motivation, Identified Regulation, and External Regulation than TD athletes.
 - Researchers believe this is the result of nurturance of external regulation and goals (e.g., providing medals & ribbons) in combination with positive verbal feedback to all participants, regardless of their performance level.
 - The motivation climate of Special Olympic athletes values competition and winning, enhancing the relationship between Ego Orientation and External Regulation.

A negative self-concept in individuals with developmental disabilities has been associated with anger, depression, and low motivation and anxiety.

- Be aware that unfamiliar or unusual physical tasks may provoke anxiety or fear in athletes with ID/DS. The dedication and support of coaches, teammates, and family members can help reduce these feelings.
 - Introduce new concepts a little bit at a time and have the athlete attempt what they feel comfortable with at the time.
 - Repetition of a given task (or portion of a task) will help increase self-confidence. Modify the # of repetitions according to each athlete's level of physical and emotional readiness.

Promote positive self-concept

Self-concept is the perception and evaluation of the self, including beliefs, feelings, and intentions.

- Children and adults with ID are especially prone to developing negative self-concepts.
- Compared to typically developed adolescents, those with ID express significantly more feelings of frustration & inadequacy and often feel that their lives are uninteresting and empty.

Elicit family and community support whenever possible! Cultivate an atmosphere of acceptance and let it empower your athletes.

Integrate competition

- Participating in task related competitions within a sport/team setting may increase the availability of contexts that allow an individual with ID to practice skills required in daily life, including self-care and social skills.
 - Try embedding fun competitive tasks within drills and warm-ups. Consider small rewards for the winners of these contests.
 - One study shows that even playing conventional board games (e.g., "Sorry") can foster healthy competition and cooperation, while promoting social skills in those with ID.
 - Consider having a team game night or "other sport" night once in a while – it will build upon the team **relationships**, camaraderie, and cohesiveness while honing competitive skills!

Incorporate tangible recognition of effort

- When athletes with ID are given medals/ribbons/trophies for sport participation, not simply winning, it provides a concrete representation of approval and effort. This can serve to enhance athletes' sense of social acceptance, thus, increasing motivation.

Promote commitment and longevity

- The longer a developmentally disabled athlete is affiliated with a sports program, the more firmly defined their role as athlete becomes, which can contribute to a more positive sense of physical competence, belonging, and acceptance.

Encourage athletes to try out various sports and roles within each sport

- With each role's distinct task demands, athletes must develop new and ultimately a more diverse repertoire of skills which can enhance their sense of physical mastery.

Adopt a positive coaching style

- Always be generous with praise, positive reinforcement, modeling, and one-on-one instruction.
- Remember...at the end of the day, it should be FUN – for you and for them.
- Many of the instructional techniques described in the Working with Athletes with Autism Spectrum Disorder overview are applicable to working with athletes with ID/DS. Review them to see what might be a good fit for your team: http://playlikeachampion.nd.edu/assets/128059/exceptionalities_asd_overview.pdf

Because life experiences contribute greatly towards the self-perception of those with developmental disabilities, it is extremely important for sport educators to infuse a sense of positive self-worth into his or her athletes to enhance their overall psychological well-being.

Read this inspirational story of gold medalist Special Olympian power lifter Chevi Peters and his coach, John Lair: http://espn.go.com/espn/feature/story/_/id/13323549/powerlifting-saved-special-olympics-athlete-chevi-peters-coach-john-lair.

References and Recommended Websites

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*. (5th ed.). Arlington, VA: Author.
- Cremers, M. J., Bol, E., de Roos, F., & van Gijn, J. (1993). Risk of sports activities in children with Down's syndrome and atlantoaxial instability. *The Lancet*, 342(8870), 511-514.
- Hassan, D., Dowling, S., & McConkey, R. (Eds.). (2014). *Sport, Coaching and Intellectual Disability*. (1st ed). New York, NY: Routledge.
- Hutzler, Y., Oz, M., & Barak, S. (2013). Goal perspectives and sport participation motivation of Special Olympians and typically developing athletes. *Research in Developmental Disabilities*, 34, 2149-2160.
- Wehmeyer, M. L. (2010). Self-determination. In: Stone, J. H., & Blouin, M. (Eds.). *International Encyclopedia of Rehabilitation*. Available online: <http://cirrie.buffalo.edu/encyclopedia/en/article/34/>.
- Weiss, J., Diamond, T., Demark, J., & Lovald, B. (2003). Involvement in Special Olympics and its relations to self-concept and actual competency in participants with developmental disabilities. *Research in Developmental Disabilities*, 24, 281-305.

Also Check Out These Websites:

- Global Down Syndrome Foundation (<http://www.globaldownsyndrome.org/our-story/about-gdsf/>)
- Inas – for para-athletes with Intellectual Disability (<http://www.inas.org>)
- National Down Syndrome Society (NDSS) (<http://www.ndss.org>)
- RallyCap Sports (<http://www.rallycapsports.org/>)
- Special Olympics homepage (<http://www.specialolympics.org/>)
- Sports Union for athletes with Down Syndrome (<http://www.su-ds.org/>)

Carrie Hastings, Psy.D.
askdoctorcarrie@playlikeachampion.org

© Play Like a Champion Today, Intellectual Disability Overview