Special Needs Athletes: Canada

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Let me win.
But if I cannot win,
Let me be brave in the attempt.

–Special Olympics Athlete’s Oath

Special Olympic Sports

- **Summer Sports**
  - Athletics (Track & Field)
  - Aquatics
  - Powerlifting
  - 5 & 10 Pin Bowling
  - Rhythmic Gymnastics
  - Soccer
  - Softball

- **Winter Sports**
  - Alpine Skiing
  - Nordic (Cross Country) Skiing
  - Figure Skating
  - Speed Skating
  - Snowshoeing
  - Floor Hockey
  - Curling

Intellectual Disability (ID)

- Intellectual disability is the leading form of lifelong disability worldwide (WHO, 2002)
- Over 500 different forms of impairment included within this group, representing highly diverse abilities, needs, and interests
- For approximately 85% of these individuals, the origin of impairment is unknown
- For the remaining 15%, the impairment results from various biological causes such as chromosomal, metabolic, and genetic
- Approximately 10 to 15% have associated impairments such as fetal alcohol syndrome, autism, visual and hearing impairments, and seizure disorders
- The origin of impairment and the possible presence of associated disabilities may affect development of the nervous system, hormonal systems, and general growth and maturation

LTAD

- LTAD = Long Term Athlete Development
- LTAD is a framework for developing physical literacy, physical fitness, and competitive ability, using a stage-by-stage approach
- The LTAD model recognizes that physical literacy is the foundation for being active, healthy, and engaged in physical activity for life
- Achieving personal best performances at all levels of competition
- LTAD provides an optimal development plan for everyone to participate in physical activity
- It also ensures that individuals who wish to excel in their sport of choice get optimal training, competition, and recovery in each stage of their athletic development
- The ultimate aim of LTAD is to optimize the “input influences” that enable individuals to achieve lifelong wellness through fitness and sport.

Why is this necessary? It’s just sports!

- In the general population, 30% of adults and 26% of children are overweight or obese (Statistics Canada, 2004)
- The weight of those with intellectual disabilities follows the general population trend
- Healthy behaviors to reduce physical inactivity and obesity are necessary for all Canadians, with or without a disability
**The Gaps**
- Inconsistency: Some Chapters offer programs for children younger than eight years of age while others do not.
-Athletes compete in sports for which they lack skills, leading to drop outs.
- Supervisors and coaches may lack expertise in teaching basic sport skills and/or technical aspects of specific sports.
- Athletes with national and international aspirations who systematically train are left off provincial and national teams despite elite performances in competition due to the current quota system.
- Athletes have limited opportunities to compete on a year-round basis.
- Competition is technically, physically, and psychologically demanding—are the athletes ready?

**Down Syndrome and Intellectual Disability of Unknown Origin (IDUO)**
- **Down Syndrome**: Accounts for 10% of the population with an intellectual disability.
- Is identifiable at birth with distinctive physical characteristics.
- Has the leading chromosomal form of intellectual disability.
- Chromosomal abnormalities may influence growth development, capacity for intensive sport training and acquisition of motor skills.
- May not be identified until individuals enter school.
- Physical growth and maturation tend to parallel patterns in individuals without an intellectual disability.
- Strength is an area that may require specific attention in training.

**Variation in Growth and Maturity**
- **Down Syndrome**: Pre-puberty growth spurt may occur earlier (9-10).
- Less dramatic than in other children.
- Sexual maturity may occur earlier than the norm in boys.
- Sexual maturity may occur later than the norm in girls.

**Critical Periods of Development**
- When does training have an optimal effect on specific capacities?
- The specific capacities — the 5 S’s of training and performance are Stamina (endurance), Speed, Strength, Skill, and Suppleness (flexibility).
- Individuals are more likely to achieve their full athletic potential if their training fits their stage of development.
- There has been little research on trainability and the critical windows of development for individuals with an intellectual disability.

**Stamina**
- **Down Syndrome**: Often have lower levels of cardiac output and lower VO2 max potential, which may limit endurance capacity.
- **IDUO**: With appropriate training, can achieve cardiovascular fitness standards comparable to peers without a disability.

**Skill**
- **Down Syndrome**: Later than average.
- High degree of variation in both rate of skill acquisition and skill quality.
- Wide variations, with some children between the ages of 10 and 15 reaching levels comparable to norms for children without a disability.
- Considerations regarding athletization must be reflected in structured skill training.

**IDUO**: Highly variable, with some children showing delay and others approaching norms for children without a disability.
- Wide variations. Need to consider other factors that influence motor skill development such as environment and systematic instruction.
- Need to differentiate between open and closed skills—closed skills may be difficult for people with an intellectual disability to acquire.

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Strength

Down Syndrome
- May be an issue linked to neuromuscular system functioning at both the central nervous system and joint level

IDUO
- Some research shows lower levels of peak muscular strength, which may not improve significantly with maturation or long-term training

Speed

Down Syndrome
- No specific research

IDUO
- No specific research

Suppleness

Down Syndrome
- Hypotonicity or low muscle tone/excessive ligament laxity has implications for suppleness

IDUO
- No specific research

Special Olympics is comprised of:

- More than 2.8 million athletes in more than 180 countries
- More than 200 affiliated Special Olympics organizations
- 700,000 volunteers around the world
- 500,000 coaches around the world
- More than 20,000 annual competitions around the world

Healthy Athletes Program (Medfest)

- People with intellectual disabilities have additional physical and psychological concerns secondary to their primary disability such as:
  - pain
  - osteoporosis
  - pressure sores
  - contractures
  - poor physical fitness
  - medication side effects
  - behavioral issues
  - oral health problems
  - bowel, bladder or gastrointestinal dysfunction
  - higher prevalence of being overweight or obese

Increased Athletic Risks

- Cardiogenic risk
- Traumatic impact risk
- Seizure risk
- Endurance risk
- Risks associated with acute infection
Cardiogenic Risk

- In all athletes under 40 years of age, the most prevalent cause of sudden cardiac death is related to the presence of a cardiac defect.
- While the prevalence of cardiac defects is not known in the Special Olympics athlete population, it is known in some of the more common NDs that cause intellectual disabilities. Fetal Alcohol syndrome, Down syndrome and Fragile X syndrome are all highly associated with defects of the heart or aorta (roughly 35%, 45% and 50% respectively).
- Some neurodevelopmental disorders (NDs) such as Williams syndrome, are even more likely (up to 75%) to be associated with cardiac defects.

- In the general population, the cardiac defect rate is around 0.9%.
- This means that about 0.9% of the general population of athletes under 40 years of age likely carry with them the number one risk factor for sudden cardiac death during athletic activity.
- While no reliable estimates for people with intellectual disabilities exist, experts in the field believe that this rate may be anywhere from 10 to 20 times more prevalent in the Special Olympics population.
- Screening for cardiac defects, therefore, is a very important step in promoting safe participation in Special Olympics.

Special Olympics athletes are much more likely to be taking medications than the general athlete population. Many of the commonly seen medications in this population (e.g., anti-psychotic and anti-seizure medications) are used on a long-term basis and consequently are often associated with long-term side effects. Osteoporosis, weight gain, sun sensitivity or potentially fatal Long QT syndrome.

Though the prevalence of Long QT syndrome is not known in the intellectual disabilities population, a recent survey of Special Olympics athletes found that 5% of athletes were taking medications which could induce Long QT as a side effect.

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Traumatic Impact Risk

- The Special Olympics Healthy Athletes program has documented that low bone density (osteopenia / osteoporosis) occurs in about one out of every five Special Olympics athletes (average age, 24) — perhaps caused by medications?
- Low bone density is correlated with an increased risk of bone fracture. A t-score (a rating of bone density) of -1.5 is roughly 4 times more likely to be associated with a bone fracture than a t-score of 0, and a t-score of -3 is more than 18 times more likely.
- A t-score of -1 or lower is considered osteopenic.
- Though fracture rates in Special Olympics athletes have not been studied, it seems plausible that fracture rates would be higher in this population, and especially in athletes taking risk medications.
- In an unpublished program evaluation of Special Olympics athletes, it was noted that 31% of athletes were taking medications which could induce low bone density.
- Athletes not on bone density-reducing meds had an average t-score of 0.0, while athletes taking these medications had an average t-score of -0.6.

Another Traumatic Impact Risk

- Some of the NDs found in Special Olympics athletes are associated with collagen and bone abnormalities, as well as macrostructural abnormalities of the spine, joints and limbs.
- The most well-known associated musculoskeletal complication is the atlantoaxial instability (AAI) often seen in Down syndrome.
- AAI can be observed by x-ray in around 15% of people with Down syndrome.
- In about 95% of these cases (13-14% of people with Down syndrome) the AAI is asymptomatic.
- While the establishment of a link between AAI and spinal cord injury has not been proven in all cases, it appears as though there is a link between spinal cord injury and AAI in the roughly 1% of people with Down syndrome who have symptomatic AAI.
- Currently, Special Olympics requires x-ray screening of all athletes with Down syndrome for the presence of AAI.

Seizure Risk

- Seizure disorders occur in roughly 26% of people with intellectual disabilities.
- It is important to note that many anti-seizure medications have behavioral side effects which the athlete may find conflict with his or her best athletic performance.
- Anecdotally, some Special Olympics athletes have been known to skip doses of their anti-seizure medications in order to reduce these behavioral side effects on the day of competition.
Many NDs are associated with metabolic abnormalities, thyroid disorders, kidney disorders, thermoregulation disorders, or extraordinary differences in pain perception. Any of these factors may predispose an affected athlete to developing heat stroke or electrolyte disturbances. While most metabolic risks can be managed with diet, proper hydration and exercise self-monitoring, it is important to note any special circumstances that may increase an athlete’s metabolic risk for sports injury and to discuss these issues with the athlete, the athlete’s coach and the athlete’s family.

Acute Infection Risk

- Special Olympics athletes are at the same risk of acute infection as the general population.
- However, they are more likely to have chronic infections or untreated/undiagnosed acute infections.
- Access to health care, reduced ability to report symptoms.
- An unpublished study of a sample population of 150 athletes who presented for medical screening at a Special Olympics MedFest event, none of the athletes complained of any urinary symptoms, however, six presented with an active urinary tract infection.

The Evaluation

- Aside from the medical risks that are specific to this population, Special Olympics has identified a number of unmet health needs which are likely to affect an athlete’s ability to perform at his or her best:
  - Vision deficits, hearing deficits, nutrition and unhealthy weight, poor oral hygiene and health, foot pain and musculoskeletal deficiencies.

Medications

- The average adult with intellectual disabilities in the US is taking seven different prescription medications.
- The average athlete who is taking prescription medications is taking 2.5 prescription medications.
- As already noted—some long-term medications have side effects which potentially exacerbate risks associated with sports participation.
  - Osteoporosis.
  - Female athletes and their families may forget birth control pills or long-term hormone therapy, such as Depo-Provera or IUC devices, are medications.

Vaccine History

- People with intellectual disabilities (particularly adults) often have difficulty accessing the health care they need.
- Vaccination histories may be difficult to obtain.
- If it is known that an athlete is lacking recommended vaccinations, the reviewing clinician should refer the athlete for vaccination.
- Lack of a vaccine history is not a contraindication to sports participation.
Sports of Interest

- Full clearance for participation is not the only option.
- In some cases, athletes may be cleared for some sports, but not for others.
- For example, athletes with a history of poorly controlled seizures within the last twelve months should not be cleared for sports involving water or high speeds like cycling or horseback riding.
- However, such athletes could be safely cleared for a sport like bowling.
- Knowing the athlete’s sports of interest can help guide the physician’s interaction with the athlete.
- Not knowing, however, is not a contraindication to sports participation.

History of Infection

- Active infection is a relative contraindication to sports participation.
- Urinary symptoms, cold symptoms and symptoms of other active infections should temporarily prohibit the athlete from participating in sports.
- This restriction, however, should be temporary and the athlete should be allowed to resume sports participation upon resolution of symptoms.

Conditions or Syndromes

- Cardiac History
- Trauma Risk
- Endurance Risk
- Psychiatric Risk
- Down Syndrome only

Cardiac History

- A history of cardiac death in relatives or a history of an abnormal electrocardiogram or an abnormal echocardiogram is a contraindication for sports participation, but should be considered in conjunction with the following:
- Contraindicated conditions due to increased risk of sudden death:
  - arrhythmogenic right ventricular hypertrophy (ARVH)
  - dilated cardiomyopathy
  - hypertrophic cardiomyopathy
  - heart infection
  - high blood pressure (>160/100)
  - hypertrophic cardiomyopathy
  - left ventricular hypertrophy
  - long Q-T syndrome
  - pericarditis
- Other conditions, such as heart defect, racing heartbeat, heart disease, heart murmur and high cholesterol may also be associated with an increased risk of sudden death, but should be considered with the overall clinical assessment of the athlete.

Trauma Risk

- Specific conditions associated with negative outcomes of traumatic impact:
  - Bone fracture, organ fracture, blood loss, brain damage, paralysis, death
  - Partial clearance to participate considered
- Neurological signs which indicate significant risk associated with trauma to the spinal column:
  - Deny participation and refer for immediate follow-up

Endurance Risk

- Conditions that predispose the athlete to negative outcomes associated with endurance sports:
  - Dehydration
  - Electrolyte abnormalities
  - Heat stroke
  - Heat exhaustion
  - Complications related to these issues
Psychiatric Risk

- Psychiatric disorders are often associated with intellectual disabilities.
- Aggressive or self-injurious behaviors, particularly within the last 12 months, must be assessed.
- In making this determination, a clinician should consider the severity of the incidents, the circumstances involved and the sports in which the athlete will be participating:
  - For example, an athlete with mildly aggressive behavior participating in an individual sport may not pose much risk to the health and safety of other athletes and therefore could be cleared for participation.
  - However, a strongly aggressive person with a frequent history of biting, scratching and gouging who wants to play a team sport may need to demonstrate significant improvement in behavior before being cleared for participation.

Currently, all athletes with Down syndrome must be screened, by x-ray, for atlantoaxial instability (AAI).

- If they have AAI, they must sign a waiver to participate in certain sports—but remember; this condition may be progressive.
- Because symptomatic AAI appears to be correlated with spinal cord injury, a physical exam of athletes who are positive for AAI is extremely important.
- Athletes exhibiting physical signs and symptoms of AAI should not be cleared for any sports participation until a parent or guardian has discussed these findings with a primary care physician or a neurologist.

Medications and Vitals

- Commonly, anti-seizure medications and anti-psychotic medications—Evaluate for side effects of osteoporosis, weight gain, sun sensitivity, constipation, and long-QT syndrome.
- Height and weight: measured without shoes, used to calculate BMI.
- Pulse: rate, rhythm, amplitude, contour, synchronicity.
- BP: measured in both arms.
  - 100-140 mmHg Systole; 50-90 mmHg Diastole.
  - > 160/100 in either arm: reconfirm, deny clearance, refer.
  - < 90/50—reconfirm, clear and refer.
  - > 20 mm/hg difference—reconfirm, deny clearance, refer.
- Oxygen saturation: should be above 90%.
- Temperature: Oral temperature under 99°F or 37.5°C, immediate referral otherwise.

Senses

- Hearing: Ideally, an audiologist volunteer and a pure tone audiometer testing at 1000, 2000, and 4000 Hz.
- Vision: tested with correction using the Lea chart. Must score 20/40 or better.

Lea Vision Chart with matching cards

Athlete Physical Examination

- Physical examination.
- Communication.
- Oral hygiene.
- Cerumen impaction.
- Heart murmur: 3/6 or higher, deny clearance.
- Hepatomegaly or splenomegaly: deny clearance.
- Neurological exam/range of motion/strength.
Levels of Clearance

- Full Clearance: 70 to 90% of athletes
  - Example: most athletes
- Full Clearance with Referrals: 10 to 30% of athletes
  - Example: athlete with sub-optimal vision correction
- Partial Clearance with Referrals: 0-10% of athletes
  - Example: athlete with seizures, cleared for bocci but not swimming
- No Clearance, Pending Further Evaluation: 0 to 5% of athletes
  - Example: athlete with active infection

The Purpose

- Remember, the purpose of the pre-participation examination is not for choosing the sport in which the athlete should compete
- The purpose is, as with all athletes, to determine if the athlete will incur a higher risk of serious injury during participation

Helpful Communication Tips

- Use Person-First language—put the person before the disability
  - “I met a young athlete from Quebec who has Down syndrome.” Not “My Down Syndrome girl from Quebec…”
- Put the person first
- Look for the person’s individuality
- Look for common ground for conversation (ask about their sport, etc.)

Strategies for Effective Communication

- Expect vastly different levels of communication abilities, from non-verbal to highly expressive
- Some will rely on nonverbal cues, sign language, photos or symbols, communication devices, blinking for “yes” or “no”
- Make eye contact, be patient, attend to body language
- Sit at eye level
- Try not to finish the athlete’s sentences
- Don’t use “baby talk”. Use clear, concise, and plain language
- Be willing to use different words
- Be willing to ask for help