

Adapted Physical Activities and Down syndrome

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Sport, competition, performance are today essential values of our society. They oppose the image of disability, even more surely when it comes to mental disability. However, for almost 20 years now, the sport gradually welcomed these specific populations, diverse and rich differences. The benefits of physical activity and sport as recognized in the general population are now extended to people with special needs whether they are people with a trisomy 21, a diabetes or obesity, for examples.

In Down Syndrome (D.S), the heterogeneity of the syndrome induced damage is even important depending on the type of trisomy, and medical management will therefore also very diverse.

History of Sports and Mental Handicap

Historically, the management of people with intellectual disabilities (ID) in sports activities dates from the late 19th, under the leadership of Dr. Edouard Seguin (1812-1880) a French teacher and physician. This teacher advocated a physiological education based on educational games, and shed what would become later the sensori-motor stages, with the work of Jean Piaget. Dr. E Seguin incorporated a general training program that integrated muscular, imitative, nervous, and reflective physiological functions. Many techniques Seguin used in his programs, such as individualized instruction and behavior management, can be found in current practice, and so they are still recognized as relevant by care teams. In 1848, Seguin immigrated to the United States in 1848, and became a major reference teacher for educating individuals with retardation. Seguin's methods and positive results served as a foundation for similar efforts throughout Europe and America. Among those later influenced by his teaching methods was Maria Montessori (1870-1952), a pioneer in teaching children with and without disabilities.

In United States of America, Dr. Samuel Gridley Howe (1801-1876) established the first public training facility in Boston. He was concerned about the conditions of persons with mental illness, persons with a hearing loss or who are blind, slaves, and groups of people who were politically oppressed throughout Europe. Both Seguin and Howe firmly believed in the importance of family and community, and wanted their schools to prepare children with disabilities to live with the rest of society.

In parallel since the mid-1900s, beginning in Scandinavia, more and more countries have sought to deinstitutionalize persons with ID and to create appropriate community supports and inclusive community care settings for them. Sports activities grow as a means of education and therapy.

Nevertheless, it will be necessary to wait for a slow evolution for young children with mental disabilities can be integrated into educational structures and later into sport practice structures.

Until the 1960s, sport competition remains a contra-indicate for individuals with ID. The first published work concludes that competition (between disabled to non-disabled participants) was not recommended for people with ID [1-3]. Some results report that this type of competitive activity caused ID among aggressive [4,5], regressive behaviour [6,7] or a chronic inability to adapt himself to the requirements of the situation

[8], strongly linked to a high levels of anxiety. According to numerous authors [8,9], this anxiety compromised learning, abstract thinking and need for achievement [10] Thus, a study carried out on anxiety state during a basketball game between young participants with ID and controls highlighted high anxiety generated inappropriate behaviours for youth with disabilities [11]. For many years, this conclusion justifies the contra-indicate of competition and practice sports. The language of disability remains in a dominant thinking of the society where it is the idea of performance that is put forward.

Nevertheless, sport for participants with ID began to be organized through the Special Olympics movement. This grew out of a series of summer camps organized by Eunice Kennedy Shriver, beginning in 1962. The goal was to learn what these children could do in sports and other activities – and not dwell on what they could not do. In 1968 the first international Special Olympics were held, in Chicago. Under the leadership of various scientific works and influences of the world of sport, a new current of thought emerged around 1975, and it is in Canada in 1977 that the concept of Adapted Physical Activities taking shape to spread in all countries

In France, the federation of education through sport for people with mental disabilities (FFESPHM in 1971) was the only one to advocate for sport in this population. The federation developed a mass education policy for all. This is an innovative approach to the world of the ID, which gradually has the opportunity to access new activities. It is the French federation of adapted sports (FFSA 1983), that takes an importance in the field of disability sport, but with a setback in its development: it deviates from the mass educational policy to focus on a more selective vision of sports practitioners: performance and competition.

Beginning in the late 1980s, work began within several countries and organizations to include athletes with disabilities in the sport system. However, the status of athletes with an ID in the Olympic movement remains controversial.

In 1986, the international association for persons with ID (INAS-FMH) was created to support elite competition for athletes with ID. Athletes with ID were included in the Paralympic Games, and more than 3500 athletes are registered to compete at an international level, whilst more than 120,000 thousand people with an ID worldwide have the opportunity to enjoy sport. Today, Special Olympics provide training and competition in a variety of sports for persons with ID.

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But, a lot remains to be done. Despite the very clear shift of the body image and on disability, persistence of an attitude of subjection to a norm remains pregnant. Moreover, the dominant position of the medical world, the right to decide for people with disabilities to whether or not access to sport is still very strong.

For the medical community, it is a question of prescribing a sports activity to improve its health, for educational and sport community, it is a question of proposing activities according to the needs for the person, namely essentially its development through social integration, for autonomy and pleasure. This presupposes an opening of the practices and sporting disciplines to non-traditional patterns.

While attitudes have changed and knowledge about etiology and treatment have improved, participants with ID still continue to be a neglected community across most countries, especially the resource poor countries, and this adds to the growing burden of ID on the community, in different countries.

What Really for a Young with Down Syndrome (DS)?

Can participant with DS practise all sports? If so, are there any risks? What adaptations are otherwise to be envisaged to avoid any incident or possible accident?

Given the increasing number of available publications on “physical activity and trisomy 21”, some conclusions were made allowing showing that disabled individuals may access a satisfactory level of motor activity as well as the development of aerobic capacity [12].

However, the results also show that physical inactivity is a characteristic lifestyle of persons with ID living in institutions [13], physical inactivity against which it is necessary to fight as for all people.

Deconditioning induced inactivity causes a mismatch of major physiologic function, and so decreased physical abilities. This causes inactivity and an even greater social isolation. Moreover, even with regular physical training, individuals with DS exhibit low peak aerobic capacities and heart rates than their peers without disabilities [14-17]. Three physiologic factors that potentially contribute to low VO_{2peak} values in persons with DS are autonomic dysfunction [18,19], reduced ventilatory capacity [20], and metabolic dysfunction [14,21,22].

Physical impairments commonly associated with DS include a higher prevalence of heart defects, muscle weakness and hypotonia, and low cardiovascular fitness [16,17,23,24] may also be factors explaining lower physical fitness in individuals with DS.

These clinical characteristics may influence body fat and levels of fitness [25] and youth with DS continue to exhibit higher obesity and lower levels of fitness compared with their peers without disabilities, even those with intellectual disabilities without DS [26]. All these factors can explain these differences and require that the establishment of a preventive framework before practicing a sport and physical activity.

Physical activity (PA) is a lifestyle factor with an important role on health across the lifespan, and activity participation is particularly important for a child's development and can have a positive impact on their quality of life and future life outcome [27,28].

Preventive Framework to Practice

Many factors may contribute to the no-participation in PA by participants with DS because trisomy 21 is associated with numerous impairments, relevant to motor development delay. It necessarily takes precaution before proposing sport. Physical activity should be planned

in a framework that protects against injury, which does not hinder the development of motor skills and which does not lead to an additional disability. It is therefore necessary to realize a medical examination of non-*contra-indication* to sport. It is also essential that people who offer an activity are well qualified in adapted physical activity.

All proposed activities must be in a playful context, to maintain an adequate level of motivation, and the most permanent possible adherence.

Finally, participants with DS are able to learn and practice a variety of sporting activities. They should be physically active as their peers and regularly participate in training in order to progress and to maintain the beneficial effects of this practice

Medical Framework to Practice

Currently, a growing number of children with DS request permission to participate in sports so that they too can join in the everyday activities that their healthy peers enjoy. As children with typical development, the practice of sport for participants with DS is based on obtaining medical authorization by the passage of a visit of no *contra-indication* in the physical practice (in France, Law of March 23, 1999)¹. This visit of no *contra-indication* is compulsory for all subjects who sign a license at a sport federation. For a basic examination, we note:

1- Interview: It allows to review the possible pathologies of the young, and to do a medical assessment with family.

2- Biometric examination: weight, height, body fat percentage, thoracic, abdominal and waist perimeters.

3- Verification of visual and hearing acuity: Visual acuity is checked (*e.g.* from images ‘type test Kay’; 1983). This examination will be necessary especially if the subject participates in sports where decision-critical component of visual information in the environment exist (*e.g.* canoeing, slalom skiing).

4- Clinical examination: The essential point is the cardiovascular examination. A rest electrocardiogram is highly recommended, because heart anatomic abnormalities are particularly associated with DS [29-31]. Indeed, several studies investigating cardiac function have reported low heart rates (HR) associated with low arterial blood pressure. About 40% to 50% of people with DS have congenital heart disease. In general, the most common anomalies are atrioventricular canal defect, tetralogy of Fallot, and patent ductus arteriosus [32], but these pathologies are well cared from early childhood. Nevertheless, echocardiographic examination is recommended for all children with DS before involvement in physical exercise, especially if they have presented a heart disease, and some other specific examinations can be proposed to parents, as a maximal treadmill or bicycle exercise.

To date, some studies have been reported some training effects on persons with DS [12,33-37] and demonstrated significant gains in cardiovascular fitness and muscular strength and endurance in a controlled trial involving a large sample of adults with Down syndrome.

American College of Sport Medicine [38] recommends training sessions from 20-60 minutes of aerobic activity, from 3 to 7 times per week with an intensity of 55-90% of heart rate (HR) or 40-80% of VO_{2max} . Such training programs seem to confirm the physiological benefits on cardiovascular function.

5- Musculo-skeletal examination: It done during the clinical

¹In France Law n 99-223- Law on the protection of the health of athletes and anti-doping control.

examination, and will be focused on pathologies of the column: atlantoaxial instability, or scoliosis for example. If these pathologies are not a systematic sport contra-indication, they must however be known, and it may be necessary to restrict sporting activities, or to provide the recognition of this pathology in the organization of sports.

Besides that, motor clumsiness characterized by hypotonia, muscle weakness and hyperflexibility have been frequently reported in trisomy 21, and may result in increased joint dislocation risks [39]. This may affect the ability to perform daily physical and / or professional activities, especially if they require balance and sufficient strength. Progressive training based on a strength work will improve muscle strength with moderate to large effects in different individuals. People with DS have the capacity to improve muscle strength of the lower and upper limbs with progressive resistance training [36].

American College of Sport Medicine [38] recommends training sessions with progressive resistance exercise; that is, a small number of repetitions could be performed before fatigue, sufficient rest was allowed for recovery between exercises and the amount of resistance was progressed as the ability of the participants increased.

Moreover, it seems essential that the motor loads of young children are the earliest to stimulate learning of postural-kinetic coordination and balance during infancy, even more, that it was during the early years life that brain plasticity is highest. [40] Reviewed reliable and positive training effects on the gross motor behavior of infants and young children with DS.

It is necessary to propose exercises that confront the young to changing situations in which he is forced to adapt and anticipate his motor responses to an unstable environment. The repetition of actions, the frequency and diversity of proposed exercises are necessary conditions for the motor patterns of the young are becoming more flexible, operational and thus successful. To improve motor memory, it seems relevant to implement specific educational strategies that use a mode of visual communication rather than verbal [41-43].

6- After this first medical investigation, specific tests can be prescribed by the medical team, as:

- Gastro-intestinal examination. Abnormalities of the gastro-intestinal tract are a common occurrence in young with DS. Currently, with early intervention from paediatricians, many of the problems may be well managed.
- Visual examination. Ocular abnormalities are common in this DS population. Visual impairment involves a loss in visual acuity. Specific ophthalmic abnormalities are associated with trisomy 21 as strabismus, nystagmus, cataracts. Many of these pathologies are treatable. Early detection and appropriate management can permit a good access in sporting activities, and contribute to maintain the individual's quality of life.
- Oral health is an important point for people with DS. The typical signs associated here were a protruding tongue (macroglossia) and dental anomalies (absent teeth, peg-shaped incisors, microdontia) or periodontal disease (gingivitis). Several recommendations can be made for practice some sports including wearing a mouth guard (e.g. rugby and or boxing).
- Un examen dermatologique peut être recommandé si le constat de peau sèche (très fréquente dans la T.21) est posé, et ce d'autant plus si le choix de certaines activités sportives est fait tel que la natation ou les sports de plein air (ski, cyclisme).

- Dermatological examination may be recommended, because dermatological problems frequently cause difficulties, especially folliculitis, which develops in 50–60% of adolescents with Down's syndrome. Skin problems include atopic dermatitis, fungal infections of the skin and nails, seborrheic dermatitis, and xerosis. These problems can be responsive to standard treatments and they are important to take in care mainly if the choice of certain sports activities is made such as swimming or outdoor sports (skiing, cycling).
- Children with DS may also have dysfunctional autonomic cardiac regulation even in the absence of concomitant congenital heart disease, which may be manifested mainly arousal from sleep. This altered response may be due to inadequate sympathetic activation or blunted vagal withdrawal and could reflect autonomic dysfunction in children with DS that may place them at increased risk for cardiovascular complications, such as pulmonary hypertension [44-47].

7- A **cardiopulmonary exercise testing** can be proposed to have a heart rate and blood pressure profile during exercise. The strict cardiovascular contraindications are the same as for sportsman (hypertrophic cardiomyopathy, valvular stenosis, chronic cardiac insufficiency, severe hypertension).

Blood samples can be prescribed (biochemistry and lipid status and thyroid). These last examinations present an interest, if the young child envisages an activity in weighty category (judo, karate).

What Proposals for the Practice of the Adapted Physical Activities in DS?

- Favor postural control work that makes use of balance activities. Activities such as climbing, gymnastics and circus arts are very appropriate.
- Train with a resistance program in order to counterbalance hypotonia. Gymnastics allows this work, and improve balance capacity.
- Approach the educational situations which make vary the sensory information sources to request environmental adaptation, anticipation and memory capacities. Artistic activities that allow learning choreography, but also ball sports that involve speed reaction and execution, and require social interaction, are very appropriate.
- Work as early as possible the endurance capacity with a regular physical activity. Although the relationship of physical activity and health outcomes has not been directly examined in people with DS, it is reasonable to assume that the findings in the general population of youth also apply to those with DS. Regular physical activity may improve the cardiovascular, metabolic, musculo-skeletal, and psychosocial health profiles of all youth. Physical training contributes to the fight against obesity. In this context, all the aerobic activities (walking, biking, and swimming) will be encouraged. While it is true that some physiological factors may limit long efforts, young with DS are however able to achieve this type of muscular exercise, some of them even showing very satisfactory performance [14].

What Can We Learn?

Today, there is no contra-indication anymore bound directly to intellectual disability induced by trisomy 21, except those for motorized

sports, aviation sports, shooting with firearms, and diving. Subjects with DS can definitely run, swim or jump like other children. If they are well supervised and if they are medically fit: sports activities are recommended. A large proportion of children and adolescents with DS may not meet the recommended amount of daily aerobic activity. The major risk is that these children develop abnormal compensatory movements (e.g. walking external rotation of hips, knees straight and feet flat open).

There is a real challenge to promote physical activity in population with DS, because in motor learning, the young will find useful acquisitions and also re-investable in his daily life.

It is preferable to propose a sport in which the young is playful interests and opportunities to meet with others, so more attractive and motivating activity.

Conclusion

This study outlines the practical ways in which positive well-being can be promoted by sports in people with Down syndrome. It emphasizes that prevention begins at birth and parents need to be informed to positive-child rearing strategies from infancy. It is also necessary to establish more community-based health promotion programs for persons with intellectual disabilities to offset the increasingly poor health status observed in this population.

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