

Down syndrome

Chapter 4

Down Syndrome: A long Term, Quality, Physical Intervention

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1. Introduction

About 1 in 800-1,000 of live born children, irrespective of gender, ethnic or racial group are diagnosed with trisomy 21 [1], clinically expressed as Down syndrome (DS) [2]. The additional chromosome results in an array of medical issues presenting higher prevalence of the ones presented by the general population [3]. For example: about 40% of individuals with DS will be diagnosed with cardiac abnormalities ranging from the simple arterial duct to the atrioventricular septal defect [4], with a high risk of secondary pulmonary hypertension [5], hypothyroidism [6] as well as obesity [7]. The fact that many individuals with DS maintain a sedentary life style, experience poorer health and have less access to health care than the general population [8], suggest that these individuals are at risk of an array of secondary health problems. nevertheless, it was established that appropriate intervention might improve the physical condition of this population [9]. The present chapter reviews the benefits of physical activity in the general population, and the physical state of individuals with DS and suggest several intervention programs that have been found useful for this population. The final part of the chapter presents a dance and drums program, which have been found useful with a group of individuals with DS and typically developing adolescents which has been running successfully for about 20 years.

2. Benefits of Physical Activity

Evidence continues to mount regarding the benefits of physical activity for physical well-being and the decrease of chronic ailment [10]. A growing body of research examining the relationship of physical activity to physiological, functional and psychological outcomes in many medical conditions [10-13] has found that physical activity is associated with physical

and psychological benefits [14]. Several studies [10,15] have showed that physical activity improves "psychological well-being", reduces anxiety and promotes healthier sleep patterns. Mounting evidence negatively correlates exercise, with anxiety, stress and depression [16].

Other positive effects of regular physical activity are: an improvement in cardiovascular and respiratory muscle function, reduction in coronary artery disease risk factors and a general decrease in overall mortality and morbidity [17]. These benefits have also been found to include enhanced feelings of well-being, enhanced performance at work, which are due to recreational and sports activities [17]. Recommendations for daily physical activities were published by the WHO [18]:

- *Physical activity need not be strenuous to achieve health benefits.*
- *Men and women of all ages benefit from a moderate amount of daily physical activity. The same moderate amount of activity can be obtained in longer sessions of moderately intense activities (such as 30 minutes of brisk walking) as in shorter sessions of more strenuous activities (such as 15-20 minutes of jogging).*
- Adults aged 18–64 should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate- and vigorous-intensity activity.
- Aerobic activity should be performed in bouts of at least 10 minutes duration.
- For additional health benefits, adults should increase their moderate-intensity aerobic physical activity to 300 minutes per week, or engage in 150 minutes of vigorous-intensity aerobic physical activity per week, or an equivalent combination of moderate- and vigorous-intensity activity.
- Muscle-strengthening activities should be done involving major muscle groups on 2 or more days a week.
- *Additional health benefits can be gained through greater amounts of physical activity.*

These recommendations can be valid for adults with disabilities

Despite those specific recommendation and related knowledge on the subject of physical activity and health, a closer look at the physical state of individuals with intellectual disability, is somewhat alarming.

3. Physical Fitness of Individuals with Intellectual Disability

Individuals with intellectual and developmental disability (IDD) have been found repeatedly as lacking in physical fitness, when compared to peers without ID [19-23]. As a result measures of poor fitness performance were demonstrated in cardiovascular endurance [24], body composition [25,26], muscular strength and endurance [27,28] and flexibility [29].

Fernhall et al [24] went so far as to state that the physical fitness of individuals with ID is so poor, that 20-30 year old men, present cardiovascular equivalent of people without intellectual disability, who are 30-40 years older, or men suffering from chronic heart failure. Many reasons have been suggested for these low levels of fitness:

1. Sedentary life style [21,30,31]
2. Low motivation for participation in physical activities [32]
3. Psychological or physiological barriers or motor passivity [33]
4. Physical characteristics such as short stature [34]
5. Lack of coordination and efficiency [35]
6. Lack of motivation during testing and a tendency to stop when uncomfortable [36].

Of all the factors examined, it was found that “inactive life style was the most harmful to physical fitness” [21,31,37]. This trend of individuals with IDD to stay less active than their peers and spend significantly more time indoors, showing a preference for indoor activities, was also found common among individuals with DS [38].

Sedentary life style is associated with high risk for developing obesity, coronary arterial diseases and heart attacks [39]. Moreover, it was established that the lack of physical fitness of individuals with multi-disability can lead to early aging phenomena and states of illness compared with peers with no such disorders [40]. The above mentioned assumption was proven by a longitudinal study from Canada. In this study adults with ID were monitored for their physical fitness and compared with a control group. The findings of this program disclosed that the physical fitness levels of the participants were low when compared to those without a disability and moreover, these low physical level was found to decline with age, over a 13 years period. In addition, the magnitude of change over these 13 years, as compared to those without a disability, was greater for male and female participants for body mass index and percentage of body fat and for female participants for cardiovascular endurance and ability to perform sit-ups. It appeared that adults with IDD such as Down syndrome may be particularly at risk for declining health, due to aging and low levels of physical fitness. Due to such alarming data, it is clear that intensive habilitative efforts must be introduced to reduce complications and

decrease the consequences accompanying old age and low levels of activity in this population [41].

4. Exercise Programs for Persons with IDD

Findings showed that regular exercise can improve the functional status and can decrease the level of assistance that people with disabilities may need in order to perform activities of daily living by increasing muscular strength, endurance, flexibility, balance, cardio-vascular and respiratory fitness [42]. Exercise can also reduce the incidence of secondary health complications in persons with disabilities (loss of cardio-respiratory and muscular function, metabolic alterations, and systemic dysfunctions), which may maintain or enhance quality of life [43].

The positive contributions that exercise programs entail have led to the implementation of various intervention programs for individuals with IDD. These programs included:

1. Stair climbing [44]
2. Walking, running, stretching and aerobic exercises [31]
3. Floor and flexibility exercises [23]
4. A mile run, use of a rowing machine, weight lifting, bicycle training [45,46]
5. Treadmill training [21,47,48]
6. Walking [49]

Individuals participating in these programs have improved in muscular endurance [31], physical fitness and reduction of pulse per minute [45], muscle strength [21,50], functional skills [47] and an improved health perception as deduced from reduced visitations to the infirmary [51]. To support Physical activity programs and in light of the success of previous exercise programs for individuals with IDD it was deduced that for individuals with Down syndrome, physical activity has similar implications positively impacting health, longevity, and productivity [21,33]. Thus, similar activity programs have also been implemented for individuals with DS at all ages.

5. Intervention Program for Children with Down Syndrome

All areas of development are equally important. Nevertheless, in the first months of life, physical development remains the underlying foundation for all future development. Babies learn through interaction with their environment. In order to do so, an infant must have the ability to move freely and purposefully. The ability to explore one's surroundings, the ability

to reach and grasp toys, to turn one's head in order to follow a moving object with one's eyes, the ability to roll over, to crawl in pursuit of a desired objective, all of these behaviors are mainly dependent upon the development of gross, as well as fine motor skills. Such physical, interactive abilities foster understanding and mastery of the close environment, and their importance to overall development stresses the importance of early intervention programs.

Furthermore, the general fitness level of children, adolescents and adults with DS is even lower than other people with IDD [52,53] and this is believed to have both a motivational as well as a physiological basis [54,55]. It is suggested that this poor state may be partly due to syndrome-specific conditions such as heart problems, but it seems also that there is a lack of expectations by stock holders resulting in poor programming for this population. Individuals with DS have a tendency to become obese from a young age [56], which leads to an adolescent and adult who is less likely to participate in physical activity. Such a poor beginning for the young child with DS has been challenged by physical activity programs. It is believed that appropriate professional involvement can advance the child with DS, and that early intervention will prevent secondary complications beyond the primary limitations compelled by DS itself [57]. In light of such believes several intervention programs have been suggested in previous years for young children with DS

Connolly and Russell, [58] concluded that an interdisciplinary early intervention program was necessary to help children with DS in early attainment of developmental tasks. Based on re-evaluating the results, it was found that achievements of the early intervention program for children with DS had long lasting results [59]. Thus it was concluded that participants in the early intervention program gained a foundation for subsequent learning and development [60,61]. These findings support implementation of long lasting intervention programs for this population, from a young age.

Another example of an attempt to evaluate specific motor training for children with DS was conducted in Sweden [62]. An intervention group consisted of 14 children and a control group of six children. The treatment began when the babies were three months old and lasted until they began to walk, focusing on increasing muscle tone, reducing incorrect patterns of movement, training typical movement patterns, and stimulating trunk rotation. The treated children performed better than the control children in all four areas measured: gross motor, fine motor, kinesthetic perception, and tactile perception.

Children with DS have been found to develop walking later than non-DS children and even later than children with other developmental disabilities [63]. In order to forward walking age in this population a special walking program has been implemented by Ulrich and her associates. Seven infants with DS ranging in age from 8 to 11 months participated in a daily walking program on a specially designed treadmill by their parents [64]. In a similar

intervention, the experimental group learned to walk with help and to walk independently significantly faster than the untrained control group. It is suggested that treadmill training should be considered as an intervention approach for young children with DS [64]. The results provide evidence that, with training and support, parents/caregivers can use these treadmills in their homes to help their infants with DS learn to walk earlier than they normally would [65].

6. Intervention Program for Adults with DS

Heller, Hsieh and Rimmer [66] found that a group of adults with DS, who participated in a fitness and health education program for 12-weeks (three practice days per week), changed their attitudes towards exercise, showed more positive expected outcomes, fewer cognitive-emotional barriers and improved life satisfaction. These findings were very promising since they imply that an appropriate educational program will enhance the participation of individuals with DS in physical activity programs.

Two groups of researchers have performed a jog/walk program for this population [67,68]. Despite the fact that the earlier group could only show minute improvements in walking ability in a group of 14 adolescents with DS after a 10 week jog/walk program, the latter group [68] demonstrated that adults with DS were able to improve their aerobic capacity when performing a systematic and well-designed aerobic training program.

Two treadmill training programs that lasted between 12 weeks and six months were held for young (mean age=24.5 years) and senior adults (mean age=63 years) with DS [69,70]. Both programs showed significant improvement in muscle strength and dynamic balance supporting a positive effect. Carmeli and associates [71], implemented a pain-free treadmill walking program for adults with DS and arterial occlusive disease. Some of the participants showed significant improvements in walking speed, distance, and duration. Other findings included the reduction of pain levels in individuals suffering from intermittent claudication. In conclusion, this program demonstrated that beside improvements of the functional capacities, medical benefits can also be achieved by a low-intensity treadmill walking program of adults with DS. An aerobic 16-week rowing training regimen in young adults with DS improved exercise endurance and work capacity of participants [72].

The accumulation of the evidence suggests that various physical activity programs for adult individuals with DS can positively and significantly improve numerous health characteristics associated with primary and secondary health characteristics of this group of clients. It is also evident that such programs can be implemented with different age groups and result with appropriate improvements for the trainees. Thus, it is recommended to implement such programs throughout the life span of individuals with DS. In order for the reader to gain some practical information for implementing such programs the next part of this chapter will convey some clinical suggestions.

7. Clinical Implications

This part of the chapter will reintroduce the reader with basic element of an exercise program, characteristics of individuals with DS that might interfere with implementing such a program and suggestions for general exercise guidelines. To properly prescribe a beneficial exercise program, one must have a basic understanding of the elements of exercise physiology and energy metabolism, as well as of the cardiovascular, respiratory, and musculoskeletal responses to exercise and training. Such specific knowledge is mandatory, when constructing an appropriate activity program for any population [73], and especially critical when dealing with populations with diminished physical capacity such as individuals with DS. At the end of the chapter A model activity program will be presented. The basic elements all sport activities should entail Are: cardiovascular exercise, strength training, balance and flexibility [74,75]. When taking into account the specific characteristics of individuals with DS the following elements should be included:

7.1 Cardiovascular exercise

Due to low levels of cardiovascular fitness of individuals with DS this is the most important element to consider, when initiating an activity program for this population. Recommended modalities include: walking, jogging, stationary cycling, and low impact aerobic dance [36]. The recommended protocol for the general population is training at an intensity of 60-80% of an individual's maximal heart rate (MHR), 3-5 days a week, for 20-60 minutes per session. But for individuals with DS, who usually show very low levels of aerobic fitness and in some cases present some heart problems, reaching a primary levels of 30-50% of the calculated MHR and gradually raising the intensity of the program is recommended. Maximal heart rate can be obtained from a graded exercise test or can be roughly predicted by subtracting the age of the individual from 220. A suggested starting protocol is a 5-10 minute continuous activity, 1-2 days a week. Once the participant achieves this level, the intensity can be increased to 40-50% MHR, for 10-30 minutes, 3-4 days a week (do not increase more than one element of the program at a time). In the later stages of the training program, intensity should be increased to 50-60%, for 15-60 minutes, 3-5 days a week [36] according to individual abilities and personal traits. Individuals can progress and regress through stages. In trained individuals a training effect can typically be seen 16-35 weeks into a program [76], but for untrained individuals, such as most with DS, results might be measurable even after 5-8 weeks of training [45,48].

Due to health issues presented by individual with IDD in general, and individuals with DS in particular (mentioned at the opening section of this chapter) It is important to receive approval to the physical activity program by a physician acquainted with IDD and DS before introducing the program. Moreover, when implementing the program constantly monitor heart rate in order to determine the intensity level of the activity and to avoid early-onset

fatigue. Recording the data, as well as time and distance parameters can be also used as a measurement for participant's achievements. Some simple test fields for measuring aerobic level of participants are the Kooper test also known as the 12-minute walk test [77,78] as well as Energy Expenditure Index (EEI), a relatively new and less familiar test, derived from the following formula [79,80]

$$\frac{\text{Mean heart rate during exercise} - \text{Mean heart rate during rest}}{\text{Velocity (in meters per second)}}$$

7.2. Strength training

Due to poor levels of muscular strength found in individuals with DS by several researchers [28,81,82] strength training should be a significant element in planning and execution of a training programs. The goal should be to maximize strength in the large muscle groups. Training intensity should be 50-60% MHR for 3 sets of 8-12 repetitions. A training effect is typically seen 10-12 weeks into the program. Circuit training is appropriate for individuals with DS. A simple program can include 2-minute stations with 30-60 second rest intervals between each station.

Program efficiency should be monitored by collecting data such as: number of lifts (of a constant weight), maximal available load for a specific muscle or muscle groups (only after a proper warm up or at the end of each session), duration of the sessions, resting heart rate or pulse per minute during training. Body composition measurements are also a good way to follow an individual's strength training progress. To compute body composition for adults with DS special regression equations have been constructed % Fat = 13.545 + 0.487 (waist circumference, cm) - 0.52 (forearm circumference, cm) - 0.155 (height, cm) + 0.077 (weight, kg) [83].

7.3 Balance training

Suomi and Kocejka [84] found that individuals with IDD possess inferior dynamic and static equilibrium abilities compared with non-IDD population. As a group, individuals with DS have been found on numerous occasions [85,86] to score significantly lower than non-DS individuals with IDD in the area of balance. The gross motor scores of this population were also significantly lower for a group with DS than for children without DS [86].

Program efficiency should be monitored by using pre to post measurements for balance and equilibrium performance. Tests could be improvised (walking a straight line, walking a high beam, standing/jumping on one leg etc) or might use standardized measurements such as: Modified Bass Test, Balance Beam Speed Test 1 (forward walking), and Balance Beam Speed Test 2 (sideward walking) [87] or elements of the Papcsy-DePaepe test and the Bruininks test for measuring balance, as these tests were validated for this population [88].

7.4 Flexibility

Flexibility is a common area of exercise training for the general population. However, because of the hypermobility and joint laxity common to most with DS, it is not a recommended activity for this population.

Despite success of the former mentioned training possibilities, individuals with DS are prone to sedentary behaviors, and can present some barriers for participation in an activity program on a regular basis. Therefore the next part of the chapter will present some barriers, as well ways to overcome such barriers on the route to a healthier and a more active life.

8. Barriers to Participation in Exercise Programs

When aiming at successful participation of individuals with DS in a physical activity program some limitations should be acknowledged:

- **Limitations set by the physical environment:** Ruuskanen and Parkatti [89] noted, that the type of residence influence exercise participation. Their findings suggest that adults living in nursing homes were found less likely to exercise than the non-nursing home residents. Yet findings also suggest that many successful physical activity programs have been implemented within residential settings for individuals with IDD [51,71].
- **Limitations set by health characteristics:** Physical limitations due to health conditions have been found repeatedly as a barrier for participation in a physical activity [109]. moreover, a study by Turk and associates regarding the health status of 63 women with developmental disability found a high prevalence of health conditions that could have an impact on exercise participation. These issues included: pain (84%), musculoskeletal conditions (59%), and bowel and bladder problems (56%) [90]. Despite those conditions, 83% of the participants reported engaging in at least one constant physical activity, including swimming, walking, using exercise equipment, and weight lifting. moreover, in a group of adults with cerebral palsy, exercise participation was not related to health status or level of impairment [91]. These studies refute, to some extent, the notion that persons with disabilities will refrain from participating in exercise due to physical or cognitive impairments.
- **Limitations set by close human environment:** Several studies have demonstrated the importance of family/caregiver involvement in exercise and weight reduction programs [92,93]. These findings are supported by the findings of Heller et al [91], suggesting that the most significant determinant of exercise participation of persons with developmental disabilities was their caregiver's perceived benefits of enrolment in such a program.

Therefore, it seems that limitations for active participation in physical activity programs by individuals with IDD and DS are not set in stone, and can be overturned with appropriate approaches alleviating different barriers.

9. Precautions before Physical Activity in DS

- Atlanto-axial instability (AAI) is a severe cervical disorder that occurs in 17% of the population with DS and characterized by increased laxity between the first and second cervical vertebrae. A possible side effect of this joint laxity is that the vertebrae may sublux and cause spinal cord injury. It is important for an individual with DS to find out if they have AAI before participation in physical activity. Contact sport activities are contraindicated when AAI is present [94,95].
- Congenital heart defects are seen in about 40% of individuals with DS, but are now usually corrected soon after birth. If a congenital heart defect is not corrected right after birth and not healed over time, it will lower the person's lifespan. Therefore, mitral valve prolapse is significantly present in this population, with 44.4-57% occurrence as compared to individuals without DS at 5-10% occurrence [96]. Therefore all individuals with DS should be evaluated by a physician prior to initiation of physical activity program, including their cardiac state [97]. A written consent should be given by the physician and their heart rate constantly monitored throughout practice.
- Thyroid hormonal deficiencies are also common in this population and cannot be detected unless appropriate blood testing is done. Hypothyroidism was found in 30% of children with DS [98]. Traditional symptoms of hypothyroidism, which might affect participation in an exercise program, are: fatigue, weakness, weight gain or increased difficulty in losing weight, muscle cramps and frequent muscle aches, depression or irritability [99]. Hypothyroidism can be difficult or even impossible to diagnose on clinical grounds in a person with DS, because of major overlap of symptoms with normal features of the syndrome [100]. Hypothyroidism can have a significant effect on participation in any physical activity and therefore its presence should be disconfirmed before physical intervention is implemented.
- Abnormal energy expenditure and substrate utilization can also be present in individuals with DS. Therefore in order to avoid lowering already inadequate intakes of several vitamins and minerals, physical exercise programs for individuals with DS should combine a balanced diet with vitamin and mineral supplementation [101].
- Impaired sympathetic response to exercise has been found in individuals with DS [102]. Such a problem can cause attenuated heart rate response to exercise, which was found predictive of increased mortality and coronary heart disease incidence [103].

- Anemia can be associated with DS and may cause fatigue and reduced ability to participate in physical activity [104]. This condition should be disconfirmed before initiation of a strenuous physical program for this population.

10. General Exercise Guidelines for Individuals with Down Syndrome

Guidelines for exercise programs for individuals with DS should be [105]:

- Collect pre-exercise medical data on each participant in order to evaluate relative and/or absolute contra-indications and precautions when initiating the program.
- Perform pre-intervention appropriate tests (see previous part of chapter).
- Obtain physician consent as well as participant's.
- Take into consideration the effects of medications on the body in relation to exercise.
- Create a multidimensional activity program that entails endurance, strength, and balance optimal for health and functional benefits [74].
- Instruct participants both generally about the benefits of physical activity, as well as specific pre-intervention instructions regarding the essentials of the activity program at hand.
- Make the program fun to participate in.
- If exercise machines are involved, label them with pictures and provide verbal explanations and encouragement.
- Provide augmented constant supervision.
- Ensure constant monitoring of heart rate through exercise duration.
- Start the program with light activity that is enjoyable and pain-free.
- Provide more visual guidance than verbal instruction [106].
- Incorporate motivational techniques (i.e., token reward system) to improve adherence [36].
- Gradually elevate the program's level of intensity in accordance with individual characteristics of each trainee (both medical and personal).
- Encourage support for the program by the surrounding human milieu.
- Construct a follow-up program teaching the clients themselves to record their own information to improve long-term adherence and empowerment.

- Ensure an emergency procedure plan for all programs especially community-based ones [74].
- Make socially acceptable elements in the program.

Referring to physical activity of individuals with disabilities, Giganc [14] commented that if we substitute relatively meaningless activities by highly valued ones, then it will be effective in maintaining positive physical activity behavior and achieving changes. Fujiura et al [107] supported this argument and stressed the importance of including physical activity programs for individuals with DS in the community.

The next program is a unique intervention program for individuals with DS that incorporates fun, social interaction, participation within the community, and meaningfulness in accordance with the remarks of Giganc and others [14,21,33,107].

10.1 Quality Dance and Drum Program for individuals with DS

A physical intervention program that meets a multitude of positive aspects has been running in a residential setting, for about 20 years, with a group of 10 young individuals with DS aged 32-35 years. Since adolescence this group has participated in movement and music recreation activities. Using the artistic product of this activity they started to present within their residential center at holidays and special occasions a show that presented their drumming and dancing skills (See **Figure 1**).



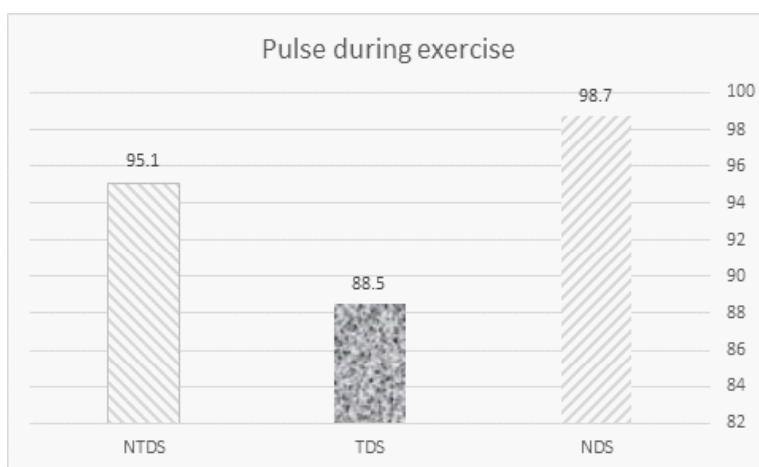
Figure 1: The dance group during performance.

As time went by, their achievements led to a growing interest in their performance, leading to a slow and steady stream of requests for external performances. In order to respond to the growing demand and upgrade their professional performance the group meets today for three, 2 hour, practice sessions a week, with increasing practice intensity before performance dates. In the past 10 years a group of non-DS/IDD children from a regular school have been integrated into the original group of DS dancers.

The benefits of the program lays in the fact that it incorporates an intense high level physical activity, several times per week, intertwined with the outgoing/happy nature of

individuals with DS, it holds a strong motivation appeal (no dropouts over a twenty-year period). The program also holds important participation and inclusion with non-IDD population contributing to the acceptance of individuals with IDD in general and DS in particular by individuals outside their world of reference. The success of the program suggests that when the motivational aspects of a program are high enough, even individuals with DS who usually prefer a sedentary life style can maintain a continuous healthy and active life.

Three groups (N=10 each) were evaluated for pulse at rest (correlated with physical fitness) and during a specific walking test (evaluating their stamina). These groups included: not trained individuals with DS = NTDS, trained individuals with DS = TDS (participating in the dance and drum group) and a NON-DS group. The age range and mean age were not significantly different. All participants dwelled within the same residential center.



These findings, despite the fact that no significant statistical difference was found between the groups present positive outcome suggesting that the trained group of individuals with DS demonstrated better results when compared to others residing in the same residential center receiving the same treatment. The concept and outcome of this program corresponds with the conclusions by Stratford and Ching [108] claiming that creative aspects such as music, movement and dance can significantly affect the development of children with DS. The inclusion of a group of non-DS dancers/singers in the group, enabled the participants with DS to further expose their friendly, outgoing nature, and spiced up their performance.

11. Conclusions

This chapter was written with the intent of introducing the poor physical status of individuals with DS and suggests some assistance in planning and implementing quality physical activity intervention programs for individuals with DS of all ages. Such programs should be interwoven throughout the different life stages and activities of the child, adolescent and adult with DS.

Aspects that were mentioned as the basis of a good physical activity (cardiovascular exercise, strength training, and balance), as well as the guidelines for such a program (mentioned above) should be addressed in the planning stage and kept during the implementation of the physical activity program. Programs that provide only fitness routines, or games experiences or remedial-type instruction can be developmentally limiting for the participant with DS. A broad habilitation concept should take into account the physical development of the individual with DS, but also the person's social, emotional and cognitive growth.

The author highly recommends the implementation of programs that will incorporate motivational factors starting at an early stage in life. Such a combination can lead to long lasting health benefits for this population.

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13. References

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