# Perspectives on Exercise Testing for Individuals With Down Syndrome

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## ABSTRACT

Despite a unique physiological profile, exercise testing is valid, reliable, and safe for individuals with Down syndrome after appropriate familiarization to the testing protocol. The purpose of this review is to provide practical exercise testing considerations for individuals with Down syndrome, including both aerobic and resistance exercise testing.

Keywords: trisomy 21, intellectual disabilities, fitness, resistance exercise, aerobic exercise

#### INTRODUCTION

Down syndrome (DS) is the most prevalent genetic form of intellectual disability (ID) and occurs in approximately 1 of 707 live births in the United States (1). While the life expectancy for individuals with DS has increased in recent years due to advancements in medical technologies, it is still comparatively lower than that of general population without DS at  $\sim 60$  years of age (2,3). The DS phenotype is caused by a triplicate copy of chromosome 21 and involves manifestations that affect multiple body systems (4). Individuals with DS tend to have increased risk for congenital disorders including heart defects, a higher prevalence of muscle weakness and obesity as well as joint laxity and other orthopaedic issues (5-7). These traits may impede regular physical functioning and present mobility challenges, thereby impacting the ability to participate in regular exercise or physical activity. This atypical physiological profile observed in individuals with DS may be the reason for the very low levels of aerobic capacity that is independent of obesity, motivation, and lack of understanding (8-12).

Targeting strategies, which enhance participation in exercise for this population, are imperative for improvement of overall health and longevity. This is particularly necessary considering the unique physiology of this group, coupled with important issues related to ID. The purpose of this review is to provide a summary of the practical considerations involved in exercise testing for adults with DS. The intended audience of this review are students and clinicians in clinical exercise physiology laboratories interested in performing exercise testing procedures for adults with DS.

# **EXERCISE TESTING**

## Safety and Understanding

Approximately 50% of newborns with DS have congenital heart defects, which are corrected during infancy or into early childhood in most Western societies (13). In fact, epidemiological work indicates that, among children undergoing cardiac surgery, ~10% of the cases are accounted for by DS (13). Exercise testing in those with corrected heart defects is considered safe with no reported adverse events in the literature to date, although no researchers have explicitly investigated the safety of exercise testing for individuals with DS. A primary concern is the individual's ability to understand and comply with testing instructions, coupled with potential behavioral issues. This is important to consider, as individuals with ID and DS may have several disorders which are dynamic over time yet have limitations in cognitive functioning and interpersonal skills (14). In general, both written and verbal instructions should be provided at a fourth grade level but can change depending on the degree of ID of the individual. Further, it is typical to have a legal guardian or caregiver present during testing or nearby if there arises a need to assist with communication and understanding. Taken together, standardized exercise testing has been shown to be valid and reliable among persons with DS (15-20).

Conflicts of Interest and Source of Funding: None

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### **Testing Considerations**

After the consent or assent process, the clinicians testing the individuals with DS should perform a pre-exercise evaluation and health and medical history with the help of the parent or legal guardian. Pre-exercise evaluation considerations for individuals with DS should follow standardized prescreening guidelines, such as those set by the American College of Sports Medicine (21). The exercise preparticipation health screening should identify individuals who are at risk for adverse exercise-related cardiovascular events and which individuals should be referred for medical clearance by a physician (21,22). While individuals with DS present with a higher prevalence of cardiovascular disease risk factors such as obesity, low physical activity, and an unfavorable metabolic profile, they are often atheroma free upon postmortem examination (23-25). In fact, while the leading cause of death for the rest of the population without DS remains cardiovascular disease, those with DS die most often from Alzheimer's disease and pulmonary conditions (2,7,25). Furthermore, individuals with DS have a reduced work capacity most likely stemming from autonomic dysfunction and balance issues that can affect testing (8,26). As part of the exercise preparticipation health screening, a detailed health history record should be collected to aid in individualizing testing procedures based on individual needs. Specifically, the health history record should inquire about congenital heart disease as well as possible atlantoaxial instability (excessive movement between the C1 and C2 vertebrae) which are common in those with DS (14).

#### Familiarization

The exercise preparticipation health screening often takes place during the first familiarization visit to the laboratory. Familiarization is critical to yield valid and reliable tests in this population, especially if performed for research purposes. By doing so, the familiarization visit allows the participant to become comfortable with the laboratory environment, which includes the staff and equipment. It also allows the individual to practice walking on a treadmill, followed by practicing the first few stages once they are comfortable. It also gives the participant and his or her parent or legal guardian a chance to ask questions or respond to suggestions for the testing visit. It is perhaps the most important visit to be conducted, as it is part of the process of earning the trust of the individual with DS, as well as his or her caregiver. While a separate familiarization visit is ideal, it may not be entirely feasible or allowed in the clinical setting. As such, try to allow for sufficient time to familiarize the person with DS before conducting the test. It is important that staff schedule enough time to physically demonstrate a particular task, followed by guided practice by the participant. Guided practice includes determining how best communication is received and understood by the individual with DS. Any communication should be succinctly presented and mixed with repeated,

positive feedback. Instructions should be given in simple 1-step terms, and staff should enlist suggestions from the primary caregiver for other useful communication strategies. As part of the guided practice, ample time must be given for the participant to interact with the staff, equipment, and protocol using these communication guidelines. The testing protocol should not be considered valid if the familiarization step is not performed.

Staff should be prepared to complete various testing tasks interchangeably, as it is common for an individual with DS to gravitate to a particular staff member(s). If this occurs, that staff member should be the one who provides most instructions, as too many staff members providing simultaneous instructions can be overwhelming and ultimately may stymie communication with the participant with DS. However, it is important to have adequate staff available for safety purposes during exercise testing. For instance, during cardiopulmonary treadmill testing, one staff member may be in front of the treadmill to easily keep the participant's attention facing forward, while giving positive encouragement. Additional staff members should be placed on each side of the treadmill to assist with balance, as needed. Balance issues are somewhat common among individuals with DS, depending on factors such as eyesight or proprioception. If handrails are used, have them used lightly with fingertips resting on top.

#### **Cardiopulmonary Treadmill Testing Protocol**

Cardiopulmonary testing is not commonly performed in the clinical setting for those with DS. However, it is used in exercise-related research settings. Walking economy is reduced (i.e., walking pattern is less economical, and these individuals tend to have reduced peak work capacity) for individuals with DS (12,26,27). Therefore, this population typically has less exercise reserve, and fatigue can occur early (12,26,27). The cardiopulmonary treadmill exercise testing protocol described in the next paragraph is the only validated protocol to appropriately assessed cardiopulmonary fitness in individuals with DS (9,28–30).

The familiarization session will determine the warmup walking speed, which will be performed with at 0% grade for a 2-minute warmup. After the 2-minute warmup, a brisk walking speed is used for the cardiopulmonary exercise test, at 0% grade for 2 minutes. The preferred brisk walking speed for most adults with DS is between 3.2 and 5.6 km h<sup>-1</sup> (2.0-3.5 mph) (27,31,32). After the first stage, each stage increases by 2.5% grade every 2 minutes until a 12.5% grade is reached. For those achieving this level of work, the protocol advances speed by  $0.8-1.6 \text{ km}\cdot\text{h}^{-1}$  (0.5-1.0 mph) every minute thereafter, until the participant reaches a jogging speed, and the grade is held at 12.5%. Participants with DS should be encouraged to hold a jogging speed for at least 1 minute or until the heart rate (HR) plateaus (32). When possible, participants should limit the use of the treadmill handrails (5,14,25). If handrails are used, the testing staff should attempt to have them used lightly with fingertips resting on top. Staff should be attentive to the participant's handrail(s) for balance. Other tests of cardiopulmonary fitness including running-only testing protocols, arm ergometry, and cycle ergometry elicit poor validity and reliability and should be avoided (12). However, dual-action cycle ergometry is valid for this population (33). Unfortunately, dual-action cycle ergometers are not common in exercise testing facilities because they have fallen out of favor in the clinical and health fitness industries.

The traditional markers of peak effort (VO<sub>2peak</sub>) for cardiopulmonary tests of individuals with DS vary from those without DS (8). For individuals with DS, peak effort is considered valid when a plateau in HR is observed with an increase in workload (31). Specifically, a plateau in HR is less than a 3-beat difference from the previous stage, or less than a 3- or 4-beat increase during the last 30 seconds of running (29,31). It is important to consider that individuals with DS have maximal HRs ~30 b·min<sup>-1</sup> lower than their age-matched peers without DS, which has been attributed to autonomic dysfunction (8,31). See Table 1 for agebased formulas to predict peak HR and  $\dot{VO}_{2peak}$  among individuals with DS (32,34). The typical peak respiratory exchange ratio (RER) often used to identify if peak effort was attained (i.e., 1.10-1.15) is often not achieved, possibly due to metabolic dysfunction in this population, but this has not been clearly ascertained in human studies and thus may be related to poor effort. Authors of previous work among persons with DS report RER values at peak exercise at 1.0 in conjunction with a plateau in HR (34). When the RER rises to 1.0, it can be used to identify if peak effort was achieved when used in conjunction with peak HRs and perceived effort (i.e., verbal and physical cues gathered throughout the visit and during an individual's familiarization session) (9,10,29). We do not generally recommend the use of rating of perceived exertion, as this has not been validated among adults with DS during a test of peak effort. A 5-point pictorial scale showed moderate agreement between HR and RPE; however, it was highly variable and not correlated for all participants, suggesting this is not suitable for all persons with DS (35). Similarly, it is difficult to assess blood pressure or blood lactate

a given test; Y = Years

during treadmill testing due to potential coordination and distraction issues. Recovery after the test is recommended, with walking at speeds like the warmup speed (slower than the brisk walking speed used during the test), followed by seated rest of  $\sim 6-10$  minutes.

# **Field Cardiorespiratory Fitness Testing**

Validation of field estimates of cardiorespiratory fitness are limited, mainly due to a general lack of coordination, stemming from balance and joint issues coupled with task understanding depending on the complexity of the field test. There are valid cardiorespiratory field tests for predicting peak aerobic capacity among individuals with DS, including 600vard run-walk (17) and the Progressive Aerobic Cardiovascular Endurance Run (16 m and 20 m) shuttle runs (17,36). Valid field tests with formulas for predicting aerobic capacity in individuals with DS are listed in Table 2. Longer field runs should be avoided in this population due to possible distractions and lack of interest (12). To ensure validity during these tests, the technician should demonstrate the test first and then complete the test with the participant or small group of participants to help provide motivation. It is important that the group not become too large because many people performing testing at one time can create a distraction, leading to poor performance. Finally, as for cardiopulmonary tests of aerobic fitness, familiarization of the field cardiorespiratory fitness tests is required for valid data.

The use of social motivators can result in a positive experience for everyone involved and is perhaps more relevant for individuals with DS. For instance, gamelike strategies can be useful to direct and/or sustain attention toward a task. A focus on having fun and providing a degree of control for the participant with DS is important in the process of obtaining a person's best performance.

## **Muscular Fitness Testing**

Muscular strength and peak torque are reduced up to 50% in individuals with DS compared with their peers without DS (37–40). Progressive resistance training has been shown to enhance both muscular strength and performance on functional tasks of daily living for individuals with DS (41). As with the general population, conducting strength

TABLE 1. Predictive equations of VO<sub>2004</sub> and HR<sub>act</sub> in individuals with DS. Formulas described in Ref. (25).

* 2pcak	peak	
Nonexercise $\dot{VO}_{2peak}$ Formulas for Individua	als With DS	
Female: $\dot{VO}_{2peak}$ (mL · min <sup>-1</sup> ) = -1,578.94 + 16.	.63 × height (cm) + 13.7	733 × body mass (kg) – 13.103 × age (y)
Male: VO <sub>2peak</sub> (mL · min⁻¹) = −1,253.657 + 16.6	3 × height (cm) + 13.73	33 × body mass (kg) - 13.103 × age (y)
Exercise-Based VO <sub>2peak</sub> Formulas for Indivi	duals With DS (Includ	ling HR <sub>peak</sub> )
Female: VO <sub>2peak</sub> (mL · min⁻¹) = −3910.338 + 18	3.069 × height (cm) + 12	2.851 × body mass (kg) − 11.189 × HR <sub>peak</sub> (b · min⁻¹)
Male: VO <sub>2peak</sub> (mL · min⁻¹) = −3910.338 + 18.06	39 × height (cm) + 12.8	51 × body mass (kg) − 13.126 × HR <sub>peak</sub> (b · min <sup>-1</sup> )
Absolute HR <sub>peak</sub> Predictive Equation for Bo	th Male and Female Ir	ndividuals With DS
HR <sub>peak</sub> (b · min⁻¹) = 181.81 − 0.665 × age (y)		
CM = Centimters; DS = Down syndrome; HR	= heart rate; KG = Ki	lograms; $\dot{VO}_{2neak}$ = the greatest rate of oxygen consumption attained in

REVIEW

TABLE 2. Field test prediction equations for peak aerobic capacity in individuals with DS.

Field Test	Formula
16-m PACERª (38)	VO <sub>2peak</sub> (mL ⋅ kg <sup>-1</sup> ⋅ min <sup>-1</sup> ) =48.23 +0.32 (No. of laps) = 0.45 (BMI, kg ⋅ m <sup>-2</sup> ) = 2.88 (sex) = 0.13 (age, y)
20-m shuttle run⁵ (39)	VO <sub>2peak</sub> (mL ⋅ kg <sup>-1</sup> ⋅ min <sup>-1</sup> ) = 21.68 + 0.62 (No. of laps)
600-yard run/ walkª (16)	<sup>.</sup> VO <sub>2peak</sub> (mL · kg <sup>-1</sup> · min <sup>-1</sup> ) = −5.24 (600-yard time, min) − 0.37 (BMI, kg · m <sup>-2</sup> ) − 4.61 (sex) + 73.64
Rockport 1-mile walk test (40)	VO <sub>2peak</sub> (L · min⁻¹) = 2.90 − 0.18 (walk time, min) + 0.03 (body weight, kg)

BMI = body mass index; DS = Down syndrome; kg = kilograms; min = minutes; PACER = Progressive Aerobic Cardiovascular Endurance Run, or a modified shuttle-run test, number of laps that can be successfully completed at pace or the sound of a taperecorded beep;  $VO_{2peak}$  = the greatest rate of oxygen consumption attained in a given test; Y = Years

<sup>a</sup>Sex: 1 = male, 2 = female

<sup>b</sup>BMI and sex need not achieve significance to be added to this model

testing is important when implementing a training program to monitor gains, which can be highly useful as a motivational tool. Individuals with DS may exhibit hypotonia and/ or some joint laxity, which can impact motor function and may result in muscle weakness or injury if not properly addressed during both training and testing (5). As such, appropriate familiarization with all equipment and testing protocols is necessary in muscular fitness testing. During the muscular fitness familiarization session, the technician should consider the array of physical characteristics unique to an individual with DS. However, muscle hypotonia should not be considered a major barrier to exercise in persons with DS, as authors of recent studies have shown a lack of significant change in serum markers of muscle damage during a 12-week resistance training protocol in individuals with DS (42). These results suggest that resistance training can be used safely to increase muscle mass and work task performance when properly administered, despite the heightened prevalence of muscle hypotonia among individuals with DS (42).

Muscular fitness testing should always begin with a light warmup, such as a few minutes of submaximal aerobic exercise followed by stretching exercises of the specific muscle groups targeted. Resistance machines or resistance bands may be best for resistance testing, for ease of coordination and balance.

Staff should consider the physical characteristics of individuals with DS, such as short stature, when fitting weight machines to facilitate a proper range of motion. A participant with DS should be appropriately assisted (spotted) to avoid hyperextension at any point of the movement due to joint laxity being prevalent among persons with DS as well as consistent reminders to breathe through the range of motion are necessary.

#### Muscular Strength: Isometric Testing

Isometric testing is feasible in this population, with standard protocols used for determining maximal voluntary contraction in both isometric handgrip and leg extension (43,44). Maximal voluntary contraction can be determined by using the highest of 3 (3-second) maximal contractions, separated by at least 60 seconds rest between each effort. Isometric testing should be performed at 30% of the participants maximal voluntary contraction for 2 minutes. Furthermore, real-time visual feedback is a critical part of reliable isometric testing for participants with DS to target and produce a specific force.

### Muscular Strength: Isokinetic Testing

A significant relationship between knee flexion or extension and aerobic capacity has been observed among individuals with DS, asserting that leg strength may be an important factor for aerobic capacity and functional fitness in this population (38,41,45). As such, isokinetic leg extension and flexion provide an ideal model to reliably obtain isolated leg strength in individuals with DS using commercially available dynamometers (43,45). Such dynamometers provide a situation where the muscle group testing can be isolated and tested in more realistic situations like walking (38,39,43). All lowerlimb strength testing should be conducted on the participant's dominant leg or dual leg when possible. If the individual with DS is unaware of their dominant leg, this can be determined by rolling a ball over to the subject and observing with which leg he or she strikes the ball. The criterion for proper lower-limb testing procedures is to have the participant demonstrate consistent extension of the leg past an angle of 25°, then immediately flex the leg beyond an angle of 75° at 60° per second (39). Determination of peak knee extension or flexion can be achieved in 2 sets of 6-10 repetitions, with 3 minutes rest between sets. The technician should follow dynamometer calibration procedures (e.g., gravity correction) and use the best of the 12-20 repetitions as the peak. Researchers have shown that peak torque of the leg will decrease as velocity increases in such movements, and as such, individuals with DS are able to produce peak torque when contracting their leg at  $60^\circ$  per second or  $\sim 20$ kicks per minute using a commercially available metronome (43,46). Using the dynamometer machines for muscular fitness testing also presents the ability to control the amount of the force on the movement arm (i.e., isotonic movement). Like aerobic testing, isokinetic testing should include a familiarization visit. It is also important that the activity is fun for all individuals and be provided with concomitant, positive verbal cues with direct, individualized feedback.

## Muscular Endurance Testing

Muscular endurance testing, such as push-ups and curl-ups, can be performed safely in individuals with DS with necessary modifications to accommodate their physical characteristics, such as visual issues, short stature, balance, and joint laxity. Working with these movements may help individuals with DS reach essential motor milestones and prevent further musculoskeletal problems.

# **Flexibility and Functional Testing**

Functional ability, in part mediated by physical fitness, may limit long-term employment and independence in this population and is thus an important consideration within exercise testing protocols (45). Functional testing that emulates activities of daily living, such as the timed upand-go test, deep trunk flexibility tests, sit-and-reach, timed stand tests, and 30-second sit-up tests have been found to be reliable in adults with DS (36,47). During tests

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of flexibility, participants with DS may struggle to keep their knees completely extended, particularly when performing the sit-and-reach test.

## SUMMARY

Exercise testing is safe, feasible, and valid in adults with DS. Exercise testing requires appropriate familiarization and individualization for valid outcomes. Supervision is warranted for all testing sessions. Having a focus on fun and enjoyment will help individuals with DS follow instructions and try their best.

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