

Physical Activity in Individuals with Down Syndrome

Chancellor's Honors Program Thesis
The University of Tennessee, Knoxville

Chelsea Spurgeon
August 2014

Physical Activity in Individuals with Down Syndrome

Introduction

Down syndrome is named after Dr. J.L. Down, who first discovered and studied the condition. It is part of a large number of disabilities known as intellectual disabilities. Intellectual disabilities are generally classified as mild or severe, but Down syndrome falls somewhere in between the two. It is present at birth, and individuals are usually diagnosed during pregnancy or shortly after birth. There are three types of Down syndrome. The most common of these involves an extra #21 chromosome, which gives the individual 47 instead of 46 total chromosomes. A chromosome breaking and then reattaching to another chromosome characterizes translocation, which is the second type of Downs. The third type, nondisjunction, occurs when a pair of chromosomes fails to separate properly during nuclear division (NDSS, n.d.). Individuals with this disability usually have difficulty with speech and interacting with others, a higher prevalence of psychiatric disorders, such as Alzheimer's, later in life, and minor physical limitations. (NCHPAD, n.d.).

Physical Activity Recommendations

While individuals with Down syndrome do generally have some physical limitations, they can, for the most part, participate in most forms of physical activity that individuals without the disability can. Because of this, their recommended amount of physical activity is also the same as those individuals with no disability. The Physical Activity Guidelines for Americans (2008) recommends at least 150 minutes of moderate intensity aerobic activity should be completed each week, if the individual is able. If they perform vigorous intensity aerobic activity, only 75 minutes are needed per week. If desired, a combination of the moderate and vigorous intensities can be performed. These should be done in bouts of at least 10 minutes spread throughout the day to gain the maximum benefit. There are health benefits associated

with physical activity, and the degree of improvement is proportional to the volume of activity. If an individual is not able to safely complete the recommended amount of exercise, it is recommended to do whatever is tolerable. It is also important to participate in muscle-strengthening exercises at least twice a week. These exercises should involve all major muscle groups. One important thing to remember before participating in any physical activity, however, is to consult a physician before beginning (DHSS, 2008).

General Considerations

While it is acceptable for individuals to follow the same activity guidelines, there are some precautions that should be considered. As mentioned above, individuals should speak with their doctor before beginning a physical activity program. This should be done to make sure the extra activity will not harm the individual. The individual also needs to understand how any medications they are taking may affect the body when exercising. This is another reason it is important to speak with a doctor. Supervision is also a good idea, especially when first beginning. This will help prevent unwanted injuries or adverse events. Incorporating behavioral therapy and motivation, such as a reward system or progress chart, will help excite individuals about the exercise, and they will be more likely to adhere to the program. Most importantly, the individual should begin with light, pain-free aerobic and strength-building activities that can be enjoyed. As the individual becomes stronger, increase the difficulty level (NCHPAD, n.d.).

Bone and Muscle Strengthening

It is also a good idea to consider a few things when strength training. These exercises should be done under constant supervision to ensure the correct form is being used. This, too, will help prevent injury. Label the machines with pictures. This will make it easier for the individual to remember how to properly use the equipment. Visual instruction tends to work

better than verbal instruction with this demographic, so try showing individuals how to perform an exercise instead of telling them. Lastly, teach them to record their own information-weight, reps, and sets-to improve long-term commitment and feelings of independence. The goal should be to maximize the strength in their large muscle groups. If they are able to see the progress they have made, they will be more likely to continue the routine (NCHPAD, n.d.).

As with anyone, any type of physical activity, no matter how big or small, will improve overall health, even if by just a small amount. Both the cardiovascular activities and muscle-strengthening activities will provide benefits to the participant. A study done by Rimmer et al (2004) provides evidence of this benefit. Over the course of 12 weeks, 52 adults with Down syndrome participated in a training program that consisted of 30 minutes of cardiovascular exercise and 15 minutes of strength exercise performed three days per week. At the conclusion of the program, the individuals in the experimental group showed significant gains in cardiovascular fitness and muscular strength and endurance when compared to the control group, which had not participated in any exercise (Rimmer, et al., 2004). It is possible that if this study lasted longer than 12 weeks, the gains may have been even greater.

Cardiovascular and Respiratory Fitness

In general, these individuals have lower overall fitness levels than their peers without Down syndrome. Several studies suggest their maximum heart rates are approximately 10% lower than those of individuals with intellectual disabilities other than Down syndrome. Training programs do improve cardiovascular fitness, but this usually occurs after a longer training program lasting four to nine months. Lower peak oxygen consumption, functional aerobic impairment, peak ventilation and heart rate, and respiratory exchange ratio could be some of the factors responsible for lower fitness levels (NCHPAD, n.d). Many individuals with

Down syndrome are overweight or obese. Individuals who choose to participate in physical activity will likely alter their weight status by decreasing fat mass and increasing lean body mass. This could help improve their overall health, as well as decrease the likelihood of developing other cardiovascular disease risk factors and health problems, such as diabetes (NCHPAD, n.d.). Physical activity, though, does not have to be structured or take place in a gym. Activities of daily living and leisure time activities such as working in the yard or going for a short walk could improve the individual's cardiovascular and respiratory fitness and overall health. A review done by Dodd and Shields proved just that. After reviewing many studies involving individuals with and without Down syndrome, they concluded physical fitness in those with Down syndrome could be improved through ACSM approved cardiovascular fitness programs. This conclusion was reached after researching many studies that date back to 2004 (Dodd, 2005).

Underdeveloped respiratory and cardiovascular systems are often an issue seen in those with Down syndrome. Exercises such as walking, jogging, and cycling on a stationary bike can help improve the fitness of both (NCHPAD, n.d.). Balance, overall strength, and muscle fitness can improve with the help of muscle-strengthening exercises. With this increased cardiorespiratory fitness and strength comes the ability to better complete everyday tasks. These are often difficult for individuals with Down syndrome to complete, but things like walking to class and carrying books or groceries become easier at strength and overall fitness and endurance increases. This, in turn, will boost self-esteem and confidence, and while neither is directly related to the individual's health, both are an important part of living a quality life.

Barriers

It may sound just as easy for individuals with Down syndrome to participate in physical activity as it does for those without the disability, but it really is not. There are several barriers

that can hinder both participation and progress. Other health problems, such as obesity and diabetes, have a big impact on whether it is even safe to participate in physical activity. Since many individuals with Down syndrome are overweight, they may be used to living a sedentary lifestyles, and changing their behaviors could take some effort, as is common with most sedentary, obese individuals. Muscle hypotonicity is a problem for younger individuals with Down syndrome. This usually gets better as the person gets older, but muscle-strengthening exercises can help as well. This does, however, limit what can be done weight-wise. The individual must be careful not to overstretch any of their muscles, which is what can happen as a result of hypotonicity (NCHPAD, n.d.). Overstretching muscles can result from trying to lift too much weight too soon. Joint hypermobility is another common problem in Down syndrome. This increases the risk of dislocating a joint, such as a shoulder or hip, so a physician should be consulted before beginning any exercise to determine the safety of the proposed activity program.

FUTURE Program

The University of Tennessee has established the FUTURE program within the College of Education, Health, and Human Sciences. This is a two-year program for students ages 18-29 with intellectual disabilities and autism, and many of the participants have Down syndrome. This program allows these individuals to take on-campus courses that teach them social skills and how to live independently. They also participate in physical education classes as part of the program. After completing the program, students receive a University of Tennessee FUTURE Post-Secondary Educational Certificate (FUTURE, n.d.).

Study Purpose

Staff members noticed that, when these students arrived on campus, some of them were overweight, and most had difficulty walking from class to class without stopping to catch their breath. Since they participate in physical education classes while here and walk around campus, many of the students are getting around much better by the end of the semester. Professors know they are getting physical activity in during the week, but they fear the students are almost completely sedentary on the weekend while at home. For this reason, faculty in the Departments of Theory and Practice in Teacher Education and Kinesiology, Recreation, and Sport Studies are conducting a study using the Fitbit Flex to determine the physical activity levels of the students in the FUTURE program during the week (while at school) and on the weekend (while at home). We want to look at the differences in activity for the students during their time at school versus their time at home using a trial period before the students know how the FitBits work. If there are differences, we hope they are much smaller by the end of the study.

Methodology

Equipment

The FitBit Flex is a wristband that can be worn all day, and it collects data such as number of steps taken, distance traveled, and calories burned. The FitBit website allows individuals to sync their data with an online account and creates graphs to compare their activity from a day-to-day basis. This data can also be compared over several months to see when the most, or least, activity is being done. There is also a food journal on the website, which can be filled out each day if one chooses to do so. There is also a FitBit app for Apple devices, and this allows wearers to compare data with peers, as they can add each other to their profile (“Fitbit,” n.d.). This was especially useful during this study, as each student had either an iPad or iPhone they used to get up-to-date data on themselves and his or her peers.

There are 12 students enrolled in the FUTURE program and all students and their parents/guardians agreed to participate in the study. They were all given FitBits to wear for trial period without knowing what they actually did. However, before they could be told what the bands were doing, a few lost or broke their Fitbits. One student did not wear it as instructed, so none of his data were able to be collected. Another individual was in a wheelchair, and the Fitbit could not pick up his “steps”. After a two-week period of time, the actual function of the Fitbit was revealed to the students. They were shown how to sync their bands to their iPads, and they were also shown the application that allows them to check on their classmates’ progress in comparison to their own. It was originally thought this knowledge would encourage the students to get in as many steps as they could each day in order to match or surpass their peers.

Due to the lack of compliance of the participants, we have only been able to look at little baseline data on a few participants. The average number of steps taken by two individuals on the first four days data was collected during baseline and can be seen in Figure 1. These figures show a small increase in physical activity for one participant (2612.6 steps pre-study vs. 2679.6 steps post-study) and a decrease in steps for participant #2 (4290.0 steps pre-study vs. 1769.7 steps post-study). Respective p-values of 0.18 and 0.91 were found, which showed this results were no significant. We hypothesized that there would be a significant increase in the number of steps taken by the participants and these findings do not support our hypothesis.

Discussion

This study was designed to observe levels in the students participating in the FUTURE program at the University of Tennessee. We found that, when at school, the students had an increased level of activity when compared to what they were doing when at home over the weekends and breaks. We believe this program, along with the ability to see their peers’

information, encouraged them to be more active and thus led some of them to meet the 10,000 steps per day threshold multiple times over the course of the study.

An intervention, such as this one, has a goal of increasing the overall physical activity of the participants. However, the individuals participating must fully understand how to use the equipment being used. This is important for accurate data collection. It is important for the researchers to motivate the participants, but not in a way that could hurt the validity of the data. This means the researchers should not tell the students to go participate in a certain activity to get their number of steps up, but congratulating them on their increase in activity and encouraging them to keep it up would be allowed. I think this intervention has the potential to be successful, but since this is the first year, I do not know believe that this trial will be as successful as we had hoped. If it continues in the coming years, though, I could see it leading to a major increase in activity once the students are made aware of how much, or how little, they are doing on a daily basis.

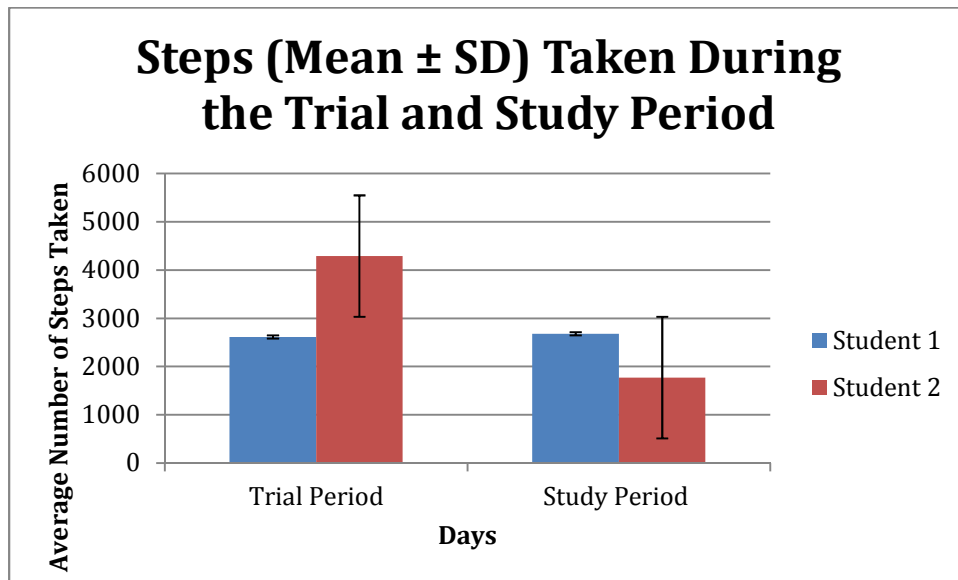
One obstacle we ran into was getting the students to wear the FitBits continuously. This is something that could be fixed with time and patience. Perhaps an education session should be incorporated into their day at the beginning of the study to inform the students what will be happening and why wearing the bands is important. Explaining how important physical activity is for them would make them more aware of what they were doing on a daily basis and could help them remember to wear the bands since they track activity. An explanation of what is considered enough activity-10,000 steps per day-would subtly encourage them to do more if they realize they are not hitting this threshold. Perhaps giving each participant a “buddy” to help them remember the bands, and vice versa, would increase the amount of data we would be able to collect as well. The students are already enrolled in a computer literacy course, and I think it

would be beneficial to teach them how to properly use the FitBit app and website in this class prior to the study beginning. This would give them time to practice and familiarize themselves with everything before the study started. Being well informed would, hopefully, excite them for the study and encourage them to wear the bands as much as possible so they would have data to look at online.

It cannot be overstated how important it is to increase the physical activity levels of this demographic. Physical activity is important for both physical and mental health. Walking is a lifelong event and something these individuals can safely do for the rest of their lives. What they learn from this study will hopefully stick with them even after it is finished, and that will help improve their health as they get older. They may decide to move on from walking and begin a new type of activity, but they will have a starting point and something to return to, if the need arises, down the road.

This intervention is a step in the right direction in trying to increase the physical activity of these students. As with most people, individuals with Down syndrome sometimes need a little “push” to get started. Once they begin the exercise, though, no matter how great or small, the benefits will be endless. Not only will their overall health improve, but their ability to go about their day-to-day activities will improve as well. Once they realize the effect exercising has on their life, it is my hope that they will continue with their routines, whatever they may be, long after they leave the University of Tennessee.

Figure 1. Average number of steps taken for two students during the trial and study periods. Student 1 took an average of 2612.6 steps during the trial period and 2679.6 steps during the study period (p-value of 0.18). Student 2 took an average of 4290.0 steps during the trial period and 1769.7 steps during the study period (p-value of 0.91).



References

- Department of Health and Human Services. (2008). Chapter 7: Additional considerations for some adults. *2008 physical activity guidelines for Americans: be active, healthy, and happy!* (pp. 41-44). Washington, D.C.: U.S. Dept. of Health and Human Services .:
- Dodd, K. J., & Shields, N. (2005). A systematic review of the outcomes of cardiovascular exercise programs for people with Down syndrome. *Archives of Physical Medicine and Rehabilitation*, 86(10), 2051-2058. doi:10.1016/j.apmr.2005.06.003
- Down Syndrome and Exercise. (n.d.). *NCHPAD : Down Syndrome and Exercise*. Retrieved January 4, 2014, from <http://www.ncpad.org/117/910/Down~Syndrome~and~Exercise>
- FUTURE: Postsecondary Education Program. (n.d.). *UT Knoxville*. Retrieved January 4, 2014, from <http://futureut.utk.edu/>
- Kruhm, M. (2000). *Everything you need to know about Down syndrome*. New York: Rosen Pub. Group.
- Make fitness a lifestyle with Flex™.. (n.d.). *Fitbit® Flex™*. Retrieved January 2, 2014, from <http://www.fitbit.com/flex>
- Rimmer, J. H., Heller, T., Wang, E., & Valerio, I. (2004). Improvements in physical fitness in adults with down syndrome. *American Journal on Mental Retardation*, 109(2), 165-174.
- What is Down syndrome? - National Down Syndrome Society*. (n.d.). Retrieved March 19, 2014, from <https://www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome/>