

Krissy Ayers

The health promotion program I would create would be an exercise and wellness class for children with Down syndrome.

Statement of Need

Pediatric obesity is a major health problem and epidemic in the United States (US). In 2011-2012, the prevalence of pediatric obesity in the US was about 17%, and affected about 12.7 million children. (20) Today, "1 in 3 children in America are overweight or obese." (5) And more locally, North Carolina is the 5th state with the highest rates of childhood obesity.

Unfortunately, pediatric obesity is very common and has many immediate and long-term negative health consequences. Children who are obese are more likely to have high cholesterol and high blood pressure, and they are at risk for cardiovascular disease, diabetes, bone and joint problems, sleep apnea, social and psychological problems, and certain cancers. (21) The prevalence of these negative effects of obesity is high. A 2010 research study reported that in 2006, 51.8% of 8 through 14 year olds at one point in the 6-year research period reported a chronic condition. (22) In addition, if this issue is not controlled then "1/3 of all children born in 2000 or later will suffer from diabetes at some point in their life." (5) Per First Lady Michelle Obama ""The physical and emotional health of an entire generation and the economic health and security of our nation is at stake." (5)

Krissy Ayers

Pediatric obesity is a serious health problem, and unfortunately it is more common in children with Down syndrome. Down syndrome is a “condition with in which a person has an extra chromosome.” It is the most common chromosomal disorder with about 6,000 babies born each year in the US with Down syndrome. (13) One study stated that up “to 30% to 50% of children with Down syndrome are obese.” (1) Several factors can cause this increase in obesity in children with Down syndrome. For example, there is evidence to suggest that the resting metabolic rate, the amount of calories burned at rest, is significantly slower in those with Down syndrome, and this puts them at risk for being heavier. (2) Children with Down syndrome also tend to be shorter. “Although not diagnostic, weight-for-height at greater than the 95th percentile indicates obesity.” (2) Research has also provided evidence that children with Down syndrome have increased amounts of leptin. (3) Leptin is a hormone that suppresses “appetite and regulates body weight.” (3) “It is positively correlated with percentage body fat, thus, it is postulated that obese individuals have some degree of leptin resistance.” (3) Children with Down syndrome also have higher incidence of hypothyroidism due to a malfunctioning thyroid gland. (4) The thyroid gland “is involved in various metabolic processes controlling how quickly the body uses energy, makes proteins and regulates hormones.” (4) “It can cause a number of symptoms, such as poor ability to tolerate cold, a feeling of tiredness, and weight gain.” (12)

An exercise and wellness class in specifically for children with Down syndrome in and around Chapel Hill, NC will help control these physiological characteristics and reduce their risk of obesity and other preventable chronic conditions such as Type 2 diabetes.

Krissy Ayers

This class would also correlate with the First Lady's national mission to decrease pediatric obesity. The First Lady created a comprehensive national initiative titled Let's Move due to the staggering rates of childhood obesity. This initiative is "dedicated to solving the challenge of childhood obesity within a generation, so that children born today will grow up healthier and able to pursue their dreams." (5)

Locally, there is a need for a pediatric exercise and wellness class for children with Down syndrome. Currently, the Triangle Down Syndrome Network (TDSN) advertises no exercise and wellness class for children with Down syndrome. TDSN is a "large nonprofit, support, resource, and advocacy organization" that "serves over 600 families in 49 counties throughout NC, with the majority of families living in Wake County." (6) The TDSN has a math and reading learning program for children with Down syndrome, and they also raise awareness by hosting a "Buddy Walk" once a year. (6) An exercise and wellness class would be a great addition to TDSN and it would encourage increased fitness levels in daily living, and decrease obesity and other obesity-related chronic diseases in children with Down syndrome.

In order to be a successful health promotion program, the exercise and wellness class must focus attention on both individual and social environment factors. The exercise and wellness class for children with Down syndrome would be successful because it would be directed at changing the intrapersonal and community levels of the Socio-ecological Model (SEM). The SEM "assumes that appropriate changes in the social

Krissy Ayers

environment will produce changes in individuals, and that support of individuals in the population is essential for implementing environmental change.”

Intrapersonally, the characteristics of children with Down syndrome hopefully will positively change from an exercise and wellness class. This class will motivate the children to adopt positive lifestyle habits, and improve their knowledge and/or belief in the association between physical fitness and health. This class will also teach them skills to make them more healthy and happy! For example, this class will teach them their exercise preferences (cardio, strength, aquatic, etc.), and how to maintain a daily physical lifestyle.

An exercise and wellness class for children with Down syndrome would target the community level of the SEM, which includes organizational support. Organizations can have “substantial influence on the health and health-related behaviors of individuals,” can provide “important economic and social resources,” and can be “important sources and transmitters of social norms and values.” (7) Being a part of this group exercise and wellness class can also be an important part of the children’s and family’s social identity.

The exercise and wellness class could also be seen as a “mediating structure.” (7) A mediating structure is an important component of community, and can include “family, informal social networks, churches, voluntary associations, and neighborhoods.” (7)

This class is an exercise and wellness informal social network, and may serve as a connection between the children and their families and the larger social environment.

Background

Children with Down syndrome are more likely to gain weight and have an increased risk for chronic health problems. Down syndrome also causes muscle hypotonicity, decreased muscle strength, joint hypermobility, and ligamentous laxity. (8) The physiological characteristics associated with Down syndrome can have an impact on an individual's participation in physical activity. However, physical fitness is especially important for this population in order to maintain and improve their health and quality of life. Despite the recognized benefits of physical activity for children with Down syndrome, many studies have "documented a more sedentary lifestyle in young people with Down syndrome compared with their typically developing peers." (8) Children with Down syndrome are "less active, less engaged in physical activity, and they reach lower levels of physical fitness and collect significantly fewer steps a day." (8) Researchers and practitioners have suggested that there are many barriers that limit physical activity in children with Down syndrome. Three main barriers to physical activity are: a lack of adapted physical activity (APA) expert instructors and coaches, Down syndrome characteristics, and parental worries. The exercise and wellness class for children with Down syndrome would tackle each of these barriers. The class would be specifically for children with Down syndrome and the classes would accommodate their physical characteristics. The class would also be cost friendly, easy accessible, and taught by

Krissy Ayers

APA expert teachers. To ease parent's worry, parents could actively participate in the exercise and wellness class right next to their child. In addition, the class would be supervised and/or organized by a DPT specializing in pediatrics. These credentials behind the class should decrease the parent's worries regarding physical activity and their child's medical and physiological conditions.

The exercise and wellness class will incorporate strength and aerobic training in fun and enjoyable activities for the children. The activities will involve all the children and they will encourage teamwork. Activities completed as a team can teach children to cooperate with others and respect rules. Teamwork can also encourage mastery of new skills, and children will get the chance to "experience personal achievement and obtain encouragement of other people with their same disorder." (8)

There will also be a social element to all of the activities for the children to "establish friendships and gain independence from family members." (9) There is research to suggest physical activity personal preference is an integral factor in determining participation. (9) Studies have also found that children with disability have the highest preference for social activities, compared with children with typical development. (9)

In addition to the exercise activities and social interaction I will consider and act upon the perceived barriers and perceived benefits. Perceived barriers are one construct of the Health Behavior Model (HBM) and they are "potential negative aspects of a particular health action," and they "may act as impediments to undertaking

Krissy Ayers

recommended behaviors.” (11) Some key barriers, also stated above, to physical fitness in children with Down syndrome are: a lack of adapted physical activity (APA) expert instructors and coaches, Down syndrome characteristics, and parental worries. These barriers will be identified and reduced through “reassurance, correction of misinformation, incentives, and assistance.” (11)

Perceived benefits is another construct of the HB, and this is the belief that this exercise and wellness class for children with Down syndrome will help decrease their obesity and their risk for obesity-related chronic diseases. (11) It will be important that the children and their families regard the exercise and wellness class as beneficial in decreasing obesity and improving their health, and believe the “anticipated benefits of taking action outweigh the barriers to action.” (11) The teachers can educate and clarify with the children, families, and caregivers the positive effects to be expected from this class. For example, regular physical activity can decrease weight, reduce the risk of obesity-related diseases (cardiovascular disease, diabetes, some cancers), improve bone strength, improve mental health, improve functional ability, and increase life span. (23) The class can also be advertised as cost friendly with zero to minimal negative side effects (example: sore muscles), and it’s fun, pleasant, convenient, and not time consuming.

Program Objectives

1. Provide aerobic exercise to children with Down syndrome to increase 50% or more of the children's aerobic capacity to within normal limits, tested by 6-minute walk test, in 12 weeks.
2. Provide total body resistance exercise to children with Down Syndrome to increase 50% or more of the children's lower extremity muscle strength and endurance to within normal limits, tested by a timed up and down stair test, in 12 weeks.
3. Provide total body resistance exercise to children with Down syndrome to increase 50% or more of the children's upper extremity muscle strength and endurance to within normal limits, tested by grocery shelving test, in 12 weeks.
4. Reduce 50% or more of the children's BMI to 18.5-24.9 in 12 weeks.
5. Using the Exercise Benefits/Exercise Barriers Scales, decrease perceived barrier score and increase perceived benefit score by 25% in 50% or more of the children.

Methods

- **Who:** Children with Down Syndrome aged 13-18 years old who are well enough to participate in the exercise program. This age group is selected because there is evidence to support children with Down syndrome become less active during their adolescent years. (18) This period of time is also extremely important to

establish good exercise habits. If good exercise habits are established as a child it is predicted that during adulthood healthy exercise behaviors will be continued.

(18) The class will be restricted to 8 children for safety reasons, and in order for all children to receive personal attention.

- **What:** A 12-week exercise program to encourage cardiorespiratory and muscular strength and socialization. The program aims to reduce BMI and increase aerobic capacity and muscular strength by engaging children with Down syndrome in fun physically active activities. The program will also encourage regular physical activity outside of the program, and the children will share what outside physical activity that have been enjoying at the start of every class. I will teach the class. I am a licensed group fitness instructor and a DPT student.

Other DPT students will be encouraged to volunteer.

- Research behind activities to be performed:
 - *Strength Training and Plyometrics:* Upper extremity work with elastic-fitness bands, adapted-medicine balls, and bodyweight combined with jump training has been shown to increase lean body mass in individuals with Down syndrome. (15) Low lean mass is detrimental to those with Down syndrome because “it is associated with decreased skeletal muscle tissue, which in turn is related with the functional capacity and the maximum oxygen consumption that is a marker of health in youths, and is associated with cardiovascular health during adulthood.” (15)

- *Aerobic Training:* Brisk walking and jogging has been found to significantly improve minute ventilation, exercise heart rate, and exercise duration in adolescents with Down syndrome. (16) Aerobic training has also been demonstrated to prevent, delay, and manage cardiovascular disease, diabetes, and obesity in those with Down syndrome. (17)
- *Strength Training and Aerobic Training:* aerobic training through ribbon wand exercises, walking through an obstacle course, and stair climbing combined with a full body strength training using body weight or therabands (for example: squats and toe raises) has been shown to improve exercise heart rate and gross motor skills, and increase strength of lower body, upper body, and trunk in those with Down syndrome. (17)
- *Physical Activity and Psychosocial Health:* Physical activity in a group setting can bring social benefits. Evidence suggests that parents noted their children with Down syndrome were more motivated “to be active when the activity was social and involved being with friends.” (18)
- **When:** The exercise program will occur over 12-weeks, starting in January 2016. The New Year signals to many as a fresh start and as an opportunity to make the New Year healthier and happier than the year before. The program will last 12-weeks in order to give children enough time to make improvements in their outcome measures. It has also been found that it takes over two months in order

to make a positive health behavior, like increased physical activity, a habit. (14)

The program will be 45 minutes and will be held two times per week.

- **Where:** The program will be held at the UNC Meadowmont Wellness Center. This center is located in Chapel Hill, NC, but is easily accessible from Durham, Pittsboro, Carrboro, and the surrounding triangle cities. The exercise class will be held in one of the center's group fitness studios, however, the center's indoor track, indoor pool, and strength training equipment would all be available for use if wanted.
- **How:** As a soon-to-be graduate of UNC's DPT program, and a certified group fitness instructor for over 7 years, I am educated and qualified to safely and successfully implement this program. For program guidance, I will collaborate with some of my pediatric physical therapy mentors to discuss the program. Some mentors are: Laurie Ray, PT, MPT, PhD, Melissa Scales, PT, DPT, PCS, Sarah Scow, PT, DPT, PCS, and Dana McCarty, PT, DPT, PCS, C/NDT. I would also meet with Dustin Buttars, MA, ACSM HFS, the Fitness Director at Meadowmont. He is in charge of all fitness programs within Meadowmont, and he will be a huge asset in implementing this program. Dustin Buttars would also be helpful in discussing the finances of the program and deciding the price per class. I have past experience volunteering for a successful group fitness class for children with disabilities at Prestonwood Country Club, and they charged \$10 per session.

Krissy Ayers

To promote this program, I will advertise on the UNC Meadowmont Wellness Center's website, and I will also provide all local public and private schools and pediatric physical therapy practices with my program brochure. I will also network with local pediatric physical therapists to increase referrals to my program.

In order to assess the program, I will provide the children and parents with satisfaction surveys once a month and I will consider taking the distance-learning course "Practical Evaluation of Public Health Programs."

Program Evaluation

To measure whether or not the program objectives were accomplished the 6-minute walk test, the timed up and down stair test, the grocery shelf test, BMI measure, and exercise benefits/exercise barriers scale will be used. The 6-minute walk test will measure aerobic capacity, the timed up and down stair test will measure lower extremity strength, the grocery shelf test will measure upper extremity strength, the BMI measure will measure body fat, and the exercise benefits/exercise barriers scale will measure perceived barriers and benefits. In order to determine if the exercise and wellness class was successful there should be a minimal clinical difference in the children's scores pre and post the 12-week program, or the children should reach the normal values for these tests and measures. For the 6-minute walk test, 54 meters is the value most commonly used as the least amount of change "that results in a clinically significant change in functional status." (24) The timed up and down stair test is completed on a 14-step

Krissy Ayers

staircase and the goal would be for the children, post-program, to finish the test in 8.1 seconds or less. (25) For the grocery shelf test an 8% improvement should be seen if the exercise and wellness class was successful in improving upper extremity strength. (26) Post-program the children's BMI should be within the healthy values of 18.5-24.9. There is no pediatric minimal clinical difference for the exercise benefits/exercise barriers scale, but an improvement of 25% was selected because with this change between pre and post program the children's perceived benefits of exercise should significantly increase, and the children's perceived barriers of exercise should significantly decrease. All of these measures will be recorded pre and post the 12-week exercise and wellness class. The children will come to class 30 minutes earlier than the normal class time to complete these measures, and myself and other volunteer UNC doctor of physical therapy students will record the measures.

The exercise and wellness class will also be evaluated in order to improve the program's practice, to increase the chance of success, and to determine if the program goals are being met. An outcome evaluation method will be used to examine the program's accomplishments, and compare the current performance with recognized standards of performance. In addition, the children and families will complete a satisfaction survey at the conclusion of the program in order to evaluate the class delivery, the children's and family's experience, and overall satisfaction.

This program will be well executed and evaluated; however, there are some limitations of this exercise and wellness class. This class does encourage outside physical activity,

Krissy Ayers

but it is not mandatory, and it does not formally measure the children's outside physical activity. Additional activity outside of the exercise and wellness class is encouraged to meet the CDC's recommended daily amount of physical activity. Also, this class does not measure long-term effects. In order to be a truly effective and successful program, the positive health behavior changes should be maintained in the long-term.

Conclusion

An exercise and wellness class specifically for children with Down syndrome aged 13-18 years old would be a great addition to Chapel Hill and the surrounding areas. The program will likely reduce BMI and increase aerobic capacity and muscular strength by engaging children with Down syndrome in fun physically active activities. It is important for children with Down syndrome to engage in physical activity because they become less active during their adolescent years, and they are at higher risk to become obese and acquire obesity-related chronic diseases. A structured and planned exercise and wellness class will encourage increased physical activity, and this health behavior change will lead to healthier and happier lives of the participating children.

References

1. Murray, MSN, BA, RN, CPNP, J., et al. (n.d.). Obesity in Children with Down syndrome: Background and Recommendations for Management. Retrieved from http://www.medscape.com/viewarticle/734672_2
2. Luke, A. (1994). Energy expenditure in children with Down syndrome: correcting metabolic rate for movement. *The Journal of Pediatrics*, 125(5), 829–839.
3. Sheela, MD, MSCE, M. (2008). *The Journal of Pediatrics*. Leptin levels among prepubertal children with Down syndrome compared with their siblings., 152(3), 321–326.
4. Endocrine Conditions & Down Syndrome. (n.d.). Retrieved from <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Endocrine-Conditions--Down-Syndrome/>
5. Let's Move. (n.d.). Retrieved from <http://www.letsmove.gov/learn-facts/epidemic-childhood-obesity>
6. Triangle Down syndrome Network. (n.d.). Retrieved from <http://www.triangledownsyndrome.org>
7. McLeroy KR, Bibeau D, Stecker A, Glanz K. An Ecological Perspective on Health Promotion Programs. *Health Education Quarterly* 1988;15(4): 351-377.
8. Alesi, M., et al. (2015). Physical Activity Engagement in Young People with Down syndrome: Investigating Parental Beliefs. *Journal of applied research in intellectual disabilities*, 1–13.

9. Shields, N., et al. (2015). The extent, context and experience of participation in out-of-school activities among children with disability. *Research in Developmental Disabilities*, 47, 165–74.
10. Becker, PT, DPT, E., et al. (2010). Participation is possible: A case report of integration into a community performing arts program. *Physiotherapy theory and practice*, 26(4), 275–280.
11. Champion VL, Skinner CS. The health belief model. In: Glanz K, Rimer BK & Viswanath K, eds. *Health behavior and health education: Theory, research, and practice*. 4th ed. San Francisco, CA: Jossey-Bass; 2008:45-66.
12. Hypothyroidism. (n.d.). Retrieved from <https://en.wikipedia.org/wiki/Hypothyroidism>
13. Facts about Down Syndrome. (2014). Retrieved from <http://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>
14. Lally, P., et al. (2010). How are habits formed: Modeling habit formation in the real world. *European Journal of Social Psychology*, 40(6), 998–1009.
15. González-Agüeroa, A., et al.(2011). A combined training intervention programme increases lean mass in youths with Down syndrome. *Research in Developmental Disabilities*, 32(6), 2383–2388.
16. Millar, A., et al. (1993). Effects of aerobic training in adolescents with Down syndrome. *Medicine & Science in Sports & Exercise*, 25(2), 270–274.
17. Lewis, C., et al. (2005). Effects of aerobic conditioning and strength training on a child with Down syndrome: a case study. *Pediatric Physical Therapy*, 17(1), 30–36.

18. Buckley SJ. (2007) Increasing opportunities for physical activity. *Down Syndrome Research and Practice*, 12(1), 18-19.
19. Shields. (2010). Identifying facilitators and barriers to physical activity for adults with Down syndrome. *Journal of intellectual disability research*, 54(9), 795–805.
20. Prevalence of Childhood Obesity in the United States, 2011-2012. (n.d.). Retrieved from <http://www.cdc.gov/obesity/data/childhood.html>
21. Childhood Obesity Facts. (n.d.). Retrieved from <http://www.cdc.gov/healthyschools/obesity/facts.htm>
22. Van Cleave. (2010). Dynamics of obesity and chronic health conditions among children and youth. *JAMA : the journal of the American Medical Association*, 303(7), 623.
23. The Benefits of Physical Activity. (n.d.). Retrieved from <http://www.cdc.gov/physicalactivity/basics/pa-health/>
24. Wise. (2005). Minimal clinically important differences in the six-minute walk test and the incremental shuttle walking test. *Chronic obstructive pulmonary disease*, 2(1), 125–129.
25. Zaino. (2004). Timed up and down stairs test: preliminary reliability and validity of a new measure of functional mobility. *Pediatric physical therapy*, 16(2), 90–98.
26. Hill. (2008). Measurement of functional activity in chronic obstructive pulmonary disease: the grocery shelving task. *Journal of cardiopulmonary rehabilitation and prevention*, 28(6), 402–408.