



# A Comprehensive Health Education Program for Individuals with Down Syndrome

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## INTRODUCTION

- ❖ Down syndrome is the most common chromosomal disorder worldwide.
- ❖ Children with Down syndrome have a high prevalence of obesity, ranging up to 70% in some studies.
- ❖ Basil JS et al. found that 47.8% of youth with Down syndrome are obese, compared with 12.1% of the general pediatric population. These youth are also frequently affected by hypotonia, hormonal differences, low physical activity, and medical comorbidities like diabetes and celiac disease.
- ❖ Early obesity increases one’s risk of developing other medical conditions including metabolic syndrome, sleep apnea, heart attack, and hypertension, among others.
- ❖ Despite the specific health and developmental needs that youth with Down syndrome have, there is minimal published data on health education initiatives focused on the population of children with Down syndrome.
- ❖ This project aims to implement and study a health education program for children and young adults with Down syndrome with the goal of reducing obesity, increasing physical strength, and increasing health literacy.

## COMMUNITY PARTNER

- ❖ GiGi’s Playhouse is a Down syndrome achievement center hosting free, therapeutic programming for individuals with Down syndrome of all ages and their families.
- ❖ I worked with Donna Rush, the executive site director, to assess the community center’s programming needs and develop an appropriate longitudinal intervention to improve health education.
- ❖ I partnered with Sara Bellanca, a special education physical therapist from Mary Cariola Children’s Center, to implement an exercise program. From the curriculum we built, Sara and I co-teach a fitness class and I teach a health education class.
- ❖ Donna Rush, Sara Bellanca, and I worked together to implement weekly health programming, evaluate the participants, and train volunteers.
- ❖ Target Population: children and young adults with Down syndrome

## COMMUNITY HEALTH IMPROVEMENT PROJECT

**Intervention:** A pilot community health intervention implemented in 2018 to create and evaluate a comprehensive health education program for children and adults with Down syndrome

**Goal:** Reduce obesity in children and young adults with Down syndrome, improve students’ physical strength, and improve students’ health literacy

**Background Evidence:** Increased exercise and nutrition education has been shown to decrease obesity and improve overall health. Particularly for children, early educational interventions supporting health autonomy have been shown to improve long term health outcomes.

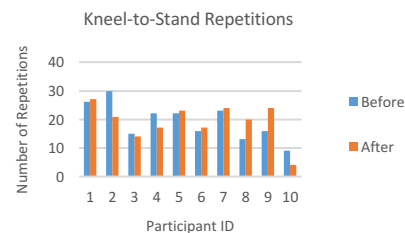
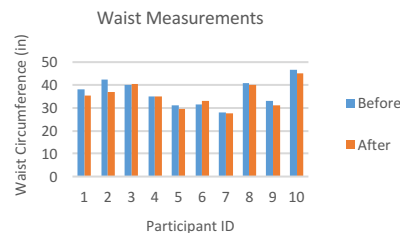
**Population:** Class met weekly on Saturday mornings over the course of 12 week sessions. Each session had 10-12 children and adults ranging in age from 8-50 years old.

**Curriculum:** The intervention consisted of an exercise class taught by Hannah Silva and Sara Bellanca focusing on the medical hurdles that people with Down syndrome struggle with, like hypotonia, joint laxity, and difficulty balancing. Example exercises include standing up unassisted, squats, ball passes, agility ladder, marches, tilts, fine motor skills and more. This was followed by a health class using lessons and play to address nutrition, hygiene, disease, and health. Example lessons include reading nutrition labels, identifying food groups, portion sizes, beverage choices, digestion, meaning of disease, hygiene, and health maintenance. Students were encouraged to engage in home exercises, a healthy eating log, and weekly homework.

**Methods:** Pre and post intervention data was recorded for 10 students over two program sessions. Student measurements were taken at the beginning and end of each session to document waist, hip, and weight measurements, in addition to maximum timed repetitions for kneel-to-stands and push-ups.

**Quantitative Results:** Recorded students lost a combined total of 40 pounds with a mean weight loss of 3.16 pounds, a mean decrease in waist circumference by 1.28 inches, and a mean increase in push-up repetitions by 4.67 push-ups. Kneel-to-stand repetitions changed by a mean decrease of 0.1. After studying the data with a Paired T test and Wilcoxon Rank Sum test, the improvement after the intervention is not statistically significant with p-values > 0.05.

**Qualitative Results:** I observed anecdotal evidence of participants making healthier food choices, displaying higher self-esteem, exercising at home, discussing healthy eating with family members, changing eating environments, attending doctor’s appointments with more ease, being involved with grocery shopping, and consistently completing homework. Representatives from newly opening Playhouse in Buffalo, NY attended program to consult on recommendations for implementing similar programming.



## IMPACT AND LIMITATIONS

Many students lost weight, improved their strength, and demonstrated increased health literacy, autonomy, and self-esteem. Since its initiation, the program has educated over 45 students. It has proved to be a valuable asset to the community and GiGi’s Playhouse with its high demand demonstrated by a student wait list.

Over the two studied sessions, 10 students attended both the initial and final classes when we obtained pre and post measurements, while 11 students attended the initial or final class. If students missed the first or last class, researchers were unable to record their initial and final measurements. At times, performance recording was affected by participants’ behavioral and communication limitations. The project has a small sample size secondary to small class sizes and inconsistent final class student attendance. Student improvements were not found to be statistically significant.

## FUTURE WORK AND SUSTAINABILITY

To further study the program, researchers should measure qualitative outcomes to assess program strength and individual impact through narratives. Researchers should also remain proactive with data collection to ensure pre and post measurements for all participants. This can be done with more follow up after the first and last sessions, particularly if participants did not attend the final session. The program could also be expanded to other regional locations to enable an increase in sample size. After further study, this pilot program could be eligible for grant participation, expansion, dissemination, and additional applications.

The community program will continue locally through the work of Donna Rush, Sara Bellanca, and several key volunteers. All health curriculum will be provided to GiGi’s Playhouse to continue the program. This project could potentially be passed on to future medical students for continued research work as well.

## REFERENCES

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