Howes C Final Assignment - Happy Campers: A Sports Camp for Children with Cerebral Palsy and Spina Bifida Who Are Overweight and Obese

**Statement of Need**

Obesity is reaching epidemic proportions in the United States. The Centers for Disease Control (CDC) estimated that in 2009-2010, more than 1/3 of US adults were obese.1 Obesity is not just an adult problem, as the CDC reports, 17% of children were obese in 2009-10 which is triple the rate of 1980.1 In 2010, the adult rate of obesity in North Carolina (NC) was reported as 27.8% and overweight as 65%.1 North Carolina adolescents’ obesity rate was reported at 13.4% and overweight at 14.6%.1

Freedman et al reported 39% of children with a body mass index of greater than 95% had at least two cardiovascular risk factors.2 Bone and joint problems have been attributed to childhood obesity.3The US has an increased prevalence reported between 8-43% of type 2 diabetes in children secondary to obesity.4 Obese children are at high risk for becoming obese adults and for children under 10 they have more than double the risk of being obese if they have an obese parent.5 A negative impact on both emotional and psychological well- being has been identified in obese children.6,7

Obesity rates for children with disabilities are 38% higher than children without disabilities.1 Children with disabilities have been shown to have disproportional lack of physical activity and fitness compared to non- disabled peers.6 Lack of physical activity, sedentary lifestyle and poor dietary choices are associated with overweight and obesity in children with disabilities.1,7 Adolescents with physical disabilities were twice as likely to report watching television more than 4 hours per day when compared to non-disabled children 7 and they tend to engage in more sedentary activities such as video and computer games compared to non-disabled children.8

Cerebral palsy (CP) is the leading childhood disability. It is defined as a group of disorders of the development of movement and posture, causing activity limitations, attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.9 In our orthopedic clinic at UNC Hospitals, it is estimated that 15% to 20% of our ambulatory children are overweight or obese.10 In 2007, Rogozinski et al reported that obesity in ambulatory children with cerebral palsy doubled from 7.7% to 16.5% over a decade.11 A 2008 study of 137 children with CP aged 2-18 showed 29.1% overweight.12 Ambulatory children (GMFCS Level I and II) demonstrated a higher prevalence at 22.7% compared to non-ambulatory children.12,13

Spina bifida is the most common, permanently disabling birth defect in the US.14 UNC Hospitals is one of 6 clinic treatment centers in NC for children with spina bifida. In our Spina Bifida Clinic at UNC Hospitals, it is estimated that approximately 1/3 of our patients are overweight or obese.15 Children with spina bifida are at risk for developing obesity.21,22 Dosa et al reports that obesity in children with spina bifida ranges from 28% to 50% and from 34% to 64% in adolescents and adults.16

Two camps available in North Carolina for children with disabilities are Camp Carefree in Stokesdale, NC and Victory Junction Camp in Randleman, NC.17,18 While both camps have weeks dedicated to children with spina bifida and cerebral palsy, there is no focus on physical activity or exercise to assist with weight management.

**Background**

Physical activity for children and adolescents to reduce obesity is supported by Healthy People 2020.19 The US Department of Health and Human Services 2008 physical activity guidelines recommend that typically developing children20  and children with disabilities 21 receive 60 minutes or more of moderate to vigorous physical activity daily.22 Taylor et al in 2005 showed an intervention effect with an 8 week exercise and education program for 41 overweight children.23 A meta-analysis by Maziekas et al reported that exercise is efficacious in reducing percentage body fat in obese children and adolescents and exercise intervention may encourage long term maintenance of the observed gains.24

Physical activities and sports for children with disabilities have been shown to increase physical, social, and emotional well- being.25,26 Adolescents with spina bifida who were more physically active reported better health related quality of life.27 Special Olympics addresses athletic participation in children with disabilities; however is geared toward children with intellectual disabilities28 Camps for children with cerebral palsy that focus on constraint induced movement for the upper limbs of children with hemiplegic CP have been reported in the literature.29 No camps related to overweight or obesity for children with disabilities were found in the literature review.

The Transtheoretical Model (TTM) can be used to promote success with physical activity through the principle of self-efficacy.30,31 A systematic review by van der Horst et al showed a positive association between physical activity and improved self- efficacy in children and adolescents. 32 For children with disabilities, it may be important to assist in promoting self-efficacy and increasing their knowledge that children with disabilities can be active and participate. Many children with disabilities don’t participate in physical activity or sports secondary to many barriers including inaccessible environments, inaccessible equipment, financial burdens, or lack of knowledge of providers of sports and recreation.39

The purpose of this project is to implement a unique, local camp to increase physical activity and exercise for ambulatory children with cerebral palsy (GMFCS Level I and II) and spina bifida who are overweight or obese. It is also to educate children about the importance of exercise and provide strategies for increasing the children’s participation in physical activity. A camp setting will facilitate peer interaction between children with disabilities and improve participation.

**Site Parameters**

Participants will be recruited to participate in the camp from UNC Hospitals Spina Bifida Clinic, Cerebral Palsy Clinic or Orthopedic Clinic. All participants will require medical clearance from a physician that allows them to participate in physical activity. The initial screening of selected participants will take place in the pediatric outpatient clinic on the ground floor of UNC Hospitals. This therapist and a physical therapy student volunteer will perform the screenings. Parking fees will be reimbursed to families. Subsequently, the camp will be held at the Chapel Hill Community Center off of Estes Dr. in Chapel Hill, NC as it is an accessible space that is air conditioned and has many of the physical activity interventions desired for the camp including a gym, climbing wall, and indoor swimming pool with zero entry. Additionally, there are paved outdoor areas for tennis and other outdoor sports activities.

**Phase 1 Intervention: Baseline Data Collection**

The initial screening will include baseline data collection on cardiovascular and anthropometric measurements. Data collected and measured will include: resting heart rate (HR), respiratory rate (RR), blood pressure, Borg rate of perceived exertion (RPE), height, weight, body mass index (BMI) calculation and pain as measured by a visual analog scale (VAS). Skinfold at triceps and subscapularis muscles and waist circumference measurements will be collected. A general flexibility screening using the sit and reach test will be performed. Additionally, the Pediatric Quality of Life Inventory (PedsQL) will be administered to the campers as will the Children’s Assessment of Participation and Enjoyment (CAPE). A baseline 6 minute walk test (6MWT) will be performed.

**Rationale for Selected Outcome Measures:**

Cardiovascular measurements (HR, RR, BP) provide baseline measures for safety as well as using HR to measure intensity of exercise performed. Target heart rate and maximum heart rates can be calculated with this baseline measurement with a formula recommended by the American College of Sports Medicine.33 The Borg RPE measures feelings of effort, strain, discomfort, and/or fatigue experienced during exercise.33 The American Physical Therapy Association Pediatrics Section has developed fitness guidelines for children and adolescents.34 Height and weight are necessary to calculate BMI. Skinfold and waist circumference measurements have been recommended as measures of fat mass or adiposity.34 Normative values in children for BMI35, waist circumference36 and skinfold37 measurements are available for comparison.

As many children with spina bifida and cerebral palsy have potential muscle and joint limitations, assessing flexibility and pain would be appropriate. The sit and reach test gives a general idea of flexibility and is included on the physical fitness test of President’s Challenge Program.38 Normative values in children do exist for comparison.34

Pediatric Quality of Life Inventory will be used to assess the impact of the exercise intervention on improvement in the child’s quality of life. This has been used previously in children with cerebral palsy.39 Quality of life scores in children with spina bifida, ages 8-20, have been shown to be lower compared to controls.40 The CAPE measures multiple dimensions of participation, including participation diversity, intensity, with whom and where participation occurs, and enjoyment.41 It is a measure that has been used in children 6-21 with or without disabilities.41

The 6MWT has been recommended for use as a core measurement in children and adolescents with cerebral palsy.42 Walking for a specified time corresponds to functional activities used in daily routines according to Verschuren.42 The 6MWT has also been used in children with spina bifida to measure exercise capacity.43

**Phase 2 Intervention: Implementation of Physical Activity Program**

The camp will be limited to 24 participants. It will be held during the summer break. The camp will be held 3 times per week for half a day in the mornings for 8 weeks duration. There will be at least one weekend day so caregivers can participate and observe their child. The children will be divided into 4 smaller groups of 6 each grouped by age. Each child will be assigned a one on one physical therapy student to monitor safety, intensity of exercise, amount of time spent exercising, assess for any adverse effects from exercise and assist campers with performing exercise as needed.

The program will begin each morning with all of the groups jointly completing the warm up and flexibility exercises for the first 20-30 minutes. Next, campers will divide into their pre-assigned group and begin one of four sports activities. Sports such as basketball, rock climbing on climbing wall, swimming, adaptive bicycle riding, running, rope climbing, tennis, kickball, and soccer will be included. These activities will be modified as necessary to allow all campers to be successful at participating. Groups will rotate to a different sport after approximately 30 to 45 minutes. They will participate in approximately 4 various sports activities each day. There will be a 15-20 minute “cool down” after the sports activities prior to campers leaving for the day. Activity will be monitored and recorded daily by the child’s assigned physical therapy student to assure levels of intensity and duration are met. Intensity for each camper will be pre-determined based on his/her baseline heart rate. If a child fatigues or can’t keep up with the daily activities, his/her program will be modified with activity gradually increased to the child’s capabilities and capacity. Activities can be modified to be less strenuous and more frequent rest breaks will be given.

On the last day of camp, the participants will be given an individualized home exercise, prescribed by their physical therapy student to assist with maintaining activity after camp has ended. This information will be reviewed with the camper and his/her caregiver(s).

**Equipment required for testing and intervention:**

We will need: pulse oximeters, sphyingomanometer with non latex cuff, stethoscope, skinfold calipers, tape measure, distance measuring wheel, goniometer, accelerometers, stop watches, pedometers, VAS to measure pain, RPE chart to measure exertion, sports specific equipment, and a first aid kit.

**Rationale for PA Intervention: intensity, frequency, duration, type of exercise and setting**

The Centers for Disease Control recommends 60 or more minutes of moderate to vigorous activity daily with vigorous activity at least 3 days week.1 The American Academy of Pediatrics has recommendations to reduce obesity in children with disabilities by increasing physical activity.44 The American Academy of Sports Medicine states, “Physical activity has a positive effect on health and is an essential component in prevention and treatment of overweight and obesity.”33 As previously reported sports activities has been shown to be advantageous for children with disabilities.25,26 A systematic review by Johnston showed strong evidence that children and adolescents with developmental disabilities benefit from participation in group exercise programs.45

**Phase 3 Intervention: Outcome Assessment**

Post camp measurements of all outcome measures will be re-assessed in the morning on the last day of camp. Additionally, camp participants will be retested at 3, 6 and 12 months on all measures to determine if they have been successful at continuing to maintain gains made from participation in the camp.

**Goals and Anticipated Outcomes:**

Upon completion of the eight week camp intervention, children with cerebral palsy and spina bifida who participate in Happy Campers Sports Camp will demonstrate:

1. Seventy-five percent of the children will demonstrate a 10% decrease in skinfold, waist circumference and overall BMI measurements.

2. Sixty- five percent of the children will demonstrate a 5% decrease in resting HR, RR, BP and Borg RPE compared to baseline measurements.

3. Seventy-five percent of the children will demonstrate 10% improvement in flexibility as measured by increased reach on the sit and reach test.

4. Ninety percent of the children will complete exercise with no increase in muscle or joint pain at the end of the camp compared to initial measurements as measured with the VAS.

5. Ninety percent of the children will demonstrate improved quality of life as measured by a 15% increase in the Physical Functioning Domain and Total Scale Score on PedsQL.

6. Ninety percent of the children will demonstrate a 10% increase in distance walked as measured by the 6MWT.

7. Ninety percent of the children will demonstrate a 10% increase in participation as measured by the CAPE.

**Evaluation:**

The purpose of this project is to implement a unique, local camp to increase physical activity and exercise for ambulatory children with cerebral palsy and spina bifida who are overweight or obese. Improvement in the outcome measures described above will demonstrate the efficacy of providing a camp environment to decrease overweight and obesity in children with disabilities. Comparison of pre and post camp and follow up at 3, 6 and 12 month outcome measures for aforementioned goals will provide information to assess the impact of the camp and assist in providing modifications to obtain preferred outcomes and future directions. Measurements of HR, RR, BP and Borg RPE are widely used cardiovascular measures. Fowler et al suggest that functional tests of walking such as the 6MWT are indirect measures of cardiorespiratory fitness.46 The PedsQL is a reliable, valid and sensitive measure providing information on physical, emotional and social health and school functioning.47Improvement, as described in the program goals, in the health related components of the PedsQL will assist in determining successful intervention through Happy Campers Camp. Improved scores on the CAPE, consistent with outlined goals, will reflect an increased participation in dimensions of participation including diversity, intensity, and enjoyment of activities and the context in which children participate.48

**Barriers/Precautions/Limitations:**

Some children may not be able to participate at the expected parameters especially initially secondary to poor fitness and conditioning. As every child has an assigned physical therapy student with them, activity can be monitored and progressed based on the individual child’s abilities. Every attempt to make each child successful at his/her own pace will be undertaken. Musculoskeletal injuries and pain could also limit individual participation or success. Many of the children have pre-existing musculoskeletal limitations. Those limitations will need to be considered in the intervention for each child to minimize risk of injuries such as strains, sprains.

One limitation of this program is that physical activity is the only component of overweight and obesity being addressed. Diet is another major component contributing to overweight and obesity not addressed in this proposal.49 A second limitation is all children may not be able to sustain an exercise program after the end of camp secondary to lack of access, lack of equipment, lack of an appropriate and safe environment to continue exercising. Another limitation of this program is that it only services a small group of children with CP and spina bifida that live in proximity to the Triangle, and it only services ambulatory children who can cognitively and behaviorally participate in the camp.

**Relevance:**

As overweight and obesity in children has reached epidemic proportions,1 Happy Campers is a unique approach to begin to address the challenge of overweight and obesity in children with ambulatory cerebral palsy and spina bifida. The camp model will promote improvement in the campers’ physical activity and participation. Despite the mentioned concerns, the camp provides a valuable and novel approach to addressing overweight and obesity in children with disabilities.

This camp could be implemented, with additional modifications, to include children with cerebral palsy and spina bifida who are non-ambulatory. Children with other types of disabilities such as Down syndrome, muscular dystrophies, genetic disorders or typically developing children who are overweight or obese could benefit from participation in the camp. The camp model could also potentially be used by the adult population for people with and without disabilities. The camp could serve as a model that could be integrated into therapists’ practice on a smaller scale around the state of North Carolina or even a larger scale at other university teaching hospitals or children’s hospitals.

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