1. **Background**

Cerebral Palsy (CP) is a neurodevelopmental condition often diagnosed in young children. It affects muscle tone, motor skills, and functional mobility as well as other deficits such as communication, cognition, and behavior1. Cerebral Palsy is not a progressive disease; however, the clinical expression of the condition can change as the brain grows and matures1. Over time, children grow in height, weight, mental maturity, etc. These changes are met with challenges. Many children experience postural disturbances and motor deficits that progress with age and growth in the early stages of CP1. For these children, not only must they go through typical hormonal and bodily changes, they must also endure possible changes in equipment needs, nutritional status, motor function, home and school environmental needs, etc. A community-based health promotion program can greatly benefit these children by providing them and their families with needed resources as they move through life. This 12-week after school program was designed to target the needs of children with Cerebral Palsy by providing them with necessary resources for physical fitness, equipment needs, and social/community support.

The program utilizes the Social Cognitive Theory model (SCT) as a framework for interventions revolving around increased physical activity in children with CP. The SCT explains that a health behavior change is made possible by a personal sense of control2. Core constructs from the SCT model, including self-efficacy and goal setting, are extremely useful in helping young patients increase their level of physical activity and create positive variance in behavior3. Before starting the program, each patient will work with a physical therapist to not only be given an initial physical evaluation but also to discuss the patient/family’s chief complaints, their goals, and what they hope to accomplish from participation in this program. Setting outcome expectancies is another key concept of the SCT that can significantly impact the ability to set and achieve goals2. We will take the time to work with each individual family to learn about their background, home environment, and other personal factors that may have an effect on a child’s participation. Once all of this is established and baseline physical levels are taken, the intervention portion can begin.

Increased physical activity is positively correlated with better health outcomes in young children with CP4–6. Progressive resistance and strength training can be used to increase muscle strength and endurance as well as improve gait and activity tolerance in individuals with CP4,5. Resistance training performed in a gym on weight machines under the supervision of a physical therapist can directly target specific muscle groups based on where an individual patient may show deficits. Resistance training has been shown to increase muscle strength as well as patient reported outcomes of perceived functional mobility4. Strength training consisting of activities such as cycling, aerobic exercise, loaded sit to stands, resistance training, and electrical stimulation has shown extremely positive effects in children with CP5. Not only is this type of training recommended to help increase muscle strength and functional mobility, it is also recommended for the psychological effects of increased competence and confidence in children5,6.

Over 12 weeks, children will be educated on how to properly exercise so they may continue with a routine and experience carryover benefits after their time in the program ends. This education and training of the target population will allow them to take charge of their own health at the intrapersonal level and hopefully experience a health behavior change based on concepts from the Social Ecological Model7. A community-based program promoting strength training not only improves quality of life through increased physical activity but also encourages children to participate by allowing them to work with other children with CP and stay motivated together6. Using the Social Ecological Model again, working closely with other children with CP as well as the instructors and families utilizes the interpersonal level in hopes to help make a behavior change. Both intrapersonal and interpersonal factors need to be present to affectively promote health changes and that is exactly what this program aims to do.

Aside from exercise, adaptive equipment can provide significant benefits to a child’s daily life in terms of their independence level with mobility, communication, activities of daily living, and participation8–10. A huge part of this program is to promote independence in children with CP, thereby influencing both individual and interpersonal levels of their lives. Therefore, an adaptive equipment evaluation/screen will be done on all children. This evaluation will assess the appropriateness and fit of devices already being used, recommend devices not already in use, predict the possible need for devices in the future, and provide referrals and resources to acquire devices. Adaptive equipment consists of but is not limited to adaptive seating, wheelchairs, walkers, crutches, standing frames, etc.

Adaptive seating such as the Flip2Sit for activity floor sitting and the Aquanaut for toileting and grooming sitting can be used to help a child improve independence and participation with self-care and play activities8. Children are better able to engage with their environments if they are provided with seating that helps control core stability and upper extremity support8. Mobility devices such as wheelchairs, walkers, and crutches allow children to move around more freely and independently9. Children report feeling more enabled to participate with peers and feel included when using assistive devices9. Using devices can create interpersonal connections that a child otherwise would not be able to make. Children not currently requiring assistive devices can still participate in this intervention should a parent chose. Many children that do not require a device at a younger age will eventually need one as they begin to grow. Using the Gross Motor Function Classification Scale (GMFCS), equipment needs can be predicted10. This can help families plan for the future financially, emotionally, and physically.

Throughout the program, several outcome measures will be used to track patient progress and evaluate the effectiveness of the interventions. Outcome measures will be taken at baseline during the initial evaluation exam and then again halfway through participation with the program and at the end of participation with the program. Two functional outcome measures (5 times sit to stand and isometric strength testing) along with a patient reported outcome measure (Cerebral Palsy Quality of Life Questionnaire) will be used to quantitatively and qualitatively measure individual patient outcomes of all participants. Other outcomes such as the Trunk Impairment Scale (TIS), Modified Ashworth Scale, Timed Up and Go (TUG) and 6 Minute Walk Test (6MWT) may be used in addition depending on a child’s functional ability and need.

The 5 times sit to stand (5xSTS) measures lower extremity strength and endurance while also looking at a major functional component of transferring11. It has been shown to be a reliable outcome measure when used on children with CP. It has excellent test-retest and inter-rater reliability and is recommended to be used as a measure of functional mobility with this patient population11,12. A positive finding on this measure would be the inability to complete the test and or decreased results from previous testing. It is expected that after participation in this program, patients would demonstrate improved results on this test, indicating increased lower extremity strength and improved transfer skills.

Isometric strength testing can be used as a quantitative outcome measure to look at specific targeted muscle groups and determine how their strength has changed throughout the duration of the program. Manual muscle testing (MMT) is the most standardized way to assess muscle strength. The medical research council scale for manual muscle testing grades muscle strength from 0-5 and is widely accepted as a clinical evaluation tool in children with CP13. Measuring standardized strength (as well as functional strength demonstrated in the 5xSTS) is important when assessing a child’s functional mobility and level of independence when completing transfers, activities of daily living, and more.

The Cerebral Palsy Quality of Life (CP-QOL) questionnaires are divided into two categories, one for children ages 4-12 and another for adolescents ages 13-1814. The CP-QOL looks at factors such as social wellbeing and participation, feelings about functioning, family health, emotional wellbeing and self-esteem, access to services, and impact of disability14. The questionnaire can be completed by the child or a primary caregiver proxy and demonstrates good reliability and validity15. Testing for functional outcomes is important; however, understanding a child’s emotions, thoughts, and feelings about their quality of life is just as important if not more important. The goal of this program is to promote independence among children with CP. It is possible that a child performs extremely well on functional outcome measures and test but does not feel confident or competent in their abilities and vice versa. The CP-QOL can help examine how a child is doing socially, how their equipment has helped them, how confident they feel to participate, and more. Getting the full picture of a patient is crucial for providing the best evidence-based quality of care.

1. **Program Goals**

Ultimately this program is designed to promote health and wellness in the CP community by providing education and resources as well as an exercise program. The program’s goals are listed below. We hope to achieve these goals by the end of the 12-week program.

1. By the end of the 12-week program, participants will improve their 5 times sit to stand time by at least 0.06 rep/second to meet the minimal detectable change of this outcome measure11.
2. By the end of the 12-week program, participants will demonstrate 4/5 strength or higher grossly across all muscle groups, indicating the strength to move fully against gravity while also being able to activate muscles against some or full resistance, which is required for successful functional mobility16.
3. By the end of the 12-week program, participants will improve their score on the CP Quality of Life questionnaire by an average of 15 points, demonstrating increased happiness with their overall quality of life when it comes to categories of friends and family, participation, communication, health, special equipment, pain and bother17.
4. By the end of the 12-week program, participants will be properly fitted with any and all equipment and pass an inspection by a trained physical therapist as well as be asked to verbally state their knowledge of proper fit and function of their equipment in order to indicate a clear understanding of their equipment needs as well as demonstrate independence with equipment use.
5. **Methods**
6. **Location**

This after school program will be held at the Stowe Family YMCA in Belmont, NC. Due to the nature of this after school program, an official membership to the YMCA is not required; however, there will be an afterschool program registration fee paid to the YMCA18. If you are already a member at the YMCA, this fee may be waived. To receive more information about cost, please contact the Stowe Family YMCA directly. The YMCA is generous enough to allow us to use a private studio room with free weight equipment, basic machines, yoga mats, and additional equipment.

1. **Staff**

The staff for this program will consist of two board certified and trained physical therapists as well as trained physical therapy student volunteers. These two physical therapists along with volunteers will be present for all scheduled sessions over the 12-week program. The therapists will be in charge of assessments (3 total assessment days- once on the first day before beginning, once at the midpoint, and once on the last day after completion of the program), performing equipment fitting screens, providing education about equipment needs, and overseeing exercises and fitness trainings. They will also be present to answer any and all questions that participants or family members may have. The student volunteers will work closely with participants on their exercises as well as education on proper use of equipment and proper form and technique when performing exercises. Students will gain great experience with patient care in a pediatric population and have the opportunity to work closely with the therapists to learn.

1. **Enrollment**

Each 12-week period has a maximum capacity of 20 participants. Participants may enroll by contacting the YMCA directly or by calling the program director. Participants and families will then be led to an online form to answer some questions and ensure that they qualify for the program. Once enrolled, participants/families will receive an email with the schedule, planned activities, contact information, etc.

1. **Schedule**

Over the 12-week period, sessions will be held 3 times per week on Monday, Wednesday, and Friday. These group sessions will be 1 hour long (excluding assessment days) from 4-5pm. Assessments will be conducted on the first Monday of the program as well as the Friday of the 6th week and the Friday of the final 12th week. These one-on-one sessions will occur from 5-8pm based on the child’s/family’s schedule. Parents/guardians are encouraged to join for these sessions to receive education as well as updates on their children. If parents wish to join for other sessions, they may do so but will be required to sit along the perimeter of the gym floor as to observe but not be in the way. Because this is an after-school program, transportation will be provided through an accessible bus to take children from school to the YMCA. Parents and guardians are also able to drive their children to the YMCA if they wish.

Non assessment day sessions will begin with group stretching and a light warm up. This allows the children time to get to know each other and encourage one another. After this, participants will break up to work on the individual exercises that were decided upon at the initial assessment. We want each participant to work on exercises that are targeted to their specific needs. If several participants require the same exercises, they will be able to work together. Several physical therapy students will be present and working with participants to ensure proper use and safety. Trained and certified physical therapists will be in the room the entire session overseeing activities and stepping in as needed. Sessions will end by coming back together as a group for a cool down.

Assessment days will be conducted one-on-one with a physical therapist and the participant and their family. Time slots will be scheduled ahead of time. During these sessions, participants will be tested using standardized outcome measures. These sessions are also when equipment screens and fitting will occur. Participant and family education will be a large part of these sessions. This is the time to ask any and all questions. Therapists are equipped with several valuable resources to share.

1. **Interventions**

As mentioned above, sessions will begin with a group warm up and stretch. This will take approximately 10 minutes. After that, participants will have 40 minutes to work on individual exercises with the help of a physical therapist or physical therapy student before coming back as a group for a 10 minute cool down. Some examples of typical deficits/impairments along with the exercises that target them are presented below. Exercises can be performed using body weight, free weights, or weight machines. Most participants will perform a mix of several exercises listed in different categories. Participants will be educated on the Rate of Perceived Exertion Scale (RPE) so they are able to voice to therapist when they feel they are “working hard” which is the goal4. They will also be able to voice when exercises are too difficult or easy and weight/intensity needs to be decreased or increased4. Therapists and volunteers will help participants progress over the 12 weeks by increasing intensity and duration of exercises.

|  |  |
| --- | --- |
| **Deficit/Impairment** | **Exercises**4,5,19,20 |
| Walking deficits | Treadmill training  Obstacle course  Assistive device training |
| Lower extremity weakness | Leg press  Loaded sit to stand  Squats  Heel raises  Toe raises  Hip abduction/adduction  Cycling |
| Upper extremity weakness | Push ups  Bicep curls  Chest press  Triceps extensions  Lateral raises  Pull ups |
| Core weakness | Quadruped reaching  Sit-ups  Tall kneeling trunk twists  Exercise ball  Planks  Bridging |
| Balance and coordination deficits | Semi-tandem and tandem stance/walking  Balance board training  Single limb stance  Stepping over obstacles  Balance on unsteady surfaces  Reaching activities  Throwing/catching |

Assessments (5 times sit to stand, manual muscle testing, CP quality of life questionnaire, additional measures as needed) will be conducted three times throughout the 12 weeks. The 5 times sit to stand is measured by asking the participant to start in a seated position and move to a standing position and back to a seated position a total of 5 times as quickly but safely as they are able11. Participants are timed and the value is recorded. Manual muscle testing will be used to assess the strength of several individual muscles as well as groups of muscles and will be graded on a scale of 0-516. The CP quality of life questionnaire is available for free and should be answered honestly by the participant. There are 52 questions relating to how a participant feels in certain situations that are graded from 1-9, 1 being very unhappy and 9 being very happy14. These evaluation tools will help provide a baseline assessment of each participant and also be used to track progress throughout the program.

During assessment days, participants are also encouraged to bring any and all equipment they may have to ensure proper fitting and use. Therapists are equipped to perform fittings for wheelchairs, walkers, crutches, standing frames, and adaptive sitting equipment as well as assess the fit of orthoses. This is also a great time for families to ask about resources for acquiring new equipment. Screenings can be performed on participants to help predict the possible need for equipment in the future as well10.

1. **Program Evaluation**

The program will perform assessments of all participants three times throughout the 12-week program, once at baseline before beginning the program, once after 6 weeks, and once at the end of the 12 week period. Final scores will be compared to baseline scores to assess improvements made by each participant. By the end of the program, we hope to see each participant increase their 5 times sit to stand time, their gross muscle strength, and their feelings about their quality of life. If the majority of participants are able to make meaningful improvements in these three outcome measures than the goal of this program will have been met.

We also will be asking all participants, families, and staff to complete a satisfaction survey online after their midterm assessment visit and their final assessment visit. This survey will ask each individual how they believe the program is going overall as well as asking specific questions relating to schedule, interventions, etc. There will also be a section to leave constructive feedback and provide comments on what is going well and should continue or what needs to be changed. Comments provided at the midway point will be taken into consideration and changes will be made in the second 6 weeks to reflect those comments as we hope to improve by the end of the 12 weeks. Surveys are a great way for the program to receive anonymous feedback to evaluate the effectiveness of the program and the satisfaction of those involved21. If participants and their families are satisfied with the results from the program, we ask that they leave us a good review and promote us to other community members with CP.

The YMCA board will also be evaluating the effectiveness of the program as well as how it affects them as beneficiaries and stakeholders22. They will be conducting safety visits and productivity screens throughout the program at a time of their choosing. The program director as well as the two therapists on staff will meet with the YMCA director to ensure a mutual understanding of the benefits this program can provide to the community.

1. **Conclusion**

This after school health promotion program will be extremely beneficial to those with cerebral palsy in our community. Having cerebral palsy can affect a child’s ability to participate in daily life in the way they wish. It can lead to deficits in strength, coordination, function, cognition, and more. Through this program, we hope to improve the lives of those involved by providing evidence-based intervention and education targeting strength, function, and mobility. This program will also connect patients and families to other individuals in their community, creating a safe space to learn from each other’s experiences and develop a support system within the community. Health promotion programs help patients advocate for themselves and work towards a healthier lifestyle. The goal of this program is to provide appropriate education about cerebral palsy in order to help patients manage their condition while also stimulating their development and obtaining the maximal level of independence possible in their daily lives.

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