Adaptive Sports & Activity Tracking for Individuals with Cerebral Palsy (CP)
September 16, 2017
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Disclosure Information
AACPDM 71st Annual Meeting
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Speaker Names:
Jennifer Miros, MPT and Sarah Hickey, PT, DPT

Disclosure of Relevant Financial Relationships
We have the following financial relationships to disclose:
We are employees of: St. Louis Children’s Hospital

Disclosure of Off-Label and/or investigative uses:
We will not discuss off label use and/or investigational uses in our presentation

Purpose:
To help medical professionals understand how to promote and start an adaptive sports and/or fitness program in their practice.
This lecture will provide information on ways to set up:

- Community sports classes
- Adaptive Triathlon events
- Intensive sports day program

Gross Motor Function Classification Scheme

I - walks without restrictions, limited advanced skills (sports, playground).
II - walks with limitations, limited outdoors and community (trouble with uneven surfaces, crowds, stairs), minimal running
III - walks with hand-held assistive device, may require wheelchair or other transportation for long distances
IV - self mobility with limitations, uses powered wheelchair, can function in sitting if supported
V - severe mobility limitations even with assistive technology, transported by others in a manual chair

[Palisano 1997]
Adaptive Sports for Individuals with Cerebral Palsy

The Role and Scope of Pediatric PT in Fitness, Wellness, Health Promotion and Prevention

FACT Sheet Pediatric Section of APTA

• https://pediatricapta.org/includes/fact-sheets/pdfs/12%20Role%20in%20Fitness%20Promo.pdf

• Key Points
  - APTA and CDC recommendation is 60 minutes daily of MVPA
  - Most children participate in >2 hrs of sedentary screen time daily
  - Known that children with chronic conditions and disabilities are less active than typically developing peers due to several barriers
  - Precautions
    - Monitor for seizure activity, follow surgical and spasticity management precautions by MD, be cautious using 1 rep max

FACT Sheet
Considerations for CP population

Pediatric Section of APTA

Strength Training

- 2-3x/week, 1-3 sets of 8-12 reps with free weights, machines, isokinetic exercise with or without resistance, able to perform 3 sets with ease before increasing

Aerobic Exercise

FITTE Principle

- F (frequency 2-4 days per week)
- I (intensity, work at 40-85% of max HR, maxHR should be considered 194 bpm)
- T (time increase from 20 min to 40 min+ per session as tolerated)
- E (type)
- E (enjoyment, MAKE IT FUN!)

Exercise and Physical Activity Recommendations for People with CP

Paper presents CP specific recommendations based on a comprehensive literature review, expert opinion and extensive clinical experience

Findings:
- Minimum frequency of 2-3x/week
- Intensity of 60-90% of peak HR or 50-65% of VO2 peak
- Minimum time of 20 min for 8 weeks with 2x/week or 16 weeks for 3x/week

Adaptive Sports for Individuals with Cerebral Palsy

Key Points

• Start Early
• MUST START
• Try to ↑ Activity AND ↓ Sedentary Time
• Include ↑ Weightbearing for patients GMFCS IV and V

How Do Typical Kids Stay Active?

• Team Sports
• Gymnastics/Tumbling
• Outdoor Play
• Playground
• Martial Arts
• Swimming
• Bike riding, tricycle riding

Why Sports?

• Sports are FUN!
• Sports Motivate
• Sports involve risk
• Sports are part of our culture
Adaptive Sports for Individuals with Cerebral Palsy

**Childhood Sports**

- What do you want your patients to get out of the experience?
- What do you want/hope to get out of the experience?

**Adaptive Sports**

- What do you want your patients to get out of the experience?
- What do you want/hope to get out of the experience?

**Expectations of Sports**

Sports are more than physical ability….

**Mental and Emotional Expectations**

For you as a therapist/supporter, and the **athlete and guardians**.
Welcome to Holland
By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared the unique experience to understand it, to imagine how it would feel. It’s like this...

When you’re going to have a baby, it’s like planning a fabulous vacation trip to Italy. You buy a bunch of guidebooks and make your wonderful plans, the Colosseum, Michelangelo’s “David,” the gondolas in Venice. You may learn some handy phrases in Italian. It’s all exciting.

After months of eager anticipation the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes and says, “Welcome to Holland.”

“What do you mean Holland? I signed up for Italy! All my life I’ve dreamed of going to Italy!”

But there has been a change in the flight plan. They landed in Holland and there you must stay.

The important thing is that they haven’t taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It’s just a different place.

So you must go out and buy your new guidebooks. You must learn a whole new language. And you will meet a whole new group of people you would have never met.

It’s just a different place. It’s a little quieter than Italy, less flashy than Italy. But after you’ve been there for a while, set you catch your breath, you feel at home. And you begin to notice Holland has tulips, Holland even has Rembrandts. But everyone you know is busy coming and going from Italy, and they’re all bragging about what a wonderful time they had there.

And for the rest of your life, you will say, “Yes, that’s where I was supposed to go. That’s what I had planned.” And the pain of that will never, ever, ever go away because the loss of that DREAM is a very significant loss.

But if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

The Basics of an Adaptive Sports Program…..

Think of the W’s
What Activity? Equipment is based on this
Where? Need a location, possibly gym space
When? Make it convenient for you and families.
Who? You will need volunteers and therapists to help with the activity you are doing. High school and college students can bring great energy and enthusiasm to your activity.
M.A.T.C.H.

• Modify the Task
• Alter Your Expectations
• Teaching Strategies
• Change the Environment
• Help by Understanding

What do typical sports do?

Swim practice…
  – Warm up
  – Skills (breathing, kicking, arms, diving, flip turn.)
  – Practice (scrimmage with each other)
  – Real games

Basketball practice…
Track and Field practice…

Camp Independence

We do similar activities that may be adapted to fit each participants’ abilities
Camp Independence

- 6 Week Day “Camp”-really an intensive day treatment program in the summer.
- Winter “Camp”-over the winter holidays
- Participants are over the age of 7
- Must be able to follow 1 step commands and have functional use of at least one extremity
- Must want to play sports

Warm Ups Instead of Stretching

EVERYONE OUT of their wheelchairs
- Allow the participants to choose the warm up exercises!
  - Themes are helpful- super heroes, cooking, animals
  - UE Stretches
  - LE Stretches
  - Modified push ups, sit ups

Skill Stations

- Balance
  - Standing balance, SLS, sitting balance
- Flexibility
  - UE stretch, LE stretch
- Coordination
- Endurance
  - 6 Minute Modified Walk/Run “Race”
Adaptive Sports for Individuals with Cerebral Palsy

Practice/Game
- Reviewing rules
- Picking teams
- Sportsmanship skills
- Winning/losing

Basketball
- Use various balls (size, weight, texture, color)
- Be flexible with the rules
- Use larger/lower goals

Baseball/Softball
- Use smaller/larger size bat
- Use smaller/larger size ball
- Velcro ball/mit/vest
- Use a batting tee
- Alter the base distance
Adaptive Sports for Individuals with Cerebral Palsy

**Soccer**

- Use walking instead of running
- Have well defined boundaries
- Reduce playing area
- Use a deflated ball, nerf ball, beeper ball, brightly colored ball
- Use a target that makes noise when hit

Excerpt taken from *Teachers Survival Guide* by Christine Stopka

**Tennis**

- Racquet size - handle length, racquet head size
- Racquet weight
- Use old/dead tennis balls to alter the speed

**Dance Assistive Devices**

- Reverse Walker
- PT assist - Hand held
- Bench Sitting
- No assistive Device
- Stander
- Lite Gait
- Canes
- Manual Wheelchair
- Power Wheelchair
Adaptive Ballet Resource

- [Link](http://bbi.syr.edu/projects/fit_in/docs/ballet_guidebook.pdf)

Martial Arts-Kajukenbo

- Blended Martial Art
- Combines the best and most effective techniques from 5 different fighting styles
  - KA-Karate
  - JU-Judo and Jiu Jitsu
  - KEN-Kenpo
  - BO-Chinese Boxing

Swimming Equipment

- Water Wings
- Puddle Jumpers
- Pool Noodles
- Life Jackets
- Neck Support
- Ankle Weights
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Swimming Equipment
- Theraquatics.com
- Ottobock Krabat Pirate

Ice Skating/Ice Hockey
- Metal Rung Chairs
- Skates on everyone
- Scrimmage vests (pennies) for seatbelts
- Walkers on the Ice
- Wheelchairs on the ice

Adaptive Cycling
- There are plenty of 3 wheeled cycle models available.
  (See Handout)
- For insurance reasons, call them “Therapeutic Mobility Devices”
It is important to have feet strapped or attached to pedals.

Group Activity

- 4 Case Examples
- 5-7 minutes to discuss in small group
- 2-5 min to present to the larger group
- Think about warm up, skills, game preparation and scrimmage ideas

Cases

- Adapt tennis for an 13 year old boy with spastic right hemiplegia who walks independently with a modified run. GMFCS II Has endurance and heat issues.
- Adapt soccer for a 12 year old girl with ataxic cerebral palsy who uses a walker-GMFCS III
- Adapt basketball for a 14 year old boy with spastic quadriplegic CP who uses a gait trainer-GMFCS IV
- Adapt baseball for a 15 year old girl with spastic quadriplegia who is pushed in a wheelchair-GMFCS V
Tennis

- Adapt tennis for a 13 year old boy with spastic right hemiplegia
- Walks independently with a modified run
- GMFCS II
- Has endurance and heat issues

What if he was a GMFCS V?
What if he was visually impaired?

Soccer

- Adapt soccer for a 12 year old girl with ataxic cerebral palsy
- Walks with a walker
- GMFCS III
Adaptive Sports for Individuals with Cerebral Palsy

Basketball

- Adapt basketball for a 14 year old boy with spastic quadriplegic CP
- Uses a gait trainer
- GMFCS IV

Baseball

- Adapt baseball for a 15 year old girl with spastic quadriplegia
- Pushed in a wheelchair
- GMFCS V

What if she was GMFCS II and visually impaired?
What if she was GMFCS III?
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Research

Motor Assessments
(Testing varies depending on ability level)

Done Pre and Post Camp
1) Timed Up and Go (TUG)
2) 5X Sit to Stand (5xSTS)
3) Shuttle Run
4) 6 Minute Modified Walk/Run Test
5) 25 Feet Walk/Run/Wheelchair
6) Hamstring Range of Motion
7) Balance Tests
8) Basketball Dribbling

The Effects of Participation in Sports Programs on Walking Ability and Endurance Over Time in Children with Cerebral Palsy

This manuscript was accepted for publication in American Journal of Physical Medicine & Rehabilitation 2017


*Maryville University, Physical Therapy Program, St. Louis
† Washington University School of Medicine, St. Louis
Study Design

A retrospective analysis of children with CP ages 6-20 years who participated in a local sports program. GMFCS level IV & V were excluded. 519 participants from 2004 to 2012. Of these, 326 participants had pre and post data recorded. There were a total of 109 subjects, many of whom attended multiple programs throughout the years.

The Effects of Participation in Sports Programs on Walking Ability and Endurance Over Time in Children with Cerebral Palsy

Significant differences in TUG for participants who were GMFCS I and III at Camp Independence and our basketball class from 2004-2012.

Significant differences in Modified 6 minute walk/run tests for participants who were GMFCS II and III at Camp Independence and our basketball class from 2004-2012.
Adaptive Sports for Individuals with Cerebral Palsy

Clinical Significance

Walking function and endurance improved as a result of attending intensive sports programs.

Higher frequency of program attendance showed improvements in TUG, m6MW and 25 ft walk/run over time.

Participation in sports programs appears to be beneficial for children with CP especially those who attend multiple programs over time.

Activity Data Collection

2013 Activity Tracker Trials

Activity Monitors TRIaled:
Fit Bit
Jawbone
New Balance Watch
Nike-In Shoe
Hip Pedometer
Garmin
Polar

Needed to be waterproof
Adaptive Sports for Individuals with Cerebral Palsy

2014 Collaborative Study with Camp Independence and SLU

Activity Monitoring using a Fitbit Flex Device

<table>
<thead>
<tr>
<th>Activity</th>
<th>Distance</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking</td>
<td>1.8 mi</td>
<td>0:30</td>
</tr>
<tr>
<td>Running</td>
<td>1.979 mi</td>
<td>0:30</td>
</tr>
</tbody>
</table>

Heart Rate Zone Analysis of Children with Cerebral Palsy Who Attend an Adaptive Sports Camp

Current Published Research
Adaptive Sports for Individuals with Cerebral Palsy

Habitual Physical Activity of Independently Ambulant Children with CP

- 52 boys, 50 girls, 8-17 yrs old, unilateral CP, GMFCS levels I and II, excluded if BTX 2-6m prior, uncontrolled epilepsy
- Used a GT3X+ accelerometer to track activity, wear the belt all waking hours for 4 consecutive days including 2 week days and 2 weekend days
- Average step count 7,541, avg 8.36 hours inactive, 2.38 hours in light activity, 0.44 hours in MVPA
- Results suggest that even the higher functioning children are NOT meeting the recommendation of 60min/day

Mitchell et al. Physical Therapy Feb 2015

Fit Kids Exercise Therapy Program

- 30 boys, 22 girls, ages 6-17, dx of any chronic disease or disability, excluded if wheelchair dependent or couldn’t understand Dutch
- 3 months 1 hr 2x/week, 3 months 1hr/week
- Found significant intervention effects for aerobic fitness, anaerobic fitness and muscle strength and HRQoL
- Measurements: Modified Bruce Protocol, Muscle Power Sprint Test (MPST), Strength subscale of BOT2, 6MWT, HRQoL
- Found that 1 hour per week is sufficient to maintain effects of training but insufficient to achieve new improvements

Kotte et al, Physical Therapy Sep 2014

The Scope of Pediatric Physical Therapy in Health Promotion and Fitness for Youth with Disabilities

- Children with disabilities have increased sedentary behaviors due to limited or inaccessible exercise options

Considerations for Health Promotion- The States of Change Model

- Exercise Parameters
  - Strength Training:
    - 2-3x/week
    - 1-3 sets of 6-15 reps
    - Able to perform 3 sets easily before increasing weight
    - 30%-60% improvement expected in 8-12 weeks
  - Aerobic Training:
    - 134 bpm is rec for estimated max HR when testing not available
    - Training HR of 107-126 bpm for deconditioned individuals and 126-155 bpm for youth who are more fit

Rowland et al, Pediatric Physical Therapy 2015
Adaptive Sports for Individuals with Cerebral Palsy

Considerations for Health Promotion - "The Stage of Change Model"

Step 2: Provide the youth and family with personalized guidance and information to help resilience healthy active behaviors and practices. Give ideas on strategies to maintain health behaviors change—ie, use a schedule board at home to remind the family to go for walks to the park or to go to the local pool or recreation center.

Step 3: Provide support to families to help them find community resources to adopt and maintain active, healthy lifestyles. Help families and youth find "champions" and develop positive relationships with community professionals.

Step 4: Be sure to come to closure when the PT sessions are over so that youth and family have a good understanding of the health message and strategies to sustain an active, healthy lifestyle. Help the youth and family identify and navigate potential barriers to maintaining an active lifestyle.

TABLE 1 Health Promotion Strategies in Pediatric Physical Therapy

The Scope of Pediatric Physical Therapy on Health Promotion and Fitness for Youth With Disabilities

Rowland, Jennifer L.; Fragala-Pinkham, Maria; Miles, Cindy; O'Neil, Margaret E.


doi: 10.1097/PEP.0000000000000098

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Health Enhancing Physical Activity in Children with CP: More of the Same is Not Enough

- Intervention recommendations must be broadened to include decreasing sedentary time (get up and stand) and encouraging light intensity activities (walk around house).

- People with CP have to start somewhere

- Stop being idle and get active!

Vercoulen et al., Phys Ther February 2014
Think Outside the Box

- Therapists can do fitness classes instead of “therapy”
- Kids and Parents can help start sports programs

What is in the St. Louis Community?

- SLCH CP Sports
- Tennis
- Skiing (Water and Snow)
- Adaptive Cycling-Cycle St. Louis
- Challenger Baseball
- Special Needs Soccer Association (SPENSA)
- Disabled Athlete Sports Association (DASA)
- Special Olympics
- Team Activities for Special Kids (TASK)
- Kids Enjoy Exercise Now (KEEN)

Programs SLCH-CP Sports Offers

- Camp Independence
- 10-12 week sessions of Dance
- 6-8 week sessions of Swimming and Open Gyms
- Tri My Best Adaptive Triathlon
Adaptive Sports for Individuals with Cerebral Palsy

2016 Tri My BEST VIDEO
https://www.youtube.com/watch?v=Rlnn_JtyxSY&feature=youtu.be

Last Week’s Event

3rd Annual Adaptive Triathlon on
Sunday, Sept. 10, 2017
Washington University's Danforth Campus Athletic Complex
www.stlouischildrens.org and go to the CP Center Website and look under Sports & Rehabilitation.

Thank You!!

If you have any questions, comments or suggestions please contact us!
You can reach us via email at jennifer.miros@bjc.org or sarah.hickey@bjc.org or call our office 314.454.2604
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- St. Louis Children’s Hospital Foundation

References

5. Rowland, Fragala-Pinkham, Miles, O’Neil. The Role and Scope of Pediatric Physical Therapy in Fitness, Wellness, Health Promotion, and Prevention. APTA Section of Pediatrics Fact Sheet.