Adaptive Recreation for Children and Youth with Cerebral Palsy (CP) and Other Childhood-Onset Disabilities (COD)

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Disclosure Information
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• Speaker Names: Jennifer Miros, MPT
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  Désirée Maltais, PhD, PT

Disclosure of Relevant Financial Relationships
We have no financial relationships to disclose.

Disclosure of Off-Label and/or Investigative Uses:
We will not discuss off-label use and/or investigational use in my presentation

Introduction
• Jennifer Miros, MPT
  – PT training in St. Louis, MO
  • Worked clinically with different pediatric populations in Cleveland, Akron and St. Louis
  – Started the Carol and Paul Hatfield CP Sports and Rehabilitation Program at St. Louis Children’s Hospital in 2003.
  – Have participated in Special Olympic Basketball, Adaptive downhill skiing and the CHAMPS program in Cleveland.

• Keiko Shikako-Thomas, PhD, OT
  – Postdoctoral fellow at CanChild Centre for Childhood Disability Research, McMaster University, Canada
  • Policies that support participation of children with disabilities in leisure activities
  • How research can inform policies?
  – OT training in Brazil
  • Work clinically with different pediatric populations
  – PhD at McGill University, Montreal, Canada
  • Determinants of participation in leisure activities in adolescents with CP
  • Quality of life of adolescents with CP, families experiences on growing with a disability

• Désirée B. Maltais, PhD, PT
  – Pediatric physical therapist (PT), developed and ran physical activity (PA) programs for children and youth with childhood onset disabilities (COD) for 15 years
  – Doctorate in (exercise) physiology from McMaster University in Hamilton, Canada
  – Associate professor at Laval University in Quebec City, Canada
  – Teaches pediatric PT to Laval PT students
  – Research at CIRRIS in Quebec City, Canada
  – Research interests:
    • What do pediatric clinical mobility tests tell us about everyday mobility?
    • What are the cognitive and physical effects of PA for children, youth and adults with neurological impairments?
    • What are the determinants of PA for children and youth with or at risk for physical disabilities?

Outline of Instructional Course
• Social and Psychological benefits of Participation in Adaptive Recreation Activities
• Physical benefits of Participation in Adaptive Recreation Activities
• Questions/Break
• Informal and Formal Adaptive Recreation Activities-ideas for all age groups
• Measures of Success
• Success Stories
• Group Discussion
Things to Ponder and we will discuss at end:

- What adaptive recreation programs have you done, that worked well?
- What were the barriers?
- How did you change the program/activity to make it better?

Definition

Particeps = part taking and
Pars + capere = to take or to share in
(Online Etymology Dictionary)

“the act or state of taking part or sharing in something” (Simpson & Wiener, 2002)

Involvement in life situation” (WHO, 2001)

Leisure Participation

- CanChild (leisure participation)
  - Involvement in formal (structured) and informal (little or no planning) everyday activities
- Occurs in many environments
  - Work, sport, entertainment, learning, civic life, religious expression

Leisure and the ICF - CY

- Participation
  - Involvement in life situations
    - Learning and applying knowledge
    - General tasks and demands
    - Communication
    - Mobility
    - Selfcare
    - Domestic life
    - Interpersonal interactions and relationships
    - Work/school
    - Community, social and civic life

Leisure and human rights

http://www2.ohchr.org/english/law/crc.htm#art31

Article 31:

1. Rest: includes the basic necessities of physical and mental relaxation and sleep.
2. Leisure: is a term that implies having the time and freedom to do as one pleases.
3. Recreational activities: embraces the whole range of more goal directed activities undertaken by choice for the purposes of pleasure.
4. Play: includes activities of children that are not controlled by adults and that do not necessarily conform to any rules.
5. Cultural life and the arts: includes both their right of access and their right to participate and undertake such activities themselves.

Leisure Participation Scenario

• 87% of children and youth participate in organized activities outside of school
  – Children who participated but stopped are 3x more likely to have lower self-esteem, have difficulty making friends, smoke, perform poorly academically

National Longitudinal Survey of Children and Youth (Statistics Canada, 2001)

Leisure participation scenario

• Children with disabilities:
  • Participation decreases as children get older
  • More passive, home-based activities, more dependent
  • 51% in the 5-14 years old range had participation restrictions in physical and social activities due to a health problem or disability.

• Adolescents with disabilities:
  (Shikako-Thomas et al., 2013; Palisano et al., 2012; Kung et al., 2012)
  • Participation in skill-based and active-physical activities is very limited
  • Most activities are done alone, with family or other relatives
  • Most activities are done at home, at a relative’s home or in the neighborhood
  • Adolescents enjoy most social and recreational activities

Participation intensity across domains

“Are you doing what you want to do? Leisure preferences of adolescents with cerebral palsy”

• Hypothesis:
  • Adolescents with CP prefer social activities
  • There will be a fair correlation between preferences for activities and actual involvement
  • Intrinsic factors contribute to preferences for certain activity types more than extrinsic factors

N=17

Play and Leisure Why is it good?

• Physical and mental health
• Enjoyment
• Develop self-concept and increase self-esteem
• Social relationships
• Social skills
• Adolescents: positive development
• Long term benefits
What is Physical Activity (PA)?

“Any bodily movement produced by the skeletal muscles that results in a substantial increase over resting energy expenditure (EE)”

Bouchard and Shephard, 1994

Indirect measurement of PA

Questionnaires, diaries/logs, surveys, interviews

• Information collected about activity type, frequency, duration over a set time period
• Total EE (PA) estimated from estimated EE for each activity
• Very feasible to use
• Children and some youth may have difficulty recalling what they did
  – Leads to PA over estimation (typical) or under estimation (if PA is not memorable)

Adamo et al., 2009

Points to consider when choosing a PA questionnaire for clinical use

1. Is the questionnaire available in the language of my target group?
2. Does the questionnaire yield valid and reliable results at least with typically developing (TD) children or youth?
3. Do the questions apply to my target group?
4. Is the questionnaire easily obtainable and is there a fee for using it?
5. How long does the questionnaire take and is it easy to score?
6. Does someone I know have experience with the questionnaire?

Adamo et al., 2009

Example of PA questionnaire items

The Habitual Activity Estimation Scale, Hay and Cairney, 2006

Direct observation, physiological estimates of EE (e.g. doubly labeled water to assess CO₂ production, heart rate), mechanical sensors of movement (accelerometers, pedometers)

• Removes need for recall
• Typically expensive, time consuming to convert data to a PA level based on EE
• Usually more accurate estimation of EE than a questionnaire, at least in the TD population
• Heart rate and mechanical sensors can provide data over small time periods over several days
  – Can give an indication of PA patterns (when the person was active and by how much)
  – Difficult to determine what the person did from direct measure results

Adamo et al., 2009

How to overcome problems with indirect PA measures

• Researchers often use both indirect and direct PA measures given the problems with recall for children and youth
• Clinicians can combine PA questionnaire results with more direct, related measures
  – E.g., one’s confidence in a PA improvement based on questionnaire results will be increased if scores on a related test (e.g. motor skills) also improve

Adamo et al., 2009

Direct measurement of PA

• Information collected about activity type, frequency, duration over a set time period
• Total EE (PA) estimated from estimated EE for each activity
• Very feasible to use
• Children and some youth may have difficulty recalling what they did
  – Leads to PA over estimation (typical) or under estimation (if PA is not memorable)

Adamo et al., 2009
Can I use a direct PA measure in the clinic?

• Commercially available pedometers might be feasible if:
  – Funds to purchase them are available
  – Walking-related PA behaviors are of interest
  – The walking pattern of the target group is not greatly different from the “norm”
  – One has access to someone with expertise with the device

What determines the level of PA of children and youth?

Correlates of PA: Children and Youth

<table>
<thead>
<tr>
<th>Biological</th>
<th>Psychological</th>
<th>Social</th>
<th>Physical Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heredity</td>
<td>Self-efficacy</td>
<td>Parental attitudes and behaviours</td>
<td>Area of residence</td>
</tr>
<tr>
<td>Sex</td>
<td>Self-concept for activity</td>
<td>Peer attitudes and behaviours</td>
<td>Availability of facilities</td>
</tr>
<tr>
<td>Adiposity and nutrition</td>
<td>Perception of barriers to activity</td>
<td>Social economic status</td>
<td>Safety</td>
</tr>
<tr>
<td>Sexual maturity</td>
<td>Perception of physical competence</td>
<td>Time spend watching television</td>
<td>Days of week and holidays</td>
</tr>
<tr>
<td>Proficiency in motor skills</td>
<td>Attitudes towards activity</td>
<td>Time spend on computer games</td>
<td>Seasons of the year</td>
</tr>
<tr>
<td>Physical Fitness</td>
<td>Beliefs about activity</td>
<td>Cultural values</td>
<td>Climate</td>
</tr>
<tr>
<td>Health status</td>
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Malina et al., 2004

Why is PA important?

Physically active adults are healthier than inactive adults

• Based on data from 110,986 participants in the 2005 Canadian Community Health Survey...
• Men and women of all ages and body sizes who are sedentary have poorer health and more activity limitations and participation restrictions due to illness or injury and than physically active individuals

Herman et al., 2012

The more physically active, the better the health for adults with chronic health conditions

Warburton et al., 2006; Myers et al., 2002
PA is somewhat related to the health of children and youth who are typically developing

- Based on 86 published papers…
- Having a low level of PA increases the odds of being over weight or obese
- Aerobic exercise training decreases blood pressure in those who are hypertensive and improves the metabolic profile (ex. fasting insulin or insulin resistance) in those who are obese or overweight
- High impact PA increases bone mineral density
- Very physically active children and youth may have higher rates of injury than those who are inactive

Janssen and LeBlanc, 2010

Why is the relationship between PA and health not more pronounced in children and youth?

- Health problems related to physical inactivity like cardiovascular disease take years to manifest and thus are often not seen until adulthood
- Risk factors for these problems however, appear in childhood and are related to low levels of PA
  - E.g. Based on data from 1732 children and youth, the odds of having a cluster of risk factors for cardiovascular disease are increased in those with low levels of physical activity (Andersen et al., 2006)

With children and youth with COD, PA can have a positive influence on…

- Cardiorespiratory endurance
- Strength
- Anaerobic capacity
- Overall fitness
- Mobility/motor skills

- Perceived athletic competence
- Self-worth
- Perception of appearance
- Social participation
- Participation in PA
- Quality of life

McPherson et al., under review

What determines the effects of PA?

1. The PA dose (intensity, frequency and duration)
2. The level of impairment, need to have sufficient physical and mental ability to perform the PA at a sufficient dose without medical contraindications
3. The activity (what is done):
   - Physical training tends to be activity specific; e.g. better chance to improve walking if walking-type PA is performed

PA dose: American guidelines for children and youth

- 60 minutes/day, most PA should be aerobic
- This 60/day should include:
  - Vigorous-intensity aerobic activity ≥ 3 days/wk (intensity = 7-8/10, e.g. brisk walking)
  - Muscle strengthening activities ≥ 3 days/wk (e.g. push-ups)
  - Bone strengthening activities ≥ 3 days/wk (e.g., running, jumping)

http://www.cdc.gov/physicalactivity/everyone/guidelines/children.html

Exercise training guidelines for children with COD

- See the National Center on Health, Physical Activity, and Disability website for specific guidelines <http://www.ncpad.org/>
- Adapt guidelines for your target population/client
- Failure to see change is often due to too low a PA dose
- If not possible to have a sufficiently high PA dose, consider changing expectations away from fitness-related outcomes; participation alone, independent of intensity (EE), has its own benefits (as we have seen)!
How to help children and youth with COD become more physically active...

1. Provide long term support (6+ months), changing a behavior (habit) takes time!
2. Include goal setting and goal attainment strategies
3. Include peers if possible (children and youth are move physically active with peers than alone)
4. Include parents (parental support)

Based on data from adults (Dombrowski et al., 2012, McGtigue et al., 2006), TD children and youth (Kamath et al., 2008) and rehabilitation studies with children and youth the COD (Löwing et al., 2009, Novak et al., 2009, Sorsdahl et al., 2010).

Take home message

1. PA is good for health, including the physical and mental health of children and youth with childhood onset disabilities
2. Consider the PA dose when designing a PA program
3. Changing PA behavior takes time and needs support (expert, peers, parents)

Informal and Formal Adaptive Recreation Activities-ideas for all age groups, but wait.....

Welcome to Holland by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability in order 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 very 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". "Holland!" You say. "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 slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice Holland has tulips, Holland even has Rembrandt.

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 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.

At times, people in grief will often report more stages. Just remember grief is as unique as each patient and family.

Dr Elisabeth Kübler-Ross’s 5 stages of Grief

- Denial
- Anger
- Bargaining
- Depression
- Acceptance
We must all have DREAMS!

We all dream of being a sports star......
But only 2% of high school athletes ever receive a college athletic scholarship.

And only 1 in 13,000 high school athletes will ever receive a paycheck from a professional team.

Statistics from the National Collegiate Athletic Association

So, we may not become professional athletes....We can alter our dreams later.

- From those dreams we could one day work at the Olympics, World Series, Super Bowl, World Cup, Tour de France, etc.
- All these championships need a team of workers to function. There are many coaches, sportscasters, producers, photographers, nutritionists, etc. making the events happen.

Childhood Activities

What do you want/hope to get out of it?

What did you get out of playing sports or participating in a recreation activity when you were younger or even now?

Participation in Sports Leads to Success

- Disabled Sports USA released survey on sports and employment for people with disabilities.
- Results confirmed belief that participation in sports improves quality of life and leads to a higher employment rate of more than TWICE that of the general disabled population of working age (68% vs 33%)

- Harris Interactive, a well-known polling and research company polled 3 groups of people with disabilities to determine if there is a correlation between sports, recreation, and successful rehabilitation. They contacted the general population of people with disabilities, Disabled Sports USA members and Wounded Warriors who had received sports rehabilitation services from the Wounded Warriors Disabled Sports Project.
- Compared to the general disabled population, DS/USA members and Wounded Warriors active in regular sports programs report higher life satisfaction, are more sociable, enjoy better physical health and a healthier lifestyle.
- Participation in sports improves all aspects of life for a person with a disability and particularly employment prospects. Sports are vital to a successful rehabilitation employment and self-satisfaction.
- DS/USA, AIG, Wounded Warrior Project and the US department of Labor sponsored the survey.

We all can play at Camp Independence.
Camp Independence

- 7 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 command
- Must want to play sports

Motor and Self-Esteem Assessments

- Done Pre and Post Camp
- **Motor**: 1) Timed Up and Go  
  2) 6 Minute Walk Test  
  3) 25 Feet Walk/Run/Wheelchair  
  4) Hamstring Range of Motion  
  5) Balance Tests
- **Self-Esteem**: 1) Pediatric Outcomes Data Collection Instrument (PODCI)  
  2) Childhood Assessment of Participation and Enjoyment (CAPE)  
  3) Impact of Childhood Neurologic Disability Scale (ICNDS)

Psychological Benefits

- Campers report on surveys, “They feel more ready to play school and community sports.”
- A camper reported, she felt the camp program helped build her **self confidence**.
- Parent reported, “Camp Independence is a complete recreational and social experience. It has been life changing-All Positive.”

Every sport/game/recreational activity can be adapted in some way.

Google Search: over 2 million sites for Adaptive Sports

What about kids that are really involved physically?

What can they do if they use a wheelchair for mobility and can’t walk?

- Swimming
- Cycling
- Skiing
- Power Soccer

"For those youth who demonstrate a belief in themselves and have the support of family, peers, and support group leaders, the negative experiences of disability provoke the development of determination and persistence."

-Barbara Brockevelt, Ph.D.  
From the Delta Gamma Website
What measures have we used at the Camp Indep. program?

PODCI
CAPE
PEDs QL
Parent Satisfaction Survey

What is Success?
• How do you measure program success vs. individual success?
• Made up measures vs. standardized measures?

Quality of life and participation

1. Adolescents:
   Participation is key for QoL
   They are ADOLESCENTS with CP

2. Parents:
   Participation is important
   Barriers in services and opportunities

CHOICE


Participation and quality of life

- Relationships between leisure participation and quality of life:
  - Physical well-being
  - Self-perception
  - Psychosocial well-being
  - Social well-being
  - Cognition
  - Negative aspects of leisure participation


Determinants of participation

- Activity limitations
  - Law et al., 2004 – Physical disabilities Palisano et al., 2011 – CP, Prechot et al., 2011, Jones et al., 2011 – DCD, Gilbody et al., 2010, Law et al., 2011 – ADHD, Raghavendra et al., 2012 – Communication needs, Bulbul et al., 2010 – ASD, Arora et al., 2012 – MDD, C, Behaviors, Orsini et al., 2011 – Down Syndrome

- Extrinsic: Lack of alternatives, financial constraints, equipment, transportation, family characteristics (activity orientation, intellectual orientation, other elements), school setting

- Intrinsic: Child’s dependency, behavior, self-perception, motivation, preferences, gender (?), age

ICF domain:
Community, social and civic life

ASSESSMENT OF LEISURE PARTICIPATION
CHALLENGES TO EVALUATION OF PARTICIPATION IN LEISURE ACTIVITIES

ICF: Measuring participation

- No clear guidelines as to how to measure “involvement in life situations”
  - What exactly constitutes “involvement”?
  - Which situations are most relevant?
- “Sets of organized sequences of activities directed toward a personally or socially meaningful goal” (Coster and Khetani, 2008, p. 643).

These goals include:
- Sustenance and physical health
- Development of skills and capacities
- Enjoyment and emotional well-being

- When is it best to measure participation? Which domains? Which settings? Who should provide the information? Are we interested in extent of participation? Extent of restriction?

More challenges…

- Most measures give quantitative data about how much or how often the child is involved or restricted
  - Is more participation better?
  - What is ‘optimal participation’?
  - How active does the child have to be?
  - Does receiving assistance indicate lower levels of participation?
  - Practical aspects – Feasible? Time-wise? Responsive?

The Subjective experience is critical!

Broad measures of participation that include leisure

- Life Habits (LIFE-H) (5+ yrs)
  1. Accomplishment of life habits (difficulty and assistance)
  2. Level of Satisfaction
     - Daily activities
     - Social roles
   - Parent report (child could also respond)
   - Short (64 items, 30-45 min.) and long (197; 2-2.5 hr) forms
   - Intra-rater, inter-rater ICCs >.77 for 10/11 categories (lower for interpersonal)
   - Validity supported (no responsiveness studies)

- Child and Adolescent Scale of Participation (CASP)
  - Extent to which children participate in home, school and community activities
  - Parent report (5-9 yrs)
  - 20 items by age expected; somewhat restricted; very restricted; untutable (also not applicable)
  - 10-15 minutes
  - Test-retest ICC>0.94
  - Validity supported (no responsiveness studies)

Children’s Assessment of Participation & Enjoyment (CAPE)

- Purpose: Recreation and leisure activities outside mandated school activities (King et al, 2004)
  - Child’s perspective ± parental assistance
    - 6-21 years
    - 30-45 minutes to administer
  - Reliability ICC .64-.77
  - Validity supported
  - Responsiveness not evaluated

- 55 items in 5 domains
  - Recreational
  - Active physical
  - Social
  - Skill-based
  - Self-improvement
- Formal & Informal
- Scoring:
  - Diversity (how many)
  - Intensity (how often)
  - Enjoyment
  - With whom
  - Where

Objective

Subjective

Performance

Diversity

Intensity

With whom

Belonging

Control

Satisfaction

Meaning

Choice

enjoyment

Belonging
CAPE and PAC

Participation and Environment Measure for Children and Youth (Coster, Law & Bedell, 2010)

Settings (25 items)
- Home
- School
- Community

Parents report (15-20 min)
Free to download


TWO ASSESSMENTS OF GOAL SETTING

Preschooler Activity Card Sort (PACS)
- To develop an occupational profile from parent’s perspective
  - If limited participation is due to child, family or environmental barriers
  - 73 activity cards; 2-6 years of age; 30 minutes
  - Q-sort methodology (with parent)
  - Cards presented one at a time, and examiner asks if child participates in the activity
  - If yes, is it with assistance or environmental accommodation.
  - If no: discussion about potential barriers to participation.
  - 5 goals are identified by the parent
  - Excellent reliability (ICC=.91, test-retest r=.93), validity supported

Perceived Efficacy and Goal Setting Scale (PEGS)
- Adapted from “All About Me”
- 24 cards. 6-9 years of age
  - Self-care, school, leisure
  - Pictures reflecting either ‘more competently’ or ‘less competently’. Child picks which is most like them. Once selected, is it a little or a lot like them?
  - Child selects activities that would like to improve in: goal-setting
  - Versions that can be administered to caregivers and to teachers as well
  - Validity supported

Help or Hinder

Lack of adapted facilities and adequate transportation were not significant obstacles perceived by parents in of younger children (St-Laurent & Émond, 2006; PALS).

BUT very relevant for parents of adolescents (Shikako-Thomas et al., 2013).
**Intervention**

**Child**
- Leisure as objective X
- Leisure as strategy
- Preferences
- Self-perception → internal control
- Cognition → ability to suspend reality
- Intrinsic motivation
  - Negative reaction to failure, mastery pleasure

**Family**
- Preferences
- Cultural background
- Information
- Resources
- Environment
- Independence, moral-religious orientation

**Environment**
- Architecture
- Resources
- Community
- Transportation
- Social supports
  - Peers, family, others!

**Policy**
- Information
  - What is available?
    - National recreation statement
  - Leveling the playing field
- Advocacy
- Evidence-based practice
- Social justice, human rights
- Policies in Canada
  - Accessibility
  - Leisure companion
  - Adapted sports supports

**Programs**

- Developing a program
  1. Identify mediators of change (predictors)
  2. Select a theoretical model
  3. Select intervention techniques and specify pathways of change (what activities and behaviour change techniques can be used to target predictors?)
  4. Operationalize intervention (how can be more acceptable for different stakeholders?)
    - *(Kolehmainen et al., 2011)*
- F-words approach:
  - Fitness, function, friends, family, fun

**Let’s talk!**

In developing programs for play, leisure, physical activities participation

A) What works best for you?
B) What were the barriers you found?
Take Home Messages

• THINK and ACT out of the box!

• What can I do??

• Keep leisure in mind, ask the question, and have fun!

“Promise me you’ll always remember: You’re braver than you believe and stronger than you seem and smarter than you think.”
- Christopher Robin to Pooh

“Remember that all things are possible—optimism is meant to be shared. If you pass the word, you will help someone believe it, too.”
- Barbara Milo Ohrbach

Thank You!!

If you have any questions, comments or suggestions please contact us!
You can reach Jennifer Miro via email at jem0061@bjc.org or office 314.454.2604

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