CanChild Webinar (April 13, 2012): The Participation and Environment Measure for Children and Youth (PEM-CY) – An innovative measure for home, school, and community

The Participation and Environment Measure for Children and Youth (PEM-CY)
An innovative measure for home, school, and community

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Assistant Professor, McGill University

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- Wendy Coster, Ph.D., OTR/L, FAOTA
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- Rachel Teplicky, M.Sc.
- Chia-Yu Lin, M.Sc.

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Learning Objectives

1. To describe the development of the Participation and Environment Measure for Children and Youth (PEM-CY).
2. To describe the psychometric properties (reliability and validity) of the PEM-CY.
3. To communicate how scores obtained from the PEM-CY provide profiles of children’s participation in home, school, and community environments.
4. To discuss implications (both clinical and research) and future directions of PEM-CY

Background and Rationale

Based on the recent World Report on Disability (WHO, 2011)...

- More than one billion people, or 15% of the world’s population, live with some form of disability.
- Nearly 200 million individuals experience considerable difficulties in functioning.

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POLL #1

According to the World Report on Disability (WHO, 2011), how many children aged 0-14 are estimated to experiencing moderate or severe disability?

A. 93 Million Children
B. 75 Million Children
C. 66 Million Children
D. 49 Million Children

Approximately 93 million children aged 0-14 experiencing moderate or severe disability.
Background and Rationale (con’t)

• “Participation reflects the extent of engagement in the full range of activities that accomplish a larger goal (caring for one’s hygiene; clothing oneself; dining with family)” (Coster & Khetani, 2008).

• Participation in daily activities is an important outcome for children and youth. Environmental factors can act as supports or barriers to child’s participation. But...

How can Participation and Environment be measured?

Challenges in Measuring Participation and Environment

• Few available measures of children’s participation and environment that are grounded in ICF and suitable for use in large-scale research

• Ambiguity in ICF-CY about how to define participation and environment

• Family perspectives are often excluded in the design of measures
Challenges Bring Opportunities

There are unique opportunities for researchers, service providers, families and other stakeholders to benefit from new measures of children’s participation and environment that:

- Are suitable for population-level research (i.e., short, can be filled out independently)
- Are comprehensive (i.e., capture all relevant settings, activities, and factors)
- That account for the viewpoints of children and youth of diverse ages, disabilities, and backgrounds

DEVELOPMENT OF PEM-CY

To develop a population-based measurement tool with information being gathered via parent-report.
Gathering Parent Perspectives on the Meaning of Participation...

1. What do parents perceive to be the **important types of activities** in which children and youth with disabilities participate?

2. What do parents identify as the **types of environmental factors** that support or hinder a child’s participation in important life situations?

3. **How do parents appraise** their children’s participation and the environmental supports and barriers to participation?

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Sample Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Disability Sample (n = 24)</th>
<th>No Disability Sample (n = 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>BU</td>
<td>McMaster</td>
</tr>
<tr>
<td>Respondent Mother</td>
<td>14</td>
<td>9</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian (Not Hispanic)</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Black</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Respondent Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate Degree</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>College Degree</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Some College</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>High School / Less</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
Implications of Study Findings for PEM-CY Design

- Incorporate parents’ descriptions of relevant activities and factors in home, school, and community settings
  - Include descriptions not depicted in the ICF-CY: child factors, activity demands, safety, available and adequate resources

- Capture ways that parents understand and judge participation
  - Participation is about frequency and engagement/involvement
  - Whether a parent desires change in their child’s participation matters

- Explicitly link participation and environment in the same measure (“folding in”)

- Ask about how parents promote participation in home, school, & community settings (i.e., their strategies)

PEM-CY

- Parent-report - takes about 30 minutes
- 3 sections: Home (10 items), School (5 items), and Community (10 items)
- Each section asks about participation and environment
  - Participation Questions:
    - How often: 8-point scale, from never (0) to daily (7)
    - How involved: 5-point scale, from minimally involved (1) to very involved (5)
    - Desire for change: Yes or No, along with 5 options to clarify the type(s) of change desired
  - Environment Questions:
    - Environmental factors and activity demands: four options including, not an issue, usually helps, sometimes helps/sometimes makes harder, usually makes harder
    - Resources: four options including, not needed, usually yes, sometimes yes/sometimes no, usually no
- We ask about parent strategies to promote participation for each setting
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**Participation and Environment**

**HOME Participation**

1) Computer and video games
2) Indoor play and games (e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)
3) Arts, crafts, music, and hobbies (e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, cooking for fun)

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### Participation & Environment: HOME Participation

<table>
<thead>
<tr>
<th>A) Typically, how often does your child participate in 1 or more activities of this type?</th>
<th>B) Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities?</th>
<th>C) Would you like your child’s participation to change in this type of activity?</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHECK ONE RESPONSE</td>
<td>CHECK ONE RESPONSE</td>
<td>IF YES, CHECK ALL THAT APPLY</td>
</tr>
</tbody>
</table>

---

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**HOME Environment**

<table>
<thead>
<tr>
<th>Do the following things help or make it harder for your child to participate in activities at home?</th>
<th>Not at all</th>
<th>Usually helps</th>
<th>Sometimes helps, sometimes makes harder</th>
<th>Usually makes harder</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The physical layout or amount of space and furniture in your home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. The sensory qualities of the home environment (e.g., amount and/or type of sound, light, temperature, textures of objects)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. The physical demands of typical activities in the home (e.g., strength, endurance, coordination)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. The cognitive demands of typical activities in the home (e.g., concentration, attention, problem-solving)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. The social demands of typical activities in the home (e.g., communication, interacting with others)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Your child’s relationships with family members in the home (e.g., siblings, parent, grandparent)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. The attitudes and actions of babysitters, therapists, and other professionals who care for your child at home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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VALIDATION OF PEM-CY

To examine the psychometric properties (reliability and validity) of PEM-CY

From May – October 2010

Date Collection:
- A web-based version of PEM-CY was developed, and hosted on a secure website
- Eligibility Criteria:
  - Self-identify as a parent or legal guardian of the child
  - Able to read English
  - Child was between 5 and 17 years of age at the time of enrolment
- Every 5th (later 3rd) participant was invited to participate in the test-retest component

Data Analysis:
- Internal consistency of the Participation Frequency, Involvement, Change, and Environment Scales was examined using Cronbach’s alpha
- Intraclass correlations were computed to examine consistency and agreement of scores across the retest periods.
- Correlations were conducted to examine the association between extent of desire for change and perceived supportiveness of the environment

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### Sample Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Respondent</strong></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>519 (90)</td>
</tr>
<tr>
<td>Father</td>
<td>44 (8)</td>
</tr>
<tr>
<td>Guardian</td>
<td>9 (2)</td>
</tr>
<tr>
<td><strong>Annual Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;40,000</td>
<td>65 (11)</td>
</tr>
<tr>
<td>40,000 – 80,000</td>
<td>137 (24)</td>
</tr>
<tr>
<td>&gt;80,000</td>
<td>354 (62)</td>
</tr>
<tr>
<td><strong>Nationality</strong></td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>213 (37)</td>
</tr>
<tr>
<td>Canadian</td>
<td>363 (63)</td>
</tr>
<tr>
<td><strong>Child Age (mean)</strong></td>
<td>11.2</td>
</tr>
<tr>
<td><strong>Child’s Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>311 (54)</td>
</tr>
</tbody>
</table>

### Child Race / Ethnicity

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian (Not Hispanic)</td>
<td>466 (81)</td>
</tr>
<tr>
<td>African-American</td>
<td>19 (3)</td>
</tr>
<tr>
<td>Latin-American or Hispanic</td>
<td>10 (2)</td>
</tr>
<tr>
<td>South Asian</td>
<td>15 (2)</td>
</tr>
<tr>
<td>Other / Missing</td>
<td>49 (8)</td>
</tr>
</tbody>
</table>

### Disability Status

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability</td>
<td>282 (49)</td>
</tr>
<tr>
<td>No Disability</td>
<td>294 (51)</td>
</tr>
</tbody>
</table>

### Top 5 Parent-Reported 1st Diagnosis in Disability Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Delay</td>
<td>71 (25.6)</td>
</tr>
<tr>
<td>Orthopaedic Impairment</td>
<td>53 (19.1)</td>
</tr>
<tr>
<td>Emotional Impairment</td>
<td>24 (8.7)</td>
</tr>
<tr>
<td>Speech/Language Impairment</td>
<td>23 (8.3)</td>
</tr>
<tr>
<td>Intellectual Delay</td>
<td>22 (7.9)</td>
</tr>
</tbody>
</table>

How Summary Scores were Obtained

For each setting (home, school, community):

• **Participation Frequency** (% maximum possible or % never)
  - Sum of all ratings except “never” responses, divided by number of ratings
  - % never responses on frequency scale

• **Participation Involvement** (average of items – range = 0-5)
  - Average of all items in which child participated

• **Participation Desire for Change** (% yes responses)
  - Number of ‘yes, change’ responses, divided by total number of responses

• **Environmental Supportiveness** (% maximum possible)
  - Sum of all ratings divided by number of items rated


How does the PEM-CY Perform?

• **Internal consistency:** moderate to very good
  - Participation Frequency: 0.59 to 0.70
  - Participation Involvement: 0.72 to 0.83
  - Environmental Supportiveness: 0.67 to 0.91

• **Test-retest reliability:** moderate to very good
  - Participation Frequency: 0.58 to 0.84
  - Participation Involvement: 0.69 to 0.76
  - Desires Change: 0.76 to 0.89
  - Environmental Supportiveness: 0.85 to 0.95

• **Negative association between desire for change and environmental supportiveness** (-0.42 to -0.59)
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**RECENT APPLICATIONS**

To communicate how scores obtained from the PEM-CY provide profiles of children’s participation in home, school, and community environments

**Ways of Analyzing Data from PEM-CY**

- Descriptive analyses of responses **across settings**:
  - E.g., Participation patterns of children with and without disabilities in home vs. school vs. community settings

- Descriptive analyses of responses **within a setting**:
  - E.g., Home participation patterns
  - E.g., Impact of home environment on participation
  - E.g., Strategies used to promote participation at home
Children and youth with disabilities are often more limited in their participation than children and youth without disabilities. When their PEM-CY scores were being compared across settings (home, school & community), which PEM-CY score reflects the LARGEST difference between the two groups?

A. Participation Frequency  
B. Participation Involvement  
C. Desire for Change  
D. Environmental Supportiveness

The largest differences (effect sizes) were found in the Environment Supportiveness scores across all settings!
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**PEM-CY Summary Scores – Home Setting**

<table>
<thead>
<tr>
<th>PEM-CY Scores</th>
<th>HOME</th>
<th>Disability Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Never Participates</td>
<td>14.0 (20.1)</td>
<td>1.8 (4.3)</td>
</tr>
<tr>
<td>Participation Frequency</td>
<td>83.0 (11.6)</td>
<td>88.0 (7.2)</td>
</tr>
<tr>
<td>Participation Involvement</td>
<td>3.4 (0.8)</td>
<td>3.8 (0.5)</td>
</tr>
<tr>
<td>Desires for Change</td>
<td>67.1 (26.5)</td>
<td>53.5 (25.9)</td>
</tr>
<tr>
<td>Environmental Supportiveness</td>
<td>70.1 (14.9)</td>
<td>86.4 (11.5)</td>
</tr>
</tbody>
</table>

Differences between the children and youth with and without disabilities were significantly different for all participation and environment scores ($p < 0.01$).

**Percentage of children who never participate in home-based activities**

- Computer and video games
- Indoor play and games
- Arts, crafts, music and hobbies
- Watching TV, videos, and DVDs
- Getting together with other people
- Socializing using technology
- Household Chores
- Personal care management
- School Preparation
- Homework
- Never participate in home-based activities

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### Mean participation frequency in home-based activities

![Radar chart showing mean participation frequency in home-based activities for children with and without disabilities.](image)

- **Computer and video games**
- **Indoor play and games**
- **Homework**
- **School Preparation**
- **Personal care management**
- **Household Chores**
- **Socializing using technology**

### Percentage of parents who desire change in home-based activities

![Radar chart showing percentage of parents who desire change in home-based activities for children with and without disabilities.](image)

- **Computer and video games**
- **Indoor play and games**
- **Homework**
- **School Preparation**
- **Personal care management**
- **Household Chores**
- **Socializing using technology**

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PEM-CY Summary Scores – School Setting

<table>
<thead>
<tr>
<th>PEM-CY Scores</th>
<th>SCHOOL</th>
<th>Disability Mean (SD)</th>
<th>ES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Never Participates</td>
<td>33.6 (24.52)</td>
<td>16.3 (15.5)</td>
<td>0.9</td>
</tr>
<tr>
<td>Participation Frequency</td>
<td>65.3 (15.7)</td>
<td>72.1 (10.8)</td>
<td>0.5</td>
</tr>
<tr>
<td>Participation Involvement</td>
<td>3.4 (1.0)</td>
<td>4.2 (0.7)</td>
<td>1.0</td>
</tr>
<tr>
<td>Desires for Change</td>
<td>70.4 (29.8)</td>
<td>38.82 (31.9)</td>
<td>1.0</td>
</tr>
<tr>
<td>Environmental Supportiveness</td>
<td>72.9 (12.4)</td>
<td>87.6 (10.7)</td>
<td>1.3</td>
</tr>
</tbody>
</table>

Differences between the children and youth with and without disabilities were significantly different for all participation and environment scores (p < 0.01).
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**Percentage of parents who desire change in school-based activities**

- Classroom activities
- Special roles at school
- Field trips and school events
- Getting together with peers outside of class
- School-sponsored teams, clubs and organization

**Percentage of parents who perceived the item as a barrier to school-based participation**

- Physical layout
- Sensory quality
- Money
- Time
- Weather conditions
- Physical demands of activity
- Cognitive demands of activity
- Social demands of activity
- Attitudes
- Relationships with peers
- Safety
- Public transportation
- Personal transportation
- Programs and services
- Policies and procedures
- Information
- Supplies

**PEM-CY Summary Scores – Community Setting**

<table>
<thead>
<tr>
<th>PEM-CY Scores</th>
<th>COMMUNITY</th>
<th>Disability Mean (SD)</th>
<th>Yes</th>
<th>No</th>
<th>ES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never Participates</td>
<td>41.4 (20.1)</td>
<td>23.4 (14.8)</td>
<td>1.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participation Frequency</td>
<td>54.5 (13.2)</td>
<td>63.3 (9.9)</td>
<td>0.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participation Involvement</td>
<td>3.5 (0.9)</td>
<td>4.2 (0.6)</td>
<td>0.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Desires for Change</td>
<td>63.2 (26.0)</td>
<td>38.0 (26.2)</td>
<td>1.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environmental Supportiveness</td>
<td>66.4 (14.2)</td>
<td>88.1 (10.9)</td>
<td>1.7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Differences between the children and youth with and without disabilities were significantly different for all participation and environment scores ($p < 0.01$).

**Percentage of children who never participate in community-based activities**

- Neighborhood outings
- Overnight visits or trips
- Community events
- Organized physical activity
- Unstructured physical activities
- Classes and Lessons
- Organizations, groups, clubs and volunteer or leadership activities
- Religious or spiritual gatherings and activities
- Getting together with other children in the community
- Working for pay

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**Percentage of parents who perceived the item as a barrier to community-based participation**

- Disability
- No Disability

**Percentage of parents who perceived the item as a support to community-based participation**

- Disability
- No Disability

**FUTURE DIRECTIONS**

*To discuss implications (both clinical and research) and future directions of PEM-CY*

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**Clinical & Research Implications**

- For parents to gain valuable information about their child’s participation and what supports/limits participation
- For service providers to describe a child’s strengths and limitations, define therapeutic goals, and identify strategies to improve participation
- For programs and services to identify the type of and the prevalence of participation issues that children and youth within their program are encountering and to identify potential environmental supports and barriers that could help inform program improvement and resource allocation
- For researchers to use in large-scale population-based research studies which can examine the similarities and differences in participation across groups of children and youth, and across environments that differ in geography, resources, or organization
Future Directions and Next Steps

**Development of Participation and Environment Knowledge Hub:**

- **Easy-to-use, readily available, and free-of-charge** materials for families, service providers, and researchers
- **Educational Modules** on Participation and Environment for various stakeholder groups
- **PEM-CY Package:**
  - Downloadable PEM-CY with automated scoring and reporting functions
  - Administration Guidelines
  - Translations (French and Spanish)

Future Research

- Examine differences in participation and environmental supports/barriers in relation to diagnosis, and type and severity of impairment.
- Examine predictors of participation (demographic factors and environmental supports and barriers).
- Further validate with larger and more diverse sample in terms of SES, race/ethnicity, geographic region
**Contact Us!**

- We are planning to post the PEM-CY (including administration guidelines and scoring) on the CanChild website in Fall 2012. Please visit our study webpage for updated information: [http://www.canchild.ca/en/ourresearch/pep.asp](http://www.canchild.ca/en/ourresearch/pep.asp)

- For more information about availability of the PEM-CY, please contact:
  - Chia-Yu Lin, Research Coordinator, Participation and Environment Project
  - Phone: 905-525-9140, ext.27548
  - E-mail: linchia@mcmaster.ca

**References**


