Participation in occupations: Profiles for children with and without disabilities

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Background and Rationale

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

• Approximately 93 million children aged 0-14 experience a moderate or severe disability.

• “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 has a positive impact on children’s health and well-being but research has shown that children and youth with disabilities are often restricted in their participation, particularly at school and in the community.

• Environmental factors can act as supports or barriers to child’s participation.

Research Questions

• How is the participation of children with and without disabilities similar and different in home, school and community settings?

• What environmental factors support and challenge participation within the home, school and community for children with and without disabilities?

Methods

- Data collected from parents using an online survey version of the Participation and Environment Measure for Children and Youth (PEM-CY)
- Newly developed measure that combines assessment of participation and the environment in three settings: home, school and community
- Completed by parent or caregiver in approximately 30 minutes
- Found to be a reliable and valid measure for children and youth aged 5 to 17 years (Coster et al, 2011)

PEM-CY

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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)

Data Analyses

- Two-way ANOVAs were used to examine differences in PEM-CY summary scores between children with and without disabilities
- Descriptive statistics were computed and radar plots were developed to enable visual analysis of the data at the item level

Sample Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>519 (90)</td>
</tr>
<tr>
<td>Father</td>
<td>44 (8)</td>
</tr>
<tr>
<td>Nationality</td>
<td></td>
</tr>
<tr>
<td>Canadian</td>
<td>363 (62)</td>
</tr>
<tr>
<td>USA</td>
<td>213 (37)</td>
</tr>
<tr>
<td>Child Age (mean)</td>
<td>11.2</td>
</tr>
<tr>
<td>Child’s Gender - Male</td>
<td>311 (54)</td>
</tr>
<tr>
<td>Disability Status</td>
<td></td>
</tr>
<tr>
<td>Disability</td>
<td>262 (46)</td>
</tr>
<tr>
<td>No Disability</td>
<td>294 (51)</td>
</tr>
<tr>
<td>Top 3 Parent-Reported 1st Diagnosis in Disability Sample</td>
<td></td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>75 (12.6)</td>
</tr>
<tr>
<td>Orthopaedic Impairment</td>
<td>50 (8.3)</td>
</tr>
<tr>
<td>Emotional Impairment</td>
<td>24 (4.1)</td>
</tr>
</tbody>
</table>


PEM-CY Summary Scores

- Differences between the children and youth with and without disabilities were significantly different for all participation and environment summary scores ($p < 0.01$) across all settings
- Effect sizes range from 0.5 to 1.7
- For each of the settings:
  - The smallest differences between the two groups were found for the Participation Frequency summary score
  - The largest differences were found for the Never Participates and the Environmental Supportiveness summary scores

PEM-CY – Item Level Analysis

Never participates in the activity

Percentage of children who never participate in home-based activities


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

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

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

- Neighborhood outings
- Community events
- Organized physical activity
- Unstructured physical activities
- Getting together with other children in the community
- Religious or spiritual gatherings and activities
- Organizations, groups, clubs, and volunteer or leadership activities

**PEM-CY – Item Level Analysis**

*Participation frequency at home, school and in the community*

**PEM-CY – Item Level Analysis**

*Participation involvement* at home, school and in the community

**Mean involvement in home-based activities**

**Mean involvement in school-based activities**


**Mean involvement in community-based activities**

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

**Participation & Environment**

**PEM-CY – Item Level Analysis**

*Environmental barriers to participation at home, school and in the community*

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

- **physical layout**
- **additional help needed**
- **money**
- **time**
- **information**
- **supplies**
- **physical demands of activity**
- **cognitive demands of activity**
- **relationships with family members**
- **attitudes**
- **social demands of activity**
- **sensory quality**
- **physical demands of activity**


Results

- Children with disabilities participate in significantly fewer occupations in their home, community and at school.
- However, from a clinical perspective, participation frequency ratings on most items are not that different between groups.
- Greater differences in participation are often seen on more complex occupations (e.g., household chores, homework).
- Differences are also seen in occupations that are more social in nature (e.g., getting together with peers outside class and in the community).
- Environmental supports and barriers are ranked similarly in both groups, but are significantly different in level.

Clinical & Research Implications

- Using the PEM-CY opens the door for discussion about participation-focused goals and intervention, with a particular on more complex, social occupations
- Learning about supports in all three settings can provide OTs and parents with potential strategies to implement in settings where barriers are encountered
- Expertise in activity and environmental adaptation positions OTs to assist parents in meeting the specific demands of home, school and community settings to support child and youth participation

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)
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

- 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: linchial@mcmaster.ca

References


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