Participation profiles at home, school and in the community: A comparison of children and youth with and without disabilities

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Disclosure Information
Speaker Name: Dr. Mary Law
Disclosure of Relevant Financial Relationships
I have no financial relationships to disclose.
Disclosure of Off-Label and/or investigative uses:
I will not discuss off label use and/or investigational use in my presentation

Participation and Environment Measure for Children and Youth – PEM-CY
• Newly developed measure that assesses participation and environmental support/barriers in three settings: home, school and community
• 25 items completed by parent or caregiver in 30 minutes
• Found to be reliable and valid for children and youth 5 to 17 years (Coster et al, 2011)
  — Internal consistency was 0.59 to 0.91
  — Test-retest reliability had ICC = 0.58 to 0.95
  — Construct validity supported by clinically important and statistically significant differences between groups of children with and without disabilities across all participation and environment scales


PEM-CY Example Participation Items

Home
- Indoor play and games; Socializing using technology; Personal care management

School
- Classroom activities; School-sponsored teams, clubs and organizations

Community
- Neighborhood outings; Organized physical activities; Getting together with other children in the community

Scoring Dimensions
- Frequency
- Level of involvement
- Desire for change


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>263 (46)</td>
</tr>
<tr>
<td>No Disability</td>
<td>294 (51)</td>
</tr>
<tr>
<td>Top 2 Parent-Reported 1st Diagnosis in Disability Status</td>
<td></td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>75 (12.5)</td>
</tr>
<tr>
<td>Orthopaedic Impairment</td>
<td>50 (16.1)</td>
</tr>
<tr>
<td>Emotional impairment</td>
<td>24 (8.7)</td>
</tr>
</tbody>
</table>

Results

- Children with disabilities participate in significantly fewer activities 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 activities (e.g., household chores, homework).
- Differences are also seen in activities 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.
- Desire for change responses can be used to guide client-centered interventions.
- Service providers can lay groundwork for future independent living by working with children and youth on more complex, social activities.
- Learning about supports in all three settings can offer service providers and parents potential strategies to implement in settings where barriers are encountered.


Contact Us!
- We will be posting the PEM-CY on the CanChild website in late 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:
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References


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