

Law, M., Coster, W., Bedell, G., Anaby, D., Teplicky, R., & Khetani, M. (June 2012). *Participation in occupations: Profiles for children with and without disabilities*. Research paper presented at the Canadian Association of Occupational Therapists Conference, Quebec City, QC.

**Participation in occupations:
Profiles for children with and without disabilities**

Mary Law, Ph.D., OT Reg. (Ont.)
McMaster University

Wendy Coster, Ph.D., OTR/L, FAOTA
Boston University

Gary Bedell, Ph.D., OTR/L, FAOTA
Tufts University

Dana Anaby, Ph.D., BOT
McGill University

Rachel Teplicky, M.Sc., OT Reg. (Ont.)
McMaster University

Mary Khetani, Sc.D., OTR
Colorado State University

CAOT Conference 2012

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.

2

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?

3

Participation & Environment

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)

4

Participation & Environment

PEM-CY

HOME Participation

1) Computer and video games
2) Indoor play and games
3) Arts, crafts, music, and hobbies

5

Participation & Environment

- 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)

6

PEM-CY

HOME Environment

Participation & Environment

Do the following things help or make it harder for your child to participate in activities at home?

CHECK ONE RESPONSE (7)

	Not an issue	Usually helps	Sometimes helps, sometimes makes harder	Usually makes harder
1. The physical layout or amount of space and furniture in your home				
2. The sensory qualities of the home environment (e.g., amount and/or type of sound, light, temperature, textures of objects)				
3. The physical demands of typical activities in the home (e.g., strength, endurance, coordination)				
4. The cognitive demands of typical activities in the home (e.g., concentration, attention, problem-solving)				
5. The social demands of typical activities in the home (e.g., communication, interacting with others)				
6. Your child's relationships with family members in the home (e.g., siblings, parent, grandparent)				
7. The attitudes and actions of babysitters, therapists, and other professionals who care for your child at home				

7

Data Analyses

Participation & Environment

- 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

8

Sample Characteristics

Participation & Environment

Variable	N (%)
Respondent	
Mother	519 (90)
Father	44 (8)
Nationality	
Canadian	363 (63)
USA	213 (37)
Child Age (mean)	11.2
Child's Gender - Male	311 (54)
Disability Status	
Disability	282 (49)
No Disability	294 (51)
Top 3 Parent-Reported 1st Diagnosis in Disability Sample	
Developmental Delay	71 (25.6)
Orthopaedic Impairment	53 (19.1)
Emotional impairment	24 (8.7)

9

Participation & Environment

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

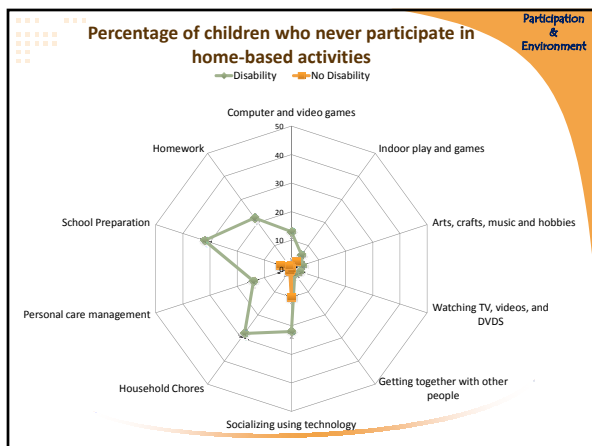
10

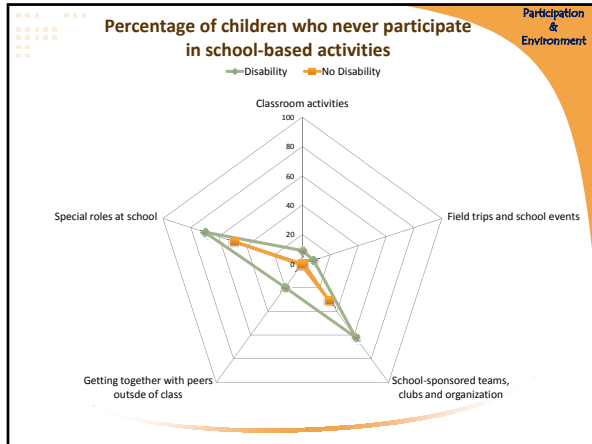
Participation & Environment

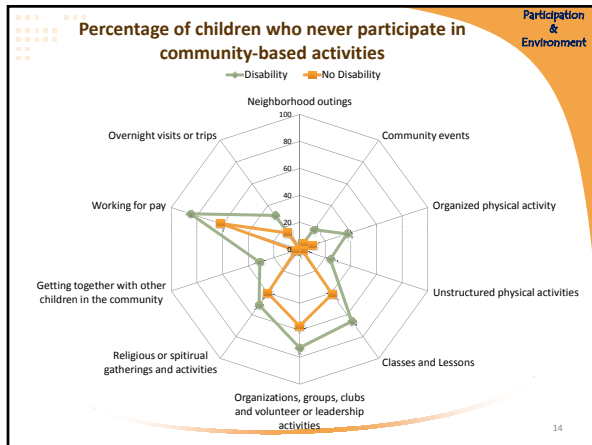
PEM-CY – Item Level Analysis

Never participates in the activity

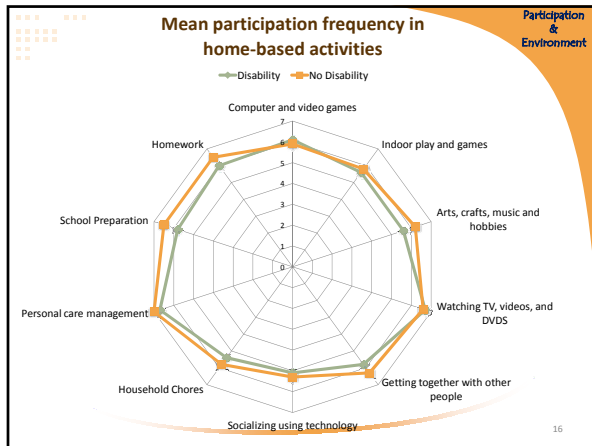
11

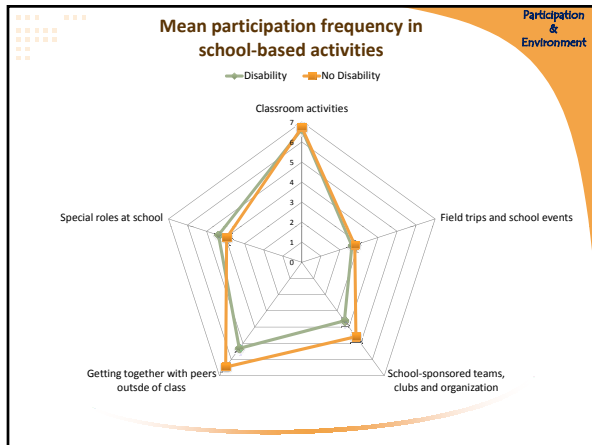


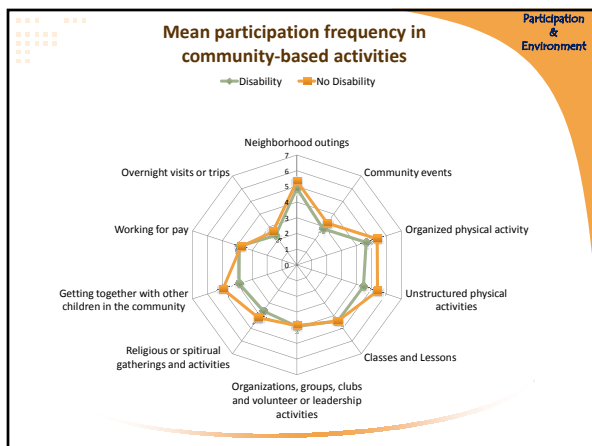


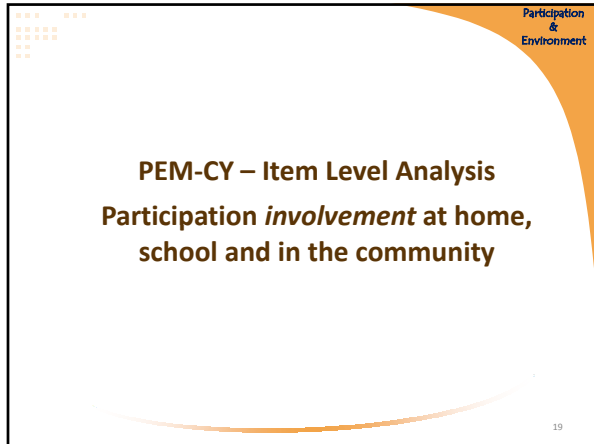


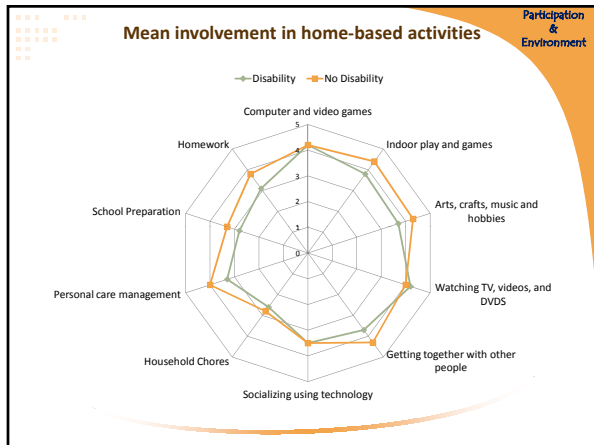
PEM-CY – Item Level Analysis
Participation frequency at home, school and in the community

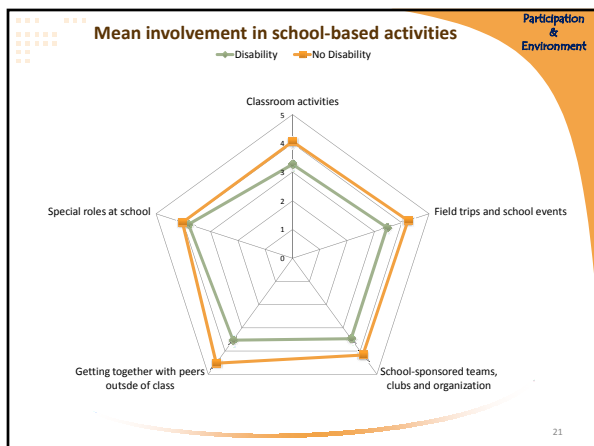


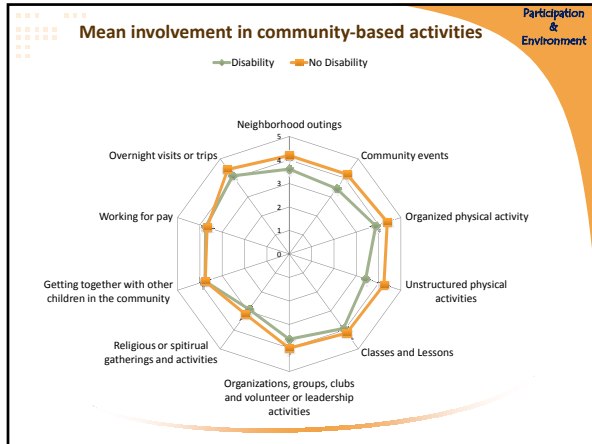




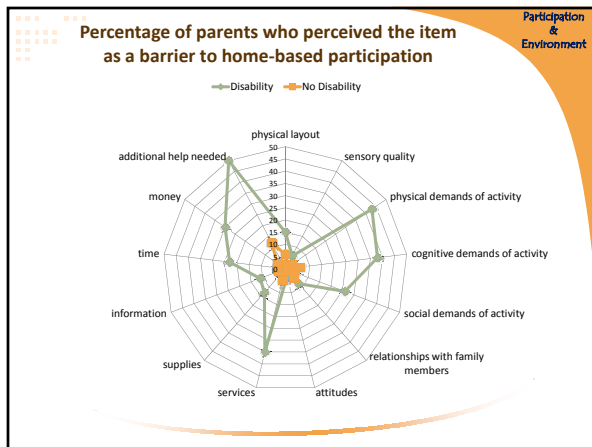


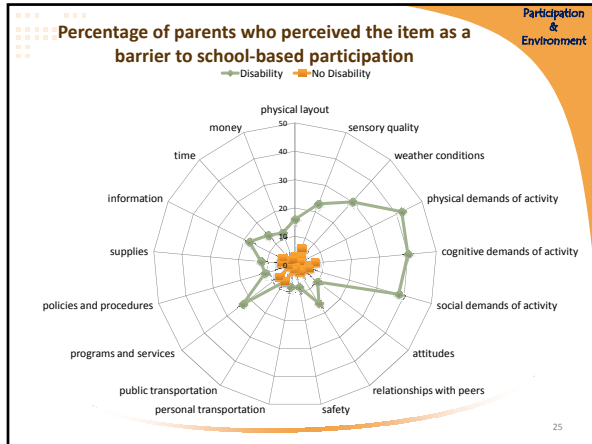


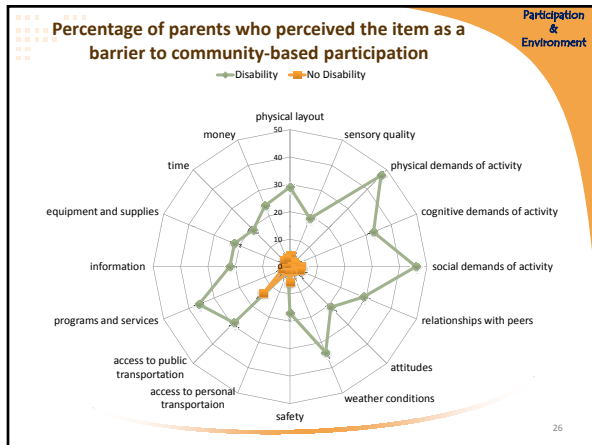




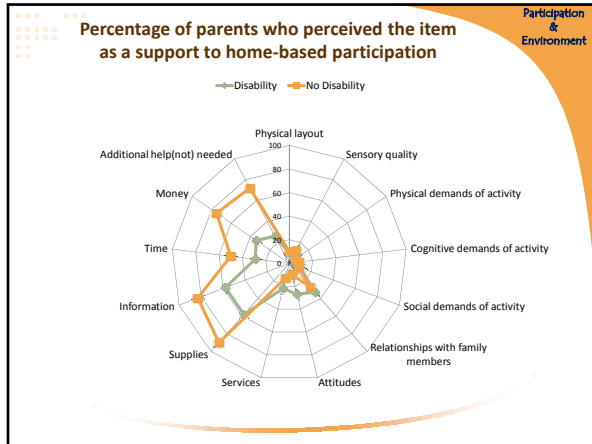
PEM-CY – Item Level Analysis
Environmental barriers to participation at home, school and in the community

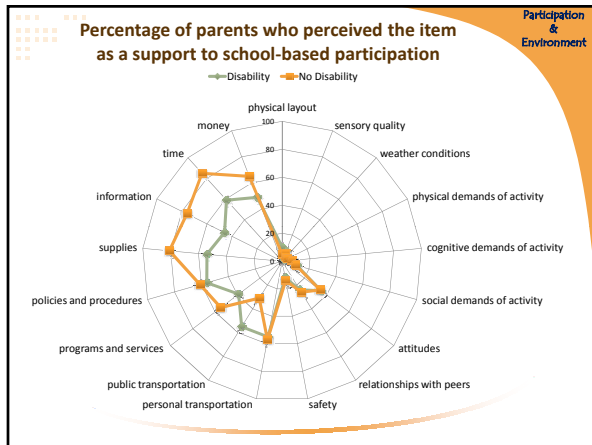


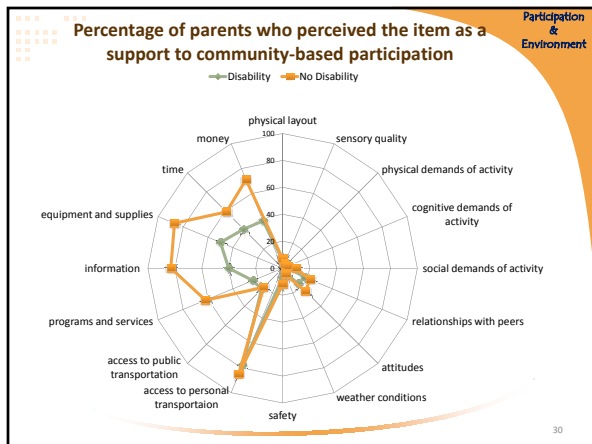




PEM-CY – Item Level Analysis
Environmental supports to participation at home, school and in the community







Participation & Environment

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.

31

Participation & Environment

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

32

Participation & Environment

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)



33

Law, M., Coster, W., Bedell, G., Anaby, D., Teplicky, R., & Khetani, M. (June 2012). *Participation in occupations: Profiles for children with and without disabilities*. Research paper presented at the Canadian Association of Occupational Therapists Conference, Quebec City, QC.

Participation
&
Environment

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: linchia@mcmaster.ca



34

Participation
&
Environment

References

Bedell, G. M., Coster, W. J., Law, M., Teplicky, R., Khetani, M. A., Lijtenquist, K., Gleason, K., Kao, Y.-C., Anaby, D., & Cousins, M. (April 2011). Participation and Environment Measure for Children and Youth (PEM-CY): Descriptive and Psychometric Findings. Poster presented at the American Occupational Therapy Association Conference, Philadelphia, PA.

Bedell, G. M., Khetani, M. A., Cousins, M., Coster, W. J., & Law, M. (2011). Parent perspectives to inform development of measures of children's participation and environment. *Archives of Physical Medicine and Rehabilitation*, 92, 765-773. doi: 10.1016/j.apmr.2010.12.029

Coster, W. J., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Lijtenquist, K., Gleason, K., & Kao, Y. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth (PEM-CY). *Developmental Medicine and Child Neurology*, 53(11), 1030-7. doi: 10.1111/j.1469-8749.2011.04094

Coster, W., & Khetani, M.A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability and Rehabilitation*, 30, 639-648.

Coster, W., Law, M., Bedell, G., Khetani, M.A., Cousins, M., & Teplicky, R. (2012). Development of the Participation and Environment Measure for Children and Youth: Conceptual basis. *Disability and Rehabilitation*, 34(3), 238-46. doi: 10.3109/09638288.2011.603017

World Health Organization (2001). *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: WHO.

World Health Organization (2011). *World Report on Disability*. Geneva, Switzerland: WHO.

Funding received from National Institute on Disability and Rehabilitation Research (NIDRR) and Canadian Institutes of Health Research (CIHR)

35
