



## The Participation and Environment Measure for Children and Youth (PEM-CY)

An innovative measure for home, school, and community

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

**Mary Law**, Ph.D., FCAOT, FCAHS  
Professor, McMaster University

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

**Mary Khetani**, Sc.D., OTR  
Assistant Professor, Colorado State University

**Dana Anaby**, Ph.D., BOT  
Assistant Professor, McGill University



CanChild Webinar Presentation – April 13<sup>th</sup>, 2012



## Research Team & Sponsors

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- Wendy Coster, Ph.D., OTR/L, FAOTA
- Mary Law, Ph.D., FCAOT, FCAHS
- Gary Bedell, Ph.D., OTR/L, FAOTA
- Mary Khetani, Sc.D., OTR
- Dana Anaby, Ph.D., BOT
- Rachel Teplicky, M.Sc.
- Chia-Yu Lin, M.Sc.

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



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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

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## 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 be experiencing moderate or severe disability?

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



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Approximately **93 million children aged 0-14** experiencing moderate or severe disability.

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## 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?**

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## 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

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## 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

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## DEVELOPMENT OF PEM-CY

*To develop a population-based measurement tool with information being gathered via parent-report.*

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## 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

Variable	Disability Sample (n = 24)		No Disability Sample (n = 17)
	BU	McMaster	Tufts
<b>Respondent Mother</b>	14	9	15
<b>Race/Ethnicity</b>			
Caucasian (Not Hispanic)	11	9	16
Black	2	0	0
Hispanic	1	0	1
Other	0	1	0
<b>Respondent Education</b>			
Graduate Degree	8	0	7
College Degree	4	3	8
Some College	1	5	2
High School / Less	1	2	0

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Variable	Disability Sample (n = 24)		No Disability Sample (n = 17)
	BU	McMaster	Tufts
<b>Child's Age</b>			
5-12	8	8	6
13-17	7	1	11
>18	0	3	0
<b>Child's Gender</b>			
Male	10	7	9
Female	5	5	8
<b>Primary Diagnostic Condition</b>			
Down Syndrome	2	3	N/A
ASD, Asperger's, PDD-NOS	7	2	N/A
Dyslexia, Learning Disability	2	1	N/A
ADD/ADHD	1	4*	N/A
Acquired Brain Injury	0	1	N/A
Other	3	1	N/A

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- ## What Parents Taught us about Children's Participation & Environment...
- **Important Activities:**
    - Parents identified **home, school, and community** activities
    - For the most part, there was consistency in responses **regardless of** whether child had disability or not
  - **Environmental Factors:**
    - Parents identified a **broader** range of environmental factors than what is reported in ICF
    - Parents identified factors specific to the **home, school, and community** settings
  - **Ways of appraising children's participation:**
    - Participation is a **multidimensional** construct
    - Experience of participation is **inextricably** linked with the environment
    - Appraising participation and environment naturally lends itself to a conversation about **parents' strategies to promote participation**
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## 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)

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## 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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HOME Participation

**A) Typically, how often does your child participate in 1 or more activities of this type?**

CHECK ONE RESPONSE

1) Every day  
2) Every week  
3) Every month  
4) Every 2 months  
5) Every 3 months  
6) Every 6 months  
7) Never

**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?**

CHECK ONE RESPONSE

1) Usually not involved  
2) Somewhat involved  
3) Usually involved

**C) Would you like your child's participation to change in this type of activity?**

IF YES, CHECK ALL THAT APPLY

1) Do more of this activity  
2) Do less of this activity  
3) Do more of other activities  
4) Do less of other activities  
5) Do not change  
6) Do not know

	A) Typically, how often does your child participate in 1 or more activities of this type?							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?			C) Would you like your child's participation to change in this type of activity?						
	1	2	3	4	5	6	7	1	2	3	1	2	3	4	5	6	7
1) Computer and video games																	
2) Indoor play and games <small>(e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)</small>																	
3) Arts, crafts, music, and hobbies <small>(e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, seeking for fun)</small>																	
4) Watching TV, videos, and DVDs																	
5) Getting together with other people <small>(e.g., interacting with peers, family, other house/guests)</small>																	
6) Socializing using technology <small>(e.g., telephone, computer)</small>																	
7) Household chores <small>(e.g., unloading, setting the dishwasher, cleaning rooms or other areas of the house, cooking, taking out the garbage, setting the table, caring for household pets)</small>																	
8) Personal care management <small>(e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup)</small>																	
9) School preparation (not homework) <small>(e.g., gathering materials, packing school bag, packing lunch, reviewing schedule)</small>																	
10) Homework <small>(e.g., daily reading, homework assignments, school projects)</small>																	

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**1) Computer and video games**

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**2) Indoor play and games**  
(e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)

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

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HOME Participation

**A) Typically, how often does your child participate in 1 or more activities of this type?**

CHECK ONE RESPONSE

**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?**

CHECK ONE RESPONSE

**C) Would you like your child's participation to change in this type of activity?**

IF YES, CHECK ALL THAT APPLY

	1) Daily	2) Four or five times a week	3) Three times a week	4) Two times a week	5) Once a week	6) Once in a while	7) Rarely or never	8) Never	9) Not applicable	1) Not at all	2) Slightly involved	3) Somewhat involved	4) Moderately involved	5) Very involved	1) No change desired	2) Do more of this type of activity	3) Do less of this type of activity	4) Do not change	
<b>1) Computer and video games</b> <small>(e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)</small>																			
<b>2) Indoor play and games</b> <small>(e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, seeking for fun)</small>																			
<b>3) Arts, crafts, music, and hobbies</b> <small>(e.g., interacting with peers, family, other household)</small>																			
<b>4) Watching TV, videos, and DVDs</b>																			
<b>5) Getting together with other people</b> <small>(e.g., telephone, computer)</small>																			
<b>6) Socializing using technology</b> <small>(e.g., interacting with peers, family, other household)</small>																			
<b>7) Household chores</b> <small>(e.g., ironing, sewing, the stove/oven, cleaning rooms or other areas of the house, cooking, taking out the garbage, setting the table, caring for household pets)</small>																			
<b>8) Personal care management</b> <small>(e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup)</small>																			
<b>9) School preparation (not homework)</b> <small>(e.g., gathering materials, packing school bag, packing lunch, reviewing schedule)</small>																			
<b>10) Homework</b> <small>(e.g., daily reading, homework assignments, school projects)</small>																			

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**A) Typically, how often does your child participate in 1 or more activities of this type?**

CHECK ONE RESPONSE

**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?**

CHECK ONE RESPONSE

**C) Would you like your child's participation to change in this type of activity?**

IF YES, CHECK ALL THAT APPLY

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HOME Environment

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

CHECK ONE RESPONSE

	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				

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

CHECK ONE RESPONSE

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

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8. Services in the home (e.g., therapists, tutors, etc.)
9. Supplies in the home (e.g., sports equipment, crafts supplies, reading materials, assistive devices or technology, picture or word schedules)
10. Information (e.g., about activities, services, programs)
11. Do you (and your family) have enough time to support your child's participation at home?
12. Do you (and your family) have enough money to support your child's participation at home?

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What are some things that you or other family members do that help your child participate successfully in activities at home?

PLEASE LIST UP TO 3 STRATEGIES

1.
2.
3.

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## VALIDATION OF PEM-CY

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

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## 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 5<sup>th</sup> (later 3<sup>rd</sup>) 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

Variable	N (%)
<b>Respondent</b>	
Mother	519 (90)
Father	44 (8)
Guardian	9 (2)
<b>Annual Household Income</b>	
<40,000	65 (11)
40,000 – 80,000	137 (24)
>80,000	354 (62)
<b>Nationality</b>	
USA	213 (37)
Canadian	363 (63)
<b>Child Age (mean)</b>	
	11.2
<b>Child's Gender</b>	
Male	311 (54)

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Variable	N (%)
<b>Child Race / Ethnicity</b>	
Caucasian (Not Hispanic)	466 (81)
African-American	19 (3)
Latin-American or Hispanic	10 (2)
South Asian	15 (2)
Other / Missing	49 (8)
<b>Disability Status</b>	
Disability	282 (49)
No Disability	294 (51)
<b>Top 5 Parent-Reported 1<sup>st</sup> Diagnosis in Disability Sample</b>	
Developmental Delay	71 (25.6)
Orthopaedic Impairment	53 (19.1)
Emotional Impairment	24 (8.7)
Speech/Language Impairment	23 (8.3)
Intellectual Delay	22 (7.9)

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## 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

Coster, W. J., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, 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


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## 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*

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## 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

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**POLL #2**

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



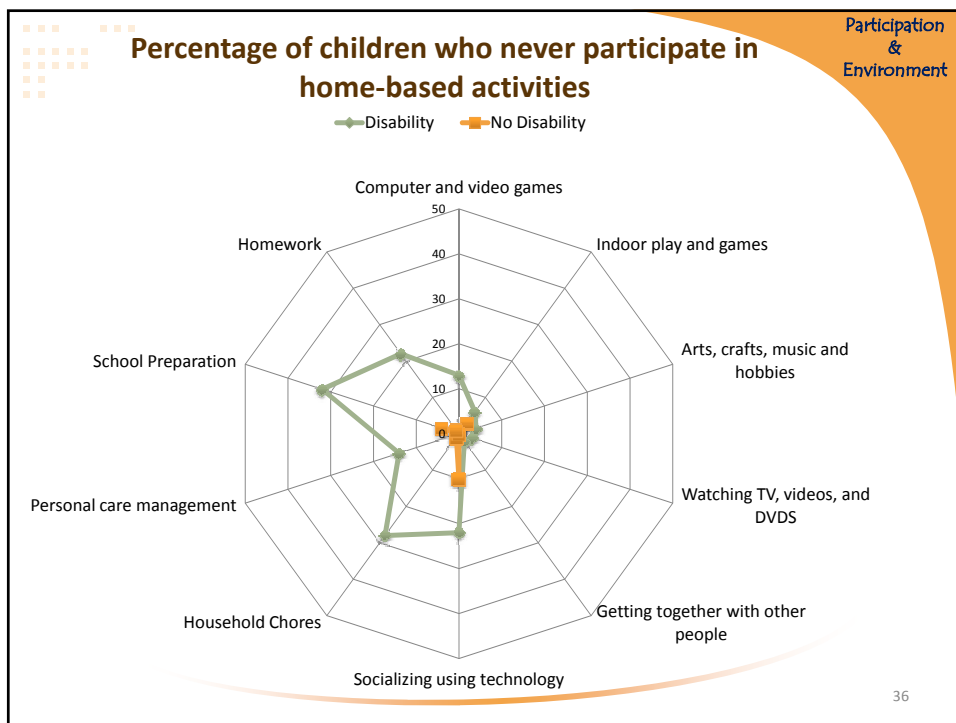
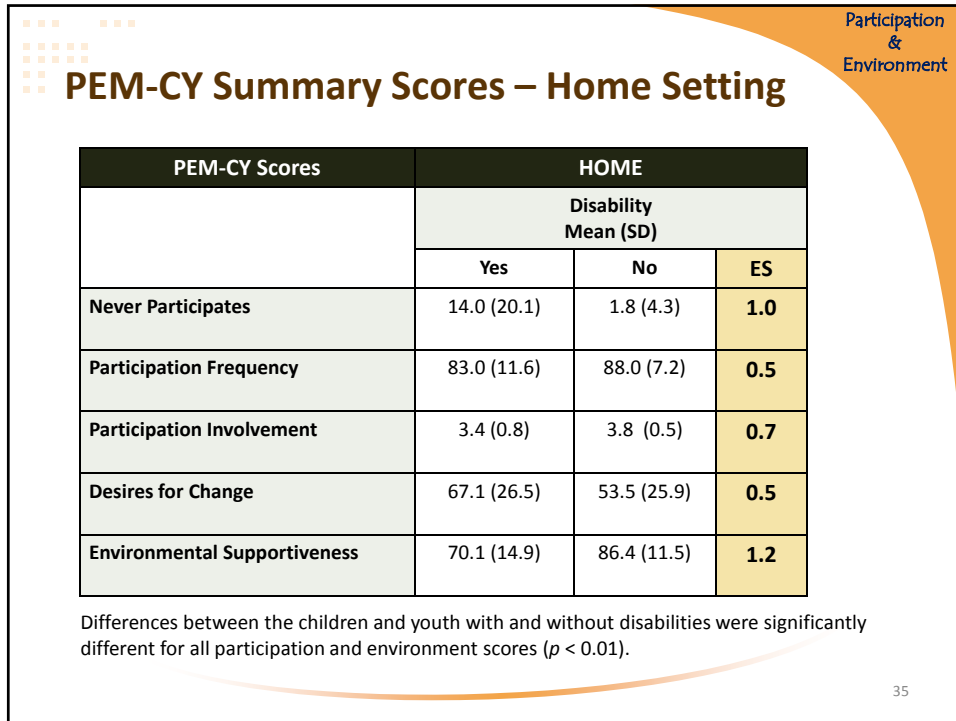
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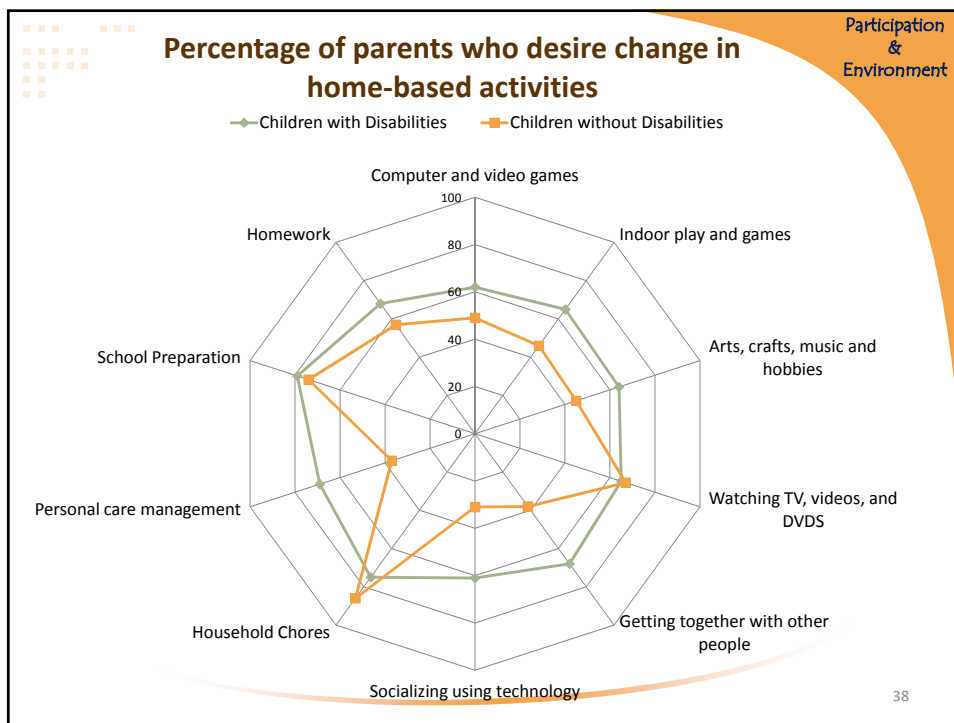
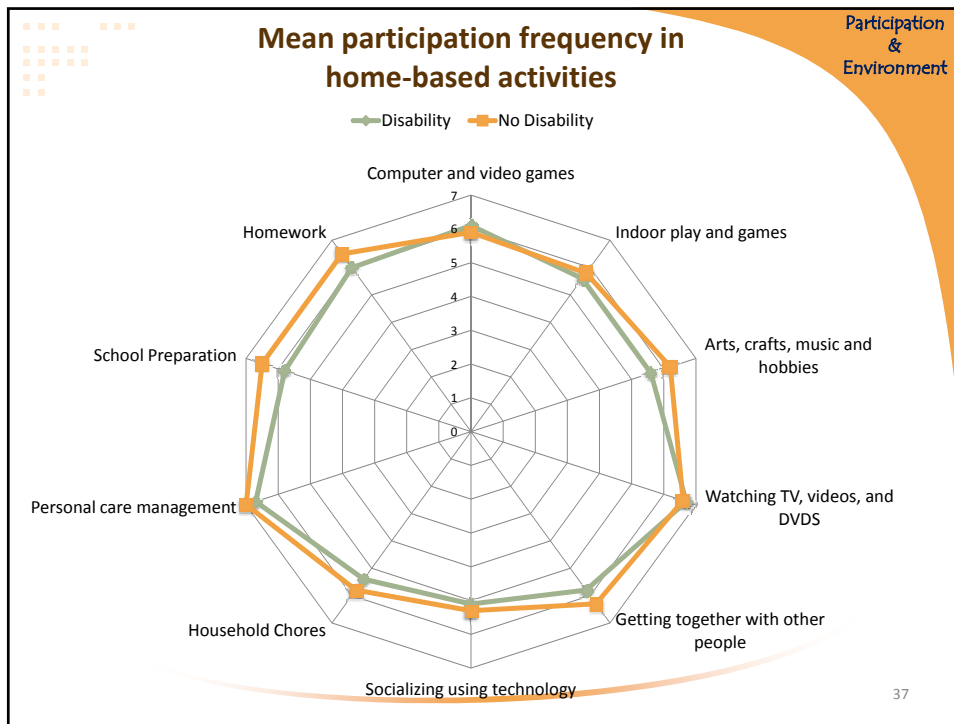
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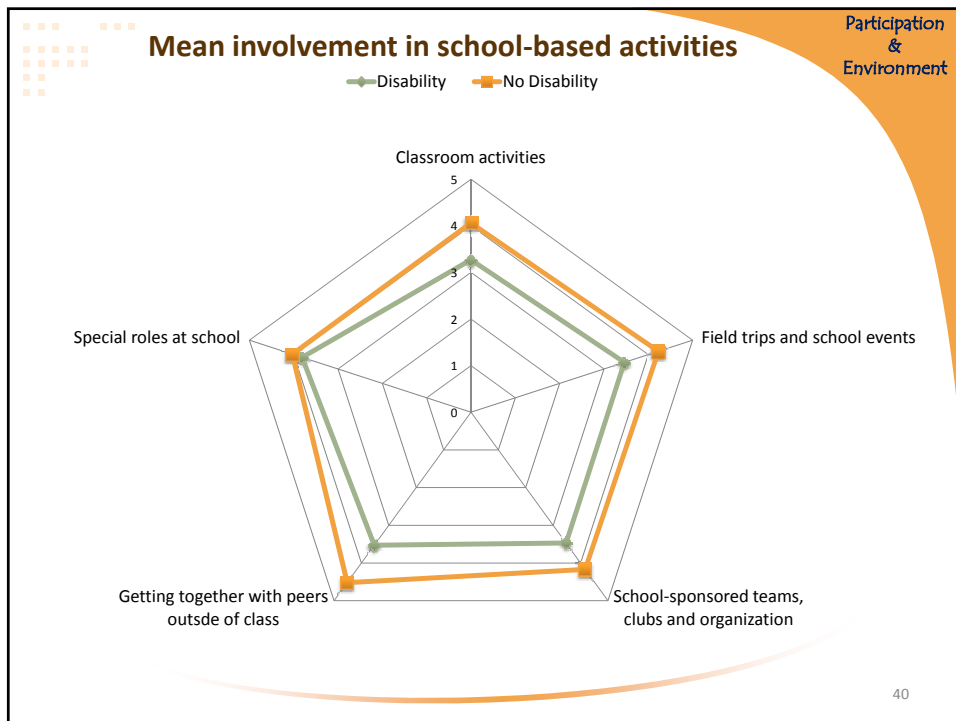
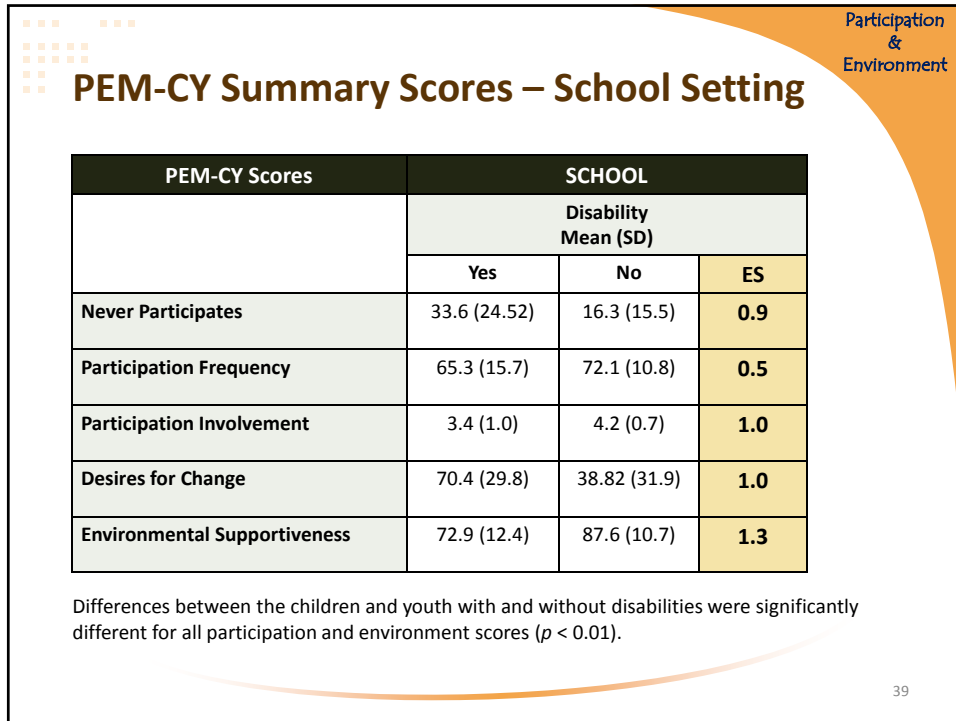


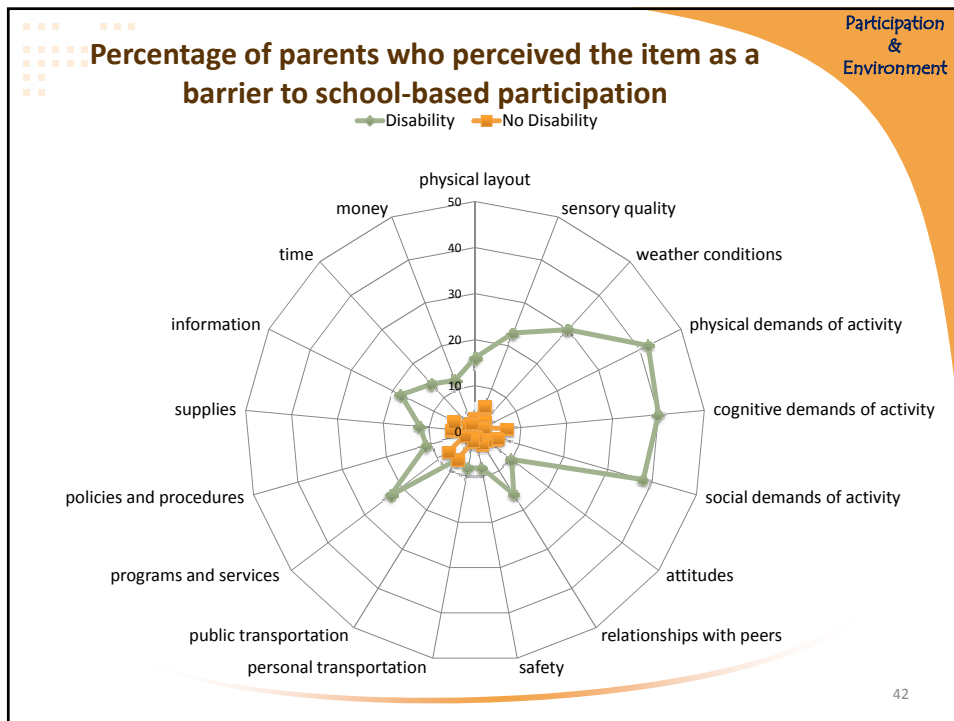
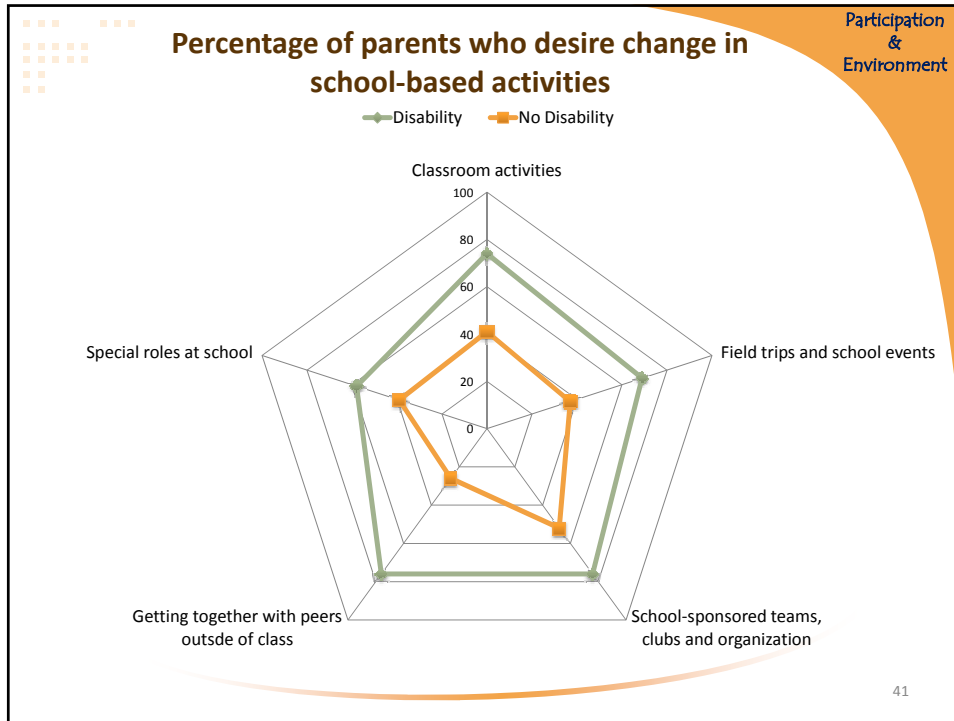
The largest differences (effect sizes) were found in the **Environment Supportiveness** scores across all settings !

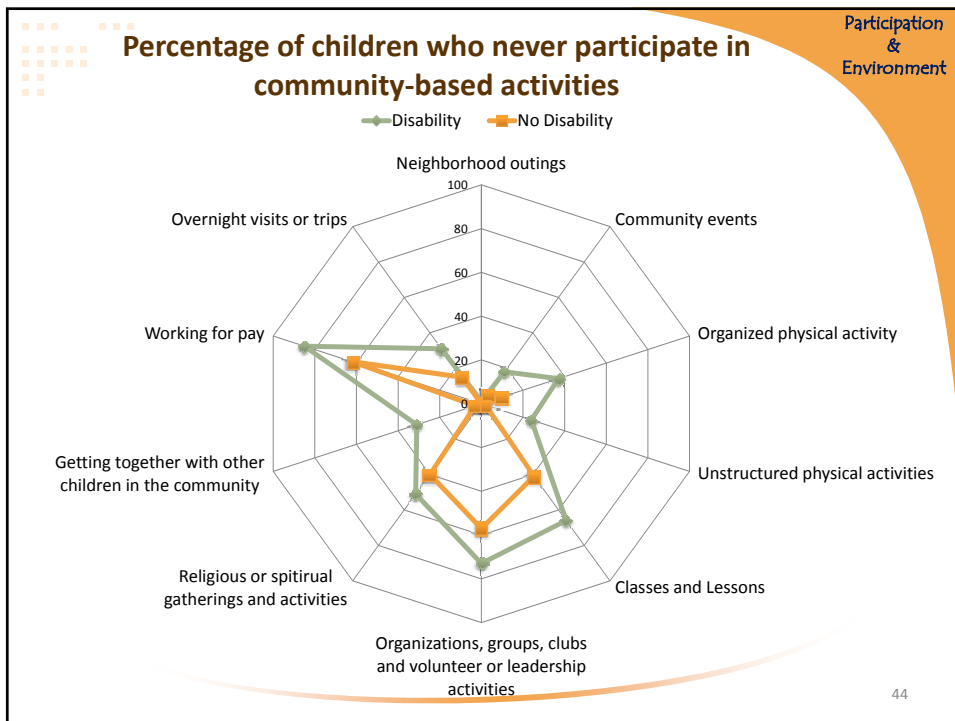
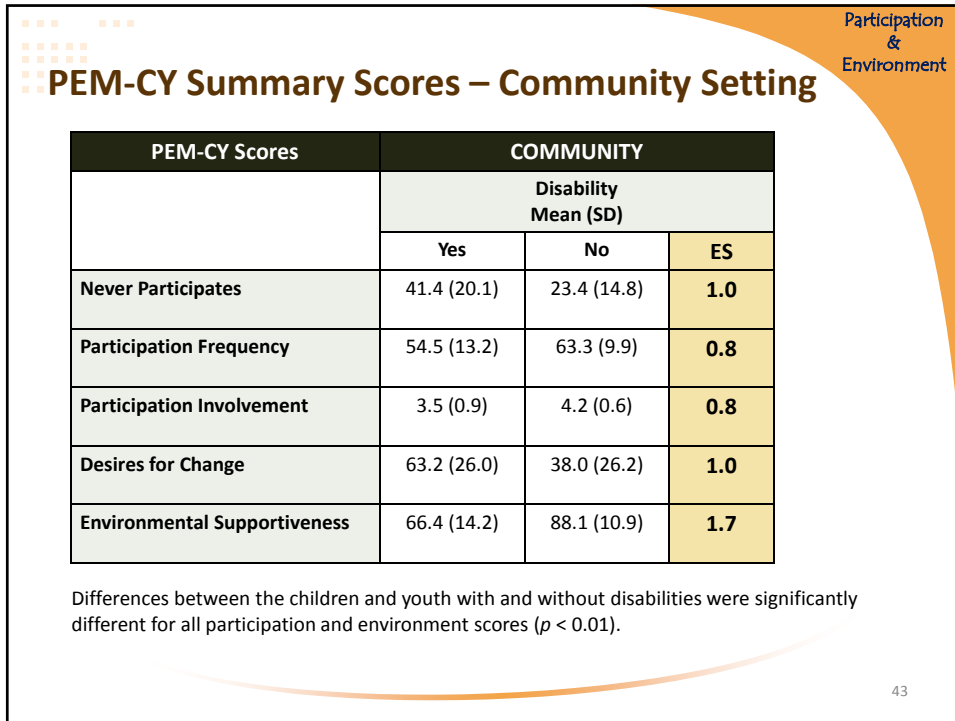
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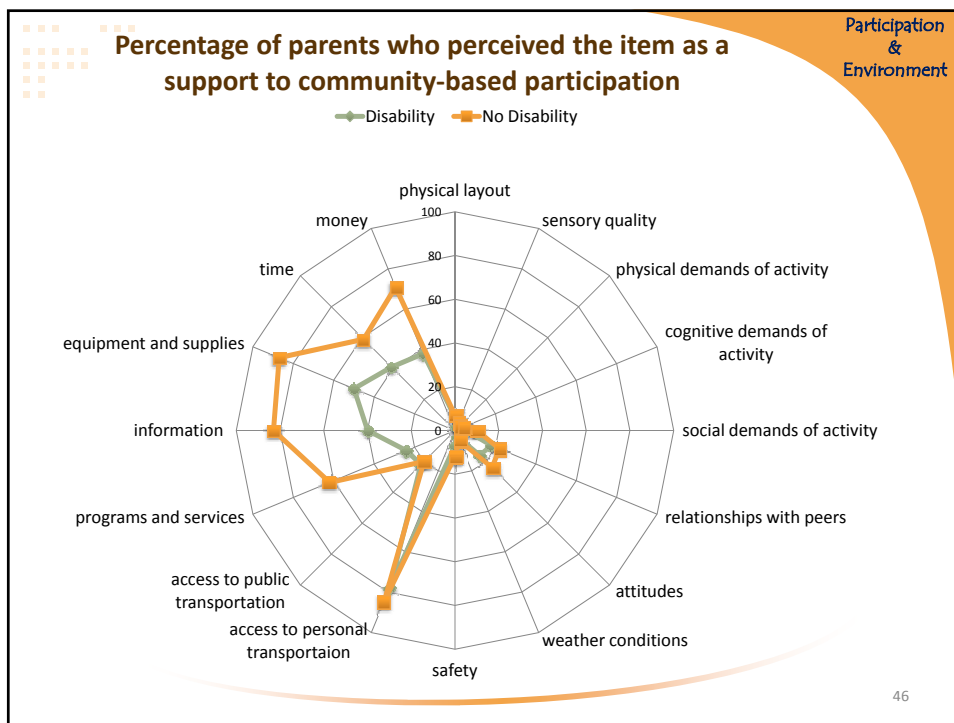
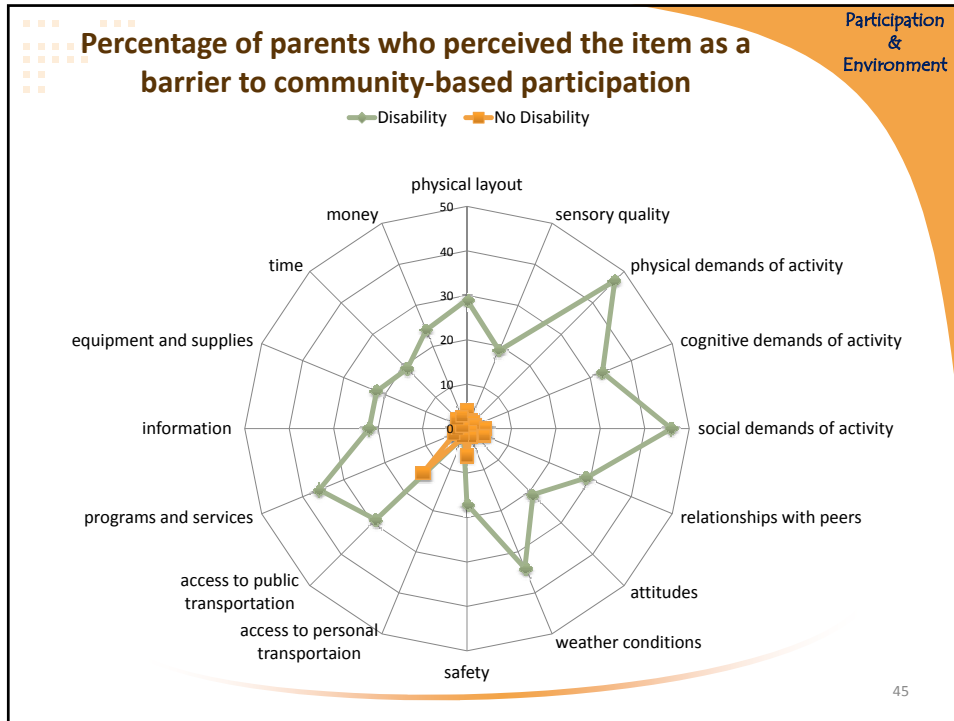














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## FUTURE DIRECTIONS

*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

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## 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)

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## 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



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## 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](mailto:linchia@mcmaster.ca)

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