

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

Its Development, Validation, and Recent Applications

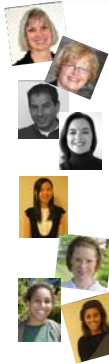
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Occupational Therapy Association of Colorado Annual Conference
October 28, 2011
9:45-10:45 a.m.



Colorado State University

The Participation & Environment Team



- Wendy Coster, Ph.D., OTR/L, FAOTA (Boston University)
- Mary Law, Ph.D., FCAOT, FCAHS (McMaster University)
- Gary Bedell, Ph.D., OTR/L, FAOTA (Tufts University)
- Rachel Teplicky, M.Sc.
- Dana Anaby, Ph.D., OT
- Martha Cousins, M.Ed.
- Kendra Liljenquist, B.S.
- Ying-Chia Kao, M.A., OT
- Mary Khetani, Sc.D., OTR
- Graduate occupational therapy students at BU and Tufts



Learning Objectives

Objective 1: To describe the development of the *Participation and Environment Measure for Children and Youth (PEM-CY)*.

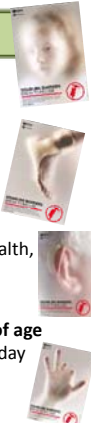
Objective 2: To describe the psychometric properties (reliability and validity) of the PEM-CY.

Objective 3: To communicate how scores obtained from the PEM-CY provide profiles of children's participation in home, school, and community environments.

Background and Rationale (1 of 3)

Based on the new *World Report on Disability* (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 that negatively impact their health, educational, and employment outcomes.
- Approximately **93 million children between 0-18 years of age** experience moderate to severe difficulties in their everyday functioning that impact their health and development.



Background and Rationale (2 of 3)

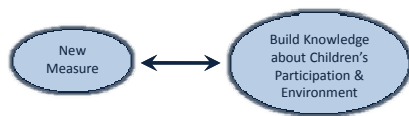
1. Participation is an indicator of Health and Well-Being
 - World Health Organization (WHO)
 - *Rehabilitation Science, Occupational Science, Disability Studies*
2. Participation is an indicator of Full Inclusion
 - Individuals with Disabilities Education Act (IDEA) & Americans with Disabilities Act (ADA)
 - *Special Education, Early Intervention*
3. Participation is a means to Positive Development
 - *Developmental Science, Community Psychology*

PL 101-336; DSC HP 2020-6, DSC HP 2020-7; WHO, 2001

Current Challenges and Opportunities

- **Challenges:**
 - 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 clearly define participation & environment
 - Family perspectives are often excluded in design of measures

Despite these challenges, our ability to promote children's participation hinges on our ability to conceptualize and measure this complex construct ...


- There are unique opportunities for researchers, practitioners, 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 kids of diverse ages, disabilities, and backgrounds

New Measure(s) of Children's Participation & Environment

Participation & Environment Project
(Coster, Law, Bedell)

National Institute on Disability and Rehabilitation Research
Grant # H133G070140, PO # GC 201985
2007-2010

Step 1: Translate participation and environment into meaningful measurement constructs (content, scaling)

Step 2: Pilot and field-test new measure(s)

Step 3: Apply new measure(s) in large-scale studies to build evidence base about children's participation patterns

Step 4: Apply results to inform design of practices that promote children's participation

Learning Objectives

Objective 1: To describe the development of the *Participation and Environment Measure for Children and Youth (PEM-CY)*.

Bedell, G., Khetani, M.A., Cousins, M., Coster, W., & Law, M. (2011). Parent perspectives to inform development of measures of participation and environment for children and youth with disabilities. *Archives of Physical Medicine and Rehabilitation*, 92, 765-773.

Bedell, G., Khetani, M.A., Cousins, M., Coster, W., & Law, M. (in press). Community, social, and civic life. In A. Majnemer (Ed.), *Clinical and research measures for children with developmental disabilities: Framed by the ICF-CY*. Mac Keith Press.

Khetani, M.A., Bedell, G., Cousins, M., Coster, W., & Law, M. (in press). Physical, social, and attitudinal environment. In A. Majnemer (Ed.), *Clinical and research measures for children with developmental disabilities: Framed by the ICF-CY*. Mac Keith Press.

Phase I: Defining the Constructs of Children's Participation & Environment

Starting Point	Processes	Expected Outcomes
<p>1. What is the purpose?</p> <ul style="list-style-type: none"> • Population-based assessment • Program evaluation/outcomes assessment • Individual/person-centered assessment <p>2. Whose voice is reflected?</p> <ul style="list-style-type: none"> • Parent-report • Child-report 	<p>1. Gathering diverse perspectives:</p> <ul style="list-style-type: none"> • Two respondents <ul style="list-style-type: none"> • Parent • Child • Two geographic regions <ul style="list-style-type: none"> • Boston, MA • Hamilton, ON <p>1. Review of existing measures</p> <ul style="list-style-type: none"> • Content • Response options • ICF-CY coverage <p>2. Prior research by investigators</p>	<p>1. What participatory situations and environmental factors should be captured?</p> <p><i>Content areas</i></p> <p>2. How should the questions be asked?</p> <p>What response format makes most sense?</p> <p><i>Scaling options</i></p>

Gathering Parent Perspectives about Participation & Environment: Research Questions

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?

Study Design

From December 2008-January 2009:

	Disability Sample (n=24)	No Disability Sample (n=17)
Recruitment	Boston, MA and Hamilton Wentworth Region, ON	Northeastern U.S.
	Maximum variation sampling strategy Recruitment flyers, notices in newsletters	Established contacts
Data Collection	90-minute focus groups, then interviews (on campus, in the community, in-home, or by telephone)	60-minute in-home interviews

Data Management: NVivo 7.0 assisted with data management, analyses, and interpretation of data from: 1) transcripts, 2) field notes, 3) analytic memos, and 4) meta-summaries

Data Analysis:

- Content and constant-comparative analyses used to code text, identify categories, and examine links between/among categories related to research questions.
- To ensure trustworthiness: 1) member-checking, 2) triangulation, and 3) recursive review and discussion of aggregate findings (descriptive terms, phrases, themes)

Sample Characteristics (1 of 2)

Variable	Disability (N=24)		No Disability (N=10)
	BU	McMaster	Tufts
Respondent Mother	14	9	15
Race/Ethnicity			
Caucasian (Not Hispanic)	11	9	16
Black	2	0	0
Hispanic	1	0	1
Other	0	1	0
Respondent Education			
Graduate degree	8	0	7
College degree	4	3	8
Some college	1	5	2
High School/Less	1	2	0

HOME Environment

Are the following available and/or adequate to support your child's participation at home?

	Not needed	Usually, yes	Sometimes, yes sometimes no	Usually, no
CHECK ONE RESPONSE ☐				
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?				

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 8 STRATEGIES

1. _____

2. _____

3. _____

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PEM-CY Home Section 3 of 3


Learning Objectives

- ✓ **Objective 1:** To describe the development of the *Participation and Environment Measure for Children and Youth (PEM-CY)*.
- Objective 2:** To describe the psychometric properties (reliability and validity) of the PEM-CY.

Coster, W.J., Bedell, G., Law, M., Khetani, M.A., Teplicky, R., Lijtenquist, K., Gleason, K., & Kao, Y. Psychometric evaluation of the Participation and Environment Measure for Children and Youth (PEM-CY). Manuscript accepted for publication in *Developmental Medicine and Child Neurology*.

Large-Scale Validation of the PEM-CY

Data collected from US and Canada via internet survey
between May-October 2010



Sample Characteristics (1 of 2)	
Variable	N (%)
Respondent	
Mother	519 (90)
Father	44(8)
Guardian	9(2)
Respondent Education	
High school or less	28(5)
Some college/technical training	79(14)
Graduated college/university	280(49)
Graduate degree	188(33)
Nationality	
USA	213(37)
Canadian	363(63)
Type of Community	
Major Urban	257(45)
Suburban	192(33)
Small Town	80(16)
Rural	24(4)
Annual Household Income	
<40,000	65(11)
40-80,000	137(24)
>80,000	354(62)

Sample Characteristics (2 of 2)	
Variable	N (%)
Disability Status	
Disability	282(49)
No Disability	294(51)
Child Gender	
Male	311(54)
Female	265(46)
Child Age (mean)	
	11.2
Child Race/Ethnicity	
Caucasian (Not Hispanic)	466(81)
African-American	19(3)
Latin-American or Hispanic	10(2)
South Asian	15(2)
Other/Missing	49(8)

How summary scores are obtained
<p>For each setting (home, school, community):</p> <ul style="list-style-type: none"> • Participation Frequency (% maximum possible or % never) <ul style="list-style-type: none"> – Sum of all ratings except “never” responses, divided by number of ratings – % never responses on frequency scale • Participation Involvement (average of items) <ul style="list-style-type: none"> – Average of all items except for ‘never’ responses to participation frequency • Participation Desire for Change (% yes responses) <ul style="list-style-type: none"> – Number of ‘yes, change’ responses, divided by total number of responses • Environmental supportiveness (% maximum possible) <ul style="list-style-type: none"> – Sum of all ratings divided by number of items rated <p>POMP = $[(\text{observed} - \text{minimum}) / (\text{maximum} - \text{minimum})] \times 100$</p>

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: 0.83 to 0.91
- **Test-retest reliability: moderate to very good**
 - Participation Frequency: 0.58 to 0.84
 - Never participates: 0.66-0.92
 - 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 (-.42 to -.59)**

Coster, W.J., Bedell, G., Law, M., Khetani, M.A., Teplicky, R., Liljenquist, K., Gleason, K., & Kao, Y. Psychometric evaluation of the Participation and Environment Measure for Children and Youth (PEM-CY). Manuscript accepted for publication in *Developmental Medicine and Child Neurology*.

Learning Objectives

- ✓ **Objective 1:** To describe the development of the *Participation and Environment Measure for Children and Youth (PEM-CY)*.
- ✓ **Objective 2:** To describe the psychometric properties (reliability and validity) of the PEM-CY.
- Objective 3:** To understand how scores obtained from the PEM-CY provide profiles of participation and environmental supports and barriers of school-age children with and without disabilities in the home, school, and community settings.

Ways of analyzing data from the PEM-CY



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

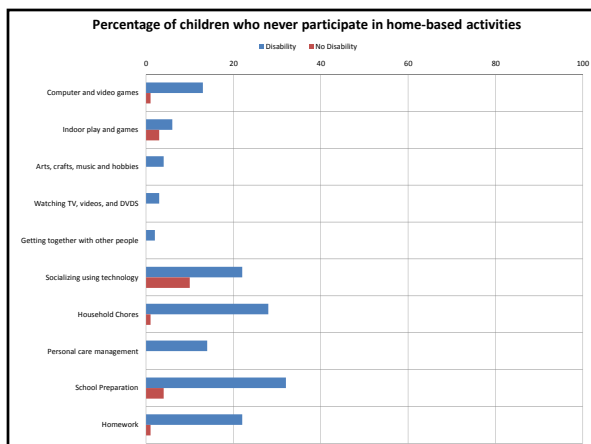
Participation and environment patterns across home, school, and community settings

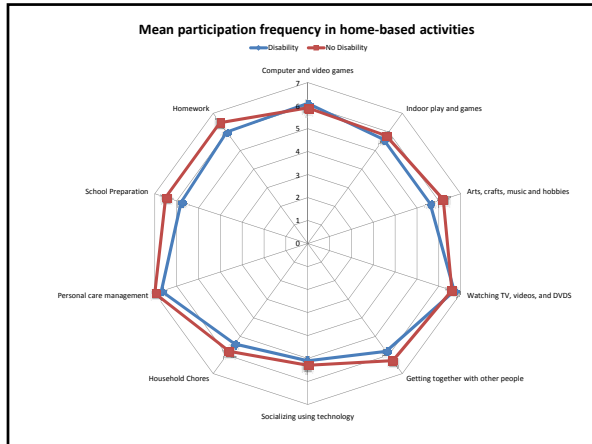
PEM-CY Scores	HOME			SCHOOL			COMMUNITY		
	Disability Mean (SD)			Disability Mean (SD)			Disability Mean (SD)		
	Yes	No	ES	Yes	No	ES	Yes	No	ES
Participation Frequency	83.0 (11.6)	88.0 (7.2)	0.5	65.3 (15.7)	72.1 (10.8)	0.5	54.5 (13.2)	63.3 (9.9)	0.8
Never Participates	14.0 (20.1)	1.8 (4.3)	1.0	33.6 (24.52)	16.3 (15.5)	0.9	41.4 (20.1)	23.4 (14.8)	1.0
Participation Involvement	3.4 (0.8)	3.8 (0.5)	0.7	3.4 (1.0)	4.2 (0.7)	1.0	3.5 (0.9)	4.2 (0.6)	0.8
Desires Change	67.1 (26.5)	53.5 (25.9)	0.5	70.4 (29.8)	38.82 (31.9)	1.0	63.2 (26.0)	38.0 (26.2)	1.0
Environmental Supportiveness	70.1 (14.9)	86.4 (11.5)	1.2	72.9 (12.4)	87.6 (10.7)	1.3	66.4 (14.2)	88.1 (10.9)	1.7

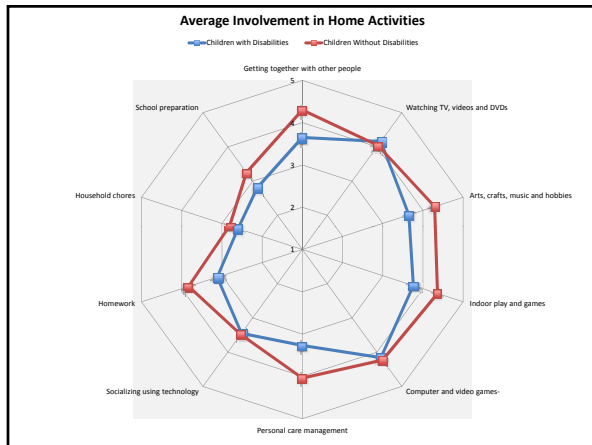
Bedell, G., Coster, W., Law, M., Teplicky, R., Khetani, M., Lijtenquist, K., Kao, Y-C., Anaby, D., & Cousins, M. (2011, April). Participation and Environment Measure for Children and Youth (PEM-CY): Descriptive and Psychometric Findings. Poster presented at American Occupational Therapy Conference, Philadelphia,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

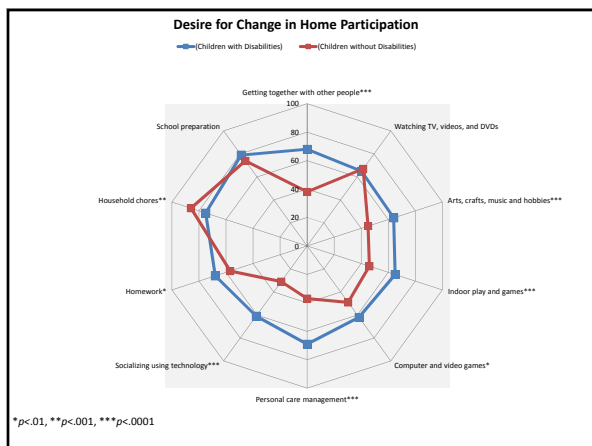
Home-Related Participation & Environment Patterns

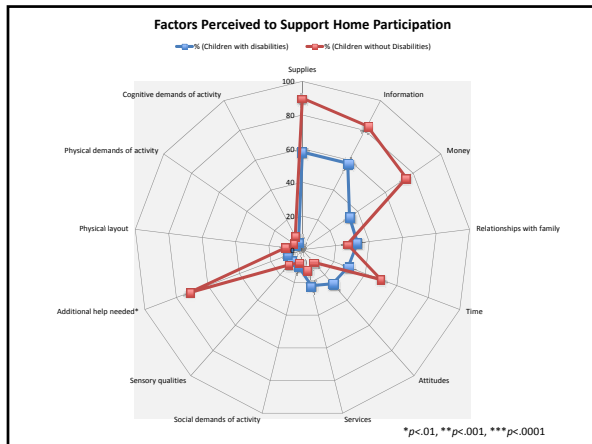
Law, M., Anaby, D., Teplicky, R., Khetani, M., Coster, W., & Bedell, G. (in preparation). Participation in the home environment among children with and without disabilities.

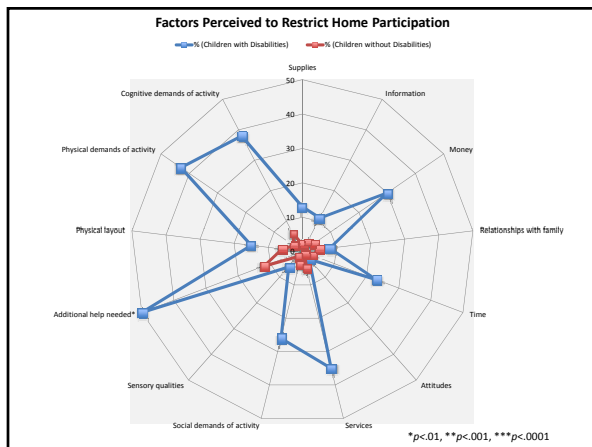












Discussion

Based on your work with children and youth with disabilities and their families, what other questions do you have about children's participation and environment?

Do you think that your question(s) could be answered using data from the PEM-CY?

Do you see additional challenges/opportunities with respect to using the PEM-CY that should be addressed in future work?

Parents' recommendations for alternative uses of measures

- Taking inventory**
"keeping track of the types of supports that are relevant for various activities, so parents can figure out ... what supports they will need to access a specific activity"
- Building awareness & shaping attitudes**
"everybody wants to help you, but people don't know how to help out...by doing... what you're doing, I think it really gives people a different sense"
- Success of the journey**
"you could... highlight small successes that lead to larger outcomes... the strategies that parents use on a daily basis"
- Strengths-based**
"everything in the school setting is based on what you're not able to do, because what you're not able to do defines what you can do, what they need to teach you... if you turn it around to what you can do, and how to use that ..."
- Fund us to develop programs**
"some funding ... if there was training for coaches, assistants, volunteers, to support the child in being successful, sometimes it's just a matter of we could educate people."
- Growth and adaptation**
"I think it should speak to a child's adaptation to progressively larger environments... ability to live in the world... and difficulties that children with special needs have in accessing our culture"

Limitations to be Addressed in our Future Work

- Sample Diversity (race/ethnicity, geographic location, income, respondent)
- Parent's perspective
- Internet vs. Mailed Survey

Future Directions and Next Steps

Participation & Environment Knowledge Hub

- Spanish and French Versions
- Paper and online versions needed to enable stakeholders to gather data via internet or by mail or in-person
- Administration and Scoring Manual
- Educational modules that summarize knowledge about participation and environment for variety of stakeholders

Funding Source: Canadian Institutes of Health Research (CIHR) Knowledge Translation Grant

How to Get Involved

Please contact:

Rachel Teplicky, M.Sc.

Knowledge Broker
CIHR Funded Project to Develop P&E
Knowledge Hub

Email: teplicr@mcmaster.ca

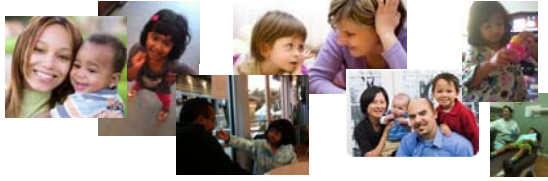
Participation & Environment Patterns of Children and Youth with Hemifacial Microsomia



www.bu.edu/slone/calls

Funding Source: National Institute of Dental and Craniofacial Research (NIDCR)
Role: Study Consultant

Young Children's Participation & Environment Measure



Khetani, M.A., Orsmond, G., Cohn, E., Law, M., & Coster, W. (in press). Correlates of community participation among families transitioning from Part C early intervention services. *OTJR: Occupation, Participation, and Health*.

Khetani, M.A., Cohn, E., Orsmond, G., Law, M., & Coster, W. (2011). Parent perspectives of participation in home and community life when receiving Part C early intervention services. *Topics in Early Childhood Special Education*. DOI: 10.1177/0271121411418004.

Predictors of Community Participation Among Young Children who have Received Part C Services and are Entering Kindergarten

- Secondary analysis of data from National Early Intervention Longitudinal Study (NEILS)
 - Which child, family, and environmental factors best discriminate between families who report full or limited participation in religious, social, and civic events as assessed when the child enters kindergarten?
 - Which child, family, and environmental factors best discriminate between families who report difficulty participating in eight other types of community activities?
- Study results will further inform final design of Young Children's Participation and Environment Measure

Funding Source: Center for Rehabilitation Research Using Large Datasets (R24) Pilot Project Program, National Institutes of Health Grant #R24 HD065702

How to Get Involved

Please contact:

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**Children's Participation and Environment Lab
(Coming Soon)**
