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

Its Development, Validation, and Recent Applications

Mary A. Khetani, Sc.D., OTR Assistant Professor, Department of Occupational Therapy Secondary Appointment, Human Development & Family Studies **Colorado State University** 

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)

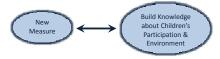
- 1. Participation is an indicator of Health and Well-Being
  - World Health Organization (WHO)
  - Rehabilitation Science, Occupational Science, Disability Studies
- 2. Participation is an indicator of Full Inclusion
  - Individuals with Disabilities Education Act (IDEA) & Americans with Disabilities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

### **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

2

### 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).



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

## 1. What is the purpose? Population-based assessment Program evaluation/outcomes assessment Individual/person-

Starting Point

- 1. Gathering diverse perspectives: 1. What participatory Two respondents
  • Parent
  - Child

Processes

- Two geographic regions

  Boston, MA
  Hamilton, ON
- 1. Review of existing measures
- Whose voice is reflected?
   Parent-report Content Response options
- Child-report
- ICF-CY coverage

2. Prior	research	by	investigato

Expected Outcomes

environmental factors
should be captured?
Content areas
I

1
2. How should the
questions be asked?
What response format
makes most sense?
Scalina options

### **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. <u>How do parents appraise</u> 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)
	Boston, MA and Hamilton Wentworth Region, ON	Northeastern U.S.
Recruitment	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

<u>Data Management:</u> 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-checkling, 2) triangulation, and 3) recursive review and discussion of aggregate findings (descriptive terms, phrases, themes)

### Sample Characteristics (1 of 2)

	Disabili	ty (N=24)	No Disability (N=10)	
Variable	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	

Sample Characteristics (2 of 2)						
Disability (N=27) No Disability (N=1						
Variable	BU	McMaster	Tufts			
Child's Age	_					
5-12	8	8	6			
13-17	7	1	11			
>18	0	3	0			
Child's Gender						
Male	10	7	9			
Female	5	5	8			
Siblings						
No	5	0	0			
Yes	10	12	17			
Primary Diagnostic Condition			N/A			
Down Syndrome	2	3				
ASD, Asperger's, PDD-NOS	7	2				
Dyslexia, Learning Disability	2	1				
ADD/ADHD	1	4*				
Acquired Brain Injury	0	1				
Other	3	1				

#### 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 that they perceived to help/finder participation 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

- Parents judged participation in terms of a greater or lesser frequency and amount, portion, responsibility, initiative, commitment
- Appraisal of participation inextricably linked to appraisal of environment
   Parents want to know how much a factor helped or hindered participation
   Parents want to know whether resources were available and adequate
- Appraising participation and environment naturally lends itself to a conversation about parents' strategies to promote participation

### **Implications of Study Findings for PEM-CY Design**

- 1. 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
- 2. Capture ways that parents understand and judge participation
  - Participation is about frequency and engagement Whether or not a parent desires change in their child's participation matters
- 3. Explicitly link participation and environment in the same measure ("folding in")
- 1. Ask about how parents promote participation in home, school, & community settings (i.e., their strategies)

Coster, W., Law, M., Bedell, G., Khetani, M.A., Cousins, M., & Teplicky, R.(2011). Development of the Participation and Environment Measure for Children and Youth (PEM-CY): Conceptual basis. Disability and Rehabilitation.

#### Participation & Environment Measure -**Version for Children and Youth** (Coster, Law, & Bedell, 2010)

- Parent-report
- Takes approximately 15-20 minutes to complete
- 3 sections: Home, School, Community
- Each section asks about participation <u>and</u> environment
- Participation Questions:

  - How often (Daily ---- Never)
     How involved (Very ---- Minimally)
     Desire for change ---- ...

    Desire for change ---- ...
- Environment Questions:
  - Child-related factors (from demographic questionnaire)
  - Activity demands (physical, cognitive, social)
  - Environmental factors (layout, social supports, attitudes, resources (time, money), services/policies)
- We ask about parent strategies to promote participation for each setting

Coster, W., Law, M., Bedell, G., Khetani, M.A., Cousins, M., & Teplicky, R.(2011). Development of the Participation and Environment Measure for Children and Youth (PEM-CY): Conceptual basis. Disability and Rehabilitation.

HOME Participation	A) Typically, <u>how after done your child gastropoles in 1 at Jacobs Askabiliss</u> of this type?	B) Think about 1 or 2 extintion of this tape that your chief participates in most other. Typically, base insided in your shift when thing these activities?	<ul> <li>Would you like your child's participation to change, in this type of activity?</li> </ul>
	ONEX DIE REPORTE S	DHECK ONE RESPONSE TO	FYES, CHECK ALL THAT APPLY
S) Computer and obtain garman	[]]][][][][][][][]	[[]][]]	
2) Induor play and games is 4, playing with lays, pustine, or beard games, playing billion or three-up)			
3) Aris, crafts, music, and hobbies in g., dung arts sind orats, ticsoning to music, playing an instrument, collecting exacting for install, stocking for furty			
A) WORLDING TH, WORLD, AND DYCH.			
5) Getting together with other people (e.g., interacting with poors, family, other (expenses))			
6) Socializing using technology (e.g., telephone, computer)			
7) Household shores In g., unlocating the dishworker, electring reason or other between 67 fine finance, second, Exemply and the gardege, setting the taken, setting for the particle, setting the			
E) Personal core management (e.g., getting dressed, choosing clotting, brushing hair or both, applying makeugt			
9) School preparation (not homework) (e.g., gethering nationals, packing school (e.g., packing lunch, necessing schoolse)			
SO) Homework In.g., daily reading, homework designments.			

Do the following tilings help or make II. harder for your oldel to participate in extintion at home?  CHECK ORE RESPONSE 22	Not an	Unually testing	Sometimes helps; sometimes makes harder	Unually makes harder
The physical layout or amount of space and furniture in your home.				
<ol><li>The sensory qualities of the home environment (e.g., amount and/or type of sound, light, temperature, textures of objects)</li></ol>	Г			
3. The physical demands of typical activities in the home (e.g., strength, endurance, coordination)	1			
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)				
T. The attitudes and actions of behysitters, therapists, and other professionals who care for your child at home				

HOME Environment	
Are the following enableia end/or adequate to expoor your child's participation at borne?  ORIGINATE STATES OF STATE	
8. Servises in the home (ag., therapish, holms, wb). 9. Sepales in the home (ag., sports applyment, cards supplies, reading materials, existing devices or behaviour or activation of sports or word scheduling.	
10. Information (e.gBook edition), services, pergames 1 11. Co you (sed your family) have enough time to support your child's participation at home? 12. Co you (sed your family) have enough more to support your child's participation at home?	
Med are some things that you or other handly members do that had your oldel perdicipates accessability in activities all toward*  PLEASE LETT UP TO 8 STRATEIRES  L.	
). ).	
Not to be reproduced without permanent of authors Cardio, Law, & Bellett  PERCY Hore Section-2 of 3	
	1
Learning Objectives	
✓ <b>Objective 1:</b> To describe the development of the <i>Participation</i>	
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., Uljenquist, K., Gleason, K., & Kan, Y. Psychometric evaluation of the Participation and Environment Measure for Children and Youth (PEN-CY). Manuscript accepted for publication in Developmental Medicine and Child Neurology.	
"	
	1
Large-Scale Validation of the PEM-CY	
Data collected from US and Canada via internet survey between May-October 2010	
13333 1333 1333 1333 1333 1333 1333 13	

Sample Character	istics (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) Disability Status 282(49) No Disability 294(51) Child Gender 311(54) Male 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 Other/Missing 49(8)

### How summary scores are 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)
- Average of all items except for 'never' responses to participation frequency
- Participation Desire for Change (% yes responses)
  - Number of 'yes, change' responses, divided by total number of responses
- Environmental supportiveness (% maximum possib

Sum of all ratings divided by number of items rated
 POMP = {(observed - minimum)/(maximum - minimum)] × 100

ency			
es			
ole)			

### 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

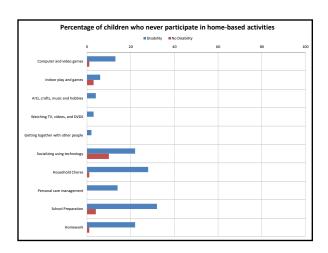
## Participation and environment patterns across home, school, and community settings

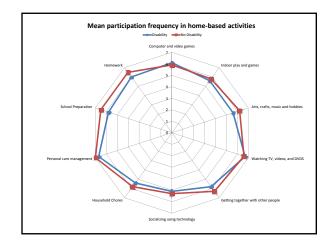
PEM-CY Scores	HOME			SCHOOL			COMMUNITY		
	Disability Mean (SD)			Disability Mean (SD)			Disability Mean (SD		
	Yes	No	ES	Yes	No	ES	Yes	No	ES
Participation Frequency	83.0 (11.6)	88.0 (7.2)	0.5	65.3 (15.7)	72.1 (10.8)	0.5	54.5 (13.2)	63.3 (9.9)	0.8
Never Participates	14.0 (20.1)	1.8 (4.3)	1.0	33.6 (24.52)	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

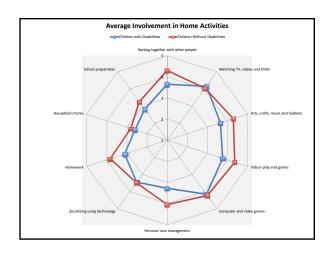
Bedell, G., Coster, W., Law, M., Teplicky, R., Khetani, M., Liljenquist, K., Kao, Y.C., Anaby, D., & Cousins, M. (2011, April). Participation and Environment Measure for Children and Youth (PEM-CY): Descriptive and Psychometric Findings. Poster presented at American Occupational Therapy Conference, Philadelphia,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

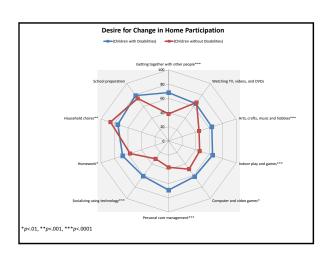
# Home-Related Participation & Environment Patterns

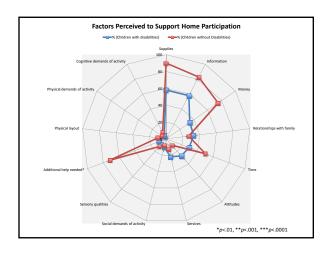
Law, M., Anaby, D., Teplicky, R., Khetani, M., Coster, W., & Bedell, G. (in preparation). Participation in the home environment among children with and without disabilities.

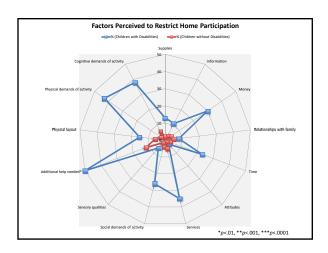












### **Discussion**

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 surplus activities, so parents can if guer out, what supports the will need to access a specific activity"	Building awareness & shaping "everybody wants to neley you but people alon't know how to help you but people what you're doing it thus, "by doing, people a different sense"							
Success of the journey you couly - highlight small successer, - highlight successer,	"everything in the school setting is based on what you're not able to do, because what you're not able to do effense 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  "Some funding — if there was training for cooches, assistants, country to the cookies, assistants, considerated the funding the cookies of the country of the c	Growth and adaptation a standard standard specific of a child's environment, which is considered to a child's environment, while the large environment, which is the in the with special needs hove in the children culture. In accessing our							

### 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. *OTIR: 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:

Mary Khetani, Sc.D., OTR

Email: Mary.Khetani@colostate.edu Phone: 970-491-6349

Children's Participation and Environment Lab (Coming Soon)