

Roundtable Discussion: How to assess and facilitate participation of children in social, family and educational environments

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Objectives

- To describe two key participation measures:
 - Child & Adolescent Scale of Participation (**CASP**)
 - Participation & Environment Measure for Children & Youth (**PEM-CY**)
- To learn more about other measures developed by colleagues in Israel
- To have lively discussion with colleagues



Child & Adolescent Scale of Participation (CASP)

Support Funding from from the Deborah Munroe Noonan
Memorial Foundation, Bank of America Trustee; Tufts
University Faculty Grants

CASP: Initial Development & Purpose

- Part of the Child & Family Follow-up Survey (CFFS) completed by family caregivers to monitor outcomes & needs of children with ABI after inpatient rehabilitation
- Informed by **I**nternational **C**lassification of **F**unctioning, **D**isability & **H**ealth (**ICF**), key literature, & stakeholder feedback

Child & Family Follow-up (CFFS)

- **Child & Adolescent Scale of Participation (CASP)**
 - Extent of participation compared to same age in home, school & community
- **Child & Adolescent Scale of Environment (CASE)**
 - Extent of environmental problems
- **Child & Adolescent Factors Inventory (CAFI):**
 - Extent of impairment
- **Other questions**
 - Services, family needs

Child & Adolescent Scale of Participation (CASP)

- Now used separate from CFFS
- With children with other diagnoses
- Broad age range
 - recommended for school-age and youth transitioning to adulthood
- Last phase of psychometric testing
- Translated in other languages including Hebrew & Arabic
- Youth version (paper in review)

CASP: Four subsections (20 items)

HOME PARTICIPATION:

1. Social/ leisure (family)
2. Social/ leisure (friends)
3. Chores / Responsibilities
4. Self-care
5. Mobility
6. Communication

COMMUNITY PARTICIPATION:

7. Social/ leisure (friends)
8. Structured activities
9. Mobility
10. Communication

***Plus open-ended questions
(e.g., strategies, equipment)**

SCHOOL PARTICIPATION

11. Educational activities
12. Social / Leisure (students)
13. Mobility
14. Using educational materials
15. Communication

HOME & COMMUNITY LIVING

16. Household Activities
17. Shopping/ Managing Money
18. Managing Daily Schedule
19. Using Transportation
20. Work Activities

Compared to other children your child's age, what is your child's current level of participation in the following activities?

- **Age expected/full participation**, *same as or more* than other children his or her age.
- **Somewhat limited**, *somewhat less* than other children his or her age [*Your child also may need occasional supervision or assistance*]
- **Very limited**, *much less* than other children his or her age. [*Your child also may need a lot of supervision or assistance*]
- **Unable**, your child *can not* participate in the activities, although other children his or her age do participate.
- **Not applicable**, other children your child's age *would not be expected* to participate in the activities.

CASP Summary Scores

- **Total scores**

- Sum item scores /
- Divide by maximum score possible (only applicable items)
- Multiply by 100

- **Subsection Scores**

- Same procedure as total but only applicable items in subsection

- **Items** (examine patterns, profiles, change)

Psychometric evidence (Bedell, 2004; 2009)

- Test-retest reliability (ICC =.94) & internal consistency (Cronbach's $\alpha \geq 0.96$.)
- Construct and discriminant validity.
 - Moderate correlations between CASP scores and scores of activity performance, impairment and environment.
 - Children without disabilities significantly higher scores than children with disabilities.
 - Responsiveness to change has not been examined.
 - Factor analyses (2 & 3 factor models)
 - Rasch Analyses (item difficulty order makes theoretical sense; 2 or 3 minor misfitting items)

CASP: Limitations

- Samples of convenience
- Lack of controlled data collection
- Combined different formats of administration
- Missing data (due to non-applicable responses)
- Combination of small size samples
- Might be measuring both activity & participation
- Might not be responsive to change over time
 - Comparison to others of same age
 - Broad versus Discrete activities

Future work

- Last phase of psychometric testing (data $n > 1500$)
- Examine changes over time from longitudinal studies
- Further develop the youth version (one preliminary study in review & very promising results)
- Further validation studies

CASP & CFFS References


- **Bedell, G.** (2009). Further validation of the Child and Adolescent Scale of Participation (CASP). *Developmental Neurorehabilitation*, 12, 342-351.
- **Bedell, G.** (2004). Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after inpatient rehabilitation. *NeuroRehabilitation*, 19, 191-205.
- **Bedell, G., & Dumas, H.** (2004). Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: A follow-up study. *Brain Injury*, 18, 65-82.

CASP, CASE, CAFI & CFFS

- Administration & scoring guidelines free & available on my website

<http://sites.tufts.edu/garybedell/>

- Contact Dr. Naomi Weintraub & Ms. Randi Garber for information about the Hebrew & Arabic translated versions



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

(Coster, Law, Bedell, 2010)

Funding from National Institute on Disability and Rehabilitation Research
(NIDRR; Dr. Wendy Coster, PI) and Canadian Institutes of Health
Research (CIHR; Dr. Mary Law, PI)

PEM-CY

- Examines participation and environmental factors across three settings
- There are PEMCY summary scores for each setting
 - Home (10 participation items; 12 environment items items);
 - 2) School (5 participation items; 17 environment items);
 - 3) Community (10 participation items; 16 environment 16 items).

DEVELOPMENT OF PEM-CY

To develop a population-based measurement tool with information obtained by parent-report.

Parent Perspectives on 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?

(Bedell, et al, 2011)

Sample Characteristics: Initial Study

Variable	Disability Sample (n = 24)		No Disability Sample (n = 17)
	BU	McMaster	Tufts
Respondent Mother	14	9	15
Race/Ethnicity			
Caucasian (<i>Not Hispanic</i>)	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

Variable	Disability Sample (n = 24)		No Disability Sample (n = 17)
	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
Primary Diagnostic Condition			
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

Key findings: Parent perspectives

- **Important Home, School & Community Activities:**
 - Overall consistency in responses **regardless of** whether child had disability or not
- **Environmental Factors in all Three Settings:**
 - Identified **broader** range than ICF
- **Ways of appraising children's participation:**
 - Participation is **multidimensional**
 - Participation is **inextricably linked** with environment
 - Appraising participation and environment naturally leads to conversation about **parents' strategies to promote participation**

Implications 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)

PEM-CY: Description

- Home, School and Community sections (parent-report ~ 30-45 minutes)
- 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

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

	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very involved	4	3 Somewhat involved	2	1 Minimally involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
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)																			
4) Watching TV, videos, and DVDs																			
5) Getting together with other people (e.g., interacting with peers, family, other houseguests)																			
6) Socializing using technology (e.g., telephone, computer)																			
7) Household chores (e.g., unloading/loading the dishwasher, cleaning room or other areas of the house, cooking, taking out the garbage, setting the table, caring for household pet)																			
8) Personal care management (e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup)																			
9) School preparation (not homework) (e.g., gathering materials, packing school bag, packing lunch, reviewing schedule)																			
10) Homework (e.g., daily reading, homework assignments, school projects)																			

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)

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 Once a week
 Few times a month
 Once a month
 Few times in last four months
 Once in last four months
 Never (**skip to Question C**)
 5 Very involved
 4
 3 Somewhat involved
 2
 1 Minimally involved
 No change desired
 Yes, do more often
 Yes, do less often
 Yes, be more involved
 Yes, be less involved
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CHECK ONE RESPONSE

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

IF YES, CHECK ALL THAT APPLY

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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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



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 3 STRATEGIES

1.

2.

3.

VALIDATION OF PEM-CY

*To examine the psychometric properties
(reliability and validity)*

Sample Characteristics

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

Variable	N (%)
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)
Disability Status	
Disability	282 (49)
No Disability	294 (51)
<i>Top 5 Parent-Reported 1st Diagnosis in <u>Disability Sample</u></i>	
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)

Psychometric Evidence

- **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)**

PEM-CY Home Summary Scores

PEM-CY Scores	HOME		
	Disability Mean (SD)		
	Yes	No	ES
Never Participates	14.0 (20.1)	1.8 (4.3)	1.0
Participation Frequency	83.0 (11.6)	88.0 (7.2)	0.5
Participation Involvement	3.4 (0.8)	3.8 (0.5)	0.7
Desires for Change	67.1 (26.5)	53.5 (25.9)	0.5
Environmental Supportiveness	70.1 (14.9)	86.4 (11.5)	1.2

Differences between the children and youth with and without disabilities were significantly different for all participation and environment scores ($p < 0.01$).

PEM-CY School Summary Scores

PEM-CY Scores	SCHOOL		
	Disability Mean (SD)		
	Yes	No	ES
Never Participates	33.6 (24.52)	16.3 (15.5)	0.9
Participation Frequency	65.3 (15.7)	72.1 (10.8)	0.5
Participation Involvement	3.4 (1.0)	4.2 (0.7)	1.0
Desires for Change	70.4 (29.8)	38.82 (31.9)	1.0
Environmental Supportiveness	72.9 (12.4)	87.6 (10.7)	1.3

Differences between the children and youth with and without disabilities were significantly different for all participation and environment scores ($p < 0.01$).

PEM-CY Community Summary Scores

PEM-CY Scores	COMMUNITY		
	Disability Mean (SD)		
	Yes	No	ES
Never Participates	41.4 (20.1)	23.4 (14.8)	1.0
Participation Frequency	54.5 (13.2)	63.3 (9.9)	0.8
Participation Involvement	3.5 (0.9)	4.2 (0.6)	0.8
Desires for Change	63.2 (26.0)	38.0 (26.2)	1.0
Environmental Supportiveness	66.4 (14.2)	88.1 (10.9)	1.7

Differences between the children and youth with and without disabilities were significantly different for all participation and environment scores ($p < 0.01$).

RECENT APPLICATIONS

How does PEM-CY provide profiles of children's participation in home, school, and community environments?

Limitations & future work

- Lack of diversity in sample (income, race, ethnicity, geographic location)
- Missing data
- Online – web based; developing paper pencil
- Additional validation needed
- Supplemental questions for use in intervention planning

PEM-CY more information

- Will be available free of charge in the near future.
at following websites :
- McMaster University (Dr. Mary Law; CanChild Center for Childhood Disability Research):
<http://www.canchild.ca/en/ourresearch/pep.asp>
- Boston University (Dr. Wendy Coster; Sargent College- Kids in Context Research Lab):
<http://www.bu.edu/kidsincontext/pep/>

PEM-CY References

- Coster, W., & Law, M., **Bedell, G.**, Khetani, M. Cousins, M., Teplicky, R. (2012). Development of the Participation and Environment Measure for Children and Youth (PEM-CY): Conceptual basis. *Disability and Rehabilitation, 34*, 238-246.
- Coster, W., **Bedell, G.**, Law, M., Khetani, M., 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 & Child Neurology, 53*, 1030-1037.
- **Bedell, G.**, Khetani, M. Cousins, M., Coster, W., & Law, M. (2011). Parent perspectives to inform development of measures of children's participation and environment. *Archives of Physical Medicine & Rehabilitation, 9*, 765-773.



THANK YOU!

- Any questions?

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