

# Participation And Environment Measure for Children And Youth (PEM-CY): Descriptive And Psychometric Findings



Gary Bedell PhD<sup>1</sup>, Wendy Coster PhD<sup>2</sup>, Mary Law PhD<sup>3</sup>, Rachel Teplicky MSc<sup>3</sup>,

Mary Alunkal Khetani ScD<sup>2</sup>, Kendra Liljenquist BA<sup>2</sup>, Kara Gleason BA<sup>2</sup>, Ying-Chia Kao MA<sup>2</sup>, Dana Anaby PhD<sup>3</sup>, Martha Cousins MEd<sup>3</sup>

(<sup>1</sup>Tufts University; <sup>2</sup>Boston University; <sup>3</sup>McMaster University)

## BACKGROUND & PURPOSE

Participation in home, school, and community activities is an important outcome for children and youth. Greater participation is associated with enhanced quality of life and reduction in health and social risk factors for children and youth with and without disabilities.<sup>1,2</sup> Children and youth with disabilities often are restricted in their participation.<sup>1,3</sup> Physical and social environmental factors can both support and hinder children's participation.<sup>4,5</sup>

There is a great need for measures of children's participation and environment that: 1) will build knowledge about key outcomes for children and youth, and 2) are suitable for a variety of purposes including population-based surveys, program outcome and intervention studies, and individualized child and family-centered intervention planning. The *Participation and Environment Measure for Children and Youth (PEM-CY)* was designed to address this need.<sup>6,7</sup>

The purpose of this study was to examine psychometric properties of this new measure: the PEM-CY.

## METHODS

Data were collected online from caregivers of school-age children and youth with and without disabilities in the United States and Canada.

Test-retest reliability was examined on a subsample of children (n=34) over a 1-4 week period via intra-class correlation coefficient (ICC; 2,1).

Internal consistency of the PEM-CY subscales was examined via Cronbach's alpha (α).

Differences in PEM-CY scores between children with and without disabilities and across age groups were examined via two-way ANOVAs.

## PARTICIPANTS

Data were collected on 576 children and youth.

- Ages ranged from 5 to 17 years (Mean = 11.16; SD = 3.08)
- 37% were from the USA and 63% were from Canada
- 54% were male and 46% were female
- 49% had a disability and 51% did not

Children with disabilities were identified as having a broad range of diagnoses (e.g., cerebral palsy, autism spectrum disorder, speech and language disorder, chronic health conditions), and a range of severity of physical, cognitive and psychosocial impairments.

The majority of respondents were mothers (91%), Caucasian (81%) and lived in families with household incomes of > \$60,000 (75%).

Respondent education was high – 81% reported that they had completed college or university.

Most families lived in major urban (45%) or suburban areas (33%) in greater Boston, MA and southern Ontario.

## About the PEM-CY

The PEM-CY is a caregiver-report instrument that examines: 1) children's participation in home, school and community activities, and 2) environmental factors that support or hinder participation in home, school and community settings.

### Participation Items

• Items are general categories or types of activities that were identified from an extensive literature review, interviews with children with and without disabilities and their parents.<sup>6,7</sup> Items are specific to each setting: Home activities (e.g., indoor play and games, watching TV, and household chores); School activities (e.g., classroom activities, school-sponsored teams, clubs and organizations, and getting together with peers outside of class); and Community activities (e.g., neighborhood outings, unstructured physical activities, and classes and lessons).

• Participation items are all rated in three ways:

- **Frequency** (*How often does your child participate in one or more activities of this type?*) – Responses range from 0 (Never) to 7 (Daily)
- **Involvement** (*Typically, how involved is your child when doing these activities?*) – Responses range from 1 (Minimally) to 5 (Very involved)
- **Desire for Change** (*Would you like your child's participation to change in this type of activity?*) – Responses are Yes or No; if yes, parent is asked to indicate the type of change (e.g., more or less frequency, more or less involvement and/or more or less variety)

### Environment Items

• Items are specific to and common across each setting such as physical layout, demands of activities, attitudes and actions of others, adequate and available services, transportation, safety, financial resources, support from others, and having time to support the child's participation.

• Environment (*Environment Supportiveness*) items are rated in one of two ways:

- **Degree of support** (Not an issue, Usually helps, Sometimes helps /Sometimes Makes harder, Usually makes harder)
- **Having available or adequate resources** (Not needed, Usually yes, Sometimes yes/sometimes no, Usually no)

## Internal Consistency & Test-Retest Reliability

**Internal Consistency** was moderate to very good ( $\alpha = 0.59$  to  $0.91$ ) for the different PEM-CY rating scales across settings:

- **Participation Frequency:** 0.59 to 0.70
- **Participation Involvement:** 0.72 to 0.83
- **Environment Supportiveness:** 0.83 to 0.91

**Test-Retest Reliability** was moderate to very good (ICC = 0.58 to 0.95) for the different PEM-CY summary scores across settings:

- **Participation Frequency** (% maximum possible): 0.58 to 0.84
- **Never participates** (% of "Never" answers on frequency scale): 0.66 to 0.92
- **Participation Involvement** (average of items): 0.69 to 0.76
- **Desires participation change** (% of "yes" responses): 0.76 to 0.89
- **Environment Supportiveness** (% maximum possible): 0.85 to 0.95

## Differences Between Children With and Without Disabilities Across Home, School & Community

| PEM-CY Scores                | HOME                 |                      |      | SCHOOL               |                      |      | COMMUNITY            |                      |      |
|------------------------------|----------------------|----------------------|------|----------------------|----------------------|------|----------------------|----------------------|------|
|                              | Disability Mean (SD) | Disability Mean (SD) | ES*  | Disability Mean (SD) | Disability Mean (SD) | ES*  | Disability Mean (SD) | Disability Mean (SD) | ES*  |
| Participation Frequency      | 83.01 (11.55)        | 88.03 (7.20)         | .54  | 65.29 (15.68)        | 72.11 (10.83)        | .51  | 54.50 (13.15)        | 63.29 (9.94)         | .76  |
| Never Participates           | 14.06 (20.07)        | 1.88 (4.31)          | 1.0  | 33.60 (24.52)        | 16.26 (15.55)        | .87  | 41.37 (20.12)        | 23.35 (14.78)        | 1.03 |
| Participation Involvement    | 3.44 (0.79)          | 3.89 (0.54)          | .67  | 3.35 (1.03)          | 4.21 (0.70)          | .99  | 3.53 (0.93)          | 4.16 (0.56)          | .84  |
| Desires Participation Change | 67.18 (26.54)        | 53.51 (25.97)        | .52  | 70.36 (29.80)        | 38.82 (31.85)        | 1.02 | 63.19 (26.01)        | 38.00 (26.15)        | .97  |
| Environment Supportiveness   | 70.07 (14.91)        | 86.43 (11.48)        | 1.24 | 72.89 (12.40)        | 87.55 (10.71)        | 1.27 | 66.37 (14.15)        | 88.05 (10.87)        | 1.73 |

\* ES=Effect Size: Small = .20 to .49; Moderate = .50 to .79; Large ≥ .80

There were moderate to large and statistically significant ( $p \leq 0.01$ ) differences between the children and youth with and without disabilities for all participation and environment scores (see table above). The largest differences (effect sizes) were in the Environment Supportiveness scores across all settings followed by the Never Participates scores. Results from the two-way ANOVA (not reported above) identified some significant age differences for the total sample, but these did not follow a consistent pattern. There were no interaction effects between age and disability group.

## DISCUSSION & IMPLICATIONS

- These findings support the reliability and validity of the PEM-CY as a measure of the important constructs of participation and environment across a broad population of children and youth both with and without disabilities.
- Results showed large differences in participation and overall environment supportiveness between children and youth with and without disabilities across all three settings. This is consistent with other reports in the literature that have documented the challenges faced by children with disabilities.<sup>4</sup> These challenges were revealed in lower frequencies of participation in various types of activities, lower general level of involvement when participating in these activities, and less overall environmental supportiveness as perceived by caregivers.
- There were few significant differences between age groups when the sample was considered as a whole.

## LIMITATIONS

- Data were collected exclusively over the Internet. It is not known if the same results would be obtained from a paper-and-pencil survey.
- The re-test sample was relatively small.
- Our overall sample was large, but it was not randomly selected. In particular, socio-economic level and race/ethnicity were not reflective of the general population in either country.
- Results reflect caregivers' perspectives, thus children's perspectives are not fully represented.

## FUTURE DIRECTIONS

The PEM-CY is a unique new instrument that can be used to improve our understanding of the participation of children and youth with and without disabilities and the environmental factors that support or hinder their participation in home, school, and community.

The PEM-CY is feasible for use in large-scale data collection efforts and thus can support population-level studies to examine similarities and differences in participation across groups of children and youth, and across settings that differ in geography, resources, or organization.

Further studies on the consistency of responses across time and with different formats (e.g., a paper and pencil version) are clearly needed. In addition, studies involving a more diverse sample in terms of socio-economic level, race / ethnicity and geographic location are needed. Further inquiry about how the PEM-CY could be used in clinical practice would be important as well.

The PEM-CY will be available for research and clinical practice use free of charge in the near future. Check our websites for updates: [www.childd.ca](http://www.childd.ca) and [www.bu.edu/kidsincontext](http://www.bu.edu/kidsincontext)

## SELECTED REFERENCES

1. King, G., Law, M., King, S., Rosenbaum, P., Kertzy, M.K., & Young, N. (2003). Conceptual model of the factors affecting recreation and leisure participation of children with disabilities. *Physical and Occupational Therapy in Pediatrics*, 23, 63-90.
2. Eccles, J.S., Barber, B.L., Stone, M., & Hunt, J. (2003). Extracurricular activities and adolescent development. *Journal of Social Issues*, 59, 865-889.
3. Bedell, G.M., & Dumas, J.M. (2004). Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: A follow-up study. *Brain Injury*, 18, 65-82.
4. Michelsen, S.I., Flachs, E.M., Uldall, P., Eriksen, E.L., McManus, V., Parkes, J., et al. (2009). Frequency of participation of 8-12 year-old children with cerebral palsy: a multi-centre cross-sectional European study. *European Journal of Paediatric Neurology*, 13(2), 165-177.
5. Law, M., Petrucci, T., King, G., & Hurley, P. (2007). Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Archives of Physical Medicine & Rehabilitation*, 88(12), 1636-42.
6. Coster, W., Law, M., Bedell, G., Khetani, M., Cousins, M., & Teplicky, R. (2010). Development of the Participation and Environment Measure for Children and Youth (PEM-CY): Conceptual basis. *Manuscript submitted for publication*.
7. Bedell, G., Khetani, M.A., Cousins, M., Coster, W., & Law, M. (in press). Parent perspectives to inform development of measures of children's participation and environment. *Archives of Physical Medicine and Rehabilitation*.
8. Coster, W., Bedell, G., Law, M., Khetani, M.A., Teplicky, R., Liljenquist, K., ... Kao, Y.C. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth (PEM-CY). *Developmental Medicine & Child Neurology*. *Manuscript accepted for publication*.

**Acknowledgements:** Funding from the U.S. Department of Education, National Institute on Disability and Rehabilitation Research, Grant # H133G070140-09