

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



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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^{1,2}. The participation of children and youth with disabilities is often restricted³. Physical and social environmental factors can both support and hinder children's participation.^{4,5}

- There is a great need for measures that:
- 1) are suitable for a variety of purposes including population-based surveys, program outcome and intervention studies, and individualized child and family-centered intervention planning
 - 2) Capture ways that parents understand and judge participation
 - 3) Explicitly link participation and environment in the same measure

The *Participation and Environment Measure for Children and Youth (PEM-CY)* was designed to address this need.^{6,7}

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

METHODS

Data was 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.

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

Differences in PEM-CY scores between children with and without disabilities were examined via two-way ANOVAs. Correlations were conducted to examine the association between extent of desire for change and perceived supportiveness of the environment

PARTICIPANTS

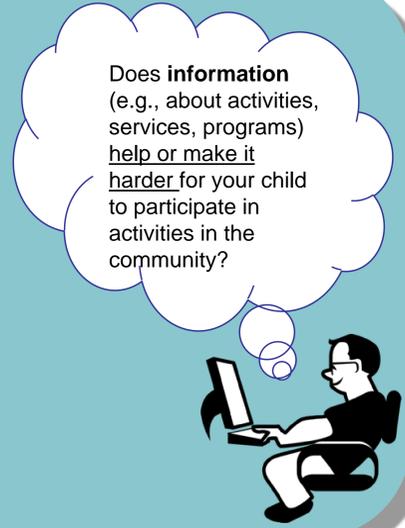
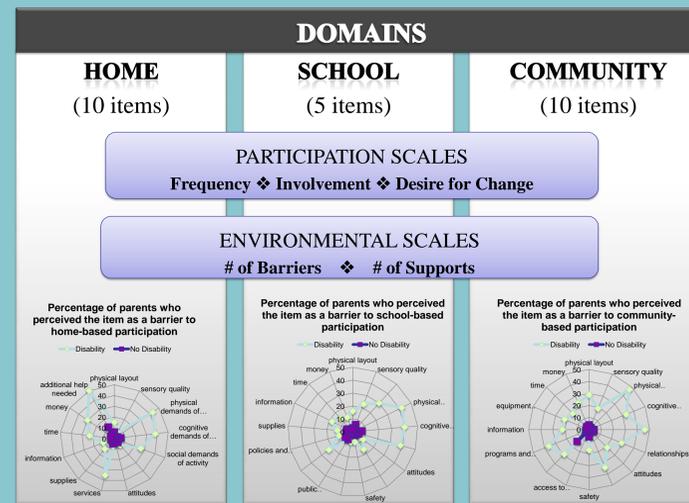
- Data were collected on 576 children and youth.
- Ages ranged from 5 to 17 years (Mean = 11.16; SD = 3.08)
 - 37% were from the USA and 63% were from Canada
 - 54% were male and 46% were female
 - 49% had a disability and 51% did not

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 Caucasian (81%) and lived in families with household incomes of > \$60,000.
- Respondent education was high – 81% 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

- Parents report
- 25 minutes
- 25 activities
- 5-17yrs
- Web-based/pencil and paper
- English/French
- Population- based



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 | | |
|------------------------------|------------------|------------------|------|------------------|------------------|-----------------|-------------------|------------------|------|
| | Yes | No | ES* | Yes | No | ES ¹ | Yes | No | 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 \geq .80; all differences were significant at the level of 0.01

! Significant negative association between desire for change and environmental supportiveness (-0.42 < r < -0.59)

DISCUSSION & IMPLICATIONS

- These findings support the reliability and validity of the PEM-CY as a measure of the 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.⁴ 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.

LIMITATIONS

- Data was collected exclusively using a web-based version. 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 representative 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 provides useful information for parents, clinicians, program managers and researchers.

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 organizations.

Further studies on the consistency of responses across time and with different formats (e.g., a paper and pencil version) are clearly needed. Studies involving a more diverse sample in terms of socio-economic level, race / ethnicity and geographic location are needed.

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.canchild.ca and www.bu.edu/kidsincontext

SELECTED REFERENCES

1. King, G., Law, M., King, S., Rosenbaum, P., Kertoy, 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. Law, M., Anaby, D., Dematteo, C., & Hanna, S. (2011). Participation patterns of children with acquired brain injury. *Brain Injury*, 25(6), 587-595.
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), 165-77.
5. Law, M., Petrenchik, 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. (2012). Development of the Participation and Environment Measure for Children and Youth: Conceptual basis. *Disability and Rehabilitation*, 34(3), 238-246.
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. *Developmental Medicine & Child Neurology*, 53(11), 1030-1037.

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