

Fostering Knowledge about Participation in Occupations for Children and Youth: Processes and Outcomes of a Knowledge Translation Project

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SC 132
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Participation & Environment

Research Team & Sponsors

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Since 2007, we have received funding from the National Institute on Disability and Rehabilitation Research (NIDRR) and Canadian Institutes of Health Research (CIHR)



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Short Course Objectives

1. Define Knowledge Translation (KT)
2. Describe why and how we used the KTA framework to guide the development of the Participation Knowledge Hub
3. Identify evaluation strategies that we are using to assess for uptake and exchange of knowledge via the Participation Knowledge Hub

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Straddling the Knowledge-to-Action (KTA) Gap



(AHRQ, 2001; CIHR, 2004; Graham et al., 2006; Sudsawad, 2013)

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Strategies for Bridging the KTA Gap

- Knowledge Translation – i.e., mechanism for impact
 - End-of-grant
 - Integrated

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Defining Knowledge Translation

"the **exchange, synthesis, and ethically-sound application** of knowledge - within a **complex set of interactions** among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system."

Canadian Institutes of Health Research

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Defining Knowledge Translation (cont'd)

"the **collaborative and systematic** review, assessment, identification, aggregation and practical application of **high-quality** disability and rehabilitation research by key stakeholders (i.e., consumers, researchers, practitioners, policy makers) for the purpose of improving lives of individuals with disabilities"

National Center for the Dissemination of Disability Research (NCDRR)

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Core Requirements for Effective KT

Who:

- The dissemination **source** must be perceived as competent, credible and trustworthy
- The intended **user** must perceive the relevance of the materials to their own needs, and understand the material in the context of their work.

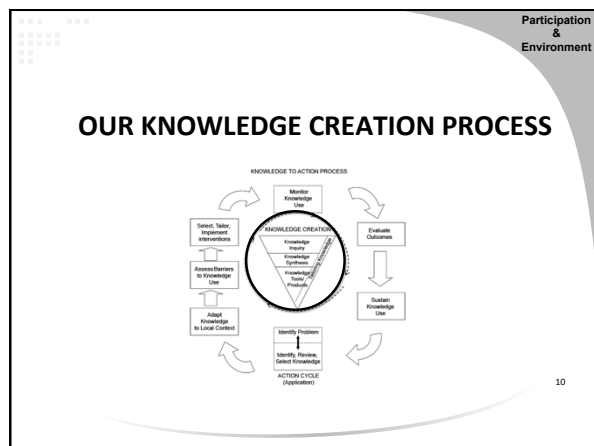
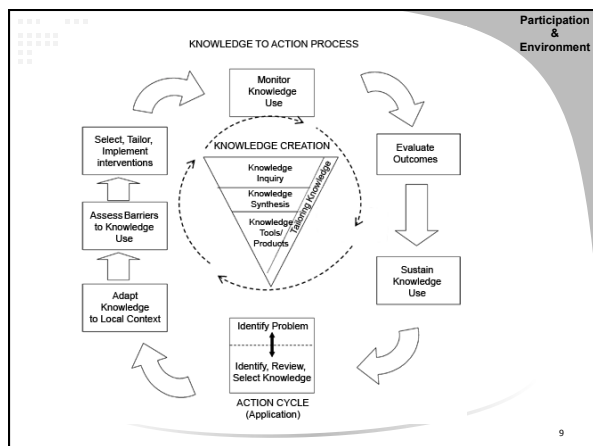
What:

- The **content** must be perceived as relevant, usable, methodologically sound, and comprehensive to users.

When and How:

- The **medium** must be timely, accessible, user-friendly and clearly understandable.

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Need for New Measures of Children's Participation and Environment

- Participation is an important outcome for children and youth. Participation is associated with children's health and well-being, reduction in health and social risk factors, and development of skills and relationships
- Children's participation influenced by child-related factors (e.g., age, gender), family-related factors (e.g., income) and environmental factors
- Children's environments may be amenable to change but has rarely been the primary focus of intervention
- Few available measures of children's participation and environment that are grounded in ICF and suitable for use in large-scale research to identify participation patterns and environmental supports and barriers to participation
- Ambiguity in ICF-CY about how to define participation and environment
- Family perspectives are often excluded in the design of measures

Coster & Khetani, 2008; Darrah, et al., 2012; King, et al., 2003; Larson & Verma, 1999; Law, 2002; Tseng & Seldman, 2002; Weisner, 2002; WHO, 2007; WHO & World Bank, 2011

Challenges Bring Opportunities

There are unique opportunities for researchers, service providers, 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 children and youth of diverse ages, disabilities, and backgrounds


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THE PARTICIPATION AND ENVIRONMENT MEASURE FOR CHILDREN AND YOUTH (PEM-CY)

2007-2010

Investigators: Coster (Lead PI), Law, Bedell
Study Coordinators: Khetani, Cousins, Teplicky

Grant # H133G070140, PO # GC 201985



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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 the child had a disability or not
- Environmental Factors:**
 - Parents identified a broader range of environmental factors 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
 - Experience of participation is inextricably linked with the environment
 - Appraising participation and environment naturally lends itself to a conversation about parents' strategies to promote participation

Bedell, G. M., Khetani, M., et al., 2011

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PEM-CY

- Parent-report - takes 20-30 minutes to complete
- Appropriate for parents of children and youth, ages 5 to 17, with and without disabilities
- 3 sections: Home (10 items), School (5 items), and Community (10 items)
- Each section asks about participation and environment, and parent strategies to promote participation in that setting

Coster, Law, & Bedell, 2010

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HOME Participation

A1 Typically, how often does your child participate in each of the following activities?
CHECK ONE RESPONSE: 1 2 3 4 5

B1 Think about each of the activities that your child participates in most often. Typically, what strategies do you use when your child does these activities?
CHECK ONE RESPONSE: 1 2 3 4 5

C1 Would you like your child's participation to change in the future or activity?
IF YES, CHECK ALL THAT APPLY: 1 2 3 4 5

Item	1	2	3	4	5
11 Conversation and other games e.g., board games, card games, or board games, playing board or card games					
12 Indoor play and games e.g., playing with blocks, puzzles, or board games, playing board or card games					
13 Reading, writing, and other school activities e.g., reading, writing, or other school activities, reading, writing, or other school activities					
14 Watching TV, videos, and DVDs e.g., watching TV, videos, or DVDs					
15 Getting together with other people e.g., hanging out with friends, meeting with friends					
16 Spending time using technology e.g., using a computer, using a tablet, using a smartphone					
17 Household chores e.g., sweeping, mopping, dusting, vacuuming, washing, and other household chores, sweeping, mopping, dusting, vacuuming, washing, and other household chores					
18 Personal care management e.g., getting dressed, brushing teeth, washing hair or hands, washing, brushing teeth, washing hair or hands					
19 School participation (see item 13) e.g., getting ready for school, going to school, participating in school activities, getting ready for school, going to school, participating in school activities					
20 Homework e.g., doing homework, reading assignments, doing homework, reading assignments					

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PEM-CY Home Section - 3 of 3

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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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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

	Not at all	Usually helps	Sometimes helps, sometimes makes harder	Usually makes harder
1) Computer and video games				
2) Indoor play and games				
3) Arts, crafts, music, and hobbies				
4) Watching TV, videos, and DVDs				
5) Getting together with other people				
6) Reading and writing				
7) Household chores				
8) Personal care management				
9) School preparation (not homework)				
10) Homework				

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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

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HOME Environment

Do the following things help or make it harder for your child to participate in activities at home?
CHECK ONE RESPONSE

	Not at all	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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Participation & Environment

Do the following things help or make it harder for your child to participate in activities at home?

CHECK ONE RESPONSE

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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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?

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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.

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How does the PEM-CY Perform?

- **Reliable and valid for children and youth 5-17 years**
 - Internal consistency was 0.59 to 0.91
 - Test-retest reliability had ICC = 0.58 to 0.95
 - Construct validity supported by clinically important and statistically significant differences between groups of children with and without disabilities across all participation and environment scales
 - Moderate to strong associations between the PEM-CY Environmental Support score when compared to summary scores on a criterion instrument, the CHIEF for Children ($r = -0.46$ to -0.60)

Coster, W. J., Bedell, G., et al., 2011; Khetani, et al., under review.

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Using the PEM-CY to Generate New Knowledge about Children's Participation

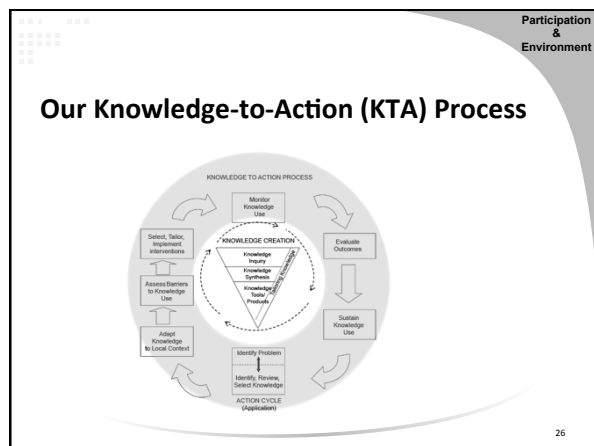
- **Descriptive analyses of responses within, between, and across settings**

UPCOMING POSTER PRESENTATIONS – PO 7076 (Saturday 12:30-2:30); RWP 4002 (Friday 2:30-4:30); and PO 3053 (Friday 9:00-11:00)

- **Additional studies in progress**
 - Predictors of participation frequency, involvement, and desire for change
 - Further validate the PEM-CY with larger and more diverse samples in terms of SES, race/ethnicity, geographic region
 - Examine differences in participation and environmental supports/barriers in relation to diagnosis, and type and severity of impairment

Bedell, Coster, et al., 2013; Law, Anaby, Teplicky, Khetani, et al., 2013; Coster, Liljenquist, et al., in press

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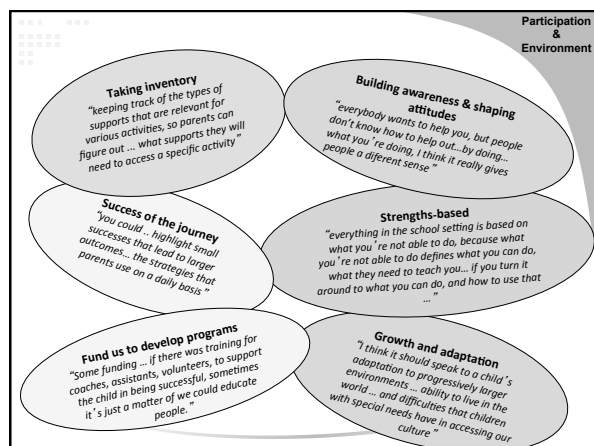


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KTA Step 1: Identify the Problem

- **We have a tool that could be helpful for:**
 - researchers to use in large-scale population-based research studies
- **We think that the PEM-CY might also be helpful for:**
 - parents to gain valuable information about their child's participation and what supports/limits participation
 - service providers to define therapeutic goals and engage in collaborative goal setting with parents and children together.
- **There is need for credible and easy-to-access tools and knowledge about child and youth participation (from this and other tools) by all 3 stakeholders**

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PARTICIPATION KNOWLEDGE HUB

2011-2012

Investigators: Law (Lead PI), Coster, Bedell, Anaby, & Khetani
Knowledge Brokers: Teplicky, Lin, Turner




CIHR IRSC
Canadian Institutes of Health Research / Institut de recherche en santé Canada

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KTA Step 2: Adapt Knowledge to Local Context KTA Step 3: Assessing Barriers and Supports



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KT Stakeholder Meeting (April 2012)

- **Day 1:** Semi-structured dialogue with parents (n=5), service providers (n=5), a researcher and a KT specialist
 1. Meeting agenda and overview of topic mailed to each participant
 2. Presentation focused on what we had learned about children's participation and environment via PEM-CY development
 3. Large Group Brainstorming: What do you want to know about child and youth participation?
 4. Small Group Discussion: How would you like to receive information about child and youth participation?
- **Day 2:** 1-hour webinar to 62 service providers, program directors, educators and researchers world-wide to introduce the PEM-CY

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Results from Stakeholder Meeting:

- **What is needed:**
 1. Knowledge Hub with tailored layout for diverse user groups (parent, practitioner, researcher)
 2. Downloadable PEM-CY with automated scoring and reports, space for note-taking
 3. PEM-CY Translations
 4. Tip Sheets and Educational Modules
- **Anticipated Barriers to Uptake:**
 - Limited time and human resources
 - Lack of access to research
 - Findings not easily translated into practice

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Task 1: Participation Knowledge Hub

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Task 2: PEM-CY – Downloadable Version for Parents

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Task 2: PEM-CY – Downloadable Version for Parents

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Task 2: PEM-CY – Automatic Reporting

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	At Home	At School	In the Community
Watching tv, getting together with other people	Classroom activities	Neighborhood activities	Community events
		School sponsored teams...	Organized physical activities
			Unstructured physical activities
			Clubs or lessons (not school sponsored)

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Task 3: PEM-CY Translations

Completed	In Progress
Spanish	Chinese
French	Dutch
Korean	Hebrew
	Icelandic
	Portuguese
	Slovene
	Turkish

- The PEM-CY is currently being used in 17 additional research studies or proposals.

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Task 4: Tip Sheets & Resources

Participation 101

MAKING IT WORK + WHEN TO MOVE ON...

In a perfect world, participation in leisure activities would always be the right mix of challenge, enjoyment and fun. However, in the real world, extra-curricular activities can involve tears, stress and feelings of dread on the part of both children and parents alike. While it is important to face challenges and to keep trying during difficult times, it is also important to make a confident decision about when to move on. Here are some things to consider when deciding whether to stick it out, or to move on and try another activity, or the same or similar activity at another time. By breaking down the issues it may be easier to identify which things will be easier to change and which may be harder to change – this may influence your decision about when to move on.

Factors related to your child/young adult:

Is your child interested and motivated to participate in this activity?

- Remember that enjoyment of an activity doesn't always happen right away, especially when the activity is new.

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Task 4: Tip Sheets & Resources

I Want to Participate In...

Hockey

You can help me to participate successfully in hockey by thinking about:

The way you interact with me:

- giving me short, simple, step-by-step instructions
- giving me more time to understand you
- using pictures to show me what you would like me to do
- showing me how to do the activity while using words to describe it
- praising me when I make progress
- giving me hand-over-hand assistance
- giving me clear and specific feedback about my performance (e.g., 'shoot the puck at the net', instead of 'shoot the puck')
- _____
- _____

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Task 4: Tip Sheets & Resources

Participation Information for Programs + Agencies

Art Lessons

Child's Name: _____ Age: _____

Our goal is to provide a positive experience for your child by understanding how we can best help him or her to participate successfully in **visual art lessons**. Thank you for taking the time to complete the questions below and we welcome your comments and feedback about our program.

What are your child's goals for this art program? Please choose from the list provided and/or add comments below.

I would like my child to:

- learn to enjoy and appreciate art
- learn to respond to and talk about art
- learn a variety of, or a specific art technique(s) (please note: _____)
- work on co-operation in a group setting

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KT Step 5: Monitor Knowledge Use KT Step 6: Evaluate Outcomes

KT Task	VALIDATION STRATEGY
Knowledge Hub	Web analytics to monitor frequency and duration of visits
PEM-CY with automated scoring	CanChild Usability Survey
PEM-CY Translations	Structured translation process involving back-translation, cultural adaptation and validation (for some languages)
Tip Sheets and Resources	CanChild Usability Survey

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CanChild Usability Survey

Asks about:


- Respondent’s familiarity with the topic
- Layout and format of the resource
- Content and usefulness of the resource
- Sample questions – rated on a scale from 1 (strongly disagree) to 7 (strongly agree)
 - This material **increased my understanding** of the topic.
 - This material will **influence the things that I do** when I am working with others.

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Participation Knowledge Hub: Future Directions!

- Online data collection using the PEM-CY for use by programs and agencies
- Preliminary Studies to Explore the Utility of the PEM-CY for Intervention Planning
- Psychometric and Cultural Validation of a Young Children’s Participation and Environment Measure (YC-PEM)




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Request for Feedback



- What do you want to know about child and youth participation?
- How would you like to receive information on child and youth participation to support your work?
- How would you want to engage with this Hub?

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For more information about the PEM-CY or Hub:

- Rachel **Teplicky**, Research Coordinator
- **Phone:** 905-525-9140, ext.26851
- **E-mail:** teplcr@mcmaster.ca

For more information about the YC-PEM:

- **Mary Khetani**, Director, Children's Participation & Environment Research Lab
- **Phone:** 970-491-6349
- **E-mail:** mary.khetani@colostate.edu
- **Weblink:** <http://www.cperl.colostate.edu>

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References

Agency for Health Research and Quality (AHRQ) (2001). Translating research into practice (TRIP)-II. Washington, DC: Agency for Health Research and Quality. <http://www.ahrq.gov/research>.

Bedell, G., Coster, W.J., Law, M., Liljenquist, K., Kao, Y.-C., Teplicky, R., Anaby, D., & Khetani, M.A. (2012). Community participation, supports and barriers of school age children with and without disabilities. *Archives of Physical Medicine and Rehabilitation*. DOI: [10.1016/j.apmr.2012.09.024](https://doi.org/10.1016/j.apmr.2012.09.024)

Bedell, G. M., Khetani, M. A., Cousins, M., Coster, W. J., & Law, M. (2011). Parent perspectives to inform development of measures of children's participation and environment. *Archives of Physical Medicine and Rehabilitation*, 92, 765-773. doi: 10.1016/j.apmr.2010.12.029.

Canadian Institutes of Health Research (CIHR). (2004). *Knowledge translation strategy 2004—2009: Innovation in action*. Ottawa, ON: Canadian Institutes of Health Research.

Coster, W. J., Bedell, G., Law, M., Khetani, M. A., 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 and Child Neurology*, 53(11), 1030-1037. doi: 10.1111/j.1469-8749.2011.04094

Coster, W., & Khetani, M.A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability and Rehabilitation*, 30, 639-648.

Coster, W., Law, M., Bedell, G.M., Liljenquist, K., Kao, Y.-C., Khetani, M.A., & Teplicky, R. (in press). School participation, supports, and barriers of students with and without disabilities. *Child: Care, Health and Development (Special Issue)*.

Coster, W., Law, M., Bedell, G., Khetani, M.A., 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.

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References (cont'd)

Graham, I., Logan, J., Harrison, M., Straus, S., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *Journal of Continuing Education in the Health Professions*, 26, 13-24.

Khetani, M.A., Marley, J., Baker, M., Albrecht, E., Bedell, G., Coster, W., Anaby, D., & Law, M. (under review). Validity of the Participation and Environment Measure for Children and Youth (PEM-CY) for Health Impact Assessment in Sustainable Development Projects.

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.

Law, M., Anaby, D., Teplicky, R., Khetani, M.A., Coster, W., & Bedell, G. (2013). Participation in the home environment among children with and without disabilities. *British Journal of Occupational Therapy (Special Issue)*, 76(2), 58-66.

National Center for Dissemination of Disability Research (NCDDR). What is knowledge translation? Technical brief number 10. 2005. Available at: http://www.ncddr.org/knowledge_trans_over.html

Sudswad, P. (2002). Knowledge translation: Introduction to models, strategies, and measures. Available at: http://www.ktdrr.org/ktlibrar/articles_pubs/ktmodels/index.html

Tseng, V. & Seidman, E. (2007). A systems framework for understanding social settings. *American Journal of Community Psychology*, 39, 217-228.

Weisner, T. (2002). Ecocultural understanding of children's developmental pathways. *Human Development*, 45, 275-281.

World Health Organization (2001). *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: WHO.

World Health Organization and World Bank (2011). *World Report on Disability*. Geneva, Switzerland: WHO.

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