

# Measuring and Promoting Participation of Children & Youth with ABI

**Gary Bedell, PhD, OTR/L, FAOTA**  
**Department of Occupational Therapy**



# Disclosures

**Dr. Gary Bedell has no interest to disclose.**

**PESG and IBIA staff have no interest to disclose.**

**This continuing education activity is managed and accredited by Professional Education Services Group in cooperation with IBIA. PESG, IBIA, and all accrediting organization do not support or endorse any product or service mentioned in this activity.**

# My Experience

- Occupational Therapy
- Interdisciplinary teams
- Measurement development
- Rehabilitation outcomes research
- Mixed methods research
- Consultation
- Teaching
- Intervention development

# Key Objectives

1. Discuss what “participation” is (*and might be*) and why it is important
2. Give overview on participation of children & youth with ABI and factors associated with their participation
3. Describe selected measurement conceptual, methodological and practical considerations
4. Guide efforts for selecting measures of participation of children & youth with acquired brain injuries (ABI)
5. Demonstrate how measurement guides efforts to promote participation of children and youth with ABI

# Participation: What it is & why important

- **“Involvement in life situations”**

*International Classification of Functioning, Disability & Health (ICF)  
(WHO, 2001, 2007)*

- **Multi-dimensional & universal**

*(Coster & Khetani, 2008; Larson & Verma, 1999; Law, 2002; McConachie, et al., 2006;).*

- **Intersection of person-task-environment**

*(King, et al., 2003; Law, 2002; Mallinson & Hammel, 2010)*

- **Key aim of rehabilitation, education & community programs**

*(Bedell & Dumas, 2004; Fougereyrollas, et al., 2014; King, et al., 2003; Law, 2002; Mallinson & Hammel, 2010)*

# Means to End

- Enables children to interact, work and live with others and function in society

*(Law, 2002; Larson & Verma, 1999; Mahoney, et al., 2003)*

- Associated with enhanced quality of life, social competence and educational

**success** *(Bedell & Dumas, 2004; Eccles, et al., 2003; King, et al., 2003; Larson & Verma, 1999; Law, 2002; Mahoney, et al., 2003; Simeonsson, et al., 2001).*

- Emphasis on participation in activities that promote **skill development**, and provide a **sense of accomplishment** and **enjoyment**

*(Eccles, et al., 2003; Fletcher, et al., 2003; Mahoney, et al., 2003; Rutter, 1987).*

# Participation of children with ABI

- Children & youth with ABI often restricted in their participation in school, home, and community life
- Associated factors:
  - Severity of injury, age, age of / time since injury, physical /social environment factors, type & level of impairment, functional skills

*(Anaby, et al., 2012; Bedell, 2009; Bedell & Dumas, 2004; De Kloet, et al., 2015; Dematteo et al., 2008; Fougeyrollas, et al., 2014; Galvin, et al., 2010; Law et al., 2011; Rivara, et al., 2012; Shuhua Foo, et al., 2012; Van Tol, et al., 2011; Wells, et al., 2009)*

- Children / youth with ABI and parents use strategies to promote participation despite obstacles

*(Bedell, et al., 2005; 2011; DeMatteo, et al., 2008; Dumas, et al., 2004; Gauvin-Lepage & Lefebvre, 2010; Glang et al., Mealings, et al., 2012; Sharp, et al., 2006)*

# Measurement: Conceptual, practical & methodological considerations

- Ambiguity in the ICF on what & how to measure
- One measure does not fit all purposes (**trade-offs**)
- Stakeholders cannot wait for the “perfect” measure



# Ambiguity in ICF

- **Same ICF domains used to classify Activity & Participation**
  - Hard to distinguish between the two (*see table*)
- **Participation broadly defined:**  
*“Involvement in life situations”*
  - What are the important “life situations”?
  - How do we measure “involvement”?

<b>*ICF DOMAINS</b>	<b>ACTIVITY &amp; PARTICIPATION (SUB-DOMAINS)</b>
<b>1. Learning &amp; Applying knowledge</b>	Purposeful sensory experiences; Basic learning; Applying knowledge
<b>2. General Tasks &amp; Demands</b>	Undertaking a single task; Undertaking multiple tasks; Carrying out daily routines; Handling stress & other psychological demands
<b>3. Communication</b>	Communicating-receiving; Communicating-producing (spoken & nonverbal); Conversation & use of communication devices & techniques
<b>4. Mobility</b>	Changing and maintaining body position; Maintaining a body position; Transferring oneself; Carrying, moving & handling objects; Walking & moving; Moving around using transportation
<b>5. Self-care</b>	Washing oneself; Caring for body parts (grooming); Toileting; Dressing; Eating; Drinking; Looking after one's health
<b>6. Domestic Life</b>	Acquisition of necessities; Household tasks; Caring for household objects and assisting others
<b>7. Interpersonal Interactions &amp; Relationships</b>	General (basic & complex) interpersonal interactions; Particular interpersonal interactions (Relating with strangers, Informal & formal social relationships, Family relationships, Intimate relationships)
<b>8. Major Life Areas</b>	Education; Work & employment, Economic life
<b>9. Community, Social &amp; Civic Life</b>	Community life, Recreation & leisure, Religion & spirituality, Human rights, Political life & citizenship <span style="float: right;"><i>*WHO, 2002, 2007</i></span>

# Differentiating Activity & Participation

## Activity

- Execution of task or action
- First 5 ICF domains
- Capacity

**What child can do**

## Participation

- Involvement in life situations
- Last 4 ICF domains
- Performance

**What child does do**

WHO, 2002, 2007; Dijkers, 2010;  
Whiteneck & Dijkers, 2009

# Social Participation & Participation

- Often used interchangeably
- **Social participation**: “taking part, involvement, engagement, doing or being with others” (Bedell, 2012)
- **Participation** involvement in activities that can be done **with or without others**

# What is important to measure?

- **Key themes important to children's well-being:**  
1) essential for survival, 2) supportive of child development, 3) discretionary, & 4) educational (McConachie, et al., 2006)
- **Directed toward meaningful & setting-specific goals:** 1) sustenance & physical health, 2) development of skills & capacities, & 3) enjoyment & emotional well-being (Coster & Khetani, 2008)
- **Performance or fulfillment of social or societal roles** (Whiteneck & Dijkers, 2009).

# Measurement:

## Varied Purposes & Levels of Focus

- **Descriptive** (describe patterns / profiles, strengths, restrictions, supports, barriers)
- **Discriminative** (differences among groups)
- **Evaluative** (change over time or related to action)

### → **To inform decision:**

- **Individualized** intervention or action planning
- **Program** development, evaluation, quality improvement
- **Population** surveillance to inform policy

\*Can have more than one purpose & focus

# Key considerations in selecting measures & approaches

- Stakeholders' information goals
  - What do you want to know?
- Best available research evidence
  - reliability, validity, responsiveness to change
- Feasibility & acceptability
  - How you can and want to measure it
    - Institutional resources and constraints
    - Respondent/administrative burden
    - Social and ecological validity
    - Philosophy/ethos

# Other considerations

- **Quantity:** How often?, How involved? How able? How confident? How important? How satisfied?
- **Quality** (key characteristics, with whom? where? how?)
- **Strengths**-based (*participation*) or **deficit**-based (*restriction*) or **both**
- **Whose view?** (child, family, peers, professionals, others)
- **Multiple or specific settings or domains** (home, school, community, social, sports, household management)



# More Considerations...

- Broad or discrete activities?
- How to account for age, developmental transitions, recovery?
- Are normative standards needed?
- Comparison to same-age peers (*or serve as own comparison*)?
- Is there a threshold of optimal participation?
- What level of precision is needed for your purposes?

# Selected measures & approaches

1. **Explicitly** assess participation
2. **Implicitly** assess participation
  - Sections / items from other measures
3. **Tailored** approaches
  - Linked to person / family-centered goals, intervention / program / research goals

<b>Explicit Participation measures</b>	<b>Implicit Other measures</b>	<b>Tailored approaches</b>
Children's Assessment of Participation & Enjoyment (CAPE)	Vineland Adaptive Behavior Scales II (VABS II)	<ul style="list-style-type: none"> <li>•Goals &amp; objectives</li> <li>•Goal Attainment Scaling (GAS)</li> <li>•Canadian Occupational Performance measure (COPM)</li> </ul>
Assessment of Life Habits for Children (Life-H)	Child Behavior Checklist (CBCL)	Clinimetric Approach
School Function Assessment (SFA)		Focused Observation
<b>Child &amp; Adolescent Scale of Participation (CASP)</b>		Focused intervention or program specific ratings
<b>Participation &amp; Environment Measure for Children &amp; Youth (PEM-CY)</b>		Focused Interview

<p>Children's Assessment of Participation &amp; Enjoyment (CAPE)</p>	<ul style="list-style-type: none"> <li>• <b>Recreation &amp; leisure outside of school (6-21; child/youth report)</b></li> <li>• Diversity (# activities), frequency, with whom, where, enjoyment, *Preferences</li> </ul>
<p>Assessment of Life Habits for Children (Life-H)</p>	<ul style="list-style-type: none"> <li>• <b>Daily living &amp; Social Roles (5-17; parent report)</b></li> <li>• Level of accomplishment (difficulty &amp; assistance) &amp; Satisfaction</li> </ul>
<p>School Function Assessment (SFA)-Participation</p>	<ul style="list-style-type: none"> <li>• <b>Elementary school participation (5-12 years, teacher/therapist report)</b></li> <li>• Extreme Limitation to full participation</li> </ul>
<p><b>Child &amp; Adolescent Scale of Participation (CASP)</b></p>	<ul style="list-style-type: none"> <li>• <b>Home, school, community compared to same age (broad age range; parent &amp; youth)</b></li> <li>• Age-expected/full participation to unable; open ended questions</li> </ul>
<p><b>Participation &amp; Environment Measure for Children &amp; Youth (PEM-CY)</b></p>	<ul style="list-style-type: none"> <li>• <b>Participation &amp; environment in home, school &amp; community (5-17; parent report)</b></li> <li>• Frequency, involvement, Desire Change, Environmental supports &amp; barriers, strategies</li> </ul>

# Implicit Participation Measures:

## Subscales (items) from other measures

1. Vineland Adaptive Behavior Scales II (VABS II)
2. Child Behavior Checklist (CBCL)

# Vineland Adaptive Behavior Scales II (VABS II)

- Parent/caregiver interview and rating forms (infancy to adulthood); and teacher rating forms (3-21)
- **Socialization domain:** “Interpersonal Relationships” (friendships, dating, social communication, and responding to others) and “Playing and Using Leisure Time” (playing and going places with friends)
- **Daily living domain:** “Personal activities,” “Domestic activities,” and “Community living activities”
- **Does child do activity?** (2= yes, usually; 1= sometimes or partially; 0=No, never; N-No opportunity)

# Child Behavior Checklist (CBCL)

- **Parent, child, youth, & teacher report versions (ages 2-18)**
- **Social Competence Domain:**
- **List three activities child most likes to take part in:**  
1) sports, 2) hobbies, activities, games, 3) organizations, clubs, teams 4) Jobs or chores
  - **Compared to same age, how much time?**  
*(less than average, average, More than average, don't know)*
- **How many friends?** (“None,” “1,” “2 or 3,” “4 or more”)
- **How many times a week does things with friends outside of school** (“Less than 1,” “1 or 2,” “3 or more”).

# Tailored Approaches

## 1. Person-centered Goals

- Short & long term goals & objectives
- Goal Attainment Scaling (*GAS*)
- Canadian Occupational Performance Measure (*COPM*)

## 2. Clinimetric approach

## 3. Focused Observation

## 4. Focused Rating Scales

## 5. Focused Interview



# Person-centered goals

1. Short- and long-term objectives (e.g., achieved or not; percent of children who achieved objectives)
2. Goal Attainment Scaling (GAS): Identify most & least favorable outcomes & intermediate levels (-2 to +2 scale)
3. Canadian Occupational Performance Measure (COPM). Visual analog (10-point) scales:  
Performance and satisfaction with performance  
related to **self-care, leisure & productivity**
4. ***GAS and the COPM responsive to intervention-related change*** (Dunn, et al., 2012; Graham, et al., 2009; 2010; Palisano, et al., 2012)

# Clinimetric approach

- Items define the construct; are meaningful indicators instead of representing underlying construct (*Dijkers; 2010; Feinstein,1987; Whiteneck & Dijkers, 2010*)
- Composite scores created from subsets of conceptually similar items from larger measures (or item banks) to address specific clinical and research questions
- Used in PEM-CY given multidimensional nature of participation & environment  
(*Coster, et al., 2011*)

# Focused Observation

- Criteria of observable & measurable behaviors (*e.g., # of social contacts in defined setting & time period; time involved in activities with others*)
- *Glang, et al.(1997) recorded the number of social contacts of three students with TBI during school to examine the effects of the “Building Friendship” intervention*

# Focused rating scales

- Ordinal rating scales to address specific goals of program
- Glang et al.(1997) rated degree to which each student was included in school life on a weekly basis with four-point scale (“not at all included” to “very included”)
- Interventionists & parents rated their satisfaction with student’s inclusion with four-point scales

# Focused Interview (Key questions)

- What are the most important activities for the child to participate in?
- What is the child's current and desired level of participation in these activities?
- What factors (child, family, environment) support or hinder the child's participation?
- What types of strategies, accommodations or interventions have been used effectively to promote the child's participation?

**Leads most directly to goal setting and action planning**

# Linking measurement results to inform action

- Individual level
- Program level
- Population level

*See Mallinson & Hammel, 2010 (use of radar plots)*

# \*Intervention Planning: Overview

- **Formal Assessment/s**
- **Focused interview** with key questions
- **Review & Summary** (synthesis of key results)
- **Goals** (measureable objectives)
- **Action Plan** (outline steps & timelines)
- **Review progress & process** (*goal achievement, what worked & did not, additional supports & barriers*)
- **Update plan and/or goals** (*as needed*)

**\*Similar key steps used in Program and Population level Assessment.**

# Illustrative Case

## John: Teenager with TBI

- 15 years old; in regular school with education classes (mainstreamed for English, History, Art and Physical Education)
- Incurred TBI 5 years ago from a car accident
- Occupational Therapy 1x week; Counseling 1x, school accommodations
- Lives in middle-income suburb in a two floor house with parents (both work), younger sister and dog
- Walks to school (rides bike in nice weather)
- Likes to spend time with cousins and go on trips with family; likes art
- Wants to meet other teenagers in school



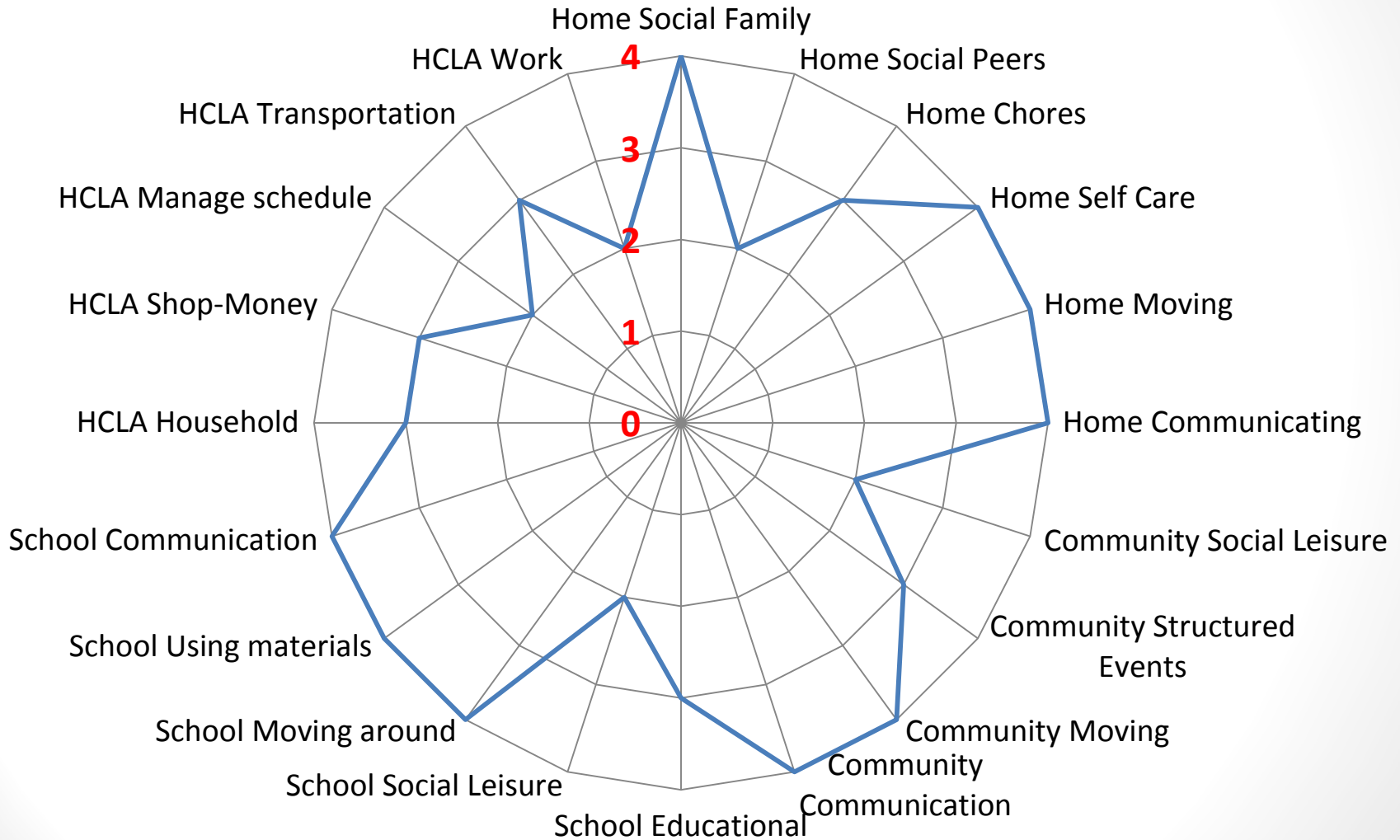
# Child and Family Follow-up Survey (CFFS)

- Child and Adolescent Scale of Participation (**CASP**)
- Child and Adolescent Scale of Environment (**CASE**)
- Child and Adolescent Factors Inventory (**CAFI**)
- Other questions about strategies, equipment, accommodations, services, child and family quality of life

<http://sites.tufts.edu/garybedell/measurement-tools/>

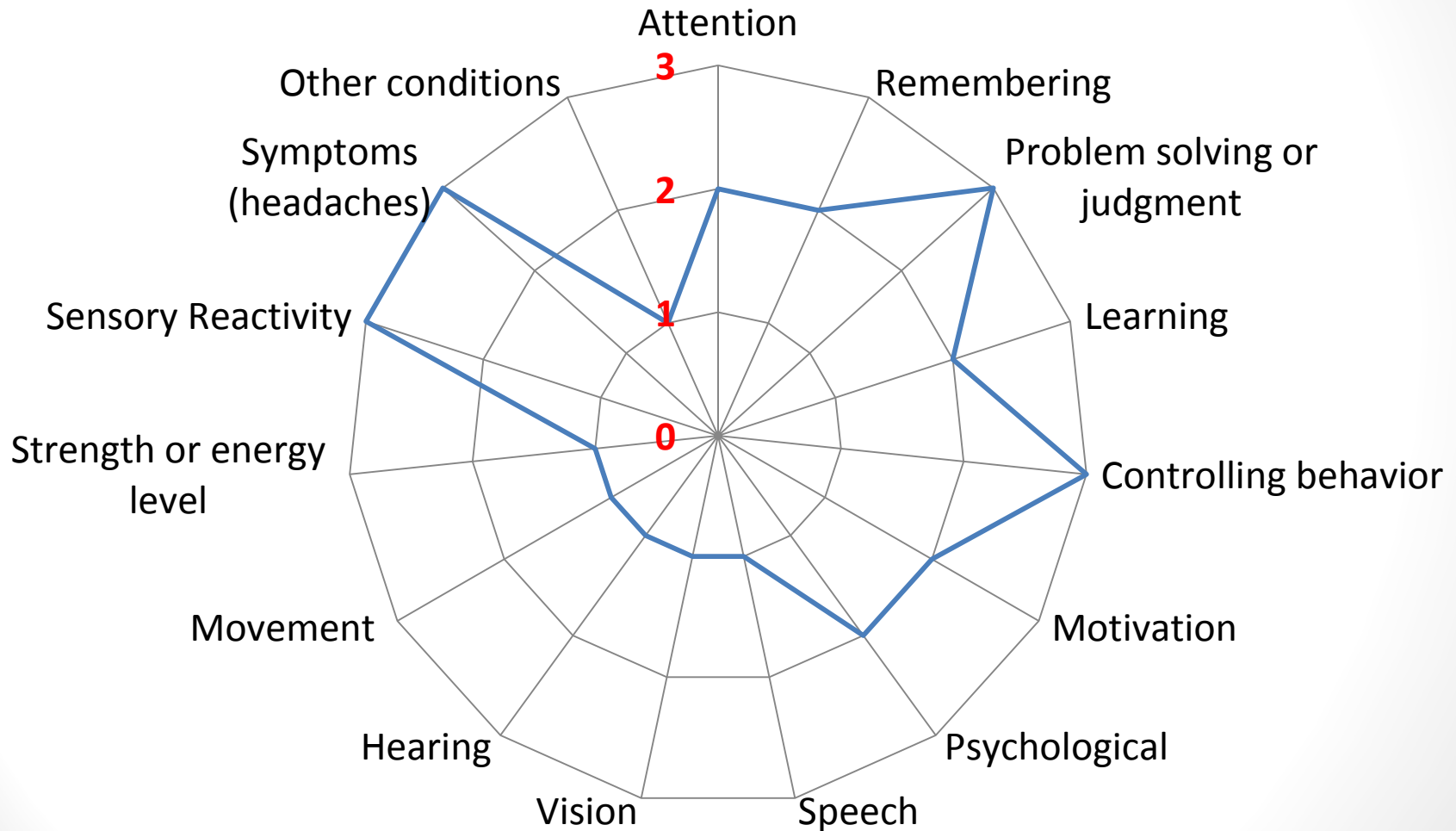
# Participation (CASP)

*1 = Unable; 2 = Very limited; 3 = Somewhat limited; 4 = Age-expected / Full*



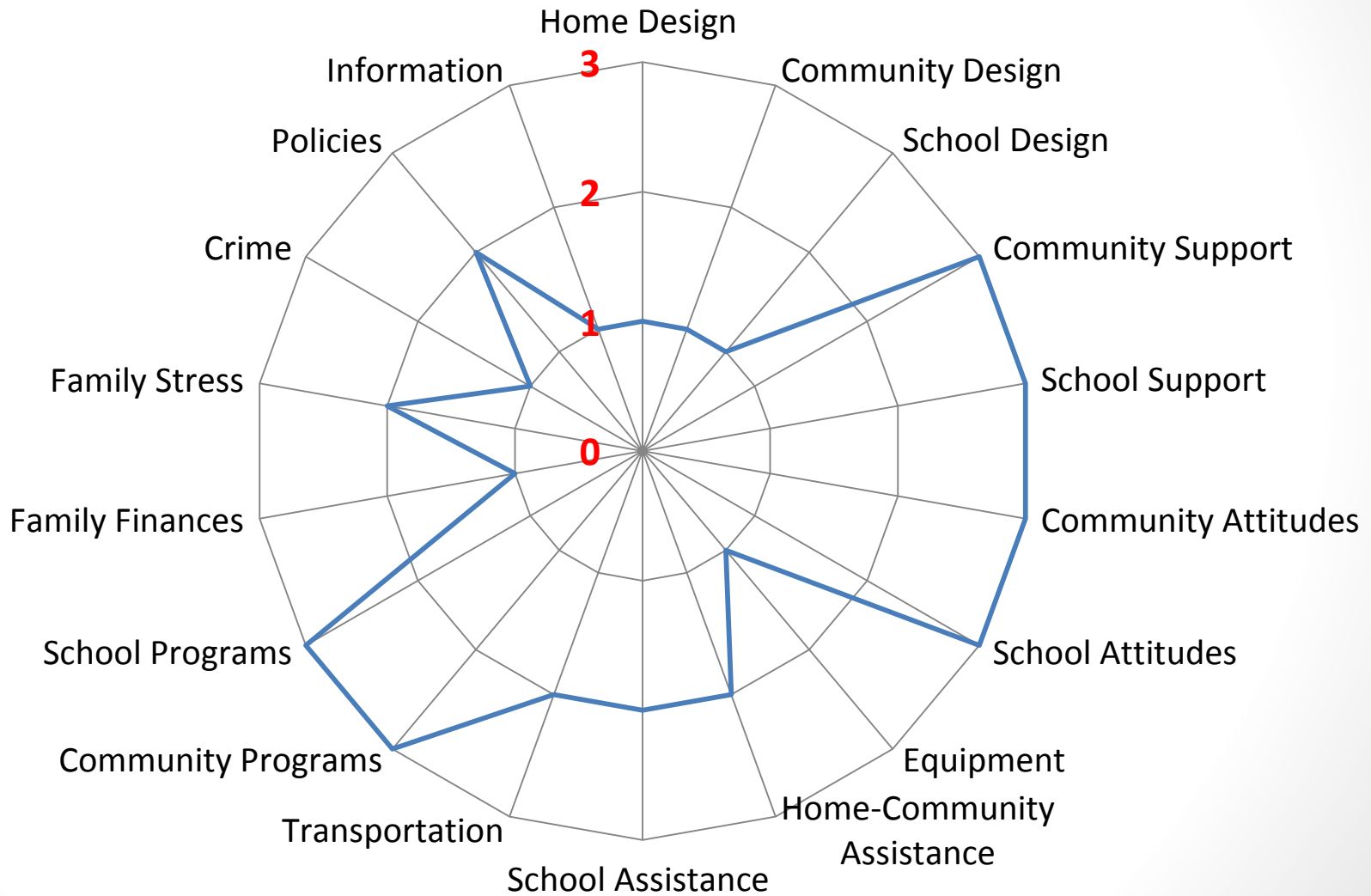
# Child factors (CAFI)

*1=No problem, 2=Little problem, 3 = Big problem*



# Environment factors (CASE)

*1 = No problem, 2 = Little problem, 3 = Big problem*



# Reported strategies, supports, strengths

- Uses SMART phone (*Calendar, gets text reminders from mother, and calls family*)
- Reviews calendar and “things to do” list before school
- Weekly things to do list posted in room
- Talks with family at dinner to discuss day and plans for tomorrow
- Asks for help
- Classroom accommodations – sits in front of room; able to record classes
- Good sense of humor; friendly
- Good physical skills
- Good communication skills

# Summary

- **Participation (CASP)**

- **Greatest restrictions (very limited):** Social leisure with friends – all settings (more in community & @ school); Educational activities with others @ school; Work
- **Somewhat limited:** Community structured events, most home & community living activities, Chores
- **Age expected/full participation:** All others

- **Child factors (CAFI)**

- **Biggest problems:** Problem-solving; Controlling behavior/activity level; Sensory Reactivity; Headaches
- **Little problems:** Other cognitive items (attention, memory, learning new things); motivation, psychological

- **Environment (CASE)**

- **Biggest problems:** Problem-solving; Controlling behavior/activity level; Sensory Reactivity; Headaches (fill-in)
- **Little problems:** other cognitive items (attention, memory, learning new things); motivation, psychological

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

- Web-based – free to parent to complete on child, download reports and share with circle of support :
- <https://canchild.ca/en/resources/248-participation-and-environment-measure-for-children-and-youth-pem-cy>
- Detailed report on John (*with radar plots*): [Detail Report for John February 24, 2016 PEM-CY.pdf](#)
- Overview report on John: [Overview Report for John February 24, 2016 PEMCY.pdf](#)

# Key Messages

- Understand your study / program specific information goals: **What do you want to know?**
- Use measures that match goals & are feasible to use and acceptable to stakeholders
- Consider best available evidence
- Assess child, family & environmental factors
- Acknowledge, leverage & build upon what families (& others) already know & do
- Might not need to reinvent the wheel
- Continue to collaborate, disseminate, & do research



# Thank You!

## Contact Information

Gary Bedell, PhD, OTR/L, FAOTA

Associate Professor & Chair

Tufts University

Department of Occupational Therapy

574 Boston Avenue, Room 217L

Medford, MA, USA 02155

617-627-2854 (phone)

[gary.bedell@tufts.edu](mailto:gary.bedell@tufts.edu) (e-mail)

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

(web-site for additional resources)

# Selected References

- Anaby D, Law M, Hanna S, DeMatteo C. (2012). Predictors of change in participation rates following acquired brain injury: Results of a longitudinal study. *Developmental Medicine and Child Neurology*, 54, 339–346.
- Beauchamp, M.H. & Anderson, V. (2010). SOCIAL: An integrative framework for the development of social skills. *Psychological Bulletin*, 136, 39-64.
- Bedell, G. (2012). Measurement of Social Participation. In V. Anderson, & M. Beauchamp (Eds.), *Developmental Social Neuroscience and Childhood Brain Insult: Implication for Theory and Practice*. New York, NY: Guilford Publications.
- Bedell, G. M., Cohn, E. S., & Dumas, H. M. (2005). Exploring parents' use of strategies to promote social participation of school-age children with acquired brain injuries. *American Journal of Occupational Therapy*, 59, 273-284.
- 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.
- DeMatteo CA, Cousins MA, Lin CA, Law MC, Colantonio A, & MacArthur C. (2008). Exploring post-injury living environments for children and youth with acquired brain injury. *Archives of Physical Medicine and Rehabilitation*, 89, 1803-1810.
- Dunn, W., Cox, J., Foster, L., Mische-Lawson, L., & Tanquary, J. (2012). Impact of a contextual intervention on child participation and parent competence among children with autism spectrum disorders: a pretest-posttest repeated-measures design. *American Journal of Occupational Therapy*, 66, 520-528.

# Selected References

- Eccles, J. S., Barber, B.L., Stone, M., & Hunt, J. (2003). Extracurricular activities and adolescent development. *Journal of Social Issues*, 59, 865-889..
- Fletcher, A. C., Nickerson, P., & Wright, K. L. (2003). Structured leisure activities in middle childhood: Links to well-being. *Journal of Community Psychology*, 31, 641-659
- Fougereyrollas, P., Lepage, C., Boissière, L., Deaudelin, I., & Doré, L. (2014). Assessment of Social Participation in Three Measurement Times in Children with Traumatic Brain Injuries (TBI) Based on Parental Perceptions. *Open Journal of Therapy & Rehabilitation*, 2, 156-165.
- Galvin, J., Froude, EH, & McAleer, J. (2010). Children's participation in home, school and community life after acquired brain injury. *Australian Occupational Therapy Journal*, 57, 118–126.
- Gauvin-Lepage, J. & Lefebvre H. (2010). Social inclusion of persons with moderate head injuries: The points of view of adolescents with brain injuries, their parents and professionals. *Brain Injury* 24, 1087-1097.
- Glang, A., Todis, B., Cooley, E., Wells, J., & Voss, J. (1997). Building social networks for children and adolescents with ABI: A school-based intervention. *Journal of Head Trauma Rehabilitation*, 12, 32-47.
- Graham, F., Rodger, S., & Ziviani, J. (2009). Coaching parents to enable children's participation: An approach for working with parents and their children. *Australian Occupational Therapy Journal*, 56, 16-16.
- Graham, F., Rodger, S., & Ziviani, J. (2010). Enabling occupational performance of children through coaching parents: Three case reports. *Physical & Occupational Therapy in Pediatrics*, 30, 4-15.

# Selected References

- 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.
- Larson, R. W. & Verma, S. (1999). How children and adolescents spend time across the world: Work, play, and developmental opportunities. *Psychological Bulletin*, 125, 701-736.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56, 640-649
- Law M, Anaby D, & DeMatteo C, Hanna S. (2011). Participation patterns of children with acquired brain injury. *Brain Injury*, 25, 587-595.
- Mahoney, J. L., Cairns, B.D., & Farmer, T.W. (2003). Promoting interpersonal competence and educational success through extracurricular activity participation. *Journal of Educational Psychology*, 95, 409-418.
- Mallinson T, & Hammel J. (2010). Measurement of participation: Intersecting person, task, and environment. *Archives of Physical Medicine & Rehabilitation*, 91, S29-33.
- McConachie, H., Colver, A.F., Forsyth, R.J., Jarvis, S.N., & Parkinson, K.N. (2006). Participation of disabled children: How should it be characterised and measured? *Disability & Rehabilitation*, 28, 1157-1164
- Mealings, M., Douglas, J., & Olver, J. (2012). Considering the student perspective in returning to school after TBI: A literature review. *Brain Injury*, 26, 1165–1176.
- Palisano, R., Chiarello, L., King, G., Novak, I., Stoner, T., & Fiss, A. (2012). Participation-based therapy for children with physical disabilities. *Disability & Rehabilitation*, 34, 1041-1052.
-

# Selected References

- Rhodes, J.E., Spencer, R., Keller, T.E., Liang, B., & Noam, G. (2006). A model for the influence of mentoring relationships on youth development. *Journal of Community Psychology*, 34, 691–707.
- Rivara, F., Vavilala, M.S., Durban, D., & Jaffe, K.M. (2012). Persistence of disability 24 to 36 months after pediatric traumatic brain injury: A cohort study. *Journal of Neurotrauma*, 29, 2499-2504.
- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry*, 57, 316-331.
- Sharp, N.L., Bye, R.A., Llewellyn, G.M., & Cusick, A. (2006). Fitting back in: Adolescents returning to school after severe acquired brain injury. *Disability & Rehabilitation*, 28, 767-778.
- Shuhua Foo, W., Galvin, J. & Olsen, J. (2012). Participation of children with ABI and the relationship with discharge functional status. *Developmental Neurorehabilitation*, 15, 1-12.
- Simeonsson, R. J., Carlson, D., Huntington, G.S., McMillen, J., & Brent, L. (2001). Students with disabilities: A national survey of participation in school activities. *Disability & Rehabilitation*, 23, 49-63.
- Turkstra, L.S., Politis, A.M., & Forsythe, R. (2015). Cognitive–communication disorders in children with traumatic brain injury. *Developmental Medicine & Child Neurology*, 57, 217-222.
- van Tol, E., Gorter, J. W., DeMatteo, C., & Meester-Delver, A. (2011). Participation outcomes for children with acquired brain injury: a narrative review. *Brain Injury*, 25, 1279-1287.
- Wells, R., Minnes, P., & Phillips, M. (2009)/ Predicting social and functional outcomes for individuals sustaining paediatric traumatic brain injury. *Developmental Neurorehabilitation*, 12, 12-23.
- World Health Organization [WHO]. (2001). *International Classification of Functioning, Disability and Health*. Geneva: WHO.
- World Health Organization [WHO]. (2007). *International Classification of Functioning, Disability and Health. Version for Children and Youth*. Geneva: WHO.