

Measuring & Promoting Participation of Children & Youth with ABI

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My Experience

- Occupational Therapy
- Interdisciplinary teams
- Measurement Development
- Rehabilitation Outcomes Research
- Qualitative Research
- Intervention Development
- Consultation / Teaching

Key Objectives

1. To guide efforts for selecting measures of participation of children & youth with acquired brain injuries (ABI).
2. To emphasize how measurement can guide efforts to promote participation of children 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; Michelson, et al., 2008).

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

- **Enables children to interact, work and live with others and function in society**
 - (Law, 2002; Larson, 2000; Mahoney, Cairns, & Farmer, 2003).
- **Associated with enhanced quality of life, social competence and educational success**
 - (Bedell & Dumas, 2004; Eccles, Barber, 2003; King, et al., 2003; Larson, 2000; Law, 2002; Mahoney, et al., 2009; Simeonsson, et al., 2001; Stone & Hunt, 2003).
- ***activities that promote skill development, and provide a sense of accomplishment and enjoyment***
 - (Eccles, et al., 2003; Fletcher, et al., 2003; Mahoney & Cairns, 1997; 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, time since injury, physical /social environmental factors, type & level of impairment, functional skills
 - (Anaby, et al, 2012; Bedell, 2009; Bedell & Dumas, 2004; 2009, Galvin, et al., 2010; Law et al, 2011; Shuhua Foo, et al., 2012; Van Tol, et al., 2011; Wells, et al., 2009)
- Children and parents use strategies to promote participation in spite of obstacles
 - (Bedell,et al, 2005; 2011; Dumas, et al., 2004; DeMatteo,et al., 2008; Mealings & Douglas, 2010; Sharp, et al., 2006)

Conceptual, practical & methodological considerations

- Early phase of measurement development
- Ambiguity in the ICF on what & how to measure
- One measure does not fit all purposes
- Stakeholders can't 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 important “life situations”?
 - How to measure “involvement”?

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

Differentiating Activity & Participation

(Whiteneck & Dijkers, 2009; WHO, 2002).

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

Social Participation & Participation

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

What 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).
- **Feedback from others to ensure social & ecological validity & feasibility**

Varied Purposes & Levels of Focus

- **Descriptive** (describe patterns; inform action)
- **Discriminative** (differences between groups)
- **Evaluative** (change over time)

- **Individualized** intervention or action planning
- **Program** evaluation & improvement
- **Population** surveillance - informing policy

*Can have more than one purpose & focus

Other considerations

- Quantity: How often?, how involved? How important? How satisfied?
- Quality (key characteristics, with whom? where?)
- Positive strengths-based (*participation*) or negative deficit-based (*restriction*) or both
- Whose view? (child, family, professionals, others)
- Multiple or specific domains or settings

More Considerations

- Broad or discrete activities
- Accounting for age, developmental transitions, **recovery**
- Normative standards; comparisons to same-age peers (or not)
- Threshold of “Optimal Participation.”

Key considerations in selecting measures & approaches

- Stakeholders' information goals
- Best available research evidence
e.g., reliability, validity, responsiveness to change
- Institutional resources and constraints

Selected measures & approaches

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

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

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

*Clinimetric Approach & the PEM-CY

- Used in PEM-CY given multidimensional nature of participation & environment
(Coster, et al, 2011).
- Items define the construct; are meaningful indicators instead of representing underlying construct.
- Advantages compared to Classical Test Theory (*e.g. factor analyses*) and Item Response Theory (*e.g. Rasch Analyses*).
(Refer to Dijkers; 2010; Feinstein, 1987; Whiteneck & Dijkers, 2010)

Clinimetric approach (continued)

- Flexible & tailored to stakeholders' goals
- Creation of composite or summary scores informed by practical considerations.
- Subsections or aggregate subsets of items from larger measures to address specific clinical and research questions.

Implicit Participation Measures: Subscales (items) from other measures

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

Vineland Adaptive Behavior Scales (VABS & 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 (age 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. Focused Observation

3. Focused rating scales

4. Focused Interview

5. Clinimetric (*already described*)

Person-centered goals

1. Short- and long-term objectives (e.g., 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
- ***GAS and the COPM responsive to intervention-related change*** (Cusick, et al., 2006; Dunn, et al., 2012; Graham, et al, 2010; Palisano, et al, 2012; Sakzewski, 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 for children with TBI.*

Focused rating scales

- Ordinal rating scales to address specific goals of program
 - Glang et al.(1997) rated degree to which 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, environmental) support or hinder the child's participation?
- What types of strategies, accommodations or interventions have been used effectively to promote the child's participation?

Older & Younger Ages

- Most measures described used with school-age children
- Some items and subsections are applicable for older youth.
- Consider adult measures/questions for older youth (*independent living, work and post-secondary education/training*) (Malec, et al, 2004; Magasi & Post, 2010; McCauley, et al., 2011).
- Consider measures for younger children (*play, preschool and family activities*) (Berg, & LaVesser, 2006; Dunst, et al., 2002; Rosenberg, et al., 2010).

Final Messages

- Use measures that match goals & are feasible
- Consider best available evidence
- Use tailored approaches & standardized measures
- Assess child, family & environmental factors
- Continued research & discussion warranted
- Collaborate, share, disseminate
- Acknowledge, leverage & build upon what families (& others) already know & do

**Handouts & references
will be posted on my web
site (see contact information**

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THANK YOU!

ANY QUESTIONS?