

Developing Measures of Participation & Environment for Children with Disabilities: Parent Perspectives

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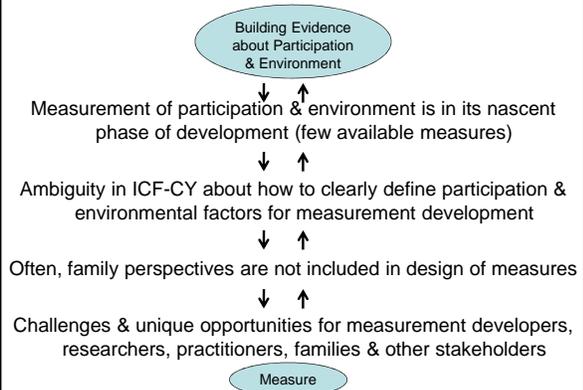
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Background

- **Participation** broadly defined in the International Classification of Functioning (ICF) as "involvement in a life situation."
- **Participation restrictions** are "problems an individual may experience in involvement in life situations."
- **Environmental factors** are the physical, social, and attitudinal features of settings where individuals live their lives.
- Participation involves engagement in activities with others in a variety of daily life settings.
- Participation enables children to learn how to interact, work and live with others.
- Children & youth with disabilities often restricted in their participation in school, home, and community life.
- Child, family, environmental ("contextual") factors associated with participation restriction.
- Greater extent of participation associated with enhanced quality of life & reduction in health & social risk factors of children with & without disabilities.

Current Challenges & Opportunities



Considerations for measuring participation

Purpose of Assessment:

- Individual, program, population

Describing Units of Variation (rating scale, response options):

- How often? How much? How important? How satisfied?

Qualities of Participation:

- Nature, key characteristics, with whom? where?

Specificity:

- Single or Multiple domains (participation by type of situation, setting)
- Global categories versus discreet categories of situations
- Situations that are condition-specific or generic

Approaches:

- Positive/strengths-based, or negative/deficit-based (restriction), or both
- Whose view? (child, family, professionals, peers)

Standards/Expectations:

- Objective (external) & subjective (internal) views of participation
- Comparison to same-age age peers or no comparison
- Accounting for age & developmental transitions

Participation and Environment Project (PEP)

Starting Point	Phase I Aim: Translate Participation and Environment into meaningful measurement constructs	Phases II & III Aim: Pilot and Field-test of New Measure(s)
1. What is the purpose? <ul style="list-style-type: none"> • Population-based assessment • Program evaluation/out comes assessment • Individual/pers on-centered assessment 	1. Gathering constituent perspectives: <ul style="list-style-type: none"> • Two respondents <ul style="list-style-type: none"> • Parent • Child • Two geographic regions <ul style="list-style-type: none"> • Boston, MA • Hamilton, ON 	1. What participatory situations and environmental factors should be represented? Content areas 2. How should the questions be asked? What response format makes most sense? Scaling options 3. Cognitive testing & feedback from stakeholders
2. Whose voice is reflected? <ul style="list-style-type: none"> • Parent-report • Child-report 	1. Review of existing measures <ul style="list-style-type: none"> • Content • Response options • ICF-CY coverage 2. Prior research by investigators	

Gathering Parent Perspectives: Research Questions

1. What do parents perceive to be the important types of life situations in which children and youth with disabilities participate?
2. What do parents identify as the types of environmental factors that support or hinder a child's participation in important life situations?
3. How do parents appraise their children's participation and the environmental supports and barriers to participation?

Study Design

Participant Recruitment: A maximum variation sampling strategy was used to recruit parents of children with disabilities, and through established contacts of students to recruit parents of children without disabilities.

Data Collection: Descriptive approach using focus groups and key informant interviews with parents of children with and without disabilities

Data Management: NVivo 7.0 assisted with data management, analyses, and interpretation of data from: 1) transcripts, 2) field notes, 3) analytic memos, and 4) meta-summaries

Data Analysis:

- **Content and constant-comparative analyses** used to code text, identify categories, and examine links between/among categories related to research questions.
- **To ensure trustworthiness:** 1) member-checking, 2) triangulation, and 3) recursive review and discussion of aggregate findings (descriptive terms, phrases, themes)

Participant Recruitment & Data Collection

	Recruitment	Data Collection			
Boston University (BU) (n=14)	<u>Where:</u> Greater Boston Area <u>How:</u> Notice in newsletter	Pilot of interview guide using focus groups and interviews (n=7)	90-minute focus groups conducted on-campus	90-minute interviews completed on-campus or public space	30-minute follow-up telephone interviews (n=10)
McMaster University (MU) (n=10)	<u>Where:</u> Hamilton Wentworth Region of Ontario <u>How:</u> Recruitment flyers and notices in agency newsletters				90-minute interviews conducted in-home, on-campus, and by telephone
Tufts University (TU) (n=17)	<u>Where:</u> Majority in the Northeast, USA <u>How:</u> Established contacts by students	60-minute in-home interviews			



Parent Characteristics (n=41)

	Boston University (n=14)	Tufts University (n=17)	McMaster University (n=10)
Age Range (years)			
30-39	1	3	1
40-49	11	9	6
50-59	2	5	3
Ethnicity			
White	11	16	9
Black	2		
Hispanic	1	1	
Other			1
Respondent (% mother)	14 (100%)	15 (88%)	9 (90%)
Education			
Graduate degree	8	7	
College degree	4	8	3
Some college	1	2	5
High School/Less	1		2

Question 2: Contextual Factors - School

CHILD FACTORS	<ul style="list-style-type: none"> • Skills and abilities (physical, intellectual, social) • Prepared • Follow-through, execution • Transitions • Preference, interest, enjoyment, personality • Medical condition • Advocacy/self-awareness
ACTIVITY FEATURES	<ul style="list-style-type: none"> • Structured and organized (or flexible) - clear goals, expectations, directions • Knowledgeable/trained/consistent staff • Small groups, positive dynamics with peers • Quiet • Quality of staff: educational assistant, coaches, teachers, and students
ATTITUDES AND ACTIONS OF OTHERS	<ul style="list-style-type: none"> • Parent as advocate • Communication with staff • Encouragement & inclusion • Peer support/mentorship/buddy system
TRANSPARENCY	<ul style="list-style-type: none"> • Invisibility (support, disability)
SAFETY	<ul style="list-style-type: none"> • Physical, social emotional safety
STRATEGIES	<ul style="list-style-type: none"> • Parent as facilitator by: 1) planning ahead; 2) exposing by breadth then depth; 3) weighing pros/cons of efforts; 4) choosing activities that their child will be successful at

Question 2: Contextual Factors - Community

CHILD FACTORS	<ul style="list-style-type: none"> • Skills and abilities (physical, intellectual, social) • Being prepared • Personality • Follow-through, execution • Transitions with ease • Preference/interest • Medical condition • Advocacy/self-awareness
ACTIVITY FEATURES	<ul style="list-style-type: none"> • Structured and organized (or flexible) - clear goals, expectations, directions • Knowledgeable/trained/consistent staff • Short duration • Adaptive equipment • Small, quiet groups, positive dynamics with peers • More versus less competitive • Effective leadership of instructors/coaches
ATTITUDES & ACTIONS OF OTHERS	<ul style="list-style-type: none"> • Parent as advocate • Communication with staff • Encouragement & inclusion • Peer support/mentorship/buddy system • Sensitivity, encouragement of community members

Question 2: Contextual Factors – Community (continued)

BROADER SYSTEMS	<ul style="list-style-type: none"> • Financial • Transportation • Flexible work schedule • Physical design (size, open space, safety, stimulation, proximity) • Professional jargon • Weather/climate • Lack of time for both the child & family (competing priorities), convenience • Self-imposed rules/limits
TRANSPARENCY	<ul style="list-style-type: none"> • Invisible (support, disability)
SAFETY	<ul style="list-style-type: none"> • Physical, social emotional safety
STRATEGIES	<ul style="list-style-type: none"> • Parent as facilitator by: 1) planning ahead; 2) exposing by breadth then depth, 3) weighing pros/cons of efforts; 4) choosing activities that child will be successful at.

Question 3: How parents understand & judge participation & environment

- Participation understood using many terms:
 - involvement, belonging, being engaged, membership, active inclusion, learning/competence, showing initiative, being proactive, being responsible for & committed, persistence, reciprocity, connecting with others, being present, showing up
- Participation inextricably linked to child, family, activity AND environment factors (“contextual” factors)
- Parents of children with disabilities emphasized importance of considering others’ expectations about child’s type or extent of participation in a specific activity, situation or setting since these vary
- Information obtained via observation (e.g. reading cues), knowing child’s daily routines & solicited/unsolicited verbal/written feedback from child & others
- Parents judged participation in terms of a greater or lesser amount, portion, responsibility, initiative, commitment (terms used above)
- More data are needed on how parents appraised the impact of “contextual factors”

Discussion

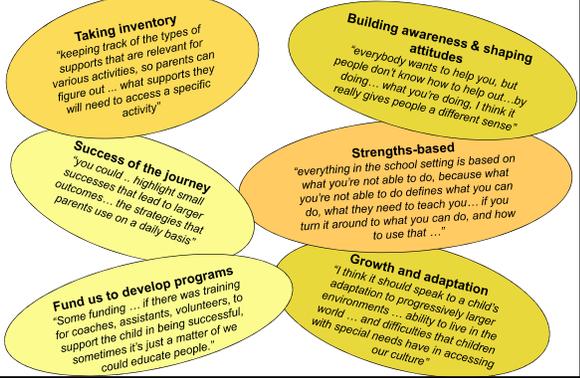
- Parents discussed & understood participation within the context of child, family, activity AND environment factors (“contextual factors”)
 - Adds to the body of evidence demonstrating the inter-relationships among these constructs (*core aspect of OT, ecological theories*)
 - Also... it’s NOT all about quantity AND “more” is Not always better
- Discussion of participation & contextual factors facilitated discussion of parent strategies to promote participation
- Content descriptions similar to and expanded on current ICF-CY categories, and domains from existing measures
- Process descriptions and key issues were similar to and expanded upon descriptions highlighted in the literature

See Reference List

Implications: Challenges & Opportunities

- Incorporate parents’ content descriptions of situations and factors in our measures.
 - Include descriptions not depicted in the ICF-CY: child factors, activity features, safety, transparency of supports, parent strategies
- Attempt to capture how parents understand and judge participation & contextual factors (process descriptions)
- Explicitly link these two constructs within the measure (“folding in”)
- If the measure is used for population-based assessment:
 - Include a reduced set of global items to inform policy and program decisions, i.e., to identify where efforts and resources need to be allocated:
 - Specific domains of participation and contextual factors of concern
 - Specific child and family demographics (e.g. disability, age, race/ethnicity, SES, geographic region)
- If this measure is used for individual service planning:
 1. Develop a larger pool of discrete items based on more detailed content descriptions by parents
 2. Attempt to facilitate discussion about parent strategies to promote participation (e.g., supplemental form)
- Incorporate parents’ recommendations for alternative uses of measures →

Parents' recommendations for potential uses of measures



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- Hamilton Family Network: www.hamiltonfamilynetwork.com
- Ontario Brain Injury Association: www.obia.on.ca
- Parents for Children's Mental Health: www.pcmh.ca
- Hamilton Area Hospital Family Support Groups

For more information about this project, please contact us:
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