Environmental Influences on the Social Participation of Children with Developmental Disabilities: Parent and Child Perspectives Informing Measurement Development

Mary Alunkal Khetani, MA, OTR/L[1], Gary M. Bedell, PhD, OTR, FAOTA[2], Wendy Coster, PhD, OTR, FAOTA[1], Mary Law, PhD, OT(C), FCAOT[3]

Boston University College of Health and Rehabilitation Sciences: Sargent College[1], Tufts University, Department of Occupational Therapy[2], McMaster University, School of Rehabilitation Sciences[3]

Background & Significance

Participation is recognized as an important outcome for children with disabilities. According to the International Classification of Functioning, Disability and Health – Child and Youth (ICF-CY), participation is defined as involvement in important life situations and **environmental factors** associated with participation include products and technology, natural and built environment, support and relationships, attitudes, and services, systems, and policies[1]. While promoting social participation and addressing environmental factors that support or challenge a child's participation are important goals for families raising children with disabilities, there is a paucity of measures that examine these two constructs based in part on the input of families of children with developmental disabilities[2,4].

This research constitutes the first phase of a larger project to develop measures of participation and environment for children and youth with disabilities. The purpose of this study was to gather parent and child perspectives of these two constructs to identify meaningful domains and item content areas that will inform development of these measures. We examined similarities and differences between responses from children with developmental disabilities and their parents related to three questions (as taken from a larger interview guide):

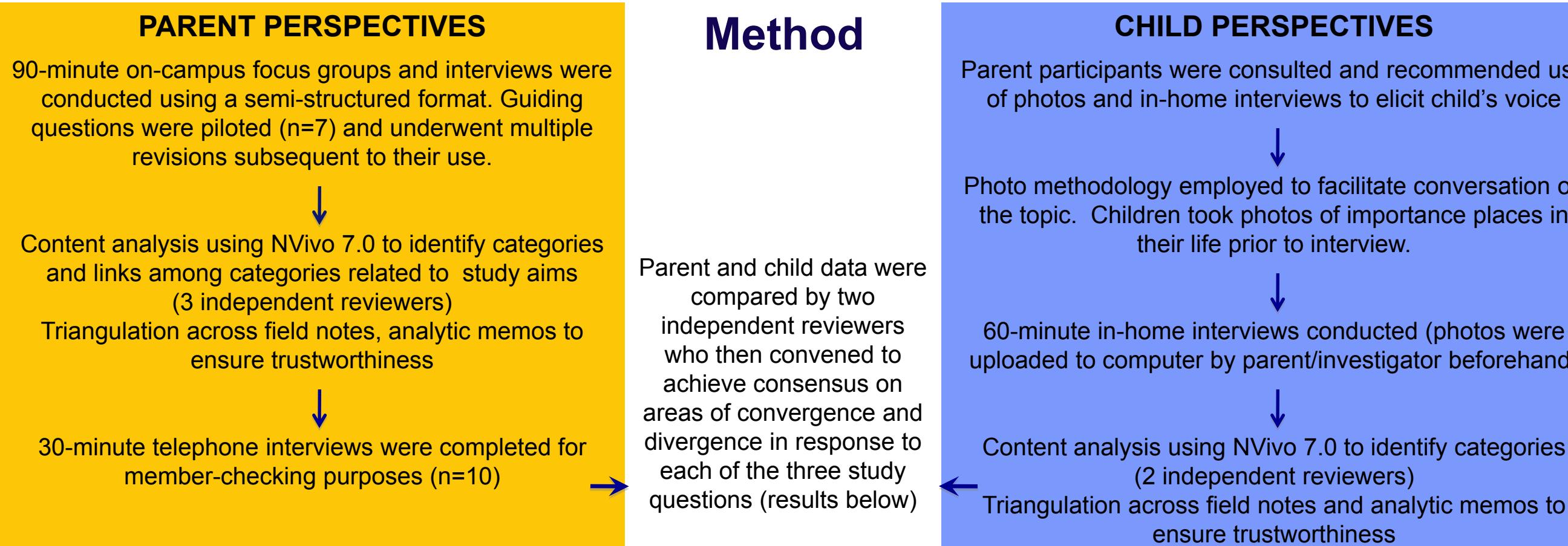Q1. What does it mean for children with disabilities to participate?

Q2. What are the important situations in which children with disabilities participate?

Q3. What types of environmental factors support or hinder the social participation of children with developmental disabilities?
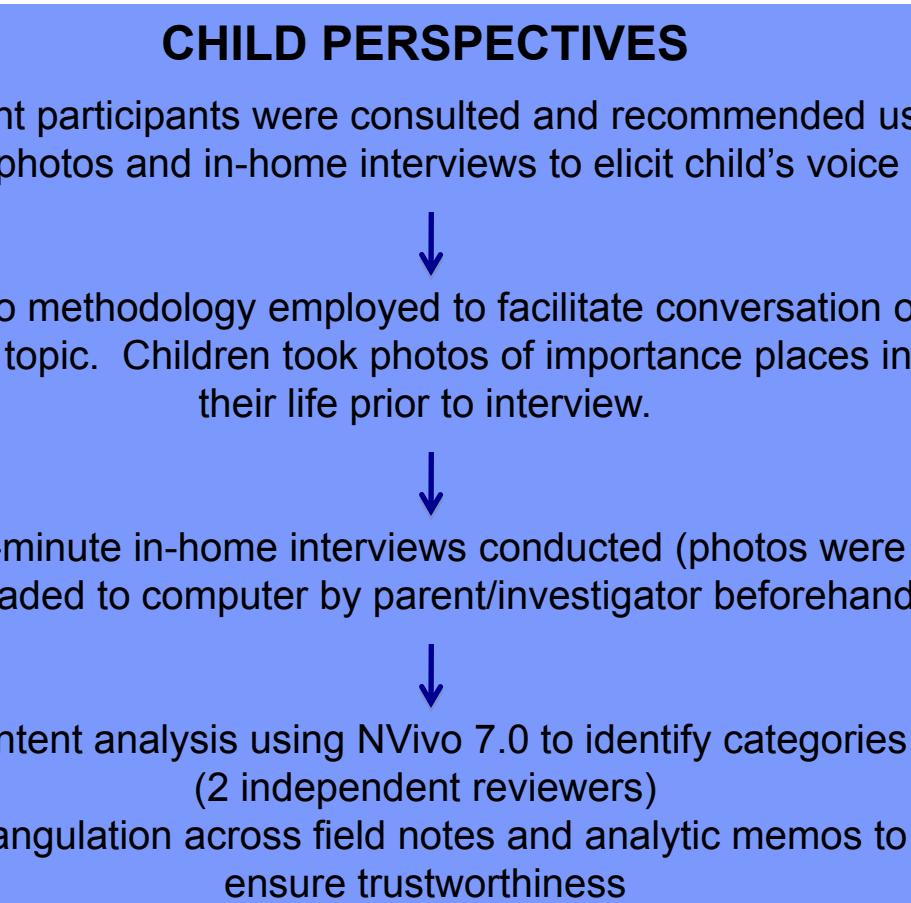
Participants

	Parents (n=15)	**Children* (n=5)**
Child's Diagnosis		
Dyslexia	1	1
VCFS	1	1
ADHD	1	1
Down Syndrome	2	1
PDD-NOS	3	1
Baraister-Winter Syndrome	1	
Asperger's Disorder	2	
Learning Disability	2	
Autism Spectrum Disorder	2	
Ethnicity		
Hispanic	1	1
Caucasian	12	3
African-American	2	1
Child's Age		
6-8 years	4	2
9-11 years	2	3
12-14 years	6	
15-16 years	3	
Gender		
Male		2
Female	15	3
Parent's Education		
High School	1	
Associates	1	
College	8	
Postgraduate	5	

* All child participants were recruited from the parent sample.

Method

PARENT PERSPECTIVES

90-minute on-campus focus groups and interviews were conducted using a semi-structured format. Guiding questions were piloted (n=7) and underwent multiple revisions subsequent to their use.

↓

Content analysis using NVivo 7.0 to identify categories and links among categories related to study aims (3 independent reviewers)
Triangulation across field notes, analytic memos to ensure trustworthiness

↓

30-minute telephone interviews were completed for member-checking purposes (n=10)

CHILD PERSPECTIVES

Parent participants were consulted and recommended use of photos and in-home interviews to elicit child's voice

↓

Photo methodology employed to facilitate conversation on the topic. Children took photos of importance places in their life prior to interview.

↓

60-minute in-home interviews conducted (photos were uploaded to computer by parent/investigator beforehand)

↓

Content analysis using NVivo 7.0 to identify categories (2 independent reviewers)
Triangulation across field notes and analytic memos to ensure trustworthiness

Parent and child data were compared by two independent reviewers who then convened to achieve consensus on areas of convergence and divergence in response to each of the three study questions (results below)

Results

Q1. What does it mean for children with disabilities to participate?

PARENTS	**CHILDREN**
Membership, belonging, connecting with others, reciprocity, responsibility, enjoyment, learning/competence, preferred, sustained, social	"to be calm, to learn, and to have a lot of fun", "it's fun", "having a good time"

Q2. What are the important situations in which children with disabilities participate?

PARENTS & CHILDREN	**PARENTS ONLY**	**CHILDREN ONLY**
HOME Backyard Play; Caring for Self; Socializing; Games	**HOME** Chores; School Preparation; Skill-building	**HOME** Prayer; Reading; Television; Dancing; Cooking/Baking *"Prayer every day calms me down"*
SCHOOL Classes; Hanging out/Socializing; After-School Activities	**SCHOOL** Sports; School Events; Therapy	**SCHOOL** Awards
COMMUNITY Outdoor Recreation; Sports; Religious Activities; Camps; Boy Scouts; Family Outings/Errands	**COMMUNITY** Appointments; Hanging Out/Socializing	**COMMUNITY** Eating out; Visiting Others; Trips; Parties *" I love to eat spaghetti here every Saturday with mom, dad, and brother"*

Q3. What types of contextual factors are associated with participation? (key differences in bold)

HOME	**HOME & SCHOOL**	**HOME & SCHOOL**
Child's Abilities: Physical health Activity Features: Structured and organized; short; predictable, adaptive equipment use and visual aids; individualized; noise Safety: Physical Safety	Child's Abilities: prepared; anticipates; follow-through/execution; transitions; responsibility/self-advocacy; **"making" choices** Attitudes & Actions of Others: **communication with professionals; parent advocate** **Strategies:** planning ahead; weighing pros/cons Activity Features: repetition; small groups; staff continuity/turnover; group dynamics Transparency: visible/invisible	Activity Features: Shifting gears; rituals and traditions; **"having" choices** Attitudes & Actions of Others: Older siblings; pets; extended family; honest friends; peer mentor/buddy
SCHOOL Attitudes & Actions of Others: Knowledgeable, engaged, supportive staff Safety: Physical and social safety		**COMMUNITY** Child's Abilities: Fear Activity Features: Short; **"Having" choices** *"a good teacher doesn't have to know you have dyslexia, just that you need to take breaks"*
COMMUNITY Child's Abilities: prepared; health Activity Features: nearby; affordable; organized (pace; size; noise) Attitudes & Actions of Others: Parent advocate Safety: Physical and social safety	**COMMUNITY** Child's Abilities: **"making" a choice; responsibility** Attitudes & Actions of Others: **communication with professionals; parent advocate** **Broader Systems: transportation; support groups; language of providers; flexible work** **Strategies:** planning ahead; weighing pros/cons Activity Features: adaptive equipment and visual aids; staff continuity/turnover; group dynamics Transparency: visible/invisible	**Attitudes and Actions of Others:** Nice physician; friends with dogs; peer mentor/buddy *"just the affection … the relief from a great day of stress"*

Discussion

Findings inform design of measures for different purposes (i.e., population research, program evaluation, individual assessment for service planning) and respondents (i.e., parents, children).[3]

I. For a population survey, we could:
1. Cover broad categories of important situations and factors reported by parents and/or children in the home, school and community (Q2 results as shown). *Specific situations and factors were also identified within each broad category and are available for use in designing an individual assessment.*
2. Cover additional factors influencing participation than depicted by ICF-CY (Q3 results as shown), including child's abilities, activity features, safety, transparency, and strategies.

II. For a parent-report measure, we could:
1. Include additional nondiscretionary situations (parents only).
2. Ask about how broader systems and policies influence community participation.
3. Emphasize choice as a personal factor influencing participation (i.e., child's ability to make choices).
4. Explicitly link situations with factors because this reflects how they were discussed by parents.
5. Ask about strategy use as it links conversations about participation and environment.

III. For a child-report measure, we could:
1. Include additional discretionary situations (children only).
2. Include broader range of relationships when describing people whose attitudes matter: parents, professionals, extended family, peers, siblings, and pets.
3. Emphasize choice as an activity feature influencing participation (i.e., having opportunities to make choices).
4. Explicitly link situations with factors because this is how we got responses from children.
5. Consider two-point response option (e.g., never, always), and frequency (i.e., how often) to gather information about extent of engagement (e.g., pray every night, eat out every Saturday).

Methodological Considerations: 1) All parents accompanied their children while taking pictures and may have influenced picture selection, and 2) Only parents were invited to review preliminary findings and confirm/disconfirm emerging themes. **Next Steps:** Compare findings with: 1) Canadian sample, 2) practitioner perspectives, 3) similar data from prior research, and 4) content coverage (and scaling options) across existing measures. We will draw upon additional findings from the larger phase of qualitative work, particularly parent perspectives about evaluating participation, contextual factors, and strategy use.

Acknowledgements & References

1. World Health Organization (2007). *International Classification of Functioning, Disability, and Health -Children and Youth.* Geneva, Switzerland: World Health Organization.
2. Coster, W.J. & Khetani, M.A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability and Rehabilitation, 30,* 639-648.
3. Bedell, G. & Coster, W. (2008). Measuring participation of school-age children with traumatic brain injuries: Considerations and approaches. *Journal of Head Trauma Rehabilitation, 23,* 220-229.
4. 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,* 1636-1642.