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. 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.

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?

Method

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

Results

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

Parents: Membership, belonging, connecting with others, reciprocity, responsibility, enjoyment, learning/competence, preferred, sustained, supported, social.

Child: 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?

Children: Backyard Play; Caring for Self; Socializing; Games

Parents: Backyard Play; Classes; Hanging out/Socializing; After-School Activities

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

Children: Physical Health; Mental Health; Communication; Social and Emotional Development

Parents: Physical and Social Safety; Communication; Social and Emotional Development

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).

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. Compare broader systems influences on 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 non-occurrentary 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 situations 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 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 different 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.

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**References**


