
Objective: To obtain parents’ perspectives on children’s participation and environment to inform the development of new measures.

Design: Descriptive design using qualitative methods with focus groups and semistructured interviews.

Setting: Focus groups and interviews with parents of children with disabilities were held on campus, in the home, and at community agencies; interviews with parents of children without disabilities were conducted in their homes.

Participants: Parents (N=42); parents of children with disabilities (n=25) from the United States (n=14) and Canada (n=11) and parents of children without disabilities (n=17) from the United States. Most children (93%) were aged 5 to 16 years. Children with disabilities had diagnoses characterized by psychosocial, learning, attention, and sensory-processing difficulties.

Interventions: Not applicable.

Main Outcome Measure: Not applicable.

Results: Parents described common life activities and environmental factors that were similar to and expanded on categories currently reported in the literature. Differences identified among parents mainly focused on impairments and challenges of children with disabilities related to activities and programs designed for them. Parents spontaneously talked about participation and environmental factors together. Their descriptions consistently included information about features of the physical and social environment and other factors that influenced their child’s participation, such as demands of the activity, parent strategies, and the child’s age, preferences, and abilities. Parents’ standards and expectations for their child’s participation often varied depending on the specific setting, activity, and situation.

Conclusions: Findings have informed the development of a parent-report measure that explicitly links participation and environmental factors specific to home, school, and community settings. Having 1 measure to assess participation and environment rather than using distinct tools to assess each construct separately should situate the child’s participation in real-life contexts.

Key Words: Parents; Children; Participation; Environment; Measurement.

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PARTICIPATION IS RECOGNIZED as an important outcome for children and youth with and without disabilities and the ultimate aim of rehabilitation. Participation is defined broadly in the ICF as “involvement in a life situation” and participation restrictions are “problems an individual may experience in involvement in life situations.” Children and youth with disabilities often are restricted in their participation, particularly in formal and informal social and recreational activities at school and in the community, and in developmentally more complex activities that are expected of older children and youth, such as household chores, shopping, and work.

Greater participation has been associated with enhanced quality of life, social competence, and educational success of children and youth with disabilities and children without disabilities. Also, there is evidence to suggest that participation in activities that provide a sense of accomplishment, enjoyment, and skill development might protect socially and educationally at-risk children and youth against later mental health, academic, and social problems.

Environmental factors are the physical, social, and attitudinal features of settings in which people live their lives. Environmental factors can both support and hinder a child’s participation in home, school, and community settings. Much of the research related to children with disabilities has focused on environmental factors that hinder participation (ie, barriers). Although the relative impact of specific environmental barriers can vary, similar types of environmental barriers have been reported in this research, including inadequate support, assistance, services, equipment, and information and problems with institutional policies, attitudes of others, and the physical design and accessibility of activity settings.

Findings from 2 studies identified that children and youth with disabilities experienced a greater number and impact of environmental barriers in school and community settings compared with the home setting. However, barriers related to physical design and accessibility of the home setting and immediate neighborhood...
commonly were reported in studies with parents of children with physical disabilities.15-18

The ICF3 and the more recent version for children and youth, the ICF-CY,19 provide a common international and interdisciplinary language to classify domains of functioning, health, and disability and have been used to guide the design of measures of participation and environment for children and adults with disabilities. However, there are challenges associated with relying exclusively on the ICF and ICF-CY to guide measurement development.20-23 The definition of participation is very broad, and it is not clear what constitutes involvement or participation.19 Al
dditional development.20-23 The definition of participation is very broad, and it is not clear what constitutes involvement or relevant life situations, particularly for children.21 Furthermore, terms used in the ICF3 and ICF-CY19 might not be fully understood or naturally used by persons responding to measures that assess participation and environment. Thus, examining how parents understand and describe children’s participation and environment is an important prerequisite for the development of parent-report measures to assess these constructs.

The present study was undertaken as the first phase of a project to develop new parent-report measures of participation and environment for school-aged children with and without disabilities. There were 3 main research questions. (1) What types of activities do parents of children with and without disabilities perceive to be important for their children to participate in? (2) What environmental factors do parents identify that support and hinder their children’s participation in important activities? (3) How do parents appraise their children’s participation and the environmental factors that support and hinder their children’s participation?

METHODS

This study used a descriptive design and qualitative methods with focus groups and interviews. Recruitment began when approval for this study was obtained from the institutional review boards of 3 universities involved in data collection. A purposeful maximum variation sampling strategy33 was used to gather information from parents who were expected to have different experiences related to their children’s participation and who were interacting with different social services, education, and health care systems. Variation was sought according to children’s age, disability type, and geographic region. Parents of children with disabilities were recruited through established contacts with agencies in the Greater Boston, MA, and Hamilton, Ontario, Canada, areas. We were particularly interested in the perspectives of parents of children with intellectual, emotional, and behavioral disabilities given the lack of evidence about participation of these children compared with children with physical disabilities as previously-described. Several agencies that provided services for these children and families were contacted by telephone to elicit recruitment sup-

port and they then distributed a recruitment flyer and placed notices in agency newsletters and electronic list serves to invite parents to join the study. A group of parents who had children without disabilities aged 5 to 16 years also were recruited through established contacts of graduate students in 1 university in Greater Boston.

Data Collection

We first conducted 4 on-campus focus groups with 10 mothers of children with disabilities in Boston. Focus groups were small and included 2 or 3 mothers because of conflicting family schedules of interested participants. One research team member facilitated the focus groups while a research assistant managed the audiotaping and took notes of observations and additional topics that arose. We then transitioned to an interview format to gather perspectives of parents of children with and without disabilities in Greater Boston and parents of children with disabilities in the Hamilton area. We switched to an interview format to encourage study enrollment by minimizing travel and providing more flexible scheduling options to participants and to obtain more in-depth information from individual participants. Parents in focus groups did not participate in the subsequent interviews. All focus groups and interviews were completed in English and lasted 60 to 90 minutes.

Two semi-structured guides were developed to elicit parents’ perspectives in this study (see Appendix). The initial set of guiding questions was used to collect and analyze data from focus groups and initial interviews. Emerging findings from focus groups and initial interviews informed the development of a revised set of questions that was used during subsequent interviews.23,34

Interviews with parents of children with disabilities in Canada and the United States were held on campus, in the home, and at community agencies, whereas interviews with parents of children without disabilities in the United States were conducted solely in families’ homes. One researcher on the team collected and analyzed data from the U.S. sample of parents of children with disabilities (focus groups, interviews). Another researcher collected and analyzed data from the Canadian sample of parents of children with disabilities. Data from parents of children without disabilities were collected and analyzed by graduate students trained and supervised by another researcher on the team. Data collected by students were reviewed with and further analyzed by this specific researcher. Data collection was stopped when data saturation was achieved (ie, information from new cases became redundant).34

Data Analyses

All interviews and focus groups were audiotaped and transcribed. Each transcript was reviewed and cross-checked with its respective digital recording to ensure accuracy before analysis. Data were analyzed using content analysis33,35 to identify categories and links among categories related to the 3 main research questions. We used NVivo 7.0,36 a text management software program, to assist with this process. We initially sorted relevant text (eg, words, phrases, quotes) from each interview to the corresponding research question and developed codes (ie, descriptive labels) to further sort the text. A codebook was created and used to sort text from subsequent interviews to help with identification of new patterns and trends reflecting parents’ common and unique experiences.

Field notes33 were used to record observations, questions, and insights related to each focus group and interview. Analytic memos35 were used to record findings that were emerging within and then across focus groups and interviews and new...
questions or topics that needed to be discussed and addressed by the research team. Summaries of emergent findings that reflected common and unique perspectives among participants were created periodically based on these discussions.

Established procedures to address the credibility and dependability of data were used to ensure the authenticity and trustworthiness of the findings. Member checking was conducted with 10 U.S. parents of children with disabilities. Parents first were sent a summary of our emerging findings for their review and then discussed the findings and provided additional feedback during 30- to 45-minute telephone interviews. Due to time constraints, member checking could not be conducted with Canadian parents of children with disabilities and U.S. parents of children without disabilities because the initial data from these parents were collected later in the research process. Triangulation was conducted by cross-checking multiple sources of data, such as transcripts and field notes for each case, periodic analytic memos, and summaries of emergent findings. In addition, data were compared to identify common and unique trends among U.S. and Canadian parents of children with disabilities and U.S. parents of children without disabilities. Dependability of findings also was ensured by having each researcher review his/her respective data for consistency. Also, we had at least 2 independent researchers conduct periodic reviews to ensure that emerging findings specific to each group of participants were consistent with our emerging findings across groups.

RESULTS

Participants

Forty-two parents participated in this study. There were 25 parents of children with disabilities: 14 from the United States (Greater Boston area, MA) and 11 from Canada (Greater Hamilton area, Ontario). There were 17 parents of children without disabilities from the United States (Greater Boston area, MA). All parents were English speaking. The children discussed by parents in this study lived at home, except for one 15-year-old girl with severe mental illness from Canada who lived in a residential setting during weekdays and at home on weekends. Parents of children with and without disabilities were similar in age, race, ethnicity, and education (Table 1). Most parents (93%) had children aged 5 to 16 years (Table 2). Three Canadian parents of older children with Down syndrome (aged 18–25y) were included in the study because of their strong interest in participating and ability to provide information based on a longer developmental period. Four parents of children with disabilities discussed 2 of their children. Most children with disabilities had ASD (45%) or mental illness (31%) and were aged 9 to 16 years (69%). Most children without disabilities (65%) were aged 13 to 16 years.

Important Life Activities and Factors That Influence Participation

Parents of children with and without disabilities identified similar important life activities across home, school, and community settings (Table 3). However, only parents of children with disabilities described activities that were modified or specialized to accommodate their children’s special needs at school or in their community. Also, parents of children without disabilities emphasized the importance of competitive, leadership, and civic activities more often than parents of children with disabilities. There were no notable differences in activities identified by parents of children with disabilities from Canada or the United States.

In addition to physical and social environmental factors, parents identified a number of other factors that influenced their child’s participation. Factors were grouped into 5 broad categories: (1) child factors, (2) activity features and demands, (3) physical environment, (4) social/family environment, and (5) services, resources, and policies (Table 4). Further analysis indicated that parents of children without disabilities did not speak about barriers as often and typically attributed their children’s limited participation to the child’s disinterest, lack of

Table 1: Parent Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parents of Children With Disabilities (n=25)</th>
<th>Parents of Children Without Disabilities (n=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>24 (96)</td>
<td>15 (88)</td>
</tr>
<tr>
<td>Other (father, grandmother)</td>
<td>1 (4)</td>
<td>2 (12)</td>
</tr>
<tr>
<td>Age range (y)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30–39</td>
<td>3 (12)</td>
<td>3 (18)</td>
</tr>
<tr>
<td>40–49</td>
<td>17 (68)</td>
<td>9 (53)</td>
</tr>
<tr>
<td>50–59</td>
<td>5 (20)</td>
<td>5 (29)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>21 (84)</td>
<td>16 (94)</td>
</tr>
<tr>
<td>Black</td>
<td>2 (8)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1 (4)</td>
<td>1 (6)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>8 (32)</td>
<td>7 (41)</td>
</tr>
<tr>
<td>College or university degree</td>
<td>8 (32)</td>
<td>8 (47)</td>
</tr>
<tr>
<td>Some college or university</td>
<td>6 (24)</td>
<td>2 (12)</td>
</tr>
<tr>
<td>High school or less</td>
<td>3 (12)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

NOTE. Values expressed as n (%).

Table 2: Child Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Children With Disabilities* (n=29)</th>
<th>Children Without Disabilities (n=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age range (y)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5–8</td>
<td>6 (21)</td>
<td>3 (18)</td>
</tr>
<tr>
<td>9–12</td>
<td>10 (34.5)</td>
<td>3 (18)</td>
</tr>
<tr>
<td>13–16</td>
<td>10 (34.5)</td>
<td>11 (65)</td>
</tr>
<tr>
<td>≥18</td>
<td>3 (10)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boys</td>
<td>18 (62)</td>
<td>9 (53)</td>
</tr>
<tr>
<td>Girls</td>
<td>11 (38)</td>
<td>8 (47)</td>
</tr>
<tr>
<td>Type of disability†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Down syndrome</td>
<td>5 (17)</td>
<td>NA</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>1 (3)</td>
<td>NA</td>
</tr>
<tr>
<td>ASD (Asperger syndrome, pervasive developmental disorder)</td>
<td>13 (45)</td>
<td>NA</td>
</tr>
<tr>
<td>Learning disability</td>
<td>4 (14)</td>
<td>NA</td>
</tr>
<tr>
<td>Attention deficit disorder (with or without hyperactivity)</td>
<td>5 (17)</td>
<td>NA</td>
</tr>
<tr>
<td>Mental illness</td>
<td>9 (31)</td>
<td>NA</td>
</tr>
<tr>
<td>Acquired brain injury</td>
<td>1 (3)</td>
<td>NA</td>
</tr>
<tr>
<td>Other</td>
<td>5 (17)</td>
<td>NA</td>
</tr>
</tbody>
</table>

NOTE. Values expressed as n (%).
Abbreviation: NA, Not applicable.
*Four parents had 2 children with disabilities.
†Some children with disabilities had co-occurring conditions.
motivation or skill level, parental restrictions, scheduling conflicts, and inconvenience getting to community activities. Only parents of children with disabilities attributed their children's limited participation to the child's specific impairments and problems with attitudes and knowledge of and communication with service providers, staff, and administrators in school and community programs.

Parents of children with and without disabilities described strategies they used to promote participation of their children, such as providing emotional and practical support, encouragement and rewards, showing interest in and asking questions about the child’s activities, and coordinating the activities and schedules of both the child and family. However, only parents of children with disabilities described that a key focus of their efforts was on preparing the child at home (eg, through skill building, previewing daily activities) to be able to participate in specific activities at school and in the community and modifying (and educating others to modify) environmental and activity features and demands to fit the child’s preferences and abilities.

How Parents Conceptualize and Appraise Children’s Participation and Environment

Parents used several terms to define participation, including involvement, being engaged, learning, interaction, competence, showing initiative, being proactive, being responsible for, being committed, persistence, reciprocity, connecting with others, feeling successful, empowerment, active inclusion, belonging, membership, and enjoyment. Parents primarily identified social and psychological qualities of participation and what their children gained or could gain through their participation. For example, a U.S. mother of a child without a disability stressed the importance of her daughter:

"Contributing to the effort of the whole, whether it is in a team effort or in an effort to do a project that doesn’t have to do with other people, but is a requirement, for example, something for school...to engage wholeheartedly in whatever she is doing...give her best self to whatever the endeavor is."

Similarly, a U.S. mother of a child with attention-deficit hyperactivity disorder described the importance of her son contributing to an activity and seeking help when needed:

"Basically doing what he can...and if he doesn’t understand, to ask us."

Parents gathered information to appraise the participation of their children and factors that influenced participation in several different ways: (1) observing the child when participating in an activity and attending to his/her verbal and nonverbal cues, (2) reviewing documentation (eg, teachers’ notes, report cards), (3) knowing the child’s daily routines, and (4) receiving solicited and unsolicited verbal and written feedback from the child, his/her peers, and other adults (eg, teacher, coach, activity instructor, therapist).

Parents identified whether their child participated in an activity; whether something helped, interfered, or was a challenge; and whether they had or lacked adequate resources or supports. Parents used general quantitative terms to describe change in their child’s participation over time, such as showing more initiative or greater responsibility during the activity or spending more time on or doing a greater portion of the activity. They did not provide finely tuned descriptions that would indicate gradations of greater or lesser participation or the impact of factors that supported or hindered participation of their children.

A few parents identified that more participation in terms of frequency (ie, how often their child participated) and extent of involvement was not always desired or expected in certain situations. For example, one U.S mother remarked that participation could involve her daughter with Down syndrome “just being present” when waiting her turn during swimming lessons at the community pool. Two U.S. mothers, 1 with a child with a disability and 1 with a child without a disability, emphasized the importance of “just showing up” for certain activities, such as religious services and holiday events. A few parents of children with disabilities identified that they were satisfied with their child just being part of the activity or group in some way. For example, 1 Canadian mother of a child with ASD expressed:

“He’s nothing special, he’s just 1 of the kids...and that means everything to us.”

Table 3: Important Life Activities in Which Children Participate (reported by parents)

<table>
<thead>
<tr>
<th>Home activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active leisure (eg, sports, backyard play)</td>
</tr>
<tr>
<td>Self-care (eg, dressing, brushing teeth, showering)</td>
</tr>
<tr>
<td>Household chores and activities (eg, taking care of room, picking up toys, cooking, taking out trash, laundry, yard work, taking care of pet)</td>
</tr>
<tr>
<td>Arts, crafts, music, reading and hobbies (eg, listening to music, playing an instrument, doing crafts, collecting things)</td>
</tr>
<tr>
<td>School preparation (eg, getting backpack and lunch ready, doing homework, reviewing and previewing daily schedule)*</td>
</tr>
<tr>
<td>Therapy services and activities*</td>
</tr>
<tr>
<td>Computer and video games</td>
</tr>
<tr>
<td>Watching television and movies</td>
</tr>
<tr>
<td>E-mail, Internet, and telephone</td>
</tr>
<tr>
<td>Play and leisure (eg, board games, puzzles, playing with toys, hide-and-seek and guessing games)</td>
</tr>
<tr>
<td>Socializing with friends and family (eg, play with siblings, play dates, conversations with house guests)</td>
</tr>
<tr>
<td>School activities</td>
</tr>
<tr>
<td>Classroom activities (eg, classes, group work, tests)</td>
</tr>
<tr>
<td>Before- and after-school activities (eg, individual and team sports, choir, clubs, council, prayer, daycare)</td>
</tr>
<tr>
<td>Field trips and school events (eg, class trips, dances, plays, book fair, fundraiser)</td>
</tr>
<tr>
<td>Helping out at school (eg, peer mentorship or supervision, lunch monitor)</td>
</tr>
<tr>
<td>Hanging out and socializing at school (at recess, lunch time, between classes)</td>
</tr>
<tr>
<td>Therapy activities (eg, occupational and physical therapy)*</td>
</tr>
<tr>
<td>Community activities</td>
</tr>
<tr>
<td>Classes and lessons (eg, music, art, computer, cooking)</td>
</tr>
<tr>
<td>Organized physical activities (eg, individual and team sports, dance, swimming, bowling)</td>
</tr>
<tr>
<td>Unstructured physical activities (eg, rollerblading, hiking, riding bike, horseback riding)</td>
</tr>
<tr>
<td>Neighborhood outings (eg, going to the library, shopping at store or mall, running errands, eating out at a restaurant)</td>
</tr>
<tr>
<td>Hanging out and socializing (eg, friends, family, clubs)</td>
</tr>
<tr>
<td>Work (eg, paper route, babysitting, dog walking)</td>
</tr>
<tr>
<td>Organizations, groups, and volunteer/leadership activities (eg, Boy Scouts, Brownies, public speaking, youth group, volunteering, helping neighbors, peer mentoring/buddy programs*)</td>
</tr>
<tr>
<td>Overnight stays (eg, camp, sleepovers, family trips)</td>
</tr>
<tr>
<td>Religious and spiritual activities (eg, services and activities at places of worship)</td>
</tr>
<tr>
<td>Community events (eg, theater, movies, museums, zoo)</td>
</tr>
<tr>
<td>Appointments (eg, haircut, doctor/dentist, therapy, nutritionist)*</td>
</tr>
</tbody>
</table>

*Reported by only parents of children with disabilities.
Parents of children with and without disabilities spontaneously talked about participation and environment together. While discussing participation of their children, they consistently included information about features of the physical and social environment and other factors that influenced participation, such as the cognitive, social, and physical demands of the activity; parent strategies; and the child’s age, preferences, and abilities.

Parents often described the interaction among several factors as influencing participation of their children and that standards and expectations for participation varied depending on the specific setting, activity, and situation. This was particularly evident for parents of children with disabilities and illustrated best by 3 Canadian mothers. One mother of a young boy with ASD described her son’s participation at camp, saying:

“He loves to be around people and most especially kids. He just doesn’t know what to do with them once he’s there. The camp was great...he did well by watching other kids...you could show him something 10 times and he won’t do it for you, but if a kid did it he’d do it.”

Another mother described how the school environment influenced the extent to which her daughter with developmental and behavioral challenges could participate, saying:

“The school is fantastic with incorporating her in gym. She does all the gym activities. She does all the regular activities in the classroom. She has an Educational Assistant that works with her. But when there’s circle time and like craft activities in the class, she does what the class is doing.”

One more mother acknowledged the importance of both physical and social environmental factors as helping her son with Down syndrome participate in a structured activity in the community:

“So, he did not learn everything...like the other kids...writing their stories and adding their art to it and all...that was a bit too complex for him. So, he worked within his range of ability, but again it was just open to kids in his age group so I think that was a really good

### Table 4: Factors Influencing Participation Across Home, School, and Community Settings (reported by parents)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Children With and Without Disabilities</th>
<th>Children With Disabilities Only</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child factors</strong></td>
<td>Abilities and skills</td>
<td>Cognitive, physical, psychological functioning and impairment</td>
</tr>
<tr>
<td></td>
<td>Age/development</td>
<td>Behavior</td>
</tr>
<tr>
<td></td>
<td>Motivation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Personality/temperament</td>
<td>Health</td>
</tr>
<tr>
<td></td>
<td>Preference, interest, enjoyment</td>
<td>Visibility of disability</td>
</tr>
<tr>
<td><strong>Activity features and demands</strong></td>
<td>Familiarity/comfort</td>
<td>Structured vs unstructured</td>
</tr>
<tr>
<td></td>
<td>Degree of challenge, competitiveness*</td>
<td>Repetition, predictability, preparedness</td>
</tr>
<tr>
<td></td>
<td>Involvement with others in the activity:</td>
<td>Designed for children with and/or without disabilities</td>
</tr>
<tr>
<td></td>
<td>Parent(s) and family or by self (home)</td>
<td>The fit between activity demands and child factors</td>
</tr>
<tr>
<td></td>
<td>Teacher, classmates (school)</td>
<td>(eg, skills and preferences)*</td>
</tr>
<tr>
<td></td>
<td>Parent, instructor, children, other community members or by self (community)</td>
<td>Involvement with others in the activity: Educational assistant</td>
</tr>
<tr>
<td><strong>Physical environment</strong></td>
<td>Physical safety</td>
<td>Physical design and organization of space</td>
</tr>
<tr>
<td></td>
<td>Distance to/ location of activity</td>
<td>Sensory characteristics (eg, type and degree of auditory, visual, tactile stimulation)</td>
</tr>
<tr>
<td><strong>Social and family environment</strong></td>
<td>Physical and emotional safety</td>
<td>Supervision and adult/child ratios</td>
</tr>
<tr>
<td></td>
<td>Comfort and familiarity</td>
<td>Being teased or bullied</td>
</tr>
<tr>
<td></td>
<td>Support from others at home, school, community settings</td>
<td>Inclusion by others: Family members and children in the neighborhood (home and community)</td>
</tr>
<tr>
<td></td>
<td>Relationships</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family involvement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Parent’s strategies</td>
<td>Staff, teachers and classmates (school)</td>
</tr>
<tr>
<td></td>
<td>Parent’s health and energy (home and community)</td>
<td>Instructors, children and other members (community)</td>
</tr>
<tr>
<td></td>
<td>Parental restrictions on child’s activities (home and community)</td>
<td>Communication between parent and school or program (school and community)</td>
</tr>
<tr>
<td></td>
<td>Competing activities and schedules for child and family (home and community)</td>
<td>Attitudes and knowledge (school and community)</td>
</tr>
<tr>
<td></td>
<td>Competence of activity group leaders*</td>
<td></td>
</tr>
<tr>
<td><strong>Services, resources, and policies</strong></td>
<td>Time</td>
<td>Location of services for children with disabilities</td>
</tr>
<tr>
<td></td>
<td>Money</td>
<td>Eligibility for services for children with disabilities</td>
</tr>
<tr>
<td></td>
<td>Transportation</td>
<td>Educated and skilled service providers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Equipment, tools, assistive devices or adaptive technology</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Institutional and program policies, systems and procedures (school and community)</td>
</tr>
</tbody>
</table>

**NOTE.** Items are relevant for all 3 settings (home, school, community) unless specified otherwise in parentheses.

*Reported by only parents of children without disabilities.

### Appraisal of Participation and Environment Is Inextricably Linked

Parents of children with and without disabilities spontaneously talked about participation and environment together. While discussing participation of their children, they consistently included information about features of the physical and social environment and other factors that influenced participation, such as the cognitive, social, and physical demands of the activity; parent strategies; and the child’s age, preferences, and abilities.

Parents often described the interaction among several factors as influencing participation of their children and that standards and expectations for participation varied depending on the specific setting, activity, and situation. This was particularly evident for parents of children with disabilities and illustrated best by 3 Canadian mothers. One mother of a young boy with ASD described her son’s participation at camp, saying:

“He loves to be around people and most especially kids. He just doesn’t know what to do with them once he’s there. The camp was great...he did well by watching other kids...you could show him something 10 times and he won’t do it for you, but if a kid did it he’d do it.”

Another mother described how the school environment influenced the extent to which her daughter with developmental and behavioral challenges could participate, saying:

“The school is fantastic with incorporating her in gym. She does all the gym activities. She does all the regular activities in the classroom. She has an Educational Assistant that works with her. But when there’s circle time and like craft activities in the class, she does what the class is doing.”

One more mother acknowledged the importance of both physical and social environmental factors as helping her son with Down syndrome participate in a structured activity in the community:

“So, he did not learn everything...like the other kids...writing their stories and adding their art to it and all...that was a bit too complex for him. So, he worked within his range of ability, but again it was just open to kids in his age group so I think that was a really good...
experience. He didn’t know the other kids. The other kids didn’t know him, but they were all in the class together. And he was in, you know, his town library.

**DISCUSSION**

Findings of this study offer additional insights from parents about important aspects of children’s participation and environment that have informed the design of a parent-report measure of children’s participation and environment. Findings are discussed as they relate to (1) the impact of disability, (2) the ICF, (3) understanding children’s participation and environment, and (4) implications for the design of measures of children’s participation and environment.

**Impact of Disability on Findings**

Overall, parents of children with disabilities from Canada and the United States and parents of children without disabilities described common important life activities and factors that influenced participation of their children. The key differences that were described were not surprising because they focused on impairments and challenges of children with disabilities and concerns related to the activities and programs designed for them. Most children with disabilities described in this study had diagnoses characterized by psychosocial, learning, attention, and sensory-processing difficulties. Thus, our findings add an important new perspective to the literature about children’s participation and environment that has mainly been based on studies of children with physical disabilities. Most life activities and influencing factors reported by parents in this study, particularly parents of children with disabilities, were similar to those reported in studies of children with physical disabilities. However, parents in this study tended to place a greater emphasis on social and family environmental factors than physical environmental factors. This differs somewhat from studies of children with physical disabilities that often highlight accommodations, transportation, and mobility-related challenges. However, Law et al found that parents of children with physical disabilities whose children also had behavioral problems reported fewer physical and more psychosocial environmental factors as hindering participation of their children. Similarly, greater emphasis on social and family environmental factors has been reported related to participation of children and youth with acquired brain injuries.

**Relationship of Findings to the ICF**

Parents in this study described important life activities and environmental factors that were similar to and expanded on categories in the ICF and ICF-CY. Most parent-reported factors that influenced participation of their children are identified easily in the ICF-CY and are important to consider when investigating children’s participation. For example, the child’s physical, cognitive, and psychosocial functioning and challenges are classified as body functioning/impairments, and the child’s skills, abilities, and difficulties executing tasks and actions are classified as activity/activity limitations.

Whiteneck and Dijkers emphasized that the ICF could be used initially to guide the content of measures, but cannot be used exclusively for this purpose given its limitations in clarity and detail and the static nature of any taxonomy. Other factors that are not clearly identified in the ICF and ICF-CY, but are reported in the literature, also need to be considered in future measurement tools and approaches investigating participation of children. Two such factors emphasized in this study, particularly by parents of children with disabilities, were features and demands of specific activities and strategies parents used to support participation of their children. Parents also emphasized factors that seem to fall under the general ICF-CY category of personal-contextual factors, such as the child’s age, preferences, motivation, enjoyment, and personality. However, personal factors are not specifically classified in the ICF-CY or ICF because of the opinion of the ICF authors that there would be too much sociocultural variability across countries and regions worldwide. Thus, recommendations are made in the ICF-CY that stakeholders address the personal factors that are most relevant to their specific settings and needs. Because of these reported limitations in the ICF, it is clear that conceptual models are needed to more fully understand the dynamic influence and interplay of multiple factors on a child’s participation in real-life contexts.

**Relationship of Findings to Understanding Children’s Participation and Environment**

Parents in this study often described the interaction among several factors as influencing their child’s participation and that standards and expectations for their child’s participation varied depending on the specific setting, activity, and situation. These findings provide support for application of ecologic models to understand the often complex and dynamic interactions among multiple person and environmental influences on a child’s participation. For example, King et al used Bronfenbrenner’s ecology of human development model as a heuristic to identify child, family, community, and societal factors that could have a direct or indirect influence on leisure and recreational participation of school-age children with physical disabilities. Using structural equation modeling, King found that the child’s functional abilities and preferences and the family’s involvement in activities were the most significant direct predictors of children’s participation. Significant indirect predictors identified by King included family cohesion, supportive relationships, and unsupportive physical, social, and attitudinal environmental factors.

Other researchers also have described the interactions and differential effects of factors that influence participation of children with disabilities by using varied research methods. For example, in a qualitative study, Heah et al found that a child’s level of independence was a key factor that interacted with a number of physical and social environmental factors to influence perspectives about successful participation based on interviews conducted with children with disabilities and their families. In a predictive study, Forsyth et al found that participation of young children with severe disabilities was influenced to a similar extent by both the child’s intrinsic impairments and environmental (physical, social) factors.

**Implications for the Design of Measures of Children’s Participation and Environment**

Our findings highlight the multidimensional nature of participation and support the conclusion that no single measurement tool or approach will be able to address all facets of participation. Parents in our study easily identified the frequency with which (ie, how often) their child participated in important life activities. Frequency of participation is an important feature of population-based measures of participation because it allows for identification of children’s profiles (eg, how they spend time) and assessment of differences related to demographic and environmental factors. Parents also discussed the nature of their children’s involvement and emphasized social and psychological aspects of participation and what their children gained or could gain from their participa-
tion; for example, emotionally and as contributors to home, school, and community life. These findings expand on those of Heah, who identified 4 important characteristics of successful participation described by children with disabilities and their parents: having fun, feeling successful, doing and being with others, and doing things independently.

We also concur with Forsyth and Jarvis that measuring environmental factors is complex and measures are needed to identify factors that influence participation of children in specific settings and activities. Consistent with other studies, many factors described by parents in our study were viewed as either or both a support or barrier depending on the setting, activity, and situation. These findings highlight the importance of examining both supportive and restrictive features of the social and physical environment in future parent-report measures.

The recurrent theme in our study was that parents’ appraisals of children’s participation and environment were inextricably linked. Researchers investigating children’s participation and environment currently use distinct tools to measure each construct and thus links between the constructs are shown analytically versus explicitly using 1 measure. Our findings suggest that these constructs need to be explicitly linked in future parent-report measures.

Study Limitations

The findings provide insights that will be useful for future measurement development; however, they should not be generalized beyond this purpose. Data were collected from a small sample of families in 2 locations (Greater Boston, MA, and Greater Hamilton, Ontario, Canada), most of whom were mothers (93%), were white (88%), and had some college education (93%). Also, it is likely that parents’ responses and the differences identified between parents of children with and without disabilities were influenced in part by the use of semistructured guiding questions, different data-collection formats, and different interviewers. Furthermore, as mentioned, we were able to conduct member checking interviews with only 10 U.S. parents of children with disabilities because of time constraints. Feedback from Canadian parents of children with disabilities and U.S. parents of children without disabilities likely would have provided additional insights to inform the design of our future measure. Also, we examined parents’ perspectives in this study because our ultimate aim was to develop a parent-report measure of children’s participation and environment. However, seeking out perspectives of children and other significant people in their lives, such as peers, siblings, and teachers, would have provided additional insights to inform measurement development in this area.

CONCLUSIONS

Findings from this study have suggested a number of important considerations for the design of parent-report measures of participation and environment for children with and without disabilities. Although our focus was to inform the design of population-based measures, the knowledge gained from this study also had implications for both individualized (child- and family-centered) and program-level assessment. These findings have informed our development of a parent-report measure currently being tested that explicitly links participation and environmental factors (ie, both supports and barriers) specific to home, school, and community settings. We expect that having 1 measure to assess participation and environment rather than using distinct tools to assess each construct separately should situate the child’s participation in real-life contexts and thus match how parents in this study understood and appraised participation of their children.

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APPENDIX 1: GUIDING QUESTIONS USED IN FOCUS GROUPS AND INTERVIEWS

Guiding Questions for Focus Group and Initial Interviews

1. What does the word “participation” mean to you? (no right or wrong answers)
2. What types of activities do you find important for your child to participate in at home, school, and your community? (Encourage parent to discuss many activities in these 3 settings.)
3. How do you know whether your child is participating in these activities?
   Probe 1: Asked another way, what types of things do you pay attention to in order to judge whether your child is participating?
   Probe 2: What if we take 1 of the activities that you came up with as an example. What would lead you to decide whether your child is participating more or less (or a lot or a little) in this activity?
4. What helps your child participate in important activities successfully? (supports)
   Probe 1: What key ingredients (people, places, things) make it happen?
   Probe 2: How do you know how much or how often these things support your child’s participation? (let’s take examples that you have described)
5. What interferes with your child’s participation in important activities? (barriers)
   Probe 1: What types of challenges or hurdles (people, places, things) make it difficult for your child to participate successfully?
   Probe 2: How do you know how much or how often these things interfere with your child’s participation? (let’s take examples that you have described)
6. Is there anything else that you would like to say about the things we discussed today?

Guiding Questions for Subsequent Interviews

Here is a table of different types of activities that have been identified by parents so far as important for their children to participate in at home, at school, and in the community.

1. Do the groupings or categories listed here make sense to you?
2. Can you think of any additional activities to add to this list?

Now let’s focus on how you describe and rate your child’s participation in some of these activities. I am going to ask you to compare your child’s participation so we can see if there are patterns of engagement. Pick 2 types of activities within each of these settings (home, school, community) that are meaningful to your child.

3. Does participation have the same or different meaning for your child in each of these activities?
4. How can you tell if your child is participating more or less in 1 activity compared with the other?
5. Which of the 2 types of activities is going well for your child? For this type of activity, what things in your child’s environment support his/her participation (people, things)? (Which support most helps your child participate in this type of activity?)

6. For the activity that is not going as well for your child, what types of challenges or hurdles (people, things) make it difficult for your child to participate successfully in this type of activity? (Which type of barrier most challenges your child’s participation in this type of activity?)

Now let’s look at similarities and differences in your child’s participation across places like home, school, and community. Pick 2 similar types of activities that might occur in 2 different settings (eg, home vs community)

7. Does participation have the same or different meaning for your child in these 2 settings?

8. How do you know if your child is participating more or less in 1 setting compared with the other?

9. How do you decide whether your child is participating more or less (or a lot or a little) in this setting? Now what about the other setting? Is it the same or different?

NOTE. The table provided to parents was a previous and less complete version of table 3 in this article.

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Supplier

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