

**ORIGINAL RESEARCH**

# Environmental Barriers and Supports to Everyday Participation: A Qualitative Insider Perspective From People With Disabilities



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## Abstract

**Objective:** To describe environmental factors that influence participation of people with disabilities.

**Design:** Constant comparative, qualitative analyses of transcripts from 36 focus groups across 5 research projects.

**Setting:** Home, community, work, and social participation settings.

**Participants:** Community-dwelling people (N = 201) with diverse disabilities (primarily spinal cord injury, traumatic brain injury, and stroke) from 8 states.

**Interventions:** None.

**Main Outcome Measures:** Environmental barriers and supports to participation.

**Results:** We developed a conceptual framework to describe how environmental factors influence the participation of people with disabilities, highlighting 8 domains of environmental facilitators and barriers (built, natural, assistive technology, transportation, information and technology access, social support and attitudes, systems and policies, economics) and a transactional model showing the influence of environmental factors on participation at the micro (individual), mesa (community), and macro (societal) levels. Focus group data validated some *International Classification of Functioning, Disability and Health* environmental categories while also bringing unique factors (eg, information and technology access, economic quality of life) to the fore. Data were used to construct items to enable people with disabilities to assess the impact of environmental factors on everyday participation from their firsthand experience.

**Conclusions:** Participants with disabilities voiced the need to evaluate the impact of the environment on their participation at the immediate, community, and societal levels. The results have implications for assessing environmental facilitators and barriers to participation within rehabilitation and community settings, evaluating outcomes of environmental interventions, and effecting system and policy changes to target environmental barriers that may result in societal participation disparities versus opportunities.

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Merriam-Webster's Dictionary broadly defines the environment as "the conditions that surround someone or something; the conditions and influences that affect the growth, health, progress, etc., of someone or something".<sup>1</sup> The disability rights movement and social model of disability have long asserted that participation restrictions are created when people with disabilities encounter barriers in their physical, sociocultural, political, and economic environments, pointing to the idea that environmental factors can disable or enable full participation as much or more so than individual impairment or function.<sup>2-4</sup> In accordance with the social model, the Social Determinants of Health model used by the World Health Organization and Centers for Disease Control and Prevention broadly conceptualizes environment as "the complex, integrated, and overlapping social structures and economic systems that are responsible for most health inequities. These social structures and economic systems include the social environment, physical environment, health services, and structural and societal factors".<sup>5</sup>

Understanding the complex relation between person, environment, and participation and the impact of these factors on health and function continues to be a major challenge and rehabilitation research mandate.<sup>6-8</sup> Although theories about the impact of environmental factors on human behavior abound, operationalizing and measuring environmental factors in a theoretically sound yet consumer-responsive manner remains difficult.<sup>9,10</sup>

The *International Classification of Functioning, Disability and Health* (ICF) has prompted a resurgence of efforts to measure environmental factors in disability and rehabilitation research.<sup>11,12</sup> The ICF provides a taxonomy of environmental factors in 5 categories: products and technology; natural environment and human-made changes to environment; support and relations; attitudes; and services, systems, and policies. Environmental factors can be facilitators (features that enhance ability to participate) and barriers (features that inhibit participation), depending on the individual's social role and context.<sup>13-16</sup>

Although the ICF provides a classification schema, additional research is needed to develop a theoretical conceptualization on which to examine complex relations among environmental factors or the relative contributions of these relations to societal participation. Therefore, the goal of this project was to develop a theoretically grounded, conceptual framework of the relations between environmental factors and participation, grounded in the first-hand experiences of people with disabilities using data from multiple projects and sites.<sup>13-18</sup> Results from this project provided the foundation for the development of items and item pools to assess environmental factors.<sup>19</sup> This study combined qualitative data from 5 projects that collected data describing the influence of environmental factors on participation and quality of life among people with disabilities. Our intent was to provide a deeper understanding of the dynamic interaction between environmental factors and participation, as reflected in the theoretical article by Magasi et al.<sup>10</sup> A richer understanding of the relation between environment factors and participation facilitates development of items to measure environmental influence from a consumer-directed perspective and informs the design of environmental

programming, systems, and policies that promote the full participation of people with disabilities.

## Methods

This study involved secondary analysis of qualitative data from 5 projects,<sup>7,13-20</sup> with people with diverse disabilities across different regions in the United States.<sup>14-16,21,22</sup> The data served as the foundation for the development of new measures of participation: Community Participation Indicators,<sup>13-15</sup> Participation Survey—Mobility,<sup>18</sup> health-related quality of life (Spinal Cord Injury Quality of Life and Traumatic Brain Injury Quality of Life),<sup>17,22</sup> and Facilitators and Barriers Survey.<sup>1</sup> Even though most of these projects were focused on conceptualizing and measuring participation or quality of life, focus group participants with disabilities repeatedly pointed to the widespread influence of the environment on their everyday participation.<sup>13-15</sup> This influence was identified beyond physical accessibility, which is a traditional focus of rehabilitation. We took advantage of the opportunity to analyze these rich data across projects and diverse disability samples to examine environmental factors critically and develop a theoretical conceptualization of the influence of the environmental on home, community, work, and economic participation. A more fully developed theoretical framework would inform rehabilitation, community, work, and system delivery and supports.

## Design

Concept elicitation through qualitative data collection is emerging as a best practice for instrument development, particularly client-centered or consumer-directed assessments.<sup>23-27</sup> A grounded theory approach, embedded in the lived experiences of people with disabilities, ensures that instrument content is socially valid and relevant to the lived experiences of the target population.<sup>3,4</sup> Grounded theory methods use constant comparative analyses to identify intra- and intergroup similarities and differences related to the phenomena of interest and thereby serve as an ideal mechanism for examining pooled data across studies, in this case multiple sites and diverse disability groups, including traumatic brain injury (TBI), spinal cord injury (SCI), and stroke.<sup>23-25</sup> Focus groups provide an in-depth, participatory means of learning how constituents of various groups perceive a phenomenon, in this case, full participation in society, and how the environment affects everyday participation.<sup>28-31</sup> Results provide a rich description of environmental facilitators and barriers that are relevant, meaningful, and socially valid.

The National Institutes of Health's Patient Reported Outcomes Measurement Information System initiative developed guidelines for instrument development that includes qualitative focus groups and interviews; investigators have adopted this approach across studies.<sup>32-34</sup> This qualitative analysis and grounded theory development processes represent an important step in the rigorous, mixed-methods approach to the development of environmental factors measures.<sup>34</sup>

## Participants

Data were available from 36 focus groups conducted with 201 participants. Each project used purposive, maximum variation sampling<sup>16,24</sup> to recruit participants with disabilities. The combined sample is diverse in type of disability, time since disability onset,

### List of abbreviations:

ICF	<i>International Classification of Functioning, Disability and Health</i>
SCI	spinal cord injury
TBI	traumatic brain injury

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