

Measuring Participation Enfranchisement

Allen W. Heinemann, PhD, Jin-Shei Lai, PhD, Susan Magasi, PhD, Joy Hammel, PhD, John D. Corrigan, PhD, Jennifer A. Bogner, PhD, Gale G. Whiteneck, PhD

ABSTRACT. Heinemann AW, Lai J-S, Magasi S, Hammel J, Corrigan JD, Bogner JA, Whiteneck GG. Measuring participation enfranchisement. *Arch Phys Med Rehabil* 2011;92:564-71.

Objective: To reflect the perspectives of rehabilitation stakeholders in a measure of participation enfranchisement that can be used by people with and without disabilities.

Design: Survey.

Setting: Community settings.

Participants: We pilot-tested a draft instrument with 326 adults who had sustained stroke, spinal cord injury, traumatic brain injury, or other disabling condition, as well as a general population sample. We administered a revised version of the instrument to a statewide sample drawn from the 2006 Colorado Behavioral Risk Factors Surveillance System that included persons with (N=461) and without (N=451) self-identified activity limitations.

Interventions: None.

Main Outcome Measure: Participation enfranchisement.

Results: We used multidimensional scaling, exploratory factor analysis (EFA) and confirmatory factor analysis (CFA), followed by rating scale analysis to evaluate the psychometric properties of the instrument. EFA identified 3 participation enfranchisement factors that describe perceived choice and control, contributing to one's community, and feeling valued; the factors were supported marginally by CFA. Rating scale analysis revealed marginal person separation and no misfitting items.

Conclusions: Participation enfranchisement constitutes a new, previously unmeasured aspect of participation—one that addresses subjective perceptions rather than objective performance—with items that are clearly distinct from more generalized satisfaction with participation. The 19 enfranchisement items describe aspects of participation that may prove useful in characterizing longer-term rehabilitation outcomes.

Key Words: Patient participation; Psychometrics; Rehabilitation.

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From the Departments of Physical Medicine and Rehabilitation (Heinemann) and Medical Social Sciences (Lai, Magasi), Feinberg School of Medicine, Northwestern University, Chicago, IL; the Rehabilitation Institute of Chicago, Chicago, IL (Heinemann); University of Illinois at Chicago, Chicago, IL (Hammel); Ohio State University, Columbus, OH (Corrigan, Bogner); Craig Hospital, Englewood, CO (Whiteneck).

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Reprint requests to Allen W. Heinemann, PhD, Rehabilitation Institute of Chicago, 345 E Superior St, Chicago, IL 60611-2654, e-mail: a-heinemann@northwestern.edu.

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THE WORLD HEALTH Organization's ICF¹ defines participation as involvement in life situations and refers to active engagement in real world activities and environments. Unfortunately, neither the ICF's definition of participation nor its taxonomy of activities and participation provides a clear mechanism to operationalize participation.

A review of participation measures indicates that the Craig Handicap Assessment and Reporting Technique² is perhaps the most widely used measure of participation in disability research.³ While both the original 38-item Craig Handicap Assessment and Reporting Technique and the 18-item Craig Handicap Assessment and Reporting Technique—short form have demonstrated good reliability and validity, they are based on an earlier conceptual framework (the *International Classification of Impairment, Disability and Handicap*⁴), provide narrow consideration of settings in which participation occurs, and were developed with limited input from people with disabilities. Other instruments used to measure participation, such as the Community Integration Measure⁵ and the Community Integration Questionnaire,⁶ were developed for specific rehabilitation populations like people with TBIs and may not be applicable to other populations. In addition, none of these instruments accounts for other influences that may affect participation—personal preferences and environmental, social, and economic factors.

In response to these limitations, a new generation of participation measures is being developed that corresponds to contemporary definitions of participation, evaluates the subjective experiences of people with disabilities, and seeks to capitalize on contemporary measurement theories such as item response theory (eg, Participation Measure for Post-Acute Care,⁷ Impact on Participation and Autonomy Questionnaire,⁸ Participation Survey/Mobility⁹). The Participation Measure for Post-Acute Care is a 65-item fixed-length measure, and a computerized adaptive testing platform has been developed as well.¹⁰ The Participation Measure for Post-Acute Care focuses on participation limitations, represents items inconsistently across domains, and is somewhat cumbersome to administer with 65 items. The computer adaptive testing version offers more efficient administration with only modest reductions in sensitivity

List of Abbreviations

BRFSS	Behavioral Risk Factor Surveillance System
CFA	confirmatory factor analysis
CFI	comparative fit index
CPI	Community Participation Indicators
DIF	differential item functioning
EFA	exploratory factor analysis
ICF	<i>International Classification of Functioning, Disability and Health</i>
MDS	multidimensional scaling
RMSE	root mean square error
RSQ	squared correlation fit index
TBI	traumatic brain injury
TLI	Tucker-Lewis index

and responsiveness.¹⁰ The Impact on Participation and Autonomy Questionnaire⁸ integrates principles of decisional autonomy within the ICF framework using 32 items across 5 subdomains. Although this questionnaire emphasizes subjective appraisals of participation across 6 of the ICF's activity and participation domains, it does not document objective performance, nor does it explore how contextual factors influence participation. The Participation Survey/Mobility assesses objective performance, subjective evaluation, participation supports (people, devices, etc.), and health-related impairments in 20 activity categories. However, it is lengthy and complex, and it focuses on mobility impairments. A limitation of many of these participation measures is that they were developed with limited stakeholder input (Participation Measure for Post-Acute Care) or focused on a limited range of disabling conditions (Participation Survey/Mobility). Furthermore, while the ICF framework describes participation outcomes as an interaction between a person's body structure and function, person factors, and environmental contexts, most measures assess participation or environmental factors; no measure describes the dynamic interplay with the environment that frames people's experiences of participation.

Other recent approaches to participation measurement emphasize perceived involvement in society, fulfilling one's potential, and self-direction. van de Ven et al¹¹ attempt to reflect people's perception of environmental and societal barriers and opportunities and how they influence participation choice and control. Their instruments link participation and context interaction and ground ratings in the experience of persons with disabilities. Townley and Kloos¹² developed the Brief Sense of Community Index that reflects themes of social connections, mutual concerns, community values, and disability acceptance for persons with mental illness residing in community settings.

We reported in 2 previous publications our methods to obtain input in defining the construct of participation as conceptualized by rehabilitation stakeholders, and to use these results to assess participation that is grounded in and socially validated by these stakeholders.^{13,14} Eighteen focus groups including 148 participants representing diverse consumers, caregivers, providers, payers, and policy-makers were held to capture the meaning of participation. We transcribed each group's discussion, then coded, analyzed, and reviewed the transcripts. We compared the perspectives of insiders—that is, people with disabilities (n=63)—with the perspectives of caregivers and important others, rehabilitation professionals, rehabilitation funders, and national policy-makers (n=75). Consumers conceptualized participation as a cluster of values pertaining to enfranchisement that included active and meaningful engagement/being a part of; choice and control; access and opportunity; personal and societal responsibilities; having an impact and supporting others; and social connection, inclusion, and membership. Although various stakeholders shared themes related to the importance and values of full participation, each group emphasized different priorities about the output required from participation assessment.

A valid participation measure should not only be psychometrically sound and easy to administer, score and interpret, but also reflect a variety of stakeholder perspectives, consider the settings in which people live, and not expect all people to value all forms of participation. It is the ultimate goal of this research team to develop such a comprehensive measure of participation from the perspective of multiple stakeholders that includes both objective and subjective assessments. While this global objective has not been achieved, major progress has been made in advancing the measurement of 1 aspect of participation that directly reflects the way people with disabilities

frame participation in their own lives. Thus, the purpose of this study is to report the development of a measure of participation enfranchisement that assesses the extent to which people feel they participate in the community in a manner that is personally valuable, as opposed to assessing actual performance of community-based activities. This study evaluated the psychometric properties of participation enfranchisement items with diverse disability and general population samples, reflecting the population for which the instrument is intended. Development of a separate measure derived from engagement items (measuring performance of community-based activities) is reported elsewhere given our collaboration with TBI Model System collaborators that proceeded in parallel.¹⁵

METHODS

Instrument Development

Mixed method approaches that integrate qualitatively derived stakeholder perspectives with the state-of-the-art in psychometrics and measurement theory are emerging as the standard for rigorous instrument development.¹⁶ Qualitative methodologies are used to develop conceptual frameworks on which instruments are based and to write items that incorporate language that reflects the first-hand experiences of the target population. After a process of cognitive testing to ensure item comprehension, measures are field-tested with the target population. Data from the field test are evaluated using methods such as item response theory, factor analysis, and multidimensional scaling to select items and determine the instrument's measurement properties.

We used this process to create a new measure that seeks to address the limitations in participation measurement described. We completed a thorough literature review of participation measures and reported the findings of the qualitative focus group work previously.¹⁴ Three aspects of participation emerged from this cross-group analysis: (1) engagement, (2) evaluation, and (3) participation enfranchisement. Engagement refers to how much one participates in activities within 3 domains (productivity, social participation, being out and about in the community), and evaluation refers to subjective ratings of satisfaction within a participation domain. We defined participation enfranchisement as a set of perceptions and values that give meaning to participation and that apply across domains. Therefore, unlike engagement and evaluation, enfranchisement is not tied to a particular activity or form of participation.

While participation enfranchisement is clearly a complex construct, we believe at its core is the assessment of whether the community in which a person participates actually values their participation. Enfranchisement is the antithesis of disenfranchisement. Examples of disenfranchisement might include being a member of a racial or ethnic group that a community or society explicitly or implicitly discriminates against, being from a different cultural background that is misunderstood and disrespected by the community, or being labeled (eg, sex offender, illegal alien) in a way that is abhorred by the community. In contrast, positive enfranchisement reflects belongingness to one's community or society.

We drafted participation enfranchisement items using as source material a comprehensive literature review and the focus group transcripts and value themes. We used a 4-category rating scale for the enfranchisement items to reflect how true each statement was for respondents—that is, to what extent the item reflected their life experiences and participation opportunities. We conducted cognitive interviews with 16 adults with spinal cord injury or TBI in Colorado, Illinois, and Ohio to ascertain that items were understood and responded to in the manner intended. Using the guide by Willis,¹⁷ we asked respondents to

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