

Participation:

Preliminary Observations and Recommendations from a Scoping Review

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Purpose

- Outline the status of the literature on measuring participation, to help frame the current projects of the center, and to make observations about future directions.
- Based on the literature reviewed.
- Filtered through biases toward behavior analysis, and developmental and ecological psychology.



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Historical Roots

- Good community – Plato's *Republic*
- Civic engagement or participation – citizens.
- The term “idiotes” was used to refer to those who chose a private life.
- Evolved from a functional description to a characterological one.
- History of disability



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The Importance of Participation

- Key social value of Olmstead, and to independent living and related movements.
- Critical component of the ICF.
- Participation emerges as the current “gold standard” of outcome to be measured.



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RTC/MCIL Background

- MCIL's mission is to increase and enhance the interdependence and full participation in the community of people with disabilities.
- T-3 A Scoping Review of Participation Literature
- Two studies



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Study #1 - Overview of Methods for Quantitative Assessment of Literature

- Derived 32 key terms from 9 conceptual models of participation.
- Tested several data bases with variations of search terms.
- Selected Psych Info as source.
- Date from 2001 to March 2009.
- 586 peer reviewed articles
- 90% agreement on exclusion and retention decisions, and 80% on reason for decision.
- 72 articles made the final cut



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Selected Findings

Studies using samples in the United States	32%
Studies using samples from countries other than the U.S.	68%
PAR reported as a method	7%
Average sample size after removing two main outliers	468
Single impairment studies	38%
Cross disability samples	62%
Most frequent impairments	CP = 15, IDD = 8, Deaf = 7, SCI = 6 (2528); TBI = 6; Blind = 5
Reported geography	10%
Instruments used	67



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Instruments Used in More Than One Study

Instrument Used to Measure Participation	Number of Studies Including
Community Integration Questionnaire	3
Pediatric Evaluation of Disability Inventory	3
Craig Handicap Assessment and Reporting Technique	2
Life Habits Questionnaire	2
Life Satisfaction Questionnaire	2
PARTS/M	2
Reintegration to Normal Living Index	2
Vineland Adaptive Behavior Scale	2
World Health Organization Disability Assessment Scale II	2



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Distribution of Respondents from Various Racial and Ethnic Groups

Racial and Ethnic Categories	Number of Studies Including	Total Number of Participants	Average Number of Participants
Caucasian or White	18	5859	325.5
African American or Black	14	1012	72.3
American Indian	5	51	10.2
Asian	7	396	56.6
Hawaiian	0		
Latino	9	523	58.1
Other	6	45	7.5
Unclear	13	45	3.5
No racial or ethnic data reported*	48		



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Some Measurement Features

Cross sectional	68%
Longitudinal	22%
Experimental	3%
Undiscerned	5%
Self- Report	50%
Direct observation (e.g., interview, clinical)	6%
Proxy report	8%
Mixed	11%
Unclear or not discernable	24%
Electronic recording	N = 1
Unclear data collection procedures (likely paper and pencil)	67%
Secondary data analysis	N = 10



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Measurement Time Frames

Time Frame	Number of Studies Reporting
Immediate report as events occurred	2
Less than a day recall	1
Past week	4
Past month	11
Over a month	6



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Study #2 - Content Assessment of Studies Using ICF as Foundation

- Readers scored 24 of the instruments used as citing the ICF as their conceptual foundation.
- One article could not be obtained.
- One article was excluded as not meeting study criteria.
- Conducted a content analysis of 22 articles.



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Selected Observations

- Nature of the shift to participation
- Three types of methods used to measure participation.
- Organizing concepts based on Action Theory
- A three-term framework for measures of participation.
- Need for descriptions of mechanism underlying interpretations of data.



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Nature of Shift to Participation

A Simple Shift in Perspective

- Some argue that the shift to participation involves a simple change in terminology - from handicap and disability; from negative language to more positive language (8, 21, 6).

A Revolution

- Measures based on the concept of handicap may no longer be valid (11, 16)



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Methodological Implications of the Use of an Interactional Model

- The shift from the term disability to that of participation is more complex than a simple shift from negative language to more positive language. It is a shift away from the physiological to the ecological; from static to the dynamic.
- A dynamic phenomenon requires a dynamic measure (4).
- But many of the efforts to develop items that measure participation focus only on the individual.



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Three Measurement Methods

- **Static Measures** Items are generic, predetermined “samples” of behavior. They do not consider the environment; leaving little option for analysis. Typically one point in time.
- **Interactive Measures** Instruments collect action data and also collect environment data; allowing for some basic, correlational analysis between the two terms. Typically one point in time.
- **Dynamic Measures** Measure both individual behavior and environmental events as they occur together in time. Measure factors over repeated instances forming a prospective study; allowing for causal analysis.



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Action Theory (From Jette et al., 2007)

- One uniform domain within the framework.
- Actions
- All actions are performed in physical, social, and cultural context.
- Actions are qualified in ways relevant to the context.
- Preconditions for actions
 - Opportunity
 - Capacity
 - Will to perform

■ Nordenfelt, L. (2003). Action theory, disability and ICF. *Disability and Rehabilitation*, 25(18), 1075-1079.



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Context or Environment

- Surprisingly few studies attempted to assess the environment directly.
- A few instruments specified the context in which the participation occurred.
- One study described it as a pesky confound.



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Subjective Measures

- Need for subjective measures noted.
- Researchers reported collecting a relatively small range of qualitative measures, including:
 - Importance, choice, and satisfaction (2)
 - Fulfillment (14)
 - Sense of belonging (14)
 - Satisfaction with choice over activities (12)
 - Enjoyment (4)
 - Satisfaction (3, 10)
 - Social recognition (5)



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A Measurement Framework

Environment	Action	Subjective Experience
Variety of contexts	Variety of Actions	Choice and Control
Barriers	Frequency	Importance
Supports	Duration	Acceptability
	Intensity	Belonging
		Satisfaction



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Impairment and Participation

- Some researchers interpret their data as showing that the participation is influenced more by restrictions imposed by the environment than any underlying health conditions.
- Others interpret their data as highlighting that impairments are the key to participation.
- Neither perspective offer clear descriptions of mechanisms of influence.



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Recommendations

- Researchers should include measures from the three-term framework (environment, action, subjective assessment) in measuring participation, unless otherwise specifically justified.
- Clarify the mechanisms linking impairment to participation, and linking environment to participation.



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Recommendations

- Support science that explores ecological concepts of disability to develop dynamic measures appropriate to a community context.
 - Explore the potential use of concepts and methods from ecological psychology, fish and wildlife biology, forestry, and other natural sciences.
 - Use analytic approaches such as SEM Hollingshead (2010) and LRM used by (2) to explore the dynamic aspects of participation.



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Recommendations

- Fundamentally, participation takes place in a community. We need truly controlled studies of participation in open community settings where participation occurs.
- Conduct experimental research to establish evidence-based practices for promoting participation (e.g., Community Engagement Initiative using dynamic measures such as EMA).



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Recommendations

- Function is to rehabilitation as participation is to community services – we need a validated participation measure consistent with the community and education settings.
- NIDRR might take a lead in developing the science of participation in community environments as a unique contribution.



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Past – Present - Future

- Reviews reflect the past.
- Today, MiCL projects are on the cutting edge – creating the current science of participation and leading to future practices



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Current MCIL Research Projects

- ***Measuring CIL Services*** shows the shift to participation is not “simple.” This project helps us understand the details of the “participation revolution,” as you will hear this afternoon.



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MiCL Studies Help Clarify Mechanisms

- The **SPARC and CHEC** measures include measures across a variety of settings that will help to “clarify mechanisms linking community accessibility and participation.”
- ***Measuring the Relationship Between HCBS and Health*** and ***Excellence in PAS*** will help to “clarify the mechanisms linking impairment to participation.”



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MICL studies push the envelope toward a natural science of participation

- ***Person X Environment Measurement Systems*** provides new, interactive measures directly measuring the environment (CHEC and SPARC for people with sensory impairment).
- ***Excellence in PAS*** provides a “new interactional model” to assess areas environment, action and subjective experience.
- ***Measuring CIL Services that Improve Community Participation*** provides a “new interactional model” to assess how CILs foster or mute community participation.
- ***Measuring the Relationship Between HCBS and Health*** provides a “new interactional model with dynamic measures” to assess how health and receipt of PAS influence community participation.



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Conclusion

- Moeller and Danermark (2007), in their attempt to measure and understand participation among deaf/blind students, seem almost to apologize for their small sample size (N= 34). Why?
- This phenomenon is extremely important – not only in disability and rehabilitation – but also for the science of constructing healthy social systems.



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Historical Comparison

- 2,500 years after Democritus articulated a theory of atoms, physicists have built several super conducting super colliders simply to try to create and detect particles that may not even exist. If they detect one, they will be mad with joy. But they do not apologize for their science.



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Participation and the Good Community

- The effort to unlock the nature of participation in community life is no less – perhaps more – central to human progress.
- If we can clarify the meaning of participation, arrange conditions in which we can reliably reproduce it (along with a sense of meaning and belonging), and measure it accurately, we will have accomplished science at its very best.



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