

# Using the BRFSS to Validate a New Measure of Participation

Gale Whiteneck, PhD

Allen Heinemann, PhD

John Corrigan, PhD

Jennifer Bogner, PhD

C. A. Brooks, MSHA

Melissa Sendroy-Terrill, MS

# What is Participation?

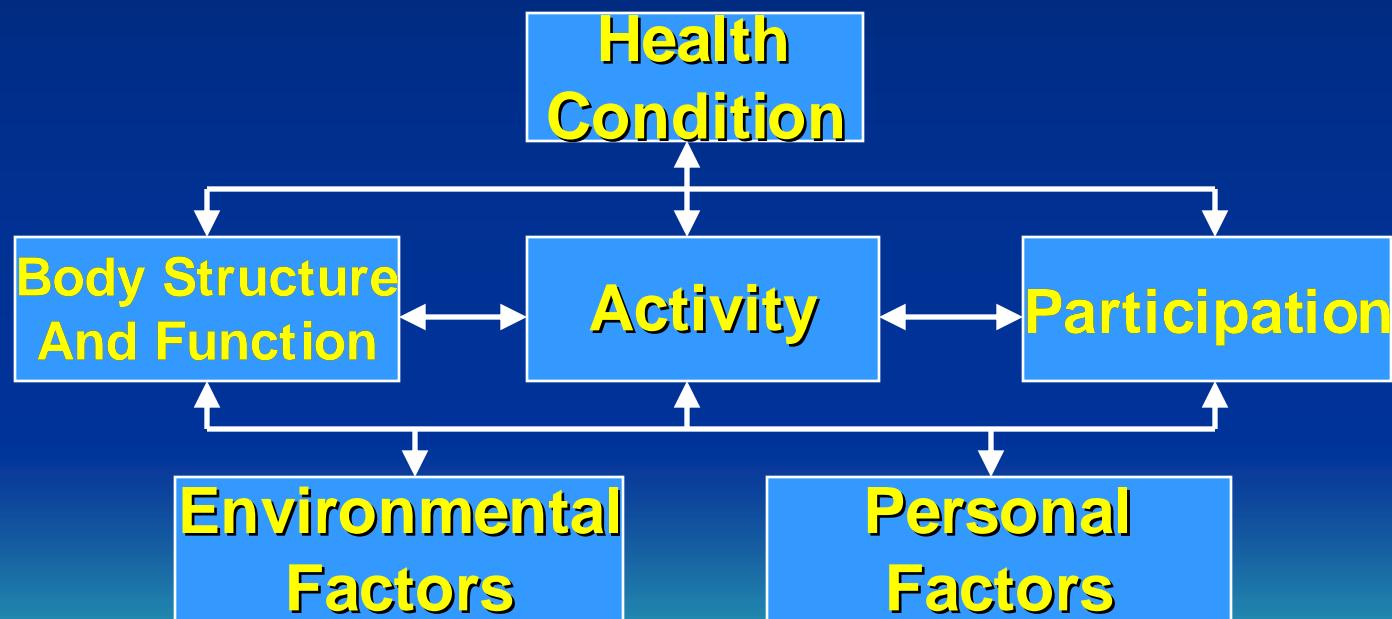
- Participation is being an active, productive member of society, well integrated into family and community life.
- Participation is fulfilling social roles:
  - Worker
  - Friend
  - Citizen
  - Student
  - Spouse
  - Parent
  - Volunteer
  - Teammate
  - Homemaker
- Participation is doing things in the community
  - Eating out
  - Shopping
  - Seeing movies
  - Voting
  - Going to church
  - Attending events

# Participation and Disability

- One of the consequences of disability may be participation restrictions
- For three decades, conceptual models of disability have distinguished among consequences of disability at the organ, person, and societal levels
- Participation is the societal level outcome of disability

# World Health Organization's International Classification of Functioning, Disability, and Health (ICF)

## ICF Model of Functioning and Disability



# Why is Participation Important?

- Participation is the ultimate outcome of rehabilitation
- Participation is what is most important to people with disabilities
- Full participation is the goal of the Americans with Disabilities Act
- Participation is a major contributor to quality of life for people with and without disability

# History of Participation Measurement

- In contrast to the long history of measuring impairments of body structure and function and measuring activity limitations, there is a much shorter history of measuring participation
- One of the first measures of participation was the Craig Handicap Assessment and Reporting Technique (CHART)

# Many Participation Measures

- Assimilation, Integration, Marginalization, Segregation Interview
- Children's Assessment of Participation and Enjoyment
- Community Integration Questionnaire
- Community Integration Measure
- Community Participation and Receptivity Survey
- Impact on Participation and Autonomy
- Inventory of Interpersonal Problems
- London Handicap Scale
- Nottingham Health Profile
- Perceived Handicap Questionnaire
- Participation Objective Participation Subjective
- Participation Measure for Post-Acute Care
- Re-integration to Normal Living Index
- Social Relationship Scale
- Social Adjustment Scale-Self Report

# No Ideal Participation Measure

- All participation measures have psychometric problems
- Some have ceiling effects; some have internal consistency and reliability problems
- There is no consensus on the best available participation measure
- Therefore a new, psychometrically-sound, agreed-upon standard participation measure is needed for future research



# Development of the Community Participation Indicators (CPI)

- Funded by the National Institute on Disability and Rehabilitation Research (NIDRR)
- Grant to the Rehabilitation Research and Training Center on Rehabilitation Outcomes at the Rehabilitation Institute of Chicago (RIC)
- Collaborators include Craig Hospital and Ohio State University, as well as RIC

# CPI Development

- 18 Focus groups including 138 stakeholders (rehabilitation consumers, primary caregivers, rehabilitation providers, payers, and policy makers) discussed what participation meant
- Extensive literature review to catalogue the items used in previous participation measures
- Qualitative analysis of focus groups and the literature review were used to write CPI items
- Pilot test of CPI on 258 people with SCI, TBI, or stroke, and 68 people without disabilities, followed by analysis and revisions

# Current CPI Questionnaire

- 55 total items; 10-15 minutes to administer
- Participation domains covered
  - Social
  - Community
  - Economic
- Participation question types
  - Objective performance questions
  - Subjective evaluation of performance items
  - Subjective assessment of participation values

# CPI Example Questions

- Objective performance items
  - “In a typical week, how many times do you socialize with friends in person or by phone?” (social)
  - “In a typical month, how many times do you eat in restaurants?” (community)
  - “In a typical week, how many hours do you spend working for money, whether in a job or self-employed?” (economic)

# CPI Example Questions

- Subjective evaluation of performance items
  - “Do you talk or spend time with your friends as often as you would like?” (social)
  - “Overall, do you participate in community activities as often as you would like?” (community)
  - How true or false is the statement: “I have the money to do the things that are important to me.” (economic)

# CPI Example Questions

- Subjective assessment of participation values
  - How true or false are the statements:
    - “I can get out and about whenever I choose.”
    - “I have choices about the activities I want to do.”
    - “I can go out and have fun.”
    - “I have the freedom to make my own decisions.”
    - “I do things that improve my community.”
    - “I spend time helping others.”
    - “I feel that I am a part of my community.”

# CPI Administration Issues

- Response categories repeated frequently
  - “None, one, two, three, four, five or more”
  - “None, 1-4, 5-9, 10-19, 20-34, 35 or more”
  - “True, mostly true, mostly false, false”
- The goal of performance items is to get accurate responses of what they actually do
- The goal of evaluation and values items is to recode their personal subjective assessments

# Why Add CPI To BRFSS

- Want to compare participation (CPI scores) among three representative samples of people:
  - 500 people without disabilities in the general population (from the BRFSS sample)
  - 500 people with typical range of disabilities in the general population (from the BRFSS sample)
  - 500 people with severe disabilities (from sample of former rehabilitation clients with SCI, TBI, or stroke)
- BRFSS standard disability screener questions identify people with and without disability in the BRFSS sample



# Results

- Factor analysis and rating scale analysis both supported the presence of two distinct factors
  - Objective performance items
  - Subjective value items
- Greater differences were found between people with and without disability in the performance items compared to the value items

# Conclusions

- The two CPI subscales may provide better measurement of the complex concept of participation
- But we are still a long way from a measure of participation that will meet the needs of disability and rehabilitation researchers and be acceptable to all the stakeholders who contributed to the development of the CPI

# Thank you

For further information  
[gale@craig-hospital.org](mailto:gale@craig-hospital.org)