

Measuring Participation in the Community & Measuring Meaningful Environments for Community Participation

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Presentation Topics

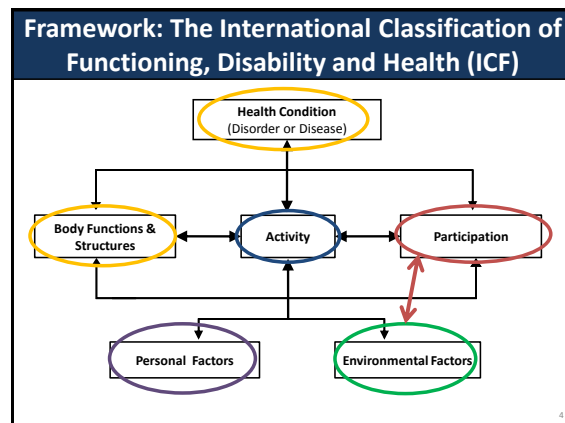
- Theoretical frameworks for participation
- Domains and components of participation
- Environmental features and participation
- Measures developed
 - PARTS/M
 - FABS/M
 - Analysis of participation in context – SEM
- Future directions

Medical & Social Models

<i>Medical Model</i>	<i>Social Model</i>
PROBLEMS are in the body PLACE of intervention is in the hospital	PROBLEMS are in the physical & social environment PLACE of intervention is the community

Missing Links

DeJong, 1979



From Classification and Models to Outcome Measures

The challenge is to develop measurement tools of community participation that are influenced by the presence or absence of environmental factors.

What do we mean by participation?
How do we select environmental factors?

Definitions of Participation: Appreciating Variability

“Participation is **involvement** in a life situation” (WHO, 2001)

Participation is a **complex construct** made up of temporal, evaluative, health-related & supportive component factors (Gray et al., 2006)

Participation is a complex and multidimensional **activity** including but not limited to meaningful engagement, access to a full range of opportunities, unrestricted by bodily impairments or disabling physical, social and political environments (Hammel et al., 2008)

Review Types of Participation Survey Questions

Measure	Time	Can do	Do	Hypothetical	Evaluative	Environment	Compared to
RNL	0	2	6	1	9	11	Self
WHODASII	0	5	6	3	8	4	Self difficulty doing
PHQ	0	0	0	10	10	2	Self to nondisabled
LHS	0	0	0	24	24	11	Self Health prevents doing
IPA	1	0	0	18	20	0	Self Possibility of doing
LIFE H	0	53	0	0	53	30	Self Difficulty in doing
CHART	13	3	15	0	1	11	Self Feel necessary
PARTS/M	40	0	20	0	55	20	Self importance, health condition, support

"ONE DOES OR DOES NOT" – YODA, STAR WARS

Selected Measures Used to Assess Disability

Measure	Limitations/ person level ACTIVITY	Limitations/ society level PARTICIPATION	Context/ Environment	Assistive Technology Included	Quality of Life
NHIS-D	XXXXX			XXXXX	
ADL	XXXXX				
FIM	XXXXX			penalty for use	XXXXX
EnviroFIM			XXXXX		
RNL	XXXXX	XXXXX			
WHO-DAS	XXXXX	XXXXX			XXXXX
SIP	XXXXX	XXXXX			XXXXX
BRFSS	XXXXX	XXXXX		XXXXX	XXXXX
MOE			XXXXX		
CHART		XXXXX			
CHIEF			XXXXX		
PARTS/M	XXXXX	XXXXX	XXXXX	XXXXX	XXXXX

Characteristics of Respondents (CORE)

Purpose: Description of the person completing the survey

Format: Web accessible format uses CORE responses to navigate respondent to relevant questions

Type: Self-report measure, 10 minutes to complete

Content: Demographics, diagnosis, secondary health conditions, general health status, social benefits, mobility device, personal assistance and transportation services

Development of the Participation Survey: Mobility (PARTS/M)

- Methods
 - Qualitative for content validity – key informant interviews & focus groups (N=125)
 - Key Questions: What do you do from the time you get up in the morning until you go to bed at night? What helps? What hinders?
 - Quantitative for reliability
 - Internal Consistency: range of domain Alpha values = .71 to .92
 - Test-Retest: range of domain Pearson values = .77 to .91
 - Computer assisted navigation sequences – pilot studies

Participation Survey: Mobility (PARTS/M)

Purpose: Self-report measurement of an individual's participation in major life activities

Development: Focus groups, key informant interviews

Format: Web accessible, 50 minutes to complete, 135 item assessment, 20 activities, 6 domains

Scoring: An overall participation score, a participation score for each of the six domains and component scores for temporal, evaluative, health-related limitations and environmental support domains

- ### PARTS/M Domains:
- Self Care**
 - Dressing
 - Bathing
 - Meals
 - Bladder Care
 - Bowel Care
 - Mobility**
 - Moving Inside Home
 - Leaving Home
 - Taking Vacation
 - Domestic Life**
 - Work Inside Home
 - Exterior Maintenance
 - Interpersonal Interactions and Relationships**
 - Parenting
 - Intimacy
 - Major Life Areas**
 - Employment
 - Volunteering
 - Managing Money
 - Community, Social & Civic Life**
 - Community Activities
 - Religious Activities
 - Active Recreation
 - Leisure
 - Socializing

PARTS/M Component Question Sequence

Participation Component	Form of Questions
Temporal (Time Taken)	How much time do you require for _____?
Temporal (Frequency)	How often do you _____?
Health-related	Is your participation ___ limited by ... (Check all that apply.) <input type="checkbox"/> Illness <input type="checkbox"/> Pain <input type="checkbox"/> Fatigue <input type="checkbox"/> Not limited
Evaluative	When ___ how much choice do you have compared to others without mobility limitations? (Choice includes how, where, when and how often) <input type="checkbox"/> A lot of choice <input type="checkbox"/> Some choice <input type="checkbox"/> Little choice <input type="checkbox"/> No choice
Evaluative	How satisfied are you with your participation in _____? <input type="checkbox"/> Very satisfied <input type="checkbox"/> Satisfied <input type="checkbox"/> Somewhat satisfied <input type="checkbox"/> Dissatisfied
Evaluative	How important is it for you to _____? <input type="checkbox"/> Very important <input type="checkbox"/> Somewhat important <input type="checkbox"/> Somewhat unimportant <input type="checkbox"/> Not important
Supportive	How much help from another person do you require to _____? <input type="checkbox"/> A great deal <input type="checkbox"/> A moderate amount <input type="checkbox"/> Just a little <input type="checkbox"/> None
Supportive	How often do you use accommodations, adaptations, or special equipment for _____? <input type="checkbox"/> All of the time <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> A little of the time <input type="checkbox"/> Never

Sample Demographics of PARTS/M & FABS/M

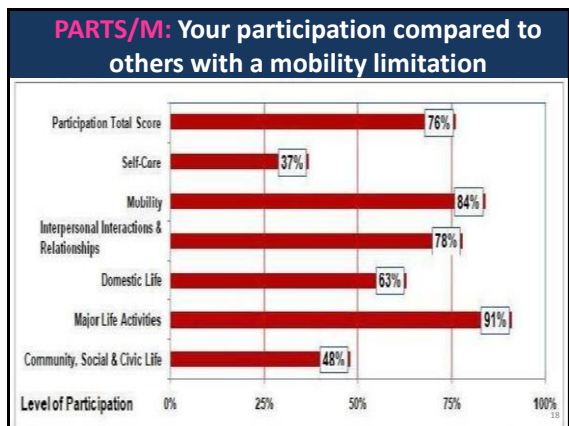
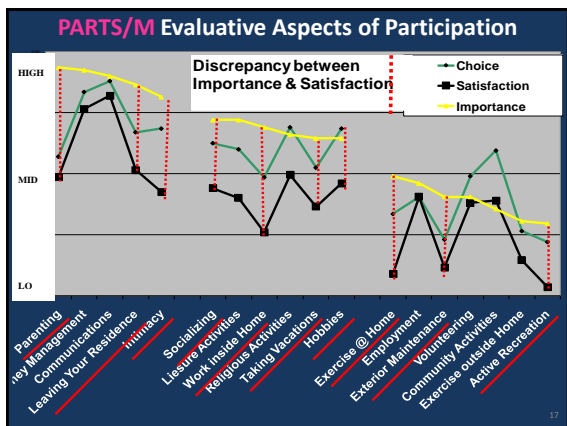
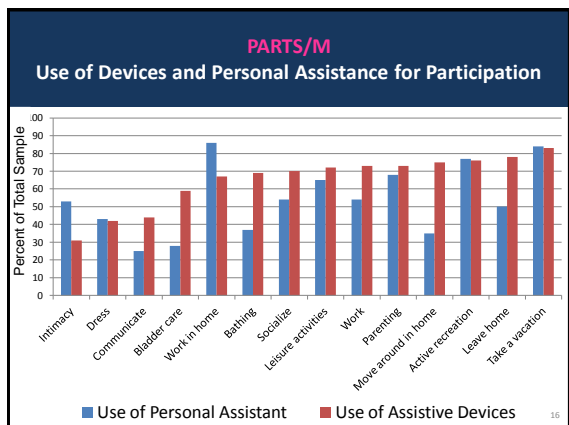
	Total Sample	Study Groups				
		SCI	MS	CP	Polio	Stroke
Sample Size	604	141	126	88	169	80
Range Test Ages	17-92	17-79	19-82	17-73	44-83	19-92
Mean Test Age	51.5	41.4	51.8	39.3	61.0	62.0
Female	57.5	25.5	80.2	47.7	76.3	48.8
Race - White	88.2	82.7	91.2	86.4	97.6	74.7
Annual Income \$25,000 +	51.3	41.6	62.0	21.0	70.1	40.9
Education - College 4 or +	62.2	70.0	68.2	34.9	73.8	43.5
Employed	26.7	29.0	17.2	38.1	34.1	8.1

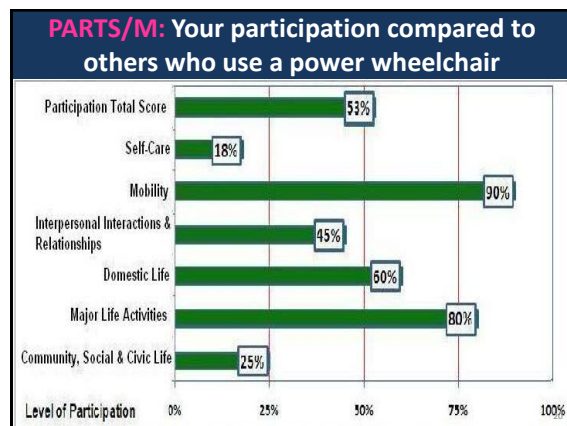
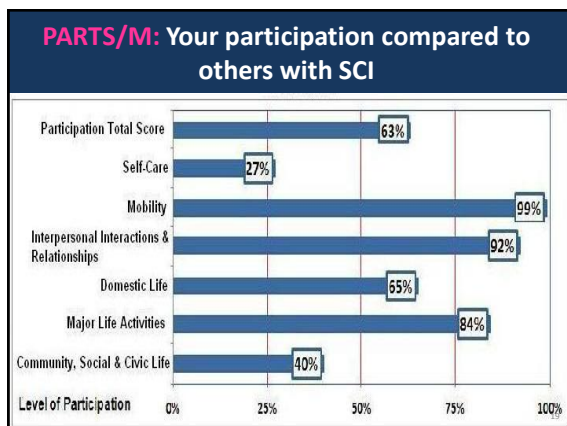
Note: All figures are in percentages except sample size and age
 SCI = Spinal Cord Injury; MS = Multiple Sclerosis; CP = Cerebral Palsy

Use of PARTS/M in Rehabilitation & Community Based Research

- Use of assistive devices and personal assistance for mobility
- Evaluation of participation by polio survivors
- Participation comparisons by diagnoses
- Participation comparisons by mobility devices

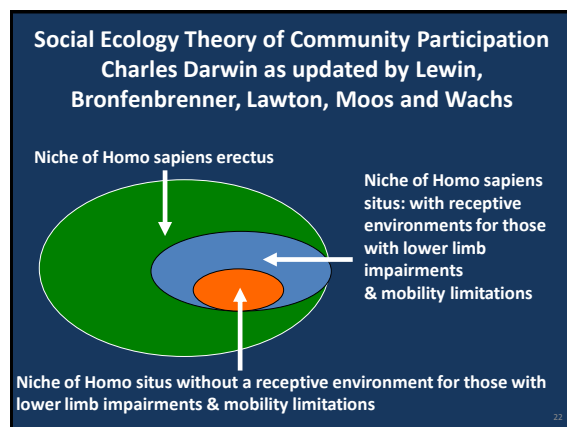
Gray DB, Hollingsworth HH, Stark SL, Morgan KA. [Participation Survey/Mobility Psychometric Properties of a Measure of Participation for People with Mobility Impairments and Limitations](#). Archives of Physical Medicine and Rehabilitation 2006;87 (2): 189-197.





Use of PARTS/M for studying participation pre-post intervention

- Medical interventions: pain medication change, UTI medication change, syringomyelia surgery,
- Acquisition of new mobility device (Standard PWC to iBOT) or adapted vehicle
- Initiation of exercise program
- Introduction of paid personal assistant

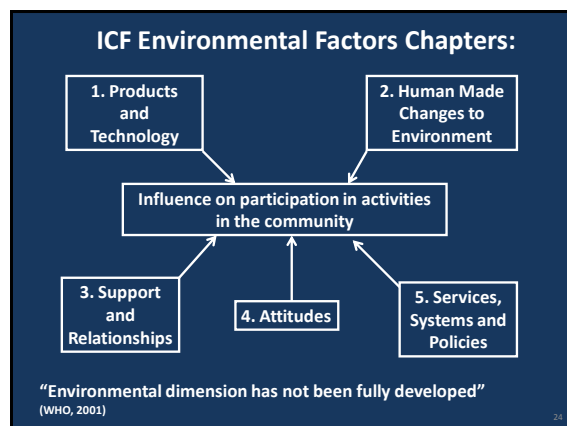


Definitions of the Environment: No GOLD Standard

Those environmental features that influence the reproductive fitness of a species (Darwin, 1859)

The environment refers to organized conditions or patterns of external stimuli that impinge on or have the probability of influencing the individual (Wachs, 1992)

The environment refers to extrinsic factors that can influence behaviors. Categorizations of these factors include: physical, social attitudinal, political factors; natural and built environment; and microenvironment, mesoenvironment, exoenvironment and macroenvironment (various – ICF, Bronfenbrenner, Fougeyrollas, Noreau & Boschen, 2010)



General Guidelines for Environmental Measures (Wachs, 1999)

- Studies are not required to measure all aspects of the environment in a single study. The scope of the environment assessed will be determined, in part, by the questions being asked
- Studies must not assess the environment in ways that violate what is known about the environment and how the environment operates
- Measure the relevant environment economically in a manner that is feasible, accurate and answers the study question

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Facilitators and Barriers Survey: Mobility (FABS/M)

Purpose: Self-report measurement of environmental features that help or hinder home and community participation

Format: Web accessible, computer-based

Development: Focus groups, key informant interviews, pilot tests

Utility: Identification of magnitude and frequency of facilitators and barriers in an individual's environment that influence participation

Gray DB, Hollingsworth HH, Stark SL, Morgan KA. A subjective measure of environmental facilitators and barriers to participation for people with mobility limitations. *Disability and Rehabilitation* 2008;30(6): 434-457.

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FABS/M: Environmental Feature Domains and Influence on Participation

Domain	Consistency	Stability
Primary Mobility Device:	.87	.56
Home Built Features 12 features (stairs, carpet, doors)	.61	.75
Community Built and Natural Features 14 features (gravel, weather, crowds)	.60	.91
Community Destination Access 13 sites	.88	.87
Community Facilities Access Domain Restrooms Transportation	.86	.76
Community Support Network 9 sites (doctor, therapist, store clerks)	.49	.67

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FABS/M: Community Built & Natural Environmental Features: Influence on Participation

	Total Responding (%)	Helps Participation (%)	ICF E Code
Winter weather	77	4	e 2250, 2253
Gravel	54	8	e 160,2108
Summer weather	69	23	e 2250, 2251
Crowds	50	3	e 2158
Rain	58	6	e 2253
Noise	19	4	e 2500, 2501
Escalators	31	68	e 1501
Curb cuts	68	88	e 1601, 1602
Ramps	67	93	e 1500
Automatic doors	73	97	e 1500
Elevators	74	98	e 1500
Flat terrain	75	98	e 2100
Paved surfaces	80	98	e 160, 2108

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FABS/M: Services and Attitudes: Influence of Attitudes on Participation

	Total Responding (%)	Helps (%)	No Effect (%)	Limits (%)	ICF (%)
Peers	34	90	7	2	e425
Friends	75	89	10	1	e420
Personal attendant	28	89	10	2	e440
Store clerks	67	88	8	3	e430
Work manager	12	81	18	1	e430
Special equipment repair	45	84	10	6	e450
Therapist	44	84	15	2	e450
Strangers	50	79	20	1	e445
Social worker	22	69	24	6	e450
Doctor's care	91	69	28	2	e450
Policies workplace	27	56	35	9	e5902

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Participation

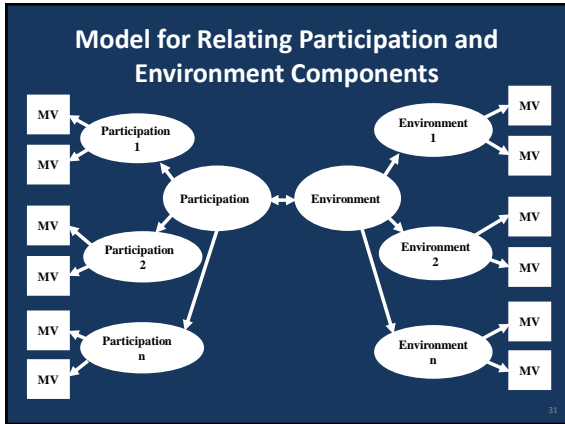
Participation is a complex and multidimensional ...
(Hammel et al., 2008)

Participation is a complex construct ...
(Gray et al., 2006)

Environment

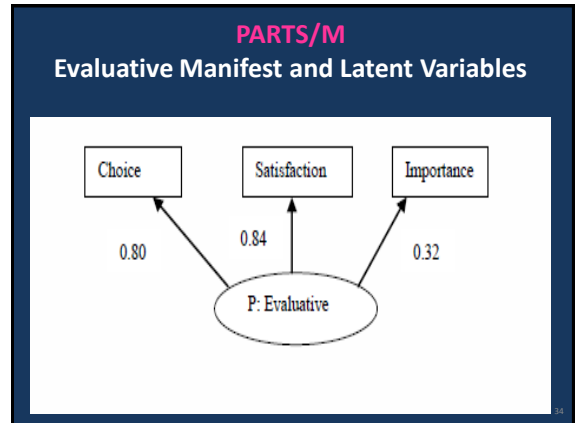
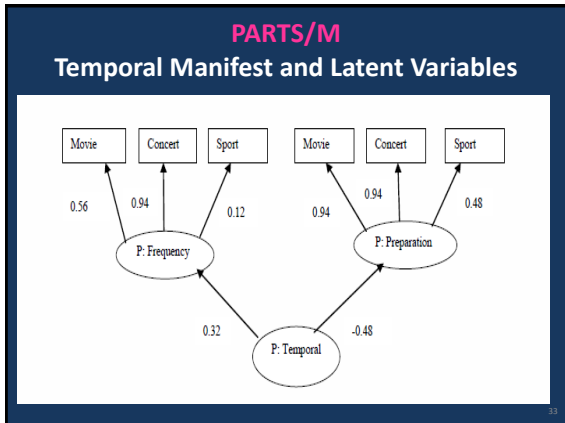
The environment refers to extrinsic factors that can influence behaviors.
(Noreau & Boschen, 2010)

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Participation (PARTS/M) Analysis of Leisure Activities

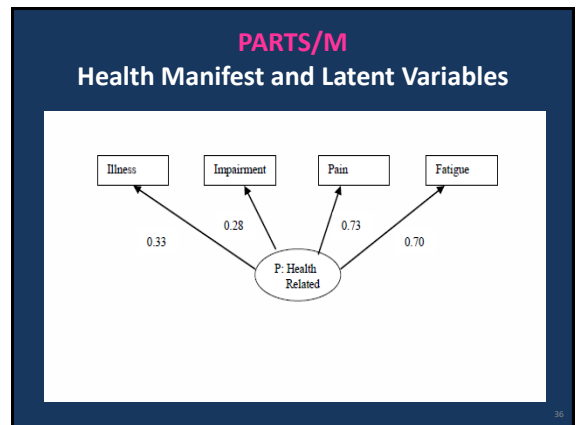
- Latent Variables
 - Temporal
 - Evaluative
 - Health Related

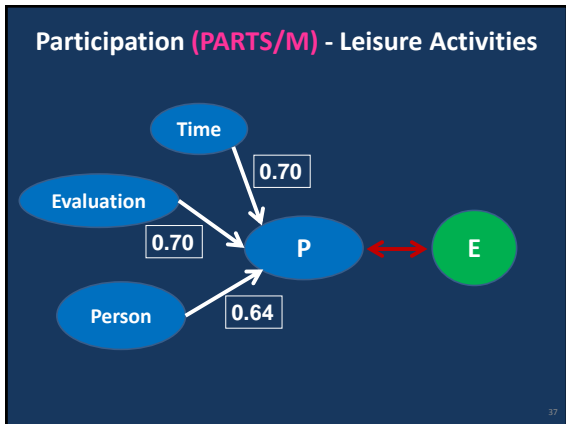


Computation Aside

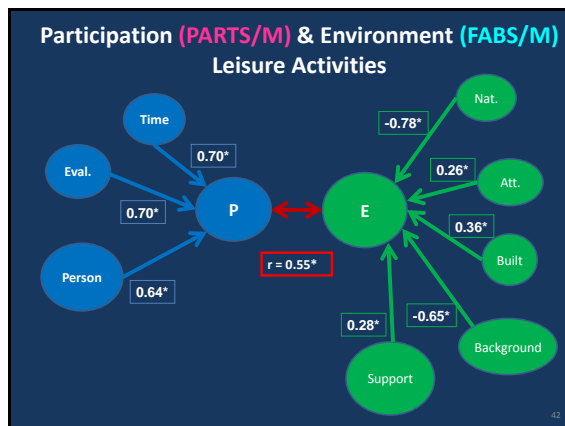
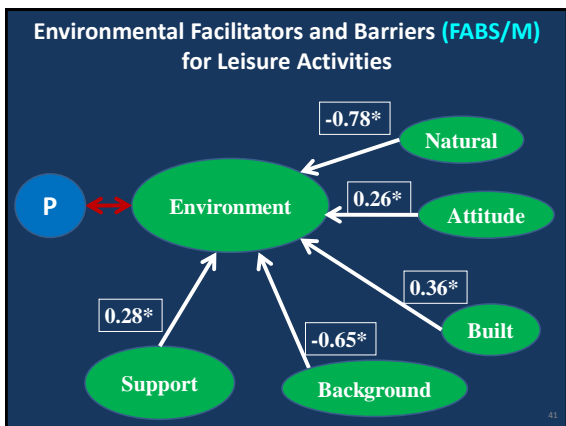
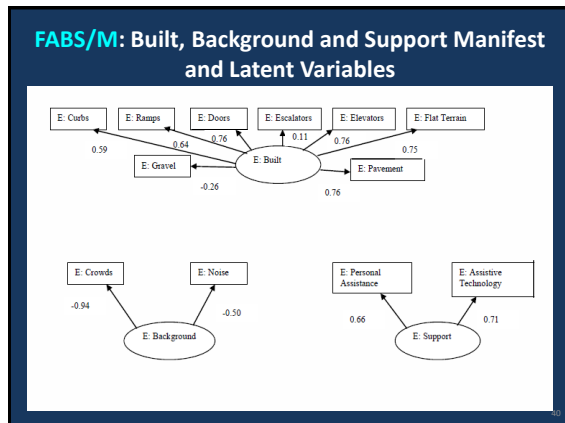
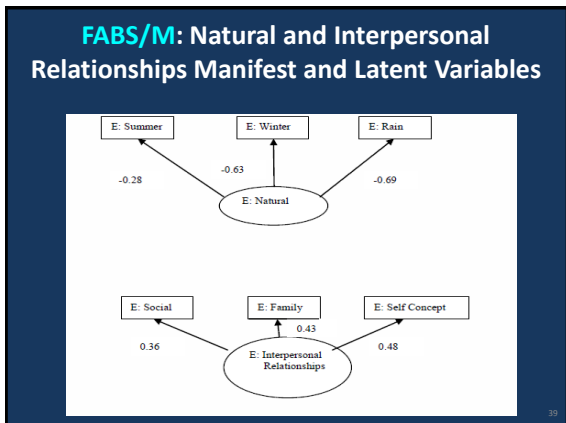
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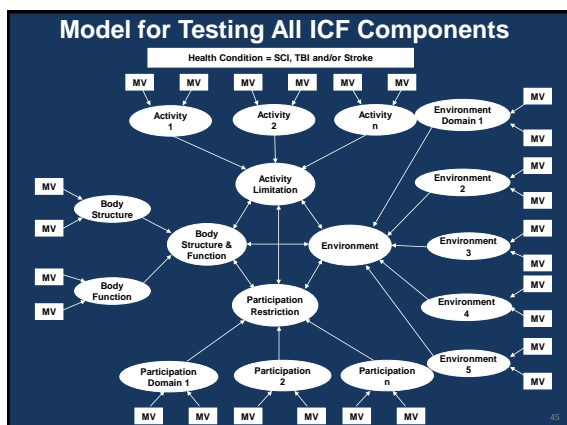
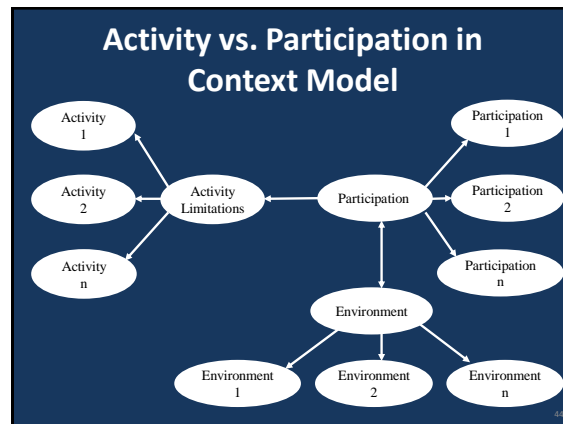
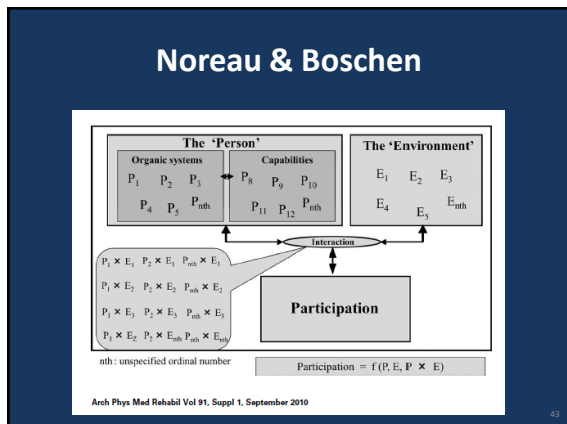
proc calis data=mysem.sem_leisure method = ML;
lineqs
  mov14 = f1 + E1,
  con14 = f1 + E2,
  spt14 = f1 + E3,
  mova = f2 + E4,
  cona = f2 + E5,
  spta = f2 + E6,
  cho14 = f3 + E7,
  sat14 = f3 + E8,
  imp14 = f3 + E9,
;
Std
  E1-E9 = 9 * U.;
Cov
  E1-E9 = 36 * T;
run;
    
```





- ### Environment (FABS/M) Analysis for Leisure Activities
- Latent Variables
 - Natural Environment
 - Interpersonal Relationships (PARTS)
 - Built Environment
 - Background Environment
 - Support (PARTS)



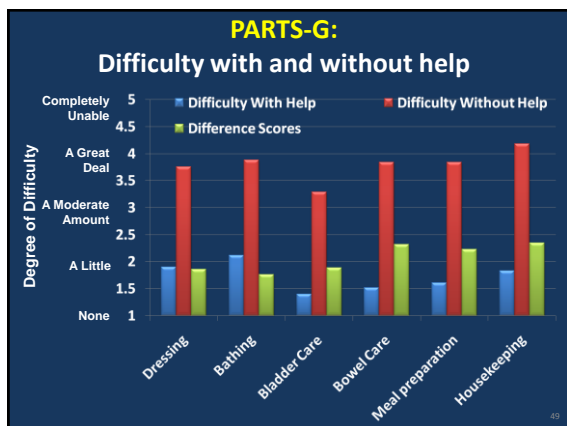


What does your measure tell us?

<http://www.youtube.com/user/karoncook#p/a/u/O/AukrpAoAYYO>

- ### Development of new measures for assessing participation and environment
- **PARTS/M** Improvements = New name **PARTS/G**
 - **Survey of Participation and Receptivity in Communities (SPARC)**
 - SPARC Combines P and E in same survey
 - **Community Health Environment Checklist (CHEC)**
 - A group of objective measures of the environment

- ### PARTS/General
- Modified frequency question
 - Added:
 - Impairment Groups: Visual and Hearing
 - Activities: Education, Exercise, Receptive Communication and Expressive Communication
 - Participant: Do yourself or direct others to do (autonomy)
 - Evaluation component:
 - Importance question to personal care domain
 - Control question to all activities
 - Difficulty with/without help and AT
 - Options to skip activities that they NEVER do



Survey of Participation and Receptivity in Communities (SPARC)

Purpose: To provide a subjective measure of participation in context

Development: Based on interviews, focus groups, and reliability testing with people who have lower limb, visual and hearing impairments

Format: Paper and computer-based, administration time is 3-5 minutes per site or 50 to 85 minutes for all 17 sites

Utility: Provides information to consumers, their families, advocates and health care providers on participation of others with similar impairments at a variety of community locations

Survey of Participation and Receptivity in Communities (SPARC)

SPARC Components

- 19 types of community sites
- Frequency of doing
- Evaluation of experience
- Influence of health
- Influence of transportation
- Influence of people at the site
- Influence of built features at the site

- ### SPARC: Participation in Place (s)
- #### Community Sites
- Your Home
 - **Grocery Store**
 - Pharmacy
 - Places of Worship
 - Restaurants
 - Visiting Homes of Friends/Family
 - Places You Work, Volunteer, or Attend Classes
 - Large Stores
 - Gas Stations
 - Doctor's Office
 - Museums/Landmarks
 - Public Parks
 - Exercise Facilities
 - Sports Arenas
 - Movie Theaters
 - Shopping Malls
 - Beauty Salon or Barber Shop
 - Durable Medical Equipment Vendors and Suppliers
 - Transportation

SPARC: No Go, Go Frequency & Importance

1. How OFTEN do you go to grocery stores? (Check all that apply.)

Never Rarely Monthly Weekly Daily I prefer not to answer

For the next question, enter 0 if you prefer not to answer

2. HOW MANY TIMES in the past month did you go to grocery stores?

Number of TIMES

1. WHY don't you go to grocery stores? (Check all that apply.)

- Do not need to go
- Have no interest in going
- Do not have enough money
- Do not have paid personal assistance
- Do not have unpaid personal assistance
- Do not have transportation
- Grocery stores are not accessible
- Background noise
- Pain
- Fatigue
- Use home delivery services
- Treated poorly by employees
- Other:
- None of these
- I prefer not to answer

3. How IMPORTANT is shopping at grocery stores?

Very unimportant Unimportant Important Very important I prefer not to answer

4. Please give the NAME and LOCATION of the grocery store you go to MOST OFTEN. (If you know the cross streets or city, please list.)

Specify only ONE grocery store:

(Enter "X" if you prefer not to answer.)

SPARC: Evaluation of Participation

5. How much CHOICE did you have in selecting this grocery store?

No choice Little choice Some choice A lot of choice I prefer not to answer

6. How much CONTROL do you have over when you go to this grocery store?

No control Little control Some control A lot of control I prefer not to answer

7. How SATISFIED are you with shopping at your grocery store?

Very dissatisfied Dissatisfied Satisfied Very satisfied I prefer not to answer

8. How do employees at your grocery store INFLUENCE your shopping?

Limit a lot Limit some Help some Help a lot I prefer not to answer

SPARC: Influence on Participation of Site Personnel Receptivity

Survey Progress Bar

9. Do people working at your grocery store ...

a. Help you in a timely manner

Never Rarely Often Always I prefer not to answer

b. Look directly at you

Never Rarely Often Always I prefer not to answer

c. Speak directly to you

Never Rarely Often Always I prefer not to answer

Survey Progress Bar

(continued)

9. Do people working at your grocery store ...

d. Treat you as a child

Never Rarely Often Always I prefer not to answer

e. Avoid you

Never Rarely Often Always I prefer not to answer

f. Solve problems for you without asking

Never Rarely Often Always I prefer not to answer

SPARC: Health Conditions and Transportation Influence on Participation

Survey Progress Bar

19. How much does PAIN limit your shopping at your grocery store?

None A little A moderate amount A great deal I prefer not to answer

20. How much does FATIGUE limit your shopping at your grocery store?

None A little A moderate amount A great deal I prefer not to answer

21. How ACCESSIBLE is your grocery store? (This includes the entrance, aisles, reaching all merchandise, etc.)

Inaccessible Accessible with difficulty Accessible Very accessible I prefer not to answer

Survey Progress Bar

23. How do you get to your grocery store? Please mark the ONE you use most often.

Walk/Roll Taxi - not adapted
 Car/Van/Truck/SUV - not adapted Taxi - adapted
 Car/Van/Truck/SUV - adapted Bus
 Paratransit None of these
 Light rail/Subway** I prefer not to answer

**Paratransit is accessible, shared-ride door-to-door transportation, example: Call-A-Ride
 *Light rail/Subway example: Metrolink

24. How difficult is GETTING TO AND FROM your grocery store?

Very difficult Difficult Easy Very easy I prefer not to answer

SPARC: Site Facilitators Influence on Participation

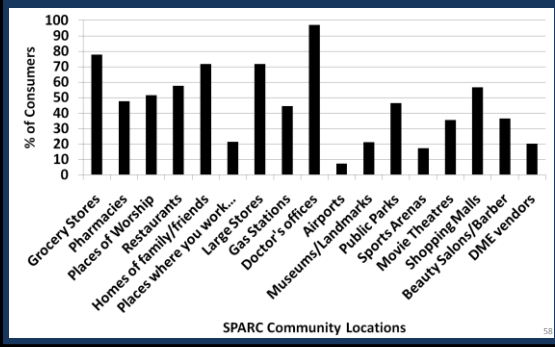
21. How accessible is your grocery store? (This includes entrance, aisles, reaching all merchandise, etc.)

Inaccessible Accessible with difficulty Accessible Very accessible

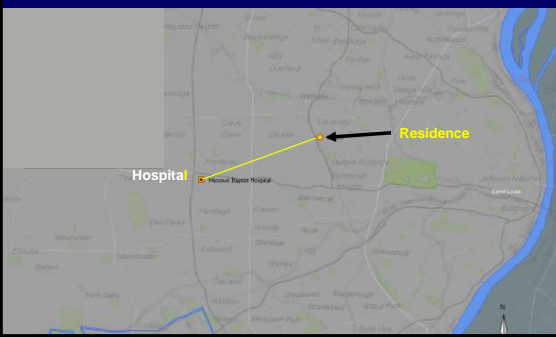
22. Check all features that are present at your grocery store.

<input type="checkbox"/> Flat sidewalk surfaces	<input type="checkbox"/> Wide/Clear spaces or aisles
<input type="checkbox"/> Curb cuts	<input type="checkbox"/> Reachable merchandise
<input type="checkbox"/> Accessible parking	<input type="checkbox"/> Accessible counters
<input type="checkbox"/> Accessible bathroom	<input type="checkbox"/> Adequate lighting
<input type="checkbox"/> Signage for accessible entrance	<input type="checkbox"/> Accessible phone (TTY)
<input type="checkbox"/> Signage for accessible features	<input type="checkbox"/> Accessible drinking fountain
<input type="checkbox"/> Level entrance or ramp	<input type="checkbox"/> Designated area of rescue assistance
<input type="checkbox"/> Automatic doors	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Loaner assistive device	<input type="checkbox"/> None of these
<input type="checkbox"/> No background noise	

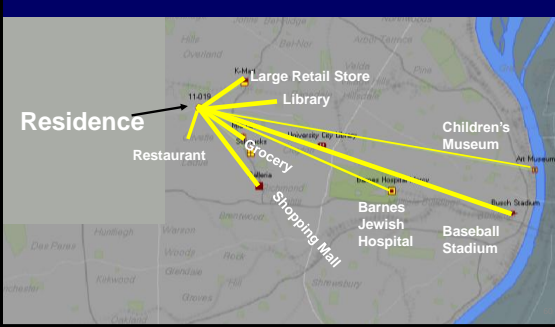
SPARC: Community Participation



SPARC: From Rehabilitation to Participation at Community Sites



SPARC: From Rehabilitation to Participation at Community Sites



Community Health and Environment Checklist CHEC/M

Purpose: Provides an **objective measure** of the physical environmental features important to persons with lower limb impairments and mobility limitations

Development: Focus groups, cognitive mapping, interviews, ranking of features, reliability testing with people who have lower limb impairments and mobility limitations

Format: Paper and computer-based survey forms, rulebooks and glossaries, administration time is 10 – 20 minutes

Utility: Provides information to consumers, their families, advocates and health care providers on accessibility of community locations

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CHEC/M

15 Key Destinations

- Government Buildings
- Major Tourist Destinations
- Performance Venues
- Large Stores
- Small Stores
- Self Care Service Providers
- Dining Establishments
- Transportation
- Health Care Providers
- Health Vendors
- Professional Service Providers
- Indoor Leisure
- Outdoor Leisure
- Religious Facilities
- Schools and Libraries

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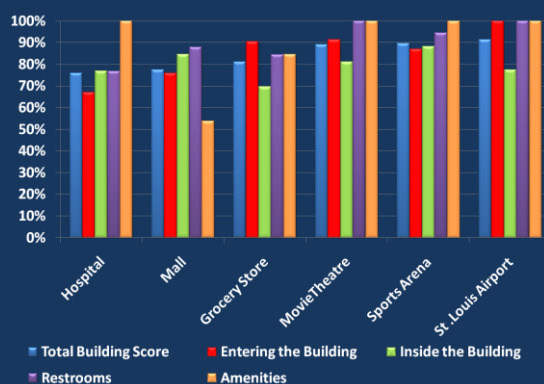
CHEC/M

22 Key Environmental Features

- Distances to Enter Building
- Accessible Parking
- Level Surfaces
- Curb Cuts
- Doors at Entrances
- Signage for Accessible Paths to Entrances
- Doors Inside the Building
- Loaner Scooters or Wheelchairs
- Signage for Accessible Elements
- Single Level
- Maneuverable Spaces
- Crowding
- Floor Surfaces
- Counters and Merchandise
- Accessible Places to Sit
- Adequate Lighting
- Accessible Restroom
- Drinking Fountain
- Accessible Phone
- Drive-through Window
- Usability
- Rescue Assistance

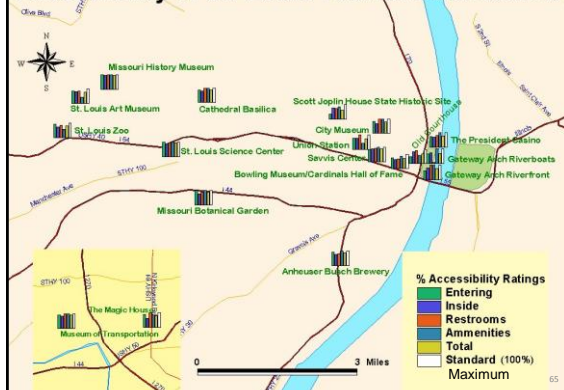
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Percent of Total Accessibility: Building and Category Features



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Accessibility of St. Louis Tourist Destinations



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The CHEC Family: Objective measures for use in assessing receptivity of community sites

General access to buildings & essential building interior features

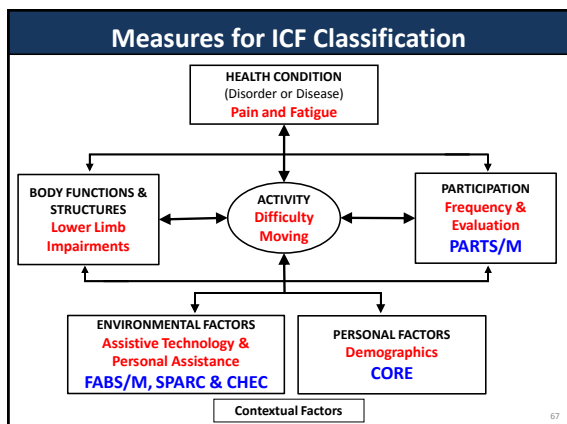
CHEC-Mobility Lower limb impairments & Mobility Limitations

CHEC-HOH Hard of Hearing
CHEC-LV Low Vision

Measures for building features specific to common community sites

CHEC-R Restaurants
CHEC-DO Health service providers
CHEC-Parks City parks
CHEC-HOW Houses of Worship
CHEC-FIT Exercise facilities

66



From Rehabilitation Hospital to Community Participation: Transitional programs & measurement gaps

Rehabilitation Hospital	Community Participation
<ul style="list-style-type: none"> •Neurological •Cardiovascular •Pulmonary •Nutritional •Bone density •Pain •FIM, ADL & ROM •Strength & Endurance 	<ul style="list-style-type: none"> •IADL S •Strength •Endurance •Community Participation? •CHART, Life H, MAP, IAP, PARTS/M...? •Environmental facilitators? •MQE, CHIEF, FABS...?

Measuring What Matters, Gale Whiteneck, 1994

To try out the surveys

PARTS/M, FABS/M, SPARC, and CHEC/M

- **PARTS/M, FABS/M, SPARC Web Demos**
 - <https://emc.wustl.edu/PARTSM/PARTSMlogin.html>
 - <https://emc.wustl.edu/FABS/FABSlogn.htm>
 - <https://emc.wustl.edu/SPRC/SPRClogn.htm>
 - Password: ACRM
 - Participant ID#: 1 to 100
- **CHEC/M Web Demo**
 - <http://emc.wustl.edu/NCPR/NCPRlogn.htm>
 - Participant ID: ACRM
 - Password: 1 to 100

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- Websites:
 - <http://www.communitychange.info>
 - <http://enablemob.wustl.edu/>