Purpose

- This project further develops and refines a system of measurement that examines person and environment interactions.
Medical & Social Models

**Medical Model**
- PROBLEMS are in the body
- PLACE of intervention is in the hospital

**Social Model**
- PROBLEMS are in the physical & social environment
- PLACE of intervention is the community

Missing Links
Framework: The International Classification of Functioning, Disability and Health (ICF)

Health Condition (Disorder or Disease)

Body Functions & Structures → Activity

Activity → Participation

Participation → Environmental Factors

Personal Factors

Research and Training Center on Measurement and Interdependence in Community Living
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?
• Can we measure participation environment interactions using a set of general environmental features?
• Can we measure participation environment interactions using a set of environmental features at specific community sites?
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)
<table>
<thead>
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<th>Time</th>
<th>Can do</th>
<th>Do</th>
<th>Hypothetical</th>
<th>Evaluative</th>
<th>Environment</th>
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“ONE DOES OR DOES NOT” - YODA, STAR WARS
## Selected Measures Used to Assess Participation in Context

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<th>Measure</th>
<th>Limitations/ person level ACTIVITY</th>
<th>Limitations/ society level PARTICIPATION</th>
<th>Context/ Environment</th>
<th>Assistive Technology Included</th>
<th>Quality of Life</th>
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Community Based Participation and Receptivity Web Based Surveys

Characteristics of the Respondent (CORE)

Participation of People with Impairments and Limitations Survey (PARTS-G)

Survey of Participation and Receptivity in Communities (SPARC)
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, assistive device, personal assistance and transportation services
Characteristics of the Respondent (CORE)

- Personal demographics
- Financial & service benefits received
- Disabling conditions
  - physical impairment
  - visual impairment
  - hearing impairment
  - cognitive impairment
  - emotional impairment
- Primary diagnosis for identified disabling condition
- Current or past secondary conditions
- Health status and health care use
- Balance, Transfer
- Assistive Device Use
- Personal Assistance Use
PARTS/G & SPARC Methods- Design

- Participants
  - Recruit and Enroll
  - Eligibility Criteria
- Initial Survey
  - Administer the CORE and PARTS-G
  - Administer the CORE and SPARC
- Reliability Survey
  - Administer the CORE and PARTS-G
  - Administer the CORE and SPARC
- Results
- Data Analysis

3-6 Weeks
Methods - Participants

- Inclusion Criteria:
  - Adults 18-75 years
  - Mobility, vision, or hearing impairments
  - Lived in the community
  - Access to a computer
  - Read English at 6th grade level

- Recruitment:
  - Variety of organizations that work with people with disabilities
  - Advertised on disability related websites
Methods - Procedures

- **Web based screener survey**
  - Eligibility determined
- **Randomly assigned to CORE/ PARTS-G or CORE/ SPARC**
- **Complete the web-based survey**
  - 2 weeks to complete
  - 2 reminders were given
  - Compensated for time spent filling out surveys by check or gift card
- **Reliability Survey completed 3-6 weeks after completion of initial survey by approximately 64% of individuals completing the initial survey**
### Stratified Sample by Impairment

<table>
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<th>Primary Impairment</th>
<th>Survey</th>
<th>Initial Survey</th>
<th>Second Survey</th>
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<td>Internal Consistency</td>
<td>Stability</td>
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<tr>
<td>Vision</td>
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<td>Hearing</td>
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## Stratified Sample by Primary Community Mobility Device

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<td>Crutches</td>
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<td>Total Cane, Crutches &amp; Walkers</td>
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### Demographics PARTS/G

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<td>111</td>
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## Participation of People with Impairments and Limitations Survey (PARTS-G)

### 24 Activities included:

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<td>Dressing</td>
<td>Leaving Your Home</td>
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<tr>
<td>Bathing</td>
<td>Religious Activities</td>
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<tr>
<td>Bladder Care</td>
<td>Community Activities</td>
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<td>Bowel Care</td>
<td>Leisure Activities</td>
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<tr>
<td>Preparing Meals</td>
<td>Exercise</td>
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<td>Moving Inside Home</td>
<td>Active Recreation</td>
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<tr>
<td>Working Inside Home</td>
<td>Socializing</td>
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<td>Outdoor Home Maintenance</td>
<td>Education</td>
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<td>Managing Money</td>
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<td>Volunteering</td>
<td>Vacation Activities</td>
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<td>Parenting</td>
<td>Communication (expressive)</td>
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<td>Intimacy</td>
<td>Communication (receptive)</td>
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<td><strong>Reliability of PARTS/G</strong></td>
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<tr>
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<td>Mobility</td>
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<tr>
<td>Pain &amp; Fatigue</td>
<td>Vision</td>
</tr>
<tr>
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<td>Hearing</td>
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## Reliability of PARTS/G

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<td>9</td>
<td>17</td>
<td>6</td>
<td></td>
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<tr>
<td>Pain &amp; Fatigue</td>
<td>0.98</td>
<td>0.94</td>
<td>0.96</td>
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<td>0.99</td>
<td>0.96</td>
<td>0.94</td>
<td>0.88</td>
<td>0.69</td>
<td>17</td>
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<tr>
<td></td>
<td>12</td>
<td>17</td>
<td>9</td>
<td>17</td>
<td>6</td>
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<tr>
<td>Major Life Group</td>
<td>0.81</td>
<td>0.78</td>
<td>0.82</td>
<td>0.76</td>
<td>0.61</td>
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<td>0.64</td>
<td>0.56</td>
<td>0.83</td>
<td>0.52</td>
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<td>17</td>
<td>23</td>
<td>13</td>
<td>7</td>
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<tr>
<td>Pain &amp; Fatigue</td>
<td>0.90</td>
<td>0.69</td>
<td>0.92</td>
<td>0.93</td>
<td>0.90</td>
<td>17</td>
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<td>0.94</td>
<td>0.68</td>
<td>0.91</td>
<td>0.84</td>
<td>0.94</td>
<td>17</td>
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<td>17</td>
<td>23</td>
<td>14</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>
Use of PARTS/G in Disability & Community Based Research

What do people with mobility, visual and hearing impairments do and how do they evaluate what they do?

- Self Care
- Leaving home
- Communicating
- Socializing

Difficulty in participation

Participation comparisons by impairment groups

Participation comparisons by device used
PARTS/ G: Minutes per day spent on self-care activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Bowel</th>
<th>Bladder</th>
<th>Bathing</th>
<th>Dressing</th>
<th>Meal Prep</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PW</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MW</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CCW</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
PARTS/G: Self-care evaluation

*Evaluation score Range 3 to 12

*Evaluation = Choice + Control + Satisfaction  Range 3 to 12
PARTS/G: Frequency of leaving the home

- Vision: 8 occurrences per week
- Hearing: 10 occurrences per week
- PW: 6 occurrences per week
- MW: 8 occurrences per week
- CCW: 7 occurrences per week
PARTS/G: Mean evaluation score for leaving the home

*Evaluation Score Range 4 to 16

*Evaluation = Importance + Choice + Control + Satisfaction  Range 4 to 16

*Evaluation Score Range 4 to 16

- **Vision**: 13
- **Hearing**: 15
- **PW**: 13
- **MW**: 14
- **CCW**: 13

* * *
PARTS/G: Evaluation of Communication

*Evaluation score Range IS 4 to 16

*Evaluation = Importance + Choice + Control + Satisfaction  Range 4 to 16

Vision | Hearing | PW | MW | CCW

Left Expressive Right Receptive
PARTS/G: Frequency of doing leisure activities

Number of occurrences per year

Vision: 320
Hearing: 360
PW: 430
MW: 380
CCW: 300
PARTS/G: Mean evaluation score for leisure activities

Evaluation Score range 4 to 16

Vision | Hearing | PW | MW | CCW

Evaluation Score
13 | 15 | 14 | 13 | 12
PARTS/ G: Mean number of times per week spent socializing

<table>
<thead>
<tr>
<th></th>
<th>Occurrences per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision</td>
<td>4</td>
</tr>
<tr>
<td>Hearing</td>
<td>5.5</td>
</tr>
<tr>
<td>PW</td>
<td>5</td>
</tr>
<tr>
<td>MW</td>
<td>6.2</td>
</tr>
<tr>
<td>CCW</td>
<td>4.1</td>
</tr>
</tbody>
</table>
PARTS/G:
Difficulty with and without help

Degree of Difficulty:
- Completely Unable
- A Great Deal
- A Moderate Amount
- A Little
- None

Difficulty With Help
Difficulty Without Help

Activities:
- Dressing
- Bathing
- Bladder Care
- Bowel Care
- Meal preparation
- Housekeeping
Your participation compared to others with a mobility limitation

- Participation Total Score: 76%
- Self-Care: 37%
- Mobility: 84%
- Interpersonal Interactions & Relationships: 78%
- Domestic Life: 63%
- Major Life Activities: 91%
- Community, Social & Civic Life: 48%

Level of Participation:

0% 25% 50% 75% 100%
Your participation compared to others with SCI

- Participation Total Score: 63%
- Self-Care: 27%
- Mobility: 99%
- Interpersonal Interactions & Relationships: 92%
- Domestic Life: 65%
- Major Life Activities: 84%
- Community, Social & Civic Life: 40%

Level of Participation:
- 0%
- 25%
- 50%
- 75%
- 100%
Your participation compared to others who use a power wheelchair

- Participation Total Score: 53%
- Self-Care: 18%
- Mobility: 90%
- Interpersonal Interactions & Relationships: 45%
- Domestic Life: 60%
- Major Life Activities: 80%
- Community, Social & Civic Life: 25%
**SPARC Methods - Design**

1. **Participants**
   - Recruit and Enroll
   - Eligibility Criteria

2. **Initial Survey**
   - Administer the CORE and PARTS-G
   - Administer the CORE and SPARC
   - 3-6 Weeks

3. **Reliability Survey**
   - Administer the CORE and PARTS-G

4. **Results**
   - Data Analysis

---

Research and Training Center on Measurement and Interdependence in Community Living
Survey of Participation and Receptivity in Communities (SPARC)

**Purpose**: To provide a subjective measure of participation in specific contexts

**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 19 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
<table>
<thead>
<tr>
<th>Demographics SPARC</th>
<th>% of Phys.</th>
<th>% of Phys.</th>
<th>% of Visual</th>
<th>% of Hearing</th>
<th>% of Hearing</th>
<th>% of Total</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total = 554</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>212</td>
<td>63.5</td>
<td>83</td>
<td>70.9</td>
<td>72</td>
<td>71.3</td>
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<tr>
<td></td>
<td>African American/Black</td>
<td>18</td>
<td>5.4</td>
<td>9</td>
<td>7.6</td>
<td>3</td>
<td>3.0</td>
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<tr>
<td></td>
<td>White</td>
<td>289</td>
<td>86.5</td>
<td>97</td>
<td>81.5</td>
<td>91</td>
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<td>Other</td>
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<td>6.0</td>
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<td>Hispanic/Latino origin</td>
<td>11</td>
<td>3.3</td>
<td>10</td>
<td>8.4</td>
<td>4</td>
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<td>Marital status</td>
<td>Married</td>
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<td>33.2</td>
<td>48</td>
<td>40.3</td>
<td>54</td>
<td>53.5</td>
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<tr>
<td>Highest grade completed</td>
<td>College 4 or more years – college graduate</td>
<td>173</td>
<td>52.0</td>
<td>75</td>
<td>63.0</td>
<td>67</td>
<td>66.3</td>
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<tr>
<td>Annual income</td>
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<td>41.1</td>
<td>32</td>
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<td>20</td>
<td>22.2</td>
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<tr>
<td></td>
<td>$15,000 –$74,999</td>
<td>155</td>
<td>51.0</td>
<td>66</td>
<td>64.1</td>
<td>64</td>
<td>68.6</td>
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<tr>
<td></td>
<td>$75,000 or more</td>
<td>24</td>
<td>7.9</td>
<td>5</td>
<td>4.9</td>
<td>6</td>
<td>6.7</td>
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<td>Test Age</td>
<td>Range</td>
<td>19-73</td>
<td>20-74</td>
<td>21-71</td>
<td>74</td>
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<td></td>
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<td></td>
<td>Mean</td>
<td>47</td>
<td>44</td>
<td>51</td>
<td>47</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Survey of Participation and Receptivity in Communities (SPARC)

Frequency of participating at community sites
Evaluation of experience
Influence of health
Influence of transportation
Influence of people at the site
Influence of built features at the site
SPARC: Participation at **19** 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 & Location

1. How OFTEN do you go to doctors' offices?
- Never
- Yearly
- 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 doctors' offices?

Number of TIMES 2

3. How IMPORTANT is participating in healthcare activities at doctors' offices?
- Very unimportant
- Unimportant
- Important
- Very important
- I prefer not to answer

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

Specify only ONE doctor's office:
Dr. Thomas Smith  2418 Burr Oak
St. Louis, MO 63109
5. How much **CHOICE** did you have when you selected this doctor's office?

- 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 doctor's office?

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

7. How **SATISFIED** are you with your **participation** in healthcare activities at this doctor's office?

- Very dissatisfied
- Dissatisfied
- Satisfied
- Very satisfied
- I prefer not to answer

8. How do employees at your doctor's office **INFLUENCE** your **participation**?

- Limit a lot
- Limit some
- Help some
- Help a lot
- I prefer not to answer
9. Do people working at your doctor's office ...
   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
   (continued)
   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
19. How much does PAIN limit your participation in healthcare activities at your doctor's office?
- None
- A little
- A moderate amount
- A great deal
- I prefer not to answer

20. How much does FATIGUE limit your participation in healthcare activities at your doctor's office?
- None
- A little
- A moderate amount
- A great deal
- I prefer not to answer

23. How do you get to your doctor's office? Please mark the ONE you use most often.
- Walk/Roll
- Car/Van/Truck/SUV - not adapted
- Car/Van/Truck/SUV - adapted
- Paratransit*
- Light rail/Subway**
- Taxi - not adapted
- Taxi - adapted
- Bus
- None of these
- 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 doctor's office?
- Very difficult
- Difficult
- Easy
- Very easy
- I prefer not to answer
SPARC: Site Facilitators Influence on Participation

21. How accessible is your doctor’s office? (This includes entrance, aisles, exam table, etc.)
   - Inaccessible
   - Accessible with difficulty
   - Accessible
   - Very accessible

22. Check all features that are present at your doctor’s office.
   - Flat sidewalk surfaces
   - Curb cuts
   - Accessible parking
   - Signage for accessible entrance
   - Signage for accessible features
   - Level entrance or ramp
   - Automatic doors
   - Loaner assistive device
   - Elevator
   - Designated area of rescue assistance
   - No background noise
   - Wide/Clear spaces or aisles
   - Accessible exam tables
   - Accessible weight scale
   - Adequate counters
   - Adequate lighting
   - Accessible phone (TTY)
   - Accessible drinking fountain
   - Other: ____________________________
   - None of these
SPARC: Participation at Doctor’s Office

Diagram:

- Participation
- Environment

Arrows indicate the relationship between participation and the environment.
SPARC: Participation at Doctor’s Office

- Participation
  - Temporal
  - Health
    - Pain
    - Fatigue
  - Evaluative
  - Difficulty

Correlation:
- Pain and Health: .97
- Fatigue and Health: .74
SPARC: Participation at Doctor’s Office

- Participation
  - Temporal
  - Health
  - Evaluative
  - Difficulty
    - Importance
    - Choice
    - Control
    - Satisfaction
SPARC: Participation at Doctor’s Office

- Temporal
- Health
- Evaluative
- Difficulty

Participation

- PAS
  - With: .98
  - With Out: .39
- AT
  - With: .75
  - With Out: .25

Correlations:
- PAS: .98
- AT: .16
- Difficulty: .89
SPARC: Participation at Doctor’s Office

Participation

Temporal

Health

Evaluative

Difficulty

Temporal: 0.07

Health: -0.52

Evaluative: 0.72

Difficulty: 1.0
SPARC: Participation at Doctor’s Office

Environment

Support

Background

Employees

Built

PAS

.85

.94

.17

Unpaid

Paid

AT

Research and Training Center on Measurement and Interdependence in Community Living
SPARC: Participation at Doctor’s Office

- Environment
  - Support
  - Background
    - Noise: 0.25
    - Light: 0.79
  - Employees
  - Built
SPARC: Participation at Doctor’s Office

- Environment
  - Support
  - Background
  - Employees
  - Built
    - Direct
      - Look
      - Speak
      - Eye Contact
      - Conversation
    - Indirect

Correlation coefficients:

- Support: 1.0
- Background: 0.90
- Employees: 0.83
- Built: 0.90
- Direct: 0.53
- Indirect: 0.39

Research and Training Center on Measurement and Interdependence in Community Living
SPARC: Participation at Doctor’s Office

Environment

Support

Background

Employees

Built

Direct

Indirect

Help

Child

Solve Prob.

Decision

.72

.54

.02

.38

.83

1.0

SPARC: Participation at Doctor’s Office

Research and Training Center on Measurement and Interdependence in Community Living
SPARC: Participation at Doctor’s Office

Environment

Support

Background

Employees

Built

Exterior

Building

Office

.91

.84

.80
### Building Exterior

<table>
<thead>
<tr>
<th>Feature</th>
<th>Score</th>
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</thead>
<tbody>
<tr>
<td>Flat Surfaces</td>
<td>0.37</td>
</tr>
<tr>
<td>Curb Cuts</td>
<td>0.45</td>
</tr>
<tr>
<td>Parking</td>
<td>0.43</td>
</tr>
<tr>
<td>Signage-Entrance</td>
<td>0.66</td>
</tr>
<tr>
<td>Ramps</td>
<td>0.45</td>
</tr>
<tr>
<td>Signage-Accessible Features</td>
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</tbody>
</table>
### Building Interior

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Doors</td>
<td>.56</td>
<td>Loaner AT</td>
<td>.51</td>
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<tr>
<td>Elevator</td>
<td>.54</td>
<td>Rescue Assistance</td>
<td>.56</td>
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<tr>
<td>Phones</td>
<td>.40</td>
<td>Drinking Fountains</td>
<td>.56</td>
</tr>
</tbody>
</table>
### SPARC: Participation at Doctor’s Office

#### MD Office Building

<table>
<thead>
<tr>
<th>Clear Spaces</th>
<th>Exam Table</th>
<th>Weight Scale</th>
<th>Counters</th>
<th>Bathroom</th>
</tr>
</thead>
<tbody>
<tr>
<td>.51</td>
<td>.69</td>
<td>.70</td>
<td>.73</td>
<td>.52</td>
</tr>
</tbody>
</table>

Research and Training Center on Measurement and Interdependence in Community Living
SPARC: Participation at Doctor’s Office

Environment

- Support: .27
- Background: .56
- Employees: -.57
- Built: -.47
SPARC: Participation at Doctor’s Office

Participation $\rightarrow$ Environment

$R = .79$
Participation (PARTS/M) & Environment (FABS/M) Leisure Activities

- Participation (PARTS/M) & Environment (FABS/M)
- Leisure Activities

- Time: Eval. (0.70*), Person (0.64*)
- P
- E
- Natural (0.70*), Attitude (0.26*), Built (0.36*)
- Support
- Background (-0.65*)

r = 0.55*

Research and Training Center on Measurement and Interdependence in Community Living
Measures for ICF Classification

HEALTH CONDITION (Disorder or Disease)
- Pain and Fatigue

BODY FUNCTIONS & STRUCTURES
- Lower Limb Impairments

ENVIRONMENTAL FACTORS
- Assistive Technology & Personal Assistance
- SPARC & CHEC

PERSONAL FACTORS
- Demographics
- CORE

ACTIVITY Difficulty Moving

PARTICIPATION Frequency & Evaluation
- PARTS/ G

Contextual Factors
Rehabilitation Hospital to Community Participation: Transition programs & measurement gaps

Rehabilitation Hospital
• Neurological
• Cardiovascular
• Pulmonary
• Nutritional
• Bone density
• Pain
• FIM, ADL & ROM
• Strength & Endurance

Community Participation
• IADL S
• Strength
• Endurance
• Community Participation?
  • CHART, Life H, MAP, IAP, PARTS/ M...
• Environmental facilitators?
  • MQE, CHIEF, FABS...

Measuring What Matters, Gale Whiteneck, 1994
Contact Information

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- Program in Occupational Therapy
- Tel: 314-286-1658   Email: graydb@wusm.wustl.edu

Holly H. Hollingsworth, PhD
- Washington University School of Medicine
- Program in Occupational Therapy
- Tel: 314-286-1630     Email: hollingsworthh@wusm.wustl.edu

Websites:
- http://www.disabilitycommunityparticipation.org
- http://enablemob.wustl.edu/