

EMERGING MEASURES OF PARTICIPATION IN ASSISTIVE TECHNOLOGY

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The Significance of Participation

Increasing participation for people with disabilities is a goal of the Americans with Disabilities Act (ADA) and the New Freedom Initiative.

The recently revised International Classification of Functioning and Disability (ICF) recognizes participation and activity as one of its four key components.

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The Problem of Participation for Wheelchair Users

90% of all wheelchair users report activity limitations.
(Harris Survey, National Organization of Disability, Wash., DC, 2000)

Only 14.7% of wheelchair users can complete their activities of daily living (ADL) mobility tasks. (HS Kaye, T Kang, MP LaPlante, Disability Statistics Report: Mobility device use in the United States, NIDRR, 2000)

Wheelchair use has doubled in the last 10 years and is growing rapidly. (HG LaPlante, AJ Moss, Assistive technology devices and home accessibility: prevalence, payment, need, and trends” Adv Data, pp1-11, 1992)

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Participation and Activity

Participation and Activity are closely linked.

- *Activity* is defined as the “execution of a task or action by an individual.”
- *Participation* is defined as “involvement in a life situation.”

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Capacity and Performance

These are 2 qualifiers used to describe how activity and participation are measured:

Capacity is the ability to execute a task or action (e.g., a clinical measurement of reach).

Performance is what an individual does in his/her current environment.

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Potential Factors Impacting Participation and Activity among Wheelchair Users

- Health Conditions
- Environmental Barriers in society (e.g., lack of curb cuts, or reliable and accessible transportation or assistive technologies, social attitudes)
- Personal Factors (emotional or attitudinal factors within the individual)

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It's important to distinguish between activity and participation

**One of ICF aims is to serve as a
framework for the scientific study of
health.**

**In order to operationalize participation,
ICF classifications must contain distinct
phenomena with clear definitions of
both activity and participation.**

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How are Activity and Participation distinguished from each other?

Jette et al. identifies distinct concepts of activity and participation. They are:

- 1) mobility activity
- 2) daily activity
- 3) participation

Jette AJ, Haley SM, Kooyoomjian JT. (2003) Are the ICF activity and participation dimensions distinct? *J. Rehabil Med*, 35:145-149.

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Activity and Participation Categories

- Mobility activities refer to basic and advanced mobility *skills*, e.g., sit to stand.
- Daily activities refer to mobility *tasks*, e.g., ADLs.
- Participatory behavior occurs in the context of performing social roles, for example, as parent, employee, and so on.

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Current Measures of Participation Rely on Self-Report Instruments

Most participation self-reports query participation in terms of both activities and social roles (e.g., ADL, work/education, social relationships, leisure, financial responsibilities).

They may measure activities and participation in terms of effectiveness, frequency, satisfaction.

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Criteria to consider when choosing a self-report instrument

1. Perspective of the instrument.
2. Reliability and validity.
3. Compatibility with current ICF definitions of participation.
4. Type of measurements: frequency, effectiveness, efficiency, quality of life.
5. Method of administration.
6. Subject/Researcher burden.
7. Targeted population.
8. Sensitivity to impact of AT.

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Perspective of Instrument

Different instruments are influenced by the particular perspective or bias with which they evaluate participation. For example:

- 1. CHART chooses normative values of participation to measure; that is, it measures what “society” expects from its members.**
- 2. The IPA chooses a subjective, person-perceived approach; that is, it asks can the individual do what he/she wants when and how they want to do it.**

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Reliability and Validity

The demonstrated reliability and validity of a self report instrument ensures that the instrument measures what it intends to measure. Many self-report instruments are new and have not been fully evaluated.

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ICF Compatibility

Most self-report instruments were developed to measure “participation restriction” or handicap, and may not be compatible with the current ICF definition of participation.

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Types of Measurement

- **Frequency of activities/participation.**
- **Efficiency or effectiveness of activities and participation.**
- **Satisfaction with activities and participation.**

The clinician or researcher needs to decide which measurements are best suited for their project needs.

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Method of Administration

Is the method of administration suitable for your study?

- Telephone administered surveys
- In-person administration
- Mail-in surveys

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Subject/Researcher Burden

Need to consider factors that can impose excessive burden to the subject or researcher/clinician.

For example:

Some surveys require only 5-10 minutes to administer; others take 40 to 60 minutes.

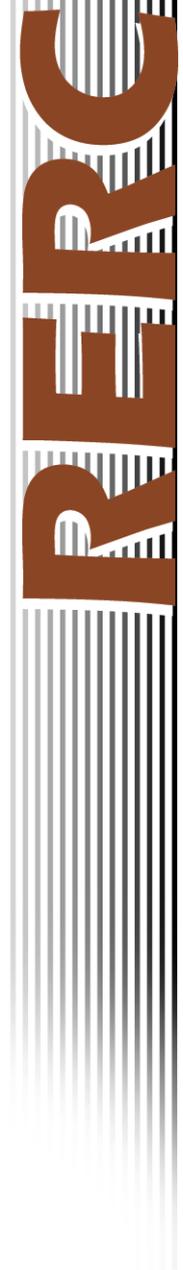
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Targeted Population

Some measures are intended for:

- Specific populations, e.g., geriatric, traumatic brain injury, or spinal cord injury.
- A particular type of functional disability, e.g., mobility.
- Others are intended for populations across all disability types.

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Sensitivity to AT Impact

Not all participation measures are sensitive to the impact of assistive technology on participation. Some ignore AT, others “penalize” its use in their scoring procedure.

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General Limitations of Self Report Measures of Participation

1. **Most participation self-reports measure “participation restrictions” or handicap. They do not capture participation and activity as it occurs in a real-world environment.**
2. **Self reports are vulnerable to many issues that affect data quality. For example, question format, wording, context can result in inconsistent responses. Frequency and rating scales in particular invite inconsistent responses across subjects.**

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Participation and Activity Monitoring System (PAMS)

A new methodology to measure activity and participation among wheelchair users. It combines activity monitoring instruments (such as accelerometers, seat sensors, & global positioning systems) with a prompted recall interview.

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PAMS is a flexible and versatile research tool.

- 1. Combines objective measurement with self report (prompted recall interview).**
- 2. Describes activity and participatory behavior in a real world environment.**
- 3. Can be used in combination with established self-report measures of participation.**

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Activity Monitoring Instruments

- **Global positioning systems (GPS) capture distance, frequency, duration, and patterns of travel activity.**
- **Seat sensors determine whether wheelchair is occupied and when a subject tilts or reclines.**
- **Wheel revolution counters.**

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Prompted Recall Interview

Queries subjects' activities and participation based on data from instrumentation over a certain time period.

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Preliminary Study Using PAMS (currently underway at Georgia Tech)

Goal of study is to measure activity and participation of subjects who receive a tilt-in-space (TIS) wheelchairs.

N = 17 subjects who use power wheelchair with TIS.

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Wheelchair Instrumentation

Subjects' wheelchairs are instrumented for two weeks with:

- Wheel revolution counter
- Seat occupancy sensor
- Seat position sensor
- GPS receiver

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Instrumentation Data

1. Time spent in chair
2. Frequency & duration of tilts
3. Average total distance traveled per day
4. Time spent wheeling in chair
5. Number of destinations per day
6. Number of unique destinations
7. Number of mobility bouts*

*A mobility bout is defined as a bout of movements initiated when a subject travels a minimum of 2 feet within 4 seconds and continues until the subjects travels less than 2.5 feet over 14 seconds.

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Wheelchair Usage Results

1. **Subjects sat in their wheelchairs for 10.2 (+/- 2 hrs per day). Actual daily usage exceeded 17 hours on at least 1 day.**
2. **Subjects averaged 50 mins of wheeling daily, with days varying from 0-135 mins over all days collected.**
3. **12% of bouts last more than 1 min; only 16% of bouts extended beyond 50 feet.**

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- 1. Power wheelchair users traveled less than their ambulatory counterparts.**
 - Healthy ambulatory adults walk between 1.5 and 2.7 miles daily. Subjects traveled avg distance of .84 miles daily.**

- 2. Avg subjects had more than 100 bouts of mobility on average day. 69% of bouts lasted < 30 seconds and traveled <25 ft.**

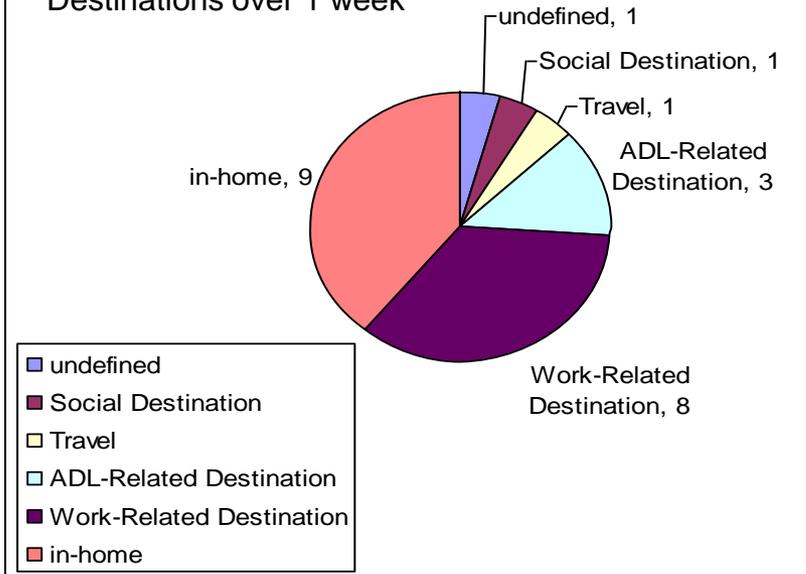
This may support idea that mobility for people who use wheelchairs functions mostly as a transition between activities or spaces.

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Examples of Instrumentation Data Summaries

GPS Information (I don't know if this is still a good example or not)

Destinations over 1 week



GPS-Based Travel Data	
	Average Business day
Daily Travel: Time (minutes)	63
Daily Travel: Distance (miles)	38
Number of Tours Daily (round-trip travel from the home)	1.5
Number of Destinations per tour	1.75
Duration per tour (hours between leaving and returning home)	6.3
Daily # of Unique Destinations	2.25
Total # of Unique Destinations during instrumentation time	8

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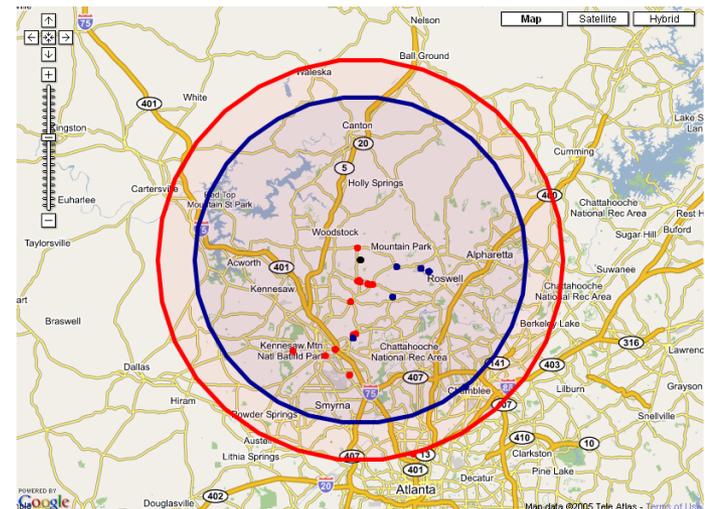
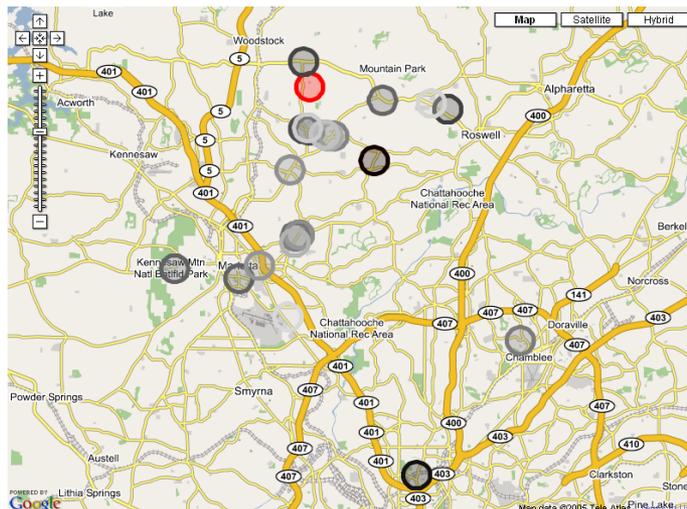
Activity patterns represented geographically

LEFT: Colored by the time spent at each destination.

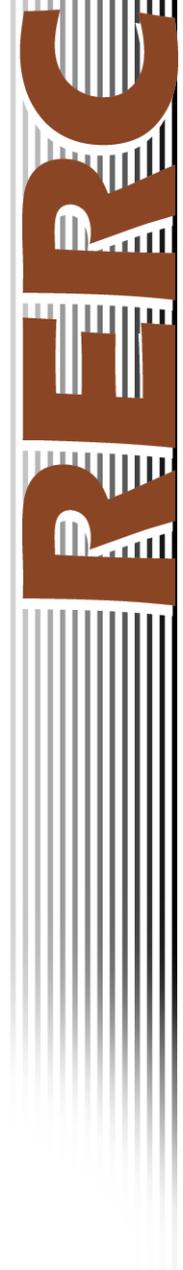
(red=home, black = short time → white = long time)

RIGHT: Colored by activity type.

(black=home, red = daily living tasks, blue = entertainment, radius of large circle is the farthest distance traveled for that purpose).



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Next 2 or 3 slides could show graphic representations of trips as they appear in Figure 2 of grant or new ones you've come up with.

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Self-Reports

1. **Prompted Recall Interview after chair is de-instrumented to capture purpose of activity at each destination.**
2. **Community Perceived Participation Receptivity Survey (CPPRS).**
3. **Home Accessibility Survey (HAS).**
4. **SF-8 (a general self-assessment health survey).**
5. **Clinician Information Form (to capture general health data).**

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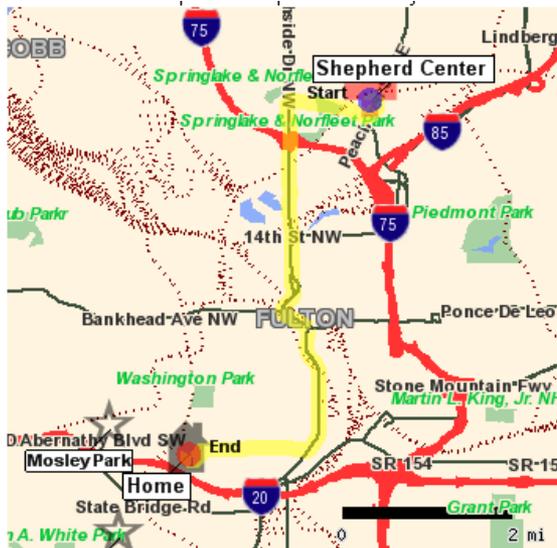
Prompted Recall Interview

GPS data are overlaid onto Geographic Information System Information. Maps are created depicting travel and destinations.

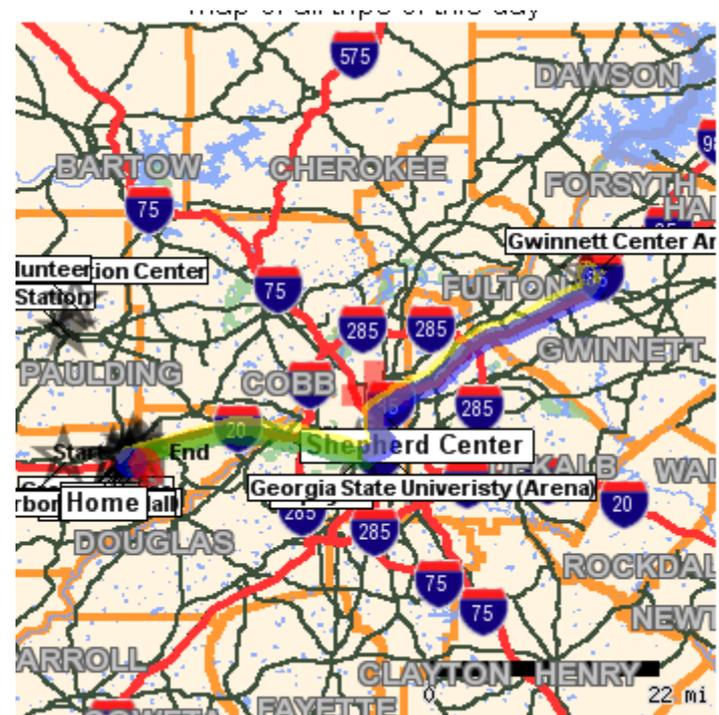
MAP here? Can it fit?

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Type of Data Available for Prompted Recall



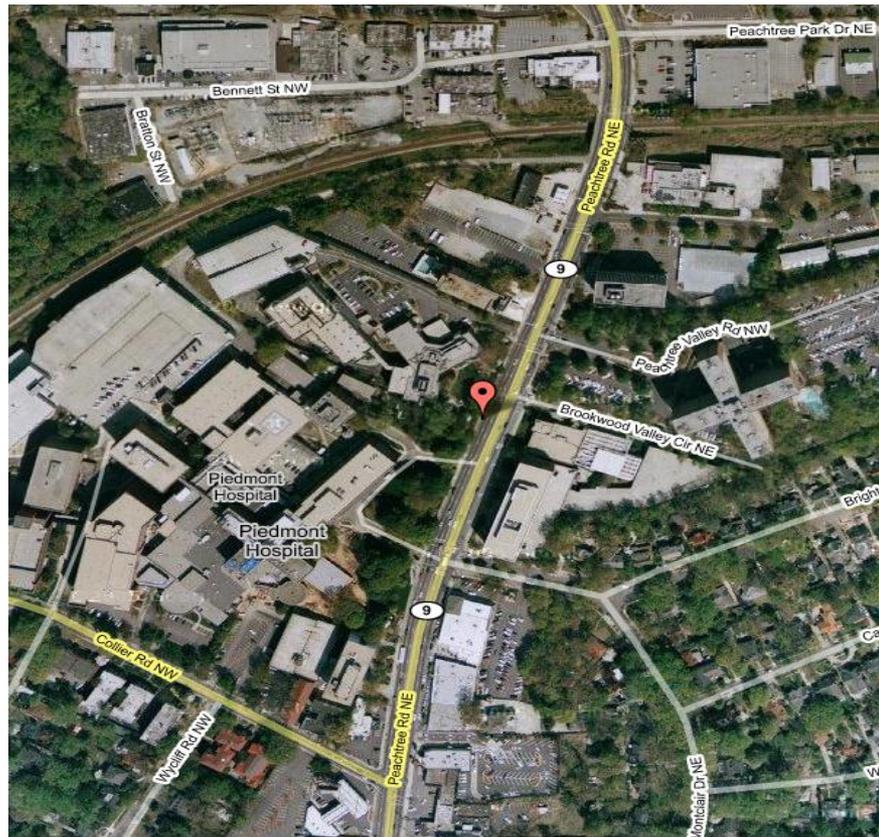
An example of GPS data showing a single trip between Shepherd Center and his home.



A single day overview for another subject. Notice the labeled habitual destinations.

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Detailed GIS Overlays Provide Context for Prompted Recall and Analysis



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Prompted Recall Interviews query:

1. **Activities for each trip***. These are categorized as: **Work/School, Daily Living Tasks, Social, Entertainment-Recreation-Leisure, Travel.**
2. **Transportation mode.**
3. **Companions or Aides.**

****Trip* is travel between 2 destinations. A *tour* is round trip to and from home including all trips and destinations inbetween.**

Sample PR Interface (Give GeoStats Credit here somewhere)

Subject ID: TS63 Travel Day: Saturday 12/10/2005

Travel Range: 12/5/2005 - 12/19/2005

[Download Data \(for all days\)](#)

Color	Trip	Start Time	End Time	Distance (mi)	Travel Mode	Activity	Destination	Map	GPS Trip	Jump Distance (mi)
Yellow	9	11:44 AM	12:46 PM	49.29	Personal Vehicle	Entertainment / Rec. / Leisure	Gwinnett Center Arena	Map & Details	9	1.01
Blue	10	3:05 PM	3:47 PM	29.09	Personal Vehicle	Daily Living Task	Popeye's	Map & Details	10	0.06
Green	11	3:58 PM	4:26 PM	20.60	Personal Vehicle	Daily Living Task	Target	Map & Details	11	0
Red	12	4:39 PM	4:46 PM	1.58	Personal Vehicle	In-Home Activities	Home	Map & Details	12	0.02

[Previous Day](#)

[Next Day](#)

[Review](#)



Subject ID TS63: Trip 11
GPS Trip 11
[Previous Day](#)
[Previous Trip](#)

[Return to Table Display](#)

[Logout](#)

[Saturday 12/10/2005](#)

[Next Day](#)

Distance from previous trip end:

[Next Trip](#)

0.00 mi

Map Views: [All](#) [Origin](#) [Destination](#)



Zoom In Zoom Out Recenter Split Trip
 Label Destinations

Trip Attributes*

Field	P	Value	N
Start	P	12/10/2005 3:58:59 PM	N
End	P	12/10/2005 4:26:35 PM	N
Distance (mi)	P	20.60	N
How	P	Personal Vehicle	N
Why	P	Daily Living Task	N
Destination	P	Target	N
Indoors/Outdoors	P	indoor	N

Destination not listed?
(The new location will use the coordinates of the end of this trip)

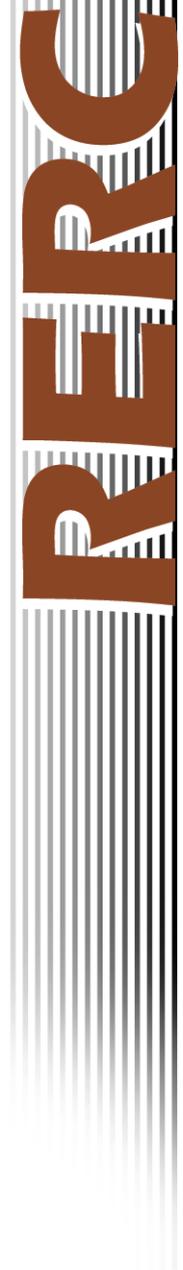
Travel Companions

- 1 Church member
- 2 Wife
- 3 Church member's wife
- 4 Son

Companion not listed?

← Single Day; ↑ Single Trip

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Can we see sample of GPS interview here as it appears in grant?

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	activity type	DESTINATIONS			WHEELCHAIR USE		
		# unique destinations (avg / day)	# visits / day	# hrs spent there /day	% time spent wheeling	# bouts of mobility	distance wheeled (feet)
Subject A	Undefined	0.08	0.08	0.5	0	0	0
	Work/School	0.46	0.54	4.1	9	22	435
	Daily Living Task	0.85	0.85	0.7	13	33	709
	Entertainment	0.15	0.15	0.3	1	2	60
	Social	0.08	0.08	0.3	2	6	103
	Home	1	1.77	15.9	11	19	821
	Total		2.62	3.46	21.8	37	81
Subject B	Undefined	0	0	0	0	0	0
	Work/School	0	0	0	0	0	0
	Daily Living Task	0.31	0.31	0.2	21	35	1681
	Entertainment	0	0	0	0	0	0
	Social	0.31	0.38	0.4	18	30	1487
	Home	0.77	1.31	16.5	2	3	199
	Total		1.38	2	17	41	68

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PAMS can be used with other self-reports

Example: Self-report data on participation from the CPPRS can be used to amplify activity and participation data captured through PAMS.

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CPPRS

- **Designed to capture activity and participation data from people with mobility disabilities. It examines:**
 - **Destinations in past month**
 - **Environmental and social barriers experienced at destinations**
 - **Rates participation experience in terms of satisfaction, choice, and importance**

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REERC

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