Measuring Activity and Participation in Outcomes Research

Frances Harris, Stephen Sprigle, Sharon Sonenblum

Center for Assistive Technology & Environmental Access

Georgia Institute of Technology

Workshop goals

We will:

- **Critically review 3 self-report measures of participation.**
- **Introduce activity-monitoring technologies used to measure wheelchair use.**
- **Discuss methodology that combines self-reports and activity-monitoring technologies to measure participation.**

The Significance of Participation

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

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

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 making participation a more urgent concern. (HG LaPlante, AJ Moss, Assistive technology devices and home accessibility: prevalence, payment, need, and trends" Adv Data, pp1-11, 1992)

Some 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 (e.g., gender, lifestyle, or emotional factors within the individual)**

Defining 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."**

Capacity and Performance

Two qualifiers are used to describe how activity and participation are measured:

- ***Capacity*** **is the individual's ability to execute a task or action in standardized environment (e.g., a clinical measurement of reach).**

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

Current Measures of Participation Rely on Self-Report Instruments

They examine:

- **activities of daily living**
- **work/education**
- **social roles & relationships**
- **leisure**
- **financial responsibilities**

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.

Craig Handicap Assessment and Reporting Technique (CHART)

- **Measures handicap (participation-restriction).**

- **"Handicap exists when individuals with impairment or disability are unable to fulfill one or more of the roles that are considered normal for their age, gender, and culture."**

Whiteneck, GG, et al. (1992) Quantifying Handicap: A New Measure of Long-Term Rehabilitation Outcomes. Arch Phys Med Rehabil V73, p519-526.

http://www.tbims.org/combi/chart/index.html

CHART's constructs include:

- ***Physical independence*** **(e.g., # of hrs per day a person requires assistance)**
- ***Mobility*** **(e.g., # of hrs per day out of bed)**
- ***Social integration*** **(e.g., # of relatives visited monthly)**
- ***Economic self-sufficiency*** **(e.g., total household income)**

Is CHART the right measure for your study?

- Societal perspective.
- Demonstrated reliability and validity.
- Intended for use by all populations.
- Approx. 15 minutes to administer.
- Telephone or in-person interview.

Impact on Participation & Autonomy (IPA)

Also, measures participation-restriction.

"participation refers more to autonomy and the *personal* fulfillment of roles rather than a *normal* role fulfillment . . ."

- **Cardol, M. et al. (2001) Psychometric Properties of the Impact on Participation & Autonomy Questionnaire. *Arch Phys Med Rehabil* V82, p210-216.**

http://www.nivel.nl/OC2/page.asp?PageID=5309

Autonomy

- **Autonomy refers to self-government or self-determination.**
- **The IPA asks "can you do what you want when you want?"**

IPA Constructs Include:

- Autonomy indoors (e.g.,) indoor mobility & ADLS
- Family roles
- Autonomy outdoors (e.g., outdoor leisure activities)
- Social life and relationships (e.g., communication)
- Work and education (e.g., paid or voluntary work)

CHART & IPA

CHART asks:

How many hours per week do you spend working in a job for which you get paid?

IPA asks:

My chances of doing my paid or voluntary work the way I want are: very good, good, fair, poor, very poor.

Is the IPA the right measure for your study?

- Person-perceived perspective
- Initial reliability and validity
- Intended for use by all populations.
- Approx. 15 minutes to administer.
- Self-administered (mail in survey)

Community Participation and Perceived Receptivity Survey (CPPRS)*

Designed to capture activity and participation data from people with mobility disabilities

Examines:

- **Locations visited in past month and year**
- **Environmental and social barriers experienced at destinations**
- **Rates participation experience in terms of satisfaction, choice, and importance**

For information contact: David B. Gray, Ph.D.,Washington University School of Medicine, Program in Occupational Therapy, 4444 Forest Park Blvd., Campus Box 8505, St. Louis , MO 63108
voice: (314) 286-1658, email: grayda@wustl.edu

CPPRS queries the following locations:

Frequent Monthly Locations

- Grocery store
- Pharmacy
- Religious institution
- Restaurant
- Family & friends
- Work, school
- Large store
- Gas station

Less Frequent Yearly Locations

- Doctor's office
- Airport
- Vacations
- Public park
- Sports arena
- Movie theater
- Shopping malls
- Beauty salon & barber shop
- DME vendor/supplier

For each location the following is asked:

- Frequency
- Paid and Unpaid Assistance
- Primary mobility device
- Importance
- Choice
- Satisfaction
- Pain & fatigue
- Overall accessibility
- Environmental facilitators
- Transportation
- Peoples' attitudes

Examples of environmental facilitator questions:

- Flat sidewalk surfaces
- Level entrance
- Floor surfaces
- Placement of merchandise in stores
- Social attitudes
- Accessible bathrooms
- Accessible parking
- Curb cuts, ramps, automatic doors

Pros and Cons of CPPRS

Advantages:

- Specific to mobility disability populations.
- Queries subjective and objective elements of participation
- Queries environmental facilitators/barriers to participation

Disadvantages:

- Subject/Researcher burden

  -Web-based version 40-45 minutes

  - Telephone interview: 60+ minutes

Current Study Using CPPRS

Goal: to measure health, activity and participation of people who use tilt-in-space wheelchairs.

CPPRS Results

1. Will summarize number and qualities of monthly and yearly destinations.
2. Will provide scores that evaluate:
   - difficulty in going to location with and without primary mobility device.
   - quality of participation at each location.
   - helpful environmental features at each location.

Summary of Destinations in one Month

Subject	PT13	PT14	PT15	PT16	PT17
Grocery Store	3	8	0	2	8
Pharmacy	2	1	2	2	2
Religious Inst.	0	0	1	2	0
Restaurant	2	2	4	10	6
Family/Friends	4	0	1	0	4
Work/School	20	2	5	2	0
Large Stores	1	4	1	8	2
Gas Stations	4	0	5	4	2

Environmental Facilitators at Each Location

Subject #	More frequent monthly locations	Less frequent yearly locations
PT13	.72*	.92
PT14	.41	.49
PT15	.55	.57
PT16	.65	.74
PT17	.69	.86

*Ratio of # of helpful features at all locations to # of features should be available at all locations.

Degree to which pain and fatigue limit participation at frequently visited locations

Subject #	Monthly Locations
PT13	5.40
PT14	8.00
PT15	7.80
PT16	7.80
PT17	5.20

Pain & Fatigue Scale:

0 = extreme pain/fatigue at all locations

8 = no pain/fatigue at any location

General Limitations of Self Report Measures of Participation

1. **They do not capture the "*performance*" of participation and activity as it occurs.**

   - **They capture what people say they do, not what they in fact do.**

General Limitations of Self Report Measures of Participation

2. Self reports are vulnerable to issues that affect data quality.
   - Question format, wording, context can result in inconsistent responses.
   - Frequency and rating scales in particular invite inconsistent responses across subjects.

Wheelchair Activity Monitoring Instrument (WhAMI)

A new methodology to measure activity and participation among wheelchair users. It combines activity monitoring instruments (such as occupancy monitor, wheel revolution counter, seat position sensor, GPS) with self-report measures.

WhAMI is a flexible and versatile research tool.

1. Combines objective measurement with self report instruments.

2. Describes activity and participatory behavior in a real world environment.

Research question determines choice of technology

Consider which measurements are needed to answer your question(s)? Examples:

- How much was the wheelchair used (expressed as distance traveled)?
- How many activities were performed outside the home?
- How often were special features on the wheelchair used?
- When and how often did the person get in and out of their wheelchair?

Different questions may require different technology or different applications of the same technology

– What was the average use (daily distance) of the wheelchair?

– What was the average use (daily distance) of the wheelchair inside the home?

Tilt-In-Space Wheelchair Study

Measure health, activity and participation of people who use tilt-in-space wheelchair

Tilt-In-Space Wheelchair Study

- How did the subject use his/her wheelchair?
  - How much time did they spend in their wheelchair?
  - How many bouts of movement did they have per day?
  - How much time did they spend wheeling?
  - What percent of the time seated in their wheelchair were they mobile?
  - What was the overall distance traveled in wheelchair daily?

- How was the Tilt-In-Space feature used?
  - How many times did the subject tilt?
  - How much time did they spend tilted?

Tilt-In-Space Wheelchair Study

- What was the nature of the trips taken outside the home?
  - How many trips per day did they take?
  - How many unique destinations did they visit?
  - What is the average number of hours per day spent at destinations?

Specific Technology

- Data logger
- Occupancy monitor
- Wheel revolution counter
- Seat position sensor
- GPS

Criteria to consider when choosing activity monitoring instrumentation

- Subject Burden
  - Size, comfort, wearability, visibility
  - Frequency of charging
  - # of researcher interactions
- Researcher Burden
  - Time to deploy
  - Time to retrieve
  - Amount of monitoring needed throughout project
  - Required data processing
- Accuracy and reliability
- Cost
- Applicability to future populations

All Purpose Data Logger

- Records data from up to 8 independent analog and 12 digital sensors.
- Hardware developed by Levo and Consonics Inc.
- Custom software samples data every 2 seconds, records only if new.
- Battery Powered (2x 3V coin cell)
- Collects more than 1 month of data, battery should last more than 1 year
- Lightweight
- Other software can be utilized (i.e. standing study)

Occupancy Monitor

To answer:

How much time did they spend in their wheelchair?

Technology

- Pressure switches
- Depends on wheelchair (sling seat flat seat pan)
- Also depends on cushion

Occupancy Monitor

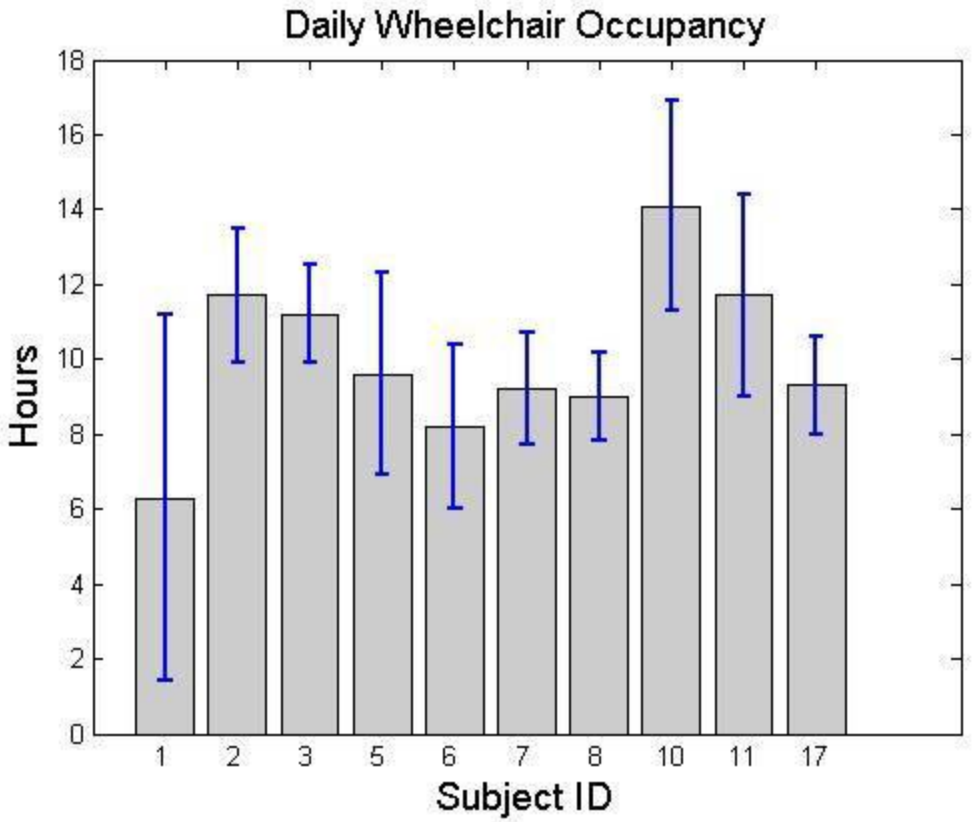
Measurements (used with data logger)

- **State of occupancy every two seconds**
- **With processing:**
  - **Total time spent in wheelchair**
  - **Number of transfers**
  - **Max duration of occupancy**
- **Integration with other data:**
  - **(with GPS) Use of wheelchair specifically inside the home**

Occupancy Monitor

- Researcher Burden
  - Data is easily interpreted
  - Monitor must be customized per wheelchair and cushion, requires validation testing
- Accuracy and reliability
  - > 95% for most subjects
  - Unusual seating configurations or subjects who are light-weight may be problematic
- Future Applicability
  - wheeled mobility
  - partial ambulators

Wheelchair Usage Results



Average: 10.2 (+/- 2 hrs per day).

Wheel Revolution Counter

To answer:

- How many bouts of movement did they have per day?
- How much time did they spend wheeling?
- What was the overall distance traveled in wheelchair daily?
- What percent of the time seated in their wheelchair were they mobile?

Technology

- Reed switch
- Neodymium Magnets mounted in plastic discs

Wheel Revolution Counter

RERC
NIDRR
catea
Georgia Tech College of Architecture

Wheel Revolution Counter

Measurements (used with data logger)

- Total wheel counts every 2 seconds
- Can calculate
  - Total distance traveled
  - Approximate speed of travel
  - Number of bouts of mobility
  - Duration of movement bouts
  - Patterns of mobility
- Integrate with other data
  - GPS and Prompted Recall
    - mobility at each destination
    - Amount of indoor mobility versus outdoor mobility
  - Occupancy
    - % of time in wheelchair used for mobility versus seating

Wheel Revolution Counter

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.

Wheel Revolution Counter

- **Subject / Researcher Burden**
  - Deployment time
  - Chair variability
  - Define and process bouts
- **Accuracy and reliability**
  - ~ 95% accurate
  - Can validate against GPS
- **Future Applicability**
  - Limited to wheeled mobility
  - Manual chairs too

Wheel Revolution Counter

- **Average 50 minutes of wheeling daily**
  - Range: 0-135 minutes
- **Power wheelchair users traveled less than their ambulatory counterparts.**
  - Subjects traveled an average distance of 0.84 miles daily.
  - Healthy ambulatory adults walk between 1.5 and 2.7 miles daily.
- **Subjects averaged <100 bouts mobility/day**
  - 69% of bouts lasted < 30 seconds and traveled <25 ft.

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

Bassett, D.R., et. al Med Sci Sports Exerc, 2000. **32**(5); Chan, C.B., et al., Obes Res, 2003. **11**(12); Schneider, P.L., et. al. Med Sci Sports Exerc, 2004. **36**(2)

Seat Position Sensor

To answer:

- How was the Tilt-In-Space feature used?
- How many times did the subject tilt?
- How much time did they spend tilting?

Technology

- Uniaxial Accelerometer (VTI Technologies)
- Lightweight
- Low power

Seat Position Sensor

Measurements (used with data logger)

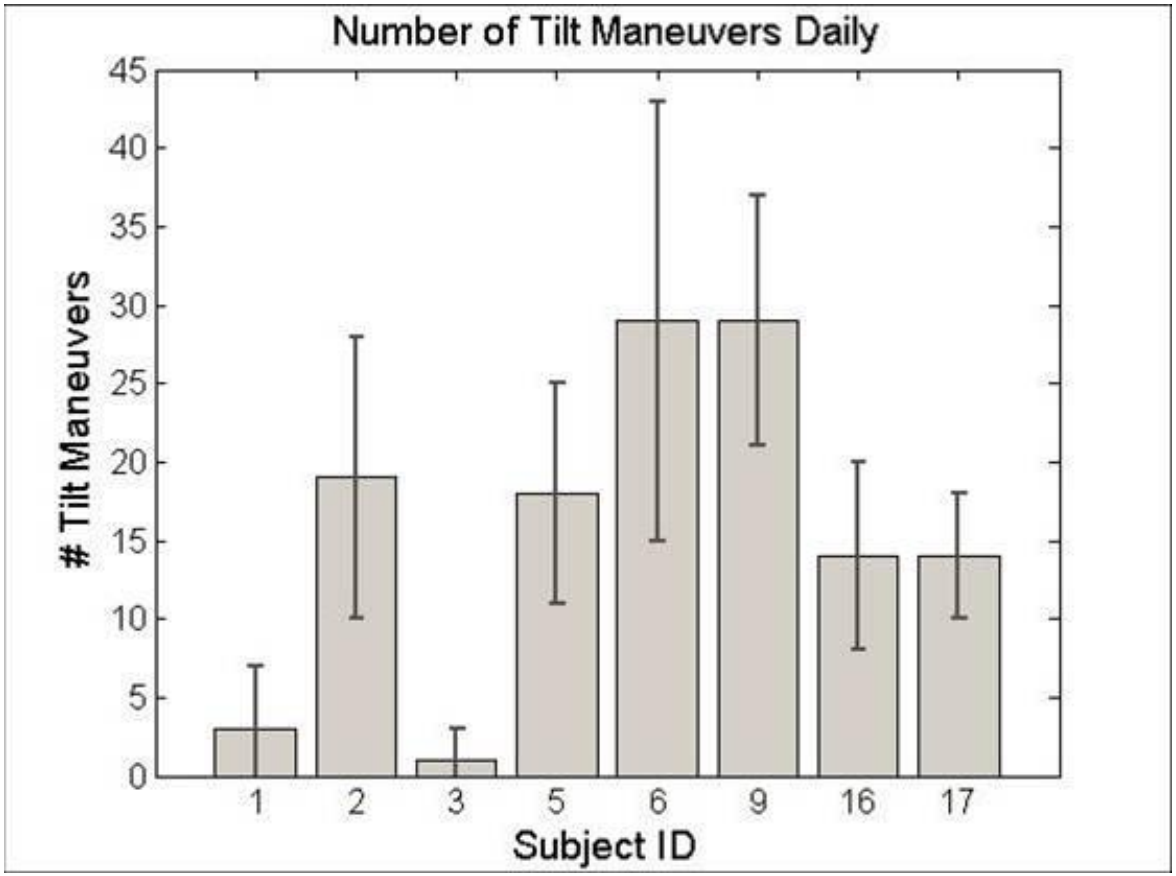
- **Acceleration value every 2 seconds**
- **With calibration, filtering and additional processing**:
  - Seat angle
  - # position changes or tilts
  - Time spent tilted more than 15º from typical seating position
  - Time spent tilted more than 40º
- **Integrated with other data:**
  - Time of day and locations of tilt use
  - prompting for questions about purpose of use
  - With different processing, use to confirm bouts of mobility or GPS trips

Seat Position Sensor

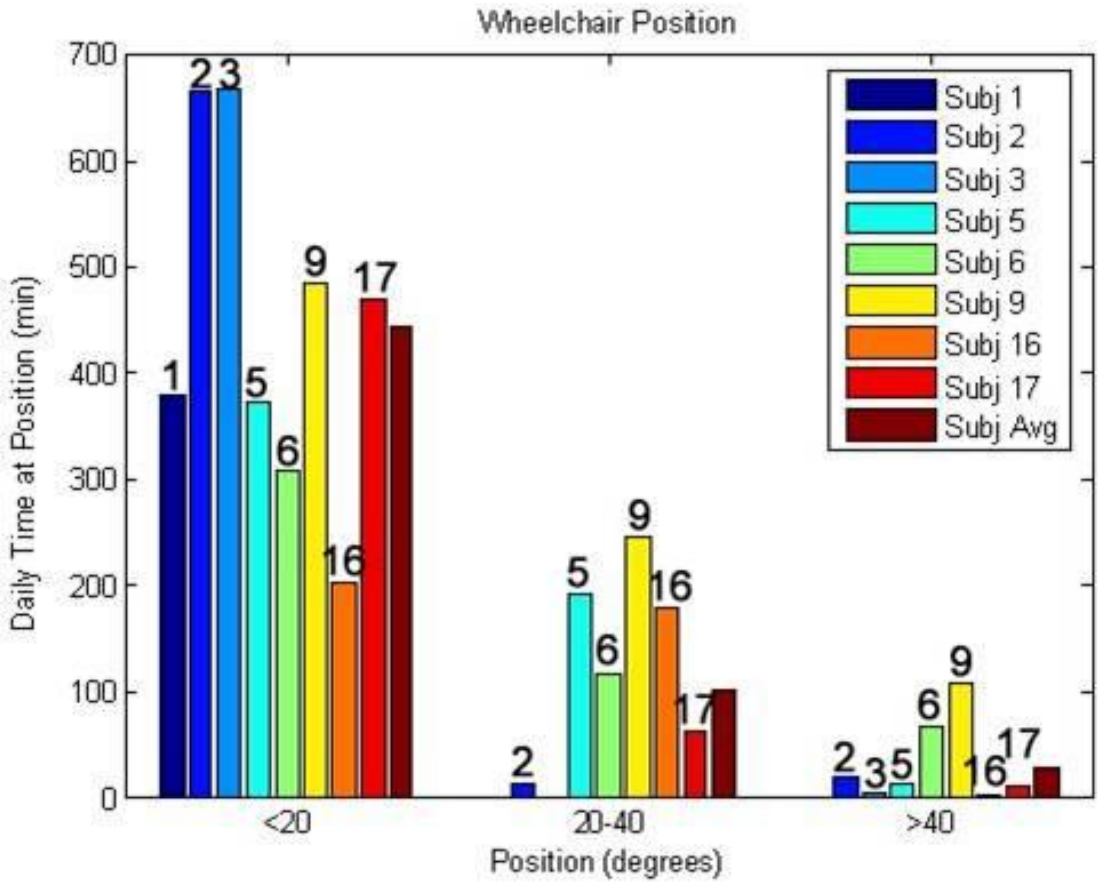
- **Subject / Researcher Burden**
  - Deployment is simple
  - Define appropriate filters, process data
  - Define “Tilt” or position change
- **Accuracy and reliability**
  - ±2º
- **Future Applicability**
  - Tilt-in-space, recline, standing wheelchairs
  - Other benefits to measuring acceleration

Seat Position Sensor

Tilt maneuver = change in position by 15° for at least 1 minute



Seat Position Sensor



Global Positioning System (GPS)

To answer:

- How many trips per day did they take?
- How many unique destinations?
- What is the average number of hours per day spent at destinations?

Technology

- Satellite navigation system (determines latitude and longitude based on satellite positions)
- Garmin receiver
- GeoStats logger

Global Positioning System (GPS)

Measurements:

- Every 5 seconds
  - Latitude and longitude
  - Heading
  - Time and date stamp
- Outdoor travel only!
- With processing
  - Distance and speed of travel
  - Frequency, duration and patterns of travel
  - Individual destinations (latitude / longitude)
  - Likely mode of transportation (ambulation, wheelchair, car or other motor vehicle)
- Integration with other data
  - With prompted recall from maps
    - Destination names, types and purposes

Global Positioning System (GPS)

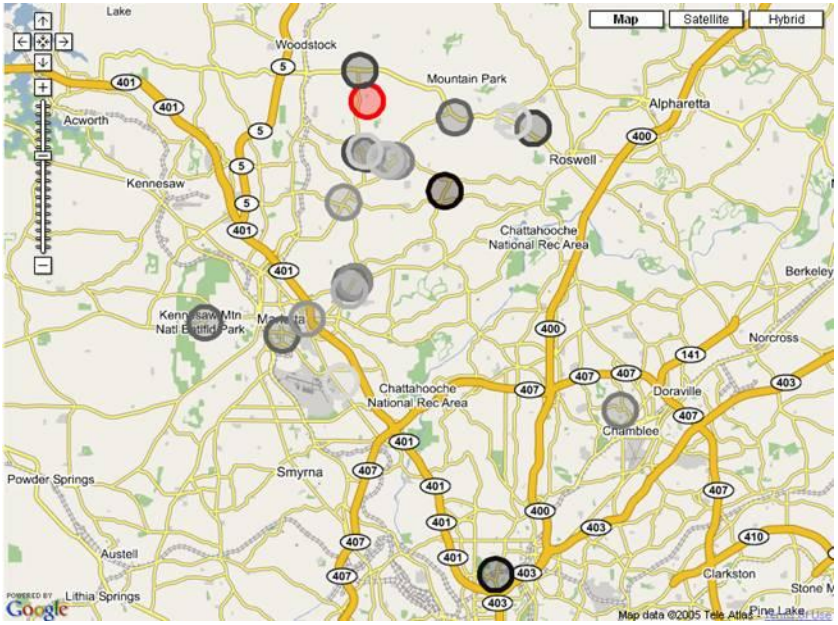
- Subject Burden
  - Interview length
  - Rely on subject memory
  - Powered by wheelchair
- Researcher Burden
  - Process raw data into “trips”
  - Prepare for Prompted Recall Interview
- Accuracy and reliability
  - 3 m at best
  - Integration of data types – prompted recall, acceleration
  - Overall amount of missed data is not known.
- Future Applicability
  - Distinguish between modes of transportation
  - Technology is improving
  - Memory limits prompted recall interview

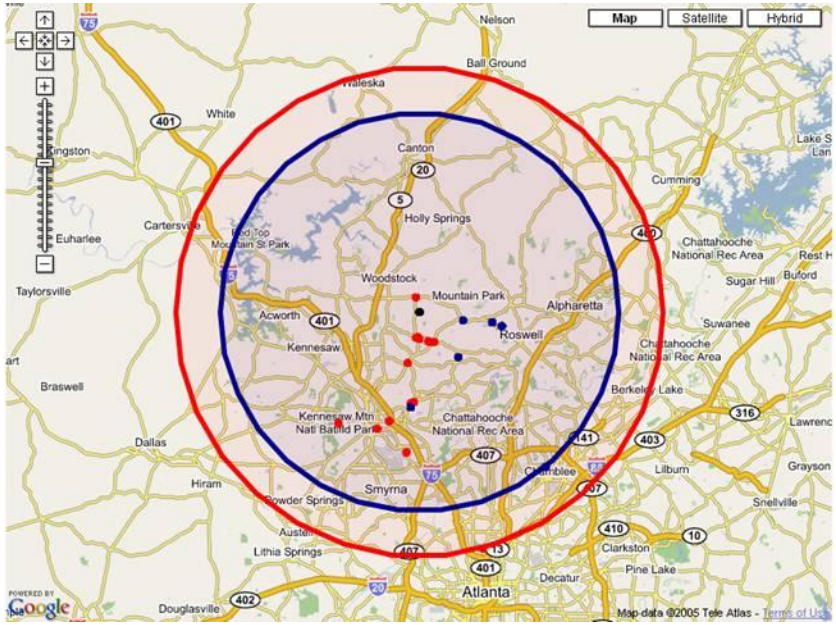
Integration of GPS, wheel revolution counter and prompted recall interview data

	activity type	DESTINATIONS # unique destinations (avg / day)	DESTINATIONS # visits / day	WHEELCHAIR USE % time spent wheeling	WHEELCHAIR USE # bouts of mobility	WHEELCHAIR USE distance wheeled (feet)
Subject A	Undefined	0.08	0.08	0	0	0
	Work/School	0.46	0.54	9	22	435
	Daily Living Task	0.85	0.85	13	33	709
	Entertainment	0.15	0.15	1	2	60
	Social	0.08	0.08	2	6	103
	Home	1	1.77	11	19	821
	Total	2.62	3.46	37	81	2128
Subject B	Undefined	0	0	0	0	0
	Work/School	0	0	0	0	0
	Daily Living Task	0.31	0.31	21	35	1681
	Entertainment	0	0	0	0	0
	Social	0.31	0.38	18	30	1487
	Home	0.77	1.31	2	3	199
	Total	1.38	2	41	68	3367

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 = farthest distance traveled for that purpose





Why we studied power wheelchair users first?

Available power

Available carrying structure

In other words: easier

To fully study A&P of wheelchair users, must …

- Be able to study manual users
  - No power; light & robust instrumentation
    - manual chairs get tossed about more than power chairs
- Be able to study partial ambulators
  - Subject becomes carrying structure
  - Added burden of multiple mobility devices

Design criteria

- Subject burden
- Researcher burden
- Accuracy & reliability
- Cost

Let's look at indoor location tracking

- GPS does not work
- Need to decide:
  - Do we want to know where people hang out in the home?
  - Do we want to track movements within the home?
  - Do we need room level or sub-room level?

Most popular technologies

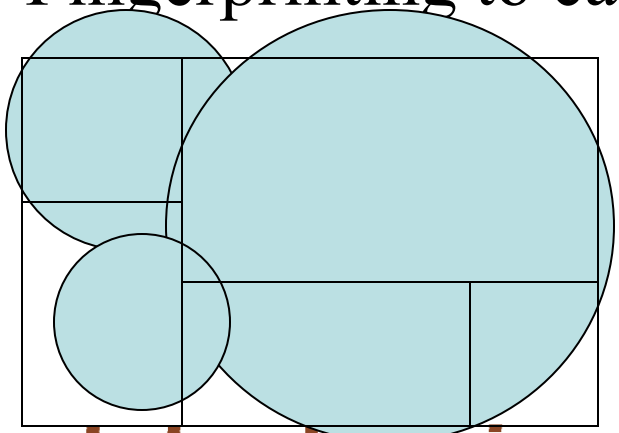
- RFID (radio frequency identification tags)
  - Tags are no problem; receivers are the problem
- Infrared
  - Have a noise problem and hates the sun
    - If other living beings can be considered ‘noise’
- Ultrasonic
  - Same noise problem
- GSM (Global Systems for Mobile Communication)
- Wi-Fi
- Bluetooth

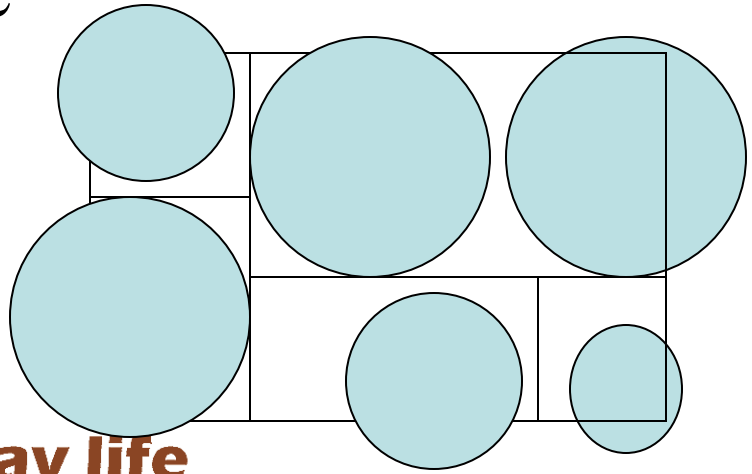
GSM and WiFi

- Similar approaches
  - GSM data: cell ID and signal strength
  - WiFi data: hub ID and signal strength
- Fingerprinting: training phase
  - walk around and collect signals at known locations
- Subjects wear receivers (phone/PDA)
- Probability algorithm used to determine location
- Accuracy <5m
- Fingerprinting can be non-trivial

Bluetooth Beacons

- Small bluetooth transmitter positioned throughout home
- Subject carries BT-enabled device (i.e., PDA)
- Two approaches:
  - Configure beacon for short range (1/room)
  - Configure beacons to overlap (3-4/house)
- Fingerprinting to calibrate





Subject and Researcher Burden

- Subject/wheelchair carries ‘data logger’
  - Small form factor will necessitate re-charging
- Deployment
  - GSM uses existing infrastructure
  - WiFi and BT plug into wall
  - Fingerprinting can be laborious
  - All require access to subjects’ homes for a few hours

Accuracy and cost

- Room level accuracy available
  - Sub-room possible
- Fingerprinting rigor improves accuracy
- Real time tracking of movement will be difficult
- Cost/instrumentation
  - GSM: phone and service; <$500
  - BT and WiFi: $1000-$1500

Summary

- Indoor location tracking is available
- Many different applications driving the innovation
- Decisions based upon research questions and the other factors discussed
- Great place to start: placelab.org

Potential Applications of MAP

- To define activity & participation categories more rigorously
- To examine mobility patterns and activities among people who use mobility aids.
- Where "performance" or real-world environment can help assess clinical need or functional outcome of an intervention.