

Issues Related to Measuring the Environment

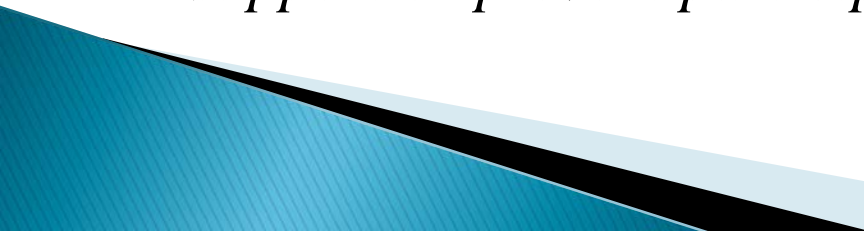
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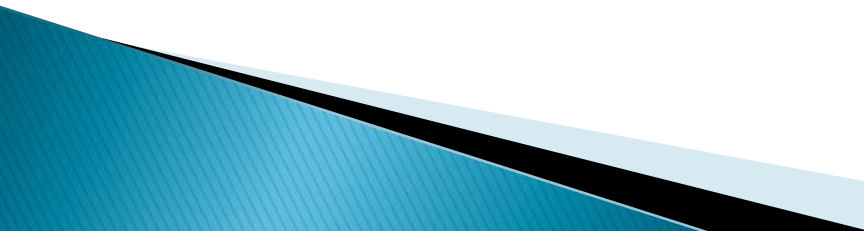
Measuring the Environment: Purpose

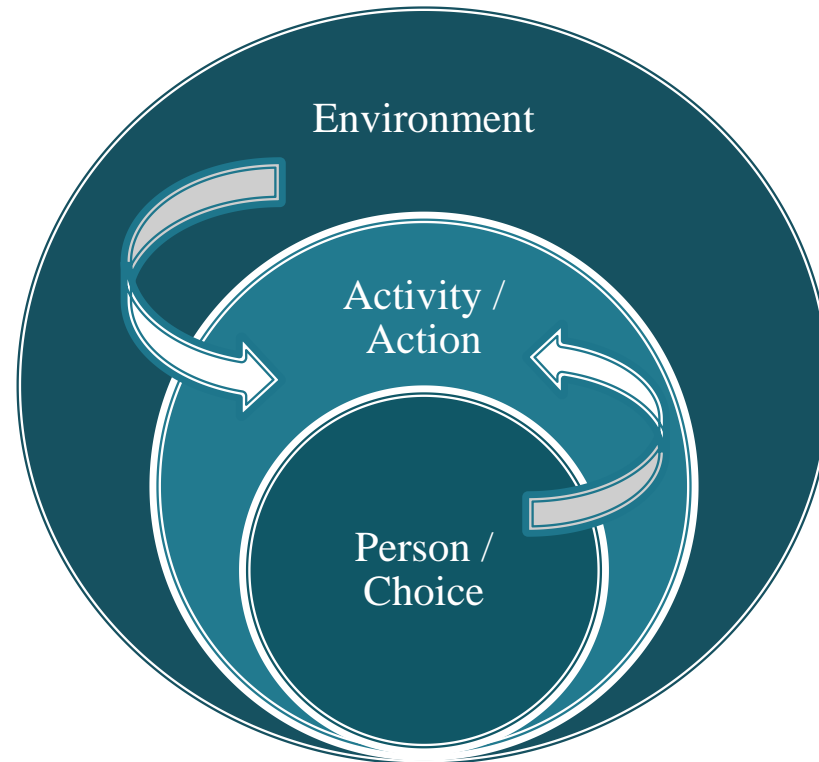
- ▶ The measurement of disability requires:
 - Person
 - Environment
- ▶ Person: identify *those at risk of participation limitations*
 - Measure the person's capacity using the SS-F & ES-F.
- ▶ Environment: identify the *contextual factors in which participation occurs*
 - Both the supports and barriers are necessary.

Measuring the Environment: Purpose

- ▶ A major objective is to understand the lived experience of persons with limitations and to facilitate their inclusion in society in the way that they would choose for themselves.
 - ▶ The impact of environment on that experience has not been adequately explored because we lack measures of the environment. We have missed an important part of the disability equation by not accounting for environmental barriers and supports in our data.
 - ▶ Therefore the original purpose of discussion of environmental measurement was to identify a way to *include related environmental facilitators and barriers that most prominently support or prevent participation.*
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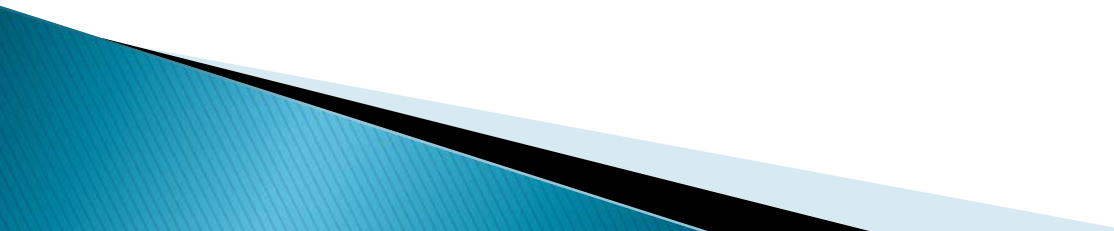
Framing the Issue: Three Interacting Elements

- ▶ **Person** – Only a person can enact a specific activity.
 - ▶ **Action or Activity** – Participation involves many different activities in a variety of domains. The individual chooses to act or not and also which activities are most important for them.
 - ▶ **Context** – The immediate environment where activity takes place and the other people involved can contribute to or inhibit the actor's participation.
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Type of Risk (limitations) +/- Environmental factors (barriers/supports) contributes to Outcomes of Activity

Two Approaches: Option 1

- ▶ *Directly* capture information about the environment in which participation occurs.
 - ▶ Measure the environment *independently* of the person.
 - ▶ Obtain information about the *general* environment on *common or universal* characteristics.
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Major Challenges to Option 1

- ▶ Which environment?

Legal, cultural, built, natural, technical, attitudinal

- Cultures vary on way things are done and who can do them
- Natural environments differ influencing the structure of built environments

- ▶ Which location in an environment?

Home, work, school, community, social group


- Different activities take place in very different environments

- ▶ Other factors influencing impact of environment include person's age, gender, ethnicity, income

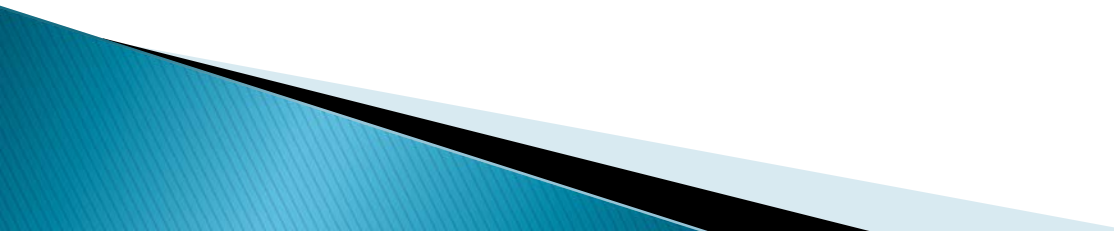
Can We Separate Environment from Participation?

- ▶ There is no *one, standard* environment.
- ▶ It is almost impossible to separate the *environment* from the individual's *participation* in fulfilling social, family and work activities.

Two Approaches: Option 2

- ▶ *Indirectly* capture information about the environment in which participation occurs.
 - ▶ Consider the particular domains of participation in which activities occur.
 - ▶ Measure the environment through the person's participation in these activities.
 - ▶ Obtain information about *activity-specific* environmental supports and barriers.
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How Do We Measure Participation?

- ▶ Participation encompasses numerous types of actions, all of which vary by socio-demographic characteristics.
 - What are the most common, universal types of participation?
 - What activities occur, or are necessary, to full participation?
 - Can we choose activities that are performed in commonplace ways or contexts?
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Organizing Participation

Domain
1

A_1

A_2

A_3

A_4

Domain
2

A_1

A_2

A_3

A_4

Domain
3

A_1

A_2

A_3

A_4

Domain
4

A_1

A_2

A_3

A_4

Domain
5

A_1

A_2

A_3

A_4

Participation Matrix

School

Getting to school

Using learning materials

Class or after school activities

Successful completion of school

Work

Getting to work

Applying for work

Using equipment at work

Attending work meetings or training

Family

Cooking or meal preparation

Shopping for food or HH items

Child care

Household tasks

Civic

Attending civic meetings or gatherings

Voting or political activities

Attending religious activities

Charitable activities or volunteering

Social

Meeting/interacting with friends or neighbors

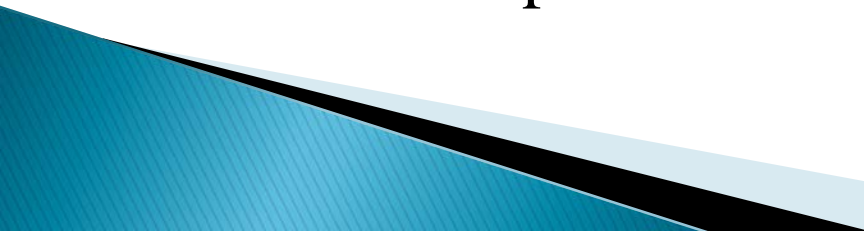
Attending sports events, movies or concerts

Visiting museums, libraries or parks

Travel or going to restaurants

Major Challenges to Option 2

Distinguishing based on “choice”

- ▶ An equally difficult separation that needs to be made is whether a person *chooses to* or *chooses not to* perform a specific activity in the available environment.
 - ▶ What is the difference between choosing *not to do* an action or being *unable to do* the action (environmental barrier)?
 - ▶ How is such a differentiation in participation knowable?
 - ▶ How do we capture *exogenous* choice – the individual’s choice independent of the environment?
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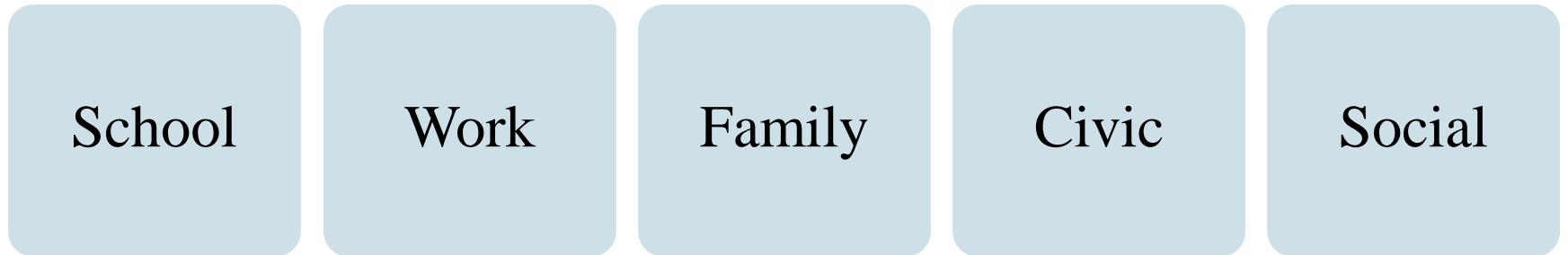
Additional Factors Associated with Choice

- ▶ Within cultural context – the freedom or restriction of choices for specific individuals.
 - Does person “qualify” to perform the action in the cultural context?
- ▶ Within specific legitimate roles – the range of acceptable behavioral choices.
 - Differences in flexibility of family type of activities compared to more formal activities in a business setting.
- ▶ Other factors contribute or restrict choice as well.
 - Age
 - Gender

Levels of Flexibility For Different Forms of Participation

- ▶ Some participation / activities are more structured than others or seen as more central than others.
 - Self-care – expectation that one will wash and dress daily
 - Family roles such as childcare – expectation that children will be fed, clothed, supervised
 - School for children, work for adults – expectation that these are necessary daily activities
 - Social activities – are more varied and flexible; take place in less formal situations than school or work

Continuum of Choice & Context



More
Constrained

Less
Constrained

How Do We Go About Measuring the Impact of Environment?

Writing Questions Discussion



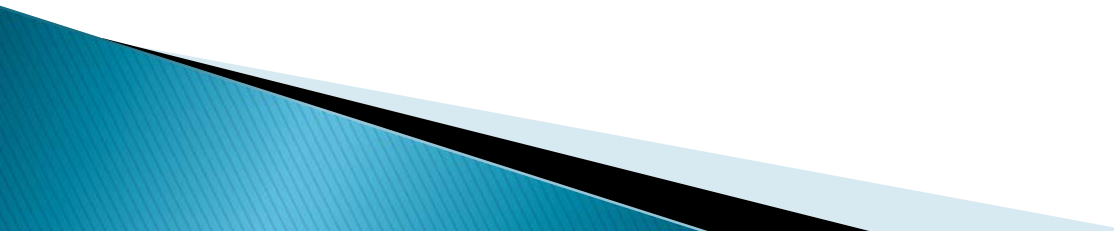
Multiple Elements Requiring Measurement

- ▶ Identification of Activity
 - Shopping
- ▶ Person's choice/preference related to Activity
 - Interest in shopping or choice
- ▶ Activity/Environment interaction – how does the specific environment impact the activity
 - Nature of type of shopping or place
- ▶ Person/Environment interaction – how does the person function in the specific environment
 - Does the environment create barriers or support participation

What Participation Domains do We Want to Measure?

- ▶ Family
 - Family holidays, celebrations
 - Household chores
 - Shopping
 - Childcare
- ▶ Civic
 - Celebrations, festivities
 - Political activities
 - Public involvement, parks, museums, libraries
- ▶ Social
 - Visiting with friends (within and outside the home)
 - Going to dinner, movies
 - Attending concerts, sports events


What Participation Domains Do We Feel Translate Cross-culturally?

- ▶ How different are family roles?
 - Does size of families or religious context influence this?
 - Do family responsibilities differ?
 - ▶ How different are civic roles?
 - Do all cultures celebrate national holidays?
 - ▶ How different are social roles?
 - Does the nature of friendship differ?
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What Approach to Writing Questions?

- ▶ Is it done?
 - *Do you do (activity)?*
- ▶ The type of difficulty to do it?
 - *Do you have difficulty doing (activity)?*
- ▶ Frequency of activity?
 - *Do you do (activity) regularly, sometimes, not often, never?*
- ▶ How has the onset of disability changed the participation in this activity?
 - *Do you do (activity) more, less or the same as prior to development of condition/impairment/limitation?*

What Needs to be Captured?

- ▶ Location of activity (or identifying nature of the action)
 - *Do you do (activity) in local establishments (larger or smaller or other variations of contexts)?*
 - ▶ Choice or volition
 - *Is the (activity) a chosen one?*
 - *Are you able to do (activity) as often as you would like?*
 - ▶ Barriers
 - *Are there factors that prevent or limit you in doing the (activity)?*
 - ▶ Facilitators
 - *Are there factors that support or make the (activity) easier to do?*
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Example of Question Detail Issues: Focus on Family Activities

- ▶ What do we want to know about the shopping activity?
 - Do you shop for household necessities such as food, clothing or household items?
(Regularly, Sometimes, Not often, Never, Someone else shops)
 - Do you usually shop for household necessities such as food?
(Yes / No)
- ▶ How to ask about choice?
 - Is this shopping frequency your preference/choice?
(Yes / No)
 - Would you like to shop more or less or the same amount as you do now?
(More, Less, the Same)

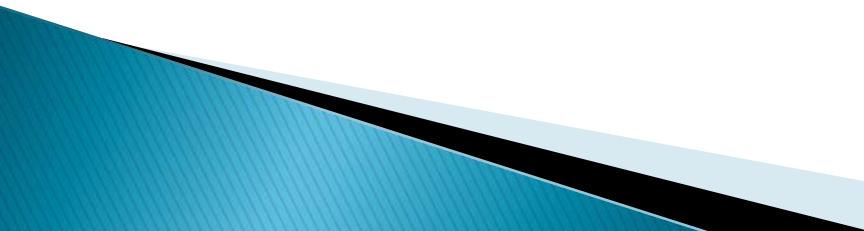
Identifying Specific Environment and Assessing Barriers

- ▶ Do we need to identify the location?
 - When you shop, do you use local markets, stores, shopping malls, (other)?
- ▶ How to identify barriers – listing or individually?
 - What characteristics of the places where you shop makes the activity difficult for you? (Transportation; Cost; Built environment of the stores; Crowded aisles; Negative attitudes of store staff, Other customers; Other?)
 - Does getting to the place where you shop make the activity difficult for you? (Yes / No)
 - Do crowded aisles in the place where you shop make the activity difficult for you? (Yes / No)
 - Do negative attitudes of the staff in the place where you shop make the activity difficult for you? (Yes / No)

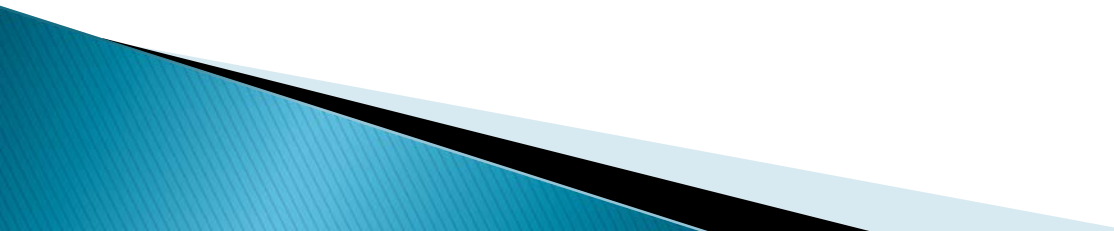
Assessing Facilitators

- How to identify facilitators – listing or other?
 - What characteristics of the places where you shop makes the activity easier for you?
 - Location; Special transportation; Positive attitudes of people who attend; Really need to test an open ended question to find out what people find helpful.
- What makes your shopping easier to accomplish?
 - Open ended question.

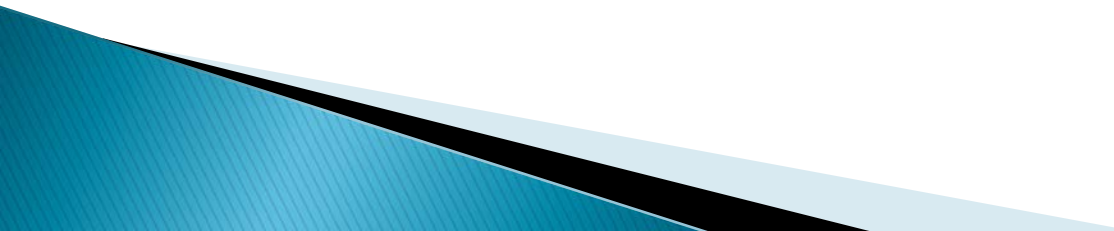
Summary of Necessary Decisions

- ▶ What specific activity domains among Family, Civic and Social are a priority?
 - ▶ Do we want to know how frequently an activity is done or just that it is done?
 - ▶ How do we want to account for choice?
 - ▶ Do we need to know about some specifics of the activity location?
 - ▶ How do we want to approach barriers?
 - ▶ How can we elicit facilitators?
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Other Examples: Family Activities

- ▶ Do you attend family activities such as holiday celebrations, birthdays, weddings or funerals?
 - ▶ Is this family activity frequency your preference/choice?
 - ▶ What characteristics of family celebrations make the activity difficult for you to participate?
 - ▶ What characteristics of family celebrations make the activity easier for you to participate?
- 

Other Examples: Social Activities

- ▶ Do you attend social activities with friends such as getting together, going to dinner, going to a movie or a sports event?
 - ▶ Is this level of frequency of social activity with friends your preference/choice?
 - ▶ What characteristics of social activities with friends make it difficult for you to participate?
 - ▶ What characteristics of social activities with friends make it easier for you to participate?
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Other Examples: Civic Activities

- ▶ Do you attend local festivals, celebrations or xxxx?
 - Regularly; Sometimes; Not often; Never
- ▶ Is this level of festival/celebration attendance frequency your preference/choice?
 - Yes; No
- ▶ What aspects of local festivals/celebrations make it difficult for you to participate?
 - Transportation; Cost; Distances to travel; Negative attitudes of people who attend; Built environment where festivals are held;xxxx
- ▶ What aspects of local festivals/celebrations make it easier for you to participate?
 - Location; Special transportation; Positive attitudes of people who attend; Really need an open ended question to test what people find helpful