Measuring the Disability Continuum in a Policy Context

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Overview

- Use of data for policy purposes.

- Data critiques from policy perspective

- Data used in this analysis

- What are the questions the data can answer?

- What are the questions the data can not answer?

- Discussion

Survey Data Use for Policy Purposes

- Disability data from surveys serves two primary purposes in addressing policy issues:
  - Prevalence
  - Outcomes
- There are many policy questions that need to be examined, but only a handful of sources of national survey data.
- Policy issues can be found at multiple levels of government as well as private organizations. The only data that can satisfy data needs at all geographic levels are the Census or the American Community Survey.

Policy Proponents' Critiques that Fault Disability Data

- Variety of prevalence estimates
- Unnecessary duplication of disability questions
- Questions about reliability and validity
- Concerns about adherence to the ADA definition

Joint Canada/United States Survey on Health (JCUSH)

- Cooperative project between Statistics Canada and National Center for Health Statistics

- Data collected by telephone interview in 2003 by Statistics Canada

- 8688 respondents: 3505 Canadians, 5183 Americans – non-institutionalized adults, aged 18 or over.

  ❑ Only U.S. data used for this analysis

- 4 different sets of disability questions

Joint Survey Methodology

- All respondents were asked all the disability questions.

- Ordering of placement of the four question sets was randomized.

- Questions reflected various concepts associated with disability, different wording, and answer categories, some which could be coded in a variety of ways.
  - Liberally – defining disability more broadly;
  - Conservatively – focusing on a more severe level of difficulty

Conceptual Representation and Nature of Answer Categories – Four Sets of Questions

- **Only one coding option possible**
  - ❑ Health utility index *(HUI) – represents basic functioning activities
  - ❑ Activity & Participation Screener† – represents complex activity limitations
- **Liberal or Conservative coding options possible**
  - ❑ Restricted Activity Screener* – represents both basic functioning activities and complex activity limitations
  - ❑ Physical Functioning Limitations† – represents basic functioning activities

* Source Canadian Community Health Survey   **† Source: National Health Interview Survey**

Two Types of Survey Questions: Basic Action Difficulty and Complex Activity Limitations

- Questions that ask about difficulties with physical, cognitive and emotional functioning can be considered to represent basic actions or building blocks which when combined allow a person to accomplish routine tasks.

- Questions that ask about various forms of participation are focused on more complex activities and make undefined assumptions about the nature of the environment in which the activities take place.

Question 1 - Prevalence:

Do the question sets have similar prevalence levels of disability?

Disability Prevalence*

- **Restricted Activities Screener**
  - U.S.　　　36.4%(L)　15.2% (C)
- **Health Utility Index**
  - U.S.:　　　19.7%
- **Activity & Participation Screener**
  - U.S.:　　　22.2%
- **Physical Functioning Limitations**
  - U.S.:　　　36.2%(L)　24.0% (C)

*Age standardized estimates

Overall Prevalence

- **Taking all measures together:**
  - Using LIBERAL cutting points:
    - U.S. - 51.4%; 103.8 million
  - Using CONSERVATIVE cutting points:
    - U.S. - 37.6%; 75.9 million

Concordance/Discordance

- Concordance refers to the consistency of answers across the various question sets. A respondent could indicate disability on 1,2, 3 or all 4 sets of questions.

- Discordance refers to the inconsistency in responses to various question sets. A respondent could indicate that they experienced functional limitations of some kind, but did not experience limitations in specific activities or forms of participation.

Question 2 – Prevalence of What:

Do question sets you use to capture the population with disabilities identify the same population?

Concordance Among Conservative Measures in the United States

- United States: 37.6% Prevalence on at least one measure –
  - One measure only – 45.28%
  - 2-3 measures - 37.25%
  - All 4 measures - 17.46%

Characteristics Differ Between Positive Respondents to a Single Question Set and to all 4 Question Sets

- Respondents to a single question set are younger, have higher education, and are less likely to be poor than respondents who answer all four sets positively. Women are more likely to respond positively to all four question sets
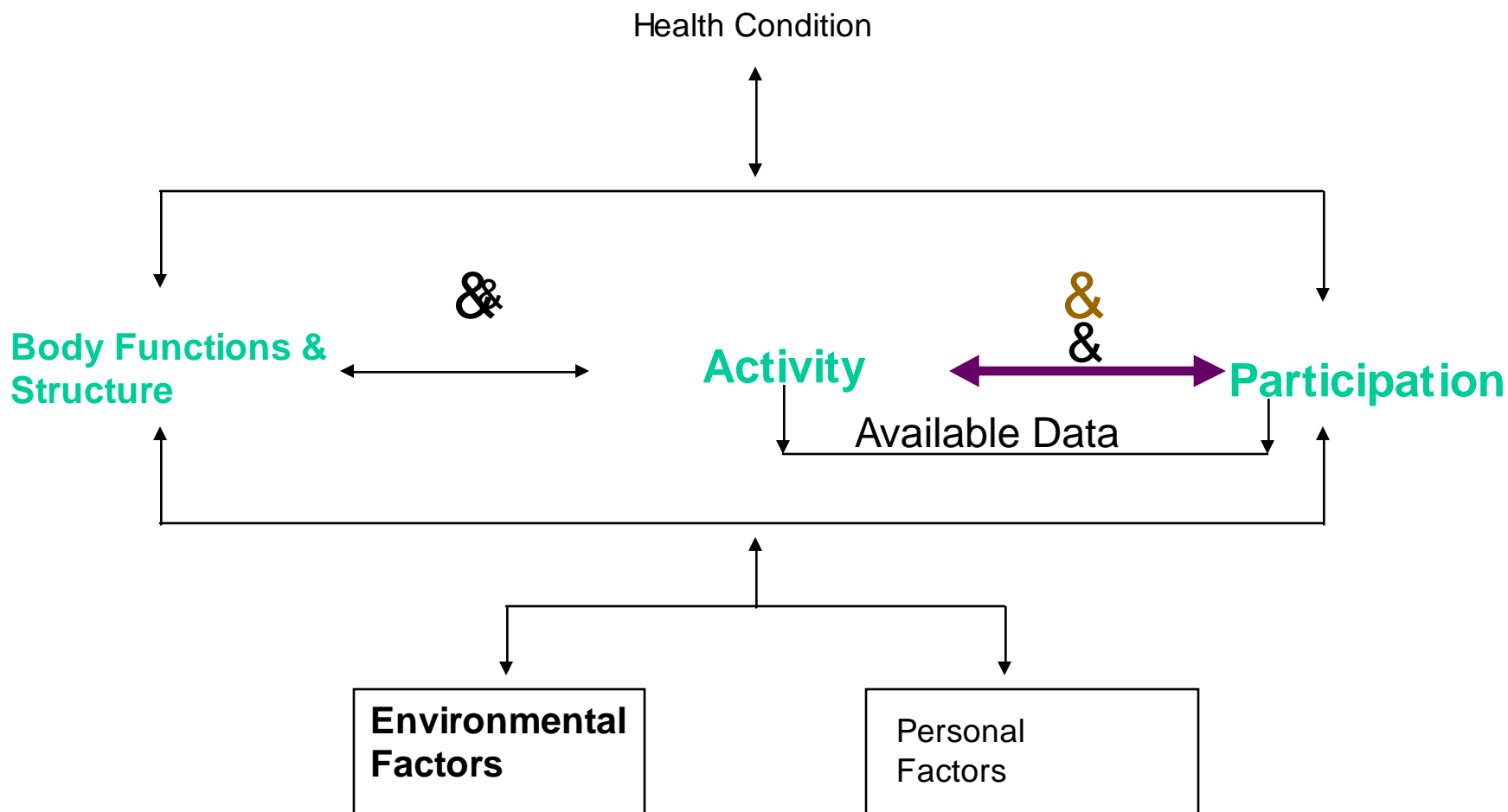
Question 3 - Outcomes :

How does policy usage of measures differ from prevalence estimates?
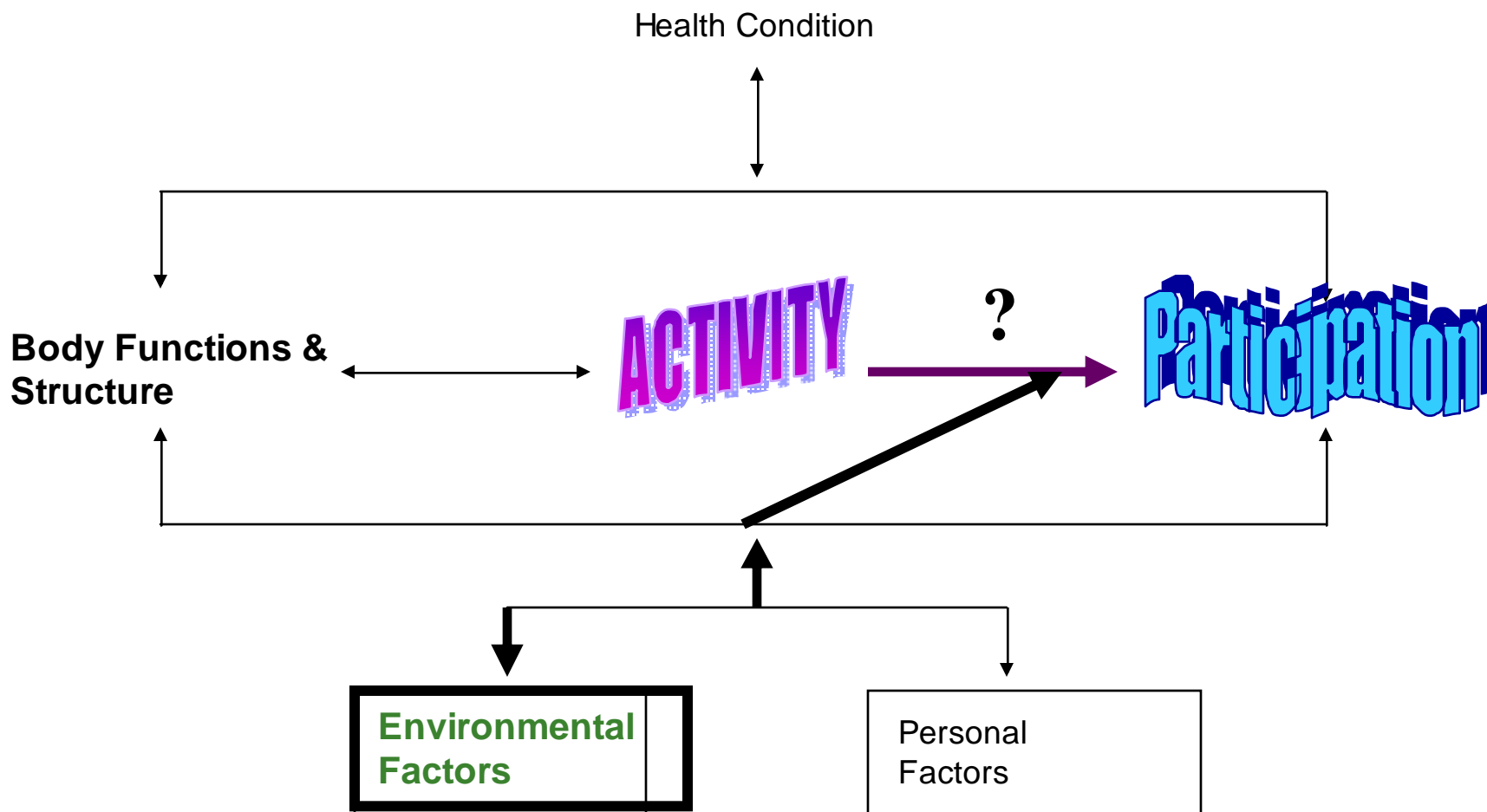
Prevalence and Policy

- Prevalence reflects the count of persons reporting a positive response to a group of questions.
  - Identifies the possible numbers who may need policy relief
- Policy seeks to develop programs to address problems – in this case those associated with disability.
  - Prevalence may or may not be an estimate necessary to satisfy information needed for policy analysis.
  - Policy questions usually require information about outcomes or about disparities between groups.
  - ADA as an example – seeks access and equalization of opportunity

Locating ADA Definition of Disability in the ICF Model and in Survey Data

Health Condition

Body Functions & Structure   &&   **Activity**   &
                                                            &   **Participation**

Available Data

Environmental Factors   Personal Factors

Source: ICF, WHO, 2001

Locating Policy Purpose of the ADA in the ICF Model and Analysis

Health Condition

Body Functions & Structure

ACTIVITY

?

Participation

Environmental Factors

Personal Factors

Source: ICF, WHO, 2001

Policy Analysis Reflecting Data and Analysis Issues: US Data from JCUSH

Basic Actions Difficulties	Complex Activity Limitations – No	Complex Activity Limitations - Yes
Neither	92.9%	7.1% A 25.5%
Physical Limits Only	57.1% B B B B B	42.9% C C 21.6%
HUI Limits Only	72.0%	28% 9.3%
Both	21.8%	78.2% 43.5%

A = Measurement problem B= Definitional problem contributing to analysis problem   C= Only respondents to fulfill ADA definition

There are Data Issues

- We don't measure all the pieces that theory indicate go into the disablement process.
  - Environment a very important missing piece
- Limitations in space prevents the inclusion of all different domains of basic functioning.
  - We miss components of basic functioning that result in complex activity limitation
- Lack of uniformity of questions create the variation in prevalence rates, but restricting questions reduce the variety of policy questions that can be addressed.

There are Also Policy Conceptual Issues

- **Confusion of the legislative intent of the ADA with the definition of disability.**

- **Creators of policy and researchers alike fail to recognize the heterogeneity of the population that the variety of policies address.**
  - Policy around long term care focuses on a measure of dependence (ADLs and IADLs)
  - At issue also is the difference between the definition of disability and the programmatic eligibility criteria

- **Disability continues to be conceptualized as a single entity with a "true" prevalence – which it is not.**