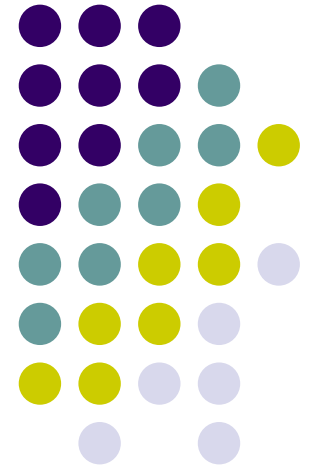
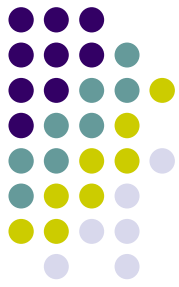


# Internationally Comparable General Disability Measures

Jennifer H. Madans  
National Center for Health Statistics  
U.S.A.



# International Activity Related to Disability Measurement: The Washington Group

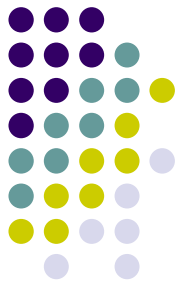


- City Groups operate under the aegis of the United Nations Statistical Commission
- They are informal groups of experts primarily from national statistical authorities who meet to address important problems in statistical methods
- Groups are named according to the location of the first meeting, thus, we are called the Washington Group



# Washington Group: Purpose

Our main purpose is the promotion and co-ordination of international co-operation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys which will provide basic necessary information on disability throughout the world.



# Washington Group: Objectives

- Develop a small set/s of general disability measures
- Recommend extended set/s of items to measure disability as components of population surveys / supplements
- Address methodological issues associated with disability measurement

# To meet these objectives, it is first necessary to:



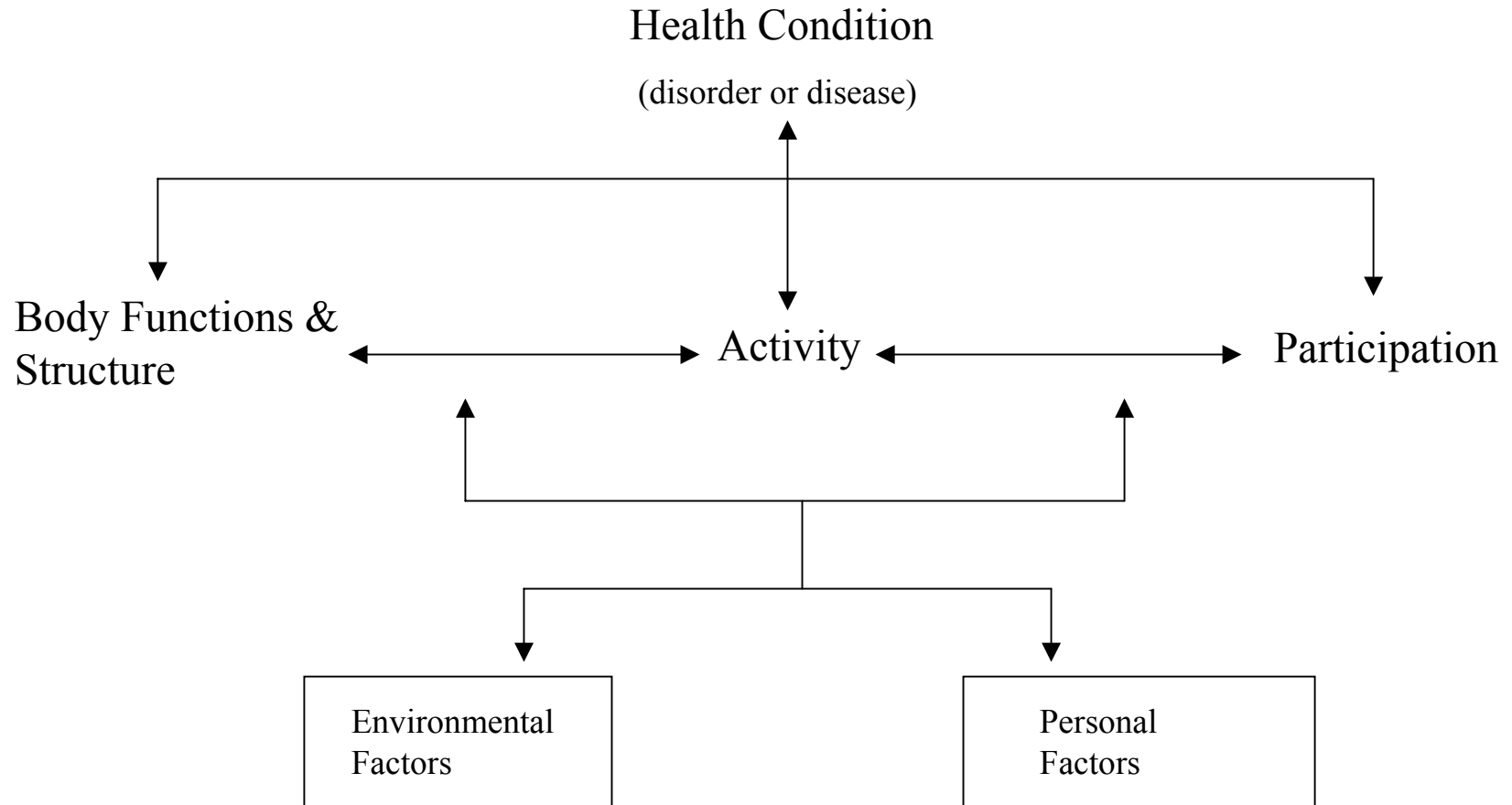
- Put some order into the discussion of disability measurement
- Clarify the purpose of data collection in order to identify appropriate measures
- Understand choices being made when time, expenses and respondent burden limit number of questions



# Summary of work to date

- **1<sup>st</sup> meeting (Washington, DC, Feb 2002):** Agreed to develop short and long sets of internationally comparable disability measures using ICF model as framework. Census questions priority.
- **2<sup>nd</sup> meeting (Ottawa, Canada, Jan 2003):** Established link between purpose and aspects of measurement via matrix.
- **3<sup>rd</sup> meeting (Brussels, Belgium, Feb 2004):** Equalization of opportunities selected as purpose of general measure.
- **4<sup>th</sup> meeting (Bangkok, Thailand, Sept 2004):** Draft of general measure agreed upon conceptually. Workgroup formed to develop implementation protocols.

# Source of Concepts for Measurement: ICF Model



Source: ICIDH-2, 1999

June 7-8, 2005 / Lima, Peru

# Moving from concept to measurement



- ICF as the conceptual model
  - Common point of reference
  - Common vocabulary
  - Does not provide measurement questions or a way to measure the concepts



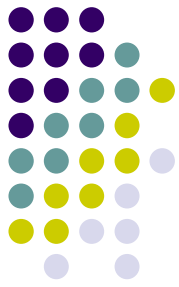
# Selection of purpose/s

## 3 major classes of purposes at aggregate level

- Service Provision
- Monitoring functioning in the population
- Assess equalization of opportunities

## 2 criteria for selection of a purpose

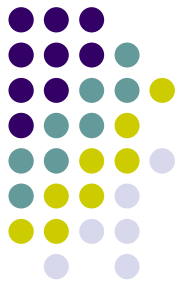
- Relevance
- Feasibility



# Purpose: Service provision

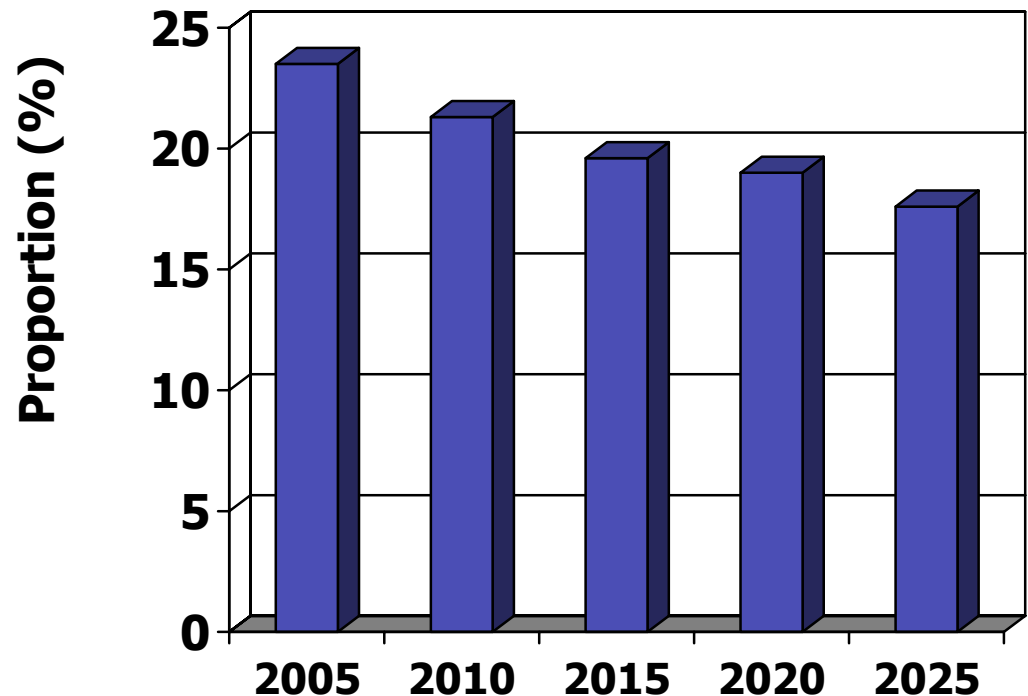
- Seeks to identify those with specific needs, usually the most serious problems
- Requires detailed information about the person and the environment
- Influenced by the organization and structure of service organizations within a particular culture

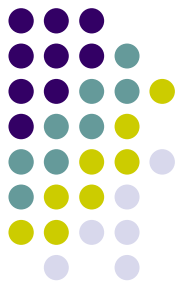
# Purpose: Monitoring functioning in the population



- **Seeks to identify all those with activity or participation limitation**
- **Response comparability problematic since participation is culturally and environmentally determined**

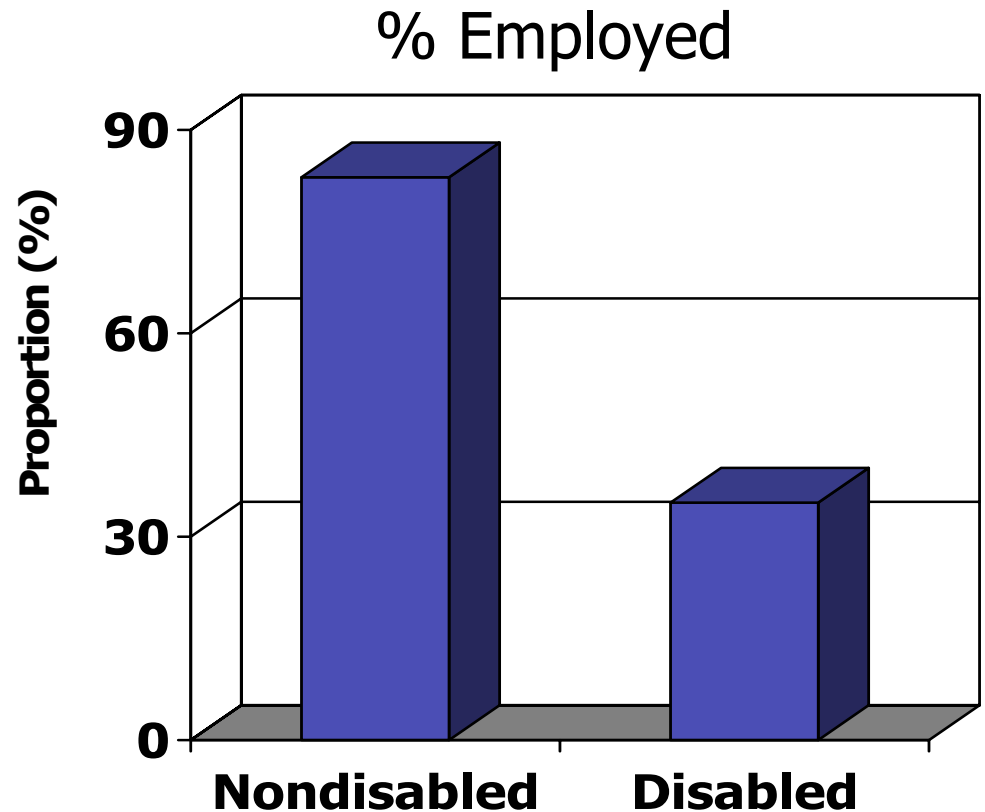
Population reporting work limitation



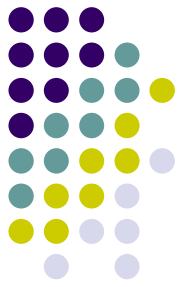


# Purpose: Equalization of opportunities

- Seeks to identify all those at greater risk than the general population for limitations in activity or participation
- Disability as a demographic

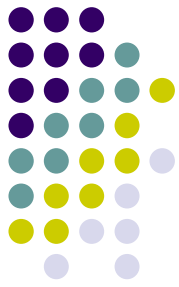


# Measurement of equalization of opportunities



- Locate the definition of disability at the most basic level of activity/participation
- This level is associated with the ability or inability to carry out basic bodily operations at the level of the whole person (i.e. walking, climbing stairs, lifting packages, seeing a friend across the room)

# Summary



Proposed approach to assessing equalization of opportunities allows:

- Development of a demographic means of understanding disability (can compare persons with and without disability)
- Connection between disability and participation can be made during data analysis
- Effectiveness of programs / policies to promote full participation can be monitored



# Possible types of questions

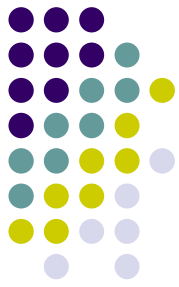
- Questions that measure various domains of functioning such as mobility, cognition, sensory functions, etc.
- A qualifier would need to ascertain that the action was accomplished without human or mechanical assistance



# Possible Question Choices

- Mobility
  - Walking
  - Climbing stairs
  - Bending or stooping
  - Reaching or lifting
  - Using hands
- Sensory
  - Seeing
  - Hearing
- Communicating
  - Understanding
  - Speaking
- Cognitive functions
  - Learning
  - Remembering
  - Making decisions
  - Concentrating
- Emotional functioning
  - Interpersonal interactions
  - Psychological well-being

# Draft questions for Censuses (general disability measure)



- 1) Do you have difficulty seeing even if wearing glasses?
- 2) Do you have difficulty hearing even if using a hearing aid?
- 3) Do you have difficulty walking or climbing stairs?
- 4) Do you have difficulty remembering or concentrating?
- 5) Do you have difficulty with (self-care such as) washing all over or dressing?
- 6) Because of a physical, mental, or emotional health condition, do you have difficulty communicating (for example understanding others or others understanding you)?
  - a) No - no difficulty
  - b) Yes - some difficulty
  - c) Yes - a lot of difficulty
  - d) Cannot do at all



# Implementation

- Questionnaire to be piloted in as many countries as possible (12+ countries have agreed to participate)
- Protocols in development:
  - Objectives and evaluation plan for field / cognitive testing
  - Cognitive test plan
  - Translation
  - Enumerator training
  - Sample design issues
  - Plan for tabulation, analysis and report writing

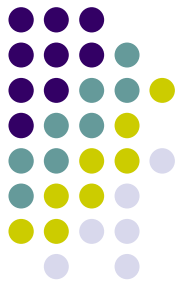


# Implementation: Objectives

## Objectives of test plan

To determine if:

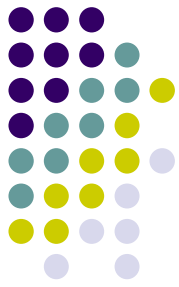
- 1) the questions are being interpreted as intended by the developers in that they are capturing the important aspects of the functional domains selected and
- 2) the questions are interpreted consistently across countries.



# Implementation: Evaluation

## Evaluation

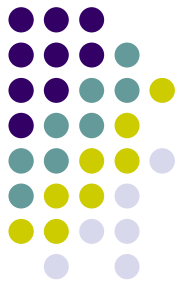
- 1) Validity:
  - a) **Content validity: How well WG question set compares with expanded disability measures**
  - b) **Criterion related validity: How well individual WG questions compare to relevant similar concept in a comparison measure**
  - c) **Face validity: Does the measure 'look to be valid'?**
- 2) Reliability: test/re-test



# Implementation: Cognitive test

## Cognitive test

- Objective: to determine if questions are being interpreted as intended and if interpretation is consistent across countries
  - **WG cognitive test more structured than usual**
  - **Ensures a greater level of standardization across test sites**
  - **Understand how the response mechanisms operate in the different countries**



# Implementation: Cognitive test

- Components of cognitive test
  - Interviewer report on problems respondent had with questions
  - Traditional cognitive probes
  - Questions derived from previous cognitive tests
  - Questions on specific aspects of functioning domains addressed by core questions



# Implementation: Field test

## Field test

- Conditions closely approximate how final study will be done
- See how WG core questions function in different countries
- Useful to compare WG set to a larger set of more detailed questions to determine whether the same population is identified by each set



# Meeting Products and Information

- Executive summary of meetings, presentations, and papers posted on the Washington Group website:
  - <http://www.cdc.gov/nchs/citygroup.htm>
- Publication of key papers in a special issue of *Research in Social Science and Disability* due this Fall