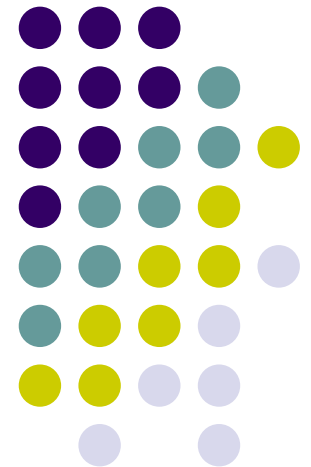
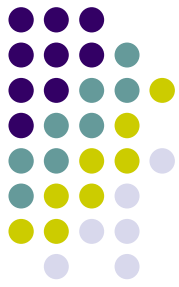


# Internationally Comparable General Disability Measures

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# International Activity Related to Disability Measurement: The Washington Group

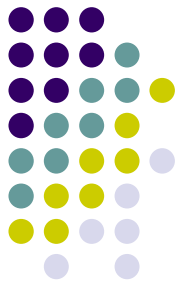


- City Groups operate under the aegis of the United Nations Statistical Division (UNSD).
- They are informal groups of experts primarily from national statistical authorities who meet to address important problems in statistical methods.
- Groups are named according to the location of the first meeting, 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

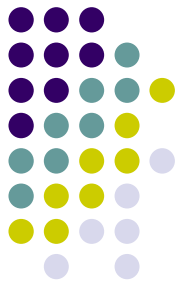
# To meet these objectives, it is first necessary to:



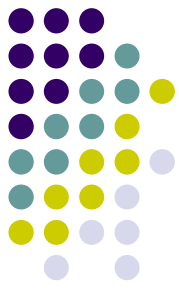
- Put some order into the discussion of disability measurement
- Clarify the purpose of data collection in order to identify appropriate measures
- Understand choices being made when time, expenses and respondent burden limit number of questions

# 1<sup>st</sup> meeting: Washington, DC 2002

## Areas of agreement



- It is important and possible to craft internationally comparable general disability measures
- Short and long set(s) of measures that are inter-related are needed
- ICF model will be used as a framework in developing disability measures
- Census questions are the first priority



## Limitations of the census format

- Limited space
- Indicated domains reflect types of questions that would identify largest population for this purpose and those most culturally comparable
- Allows some flexibility for additional culturally relevant questions for specific countries

## 2nd meeting: Ottawa, Canada 2003

### Linking purpose with measurement



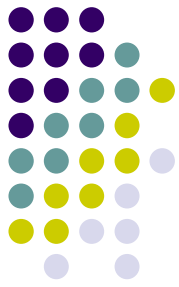
- Disability measurement matrix: Conceptual matrix linking the purpose of a general disability measure with conceptual definitions and question characteristics.
- Empirical matrix: An evaluation of the characteristics of general measures currently in use according to the dimensions of the matrix.
- The matrices helped us identify gaps in disability measurement.

# 3<sup>rd</sup> meeting: Brussels, Belgium 2004

## Purpose Dictates Question Type



- Disability is multidimensional
- We cannot know the single “true” disabled population
- Different purposes are related to different dimensions of disability or different conceptual components of the model
- Different purposes require different types of measures



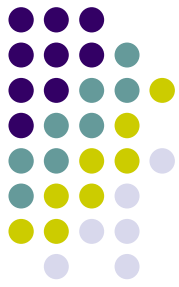
## Selection of purpose/s

### 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

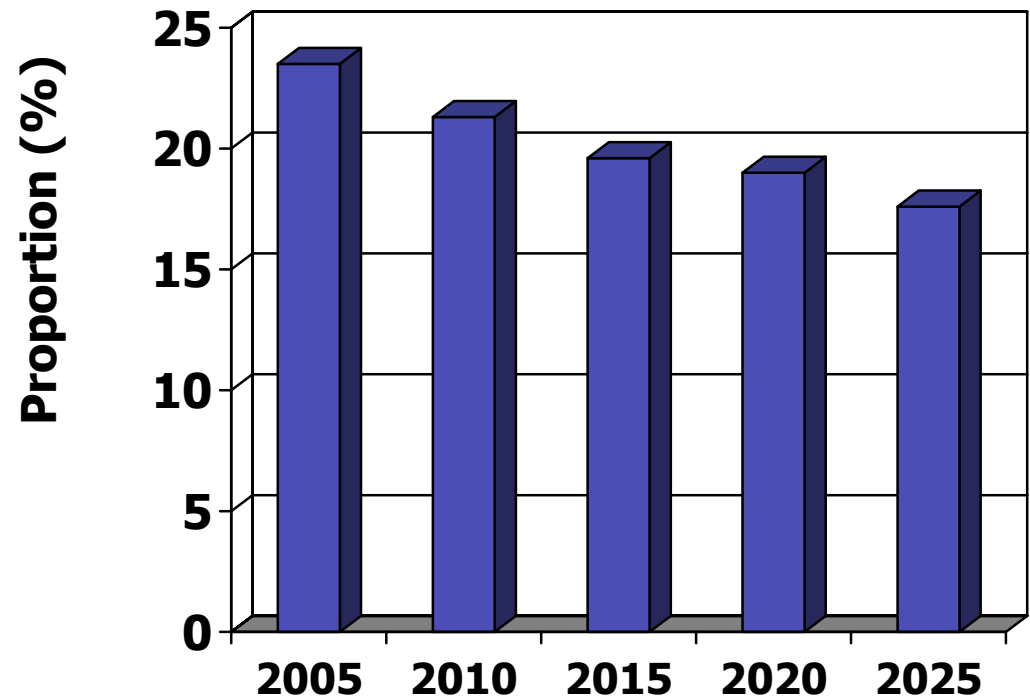
- Seeks to identify those with specific needs, usually the most serious problems
- Requires detailed information about the person and the environment
- Influenced by the organization and structure of service organizations within a particular culture

# Purpose: Monitoring functioning in the population



- Seeks to identify all those with activity or participation limitation

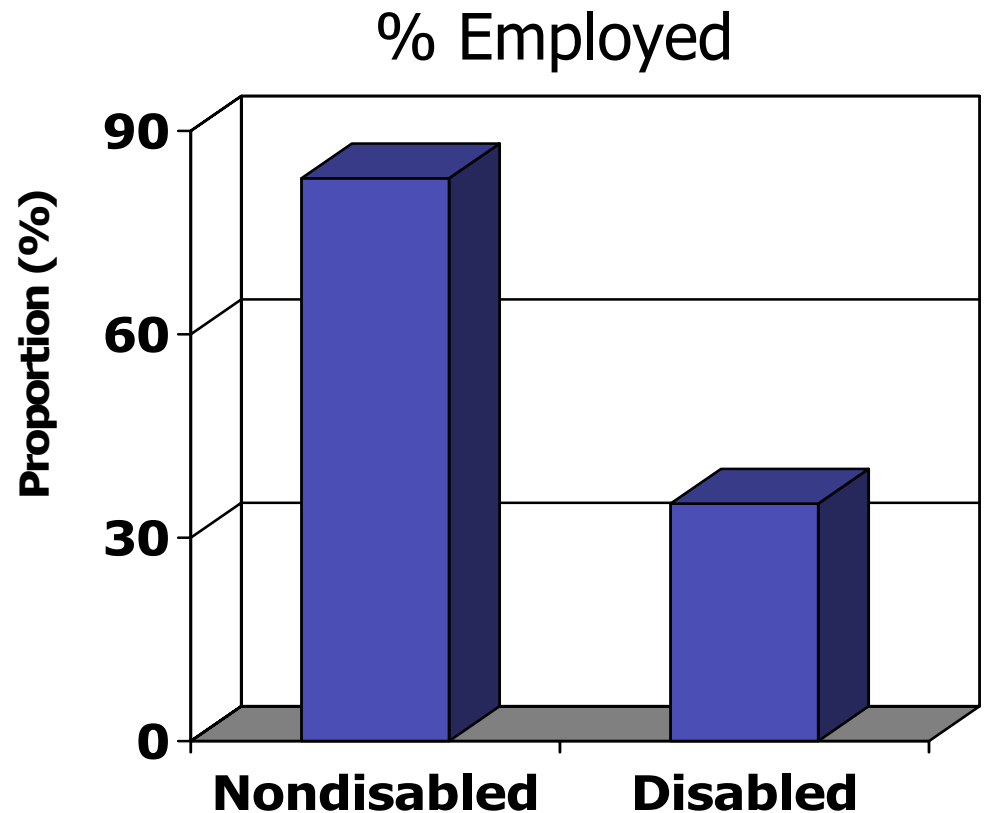
## Population reporting work limitation

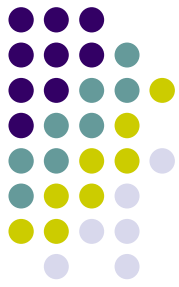




# Purpose: Equalization of opportunities

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

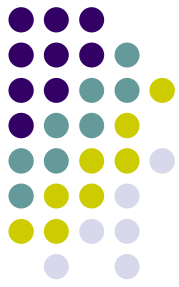




# Applying criteria to select purpose

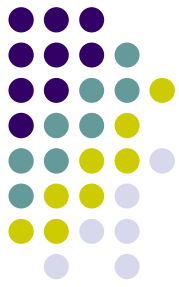
- Service provision:
  - Level of detail necessary not feasible in a census format
  - Nature of service provision varies across cultures
- Monitoring functioning:
  - Response comparability problematic since participation is culturally and environmentally determined
- Assessing equalization of opportunities:
  - If we conceive of disability toward the most basic elements of activity, without tying it to participation, we limit the number / types of questions thus enhancing feasibility

# Purpose chosen for an internationally comparable general disability measure



- Highest priority given to assessing equalization of opportunities
- Identifies a broad subpopulation which can be further examined
- Versatile
- Partially fulfills purpose of monitoring limitations in functioning
- Can be used as a demographic

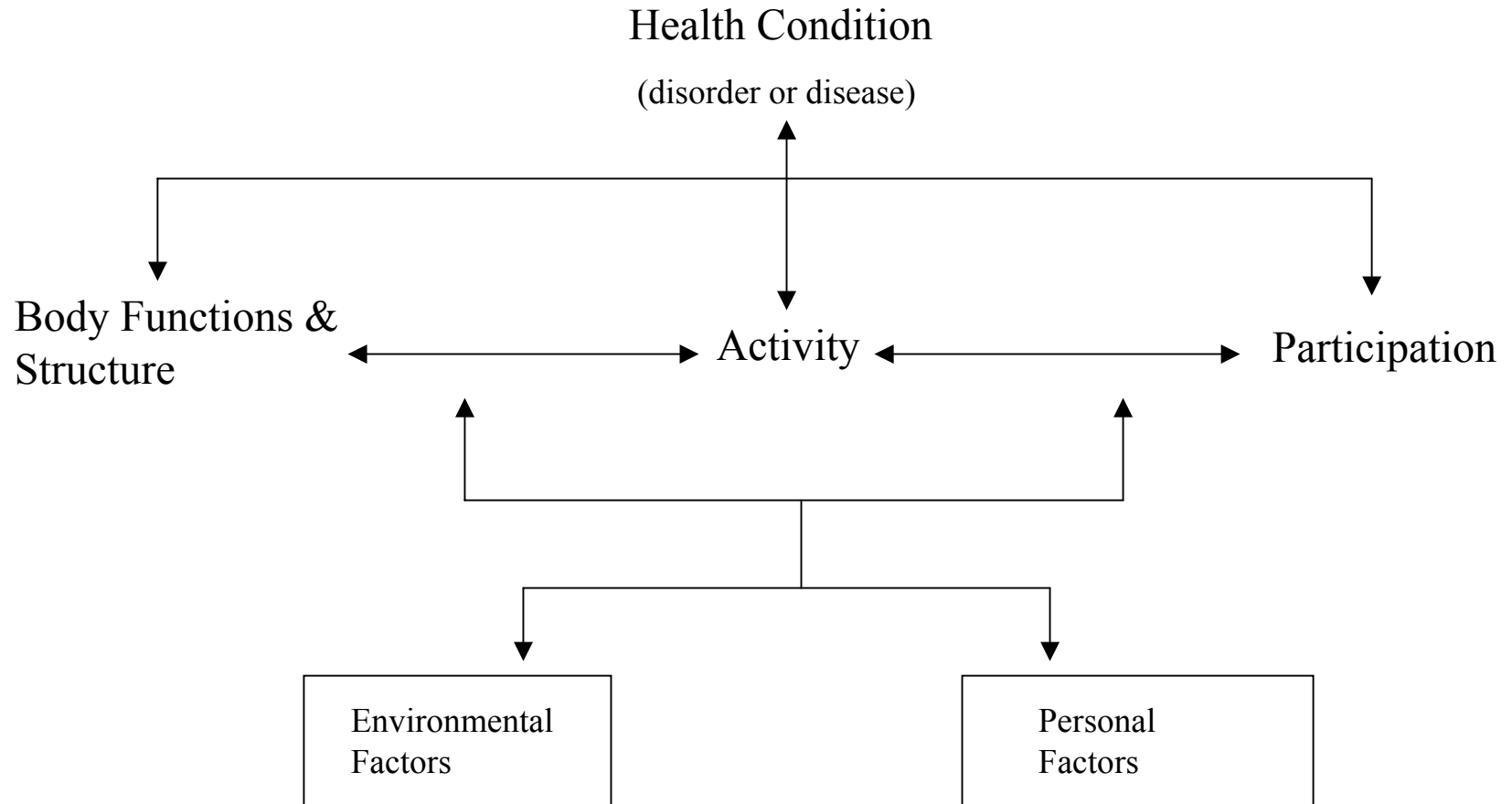
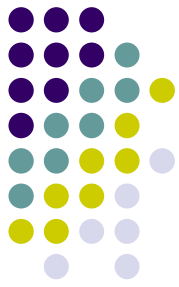
# Summary



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

# Source of Concepts for Measurement: ICF Model



Source: ICIDH-2, 1999

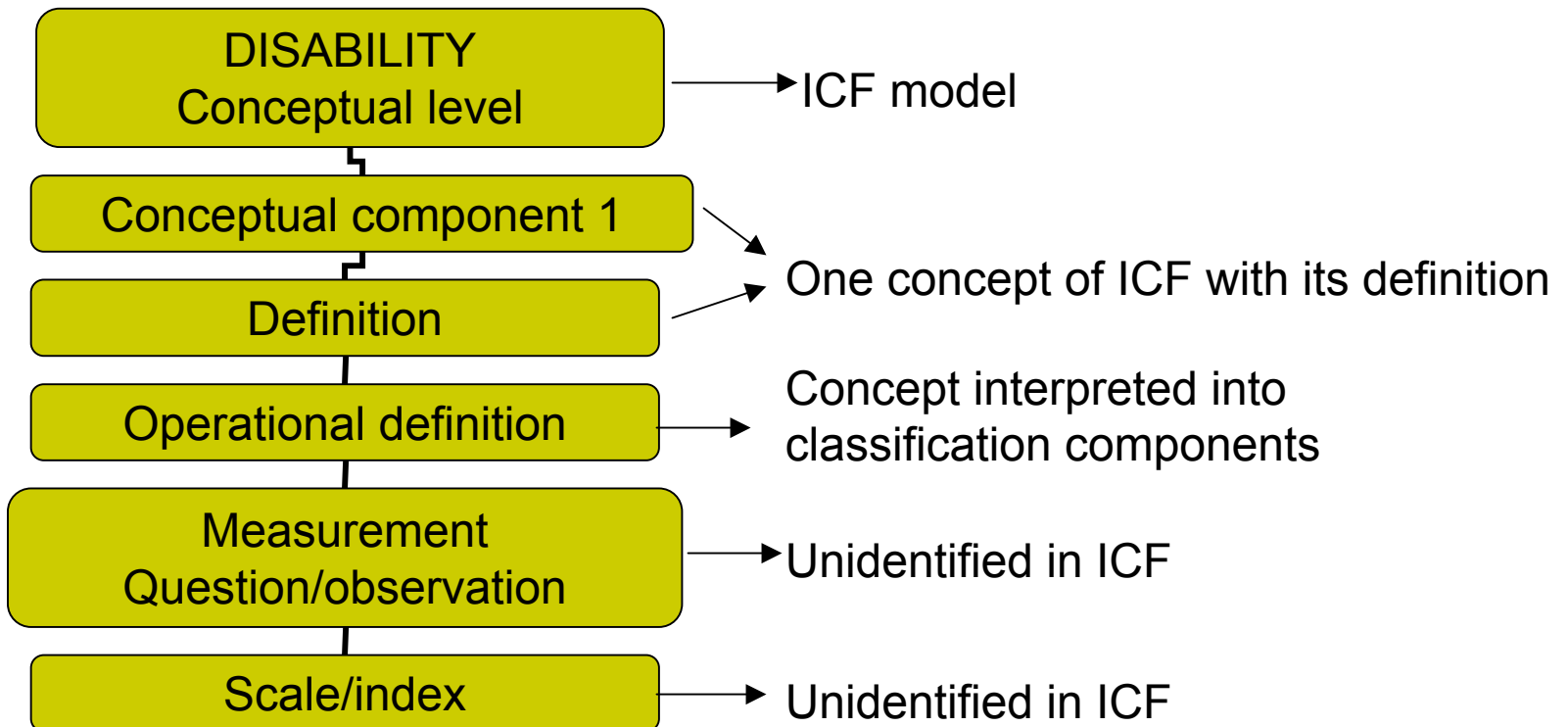
April 14, 2005 Jamaica



## 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
- We also need to provide a model and language for measurement

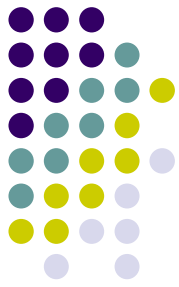
# Methodological components as defined by the ICF



# Measurement of equalization of opportunities

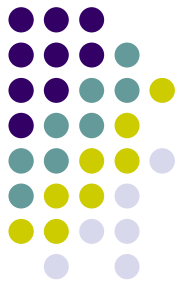


- Locate the definition of disability at the most basic level of activity/participation
- This level is associated with the ability or inability to carry out basic bodily operations at the level of the whole person (i.e. walking, climbing stairs, lifting packages, seeing a friend across the room)



## 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

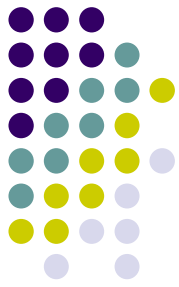


# Possible Domains of Question Choices

- 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

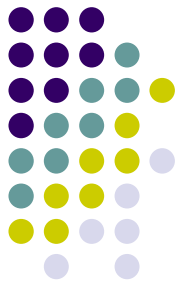
# 4<sup>th</sup> meeting: Bangkok, Thailand

## Census Questions, Pilot Testing Plan



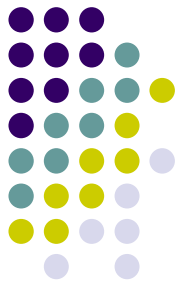
- Draft questions agreed upon conceptually, but wording revisions required prior to pilot testing
- New team formed to develop procedures to implement the general disability measure (short form)
- Decisions re: development of extended measurement set/s

# Draft questions for Censuses (general disability measure)



## Response categories: No, some, a lot, unable

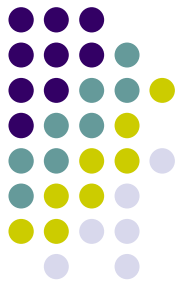
- 1) Do you have difficulty seeing even if wearing glasses or are you blind?
- 2) Do you have difficulty hearing even if using hearing aid/s or are you deaf?
- 3) Do you have difficulty walking or climbing stairs?
- 4) Do you have difficulty remembering or concentrating?
- 5) Do you have difficulty with (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 or being understood?



## Next Steps for the WG

- Develop testing protocol and pre-test recommended general questions by May
- Review results of methodological testing of general measures conducted in various countries
- Test one or two candidate general measures in several countries (particularly developing countries) and report results at the next meeting

## Next Steps for WG (continued): Development of extended measurement set/s



- Purpose: assessing equalization of opportunities
- Additional questions to be developed in the area of basic activities (related to current 6 domains and also covering additional domains)
- Module that will go into existing national surveys
- Paper to be developed examining aspects of participation (P) that are and are not covered in current surveys; how environmental factors (E) are to be included; and how the “at risk” population identified via the extended set links to P & E



## Implementation team

- Questionnaire to be piloted in as many countries as possible (11+ countries have agreed to participate)
- Protocols to be developed in 4 month timeframe:
  - Objectives and evaluation plan for pilot / cognitive testing
  - Plan for cognitive testing
  - Translation
  - Enumerator training
  - Sample design issues
  - Plan for report (including tabulation and analysis)
- New workgroup formed to develop protocols and workshops



## Meeting Products and More Information

- Executive summary of last three meetings posted on the Washington Group website along with presentations / papers from the meetings:
  - <http://www.cdc.gov/nchs/citygroup.htm>
  - <http://www.un.org/depts/unsd/citygrp>
- Long range plan will be available soon
- Publication of key papers in a special issue of *Research in Social Science and Disability* due this Fall

# Levels of Measurement to Capture Activity and Participation

