The disability process and WHO classification systems: past, present and future

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Overview

- → **Comparability problems with disability data**

- International Classification of Functioning (ICF)

- Conceptual issues

- Measurement approaches and issues

- Estimating the global prevalence of disability – a comparison of three approaches

- Conclusions

A Tower of Babel:
Disability Rates from Surveys Across the World

Source: DISTAT – UNSD 2003

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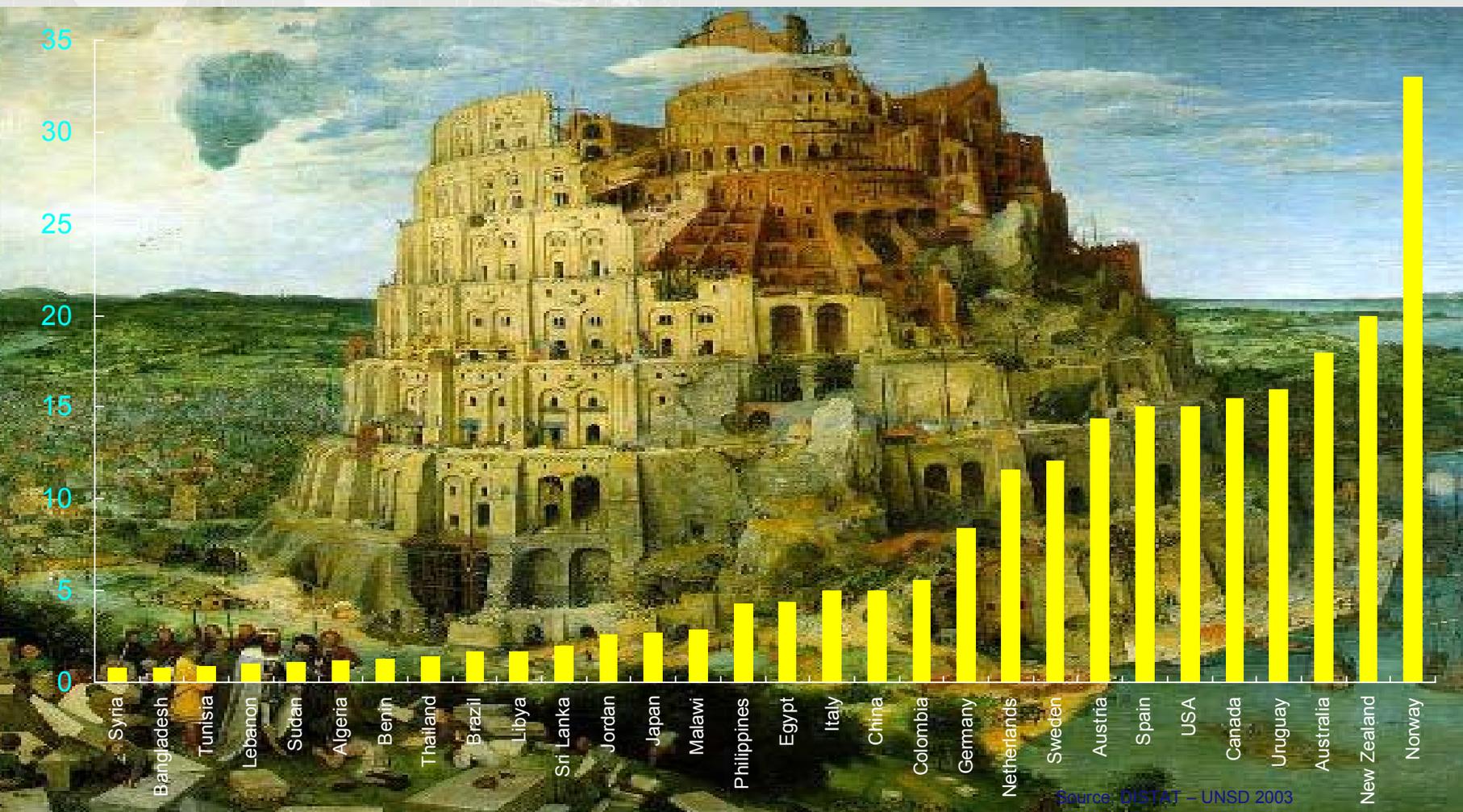
Disability census and survey questions

"Is there a person in the household who is totally blind, totally deaf, totally dumb and/or with a disability in one or more legs or arms?

Sri Lanka, Census 1981

"Any case of blindness, deafness and muteness, deafness (only), loss of arm, leg or both, deformity of right / left hand / foot and full paralysis is known as disability."

Iran, Census 1986

Does anyone in your household ever have any difficulty in doing day to day activities because of a physical, mental or emotional (or other health) condition?
Has this difficulty lasted, or is it expected to last 6 months or more?
If YES to 1.1 and 1.2, how would you describe your difficulty?
Does anyone in your household need assistance to do day to day activities?

Namibia & Zimbabwe National Disability Survey, 2003

"Do you need someone to help with, or be with them for, self care activities? For example: doing everyday activities such as eating, showering, dressing or toileting".

Australia, Census 2006

How questions shape numbers
Uganda 1991 & 2001 censuses
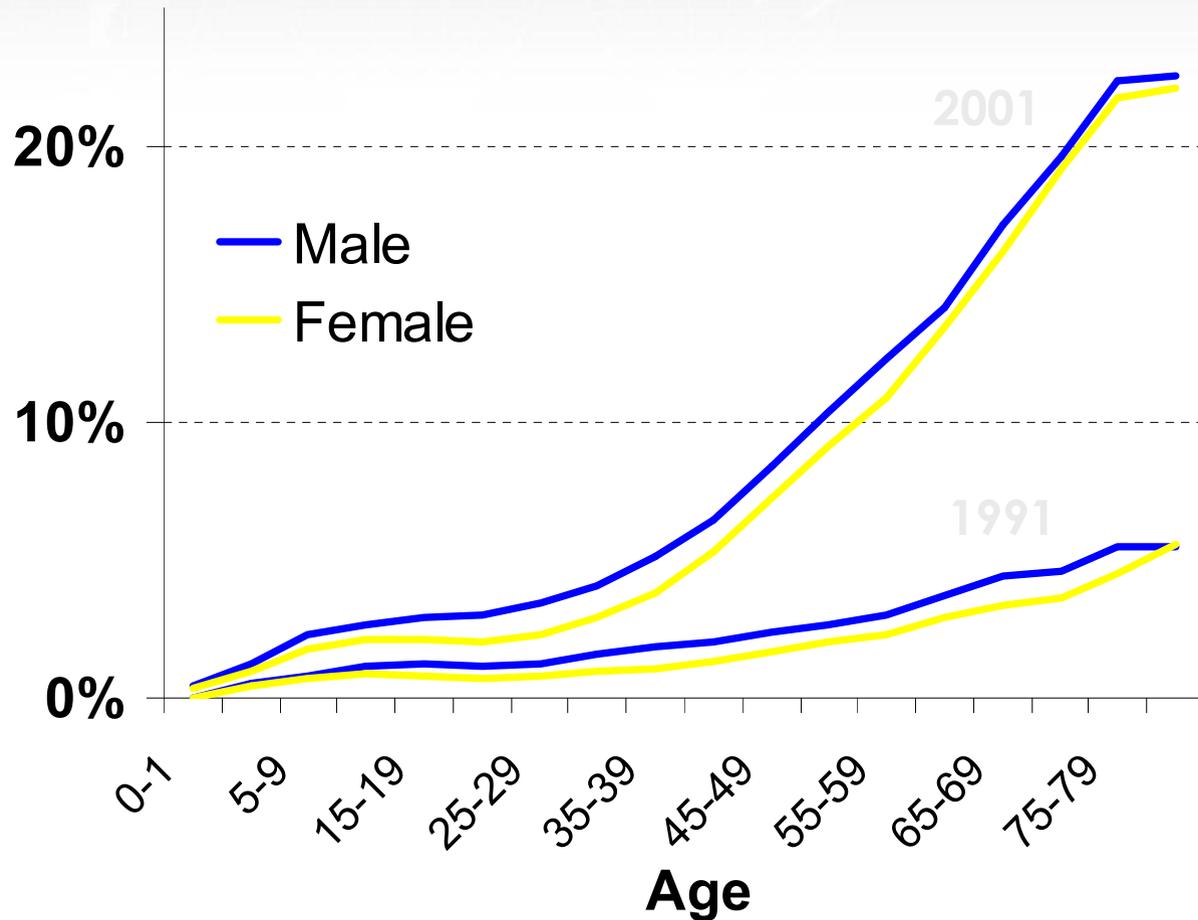
2001: Do you have any difficulty in moving, seeing, hearing, speaking or learning, that has lasted or is expected to last 6 months or more?

1991: Is anyone in the household disabled?

Male
Female

20%

10%

0%

2001

1991

0-1 5-9 15-19 25-29 35-39 45-49 55-59 65-69 75-79

Age

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International Classification of Functioning, Disability and Health (ICF) – WHO 2001

Body Functions & Structures

IMPAIRMENTS

- Pain
- Seeing
- Breathing
- Heart function

Intervention:
- Medication
- Eye glasses
- Surgery
- Functional stimulation devices

Activities & Participation

ACTIVITY LIMITATIONS PARTICIPATION RESTRICTION

- Walking
- Communication
- Washing
- Domestic responsibilities
- Work & Education
- Community life

Intervention:
- Prostheses
- Wheelchair
- Rehab
- Exercise

Environmental Factors

Barriers & Facilitators

- Buildings
- Work equipment
- Attitudes
- Support & Relationships

Intervention:
- Ramps
- Workplace modification
- Destigma. Campaign

From a traditional to an ICF based approach

Traditional approach

- Diagnosis & impairment based

- Categorical

- Focus on certain predefined groups

- Context exclusive

ICF approach

- Multidimensional

- Continuum

- Universal focus

- Context inclusive

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What is ICF classifying in A/P domains?

- **A**ctivity limitation versus **P**articipation restriction
- Performance ("does do") or capacity ("can do")

Capacity versus performance

- Performance measures difficulty in doing domain tasks in the current environment
- Capacity measures difficulty in doing domain tasks in a standardized environment
- eg. for seeing a standard environment might involve clear air and normal levels of good lighting
- Performance changes with changes in the environment, whereas capacity does not
- How far does a questionnaire need to go in defining normative environment?

Health and Disability Continuum

Single domain

Seeing Functions

10/20

Mild-Moderate vision impairment:
Needs eye glasses, contact lenses…

2/20

Severe vision impairment:
Needs operation
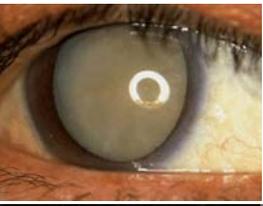
1/20

Complete vision impairment (blind):
Needs assistance –
pension, device, assistant
environmental modifications

Multiple domains

Cognition

Self Care   Social   Education   Social
                                activities

Overa

Mobility

Hearing

Vision
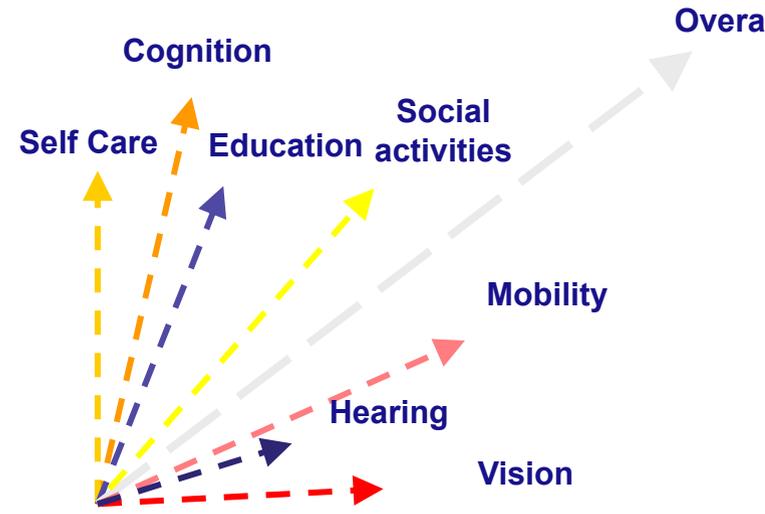
Challenge for the development of a health state/disability interview instrument
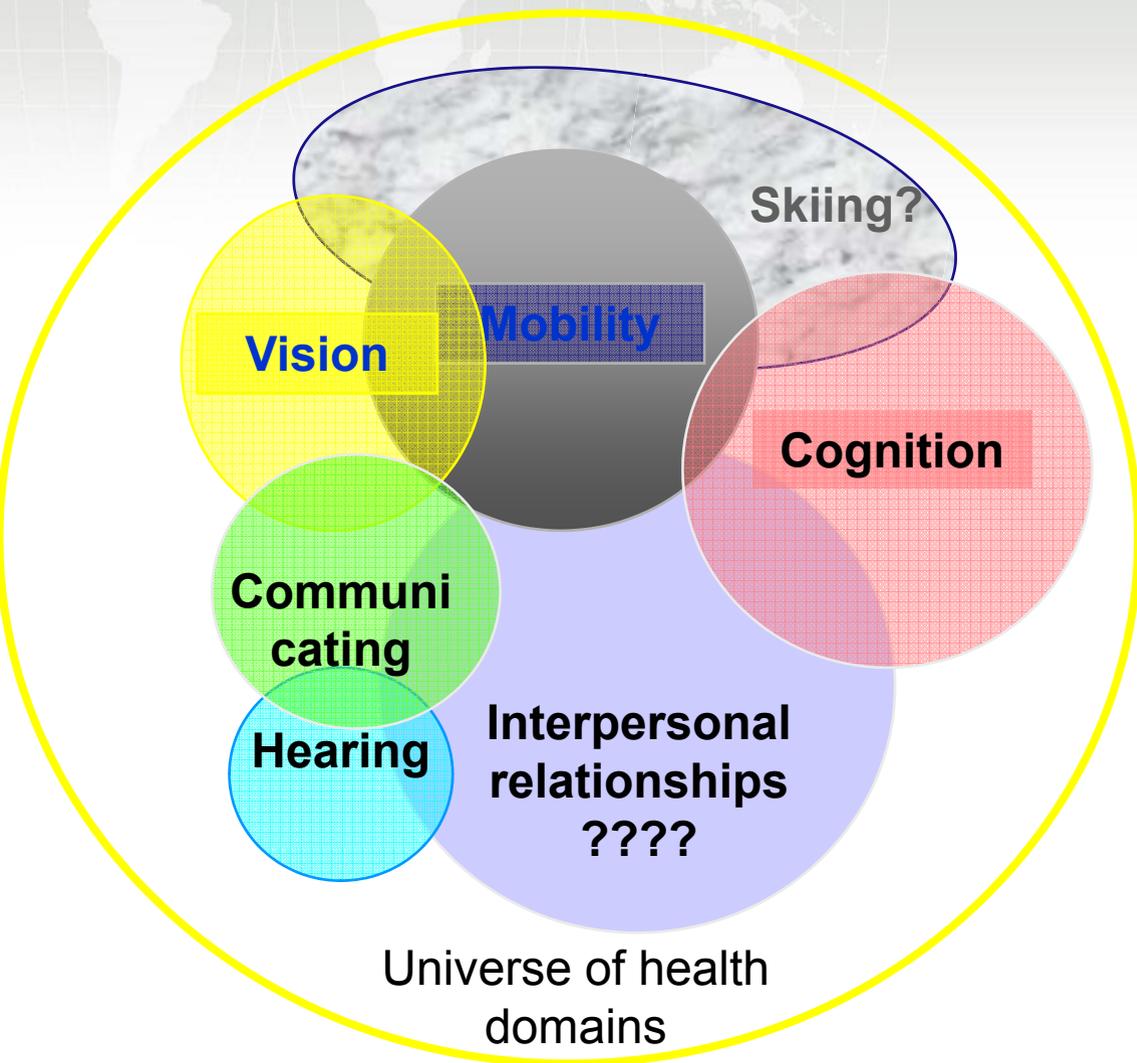
Identify the <u>most parsimonious</u> set of health domains with the <u>highest explanatory value.</u>

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Survey and census instrument development and multicountry studies

- Washington City Group (UN Stats, NHS)

- Budapest Initiative (UNECE, EUROSTAT, WHO)

- WHO Multicountry Study 2000-2001

- WHO World Health Survey 2002-2004

- WHODAS II instrument

- WHO SAGE surveys 2005+

- GBD 2005 study – disability weight surveys

Self reported mobility

Self responses by country
Mobility
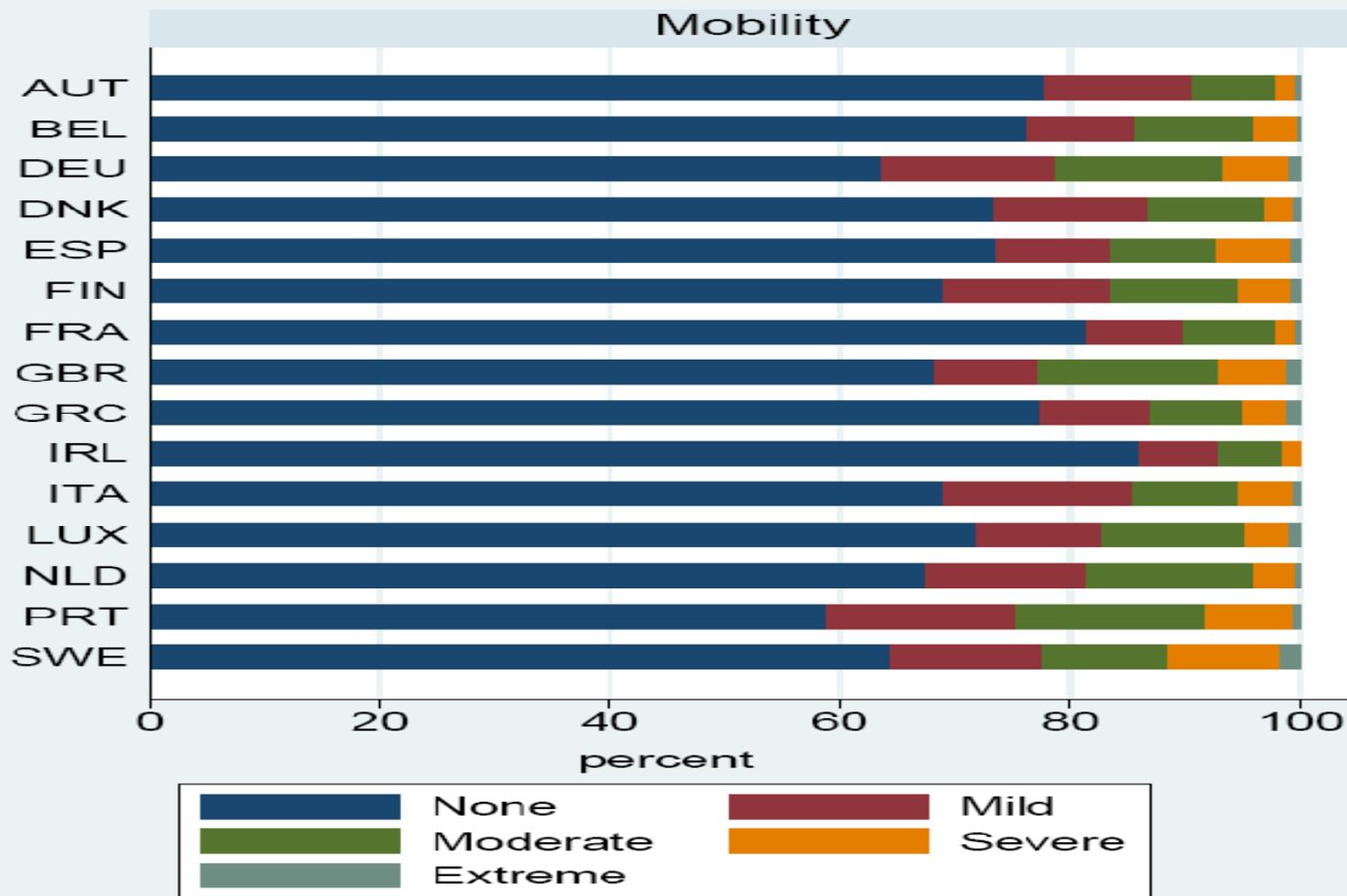
World Health Survey: multi-domain functioning levels by age (n= 250,000)

Legend: mobility, self, pain, cognition, personal, vision, sleep, affect

X-axis: Age in years

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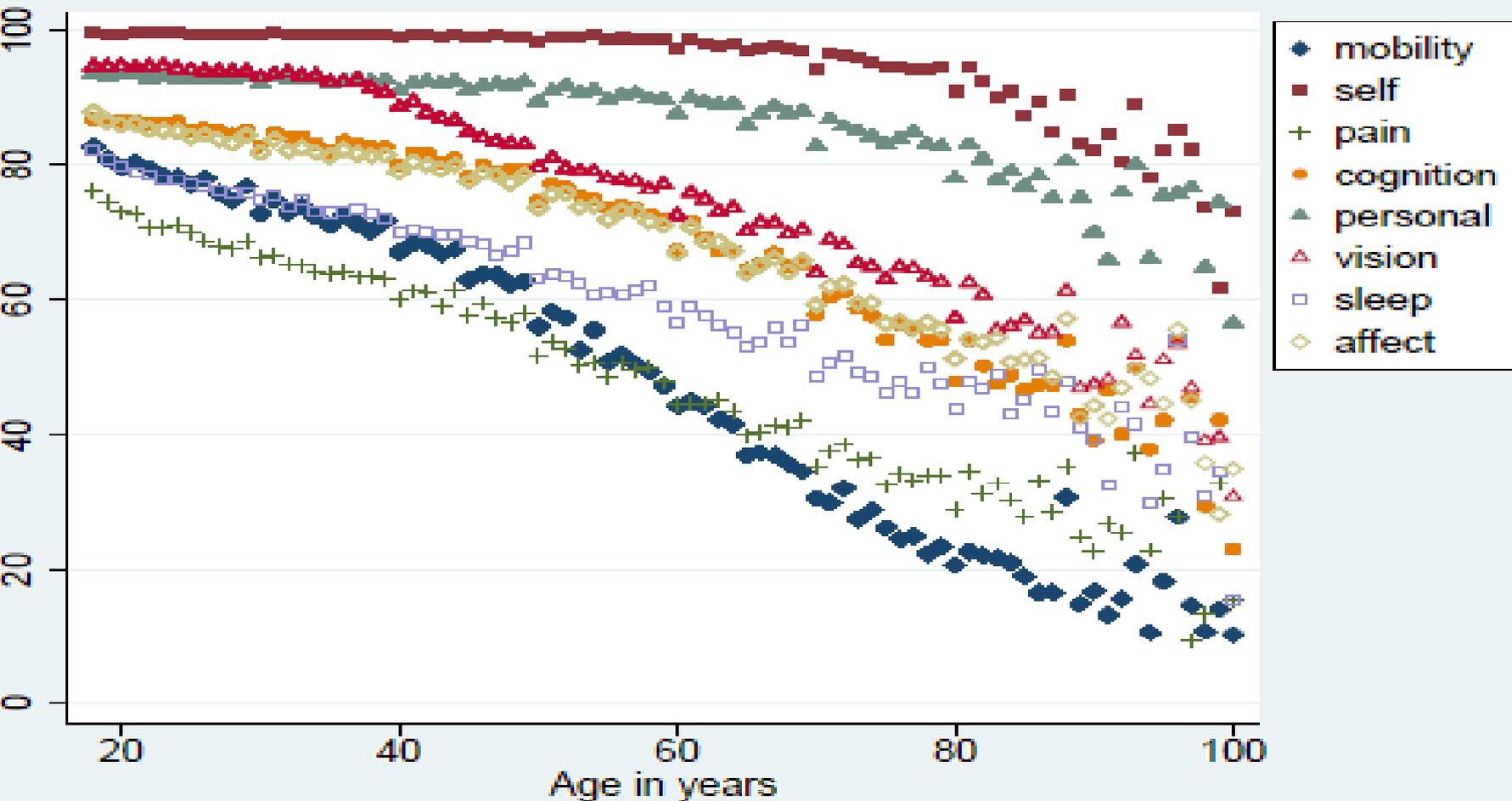
WHS 8 Domain Composite Versus Income per Capita

Females

Age-standardized SR8 vs LN GDP per capita [in 2003 USD]
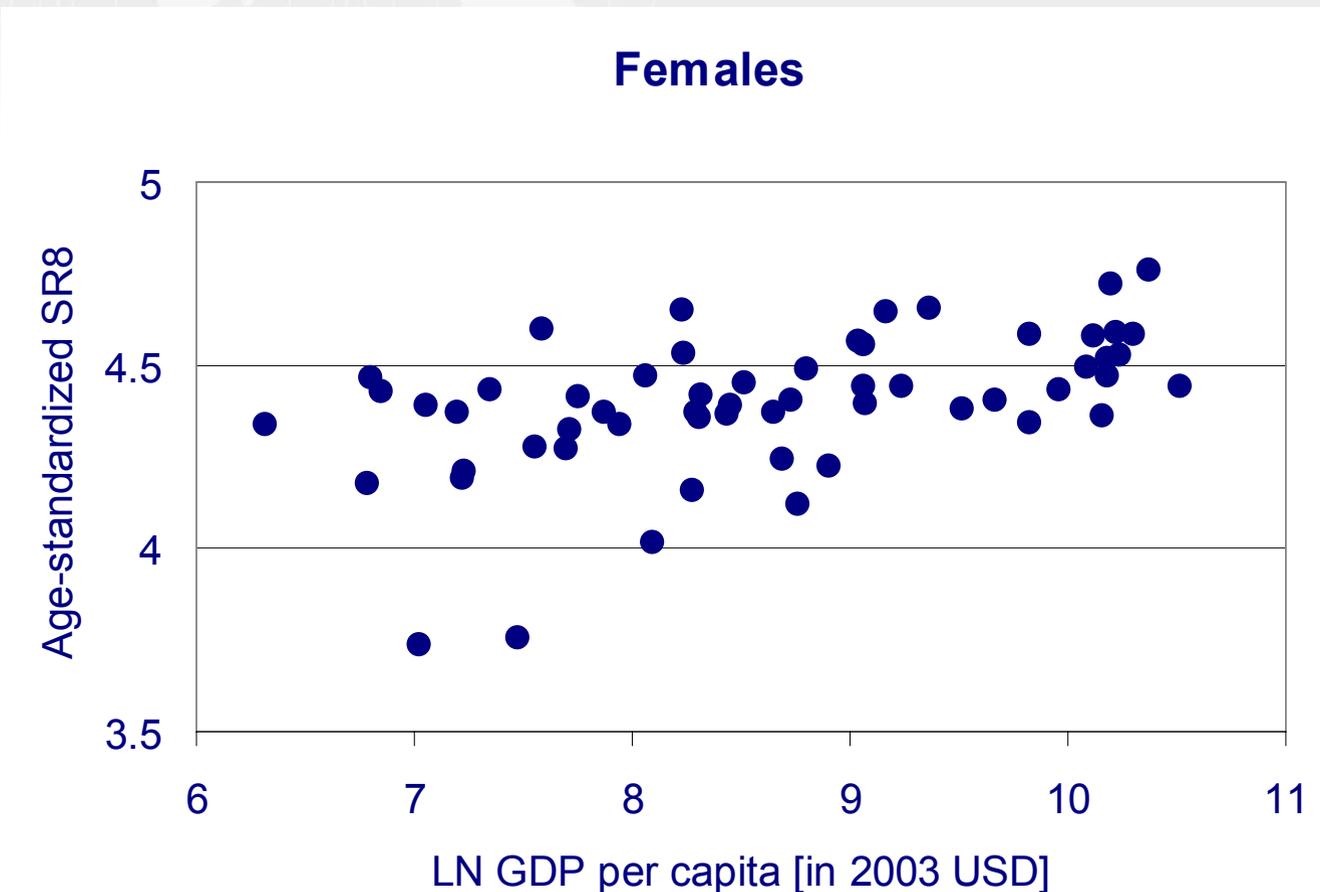
Defining "disability" and "loss of health"

- Counting disabled people → need threshold

- Summarizing loss of health across domains (continuous)

Two broad approaches to summarizing across domains:

- Define domain-specific scoring functions and sum across domains., eg. WHODAS-II, SF

- Obtain health state valuations for multi-domain health states. Define or fit a valuation function to generate an overall health state valuation for each possible set of functionings (levels in core health domains).

Global Burden of Disease (GBD) – Recent WHO Activities
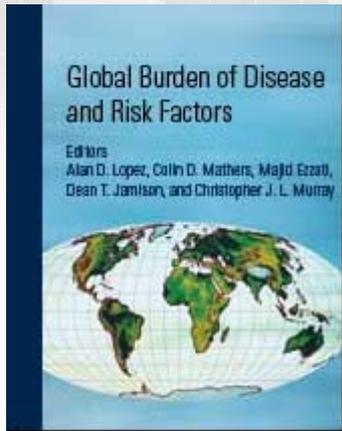
2006	Global Burden of Disease and Risk Factors (Lopez, Mathers et al, OUP). DCP2 project
2008	Global burden of disease: 2004 update Revised projections 2004-2030
2009	Country level estimates released
	Healthy life expectancy (HALE) 2007
	Global health risks (28 risk factors)
2010	GBD 2005 (1990 and 2005, 21 regions Complete update (consortium: IHME, WHO, Harvard, Hopkins, University Queensland, funded by Gates Foundation
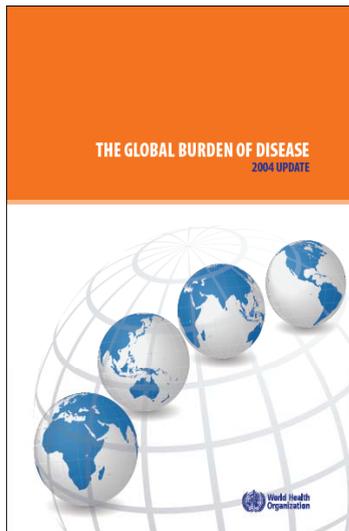
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The DALY quantifies "health"

- The DALY is now conceptualized as quantifying "health" not the goodness of health (the original conceptualization) or wellbeing/QoL
- Health conceptualized in terms of human functioning capacities in a set of domains/dimensions of health
- Disability is seen as synonymous with loss of health
- Decrements in health are decrements in functioning capacity in one or more health domains
- Above a certain threshold in a domain, improvements may be seen as "talent" rather than increasing "health"
- Does health end at the skin? What about aids?
- GBD considers some aids close to the skin as improvements in health (contacts, glasses, hearing aids, basic mobility aids)

Health state valuations (HSV)

- Reflect preferences for health states on an interval level scale (0 is full health and 1 is a state equivalent to death)

- 22 indicator conditions valued using person trade-off methods (PTO) – these used to define 7 disability classes

- For other conditions, distribution across the 7 classes assessed by experts by comparison to the 22 indicator conditions (treated, untreated x age, sex)

- GBD 2000-2004 uses mostly GBD 1990 weights supplemented by weights from the Dutch disability weight study (Stouthard et al 1997)

Healthy life expectancy (HALE) for 2007
Just released in World Health Statistics 2009
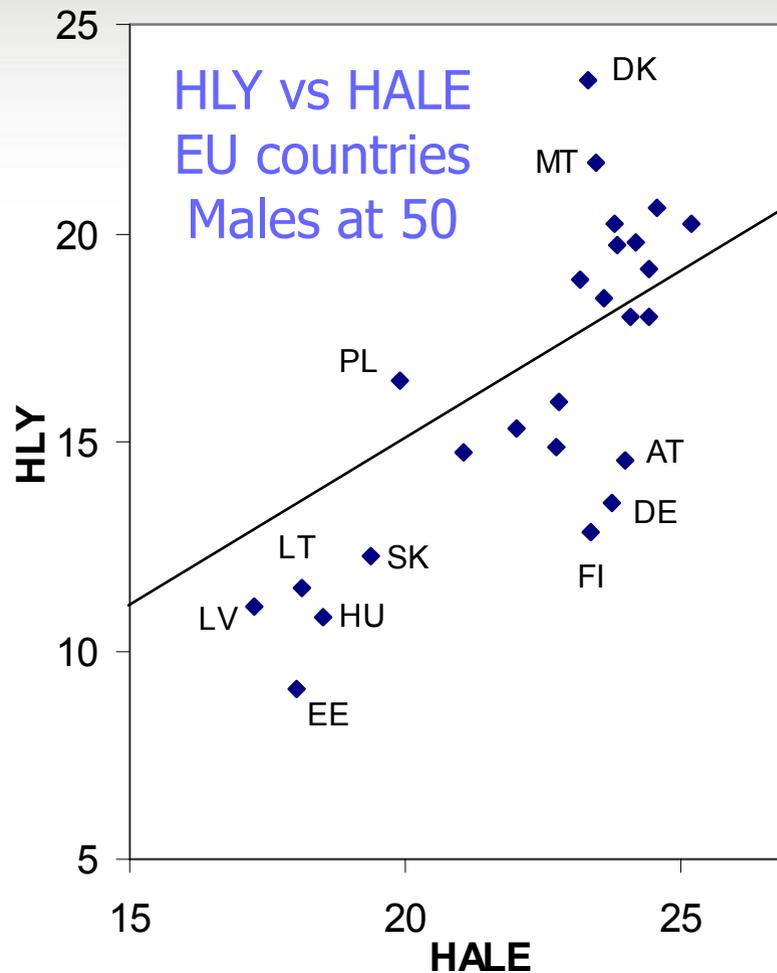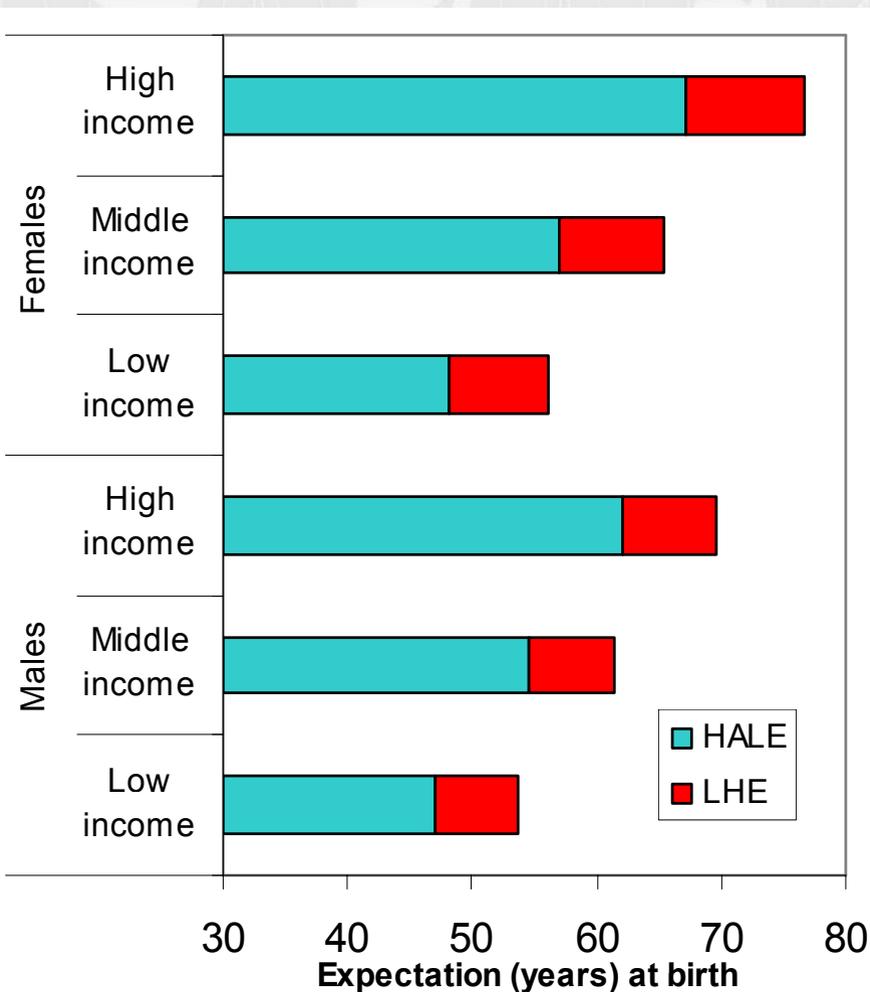
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Imputing overall disability prevalence - WHS

- A composite score was calculated across the 8 health domains using a Rasch model (IRT-based)

- Composite score scaled to range 0 (no difficulties) to 100 (extreme difficulty in all domains)

- Threshold for "disability" chosen as 40 – based on average score for respondents classified as having arthritis, angina, asthma, diabetes or depression (diagnostic scales based on self-report symptoms)

Imputing overall disability prevalence – GBD

- Add prevalence x DW across all 633 disease and injury sequelae

- Adjustments for comorbidity (Mathers et al 2004)

- Prevalence of disability in 7 classes by age, sex, region

- Severe disability (class VI and VII): blindness, Down's syndrome, quadriplegia, severe depression or active psychosis

- Moderate and greater disability (class III+): symptomatic angina, arthritis, low vision (6/18 – 6/60) or alcohol dependence

Global prevalence of disability, GBD 2004

Moderate and severe disability

Severe disability

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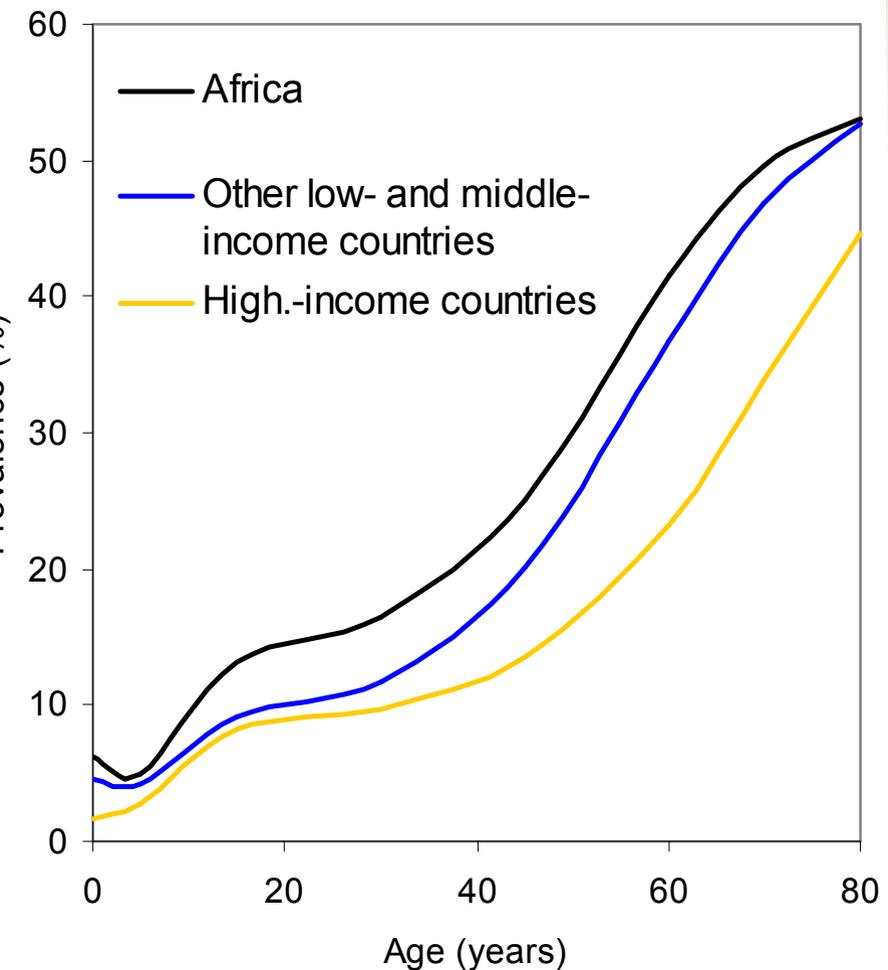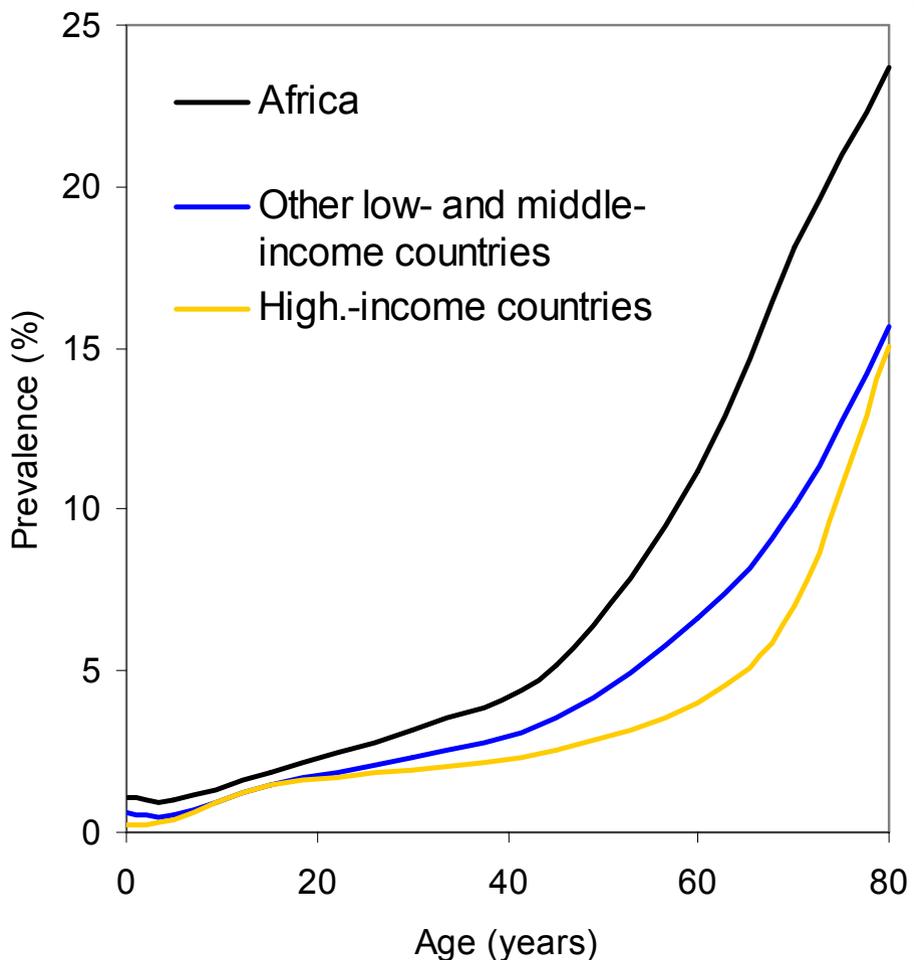
Prevalence of disability – three methods
Average, 10th and 90th percentiles

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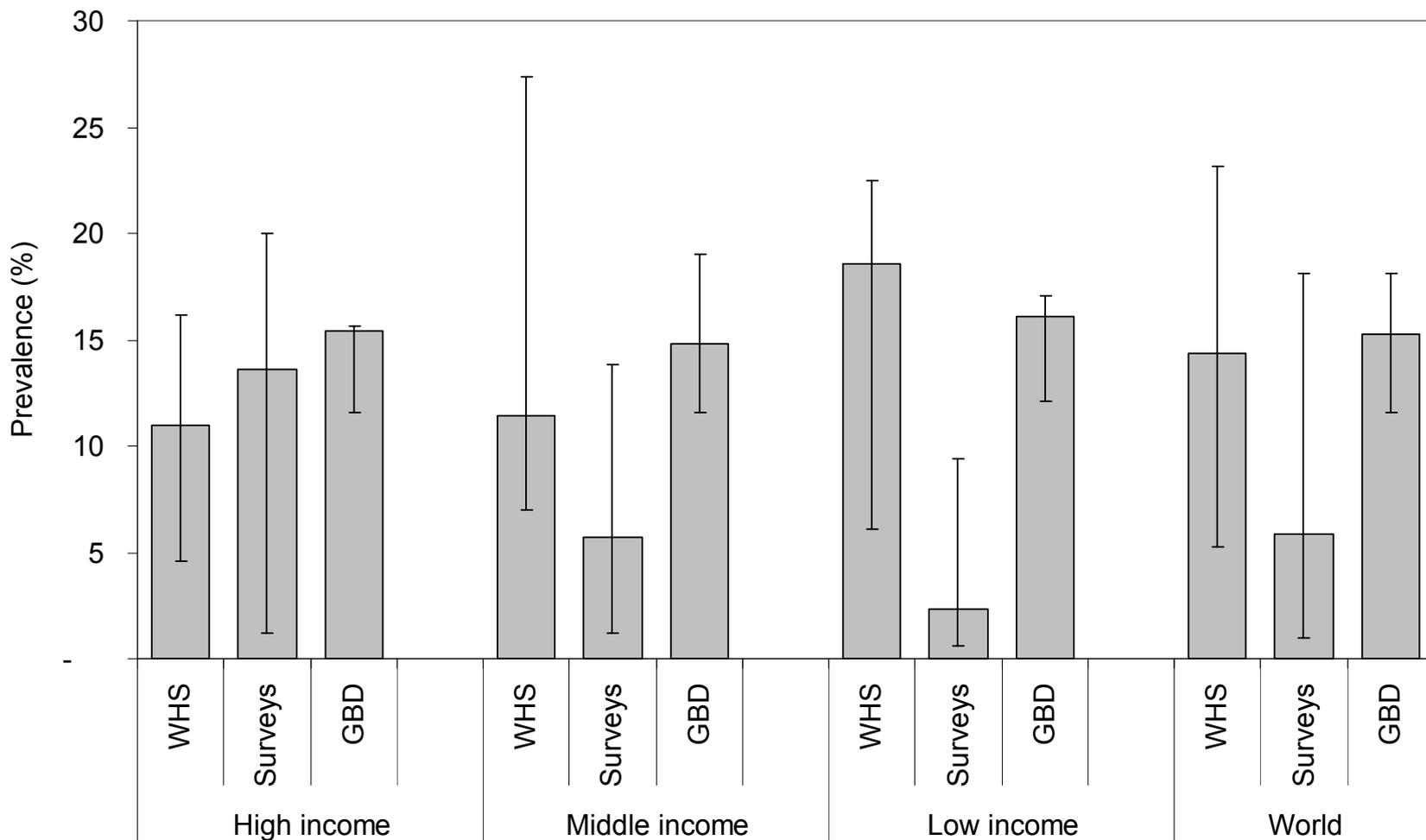
Disability prevalence in selected EURO countries

World Health Organization
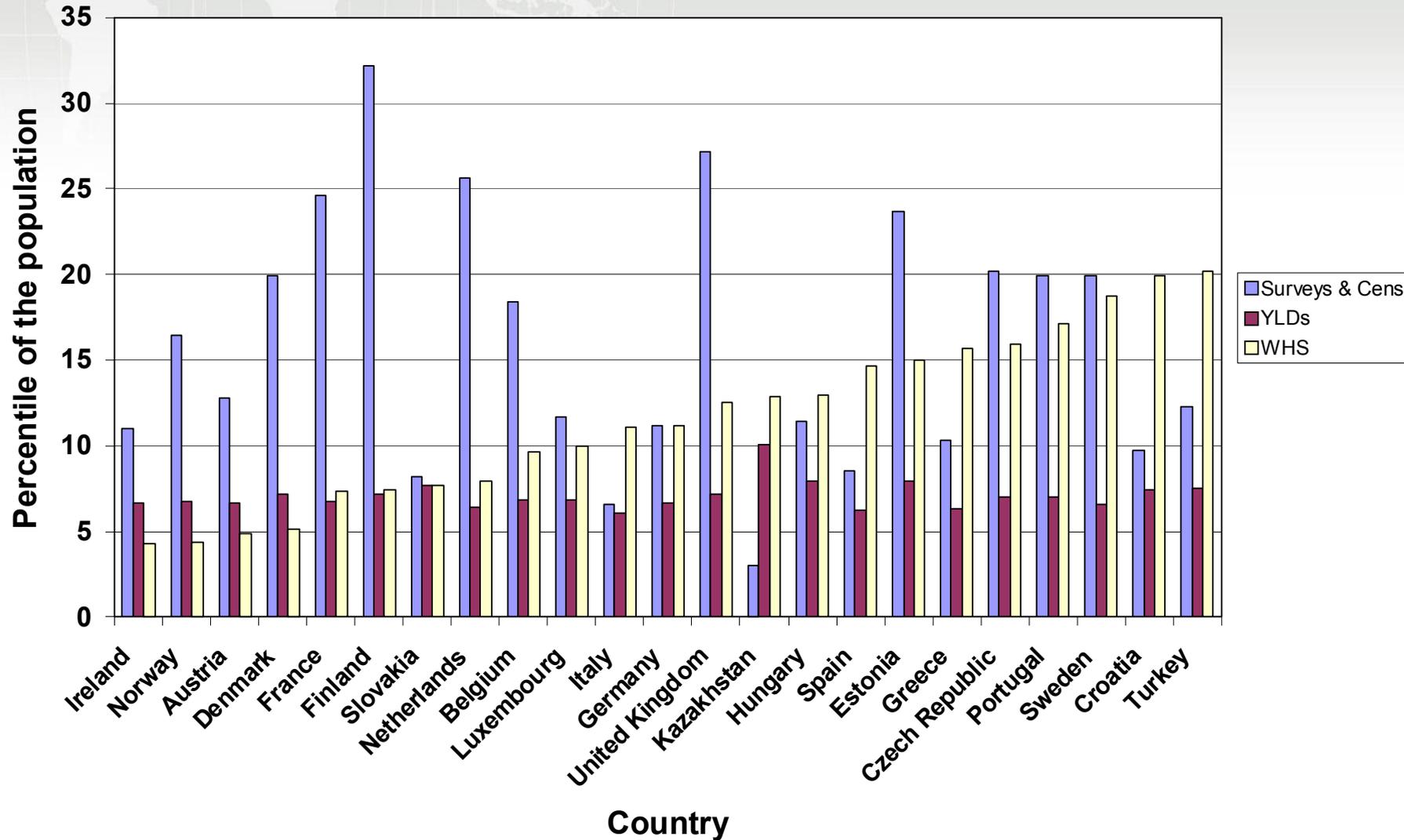
Conclusions

- ICF provides a classification of domains of functioning BUT NOT YET guidance for measuring prevalence or severity of disability
- Self-reported functioning in multiple domains not comparable across countries even with identical survey methods
- GBD approach has involved expert judgement and limited empirical evidence on comorbidity
- Two possible strategies:
  - Develop low-cost functional performance tests with minimal DIF for use in household surveys
  - Develop self-reported items potentially including new generations of vignettes or other novel strategies with minimal DIF for use in household surveys

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Measured Performance Tests

1) Can low-cost functional performance tests be standardized and fielded in household surveys?

2) How much of a complex domain can be captured with a simple test?

3) How much are functional performance tests confounded by motivation?

4) How much DIF is there for functional performance tests?

5) What to do about domains such as affect and pain for which tests have not been developed?

GBD 2005 strategy for revising the disability weights

- Measurement in community samples in diverse settings (e.g. Tanzania, Mexico, India, Philippines)
- Sequelae presented with brief word descriptions capturing most salient aspects of functioning and symptoms for the average case
- Main response task based on paired comparisons
- TTO for a number of moderate severity conditions
- Internet survey for remaining sequelae
- Modified PTO for mild conditions
- Explicit analysis of cross-population variability