

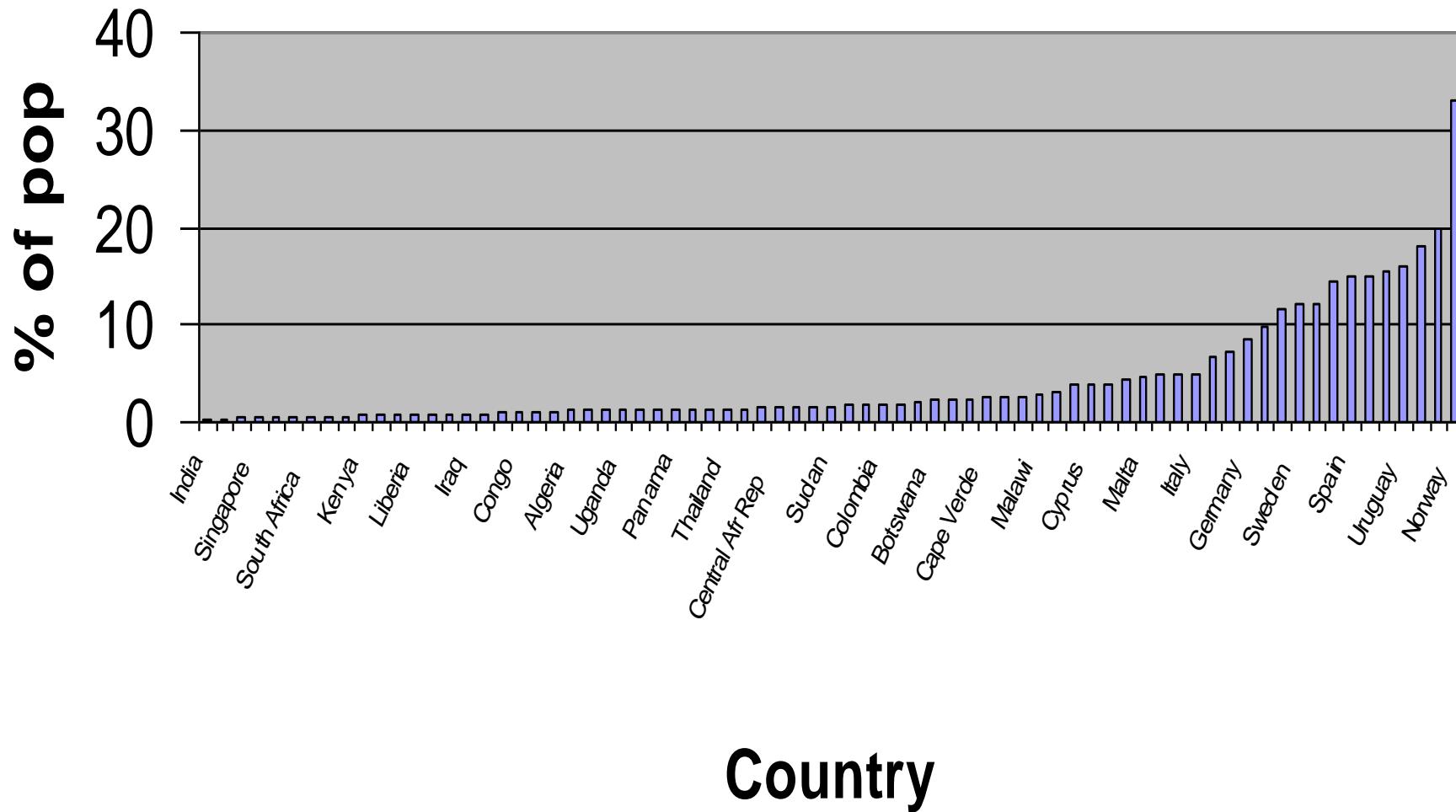
The ICF and statistics on disability and health

*Classification, Assessment, Surveys and
Terminology (CAS/EIP)*
World Health Organization
Geneva

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UN Disability Statistics



UN Disability rates

- **Wide inter-country variation**
 - 60 fold difference (0.2 - 30%)
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- **Reliability**
 - unknown - not measured
- **Construct validity**
 - not sure what is being measured

Possible explanations for between country variations

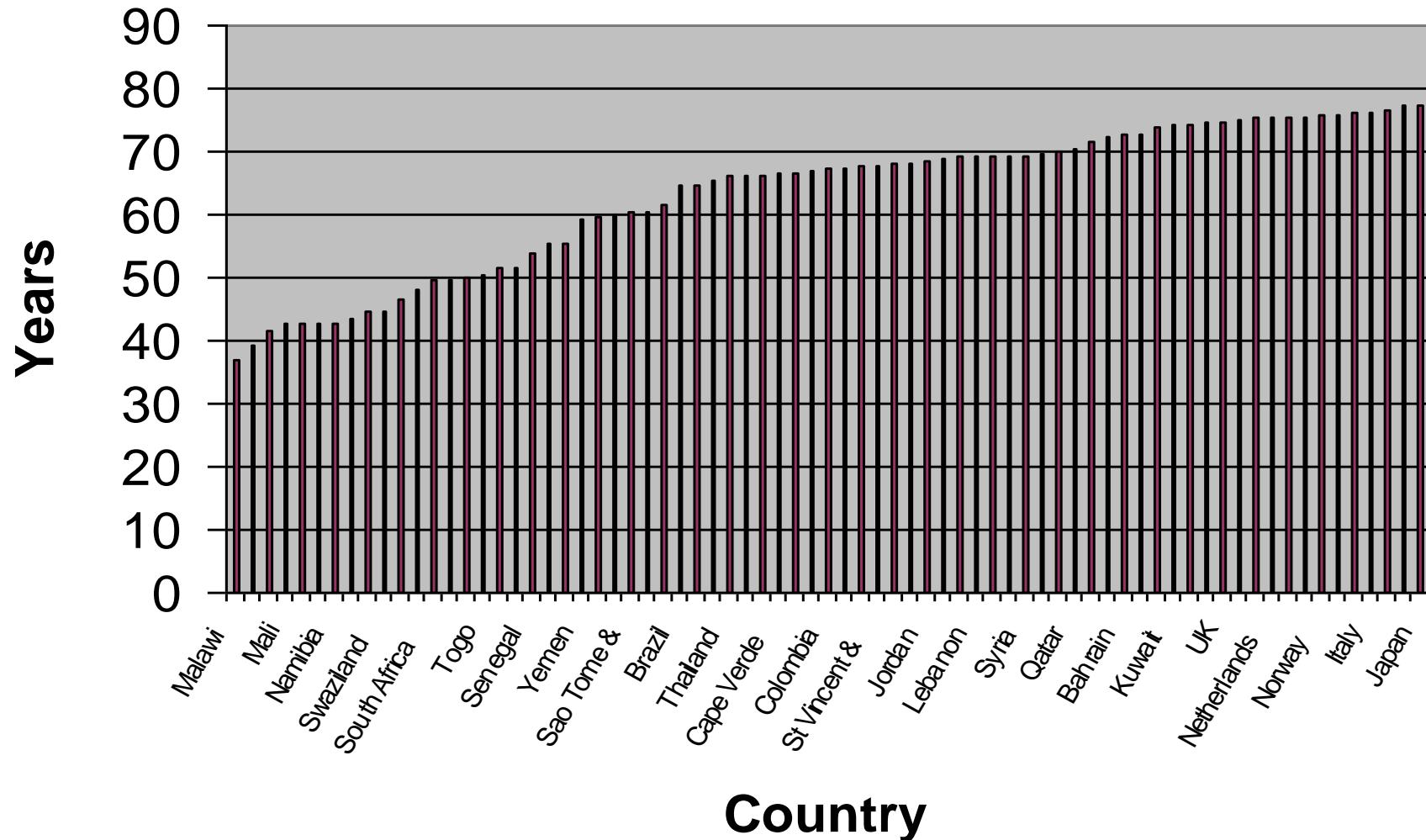
□ real differences

- levels of development
- different environments
- population age structure
- time of data collection

□ Methodological differences

- Census vs surveys
- different concepts of 'disability'
- different domains
- different questions
- different levels of severity

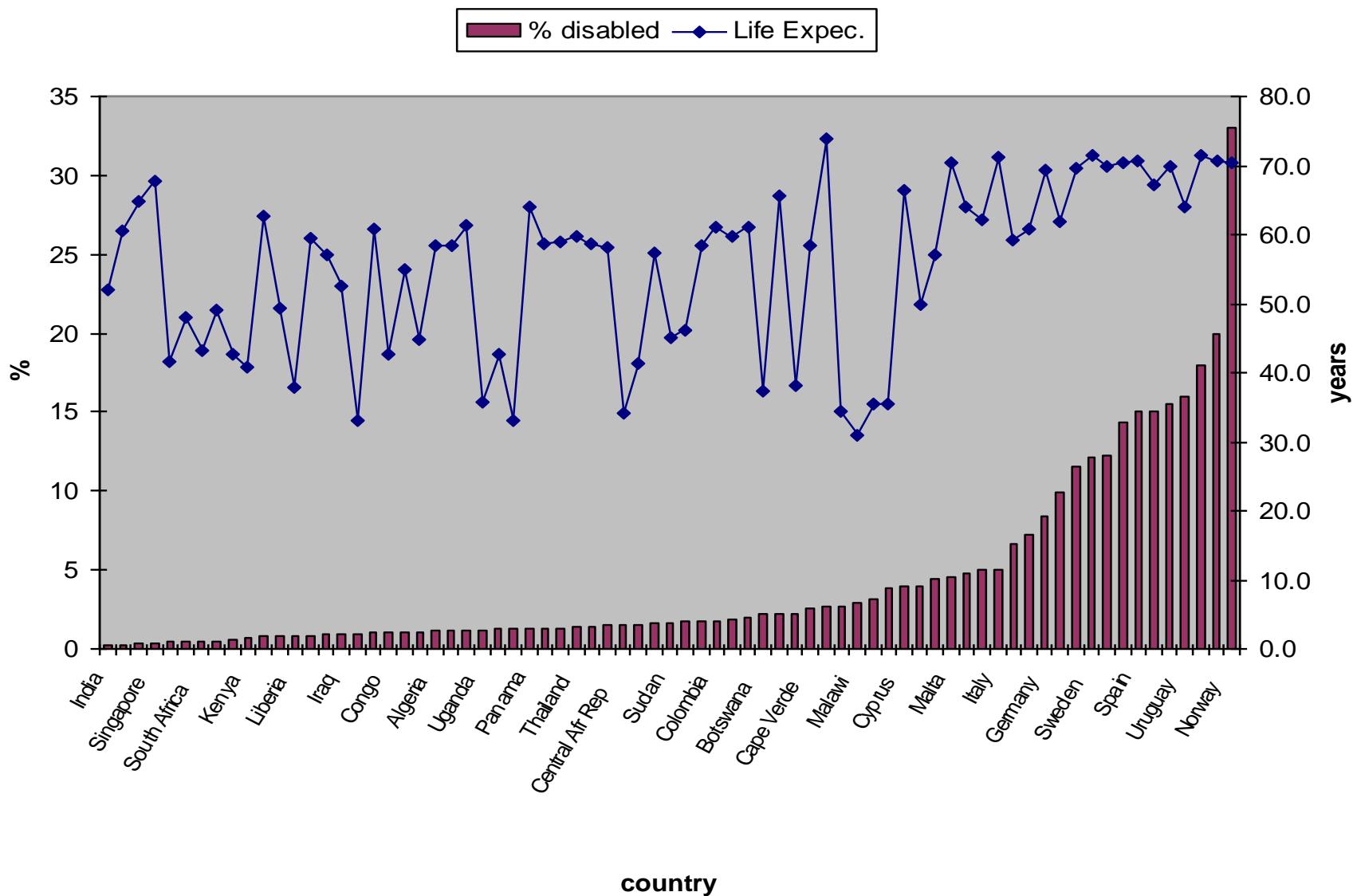
Life expectancy at birth 2000



Life expectancy

- Measuring number of years people are expected to live based on mortality statistics in countries
- Reliability: Good
 - different measurements give similar results
- Differences indicate real and expected differences between countries
 - developed vs developing
 - responsive to health interventions
 - internationally recognised consensus measure
 - used in different indices: Human development index; Health system performance
- Need indicators with similar properties for disability

Life Expectancy and % disabled



Life expectancy and % disabled

- No relationship between country differences in % disabled and life expectancy

Country	% disabled	LE (yrs)
Japan	2.7	73.8
Malawi	2.9	30.9

- disability measure lacks face validity

LE and % disabled (2)

- **Disability levels cannot be explained by other covariates, such as**
 - age structure
 - development level
 - life expectancy
 - education level
 - economic level
 - other contextual variables...
- **as disability % goes up, more face validity**
- **Current disability statistics are not clear**

What is wrong with disability statistics

- Not holistic**
 - focus more on the physical (vision, hearing and mobility and severe mental handicap) than mental health
- not multi-dimensional**
 - usually activity limitation or impairments or mix
 - very limited in terms of participation and environmental factors
- not comparable mainly because not using common conceptual framework**

What is wrong with disability statistics (2)

- poor reliability and validity - even if measure is reliable cannot compare if not same conceptual framework
- traditionally, used set definitions of disability as input (blind, deaf, physically disabled, etc.) - no measure of individual domains within each category
- threshold is set at outset and cannot be changed and need new set of data for each purpose

Disability and health surveys: Same and different

Health surveys

- health condition**
- cause of health condition**
- risk factors**
- prognosis**
- health system interventions**
- satisfaction**

Disability surveys

- health condition**
- level of functioning at body, person and societal level**
- assistance required**
- other facilitators and barriers**
- satisfaction**

WHO World Health Survey

- Uses ICF domains
- these domains are based on international consensus
- domains lend themselves to empirical validation for cross-population comparability
 - calibration tests
 - vignettes
- 20% of domains explain 80% of variance in health level
- summarise data into summary measures of population health

Level of health across 6 core ICF domains

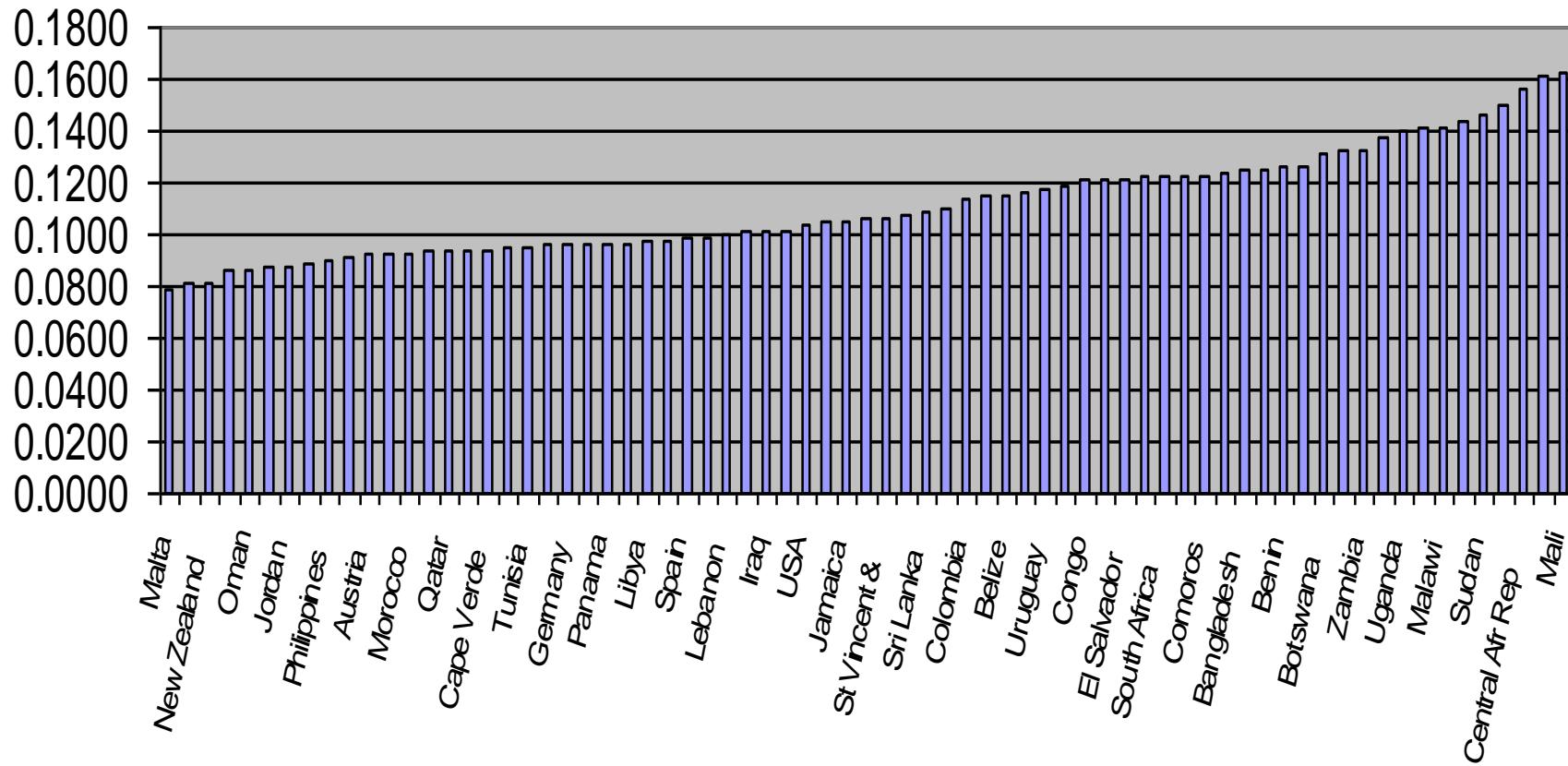
- 6 core ICF domains used to measure level of health
 - Cognition *understanding - communication*
 - Mobility *moving around*
 - Self-care *washing, toileting, eating*
 - Affect *depression, anxiety*
 - Pain *physical bodily pain*
 - Usual activities *housework, work, school*
- Measured in standard surveys
 - WHO multi-country Survey Study in 61 countries 2000-2001
 - Adjusted for self-report bias

Level of health across 6 core ICF domains (2)

- Aggregate the level across whole population
- Cross country comparisons
- Less variation than current disability statistics because:
 - identical concepts being measured
 - same method of measurement
 - reliability measured and ensured
 - self-report bias is adjusted for

Average levels of health

(yrs lived with disability expressed as fraction of total number of years)



Using ICF for both disability and health statistics

- According to ICF, disability and health are defined across the same domains
- Surveys assess the same set of domains
- questions measuring the same thing at different levels
 - impairment
 - capacity & performance
- Key issue is the definition of a threshold level for which you define any disability for a given domain
- Threshold is arbitrary and can be set at different levels for different purposes

ICF Checklist

Part 1 b: IMPAIRMENTS with BODY STRUCTURES

- Body structures are anatomical parts of the body such as organs, limbs and their components.
- Impairments are problems in body function or structure as significant deviation or loss.

<i>First Qualifier: Extent of impairment</i>	<i>Second Qualifier: Location</i>
0 No impairment	0 More than one region
1 Mild impairment	1 right
2 Moderate impairment	2 left
3 Severe impairment	3 both sides
4 Complete impairment	4 front
8 Not specified	5 back
9 Not applicable	6 proximal 7 distal

<i>Short List of Body Structures</i>	<i>First Qualifier extent of impairment</i>	<i>Second Qualifier location</i>
x1. STRUCTURE OF THE NERVOUS SYSTEM		
x110 Brain		
x120 Spinal cord and peripheral nerves		
x2. THE EYE, EAR AND RELATED STRUCTURES		
x3. STRUCTURES INVOLVED IN VOICE AND SPEECH		
x4. STRUCTURE OF THE CARDIOVASCULAR, IMMUNOLOGICAL, AND RESPIRATORY SYSTEMS		
x410 Cardiovascular system		
x430 Respiratory system		
x5. STRUCTURES RELATED TO THE DIGESTIVE, METABOLISM AND ENDOCRINE SYSTEMS		
x6. STRUCTURE RELATED TO GENITOURINARY SYSTEM		
x610 Urinary system		
x630 Reproductive system		
x7. STRUCTURE RELATED TO MOVEMENT		
x710 Head and neck region		
x720 Shoulder region		
x730 Upper extremity (arm, hand)		
x740 Pelvis		
x750 Lower extremity (leg, foot)		
x760 Trunk		
x8. SKIN AND RELATED STRUCTURES		
ANY OTHER BODY STRUCTURES		

- One component- One page
- Salient Categories (169 out of 1494) at-a-glance
 - Impairments with Body Functions
 - Impairments with Body Structures
 - Capacity and Performance in Activity and Participation Domains
 - Environmental Factors
 - Other Contextual information
- Additional notes
- Available for Clinicians

WHO Disability Assessment Schedule - WHO-DAS II

- Validated across number of countries and conditions
- based on ICF domains

What is disability?

- **Outcome of interaction:**
person's health condition + contextual factors = DISABILITY
- **This outcome of disability can be described at 3 levels:**
 - body (impairment of body function or structure)
 - person (activity limitations measured as capacity)
 - society (participation restrictions measured as performance)
- Plus description of contextual factors - personal and environmental

Body functions and structures

- **Body functions** (b - codes) are the physiological functions of body systems (including psychological functions)
- **Body structures** (s -codes) are anatomical parts of the body such as organs, limbs and their components
- **Impairments**
 - are problems in body function or structure as a significant deviation or loss
 - are the manifestation of an underlying pathology
 - can be temporary or permanent; progressive, regressive or static; intermittent or continuous; slight through to severe

Activities and Participation

- **Activity** is the execution of a task or action by an individual
- **Participation** is involvement in a life situation
- **Activity limitations** are difficulties an individual may have in executing activities
- **Participation restrictions** are problems an individual may experience in involvement in life situations

Constructs for A and P: Capacity

- ‘Just me’ - inherent ability**
- person’s ability to execute a task or action**
- notion is independent of environment**
- measurement within an environment (standard environment)**
- compared to individual without a similar health condition**

Constructs for A and P: Performance

- ‘Me plus my context’ - outcome**
- what a person does or what happens in his or her current environment**
- notion is dependent on environment -**
 - when the environment is facilitating, the outcome is improved functioning;**
 - when the environment is hindering, the outcome is worsening disability.**
- compared to individual without a similar health condition**

Environment

- ICF Part 2: Contextual factors has two components:
 - personal factors (not classified in ICF)
 - environmental factors (ICF EF Section)
- Environmental factors (EFs) are external factors that make up the physical, social and attitudinal environment in which people live and conduct their lives
- EFs form part of both the immediate and distant or background environments

Environment and functioning

- **Body Function/Structure and Activity:**
 - independent of E for definition
 - manifestation of latent health condition *may occur through impact of EFs*
 - aggravation of existing impairment or **Activity Limitation**
 - measurement of function, structure or activity within an environmental context

- **Participation:**
 - environment is integral to the definition
 - description of environmental factors is part of description of participation
 - changes in environment causes changes in participation

The added value of ICF...

- **comprehensive approach for describing functioning at body, person and societal level.**
- **common framework for**
 - needs assessment
 - selection of a targeted population (e.g. eligibility for benefits)
 - comparison within and across different people
 - monitoring and evaluation within and between interventions
 - prioritisation of interventions
- **common language for communication**

Conclusion on ICF

- Descriptive tool (not evaluative)
- provides common framework
- allows for clear continuum: health and disability statistics use the same framework
- provides profile of individual domains
- allows different thresholds for same data set

Conclusions: general

- Current international ‘Disability Statistics’ are problematic
- Census and survey data could be expressed in ICF terms, thereby:
 - increasing conceptual clarity
 - reliability
 - comparability
- ICF domains as basis for health and disability statistics

Contacting WHO

www.who.int/classification/icf

How can we include the information matrix and EFs?

- Wording and sequence of questions**
 - ‘What difficulty do you have in....?’
 - ‘What happens in your usual/current environment?’
 - ‘What features of the environment make it easier or more difficult for you to...?’
- Cognitive testing of what context people have in mind when reporting difficulties**
- Ask about a wider range of domains and environmental factors**
 - involvement in civil society, friendships, caring for others, etc.
 - attitudes, natural environment, design of land areas, systems and policies, services such as housing, political, legal, etc.

Disability and health surveys: common ground

- Health of a population
- List of domains

Vision
Hearing
Speech
Digestion
Bodily excretion
Fertility
Skin & disfigurement
Breathing
Pain
Affect
Sleep
Energy/vitality
Cognition

Communication
Mobility and dexterity
Self-care
Usual activities
Social functioning