

# **Goal 8: Improve the *reliability and comparability of disability data***

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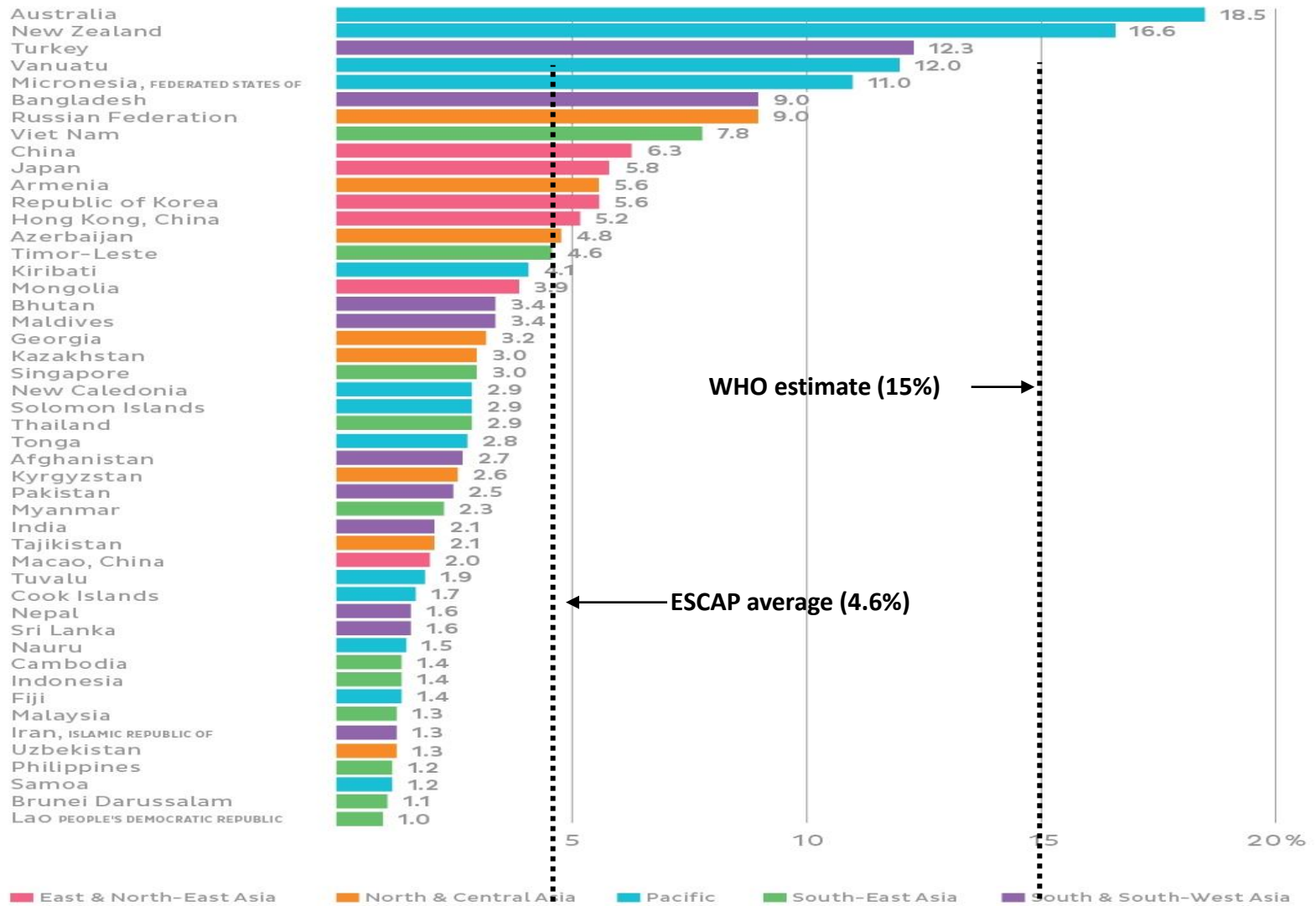
# Targets

- **Target 8.A**
  - **Produce and disseminate reliable and internationally comparable disability statistics in formats that are accessible by persons with disabilities**
- **Target 8.B**
  - **Establish reliable disability statistics by the midpoint of the Decade, 2017, as the source for tracking progress towards the achievement of the goals and targets in the Incheon Strategy**

# Indicators for tracking progress

- 8.1 Disability prevalence based on the International Classification of Functioning, Disability and Health (ICF) by age, sex, race and socioeconomic status
- 8.2 Number of Governments in the Asia-Pacific region that have established, by 2017, baseline data for tracking progress towards achievement of the Incheon goals and targets
- 8.3 Availability of disaggregated data on women and girls with disabilities in mainstream development programmes and government services, including health, and sexual and reproductive health, programmes

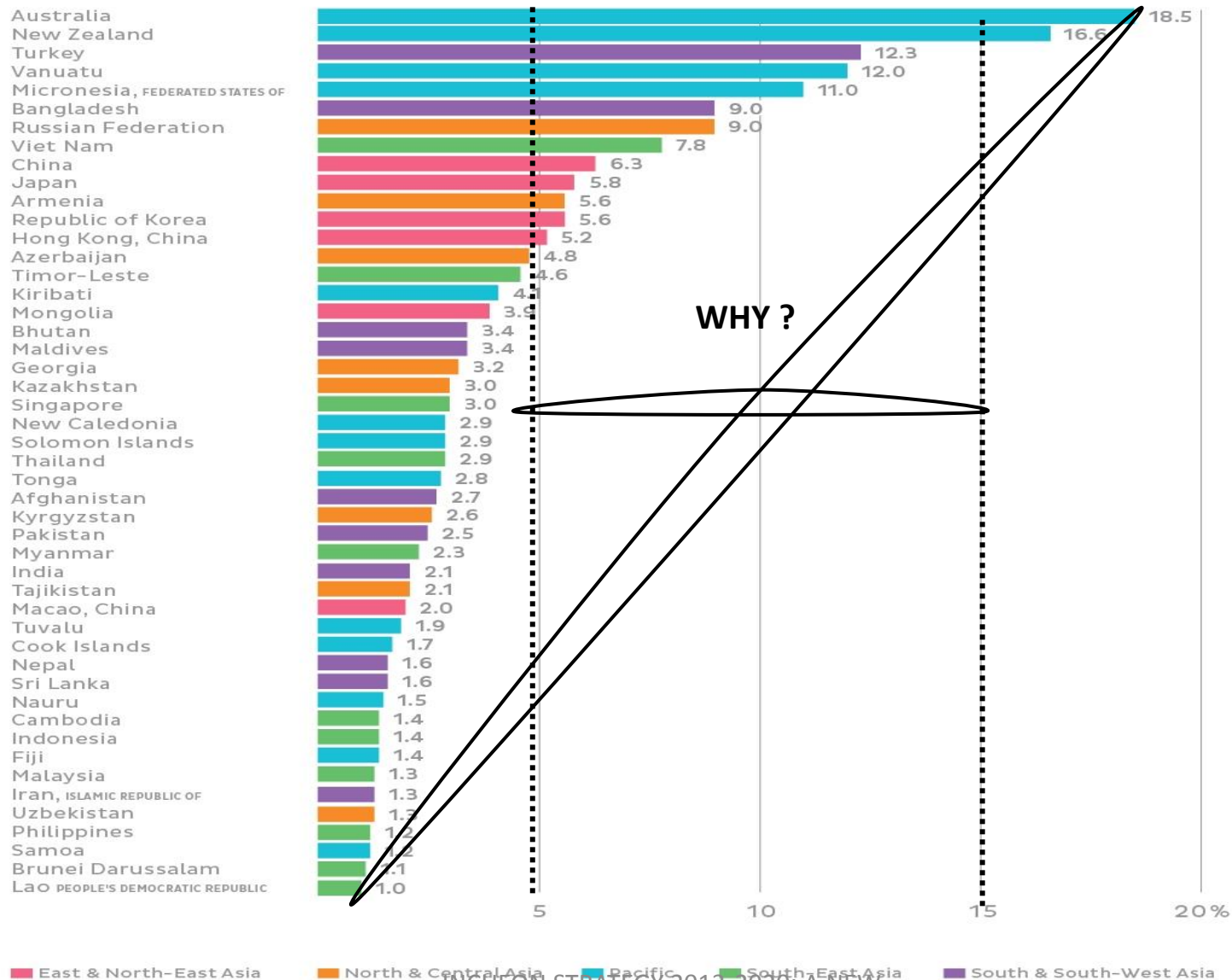
“To make people count, we have  
to count people right”.



SOURCE: ESCAP ANALYSIS BASED ON ESCAP DISABILITY SURVEY, 2011, AND EMAIL COMMUNICATION WITH GOVERNMENT DISABILITY FOCAL POINTS DURING 2012.

# Disability at a Glance 2012

## Large variations in country-specific disability prevalence



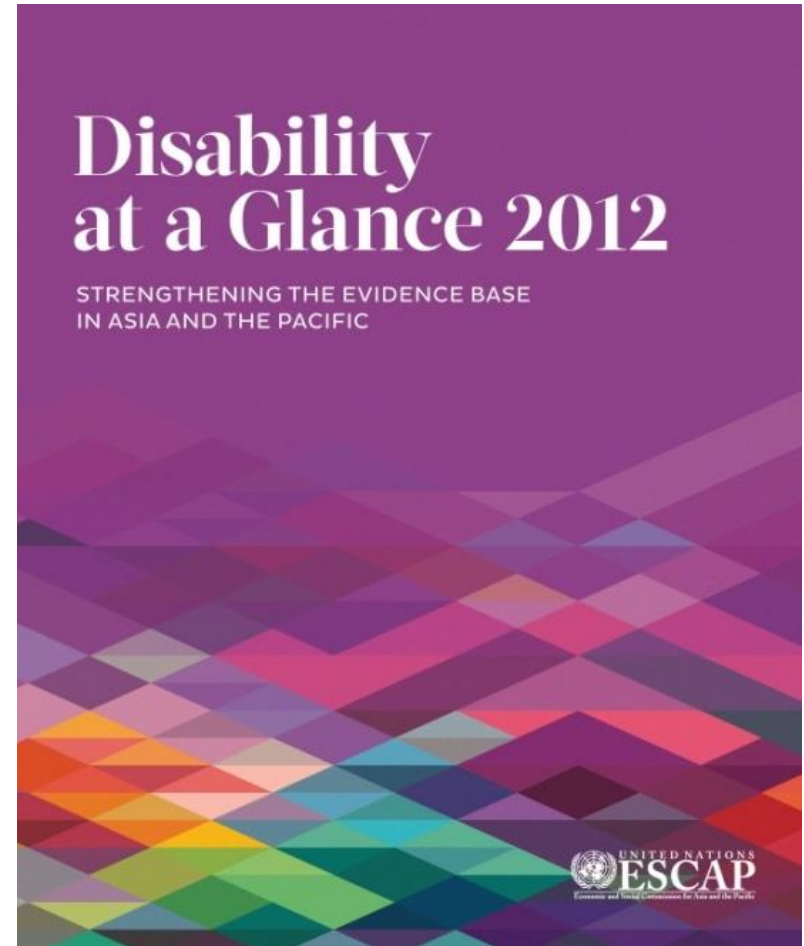
# Why the difference ?

Lack of accurate & comparable data.....

- Differences in the conceptualization and definition of disability
- Differences in purposes of data collection
- Differences in methods of data collection

Interplay of these parameters affects quality of data

Various estimates may not point to actual differences in the number of persons with disabilities, but rather to different dimensions of disability





	<b>Australia</b>	<b>Lao PDR</b>
<b>Purpose of collecting disability data</b>	<ul style="list-style-type: none"> <li>•To measure the prevalence of disability.</li> <li>•To provide a demographic and socioeconomic profile of persons with disabilities.</li> <li>•To identify support needs for persons with disabilities and older persons.</li> </ul>	<ul style="list-style-type: none"> <li>•To provide information on the population and their living conditions.</li> <li>•To identify development plans, including education, employment, housing and construction, water and electricity supply.</li> </ul>
<b>Underlying approach for disability</b>	Focusing on interaction between individuals and external environment	Impairment
<b>Number of disability questions</b>	75	3
<b>Types of questions</b>	<ul style="list-style-type: none"> <li>•A set of screening questions using ICF domains from the body functions, body structure, activities and participation components used.</li> <li>•Personal interviews with people identified or proxy interviews followed to ask about assistance needs and received in carrying out core activities, internet use, participation in community, schooling and employment restrictions.</li> </ul>	1. Is there any disabled person in this household? (Yes/No) 2. What type of disability does he/she have? (Visual, deaf/dumb, arm/leg, multiple, other) 3. What is the cause of disability? (since birth, war accident, drug addiction, diseases, others)
<b>Degree of severity of impairment identified</b>	Mild-moderate-severe-profound	Does not address severity directly, either “Yes” or “No”.
<b>Data collection instrument</b>	Survey of Disability, Ageing and Carers	Population and Housing Census
<b>Recorded disability prevalence</b>	<p><b>18.5 per cent (total)</b></p> <p><i>of which</i></p> <p>Mild: 5.6 % : Moderate: 3.0 %</p> <p>Severe: 2.9 % : Profound: 2.9 %</p> <p>Other restrictions: 4.1 %</p>	<b>1.0 per cent</b>

7/5/2013

# Method for data collection

- **Population Census**
- **Surveys**
  - **Dedicated Sample Survey for Disability**
- **Administrative collections and registers**

# The Population Census

- Advantage of providing complete population coverage.
  - including a disability module on a non-disability survey will be useful because **disability data can be combined with the other social and economic data** collected to analyse the experiences of PWD
  - maximum use of the resources, (time, resources used in preparing for the data collection, personnel and resources collecting, processing, and analyzing the data on a regular basis.
- **Difficult to collect accurate information** about disability because limited number of questions (4 to 6 general disability questions)
- **Undercounting children with disabilities and people with mild or moderate disabilities** ( because response 'Yes or No' only). - survey relies on self-identification of disability.
- Census : Crude measure of disability but useful.
- Data from any survey/census is only as good as the questions asked, and the ability of the interviewers who ask them.

# Surveys

- Focus on specific issues to answer specific questions about a population - detailed questions on disability.
- Helps reduce the number of false positive and negative responses = more accurate prevalence measure.
- A sample survey is an independent survey on disability or a disability module added to an existing survey
  - Sample surveys are cheaper than censuses, but the size of the sample affects the quality of the data,
  - e.g. **Australian** Survey of Disability, Ageing and Carers every 5 years since 1981- private households and cared accommodations

# Administrative collections & registers

- Data collected as part of the normal operation of some service or programme.
- E.g. information in registration form. These collections provide useful information on the characteristics of people accessing disability services as well as details about the services provided.
- Cannot give an accurate measure of disability prevalence since there is no guarantee of coverage and they tend to incorporate double counting.
- The quality of administrative register data is closely related to the quality of the administrative system, in particular, how well it has been maintained and how closely the concepts align with the disability concepts of interest administrative data collection (general purpose **administrative systems or administrative registries**)

# Administrative collections and registers

- data about children in special education programmes is an indication of participation rates in education;
- general invalid pension registries are often organized by disease or impairment; and domestic care allowances help to track rates of children and adults with severe disabilities.
- Often these data are **collected annually, which provides a source for trend** data on the prevalence of impairments or disabilities
- Information collected is limited to people receiving services,
  - limited coverage - unmet needs need to be acquired elsewhere
  - not good sources for estimating overall disability prevalence.

# DATA COLLECTION METHODS FOR DISABILITY STATISTICS: A COMPARATIVE SUMMARY

CRITERION	CENSUS	SURVEY	REGISTER
PERIODICITY	Poor	Good	Very good
GEOGRAPHICAL COVERAGE	Very good	Poor	Very good
ABILITY TO OBTAIN DISABILITY INFORMATION	Poor	Very good	Very good
ABILITY TO ESTIMATE BETTER DISABILITY PREVALENCE	Good	Very good	Poor
ABILITY TO IDENTIFY PERSONS REQUIRING SPECIAL SERVICES	Poor	Good	Very good
ABILITY TO CAPTURE AND LINK NON-DISABILITY WITH DISABILITY CHARACTERISTICS	Good	Very good	Poor

# Disability Statistics Malaysia

DEPARTMENT	DATA COLLECTION
Statistics Department	Census - question on disability included
Social Security	Data on disability due to work related injuries
Ministry of Health	Health and Morbidity Survey - Specific Data on detection of disabilities children 0-18, Data on Adults with disabilities initiated 2012
Ministry of Education	Data on children receiving special education and those in higher education
Ministry of Women, Families and Community Development	Registry of Persons with Disabilities



# Disability Statistics Malaysia

REGISTRY - 458,835 registered with Social Welfare Dept

## SURVEY

- National Health Morbidity Survey II 1996 overall prevalence of disability 6.5%
- Specific disabilities
  - World Health Survey 2002 – 21.7% adult above 18 yrs perceived poor vision
  - National Eye Survey 1996 - 2.7% low vision/blind
  - National Ear and Hearing Survey 2005 - 17% with hearing impairment. 3.8% moderate to profound hearing loss
  - **NHMS III 2006 0.63% have a physical disability**
  - NHMSIII on mental disorders 11.2% among adult and 20.32% among children
  - Learning disabilities – screening at 7 years in school

CENSUS year 2000 – 1% with disability

# Malaysia - statistics

- Use ICF concepts in disability data collection where disability phenomenon has been described with greater clarity and precision
  - National Health Morbidity Survey in 2006
  - registration format for PWD

# Increasing prevalence

disability prevalence is affected by:

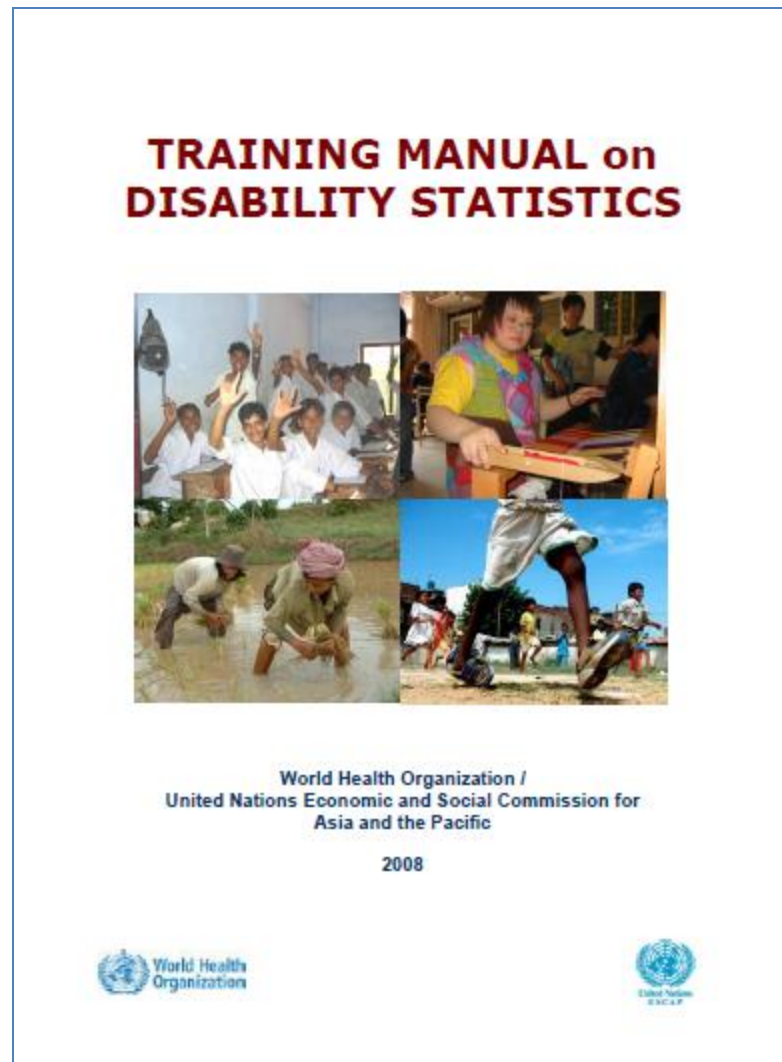
- **Population ageing**
  - **Non-communicable diseases**
  - **Road traffic injuries**
  - **Natural disasters**
- 
- Ageing is major influence on disability,
    - as older persons become frailer and more vulnerable to physical and mental conditions

# Ageing

- disabilities include sight impairment and blindness, hearing impairment and deafness, musculoskeletal diseases and mental disorders.
- Disability caused by musculoskeletal diseases (including chronic rheumatic diseases) cover about 200 conditions which affect joints, bones, soft tissue and muscles. Alzheimer's disease, characterized by progressive mental deterioration, is the most common form of dementia in older persons across Asia and the Pacific.

# Washington Group on Disability Statistics

- In 2001, the **Washington Group on Disability Statistics** was **formed** to facilitate the comparability of data around the globe
- Task : to come up with general disability questions that can be used in censuses and national surveys.



# Recomendation

- **Harmonizing concepts, definitions and methodologies**, which would help to promote comparability and reliability of disability-related data at both the national and international levels,
  - short set of questions developed by the Washington Group for use in national censuses
- Approaches to **increase general awareness** on disability in the population.
  - encourage family members to properly report and register persons with disabilities

*Thank you!*

**make** the  
right **real**

“To make people count, we have to count people right”.