

UN Regional Meeting on Disability Measurement and Statistics  
Bangkok, Thailand, 26-28 July 2016

# WHO's current work on disability data

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WHO Geneva

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2006: CRPD

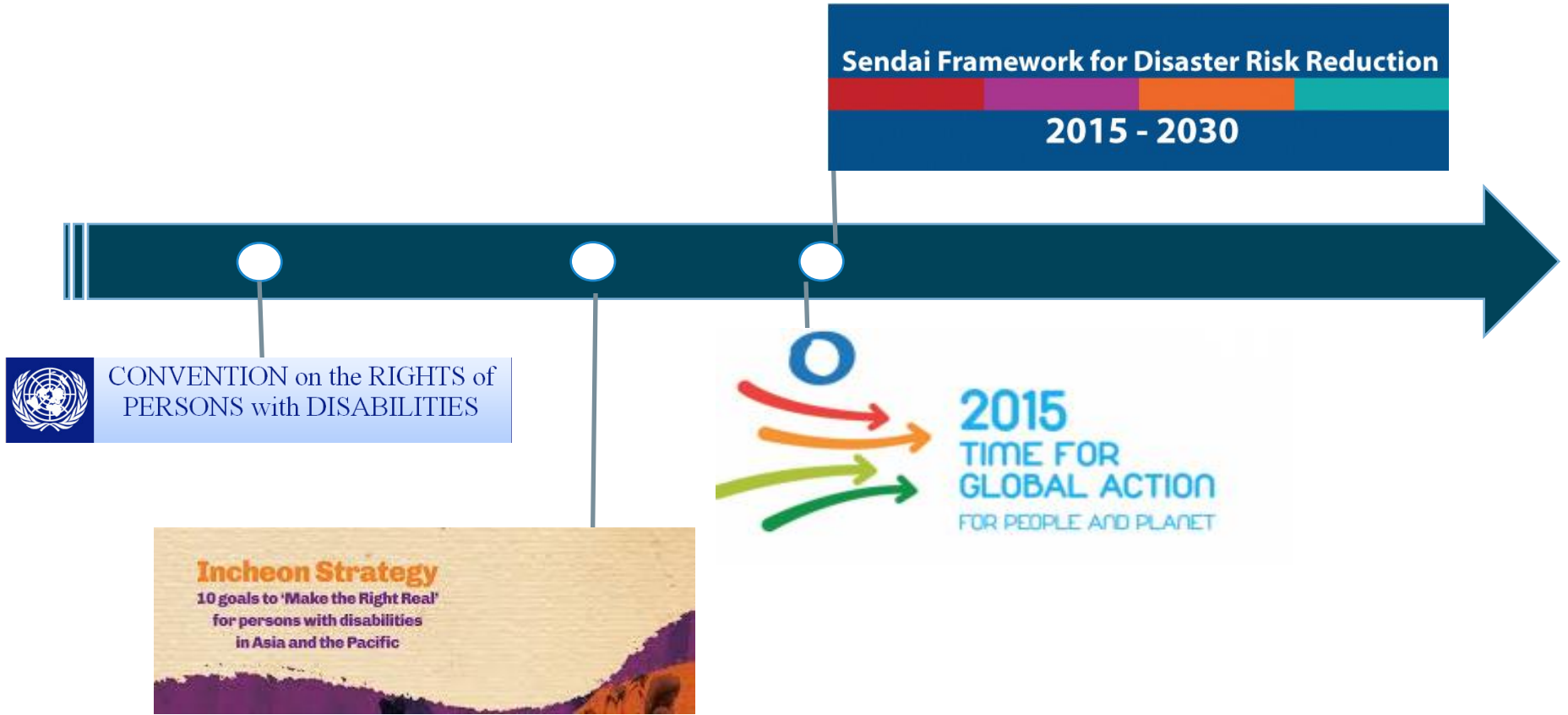


## CONVENTION on the RIGHTS of PERSONS with DISABILITIES

Persons with disabilities have to be able to participate in society  
“on an equal basis with others”

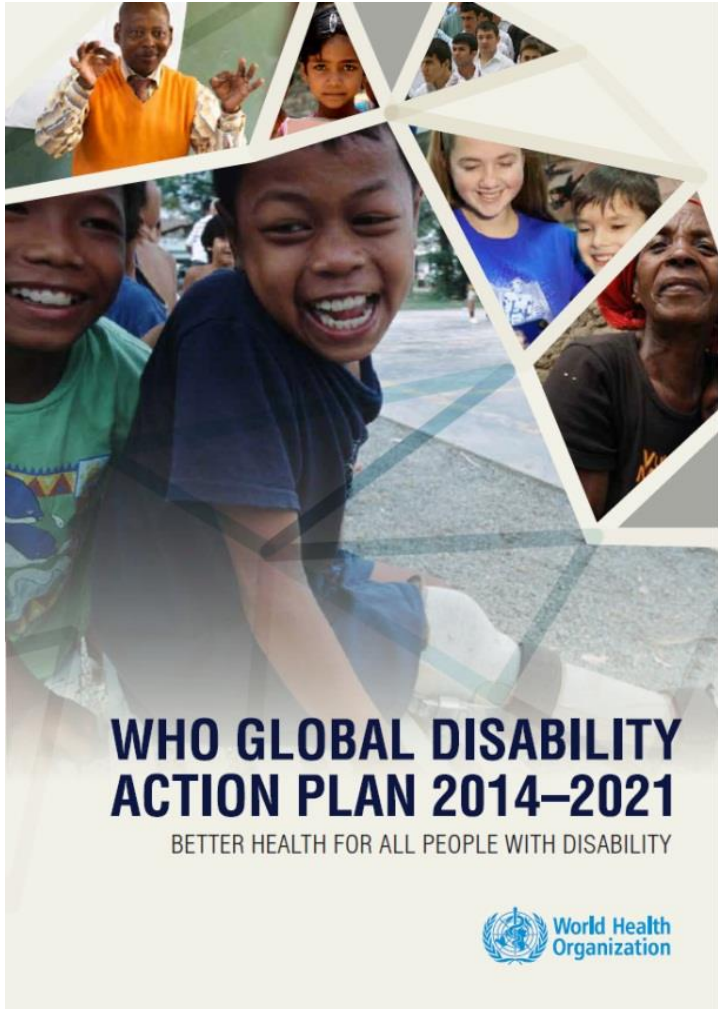
**Article 31** - Statistics and data collection

Statistical and research data for policy implementation



- Regional and national agendas
- UN Organizations





1.

2.

3.



# Purposes for collecting disability data

1. To determine the overall population **prevalence** of disability;
2. To identify the **existence and extent of the inequality**;
3. To **monitor** the effectiveness of concrete actions and policies at the national level; and
4. To **formulate policy recommendations**.

**Where all these data should  
come from?**

# Disability Data

## Censuses

1), 2), 3)

## Country Specific Surveys

1), 2), 3), 4)

## Disability Surveys

1), 2), 3), 4)

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## Administrative data

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What is about disability data coming from registers?

**Not useful for disability prevalence**



# WHO is working on ...

Censuses

Country Specific  
Surveys

Disability  
Surveys

Brief MDS

MDS

- What are the data collection approaches?
- Which disability data are we collecting?

# ICF

International  
Classification of  
Functioning,  
Disability  
and  
Health



World Health Organization  
Geneva

# Key ICF Concepts



Intrinsic capacity of the body

The result of the interaction of capacity with the environment and the person

# Key ICF Concepts

**Capacity** is the inherent or intrinsic feature of a person to do an action or execute a task  
“under the skin”

**Performance** is the doing of an action or execution of a task in the actual context of the individual  
“the lived experience”

# Why is it fundamental to have information about both?



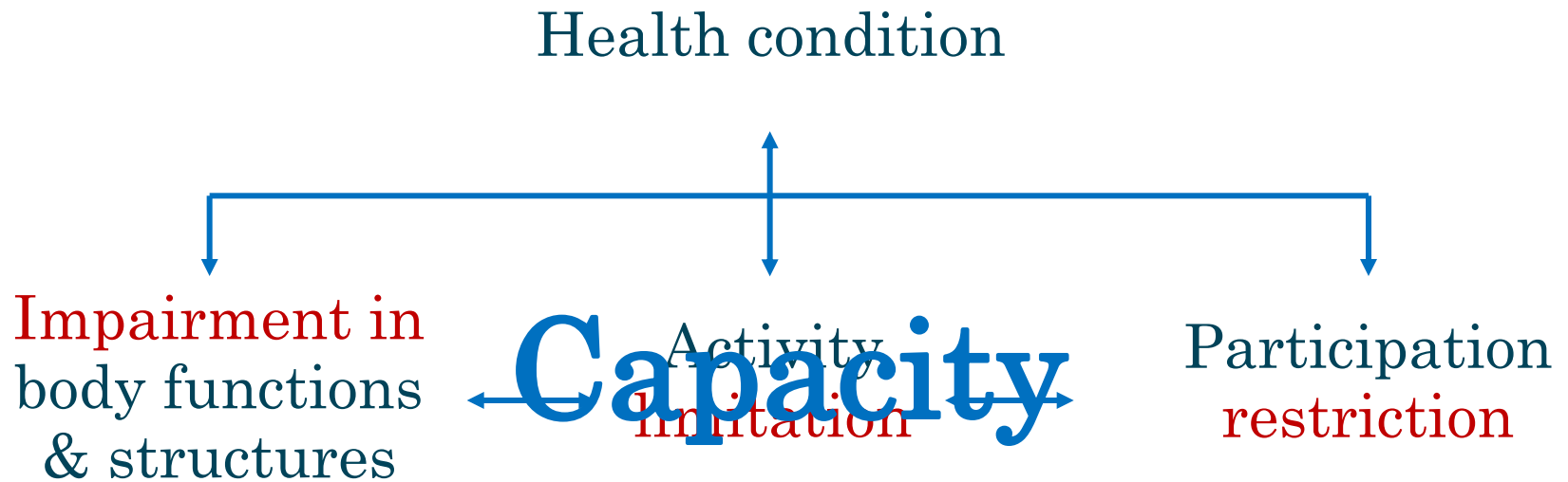
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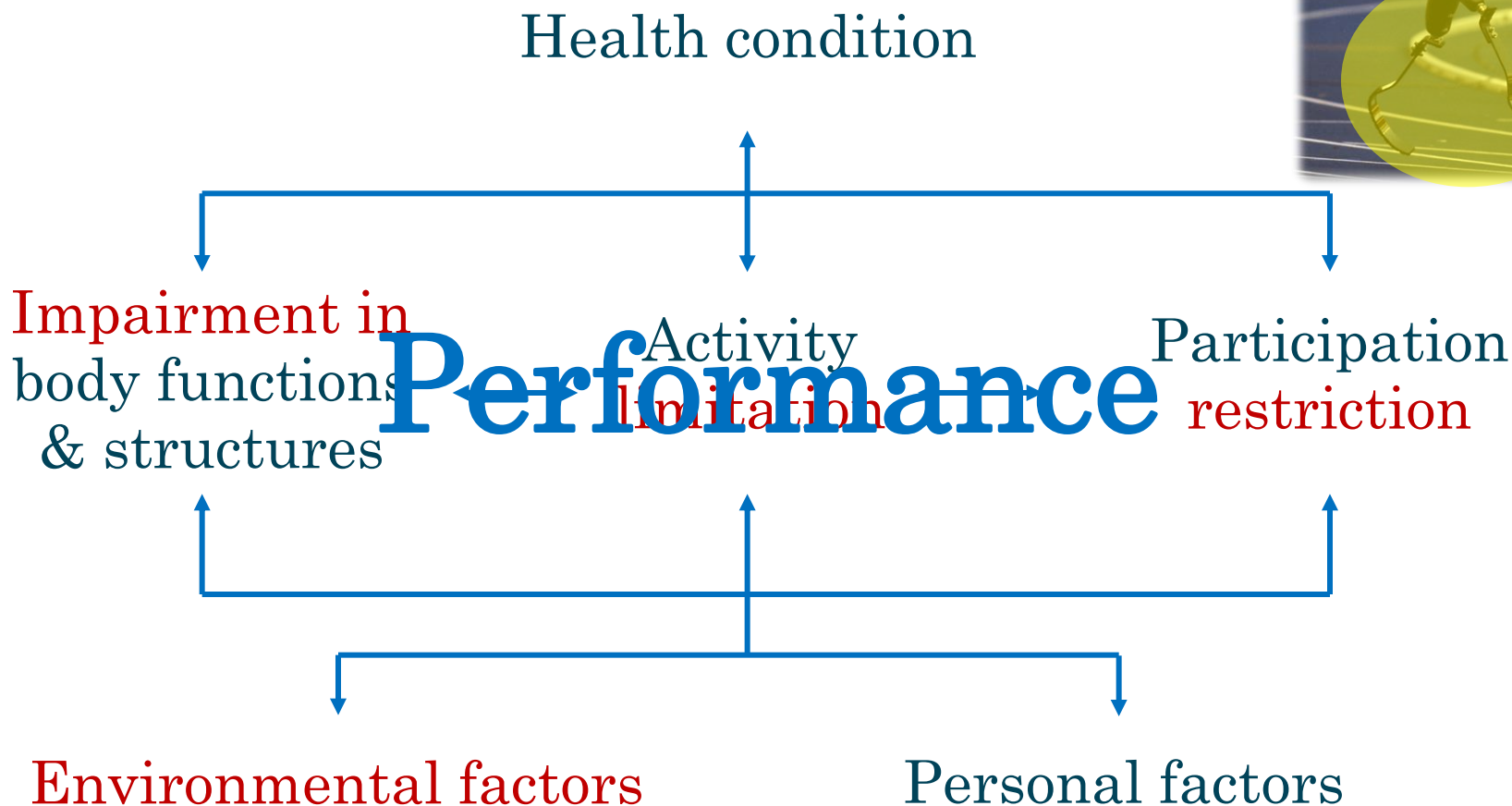


# Which information on disability is needed ?





# Which information on disability is needed ?



## Section 4000 Performance

How much of a problem is getting out of your home for you?

1 None	2	<del>3</del>	4	5 Extreme	8 <i>Don't Know</i>
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SCI



Migraine

## Section 5000 Capacity

How much difficulty do you  
have moving around **because**  
**of your health?**

1 None	2	3	4	<del>5 Extreme</del>	8 Don't Know
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# Model Disability Survey (MDS)



**World Health  
Organization**



**THE WORLD BANK**

# Fundamental modules

## Section 3000 A

Environmental  
factors

## Section 4000

Performance

## Section 5000

Health  
Conditions &  
Capacity

## Section 3000 B

Personal  
assistance,  
assistive  
devices,  
facilitators

# Fundamental modules

## Section 3000 A

Environmental  
factors

## Section 4000

Performance

## Section 5000

Health  
Conditions &  
Capacity

## Section 3000 B

Personal  
assistance,  
assistive  
devices,  
facilitators

## Section 1000

Socio-  
demographic  
Characteristics

## Section 2000

Work History  
and Benefits

## Section 6000

Health Care  
Utilisation

## Section 7000

Well-Being

## Section 8000

Empowerment

# Development process

## PHASE ONE

### MAPPING

### DRAFTING

- A) Review available surveys
- B) Statistical analysis with microdata
- C) Draft of a Zero MDS version
- D) Expert Consensus
- E) Alpha Version

Nov  
2011

Dec  
2012

## PHASE TWO

### TESTING & FURTHER DEVELOPMENT

- Cognitive testing
- Pilot studies

Aug  
2013

## PHASE THREE

### IMPLEMENTATION

- National Disability Surveys:
- MDS as stand alone survey
  - Addition of Brief MDS existing surveys and data collection platforms

Nov  
2014

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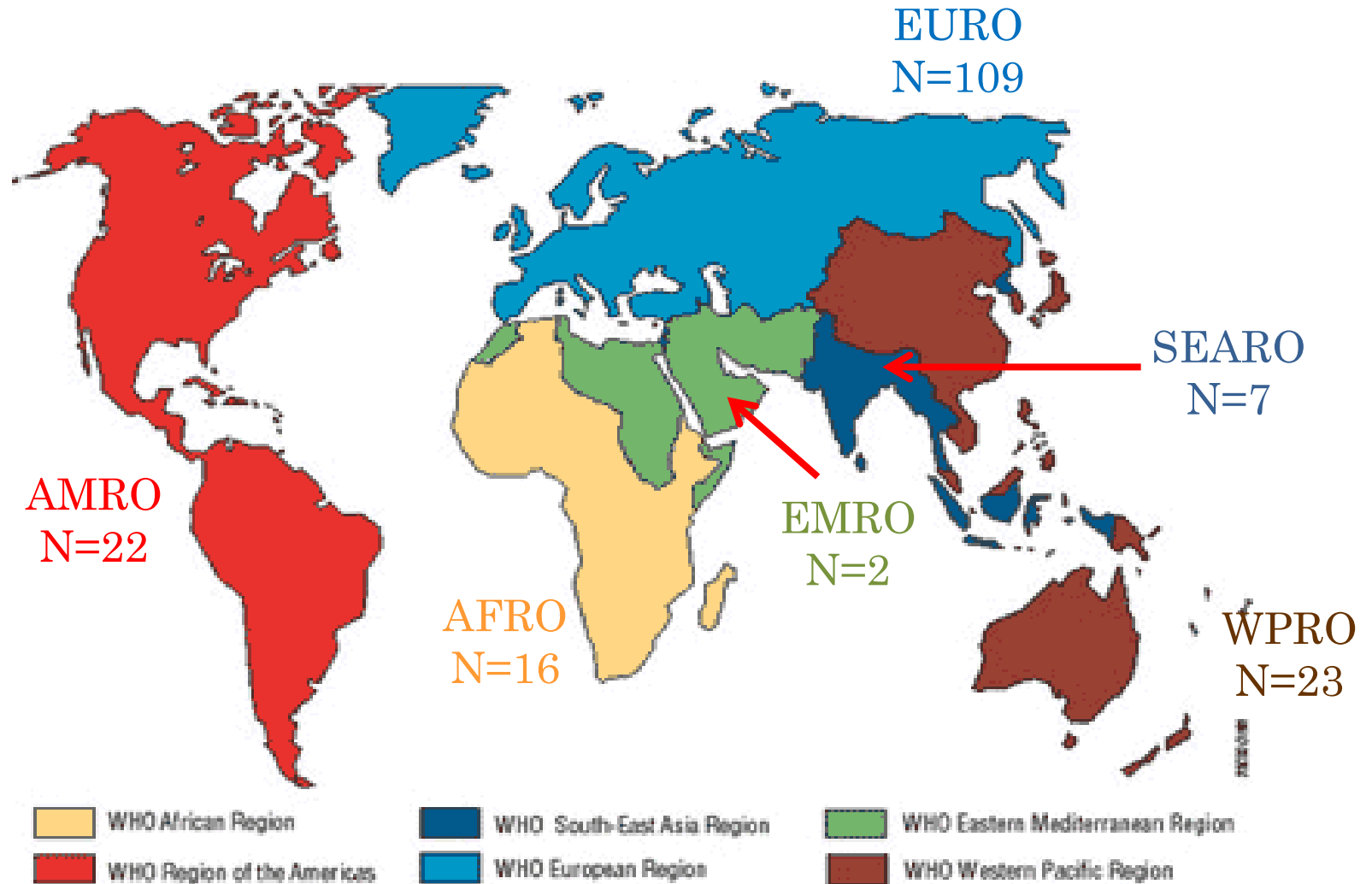
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2014



# 179 Health and Disability Surveys



# Preparatory phase

- <http://disabilitysurvey.checkdesign.de/>
- *Oberhauser C, Chatterji S, Sabariego C, Cieza A.* Development of a metric for tracking and comparing population health based on the minimal generic set of domains of functioning and health. *Popul Health Metr.* 2016 May 12;14:19. doi: 10.1186/s12963-016-0088-y.
- *Sabariego C, Oberhauser C, Posarac A, Bickenbach J, Kostanjsek N, Chatterji S, Officer A, Coenen M, Chhan L, Cieza A.* Measuring Disability: Comparing the Impact of Two Data Collection Approaches on Disability Rates. *Int J Environ Res Public Health.* 2015 Aug 25;12(9):10329-51. doi: 10.3390/ijerph120910329.
- *Sabariego C, Oberhauser C, Posarac A, Bickenbach J, Kostanjsek N, Chatterji S, Officer A, Coenen M, Chhan L, Cieza A.* Response to Madans et al. Comments on Sabariego et al. Measuring Disability: Comparing the Impact of Two Data Collection Approaches on Disability Rates. *Int. J. Environ. Res. Public Health*, 2015, 12, 10329-10351.

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# Cognitive testing

Three rounds: 2013, 2014, 2015

## Institutions

- National Center for Health Statistics, US
- Institute for Survey Research, University of Michigan, US
- Statistics Norway, Norway
- Institute for Public Health and Health Services Research, Ludwig-Maximilians-University Munich, Germany

## Countries

- US, Cambodia, Malawi, Nepal, China and UK

COUNTRY	RESPONSIBLE INSTITUTION	DATA COLLECTION	SAMPLE SIZE ADULTS	SAMPLE SIZE CHILDREN	STATUS
<b>Cambodia</b>	<ul style="list-style-type: none"> <li>• Statistics Norway (SN)</li> <li>• National Institute of Statistics Cambodia</li> <li>• WHO</li> </ul>	Aug 2014	500	500	<ul style="list-style-type: none"> <li>• Data analyses completed</li> <li>• Report being prepared by SN</li> </ul>
<b>Malawi</b>	<ul style="list-style-type: none"> <li>• Statistics Norway (SN)</li> </ul>	Mar 2015	500	500	<ul style="list-style-type: none"> <li>• Data analyses pending</li> </ul>
<b>Pakistan</b>	<ul style="list-style-type: none"> <li>• Ministry of Health</li> <li>• Pakistan Bait-ul-Mal*</li> <li>• WHO</li> </ul>	Feb & Mar 2015	3977	-	<ul style="list-style-type: none"> <li>• Data analyses completed</li> <li>• Report available</li> </ul>
<b>Oman</b>	<ul style="list-style-type: none"> <li>• Ministry of Health</li> <li>• WHO</li> </ul>	Oct & Nov 2015	300	300	<ul style="list-style-type: none"> <li>• Data collection completed</li> <li>• National survey being planned</li> </ul>
<b>Brazil</b>	<ul style="list-style-type: none"> <li>• Ministry of Health</li> <li>• WHO - OPAS</li> </ul>	Middle 2016	2000	tbd	<ul style="list-style-type: none"> <li>• In planning</li> <li>• Test for inclusion of modules in the national health survey of 2017</li> </ul>

\*Pakistan Bait-Ul-Mal (PBM) is one of the major public sector organizations and has been delivering since 1992 Social Protection program in terms of cash, in- kinds, care and services addressing almost every needy segment of the society.

## **VERSION ZERO (Dec 2012)**

**Expert meeting - 5th Dec 2012**

## **ALPHA VERSION**

**Expert appraisal Norway - March 2013**

**First revised Alpha version (March 2103)**

**Expert Meeting - 29-30 April 2013**

**Second Revision of the Alpha Version (May 2013)**

**1st Round of Cognitive Testing**

**Revised Alpha version - 1st round cognitive testing (Oct 2013)**

**2nd Round of Cognitive Testing**

**Revised Alpha version - 2nd round cognitive testing (July 2014)**

**Preparatory work national survey Chile (Nov 2014)**

**Revised Alpha version after preparation in Chile (Nov 2014)**

**MDS Group Intern Meeting, July 2015 – results pilot studies (Cambodia, Pakistan, Malawi) and preparation for the national surveys (Sri Lanka and Chile)**

**CURRENT MDS ALPHA VERSION (July 2015)**

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# National Surveys – 2015



## CHILE

- Data Collection: June to August 2015
- Sample: 12.000 individual interviews

## SRI LANKA

- Data Collection: February to April 2015
- Sample: 3.000 households





# National Surveys



**PANAMA**

Planned data collection: October-December 2016

**PHILLIPINES**

Planned data collection: January – February 2017



**Pakistan**

Planned data collection: 2017



# Regional Surveys



**DUBAI, United Arab Emirates**

Planned data collection: October-November 2016

**ADAMAWA, CAMEROON**

Data collection: April– June 2016



**Tehsil Pindi Gheb, Pakistan**

Data collection: April– June 2016



# Included in existing surveys



## Chile

- MDS Brief Version
- National Health Survey 2016

## BRAZIL

- MDS Brief version
- National Health Survey 2017



# Model Disability Survey (MDS)



**World Health  
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# Capacity



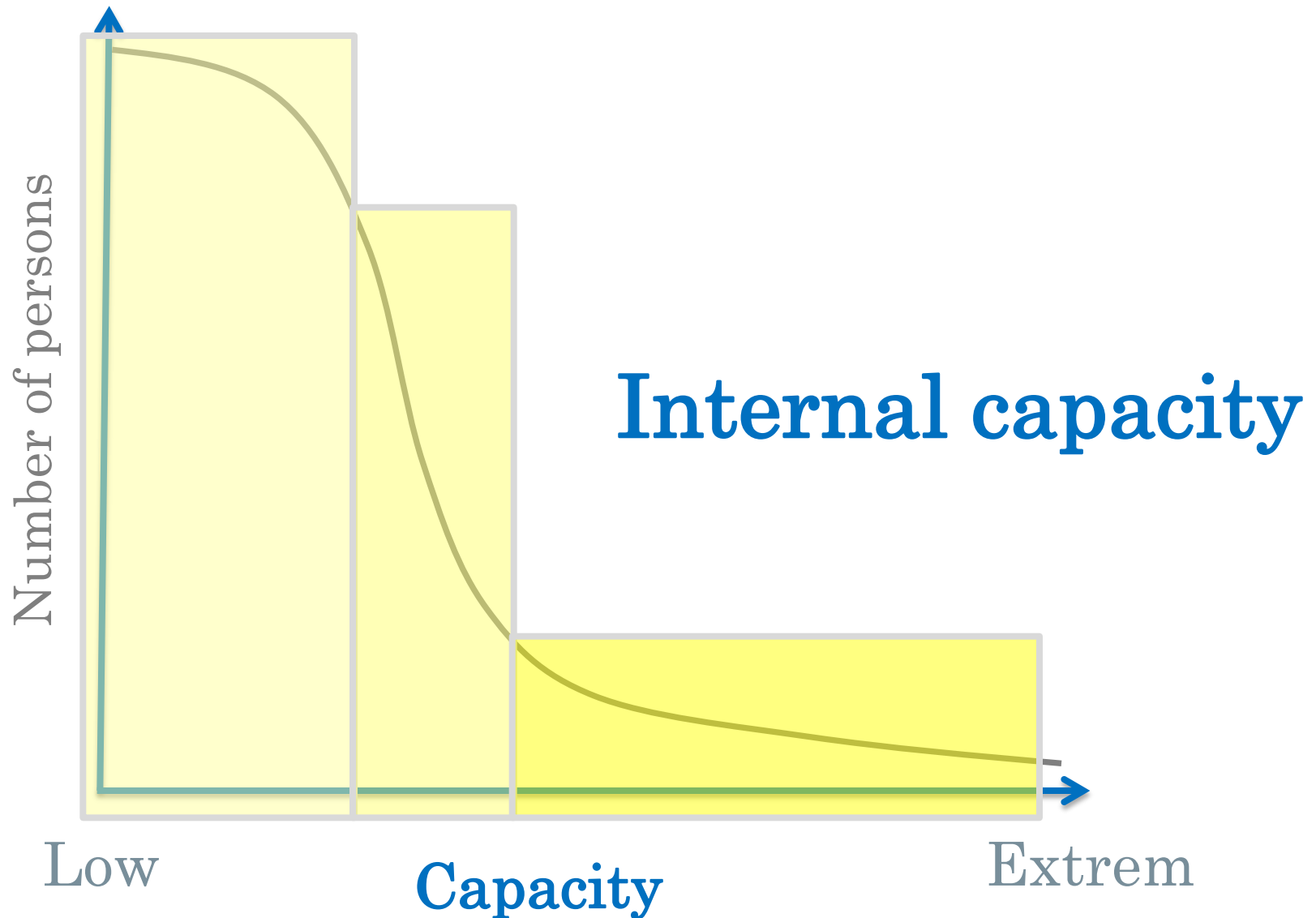
# Performance



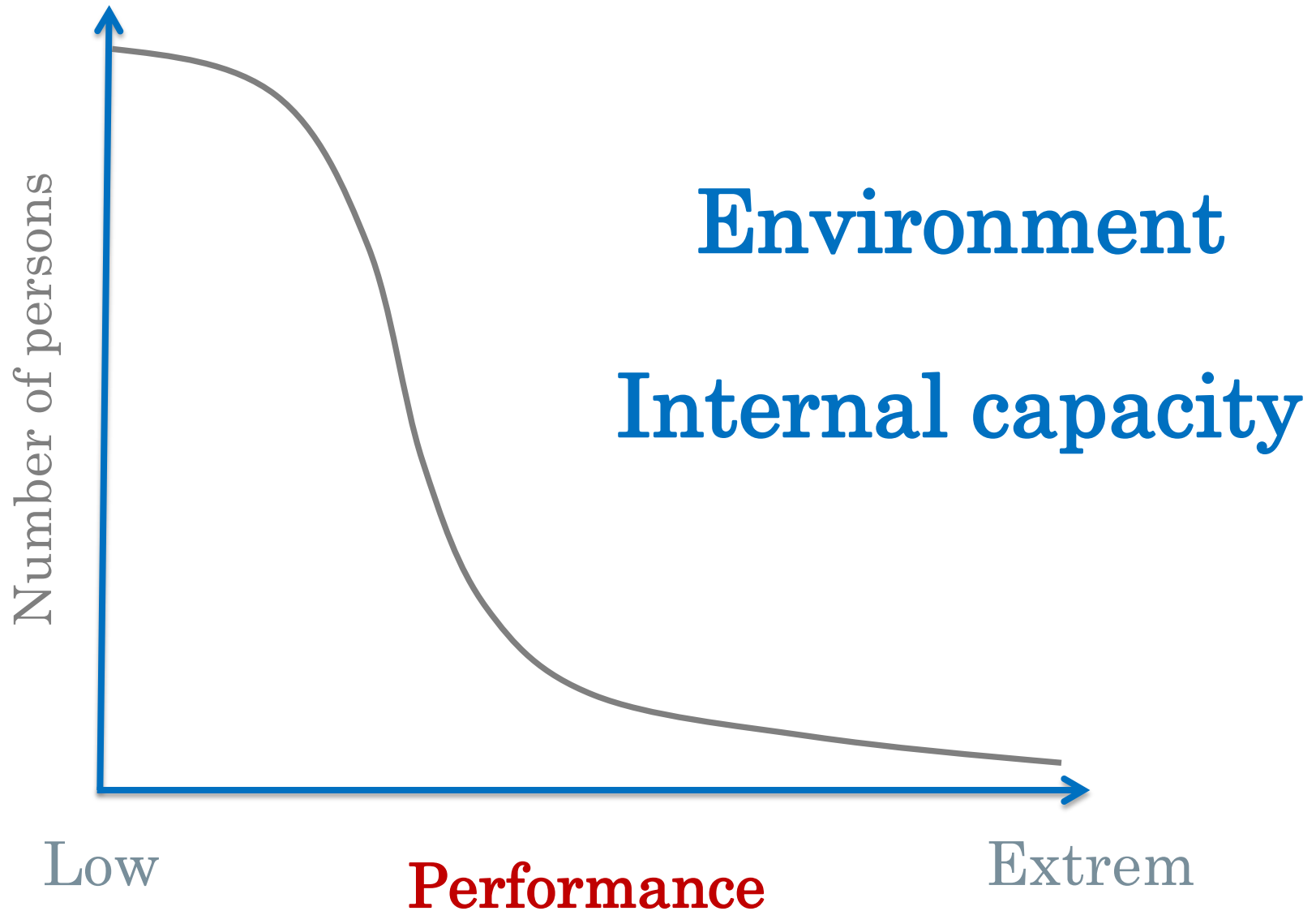
Intrinsic capacity of the body

The result of the interaction of capacity with the environment and the person

Both capacity and performance are in a continuum and are unidimensional



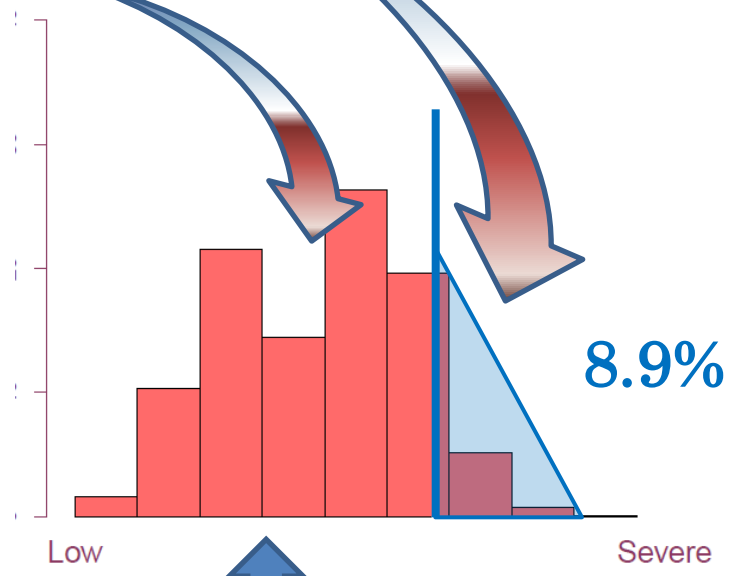
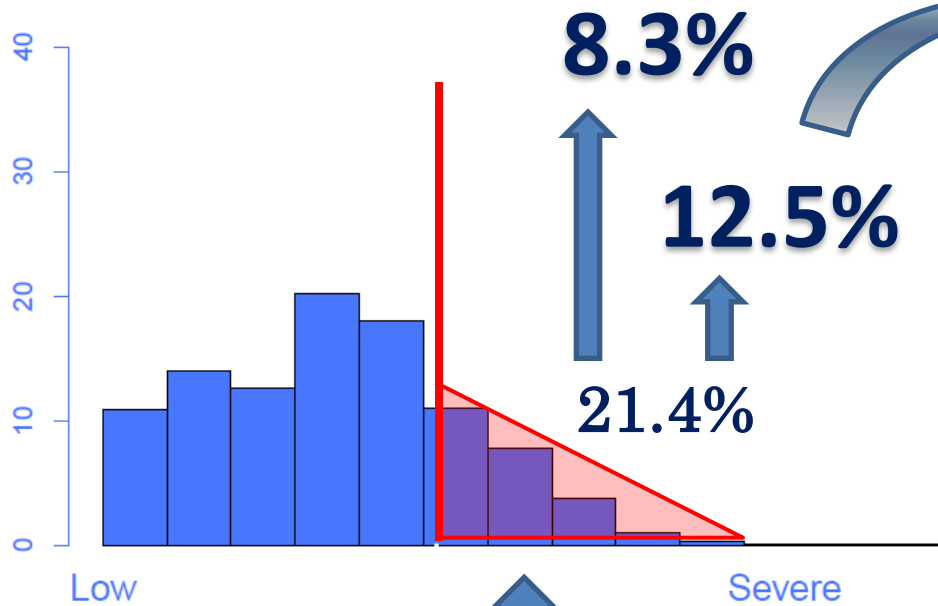
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# CHILE (N=12265)

## Capacity

## Performance

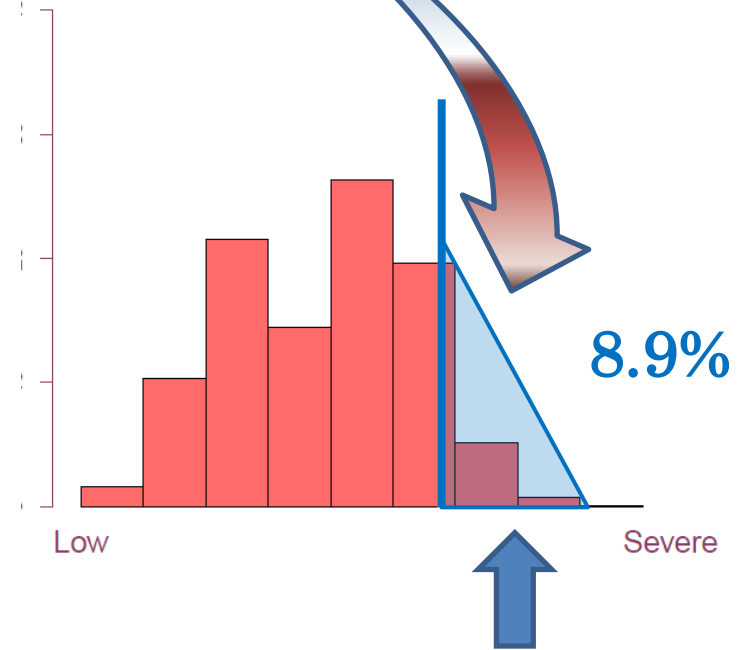
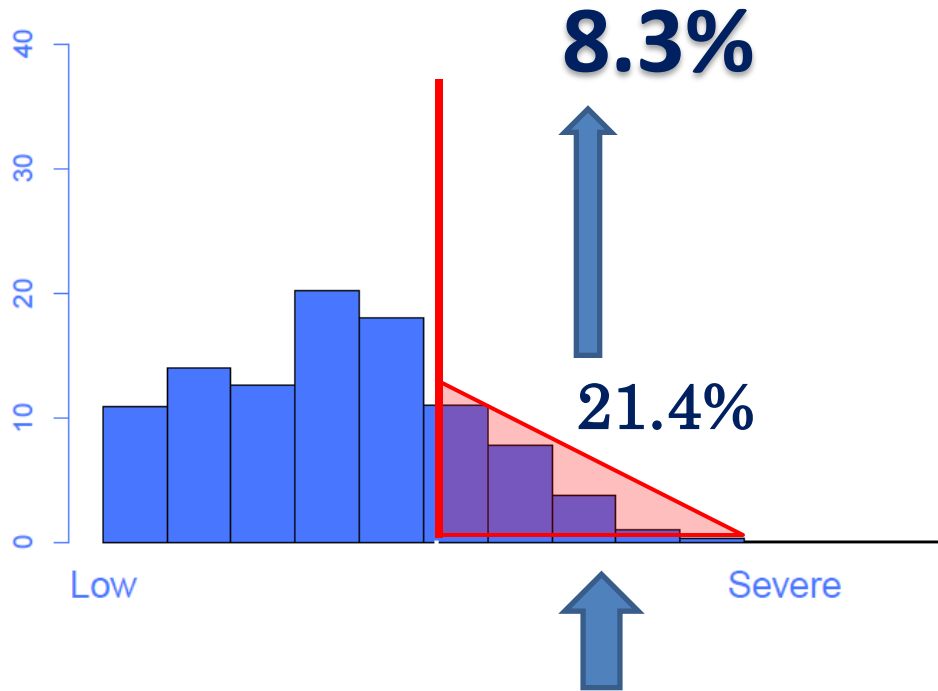




# CHILE (N=12265)

## Capacity

## Performance



# GOAL 11

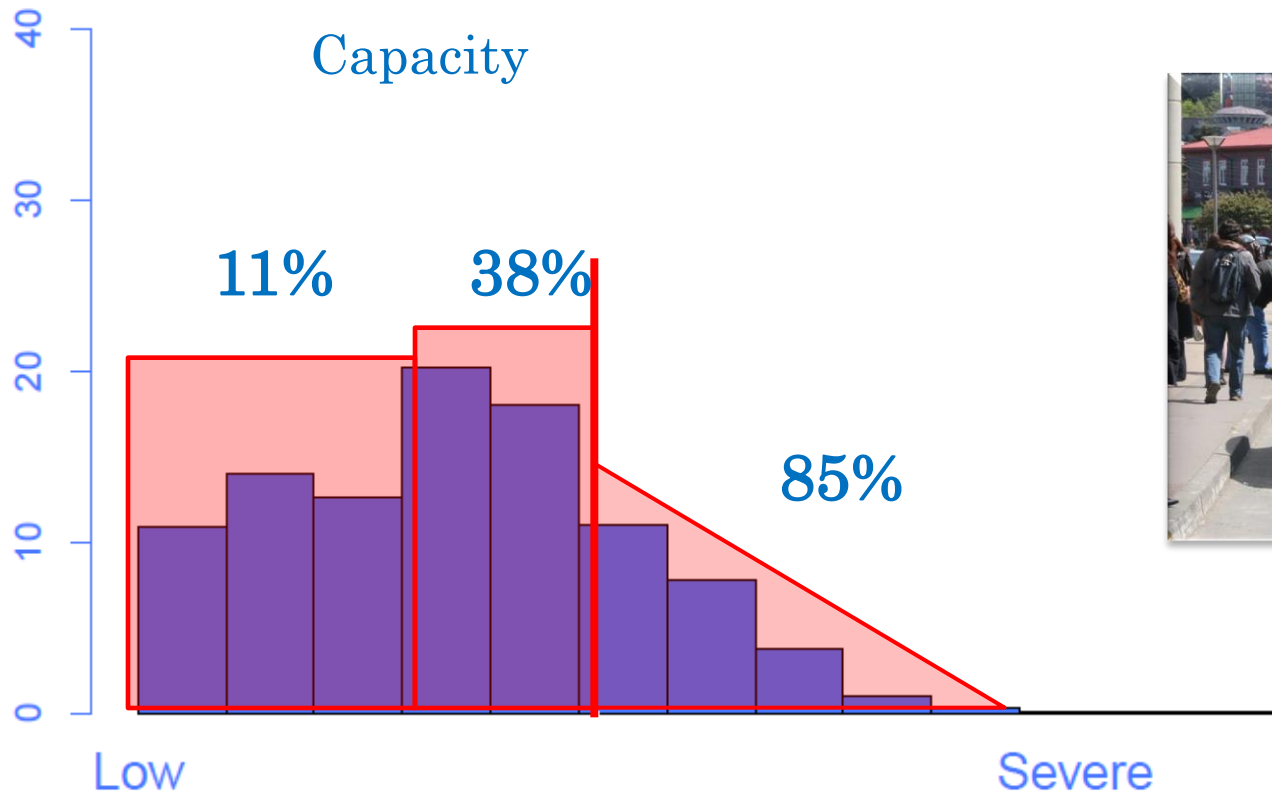
# Chile

SUSTAINABLE DEVELOPMENT GOALS



## 11.2.1 Proportion of population that has convenient access to public transport

% who have problems using transportation



13%

26%

57%

Experienced barriers

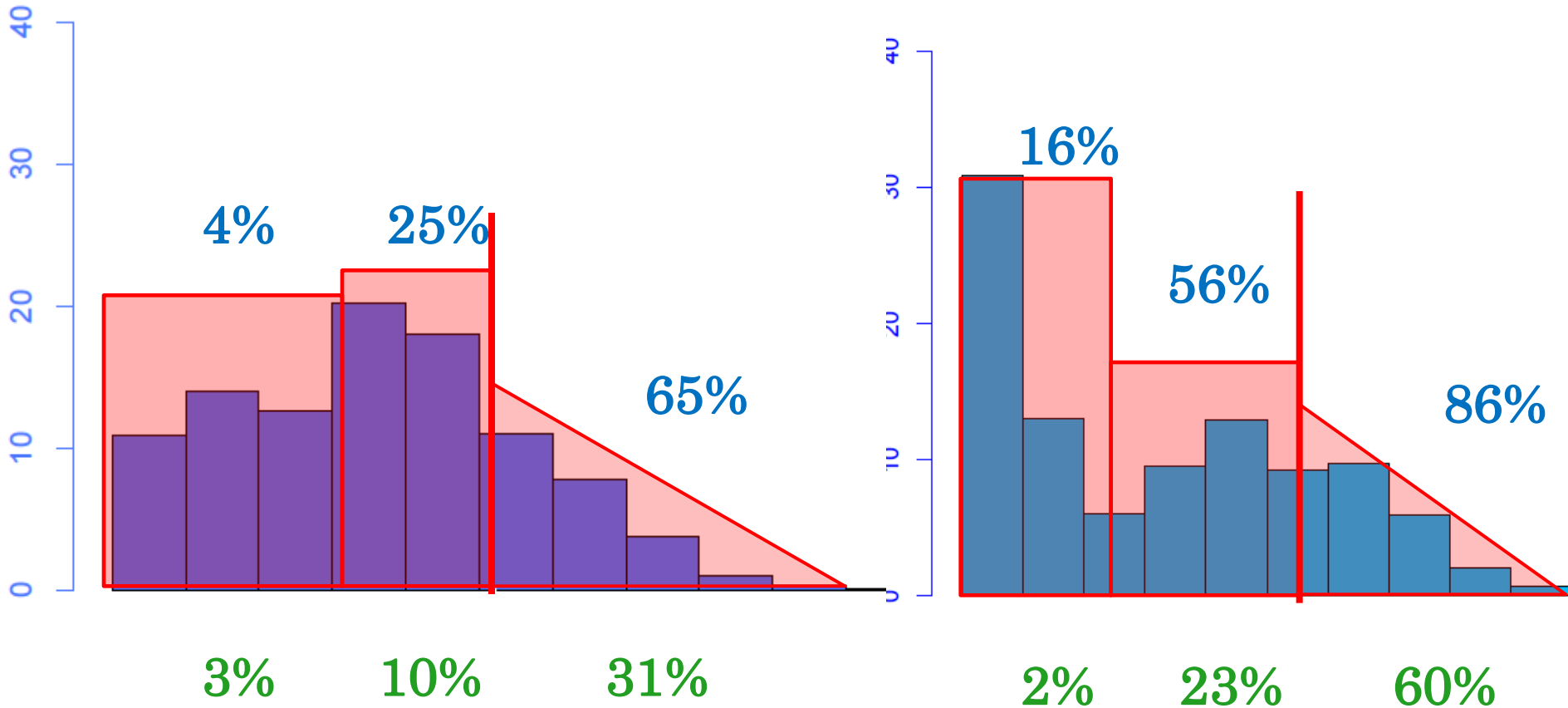
# GOAL 8

# Chile & Sri Lanka

SUSTAINABLE DEVELOPMENT GOALS



% who have problems getting things done at work



Experienced Barriers at the workplace

# GOAL 6

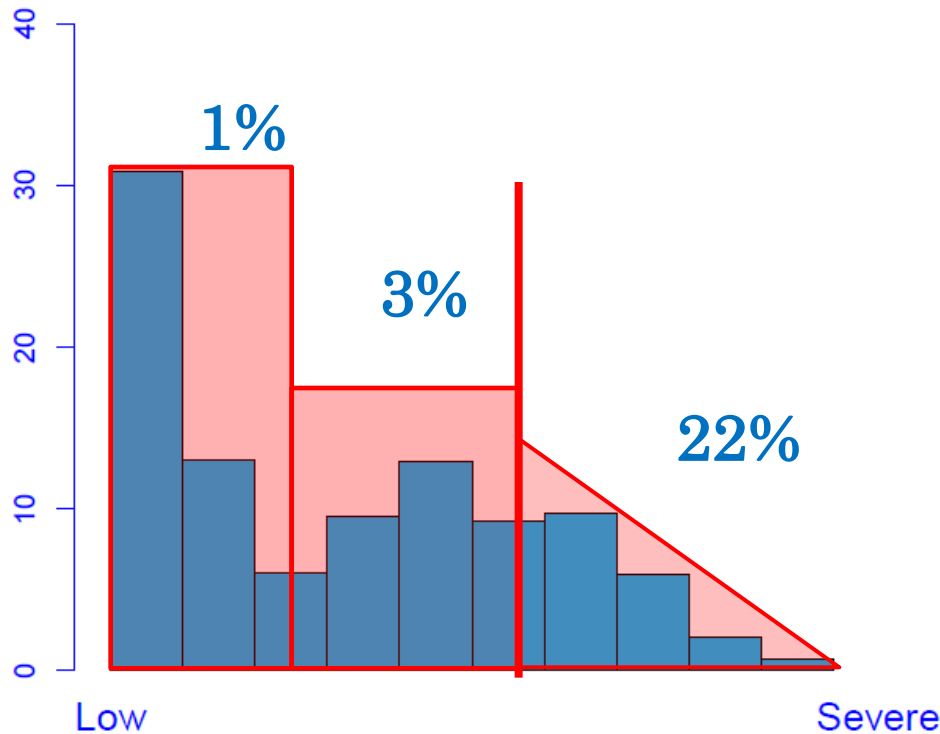
## Sri Lanka

SUSTAINABLE DEVELOPMENT GOALS



### 6.2.1 Proportion of population using safely managed sanitation services

% who find hard or very hard to use the toilet of the dwelling



# Collaboration between WHO and countries

- Close collaboration with the countries
  - Training
  - Analyses
  - Reporting
- We encourage the collaboration among the statistical office, ministries and UN organizations