

# United Nations Children's Fund (UNICEF)

## Data on children & disability



# UNICEF's global work on statistics and monitoring the situation of children & women

- **Supporting data collection**

- Multiple Indicator Cluster Surveys (MICS) in +/- 100 countries worldwide
- Together with DHS, most important source of data to track progress against the Millennium Development Goals

- **Leading data analysis**

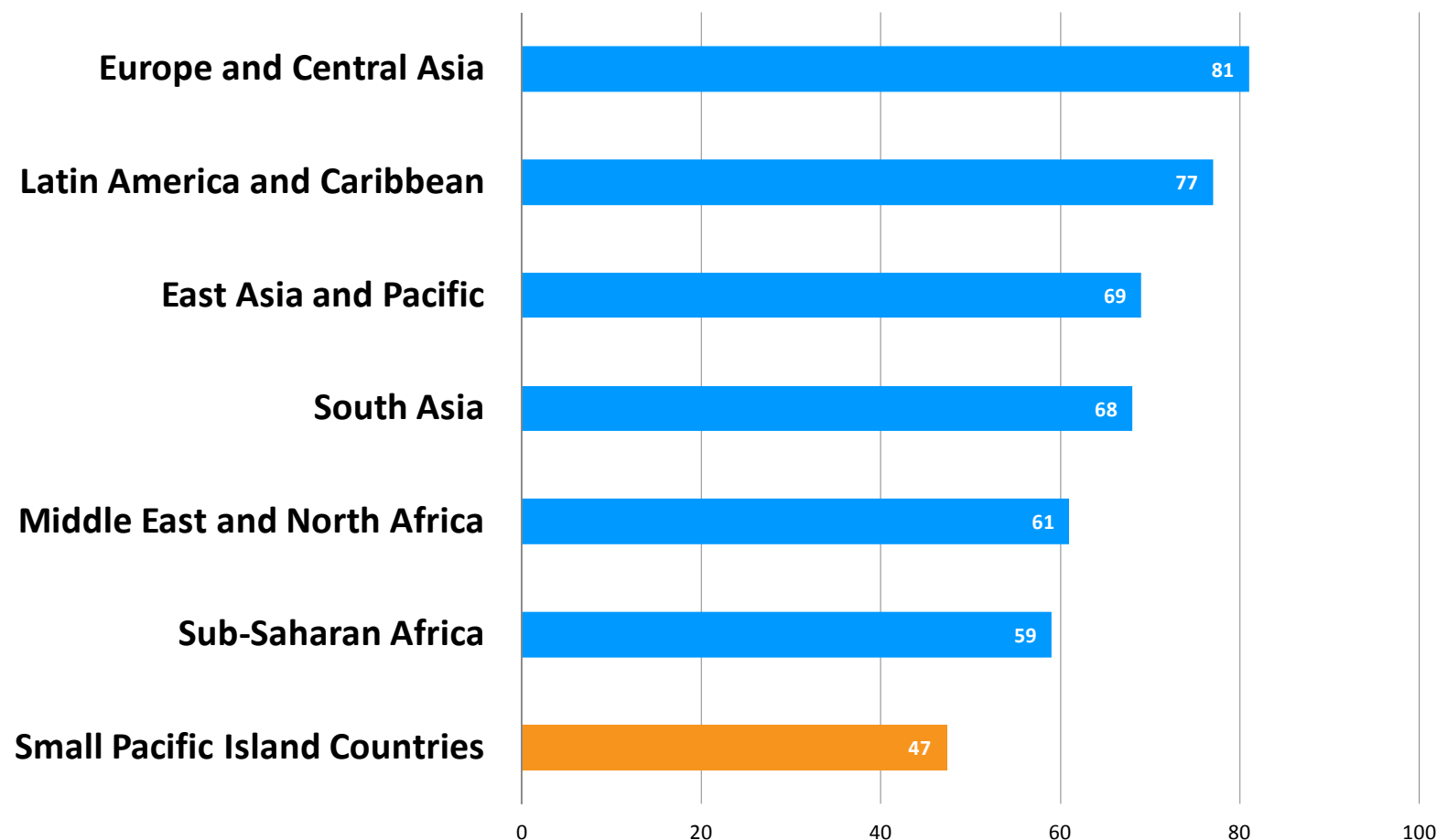
- New methodologies and tools for child and maternal mortality, immunisation, water and sanitation, child disability, ECE, etc.
- Global databases on key indicators
- Disaggregating data by gender, geography, wealth, etc.

- **Enhancing data dissemination**

- Statistical publications for planning and monitoring purposes
- Enhancing (online) access to data ([childinfo.org](http://childinfo.org))

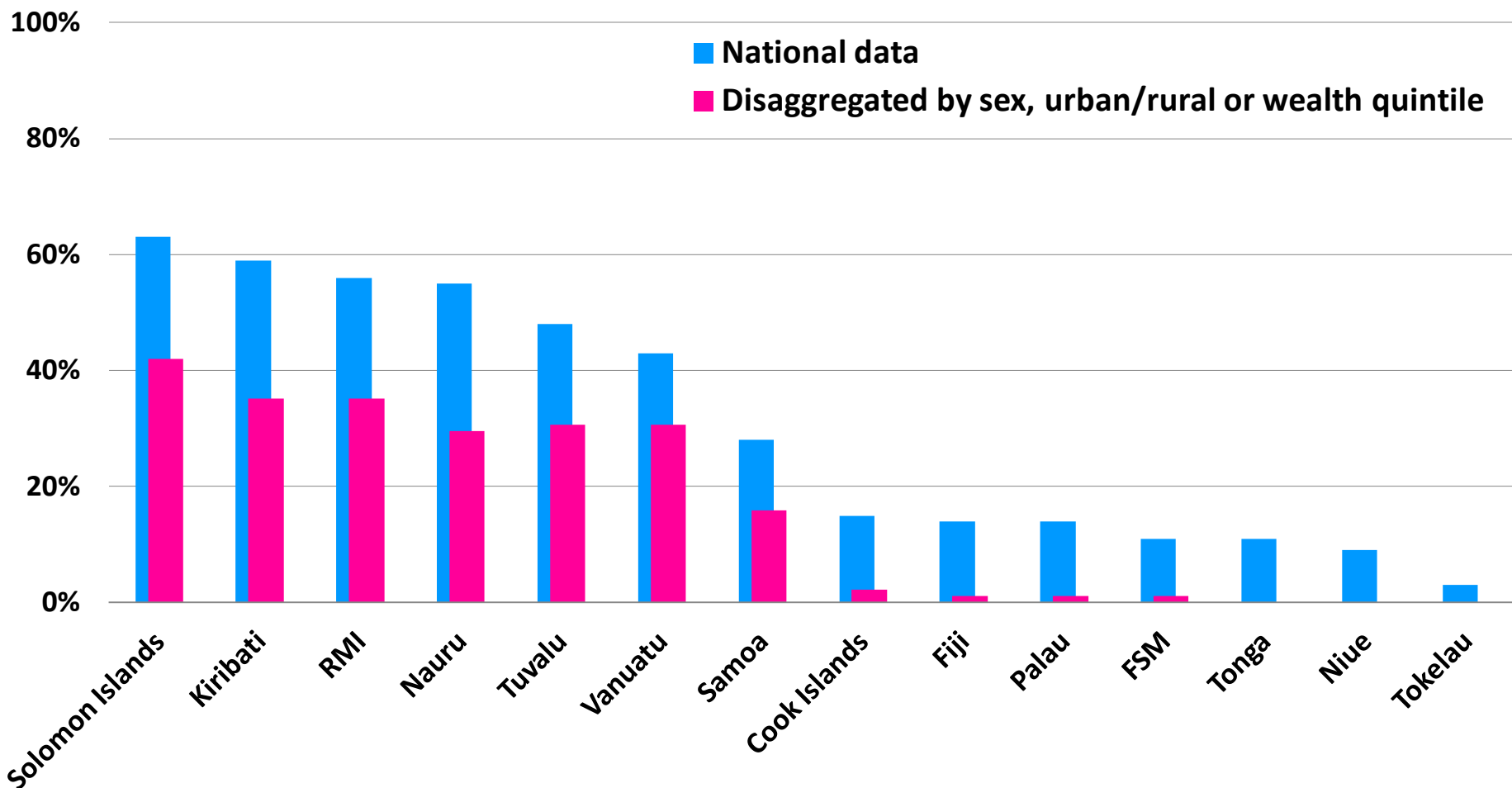
# Statistical capacity in small Pacific Islands is lower than any other region in the world

Statistical Capacity Indicator (0=lowest, 100=highest) by Region, 2012

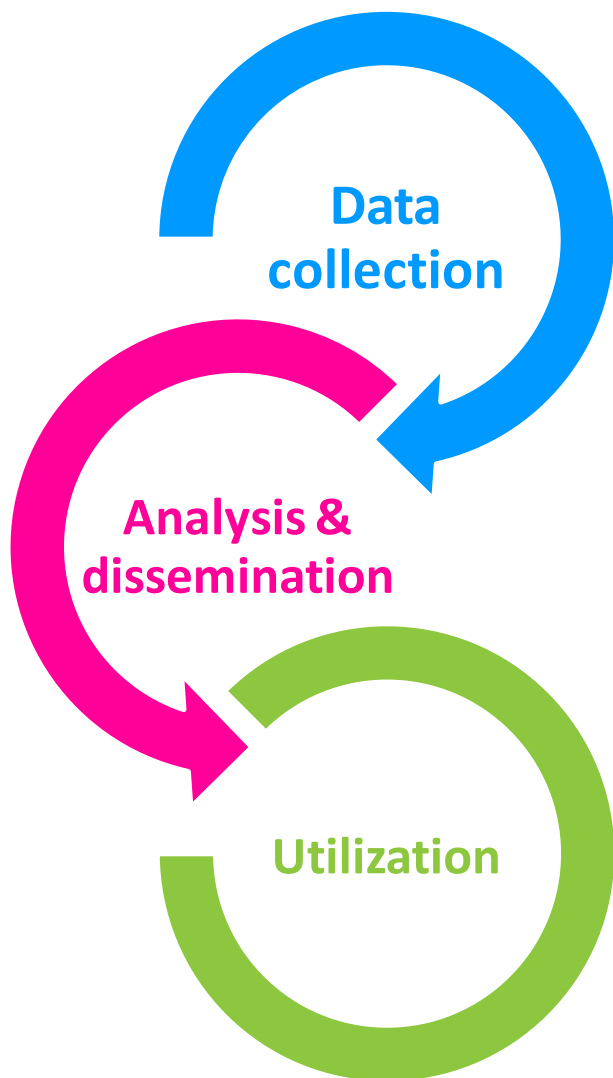


# Availability of data on children and women relatively low but improving

Percentage of Global UNICEF indicators available (out of 88 in total) by country, 2012



# UNICEF Pacific key activities on statistics



- Vanuatu 2013 Demographic and Health Survey (DHS/MICS)
- Sentinel Site Monitoring (impact of triple f crisis)
- Children's Atlases of Social Indicators
- Kiribati profile of child poverty
- Disability statistics
- Building statistical literacy among data users



# Disability Statistics in the Pacific

# Video: statistics on disability



# Disability Statistics: Why?

## GLOBAL

- **Increasing International Attention and Action.**
- **The Convention on the Rights of Persons with Disabilities (CRPD).**
  - Adopted in 2008
  - Ratified by 130 countries globally, 4 PICs, 6 signed.
  - Article 31 - States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention
- **UN High Level Meeting on Disability** – 23 Sept, 2013, day before UN General Assembly.
- **Increasing Action Across UN System** to address rights of people with disabilities.
- **Post 2015 Agenda** - The report of the High Level Panel of Eminent Persons on the post 2015 Development Agenda explicitly states that (among other groups) those with disability must not be 'left behind' and calls for all data to be disaggregated by disability.



# Disability Statistics: Why?

## REGIONAL

### **Asia Pacific Disability Decade (2013 - 2022), UNESCAP “Incheon Strategy”**

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

- **Target 8.A and 8.B:** Produce and disseminate reliable and internationally comparable disability statistics, establish reliable disability statistics by the midpoint of the Decade, 2017, to track progress towards the achievement of Incheon goals and targets.

### **Forum Disability Minister’s Meeting 2012 and Pacific Regional Strategy for Disability (PIFS)**

- **Calls** for increased efforts to assist countries to collect and analyse relevant data to improve understanding of situation of people with disability.
- **Urges** National and regional stakeholders to work together to increase the disability data, research and knowledge and use this to better inform decision making.

# Purpose of disability statistics

## 1. Monitoring population level of functioning:

- Need to know 'how many' to make it a key issue in policy-making
- Evaluating interventions designed to prevent or minimise disability

## 2. Designing service provision:

- Making general services more inclusive
- Specific services targeted at disabled people (e.g. prosthetic devices, rehabilitation services)
- Efficient allocation of resources

## 3. Assessing the equalization of opportunity:

- Assess the impact of having a limitation & inequities
- Reporting for CRPD

# Towards standardization & harmonization

1. International Classification of Functioning, Disability and Health (ICF)
2. Washington Group on Disability Statistics (WG) questions for censuses and surveys (add-on)
3. UNICEF/WG Module on Child Functioning and Disability for censuses and surveys (add-on)
4. WHO/WB Model Disability Survey (dedicated, stand-alone survey)

# Recommended WG Short Set of Questions

*The next questions ask about difficulties you may have doing certain activities because of a health condition.*

- 1. Do you have difficulty seeing, even if wearing glasses?*
- 2. Do you have difficulty hearing, even if using a hearing aid?*
- 3. Do you have difficulty walking or climbing steps?*
- 4. Do you have difficulty remembering or concentrating?*
- 5. Do you have difficulty (with self care such as) washing all over or dressing?*
- 6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?*

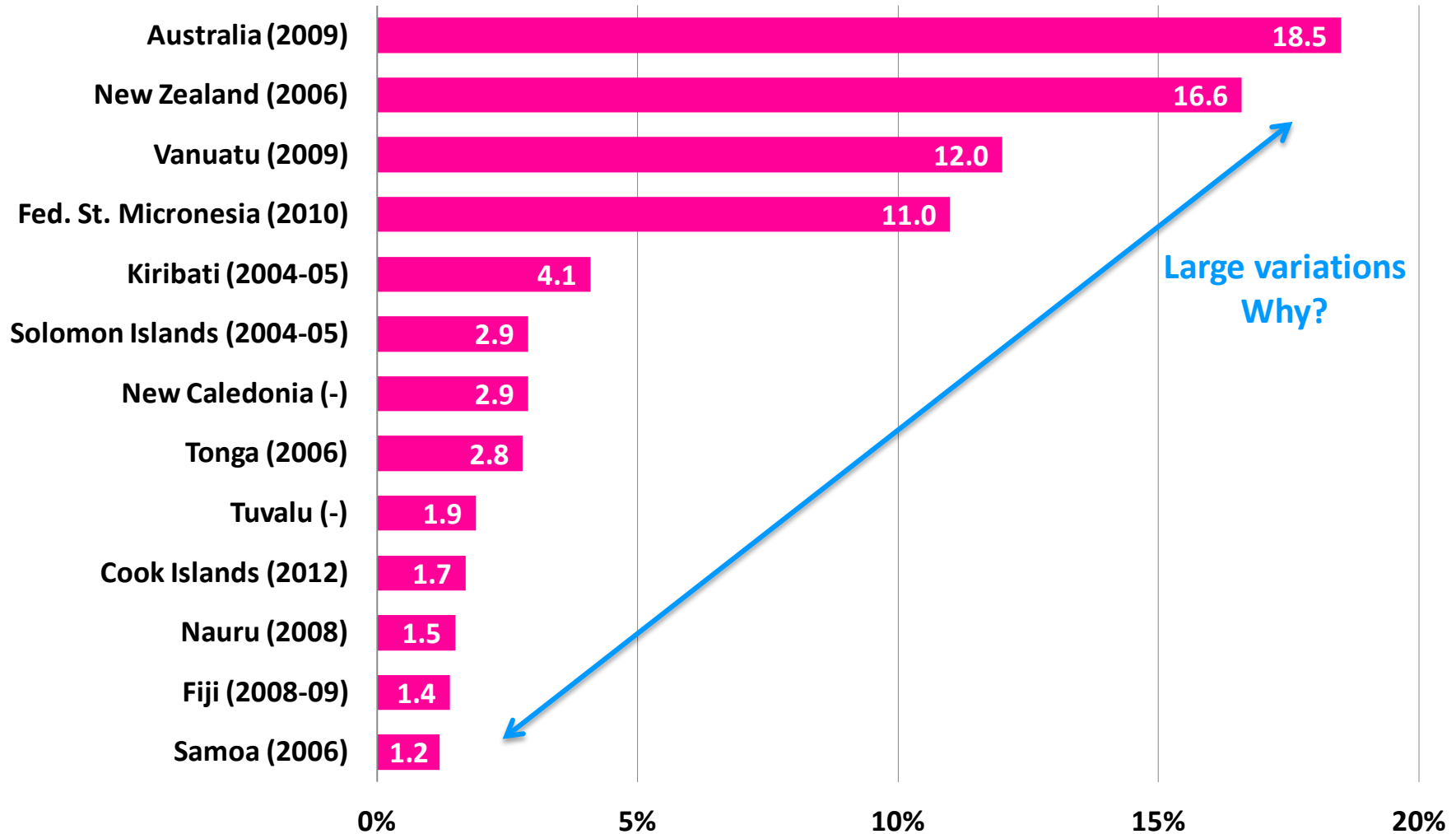
- Each question has **four response categories**: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all. The severity scale is used in the response categories in order to capture the full spectrum of functioning from mild to severe.
- **Recommended cutoff**: Disabled includes everyone with at least one domain that is coded as a lot of difficulty or cannot do it at all.

# Challenges in measuring childhood disability

- Questions addressed to adults are inappropriate or different in kind for children (e.g. falling over, reaching and stretching, behavioural problems)
- Questions addressed to children are sometimes inappropriate for adults (e.g. crawling, running, communicating)
- When should developmental delay be regarded as disability
- Parental knowledge of norms, standards and children performances
- Variations by culture
- Does one look at what child can do, does do, wants to do or is allowed to do? Importance of the family and social context

**=> A *Module on Child Functioning and Disability* is currently being tested by UNICEF in collaboration with Washington Group on Disability Statistics and will be available for countries shortly.**

# Disability prevalence in Pacific



Source: UNESCAP (2012) Disability at a Glance. Based on data submitted by governments. Data are not available for American Samoa, French Polynesia, Guam, Marshall Islands, Niue, CNMI, Palau, and Papua New Guinea.

# Different data sources in PICs

- **Disability questions in censuses (11 out of 14 PICs):**
  - Cook Islands (2011), Fiji (2007), FSM (2010), Nauru (2011), Niue (2011), RMI (2011), Samoa (2011), Solomon Islands (2009), Tonga (2006), Tuvalu (2012), Vanuatu (2009)
- **Dedicated national disability surveys (6 PICs):**
  - Cook Islands (2001), Fiji (2010), Kiribati (2005), Samoa (2005), Solomon Islands (2005), Tonga (2006)
- **Disability questions in other surveys (4 PICs):**
  - Fiji (EUS 2011), Samoa (DHS 2009), Tonga (HIES 2009 & DHS 2011), Vanuatu (DHS-MICS 2013)
- **Registers:**
  - Admin data collected by Ministries of Education, Health, Social Welfare, NGOs, etc. Most countries (?)

# Different types of questions in censuses

- **“Do you have a disability?”** + List of conditions:  
*Niue, Samoa, Tuvalu*
- **Activity-based questions:**
  - with severity scale: *FSM, Nauru, RMI, Solomons, Vanuatu*
  - without scale (yes/no): *Cook Islands, Fiji*
- **Mixed approach:** *Tonga*
- **No disability question:** *Kiribati, Palau, PNG*



# Illustration: Impairment versus Interaction

- **Samoa Census 2006: 1.2%**

P14. Any disability?

P15. Select only **one** most serious type of disability

1. Speech
2. Visual
3. Hearing
4. Slow learner
5. Emotional/Mental
6. Autistic
7. Epileptic
8. (Physical like stroke)
9. Others

- **Vanuatu Census 2009: 12%**

P15. This question asks about *difficulties* this person may have, doing certain activities because of a health problem. *Does this person have difficulty in:*

a. Seeing, even wearing glasses?

b. Hearing, even if using a hearing aid?

c. Walking, or climbing steps?

d. Remembering or concentrating?

ND = No difficulty at all

SD = Some difficulties

CD = Cannot do at all

# ‘Do you have a disability?’

Asking some variant of this question generates the lowest rates of disability because:

1. The word “disability” has very **negative connotations**. People may feel stigma or shame at identifying themselves as disabled.
2. The word “disability” often implies a **very significant condition**. Perception that their situation is not severe enough to be considered a disability.
3. Disability is interpreted relative to some unspoken **cultural standard** of what is considered normal functioning. This may vary across various cultures, age groups, or even income groups.

# General rules of thumb

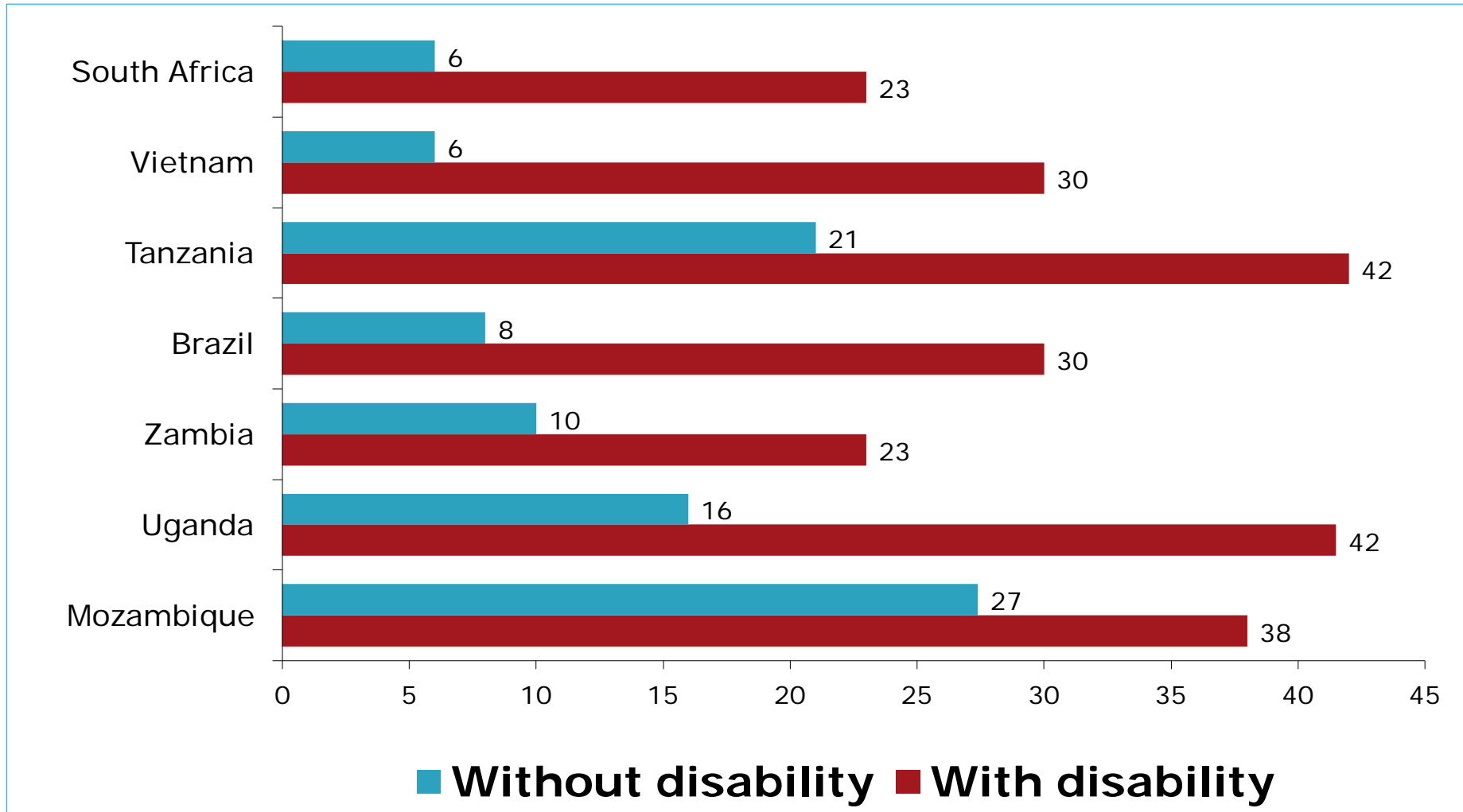
- Questions should be based on functionality.
- Questions should focus on basic core activities.
- The word “disability” should not be used. Avoid derogatory language.
- Responses should be scaled rather than yes/no
- A range of prevalence should be reported for various levels of severity, rather than a single prevalence rate.

# Limited analysis & dissemination in Pacific

- Presentation of disability data is usually limited to tabulations showing the number of disabilities present in the population
- Cross-tabulations with other characteristics are not usually made, but are critical for informing policy:
  - Socio-economic profiles of persons with disabilities
  - Comparing persons with and without disabilities in terms of access to education, employment, etc. (= measure of social inclusion / equalization of opportunities)
- UN Guidelines and Recommendations for tabulations and dissemination strategies are available
- Importance of metadata to contextualise statistics

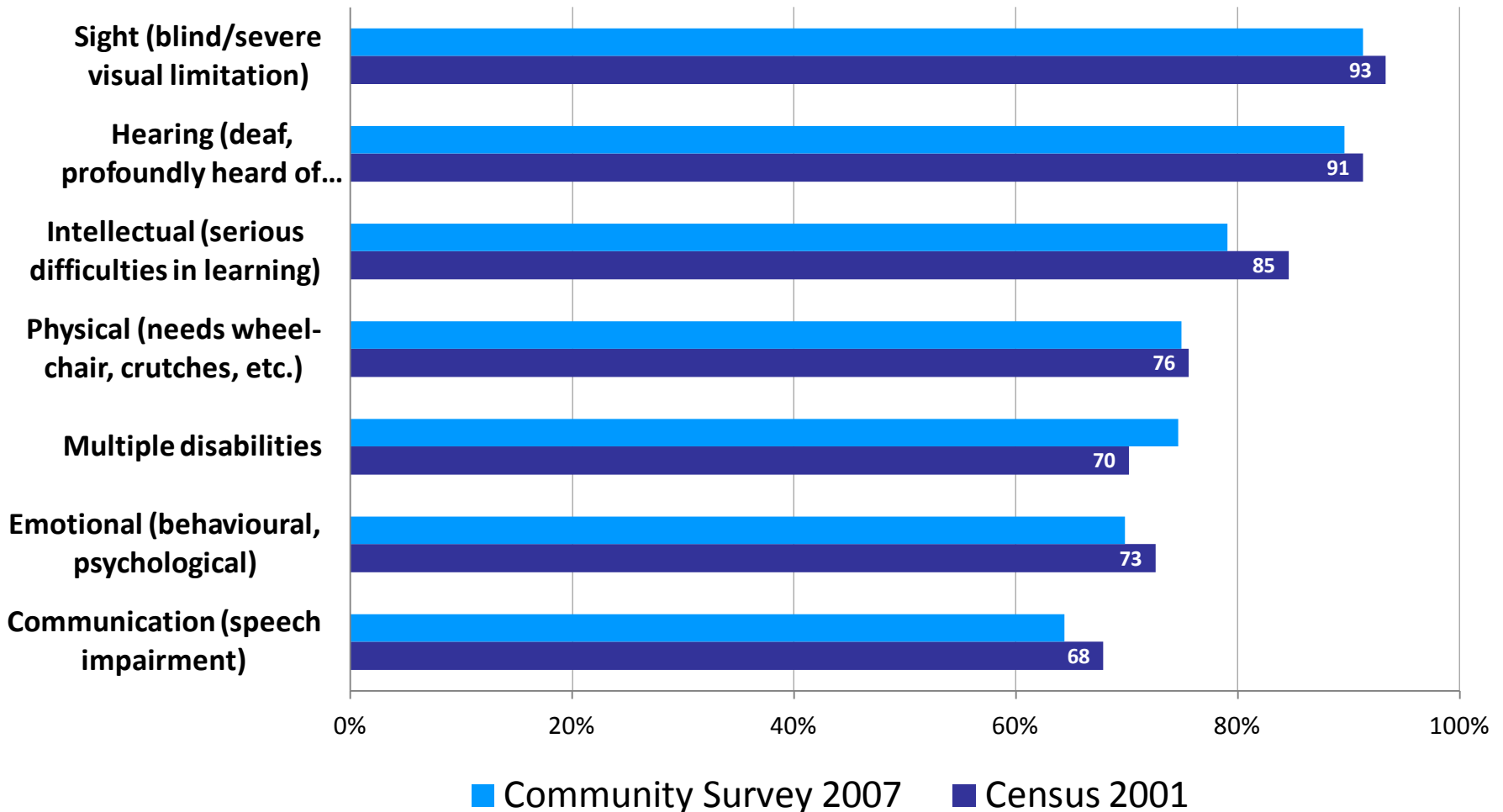
# Illustration: equalization of opportunities

Population aged 15 years + who never attended school, by disability status (%)



# Illustration: profile of children with disabilities

South Africa: Percentage of children with a disability of compulsory school-age (7-15 years) attending an educational institution by disability type, 2001 & 2007



# Conclusions

- **Strong commitment to improving disability statistics globally and in the Pacific**
- **Current/emerging international standards:**
  - *Census/surveys*: Washington Group Short/Long Set of Questions (adults), WG/UNICEF Module (children)
  - *Stand-alone surveys*: WHO Model Disability Surveys
- **A lot of disability data has been *collected* in Pacific countries through:**
  - Censuses (11 PICs), dedicated surveys (6 PICs), disability questions in other surveys (4 PICs)
- **But: *comparability, analysis and dissemination* of census and survey data weak**

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