ESA/STAT/AC.320/14

Expert Group Meeting on Data Disaggregation
27-29 June 2016
New York

Everybody Counts: Disaggregating routine data by disability in eye health projects

By Pauline Thivillier


Sightsavers
Everybody Counts
-
Disaggregating routine data by disability in Eye Health Projects

Relevance of disaggregation

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- 2030 Agenda and ‘Leave No One Behind’
- 11 SDG indicators require disaggregation by disability
- Some also require disaggregation by age, sex and wealth
- Comparability of data at global level
- National statistical systems are faced with significantly increased data requirements – including sub-national level

Problem statement

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Research question:

‘How can data disaggregated by disability be collected on a project level in a resource-efficient way that is useful to policy and decision makers?’

- Focus on project level and access to health services
- Learning can be applicable in other contexts

Problem statement

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Objectives:

1. Understand whether people with disabilities are accessing our services

2. Build the evidence base on how to disaggregate routine data by disability and advocate for the need to disaggregate data by disability

3. Make Sightsavers' projects more inclusive of people with disabilities.

Methodology

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India (Eye Health)	Tanzania (NTD)	Malawi (NTD)
☐ Washington Group Short Set	☐ Washington Group Short Set	☐ Washington Group Short Set
☐ Census Question	☐ Sex	☐ Sex
☐ Sex	☐ Age	☐ Equity Tool
☐ Age		

- The Washington Group Short Set of Questions and Equity Tool are both designed for surveys (Census and DHS)
- These were applied in a programme setting

Methodology

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- Integration in routine data collection tools at hospital and primary care level – paper and electronic systems

- Monthly reports developed and shared for analysis in Excel and Stata (software)

As this is a pilot we also collected data on:

- ✓ Experiences of people involved in the project ***[not addressed today]***
- ✓ Quality of the data collected

Concrete examples of data sources - Definition of disability

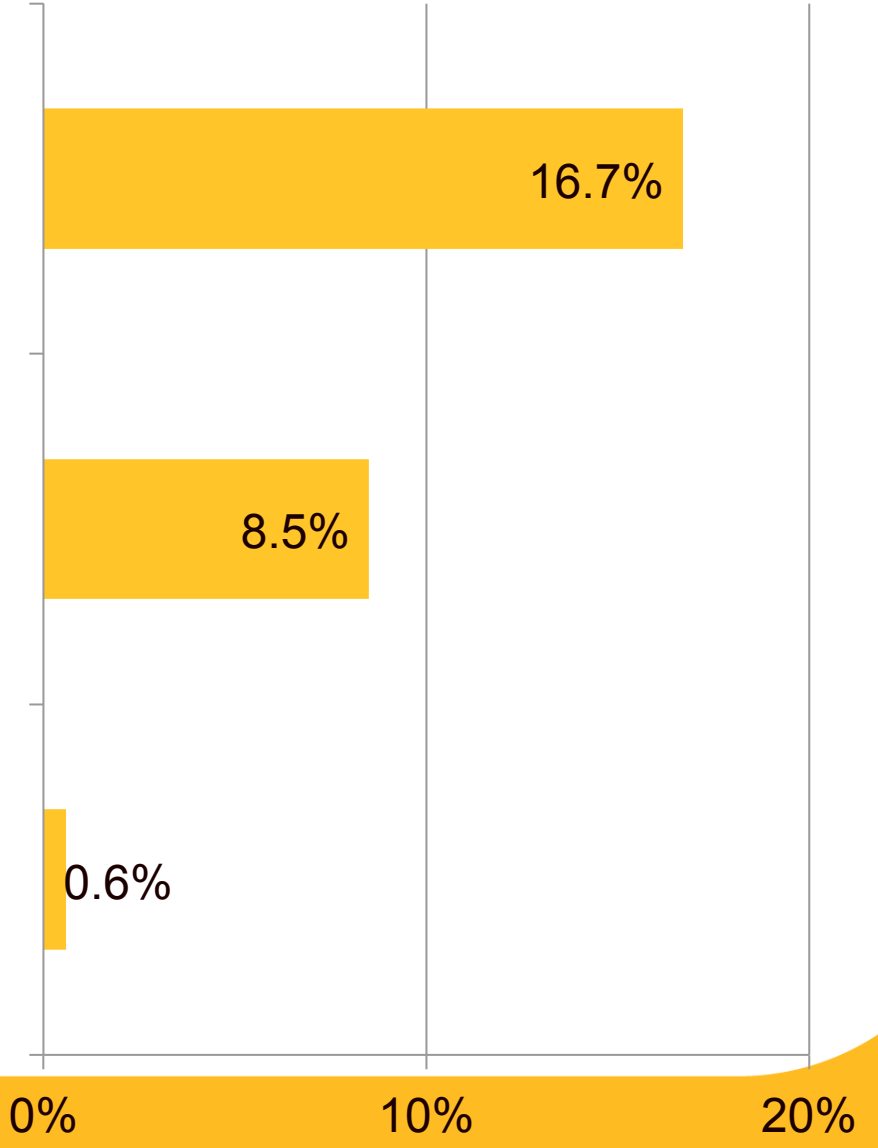
In India

16.7% of project clients report **severe or completely limiting difficulties** in at least one domain.

8.5% when we exclude the sight domain.

0.6% when we ask them directly if they are ‘disabled’

(Sample size: 24,518)



Concrete examples of data sources – Location of services

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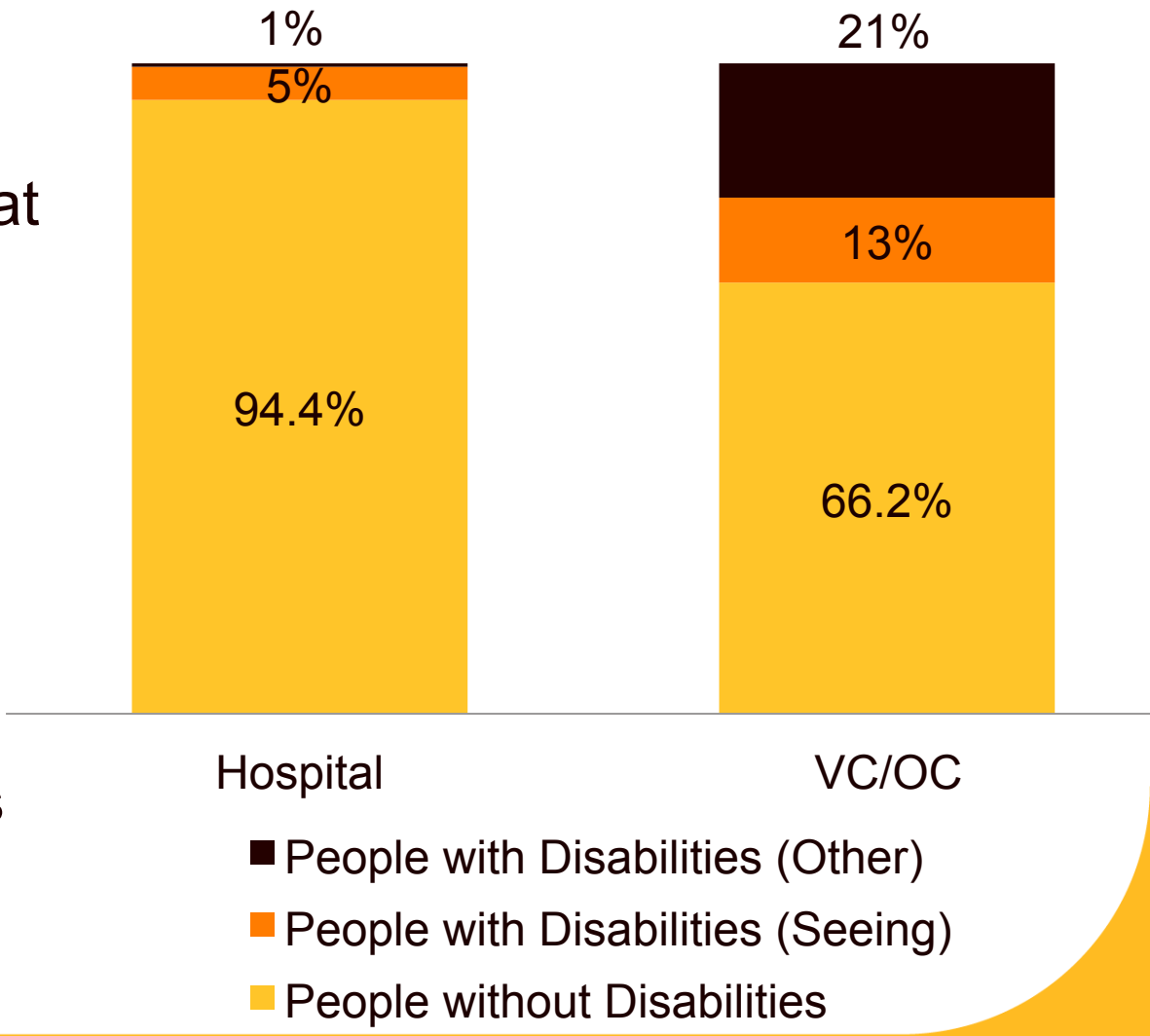
In India

24,518 were examined at hospital and primary centres

Prevalence of disability at hospital is 6%

Prevalence of disability at the primary centres is 33%



Concrete examples of data sources – Type of services

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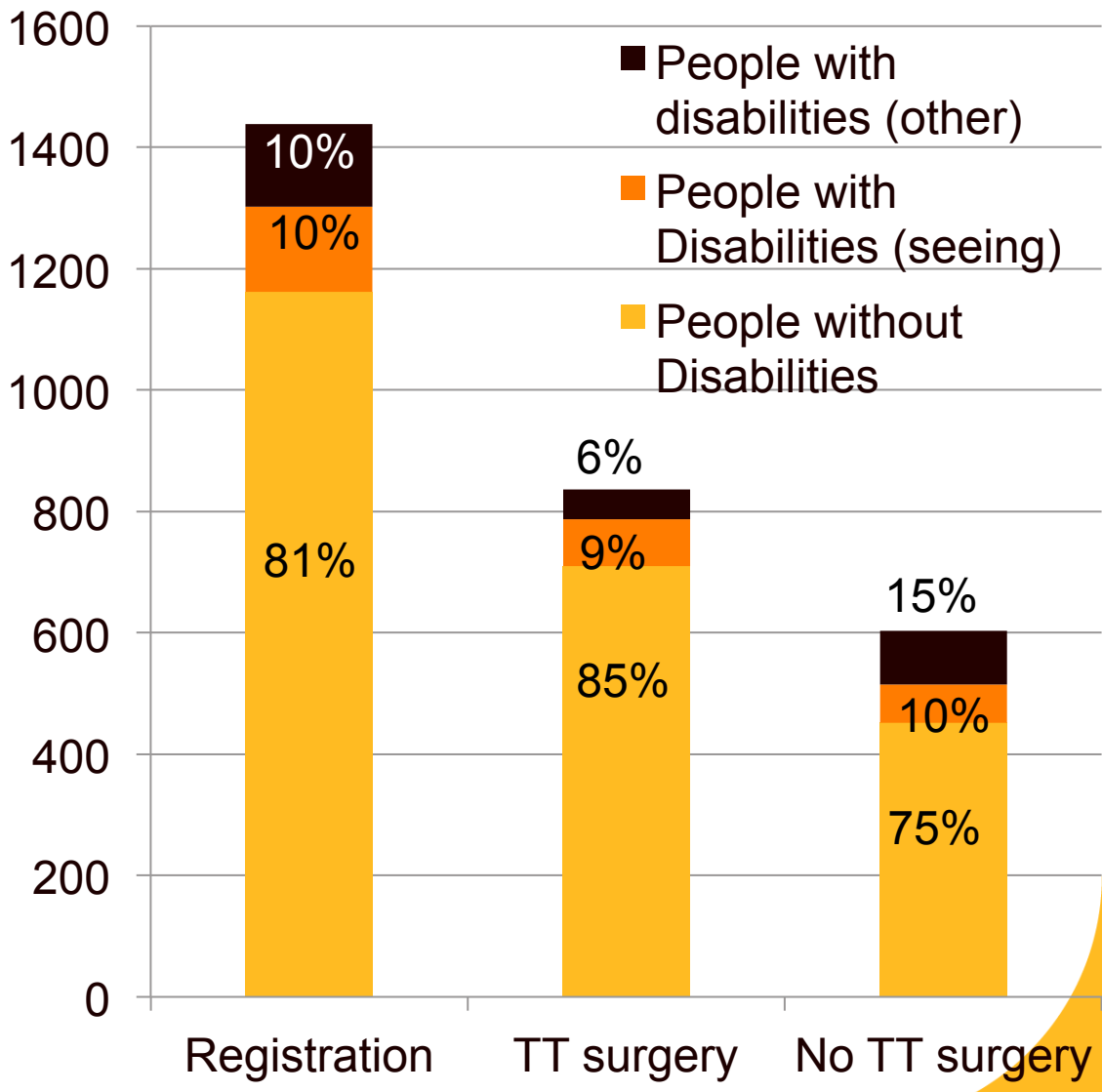
In Tanzania

Partner : MoH

1439 people registered at TT camps

Prevalence of disability at registration (20%)

Including a lot of difficulties in domains other than seeing (10%)



Concrete examples of data sources – triangulation with other variables

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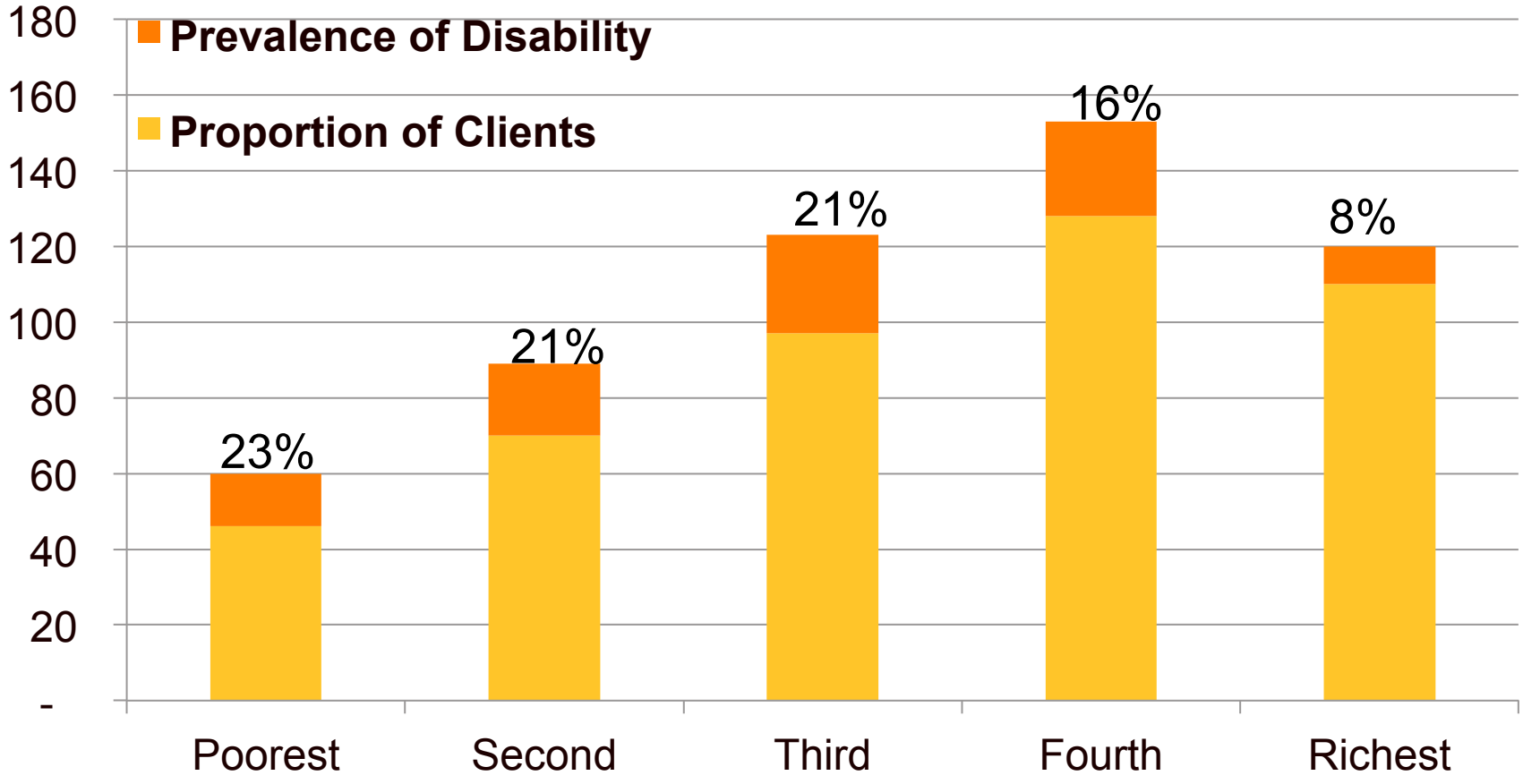
Sex (India): Inconsistency between the sexes as to how difficulties in functioning translate in to what they consider to be a disability.

Age (India and Tanzania): Positively associated with disability

Wealth (Malawi): Highest prevalence of disability in the poorest quintiles

Concrete examples of data sources – triangulation with other variables (wealth)



Challenges

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Disability is a concept highly dependant on **contextual and cultural factors**

- ✓ Emphasis on sensitisation/training & translation

Data collection systems can be resistant to change

- ✓ Integrate in existing tools & process

Buy-in & Ownership

- ✓ Equip all stakeholders with necessary knowledge & tools

Planning & Monitoring

- ✓ Identify the optimal place in the health service ‘journey’
- ✓ Review approach based on qualitative feedback

Guidance available for this pilot

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Before the start of the pilot:

- Literature review of existing disability data initiatives
- Washington Group Guidance
- Equity Tool Guidance

At the end of the pilot, we will publish:

- Standardised training materials
- Technical guidance for governments and NSO
- Policy Brief

All guidance are available on the following websites:

- http://www.sightsavers.org/everybodycounts/
- http://www.washingtongroup-disability.com/
- http://www.equitytool.org/

Priority issues to be addressed

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Comparability of data at international level

India	Tanzania	Malawi
2011 Census: 4.3%	2012 Census*: N/A	2008 Census*: 4%
Telengana Study*: 7.5%	2008 Disability survey*: 12.2%	
Pilot: 8.5%	Pilot: 19%	Pilot: 5.14%

*** Use of the WG Short Set**

Priority issues to be addressed

- **Sensitisation** on disability is needed before data is collected
  - ✓ Data Collectors reported that the training and pilot had a 'transformative effect'.

- **Guidance** and support for NSO
  - ✓ Civil Societies and others have a role to play and can support NSO regarding disaggregation of data.

- Links to **service provision** (esp. for the disability questions)
  - ✓ Closing the loop – use of the data to improve service provision.

Thank you!

For more information visit:
http://www.sightsavers.org/everybodycounts/