Using WG data from big data sets to identify invisible groups

9th November, 2018

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Original scope of work

Approached by the WFDB:

To support work towards a new Global Report on Deafblindness

Together with Morgon Banks, Research Fellow in Disability and Global Health, ICED

Original scope of work

- Review the literature
  - Measuring deaf-blindness: approaches and definitions
  - How common is it, what are the causes
  - Impact of deafblindness on key life areas

- Quantitative Analysis using ICED data: How common is deafblindness, who does it affect (e.g. age, sex) and how does it affect them (e.g. access to school or work)

- Review of available external data sets for further analyses

Measuring deafblindness

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- Many approaches in the literature
  - Often Clinical
  - Specific Scales e.g. Deafblindness Severity Index (DSI)

Nordic Definition of deafblindness (used by the WFDB)

Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus deafblindness is a distinct disability.

Deafblindness measure

Questions on seeing and hearing:

- Do you have difficulty seeing (even when wearing your glasses)
- Do you have difficulty hearing (even when wearing your hearing aids)

Response categories: No difficulty, some difficulty, a lot of difficulty, cannot do

Wide	"Some" or greater difficulty seeing or hearing + "some" or greater difficulty in opposite domain
Moderate	"Some" or greater difficulty seeing or hearing + "a lot" or greater difficulty in opposite domain
Severe	a lot" or greater difficulty seeing or hearing + "a lot" or greater difficulty in opposite domain

Hypothesised that this would meet Nordic Definition: *combined* vision and hearing impairment of such severity that it is *hard for the impaired senses to compensate for each other*

What do the data say?

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ICED Surveys of Disability					
Country	**Year**	**Region**	**Sample Size**	**Sampling Design**	**Funder**
Cameroon	2013	Fundong Health District, North West Cameroon	4,056	Cluster Sampling with Probability Proportionate to Size	CBM Germany
India	2014	Mahabubnagar District, Telangana State, India	4,056		CBM Germany
Guatemala	2016	National	13,800		CBM LARO, UNICEF and CONADI

How common is deafblindness?

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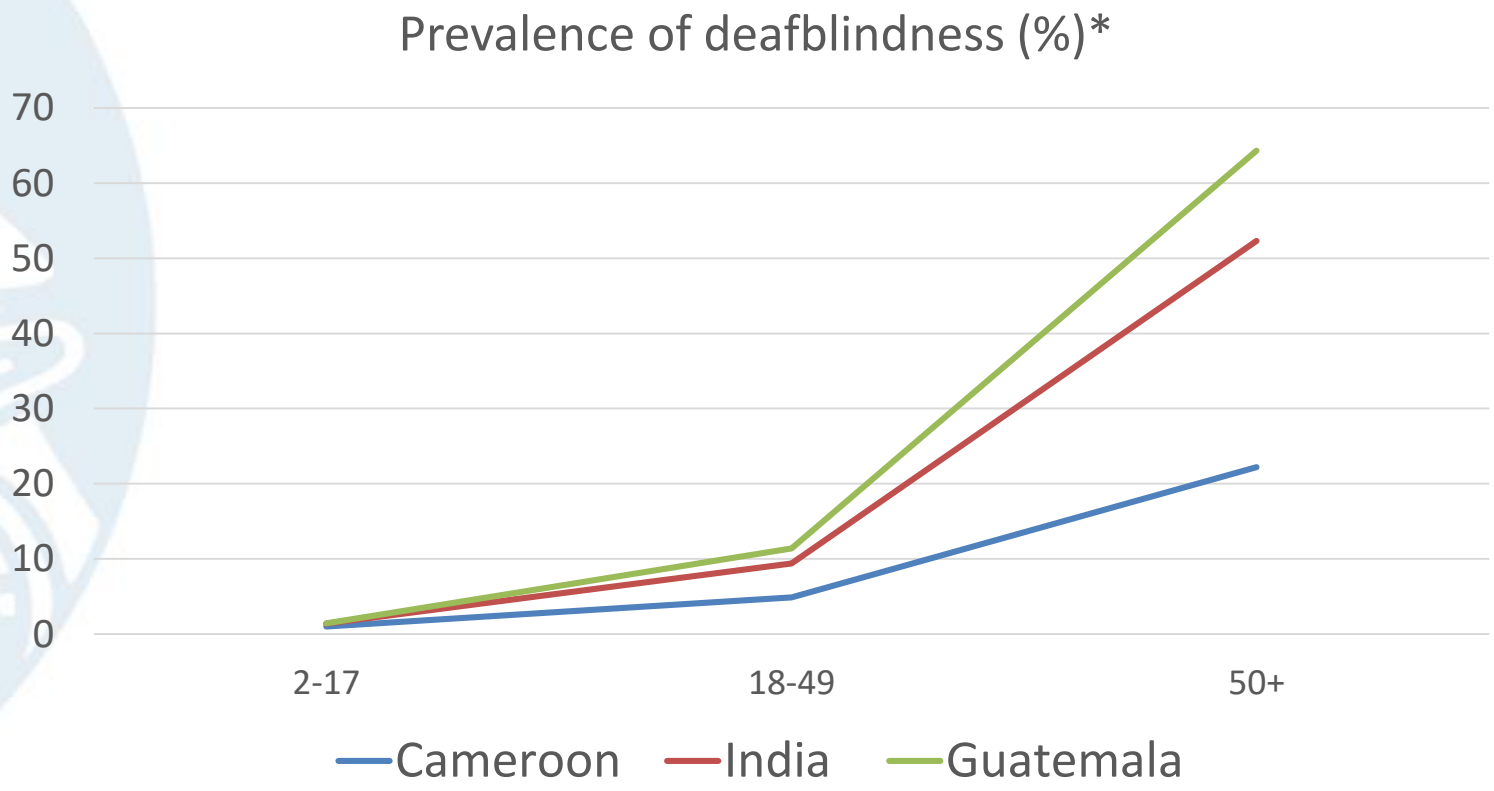
All age prevalence of deafblindness in Cameroon, India and Guatemala			
	Wide	Moderate	Severe
Cameroon	6.2%	1.2%	0.3%
India	7.9%	2.6%	0.5%
Guatemala	2.4%	0.8%	0.3%

Who is deafblind?

- No difference by gender in any country
- Big increase by age group in each country



*wide threshold shown but similar trend by age across thresholds

Limitations of these data

- Small surveys powered for overall disability prevalence, not smaller sub-groups
  - Prevalence estimates low power (small numbers limit ability to extrapolate to whole population)
  - Strongly associated with age so very few participants in younger groups
    - Limits further analysis e.g. school (children), working age population etc.

Secondary Data Analysis

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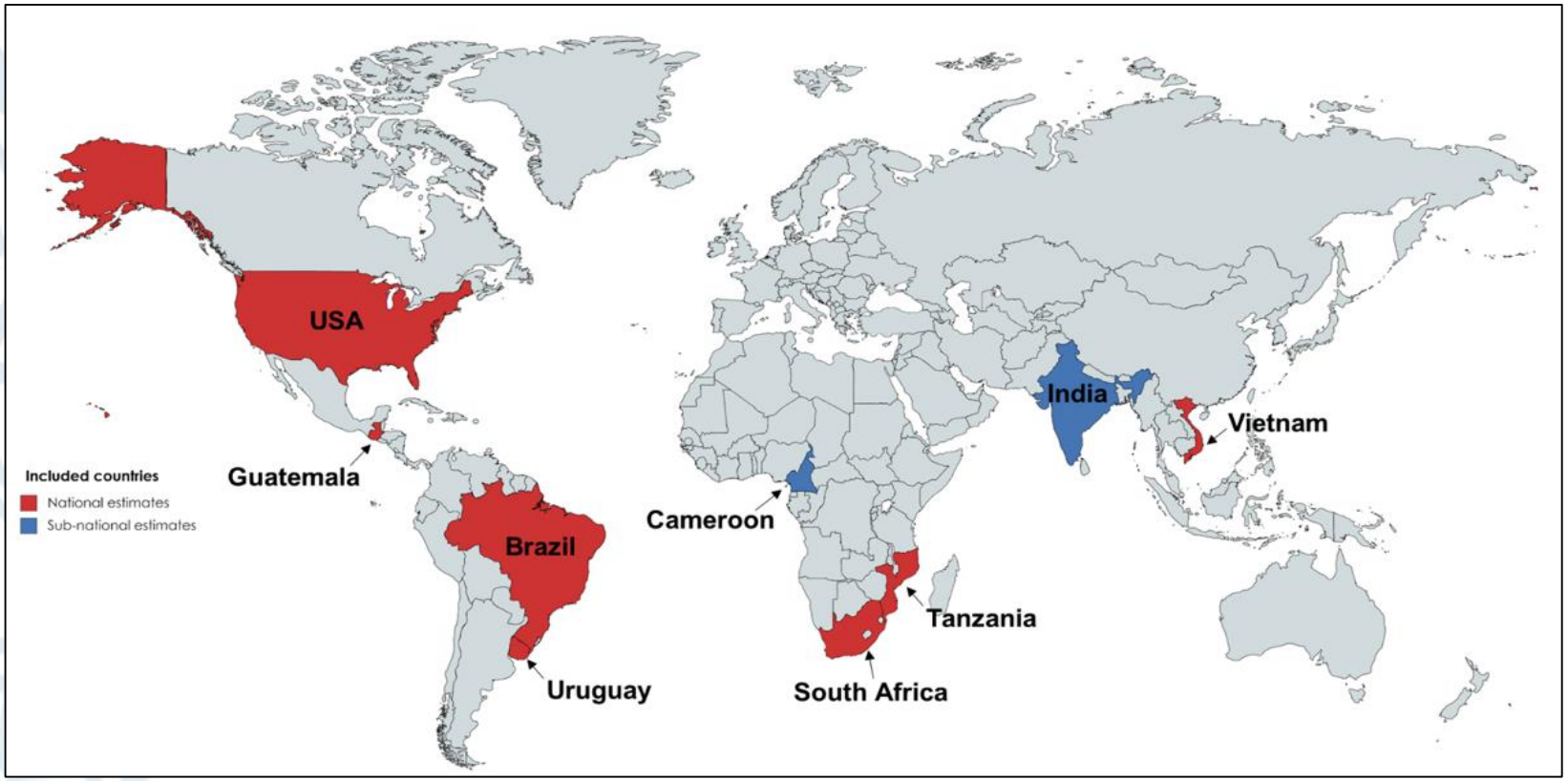
- World's largest archive of publicly available census samples
- Consistent data coding to facilitate comparative research
- Free of charge on request
- Sought census datasets that had used the Washington Group Short Set for comparability

Census	Question(s) on vision and hearing
Botswana (2011)	Does any listed person in the household have any of the f
Cambodia (2008)	If the person is physically and/or mentally disabled, give t
Cameroon (2005)	Does [the respondent] have any serious disability that lim sight (Y/N) b. hearing (Y/N)
Colombia (2005)	Does [the respondent] have permanent limitations for: sig
Ecuador (2010)	[For all persons who reported having a permanent disabil than one answer is allowed): Visual (blindness)? Auditory (deafness)?
Haiti (2003)	Does this person have a disability? (Check as many boxes as apply): a. Blind; b. deaf
Iran (2011)	Does any member of the household have at least one of the following? (up to three per member) a. blindness; b. deafness
Ireland (2011)	Do you have any of the following long-lasting conditions or difficulties? Deafness or a serious hearing impairment (Y/N) ; Blindness or a serious visual impairment (Y/N)
Kenya (2009)	What type of disability does [person] have? (List not more than three) a. visual; b. hearing
Malawi (2008)	Does [the respondent] have difficulty or problems in the following? Type of disability: a. Sight b. hearing (Y/N)
Mexico (2015)	Does [the respondent] have difficulty doing the following activities in his or her daily life: a. Seeing, even when using glasses (Yes/No); b. Hearing, even when using a hearing aid (Y/N)
Mozambique (2007)	Does [the person] have any disability? If yes (select): a. blind; b. deaf
Sudan (2008)	Does [the respondent] have any difficulty in moving, seeing, hearing, speaking or learning? (Mark all that apply) a. difficulty hearing; b. deaf; c. difficulty seeing; d. blind
USA (2010)	Is this person deaf or does he or she have serious difficulty hearing? (Y/N) Is this person blind or does he or she have serious difficulty seeing even when wearing glasses? (Y/N)
Venezuela (2001)	Does [the person] have any disability? If yes (select): a. blind; b. deaf
Ghana (2010)	Does [the respondent] have any serious disability that limits his or her full participation in life activities (such as mobility, work, social life, etc.)? Sight (Y/N) ; hearing (Y/N)
Indonesia (2010)	Washington Group questions for sight and hearing (response options: none, some, total).
Brazil (2010)	Washington Group questions for sight and hearing
South Africa (2011)	Washington Group questions for sight and hearing
Tanzania (2012)	Washington Group questions for sight and hearing
Uruguay (2011)	Washington Group questions for sight and hearing
Vietnam (2009)	Washington Group questions for sight and hearing

Much easier said than done – recent surveys up to 2016, and yet very few used WG questions, or used them with the correct response options

Datasets



Washington Group from Census: Indonesia, Brazil, South Africa, Tanzania, Uruguay and Vietnam

ICED Datasets: Guatemala (nationally representative), Cameroon and India (both region-level)

How common is deafblindness?

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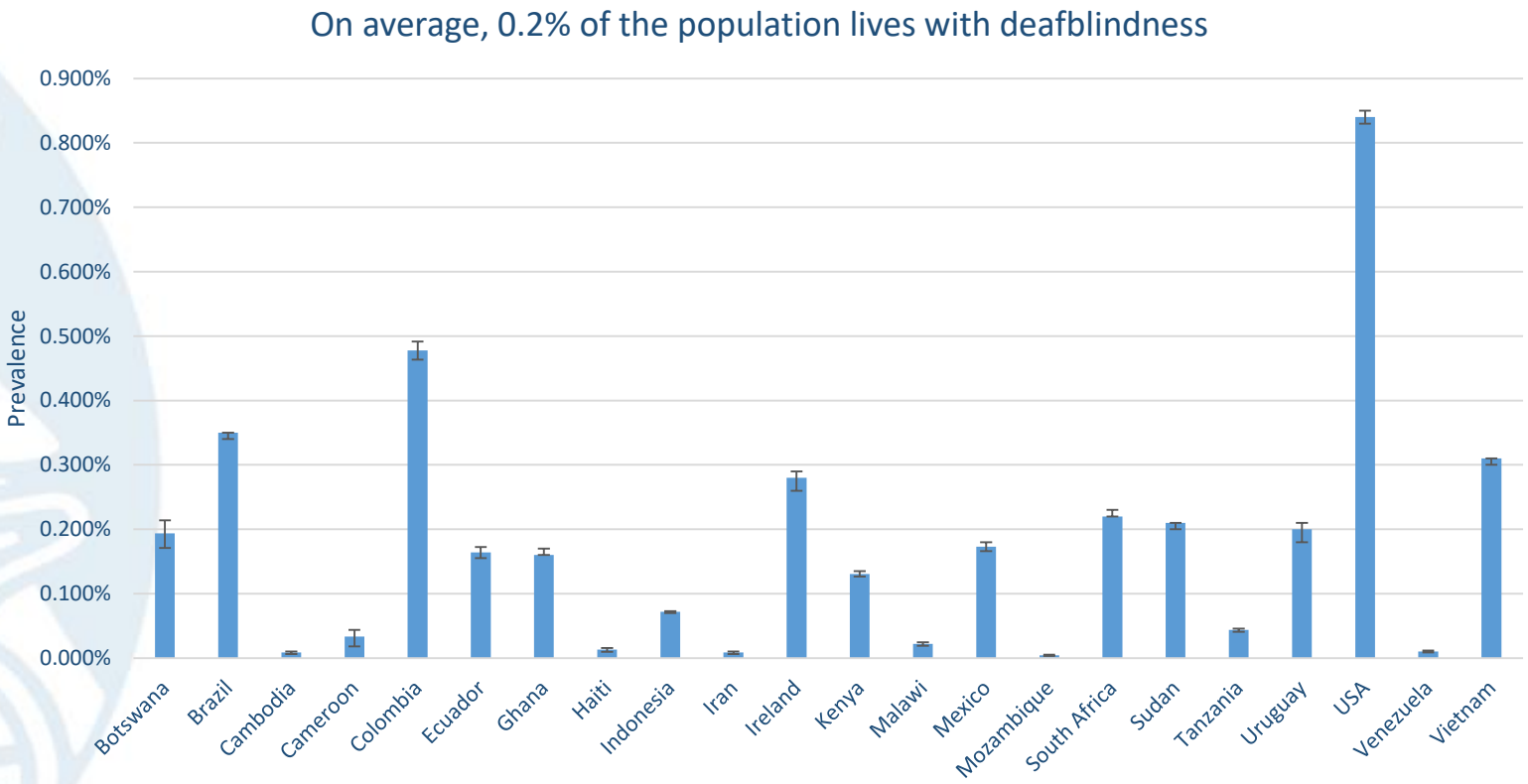
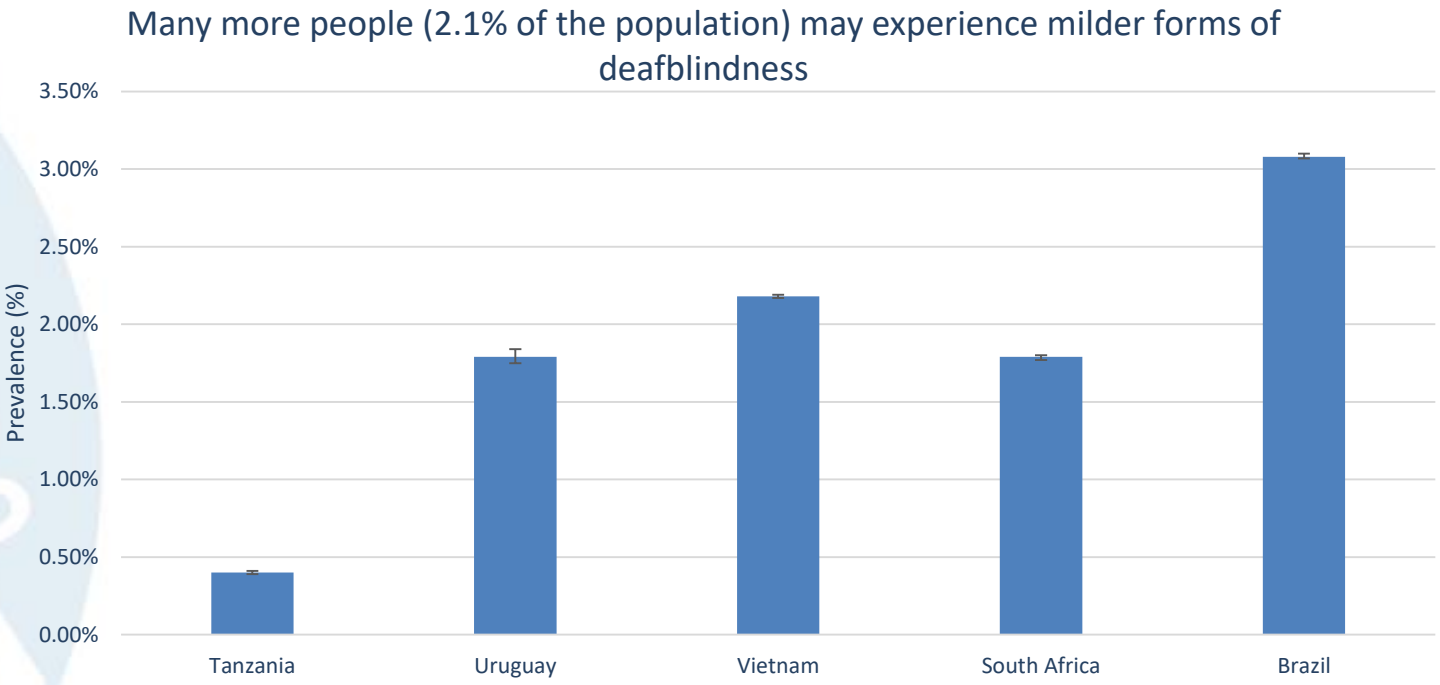


- Binary yes/no deaf and blind or “severe difficulties hearing/seeing” in many datasets
- WG a lot of difficulty hearing + a lot of difficulty seeing (for comparability of severity of limitation with binary options)

- Increasing prevalence with age irrespective of measurement method used
- Slightly higher in women than men in most countries irrespective of method used

How common is deafblindness?



- WG some or greater difficulty in seeing and heading
- Can only make these inferences if questions asked on a scale as in WG

How does deafblindness affect people's lives?

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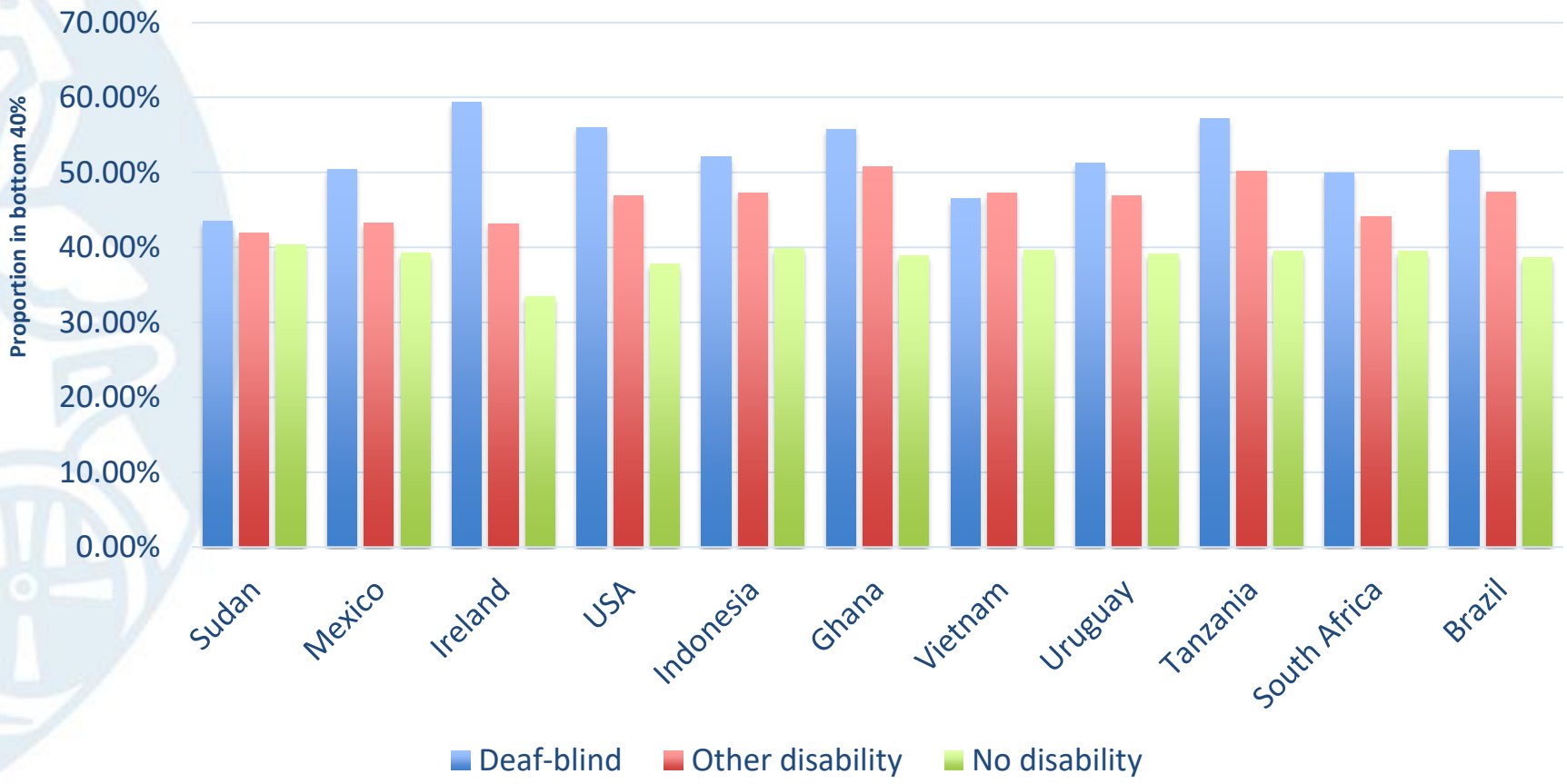
Persons with deafblindness are 18% more likely to be poor compared to persons with other disabilities and 51% compared to persons with no disabilities*



*adjusted for household size, dependency ratio, rural-urban divide

How does deafblindness affect people's lives?

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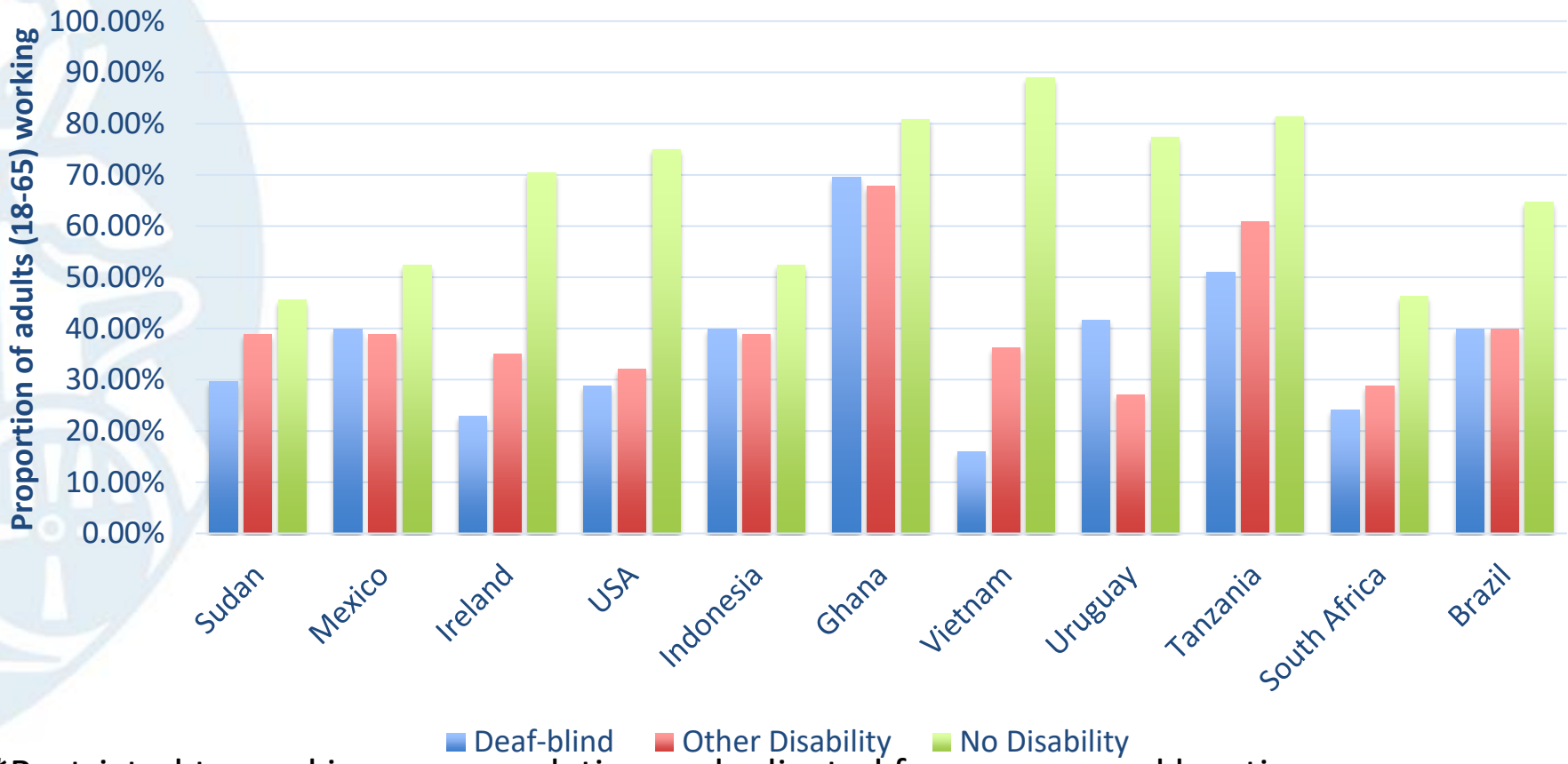
Persons with deafblindness are 10 times less likely to be working than people without disabilities across countries, and 30% less likely to be working than people with other disabilities*



*Restricted to working age population and adjusted for sex, age and location

How does deafblindness affect people's lives?

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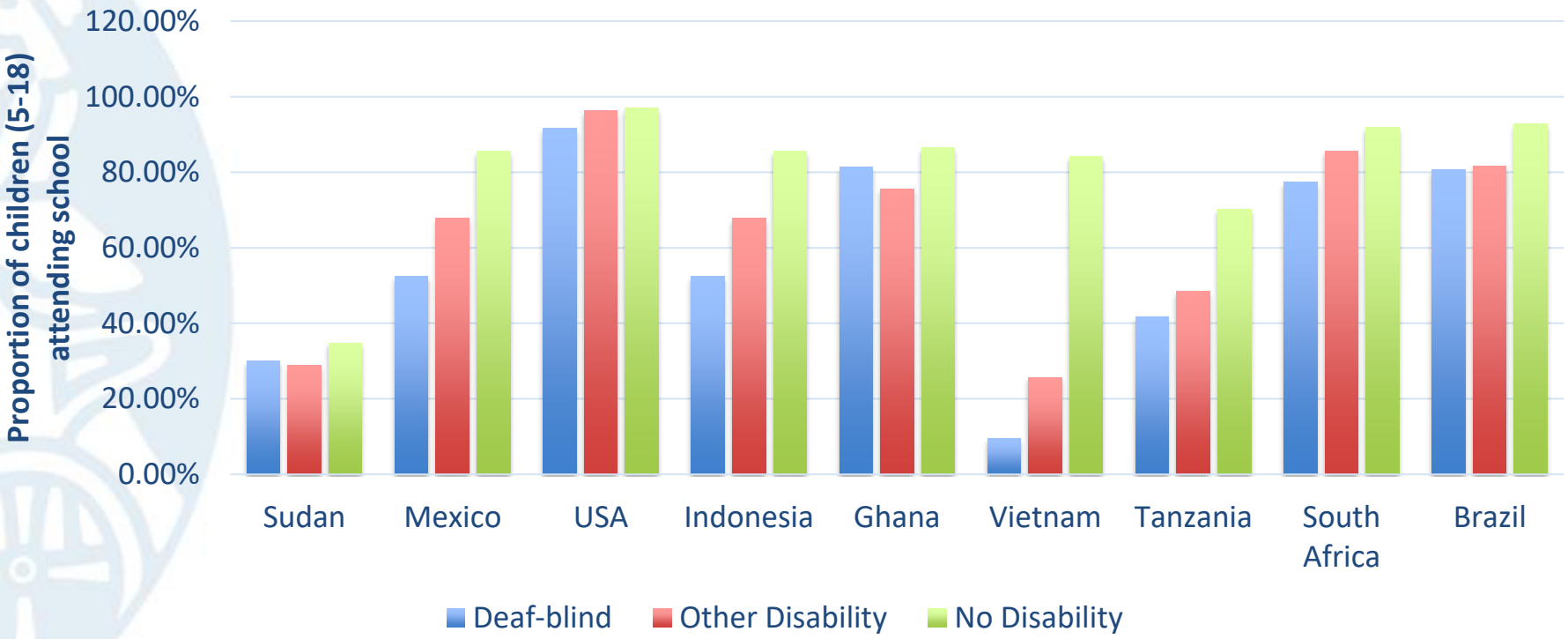
Children with deafblindness are 17 times less likely to be in school than children without disabilities and twice less likely to be in school than children with other disabilities



*Restricted to schoolage population and adjusted for sex, age and location

So what?

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- It appears that invisible groups ***can*** be captured in big datasets using the WGQs
- We can therefore start to undertake more nuanced data analysis to estimate the prevalence of different functional limitations, or different combinations of functional limitations
- We can also start to differentiate between differences in participation ***amongst*** persons with disabilities
- ***But*** these datasets need to be very large to provide enough data to create robust (meaningful) population estimates
- Repositories like IPUMS can be a great resource – but openly available data using WG is still not very common

Thank you!

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