

Disability measurement and statistics - the state of the notion

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Outline

- Why are stats important in relation to the UNCRPD?
- Factors that affect disability statistics
- Review of question wording as a factor
- South African work on developing a disability question for Census 2011: focus group and national survey results
- Effects of question wording in this work

Importance of Stats for UNCRPD

- Analysis of conditions
 - Baseline for monitoring change
 - Determining needs
 - Motivation for policies
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- All these need good data that are understood

Disability statistics currently

- Growing interest and research
- Wide variability
 - Not sure if measuring the same thing
 - Cannot compare across countries
 - UNCRDP requires comparability for monitoring at a regional and global level
- Three levels of factors affecting statistics:
 - Population – well understood
 - Individual – not well understood
 - Methodology – reasonably well understood

Population factors

- Population demographics:
 - ageing population = high prevalence
 - Contribute more in older populations than younger ones
- level of development of the country and access to health care services: what happens in managing injuries and illnesses?
- curable health conditions persisting: e.g. untreated middle ear infections leading to permanent hearing loss;
- level of industrialisation and use of cars: more developed countries have higher rates of injuries

Individual factors

- a person's overall sense of independence and identity,
- social inclusion or exclusion,
- overall disadvantage experienced (e.g. limited access to education and employment),
- poverty resulting from the impairment,
- access to health care services – having a diagnosis to report,
- age of the person,
- cultural beliefs and notions of health and functioning,
- racial, ethnic and gender identities,
- level of education,
- socio-economic status,
- access to knowledge and resources.

Some of the Methodology factors: question wording

- question wording
 - ‘have’ vs ‘suffered’
 - ‘Disabled/disability’ vs ‘difficulty’
- response options provided
 - ‘yes/no’ response options – all or nothing; fewer people indicate ‘
 - more response options - grading from ‘no difficulty’ through to ‘extreme difficulty/unable to do’; people with mild difficulties more comfortable saying ‘yes, some difficulty’
- Including a notion of severity within the question wording (e.g. ‘do you have a serious disability....?’).
 - ‘serious disability’ – ‘yes’ by people with mild, moderate and severe difficulties; Can mean quite different levels of difficulty and therefore not very useful.

Question wording

- Depends on societal attitudes to disability:
 - Disabled people as marginalised group: ‘Are you deaf, blind, crippled or mentally retarded?’ ‘God forbid someone has a disability, but if they do are they.....?’ (low prevalence estimates)
 - Role of environment as paramount: ‘What is it about transport in your town that prevents you from using it? (not sure what prevalence)
 - Disability as a complex, multidimensional phenomenon: Range of different questions (range of prevalence estimates) (e.g. WHO’s ICF)
- No single definition or measurement or statistics – need to understand what we are measuring to understand the statistic

The South African studies: 'Disability' vs 'Difficulty'

- Qualitative and quantitative information on how people in South Africa
 - understand and view the notion of disability and
 - how this affects their answers to different questions on disability.
- 3 question sets:
 1. 'Are you disabled?' (Yes/no/sometimes)
 2. South African Census 2001: Do you have any serious disability that prevents your full participation in life activities (such as education, work, social life)? *MARK ANY THAT APPLY.*
 - None, Sight, Hearing, Communication, Physical, Intellectual, Emotional (Yes/no response options)
 3. Washington Group (WG) Short Set which asks about 'difficulties' in doing a range of activities.

Washington Group Short set for Censuses

- Do you (or does the person) have difficulty in doing any of the following (because of a health condition)?
 - 1 = No difficulty 4 = Unable to do
 - 2 = Some difficulty 5 = Don't know
 - 3 = A lot of difficulty
- Seeing (with glasses if he/she wear(s) them)?
- Hearing (with a hearing aid if he/she wears one)?
- Walking a kilometre or climbing a flight of steps
- Remembering?
- Concentrating?
- With self-care, such as washing all over or dressing?
- In communicating in his/her usual language, including sign language (i.e. understanding others or being understood by others)?
- Joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?

Aims of the studies

- How do South Africans understand disability and difficulty?
- How easy is it to answer questions about difficulty and what frame of reference do they use in answering questions on disability?
- What are the differences between responses for the three question sets: 'Are you disabled?', the Census 2001 question, and the WG Short set with an additional community participation question?
- What sectors of the population are counted in or out for each of the three question sets?
- What are the effects of having different response options – i.e. binary versus four response options.

Focus group study

- 26 focus groups across urban/rural and different language groups:
 - 21 with adults about themselves:
 - 9 groups: 'disabled'
 - 6 groups: 'Unsure'
 - 6 groups: 'Non-disabled'
 - 5 groups with parents of children:
 - 3 groups: disabled children
 - 2 groups: non-disabled children
 - Complete standard questionnaire before the group
 - Discussion on: what is disability, what is difficulty, reactions to questions, response to scenarios
 - Tape recorded, transcribed and translated into English
 - Analysed using Atlas-ti thematically

National Survey

- 1508 Enumeration Areas (EA) – 4 households in each EA
- population based survey of 6032 households (4705 useable data)
- >11 000 individuals 15 years and older
- Three questionnaires:
 - a household questionnaire: head or most knowledgeable member of the household;
 - an adult questionnaire: all household members 15 years and older who could respond for themselves;
 - a Living Standards Measure (LSM) questionnaire: respondent on the household questionnaire at end of HH questionnaire.

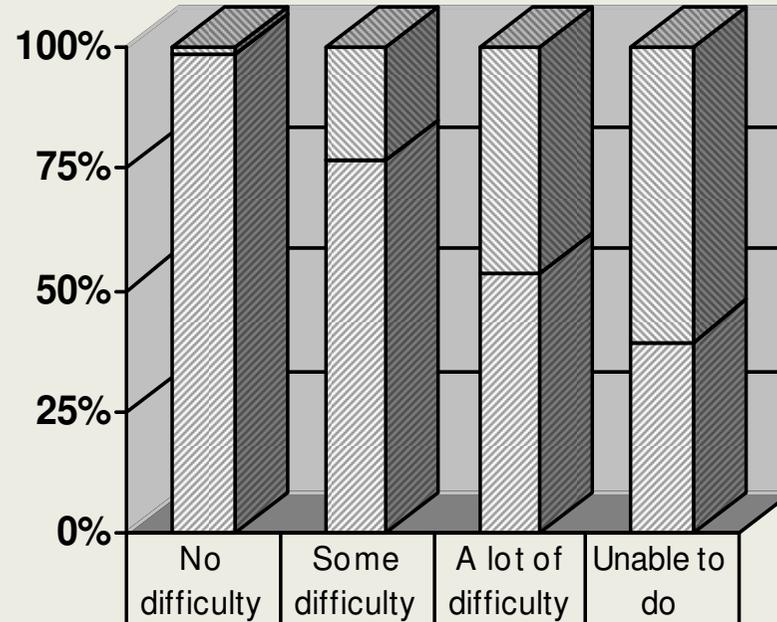
What is disability?

- Disability is.....
 - Permanent
 - Visible and physical
 - Not 'curable' or 'solvable'
 - 'cannot do anything by themselves' vs 'can't do' only in impaired domain of functioning
 - 'Them' and 'us' across all groups
 - Not positive connotation
- 'Difficulty' vs 'disability'
 - Difficulty is less severe than disability and can be solved;
 - disability includes difficulty but difficulty does not include disability

Ease of answering the Questions

- Reactions to questions:
 - ‘right’
 - ‘not too long’
 - ‘acceptable’
 - ‘easy’
 - reflected own lives
- Need for clear references
- Frame of reference: ‘usually’, ‘normally’; with and without assistive devices

Un-weighted responses for WG revised set compared to the Census 2001 question (Household Questionnaire responses only)



	No difficulty	Some difficulty	A lot of difficulty	Unable to do
Disabled (census question)	15.2%	23.32%	46.80%	60.63%
Not disabled (census question)	98.48%	76.68%	53.20%	39.37%

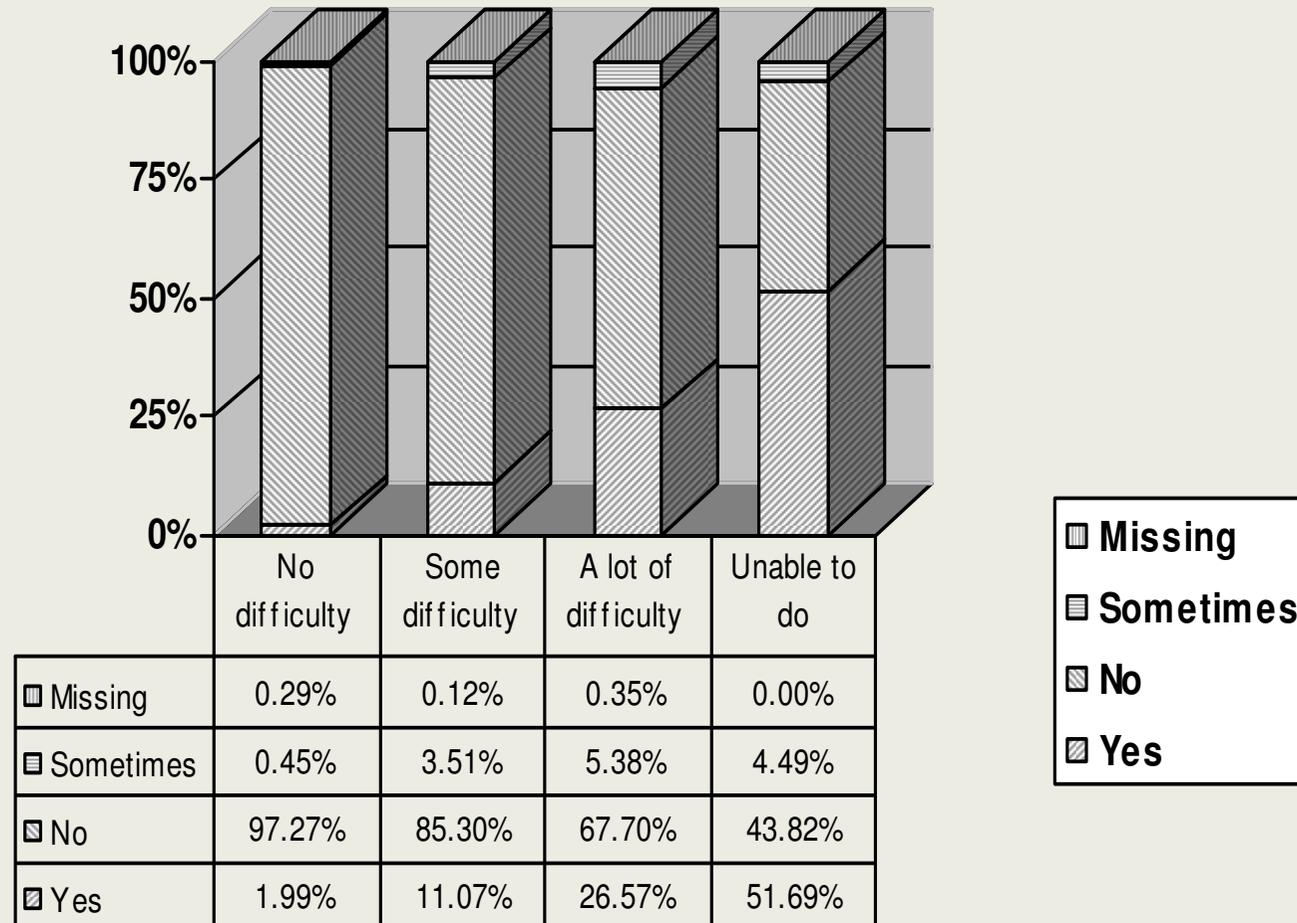
Disabled (census question)
 Not disabled (census question)

Response to question of WG revised set

'Difficulties' Qs vs Census 2001 question (Stats SA survey, 2006)

- More severe difficulties on proposed Qs = more likely to 'yes' on Census 2001
- 'Unable to do' one or more activities on WG:
 - 61% said 'yes' to Census 2001
 - 39% said 'no' to Census 2001 (missed on Census)
- 'A lot of difficulty' on one or more activities on WG
 - 47% = 'yes' to Census 2001
 - 53% = 'no' to Census 2001 (missed on Census)
- 'Some difficulty on one or more activities on WG'
 - 23% = 'yes' to Census 2001
 - 77% = 'no' to Census 2001 (missed on Census)

Un-weighted responses to the WG Short Set compared to 'Are you disabled?' (Adult questionnaire)



Responses to WG Short Set questions

'Difficulties' Qs vs 'Are you disabled?'

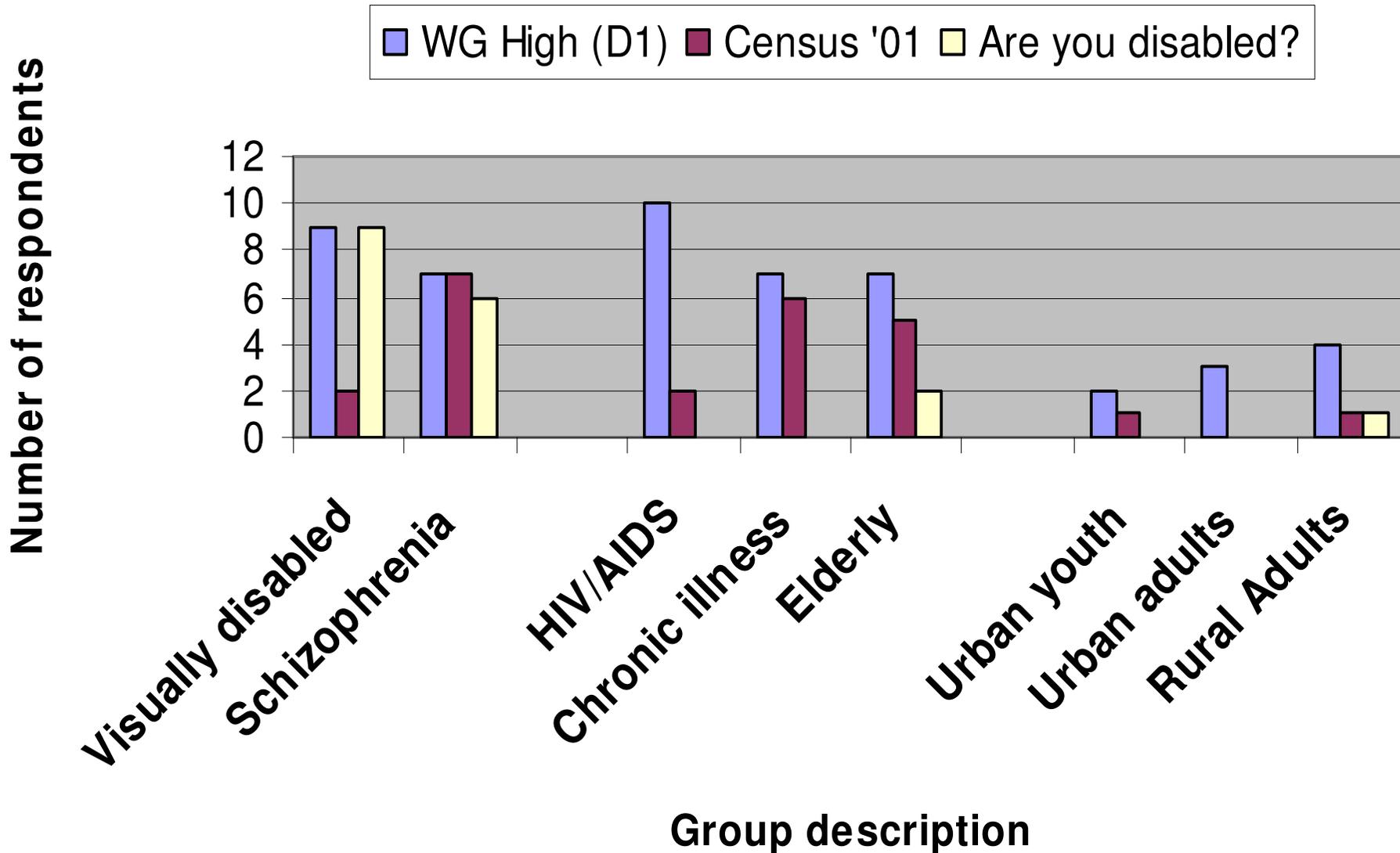
(Stats SA survey, 2006)

- More severe difficulties on 'Difficulties' Qs = more likely to say 'yes' to 'Are you disabled?'
- 'Unable to do' one or more activities on WG:
 - 52% said 'yes' to 'Are you disabled?'
 - 44% said 'no' to 'Are you disabled?'
 - 4% said 'sometimes' to 'Are you disabled?'
- 'A lot of difficulty' on one or more activities on WG
 - 27% = 'yes' to 'Are you disabled?'
 - 68% = 'no' to 'Are you disabled?'
 - 5% = 'sometimes' to 'Are you disabled?'
- 'Some difficulty on one or more activities on WG'
 - 11% = 'yes' to 'Are you disabled?' (!!)
 - 85% = 'no' to 'Are you disabled?'
 - 4% = 'sometimes' to 'Are you disabled?'

Population counted in or out for 3 sets of questions

- Counted in with WG Short set:
 - Elderly people
 - People with HIV/AIDS or other chronic conditions
 - People self-identifying as having a difficulty but not as being disabled
- Census 2001 and 'Are you disabled?':
 - Exclude most of above
 - 'Yes' on Census 2001 = mild (23%), Moderate (47%), unable (60%) on WG – mixed severity indication on 'serious disability'.
- WG counts in a broader population and does not exclude anyone.

Number of respondents identified as disabled by 3 Q sets (focus groups)



Estimates for popⁿ 15 yrs+ using 'difficulties' Qs?

(Stats SA survey, 2006)

- Response on one or more activities out of 7 activities
 - 67.7% of adults = no difficulty
 - 19.9% of adults = some difficulty
 - 9.9% of adults = a lot of difficulty
 - 2.5% of adults = unable to do
- Total with difficulties (disabled) = 32.3% of 15+ yr old population (broad inclusive definition of target population)
- 12.4% = a lot of difficulty or unable to do. (stricter definition of target population)

Response options

- 'yes/no' gives little room for 'borderline' responses
- Move to 4 or 5 response options – allows for response of 'some' - 'a lot' of difficulty
- Provides a valid measure of severity which is missing from 'serious disability'
- Cutoff points set at analysis for binary variable – more than one point possible

Proposed Census 2011 questions

Part 1: Do you (or does the person) have difficulty in doing any of the following because of a health condition?

- Seeing (with glasses if he/she wear(s) them)
- Hearing (with a hearing aid if he/she wears one)
- Walking a kilometre or climbing a flight of steps
- Remembering
- Concentrating
- With self-care, such as washing all over or dressing
- In communicating in his/her usual language, including sign language (i.e. understanding others or being understood by others)
- Joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can

Response options:

- **1 = No difficulty**
- **2 = Some difficulty**
- **3 = A lot of difficulty**
- **4 = Unable to do**
- **5 = Don't know**

Social science that makes a difference

From where and to where

1. From where?

- Poor measures with little understanding of what measuring
- Exclusive measures – limited analysis possible
- Culturally emotive terms

2. To where?

- Much clearer measures and understanding of what we are measuring
- Inclusive measures – more mainstreamed and extensive analysis is possible
- Neutral terminology