

## Why the Washington Group Questions ask about ‘difficulties’ and not ‘disabilities’ - how a single word can make a difference

Historically, across many cultures, being disabled has been seen as a negative trait and something that often leads to social exclusion. This pejorative term can make survey respondents hesitant to respond to questions that ask if they are ‘disabled’ or ‘have a disability’. There may be incentives to self-identifying as disabled particularly if there are disability-focused benefits available; the related stigma, however, remains. Hence, a different approach was sought to identify people by focusing on ‘difficulty’ doing certain basic, universal activities rather than ‘disability’.

Descriptions of people’s understanding of the words ‘disability’ versus ‘difficulty’ provide some insight into how they formulate responses. When asked what ‘disability’ means, both self-identified disabled and non-disabled South African respondents described this word as something permanent and non-fixable, and indicating a loss that could be a loss of functioning or of family members (Schneider 2012). A similar explanation was given by villagers in Kenya who identified orphans as disabled (Gona et al. 2006). When asked what ‘difficulty’ means, these same South African respondents described it as something less permanent than ‘disability’ and able to be changed or managed. ‘Disability’ was described in terms of severity and as an all-or-nothing status. Disabled people were described by non-disabled respondents as unable to do anything, and their disability was most often located in the physical or sensory domains (Schneider 2009):

“When I think of disabilities, I always think of people in wheelchairs or blind. I do not actually think of those people who cannot see in a distance or with emotional or social problems.”

So let’s consider how people with and without disability respond to questions about ‘difficulty’ versus ‘disability’ to determine the effect of wording on these responses and the results from these different wordings of questions wordings (Schneider 2009; Schneider et al. 2009).

The questions (Box 1 below) compare three different question formulations: (i) the Washington Group Short Set (WG SS) formulation: ‘Do you have difficulty [in doing various activities]’; (ii) the questions used in the 2001 South African census: ‘Do you have a disability that prevents you from participating in everyday life, and if yes, what type?’; and (iii) the question ‘Are you disabled?’. The categories of respondents who were asked these 3 sets of questions included. 1) Those who self-identified as ‘non-disabled’ (recruited from the general population, not reporting any impairments or chronic conditions and referred to as Nondisabled). 2)

Those who self-identified as 'disabled' (recruited from various disabled people's organisations and referred to as Disabled). 3) Those with known chronic conditions, such as HIV, hypertension, diabetes, etc. (recruited from chronic diseases clinics at large public hospitals and referred to as Chronic).

Box 1: Disability Question formulations analysed

### 1. WG SS questions

Do you have difficulty in doing any of the following? (1 =No difficulty; 2 = Some difficulty; 3 =A lot of difficulty; 4 = Unable to do; 5 = Don't know)

- a) Seeing (even with glasses, if you wear them)
- b) Hearing (even with a hearing aid, if you wear one)
- c) Walking a kilometre or climbing a flight of steps
- d) Remembering
- e) Concentrating
- f) With self-care, such as washing all over or dressing
- g) In communicating in your usual language, including sign language (i.e. understanding others or being understood by others)

### 2. South Africa 2001 census question

Do you have any serious disability that prevents your full participation in life activities (such as education, work, social life)?

0 = None

1 = Sight (Blind/severe visual limitation)

2 = Hearing (deaf/profoundly hard of hearing)

3 = Communication (Speech impairment)

4 = Physical (e.g. needs wheelchair, crutches or prosthesis; limb, hand usage limitations)

5 = Intellectual (serious difficulties in learning)

6 = Emotional (behavioural, psychological)

### 3. 'Are you disabled?'

Respondents in all three groups (Nondisabled, Disabled and Chronic), reported having difficulties (WG questions), Disabled respondents reported the most difficulties and Nondisabled respondents the least. Disabled respondents often reported 'having a disability' (question 2) and 'being disabled' (question 3). Exceptions were some Disabled respondents who said they did not have a disability as they participated in everyday life (question 2), and some deaf respondents who said they weren't disabled, but would use the label for purposes of eligibility to receive the disability social assistance grant.

Chronic respondents (including a number of older people) most often responded with 'not disabled' (question 3) and 'not having a disability' (question 2) but reporting a number of difficulties (WG questions). Nondisabled respondents all said they 'do not have a disability' (question 2) and are 'not disabled' (question 3). One respondent said that since he had heard that the questions were about disability, he said 'no' to all questions, as he is not disabled. This response indicates the importance of not introducing these questions with the word 'disability', as it can taint the responses.

A national survey in South Africa further tested these questions [Schneider, et al 2009], and found that 61% of people reporting 'unable to do' on one or more of the WG SS questions also reported 'having a disability' (question 2), with 39% being 'not disabled' (question 3). On the other end of the spectrum, 23% of people who reported only 'some difficulty' on the WG SS (i.e. mild functioning limitations) also reported 'having a disability' (question 2). There is no direct match between reporting difficulties and identifying as disabled or non-disabled in responses to survey questions.

In summary, people may be unwilling to self-identify as disabled, but may report difficulties in the basic activities included in the WG-SS. For example, older people and people with chronic illness report having difficulties but do not identify as being disabled. All people who report being disabled or having a disability also reported having difficulties although there were variations in the severity of difficulties reported. This reflects the continuum of disability and functioning from mild to very severe.

Questions that ask about difficulties in these basic universal activities describe an individual's functional status independently of their identity as disabled or non-disabled. People with difficulties in doing these activities are at greater risk than the general population for participation restrictions due to environmental barriers they face. Measuring these barriers and levels of participation requires additional questions to complement the WG-SS. Questions that use the terms 'disabled' or 'disability', on the other hand, seem to be unclear in what they measure – some combination of identity and functional status.

Gona, J., Hartley, S. & Newton, C., 2006. Using participatory rural appraisal (PRA) in the identification of children with disabilities in rural Kilifi, Kenya. *Rural and Remote Health*, 6, p.553. Available at: <http://rrh.deakin.edu.au>.

Schneider, M. et al., 2009. Measuring disability in censuses: The case of South Africa ☆ *ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap*, 3(3), pp.245–265. Available at: <http://linkinghub.elsevier.com/retrieve/pii/S1875067209000509> [Accessed January 9, 2012].

Schneider, M., 2009. The difference a word makes: responding to questions on "disability" and "difficulty" in South Africa. *Disability and rehabilitation*, 31(1), pp.42–50. Available at:

<http://www.ncbi.nlm.nih.gov/pubmed/19194809> [Accessed January 9, 2012].

Schneider, M., 2012. *The social life of questionnaires: Exploring respondents' understanding and interpretation of disability measures*. University of the Witwatersrand. Available at:  
<http://wiredspace.wits.ac.za/handle/10539/45/browse?value=Schneider,+Marguerite&type=author>.

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