Measuring disability in censuses: The case of South Africa

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Abstract

This paper reports on findings from the South African census content research to develop a disability set of questions for Census 2011. The findings of this research are used to determine, firstly, whether the Washington Group on Disability Statistics (WG) Short Set (revised for the South African context) is an appropriate set of questions to measure disability in Censuses, and, secondly, whether it is sufficient to ask about basic domains in order to identify the population at risk of experiencing disability related disadvantage and discrimination. The methodology is a national survey using a population based representative sample. The focus of the research were two sets of questions: the first being the Short Set for Census proposed by the WG, and the second being the disability questions used in the 2001 South African Census. The survey comprised three questionnaires: a Household Questionnaire with one member of the household responding for the whole household; a Living Standard Measure (LSM) questionnaire administered to the same person about the whole household; and an adult questionnaire administered to all household members 15 years and older who could respond for themselves. The findings support the use of the revised WG Short Set as an appropriate Census measures. It captures a broader and more inclusive population as having difficulties compared to that captured on the Census 2001 disability question, without excluding the Census 2001 population captured as disabled. The results are inconclusive with regard to the sufficiency of basic domains as a measure of the population at risk. Further testing is required to understand how people understand and respond to questions

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Cet article rend compte des résultats d’une recherche sur le contenu du recensement sud-africain en vue de développer un ensemble de questions sur le handicap pour le recensement de 2011. Les résultats sont utilisés pour déterminer, premièrement, si le module proposé par le Washington Group de Statistiques sur le Handicap (WG) (révisé pour le contexte sud-africain) est un ensemble de questions approprié pour mesurer le handicap dans les recensements et, deuxièmement, s’il est suffisant d’interroger sur les domaines de base pour identifier la population susceptible de faire l’expérience du désavantage et de la discrimination liés au handicap. La méthodologie est celle d’une enquête nationale utilisant un échantillon représentatif de la population. La recherche se centre sur deux ensembles de questions : premièrement, le module pour le recensement proposé par le WG et, deuxièmement les questions sur le handicap utilisées dans le recensement sud-africain de 2001. L’enquête comprend trois questionnaires : un questionnaire « ménages » avec un membre du ménage répondant pour le ménage entier; un questionnaire de Mesure du Standard de Vie administré à la même personne a propos du ménage entier ; et un questionnaire « adulte » administré à tous les membres du ménage de 15 ans et plus qui peuvent répondre pour eux-mêmes. Les résultats soutiennent l’utilisation du groupe de questions proposées par le WG comme mesures appropriées pour le recensement. Ce groupe de questions délimite une population plus large et plus englobante de personnes ayant des difficultés que la question sur l’incapacité posée dans le recensement de 2001, sans exclure la population handicapée délimitée par cette dernière. Les résultats ne permettent pas de conclure si les domaines de base sont une mesure suffisante de la population ciblée. D’autres tests sont nécessaires pour savoir comment les personnes comprennent et répondent aux questions telles que « Avez-vous des difficultés pour prendre en charge vos responsabilités au sein du ménage ou dans votre travail quotidien ? ».

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Mots clés : Mesures de recensement ; Handicap ; Afrique du Sud ; Difficulté

Introduction

“If you can’t measure it, you can’t manage it!”
(Manuel, 2006)

We begin this paper with a quote by the South African Minister of Finance that illustrates the importance given by a government minister to developing accurate measurements for statistics in order for appropriate policies to be developed and implemented. If a country is not able to measure an aspect like disability, then this cannot be appropriately addressed. This paper reports on the result of work undertaken by Statistics South Africa (StatsSA) to develop an accurate measure of disability.

Large differences in disability statistics are currently observed internationally due to a lack of consistency in what is being measured as ‘disability’. The United Nations Statistical Division (UNSD, 1990a) cautions that due to the differences in the concepts and methods used to identify persons with disabilities, prevalence rates should not be compared across countries. People with disabilities experience significant discrimination resulting in disadvantage in the domains of...
education, work and social inclusion (Elwan, 1999; Schneider et al., 1999; Altman & Berstein, 2008). It is therefore important to accurately monitor levels of disadvantage and discrimination by identifying the population at risk and analysing the degree to which these people experience disadvantage and discrimination. In addition, the measurement of a population’s functional status is recognised as being an important component of health status measures (Task Force on Health Status, 2005) and disability statistics are the vehicle for obtaining these measures.

International initiatives such as the Washington Group on Disability Statistics (WG) (Madans, 2004) and work by the World Health Organization (WHO) in collaboration with the United Nations Economic and Social Commission for the Asia-Pacific region (UNESCAP) (WHO/UNESCAP, 2008) are concerned with how to measure this population accurately and in a manner that is inclusive of all people with difficulties and not only the marginalized ‘disabled’. While there are a number of initiatives looking at disability measures, the work of the WG and WHO/UNESCAP are seen as the most significant as they have the widest global reach.

The WHO’s International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) defines disability as the outcome of the interaction between a person’s health condition and the context in which the person lives. The outcome of the interaction is described at three levels of functioning. The first is that of body level (function and structure) where difficulties experienced are called impairments. The second level of functioning is the person level, which describes the execution of complex tasks and actions by an individual bringing together a range of different body level functions and structures. This is referred to in the ICF as the Activity component, and experienced difficulties are referred to as activity limitations. The third level of functioning is that of the societal or ‘person within context’ level. This is referred to in the ICF as the Participation component and is defined as the involvement in life activities, and the experienced difficulties are called participation restrictions. The ICF asserts that a person with disability can have difficulties at any one of the three levels of functioning or a combination of one or more levels. The implications of this is that in order to identify the population at risk it would be necessary to ask questions covering all levels of functioning. However, in the self-report context (as is the case in censuses and surveys), it is important to select a level of functioning that a person can report on most accurately. This has been identified as being the person level or activity.

The census measures developed by the WG are focused at the person level, where basic activities and one complex activity (self care) are measured without assistance (except for seeing and hearing). This WG Short Set (SS) comprises six questions covering six domains of basic activities (i.e. person level and touching on the body level): seeing, hearing, walking and climbing steps (lower body mobility), remembering and concentrating (cognition), self care (which includes a component of upper body mobility – a basic activity – in the acts of dressing and washing) and communication (Altman, Madans & Rasch, 2005). The purpose of the WG SS is to identify people who have difficulties and use this information as a demographic variable to analyse outcomes.

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1 The distinction between basic and complex activities is a pragmatic one and is made with reference to the ICF A/P domain chapters. Chapters 1, 3 and 4 are considered basic activities and 7, 8 and 9 complex ones. The other chapters fall somewhere in between. The theoretical constructs of A and P are retained with each being made up of both basic and complex domains. Thus a person’s ability to carry out the complex activity of work is theoretically measurable at the person level (Activity) as well as the societal level (Participation). The use of a pragmatic distinction is made in view of the ongoing debates on how to use the Activity and Participation classification. The ICF (WHO, 2001) itself provides four different options for how to use this classification (see appendix 3 in the ICF full version). This paper does not engage in this debate but we do recognise this debate as an important and ongoing one.
of employment, education, social inclusion and general societal participation (not in the strict ICF technical sense but in a lay or colloquial sense of participation). This analysis uses the demographic questions together with separate questions asked on the major areas of complex activity (employment, education and social inclusion) plus on environmental barriers. The WG SS should identify the population at risk and uses other indicators (e.g. employment and educational status) as measures of participation in these activities by this population at risk (Altman et al., 2005; Madans, 2004). This is in contrast with the ICF that would require these complex activity questions to be asked as part of the identification of the population at risk.²

The questions that arise are twofold for the purposes of this paper.

Is the WG SS effective as a measure of people at risk of the disadvantage and discrimination of disability? This can be answered by looking at the trends observed in responses to the WG SS (asking about difficulties) compared to questions that ask specifically about ‘disability’ or being ‘disabled’ and the factors that affect these differences. To be effective the WG SS should be as inclusive as possible and provide the same and more information as the Census 2001 question used in South Africa.

Is the WG SS sufficient to identify persons defined by the ICF as being disabled or is it necessary to ask more complex activity questions as well to ensure a comprehensive identification of the population at risk? For example, if a person has difficulty with work or schooling, household responsibilities, or joining in community activities (all complex activities) will they also have difficulties in one or more basic activities? If not, then we need to ask questions complex activities to identify the full population at risk. Cambois et al. (2005) analysed data from the French survey on disability and found that most people who had difficulties with self-care (a complex activity) also had physical, visual or time orientation difficulties (all basic activities).

This paper describes the South African findings in relation to these two questions.

**Methodology**

**Aims and objectives**

The aims of this study are twofold:

a) to test the comparative effectiveness of the revised WG SS (revised WG SS) as a measure of disability for the South African Census in 2011 relative to the Census 2001 measure. The effectiveness is measured by a comparison of the revised WG SS with the Census 2001 in relation to:
- the reporting of trends that are similar to known trends (e.g. increasing prevalence of difficulties with increasing age);
- the inclusivity of the measure;
- the ability to provide clear information on the severity of difficulties;

b) to provide evidence on the effectiveness of using the SS of basic activity questions to identify the population at risk of experiencing disadvantage and discrimination compared to the additional use of questions on complex domains (i.e. joining in community activities, taking care of household responsibilities and day to day work).

² Although an important debate, as noted in footnote 1, the issue of whether the person level is measured as capacity or performance (see ICF coding guidelines (WHO, 2001) is not addressed. This is too large an issue to tackle in this paper.
Background to the study

The content research undertaken by StatsSA included two phases. The first was a qualitative study comprising of 26 focus groups including parents of children (disabled and non-disabled), people with sensory, physical and psychiatric disabilities, people with chronic illnesses (including HIV) or who were elderly, and people with no visible or known disabilities. The aim for this first phase was to test the responses and reactions of disabled and non-disabled participants to a schedule of proposed disability questions (the WG SS). The second phase was a national population based survey run in November 2006 (see StatsSA, 2007) and is the focus of this paper.

A recommendation arising from the focus group research (Schneider & Couper, 2007) stated that the WG core set of questions should be slightly modified. The revisions proposed included:

a) adding a reference for distance in the question about walking and climbing steps – i.e. ‘walking one kilometre’ and ‘climbing a flight of steps’;
b) separating the cognition questions into two – one each for remembering and concentrating;
c) adding a question on ‘joining in community activities’ to try and capture people with psychiatric illness.

The population based sample survey was used to further test these revised questions (revised WG SS) to determine whether trends noted in the qualitative testing phase were pertinent for the whole population. This paper reports on the findings of the population based sample survey. The qualitative phase has been reported on in detail in a related paper by Schneider (2009) and in the original report for StatsSA (Schneider & Couper, 2007).

Sampling frame

The sampling frame used was based on StatsSA’s Census 2001 Master Sample. A total of 6032 dwelling units were sampled. Useable data were collected from 78% of the sample (4705 dwelling units). It should be noted that the sample was small and biased, with over-sampling in tribal areas. Furthermore, the survey was not administered with the intention of deriving national estimates of disability in South Africa but rather to provide a more representative assessment of the performance of proposed questions than that obtained from the focus group research where participants were purposively sampled and small in number. Thus all survey estimates provided are tentative.

Data collection tools

The Census 2001 question presented in Table 1 included the words ‘serious disability that prevents participation’. For these questions, binary response options (‘Yes’ and ‘No’) were utilized. A person was therefore classified as disabled if they said ‘Yes’ to one or more of the impairment categories listed.

Table 2 presents the revised WG SS set of questions.

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3 According to StatsSA (Additions to Census 2001 Concepts and Definitions, February 2004. http://www.statssa.gov.za/census01/html/AddDefsInV2.asp. Any settlement area that is not classified urban, is classified as rural. Rural areas are subdivided into tribal areas and commercial farms.
Table 1
Census 2001 questions on disability.

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the person have any serious disability that prevents his/her full participation in life activities (such as education, work, social life)?</td>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Sight (blind/severe visual limitation)</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Hearing (deaf/profoundly hard of hearing)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Communication (speech impairment)</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Physical (e.g. needs wheelchair, crutches or prosthesis; limb, hand usage limitations)</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Intellectual (serious difficulties in learning)</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Emotional (behavioural, psychological)</td>
</tr>
</tbody>
</table>

Three questionnaires were used in the survey: a Household Questionnaire, a Living Standard Measure (LSM) Questionnaire and an Adult Questionnaire (refer to Appendices A and B for the Household and Adult Questionnaires respectively). Completion of the Household and LSM questionnaires was done by the head of the household or a responsible adult. The Adult Questionnaire was completed with all persons 15 years and older within the household who could respond for themselves. No proxy interviews were conducted for the Adult Questionnaire. The mode of administration was face to face interviews in the language of preference of the respondent.

Analysis

The results, unless specified otherwise, are for the age group 15 years and older. The data used are both weighted and un-weighted, depending on the questionnaire data used. Weighted data are reported as a proportion of the population, whereas un-weighted data are reported as a proportion of the respondents. Only the Household Questionnaire data were weighted. The results presented are unadjusted as it was felt to be premature to provide age- or sex-adjusted estimates until there is a clearer understanding of how disability measures work and a decision is made as to what standard population should be used in the adjusted estimates.

Table 2
Proposed set of questions on difficulty (revised WG Short Set).

<table>
<thead>
<tr>
<th>Question</th>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>GENERAL HEALTH AND FUNCTIONING</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have difficulty in doing any of the following?</td>
<td>1</td>
<td>No difficulty</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Some difficulty</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>A lot of difficulty</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Unable to do</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Don’t know</td>
</tr>
<tr>
<td>a) Seeing (even with glasses, if you wear them)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Hearing (even with a hearing aid, if you wear one)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Walking a kilometre or climbing a flight of steps</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Remembering</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Concentrating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) With self-care, such as washing all over or dressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) In communicating in your usual language, including sign language (i.e. understanding others or being understood by others)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>h) Joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3
Calculation of overall composite scores on the proposed set of questions (revised WG Short Set).

<table>
<thead>
<tr>
<th>Difficulty Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>No difficulty</td>
<td>Responses to all 8 of the questions on functioning indicated ‘no difficulty’</td>
</tr>
<tr>
<td>Some difficulty</td>
<td>Responses to one or more of the 8 questions indicated ‘some difficulty’; no responses indicated ‘a lot of difficulty’ or ‘unable to do’</td>
</tr>
<tr>
<td>A lot of difficulty</td>
<td>Responses to one or more of the 8 questions indicated ‘a lot of difficulty’; no responses indicated ‘unable to do’</td>
</tr>
<tr>
<td></td>
<td>Responses of ‘some difficulty’ could have been included in this category for some domains</td>
</tr>
<tr>
<td>Unable to do</td>
<td>Responses to one or more of the 8 questions indicated ‘unable to do’</td>
</tr>
<tr>
<td></td>
<td>Responses of ‘some and a lot of difficulty’ could have been included in this category for some domains</td>
</tr>
</tbody>
</table>

Analysis of the data was done by way of descriptive statistics (i.e. frequencies and cross-tabulations). Analysis of the data was done using the statistical package SAS. A fuller description of the methodology is available in the original report (StatsSA, 2007).

Results

The results for the revised WG SS are presented first, followed by a comparison of these with results for the Census 2001 question in order to determine the effectiveness of the revised WG SS. We present the overall composite scores of the proposed set of questions and the association between various demographic variables and levels of difficulty.

The final section presents the results of the analysis of the use of basic activities compared to the additional use of the three complex activity questions. The basic domains comprise the first seven questions as they appear on the proposed set of questions on the Adult Questionnaire (i.e. Q1 a–g). The complex domains comprise ‘joining in community activities’ (Q1 h), ‘taking care of Household responsibilities’ (Q3 p) and ‘Day to day work/ school work’ (Q 3 q) as they appear on the Adult Questionnaire (See Appendices A and B).

Results for the revised WG SS

Composite scores for responses on the revised WG SS

Table 3 describes how the overall composite score was calculated for each response category. Each respondent was only counted once in one of the four response categories. The category in which a respondent was placed was determined by the most severe response that a respondent used on any one of the questions. The same analytical procedure was applied to the eight individual questions.

Estimates shown in Fig. 1 below are for weighted household data for the population 15 years and older. The overall composite score for the revised WG SS show that 67% of respondents 15 years and older reported having ‘no difficulty’ on any of the eight domains of activities. For the response options of ‘some difficulty’ and ‘a lot of difficulty’, estimates of 20.24% and 9.86% were noted respectively, and 2.48% of respondents reported that they were unable to do at least one of the prescribed activities.

Composite scores for the revised WG SS analysed by different demographic factors

These Household Questionnaire results presented in Fig. 1 were analysed using cross-tabulations by a number of independent demographic variables. These variables included:
The Household Questionnaire responses were given by proxy, viz. usually by the head of the household on behalf of members of their household. Table 4 summarises these cross-tabulations. Some of the more important results from Table 4 are highlighted below for the different demographic factors.

**Age.** The most prominent effect is that of age. There is a positive relationship between age and the number of respondents indicating having difficulties. As age increases so the number of people with difficulties increases. This trend is observed through all age groups, where the estimates increase for all response options. Furthermore, the oldest age group showed a notable increase in the categories of ‘a lot of difficulty’ and ‘unable to do’ relative to other age groups. The youngest age group (15–24 years) showed the least difficulty in all response categories.

**Sex.** The results show that more women tend to report difficulties than their male counterparts across all three response categories, with 36% of women reporting difficulties compared to 29% of men. This is not an effect of a proxy response as this pattern was valid for respondents as well as non-respondents to the Household Questionnaire. One possible explanation is that women, as bearers and caregivers of children and their health, are more likely to be more aware of their own health problems and the consequences of these in terms of functioning.

**Marital status.** A positive relation is noted between marital status and levels of difficulty. There is an increase in the identification of level of difficulty across all response options, from the first category of comparison (‘Never married’) to the last category of comparison (‘Widow/widower’). The trend observed in this instance is similar to that noted for the variable of Age. It is suggested
Percentage of respondents indicating ‘some difficulty’, ‘a lot of difficulty’ and ‘unable to do’ for the composite revised WG Short Set responses by different demographic factors (household questionnaire for respondents 15 years and older) (source: StatsSA, 2007).

<table>
<thead>
<tr>
<th>Response category</th>
<th>Demographic factors (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response category</td>
<td>Age</td>
</tr>
<tr>
<td></td>
<td>15–24 yrs</td>
</tr>
<tr>
<td>No difficulty</td>
<td>85.0</td>
</tr>
<tr>
<td>Some difficulty</td>
<td>9.90</td>
</tr>
<tr>
<td>A lot of difficulty</td>
<td>3.60</td>
</tr>
<tr>
<td>Unable to do</td>
<td>1.16</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Response category</th>
<th>Demographic factors (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response category</td>
<td>Population group</td>
</tr>
<tr>
<td></td>
<td>Black African</td>
</tr>
<tr>
<td>No difficulty</td>
<td>65.15</td>
</tr>
<tr>
<td>Some difficulty</td>
<td>20.42</td>
</tr>
<tr>
<td>Unable to do</td>
<td>2.78</td>
</tr>
</tbody>
</table>
that age has a substantial bearing on the effect produced, as persons who fall in the category of ‘Never married’ (least difficulties) tend to be younger than divorced or widowed respondents, who report higher levels of difficulty and who tend to be older.

**Highest level of education.** Lower levels of education (none or primary education) are associated with the highest rate of reported difficulties. This can be interpreted in two ways; firstly, low levels of education result from the difficulties because of limited accessible educational facilities (Howell, 2005); or, secondly, low levels of education lead to increased difficulties (e.g. because of low levels of employment and hence limited financial means to access health care services). A combination of these two interpretations is also possible. In contrast, people with Grade 12 have the lowest level of difficulties. The reason for the slight increase in difficulties for the group with tertiary education is not clear. It could however be associated with the fact that people in this category are also older.

**Population group.** The results show that Black Africans have the highest prevalence of “a lot of difficulty” (10.95%) and “unable to do” (2.64%). Indian/Asians have the lowest rate of “some difficulty” (12.27%) and almost the same levels of “a lot of difficulty” (11.20%), suggesting that with this population group a problem is more likely to be seen as resulting in “a lot of difficulty” than in only “some difficulty”. The results are, as for sex, complicated by the fact that Africans are historically disadvantaged in South Africa and are therefore poorer and with lower education and less access to health care services. Black Africans make up 79% of the total population in South Africa, with Whites, Coloureds and Indians making up 10%, 9% and 3%, respectively (StatsSA, 2001).

**Employment status.** Employment status was calculated using the categories employed and unemployed and/or economically inactive. This division of categories was done in accordance with the broader definition of unemployment which includes people who are no longer looking for work (StatsSA, 2001). Amongst unemployed or economically inactive persons there was a substantially higher proportion of individuals with “a lot of difficulty” or who were “unable to do” one or more activities. This is in line with low levels of employment among people with more severe disabilities (StatsSA, 2005; Schneider et al., 1999).

**Living standard measure (LSM).** The LSM for households was calculated from responses to the LSM Questionnaire. The 10 LSM were collapsed into three main categories for comparative purposes. These categories were:

- LSM 1–3 (Low);
- LSM 4–6 (Middle);
- LSM 7–10 (High).

Individuals in the higher LSM levels have a lower prevalence of difficulties relative to other LSM groups. This finding is again closely related to access to services, level of education and employment status. This finding also reflects the close relationship between disability and poverty (Elwan, 1999).

**Geographical location.** For the study, urban and rural divisions were based on the classifications of the areas as per the 1996 Census. Results show that individuals with ‘some difficulty’ are
prevalent in both urban (20.35%) and rural contexts (19.57%). People with “a lot of difficulty” or who are “unable to do” are more likely to be living in rural areas with 15% of rural dwellers reporting these two categories combined compared to only 10% for urban dwellers. This could be attributed to the lack of services in rural areas as well as the reality or perception that the problem is exacerbated by the lack of health and social services. This finding is consistent with that found in the first national survey on disability conducted for the South African National Department of Health in 1998. (Schneider et al., 1999).

Comparison of the revised WG SS of Questions (‘Difficulty’) and Census 2001 Question (‘Disability’)

The data from the household questionnaire show that the revised WG SS yields a higher prevalence of disability than the Census 2001 question, viz. 33.24% vs 12.1%, respectively for the population 15 years and older. The data for both of these questions comes from the survey undertaken by StatsSA in 2006. The 2001 Census disability prevalence estimate (obtained in Census data collected in 2001) was calculated giving an estimate of 6.1% for the population 15 years and older in 2001 (compared to 5% calculated for the whole population) (StatsSA, 2005). The difference in responses given between 2001 and 2006 on the same question (Census 2001 question) raises some questions about the possible effect of the survey context. The current (2006) survey was all about difficulties due to a health problem while the Census 2001 was about a lot more. Further discussion on this issue is not warranted within the confines of this paper but have been noted by others (Meltzer, 2003).

Fig. 2 below compares the prevalence rates from the revised WG SS with those from the Census 2001 question as asked in the Household Questionnaire.

Considering the responses for the revised WG SS (difficulties) in relation to the Census 2001 question (disabled or not), 23.32% of people who reported as having ‘some difficulty’ were also identified as being disabled on the Census 2001 question. Similarly, 46.80% reporting ‘a lot of difficulty’ and 60.63% reporting being ‘unable to do’ were captured as disabled by the Census 2001

![Fig. 2. Weighted responses for the revised WG Short Set compared to Census 2001 questions (Household Questionnaire) (source: StatsSA, 2007).](image-url)
question. The more severe categories yield the best correspondence between the two question sets. The 23% of ‘disabled’ respondents with only ‘some difficulty’ put in doubt the consistency of the reference of ‘serious disability’ provided in the Census 2001 question, suggesting that this question does not provide reliable information on severity. The provision of four response options for the revised WG SS allow respondents to use a more nuanced response compared to a stark categorisation of ‘seriously disabled’ or not (i.e. yes/no response options).

**Individual domains of the revised WG SS of questions**

Fig. 3 presents the results for the individual questions of the revised WG SS. The most prevalent difficulties are those for the activities of seeing, walking and climbing steps and remembering. The least prevalent difficulties are for self care and communication. These trends are the same as found in the national disability survey of 1998 (Schneider et al., 1999) and the Census 2001 (StatsSA, 2005).

![Fig. 3. Weighted responses on individual questions and combinations of revised WG Short Set questions (Household Questionnaire) (source: StatsSA, 2007).](image-url)
As seen in Fig. 3, the results indicate a high proportion (relative to other domains) of the population 15 years and older reporting ‘some difficulty’ seeing even with glasses, which can be explained by a variety of reasons including a high awareness of difficulties in seeing as vision testing services and provision of glasses are generally relatively widespread, and/or some confusion with the phrase ‘even with glasses’ that might have been ignored by a number of respondents with their response being ‘without glasses’. The responses for the question on ‘joining in community activities are not presented in Fig. 3 as they are discussed in the next section.

Comparative analysis of the basic and complex activity domains

This section compares responses to the revised WG SS (basic activities) to responses on the three complex domain questions. The importance of this, as discussed in the introduction, is that if difficulties on complex domains are always (or nearly always) accompanied by difficulties on basic questions, it would be sufficient to ask questions on basic domains to identify the population at risk for disability related disadvantage and discrimination. It would, of course, not provide sufficient information on the experiences of disability. Further questions on complex activities and environmental barriers are required for this.

Table 5 presents the results for composite responses on the revised WG SS (excluding the question on ‘joining in community activities’). The composite scores were obtained by including all respondents with any response of ‘some’, ‘a lot’ or ‘unable to do’ as ‘disabled’ and all other respondents (only reporting ‘no difficulty’) as non-disabled. The composite score was cross-tabulated with the four response options for each of the three complex domain questions (see Q1 h, 3p and 3q in Adult Questionnaire – Appendix B). Table 5 presents results both within ‘disabled’ and ‘non-disabled’ and within each of the response options for the complex questions (row and column percentages). While ‘Missing’ responses are included for the sake of completeness, they are not discussed as the number of respondents are very small.

The responses show a similar pattern for all three of these complex domain questions. The main trends are as follows:

a) comparing ‘disabled’ and ‘non-disabled’ on basic domain scores, the results indicate that few people report difficulties on the complex domains without also reporting difficulties on basic domains:

- 85.7, 86.9 and 89.3% of the respondents (respectively for questions 1, 2 and 3 in Table 5) who reported having difficulties (being disabled) on the basic domains, reported having ‘no difficulty’ on the three complex domain questions. The remaining respondents reported being disabled and having difficulties on the complex domain questions (10.6, 13 and 14.2% respectively). These people have difficulties in basic activities that do not extend into complex activity limitations;
- a very high majority of respondents (99.2, 97.7 and 98.1%, respectively) who reported ‘no difficulties’ (i.e. non-disabled) also reported ‘no difficulties’ on the complex domain questions. The remaining minority of respondents (0.7, 3.9 and 1.6%, respectively) reported difficulties on the complex domain questions but none for the basic domains. These latter respondents are of interest as they represent the (supposedly) ‘missed’ population that have complex activity limitations but no basic activity limitations.

b) within individual response options for complex domains in terms of ‘disabled’ and ‘non-disabled’:

...
Table 5
Percentage of Respondents reporting difficulties on basic activities (composite scores on the revised WG Short Set) compared to three questions on complex domains of functioning (adult questionnaire) (source: StatsSA, 2007).

<table>
<thead>
<tr>
<th>Complex domains</th>
<th>Disability status for revised WG SS (%)&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Disabled (have difficulties)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Within disabled&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Within complex domain Q response options&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Non-disabled (have no difficulties)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Within non-disabled&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Within complex domain Q response options&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td><strong>Difficulty joining in community activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No difficulty</td>
<td>89.3</td>
<td>99.2</td>
</tr>
<tr>
<td>Some difficulty</td>
<td>5.9</td>
<td>0.2</td>
</tr>
<tr>
<td>A lot of difficulty</td>
<td>2.4</td>
<td>0.1</td>
</tr>
<tr>
<td>Unable to do</td>
<td>2.3</td>
<td>0.4</td>
</tr>
<tr>
<td>Missing</td>
<td>0.1</td>
<td>0.4</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Difficulty taking care of household responsibilities</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No difficulty</td>
<td>86.9</td>
</tr>
<tr>
<td>Some difficulty</td>
<td>8.2</td>
</tr>
<tr>
<td>A lot of difficulty</td>
<td>3.3</td>
</tr>
<tr>
<td>Unable to do</td>
<td>1.5</td>
</tr>
<tr>
<td>Missing</td>
<td>.0</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Difficulty with day to day work/school</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No difficulty</td>
<td>85.7</td>
</tr>
<tr>
<td>Some difficulty</td>
<td>9.3</td>
</tr>
<tr>
<td>A lot of difficulty</td>
<td>3.2</td>
</tr>
<tr>
<td>Unable to do</td>
<td>1.7</td>
</tr>
<tr>
<td>Missing</td>
<td>.1</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>

<sup>a</sup> Disabled = some difficulty, a lot of difficulty or unable to do; not disabled = no difficulty.

<sup>b</sup> Column percentage.

<sup>c</sup> Row percentage.
• just under one third of all respondents who reported ‘no difficulty’ on the complex domain questions, reported difficulties on the basic domain questions (‘disabled’). This would be, for example, people who have difficulties but these do not interfere with functioning in the more complex domains. The remaining two thirds of respondents reported no difficulties on either basic or complex domains;

• a high proportion of respondents (93.4, 69.4 and 76.4%, respectively) reporting ‘some difficulty’ on the complex domain questions also reported difficulties on the basic domain questions (‘disabled’). It is not clear why less people reporting difficulties in ‘taking care of household responsibilities’ and ‘day to day work/school work’ have difficulties in basic activities. There is a difference in the nature of these activities. Household responsibilities and day-to-day work are activities that are necessary to do every day, while ‘joining community activities’ is not an activity that necessarily occurs every day and is more influenced by personal desires than the former two activities. The necessary activities can be difficult to execute for reasons that are not ‘health’ related, (e.g. not having the time or financial means). However, this explanation is only tentative and requires further investigation;

• the results for ‘some difficulty’ are replicated with higher proportions and less differences for the response options ‘a lot of difficulty’ and ‘unable to do’ on the complex domain questions. The majority of people with such difficulties on the complex domains also have difficulties on the basic activities;

• just over two thirds of respondents who have no difficulties in basic domains (‘non-disabled’), reported ‘no difficulties’ on the complex domain questions. The remaining one third of respondents who are ‘non-disabled’ (i.e. no difficulties on basic domain questions) vary in their responses to the complex domain questions. For the activity of ‘joining in community activities’ the responses of ‘any degree of difficulty’ (some, a lot or unable) are below 8%, suggesting again that very few people who have no basic activity limitations have difficulties in joining in community activities. For the other two complex activity questions, the results show that 30.6 and 23.6% (respectively for questions 2 and 3) of respondents have no difficulties on the basic activities but do have ‘some difficulties’ in the complex ones;

• The responses for ‘a lot of difficulty’ and ‘unable to do’ for all three complex activity questions are very low for people without basic activity limitations, and hence, are negligible.

Discussion

This paper aims to test the effectiveness of the revised WG SS as a measure of disability for the South African Census in 2011 and to provide evidence on the use of a Short Set of basic activity questions to identify the population at risk of experiencing disadvantage and discrimination because of activity limitations.

Performance of the revised WG SS as a Census 2011 disability schedule

The revised WG SS is a measure that has shown itself to be effective for use in a Census. The reasons for this include the inclusiveness of the measure and the demonstration of trends in the results that fit well with what we know about disability statistics.

Inclusiveness of the measure of disability

The results presented in Fig. 1 indicate that a higher population estimate for disability is likely to be obtained in the Census than previously obtained in South Africa using questions asking
about ‘serious disability’ (e.g. the Census data collected in 2001). The reasons for this is linked to a number of factors that produce a more inclusive disability measure, such as the wording of the question and the response options used.

In terms of the wording of the question, asking about difficulties is clearly seen as more ‘acceptable’ as a question than asking about ‘disability’. This is confirmed by results obtained in the focus group phase of the research where people described ‘disability’ as being permanent, not ‘curable’ or ‘solvable’ and referring to a condition that ‘can not be changed’ and where a person ‘is unable to do anything’ (Schneider, 2009; p47). Difficulties on the other hand can be ‘cured’ and ‘solved’. Focus groups participants with chronic illnesses (including HIV) or who were elderly, rarely responded as being ‘disabled’ (on Census 2001 question) but did report having difficulties on the WG SS. Ravaud, Letourmy and Ville (2002) showed a similar finding with older people reporting activity limitations (similar to difficulties in this paper) but not identifying themselves as disabled.

A similar effect of question wording where one term is more emotionally loaded than the other was reported by Goddard (1990, cited in Meltzer, 2003). Asking someone if they ‘have’ (the neutral term) rather than ‘suffer from’ (the emotionally loaded term) an illness increases the self-reported estimates of morbidity. A person may have an illness but not necessarily suffer from it (Meltzer, 2003).

In terms of response options, the revised WG SS uses four response options (no, some, a lot, unable) and the Census two (yes/no). The notion of human functioning (and disability) being on a continuum as encapsulated by the ICF (WHO, 2001) is best captured through using at least four response options. This acknowledges that there are differences in the degree of difficulty one person has compared to another and between different activities for the same person. The use of a yes/no response format forces a person to make a choice about whether they fall in or out of a categorical group, while giving four response options (or five as done in the ICF [WHO, 2001]), allows the person to report having minor difficulties without feeling that this would put them into the ‘yes’ category of ‘being disabled’. The results in Fig. 2 highlight the fact that many people who reported having ‘some difficulty’, answered ‘no’ to having a ‘serious disability’ (Census 2001 question).

**Demonstration of ‘known’ trends**

The results in Table 4 highlight the trend of increasing estimates for difficulties with increasing age. A review of the disability statistics reported on in the UN Statistics Division’s database on disability (UNSD, 1990b; Bajekal et al., 2004; Schneider et al., 1999 and many more), demonstrates this trend no matter what the question asked. The estimates vary but the trend remains.

The results presented in Table 4 indicate that there are further differences in response rates for LSM status, educational achievement, employment status, and marital status. It appears that the older, poorer, less educated, unemployed and widowed or divorced respondents have a greater propensity to report having difficulties. These trends are not as clearly established in the disability survey literature as the one for age, but were similar in the two national data sets on disability in South Africa (Schneider et al., 1999; StatsSA, 2005).

**Comparison of the revised WG SS with the Census 2001 disability question**

The results presented in Fig. 2 indicate that the Census 2001 question provides not only limited information on the severity of the disability but also excludes many people who report having significant difficulties. All (except for 1.5%) respondents who were identified as being disabled on the Census 2001 were also reported as having difficulties on the household questionnaire (proxy
reporting). Similarly, the comparison between the revised WG SS and the question ‘Are you disabled?’ on the Adult Questionnaire (direct reporting) showed that only 1.99% of people who said they are ‘disabled’ reported having no difficulties (StatsSA, 2007). The Census 2001 question also identified as disabled 23% of people who only had ‘some difficulty’. These could be people who self-identify as being disabled more for political reasons than based on the severity of their difficulties, who reported their difficulty with use of technological or personal assistance or are people with disfigurements or Albinism who do not experience any activity limitations but do experience significant discrimination and, therefore, identify as disabled. From these results we see a confused picture of severity emerging from the Census 2001 despite the question wording being ‘serious disability’. The revised WG SS provides a more graded reflection of severity through the use of more than one response options and not embedding a severity level within the question wording.

**Basic versus complex domains**

As discussed in the introduction to this paper, there is some debate as to the effectiveness of the WG SS, which only asks about basic activities, in identifying the full population at risk of disability related disadvantage and discrimination. The debate is not whether complex activities are important in disability measurement, but only whether they are necessary in identifying the population at risk in order to create a demographic variable for further analysis. The results from this study suggest that using questions only on basic activities would exclude only a few people who have difficulties on complex activities. However, the results for the complex domain ‘joining in community activities’ are somewhat different to those for ‘taking care of household responsibilities’ and ‘day to day work’ but only for people who have ‘some difficulty’. More people with activity limitations in ‘taking care of household responsibilities’ and ‘day to day work’ than in ‘joining in community activities’ are ‘missed’ when only asking about basic activity limitations. Furthermore, there are more people with basic activity limitations than with complex activity limitations. This highlights how people find ways of managing basic activity limitations in order to avoid experiencing complex activity limitations.

These results highlight the difficulty in creating a simple and clear measure of complex domains. Current work is being undertaken by the WG and UNESCAP on testing questions in a qualitative manner to ascertain how people understand them and what they think of when answering (Miller & Willson, 2009). The first author is involved in doing some of these interviews in South Africa and very preliminary anecdotal evidence suggests that the understanding of these three questions is wide encompassing difficulties due to health problems but also due to non-health aspects such as lack of financial means or time to fulfil these activities. More investigation is required before concluding whether the respondents ‘missed’ by the revised WG SS should even be counted into the population at risk for disability. It could be that the respondents with difficulties in the complex domains are in fact reporting non-health difficulties and are not part of the population of interest for disability statistics.

The results, while inconclusive, suggest that the basic domain questions are necessary in identifying people with varying levels of difficulties in complex domains but possibly not entirely sufficient.

**Some methodological considerations**

The survey results for the Census 2001 question differed to the results obtained in 2001 for the population 15 years and older. The survey yielded an estimate of 12% for this questions
compared to 6.1% for the actual Census data collected in 2001. The context of the household survey is one that could have influenced the results gained in comparison to results from Census as carried out in 2001, where disability was just one question out of many, and not the focal topic. Respondents would have developed a heightened awareness of difficulties by the time they were asked the Census 2001 question in this study at the end of the Household Questionnaire. The Census 2001 disability question was deliberately placed at the end of the Household Questionnaire after the set of questions on difficulties in order to avoid any negative connotations on ‘disability’ contaminating responses on questions about difficulty. The final test will be the full Census in 2011 and comparison of those results with the full Census 2001 results. The effect of survey context and question placement have been documented in other surveys (Meltzer, 2003; Bajekal et al., 2004).

The conclusion is that the revised WG SS is a more inclusive measure and still provides the same information as that collected on the Census 2001 question. The 1.5% of the population who were ‘disabled’ on the Census 2001 question but ‘non-disabled’ on the revised WG SS (i.e. were ‘missed’) could be either errors in responses or could reflect some people who consider themselves disabled but who do not have any activity limitations, such as a person with Albinism or disfigurement.

Conclusions

Analysis of the household survey data shows that the revised WG SS measures a broader notion of disability than that was measured in Census 2001, hence identifying a population larger than but inclusive of the population identified by the Census 2001 question. The findings are not conclusive as to the effectiveness of identifying the population at risk for disability-related disadvantage and discrimination using only basic domains of functioning, rather than including questions on more complex domains. Further research is required to understand these findings.

From the focus groups, it is apparent that people would rather answer in the affirmative to questions on having difficulties as opposed to having a disability as established in the first phase of this census content research (Schneider, 2009). This together with the face validity of the results confirm that the revised WG SS is a relevant Census measure of disability.

Appendix A. Household Questionnaire – disability questions (For full questionnaire refer to Statistics South Africa, 2007)

The following questions ask about any difficulties that the person has because of a health problem or condition.

**11 GENERAL HEALTH AND FUNCTIONING**

**Does the person 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 (with glasses if he/she wear(s) them)
b) Hearing (with a hearing aid if he/she wears 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 his/her usual language, including sign language (i.e. understanding others or being understood by others)
h) Joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can.

12 GENERAL HEALTH AND FUNCTIONING
Does the person use any of the following?
1 = Yes
2 = No

a) Eye glasses
b) Hearing aid
c) Walking stick or frame
d) A wheelchair
e) Chronic medication

13 DISABILITY
Does the person have any serious disability that prevents his/her full participation in life activities (such as education, work, social life)?
Mark any that apply
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)

Appendix B. Adult questionnaire (disability questions only; for full questionnaire refer to Statistics South Africa (2007))

NOTE: The respondent for this questionnaire should be 15 years or older.
1. GENERAL HEALTH AND FUNCTIONING
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 (with glasses if you wear them)
b) Hearing (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)
h) Joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can
2. GENERAL HEALTH AND FUNCTIONING
Do you use any of the following?
1 = Yes
2 = No

a) Eye glasses
b) Hearing aid
c) Walking stick or frame
d) A wheelchair
e) Chronic medication

3. HEALTH CONDITIONS/PROBLEMS IN THE LAST 30 DAYS
In the last 30 days, did you have difficulty with any of the following because of a health condition or problem?
1 = No difficulty
2 = Some difficulty
3 = A lot of difficulty
4 = Unable to do

a) Seeing and recognising a person you know from 7 meters away (e.g. across a street) (with glasses if you wear them)
b) Seeing and recognising an object at arm’s length (with glasses if you wear them)
c) Hearing someone talking on the other side of the room in a normal voice (with a hearing aid if you wear one)
d) Hearing what is said in conversation with one other person in a quiet room (with a hearing aid if you wear one)
   Standing for long periods such as for 30 minutes
e) Walking a long distance such as a kilometre (or equivalent)
f) Concentrate on doing something for 10 minutes
g) Remembering to do important things
h) Learning a new task, such as learning how to get to a new place
i) Washing your whole body
j) Getting dressed
k) Generally understanding what people say
l) Talking or signing clearly so people can understand you
m) Starting and maintaining a conversation
n) Dealing with people you do not know
o) Maintaining a friendship
p) Taking care of your household responsibilities
q) In your day-to-day work/schoolwork

References


