

Testing a disability schedule for Census 2011:

Summary report on 26 focus groups

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Glossary and abbreviations

- WG Washington Group on Disability Statistics
- Stats SA Statistics South Africa
- WHO World Health Organization
- ICF International Classification of Functioning, Disability and Health
- D1 Composite score for disability status using response options from 'some' through to 'unable to' do an activity for the 6 core questions.
- D2 Composite score for disability status using response options 'a lot' and 'unable to' do an activity for the 6 core questions. This measure was not used in this study.
- D3 Composite score for disability status using the response options 'unable to' do an activity for the 6 core questions.
- ED1, ED2 and ED3 Composite scores calculated in the same way as for D1, D2 and D3 but for the extended set of questions.

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Executive summary

Background and methodology

This study uses a series of 26 focus groups to examine the nature of responses to a proposed set of questions developed by the Washington Group on Disability Statistics for use in Censuses. The South African study is aimed at testing these questions with the specific view of using them in the Census 2011. These questions consist of six core questions relating to difficulties people have in doing a series of activities including seeing, hearing, walking and climbing stairs, remembering and concentrating, self care and communicating. The South African set of questions included a further question on difficulties people have in participating in community activities like anyone else.

The focus groups consisted of five groups of parents of disabled (3 groups) or non-disabled (2 groups) children, and 21 groups of adults with and without disability. The adult groups were divided into three groups based on an allocated disability status. Nine groups were categorised as 'disabled' and included people with head injuries, schizophrenia, physical, visual or hearing impairments of varying degrees. Six groups were categorised as 'unsure' and included people living with HIV/Aids, people with other chronic illnesses and older people. The last six groups were categorised as 'non-disabled' and included youth and adults up to the age of 60 years.

The groups were given a standard questionnaire to complete prior to the start of the group discussion and the questionnaire formed the basis of the focus group discussion. The groups were run in the language of the participants and the tape recordings transcribed and translated into English where necessary.

Results

The findings are presented in two sections – the quantitative and the qualitative results.

Quantitative results

The Washington Group (WG) core set clearly identifies a population that is much wider than that identified by either the Census 2001 questions or a simple question asking 'Are you / Is your child disabled?'. The similarity of the Census 2001 and 'Are you disabled?' responses on the overall composite figures remains in the analysis by different variables, although is not borne out in the individual group responses. For the individual groups, the people might identify themselves as disabled but not as having a serious disability that prevents them from participating in daily activities. Thus, these two question sets are not necessarily picking up the same population as being disabled, but do give similar estimates of disability.

The WG's questions seem to be easier to respond to especially in the mild and moderate categories of difficulty. This is confirmed by comments made in the group discussions about 'difficulties' being less severe and more readily endorsed than questions about being 'disabled'.

The core set of the WG seems to be adequate to provide a census-based estimate (and good local level data), as it seems to provide an estimate of people with difficulties. However, there is a role to play for population-based sample surveys to complement the Census data with a more detailed set of questions to capture the population more fully but at a national, provincial and possibly regional level. Furthermore, the use of additional domains of learning, social interactions and emotional functioning add a significant amount of 'yes' responses and their role in this should be investigated further.

Qualitative results

The overall impression given by the participants across all the groups is that disability is a permanent feature of an individual; it renders a person dependent on others as they are unable to do anything for themselves; it is predominantly a physical and visible attribute although it was acknowledged that other less visible factors can also determine disability; it is not 'solvable', 'curable' nor 'can it be changed'. There is a strong notion of 'them' and 'us' expressed by the non-disabled and 'unsure' participants and even by some of the disabled participants about impairments different to theirs.

This understanding of disability suggests that there is a strong association with the term 'disability' and that this is not a positive one. This leads to people not wanting to self identify as being disabled. This has important implications for the wording of questions on the Census schedule. The quantitative results bear this out as the disability status estimate was much higher for the WG core set (D1) that used the term 'difficulty' rather than 'disability'. The comments in the non-disabled and HIV/Aids groups also highlight this when they comment on the questions not being relevant to them as they are not disabled.

In general, the WG's questions were seen as being good questions, easy to answer and not too long to remember. Few problems were noted with the questions themselves. The questions were seen as reflecting people's lives. Although the 'non-disabled' groups were clear that since the questions were about 'disabled' people and they were 'normal' they must say 'no' to all the questions.

There were few problems associated with the time references used in the questions on the environment and extended questions, but some people did not understand the need to average out for the whole period rather than thinking about each day. The scope of the questions was seen either as being only about disabled people or about the general population. The frame of reference generally used (when indicated) seemed to be what was done 'normally' or 'usually' and included use of assistive devices.

Recommendations

The WG core set of questions should be modified according to the findings from the focus group discussions and tested further starting with a population-based sample survey to determine whether trends noted in this study are ones that are replicated for the whole population. In addition, further qualitative research on the cognitive understanding of the questions should be undertaken.

Section 1: Background

Statistics South Africa (Stats SA) is developing a comprehensive census research programme on census methodologies and content development. As part of this process, the schedule for disability was identified as requiring testing in terms of its efficacy. The tender (Stats SA 12/05) for undertaking this testing process was awarded to the Child, Youth, Family and Social Development (CYFSD) research programme of the Human Sciences Research Council (HSRC) in December 2005. This report sets out the process of doing this research as well as the findings arising from it.

1.1 Terms of reference

The terms of reference as set out in the tender specifications from Stats SA are as follows:

1. Plan a series of focus group sessions to gather the pertinent qualitative information to inform the development of a disability schedule.
2. Conduct these focus group sessions to collect data to answer the questions as set out in the aims of the study below.
3. Compile a report on the research and its findings.
4. Meet with representatives of Stats SA at pre-determined intervals to discuss the progress of the work.

1.2 Aims of the study

The aims of the study were to test participant's reactions to a standard schedule of disability questions and to gather other information relevant to the measurement of disability. The information gathered using focus groups will be used to inform the finalisation of the schedule to be tested as well as field procedures relevant to disability. The schedule to be tested was the set of questions for Censuses developed by the Washington Group on Disability Statistics.

The specific questions that were asked in the study were the following:

- What is the participants' understanding of the concept 'disability'?
- Is the WG schedule of census questions on disability consistent or does their interpretation differ across different subpopulations?
- Are there issues not covered in the schedule of questions that are important to participants?
- Do the participants feel that the issues covered in the schedule of questions are relevant?
- What kinds of disability information about themselves do participants consider to be most sensitive?

Section 2: Theoretical framework

Understanding disability and its measurement is essential if accurate policies and programmes are to be implemented to mitigate the effects of experiencing disability. Disability is a complex and multifaceted phenomenon and comprises a number of different aspects that further interrelate in a complex manner (WHO, 2001). These aspects include the health condition, functioning and level of independence of the person, the external physical, social and attitudinal environment, the person's quality of and satisfaction with life, and the level of disadvantage and social exclusion experienced by the person (Schneider, et al., 2003). These different aspects have different policy implications, such as need for prevention programmes for the health condition; surgical, medical and rehabilitation services for impairments and activity limitations; as well as awareness raising programmes and legislation to ensure that disabled people are fully integrated into society.

A useful generic definition of disability is that given by the World Health Organization in the International Classification of Functioning, Disability and Health (ICF) (see www.who.int/classification/icf for more detail on the ICF). Disability is an outcome of an interaction between a person's health condition (e.g. illness, trauma/injury, disorder) and the context in which that person lives (WHO, 2001). More specific definitions can be derived from this generic definition and based on specific purposes and measures used.

The context is made up of both internal factors (age, sex, other health conditions, personality and coping style) and the factors external to the person including the physical, attitudinal and social/policy environment. The outcome can be described at three levels – body level (structure and function of individual body systems and parts), person level (doing activities such as walking, learning, communicating, etc.) and societal level (participating in activities in a person's usual environment taking the effect of the environment into account). The level most useful for including in self-report surveys or censuses is the person level where questions are asked about difficulties people have in doing various activities. However, full description of disability (e.g. to describe functioning of a country's population functioning) should include data on all three levels of outcome as well as a description of the environmental factors that play a role in determining levels of functioning and the internal. However, for purposes of the census the focus is on collecting information at the person level and some indications of the environmental factors.

The large differences in disability statistics currently observed internationally suggest that there is little understanding or consistency in what aspects of the disability experience are being measured. In order to ensure that disability statistics are useful for policy development and implementation, we need to understand what population they describe. Furthermore, this would allow for cross-country comparability for disability statistics.

The need for disability statistics has undergone a significant change over the last 50 years, from a need to count the number of people who are 'blind, deaf, crippled or mentally retarded' (presumably for purposes of documentation and provision of institutions), through to a more integrated notion of functioning and disability as a universal human phenomenon. Disability is just as much the experience of a person with severe cerebral palsy who uses a wheelchair as it is that of an elderly gentleman who has had two hip replacements and who uses a walking stick to get around. It is also as much about the 45 year old's experience of not coping in noisy or group situations because of a moderate hearing loss as well as that of the child born deaf.

By accurately measuring population functioning we can undertake analyses on the role of disability in determining social exclusion, reasons for unemployment, levels of poverty, educational attainment, general disadvantage, and so on. The statistics provide a basis for deciding on levels of service provision, as well as measuring outcomes of health interventions. For example, the effectiveness of providing treatment for HIV/Aids can be measured in terms of levels of functioning of the population rather than only through weight-gain and CD4 counts.

The current status of disability statistics globally shows large differences across different regions. Low and middle income countries generally show lower prevalence rates than high income countries. The United Nations Statistics Division shows variations from 0,2% (India) through to 33% (Norway) in its disability database where data received from countries are presented. (cf. unstats.un.org/unsd/disability). These results are not comparable and cannot be said to be measuring the same thing. Some methodological factors have been clearly recognised as explaining these inter-country differences in disability prevalence. These factors include:

- The type and wording of the questions used in the data collection instrument: e.g. 'are you deaf, blind or crippled?' vs 'do you have difficulty hearing, seeing, walking, etc.';
- The definition of disability used : e.g. using 'severe' level responses only vs including responses indicating a mild difficulty;
- The survey method : e.g. using self report vs observation or health examinations;
- The population demographics: high income countries typically have a larger proportion of older people than low income countries. The sharp increase in prevalence of disability in the ages 60 years and above contributes to a higher prevalence in high income countries;
- Level of industrialisation, use of cars and the resulting injuries, and the availability of health care services to treat severe injuries: i.e. having injury survivors with permanent impairments vs a high case mortality rate among injured people.

These are factors that operate at the *population level*. There are a number of *individual level* factors that will also play a role in whether people identify themselves as having a difficulty or not. These factors are less well understood but include aspects such as sense of self, level of independence, attitudes to disability and cultural beliefs. More research is required to better understand these factors.

The Washington Group on Disability Statistics (WG) under the auspices of the UN Statistics Division has as its objective to 'guide the development of a small set(s) of general disability measures suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic, necessary information on disability throughout the world' (UNSD, 2004, p9). The WG has developed a set of 6 core questions that are currently being tested in a number of countries. The questions use the Activity component of the ICF as the basis for the questions and are as follows (Washington Group, 2004):

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty with self care, such as washing your body or dressing?
6. Because of a physical, mental or emotional health condition, do you have difficulty communicating, (for example, understanding others or others understanding you)?

The response options for all 6 questions are the same, being:

- a) no – no difficulty
- b) yes – some difficulty
- c) yes – a lot of difficulty
- d) cannot do at all.

Disability statistics are necessary at a national level. In order to be useful they need to be clearly understood. At this point, we are still lacking this clarity at both a national level and an international level. At the national level, we need to develop a better understanding of what a prevalence rate of 5% represents in terms of people's needs, and at the international level we need to understand to what extent disability statistics are comparable. Does 5% in South Africa represent the same thing as 14% in Australia, and hence does Australia have more disability and, if yes, why? Or is this difference representing a very different notion of what it means to have difficulty in doing various activities? The focus group study provides some initial insights into how people respond to the questions on disability and functioning.

Section 3: Methodology

The study design is qualitative as this allows for a productive exploration of the issues related to people's understanding of the questions proposed for Census 2011 as well as the notion of disability and difficulty. The qualitative methods are complemented by the administration of a questionnaire to collect basic demographic information on the participants as well as their responses on the proposed questions. The use of the questionnaire also allows the introduction of the questions to the participants prior to the discussion on these very questions.

3.1 Distribution of the focus groups

The focus groups were stratified according to disability status, urban vs. rural, adult vs. parent of a child, type of disability and range of chronic conditions, province, population group and language spread. This resulted in 26 groups as set out in Appendix 1.

Disability status as disabled, non-disabled and unsure was determined by the researcher. 'Disabled' people are those who clearly identify themselves as disabled for one or more reasons. 'Non-disabled' people are those who are not likely to identify themselves as disabled, and 'unsure' are those people who have chronic conditions such as asthma, hypertension, HIV/Aids, etc. or are elderly and who might or might not identify themselves as disabled. This status was allocated to the groups *a priori* with no consultation with people as to how they would in fact identify themselves. The analysis reviews the findings on how people identify themselves in relation to this allocation of status in the different questions asked.

3.2 Research instruments: Discussion guide and questionnaire

The two instruments developed for this research included the questionnaire to be administered individually prior to the discussion and the discussion guide for the group discussion. Both instruments are included in the appendix (Appendix II and III)

a) Questionnaire:

The questionnaire aimed to provide basic demographic information on the focus group participants, as well as record their responses on four sets of questions related to disability. These sets included:

- A question on their self-identified disability status: 'Are you disabled?' or 'Is your child disabled?'
- The Census 2001 questions on disability;
- The 6 core questions developed by the WG for use on censuses plus an additional question on participation as well as a two-part question on environmental factors. These last two questions are not part of the WG core questions but there have been suggestions that these questions be included as part of the WG core set of questions. The Participation question was taken from the World Health Organization's WHO-DAS II and has also been used on various WHO surveys such as the World Health Survey. The question on environmental factors was drafted based on the Craig Hospital Inventory of Environmental Factors (CHIEF) version 3.0 developed by Whiteneck and his colleagues in Englewood, Colorado. (Craig Hospital, April 2001).
- A set of further questions set out by the WG to allow for testing of the core set across various countries. These questions cover the same domains as those in the core set but with two to five questions per domain. There are also some additional domains covered that are not explicitly covered in the core set, such as learning, social interactions and psychological functioning.

Questionnaire translation was undertaken in all official languages except for Venda and was administered using South African Sign language to the deaf participants. The questionnaire was administered in different ways depending on the level of literacy of the participants. In groups where the participants were very literate, they were given the questionnaire to read and complete by themselves or the facilitator read the questions and individuals marked their own responses. Where the participants were not literate the questionnaire was administered by the focus group facilitator, note taker or observer to each individual prior to the start of the group discussion. In groups of blind or partially sighted individuals, the facilitator read the questions and the observers and note taker assisted the participants in marking their responses. The deaf participants had the questionnaire administered using sign language and they marked their own responses.

There are two versions of the questionnaire – one for adults responding for themselves and the other for parents responding about their child or ward.

b) Discussion guide:

The discussion guide was developed with the Terms of Reference of the study in mind. The focus of the guide was on the following:

- Eliciting reactions from participants on the questions in the questionnaire in terms of difficulty in understanding, embarrassment, sensitive topics, time reference and ability to answer within those time periods, or any other comments,
- Conceptualisation of the notion 'disability' generally and in contrast to the notion 'difficulty'.
- Relevance of the content covered in the questions and need for further questions.
- Sensitive issues in the area of disability.

The approach used was to elicit discussion about the participants themselves as well as their reaction to various scenarios on hypothetical people with or without difficulties. This approach allowed for investigating individual's responses in relation to the responses they would give to the same scenarios administered across all or most groups. The scenarios were about adults for the adult groups and about children for the parent groups.

3.3 Participant demographics

Tables 1 and 2 present the demographic profile of the participants.

Table 1: Demographic profile of the focus group participants – Parents of children and their children (N = 38)

Living context	Age - child		Age - parent		Sex - child		Sex - parent		
Independent	27	0 - 2 yrs	3	<30 yrs	5	Male	22	Male	3
With personal attendant	9	3 - 10 yrs	15	30 - 49 yrs	31	Female	9	Female	35
Institution / Hospitalised	2	11 - 18 yrs	12	50+ yrs	2	Missing	7	Missing	0
		19 + yrs	8						

Education level of parent		Marital status of parent		Employment status of parent	
No schooling	2	Married civil/religious	15	Employed	17
Primary school	6	Married traditional/customary	8	Unemployed or economically not active	17
High school	20	Living together like married partners	2	Missing	4
Certificate	2	Never married	6		
Degree/Diploma + postgrad	5	Widower/widow	4		
Other	2	Separated	2		
Missing	1	Divorced	1		

Table 2: Demographic profile of the focus group participants – Adults (N = 185)

Living context		Age		Sex	
Independent	125	<=30 yrs	76	Male	71
With personal attendant	40	31 - 60 yrs	90	Female	108
Institution / Hospitalised	11	61+ yrs	12	Missing	6
Missing	9	Missing	7		

Education level		Marital status		Employment status	
No schooling	7	Married civil/religious	41	Employed	108
Gr 0	3	Married traditional/customary	17	Unemployed or economically not active	Figure?
Primary school	36	Living together	4	Missing	Figure?
High school	91	Never married	95		
Certificate	11	Widower/Widow	10		
Dip/Deg + postgrad	25	Separated	3		
Don't know	3	Divorced	12		
Missing	9	Missing	3		

3.4 Data collection procedures and transcriptions and data entry

The participants were recruited through networks of the disability sector for all the groups allocated as 'disabled', health care provision and HIV/Aids networks for the groups allocated as 'unsure' and through general contacts for recruitment of people to match the criteria for the groups allocated as 'non-disabled'. The participants were given refreshments before, during or after the group discussions and were paid an honorarium of R100 each. Any transport costs incurred were also reimbursed.

The participants were each asked to complete and sign the consent form prior to participating in the group discussions. The tape recordings were transcribed into the original language and translated into English. The responses to the questions on the questionnaires were captured onto SPSS for statistical analysis.

3.5 Analysis

The qualitative information was analysed thematically using the computer software Atlas-ti. The transcripts were coded and analysed in terms of consistency of responses across groups, overall patterns of response for the participants stratified by allocated disability status.

The quantitative data were analysed using basic frequencies and crosstabulations with various recoding of variables (e.g. age into categories). The results are presented using percentages for the adult groups as the number of participants was sufficiently high (N = 185) to warrant this approach. The parents of children groups had an N of only 38 and so numbers rather than percentages are presented.

3.6 Ethical clearance

Ethical clearance was obtained from the University of the Witwatersrand's Human Research Ethics Committee (Medical) prior to the start of the focus groups.

3.7 Structure of the summary report

This summary report presents a selection of the main findings from the analysis. The more detailed results are available in the full report. The findings presented include the analysis of the responses of the Washington Group core versus extended set of questions, and the responses given on the Washington Group questions compared to the Census 2001 question and the question 'Are you/Is your child disabled?'

For the qualitative analysis the main themes reported on are the reactions to the core set of questions, issues of scope and frame of reference of the questions, and the understanding of what disability entails. The reactions to the scenarios presented in the focus groups are not discussed in this report.

Section 4: Quantitative analysis of questionnaire data

This section presents the quantitative results from the questionnaire analysis using basic frequencies and cross-tabulations. The results for the parent and adult groups are presented separately.

The analysis for the quantitative data included the following:

- The WG core and extended question set responses were recoded to binary variables reflecting two extreme measures of disability D1 (high estimate) and D3 (low estimate). D2 (middle estimate) was not computed for this analysis.

The response options for the WG set of 6 questions (plus the additional question on participation) were 'no difficulty', 'some difficulty', 'a lot of difficulty' and 'unable to do'. In order not to lose the richness of the four response options (and hence the notion of a continuum of functioning), the analysis is done using different definitions of 'disabled'. The WG analysis strategy proposes 3 different definitions as follows (see WG documents at www.cdc.gov/nchs/citygroup.htm):

D1 = 1 if response is *some difficulty*, *a lot of difficulty*, or *can't do at all*, else = 0

D2 = 1 if response is *a lot of difficulty* or *can't do at all*, else = 0

D3 = 1 if response is *can't do at all*, else = 0

Similarly for the extended set of questions:

ED1 = 1 if at least one extended question in a given domain has a response of *some difficulty*, *a lot of difficulty*, or *can't do at all*, else = 0

ED2 = 1 if at least one extended question in a given domain has a response of *a lot of difficulty*, or *can't do at all*, else = 0

ED3 = 1 if at least one extended question in a given domain has a response of *can't do at all*; else = 0

- The responses on each individual domain core and extended questions were compared, as were the overall responses to a composite of the core and composite of the detailed question responses.
- Frequencies were calculated for the responses to the three different sets of questions on disability – 'Are you disabled?' vs WG core set of questions (6 + 2) vs Census 2001 questions.

No statistical significance tests were applied as numbers are small and the sample purposively selected. Trends in the data are reported and suggestions for further research are presented in the conclusions to the report.

4.1 Results for the core and extended sets of questions

The results for both the adults and children show, as expected, that using a different cut off in the responses (or on the continuum of functioning) produces quite different estimates of prevalence for both the core and extended set of questions. This can be observed by comparing the individual domain and overall results for the D1 vs. D3 or ED1 vs. ED3 figures.

The extended questions do not seem to add much to the overall results for either children or adults when looking at the comparison of D1 to ED1, i.e. the overall scores for the higher estimate for the core versus extended sets *without* the three additional domains in the ED1 score. In other words it does not seem to make a difference if one asks the single question on vision – Do you have difficulty seeing even if wearing glasses? – or the two separate questions in the extended set. However, there appears to be some difference when looking at the low estimates – D3 vs. ED3 (also without the three additional domains). This will require further testing in a large population sample to determine whether this is a real difference or not.

For both adults and children the additional 3 domains do seem to make an important difference which would need to be tested statistically to confirm the trend.

Table 3: Responses on core (D) and detailed (ED) questions from WG – Adults (N=185)

Core Domain (N=185)	D1 (High)		D3 (Low)		ED1 (high)		ED3 (Low)	
	Number disabled	%	Number disabled	%	Number disabled	%	Number disabled	%
Vision	58	31,4	11	5,9	54	29,2	17	9,2
Hearing	29	15,7	5	2,7	44	23,8	13	7,0
Mobility	57	30,9	14	7,6	61	33,0	15	8,1
Remembering	75	40,5	5	2,2	68	36,8	3	1,6
Self-Care	20	10,8	4	2,2	45	24,3	17	9,2
Communicating	44	22,2	2	1,1	56	30,3	2	1,1
*Participation in community activities	37	20,0	4	2,2	-	-	-	-
**Learning	-	-	-	-	69	37,3	6	3,2
**Social interactions	-	-	-	-	69	37,3	6	3,2
**Emotional functioning	-	-	-	-	156	84,3	102	55,1
D: Overall without participation	126	64,9	33	17,3	-	-	-	-
D: Overall with participation	127	68,6	33	17,8	-	-	-	-
ED: Overall without additional domains	-	-	-	-	128	70,3	45	24,3
ED: Overall with additional domains	-	-	-	-	166	85,4	119	64,3

* The Participation question is not part of the 6 core WG questions.

** Those added in the extended set and were not covered in the core set of 6 questions.

Table 4: Responses on core (D) and detailed (ED) questions from WG – Parents of Children (N=38)

Core Domain (N=38)	D1 (High)	D3 (Low)	ED1 (High)	ED3 (Low)
	Number disabled	Number disabled	Number disabled	Number disabled
Vision	8	1	14	2
Hearing	8	1	7	2
Mobility	14	6	18	10
Remembering	21	8	25	11
Self-Care	17	10	19	12
Communicating	20	7	23	12
*Participation in community activities	22	8	-	-
**Learning	-	-	19	13
**Social interactions	-	-	22	10
**Emotional functioning	-	-	27	26
Overall without Participation	28	12	-	-
Overall with Participation	28	12	-	-
Overall without additional domains	-	-	27	15
Overall with additional domains	-	-	33	28

* The Participation question is not part of the 6 core WG questions.

** Those added in the detailed set and were not covered in the core set of 6 questions.

While the difference between core and extended questions does not seem to be an important one when only considering the composite score (6 questions together), for individual domains (single questions) the extended questions seem to make a difference. Generally this trend is for the extended questions to produce higher scores (i.e. more people identified as being disabled) although this is not true for all domains.

For adults:

- the domain of remembering and concentrating shows a lower score for the extended questions than for the single one for both the 'high' and 'low' definitions;
- the domain of hearing shows a relatively big difference on both the low and high estimates with the extended set giving higher scores for both;
- Mobility and vision do not show much difference between the single and extended questions;
- For self care there is a big difference between the single and extended questions for both the 'high' and 'low' definitions. The extended question 'Do you have difficulty staying by yourself for a few days?' (Q33) elicited a number of responses of 'difficulty'. But comments made by some participants suggest that this could be interpreted in different ways; for example, being scared to stay alone but being quite capable of functioning on the level of 'self care', thus not because of a health condition.
- For communication, there was a difference in the 'high' definition scores with the ED1 being higher than the D1. However, this is not true for the 'low' definition (D3 and ED3) although these latter figures were very low.

For children as reported by their parents:

- For the domains of vision and mobility, the extended questions seem to increase the number of children reported as having difficulties (contrary to the findings for adults);
- There is some difference between the single and extended questions for remembering and concentrating and the communicating domain.

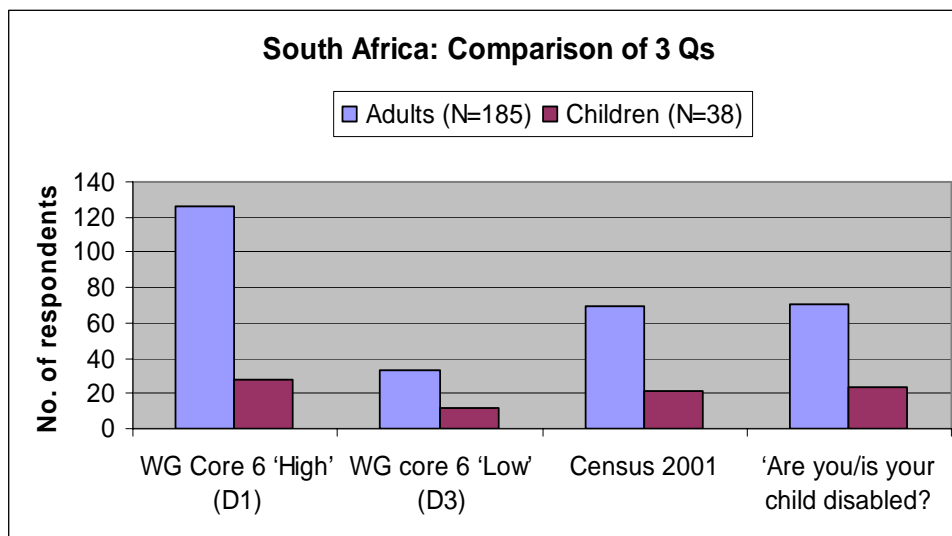
The question on participation added to the six core questions in this study, does not seem to have made any significant difference to the overall scores for either the 'high' or 'low' definitions and was similar for both children and adults. However, the reflection by the group of people with schizophrenia on the usefulness of this question to capture their experiences provides an argument for retaining it.

While these results show interesting trends, more research is required using representative samples to try and determine the extent to which they are real or merely artefacts arising from the purposive sampling used in this study.

4.2 Analysis of the Census 2001 and 'Are you disabled?' questions in relation to the WG core questions

The Census 2001 questions were analysed using a composite score of positive responses on one or more of the listed options except for the 'none' option. As for the composite score for the WG questions, each individual is only counted once no matter for how many domains they gave positive responses. Figure 1 presents the comparison between the three sets of questions.

Figure 1: Comparison of results for Census 2001 questions, WG composite on core questions and Self-identification as disabled



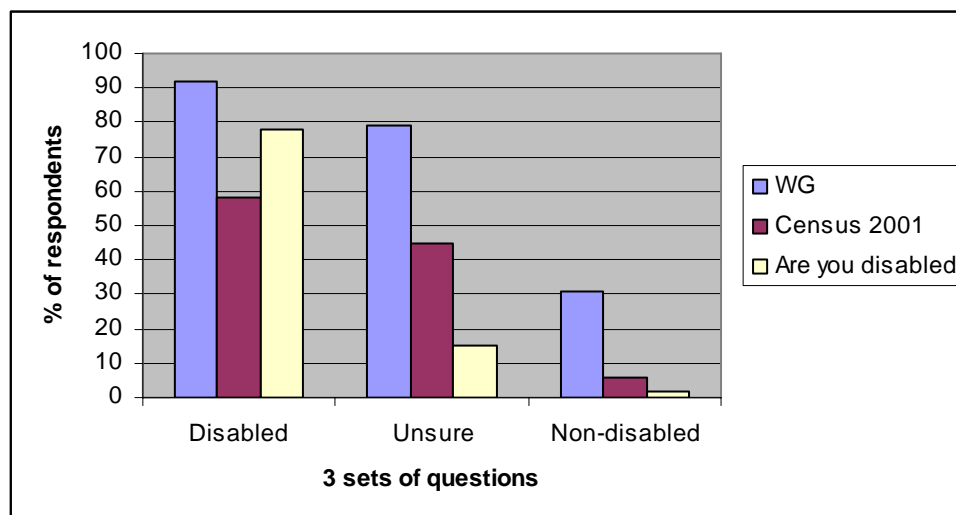
Of interest is the similarity between the scores for the Census 2001 and 'Are you disabled' results for both adults and children suggesting that the Census 2001 question was counting people who self-identified or are identified by others (by proxy respondents) as disabled. This is not surprising as the wording of the Census 2001 question included the term disability. However, the respondents are not always the same as discussed in the next section.

The WG 'low' definition result is lowest for both adults and children suggesting that this is picking up people with significant difficulties in functioning only. This further suggests that people who self-identify or are identified by others as disabled do not necessarily have the most severe difficulties ('unable to do').

The high D1 scores for both children and adults probably reflect a high proportion of people with mild or moderate difficulties that responded as having 'some difficulty'. These people clearly do not see themselves or their children as being disabled but are willing to report some difficulty in functioning in the 6 domains covered in the WG core questions.

Allocated disability status

Figure 2: Percentage of respondents in each allocated disability status category identified as 'disabled' on each of three question sets



The trends of note are:

- The WG and 'Are you disabled?' questions identified the 'disabled' allocation generally accurately, while the Census 2001 questions were not as accurate.
- The 'unsure' group was generally identified by the WG as 'disabled', and to a lesser extent by the Census 2001 questions. However, the 'Are you disabled?' question only identified very few as disabled.
- The 'non-disabled' were most frequently identified as 'disabled' by the WG questions.

Figure 3: Number of adult respondents counted in as disabled on the three question sets by individual group

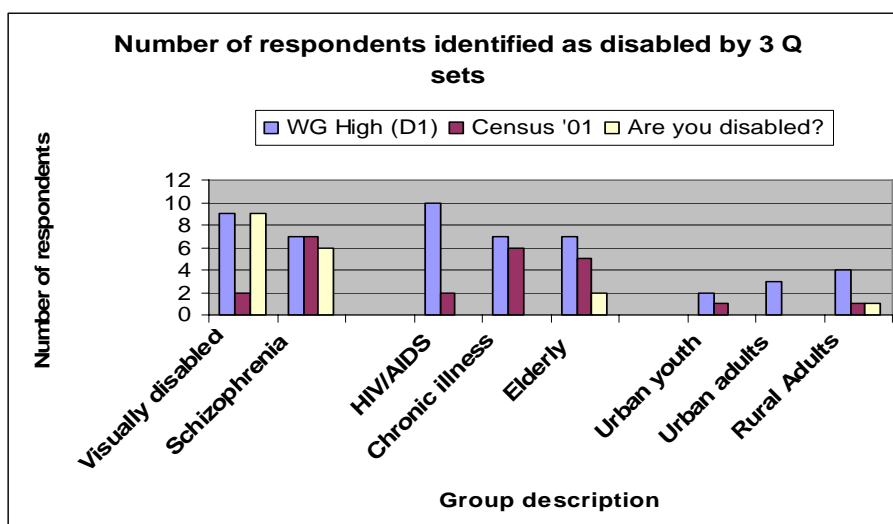


Figure 3 presents the response patterns for a selected number of groups from the 21 adult groups. The 'visually disabled' and 'schizophrenia' groups were 'disabled' groups, 'HIV/Aids', 'chronic illness' and 'elderly' were 'unsure' groups and the remainder were 'non-disabled' groups. The full table of results for all 21 adult groups is presented in Appendix IV.

Some interesting points to note are:

- The physically and visually impaired groups were less likely to respond as 'disabled' on the Census 2001 questions compared to their responses on the other two questions. This is explained by comments made that they do have difficulties in some areas related to their specific impairment but are able to do most of what they would like to do – they are participating in life. Thus, they do not 'have a serious disability that prevents their full participation in life activities.' However, all these respondents also said 'yes' to 'Are you disabled?'
- For the 'unsure' group, the trend is a strong endorsement of having difficulties (WG core set), varied responses on the Census 2001 questions, but strong rejection of the notion of being 'disabled'. This again is reflected in the comments made during the group discussions. Participants acknowledged having difficulties but not that they were disabled.
- For the 'non-disabled' group, the youth and adults were generally clear that they did not have any difficulties and were not 'disabled'. The two exceptions are the adults in the two rural groups, where they did indicate some difficulties but maintained the position of 'no serious disability affecting their participation in daily activities' or 'not being disabled'.

4.3 Summary

The WG core set clearly identifies a population that is much wider than that identified by either the Census 2001 questions or a simple question asking 'Are you / Is your child disabled?'. The similarity of the Census 2001 and 'Are you disabled?' responses on the overall composite figures remains in the analysis by different variables, although is not borne out in the individual group responses. For the individual groups, the people might identify themselves as disabled but not as having a serious disability that prevents them from participating in daily activities. Thus, these two question sets are not necessarily picking up the same population as being disabled, but do give similar estimates of disability.

The WG questions seem to be easier to respond to especially in the mild and moderate categories of difficulty. This is confirmed by comments made in the group discussions about 'difficulties' being less severe and more readily endorsed than questions about being 'disabled'.

The core set of the WG seems to be adequate to provide a census-based estimate (and good local level data), as it seems to provide an estimate of people with difficulties. However, there is a role to play for population-based sample surveys to complement the census data with a more detailed set of questions to capture the population more fully but at a national, provincial and possibly regional level. Furthermore, the use of additional domains of learning, social interactions and emotional functioning add a significant amount of 'yes' responses and their role in this should be investigated further.

Section 5: Qualitative results - parents of children

This section presents the results from the 5 focus groups of parents responding about their children. The analysis is presented in themes taken from the terms of reference, viz.,

1. Reactions to the questions from the questionnaire
2. What people understand by the notion of disability and difficulty

When verbatim quotes are provided they are in English translated from the original language where relevant. If the quote used requires some edits to make it more easily understood these edits are placed in [.....]. When a lengthy quote is presented, gaps where information has been omitted are indicated by '.....'. The quotes are all presented as italicised text and the speakers are referred to as the 'Participants' with a number indicating a different participant. The moderator of the group is indicated as such as well. If no mention is made of participant or moderator, it indicates that the quote is from one person only. The group from where the quote is taken is indicated either in the text preceding the quote or in square brackets [....] after the text of the quote.

There were 5 groups where the participants were parents of children. Two of these were with parents of non-disabled children and the other three were with parents of disabled children. The groups were:

- English urban parents of disabled children
- Xhosa urban parents of disabled children
- Swati rural parents of disabled children
- Swati rural parents of non-disabled children
- English urban parents of non-disabled children.

5.1 Reactions to questions

All the groups reported that there was no problem with the layout of the questionnaire. All participants, both urban and rural, commented that the layout was easy and 'straightforward' and the questions easy to understand and easy to remember. Some points of note raised by the parents are presented below.

- 'Age related' questions: A parent from the Xhosa urban group of mothers of disabled children queried the appropriateness of the question for very young children.
- Sensitivity of questions: Most participants felt that the questions were not sensitive to answer.
- Individual core questions: One participant in the group of English urban parents of disabled children said that if 'learning' were part of the question it would have changed her answer. It was felt by this group that the education question was not covered adequately. Another participant made an interesting comment:

But I think for my son, if there's something very interesting for him he can remember it. And he'll remember it forever. He can concentrate on it as well because it's something of interest, but for him to learn to do something is a lot more difficult because he can't recognise numbers or letters. So that's two different things in my case.

There was general agreement in this group that 'learning' should be part of the question on 'concentrating and remembering'.

5.2 What is disability?

5.2.1 Understanding disability

Participants in the groups had varied responses to the question "What is understood by the word 'disability'?" But the first and immediate response from a group of English urban mothers with non-disabled children was to describe 'visible disabilities', namely,

One leg is off or the arm is off

If you say it's physically [disabled], because you have to be minus a limb - and that will mean that your child will not be able to participate in anything.

Participants from different groups were able to define the word 'disability' by using phrases or words, for example 'lacking', 'backward', 'crippled', 'mentally disturbed' or 'mental damage', 'sub-normal' or 'not normal', and 'paralysed'.

Another participant from the rural Swati mothers of non-disabled children described disabled children as those who are able to receive a social grant.

A disability is when you go to social services and you say your child has a disability. You want a grant for your child.

The English urban group of mothers with disabled children described the broad spectrum of disability affecting different aspects of a child – mental and physical.

Autistic children don't have any physical or outside symptoms. You can't see them until they start acting funny. They just stare.

There were some positive views but only from the group of English urban mothers with disabled children:

A person with a disability is just one that operates and goes about life in different ways.

In all groups of mothers with or without a disabled child, whether urban or rural, comparing children to others was commonly used as a point of reference. These aspects helped the mothers to understand who is disabled. Phrases used were

If you compare children of different ages and how they would normally be evolving or growing, that child [the disabled child] you would find would be backward, not growing at the same pace.

5.2.2 Health and disability

Groups made the differentiation between health and disability by referring to disability as a permanent condition and that 'He [the disabled person] has a problem for life.'

Health was understood to be a temporary illness with a cure. The person is sick but his ability to participate or function is not affected in the long term.

I'd say it's more HIV/Aids for a health problem. With disability he battles to participate.

However the boundary between health and disability did get complicated when a person with arthritis was described. The rural group of mothers with disabled children, made their point of view clear by describing a person with arthritis as being 'not disabled' unless his walking is affected and 'he is not in a condition of working' or for a child if s/he 'cannot go to shops'.

5.2.3 Disability and difficulty

Making a difference between 'disability' and 'difficulty' was not very clear to the participants. They reported that a 'difficulty is an inability to do something'. However they agreed, 'they go hand in hand'.

5.2.4 Attitudes towards disability

The attitudes of the community towards children with disabilities present important environmental barriers. Mothers with disabled children described some of their negative experiences of being in public places with their children. One mother related her story of shopping with her child:

Why is it when you see someone with a disability that people are sometimes repulsed or reach the opposite side of a shopping mall?

One mother with a disabled child thought there are positive benefits for the community if they understand someone with a disability:

With the connotation that we all grew up with you won't know disability until you've encountered it. It teaches a lot of tolerance for people with disabilities.

Section 6: Qualitative results - adults responding for themselves

This section presents the information from the 21 focus groups of adult participants responding for themselves. The groups are presented in 3 parts according to their allocated disability status: the 'disabled', 'unsure' and 'non-disabled' groups.

The quotes are presented in the same manner as for the groups of parents in the preceding section.

Similar themes are used in the analysis as that for the parent groups. However, since the adult groups were more in number, more details emerged in the analysis. The first topic is that of reactions to the questions, followed by 'What is disability?' Within each of these, the sub-themes are similar but exactly the same as those presented for the parents of children groups.

6.1 Analysis of responses from 'non-disabled' groups

The six groups that were allocated the status of non-disabled were the following:

- English urban youth;
- Xhosa rural youth;
- Afrikaans rural adults;
- English urban adults;
- Sotho rural adults;
- Sotho urban adults.

Being allocated the status of 'non-disabled' did not preclude the participants from giving responses indicating some or a lot of difficulty or even 'unable to do' on one or more of the questions on functioning.

6.1.1 Reactions to questions

The overall reaction to the questions by the non-disabled groups was that the questions were good and not difficult to understand. The general sentiments on the questions are summarised in the quotes below from the rural youth group:

Moderator: Say what you like and don't like about the questionnaire.

Participant 1: I can say that it was simple and I easily understood the questions.

Participant 2: I also found it to be simple because it was easy to answer the questions. I didn't find any difficulties.

a) Recall period and distance reference:

The time periods used predominantly in the extended questions (last 30 days/last month, last 12 months and last seven days) did cause some difficulty for the non-disabled groups as they had difficulty in remembering the period asked about and possibly ignored the specified time reference. For example, from the Afrikaans rural adult group:

Moderator: Could you easily remember the last 12 months?

Participant 1: It wasn't easy for me to remember.

Moderator: What would be an easier period of time to remember?

Participant 1: Last week is sometimes difficult!

Participant 2: Ja, last week would be easy to remember.

One participant in the Afrikaans rural group seemed to understand the time reference as having to respond about the whole period, rather than an average for that period.

It's difficult to say how I have been feeling for the last month. I mean, how much time was spent being happy and how much time being unhappy. There's not a lot of space on the form for filling that in.

b) Sensitivity of the questions:

While most of the group participants felt comfortable answering the questions, there were some comments about some aspects that were seen to be sensitive, such as the questions on emotional functioning.

c) Difficulty with answering questions and use of response options:

Very few comments were made on any difficulties people had with answering the questions and using the response options. The response options were seen as easy to use and the questions easy to answer.

d) Scope of questions:

One of the aspects of the scope is whether the participants who were non-disabled felt the questions were also relevant for them or not. There was quite a strong indication from non-disabled participants that the questions are about disability and only for disabled people and, hence, did not pertain to them.

From the English urban youth group:

It is aimed at people who have a disability of some sort.

For me that question is not that much sensitive seeing as it is directed towards the disabled person. For a person who is not disabled it is like irrelevant.

e) The frame of reference used by the participants in responding:

In terms of the frame of reference used by respondents, the issue is whether they consider a specific occurrence of an activity or an average of all occurrences or even only the best or worst occurrences of that activity. When asked what people took into account in responding and how they decided to respond, the responses indicate a wide variety of factors and in effect different frames of reference. These would depend 'what mood you are in', 'personal opinion', 'compare it to yourself', 'based on your experiences', or.....

I just think that you need to put this in context because as we said, I would have answered some of them differently if I didn't think this was about disability.

6.1.2 What is disability?

Disability is seen in many different ways by the different non-disabled participants and some of the more salient themes are presented below.

a) A universal versus minority view of who is disabled

The views of the non-disabled participants varied between the two views, one being that disability is about everyone and the other that disability is only about 'them, disabled'. While there was quite a strong sense of 'them disabled' versus 'us normal' coming out in many of the comments in the different groups, for some participants (e.g. the English urban group), the focus group discussion generated an awareness of the universality of disability.

Moving from a minority group perspective (a majority view across the non-disabled groups).....

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.

...to a more universal perspective....

If it comes to a push we are all disabled because we all have things that we can't do.

Everybody has a disability. It all depends on how I see the other one and how that other one sees me.

b) Disability as physical and visible

There was as strong sense from most of the groups that disability is something visible and a physical problem. This was expressed in a number of the groups quite clearly when asked the question 'what is disability?' or 'who is disabled?'

I think it is someone who is deformed

..... having a disability is not to have the use of all of one's limbs. It's a visible disability, as in the case of having lost an arm, an eye, or your hearing. That is how I see someone who is disabled.

With some recognition that people with mental illness are also disabled....

A mentally ill person is disabled. There are such people who can't think and do things like normal people.

c) Disability as a permanent problem

The notion of permanency was prominent in how people understood disability. The most common view was that disability is something permanent rather than temporary and that disabled people cannot change their status whereas non-disabled people can alter their functioning. This understanding supports the sense of disability being understood as an activity limitation at the person level as described in the section below on activity limitation, rather than something that can be altered given different contexts. For a problem that can be corrected 'such a person needs motivation' to correct it and this is not a disability.

d) Disability as activity limitation

In the introduction the description of disability comprised three levels of difficulty – body, person and societal. The use of the notion of disability as an activity limitation by participants provides some indication as to the level of description that is considered by the participants when they responded to the questions. The main points made by the participants are around the permanency of the condition and the fact that the difficulty remains no matter what support is provided. This highlights what the individual can or cannot do rather than what happens in the context of their usual environment.

[Unable to do] day- to-day, washing, walking, read, like things that are required like brushing your teeth, taking care of yourself, going to the shops etc.

Being unable to do certain activities. The day-to-day normal activities.

e) Level of independence

A recurring theme among the groups of non-disabled participants was that of disabled people being unable to do things for themselves and hence being dependent on others to do various activities. These participants also raised the issue of the criterion for disability being 'unable to do entirely', such as the comparison made between a person who is disabled (unable to do anything) versus one who is only overweight in their ability to climb stairs only.

[A disabled person is] somebody who can't do anything for himself.

An overweight person can go up the stairs even though it might take a longer time but a person in a wheelchair won't be able to.

f) Disability as loss of participation in social life

One of the important features of being disabled is being socially excluded not because the disabled person desires this but because of barriers in society that prevent the person from participating. Such barriers include inaccessible physical environments, negative attitudes of people, etc.. An understanding of what causes this loss of participation is not well reflected in the comments made by the non-disabled participants but there were a few comments that did highlight this sense of social exclusion. The following quote does not consider the possible role of the environment, but only that of the individual:

It's a person who will never join the community at all for the rest of their lives but non-disabled person can join anytime.

g) Difficulty versus disability

The difference between difficulty and disability was not uniformly discussed in all the groups and certainly within the non-disabled groups there were few comments on the issue. However, one comment from the English urban youth group brings some initial pointers on what would be deemed a difficulty. This is in contrast to the notion of disability being 'unable to do'.

...difficulty sound[s] like it can [be] done but harder.

h) Health problem and chronic illness in relation to disability

The proposed questions in this study use the concept of 'a health problem' in the introductory phrase to contextualise the questions. This is to avoid, for example, someone saying they have a lot of difficulty communicating because of a second language problem rather than a difficulty arising from a health condition. The view coming out of the non-disabled groups is that disability and health are two separate entities. The following comments provide some indication of the views from the different groups on this relationship as well as what constitutes a health problem.

Examples of responses to 'what is a health problem?' are:

Many people still see health as physical, it is a physical thing, not necessarily a concentration thing or a this or that or a depression or an emotion.

For me health is more about constant coughing.

Viewing a health problem from an intervention perspective:

.....the medical aid will that take care of that, that is a health problem.

And on the relationship of health to disability from the same group:

..... a disabled person does not necessarily mean he is not healthy, cause I mean, I think health and disability are two different things.

However, one comment did make a causative link between health and disability

I think that sometimes disability and health can be linked together because..... you are disabled because of a health problem.

Closely related to the issue of health and disability is that of chronic illness. In relation to HIV/Aids the participants suggested that people with HIV/Aids are not disabled. Similarly for a person with diabetes:

I could be diabetic and I take my medication everyday, no one will know of my disability. It does not mean I am physically challenged in any way. I think, calling someone disabled when he is diabetic, does not suit.

One group reflected on the issue of depression in relation to whether it is a disability or not and commented as follows:

Moderator: So when do you think that that depression becomes a disability?

Participant 1: When it takes longer.

Moderator: When it takes longer?

Participant 2: No, I think it is when patients need professional [assistance].

6.2 Analysis of responses from 'Disabled' groups

This section presents the results from the nine 'disabled' focus groups. All these participants had a mix of ages and sex as the focus was on the disability rather than age or sex, but all were adults over the age of 18 years. The participants were only recruited into a specific language group if they felt confident of being able to respond in the allocated language of the group.

The groups included:

- English/Afrikaans urban adults with head injuries (originally the pilot group)
- English urban adults with physical impairments
- English/Afrikaans urban adults with a psychiatric illness
- English urban adults with visual impairments
- Sign language urban deaf adults
- English urban hearing impaired adults
- Tsonga rural adults with a psychiatric illness
- Tsonga rural adults with visual impairments
- Tswana rural adults with physical impairments

The allocated status of 'disabled' did not preclude these participants from responding negatively to any of the questions on functioning.

6.2.1 Reactions to the questions

The general feeling was that the questions were not difficult to understand. The questions were 'right', 'not too long', 'acceptable' and 'easy', to quote some terms used in the different groups.

a) Recall period and distance reference

While few participants expressed difficulty in the time references, a number indicated that they either ignored them or did 'not really use' them. The head injury group had an extensive discussion on the use of the time references and indicated that most of them used a sense of what 'normally' or 'usually' happens and tended to ignore the time references.

For example 12 months for us is like forever, you can't even remember what you were doing, so I just answer remembering what I "normally" do.

b) Sensitivity of the questions

Some participants felt that some of the more personal questions were a bit sensitive while others had no problems with any of the questions. The areas raised as being too sensitive to ask about were sexuality and sexual relationships, sexually transmitted diseases and toileting. The comments varied from clear statements on what was acceptable to ask and what was not, through to comments on how participants felt on being asked some of the questions where the questions had been felt as 'hurtful' (e.g. the questions on emotional functioning). While some questions might be sensitive, it was made clear by a number of participants that it is nevertheless important to ask them so that the reality of the participants' experiences could be conveyed to the general public.

I did not [experience] anything which I think was not proper for us to be asked. I feel glad to be asked these types of questions.

For deaf participants, the two sensitive issues were about questions on reading and writing ability and asking 'Are you disabled?'. The following quote highlight these.

.....but one of the questions that Deaf people are very, very sensitive about is their level of being able to read and write. Deaf people don't really want to say that they can't really read and write, because they know that if they say that, people will think that they are stupid. You know, and how can they not read and write if they've been to school for 12 years!

c) Difficulty answering the questions and response options

Most participants felt that it was easy to answer the questions and the comments on the response options varied between being 'just right' through to being 'too many'. Some participants expressed having a problem in understanding how to answer and wanting to make sure that the response was given according to what the expectations were.

The questions were not easy. While one was being asked, one was also asking oneself as to whether one's answer was the expected answer.

d) Scope of questions

Contrary to the non-disabled groups, the disabled groups had very few comments to make on the scope of the questions. One comment was that the scope should be on 'special needs of people with disabilities'. This was raised when discussing the issue of someone who is overweight and whether that person's difficulties in walking and climbing stairs or self care should be included in a national statistics of disability.

I disagree [with the inclusion of overweight people into the national statistics on disability]. That won't be a correct percentage of the special needs of people with disabilities. They should be differentiating between a normal problem or normal health problems versus disability.

For the participants in the disabled groups, the comments were focused on the benefits they experienced in answering the questions as well as the need to show to the general public what it is like to be disabled. This is contrast with the comments from the non-disabled groups which focused more on the need for accurate statistics.

I am just happy that the people out there ask US as disabled people what we feel, and what we want and at least they ask us directly so that they can act accordingly.

e) Frame of reference used by participants in responding

The disabled participants seemed to answer the questions as they saw themselves in the present according to how they 'normally' or 'usually' function. The hearing impaired group commented that they took into account what happens 'in the past', 'normally' and 'usually, in the walk of life'. This was echoed by a participant from the head injury group who said 'I just answer remembering what I normally do'.

In the deaf group the issue of whether to take into account communication with other deaf sign language users versus communication with hearing people was raised. Depending on which context is considered the responses would be very different.

It's the same problem that we have because obviously, there's no problem communicating... there is no problem participating in Deaf community activities, which is then part of the community. You know, if we look at the Deaf community, we've got Deaf ... and Deaf marches and Deaf social things - and we have no barriers there.

These comments on how the context is taken into account provide some potential insight into whether participants are taking the person or societal level of functioning into account when responding. The comments on the question on participating in community activities suggest that the societal level is most likely being considered. However, this requires further investigation before any conclusions can be reached.

f) Comments on core and non-core sets of questions on functioning

As for the non-disabled groups, there were few comments made directly about the core set of questions. The questionnaire was seen as quite broad and not always specific enough for the different types of impairments represented in the disabled groups.

I personally feel that this questionnaire should have elaborated a bit more because I think every person's situation is too unique to just ask these questions to that person. Because there is some stuff with my personality - stuff I'm battling with - that I couldn't address on this questionnaire.

I didn't find anything about people in wheelchairs.

It is important that the questions do reflect people's experiences if the data obtained are to provide information on how to meet needs of people with various degrees of difficulty. On the whole, the participants felt that the questions did reflect and describe their particular experiences despite the 'broadness' of the questions.

In terms of specific individual questions, there were a few comments that suggested some misunderstanding of what the question was asking. This was particularly noted for the core question on communication difficulties and specifically linked the introductory phrase. It seems that the introductory wording 'Because of a physical, mental or emotional health condition' was seen as the crux of the question rather than the part about communication.

One visually impaired participant commented on the 'seeing and recognising' questions by saying that she found it problematic to answer as she can recognise an object by feeling rather than seeing it. The core question only has the term 'seeing' and this quote might be one argument for keeping the word 'seeing' rather than using 'recognising'.

I did have a bit of a problem when you talked about seeing and touching because I can touch an object in front of me [and recognize it], but I can't see it.

The deaf participants had an issue with the question on communication and felt that it should have a phrase added that makes reference to use of sign language. So the question would ask about difficulties a person has communicating using verbal or sign language. Without the reference, deaf sign language users would answer either assuming the context of sign language and thus have no difficulties or assume only a verbal context and have 'a lot of difficulty'.

The deaf group explained that they might well respond as having 'some' or 'a lot of difficulty' with walking and climbing stairs, because of problems with balance they often experience.

.....with no. 14 [difficulty walking and climbing stairs], if you think about walking and climbing steps... for us at night... if we put 'yes' there then you might think that we are physically disabled - but we are not. But at night time, if it's in the dark and because we are deaf, we don't have... we find ourselves imbalanced. No, not imbalance. We have a poor sense of balance.

The questions on functioning were introduced generally by the phrase 'because of a health problem'. The term 'health problem' raised some concerns with participants as they did not equate loss of functioning or disability with health as such. This is discussed in further detail in 6.2.2, but the following quote from the deaf group sets the scene for further discussion below.

It's a bit confusing [the use of a 'health problem'] because Deaf people don't see the deafness as a health problem - but that's how it's being seen as here.

Participants from the urban psychiatric group provided a strong argument for including questions on stress to obtain a comprehensive picture of their difficulties. Stress together with questions on medication and sleep, energy and waking up were seen as three important aspects to ask about. For the deaf group, questions about balance were seen as important to ask and difficulties would be reflected in responses given to questions on walking and climbing stairs.

6.2.2 What is disability?

In addition to the themes discussed in the section for non-disabled groups, the themes of terminology and self-identified disability status were also raised by the disabled groups. While an effort has been made to differentiate clearly between different themes, at times the distinction becomes blurred. Some of the comments attributed to one theme could easily have been used for another theme. Thus the differentiation into themes should not lead the reader to think that they are independent of each other. The complexity of what is disability does not sanction such a reading.

a) A universal versus minority view of who is disabled

The disabled participants, on the one hand, want to be integrated into mainstream society and have access to the same opportunities as everyone else, but on the other hand they seem to have a notion of themselves as being different and having something that cannot be changed. One of the themes expressed often was that disabled people are not disabled in every domain of functioning – only in the one linked to the specific impairment. This led the disabled participants to talk about being normal and wanting to be treated as such. The notion of 'normal' was raised a number of times. However, there were no clear statements suggesting that disabled people have a universal versus a minority perspective.

The participants with schizophrenia expressed what seems to be a universal perspective in saying that no one is in fact normal.

Moderator: What does it mean to be normal?

Participant: No one is normal.....Most people in the world have difficulties - but not all of them in the same way.

A visually impaired participant describes being normal:

Moderator: Normal, okay, normal in what, what does it mean to be normal?

Participant: Normal to be a person, the only thing that I can't do is that I can't see, you see I can't see.....

b) Disability as physical and visible

There was a strong sense of disability being a physical and usually visible attribute. There were, however, also many comments on the inclusion of less visible conditions in disability. These were spread across the groups but most prominent in the two psychiatric groups. The other groups acknowledged that disability could also comprise severe psychiatric problems. A participant with schizophrenia stressed that for him, his disability is not physical.

Ja, because our problem is not physical. It is because we can't function in society that we need a grant. It's because of the difficulties we can't overcome in the real world. So that is our disability.

Another participant with schizophrenia described how he had initially thought the problem was spiritual and then, through using medication, understood the chemical nature of the illness. The discussion then moves onto whether there are physical aspects to schizophrenia.

Physically, there is a lot of pain. It's not imaginary or hallucinatory...But physically there is pain. Definitely - in the brain.

The visually impaired participants felt strongly that depression is not a disability but did concede that a severe psychiatric condition would be disability because:

.....that person can't really do what we can do, because of the mind.

c) Disability as a permanent problem

The notion of disability as being something permanent came out strongly in the disabled groups as it did in the non-disabled group. Another variation is that disability is something one is born with rather than acquiring it later in life.

...to be disabled is to live with something you cannot change or it does not have a solution: but it is related to what a person think. For example, I'm blind I cannot change the fact that I'm blind even if I can be trained I will not see. This is what we call disability.

d) Disability as activity limitation

While the disabled participants had a strong sense of disability being difficulties in doing various activities, this was in conjunction with numerous comments about disability being as much about the context as about the individual's difficulties in various domains of functioning. This is in contrast with the non-disabled group that mainly highlighted the person's level of functioning or activity limitations with little reference to the role of the physical and social environments.

Descriptions of activity limitations that typically would signal disability included the following:

Disabled means can't get up and walk

..... disability is a state in a person which makes him/her unable to do what other people can do on account of him/her being disabled.

e) The individual as the locus of the problem and source of change

Disabled people are more likely to understand the role of environmental factors in determining their overall functioning. They do not see disability as something that is only within them. Furthermore, the majority of the disabled participants had strong views on the role of the physical and social environment in their experiences and so did not comment much on the role of the individual in making choices about changing their functioning.

f) Level of independence

Similarly to the non-disabled group, the theme of disabled people being dependent on others or technological devices for assistance came across strongly in the disabled groups. Disabled people need assistance and this is one of the features that determine if someone is disabled or not.

People who are disabled are the ones who cannot do things for themselves

But that [disabled] is the wrong word, it means you can't do anything, and we are doing things

This last quote suggests that while the common understanding is that disabled people cannot do anything, disabled people want to dispel this notion by showing that they can do many things.

g) Disability as loss of participation in social life and role of environmental factors

The disabled group participants were very strong in highlighting the important role that the physical and social environments play in determining whether a person is disabled or not. Environmental factors interact with a person's activity limitations to result in a participation restriction or not depending on whether the factors are barriers or facilitators. The responses provided by participants on whether they had difficulties in doing various activities were often contextualised and hence provided a measure of participation and not only of activity limitation. This is in contrast to comments that suggested disability is not changeable, reflecting more the activity limitation than the participation restriction.

A participant from the head injury group described why he does not go to parties and the stadium any more. He describes both activity limitations (difficulty in climbing stairs) as well as the attitudes of others, albeit possibly assumed attitudes, as being the reasons.

Moderator: so why don't you go to parties and the stadium anymore, what makes it difficult?

Participant 1: Physically I am not 100% well,...so it is difficult to climb stairs and be in a crowd of people, lots of people pushing. So it is not easy for me...

Moderator: Any other reasons why you don't go?

Participant 1: Probably because of my disability and the way I think about what other people might say ...about me, saying 'this one is disabled but he is mixing himself', so it is best if I keep away. And be by myself.

One participant with schizophrenia describes how different contexts will create different levels of stress and be more or less likely to trigger a schizophrenic episode.

Ja, but I wouldn't go back to a CD store that sells rock music, because there were one or two bands that I listened to that seriously disturbed my whole thoughts and my whole being. I wouldn't like to be confronted with it. So there's a classical music store and a jazz music store that I've worked for, and that was cool because it's just the instrumentals.

Visually impaired participants made the point that when presented with a printed text they are very disabled but are not at all disabled when presented with the same information in Braille format.

Participants in the deaf group commented as follows:

The Deaf are disabled because we don't have access. But if we need an interpreter... at the moment, the situation today in South Africa, we are disabled because we don't have access to universities and we don't have enough interpreters.

h) Difficulty versus disability

The discussions on the difference between disability and difficulty centred on the notion that difficulties are not permanent and can be 'cured' while disability cannot be changed and remains permanent. A difficulty is thus a less serious problem than a disability.

Disability is something like when you really need assistance all the time, and the brain actually causes the whole disability, but difficulty is like having difficulty hearing or seeing, not being blind as such, just having difficulty with seeing maybe. I need reading classes to read, that is a difficulty

For difficulties, one can change or can have a solution unlike disability there is no solution there.

i) Health problem and chronic illness in relation to disability

Many of the groups raised the issue that health and disability are not the same thing but are related. However, some participants felt strongly that there is no relationship between health and disability especially when the impairment is long standing, unchanging and unlikely to be 'cured'. The notion of health seems limited to an illness or disease (e.g. 'aches and pains') and not including a static condition such as blindness.

The majority of the urban physically disabled participants said that they did have health problems but went on to describe these as 'infections, bladder infections, lung problems from time to time, there are lots of things', 'pressure sores' and 'diabetes'. A participant commented that he doesn't see 'disability as a sickness'.

The visually impaired participants were all adamant that someone who is in the final stages of HIV/Aids is not disabled. But when the moderator raised the fact that the person with HIV/Aids was so ill that they cannot get out of bed, one participant did accept that the person is disabled 'because that person can't do the daily functions. They are disabled to do anything for themselves.'

The deaf group participants were confused by the use of the term 'health problem':

j) Terminology

The disabled groups had much to say about the use of different terms for disability.

The hearing impaired group felt that 'disability' stigmatises a person. This group comprised of people with acquired hearing impairments who described themselves as having mild to severe difficulties in hearing and other domains of functioning, but clearly did not identify themselves as disabled and did not associate with the disability movement.

In contrast, the participants in the deaf group were very conscious of the political use of the term 'disability' and identifying oneself in a way that would allow access to resources destined for disabled people.

I think that I would like to support the word disability and that I am disabled, because I then have lots more access if I say that I'm disabled.

I am disabled - I accept that - but it depends if I'm going to be using it in a political way or not. Like if I'm going to be fighting for disability grants or something, then I will say that I'm disabled because I'm relying on the government - and it's a political thing.

k) Self-identified disability status

While the groups were all allocated a disability status, this does not mean that the participants themselves would identify themselves as having the allocated status. The participants in the head injury group expressed difficulty in deciding whether they are disabled or not.

I wouldn't know, it varies, I don't know what to tell people about myself. I am an in between person. I don't even know how to classify myself.

The Deaf group reinforced their discomfort at the use of the term 'disabled' in relation to their status:

That question of, are you disabled or are you not disabled. I wasn't quite sure how... that was a sensitive question. Are you deaf or are you hearing, that's all - not am I disabled or not disabled.

6.3 Analysis of responses from 'unsure' groups

The allocation of disability status as 'unsure' reflects one of the crucial questions for this study. These participants all experience some form of ill health or a 'health problem' and are likely to be experiencing some impairments and activity limitations to a greater or lesser extent. The use of questions on 'any difficulties' is precisely to see whether these people do report having such difficulties while they might not report having a 'disability' or being 'disabled'. For example, these participants had quite a few comments on the theme of 'severity' of the problem. This could be understood as being a way for them to separate themselves from what they would see as 'disability' (and the associated stigma) versus the 'difficulties' that they experience. The difference in disability status as reflected in the WG core set composite score (D1), Census 2001 and 'Are you disabled?', suggests that this group of people with 'unsure' status are happier responding positively to the questions about 'difficulties' than about 'disability'.

The six groups included in this section are the following:

- Zulu urban (small town) older people
- Tswana rural older people
- English urban people with chronic illness
- Tsonga rural people with chronic illness
- Xhosa rural people living with HIV/Aids
- English urban people living with HIV/Aids

6.3.1 Reactions to the questions

As for the other groups, these participants did not have any strong objections or difficulties with the questions asked on the questionnaire. They found them generally easy to understand, 'great', 'interesting' and 'clear', not too long to remember and comprehensive in their coverage.

These are typical responses from the older Zulu participants:

Participant 1: For me everything was clear I did not have any problems.

Participant 2: For me also there was nothing difficult because they ask about what is happening in our real lives.

Participant 3: They phrased these questions the right way because they are specific when they talk about different types of disability. I am able to answer everything that is there.

a) Recall period and distance reference

There were mixed comments on the issue of the time periods and distance reference. Older Zulu participants commented that the recall periods were not problematic.....

'if it was something important to you or if you had a bad experience' and 'if you had a bad experience you will remember'.

A misinterpretation of the time reference was that the time reference was seen to mean one had to be in that state the whole time in order to note it as present rather than taking an average over the period referred to.

They can't give someone a time frame – you can't be depressed for the whole month, some other days you're happy, you can go to work or wherever you want to go to.

b) Sensitivity of the questions

As for the other groups, there were few questions that were seen to be too sensitive to be asked on a census or survey except for questions on a person's HIV status.

c) Difficulty answering the questions and response options

There were no significant comments made on any difficulties participants had to answer the questions or use the response options. Participants with HIV/Aids suggested that the questions should allow for much more elaboration by the respondent and not be limited by the response options.

So, I think, there must be open-ended questions and elaborations.

d) Scope of the questions

As for the disabled groups, they did not have many comments on the scope of the questions. This could be explained in part by the comments made about the way the questions reflected their daily lives and hence there was no need to query or discuss the scope any further. This is illustrated by the comments made that the questions are 'very important' and the following quote from an older Zulu participant:

And what I liked a lot about these questions is that there are things that happen in our daily lives which we are not willing to discuss with people around us because they might look down on us. But here we get a chance to voice those things out.

A participant living with HIV/Aids expressed his worry at the breadth of scope introduced by using the term 'disability'.

For me, the questions in the questionnaire were too general.....It won't give you the direct or clear point of maybe the questions that you want to answer - because this word disability, it's so broad. And at the same time, other people, they exclude themselves from it. They refer disability to other people.

e) Frame of reference used by participants in responding

Few comments provided some elucidation on the frame of reference that participants used to answer the questions. Some seem to use the 'health problem' as the link into answering the questions, whereas others were confused as to the context that they should consider in answering the question on community participation. Lastly some found the question on disability very broad, but did not indicate further the extent to which this 'broadness' affected their answers at all.

A Xhosa participant living with HIV/Aids commented on difficulties with the community participation question.

I am going to go back to the question there, yes, we understood it but I wish that the question could specify which problem is referred to or directed at. For an example, if I am living with HIV, do you mean people are discriminating against me or is it a problem to me because I am living with HIV in the community that I am living with? It should specify what it really requires, what problem it is referring to.

f) Comments on core and non-core sets of questions on functioning

The comments made about the core set of questions were few and related to the introductory phrase to the communication question (Question 17), the issue of 'even if wearing glasses' in the seeing question (Question 12), understanding the question on participation (Question 18).

A participant with schizophrenia showed that the understanding of the introductory phrase in the communication question – 'because of a physical, mental, or emotional health condition' – was problematic. They seem to have focused on the emotional aspect of the question rather than on the communication part.

The older Zulu participants felt strongly that the questions reflected their situation as shown by the following quote from one of the participants.

And what I liked a lot about these questions is that there are things that happen in our daily lives which we are not willing to discuss with people around us because they might look down on us. But here we get a chance to voice those things out.

A different take is reflected in the comments made by the English urban group of people living with HIV/Aids. They seemed to be fixed on the idea that the questions were about disabled people and not about themselves as people living with HIV/Aids. It would be interesting to ask them similar questions but without any introduction or mention on disability and see what their reaction would be in that context.

Okay, the question was tricky because you are coming here for HIV/Aids.....We can do anything with our status. That is why the questions for us were difficult because now you see the people who are disabled, we are thinking, the people who are living in the community. We don't think about us. That is why the question was tricky..

6.3.2 What is disability?

a) A universal versus minority view of who is disabled

The urban group of people living with HIV/Aids raised the issue of whether these questions were really for them and not the disabled people. This suggests a minority perspective in relation to disability. Although some other participants in the same group showed a more universal perspective in their comments:

I thought the questions were about us - about HIV and Aids.

The participants in the Xhosa rural group of people living with HIV/Aids also commented on the fact that they do not consider themselves disabled, suggesting that they have more of a minority perspective rather than a universal one. Disability for them is not having any kind of difficulty related to a health problem, but rather a group of people that cannot do anything for themselves.

While the Tswana rural group of older people had a strong sense of needing to ensure that disabled people are treated well, they still talk about 'them' which reflects a minority perspective.

We must make sure that they also participate in community activities and interact with other people; after all they are also human.

b) Disability as physical and visible

There was much discussion on whether disability is a visible and physical attribute or something more than that. The comments are strongest on disability being visible and physical but do indicate quite a wide variety of other perspectives.

There are many types of disabilities one would be mentally ill or physically disabled

The perspective of disability being more than just physical and visible was shared by the participants in other groups although some participants retained the narrower view.

A disabled person is a person without hands or eyes.

A disabled person is somebody with no legs.

For me, disability means physical disability. It means that you can't walk; you can't do things for yourself.

c) Disability as activity limitation

The comments highlight the fact that disability has to do with overall functioning and can be understood to mean activity limitations in the sense set out in the initial sections of this report.

They can't do the things that we take for granted, in our everyday life, walking, seeing, hearing, maybe they have got a mental problem and they can't look after themselves and have to have a companion.

I am not disabled but there are times when this pain is severe that I can hardly wash myself but I am not disabled.

Participants also discussed the role of environmental factors in determining whether a person is able to function or not.

He is disabled because if we are to go on steep [hill], he is going to battle or not do it at all and that makes him at that time disabled.

d) Level of independence

The issue of severity also highlights the sense that disability is all or nothing. Comments made by participants suggest that a person who cannot do anything is disabled but if the person can do some things they are not necessarily disabled. But on the other hand, a number of the quotes refer to blind or deaf people as disabled although these people are recognised as being able to do many things for themselves. The most commonly used phrase to describe a disabled person was some variation of 'unable to do anything'.

A person who cannot do anything for themselves is a disabled person.

A disabled person is someone who is always on the wheelchair and cannot do anything for him or herself. They rely on family members for help. This we call a disability.

Participant 1: ...disabled is when you can't do anything

Moderator: So do you see yourself as being disabled or not?

Participant 1: No, I don't think so because I can still walk and I can still see.

But some participants with HIV/Aids raised the issue of self-identification being important in determining one's disability status.

I think, if you have this sore or whatever that she talks about, and you feel disabled because of it, then you are disabled but if you feel you are not disabled, then you are not.

e) *Disability as a loss of participation in social life and roles of environmental factors*

A number of participants commented on the role of environmental factors or context in determining whether they experience difficulties or not.

I took a course on selling houses, property and I realised at that time it was mostly talking in a group and my inability to hear in the forum where there is more than one person talking at the same time, would make it extremely difficult and embarrassing to do the job.

f) *Difficulty versus disability*

The participants from the 'unsure' groups had much to say about difficulty versus disability. They generally felt that disability was more severe than difficulty but that disabled people did experience difficulties. Difficulty is also seen as something that one experiences commonly, as expressed by a participant from the participant with a chronic illness.

Having difficulties is familiar because when one is sick they might have a difficulty in doing anything for themselves.

A disabled person is someone who is always on the wheelchair and cannot do anything for him or herself. They rely on family members for help. This we call a disability. Then a person with difficulty is a person who has stress from different illnesses for example, heart problems. So when they have to do things they face difficulties. So this person is having a difficulty not disabled.

But they do acknowledge that disabled people have difficulties.

g) *Health problems and chronic illness in relation to disability*

The issue of whether health and disability are related was discussed in the different groups. This section also looks at the relationship of HIV/Aids and disability as well as other chronic illnesses.

An older Zulu participant made it clear that being sick is not being disabled.

Moderator: Yes like I can use my hands but I cannot use them now because of the pain maybe does that mean I am disabled?

Participant 1: You are sick not disabled.

The question 'Are you disabled?' caused problems for a participant with a chronic illness where this person has a number of chronic illnesses but did not know how to answer the question, while another participant was clear in responding 'no'.

Participants living with HIV/Aids had some clear positions on the difference between disability and HIV/Aids and expressed mixed views on whether people living with HIV/Aids are disabled or not.

It is better when you are disabled.because with the HIV status there is a strong attitude.

Moderator: The people who have HIV, do they say that they have disabilities? Do they think of themselves as having a disability?

Participants (a couple): No.

Participant 1: Not yet.

Participants (a few): Sometimes.

Participant 2: I think it's because they want a disability grant.

..... but does this mean, that I am HIV positive and I am at stage 3, have TB and all these other diseases, I am disabled? Why do we say we are disabled?

h) Self-identified disability status

Of interest with these 'unsure' groups is to see whether they would identify themselves as disabled or not. A participant with a chronic illness was quite clear that she was not disabled and feels the group discussion helped her come to that understanding.

I was saying that I have learnt a lot about a difficulty and a disability, and to know for sure what the difference between the two is. Also to know in which group do I fall. All of us here are ill and we are not disabled but having difficulties.

A participant living with HIV/Aids said he was confused as he had come to the group as a person with HIV/Aids only to find that he is asked questions on disability. Since he is not disabled he found this confusing. Other participants living with HIV/Aids also felt strongly that they are not disabled.

Moderator: Are you disabled?

Participant 1: They say so. They are discriminating because we are not feeling good when we are called disabled.

Participant 2: I think they should have it or call it something else, not disabled.

Section 7: Discussion of Results

This section aims to bring together the information provided in the results chapters and answer the questions posed at the beginning of the study. The main focus of the analysis is on the differences due to allocated disability status and not on geographical, sex or age differences. Where obvious differences were noted for the rural and urban groups these are highlighted. Some minor trends were noted in the quantitative analysis, but the numbers are too small to be conclusive. However, they can be noted for further investigation in a larger sample survey.

7.1 Understanding disability

The overall impression given by the participants across all the groups is that disability is a permanent feature of an individual; it renders a person dependent on others as they are unable to do anything for themselves; it is predominantly a physical and visible attribute although it was acknowledged that other less visible factors can also determine disability; it is not 'solvable', 'curable' nor 'can it be changed'. There is strong notion of 'them' and 'us' expressed by the non-disabled and 'unsure' participants and even by some of the disabled participants about impairments different to theirs.

This understanding of disability suggests that there is a strong association with the term 'disability' and that this is not a positive one. This leads to people not wanting to self-identify as being disabled. This has important implications for the wording of questions on the census schedule. The quantitative results bear this out as the disability status estimate was much higher for the WG core set (D1) that used the term 'difficulty' rather than 'disability'. The comments in the non-disabled and HIV/Aids groups also highlight this when they comment on the questions not being relevant to them as they are not disabled.

7.2 The effectiveness of the WG core set of questions

The WG core set of questions is proposed as a possible set of questions to be used for the Census 2011. In terms of the quantitative analysis, the results clearly show that the WG D1 estimate identifies many more people as having difficulties than either the Census 2001 or 'Are you disabled?' question. It seems that the Census 2001 question might have caused many disabled people to say 'no' because of the phrase 'serious disability that prevents you from participating in life activities'. This is substantiated by the comments made by disabled people that, while they have a vision or physical impairment, they are not prevented from participating fully in life activities. Furthermore, the quantitative results indicate that the visually and physically disabled groups did not respond as disabled on the Census 2001 questions but did on the WG core set and the question 'Are you disabled?'.

The low estimate using the WG (D3) gave a lower estimate than either the Census 2001 or the 'Are you disabled?' question. This suggests that the D3 measure only identifies people with very severe difficulties while the Census 2001 and 'Are you disabled?' questions include identification of people with less severe difficulties as also disabled.

7.2.1 Reactions to the WG core and extended sets of questions

In general, the questions were seen as being good questions, easy to answer and not too long to remember. Few problems were noted with the questions themselves. The questions were seen as reflecting people's lives. Although the 'non-disabled' groups were clear that since the questions were about 'disabled' people and they were 'normal' they must say 'no' to all the questions.

There were few problems associated with the time references used in the questions on the environment and extended questions, but some people did not understand the need to average out for the whole period rather than thinking about each day.

The scope of the questions was seen either as being only about disabled people or about the general population. The frame of reference generally used (when indicated) seemed to be what was done 'normally' or 'usually' and included use of assistive devices.

7.2.2 Comparison of the disability estimates from WG core set (D1), Census 2001 questions and 'Are you disabled?'

The WG core set clearly identifies a population that is much wider than that identified by either the Census 2001 questions or a simple question asking 'Are you / Is your child disabled?'. Looking at the groups individually, we see that people might identify themselves as 'disabled' but not as 'having a serious disability that prevents them from participating in daily activities'. This was most apparent in the disabled groups and is explained by the comments that they are disabled but can do many things.

The WG questions seem to be easier to respond to especially in the mild and moderate categories of difficulty. This is confirmed by comments made in the group discussions about 'difficulties' being less severe and more readily endorsed than questions about being 'disabled'.

The core set of the WG seems to be adequate to provide a census-based estimate as it seems to provide an estimate of people with varying degrees of difficulties. However, there is a role to play for population-based sample surveys to allow for a more detailed set of questions to be asked in order to capture the population more fully. Furthermore, the use of additional domains of learning, social interactions and emotional functioning add a significant amount of 'yes' responses and their role in this should be investigated further. Censuses are only one source of data for disability statistics.

Section 8: Recommendations

This last section sets out the recommendations arising from the qualitative and quantitative analysis undertaken for the study. Three areas of recommendations are considered.

- What questions should be used in the Census
- What additional questions should be included in surveys
- What further research is required to provide more evidence of the effectiveness of these questions?

8.1 Questions for Census 2011

The evidence arising out of this study suggests that the WG core set provides a good potential measure of disability. The responses obtained from the three groups of allocated disability show that there is a good correlation between the different disability statuses allocated, the responses on the questions and the comments made by participants in the respective groups. The ability to predict a participant's responses on the WG core set seems to be easier than on the other two sets of questions.

However, the following changes are proposed:

- The introductory phrase 'because of a health problem' should be carefully explained and some examples given to ensure that people understand the link between that and difficulties they would report on.
- The introductory phrase for the question on communication (Q17) should be changed.
- The phrase on the 'seeing' and 'hearing' questions that says 'even if wearing glasses' and 'even if wearing a hearing aid' can be retained but training of interviewers should stress the importance of explaining the context. Even if a person is not wearing glasses or a hearing aid (and even if they don't know if it would improve vision/hearing) they should still respond to the question.
- The question on participation should be retained as it did reflect some important aspects of some participants' experiences, especially for the psychiatric groups. However, it should be clarified and interviews sensitised to the need to stress the context of a health problem.
- The question on environmental factors requires more investigation before it can be applied. It needs to be shortened as well.
- Any mention of disability should be avoided in the wording as well as in the training of interviewers to ensure that the context of 'disability' does not influence the responses.
- If space permits, a question on learning should be added to make the questions more relevant for young children.

8.2 Questions for surveys

A number of additional questions were proposed by the different groups. These are ideal for inclusion on a more detailed questionnaire such as a disability survey or as a module on other surveys. These additional areas for questions include:

- More questions on mental functioning;
- Transport including public transport;
- Accessibility of public and specifically work places for disabled people;
- Availability of services;
- Employment issues;
- Attitudes of others towards disabled people;
- Difficulties that wheelchair users have in climbing a steep or a standard ramp rather than walking or climbing stairs;
- Personal assistance;
- More on needs such as home care;
- Stress;

- Something about waking up in the morning (more specifically for people with depression and bipolar disorders);
- Medication;
- Balance;
- Educational and health services needed and received by disabled children.

In addition, some changes to the extended set are proposed.

- The phrase 'recognise' should be omitted from or explained for the vision questions.
- Any time references should be clearly explained if these are retained.
- The context of a health problem should be clearly explained and any reference to disability omitted.

8.3 Further research

This study is the first step in a process to test the disability schedule for Census 2011. There are a number of further pieces of research required to complement this study before a final conclusion can be made on the suitability of the WG core set modified as suggested above.

The next step is to test the WG core set and extended set on a larger population-based sample to check whether the trends noted in the quantitative analysis are real or not. This survey should include the following:

- The WG core set with the participation and modified environmental questions;
- The extended set of questions with the emotional functioning questions replaced possibly by ones from the WHO DAS II;
- The Census 2001 questions placed towards the end of the interview;
- The additional areas listed above; and
- Ending off with a question 'Are you disabled?'.

The survey should include in the analysis, a calculation of all three estimates for the WG core set, i.e. D1, D2, and D3. This would allow an assessment on which of the three would be the best estimate to use for different purposes.

A further study should do a more detailed individually focused cognitive testing of the questions. This would entail interviewing around 100 respondents, asking them the core set to be used for the census and asking a series of questions after each question. This would include asking the respondents to repeat the questions, to say what they were thinking about when asking the questions, and asking what they understood by different words used in the questions.

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Appendix I: Distribution of the 26 focus groups

No.	Group	Disability status	Disability type	Age	Geographical area	Race	Language	Province	Location
1	Visual impairment	Disabled	Low vision or Blind	Adult	Rural	Black	Tsonga	Limpopo	Tulama-hashe
2	Visual impairment	Disabled	Low vision or Blind	Adult	Urban	Mixed	English	Gauteng	Pretoria
3	Hearing impairment	Disabled	Hearing	Adult	Urban	Mixed	English/ Afrikaans	Gauteng	Johannesburg
4	Deaf	Disabled	Deaf	Adult	Urban	Mixed	English/ SA sign language	Western Cape	Cape Town
5	Physical impairment	Disabled	Physical	Adults	Urban	Mixed	English/ Afrikaans	KwaZulu Natal	Durban
6	Physical impairment	Disabled	Physical	Adults	Rural	Black	Tswana	North West	Garankuwa
7	Psychiatric illness	Disabled	Mental	Adults	Rural	Black	Tsonga	Limpopo	Tulama-hashe
8	Psychiatric illness	Disabled	Mental	Adults	Urban	Mixed	English/ Afrikaans	Gauteng	Pretoria
9	Chronic illness	Unsure	-	Adults	Urban	Mixed	English/ Afrikaans	Gauteng	Johannesburg
10	Chronic illness	Unsure	-	Adults	Rural	Black	Tsonga	Limpopo	Tulama-hashe
11	Older people	unsure	-	Adults	Rural	Black	Tswana	North West	Makapanstad
12	Older people	unsure	-	Adults	Urban	Black	Zulu	KwaZulu Natal	Newcastle
13	People living with HIV/Aids	unsure	-	Adults	Urban	Mixed	English/ Afrikaans	Western Cape	Cape Town
14	People living with HIV/Aids	unsure	-	Adults	Rural	Black	Zulu	Eastern Cape	Lusikisiki
15	Coloured community	Non-disabled	N/A	Adults	Rural	Colour-ed	Afrikaans	Western Cape	Langebaan
16	Youth	Non-disabled	N/A	Adults	Urban	Mixed	English/ Afrikaans	KwaZulu Natal	Durban
17	Youth	Non-disabled	N/A	Adults	Rural	Black	Xhosa	Eastern Cape	Qumbu
18	Adults	Non-disabled	N/A	Adults	Urban	Black	Sotho	Free State	Bloemfontein
19	Adults	Non-disabled	N/A	Adults	Rural	Black	Sotho	Free State	Near Kroonstad
20	Adults	Non-disabled	N/A	Adults	Urban	Non-Black	English /Afrikaans	Gauteng	Pretoria
21	Intellectual impairment	Disabled	Intellectual	Child / adult	Urban	Non-Black	English/ Afrikaans	Gauteng	Johannesburg
22	Intellectual impairment	Disabled	Intellectual	Child / adult	Urban	Black	Xhosa	Eastern Cape	East London
23	Any impairment	Disabled	Mixed	Child / adult	Rural	Black	Swati	Mpumalanga	White River
24	Parents	Non-disabled	N/A	Child	Rural	Black	Swati	Mpumalanga	White River
25	Parents	Non-disabled	N/A	Child	Urban	Mixed	English/ Afrikaans	Western Cape	Cape Town
26 (pilot)	Brain injured	Disabled	Brain injury	Adult	Urban	Mixed	English	Gauteng	Pretoria

Appendix II: Questionnaire (adult version)

Questionnaire on functioning questions for Census 2011:

Adults

Questionnaire number:

SECTION A: Background questions

To be completed by office:

1. Questionnaire number:
2. Focus group code:
3. Facilitator name:

Read the following questions and answer them by marking the relevant response option or options for each question.

4. **What is your current living situation? Mark one only**
 - a) Independent in the community (as in functioning independently)
 - b) Living with personal attendant
 - c) Living in an institution or hospitalised

5. **Are you disabled?** a) Yes b) No
 - If yes, please state what your disability is or disabilities are.
-

6. **Do you have any serious disability that prevents your full participation in life activities** (such as education, work, social life)? *MARK ANY THAT APPLY.*
 - a) None
 - b) Sight
 - c) Hearing
 - d) Communication
 - e) Physical
 - f) Intellectual
 - g) Emotional

7. **Sex:** a) Male b) Female

8. **Age in years:** _____

9. What is the highest level of education you have reached?

99 = no schooling 00 = Grade 0 01 = Grade 1/Sub A 02 = Grade 2/Sub B 03 = Grade 3/Std 1 04 = Grade 4/Std 2 05 = Grade 5/Std 3 06 = Grade 6/Std 4	07 = Grade 7/Std 5 08 = Grade 8/Std 6/Form 109 = Grade 9/Std 7/Form 2 10 = Grade 10/Std 8/Form 3/NTCI 11 = Grade 11/Std 9/Form 4/NTC II 12 = Grade 12/Std 10/Form 5/matric/NTCIII 13 = Certificate with less than Grade 12 14 = Diploma with less than Grade 12	15 = Certificate with Grade 12 16 = Diploma with Grade 12 17 = Bachelor's degree 18 = Bachelor's degree and diploma 19 = Honours degree 20 = Higher degree (masters, doctorate) 21 = Other 22 = Don't know
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10. What is your current marital status?

- 1 = Married civil/religious
- 2 = Married traditional/customary
- 3 = Polygamous marriage
- 4 = Living together like married partners
- 5 = Never married
- 6 = Widower/widow
- 7 = Separated
- 8 = Divorced

If both civil/religious and traditional marriage, indicate Civil/religious

11. The following questions are about your employment status

11.1 In the last 7 days before today, did you do any of the following for one hour or more?

- a) Worked for PAY (in cash or kind), PROFIT or FAMILY GAIN
- b) Ran or did any kind of business, big or small
- c) Any farming, construction or maintenance activities
 - 1 = Yes ... Skip to Question 11.3.
 - 2 = No Go to Question 11.2.

11.2 If No to Question 11.1:

Even though you did not do any of these activities in the last seven days, do you have a job, business, or other economic or farming activity that you will definitely return to?

- 1 = Yes
- 2 = No

Note: For agricultural activities, the off-season in agriculture is not a temporary absence.

11.3 Please indicate which of the following describes your employment status best

- 1 = Formal Registered (Non-farming)
- 2 = Informal Unregistered (Non-farming)
- 3 = Farming
- 4 = Unemployed/Not employed ... Skip to Question 11.5.

11.4 Are you permanently employed, employed on contract or casually employed?

- 1 = Permanent
- 2 = On contract
- 3 = Casual (includes volunteers)

11.5 In the last seven (7) days, please indicate if you did any of the following activities, even for only one hour?

Question	YES	NO
a) Run or do any kind of business, big or small, for yourself or with one or more partners? Examples: Selling things, making things for sale, repairing things, guarding cars, brewing beer, hairdressing, crèche businesses, taxi or other transport business, having a legal or medical practice, etc.	1	2
b) Do any work for a wage, salary, commission or any payment in kind (excl. domestic work)? Examples: a regular job, contract, casual or piece work for pay, work in exchange for food or housing.	1	2
c) Do any work as a domestic worker for a wage, salary, or any payment in kind?	1	2
d) Help unpaid in a household business of any kind? Examples: Help to sell things, make things for sale or exchange, doing the accounts, cleaning up for the business, etc. Don't count normal housework.	1	2
e) Do any work on your own or the household's plot, farm, food garden, cattle post or kraal, or help in growing farm produce or in looking after animals for the household? Examples: ploughing, harvesting, looking after livestock.	1	2
f) Do any construction or major repair work on your own home, plot, cattle post or business or those of the household?	1	2
g) Catch any fish, prawns, shells, wild animals or other food for sale or household food?	1	2

If you answered NO to all questions in 11.5 then answer question 11.6.

11.6 If No to all parts of Question 11.5:

What is the **MAIN** reason that you did not have work in the last seven days? Only mark **ONE** answer.

- 01 = On holiday or special leave
- 02 = Scholar or student
- 03 = Too young to work
- 04 = Home-maker or housewife
- 05 = Pensioner or retired person/too old to work
- 06 = Unable to work due to illness or disability
- 07 = On maternity leave
- 08 = Seasonal worker not working presently
- 09 = Does not choose to work
- 10 = Could not find work

SECTION B

The next questions are about difficulties you may have doing certain activities because of a HEALTH PROBLEM

		No	Yes		
		No difficulty	Some difficulty	A lot difficulty	Unable to do
12	Do you have difficulty seeing, even if wearing your glasses?	1	2	3	4
13	Do you have difficulty hearing, even if using your hearing aid?	1	2	3	4
14	Do you have difficulty walking or climbing steps?	1	2	3	4
15	Do you have difficulty remembering or concentrating?	1	2	3	4
16	Do you have difficulty with self-care, such as washing all over or dressing?	1	2	3	4
17	Because of a physical, mental, or emotional health condition, do you have difficulty communicating, (for example understanding or being understood by others)?	1	2	3	4
18	Do you have any difficulty joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	1	2	3	4
<p>19a i) In the past 12 months, how often has your physical environment been a problem for you?</p> <p>By physical environment we mean buildings, roads, transport, access to information and so on.</p> <ol style="list-style-type: none"> 1. Daily 2. Weekly 3. Monthly 4. Less often than monthly 5. Never (Skip 18 a ii) <p>a ii) When this problem occurs has it been a big problem or little problem?</p> <ol style="list-style-type: none"> 1. Big problem 2. Little problem <p>19b i) In the past 12 months, how often have the support and attitudes of people been a problem for you?</p> <ol style="list-style-type: none"> 6. Daily 7. Weekly 8. Monthly 9. Less often than monthly 10. Never (Skip 18 b ii) <p>b ii) When this problem occurs has it been a big problem or little problem?</p> <ol style="list-style-type: none"> 1. Big problem 2. Little problem 					

SECTION C

The following questions are similar to the ones you have just answered but go into more detail. Remember that these are about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

	Circle ONE response that best fits what you feel	No	Yes		
		No difficulty	Some difficulty	A lot difficulty	Unable to do
20	Do you have difficulty seeing and recognizing a person you know from 7 meters away? E.g. across a street	1	2	3	4
21	Do you have difficulty seeing and recognizing an object at arm's length?	1	2	3	4
22	Do you have difficulty hearing someone talking on the other side of the room in a normal voice?	1	2	3	4
23	Do you have difficulty hearing what is said in a conversation with one other person in a quiet room?	1	2	3	4
24	Do you have difficulty moving around inside your home?	1	2	3	4
25	Do you have difficulty going outside of your home?	1	2	3	4
26	Do you have difficulty walking a long distance such as a kilometer (or equivalent)?	1	2	3	4
27	Do you have difficulty in using your hands and fingers, such as for picking up small objects or opening and closing containers?	1	2	3	4
28	Do you have difficulty concentrating on doing something for ten minutes?	1	2	3	4
29	Do you have difficulty remembering to do important things?	1	2	3	4
30	Do you have difficulty washing your whole body?	1	2	3	4
31	Do you have difficulty getting dressed?	1	2	3	4
32	Do you have difficulty feeding yourself?	1	2	3	4
33	Do you have difficulty staying by yourself for a few days?	1	2	3	4
34	Do you have difficulty generally understanding what people say?	1	2	3	4
35	Do you have difficulty starting and maintaining a conversation?	1	2	3	4
36	Do you have difficulty learning a new task, for example learning how to get to a new place?	1	2	3	4
37	Do you have difficulty analysing and finding solutions to problems in day to day life?	1	2	3	4
38	Do you have difficulty dealing with people you do not know?	1	2	3	4
39	Do you have difficulty maintaining a friendship?	1	2	3	4
40	Do you have difficulty getting along with people who are close to you?	1	2	3	4
41	Do you have difficulty making new friends?	1	2	3	4

How much, during the past 30 days/ month		All the time	Most of the time	A good bit of the time	Some time	A little of the time	None of the time
42	Did you feel very nervous?	1	2	3	4	5	6
43	Have you felt so down in the dumps, nothing could cheer you up?	1	2	3	4	5	6
44	Have you felt calm and peaceful?	1	2	3	4	5	6
45	Have you felt down-hearted and depressed?	1	2	3	4	5	6
46	Have you been happy?	1	2	3	4	5	6

Thank you for your time!

Appendix III: Discussion guide for focus groups on a disability schedule for Census 2011: Adult Version

On completion of the individual questionnaires, the group discussion will begin.

Topics for discussion – not to be read out

- What is the participants' understanding of the concept 'disability'?
- Is the WG schedule of census questions on disability consistent or does their interpretation differ across different subpopulations?
- Are there issues not covered in the schedule of questions that are important to participants?
- Do the participants feel that the issues covered in the schedule of questions are relevant?
- What kinds of disability information about themselves do respondents consider to be most sensitive?

Introduction by facilitator stating the aims of the group discussion and basic rules for the discussion.

- What is the HSRC?
- What is Stats SA?
- What is the project about?
- Ground rules:
 - Speak up and if possible only one person at a time to get a good quality tape recording
 - First name basis (to be negotiated depending on group structure)
 - Signing of consent and what it means (confidentiality of information on transcripts – no names linked to comments)
 - There is no right or wrong view and we need to respect each other's opinions
 - Length of group discussion
 - Adults representing themselves report for themselves.

Structure of discussion

1. Think back to the questions you answered just now.

- a) Were there any questions that were :
 - Difficult to understand?
 - Confusing in the way they were worded/asked?
 - Embarrassing to answer?
 - Difficult to remember long enough to think of an answer?
 - Difficulty in deciding how to answer?
 - Other problem.....?
- b) I want you to tell me what you think about the following:
 - Use of the words 'last 4 weeks', in last '12 months' and most questions did not specify any time – did it make sense and were you able to think back to those time periods of 4 weeks or 12 months?
 - What does the distance of 7 metres mean to you?
- c) When you answered, what did you compare ability to?
If the participants are not clear on this then use the following prompt: Did you compare yourself to someone of the same age and sex and, or something else?

- 2. Now I will give you some answers/ responses that people gave on the questions.**
- **You must describe for me the people who gave these answers. What type of problems (or no problems) do they have that made them answer like they did?**
 - **Tell me also what you think made these people give these answers.**

- Siphso says he has some difficulty joining in community activities in the same way as anyone else can.
- Saul said he has a big problem at least once a week with the support and attitudes of people.
- Mary said she has a lot of difficulty communicating with others.
- Peter said he has a lot of difficulty with walking and climbing stairs.
- Lena said she has no difficulty remembering or concentrating.

Include these last 3 if there is time.

- *Sarah said she has some difficulty with self care such as washing all over or dressing.*
- *John said he is unable to hear even with a hearing aid.*
- *Daniel said he has some difficulty seeing even when wearing glasses.*

- 3. Now we will do this the other way around. I will describe someone and you must tell me what answer that person would give for the two following questions. Also tell me if you would say these people are disabled or not.**

You will each have a turn to tell me what you think the person would answer and the rest of the group can comment on whether they agree or not and why.

- a) Joseph can walk up to 200 metres without any problems. But he feels tired after walking one kilometre. He has no problems with day-to-day physical activities, such as carrying food from the market.
- Does Joseph have difficulty with walking or climbing steps?
 - Does Joseph have difficulty in joining community activities in the same way as anyone else?
- b) Rose enjoys her work and socialising. She is generally satisfied with her life but gets depressed every three weeks for a day or two. When she is depressed she loses interest in doing what she enjoys. However, she can still do her day to day work.
- Does Rose have difficulty with self care such as washing all over or dressing?
 - Because of a physical, mental or emotional health condition, does Rose have difficulty communicating?
- c) Jill has no problems with walking or running. She jogs four kilometres twice a week.
- Does Jill have difficulty with walking or climbing steps?
 - Does Jill have difficulty in joining community activities in the same way as anyone else?
- d) Thomas has pain in his joints and the pain is there almost all the time. It gets worse during the first half of the day. He feels uncomfortable when moving around, holding and lifting things.
- Does Thomas have difficulty with walking or climbing steps?
 - Does Thomas have difficulty in joining community activities in the same way as anyone else?

- e) George is blind and lives in a very rural area. His family does not allow him to leave the house. They are worried he will get hurt. His family tells him that he is a burden to them. This upsets him and he cries.
- Does George have difficulty with walking or climbing steps?
 - Does George have difficulty seeing, even if wearing glasses?
 - i) In the past 12 months, how often have the support and attitudes of people been a problem for George?
 1. Daily
 2. Weekly
 3. Monthly
 4. Less often than monthly
 5. Never
 - ii) When this problem occurs has it been a big problem or little problem?
 1. Big problem
 2. Little problem
- f) Bonggi can dress and undress herself but takes much longer than everyone else. She is able to bathe and groom herself but it takes a big effort. She can feed herself.
- Does Bonggi have difficulty with self care such as washing all over or dressing?
 - Does Bonggi have difficulty joining in community activities in the same way as anyone else?
- g) Lucas cannot concentrate for more than 15 minutes and has difficulty paying attention when people talk to him. He starts a task but does not finish it and often forgets what he is doing. He knows people's names but cannot go to the shops by himself.
- Does Lucas have difficulty with self care such as washing all over or dressing?
 - Does Lucas have difficulty remembering and concentrating?
 - Does Lucas have difficulty joining in community activities in the same way as anyone else?

Include these if there is time:

- h) Alison is 30kg overweight for her height. She gets out of breath easily when doing household chores or carrying the shopping. She has to stop frequently to catch her breath.
- Does Alison have difficulty with self care such as washing all over or dressing?
 - Does Alison have difficulty with walking or climbing steps?
- i) Miriam has difficulty climbing up and down the stairs and walking. She is not able to go out as much as she would like to but has many friends who come and visit her at home. Her friends find her a source of great comfort.
- Does Miriam have difficulty joining in community activities in the same way as anyone else?
 - i) In the past 12 months, how often has Miriam's physical environment been a problem for her? By physical environment we mean buildings, roads, transport, access to information and so on.
 1. Daily
 2. Weekly
 3. Monthly
 4. Less often than monthly
 5. Never (Skip a ii)
 - ii) When this problem occurs has it been a big problem or little problem?
 1. Big problem
 2. Little problem

- j) James has to use a magnifying glass to read small print or look at details on pictures. He also takes a while to recognise objects if they are too far from him.
- Does James have difficulty seeing even if wearing glasses?
 - Does James have difficulty with self care such as washing all over or climbing steps?
- k) Susan does not hear very well when people speak to her softly or from a distance. She has no problem having a normal conversation when she is near the person and when the sound is a bit louder than normal.
- Does Susan have difficulty hearing even if using a hearing aid?
 - Does Susan have difficulty joining in community activities in the same way as anyone else?
- 4. We have talked a lot about answers that you and other people give to the questions. Think about how you (and others) answered the questions we asked earlier on. What made you decide if you have a problem or not or what makes other people decide if you or them have a problem?**
- If people find it hard to talk about then use the following prompts:*
- *How long the difficulty has lasted (or is expected to last)*
 - *Whether medication or surgery or some assistive device could make a difference*
- 5. What does 'disabled' or 'disability' mean to you? What determines if a person is disabled or not?**
- 6. What questions or topics do you think are sensitive for disabled people? Do you think we can ask questions about these aspects?**
- 7. What did you think about the format of the questions and layout of the questionnaire?**
- 8. Are there any other aspects that you think are important to raise about asking questions on disability for the Census?**

Thank you and I hope you enjoyed the discussion.

Appendix IV: Responses on the three main question sets by individual group (Adult groups only)

Group	WG D1 (6 questions)		Census 2001		'Are you disabled?'	
	Disabled	Non disabled	Disabled	Non disabled	Disabled	Non disabled
'Disabled'						
English head injury urban	8	0	6	2	6	2
Sign language urban deaf	7	0	6	1	4	0
English urban psychiatrically ill	7	1	7	1	6	2
English urban visually impaired	9	0	2	7	9	0
English urban physically impaired	6	0	3	3	6	0
English urban hearing impaired	6	0	6	0	5	2
Tsonga rural psychiatrically ill	7	2	7	2	9	0
Tsonga rural visually impaired	9	1	5	5	10	0
Tswana rural physically disabled	8	2	4	6	7	3
'Unsure'						
English urban HIV/Aids	10	0	2	8	0	9
English urban chronic illness	7	0	6	1	0	7
Zulu urban older people	7	2	5	4	2	7
Tswana rural older people	5	5	5	6	2	8
Tsonga rural chronic illness	10	0	6	4	4	6
Xhosa rural HIV/Aids	3	4	0	8	0	8
'Non-disabled'						
English urban youth	2	7	1	8	0	9
Sotho urban adults	3	7	0	10	0	9
English urban adults	0	9	0	9	0	9
Xhosa rural youth	0	8	0	8	0	8
Sotho rural adults	8	1	1	9	0	7
Afrikaans rural adults	4	5	1	9	1	9