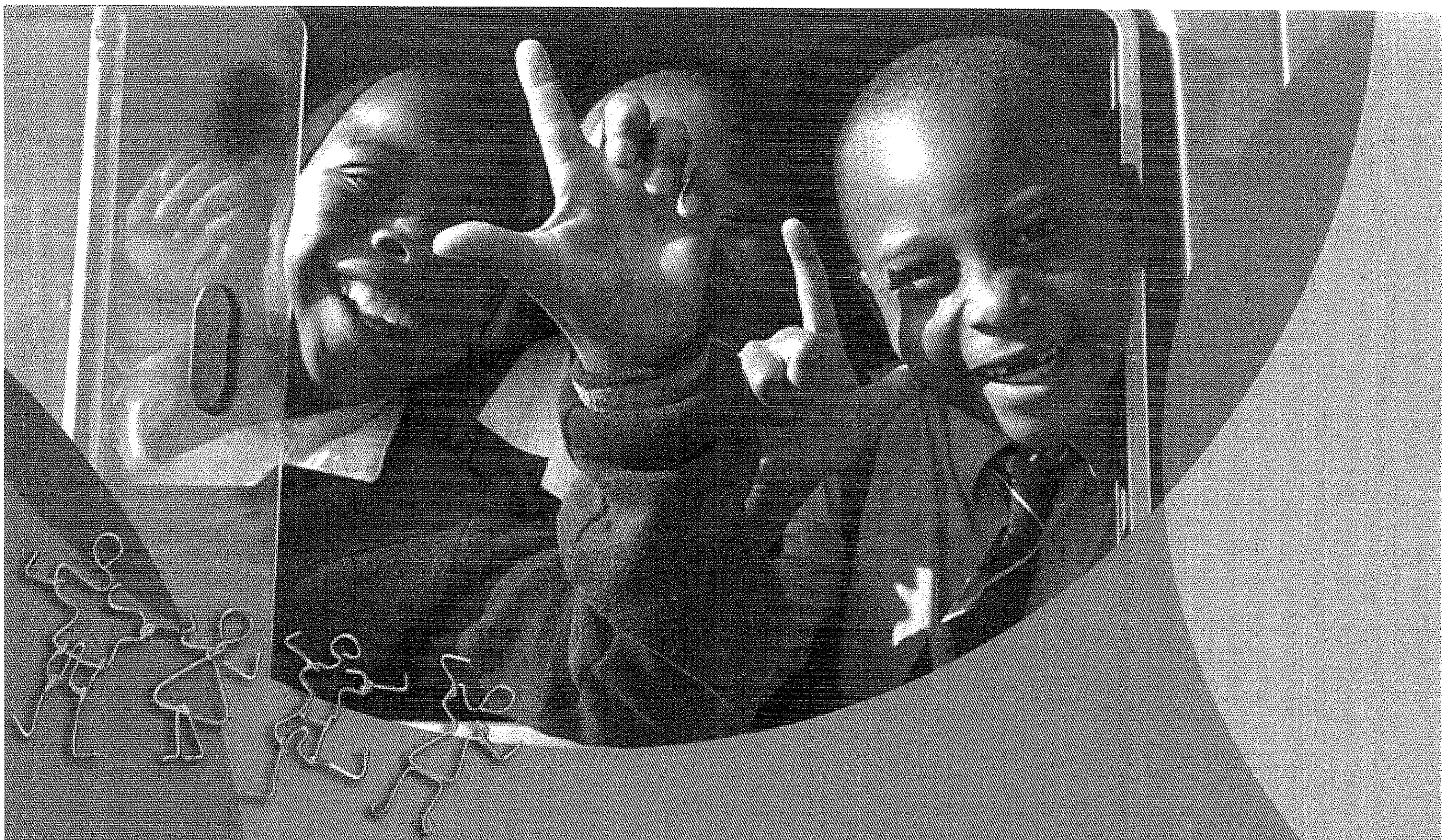

Testing a disability schedule for census 2011: report on 26 focus groups

Commissioned by Statistics South Africa, Pretoria, South Africa

June, 2006

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Presented to Statistics South Africa
By Child, Youth, Family and Social Development
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Margie Schneider
Jacqui Couper

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Acknowlegements

The assistance of the following people are gratefully acknowleged in the completion of this study:

- Zakes Langa and Bongiwe Mncwango from Knowledge Systems at the HSRC
- Letia Poto, Sibongile Vilakazi and Esther Manabile from CYFSD
- The various organizations of disabled people who assisted with the recruitment of the focus group participants

Glossary

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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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 predetermined 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.

Specifically, the questions asked in the study were the following:

- What are the participants' understandings 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?

1.3 Use of the data

The information obtained from this study will be used to inform the development of a disability schedule for disability to be tested through a national survey followed by other testing procedures prior to the piloting of Census 2011. In addition the information will be used to develop a set of questions that could be used on regular data collection platforms undertaken by Stats SA.

The data also provide some insight into how different population groups in South Africa understand and respond to questions on functioning and disability. This information assists in the understanding of who the disability statistics are counting and what the needs are of the people counted as being disabled.

1.4 Structure of the report

The report presents an introductory section which sets out the theoretical issues related to measurement of disability and how these relate to the study, followed by a detailed section describing the methodology used and the different instruments developed for the study. The results are presented separately for the quantitative and qualitative data and also for the groups of adults and those of parents of children. The discussion will bring together the overall findings from the quantitative and qualitative data to answer the questions posed in the study. The report ends with a section on conclusions and recommendations for the Census disability schedule, questions for use on sample surveys and further research required on the disability schedule. References and appendices are also provided.

1.5 Link with the Washington Group on Disability Statistics

The questions used in this initial testing of the disability schedule for census 2011 were developed by the Washington Group on Disability Statistics (WG). The WG is in the process of testing these questions in a number of countries around the world. The current South African study is seen as one such test and the results will, therefore, be forwarded to the WG as part of their overall testing process.

1.6 Use of language terms

The English form of the language terms for the different South African languages are used in this report. These are English, Afrikaans, Zulu, Tsonga, Sotho, Tswana, Xhosa and Swati. This is in contrast to the vernacular use of the terms such as Zulu, Tsonga, Sotho, Tswana, Xhosa and Swati.

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, Hurst, Miller and Ustun, 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.

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 (cf. http://unstats.un.org/unsd/demographics/sconcerns/disability). 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.

2.1 The need 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. This latter notion reflects that everyone experiences more or less problems in functioning (disability) at some point in their life. Disability affects everyone and not just about a small group of marginalised people (WHO, 2001). 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. Thus functioning and disability are two ends of the continuum of human functioning.

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.

For the disability sector, these statistics provide a means of advocating for inclusive policies (OSDP, 1997) and use of approaches such as Universal Design that ensure that needs of all users are taken into account in the design of the built environment and land use (see www.**design**.ncsu.edu for details on this approach).

2.2 Policy implications of disability statistics

Within the Disability Rights Movement there has been much written on the experiences of disabled people. However, this literature has, by and large, taken as a given who makes up the group of 'disabled people'. In order for disability statistics to be used for policies aimed at promoting human rights and equalisation of opportunities for disabled people, we need to understand who these statistics represent.

The field of public health has also started to publish on the experiences of living with chronic conditions. Some of the more prominent conditions studied include arthritis (Hill, Bird and Thorpe, 2003; Lapsley, et al, 2002), Glaucoma (Green et al, 2002), and diet related chronic conditions (Gregory, 2005). The global burden of disease work has shown that chronic conditions are increasing in prevalence and people are experiencing the consequences of living with these conditions. (WHO, 2000, Annex Table 4). If health interventions for prevalent chronic conditions are to be effective we need to understand the consequences of these conditions and the related interventions beyond the clinical context. We need to understand their effect in people's everyday contexts.

2.3 Defining disability

The ICF defines disability as an umbrella term for the outcome of the interaction between a person's health condition and the context in which that person lives. (see www.who.int/classification/icf for more detail on the ICF). Within this broad definition, a range of 'cutoff points' or 'sub' definitions can be specified.

The ICF states that the outcome of the interaction can be described at three levels. The first is that of body level where difficulties experienced are called impairments. Hearing loss, loss of emotional control, stuttering, loss of a limb, and so on are all examples of impairments of body function or structure. The main focus of intervention for impairments would be accurate diagnostic, curative and rehabilitation services generally provided by the health system. The identification of impairments in self-report format is not reliable as the responses would be sensitive to factors such as access to diagnostic services and recognition of the impairment. The body level or prevalence of impairments is not a good aspect of disability to measure in a self-report format.

The second level of functioning outcome is the person level which describes the execution of complex tasks and actions by an individual in a (mostly) conscious manner and bringing together a range of different body level functions and structures. This is referred to in the ICF as the Activity component. It is measured by the construct of capacity which refers to a person's ability to execute the task or activity in a standard or specified environment. This would include, for example, measuring a person's ability to hear and understand a conversation without a hearing aid in a quiet room with only one or two other people. Similarly, the activity of walking would be assessed in an environment where the surface is smooth, non-slippery and flat and without the aid of a walking stick. This is typically the type of measurement undertaken in a rehabilitation clinic by rehabilitation therapists and provides an indication of the person's inherent ability to do the task or activity as a baseline measure. This is usually measured without personal or technological assistance. The focus of intervention for this level will be individually based rehabilitation (e.g. building up muscle strength to improve walking) as well as provision of assistive technology.

The third level of functioning outcome is that of the societal or 'person within context' level. This is referred to in the ICF as the Participation component and is measured through the construct of performance. Participation is defined as the involvement in life activities and describes what activities the person does in fact get involved in given their usual or current environment (home, work, school, recreation, shopping, etc.). This component describes the combined effect of the inherent ability of the individual as well as environmental factors external to that person. If we consider the walking example further, a person may have some inherent difficulty walking (i.e. mild activity limitation in walking), but is not 'involved' or participating in walking because of the steep incline of the path just outside their dwelling. The person's participation restriction is therefore moderate or severe for walking. The same person in a different environment and with the use of a walking stick might have no participation restrictions in walking. Similarly, someone with a mild activity limitation in communicating because of dysarthria (impairment of facial musculature) could have very different experiences in different contexts – one with a supportive and patient listener versus one with an impatient and intolerant listener. The activity limitations remain the same but the participation restrictions will vary. (Schneider, et al, 2003).

The difference between activity and participation is in itself a useful measure as it provides a good indication of where the interventions should be focussed – on the individual or the environment. Activity (A) and Participation (P) (person and societal levels) are aspects of disability that are relatively easy to measure using a self-report format. They require a person to describe their daily experience and thus rely less on access to diagnostic and other services. Thus A and P are useful components to measure when collecting disability statistics at the population level.

The ICF (WHO, 2001) provides a good framework for describing the functioning of a person or of a population. However, it does not provide a good conceptual framework to analyse and describe other aspects of the disability experience such as the sense of independence, quality of and satisfaction with life, social exclusion, isolation and disadvantage. These are broad, multidimensional aspects that, in themselves comprise a number of components and interrelationships requiring careful consideration in defining and measuring them.

2.4 Measuring disability

As discussed above, the use of the body level component as the unit of measure in self-report surveys is not an appropriate approach. Self-report measures of disability using Activity and Particpation provide a more feasible component to measure in Censuses or surveys. The problem remains, however, that these theoretical constructs for Activity and Participation put forward by WHO in the ICF (WHO, 2001), are not easily measured in the format of a Census or brief survey. The limitations are the space available for the questions as well as training of enumerators. This makes it difficult to ensure that both Activity and Participation are measured as well as ensuring that the enumerators are sufficiently skilled to explain the required context or environment for the participants (standard for Activity and usual or current for Participation). A question asking about any difficulties a person has in walking, communicating, self care, etc. can therefore be answered with every participant using a different frame of reference in getting to their answer.

Some participants might consider in their frame of reference, all their different environments, average out their difficulties and answer using this average. This is more of a Participation measure. Others might consider their best environment which includes the assistive devices and personal assistance they use and thus also provide a Participation measure. This could be an underestimation of their capacity to execute the Activity. Other participants might consider the most difficult environment they encounter without any assistance and this might be closer to the measure of Activity. This could be an overestimation of activity limitation if their worst environment has many barriers or hindrances. Lastly, participants might consider their inherent capacity and disregard their usual environments. This would be the closest response to Activity. What frame of reference do participants use when answering questions?

A notable example of the benefits of using both measures of Activity and Participation in a juxtaposed manner is provided by Eide and Loeb (2005) where they show clearly in a population based survey in Malawi how the prevalence of activity limitations is greater than that of participation restrictions. This indicates that people are clearly experiencing a significant benefit from their environment thus reducing the participation restrictions. However, the notion of environment was limited to that of personal and technological assistance. This might, therefore, have underestimated the participation restriction when considering aspects such as stigma and inaccessible buildings and transport. Thus, their work still does not fully answer the question on what people are using as their frame of reference when answering the questions.

The difficulty in juxtaposing measures of Activity and Participation in Censuses and surveys, and the use of different frames of reference by different participants means that we are not clear on who is being counted into disability statistics. The discussions from the focus groups will provide some evidence as to what people are using as their frame of reference. However, this evidence remains limited as it is in fact quite difficult for a respondent to unpack what is often a quick and automatic response to a question such as ‘Do you have difficulty hearing even if wearing a hearing aid?’.

The frame of reference described above is limited to the extent to which different environments are taken into consideration by participants and relates to the description of individual functioning. The reference to environments does include physical, social and attitudinal aspects. Thus factors such as stigma resulting from negative societal attitudes are included in this conceptualisation of the environment. (WHO, 2001). However, the other factors that have been noted above are also important to review in terms of their influence on people’s responses. These include a person’s overall sense of independence, social inclusion or exclusion and isolation, overall disadvantage experienced (e.g. limited access to education and employment), poverty resulting from the impairment, access to health care services, age of the person, cultural beliefs and notions of health and functioning, and so on. The information arising from the focus group discussions provides some indications of how these factors are influencing people’s responses.

Studies reviewing the experiences of disabled people show clear patterns of experience, such as low education levels, loss of employment opportunities and high levels of unemployment (Burchardt, 2003; Eide and Loeb, 2005; Elwan, 1999; Schneider, et al, 1999), social isolation and exclusion (Burchardt, 2003; Jenkins and Rigg, 2003; Lapsley et al, 2002; Manderson et al, submitted), stigmatisation, and higher levels of poverty than the general population (Burchardt, 2003; Elwan, 1999). These are clearly factors that describe the experience of disability, but the question remains as to whether people take these into account as part of their frame of reference when responding to questions on disability.

2.5 Disability statistics

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 of 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.

Eide and Loeb (2005) report on a literature review that "showed as expected that there is little data on disability in low-income countries in general. A few overview articles describe existing data as suffering from poor quality, lack of comparability and limited applicability." (2005, p4). In South Africa, three recent data collection exercises have yielded 3 different national prevalence rates. The 1996 Census yielded a prevalence rate of 6.7% (Statistics South Africa, 1998), followed by the national baseline survey undertaken for the Department of Health in 1998 which yielded in a prevalence rate of 5.9% (Schneider, et al, 1999). The last prevalence rate is 5% obtained on the 2001 Census (Statistics South Africa, 2003). While these differences are not large, they do show some differences due to the wording of the questions used in the three sets of data. For example, the 1996 Census used the phrase 'any serious sight, hearing, physical or mental disability', while the 2001 Census used the phrase 'any serious disability that prevents his/her full participation in life activities'. The effect could be that 'preventing participation in life activities' denotes a more severe experience than merely reporting the presence to a disability, giving the lower prevalence estimate for 2001. The other population level factors would have had minimum effect as the demographics are constant and the methods are all population based.

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 on www.cdc.gov/nchs/citygroup.htm):

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 all over 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.

In this format no context is specified except for the first two questions on seeing and hearing,[1] and the participant is left with having to choose which context to consider, i.e. they have to set their own frame of reference.

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 as well as 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 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 do respond to the questions on disability and functioning.

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[1] For these domains it was decided by the WG that use of eye glasses particularly but also of hearing aids was so prevalent that asking the question without reference to their use would result in unrealistically inflated rates for disability prevalence.

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

In deciding on the distribution of the focus group, a number of stratification variables were applied. The main issue is that the Census questions would be applied to the whole population and that the aim is not to 'count' only people who are clearly identified by themselves and/or others as disabled, but also to see how people without any obvious disability would respond. Disability statistics are not about disabled people only but about the functioning of the whole population. These stratification variables included the following:

- disability status as disabled, non-disabled and unsure; 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, 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 and three different measures – the question asking 'Are you / Is your child disabled?', the Census 2001 questions and the Washington Group set of 6 questions (plus a Participation and Environment question).
- Geographical location: urban and rural
- Whether answering for oneself or about one's child or ward – only self report and no proxy adult reports
- Type of disability and range of chronic conditions: visual, hearing, and physical impairments, psychiatric illness, head injury, chronic illness, HIV/AIDS, old age, youth, adults, and for children intellectual or other impairments, or not disabled.
- Provincial spread: all provinces were targeted except for Northern Cape.
- Population group and language spread: English, Afrikaans, Tsonga, Tswana, Zulu, Xhosa, Swati, and Sotho were all used in the different focus groups.

This resulted in an allocation of 26 groups as set out in Table 1 below. Only two changes were made during the course of the data collection. The pilot group with a group of people with a head injury was felt to be sufficiently successful to be added to the list of groups increasing the number to a total of 26 groups. The other change was to replace the group of people living with HIV/AIDS planned for a rural area in KwaZulu Natal with one run in Lusikisiki in the Eastern Cape. This latter change arose after discussions with knowledgeable people in the field of HIV/AIDS who indicated that the high level of stigma in rural areas, especially in KZN, would make it difficult to recruit participants who were open about their status and willing to participate in the group.

Table 1: 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	Tulamahashe
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	Tulamahashe
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	Tulamahashe
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	Coloured	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

In Lusikisiki, the project run by Medecins Sans Frontiere as well as the presence of the Treatment Action Campaign made it much easier to recruit participants for the group without fear of breach of confidentiality. The criteria for the HIV/AIDS group were that the participants be open about their status and willing to discuss openly about how they would respond to the questions in view of their positive HIV status.

The group intended as a pilot was added to the 25 planned groups as it provided useful information on people with head injuries.

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 I and II)

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 asking about 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 Washington Group 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 two such questions should 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.

The questionnaire was developed using the current Stats SA Census questions for education, marital status and employment as part of the background information for each participant.

Questionnaire translation was undertaken in all official languages except for tshiVenda and was administered using South African Sign language to the Deaf participants. The translation was undertaken in a group context with translators from most of the languages discussing and then translating the concepts. The translation were checked by a third person. The outstanding languages (Swati, Xhosa and southern Sotho) were translated by people using the completed translations in related languages as guidelines.

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. The versions are the same except for duplication of some questions in the parents of children questionnaire to elicit information on the parent's as well as the child's sex and age, and omission of one question on ability to stay on one's own which was not felt to be appropriate for children. In addition, some of the examples given in questions were changed to make them more relevant to children and the wording of the question was changed from the adult version of 'Do you have……?' to 'Does your child have….?'. The full questionnaire is presented in Appendix I.

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.

While the discussion aimed to standardise the structure of the discussions across all the groups, this was not possible as each group developed its own dynamic and flow of conversation.

The discussion guide was not translated into the official languages prior to the running of the groups. The facilitators were trained to understand the content of the guide and translated at the time of running the groups.

The full discussion guide for the adult groups is presented in Appendix II. The discussion guide for the groups of parents only differed in the ay the question was phrased to reflect difficulties that children of the named person had.

3.3 Participant demographics

Tables 2 and 3 present the demographic profile of the participants. The profile of the adults is presented separately from that of the parents and their children. The children reported on by their parents varied quite extensively in their ages, ranging from young children through to adult children with intellectual impairments that would require their parents to respond for them on questions in a Census or other survey. Most parents had completed high school or higher and only half were employed. Most of the children were male and most of the parents mothers.

Table 2: 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 3: 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	
Primary School	36	living together	4	Missing	
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		

The adult sample showed a wide range of ages as expected from the stratification. The majority were women, and the education levels varied with the majority having primary or high school education. Just over half of the participants were employed. The majority had never been married. Of interest would be to see whether these trends are replicated in a larger population based sample survey.

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 target for each group was 8 participants and the number ranged from 6 – 11 participants. The average size of the groups was 8.8 participants.

The participants were given refreshments before, during or after the group and were paid an honorarium of R100 each. Any transport costs incurred were also reimbursed.

The groups were in a quiet room available at an accessible location and the discussion was tape recorded using two tape recordings. The facilitator was trained to administer the questionnaire and discussion guide and on interviewing techniques. The note taker was requested to take notes of the proceedings to provide a further back up for the tape recording.

The participants were each asked to complete and sign the consent form prior to starting the group. If a participant was not able to sign the facilitator signed as witness to a verbal agreement. The aims and objectives of the project, process of the discussion as well as the role of the HSRC and Stats SA were explained verbally and the information sheet with this information was given to the participants to take home. The information sheet also had a phone number of the project coordinator that could be used if the participants had any further issues to discuss after the group had been completed. The information was not translated from English.

The groups that were allocated as English or Afrikaans had participants who were able to participate in either of these languages. These groups were often mixed in relation to population group and included White, Indian, Coloured and Black participants.

The tape recordings were transcribed into the original language and translated into English. The names of the participants were not used on the transcriptions with different names, initials or merely 'R' for participant used depending on the transcriber.

The responses to the questions on the questionnaires were captured onto SPSS for statistical analysis.

3.5 Analysis

The data were analysed separately for the adult and parent groups. The qualitative information was analysed thematically using the computer analysis 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 predominantly.

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.

The focus of the analysis is to identify trends in the responses to questions and in the comments made and to recommend ways in which these trends can be investigated further to confirm or reject them.

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. The certificate is included in Appendix III.

Section 4: Quantitative analysis of questionnaire data

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

The analysis for the quantitative data included a number of phases:

- Firstly, the WG core and extended question set responses were recoded to binary variables reflecting two extreme measures of disability as described below. 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. This reflects the WG analysis strategy set out for the country tests. The composite or overall scores were computed using the 'disabled' proportion for each of the recoded core and extended questions. This means that if a person responded as having difficulty in one or more domains, they would have only been counted once. For the detailed set of questions, the result for each of the domains are computed using the recoded binary variables for all the questions in one domain. For example, vision had 2 questions in the detailed set and both were used to compute the overall ED result for vision (ED1 and ED3). The domains had varying numbers of extended questions: vision, hearing, concentrating and remembering, communication and learning each had 2 questions; self care had 3 for children and 4 for adults; mobility and social interaction each had 4; and emotional functioning had 5 questions.
- Secondly, 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.
- Thirdly, both of the above were analysed further using crosstabulations with the variables of age, sex, allocated disability status and geographical location applied as standard analytical variables. Only those results that show interesting trends are presented.
- Fourthly, the responses to the Environment questions (Q19 a and b) are briefly reviewed and discussed.
- Lastly, an analysis of the response to the question on environmental factors (Q19a and b) will be done separately as the response options were complex and the impression is that these questions were not clearly understood.

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 Analysis of the WG core and extended sets

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'. For ease of analysis, these need to be transformed into binary variables. 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 a positive response indicating disability. 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

Clearly, D1 is the broadest definition of a disability and would yield the highest prevalence estimate and D3 is the most limited yielding the lowest estimate. For the current study only the two extreme measures were used. The results of measures are presented in Table 4 and 5 below for adults and children respectively. The estimate for D2 was not calculated but would be in between the estimates for D1 and D3.

The WG has set out a strategy for calculating prevalence estimates based on the responses. However, this has not been applied to these data as the sample is not representative and the aim is not to determine prevalence estimates but rather to compare the performance of different sets of questions. What is of interest is to show the differences obtained using the different response cut off points and in comparison with the other measures.

Similar to the core questions, the presence of disability needs to be coded for the extended questions. Within each domain, the definitions of disability used are the following:

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 analysis here is done as for the core questions but where the two, three or four questions for the domains are included in the single domain estimate. Again the middle estimate, ED2, has not been included. The results for the detailed set of questions are presented in Tables 4 and 5 below together with those for the core set.

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 does appear to some difference when looking at the low estimates – D3 versus ED3 (also without the three additional domains). This will required 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 4: 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.

** The domains with 2 asterisks are those added in the extended set and were not covered in the core set of 6 questions.

Table 5: 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.

** The domains with 2 asterisks are 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 across the six domains of functioning, for individual domains the extended questions do seem to make a difference. Generally this trend is for the extended questions to produce higher scores (i.e. more people being 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. Of interest here would be to determine the effect specifically of the question 'Do you have difficulty staying by yourself for a few days?' (Q33). A few comments made by participants in the focus groups 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'. This would need to be tested on a larger sample.
- 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:

- The extended questions seem to have a significant effect on the scores for the domains of vision and mobility (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.

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 Environmental questions (Q19 a and b)

The two questions on environmental factors were added to the WG six core questions to see whether the responses provided would yield useful information to complement the questions on individual functioning. The questions were based on work undertaken at the Craig Hospital in the USA. The original question was as a single question with the physical and attitudinal environments included in one question. The two environmental aspects were separated after discussions with the translators group. The results on these questions are not clear at this point. Firstly, the current version is very long to include in the Census, and, secondly, there seems to be different views on how to consider the environment by the participants. There seemed to be some confusion on how to respond to the environmental questions and it is not clear whether the notion of 'because of a health problem' was maintained when answering. The results for question 19 a and b for the adult participants are presented in tables 6 and 7 below crosstabulated by the overall score for the WG core set (D1) and the allocated disability status.

Table 6: Responses by adults on problems with the physical environment by allocated disability status and WG core set composite score. (N=185)

Frequency of problem	Disability status on WG core set		Allocated disability status		
	Disabled	Non-disabled	Disabled	Unsure	Non-disabled
Daily	22	3	13	9	3
Weekly	12	1	6	5	2
Monthly	13	2	6	9	2
<monthly	25	17	20	8	15
Never	41	28	27	19	29
Size of problem when it occurs (only if indicated a problem above)					
Big	44	12	25	19	13
Little	38	11	26	14	11

Table 7: Responses by adults on problems with the attitudes of people by allocated disability status and WG core set composite score.

Frequency of problem	Disability status on WG core set		Allocated disability status		
	Disabled	Non-disabled	Disabled	Unsure	Non-disabled
Daily	10	1	9	2	1
Weekly	11	0	6	4	1
Monthly	15	1	10	7	0
<monthly	23	18	15	14	15
Never	48	24	31	20	26
Size of problem when it occurs (only if indicated a problem above)					
Big	38	5	24	12	7
Little	39	21	21	27	17

The adult responses indicate that the 'disabled' participants were the most likely to indicate a problem with both the physical and the attitudinal environments. However, quite a large number of 'non-disabled' participants also indicated some problems as well as many 'disabled' participants indicating that they never have problems. While the results suggest that the question is picking up some useful information, further data and analysis if required to determine whether the information provided does reflect problems arising from the interaction between the person's impairments or health problem and the environment.

The results for the children are more clearcut as reported by their parents. The disabled children's parents generally reported problems with both the physical and attitudinal environments while the parents of non-disabled children did not report any problems. These results are presented in Table 8. The results for the allocated status and WG core set were very similar for the children and so only the information from the WG core set is presented. Parents of disabled children clearly experience frequent problems with both the physical and attitudinal environments and when these problems occur they tend to be big problems.

Table 8: Responses by parents on problems with the physical and attitudinal environments by disability status on WG core set composite score. (N=38)

Frequency of problem	Physical environment		Attitudes and support of others	
	Disabled	Non-disabled	Disabled	Unsure
Daily	18	0	14	0
Weekly	1	0	0	0
Monthly	1	0	2	1
<monthly	1	2	5	0
Never	6	8	5	9
Size of problem when it occurs (only if indicated a problem above)				
Big	20	0	17	2
Little	1	2	7	1

4.3 Analysis of the Census 2001 and 'Are you disabled?' 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 should have been counted only once no matter for how many domains they gave positive responses. The results for Census 2001 are presented in Table 9 together with the composite WG scores for the 6 core questions and the results for the question 'Are you / Is your child disabled?'.

The results for the question on self identification or identification of one's child as disabled was analysed as a simple frequency. The results are also presented in Table 9 below.

Table 9: Comparison of results for Census 2001 questions, WG composite on core questions and self identification as disabled

	WG Core 6 'High' (D1)	WG core 6 'Low' (D3)	Census 2001	'Are you/is your child disabled?
Adults (N=185)	126 (68.1%)	33 (17.8%)	69 (39%)	71 (38.4%)
Children (N=38)	28	12	21	23

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 others (by proxy respondents) as disabled. This is not surprising as the wording of the Census 2001 question included the term disability.

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 calculation of the results for the middle definition of disability on the WG core questions (D2) might well provide results that match with both the Census 2001 and 'Are you disabled' results.

The high D1 scores for both children and adults probably reflects 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.

Again these are merely trends that require further investigation to be confirmed as true or thrown out as false.

4.4 Analysis of composite scores by age, sex, education level, allocated disability and geographical location

The results presented above show clear trends between the different measures of disability used. This section takes this analysis further to see whether there are trends across the participants when age, sex, allocated disability status and geographical location are considered. Results from simple crosstabulations are presented. The analysis is limited to the higher WG composite score (D1), the composite Census 2001 score and the question 'Are you/is your child disabled'. Furthermore, because of the small number of parents that participated in the study (N=38), this analysis is not useful. Thus the results are only for adults responding for themselves about their own functioning. The figures presented in the tables below are all numbers rather than percentages. The 'Y' indicates a 'disabled' status as identified by the participant and the 'N' indicates a non-disabled status.

4.4.1 Age

The age variable was categorised into three categories – up to 30 years of age; 31 – 60 years and 61 years or older.

Table 10: Positive identification of disability by age of Adults (N=185)

Question set	<=30 yrs		31-60 yrs		61+yrs	
	Y	N	Y	N	Y	N
WG core (D1)	41	33	68	20	11	1
Census 2001	18	58	45	45	6	6
Are you disabled?	24	48	40	46	2	9

Of note are the following:

- WG questions yielded more positive identifications in the younger age group than negatives, while it is the opposite for the other two question sets. This suggests that younger people are more likely to respond positively to questions on 'difficulty' than 'disability'.
- This trend is similar for the other two age groups.

4.4.2 Sex

Table 11; Positive identification of disability by sex of Adults (N=185)

Question set	Male		Female	
	Y	N	Y	N
WG core (D1)	49	20	72	34
Census 2001	36	35	35	72
Are you disabled?	37	33	30	71

There is a similar trend with sex as there is with age. The WG questions elicit many more positive responses than negative ones for both males and females. There are no important trends between the sexes probably due to the oversampling of women relative to men, but this should be investigated further on a larger sample.

4.4.3 Allocated disability status

Table 12; Positive identification of disability by allocated disability status of Adults (N=185)

Question set	Disabled		Unsure		Non-disabled	
	Y	N	Y	N	Y	N
WG core (D1)	67	6	43	10	16	38
Census 2001	48	25	24	31	3	53
Are you disabled?	62	9	8	45	1	51

The allocated disability status was an externally imposed categorisation based on the assumption made by the researchers. The actual status as indicated by the figures on the table were the identification provided by the participants themselves through their responses on the questions.

The trends of note are the following:

- 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 were 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.

4.4.4 Education

The WG questions seem to identify more people as being disabled than the other questions. This is true across all education levels except for the post schooling qualifications. However these numbers are very small and the trend should be tested further. If this trend is sustained through further testing, the reasons for it remain unclear.

Table 13: Positive identification of disability by education of Adults (N=185)

Question set	No schooling/ Gr 0		Primary school		High School / Certificate		Dip/deg postgrad		Other	
	Y	N	Y	N	Y	N	Y	N	Y	N
WG core (D1)	9	0	29	7	69	31	10	15	2	1
Census 2001	3	4	18	18	38	64	5	20	2	1
Are you disabled?	6	5	14	20	39	57	8	17	1	2

4.4.5 Geographical location

Table 14: Positive identification of disability by geographical location of Adults (N=185)

Question set	Urban		Rural	
	Y	N	Y	N
WG core (D1)	70	31	50	23
Census 2001	39	63	30	46
Are you disabled?	34	63	32	40

The WG questions are more likely to identify people in both areas as disabled. No important differences between urban and rural, although this should be investigated further through a population based sample survey.

4.4.6 Individual group responses on the WG core set, Census 2001 and 'Are you disabled?' questions

The responses highlighted in Table 15 are those provided by the majority in the group or the range of the responses on the composite scores for the three sets of questions: The WG 6 core questions (D1 without participation), Census 2001 and 'Are you disabled?'. Only the adult groups are presented.

The results confirm the earlier reported findings that the WG core (D1) identifies many people with some degree of difficulty on the different domains. Some interesting points to note from the table are as follows:

- The low endorsement rates for the Census 2001 questions by the physically and visually impaired groups relative to their responses on the other two questions. This is reinforced by comments made in the groups discussion where they would indicate that they do have a disability and 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. Thus, they would *not* say 'yes' to having 'a serious disability that prevents their full participation in life activities.'
- 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

groups 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'.

Table 15: Responses on the 3 main question sets by individual group

Group	WG D1 (6 questions)		Census 2001		'Are you disabled?'	
'Disabled'						
	Disabled	**Non disabled**	**Disabled**	**Non disabled**	**Disabled**	**Non 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

4.5 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 more 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 including comments on questions or areas omitted and questions that are too sensitive.
2. What people understand by the notion of disability and difficulty
3. Responses given in relation to the scenarios

The first theme provides information on how to change or refine the questions for the survey as well as provide indications as to areas that could be usefully included in a survey questionnaire. The second section provides a review of how disability is understood in the South African population as reflected by parents of children with different levels of difficulty in functioning or disability. The notion of 'difficulty' is also contrasted to that of 'disability' to show how prevalence estimates using the two different terms would be different. The last section also provides some useful qualitative information on how we can start making some sense of what is being measured when we ask questions for 'disability statistics'.

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. They are as follows:

- 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'. However, one participant from the East London group made a suggestion concerning the type of question used,

> *I think we might use true and false you know.*

But another participant replied, saying that

> *a multiple choice question - it's confusing, because it's very academic so I think it also contributes in difficulties sometimes a lot you know.*

5.1.1 General comments about the questions

a) Understanding and remembering the questions

Most participants found the questions easy to understand and easy to remember. For most participants, the questions were not confusing. However, there were some comments about the questions in terms of the context specified.

- 'Health problem'

There were two participants from the English urban group with disabled children who were 'confused' about the heading of the core questions that required answers 'because of a health problem...' and why the questions around disability were classified as 'health problems':

> *On top of the questionnaire's date because of health purposes ... what is the reason for that?*
> And
> *Like if somebody has a disability and you'd go for a checkup and stuff like that, so why do you label it on health purposes? That is what I don't understand.*

This issue comes up again when we look at what is disability and how people react to the notion of disability being a 'health' issue.

- 'Age related' questions

There was some response from only the Xhosa urban group of mothers of disabled children about the appropriateness of the question for a very young child. A participant felt that the questions for the very young child, under a year were not clear as the child had not yet developed and problems were not yet known.

> *I think next time, to other questioners you must divide them because there are zero to two years so they are not qualifying to other questions which are appearing in your answer sheets you see, the one year old [of] Z, some of the questions are going to take time for Z to understand the child, maybe she is going to see the progress for the child after a year.*

Another participant agreed,

> *So the next time where I cater for the people who are having zero to one year because there are sitting doing nothing, because there is nothing they are going to answer on the questions.*

b) Difficulty to answer

One participant did not know how to answer the question (the exact question not mentioned, perhaps "Are you disabled?") as her child was born with a finger deformity and "*so, I kind of said yes, because it's not a disability as such, but she has difficulty in picking up..*"(meaning with hands). This confusion highlights the terms understood by disability as compared to difficulty. This is discussed further in the disability section.

c) Time period of questions

None of the participants had any difficulty with the time period in the questions, for example, four weeks or in the past year. However one participant in the urban group mentioned that it was easier to remember 'the past month' whereas someone in the rural group thought it was easier to remember a year period. Only one participant from the East London group said

You are not observant in some cases so it's not easy to remember whether the child you know in the past four months was very active or not because sometimes he is hiding.

However another participant put remembering events into context,

If it was a major thing, even if it was ten years, ago, you will remember it. But if it's like minor things ...then four weeks is fine.

d) Sensitivity of questions

Most participants felt that the questions were not sensitive to answer. An urban mother jokingly mentioned that the question asking her 'sex' was sensitive and she would rather the word 'gender' be used. Only one of the participants, a rural mother with a non-disabled child, thought it was insensitive to ask someone who is blind if he can see.

It might happen that these questions will offend them it will be like you are laughing at him. You cannot ask someone who is blind a question like 'as you are wearing these glasses can't you see anything'.

And

you cannot ask a blind person that does he have difficulties in seeing when he is not wearing glasses; I won't allow you to ask my child that question.

5.1.2 Core questions

Specific mention was made of the six core disability questions. Comments made across the groups included:

I find this section just fine. I don't have a problem. From 12 to 18 it's just right

No problems either.

It's fine

I also think it's fine

I think these questions are quite right to be asked so that you can get all answers.

There was a discussion about question 15 (Does your child have difficulty in remembering or concentrating?) in the English urban group of mothers with disabled children. There was a discussion about whether the concept of 'learning' should be added to 'remembering or concentrating'. One participant 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.

Those kids can remember some of the things [but] they cannot concentrate in a classroom. They cannot forget what they want but on the other hand they can ignore some things.

Some mothers in the English urban group felt that their disabled children's ability to concentrate and remember is inconsistent but learning is a different ability or skill. So by adding ‘learning’, it gives question 15 more structure and an educational context. There was general agreement in this group that ‘learning’ should be part of this question.

> *Sometimes they can concentrate and sometimes they can remember but if you take it at a broader context [of learning], then it's difficult.*

There was some discussion in this same group around the understanding of 'concentration'. It was felt that the ability to concentrate comes from intelligence. Some thought that the word ‘discipline’ should be used instead of concentration.

> *Do we really need concentration? I think it must be discipline.*

However the participants accepted the word ‘concentration’.

5.1.3 Specific comment on ‘non core’ questions

In relation to the other questions on functioning, the following point were noted by the participants.

- ‘anxiety’ versus ‘nervous’: A participant from the Xhosa urban group of mothers with disabled children found the difference between ‘nervous’ and ‘anxiety’ difficulty to understand, in question 47.

- Question 4: The group of mothers with disabled children discussed question four, and a clarification was suggested that “at home” be included in the response option: “living with a personal attendant”.

- Question 19 (Physical and attitudinal environment): The feeling among only the group of English urban mothers with disabled children was that asking questions about attitudes towards children with disabilities was not going to change the plight for the child itself.

  > *This series (of questions) is not going to change the attitude. The Government can give us the whole physically, but nothing will change the attitude.*

  Another participant in the same group felt it was a

  > *waste of questioning because all they need is to be told there needs to be wheelchair ramps and they know that.*

  This group of urban mothers felt strongly that they, representing organizations for children with disabilities, and the government know that both the physical environment and attitudes towards children with disabilities is inadequate. They felt that asking the question 19 was a “waste of time” as the government knows that physical changes must be made to the environment to make it more accessible for children with disabilities. They also said that attitudes towards children with disabilities were not going to change anyway so there is no need to ask these questions.

5.1.4 Suggested questions for further research

a) Disability services: Health and education

The group of English urban mothers with disabled children felt that there were some questions that should have been asked about their children. This group raised their concern that both health and especially educational services for children with disabilities were not known. They felt strongly that educational and health services were much more a priority and influenced their lives more, than understanding the attitudes of the community towards their children. They, therefore, suggested replacing question 19 (In the past 12 months, how often has your physical environment and support and attitudes of people been a problem to you?) with questions around services for children with disabilities. This group compiled a list of questions they thought should be included in a questionnaire around disability. These questions and other comments are as follows:

I've put here which services, over the last year have you accessed for your child? Or do you need something like that.

> *Or let's put it this way: 'Due to your child's disability, which services have you used over the last year? Or what services would you expect to use in the next five months or so?'*
>
> *Then they [the government] know they have so many thousand people who need hospital services and so on.*
>
> *if I had got any I'd want to know is how many people are disabled in certain sections. I'd want to know are they receiving any funding? Are their parents funding them? And how can we fund them? Are they receiving any schooling and any health benefits? That's what you need at the end of the day. So if that's what parents of people with disabilities need I think the question should be targeted to answer those. Because if the government is willing to provide on social spending for health and education then those are the questions [that] need to be asked.*

Services for children with disabilities was a recurring theme in the discussion as the participants thought that the questions around the impairment, for example communication or hearing, is only "one part and the other is facilities" (namely educational and health facilities).

> *Regarding the question. I think somehow you need to slot in, 'do you need special needs education?' 'Do you need special requirements?' Or 'does the child need special care or attendance?'*
>
> *We talked about services and we haven't talked about the education on where the child is at the moment. Isn't that important as well?*

The Swati rural group of mothers with non-disabled children were also concerned about services for children with disabilities. They wanted to know;

> *If there could be a question asking if the child is willing to go to a sign language school.*
>
> *And if there could be a question asking if has child ever been taken to the doctor for check-ups.*

b) Acceptance of the child with a disability:

More direct questions were suggested around the acceptance of children with disabilities. The English urban group of mothers with disabled children would like to ask the public

> *What makes you (the public) scared of a person with a disability?*

And

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

From another point of view the Swati rural mothers with non-disabled children wanted to ask the parents of disabled children

> *Yes. There should be a question asking if you accept your child as he is.*

5.1.5 Background and other information

The Swati rural group of mothers wanted more information about the child with a disability. They suggested that the following information should be asked,

> *I think they should add one question here that would ask about the time that, that child has been on that situation.*
>
> *And the time that he got that disability or was the child born with it.*

The English urban group of mothers with disabled children also wanted more information on the content of education as indicated in the following quote:

> *Are they (disabled children) having sexual education? Is your child receiving state benefits? Are you receiving health benefits from the state? Yes or no. If yes, which grant is it and what is the amount that you are receiving?*

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".

A Swati rural mother of a non disabled child described her understanding of disability in children as follows:

> *signs that you can use to identify that this person is disable is when they are being taught at school there is no concentration and teachers notices that he is disabled.*

Another participant from the same group related disabled children to 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 non-disabled children understood disability mainly in terms of 'visible disabilities' even though they understood it could affect other aspects of a child.

> *I would say, maybe the child would be emotionally, mentally, physically or psychologically ... not necessarily disabled, but lacking*

It's a disability like when people are crippled, or you can be mentally disturbed – it's also a disability.

Swati rural and English urban mothers with disabled children were, naturally, able, from their experience to better describe their understanding of disability. Their description included the following:

Was able, disabled. Was connected, disconnected.

No longer optimally able

Has difficulty in doing things.

Disabled are like something you should do but you can't do it.

And this was followed with the immediate response *That's unable.*

Swati rural mothers gave good descriptions of their children with disabilities saying

I regard my child has a problem because she cannot do a thing and cannot play with other people.

Mine has got a problem of not doing what other people do. He has a mental problem.

He [my son] goes to school but he forgets what has been taught and sometimes he writes things and not finish it.

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

If you have a mental and a physical disability in one child then you've got more than enough

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.

And

Blind people go about in their lives just a little bit different from us.
Disabled people have abilities and they have feelings.

The English urban group with non-disabled children showed some understanding that children with disabilities could behave in different ways.

you get the passive child, and you'll get your child that is forever aggressive.

There are also personality differences:

Moderator: So you would make a very clear distinction between something that's personal and something that is a disability?
Several participants: yes.

5.2.2 Comparison of disabled children to others

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

> *You see that your child has a problem when you look at other people around you. You compare what other children do and what your children do.*
>
> *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.*
>
> *When you give birth, you will find that your child is like other children, and you do not see problem, but after three to four months, you will find out that this child is lacking somewhere, and she is left behind to other children of her age. She cannot do some things.*
>
> *This child is not normal because when the time goes on, we can see that this son is not like other children.*
>
> *A child that cannot do most of the things that other normal children can do.*
>
> *If a child is missing one limb, he'll automatically be slower than a normal child when doing something.*
>
> *He cannot do what other children are doing.*
>
> *When you are disabled its like when you cannot do things by yourself, like other child[ren].*
>
> *I think if you compare it to a child who doesn't have a disability it's easier to see some difficulty to do what the other one is doing.*

A participant in the Xhosa urban group of mothers of disabled children said the same thing in a different way:

> *I cannot compare my child to other children because he is totally out with other children; like he is violent ... and sit in the middle of the road... you see, I cannot call him like other children.*

Comparing children to each other not only helped mothers identify their children as disabled but also assisted them to understand the severity of disability.

> *I think we have to use it [understanding some difficulty to a lot of difficulty] against something [the normal].*

Participants used a comparison between the normal all the time to make their decision about whom and what aspects make a person disabled. A normal person is described as someone who "is healthy".

5.2.3 Disability and function

Participants clearly link disability to 'performance', 'participation' or 'function', and in the case of a child, this involves playing with toys and attending school.

> *It was a disability because it kept my children [from] achieving certain things in their natural performance of entertainment or sport.*

And someone with a disability is

> *When a person is unable to participate on different activities with other people then I can tell. When a person cannot do some of the things.*
>
> *Like I am disabled because there are certain jobs that I cannot do them any more.*

The Xhosa urban group of mothers with disables children described

> *When you are disabled it's like when you cannot do things by yourself, like other child I know he has Down syndrome; it's something that is not allowing you to perform some duties, but I won't know because I am not Down syndrome.*

5.2.4 What is not a disability

It is helpful to look at what participants thought was not a disability

> *If someone has a drinking problem, that doesn't mean to say the person is disabled!*

People with a drug and an excess weight problem, suffering from stress, and hypertension were not considered to be disabled.

> *When you have severe high blood and you take medication you become okay so he is not disabled*

However a person who "cannot breathe well because of diabetes [or asthma]" could be considered to be disabled, but no explanations are given. An assumption could be that this person has difficulty in moving or functioning due to shortness of breath.

Relating specifically to children, those who "cannot concentrate but can do all things", "play at home", "sometimes forgets", "can write something that makes sense but her hand is always shaking" were not considered disabled. This touches on the issue of severity of the difficulty determining whether it is a difficulty or a disability.

5.2.5 Health and disability

Groups made the differentiation between health and disability by referring to disability as a permanent condition.

> *It would be like most of the time.*
>
> *There is no way they can cure me.*
>
> *A disabled person needs help in everything that he does and the one with high blood is sick.*
>
> *He 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.*

And when asked whether one could attend a function with a health problem compared to disability

> *It would depend on the health problem. For instance, if my son couldn't attend a festival because he had flu or something I wouldn't bother. I'd just say no because it's not an issue.*

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".

The group of Xhosa urban mothers of disabled children also commented that the boundary between an illness and disability is not always so clear.

> *I was thinking, it's.... a medical problem can also be a disability like if you have arthritis for many years like you also have a disability, what ever problem you might have but you can combine in two.*

> *When you are old having arthritis you fall under disabled then you qualify for that disabled grant.*

So although the boundary between health and disability is unclear, the distinction could be understood when the function or role of a person or child, is affected on an extended time period, or even permanent level.

5.2.6 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" and "It's an inability. It's a difficulty." However they agreed, "they go hand in hand." The word difficulty goes together with disability.

5.2.7 Perception of disability

Even though a person's ability to 'participate' can be used as a guide for identifying someone as disabled, this is not the full picture. Perceptions of disability can differ from person to person.

An English urban mother with a non-disabled child related;

> *I saw it [child's stuttering problem] as a disability, but the doctor told me it's not a disability to them. It's just a minor setback.*

and in contrast another mother in the same said:

> *My daughter also stutters but I don't see it as a disability because she's now in matric and has achieved so many goals with her stuttering since she was small*

but

> *For my daughter [mentioned by first mother] it's a disability for her. I feel that it could block my child's self confidence or achievement.*

Another facet to understanding who is disabled can be the comments of a community; "how society labels you" or even what a person can gain by being disabled, for example a disability grant.

> *Now I look at the disability. He's sitting in a wheelchair but he's got a wife because there's a child on his lap- and then he sits and pushes his wheelchair. But he doesn't regard himself as disabled. Only to the social services he will regard himself as*

someone with a disability.

Another aspect to describing someone or oneself as disabled relates to a person's own personality, acceptance of a condition and approach to life.

> *That is a disability [children with poor vision] for me again, but I'm sure that for someone else it's not a disability. I suppose, it is how you as a parent can adapt to a certain thing in your child's life - or accept it. I suppose that it's also how people's perceptions are about these things – how they accept certain things.*

5.2.8 Attitudes towards disability

The attitudes of the community towards children with disabilities cannot be disregarded in this discussion as it forms part of understanding of disability. 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:

> *Like the minute he starts screaming at me people shout at me that I don't teach my child well.*

> *You often find especially with the intellectual disabilities, they often squawk. People become scared especially at the movies.*

This prompted the question

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

> *Some kids you can't go in public with them. If he sees many people he is not happy, he becomes violent.*

> *Even if there is some gathering around I am reluctant for her to be part, but I know that I am hurting her, and I take her to that social gathering.*

Another mother said that people have shouted at her saying:

> *You know that your child is not like other children, you want to kill this child because you do not like him.*

A participant from the Xhosa urban group of mothers with disabled children made a strong but clear statement:

> *Someone who has disability it's obvious is not 100% like me. I am not disabled so I am 100%, so someone who has disability is not equal with someone who is normal. We have to treat those who are disabled with junior respect - that's what I think.*

Although the public or community is generally negative towards children with disabilities, there is a need for them to belong to a group. Some mothers of disabled children from the English urban group described this as follows:

> *The funny thing is that if you've got a Down syndrome and put her with a bunch of Down syndrome people she will automatically communicate. But if you put a Down syndrome child with other normal people he will soon retire before anyone because he is feeling shy and he actually doesn't know what to say.*

> *With all the sport and organizations for disabled people you can see how many people are disabled out there, they accept who they are out there.*

I've never given up on my son. He is now a tennis player and he plays so well. And he is only going to improve because now he is in a group.

If my son were to meet your son they would connect even though they have different disabilities.

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.

5.3 Responses to scenarios

In this section we report on the responses given by the participants on the different scenarios presented. The first set of scenarios presented the response given by a hypothetical person about their child and the participants were asked to imagine that person and describe what problem led them to give that response. Depending on the way in which the discussion developed in the groups, a greater or smaller number of scenarios were presented.

Table 16: Summary descriptions given by parents of disabled and non-disabled children to the scenarios of hypothetical responses to the questions

	Sipho	**Saul**	**Mary**	**Peter**
Is s/he disabled?	Disabled and not disabled	Disabled and not disabled	Disabled and not disabled	Disabled
Degree of disability	Not described	Big problem weekly with attitudes of others	Not described	Not described
Consistency between groups	Poor	poor	poor	good
English Urban non-disabled group	'Shy',	'other children are shy', weekly big problem with attitudes of others	'introvert', 'personality of child – shy',	'disability with legs',
English Urban disabled group	'doesn't want to be involved', 'can't communicate', 'Downs Syndrome'	-	Child is autistic,	-
Swati Rural disabled group	'Isolating himself',	'Saul is a single parent',	'Problem meeting and talking to people',	'Child cannot walk on stairs', 'child is disabled'.
Swati Rural non-disabled group	'has problem', 'feels comfortable alone',	'people have negative attitudes towards child', discrimination towards child,	'cannot talk and cannot use sign language', child is disabled.	-
Xhosa urban disabled group	'is disabled',	Child is disabled	'Cannot answer in class and is laughed at'	-

The responses in Tables 16 and 17 summarise the responses provided in the text below Table 17. The description of the scenarios are also provided in the text. The full scenarios can be found in the discussion guide in Appendix II. Brief synopses are given below in the detailed presentation of responses.

Table 17: Responses given by parents of disabled and non-disabled children to the questions asked of hypothetical descriptions of children with various difficulties

Scenario person (allocated disability status in brackets)	Is s/he disabled?	Degree of severity	Consistency between groups?
Joseph (unsure)	No (4 groups) and yes	Not described	Reasonable
Rose (non-disabled)	No	Not described	Good
Jill (non-disabled)	No	Not described	Good
Thomas (disabled)	Yes and no	Not described	Poor
George (disabled)	Yes	Big problem (daily)	Good
Lucas (disabled)	Yes and no	Not described	Poor

The responses to the scenarios are discussed in further detail below.

1. Sipho says his child has some difficulty in joining in community activities in the same way as anyone else.
The urban non-disabled group referred to Sipho as

> *Maybe shy, child is pushed down and made to feel that he or she wasn't capable.*

The English urban group of mothers with disabled children gave a variety of reasons from flippant ones ('It's a Christmas parade and he's Jewish') to 'He's on a wheelchair' and other reasons ranging from an illness 'cholera', or the lack of will to be there ('he doesn't want to be involved'). They also added other reasons, which included 'can't communicate', 'maybe his whole body does not want to be there.' or even 'Down syndrome'.

The Swati rural group of mothers with disabled children agreed that a child who is

> *isolating himself from other people is a problem in its own because you have to associate yourself with people.*

Swati mothers with non-disabled children from a rural area made an interesting observation:

> *I think this child has a problem, because [children] of his age do not do what he is doing. This child thinks he does not qualify to play or hang around those children.*

And

> *I think a child has a problem ...and this child feels comfortable when he is alone.*
>
> *Sipho has a problem of his child because he wants to isolate himself.*

The Xhosa urban group of mothers with disabled children related,

> *It's because her child is disabled that is why she is giving that answer, she has a problem of her child for mingling with other children in their vicinity.*

2. Saul said he has a big problem at least once a week with the support and attitudes of people towards his child.
The English urban group with non-disabled children thought that Saul's child had a problem of...

> *Not communicating with the children maybe, because some of the children are shy.*

They identified this as a big problem if it occurs "weekly"

The group of Swati rural mothers with disabled children thought that Saul did have a problem

> *Maybe Saul is a single parent he stays with his baby girl*

and

I would have a problem because people end up giving bad names for these people.

The group of Swati rural mothers with non-disabled children related,

I think he has a problem because he has figured it out that people have negative attitude towards her.

Saul has a problem that his child is being discriminated. But I think the community feels that they won't be able to hang around this child and they discriminate her.

Yes there is a discrimination in there maybe this child is disabled and Saul has a problem that the community does not want to accept that a child has a problem and *I think the community see that this child does not fit in what they do.*

Maybe this child is disabled and they feel that she won't fit to participate on what they do.

The Xhosa urban group of mothers of disabled children also thought that Saul's child was disabled,

His father has a problem because he is not accepting the problem of his child and he thinks that, the child is not welcomed by other children, because of that disability.

3. Mary said her daughter has a lot of difficulty communicating with others.

English urban mothers with non-disabled children explained that

The child could be an introvert. It could be personality also - a shy type of child. I don't really think it would be so much a case of the child being disabled.

The English urban mothers with disabled children related the reasons as being

You [Mary's child] have autism.

The Swati rural mothers of disabled children said that Mary's child

has a problem of meeting and talking to people.

And

maybe people do not give her right answers.

The Swati rural mothers of non-disabled children said,

This child gives Mary a problem because she cannot communicate with other people.

I think this child can not talk at all and she cannot use sign language.

I also say Mary has a problem if a child cannot sign language and the community laughs at this child and this child does not want to go out to the community now. All participants from this group agreed that a child who has difficult communicating with others is disabled.

One of the participants in the Xhosa urban group of mothers with disabled children personalised Mary's problem to that of her own child

> *What makes him to have a problem maybe is that, at school the teachers may ask his child a question and ask him to write it on a blackboard, and the child would not know the answer, so other children will laugh at him ...like my child... so the child would not see the need of playing with those children because they laugh at him.*

4. Peter said his son has a lot of difficulty with walking and climbing stairs.
The English urban mothers of non-disabled children said

> *Maybe his child has got a disability with his legs. Maybe he's got one leg or one crippled leg for instance.*

The Swati rural mothers of disabled children said that

> *Maybe he saw other children walking long distances so he feels that his own child has a problem since he cannot walk on stairs.*

And also

> *I think a child has a problem because I think a child is disabled since he cannot climb stairs. If a child has not problem of disability he would be able to climb stairs.*
>
> *When a child feels that she wants to do something and cannot that is a problem.*

5. Joseph: tires when walking 1 km but can walk 200m.
There was agreement between all groups, except the East London group, who felt that Joseph, had no problem and was not disabled although there was some discussion of the walking distances expected of different age children. Urban mothers with disabled children felt Joseph could have "some difficulty walking" although admitted that

> *To us sitting knowing him in a disability sector so we going to keep focusing on difficulties.*

The Xhosa urban group, perhaps with a similar bias said,

> *that's why he gets tired because he walks a long distance and he is disabled.*

6. Rose: gets depressed every 3 weeks for a few days.
All groups thought that she did not have difficulty in self-care and communicating and was not disabled and should not receive a disability grant.

7. Jill: runs around the neighbourhood with no problems
Once again, all groups, except for the Xhosa urban group, thought that Jill was not disabled and could participate fully in community activities. The Xhosa urban group said,

> *Rose does not have a problem, but when she is not feeling well she cannot do anything. When she is hurt she cannot do anything as a disabled person, or someone has said something that caused him to be hurt.*

8. Thomas: joint pain and arthritis
English urban mothers of non-disabled children thought that Thomas would have difficulty

> *because you'll get pains in the joints when you do that.*

English urban mothers with disabled children agreed that Thomas has a lot of difficulty, which would make him disabled, depending on the severity of the pain. But they related other reasons for painful joints,

> *I don't think Thomas is disabled. He could have Aids. He could have joint infection or could just be ill.*

or

He has arthritis, he has a problem. And in this case *is not disabled.*

The Swati rural group of mothers with disabled children thought,

If he is able to move his toys around, it shows that he has no problem.

A participant from the Swati rural group of mothers with non-disabled children personalized Thomas' problem and felt that he did have a problem and was disabled

because there are certain jobs that I can not do and there is no way they can cure me.

The Xhosa urban group of mothers considered that

he [Thomas] does have a problem but medical problem that can be cured.

9. George: blind and lives in a rural area

All the groups agreed that George could not see because he was blind and he had a big daily problem with the support and attitudes of people. The English urban group of mothers with non-disabled children described blind people positively:

They can read and write, they can read Braille, they can even type. They've got Braille reading and Braille typing - that is not a disability. But it's like when I was a doctor before - and then I was in a car accident. Now I'm blind, that doesn't make me illiterate. For his family it's a big problem.

The Swati rural group of mothers with disabled children made various comments about the family's attitude to George. One participant felt that

They [the family] are mistreating him.

And another said

His family is scared that he is going to get injured.

Although it was agreed that it is not the right way of treating a person, the following comments were made:

but they are protecting him from getting hurt.

Another suggested

If a family can not assist him from getting things done by himself there are people who can help.

I think they should not lock him up in the house maybe you will find that he has no stick that he uses.

The Swati rural group of mothers with non-disabled children had different views about whether George had difficulty in walking. The reasons given were

because whenever he walks there must be someone helping him.

And

I think he does not have a problem of climbing stairs but the problem is that he is blind.

The problem was described not so much as a physical problem of climbing stairs or walking but "because he is blind".

This group was quite critical of the family:

I think the family as well has a problem.

They (the family) should assist George so that he can get things done by himself.

> *And George can get used to his environment only if they show him around.*

They also commented as follows:

> *He might end up being disabled because of the fact that he is staying on one place always.*

Another participant thought,

> *His family is ashamed of him you know most of the time we people turn to hide these disabled people because we are ashamed of them. We sometimes don't even take these people for disability grant.*

The Xhosa urban group of mothers with disabled children agreed that George has a problem

> *because he is blind, so I have accepted that when someone is blind there are things that he can find difficulties to do.*

10. <u>Lucas</u>: difficulty paying attention and concentrating for more than 15 minutes.

The English urban mothers with non-disabled children did not consider Lucas to have difficulties in self-care. They agreed that he did have difficulties in remembering and concentrating, and joining community activities.

> *He will, because at the end of the day, he's going to forget the task that they gave him.*

The Swati rural mothers with disabled children did not consider Lucas to be disabled

> *He is not disabled but he forgets.*
> However if "*he cannot go to the shops, he is disabled*".
> *He is a slow learner and when going to shops he will never come back.*

In summary, the participants in the groups described people with disabilities as those whose ability to function was affected. The focus was more on the functional abilities or inabilities of the person rather than the impairment itself. The groups also highlighted the problem of the individual with a disability as compared to the public or community taking responsibility or accepting people with disabilities.

5.4 Summary

The parents of disabled and non-disabled children had no major problems with the questions proposed for the Census 2011. They provided suggestions for changing some of the questions and adding concepts that relate more for children, such as aspects of learning, and asking more about services needed and received.

Their understanding of disability focused primarily on the physical and visible aspects of functioning although they did acknowledge the mental aspects of disability. Parents of disabled children felt strongly that the attitudes of the general public are not conducive to integrating disabled children.

The participants described people with disabilities as those whose ability to function was affected. The focus was more on the functional abilities or inabilities of the person rather than the impairment itself. The groups also highlighted the problem of the individual with a disability as compared to the public or community taking responsibility or accepting 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.
Quotes are presented as given in English or translated into English by the participants. As for the parents of children groups, any edits or changes are notes in square brackets [....].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.

Similar themes are used in the analysis as for the parent groups. However, since the adult groups were many more in number, more details emerged in the analysis. The first topic is that of reactions to the questions, followed by 'What is disability?' and ending with responses provided for the different scenarios. 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

This section presents the comments made by participants in a general manner about the whole questionnaire. This is followed by comments made specifically about the core set of six questions plus the community participation and environmental questions, the detailed set of questions on functioning and the background questions. The section ends with comments made on further questions to be added or areas to be covered when collecting information on disability and functioning.

6.1.1.1 General comments about the questions:

a) Understanding and remembering:

The overall reaction to the questions by the non-disabled groups were that the questions were good and not difficult to understand or remember long enough to answer them. Although one participant from the Sotho urban group did say the following:

> *The questions are structured to target classy people - not just anyone because they are not straightforward questions; they want you to think.*

However, the general sentiment on the questions are summarized in the quotes below from the rural youth group:

Moderator: *Say what you like and don't like about the questionnaire.*
Participant: *I can say that it was simple and I easily understood the questions.*
Participant: *I also found it to be simple because it was easy to answer the questions. I didn't find any difficulties. It was okay because too much explaining takes a lot of time in answering.*
Participant; *I also liked the questionnaire.*

………

Participant: *I also found it alright because I could say my complaints*

The urban youth group echoed these in the comment "I think they are straightforward", as did the Sotho rural group in their comments "No, they [the questions] were all understandable" and "No, we think everything is fine there is no other way to change it."

b) Recall periods and distance reference:

The time periods used in the questions (last 30 days/last month, last 12 months and last seven days) did cause some difficulty for the non-disabled groups as reflected in the following quotes. The quotes suggest that people sometimes have difficulty in remembering the period asked about and possibly ignore the specified time reference.

From the Xhosa rural youth group:

Moderator: *How did you find these questions that say with "in the last seven days or in the last twelve months"? Were you comfortable with them? Maybe if they didn't give you a time frame it would not have given you a problem. Or did it?*
Participant 1: *I think it was a bit of a problem. They shouldn't have put it that way. They could have said from such a month to such a month and not the way they put it.*
Participant 2: *They could have asked it in a two weeks time frame and not in a month time frame. A month time frame seems a bit long.*
Participant 3: *I feel since this is happening now, it should only apply to the current period and not before that. They shouldn't ask us about what happened a long time ago.*

From 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.*
Participant 3: *They say 12 months, but I say daily. For instance, ... buildings and roads, and the kids play cricket in the road. The people drive like crazy over the stop streets... so that happens daily.*

From the Sotho rural group:

Those questions to me were a bid confusing to me and did not quite understands them. When you talk of those seven days one has to go back to what was I doing on that day you know so to me they were a bid boring.

The Urban English group did not experience any problems with the time references.

With the reference to seeing at a distance of 7 metres or walking one kilometre, the participants felt that a clearer reference should be provided such as suggested by one of the Afrikaans rural group participants:

> *Maybe they should say how many strides or steps so that the older people can also understand it.*

No other significant comments were made concerning the distance reference.

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.
Moderator: Were there any questions that were difficult to answer?

………

Participant: Yes, it's basically that last one. 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.

c) 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. Some of the comments related to the topics covered as reflected in the comment made in the English urban youth group in relation to asking more directly about being 'mentally challenged':

> *There is no one that is going to walk up to you and tell you that he or she has a mental disorder or problem. We understand why you do not put it in the paper. But if you want to talk about disability, it is one.*

A participant in the English urban group felt that overall the questions were rather personal.

> *For me it is, it goes more to my private life a lot, ja and some of the things I am not comfortable with them.*

In this same group some participants felt that the questions on psychological or emotional functioning were sensitive.

Moderator: Okay, did everybody, did anybody else find the questions sensitive? (silence) No, no?
Participant 1: Especially the last questions, they were asking about.
Moderator: The emotional questions, okay, 'did you feel nervous?', those questions?
Participant 1: Ja.

The suggestion was made that a 'softer' rewording through the use of an introductory phrase might make people feel more comfortable answering the questions.

> *And then also these questions at the back here, I think that they are sensitive, and some of them - in the introduction might be a good sort of, 'Some people sometimes feel a little bit nervous or unhappy, how about you? Have you ever experienced something like that?' - to make it sort of, - people feel a little bit more comfortable with those questions and say, well it is okay if you feel depressed or nervous or this or that....*

One of these participants disagreed and expressed the feeling that since the questions were about disability they did not pertain to him and hence he did not find them sensitive.

> *No, for me I didn't see anything wrong, just that there was too much towards the disabled person, for a person who is not disabled it is like a waste of time.*

The Sotho rural group did not find the questions sensitive and didn't 'think they will hurt in any way'.

d) 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. One English urban participant described the response option of 'a lot of difficulty' as meaning 'too much difficulty' and concurred with the other participants in this group that the response options were easy to use and the questions easy to answer.

The comment was made, however, by the same group, that the use of examples might clarify the question on concentrating and remembering to highlight the difference between something that might happen occasionally and not be a problem versus something that might be a real problem.

> *And this one, this question about, remembering and concentrating - I think that example that you gave there was something that could of made it much clearer - 'Have you ever forgotten where the shops is?' or something like that. I mean, I have never forgotten something like that, but I have forgotten to buy toothpaste which sort of - there is a scale of - I think maybe an example in there or something like that.*

e) Scope of questions:

There a number of comments made relating to the scope of the questions, such as what was understood to be the aim of asking the questions. One of the aspects of the scope is whether the participants who were non-disabled felt that the questions were also relevant for them or not. There was quite a strong indication from participants that the scope of the questions was disability and only for disabled people and, hence, did not pertain to themselves. Although, in some groups (e.g. the English urban youth group) the discussion itself generated a different perception of the scope.

From the English urban youth group:

Moderator: What do you think we are trying to pick up with these questions?

Participant 1: Obviously, people with disabilities. Ja, I mean that is pretty obvious.

Participant 2: I would not say people that are particularly with disabilities, I would say, it could be mainly aimed at people that have got hearing or similar problems.

Participant 3: Or older people because many adults would have problems going outside, they would prefer that they stay at home alone for short periods of time.

Participant 4: For us, it is not as M is trying to say, for us, all these questions seem, I mean, we do not take note of facing very small and insignificant [difficulties] because we are abled bodied or ordinary or whatever it might be called but it seems if weren't and we had some sort of disability, then, these questions would be more sort of evident.

………

Participant 5: I agree, I think it is aimed a lot at people with either physical or emotional or whatever disability, I do not think, for me, it does not come as a point - for me, it is not really aimed at us. It is aimed at people who have a disability of some sort.

Participant 6: I feel the same.

Some participants in the English urban youth group acknowledged the breadth of the scope of the questions but suggested that because of this breadth, the scope should be narrowed.

> *I think we can narrow it down because you cannot account for everybody's disability. The questions that are brought here, they basically cover everything that possibly could be wrong.*
>
> *I think this covers everything, but personally, I do not feel that it is targeting particularly disabled people. I mean, some of the questions like, "Do you have difficulty maintaining a friendship"? I mean, suppose you answered yes, does it mean, you cannot park in the same parking, you know what I mean? Majority of it is focussed on disabled people, I mean, things like washing your body, I mean, that is for someone who has difficulty in doing that, but general questions like income, [work] status, emotional status all those things, I mean, that could be anyone. I think it is from that aspect that it covers everything. The normal persons, the working persons, till the disabled people.*

One of the participants in the English urban adult group expressed the opinion very strongly that the questions were about disabled people only and that he was not targeted in anyway since he is not disabled.

> *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, because most of the questions are for, are tended towards the disabled person, even those questions that says, do you have difficulty feeding yourself – for me ... for a disabled person I don't think that it is irrelevant in a sense that maybe the aim of that research is to see how far the disabled are supported or maybe how many are there.*

A comment by a participant in the Sotho urban group raised an interesting insight into what the scope of the questions might be in terms of general levels of productivity. It could be that the comment only refers back to the employment status questions, or it could be broad in its perspective in investigating the relationship between productivity and disability.

> *The way I see it is that they want to assess productivity and I wouldn't say for citizens or people but to see how able they are to contribute to the economy or contribute to social well-being.*

Some comments were made as to the usefulness of asking these questions.
From the Sotho urban group:

> *I think that's the most important thing because at the moment Government cannot do proper planning because they don't have the correct figures of blind people or deaf. This could help because then these people get to voice their needs*

Similarly from the Sotho rural group:

> *According to me, I think it will help people because this is their need, so the government should know that when we count people, there are so many blind people and so on.*

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

As indicated in the introduction to this report, one of the aspects that we need to understand in how people respond to questions on functioning and disability is the frame of reference that they use in responding. Do people consider a specific occurrence of an activity or an average of all occurrences or even only the best or worst occurrences of that activity? The quotes presented here provide some indications as to the frame of reference used by the participants.

When asked what people took into account in responding and how they decided how to respond, the responses indicate a wide variety of factors and in effect different frames of reference.

A participant from the Afrikaans rural group said:

> *It would depend on the circumstances and what mood you are in. I'm like that!*

The English urban youths said the following in response to the question on how they decided or whom they compared themselves to in giving their answers:

> *Personal opinion.*
>
> *Ja. You compare it to yourself.*
>
> *You formulate your answers by – you personally feel and know based on your experiences, your own knowledge, your own attitudes towards outside world.*

One English urban youth described how he initially had quite a narrow frame of reference, i.e. that difficulties walking and climbing stairs could only be due to a physical impairment, and only thought about other reasons a while after he had answered.

> *The problem is, we did not realize that when we answered on that stairs question, it only struck me a couple of minutes later and I did think about it. There are numerous reasons [why a person may have a difficulty with climbing stairs].*

A comment by a participant in the English urban adult group indicated that the context of a health problem was being considered when responding:

Participant 1: Ja, I also picked that up as well because my problem with the physical environment is traffic……It is a big problem.
Moderator: And have you marked it as a big problem?
Participant 1: No, I said never (laughter), because I thought that you were talking about disability and physical environment so I thought okay, you were wanting, you don't want my traffic problem.

Another participant from the same group commented on the context of 'disability' being crucial in the responses that he/she gave. The term 'disability' seems to set the frame of reference for this person's responses.

Participant 1: I think it is much easier to answer these physical, you know this is it difficult to climb steps, that is easy for me to answer, but difficulty in remembering or concentrating, you know I mean, yes, I often have, forget this or that, but is it important or is it not important, so within this context, within a health context and within an disabled context I thought, well no, well sometimes you forget to buy sugar at the shop.
Moderator: Ja, what are you comparing yourself too?
Participant 1: Exactly that is, I don't know. I sat there and I thought well I am now comparing myself with what I heard this group was about sort of a disabled context, that is what I was comparing myself too.

This participant goes on to say:

> *But if this question was in a Census and there wasn't so much focus on disabled or health whatever, I might say yes, quite frequently, because I forgot to buy toothpaste*

> *yesterday, or I couldn't concentrate, you know it is sometimes, you know it is very vague, some of these questions. It needs to be put into some sort of context because in different contexts you are going to answer differently.*

This view is shared by another participant:

> *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.*

The frame of reference as determined by the term 'disability' did not limit the responses given by another participant in the English urban adult group, highlighting the individual nature of what a respondent uses as their frame of reference:

> *When you look at this question, the questionnaire, and you focus on yourself, a lot focuses on the issues that it is about the disabled person, there are a lot of questions that you can answer and you can relate to them so for me, even though it is for disabled people, but I could answer it, and I could, I could get to know myself from the questions that you know, it wasn't like, it was specifically really meant for disabled person, cause I could answer the questions as honest, I didn't picture myself as a disabled person but I answered as a normal person.*

6.1.1.2 Comments on core set of six questions on functioning

There were not many comments made on the six core questions covering the domains of vision, hearing, mobility, self care, communication and cognition or the seventh question about community participation. General comments about the questions have already been discussed in the 'General comments' section above. The main themes that arose in participants' comments related to the use of the term 'disability' as a context setting notion and the focus on the physical sense of most of the questions rather than considering other reasons for having difficulties which, at face value, seem to be physical difficulties. Both these themes are important to note when determining the frame of reference used by participants in responding to the questions on the Census. One participant from the English urban youth group highlighted the focus on a physical reason for a difficulty. He showed that once he had answered the question he then thought more about other possible reasons for having difficulties in walking and climbing stairs particularly.

Moderator: *So the words concentration and remembering did not do it for you?*

Participant 1: *No...concentration is a mild way of putting it across because that would be the best way to ask the question but ...they do ask questions like climbing the stairs, they might not be physically challenged or disabled or with broken limbs or whatever it is, but the might have a phobia about stairs, that is a mental disorder which results in their fear of climbing the stairs. But obviously, that was not asked so much.*

……

Participant 1: *The problem is, we did not realize that when we answered on that stairs question, it only struck me a couple of minutes later and I did think about it. There are numerous reasons [for having difficulty walking or climbing stairs].*

The first theme of using the term 'disability' to set the context has been highlighted in quotes provided in the preceding section on the frame of reference as well as the following quote from the English urban adult group.

> *I saw that one [reference to health problem], but I still have a problem, still on section B, number 15 [question on concentrating] and 18 [question on participation*

> *in community activities], I don't know how you can prove that it relates to disability, because you can have difficulty remembering and concentrating just because of stress or something or number 18 as well, if you are very shy it does not mean that you are disabled. So I don't know why, that question, maybe it has to do, be explained a bit.*

The questions on the physical and attitudinal environment raised some concerns in relation to the context that was being asked about. The one quote given above from a participant in the English urban adult group highlighted the fact that she experiences many difficulties with her environment but since these are not due to a health problem she did not respond positively to that question. The quote is presented in the preceding section on the frame of reference. This has important implications for how the questions are presented if responses reflecting difficulties due to a health problem are to be provided rather than difficulties not due to a health problem.

6.1.1.3 Comments on non-core set of questions on functioning:

The main comments made about the non-core questions on functioning were those concerning emotional functioning. The comments made by participants suggested that these questions (cf Q42 – 46 on questionnaire in Appendix I) raised concerns for the participants. The main themes raised were the common occurrence of experiences like depression and whether this warranted giving a positive response or not to the question.

The comments made by the Sotho urban adult group stressed the fact that emotional problems are 'normal' occurrences in life and they, therefore, were reluctant to respond as having some difficulty, probably because such a response would be seen as indicating 'disability'.

> *That's why we said that when it's translated to Sotho then it's difficult to understand because when you start with English it says "Are you nervous sometimes?" and according to me being nervous is normal. Everybody gets scared especially when you are driving and you see a truck in front you become nervous or unsettled.*

Similarly the English Urban adult group expressed the dilemma about whether depression is about being disabled or not.

> *……[My employer] can say that they are restructuring today and me and J get letters of retrenchment, we are loosing our jobs, it means that our salaries are gone they are out of the window, but it doesn't mean if I am going to, you know, just go home and get into my blankets and sleep and cry and J is, you know, from tomorrow going to start knocking at doors looking for a job. We are both depressed you know for the same reason and it doesn't necessarily qualify me to be disabled because J is also suffering the same thing.*

One participant in the Afrikaans rural adult group reflected on the difficulties in answering these questions:

Moderator: *What was difficult? Was it difficult to remember how long you were feeling like that - or what was difficult? Was it to be able to recognise that I felt like that or not.*

Participant : *Ja, to recognise it. To think back for that month and to remember how I was feeling. What I really want to say, it's difficult to put it down on paper.*

6.1.1.4 Comments on background questions

The background questions that raised the most concerns and problem were the questions on employment. While these were not in fact being tested as such, the comments are nevertheless presented here. Some of the comments indicate confusion, questions that are too long and difficulty in working out how to respond given the options.

From the Sotho urban adult group:

> *...[the employment question is] not very clear, you know most of the times when you fill in forms they do ask for place of employment but this one can be confusing at times.*
>
> *...[N]umber 11.5 [one of the employment questions] it's too long by the time you finish reading it you can't remember a thing.*

From the Afrikaans rural adults group:

Participant 1: *With the work opportunities... With the formal and the informal... like not everybody is working. Some people are unemployed. It does affect you a little bit when you are sitting at home, especially for someone like me who is doing seasonal work and am sometimes at home and sometimes at work.*

Moderator: *Does it embarrass you a little?*

....

Participant 1: *I would say it's just a little bit... not personal... but how can I put it....Embarrassing. For instance, I'm a fisherman and I catch snoek. Now, you can't always get snoek, and here they're asking: are you working or unemployed? With snoek fishing it's not like that. Look, on a day like today we can't go to sea. Now, I'm a fisherman and nowhere does it say, while the weather is good. They only ask, are you a fisherman or do you catch fish - and so on. So it's difficult to answer that one directly. Another one asks about your income. Now how can you say that you've got full-time employment when the fish isn't always there? That throws you out a little bit.*

From the English urban adults group:

Participant 1: *And according to like myself, I am not unemployed, but I work on contract it is like I am confused what to answer, because I am working, I am on contract and it becomes a problem for me to say I am unemployed, you know, I can say that I am on contract.*

Moderator: *That is right, it comes out later.*

Participant 1: *I can answer in 11.14 there is that, if I say that I am unemployed or I don't have an option, but there is an option there for me on 11.14, I can say that I am on contract, but the thing is that I cannot answer here, [if] I never answered on 11.3.*

Moderator: *Because it was unclear to you.*

Participant 1: *It was unclear to me*

Participant 2: *I would also agree with that, I also had a question mark, registered as what? You know, is it UIF or as I don't know, that is very unclear.*

It is clear that these problems could to a large extent be solved by ensuring adequate clarifications and information by the interviewers.

6.1.1.5 Suggestions for further questions

There were few suggestions for additional questions or areas to be asked about on surveys or the Census. The main theme of comments was to include additional information on mental health issues.

From the English urban youth group:
Moderator: *Any questions that you feel were are leaving out and it is very, very important?*
Participant: *I think you emphasize too much on people's mental problems and the reason I ask is, the majority of the response are of the people with physical problems. I mean, if you have a mental disorder and you ask about social and things, to me, that did not emphasize that much...if you are mentally challenged.*

6.1.2 What is disability?

Disability is seen in many different ways by the different participants and the main themes arising from the non-disabled groups relate to aspects such breadth of the definition (including a marginalised group only or affecting all people), the physical and visible nature of disability, permanency of the condition, disability as activity limitation, level of independence, the individual as the locus of the problem and source of change, disability as a loss of participation in social life, ageing and disability, difficulty versus disability, and lastly disability and health. These are described below in relation to quotes from the different groups.

6.1.2.1. A universal versus minority view of who is disabled

The view of what disability is can be seen either as something that is about a small minority group of people with the world's population being divided into disabled and non-disabled people, or it can be viewed as a feature of everyone and that a whole population can be described in terms of their functioning and the description would be a continuum from full functioning to full disability. The views of the non-disabled participants varied between these two views, although 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 within themselves of the universality of disability.

The Sotho urban adults and Xhosa rural youth expressed a more universal notion of disability.
From the Sotho urban adult group:
Participant 1: *One can say disability means everyone is disabled up to a certain level when we will say this person is crazy but all of us are crazy. So I think it's applicable to everyone of us.*
Moderator: *Yes it all depends on levels.*
Participant 2: *Yes levels of craziness because naturally we are crazy.*

From the Xhosa rural youth group:
Participant 1: *A disabled person in a wheelchair can't climb a tree.*
Moderator: *If there's something I can't do am I disabled?*

Participant 2: If it comes to a push we are all disabled because we all have things that we can't do.

The English urban youth expressed both the minority as well as the universal view of disability. Starting with the minority perspective:

> *When I think of disabilities, I always think of people in wheelchairs or blind. I do not actually think of those people who cannot see in a distance or with emotional or social problems. So, it [the focus group discussion] does make me realize that the disabled people are not only those that are in wheelchairs or who cannot walk or with physical problems.*

And moving onto the universal perspective:

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

The notion of universality is important as a concept in understanding how the proposed questions are being answered. If people feel that any type or problem can be noted as some degree of difficulty, then the questions can be seen as identifying not only the more severe 'traditional' disabled population. A participant in the English urban youth group expressed the following view:

> *To add on, I think there are some of the abled bodied people who have some sort of mental attitude, who have difficulty in remembering things, people with tension disorders, something like Alzheimer's disease or something like that.*
>
> *The point that I was going to make is that, it is the scope that they [the questions] have given us, it is large, that sort of, it is broad enough to say, okay, a person is born with a disability, a person has had an accident that has made them in some way impaired, a person has contracted an illness and it resulted in them becoming slow, it could be [congenital] or something like that, so, it can kind of, I mean, it is very broad.*

While there was some indication by some of the participants that disability is a universal notion, the majority view remains the notion of 'disabled people' being different from 'normal people' as expressed by a participant in the Sotho rural group in response to 'what is disability?':

> *Well it's a lot of things - it is someone who is not able to do things as normal people do. It can be a lot of things like blindness (etc.) and some are born with it, like my daughter she can walk, hear but she can't see.*

6.1.2.2 Disability as physical and visible

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

From the English urban adult group who said the following in response to the question 'who is disabled?'.

Participant 1: I think it is someone who is disformed, deformed

………

Moderator: You wouldn't think that a person who has any psychological problem is disabled?

Participan 1: No.

From the Afrikaans rural adults:

> *According to me, 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.*

And

> *Ja, I would say a disabled person is someone who can't help himself because of his disability. Some people are only slightly disabled...*

From the English urban youth:

Moderator: *What does it mean to be disabled?*
Participant1: *Someone in a wheelchair.*
Participant2: *Blind.*
Participant3: *Someone with mental problems.*
Participant4: *I think it [is] varied, very much. For others it can be small or on large scale. Something small like it could be small sight problem or complete blindness or small, slight disability with a hand or one hand or not being able to use both hands or something like that.*

This last participant (P4) expresses the notion of different levels of severity and touches on the notion of universality.

A further comment from the English urban youth group reinforces the notion of disability being something visible:

> *......so I think we, it is, most of us think that disability is something that you see with your naked eye and I don't know how we are going to change that, because, yes a person who has a mental problem – it is obvious because he is not doing the normal things that people do. He talks to himself, you know, that person is obvious but a person who is normal, you are looking at him and he is normal you can never consider disabled, so.*

Some participants indicated that it could be more than just a visible and physical problem. As indicated by one Sotho urban adult participant

> *Disabled doesn't necessarily mean physically only - it could be mentally as well*

And a participant from the Xhosa rural youth group:

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

The Sotho urban adult participants also highlighted the many different types of impairments that could be termed 'disability' but these tended to be ones that are easily identifiable.

Participant1: *It also has many dimensions, I mean when you talk about disabled, what is the meaning of disabled? Disabled can mean a person who cannot perform or a person who is physically impaired. It can mean a person who can't even communicate, so it has so many dimensions. So when you talk about disabled it's so broad.*
Participant2: *Yes, because some of the disabilities are hereditary, you are born with but some were probably born normal and became involved in a car accident and all of a sudden I cannot go to work because I'm on a wheelchair, then I am disabled because I cannot use my body.*

6.1.2.3 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.

A participant from the Sotho urban group expressed this notion of 'alteration' with a second participant suggesting that this alteration comes from the person's motivation:

> *Moderator:* *So if a person has a problem but the problem can be corrected somehow, can we really say that person is disabled?*
> *Participant 1:* *No they are not disabled.*
> *Participant 2:* *Such a person needs motivation.*

Another participant in the same group comments that even if there is support the disability status remains:

> *There's a permanent disability even if you can have support, that permanent disability makes Government to be your support system.*

A participant in the Xhosa rural youth group adds that when something is missing it's the 'missingness' that determines the disability rather than the fact that the person can run very well. This participant is looking at the loss of a limb, i.e. impairment of body structure, as disability.

Participant 1: *There's a man in the SA athletics team. He has no legs but he runs faster than a guy with both legs.*
Moderator: *Is that man disabled?*
Participant 2: *Yes. There's something missing in his body.*

A participant in the Xhosa rural youth group did raise the possibility of disability being temporary if during that period the person was not able to do things for him or herself.

> *Moderator:* *If a person has a bunion under his feet, is that a disabled person?*
> *[All talk at the same time.]*
> *Participant 1:* *A bunion is not an illness but it's not curable.*
> *Participant 2:* *I think a person is disabled if at that particular period she can't do some things for him/herself.*

The possibility of a temporary disability was raised by a participant in the English urban adult group but was related to the allocation of temporary Disability Grants to people with illnesses such as TB or HIV where the situation could change – cure for TB or increase in CD4 counts for HIV.

> *As you had there when you were discussing, that is where I got the information from – it is like, when they declare you disabled they need to declare you whether you are permanently disabled or are you temporarily disabled. Now with HIV/AIDS and TB and stuff you get people getting TB for only six months and they get a disability [grant], and they are declared disabled for that time you are disabled, because for that time you cannot do anything for yourself.*

And more generally by the same group:

Moderator: *Does everybody agree that disability can be temporary and come and go?*

Participant1: *Ja.*
Participant2: *Ja.*
Participant3: *Depression for instance you wouldn't know when you are going to be fine, it could take you three months or two years, and as I say I know some people and they have been depressed for years, there is nothing that they can do for themselves, so I agree with her.*

Further discussion in the English urban adult group raised the issue of duration as being a determining factor in deciding whether depression can be termed disability or not.

> *I think again maybe [tape unclear] we can also put [tape unclear] on there, because sometimes we are depressed but because we are depressed does not mean that we are disabled. Maybe you are depressed for that week because something happened to you, but that does not mean that you are disabled, but sometimes that depression is long [tape unclear]. Maybe it can then be classified as disabled. So maybe it can just be a duration, for maybe three months.*

6.1.2.4 Disability as activity limitation

In the introduction the description of disability comprised three levels of difficulty – body, person and societal. This section looks at the notion of disability as being an activity limitation. The use of this notion by participants provides some indication as to the level of description that is considered by the participant when they responded to the questions. The main points about the notion of activity limitations that are made by the participants are around the permanency of the condition and the fact that the difficulty remains no matter what support is provided.

From the Sotho urban adult group expressed the fact that the difficulty with walking remains even with the use of a wheelchair:
Moderator: *But you can get around in a wheelchair.*
Participant: *The remedy is the wheelchair but the problem is that she is still disabled, so do understand now when I say it's a broad concept.*

From the Xhosa rural youth
Moderator: *What about a person who is crippled but can [go] anywhere he wants to? Can even be involved in sports like swimming? Can we say such a person is disabled?*
Participant 1: *That person is disabled because there are things he can't do as a cripple.*
………
Moderator: *If a crippled person can go around and look after sheep or cattle, is he disabled?*
Participant 2: *If we are walking with a crippled person and we are being attacked, he won't be able to run.*
Participant 3: *Also that crippled people can't walk a distance without resting a bit. The crippled leg gets tired and needs to be rested.*

The English urban youth described the activities that a disabled person would not be able to do:
Participant 1: *Day to day, washing, walking, read, like things that are required like brushing your teeth, taking care of yourself, going to the shops etc.*
Participant 2: *Unable to do a task.*
Participant 3: *Relying on others.*

………

Participant 4: Being unable to do certain activities. The day to day normal activities.

A participant from the English urban adult group describes when a person can be called 'disabled' based on whether the person has activity limitations or not.

> *I think the moment that any disability, that say for instance depression sort of alters your normal functioning as a mother, as a person, as a worker whatever, I think then I would classify somebody as disabled, and over I mean, I am also not talking about two days or three days, maybe then, over a certain period say for instance six months or something like that, then I would say that person was disabled.*

6.1.2.5 The individual as the locus of the problem and source of change

Related to the notion of activity limitations is that of the problem being the individual's responsibility presumably as the activity limitation describes functioning at the person level. This notion was expressed most strongly in relation to depression and whether people have a choice as to how they are functioning.

The participants in the English Urban youth group discussed the issue of choice and implied that a disabled person does not have the choice to change whereas the non-disabled person does.

Participant 1: You have a choice if you are an introvert. You can still go out and meet people if that is what you want.
Participant 2: And a disabled person is limited.
Participant 3: And there are things that a disabled person cannot do, like chores.

This view was further reflected in the comments by a participant in the English urban adult group in relation to depression specifically:

Participant 1: But can I also say, say for instance six months after the time you are still depressed, you still feel bad, you have been to doctors you take your medication and they can't help you, you still just feel so depressed you just don't want to go out of your home.
Moderator: Would that classify you as disabled or not? (laughter)
Participant 1: You are not disabled, you just don't want to get out of this thing that you are in.

And by another participant from the same group:

Moderator: You think you make a choice to be depressed or not to be depressed?
Participant: Well you can't choose to be depressed really but you choose not to help your situation, you know what I am saying, you don't choose to be depressed, you choose not to help yourself in a desperate situation.

A participant form the Xhosa rural youth group described this issue of choice as follows:

> *A disabled person is not one who doesn't want to do things for himself but one who is not able to.*

6.1.2.6 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. This section brings together comments made with regard to levels of independence as a factor in deciding whether someone is disabled or not. Some of the comments also raise the issue of the criterion for disability being 'unable to do entirely', such as the comparison made between a person who is disabled versus one who is only overweight in their ability to climb stairs.

From the Xhosa rural youth group:

Moderator: *How would you describe a disabled person? What kind of a person is that?*

Participant 1: *Somebody who can't do anything for himself.*

………

Moderator: *Okay, a wheelchair bound person has difficulty going up the stairs. But an overweight person has difficulty going up the stairs too. Does it mean he is disabled?*

Participant 2: *An overweight person can go up the stairs even though he might take a longer time but a person in a wheelchair won't be able to.*

…………

Moderator: *What about a person who is blind but is able to do things like cooking and all other chores at her place?*

Participant 3: *That person is disabled. She can only do things at her place because she knows every corner of the house but she can't do things that other people can do outside their houses.*

This last comment reflects on the ability to do things in a familiar environment versus an unfamiliar one where the person loses their independence once they go into an unfamiliar or unadapted environment. This brings the societal level of functioning into the picture.

One participant from the English urban youth group also reflected this inability to do things for oneself.

> *I would definitely classify them as disabled. They rely on other people to help them.*

And similarly from the Sotho rural adults who said the following:

Moderator: *So you say if that person can do things for himself then he is not disabled.*

Participant: *Yes, he is not disabled.*

And from the same group:

> *It [disability] is someone who cannot get assistance anywhere or someone who cannot do anything for himself/herself. I also have a daughter who was born normally with everything but when she was a year old we realised she could not walk or talk and now she is three years old. I think that kind of person is disabled because even if she gets assistance she still cannot do anything for herself.*

6.1.2.7 Disability as loss of participation in social life

One of the important features of being disabled is often the inability to be involved in social life and being socially excluded not because the disabled person desires this but because of barriers in society that prevent the person from participating, such as inaccessible physical environments, negative attitudes of people, and so on. 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. Participants from three groups made comments on this aspect:

From the Sotho urban adult group in response to the question 'Who is a disabled person?':

> *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.*

From the English urban youth in response to 'What is disability?' although the reference here could also be to a psychiatrically ill person showing anti-social behaviour:

> *Also, I think it has to do with social problems.........I think that would be a disability on its own.*

From the Sotho rural adult group where the participant made comment that seems more positive saying that disabled people can be part of social life but then qualifies by saying they are not seen as disabled.

Moderator: *So what about a blind person?*
Participant: *Yes, they are not disabled because they can do things with people.*

6.1.2.8 Ageing and disability

Older people experience significant difficulties in doing various activities. However, they rarely consider themselves or are considered by others as being disabled. Of interest to this study is how older people are seen in relation to disability or not. These few comments shed some light on this issue from the non-disabled participants who are either youth or adults below the age of 60 years.

One participant from the Afrikaans rural adult group described an older person as having difficulty but did not go on to specify whether this person would have a disability.

> *When a person gets older, your limbs also stiffen up, and it is difficult for an elderly person to lift his legs above a certain height. So a lot of elderly people battle with climbing stairs.*

While one English urban adult felt that because of being an older person the person described in the Joseph scenarios would not be problems with walking.

> *My instinctive feeling was that this [in response to Joseph scenarios] is an older person. So, therefore, I don't think he has got problems walking, no, no, climbing steps within reasonable [time]... three, maybe two storey he would be able to do. it.*

6.1.2.9 Difficulty versus disability

The difference between difficulty and disability was not uniformally 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.*

6.1.2.10 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.

From the English urban adult group in response to 'what is a health problem?':

Participant 1: I think it is a problem that you have on a day to day basis.
Participant 2: 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.

Participant 3: For me health is more about constant coughing.

Or 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:

Moderator: So you have separated health from disability as well? So health problem is not related to being disabled, so you can be healthy disabled person, is that what you are saying?

Participant 1: That is what I am saying.

………

Participant 2: Ja, I agree with that, a disabled person does not necessarily mean he is not healthy, cause I mean, I think health and disability are two different things.

Participant 3: Maybe we should ask ourselves the question, what is disability? What is it? Because if your mind is not working properly, you can say that you are disabled because there is nothing that you can do. For example, like let's say depression - I think people who are staying at home and not working because they are depressed for years, so what is that?

Participant 4: That falls under the health.

However, one participant from this English urban adult group did feel that there was a causative link between health and disability

> *I think that sometimes disability and health can be linked together because, in most cases someone can be found disabled because of a… for instance you can be involved in a car accident and then after some time you are found in a wheelchair, you are disabled because of a health problem.*

And this is reinforced by another participant responding to the preceding comment:

> *I think that I agree with [participant in preceding quote], because [tape unclear] it is because of something that is happening in your body, I think they are linked, [tape is unclear] and then become disabled, it means that health and disabled is linked.*

Closely related to the issue of health and disability is that of chronic illness. The common view (although incorrect) among the poorer sectors of the South African population is that one can be eligible for a disability grant merely because of having a chronic illness such as hypertension, diabetes, asthma or HIV/AIDS. Some of the comments made by the non-disabled participants reflect this and also shed light on how the relationship between disability and chronic illness is perceived. In relation to HIV/AIDS the participants from the Xhosa rural youth had this to say, although the notion of 'naturally disabled' is not explained:

Moderator: Are people with HIV/AIDS disabled?

Participant 1: No.

Moderator: But they also get the disability grant.

Participant 1: They are not naturally disabled but because of their condition they are said or taken as being disabled.

Similarly a participant from the English urban youth group had this to say about diabetes although his use of the terms 'disability', 'physically challenged' and 'disabled' suggest some confusion in the understanding of these terms:

> *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.*

The issue of depression came up quite frequently triggered by the scenarios on 'Rose' which talked about depression. The general sentiment was that depression is not a disability but something that most people experience, as expressed by participants from the Xhosa rural youth group:

> *Moderator: So, if you are depressed you are not disabled?*
> *Participants: No.*

And from a participant from the English urban youth group:

> *Though I don't agree that a depressed person can be disabled. I don't agree there.*

The English urban adult group reflected on this issue of depression further and commented as follows:

Moderator: So when do you think that that depression becomes a disability?
Participant1: When it takes longer.
Moderator: When it takes longer?
Participant2: No, I think it is when patients need professional [assistance].

A participant in this same group went onto describe when depression might be seen as a disability:

> *I think the moment that any disability, that say for instance depression sort of alters your normal functioning as a mother, as a person, as a worker whatever, I think then I would classify somebody as disabled, and over..., I mean, I am also not talking about two days or three days, maybe then, over a certain period, say for instance six months or something like that, then I would say that person was disabled.*

6.1.3 Responses to the scenarios

The scenarios were presented in two ways:

- as a hypothetical response and the participants had to describe the person who would give that response,
- and as a scenarios describing a hypothetical person and the participants had to give the responses they think the people described in the scenarios would give to the core set of questions proposed.

Because of the very individual nature of each group and the direction the discussions took in each, not all the scenarios were presented or discussed in the same level of detail. Thus some groups did not have responses for some of the scenarios. This applies to both Tables 18 and 19 below.

The responses given suggest that for the scenarios on participation in community activities (Sipho) and support and attitudes of others (Saul) the participants did not necessarily retain the context of a health problem and were rather describing people that have difficulties not necessarily related to a health problem. For the scenario on communication (Mary) people were varied in their descriptions across the groups. The scenario on a lot of difficulty with walking and climbing stairs (Peter) elicited consistent responses in terms of the physical difficulties described although it was not limited to a physical difficulty – one group described Peter as having a phobia. The scenario on remembering and concentrating (Lena) generated descriptions that correctly indicated no source of difficulty. However, the point was made by the English urban youth group that while she might have no difficulty in remembering and concentrating, she might well have difficulties in another domain of functioning, such as being blind.

Table 18: Descriptions given by non-disabled adult participants to the scenarios of hypothetical responses to the questions

	Sipho[2]	Saul[3]	Mary[4]	Peter[5]	Lena[6]
Is s/he disabled?	Not clear	Not indicated	Not indicated or unknown	Could be disabled	Not disabled
Degree of difficulty	Not clear	Not specified	Not specified	Not specified	Not specified
Consistency between groups	All indicated something about shyness or low self-esteem	Varied descriptions	Wide range of descriptions from deaf, blind to shy	Some consistency in physical difficulty but also indicated a phobia	Some consistency in describing a physical difficulty
English urban youth	Possibly wheelchair user; not necessarily disabled	-	Could be blind; don't know if disabled	Is disabled; has difficulty walking	-
Xhosa rural youth	-	-	-	-	-
Sotho urban adults	Isolation, shy, could be disabled	He behaves differently	-	Is a coward; has arthritis or a phobia	-
English urban adults	Shy or physically disabled	Need more information; could be disabled and others are not helping him	Deaf	-	Has disease – depression or amnesia
Sotho rural adults	Unfit, low self-esteem, shy	-	not clear what her problem is	-	Has no problem
Afrikaans rural adults	Something preventing him from participating	Second language problem or severely disabled and bedridden	Shy person	Problems with knees or feet; lack of assistive devices	

For the scenarios given in Table 18 there is not an allocated disability status, but those in Table 19 do have an allocated disability status.

In Table 19, only those scenarios that were discussed by two groups or more are included.

The consistency of response between the groups (and even within the groups) varied across the different scenarios. Those that were relatively clear (e.g. Joseph, George and Lucas) in the type of difficulty the person has, also produced good consistency across the groups. The variations that were noted were between 'no' or 'unsure' disability status and 'no' or 'some' difficulty. The scenario that produced inconsistent responses between the groups was for Rose and this one dealt with the issue of occasional depression, a topic yielding significant comments across most groups as discussed above.

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[2] Sipho – Difficulty joining in community activities
[3] Saul – problem with support and attitudes of others
[4] Mary – Difficulty communicating
[5] Peter – difficulty walking and climbing stairs
[6] Lena – no difficulty remembering and concentrating

Table 19: Responses given by the non-disabled adult participants to the questions asked of hypothetical descriptions of adults with various difficulties

	Joseph[7] (Unsure)[8]	**Rose[9] (non-disabled)**	**Thomas[10] (disabled)**	**George[11] (disabled)**	**Lucas[12] (disabled)**	**Alison[13] (non-disabled)**	**Bongi[14] (unsure)**
Is s/he disabled?	Mostly 'no' and one unsure	Yes and no	Yes but one group said 'no'	Yes	Not specified	'no' and 'perhaps'	Not specified
Degree of difficulty	None to some	None to some	Varies but mostly 'some' to 'a lot'	Varies for walking; big daily problem with attitudes	Varies for all 3 questions – between 'no' and 'some'	'No' and 'Some'	'no' to 'some'
Consistency between groups	good	poor	reasonable	Good on attitude question; poor on walking question	Good	reasonable	reasonable
English urban youth	No and some difficulty walking; Not disabled	No difficulty with self care; is disabled	A lot of difficulty walking and community participation; is disabled	A lot of difficulty walking; a daily and big problem with attitudes of others; is disabled	No or some difficulty in self care; difficulty in community participation	Some difficulty in self care; may be disabled	Some difficulty with self care; no and some difficulty in community participation;
Xhosa rural youth	-	No difficulties	Not disabled	-	-	-	-
Sotho urban adults	Not disabled	Difficulty with communication; not disabled	Has an illness; some difficulty walking	-	-	No difficulty in self care; difficulty in walking; not disabled	-
English urban adults	Older person so not a difficulty; some difficulty in community participation	No difficulty with self care; no communication difficulties	some difficulty walking	-	No difficulties	-	No difficulties
Sotho rural	Some	Has	Cannot	-	No	-	-

---

[7] Joseph – gets tired walking 1 Km

[8] The disability status in brackets is that allocated at the outset when writing the scenarios and is allocated in the same manner that the disability status was allocated to the focus groups.

[9] Rose – occasional depression

[10] Thomas – pain in joints especially mornings

[11] George – blind and living in a rural area

[12] Lucas – poor concentration

[13] Alison - overweight

[14] Bongi – slow in getting dressed

adults	difficulty walking	difficulty with self care and communication	walk; no difficulty in communityp artici-pation		difficulties		
Afrikaans rural adults	Difficulty walking; unsure about disability status	No difficulty and responses varied from 'definitely disabled to not disabled	Yes has a difficulty with walking	No difficulty walking; difficulty seeing and daily big problems with attitudes of others.	No difficulty in self care or community participation; difficulty with concentration	Some difficulties in self care and walking	Has difficulties with community participation

The other scenarios (Thomas, Alison and Bongi) produced reasonable but not good consistency in responses. This is probably due to the more vague nature of the difficulties described for each of these three scenarios.

6.1.4 Summary of points raised by non-disabled groups

The non-disabled group found the questions generally easy to answer and did not raise any significant problems with any of the questions. The response options were felt to be easy to use. The comment was made that some more examples would make the question on concentrating and remembering easier to answer. The time references were seen as problematic to some extent, as people felt they could not remember for the full period and were not clear on whether they should respond about every part of the period or give an average. The questions on emotional functioning were the only ones that were seen as possibly sensitive. These questions also raised quite some discussion on the whole issue of depression and what is normal or not and when do emotional difficulties become disabilities.

The questions on employment were seen as complicated and the response options were not always understood well or did not fit what the person thought they should answer.

The frame of reference used by most of the respondents was significantly affected by the use of the term disability in the early part of the questionnaire. There was a strong focus on responding at the person level rather than taking into account all the different environmental and social contexts of the person. The context of a health problem seemed to be noted but not always taken into account.

The participants' understanding of disability varied between one of a minority group versus a universal perspective. The notion of disability being a visible and physical characteristic was a strong theme in most of the groups although there were also a number of comments that go beyond this characterisation. Disability is seen largely as a permanent feature of the individual and not changeable through any intervention. The focus of the comments was on the person level of functioning or activity limitations with little acknowledgement of the role of environment in creating disability. The notion of choice was a significant characterisation of the difference between disabled and non-disabled people with disabled people not having a choice about whether they can do an activity or not.

Independence is an important factor that seems to determine if a person is disabled or not with disabled people largely being dependent on others to assist them with doing activities. A disabled person is seen as not being able to do anything for themselves.

The relationship between health and disability is such that the two are seen as separate, although some participants did highlight that a health problem is often a causative factor for disability. Chronic illness such as diabetes and HIV/AIDS were not seen as disability.

The responses given to the scenarios varied across the groups and sometimes within groups as well. This highlight the many different ways in which disability is understood as well as indicating that the less 'visibly' clear the scenarios the more likely it is that the responses were not consistent.

6.2 Analysis of responses from 'Disabled' groups

This section presents the results from the nine focus groups with participants who were in groups allocated as disabled. Eight of these were indicated in the distribution of the groups in the tender proposal and the ninth one was the pilot group which was sufficiently similar to the others to include as a full group. 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. Similarly, the allocation of the language denotes the main language used during the running of the group but does not indicate that this was necessarily the participants' first language. However, the participants were only recruited if they felt confident of being able to respond in the allocated language of the group.

These groups included the following:

- 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

This section presents the results on general comments about the whole questionnaire, comments made specifically about the core set of six questions plus the community participation and environmental questions, the detailed set of questions on functioning and the background questions not asking about functioning. The section ends with comments made on further questions to be added or areas to be covered when collecting information on disability and functioning.

6.2.1.1 General comments

a) Understanding and remembering

The general feeling about the ability to understand the questions were positive with participants indicating that they did not find the questions difficult to understand. The questions were 'right', 'not too long', 'acceptable' and 'easy', to quote some terms used in the different groups.

Participants from the head injury group felt that the problem was not in understanding the questions as much as in understanding how to answer them. One participant from this group felt the questions were too broad and did not deal with specific issues sufficiently. A similar comment was made by a participant in the urban psychiatric group where he said:

> *Was just a bit confused as to what the answer should be. Sometimes I circled the answer before I looked at the rest of the answers.*

One participant in the rural psychiatric group has some problems with understanding and answering the questions. He was the only one in the group that raised a difficulty. His explanation was as follows:

> *In my view, these questions were difficult because they tickle the mind. They need one's mind to be work, yet my mind has a problem.*

These comments overall suggest that the questions are not difficult to understand for any of the groups.

b) 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.

Participant 1: Ja, it is difficult as D has said, you have to remember things and some we already have forgotten. And again it is a little too long – with head injuries we have a problem of forgetting and you can only remember when you see someone doing something that you also have to do.

Participant 2: 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.

Moderator: How many of you used this idea of "normally"?

Participant 3: I didn't use it

Moderator: so what were you thinking about when answering the questions about last 5 or 7 days.

Participant 3: I would use the word "usually".

Participant 4: I used "normally"

Participant 5: I pretty much ignored the time frames but also tried to take it into consideration

Participant 6: I ignored it.

Two participants in the rural physically disabled group had contradictory views on the time frame with one saying

> *I say [it was] easy*

and the second one saying

> *I don't think there is anyone who can remember something that happened in the past twelve months.*

The first participant replied

> *Excuse me, when I said they were easy, I was talking about me because I still recall the moment of sadness and happiness I had that time. That's why I say they [the time references] were easy for me.*

c) Sensitivity of the questions

The issue of the sensitivity of the questions varied with some participants feeling 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'. There were comments made that even if the questions might be sensitive it would still be important to ask them so that the reality of the participants' experiences could be conveyed to the general public.

The following quotes highlight these themes.
From the head injury group about the questions on emotional functioning:
Participant 1: *I find something in the question - they were hurtful; they so much hurt you when you answer them. For example: Do you feel depressed or down sometimes - that question just reminds you of who you are. It's like asking a malnourished child if [he] is hungry or not. I am afraid they are too hurtful. Look at me I am [a] broken spirit and you ask me to confirm that I am depressed; I just think they are too direct.*
Moderator: *Do you think this is too hurtful and sensitive to ask about?*
Participant 1: *Yes, we're not the same emotionally, there are things I can't take, so the questions just remind me where I am.*
Moderator: *N, you're shaking your head, does that mean you don't agree?*
Participant 2: *These are the kind of questions which I don't know how you are going to do this but this must be elevated. These people must see how we are, how we feel as physically challenged and disabled, they must know about us.*
And a third participant concurred with participant 2 in saying
Participant 3: *Some of the topics can be hard and sensitive but they can provide answers to other people.*

From the urban physically disabled group on being asked what sort of questions would be too sensitive:

> *I am talking about my disability. I don't like somebody questioning me, my injuries.*

And from another participant

> *I agree, sex life, that is private.*

From the urban psychiatric group on being asked about sensitive questions
Participant 1: *Maybe if you have a fungus or something.*
Moderator: *So very specific kinds of health problems that you wouldn't want to talk about.*
Participant 1: *Ja.*

………

Participant 2: *Sexual relationships*
Participant 3: *Transmitted diseases*

………

Participant 4: *but the main thing is that your name won't be connected to the papers.*

In the urban visually impaired group a few participants raised the issue that they were not happy to respond to these questions in a group context with non-disabled people but would be happy to answer on a one-to-one basis or in a group of visually impaired people as was the case for the focus group context. There objection was related to the stigma attached to being identified as disabled in a group of non-disabled people.

> *Unless it is in this situation because we know that most of us here we are blind, so we don't have a problem, but not all of us will feel free saying 'yes' about whatever you asked in front of other people who we also think are able bodied, but if it is us only, we don't feel embarrassed......Lets say for instance, I was out there, you called in my community, it is not all of us who feel free disclosing our disability and our difficulties in front of the so called everybody, but if it is us only we are very free saying everything......Let's say that you go into my community, I stay in G – you will find even if you will invite the whole community, I would go, or I wouldn't just go, because I am not going to feel free that you are going to ask us me my disability, people start raising eyebrows – I can't consent.*

In the rural psychiatric group, some comments were made about the positive experience of being asked the questions as highlighted by two participants:

Participant 1: *It makes me feel relieved. The condition in which I am cannot change my situation, but it makes me realise that I am not the only one experiencing this problem; that there are others like me. I feel at ease with these questions. They make me accept my condition.*

And

Participant 2: I did not [experience] anything which I think was not proper for us to be asked. I feel glad to be asked this type of questions.

For the urban Deaf group, the two sensitive issues were about questions on reading and writing ability and asking 'Are you disabled?'. The following quotes highlight these.

> *I think the whole issue around having to write... the Deaf are very sensitive about... one of the questions we're going to discuss is sensitivity when answering questions... 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! And they are correct, but the education system has failed and not themselves. But the problem is that there's huge miscommunication, and Deaf people are reluctant to access things because they know they're going to have to rely on writing and reading. And to ask a question about this is very difficult because most Deaf people will say, no, they read and they write fine even though inside their hearts they know that they don't. But they don't want to say that they don't.*

However, another participant indicated that despite this sensitivity, there should be a question on reading and writing ability anyway.

Moderator: *Was there anything that you were embarrassed about that came up in the question here?*

Participant: *Maybe the first question, the yes/no. To be disabled or not. 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.*

d) 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 of the comments raised were about the problem in understanding how to answer and wanting to make sure that the response was given according to what the expectations were.

A participant in the rural visually impaired group said

> *The questions were simple but complicated when it comes to the choosing part. [i.e. selecting the response option]*

A participant in the head injury group felt that the response options for the question 'Are you disabled?' were too stark with only 'yes' or 'no' and he struggled to decide which one to use especially as the group expressed that head injured people did not fit into either physical or mental disability.

> *I tried to look at it very similarly at how I …. and the honest truth, it didn't change at all, but I find that it lacks the grey area, in other words your answers was 'yes' and 'no' and there was no 'maybe' for somewhere in the middle, in other words it was very, very difficult to answer.*

Another participant from the same group raised the issue of 'meeting the expectations' as far as the responses:

> *I think maybe one can be afraid of answering and maybe you might be conscious of what the questionnaire is looking for or the effect of the answer on the person. So one might be inclined to give the answer that they think the person is looking for. One must be careful with the words…[makes example of answering on depression]… one might just say an answer not to look bad or try not to be too negative.*

This same apprehension was expressed by a participant in the rural psychiatric group.

> *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.*

e) Scope of Questions

Contrary to the non-disabled groups, the disabled groups had very few comments to make on the scope of the questions. A participant in the urban physically disabled group made the following point:

Participant 1: [T]here wasn't much on disability
Moderator: There wasn't much on disability?
Participant 1: Not really
Moderator: OK, what would be a question that was on disability?
………[Much distortion on tape and many participants talking all at one]
Moderator: OK, to touch more on the needs
Participant 1: Ja, like home care
Moderator: So you think we should ask questions like whether you need it, whether you have access to it?
Participant 1: Ja

This same group also expressed a view that the scope of the questions 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.

Moderator: Alison [scenario of person who is overweight] would be part of that statistic, that 5% [hypothetical prevalence estimate used in the discussion]
Participant 1: She is part of the country

Moderator: *So you are happy for her to be counted in.*
Participant 1: *Yes*
Moderator: *What do other people feel?*
Participant 2: *I agree*
Moderator: *S, your face looks like you might be disagreeing.*
Participant 3: *I disagree, that won't be a correct percentage of the special needs of people with disabilities. They should be differentiating between normal problem or normal health problems versus disability……… We might understand …..uhm uhm someone might have an infection that is not related to a disability, but it is related to a health problem, not to disability. So the statistics outcome should be specific to people with disability.*

Participant 3 goes onto to explain himself further:

> *It is all kinds of cross disabilities, because I think if we as organizations of disabled persons, when we approach government or whoever need to know the statistics, they need to reflect the correct number of people with disabilities, until maybe there is a gap or understanding the kind of disabilities that somehow the questions that will be rephrased on the questionnaire. But the question that asks you if you have any disabilities, then you say yes, that one should be corrected specifically in terms of giving the correct percentage. She doesn't follow in the correct category of disability but she follows in the health problems category.*

But the question remains as to who should be counted as being disabled.

There were a few more comments made on the usefulness of asking the questions on disability and functioning. For the participants in the disabled groups, the focus was 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.

In the rural psychiatric group the comments made were as follows:
Participant 1: *They are suitable questions as you ask us the disabled and we answer so that those who are not disabled may be able to understand because it is us the disabled who are speaking.*

And
Participant 2: *It makes me feel relieved. The condition in which I am cannot change my situation, but it makes me realise that I am not the only one experiencing this problem; that there are others like me. I feel at ease with these questions. They make me accept my condition.*

A participant in the head injury group commented on the importance of asking disabled people what they think and she felt that these questions provided such an opportunity.

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.

f) Frame of reference used by participants in responding

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

In terms of the environmental factors considered, it seems that people responded about themselves or the scenarios. The response they gave about the degree of difficulty was based on whether the person in the scenario or themselves had support from others or not or whether they used their walking stick, and so on.

From participants in the head injury group in response to the scenario about George, who is blind and has a problematic family situation:

Participant 1: *That is a problem I am talking about, maybe walking and climbing the stairs won't be a problem but there is nobody to help him go out.*

Participant 2: *I think this will be a problem because he is prevented from home to go out.*

Participant 3: *He might not have a lot of difficulty to interact but his current situation has not made it simple for him. [highlighting role of family in preventing him from doing the activity.]*

Moderator: *So how would he answer the question.*

Participant 4: *a lot of difficulty [with walking and climbing stairs].*

Another participant in the head injury group described how she answered the questions about difficulties walking and climbing stairs by taking the use of her walking stick into account.

Moderator: *What did you answer to that question [difficulty walking and climbing stairs]?*

Participant 1: *very much difficulty*

Moderator: *Did you think about your answer, very difficult, what is the difficulty about?*

Participant 1: *I use the stick to get to balance walking up and down the stairs in one hand and the other I hold my crutches.*

Moderator: *When you said you had a lot of difficulty on the question, was it the difficulty still using the walking stick?*

Participant 1: *Yes*

Moderator: *Tell me what picture did you have in your mind when answering that question?*

Participant 1: *Not a picture but what was happening to me, when I walk on the stairs with my crutches.*

A participant from the urban physically disabled recounted how his environment has changed significantly over the last two years and he would have answered very differently for each environment.

Participant: *My environment was completely different to where I live now.*

Moderator: *So you would have answered very differently two years ago?*

Participant: *yes*

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. But we must realise, for example myself, I'm also part of the Muslim community and I have huge barriers when it comes to when they are celebrating Eid and things like that. So I'm not sure how on earth to answer number 18. [difficulties in participating in community activities].*

In a similar vein the following comment from a participant in the head injury group highlighted his dilemma about how to take the context into account.

> *……there was a question about socializing, I don't go to social gatherings anymore, I used to go to the stadium all the time, but not anymore. So when the question says socializing does it mean parties. So it's been difficult to understand what they mean by socializing. Could I go to parties anymore?*

These comments on how the context is taken into account provides some potential insight into whether participant are using 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.

6.2.1.2 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 and the non-core set and so the comments for both are discussed together in this section. The general comments made about the ease of understanding and responding discussed in the preceding section pertains to the core questions as well as the extended set.

The questionnaire was seen as quite broad and not always specific enough for the different types of impairments represented in the disabled groups. For example, from the urban psychiatric group:

Participant 1: *It's a very nice questionnaire but it is very general. It's not like specific.*
Participant 2: *It's not too personal.*
Moderator: *P, do you like that? The fact that it wasn't too personal?*
Participant 2: *Sometimes I like more personal questions because it's sometimes quite a revelation to see exactly what your overall status is when you see your situation on paper. It's a bit therapeutic sometimes to get stuff out if it's more personal. But no, I think it was great.*

And further from this same group:

Moderator: *So do you feel if we ask these questions in the census, we will pick up how many people have difficulties like you have difficulty, if we just ask those first questions in section b?[core set of 6 questions]*
Participant: *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.*

Of interest here is also to determine the extent to which participants felt that the questions reflected their own experience. 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 but some did feel the questions were too broad.

From the hearing impairment group:

Yes, I think so. Reasonable for everybody that is hard of hearing.

From the head injury group:

Moderator: *Did you find the questions made sense in terms of your experience?*
Participant: *Yes, it did.*

However, one participant from the urban physically disabled group did not feel that it did sufficiently his experiences.

Moderator: *Did you feel that the questions asked about your experience enough.*
Participant: *No*
Moderator: *OK, let's talk about it. Why do you say 'no'?*
Participant: *I didn't find nothing about people in wheelchairs.*

While a participant from the urban psychiatric group commented on not being sure how to apply his own situation.

Moderator: *Did it feel confusing in the way they were worded? That you weren't quite sure what the question was referring to?*
Participant 1: *No.*
Moderator: *You always were clear on what the question was asking?*
Participant 1: *Yes. It wasn't the questions that confused me. I just wasn't too sure about my own situation - how to apply it to the question.*
Participant 2: *Ja, same here.*

The quote from the participant in the head injury group about the questions on emotional functioning being 'hurtful' as it reminds him of his own situation shows a reflection of his experience. The quote is presented above in the section on sensitive questions.

Similarly, a participant from the urban psychiatric group commented as follows:

Participant 1: *This question 37 of section C: do you have a problem to analyse everyday problems and to find a solution? That is the one that I mark the highest for this problem, because you know, [if] I'm in a stressful situation... like in an 8-hour job. It's a totally different ballgame ... sitting ... or going to the shops or whatever.*
Moderator: *Okay, so you feel you have a lot of difficulty...*
Participant 1: *Like stress.*
Moderator: *Ja, related to stress. But you didn't find the question quite...*
Participant 1: *No, it was nice.*

This participant concludes by saying:

Section B, question 17 [difficulty with communication] and 18 [participation in community activities], and as I've said, Section C, question 37, it's the most relevant questions for me. [Although this participant used the introductory phrase rather than difficulties in communication question as the crux of question 17 – cf below in this section.]

What did come out quite often were suggestions for further question to be asked to get a better picture of the experiences. These are discussed below in the section on suggestions for further questions.

In terms of specific comments about 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.

This comment was made in the urban psychiatric group:

Participant:	*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.*
Moderator:	*Do you feel the questions tapped that to some extent? If we look at questions 12 to 19...[core set of questions]........Do you think that those... if we wanted in the country, through the census, to find out how many people have difficulty functioning like you have difficulty...*
Participant:	*Ja, this defines whether it's physical or mental.*
Moderator:	*In those first few questions.*
Participant:	*Ja, if you answer 17: because of physical or mental or emotional health... [question on communication difficulty]*
Moderator:	*That's about communication.*
Participant:	*If you answer that one then you will see it's mental and not physical.*

In the urban visually impaired group, one 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 there was when you talk 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 group 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 signed 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 also felt that the question on hearing should be changed to omit the phrase 'even with a hearing aid'.

> *I don't know what to say. What is this to do with a hearing aid? I don't use a hearing aid. For example, some deaf people use a hearing aid and others don't use a hearing aid at all, and there is no way I can hear a word. So that question I think needs to be changed. .... [M]aybe it just needs to indicate like are you deaf or are you hearing? Do you wear a hearing aid? What do you wear a hearing aid for? That would be a better question*

The deaf group also 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.

> *Okay, the other thing here 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.*

In question 19 a) on problems with the physical accessibility of the environment, the same group had problems with lumping physical accessibility (buildings, roads, etc.) with access to information. They felt a Deaf person would primarily have problems with accessing information and not with the other 'physical' aspects. They went on to say that the words 'access to information' should also be simplified as many Deaf people would not understand them.

It should be borne in mind that while some of the suggestions are useful for including in a longer set of questions for a survey, they are not necessarily practical for a Census set of questions. However, the comments provide some insight into the type of problems respondents are likely to have with the questions.

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 the section on what is disability below, 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 deaf as a health problem - but that's how it's being seen as here. So what we're doing, we're explaining the examples so you would be able to blame the strike... you would be able to say that you're experiencing problems of transport if it's because of the strike, but you could be experiencing problems of transport when you went to ask for your ticket and the guy couldn't understand you because he doesn't use sign language. So then that would be - that's because of your deafness. So that was what we were just trying to do.*

6.2.1.3 Comments on background questions

As for the non-disabled groups the majority of the comments made about the background questions related to the employment questions. Some comments related to the fact that disabled people are more likely to be unemployed and hence that employment issues are important to ask about, while others related to the confusion they experienced in trying to answer question 11.1 – 11.6 on employment status.

From the urban physically disabled group the issue of employment for disabled people was raised:

Participant 1: Some questions about the employment
Moderator: you didn't like them?
Participant 1: Ja, because there is not much you can do for us, disabled people
Moderator: How did you feel about answering those questions?
[No response]

Moderator: *Do you feel those are important questions to ask or do you think we shouldn't ask them?*
Participant 1: *Ja, they are important [rest of sentence inaudible].*

This was echoed by a participant in the rural psychiatric group:

I have difficulty concerning employment. For example, I may need employment, but fail to secure any on account of my being mentally disabled.

The confusion experienced in answering the employment questions was raised most strongly by the Deaf group:

> *These questions are going to be difficult, not just for deaf people but for anybody who is a second language user. Even to explain... I mean, it's skipping and going to... I mean, it would be much better if they just ask them less specific questions.*
>
> *The yes and no question about the work and skipping back and going on - that was terribly confusing. That was 11.1, and that whole section was confusing section 11.*

For example, work for pay, running a business, salaries... you've got to yes/no if you haven't got that, and then jump down to the next number. That was all totally confusing. It just needs to be clear. You know, do it in a simple way and give examples.

However, a participant in the urban psychiatric group also indicated some difficulty:
Participant: *There was one section where I was a bit confused - the one with the working situation stuff. But the rest was fine.*
Moderator: *That is quite a difficult section. So you found that quite a difficult section.*
Participant: *Not extremely, it was just a bit... here and there I wasn't too sure how to answer it - but it was fine.*

6.2.1.4 Suggestions for further questions

Many suggestions were made as to questions or topic areas that could be added to make the questions on functioning more specific and relevant to pick up all experiences on disability. The areas suggested include:

- 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.

Participants from the urban psychiatric group provided a strong argument for including questions on stress to obtain a comprehensive picture of his difficulties. Stress together with questions on medication and sleep, energy and waking up were seen as the three aspects on which this group would like to see questions.

Participant 1: *I'm going to say again, stress changes the whole thing. Different types of stress, like in deadlines and stuff.*
Moderator: *Okay, so some question about stress.*
Participant 2: *Also work related stress.*
Moderator: *So general stress, as well as specifically work related stress. Any other questions?*
Participant 3: *I just wanted to say that there are jobs out there, or there's certain stuff, like protected labour that I can function in normally, but that is if there is no stress. In most jobs out there, I can't function properly. I did two jobs last year and it was chaos. Participant 2: And even if there is no stress for a normal person, I create my own stress.*
Moderator: *So it's both issues of stress and understanding where it comes from.*

For the Deaf group, questions about balance were seen as important to ask about. In part this would explain responses indicating some difficulty with walking and climbing given by Deaf people when it does not indicate a physical disability.

Participant 1: *Ja, because some of it is disability and some is just related to our Deafness. Maybe other people might disagree with me, but that's what I feel. And also, some people are frightened to go in lifts because they have a balance problem - or in planes as well.*
Participant 2: *I think there are also other problems people have. They don't have difficulty sort of walking or climbing steps normally, but sometimes in certain situations, they would experience balance problems that would be quite scary. It's not just deaf... I think there should be a question about the balance. I don't know how you would word it - I'm not sure what words you could use - but to differentiate it from say, somebody who finds it difficult to climb stairs.*

6.2.2 What is disability?

As for the non-disabled group, a number of themes arose from the comments made by the participants in the disabled groups. In addition to the ones discussed in the section for non-disabled groups, the themes of terminology and self-identified disability status are discussed. The theme of ageing and disability has been omitted as there were no significant comments made in relation to this theme. While an effort has been made to differentiate between different themes, at times the distinction becomes blurred. Some of the quotes provided under 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.

6.2.2.1 A universal versus minority view of who is disabled

The issues raised in relation to a universal versus a minority perspective by the disabled groups was different to that of the non-disabled groups. The disabled participants are the 'them' and they do not want to be seen as separate from the rest of society. There seems to be two aspects to consider. On the one hand the disabled participants 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 not clear statements suggesting that disabled people have a universal versus a minority perspective.

The participants in the urban psychiatric group raised this notion and 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 1: *No one is normal.*
Moderator: *Okay, K says no one is normal. But we all use the word normal. I mean, M just used it. I mean, what is it…?*
Participant 2: *To be able to do everyday life work, like earning a salary and being able to cope on your own.*
Moderator: *Okay, so being independent and coping on your own - earning a salary.*
Participant 2: *Married with kids. Full-time job.*

And the discussion went on to:

Participant 1: *Most people in the world have difficulties - but not all of them in the same way.*
Participant 3: *I agree.*

A participant in the urban visually impaired group raised the point about disabled people being able to do many things and highlights the importance of the context.

> *The question is how do you see disabled? What is the meaning of disabled, why do you say that blind people are disabled or people in wheelchairs are disabled just because they can't use their legs, disabled in that sense they can't walk, but they can, they are able to do many things, whatever. If I said for instance, it depends on what, in what situation you are.*

In the same group a participant describes this as 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, I can't see, you see I can't see………*

A participant from the rural psychiatric group highlighted the sense that non-disabled people do not want to have disabled people around them suggesting an experience of being seen as a minority group.

> *He has difficulty; he might imagine that he is not acceptable to them. They might think that he is suitable because he is a disabled person. Very often, the able bodied people do not want the disabled to participate in activities with them. They regard the disabled simply as people who want to interfere into their affairs.*

A participant from this same rural psychiatric group suggests that disabled people are a separate group:

> *Disability is something in a person which is not present in the lives of other people.*

6.2.2.2 Disability as physical and visible

While there was a strong sense of disability being a physical and usually visible attribute of someone, there were many comments made on the inclusion of less visible conditions as part of what disability is. 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 such as expressed by a participant in the urban physically disabled group.

Participant 1: *Schizophrenia is so shocking, definitely disabled*
Moderator: *So disability is not just about physically disabled.*
Participant 1: *No, about mental capacity as well*
Moderator: *OK. V. Do you agree?*
Participant 2: *Yes*

A participant in the urban psychiatric group stresses 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.*

But other participants in the same group had varied perspectives, with some saying disability is a physical problem, while others highlighted the functioning aspect rather than the physical difference.

Moderator: *What's a disability?*
Participant 1: *Physical.*
Moderator: *G says it's something physical.*
Participant 2: *Something that you experience on a daily basis that prevents you from functioning normally in society.*
Moderator: *Any other ideas?*
Participant 3: *A shortcoming of some kind.*
Moderator: *Can you give me some examples?*
Participant 3: *Let's say someone lost his or her arm in a car accident, then that person has a shortcoming. Other people still have their arms and hands and stuff, but this particular person lost it.*
Moderator: *G, I want to come back to you because you said disability is a physical thing.*
Participant 1: *Ja, it's not schizophrenic.*
Moderator: *So schizophrenia isn't a disability?*
Participant 2: *Not for me.*
Moderator: *Okay. G, for you?*
Participant 1: *No, I think it is a disability in a different sense of the word.*

One participant from the urban psychiatric group 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.

Participant 1: *The problem that I had with schizophrenia is that without the medication…… Because it is a chemical imbalance. I never believed that… I always thought it was a spiritual thing. But once the chemicals change with the medication, you stabilise……..Because it's physically a voice that talks to you also, and it will tell you to do something, and because you are so deep, you will do it.*

Moderator: *Now, is that a disability?*
Participant 1: *Ja, it's a disability.*
…………
Participant 2: *I think one must distinguish between a mental disability and a physical disability.*
Moderator: *Okay, tell me a bit more?*
Participant 2: *Well, physically there's nothing wrong with us basically. People who are blind and who can work in a call centre or wherever… but our people can't take stress and stuff, so…*
Participant 3: *I disagree with that. Physically, there is a lot of pain. It's not imaginary or hallucinatory…But physically there is pain. Definitely - in the brain.*

The urban 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.*

The rural visually impaired group described a person who is slow as being disabled:

> *This one is disabled, which means that his mind is slow. His mind is slow to catch up, he is having a difficulty.*

When asked by the moderator whether people with mental illness are not also disabled, the participants from the rural physically disabled group agreed although they did stress the fact that 'most of the time it's a physical problem' and concluding with the following statement:

> *As long as you have a certain disease in your body, you are disabled*

This in itself raises other issues about the relationship between health and disability which is discussed further below.

6.2.2.3 Disability as a permanent problem

The notion of disability as being something permanent that cannot be changed 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. Phrases such as following highlight the theme of permanence as well as not being able to cure or change the disability.

> *I'll say it is final. [urban physically disabled group]*

And from the urban visually impaired group
Participant 1: *You are depressed that is not a disability.*
Participant 2: *It is an illness.*
Participant 3: *It is an illness that one, if you can get the right attention, if it can be attended to, then it can be rectified.*

Participants from the rural visually impaired group were very clear in their description of the aspect of permanency as being a feature determining whether someone is disabled or not. In contrast to a disability, a difficulty can be changed or overcome. But this is discussed further below.

Participant 1: *…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.*
Participant 2: *According to me W is having a difficulty, because a difficulty can be changed. Like when one decides not to go to the bash one can be*

persuaded to go. But when she is blind I cannot change that, because she is having disability.

A participant from the urban visually impaired group described how disability could be seen as permanent or temporary but this was clearly within the context of access to a temporary or permanent Disability Grant, a state disability benefit.

Moderator: And do you think, if I understand correctly what you are saying is to be disabled it has to be a permanent thing?
Participant: No, it may be temporary or it may be permanent, hence that is why with our, when we go and apply for our disability grants, that is why we go to a district surgeon, the district surgeon is the one who can say, with a final diagnosis am I permanent or temporary and if he does not fill in that portion the very right way.

When challenged on his statement concerning the presence of 'a certain disease in your body' as determining disability, a participant in the rural physically disabled group went onto say that a person is not disabled because of a disease such as asthma highlighting the 'incurable' nature of disability.

Moderator: So, you mean any other disease, I have asthma, am I disabled?
Participant 1: No, you are not disabled. I was just saying if you have a problem with some other parts of your body
Moderator: But that can also include me because I have asthma, I have a problem with my lungs, so am I disabled?
Participant 1: No!
Moderator: Why are you saying that I am not disabled?
Participant 1: Because you can be healed.

6.2.2.4 Disability as activity limitation

While the disabled participant 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 level of functioning or activity limitations with little reference to the role of the physical and social environments.

When asked about the degree of difficulty that determines whether disability is present or not, the participants from the urban hearing impaired group gave a range of degrees of severity suggesting that the degree of activity limitation is not the only factor determining whether someone is disabled or not. The severity of the limitation should also be taken into consideration.

Participant 1: Unable to do
Participant 2: Some difficulty
Participant 3: I also think some difficulty
Participant 4: A large amount of difficulty

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

> *Disabled means can't get up and walk [Urban physically disabled group]*
>
> *Being unable to do an ability. [Urban visually impaired group]*

> *Like I was going to say because of his mental condition sometimes he cannot remember things, important things that he must do, or sometimes he can't do, he can't differentiate between right and wrong [Urban visually impaired group]*

> *....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. Disability is in different forms - there is mental disability, disability to hear, disability of being paralysed and things like that. The disabled person is unable to do things. [Rural psychiatric group]*

> *....disability is when you have some defect, maybe in your hands or your feet. These not well coordinated, or having some mental defect which makes [he/she] not to think properly like other people. [Rural psychiatric group]*

> *.....disability is when a person is unable to do what other people are able to do. He/She is unable to do as a result of having been born with a defect. It may be a mental defect or some other physical defect in the body. [Rural psychiatric group]*

> *Not being able to work properly, can't do garden work, you are always tired [Urban hearing impaired group]*

6.2.2.5 The individual as the locus of the problem and source of change

Of interest to note is the difference between this theme for the non-disabled and disabled groups. Disabled people are more likely to understand the role of environmental factors in determining their overall functioning. They do not see it as something that is only within themselves. 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. Since there were no comments made that clearly reflected this theme, no quotes are presented here for this section.

6.2.2.6 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 from the discussions in the disabled groups. Disabled people need assistance and that is one of the features that determines if someone is disabled or not.

A participant from the urban hearing impaired group describes disability as being

> *I would say when you are completely paralyzed ....You have to have someone to help you with everything*

This is echoed by a participant from the head injury group:

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

And from the urban physically disabled group:

> *I don't like the word disabled, it means you can't do like nothing*

And contrasts this with

> *But that 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.

Two participants from the urban visually impaired group also expressed the common view of disabled people not being able to anything.

Moderator: *Tell me what you understand by, what does it mean to be disabled?*
Participant 1: *Disabled is that you can't do anything.*
Participant 2: *Being unable to do things, stuff whatever.*

6.2.2.7 Disability as loss of participation in social life and role of EFs

As indicated in the discussion on activity limitations, the disabled groups were very strong in highlighting the important role that the physical and social environments or context plays in determining whether a person is disabled or not. This section presents comments that were made reflecting this aspect. 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 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 anymore and the stadium, 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.*
Moderator: *so that's how your limitations affected your social life?*
Participant 1: *Yes*

One participant from the urban psychiatric group 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.*

When asked what accommodation they would most like to experience, a participant from the urban psychiatric group said the following with the assumption that this would require a change in attitudes of others towards people with schizophrenia.

> *That we can still function normally in society.*

The discussion in the urban visually impaired group looked at the issue of when a disability happens or goes away based on the environment.

Moderator: *Are there times that when you are, being blind isn't being disabled?*
Participant 1: *Sometimes.*
Moderator: *When?*

Participant 1: For instance if you have now even given us these statements and they are in print then now my disability is exposed. I cannot read this document, but in other circumstances I can do things.
Moderator: *……So now is your disability, is your disability because you are blind or because I didn't give you a Braille sheet?*
Participant 2: I think my disability here is exposed because I cannot read this sheet.
Moderator: *Why can't you read it?*
Participant 2: Because I cannot see what is here and I am not sure if there is anything here.
Moderator: *Now if I give it to you in Braille?*
Participant 2: Then my disability is cured.

For the Deaf group the issue concerning the environment was about the difference between communicating with other Deaf people who use sign language versus with hearing people who do not use sign language.

> *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. But we must realise, for example myself, I'm also part of the Muslim community and I have huge barriers when it comes to when they are celebrating Eid and things like that.*

And in a similar vein other participants in the same group comment as follows:
Participant 1: 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.
Participant 2: I think in many ways it's unfair. I mean, I believe we are disabled. We are disabled because we don't have opportunities.

6.2.2.8 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.

Comments from participants in the urban hearing impaired group reflect this difference.

> *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*
>
> *Finding it hard to do something [is a difficulty]*

The participants in the urban psychiatric group had some interesting definition of a difficulty.
Moderator: *What does it mean to have a difficulty?*
Participant 1: It's like a problem that you didn't foresee. It is out of the ordinary - out of the everyday.
Participant 2: Something that is difficult to do. Something that perhaps you can't do... Or perhaps it's difficult to do also.

Participant 3: It can also sort of be a challenge for someone. Someone might have difficulty, and then you get some people who embrace the opportunity of trying to face some difficulties and to see if they can cope with it.
Moderator: P, do disabled people have difficulties?
Participant 4: Oh definitely. Definitely.
Moderator: All people with difficulties, are they all disabled?
Participant 4: Yes. They are not given the same opportunities.
Moderator: Let me just clarify, if people have difficulties, then they will be disabled?
Participant 5: No way.

The following comments from the rural visually impaired group highlights the aspect of possible change.
Participant 1: To have a difficulty is something which I'm faced with like not having things you would like to have. For difficulties, one can change or can have a solution unlike disability there is no solution there.
Moderator: Is there anyone who wants to add on what was said?
Participant 2: I would like to say having difficulties is something which has to have a solution at the end of the day; disability does not have a solution.

A comment from a participant in the rural psychiatric group suggests that difficulty is when it occurs after birth and disability when it occurs at birth.
Participant 1: I have difficulty concerning employment. For example, I may need employment, but fail to secure any on account of my being mentally disabled.
Moderator: is that disability or difficulty?
Participant : To me, that is difficulty, because I was not born with this disability. I am experiencing at present. It happened to me along my journey through life. This stresses me because I want to know how I was in my former state. There is a difference between my present state and my former state.

6.2.2.9 Health problem and chronic illness in relation to disability

The issue of whether disability is a health problem or not was an important topic of discussion in the disabled groups with many of the groups raising the issue that health and disability are not the same thing but were 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 and not including a static condition such as blindness.

The participant in the urban hearing impaired group reacted to the phrase 'because of a health problem' as they did not feel that the functioning of their ears and eyes were aspects of health.
Participant 1: You know what worries me, I don't think of my ears and eyes as health
Moderator: Other people, do you think of your ears and eyes as health.
[General discussion in the group. No particular responses identified.]
So you would put it as a health issue?
Participant 2: Yes
Moderator: What about you?

Participant 3: The natural thing is to look at your physical function and then a bodily function

Moderator: So your eyes and ears, you don't consider them as you bodily function.

Participant 3: No, not really

Participant 4: My dear, if you can't see ....

Moderator: But is that a health problem.

Participant 4: No, I wouldn't say a health problem

Moderator: What about you, do you think your eyes and ears are part of your health?

Participant 5: They are very important

Moderator: Do you think they are important because they are part of your health or because or because they are part of something else?

Participant 5: They are part of your health

Participant 6: I don't think they are part of your health, I look at health as my aches and pains. Like when I have a cold, that is health

Moderator: So what are your eyes and ears part of then?

Participant 6: Physical

Moderator: Physical what?

Participant 6: Abilities

The participants in the urban physically disabled group also expressed clear thoughts on what comprised health, but with some different opinions about the scope of the term, narrow illness versus broad conceptualisation.

Participant 1: Something similar to AIDS

Participant 2: For me, health is a broad issue. It is about nutrition, rehabilitation – it's everything that you cannot just have a straight forward answer for health. It is broad to me, that is why I have a problem of saying now you are referring us to disability to health problems, but to my understanding it is a broad issue. I don't think amongst ourselves here you can say health doesn't mean sickness but it is a broad issue about human beings as a person

Moderator: So it is not just about feeling ill?

Participant 2: No

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'. But one of these participants also said that he doesn't see 'disability as a sickness'.

This was reinforced by the comments made by the urban visually impaired group. *Participant 1: I think you can have a disability but it is not a health hazard to you, like my blindness, my blindness is not a hazard to me, I know that I am blind but I forget that I am blind.*

………

Moderator: What do you understand by health problem? D, what do you mean by health hazard?

Participant 2: Like for instance you would say if it is a health hazard it is, let say my health, I am sick and this sickness in me it may be chronic and, now, that because it is chronic brings difficulties to me. And I know that maybe if I *can go when it is raining automatically during the evening I would be having a problem. I know that maybe I stand on the sun for too long, it is going to hit back on me. It is a hazard because those are things that can be prevented. If I didn't go to the sun I wouldn't be sick; if I didn't go out while it was raining I wouldn't be sick. So automatically it is a hazard, it is something that can be prevented.*

………

Moderator: So you say that your blindness is not a health hazard, that is what you said? Why do you say that your blindness is not a health hazard?

Participant 2: Um, okay I am blind, I am blind, but it does not, my blindness does not prevent me doing one, two, three, it is there to stay and it does not bring, it is of no danger to me.

The discussion in this group continued looking at how disability and health are related.

Moderator: When I asked you the question think about difficulties you have because of the health problem, okay, what does that mean to you?

Participant 1: I would say a health problem, I would take an example myself, a health problem is if you -, I am called chronical, chronical medicine, but the thing is if I doesn't take it, then I do have a problem, you know. It can push up my blood sugar level. It can push up my, my blood pressure too and if I don't use that stuff and I do have a health problem because that automatically - if I don't take it I am going to - something is going to happen to me.

Participant 2: We took our blindness and put to health of which really that question is more trickier because it is not due to health. Maybe like for instance E, if E was not totally blind because of the sugar diabetes automatically, with him it is health but with me it is not health. I am not blind because of health it is a condition.

Moderator: Because of measles, okay, so you don't see your blindness as a health problem? Or a health condition?

Participant 2: No, because my blindness is from birth.

The urban visually impaired group 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':

> *It's a bit confusing because deaf people don't see the deaf as a health problem - but that's how it's being seen as here. [in the questionnaire]*

The participants from the rural physically disabled group used the concept of disability comprising a 'certain disease' but clarified that the 'certain disease' cannot be 'healed'. when challenged by the moderator.

Participant 1: As long as you have a certain disease in your body, you are disabled.

Moderator: So, you mean any other disease, I have asthma, am I disabled?

Participant 1: No, you are not disabled. I was just saying if you have a problem with some other parts of your body

Moderator: But that can also include me because I have asthma, I have a problem with my lungs, so am I disabled?
Participant 1: No!
Moderator: Why are you saying that I am not disabled?
Participant 1: Because you can be healed.

6.2.2.10 Terminology

The non-disabled groups did not raise any significant issues around disability. In contrast, the disabled groups had much to say about the use of different terms for disability.

One participant in the urban hearing impaired group stated categorically that the term 'handicap' was far better than 'disabled'.
Participant 1: I want to turn it around a little bit, instead of using the word disability let's use the word handicapped
Moderator: Tell me why.
Participant 1: I think it explains it far better, what is your handicap. You can have a handicap in walking, in seeing, in understanding somebody, there are a thousand and one handicaps and that I think is more expressive than disability. Mentally to me, disability is somebody that is somebody that is lying in the gutter and can't get up, he is disabled. Completely. Handicap is a far better work. You find the signs, this parking is for handicapped people, that can be a wheelchair case or somebody that needs a walking stick, who can't walk more than a 100 meters

………

Participant 1: I use the word handicap. Handicap doesn't put a stigma on the person
Moderator: Do you think the word 'disability' puts a stigma on a person?
Participant 1: Yes, because then you have to have a [wheel] chair.
Moderator: So, disabled means you have to have a wheelchair?
Participant 1: Yes. It seems to be the case, yes.

………

Moderator: So you think 'handicap' describes it better?
Participant 1: Far better, yes
Moderator: Tell me why you think it describes it better?
Participant 1: Well, at the moment, in a South African connotation, disabled people you associate with a wheelchair, you see the sign, and it has a wheelchair, if they don't have a wheelchair then they can't be disabled.

The participant who expressed these views had some support from the other participants in the group. The 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, which has fought to move away from using the term 'handicap'.

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.*

But this participant goes on to voice misgivings about using the term to describe him/herself:

> *That word "disabled" means that you can't do something, and I do feel that I am normal. For example, if I'm with my deaf community and we are all using sign language and a hearing person who doesn't know sign language comes in, that person then is automatically the disabled person. And we are all able - but that person is disabled. So it depends on the situation. But in the apartheid time, black people were disabled because they didn't have access at that time. There was no equality. So that means that they were disabled. And now that there is no more apartheid, therefore everybody is able.*

6.2.2.11 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. This section presents quotes from participants highlighting this theme.

The participants in the head injury group expressed difficulty in deciding whether they are disabled or not and commented on the frustration of using a 'yes/no' response format.

Moderator: *If I asked on the census questions 'are you disabled?', what would you answer?*

Participant 1: *same as D, I am not disabled*

Moderator: *What would your answer be, yes or no?*

Participant 2: *when it comes to narrowing to 'yes' or 'no', it's a bit difficult but I would say 'no'. I am also a normal person - unfortunately today I am classed as a disabled person.*

………

Participant 2: *[U]nless the person can deal with this problem, I don't know where to put head injury people, because we are not as much physically challenged than mentally challenged. It all goes down to one person saying I am okay and cope with all that has happened to you. Try to avoid the word disability but acknowledge that you have a problem, because if you don't say your problem and you are in a social environment people might mistaken your way of doing things as a result of your problem to something else. I find I cannot answer the question, because it is not a mental disability and it is not a physical disability. So it is a question of words. So it is important to get the correct word, otherwise you are not going to get the answers you are looking for.*

………

Participant 3: *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 urban physically disabled group were clear that they are disabled, as were the urban psychiatric group as expressed by one of participant:

> *I'm now disabled but I can still carry on with my day-to-day life. I don't feel labeled.*

A participant from the rural psychiatric group described their status as

> *It is disability - spiritual and mental disability.*

The Deaf group reinforced their discomfort as 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.*
>
> *For example, some people accept that they are disabled; some people refuse and they say that they are not disabled. My body is fine. The only thing is that I cannot hear - and that's all. So I am not disabled, and some are sensitive about that. I'm not sure that most people… you know, the majority of the deaf might not…*

But also recognize the political expediency of using the term:

> *I'd just like to add something. 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. Therefore, I would then say that I am disabled. So most would say that they are disabled. So if there's an application form or whatever, the deaf would automatically put disabled although they would not do it freely. Because if they say they are not disabled, then they wouldn't get the benefits. But that is the only reason they would put it - although they felt that they weren't disabled.*

6.2.3 Responses to scenarios

The two tables below present the responses provided by the participants to the different scenarios. Table 20 presents the descriptions given by participants of people who gave hypothetical responses on the questions. Only those scenarios that were discussed in 2 or more groups are presented.

Table 20: Descriptions given by adult participants to the scenarios of hypothetical responses to the questions

	Sipho[15]	**Saul**[16]	**Mary**[17]	**Peter**[18]	**Lena**[19]
Is s/he disabled?	Yes (2 responses0	No (1 response) but also suggests yes in other responses	No (1 response)	Not indicated	No (1 response)
Degree of difficulty	Not indicated	Not indicated	Not indicated	Not indicated	Varied
Consistency between groups	varied	Varied	Varied	Varied	Varied
Urban Head injury	Low self esteem; frustrated by environment; through many hurts; physical problem; is	-	Can't find words; concentration problem; anti-social	-	-

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[15] Sipho – difficulty joining in community activities
[16] Saul – problem with support and attitudes of others
[17] Mary – difficulty communicating
[18] Peter – difficulty with walking and climbing stairs
[19] Lena – Do difficulty remembering and concentrating

	disabled				
Urban physically disabled	Doesn't like atmosphere; transport problem; can't use assistive devices; can't get to people	People feel sorry for him;	-	Access problem; range of reasons	-
Urban psychiatric	Middle age crisis; shy; paranoid; worried about what people will say; physical problem	Teenage crisis; schizophrenia; low self identity.	Problems with concentration and remembering	Sick from childhood; needs personal assistance; paranoid about walking downstairs;	Not disabled; could be in a wheelchair.
Urban visually impaired	Shy; shameful of disability; excludes himself and is excluded; is disabled	Has experienced discrimination and negative attitudes from others	-	-	Confident; independent; good listening skills; may or may not be disabled.
Urban Deaf[20]	-	-	-	-	-
Urban hearing impaired	Because of environment struggles to hear	Not getting on with people	People don't hear her properly and so mistreat her	Hip or knee problem	Age and short attention span; recent illness
Rural psychiatric	-	-	-	-	-
Rural visually impaired	Lazy; people don't accept his condition	-	-	-	-
Rural physically disabled	Shy, can't speak properly	Short tempered; not friendly; can't be disabled	Shy; not disabled	Problem with legs; uses crutches and does not have enough support	Forgets very easily.

The disabled group participants responded to the hypothetical responses by describing people that are very similar to the type of disability they experience. For example, the urban hearing impaired group described people as having a hearing loss and not being understood; the urban visually impaired group described the people as having experiences of being excluded because of being disabled; and the urban psychiatric groups described people as being schizophrenic. This resulted in very little consistency between the groups in describing the people who responded.

There was a strong theme of discrimination and exclusion presumably because of their own experiences of being disabled although this was not said as such in most groups.

In Table 21, only those scenarios that were discussed by two or more groups are included. These are the responses given by the participants to the core questions for the described people in the different scenario.

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[20] The Deaf group took so long to complete the questionnaire that there was no time to discuss any of the scenarios.

Table 21: Responses given by the disabled adult participants to the questions asked of hypothetical descriptions of adults with various difficulties

	Joseph[21] (Unsure)[22]	**Rose[23] (non-disabled)**	**Thomas[24] (disabled)**	**George[25] (disabled)**	**Jill[26] (non-disabled)**	**Bongi[27] (unsure)**
Is s/he disabled?	Yes and no or can't say	Yes and can't say;	Yes, no and maybe for disabled	Yes	No (1 don't know)	'No', 'yes' and 'maybe'
Degree of difficulty	'no', 'some' and 'a lot' for walking; yes and can't say for community participation	'no' and 'some' for all domains	No, some and a lot for walking and community participation	'no' or 'a lot' for walking; 'unable' for seeing; daily, big problem with attitudes of others	None	'No', 'some' and 'a lot' for self care and community participation;
Consistency between groups	poor	reasonable	poor	good	good	poor
Urban Head injury	'A lot' for walking; yes for community participation; yes or can't say for disabled	'No' for self care; 'no' and 'some' for communication; 'no' for hearing	-	'a lot' for walking and community participation	'no' for walking, community participation and self care	-
Urban physically disabled	'some' for walking; can't say for community participation	'some' for self care and communication; 'yes' and 'can't say' for disabled	'some' for walking; 'no' for community participation; not disabled	'no' for walking; 'unable' for seeing; has a daily and big problem with attitudes of others; is disabled	-	-
Urban psychiatric	'no' and 'some' for walking; 'no' for community participation; not disabled	'no' and 'some' for self care; 'some' for communication; can't say if disabled	'varies' for walking; no response for community participation; 'don't know' for disabled	'a lot' for walking; 'unable' for seeing; daily big problems with attitudes of others;	'no' for walking; 'don't know' for community participation and disabled	'no' for self care and community participation; 'yes' and 'no' for disabled

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[21] Joseph – gets tired walking 1 Km

[22] The disability status in brackets is that allocated at the outset when writing the scenarios and is allocated in the same manner that the disability status was allocated to the focus groups.

[23] Rose – occasional depression

[24] Thomas – pain in joints especially mornings

[25] George – blind and living in a rural area

[26] Jill – jogs twice a week

[27] Bongi – slow in getting dressed

				is disabled		
Urban visually impaired	'no' for walking and community participation	'no' for self care and community participation	'some' for walking; 'don't know' for community participation; may or may not be disabled	'no' and 'yes' for walking; 'unable' for seeing; is disabled	'no' for walking and community participation	'no' and 'some' for self care; 'don't know' for community participation; maybe disabled
Urban Deaf	-	-	-	-	-	-
Urban hearing impaired	'no' for walking; 'yes' for community participation; not disabled	'some' for communication; 'no' for self care.	'a lot' for walking and community participation; 'yes' and 'no' for disabled	'a lot' and 'unable' for seeing; big daily problem with attitudes of others; ; very disabled; family is disabled	'no' for walking; 'depends' for community participation; not disabled	'a lot' for community participation and self care; 'yes' and 'not necessarily' disabled
Rural psychiatric	'has difficulties'; 'no' and 'yes' for disabled	'some difficulties'	Is disabled	'yes' for walking (because prevented); 'yes, small' problem with attitudes of others	-	'some' for self care and community participation; is disabled.
Rural visually impaired	'no' for walking; not disabled	'some difficulty'	Is disabled	For walking 'no' and 'yes' (because prevented); Is disabled	-	Is disabled
Rural physically disabled	'no' for walking	'no' for self care and communication	'no' for walking	-	'no' for walking and community participation	-

The scenarios that were clearly disabled or non-disabled produced response from the participants in line with this and with good consistency between the groups (cf George and Jill). The responses given for difficulties with walking for George were 'no' and 'a lot'. The participant who said George has 'a lot' of difficulties justified her response by saying that because he is prevented by his family from going out, his muscles become stiff and so creates the difficulty. The other scenarios produced inconsistent responses.

6.2.4 Summary of points raised by non-disabled groups

The participants in the disabled groups had few problems with the questions in terms of understanding or answering them. They did not always find the time references useful and tended to ignore them. Some of the main issues that they raised were around the lack of specific questions about their disability and the needs of disabled people, the problems with using the context of a 'health problem', and sensitive questions being around sexuality, toileting and specific impairments. Comments were made that while some questions (e.g. on emotional functioning) were hurtful as they reflected too starkly one's situation, these questions were important to ask to make sure people understand what it means to be disabled.

These groups said that the questions did reflect their own situation but they wanted more detailed questions on aspects such as needs of disabled people and the effect of stress.

The disabled groups provided much interesting insights into how they understand the context of disability. In contrast to the non-disabled groups, these groups raised the importance of the environment in determining disability. They provided insight into the differences in using the term disabled where it can be used politically to access service. But they also indicated that they did not see themselves as disabled in the sense of not being able to do anything as they are able to do a lot.

The group had strong views on disability and health not being the same. They gave the argument that health is something that can be cured whereas disability cannot change. They also described difficulty as something that can be done but with more effort and something that can be resolved, whereas disability cannot be resolved. This also confirms the notion of disability as being a permanent feature of an individual.

6.3 Analysis of responses from 'Unsure' groups

This section presents the response from the third and last groups of participants – the 'unsure' groups. The groups were of older people (2 groups), of people with chronic illnesses (2 groups) and of people living with HIV/AIDS (2 groups). The allocation of languages varied as did the geographical location. The race and sex were not taken into account in the selection of the participants, although one group landed up being all female, viz. the Xhosa rural HIV/AIDS group.

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 focus of the questions as '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'. Thus the responses provided by these participants are of particular interest in understanding how people respond on the questions on functioning and disability. 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 might well have been happier responding positively 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 two sections presenting results from the non-disabled an disabled groups, this section presents the results on general comments about the whole questionnaire, comments made specifically about the core set of six questions plus the community participation and environmental questions, the detailed set of questions on functioning and the background questions not asking about functioning. The section ends with comments made on further questions to be added or areas to be covered when collecting information on disability and functioning. The sections on the core and detailed set of functioning questions are presented together as there were very few comments made by the groups.

6.3.1.1 General comments

a) Understanding and remembering

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, not too long to remember and comprehensive in their coverage. These and other themes are reflected in the quotes from the different groups.

From the Zulu urban group of older people:

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

Participant 2: *For me also everything was clear and there is nothing I can complain about.*

Participant 3: *For me also there was nothing difficult because they ask about what is happening in our real lives.*

Participant 4: *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.*

From the Tsonga rural chronic illness group when asked whether the questions were easy or difficult:

Participant 1: *They were not difficult because we are familiar with the situations we were asked about.*

Participant 2: *No they were not confusing. All was fine. There were no confusing questions.*

The English urban chronic illness group noted that the questions were 'great', 'interesting' and 'clear' and when asked if there were any words that were confusing commented:

> *No. Well in my opinion everything was basically, you know, written out clearly. So I don't know about anybody else, but it was clear for me to understand what it was about.*

One participant in the English urban group of people living with HIV/AIDS expressed that she had difficulty understanding the term 'conversation' but resolved that is was really an issue of not being a native speaker of English and answering the questions in English. Her comment highlights the importance of making the questions understandable.

Participant 1: *I think it's a misunderstanding of the English - the way they write it. Because, sometimes English is... I've got the question but I write it... I don't know the meaning and then I may just leave it out. I answer the question, but these words... I just think in my mind, what is the meaning of this word.*

Moderator: *Oh, conversation.*

Participant 2: *It's when you're talking to each other. When you are talking to me, we are having a conversation. If you are talking about your son or something - that is a conversation.*

Moderator: *So would your suggestion be, that obviously, this be translated into somebody's home language?*

M: *No, I'm just getting most of my mind, what is the meaning of this? I mustn't bother with it. I must skip it.*

Although another participant in the same group said

> *Yes, I think that all the questions are right and understandable. I don't think there's a question that's confusing. It's just the English. English is not a language... we're not talking English everyday. But the questions are easy.*

The Xhosa rural group of people living with HIV/AIDS and the rural group of older people did not have any problems with the questions except for the repetition of questions, i.e. the core and extended set of questions on the same domains.

There were some difficulties noted in understanding the questions, but these seemed to be at a conceptual level where the participants were hesitant about the scope of some of the questions. A participant from the Zulu urban group of older people was confused about the concept 'disability' and presumably the frame that he or she should use in answering the questions:

> *The question regarding disability is a bit difficult to understand.*
>
> ………
>
> *The word disability can mean many things in your body.*

b) Recall period and distance reference

There were mixed comments on the issue of the time periods and distance reference. Participants in the Zulu urban group of older people 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'*.

Another participant from this group went on to say that

> *There was not a problem because you are asked about something that happens to you, something that you know and you know the feeling of that thing.*

The English urban chronic illness group felt comfortable with the recall periods although they did say that *'last year, I have forgotten about'*.

In contrast participants in the English urban group of people living with HIV/AIDS, made comments that suggested that the recall periods might be problematic for them.

Moderator: *Are you able to think back four weeks ago?*
Participant 1: *Not yet.*
Participants (several): *No.*
Moderator: *Okay, and 12 months?*
Participant 2: *No!*
Participant 3: *That's worse!*
Participant 4: *Seven days is better.*
Participants (several): *Yes.*
Participant 5: *Ja, a week or seven days.*
Participant 6: *Even 30 days - that's too much. I forget a lot of things, but I don't forget ... - that was 1999! The smaller things I forget, but I don't forget when I was diagnosed [with HIV]. I think the question is right when they ask the last 12 months if it is a thing that you don't forget - or you can't forget it easily. But things that are easy to forget, you must just ask for a seven-day period. But things you don't forget easily, you can ask 30 days or one year.*
Participant 7: *Because I even don't forget last month's things. Like in December, when somebody stabbed me, I remember the day. So you must forget the smaller things, but the bad things that happen to you, one can't forget that.*

The Xhosa rural group of people living with HIV/AIDS seemed to interpret the recall period very literally and found it quite hard to keep to the specified period:

Participant 1: I never thought they would ask about something that happened in the past. I had to think of what happened? I had to think what happened in the last four weeks.
Participant 2: I wished they did not ask about 'last month' but maybe they should have asked something like, "what are the challenges that you came across last year", I think what would sound much better to me, not to specify last month only. If they put a time frame of a year at least.
Participant 3: And some of the information we did not give out because the question was in the 'last 4 weeks'. And what if something happened in December?
Participant 4: True, and that did not happen in the last four weeks.
Participant 5: And if there is, you think of the date, trying to get the exact date and you want to tell about it, say it happened in January but because of the time stipulated, you are going to say it happened in February.
………
Participant 6: And sometimes, it happened but you cannot recall exactly when.
Participant 7: If they have to put a time frame, let it be a longer time.
Participant 8: It is same like when they say, "last day", it could be something that happened in January, so, this time is not really clear.
Moderator: You prefer to be asked, if it happened and not give time frame?
Participants (several): Yes

Similarly, the Zulu urban group of older people interpreted the time reference to means one had to be in that state the whole time in order to note it as present.

> *They give you a time frame of four weeks, - they want to know if were nervous, down spirited or depressed 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. And if you're happy, you forget about the things that make you to feel depressed. And you can't measure depression in terms of time frame. So that's why I am saying they were confusing.*

The distance reference raised some concerns as well and the general sentiment was that the best way to present the seven metre or one kilometer distance was to give a concrete example.
The Xhosa rural group of people living with HIV/AIDS commented as follows:

> *Participant 1: I do not think that it is all of us that understand the metres. I could be understanding and what about the others, I think, it is not everybody that understand this system of measuring.*
> *Participant 2: We were ticking because we had to make an estimation.*
> *Moderator: You say it was difficult to estimate?*
> *Participants (several): Yes.*
> *Moderator: So you prefer to have?*
> *Participant 1: That if I see something at a distance and not the metres.*

The English urban group of people living with HIV/AIDS commented on the need for a clear reference:

> *Oh, it was not easy for me, but I've got to include there because they talk about across the street. Across the street, okay, I will recognise my friend. But the seven*

> *metres… I'm not good on metres and kilometres! So to include the "across the street" just helped me to give the answer.*

While another participant remarked that for him it was easy as he '*was a tiler and I used a tape measure'*.

The Zulu urban group of older people did not have any problems with the distance reference.

c) 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. Comments such as the following reflect these sentiments.

> *I do not think there are any since we have answered everything.* [Zulu urban group of older people]
>
> *No we were not embarrassed, we were free to answer. [Tsonga rural chronic illness group]*
>
> *Yes it [the questionnaire] is acceptable. And they [disabled people] are not embarrassed and they do not feel offended. [Tsonga rural chronic illness group]*
>
> *All these questions are general there is nothing wrong with them [Tswana rural group of older people]*

The problematic question or topics were seen as being questions about one's disability status (e.g. HIV status) and questions on marital status. The Tsonga rural chronic illness group suggested that

> *….being called by your disability like saying "this blind person" this makes them feel offended. But when a blind woman is asked whether she is married or having children these questions do not offend them. These questions are acceptable.*

Whereas participants in the Tswana rural group of older people expressed strong views about being asked questions on marital status:

Participant 1: *Yes, some of the questions were embarrassing like the one that asks about our marital status.*
Moderator: *Is it embarrassing if you answer that in front of other people?*
Participant 1: *Sometimes you find that it's a customary marriage, and some people don't know that you have separated with your partner, and then he goes and marries someone else, people will know that we were not legally married.*
Participant 2: *You see now, that's what we are talking about.*
Moderator: *Are you saying it will be better if we ask you in private not in a group discussion?*
Participant 2: *Yes its embarrassing in group discussion especially if there is someone here you don't see eye to eye with, they will go around telling people about your private affairs, and the whole world will know about me. Some of the questions are very personal and confidential.*

A participant from the English urban group of people living with HIV/AIDS felt strongly that asking one's disability or HIV status was very sensitive.

> *Sometimes, maybe when people ask directly, why are you disabled. Take for instance a person who is in a wheelchair, which means that person needs to go back to the situation where he or she… the disability. Or for instance, in the case of HIV-positive*

> *people who might be called disabled... it will make them uncomfortable to be called that they are HIV-positive. Sometimes, if the questionnaire asks you directly what causes you to be disabled - something like that. Trying to recall... trying to be specific about your disability. Things like that, but I'm not quite sure...*

The only comment made by the English urban chronic illness group was that the questions '*make you feel very sad.*'

d) Difficulty answering the questions and response options

When asked about any difficulties participants had to answer the questions or use the response options, the Tsonga rural chronic illness group and the Zulu urban group of older people said they had no difficulties.

A strong feeling that was expressed in the Xhosa rural group of people living with HIV/AIDS was that the questions should allow for much more elaboration by the respondent and not be limited by the response options.

Participant 1: You know, where it says "Were you abused [reference to the questions on emotional functioning] in the last four weeks? Maybe you are expecting a person to respond by saying, one day, this and that happened and maybe the interviewee does not like the idea of just ticking. The idea of ticking that, it happened, it did not, it happened seldom or it happened frequently. You might have liked it to be in that way or having the interviewee specifying in her own words what happened, like, one day, I was abused by this man and so on, doing this and that or do you find it to be alright in this fashion?

Participant 2: No, no, no, I do want to say it is right because to me, it looked like a close-ended question whereby you were expected to say No or Yes but what we wanted was elaboration. So, I think, there must be open-ended questions and elaborations.

Participant 3: And I feel that it should not be stated that, "a little bit" or "a lot", I believe that there are degrees of these things; for an example, a little bit, a bit more, in fact you find that, sometimes, the difference is very small or not there at all. If you had a Yes or and a No, and then let the person elaborate if she wants to.

Although this was contrasted by the following comments from the same group:

Moderator: And how do the others feel?

Participant 1: We do not see this the same, some of the people are lazy to write just like me, when it is a Yes or a No, I just for that.

Participant 2: I think that was a good way of putting it because with some people, they are not lazy to tell a story and if you have to record that, where will that space come in? For, I think it is just right.

Participant 3: Same here.

One participant in the English urban chronic illness group felt that she had difficulty answering but not because of the structure of the questions but rather because of her own fragile emotional state.

> *I had a bit of difficulty because of the situation that I am in at the moment, you know being depressed and loosing two kids and then being emotional at the same time, so I had a bit of difficulty with the questions, you know like, when I was here at the*

> *hospital the last time, when I went to the Eye Clinic and they said to me it was my right eye, I have got early stages of cataracts and I think from the last time to now it actually deteriorated a lot so, you know it is stuff like that, because it actually depresses me because knowing that you have got kids and being in the situation that you are, sorry I am getting a bit emotional, and it actually you know at times you are not sure how to respond with something like this*

And another member of this group felt unsure how to answer and so reported no difficulty when in fact he/she did have some quite significant difficulties. It would have been interesting to ask this participant if the reticence was because of the introduction of the concept of disability quite early on in the questionnaire.

> *Well in my case I am not sure how to, I just filled it in as No, but even if I have to walk long distance it is a real mission for me, you know I mean even like going somewhere, I mean I can't even see the numbers of the bus, so I basically have to ask somebody, because that is how, but I filled it in as No, because I wasn't sure how to.*

The English urban group of people living with HIV/AIDS discussed the response options and tried to give some definitions of these.

Moderator: *What do you think they mean by some difficulty versus a lot of difficulty? U, how would you think to yourself, oh, I've got some difficulty - or how will you come to the conclusion that you've got a lot of difficulty?*

Participant 1: *I would say I've got some difficulty if I don't know something or I don't understand something. But at the end of the day, I would know some things.*

Moderator: *And a lot?*

Participant 1: *And with a lot you always know that there are some things.... You don't know that only.*

Moderator: *And then when will you say completely unable?*

Participant 1: *You don't understand at all.*

Participants (several): *Yes.*

………

Moderator: *When will you say you have a big problem and when will you say that you have a little problem?*

Participant: *If it's a big problem, that problem you can't solve. Then you discuss that problem with someone else and you can get some views from others - that is if it's a big problem. But if it is a minor problem, you can solve it yourself. Or you can speak to someone else. You just need two or three people to discuss it - and you can solve it.*

e) Scope of the questions

As for the disabled groups, these groups 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 a participant in the Zulu urban group of older people.

> *And what I liked a lot about these questions is that there are things that happen in our daily lives of which we are willing to discuss them with people around us because they might look down on us but here we get a chance to voice those things out. And*

> *what I disliked is the fact that we have a closed-ended questions like the one that says, 'are you disabled' because I think there is a lot that I waned to say.*

And from a participant in the English urban group of people living with HIV/AIDS

> *Ja, the format of the questionnaire is not difficult. It's all right, but next time, let's try and be specific: each and every question just specific why you ask this question for this and this and this. Like now you're asking a question, and through my status I can [link]... it out to my status. Although you are not talking about my status, but since the question is similar to the thing that I am, I can briefly [answer] as I know who I am. But it can be better if they are more specific.*

And from the same group, another participant

> *I think these questions were nice for me because they make something... they don't judge another person. Because you can have peripheral neuropathy; you can't walk. The people can judge you: that guy is disabled - but he didn't know you, that that guy is disabled. Peripheral neuropathy... for some things you can get treatment and then it is better - the disability is gone. The questions are good for me - because that is the life skills.*

A participant from the English urban group of people 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. And it worries me because even this questionnaire would be administered to the public...This disability, I don't know whether it's a concept or what. 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.*

There was only one comment made about the usefulness of asking these questions and this was not so much in terms of the need for correct information, but rather on whether the information would result in any significant changes. This was raised by a participant in the Xhosa rural group of people living with HIV/AIDS.

> *I would like to find out from you ladies [facilitator and note taker], what is the purpose of this, and what is going to happen, who is going to benefit. In terms of things like infrastructures, because they are the cause of the problems we are experiencing especially here in the rural areas. Is there anything that you will assist us with the problems that we have?*

f) Frame of reference used by participants in responding

Few comments provided any 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.

From the Zulu urban group of older people, the issue of the 'broadness':

Moderator: *Okay did you find anything difficult to understand on the questions that are on the questionnaire?*
Participant: *The question regarding disability is a bit difficult to understand.*
Moderator: *You are saying a question related to disability is difficult?*
Participant: *Yes.*

Moderator: *What makes you say that?*
Participant: *The word disability can mean many things in your body.*

From the English urban chronic illness group, the use of 'health problem' to frame their answers

Moderator: *Did you have difficulty seeing or walking because of a health problem or did you just answer, not related, it could be emotions?*
Participant 1: *My own health problems, definitely.*
Participant 2: *... questions bring to light any minor health problem that you had, that is out of your mind when you answered the questions.*

From the Xhosa rural group of people living with HIV/AIDS, the 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.*

6.3.1.2 Comments on core and non-core sets of questions on functioning

The themes arising from the discussions pertaining to the core and non-core sets of functioning 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), and queries about the questions on emotional functioning at the end of the questionnaire (Questions 42 – 46).

The English urban group of people living with HIV/AIDS 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.

Participant 1: *Another question that is difficult is the one that is asking about the emotional problems. I don't know whether... you could not convince others because of your emotional state. So that is not easy for me! Ja, it's this question.*
Moderator: *Because of a physical, mental, emotional health condition, do you have difficulty communicating.*
Participant 1: *Hmm.*
Moderator: *For example, understanding others or being understood by them.*
Participant 1: *Hmm. For me, it was not easy to answer because sometimes you get emotional... emotional because of your ill-health, so I don't know how to answer it because sometimes you will find that you get emotional in a particular or in a certain situation, but maybe not because of your health but because of maybe your personality or other elements. So it was not clear to me.*
Moderator: *So you mean that it must be more clear that it's because of the health problem.*
Participants (several): *Hmm.*

The same group also made a comment about the phrase 'even if wearing glasses'. They felt there should be space for the respondent to provide clarification.

> *If they can say, support your statements like... support your statements. Like the question, is it difficult for you to see when you are wearing glasses... so if there was a thing that was saying, please support your statement... I have no glasses and I can't see.*

The group went onto to have the following discussion:

Participant 1: That question, is it difficult to see when you wear glasses, I can't see but I have no glasses! I don't know what to choose.
Moderator: Do you have difficulty with the question or do you have difficulty seeing?
Participant 1: Even if you are wearing glasses.
Moderator: So even if you are wearing glasses like M and she still has difficulty seeing.
Participant 1: Hmm.
Moderator: Are you saying you can't see because you don't have glasses.
Participant 1: Hmm.
Moderator: You need glasses. Okay. So how would you prefer this question to read? Would you prefer for it to read: do you have difficult seeing?
Participant 1: Hmm.
Moderator: Without the glasses.
Participants (several): Yes.
Participant 1: And do you have difficulty hearing without that hearing aid.
Moderator: Take out. It's question 13.

The participants from the Xhosa rural group of people living with HIV/AIDS raised the issue of what was meant in the community participation question. They felt that it should clarify whether it is about the attitudes of others towards a person who is HIV positive, or difficulties that an HIV positive person has living in their community, although these two issues are clearly not mutually exclusive.

Participant 1: Okay, here is my question, I did not understand the part where we were asked what kind of problems did we encounter from the people. We had a lot of problems and that is why I am saying these things, the two of them should be taught together because they fit together. So, I did not understand what was needed here, were they looking for the real problem experienced or the general ones that are we come across as we meet with different people?
Participant 2: 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.

The participants in the Tswana rural older group raised issues with the questions on emotional functioning. They seemed to think that the response required was an all or nothing one. They did not seem to understand the idea of an averaging out over the time period specified.

Moderator: The confusing ones, what were you saying, Sir?

Participant 1: The one that confused me the most was the last question, I think from 42 to 46.
Moderator: The one that says from 1 to 6?[describing the response options]
Participant : Yes, that one, that asks if during the past four weeks were you nervous, I mean you can't be nervous for the whole four weeks and the somewhere I marked 'no', and another question follows and ask you if during the past four were you happy and I marked 'yes'.
(The Moderator laughs)
Participant 2: I agree with you

An important aspect of reviewing the core questions is to determine whether people felt that these questions reflected their own lives and experiences. If they do reflect people's experiences then this would suggest that the questions are correctly targeted.

The Zulu urban group of older people felt strongly that the questions did reflect their situation and shown by the following quote from one of the participants. The quote also highlights the negativity linked to being asked 'are you disabled'. This contrast between the core set and the 'are you disabled?' questions is also reflected in the different estimates obtained on each of these as discussed in the section on the quantitative analysis.

> *And what I liked a lot about these questions is that there are things that happen in our daily lives of which we are willing to discuss them with people around us because they might look down on us but here we get a chance to voice those things out. And what I disliked is the fact that we have a closed-ended questions like the one that says, 'are you disabled' because I think there is a lot that I wanted to say.*

This sentiment was echoed by the Tsonga rural chronic illness group:

> *I have a child like Bongi [one of the scenarios]. You will wake her up, bathe her and dress her up but she is going to take time in wearing [putting on] a sock. She will sit and forget that she was wearing a sock. She will sit and then remembers that she was wearing a sock is then that she will put on the other sock.*

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. But the questions, they come for disabled people. And then ask if you have answered the question, you are too outside. So the people who are disabled in the community. Because you are not disabled. 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.*

Although two other participants in the same group did feel that the questions were relevant to their lives.

Moderator: Did some of the questions make you think about yourself?
Participant 1: Some of them. Because another question, they are talking about myself. For example, the question about if you wake up in the morning, you can run away because… it is direct that question. I can't think for the other person next to me.
Moderator: N, you want to say something?

Participant 2: I thought the questions were about us - about HIV and Aids. So I support my colleagues.

6.3.1.3 Comments on background questions

The only two points made by the six groups in relation to the background questions were on the question on their current living situation (Question 4) and the employment questions as for the other groups (Questions 11.1 – 11.6).

One participant in the English urban chronic illness group had the following to say about their current living situation.

Participant 1: (unclear) living in an institution or hospitalized, my case I have lost everything, I am living with a brother in a house, he has taken us in.
Moderator: So you don't fit into either.
Participant 1: (unclear), living in an institution or hospitalized I am not.
Moderator: Okay, so you wanted another, you would want another category?
Participant 1: No, I want to know where.
M: Where you fit in?
Participant 2: I have a similar, ja, I had a similar question that I asked J [the facilitator]
Participant 3: I had a similar question basically, where being, my husband and I being unemployed and the flat that we were staying in, we were evicted due to the fact that we are unemployed, because we couldn't come up with the rent and our pastor has taken us in at the local church where we attend, so that is one of the questions that I asked, the first question and I think what, in that category when you have three answers there basically in order to choose from they should put another one to say 'other', you know.

The employment question was raised by only one group, the English urban group of people living with HIV/AIDS.

Participant 1: The one question was confusing. It was the question that was calling word voluntary and ... Because I remember in the question, if you had something, then the voluntary, you can't get everything. It was confusing sometimes.
Moderator: Because volunteers don't earn any money, whereas casual workers do.
Participant 1: Definitely.

6.3.1.4 Suggestions for further questions

The suggestions provided by the 'unsure' groups on further topics and questions to be added included the need to have questions that are more 'specific' suggesting that this should relate more specifically to the type of problems experienced in this 'unsure' group. The issue of attitudes and treatment of disabled people was also raised as an area that required questions.

The English urban group of people living with HIV/AIDS continued in their theme of not feeling that the questions addressed them specifically.

> *Ja, the format of the questionnaire is not difficult. It's all right, but next time, let's try and be specific: each and every question just specific why you ask this question for this and this and this. Like now you're asking a question, and through my status I can ... it out to my status. Although you are not talking about my status, but since the*

> *question is similar to the thing that I am, I can briefly as I know who I am. But it can be better if they are more specific.*

The Tswana rural groups of older people felt strongly about the way disabled people are treated.

> *This thing about that blind man, let me say hiding a disabled person, its not supposed to be like that because he is also a human being just like any other person, people need to be informed not to hide a disable person away from others but to take him outside, he needs to be accepted so as to feel comfortable about himself, he is not different from any other person.*

6.3.2 What is disability?

Of interest in this group of participants allocated an 'unsure' disability status is the extent to which they identify or not with being disabled versus having difficulties. This section will review the themes that were raised in the different discussions on what is disability.

6.3.2.1 A universal versus minority view of who is disabled

The English urban groups of people living with HIV/AIDS raised the issue of whether these questions really were for them rather than for disabled people. This suggests a minority perspective in relation to disability.

> *Okay, the question was tricky because you are coming here for HIV/Aids. But the questions, they come for disabled people. And then ask if you have answered the question, you are too outside. So the people who are disabled in the community. Because you are not disabled. 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.*

Although some other participants in the same group showed a more universal perspective in their comments:

Moderator: *Did some of the questions make you think about yourself?*
Participant 1: *Some of them. Because another question, they are talking about myself. For example, the question about if you wake up in the morning, you can run away because... it is direct that question. I can't think for the other person next to me.*
Moderator: *N, you want to say something?*
Participant 2: *I thought the questions were about us - about HIV and Aids. So I support my colleagues.*

Another participant in this group of people living with HIV/AIDS grappled with the notion of a broad or narrow perspective on disability. Clearly, this participant has a more minority focus and the questionnaire is challenging that, but does make it difficult for the person to understand how to answer.

> *For me, the questions in the questionnaire were too general. And it worries me because even this questionnaire would be administered to the public... This disability, I don't know whether it's a concept or what. 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. And I said in the first place, that to me disability is only the physical disability or physical indications that this person is disabled. But it will need people to understand that disability is not only a physical thing. It might*

> *also be other things. Like with the HIV we were talking about that there are people that are also classified as disabled. And I also understand that there are other issues like the other disorders that may also be evident and also fall in this disability field. So it is a very broad concept. It needs to be… it is too much an area for me. I couldn't grasp it at the first point, but I'm just worried about other people who might also have this questionnaire, because some of the people, they just think that maybe in a certain way that… I described disability in the first place.*

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.

Participant 1: I mean, if her or his fingers can move and do everything, there is nothing wrong with that person, just being lazy.

Participant 2: A person that cannot pick up say a spoon because the fingers are not working, or are not there, that is more like a crippled person and that is a disabled person because he or she cannot make use of his or her fingers. An overweight person is just lazy to move the fingers around and that is not overweight.

Participant 3: A question similar to this one, where the question is about using fingers.

Moderator: And what did you tick?

Participant 3: I said, I can and that does not make me a disabled person. Being crippled and overweight are two different things.

………

Moderator: You mentioned to us that you have a problem of hearing well, would you consider yourself disabled?

Participant 4: I am not disabled, the thing is that, I cannot hear very well if a person is far away from me.

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' suggesting 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.*

6.3.2.2 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 stronger on disability being visible and physical but do indicate quite a wide variety of other perspectives.

From the Zulu urban group of older people, there was recognition that disability is more than just the visible and physical.

> *There are many types of disability one would be mentally or a part of the body. Maybe a person does not understand well what is being said and other one would be if someone if the part of the body is not okay.*

And other participants from the same group added the following comments on how one can decide whether a person is disabled or not:

> *By what person say or does.*

> *If a person can not use parts of the body.*
>
> *I say there are different types of disability one would be in the body and the other one would be in mind. The way person behaves.*
>
> *One would not control his or her saliva then you can tell.*
> *A person who can not control parts of the body and he does not know other people.*
>
> *It differs one can not do things by himself he needs help and others would just talk whatever that comes to mind. One would be slow thinker and one would talk things that do not make sense.*
>
> *A person who does something wrong often and they get fed up easily.*

The perspective of disability being more than just physical and visible was shared by the participants in the Tsonga rural chronic illness group although some participants retained the narrower view.

> *There are different types of disabilities, like to be physically disabled / disabled in one's mind. This lead to how the brain functions. If the brain is not well one will not have power to do whatever is expected of them.*
>
> *A disabled person is someone who is not able to do things for themselves, and always sleeping.*
>
> *A disabled person is a person without hands or eyes.*
>
> *A disabled person is somebody with no legs.*
>
> *To be disabled is when one does not have hands because He /she will not be able to do anything for themselves. Even if the person does not have legs, that person is disabled because she / he will not be able to walk.*

The participants in the English urban group of people living with HIV/AIDS were more categorical in their perspective of disability as being a physical and visible attribute.

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

And gave the example of someone who looks 'normal' but does not function 'normally' as indicated by having failed the same school year a number of times.

Moderator: *He is disabled.*

Participant 1: *But he is normal. He's normal; he's looking like you.*

………

Participant 2: *I also want to say something. I think all these questions in this questionnaire bring another thing in my mind: we can't just say a disability is all about physical appearance. There are also mental disorders which are disabilities. Because if we hear now you are talking about other things that make a person to not function, but if you look at that person, the person is fine. He can hear and he can see - but there is still a disability because his or her function has been hurt. So I think I don't know who is declaring when it's a*

> *disability! It's not only a person who is blind or crippled or whatever that is disabled. Other things should also be added.*

A further comment from this group highlighted the fact that often one cannot see if a person is disabled:

> *The sign languages you see. You can't see when the people are disabled. Most times for disabled people... sometimes, they can't talk. The people who are blind, but they are wearing the shades. You can't see that people are disabled.*

6.3.2.3 Disability as a permanent problem

There were few comments that spoke to the notion of disability being something permanent. The one comment was made by a participant in the English urban group of people living with HIV/AIDS.

Moderator: *So when you think about it as a committee whether you classify a disability or not, is it when it's been very long or if it can be corrected by surgery, does that make a difference? If you can go into the hospital and have an operation, is it still a disability?*

Participant: *For me, I don't think so. I think there is a temporary disability. For example, if you have TB and you can't walk, you have a disability for six months. The doctor gave you a disability grant for six months. That is a temporary disability because you can't work. You can't walk a long time - that's a temporary disability. After six months you will be all right to go to work*

The other comment was in fact raising the question as to whether the questionnaire was trying to ask about both temporary as well as permanent disability. It was made by a participant in the Xhosa rural group of people living with HIV/AIDS.

> *I would like clarity on this, this disabled person, means a person who cannot do these things as they have mentioned, being unable to wash self or talk because s/he is sick. A person can be in that situation for say, a month, like this month and the next month be able to do them again. Or are you looking for someone that is born disabled or a person that has become disabled because of an accident. You can have a person that is disabled because s/he was born like that and you can be disabled because you had an accident or something happening to you or sometimes, you find a person being blind when s/he could see and in just a flash, turn blind.*

6.3.2.4 Disability as activity limitation

In this section we consider the difficulties at the whole person level or difficulties in functioning. 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. Some of these are presented below and are generally responses to the question on what does it mean to be disabled or how do you know if a person is disabled.
From the Zulu urban group of older people

> *I tell by what that person does.*
>
> *If you cannot do things that you like at that time you are disabled.*
>
> *If you go to a doctor and he gives you glasses and still you can not see it means that you are disabled.*

From the English urban chronic illness group

> *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.*
>
> *Sometimes you can't even use the toilet, you can't even help yourself that is a difficulty.*

From the English urban group of people living with HIV/AIDS

> *For me, disability means physical disability. It means that you can't walk; you can't do things for yourself. Like you've got to have an assistant or a person to help you. But you can maybe go to work or you can do ... work.*
>
> *So to me, disability is all about when you're not able to do things that you used to do.*
>
> *I think it is a disability because you must use your hands to work. Because if you have pain when you have to work... and the problem with the knees.*

Moderator: *Do you decide that somebody has a disability when they are 30 kilos overweight, or do you decide that somebody has a disability because they can't do what they did before?*
Participant: *Yes, they can't do the things that they did before.*

The Xhosa rural group of people living with HIV/AIDS talked about having an activity limitation but not being disabled.

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

This same group also discussed the role of environmental factors in determining whether a person is able to function or not. This touches on the discussion below on participation but is raised here to contrast with the notion of activity limitation where no mention is made of environment.

> *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. [steep hill is a barrier]*
>
> ………
>
> *For an example, speaking about me, I can walk up the stairs but if I were doing that for a longer time, I battle, my knees want to give in, and they become sore. If it is a climb maybe like a mountain or hill, I am not managing because I have that chest tightness but I cannot say I am disabled. [steps are a barrier]*
>
> ………
>
> *It could be like this, a person having eyes but not see, having ears but not hear, have hands but cannot use, but if a person can do something for him/herself, even if he or she is blind, deaf or have no legs, but if he or she can do something for him/herself, that person is not disabled. But if a person has all of these but cannot do anything for self, that person is disabled. If I have to do something for that person, it means that person is disabled. [role of personal assistance as a facilitator]*

6.3.2.5 The individual as the locus of the problem and source of change

In the non-disabled groups there were many comments made on the role of the individual as the locus of the problem and the source of change. The disabled groups were clear that the environment rather than the individual were the locus of the problem and source of change. In the 'unsure' groups no comments were made that suggested either position.

6.3.2.6 Level of independence

In this section we present themes that talk about independence as well as level of severity as determining whether a person is disabled or not. This issue of severity also highlights the sense that disability is all or nothing. Most of the quotes in this section suggest that a person who cannot 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'.

From the Zulu urban group of older people:

> *A person who cannot do anything for themselves is a disabled person. A sick person is a person who has leprosy – that person cannot do anything for themselves so they are disabled. That person will depend on other people to do things so these people are disabled. I just do not know how to put it but the person who cannot do things for themselves is a disabled person.*

From the Tsonga rural chronic illness group, with an interesting note about blind people not being disabled because they can do whatever they want.

> *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.*

> *A disabled person is someone who cannot do anything for themselves they have to be bathed, dressed, fed, picked up and being put onto the wheelchair, always sleeping this is a disabled people. But mentally ill people, blind people are not disabled because they can do whatever they want to do.*

> *A disabled is a person who depends on other people to do things for them. For example, to go to the toilet, when to have water or food. They do not say anything someone has to think for them they are like an infant that is a disabled person.*

One participant in this group made the link between so-called disabled people who are able to function very well and the participants in the group who all have a chronic illness. She is quite surprised to see that in fact disabled people are able to function independently. Of interest is that recruitment for this group of people with chronic illness was done by a person who is blind.

> *The people we say are disabled are like us all because we were not ill but now we are we now fall under the group of sick people. D is a blind person but she uses her phone like a person who sees. She can store people's numbers without the next person's help, or asking where is A or where is B she does these things on their own. She does that to the surprise of many people.*

From the English urban chronic illness group

Participant 1: *...disabled is when you can't do nothing*
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.*

> *They [disabled people] 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.*

Moderator: *Does a difficulty mean a disability?*
Participant: *Not necessarily, because a disability is something else, disability is when you can't do nothing for yourself.*

From the English urban group of people living with HIV/AIDS
Participant 1: *Okay, in my view you are disabled when people can't do the things they used to do before. As I understand it, disabled means somebody who can do nothing. They need everybody to do their things for them.*
Moderator: *And U, what decides whether a person is disabled or not?*
Participant 2: *For me, I would decide when the person can't do things for himself or herself. You see, that person is disabled. If that person is disabled... if that person can do something like just selling sweets or chips. Sit down there by the stalls; they can sell some sweets there. At least they are not disabled in their minds. It's just your hands or your legs or whatever. But in your brain there are a lot of things that you can do. Nobody is disabled. Because those people, they can be disabled by the legs - but they can do the computer. They can use anything. I don't think those people are disabled.*

From the Xhosa rural group of people living with HIV/AIDS

> *A person who cannot do things for him/herself.*
>
> *A person who cannot talk, crippled.*
>
> *You could have hurt yourself somewhere in your body but be able to do things like normal, things that you are used to doing but that part where you had hurt yourself, show that it is not the same as the others, that you are affected in that particular area. In that case, I would say, you are able.*

But some participants in this group also raised the issue of self identification being important in deciding 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.*

And followed by an example of someone in the group who feels very clearly that she is not disabled.
Participant 1: *I do get tired when I have to walk or climb steeps, steeps up or down, I get tired.*
Moderator: *Would you call yourself disabled? The fact that you get tired, does that qualify you as a disabled person?*
Participant 1: *Not at all. I just get tired and not disabled.*

The issue of severity was raised by some participants as a factor to consider in deciding whether they or someone else are disabled or not.
From the Xhosa rural group of people living with HIV/AIDS

Participant 1: No, you just forgot where you put it at that particular time, but like you say, you remembered some time later. A disabled person would not remember and it will be something else maybe within a short space of time, that is not okay, that is what I call disabled.
Participant 2: Not remembering one thing, that is not bad but forgetting most of the time, that is a problem.
Participant 3: An example, some of you could have forgotten my name, that is not bad because it can happen, but if a person that stays with me forgets who I am, that is a problem. Look, I did not forget that I was invited to this session.

From the Tswana rural group of older people
Moderator: Sir, if you say your leg is injured and sometimes you can't walk especially a long distance, is that a problem to you? Do you say he is disabled?
Participant: He is partially disabled.
Moderator: If we say someone is partially disabled, what do we mean?
Participant 1: Is just that he can still do things but if his leg is painful, he can't do anything.
Participant 2: Yes, just like me, if had rained I usually have a problem.
Moderator: With that problem, would you say, you're partially disabled or totally disabled?
Participant 2: I think I am partially disabled.

This group went onto discussing the case of someone having asthma and having difficulty climbing stairs because of that.
Participant 1: It's not that he is disabled, he can do whatever he wants to do it's just that he is asthmatic, that's all.
Participant 2: I still say he is disabled because I have seen how is difficult it is for my co-worker to do things because he has got asthma
Moderator: Does he take medicines?
Participant 2: Yes, even though he takes medicines he still feels weak, he can't manage, he has got no power.
Participant 3: The way I understand the question he is not disabled, maybe if has a big problem walking a long distance it can be an illness not to say he is disabled.

6.3.2.7 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.
From the English urban chronic illness group
Participant 1: It [whether you experience difficulty or not] depends on what type of occupation you are involved in.
Moderator: Okay.
Participant 1: I took a course on selling houses, property and I realized 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, so it became, that job I had to exclude from any possibility of doing.

………

Then it became a disability, that particular occupation, I can do other things, with headphones I don't have a problem, so I can do

> *other things quite, with the same problem same difficulty it doesn't set a problem doing that job with assistance, like headphones.*

From the English urban group of people living with HIV/AIDS

> *He [George in the scenarios] is disabled because a blind person... especially in the rural areas... if you do understand or not the situation... there are no proper roads - nothing. You have to go... I mean, there are no roads - not like here. Sometimes, you will find a blind person walking down the street ... going to the blind association. That person can walk there because it's a tarred road and use that stick. Maybe this man doesn't even have that stick to show him the way to go. So I think he is disabled, because all the time, he needs somebody else to help him to go to the shop or elsewhere. So he is disabled.*

The Xhosa rural group of people living with HIV/AIDS did not seem to think that anything could be done to facilitate a disabled person's participation in community activities:

Moderator: In other words, he will have problems taking part?
Participant 1: Exactly.
Participant 2: There is nothing that he can do.
Moderator: You all agree that a disabled person would have a problem taking part in community activities?
Participant : Yes.

6.3.2.8 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 Tsonga rural chronic illness group.

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

Another participant in the same group went on to say that disability and difficulty are not the same.

> *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.*

The English urban chronic illness group also described the two as being different and suggesting that difficulty is less severe than disability.

Moderator: Does a difficulty mean a disability?
Participant 1: Not necessarily, because a disability is something else, disability is when you can't do nothing for yourself.
Moderator: So you can have a difficulty but you are still not disabled?
Participant 1: Ja, you are still not disabled.
Participant 2: Disabled is when you are seeing someone in a wheelchair, who needs hospitalization who can't do very much for himself.

And this group goes onto identify themselves as having difficulties rather than disability, but with the last participant raising the issue of context as being important in determining disability.

Moderator: Would you think of your chronic illness whether it is arthritis, lungs, asthma as a difficulty or a disability?
Participant 1: Difficulty.
Moderator: Difficulty. F, do you think it is a difficulty?
Participant 2: Difficulty.
Moderato: Not a disability?
Participant 2: No.
Participant 3: It depends on what type of occupation you are involved in.

But they do acknowledge that disabled people have difficulties.
Moderator: Can I just ask another thing? People who are disabled do they have difficulty?
Participants (several):Yes.
Participant 1: Sometimes you can't even use the toilet, you can't even help yourself that is a difficulty.

A participant from the Xhosa rural group of people living with HIV/AIDS describes how she has difficulty climbing steps but does not see this as disability.
Participant 1: I do get tired when I have to walk or climb steps, steps up or down, I get tired.
Moderator: Would you call yourself disabled? The fact that you get tired, does that qualify you as a disabled person?
Participant 1: Not at all. I just get tired and not disabled.

6.3.2.9 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.

A participant in the Zulu urban group of older people made it clear that being sick is not being disabled.
Moderator: Yes like i can use my hands but i can not use them now because of the pain maybe does that mean I am disabled?
Participant 1: You are sick not disabled.
Moderator: I am sick not disabled.

The question 'Are you disabled?' cause problems for a participant in the English urban chronic illness group 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'.
Moderator: You had no problems? How did other people respond to the question, are you disabled?
Participant 1: No.
Participant 2: I didn't understand that because I have got like high blood, I have got problems with my bladder, I have, sometimes I am tired, so I didn't know what to fill in there.
And the discussion in this same group went on to look at when an illness becomes a disability in relation to the husband of one of the participants who has become quite ill.
Moderator: He is very sick and he might not go back to work?
Participant 1: Yes (unclear) tumor in the brain, angiogram to take place at the end of the day or the end of that year, (unclear) total disabled case, go back to his job.

Moderator: What do you think as a group?
Participant 2: If a sickness becomes serious.
Moderator: If a sickness becomes serious then?
Participant 2: He is going to become disabled.

The groups of people living with HIV/AIDS had some clear positions on the difference between disability and HIV/AIDS. The English urban group had this to say:

Moderator: Are the attitudes towards people with disabilities the same as the attitudes towards people with HIV?
Participant 1: Yes.
Participants (several): No.
Participant 2: It is better when you are disabled. Because with the HIV status there is a strong attitude. Because the people, they didn't know about HIV…The people, if they see that you are HIV-positive, they don't want to take your spoon; they don't want to take your chair where you are sitting. But if you are disabled… you can eat with people who are disabled, but a lot of people, they don't want to sit with the people who are HIV positive.

The same group expresses mixed views on whether people living with HIV/AIDS are disabled or not.

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. They don't want to go to work. So he says, shame, I'm HIV positive. I can't do this and I can't do that. I can't eat this and that.
Participant 3: And sometimes I can't get a job because they need your status on whether you HIV negative or HIV positive. So if they find that you are HIV positive, they just chase you away from work. Then you have to get some money to buy food for yourself.
Moderator: If you filled out a questionnaire, would you say that you had a disability or not? Would you think of yourself as having a disability or not?
Participants (many): No!
Participant 4: It just depends on how you see yourself. Are you seeing yourself as disabled, or are you seeing yourself as having the virus - but you're healthy - things like that. It depends on the person. Take for instance a person with full-blown AIDS: a person who is bedridden and who can't go to work - can't do anything, that person may describe him or herself as disabled. He can't work - he can't do anything. So it depends on the person.

A participant from the rural group of people living with HIV/AIDS expressed a worry that she was being forced to take on an identify of being disabled.

> *As we are living with HIV, that when we are at stage 3 and 4, we have to get a disability grant. It is not something that we want, this disability grant but I just wonder why the government is putting it as a disability grant. Why? I am not saying we do not want it, we do 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?*

A similar discussion occurred on the issue of depression as took place in the other non-disabled and non-disabled groups. The urban group of people living with HIV/AIDS made it clear that they did not consider depression as being a disability.

Participant 1: No. Maybe she has depression or stress, but she is not disabled.
Moderator: If you have depression or stress, are you disabled?
Participants (a few): No.
Participant 2: She is not disabled. I think she forgets it because of stress.
Moderator: Okay, so a person who has a depression is not disabled?
Participants (several): No.

While another participant in this group reflected on whether she is disabled when she gets so depressed that she cannot get up and function. Her colleagues remark on the difficult question she is asking.

Participant 1: When I am depressed, I only want to sleep and being alone, not having anyone next to me and no radio playing. I want to sleep over, I want nothing else. So, I am not sure, am I disabled at that moment?
Moderator: Would that constitute disablement at that time?
Participant 1: I would be disabled due to complications of depression, maybe, I do not know.
Participant 2: Shoo, your questions are difficult.
Participant 3: I do no think that a depressed person is disabled.

The Tswana group of older people reflected on whether having difficulty walking because of severe asthma counted as a disability or not. The feelings were mixed.

Moderator: What if he says he has a problem with going up the stairs or with walking?
Participant 1: It can be disability, if his body cannot function well; I agree that he can be disabled. So many people have asthma; you can see that he there some other things he cannot do.
Participant 2: It's not that he is disabled, he can do whatever he wants to do it's just that he is asthmatic that's all.
Participant 3: I still say he is disabled because I have seen how is difficult it is for my co-worker to do things because he is got asthma

6.3.2.11 Self identified disability status

Of interest with these 'unsure' groups is to see whether they would identify themselves as disabled or not. A participant in the Tsonga rural chronic illness group 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 under. All of us here are ill and we are not disabled but having difficulties. Even the blind people are not disabled, they are just blind, and they can do things for themselves. Like when you go to their school they do not like it when you stare at them. They can even jump from their wheelchairs asking what you are looking at. They want to be treated like anybody else.*

A participant from the English urban chronic illness group was less clear and she expressed difficulty in deciding whether she is disabled or not given her circumstances.

> *I had a bit of difficulty because of the situation that I am in at the moment, you know being depressed and loosing two kids and then being emotional at the same time, so I had a bit of difficulty with the questions, you know like, when I was here at the*

> *hospital the last time, when I went to the Eye Clinic and they said to me it was my right eye, I have got early stages of cataracts and I think from the last time to now it actually deteriorated a lot so, you know it is stuff like that, because it actually depresses me because knowing that you have got kids and being in the situation that you are, sorry I am getting a bit emotional, and it actually you know at times you are not sure how to respond with something like this*

One participant from the same group described himself as being disabled for a particular occupation because of his hearing difficulties but not as generally disabled.

Moderator: *So would you say that it made it a disability for you?*

Participant: *Then it became a disability, that particular occupation, I can do other things, with headphones I don't have a problem, so I can do other things quite, with the same problem same difficulty it doesn't set a problem doing that job with assistance, like headphones……I can do a lot of things I am not disabled, from the particular occupation [estate agent] I felt precluded me from contributing and I funnily enough tried it with a hearing aid and it is only sophisticated hearing aids that can help you in circumstances where more than one person speaking at the same time.*

A participant from the English urban group of people 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 finds this confusing.

> *Okay, the question was tricky because you are coming here for HIV/Aids. But the questions, they come for disabled people. And then ask if you have answered the question, you are too outside. So the people who are disabled in the community. Because you are not disabled. 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.*

The participants in the Xhosa rural groups of people 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.*

6.3.3 Responses to scenarios

The two tables below present the responses provided by the participants to the different scenarios. Table 22 presents the descriptions given by participants of people who gave hypothetical responses on the questions. Only those scenarios that were discussed in 2 or more groups are presented.

Table 22: Descriptions given by 'unsure' adult participants to the scenarios of hypothetical responses to the questions

	Sipho[28]	Saul[29]	Mary[30]	Peter[31]	Lena[32]
Is s/he disabled?	Yes and no	Yes and no	Not clearly indicated	Yes and no	Not disabled
Degree of difficulty	Not indicated	Not indicated	Not indicated	Not indicated	None
Consistency between groups	poor	poor	poor	poor	good
Zulu urban older people	Jealous; ashamed of himself; 'not well in terms of health'; depressed; disabled	Was not good to community; disabled so attracts attention;	Selfish; shy; does not trust herself; mentally disturbed	Disabled; chest problem; 'bones' problem;	-
Tswana rural older people	Not disabled;	Not disabled; does not like people	Problem with communication not with disability; 'does not have good heart'; self-centred;	Can be disabled and 'not disabled'; can have illness;	No problem – 'in a good state';
English urban chronic illness	Stressed; family problems; no transport; not open minded; no money.	Suicidal; no support from friends; not used to being with people;	Emotionally or physically hurt; reserved; shy.	-	Healthy; 'younger than I'; 'in control'.
Tsonga rural chronic illness	May be disabled or not; 'has certain disease'; people not kind so stays indoors.	-	-	Wheelchair user; lazy – not disabled;	-
Xhosa rural HIV/AIDS	-	-	-	-	-
English urban HIV/AIDS	Worried about discrimination; seen to be HIV+; not disabled	Denial; did not accept and is not accepted status; did not tell community his HIV status; not disabled; he's sick;	Difficult to go to community with HIV status – lack of communication;	'Peripheral neuropathy'; not disabled	Has a health problem like HIV+;

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[28] Sipho – difficulties in joining in community activities
[29] Saul – problem with support and attitudes of others
[30] Mary – difficulty with communication
[31] Peter – difficulty walking and climbing stairs
[32] Lena – No difficulty remembering and concentrating

The participants in the groups related their descriptions of these hypothetical respondents was very linked to their own experiences. This was particularly strong in the urban HIVAIDS group where the reasons given for all the problems experiences were related to HIV status, even the person with no difficulty was seen as being HIV positive but still healthy.

In Table 23, only those scenarios that were discussed by two or more groups are included. These are the responses given by the participants to the core questions for the described people in the different scenario.

Table 23: Responses given by the 'unsure' adult participants to the questions asked of hypothetical descriptions of adults with various difficulties

	Joseph[33] (Unsure)[34]	**Rose[35] (non-disabled)**	**Thomas[36] (disabled)**	**George[37] (disabled)**	**Jill[38] (non-disabled)**	**Bongi[39] (unsure)**
Is s/he disabled?	Mostly not disabled; one 'disabled in mind'	Mostly not disabled' one 'disabled in mind'.	Yes and no in one group only;	Is disabled (2 groups)	Not disabled	Difficulty; disability of the mind; is disabled
Degree of difficulty	Some or no for walking; no for community participation;	Yes and no for self care and communication	Yes and some for walking; no, some and 'definitely' for community participation	Yes and no for walking; 'daily' and unclear for attitudes of others;	No for all	No for self care; no and yes for community participation.
Consistency between groups	reasonable	reasonable	reasonable	reasonable	good	reasonable
Zulu urban older people	No on walking; yes on stairs; No problem for community participation	No problem with self care or communication;	Yes for walking; some problem with community participation	Problem to take a taxi; unable to see; daily problem with attitudes of others	No problems walking or community participation	No problem with self care and community participation;
Tswana rural older people	Not disabled; no for walking and community participation;	Yes for self care; no for communication; not disabled;	'Some' for walking; no for community participation;	no and yes for walking;	-	-
English urban chronic illness	Healthy; some for walking; no for community participation	No for self care; yes for communication;	Yes for walking; definitely for community participation	'can't walk'; not clear on attitudes of others.	No for walking and community activities;	No for self care; yes for community participation;
Tsonga rural chronic illness	Disabled in mind;	Disability in her mind;	Yes for walking and community participation.	No for walking; yes disabled	-	Disability of the mind; a difficulty;
Xhosa rural HIV/AIDS	-	-	-	-	-	-

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[33] Joseph – gets tired walking 1 Km

[34] The disability status in brackets is that allocated at the outset when writing the scenarios and is allocated in the same manner that the disability status was allocated to the focus groups.

[35] Rose – occasional depression

[36] Thomas – pain in joints especially mornings

[37] George – blind and living in a rural area

[38] Jill – jogs twice a week

[39] Bongi – slow in getting dressed

English urban HIV/AIDS	Not disabled;	Not disabled;	Not disabled because can take pills; is disabled because affects functioning;	Is disabled	Not disabled;	Is disabled.

In contrast to the disabled and non-disabled groups, the 'unsure' groups were literally 'unsure' in their responses about these hypothetical people. The only exception is Jill with no problems. The nature of the group moderation on these groups meant that the scenarios were not fully discussed.

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 questions asked initially are as follows:

- What are the participants' understandings 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?

While it would be interesting to see whether there are any differences in comments made by participants in relation to sex, geographical location, employment status and different education levels, this was not possible. The groups were in general mixed in terms of sex and population group and no discussion focussed on whether people were employed or not nor their education level. The main focus of the analysis is on the differences due to allocated disability status. 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 make much of these. 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.

7.1.1 Parents of children

Participants described and discussed what they meant by the term 'disability' using two approaches: parents referred to common words used to label children with disabilities, for example "backward" cripple" "unable" or they made a comparison to the normal child, and in particular what a normal child could or could not do.

Mothers with children who had disabilities had naturally a better understanding of disability and they could describe it more easily and broadly. They were also more positive about children or people with disabilities, and were the only ones who mentioned the benefit, (e.g. learning tolerance) of interacting with people with disabilities.

The role of the community is part of understanding who is disabled or not. This aspect is underestimated in the understanding of disability. Attitudes play a vital role in the acceptance and well being of people or children with disabilities. Negative attitudes can isolate a child with a disability making the situation worse. A person could also use a 'gain' or incentive, for example a disability grant, to identify himself as disabled. The feedback a person receives from the public is formative in the understanding a person may develop about himself with regards to being disabled. Society does not often admit to being prejudiced against people with disabilities and largely blame the individual. The mothers in the urban group identified this as 'a fear of people with disabilities' and they would justifiably like to know the reasons for this reaction. Perhaps this is a defense reaction of 'attack' by putting the blame onto people with disabilities.

All the mothers used 'comparison' as a frame of reference, to compare their children with disabilities to other 'normal' children. This helped them to identify that their child had a difficulty or disability. Comparing children to each other also gave the mothers a tool to make a statement on the severity of disability, namely some difficulty (slightly worse than normal) to a lot of difficulty (a lot worse than the normal). All mothers regardless of whether they are from a rural or urban area, have a disabled child or not, use comparison in answering questions about their children. Comparing children is therefore a useful tool to use in questioning mothers about their children as it is culturally appropriate, as the mothers are comparing children of the same culture and norms.

All participants agreed that disability is a permanent condition that affects the functioning of a person. This understanding helps to sort out some of the boundaries between an illness and disability. There is always a loss of ability or functioning of a person who is disabled. Although there is criticism that this is a negative view, based on inabilities, whereas people with disabilities have abilities, it does help us to understand and identify a person who has a permanent disability.

Participants referred to a health problem as temporary illness with a cure. Disability was seen as a permanent condition that affected the functioning of a person. So where there is confusion about the boundary between health and disability, the participation or functioning of a person must be examined. This will in the end determine whether someone could be considered disabled or not. So in the census questionnaire, the statement is "the next questions ask about difficulties you may have doing certain activities because of a health problem". This in fact might cause confusion for the participant as a 'health problem' is considered a temporary curable condition. Another word should probably be used.

The negative attitude that "disabled people should be treated as juniors" of one of the participants, in the Xhosa urban group of mothers with disabled children could have had an influence on the group dynamics and freedom to express their views.

7.1.2 Non-disabled adults

These groups expressed a strong notion of 'them disabled' and 'us normal'. They perceived disability to be a visible and physical attribute although this notion was challenged in the English urban youth group where the discussion itself generated a broader conceptualisation of what disability entails, including aspects such as phobias.

The groups had a clear notion of disability being a permanent feature and that there is no cure or solution to disability. The focus was on activity limitations that people have and that the problem lies with the individual. However, they did comment on the fact that a disabled person cannot choose to change, unlike a person who has a difficulty or an illness where a cure or solution can usually be found. The group participants had little awareness of the role of environmental factors in determining disability.

Disability and health were seen as separate and people living with HIV/AIDS are not seen as disabled nor people with chronic illness. However, the comment was made that most disabilities originate in some health problem or other such as an illness or an accident.

In responding to the scenarios, the non-disabled groups gave clear and consistent descriptions and responses when the problem was clear cut (e.g. difficulty walking or blindness) but varied in their responses when the problems were less clear cut (e.g. difficulty with concentrating and remembering).

Most of the participants felt that the questions did not reflect their experiences and were not relevant to themselves. This is confirmed by the responses on the three measures where the youth groups and urban adult groups showed consistently a 'non-disabled' status for the WG core set (D1), Census 2001 questions and the question 'Are you disabled?'. Only the rural adult groups showed some positive responses mainly on the WG core set.

7.1.3 Disabled Adults

The disabled group participants also espoused a notion of disability as being about 'us disabled' versus 'them' suggesting that they see themselves as a separate group. This was most pronounced in those groups where the participants were disability activists (e.g. physically disabled, visually impaired and Deaf groups) and less in the groups of people with hearing impairment and psychiatrically ill.

The groups of disabled adults also expressed the notion that disability is a permanent attribute with no recourse to a 'cure' or solution. A difficulty on the other had a solution. The sense of a disabled person being unable to do anything was a strong theme although this was tempered with discussions on how many of the disabled participants feel that they are able to do very much and are only limited in the areas of their specific impairments. This seems to be a contradiction in the understanding between an 'completely unable' vs 'only unable in one domain of functioning.' This is linked to the politics of disability and the need to identify oneself as disabled in order to access services, as was expressed in the Deaf group.

There seemed to be various perspectives on whether the notion of disability is an activity limitation or a participation restriction. While the sense of disability as not being 'curable' favours an activity limitation perspective, these groups also made many comments on the role of environmental factors in creating disability. These include the use of assistive technology, personal assistance and the attitudes of others. One blind participant described how her disability became evident when the questionnaire was presented in text and not in Braille. Her disability would be 'cured' if the questionnaire were presented in Braille.

In terms of health, these groups did not see health and disability as being linked. In fact some (Deaf group) found the use of the phrase 'because of a health problem' difficult to understand and read the questions as 'because of your Deafness' in stead. Health was seen as something that could be 'cured' whereas disability cannot. Aspects such as ears and eyes were seen as part of functioning and not of health. Health was seen as aches and pains.

These groups had some discussions on terminology for disability. The head injury group expressed problems with the term disabled as they were not sure how they fit within this terminology. They were also concerned with the sense of the term as being 'unable to do anything'; whereas they did not feel this applied to them at all.

The descriptions and responses provided for the scenarios was interesting in that the participants almost always described the hypothetical people as having the same impairment as themselves. So the physically disabled groups described the hypothetical people as having a physical disability, the schizophrenic group described them as having schizophrenia, and so on.

All the participants identified themselves as disabled except for most of the hearing impaired group and the Deaf group. The hearing impaired group had become hearing impaired mostly as they got older and did not identify as disabled. The Deaf group were clear that deafness is not a disability but that they did identify as disabled in order to access services such as a disability grant and other educational services.

7.1.4 'Unsure' adults

These participants felt that the questions were for disabled people and not themselves, although they did indicate that the questions did resonate with their own experiences and situations. This was expressed most vehemently by the groups of people living with HIV/AIDS who said that they were not disabled. This is reflected in their responses to the questions where they responded as 'non-disabled' on the Census 2001 and 'Are you disabled?' questions but came up as having difficulties on the WG core set of questions.

As for the other groups, these groups understood disability as being a permanent feature of an individual, being physical and visible but including aspects of behaviour as well. They also saw disabled people as not being able to do anything for themselves and needing assistance. They did not have significant awareness on the role of environmental factors in creating disability and made comments for example, that disabled people cannot participate in community activities if they cannot walk, see or hear. This shows a lack of awareness of all the possible adaptations possible to facilitate such participation, such as Braille printing, accessible venues, sign language interpreters, etc.

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. This section reviews the qualitative comments and quantitative analysis in relation to these questions to determine how well they have worked, how different groups interpreted them and the extent to which they reflect people's experiences.

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 your full participation in life activities'. This is substantiated by the comments made by disabled people that they have a vision or physical disability but 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. A further analysis would be to calculate the D2 estimate for the WG core set and see how it relates to the other two measures.

7.2.1 Reactions to the WG core and extended sets of questions

Each group provided many reactions to the questions and these are summarized below. In general. The questions were seen as being good questions, easy to answer and not too long to remember, and relatively easy to answer. Few problems were noted with the questions themselves.

7.2.1.1 Parents of children

All the groups reported that they did not have any difficulties with the layout of the questionnaire and understanding the questions. The time period was easy to understand and remember for most people. The questions were not thought to be sensitive and nearly all the participants felt comfortable answering the questions.

There is debate about the use of the word 'health problem' and people interpret this in many different ways. For some, they consider a health problem to be related to illness. So a person with a disability, as any normal person can be fully healthy and well or s/he can have a health problem or illness. From the comments in this study, people have responded to the concept of a 'health problem' as an illness, like AIDS, arthritis or cholera, but this does not necessarily affect the functioning of a person. Perhaps the word 'health condition' is more user friendly and does not link to necessarily a problem.

The criticism that the questions are not age appropriate for the very young child of under one year is valid. These questions are broad questions to cover all ages. In fact there are no valid survey type questions for the young child. The most commonly used questions are those comparing children to the same age but these are also not valid for children under one year. On the other side of the argument, the accurate diagnosis of a disability in a child under two years is cautioned, as there is the possibility of changes with maturation and early intervention. In the severely affected children with disabilities, it is easier to be more certain of a diagnosis. This aspect, namely to identify children with disabilities under the age of two years probably has to be accepted as a limitation of any survey or census.

Mothers of disabled children suggested that 'learning' be added to the question 'Does your child have difficulty in remembering and concentrating?'. This group made valid remarks about remembering and concentrating being inconsistent and dependent on the will and interest of the child. Whereas learning requires a child to function in a different context, namely educational and requires a new skill. There is a debate internationally whether 'learning', should be included in the question. Learning adds a broader context in which the mother can respond to the question. And essentially this is the functional requirement or role of children as they mature into adulthood. An inability to fulfill the learning role of a child would indicate a functional limitation. Of interest to note is that the additional of questions for the domain of 'learning' in the detailed set of WG questions, increased the positive identification of disability to an important degree.

7.2.1.2 Non-disabled adults

These groups found the questions easy to answer and had few difficulties. The response options were used without problems. The time references (recall period of 12 months, last month, last 7 days, etc.) were seen as manageable, although many participants said they in fact ignored these as and felt that two weeks would be easier than one month. They did not seem to think about an average response across the time period specified and felt they could not remember everything that happened. They also expressed the need for a clear reference for the distance measures used in questions. For example, to use 'across the road' is much easier to respond to than '7 metres' except for the tiler who felt that he was quite familiar with the notion of 7 metres!

The participants did not report any questions to be sensitive, except for a sense, generally, that the whole questionnaire was quite personal. Some comments suggested that the questions on emotional functioning could be rephrased to include an introductory phrase to 'soften' them. This could be something like 'Some people feel a little nervous or unhappy. How often have you felt happy or sad?'

The scope of the questions were seen as being clearly about disabled people. This was in part because of the introduction of the discussion as being about disability statistics, and the use of the question 'Are you disabled?' at the start of the questionnaire. Another aspect of the scope related to problems that occur as a common feature of life (e.g. feeling depressed briefly, forgetting to get something at the shops) and a more severe problem such not recognising anyone or feeling depressed over an extended period. The participants felt that more concrete examples would be useful to differentiate between these two levels of severity.

The questions were seen as being useful as they provided a means for government to get some accurate statistics on disability and the needs of disabled people.

The participants' comments suggest that they use a variety of different frames of reference in answering the questions, such as 'mood', 'circumstances', personal opinion based on experience and knowledge, as well as within a 'health problem' context. They also suggested that not all difficulties in concentrating and remembering, for example, could be attributed to a health problem.

The participants felt there should be more questions on mental health aspects.

7.2.1.3 Disabled adults

As for the other groups, these participants did not experience any major problems with the questions. However, there was a general sense that the questions were not specific enough to cater for their own impairment aspects nor about the needs of disabled people.

The time references were generally ignored and the notions of what happens 'usually' or 'normally' were used as the reference to answer the questions.

Some problems were note with the introductory phrase of the question on communication (q17). Some participants seem to focus on the word 'emotional' and not on the communication sense of the question. The use of the phrase should possibly be reconsidered. Similarly, the term 'seeing and recognise' used in the vision extended questions resulted in a Blind participant responding that she has no difficulty as she recognises by touch. The core question does not use the term 'recognise' and should possible remain as such.

The Deaf participants indicated that many Deaf people might respond as having some difficulty in walking and climbing stairs because of a balance problem rather than a physical problem. They also requested that access to information be separated from the physical environment in Q 19 a) on the physical environment. They feel that Deaf people would have problems with access to information but not to buildings and roads.

The participants indicated that questions on toileting, sexuality, sexually transmitted diseases and direct questions about a person's impairment were all sensitive questions to ask. One participant in the head injury group felt that the questions on emotional functioning were 'hurtful' as they reminded him of his rather sad situation. However, he also said that it was still important to ask these questions. This was reflected in a number of groups where people felt it was important for the public to understand what it means to be disabled. The Deaf group felt that asking questions on reading and writing was a sensitive area for Deaf people because of the poor educational levels reached by Deaf people in a written language. However, they also agreed that it was still important to ask the question.

Some of the participants expressed worry that they were not sure how to answer in the expected manner. This is a point to note in administering the questions that the respondent should be made to feel comfortable with the response options and not feel that there is a right or wrong answer. Some participant felt that the yes/no response options were too limited. However, this does not apply to the WG questions.

The scope of the questions was felt to be too general and not specific enough for the individual's needs. One group also raised the issue that if people with difficulties linked to being overweight, for example, are counted this would not give an accurate picture of how many disabled people there are in South Africa and the needs of disabled people. This reflects a narrow sense of what are difficulties and also still leaves us with the question as to who counts as disabled or not! Being overweight is not seen as a disability and was not understood to be part of what should be counted in disability statistics. This reflects a narrow view of what disability and difficulties involve.

The usefulness of the questions was seen not so much as providing accurate data, but rather as a way to show the general public what it is to be disabled. Some participants also felt that asking disabled people what they think is a positive thing.

In the frame of reference used in answering questions, the participants included use of assistive devices and personal assistance. They answered according to how they function with assistive devices such as walking aids. Similarly, the Deaf group raised the issue of including a phrase for the question on communication to refer to sign language as well as spoken language. They felt that including such a reference would allow Deaf people to answer as having no difficulty, whereas they would have severe difficulty in communicating in only spoken language.

The participants on the whole felt that the questions were relevant for their situations, despite the comment about lack of specific content. One participant in the schizophrenic group stated that the question about solving problems (q37) was particularly relevant for him.

These groups had a long list of additional questions that they felt should be included. Many of these are more appropriate to include on a survey than a Census format. These questions are as follows:

- 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.

7.2.1.4 'Unsure' adults

These participants also had no major difficulties with the questions. However, they did have difficulties with the time references. Many took the various time reference literally and said that it was very difficult, for example, to remember how he or she felt every moment of the last month for questions on emotional functioning. They also expressed the need to have concrete examples for the distance references.

These groups also had some problems with the introductory phrase for the communication question and responded to the content of the phrase rather than to difficulties with communication. They also had problems with the phrase 'even if wearing glasses' and suggested that it be deleted but to have a separate question asking whether they have glasses or not.

Sensitive questions were seen as being those asking about someone's disability status or more specifically HIV status and this was most strongly expressed by the two HIV/AIDS groups. The one rural group of older people felt that the questions on marital status were also somewhat sensitive.

The people living with HIV/AIDS in both groups as well as the Deaf participants felt constrained by the response options and wanted to have more open ended questions where they could then describe their own situation. Some of the participants felt unsure how they should respond especially on the question 'Are you disabled?'. They felt on the one hand that they had many problems but did not feel comfortable identifying as being disabled.

These groups did not make many comments on the scope of the questions. Although they did comment on the fact that the questions clearly reflected their own lives and situations and felt very comfortable answering the questions about difficulties (WG core set). This is also reflected in their responses in the quantitative analysis where they responded as having difficulties on many of the WG questions.

In terms of a frame of reference for answering the questions, these participants seemed to use the notion of a health problem as a link to answering. They found the question on participation difficult to answer as they were not sure what the scope of that question was. The HIV/AIDS groups felt that it should be more specific in this same question. The HIV/AIDS groups also expressed a strong opinion that questions about disability were not about them and their experience and that the questions should include more specific questions about their experience. However, some of the participants in these two groups also indicated that they identified well with the WG core of questions, even if they did see themselves as disabled. This attitude was also reflected in the responses of the HIV/AIDS group in the quantitative analysis.

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?'. 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. In 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. This suggests that they are not 'prevented from participating in daily activities'.

The WG questions seem to be easier to respond to especially in the more 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.

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 'allocated status', 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, some 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 in 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 should be formulated are as follows:

- 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 place of using the core set of six WG questions, the extended set of questions should be used. However, the emotional functioning questions should be reviewed and questions that ask about activity limitations be used rather than the current ones. The questions used by WHO on the WHO DAS II could be investigated as a possibility. The additional domains of social interactions and learning should definitely be included.

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

- The phrase 'recognise' should be omitted from or explained for the vision questions.
- The time references for emotional questions should be clearly explained if those questions 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 test 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;
- 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 of which of the three would be the best estimate to use for different purposes.

A further study should do a more detailed individually focussed 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 respondent to repeat the questions, to say what they were thinking about when asking the question, and asking about they understood by different words used in the question.

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Appendix I: 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 <u>one</u> 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/SubA
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 1
09 = 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

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/religiou

11. **The following questions ask 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 <u>MAIN</u> 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 ask 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

19 a i) In the past 12 months, how often has your physical environment been a problem for you? 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 18 a ii)

a ii) When this problem occurs has it been a big problem or little problem?

1. Big problem
2. Little problem

19 b i) **In the past 12 months, how often have the support and attitudes of people been a problem for you?**

6. Daily
7. Weekly
8. Monthly
9. Less often than monthly
10. Never (Skip 18 b ii)

b ii) When this problem occurs has it been a big problem or little problem?

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 analyzing 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 of the time	Most of the time	A good bit of the time	Some of the 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 II: 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 are the participants' understandings 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 on aim 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 – 1 – 2 hours
  - 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 for 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.**

- Sipho 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 is can walk up to 200 metres without any problems. But he feels tired after walking 1 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 3 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 4 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

  b ii) When this problem occurs has it been a big problem or little problem?
    1. Big problem
    2. Little problem

f) Bongi 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 Bongi have difficulty with self care such as washing all over or dressing?
- Does Bongi 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 to 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 him?*** *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 recognize 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 problems 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.