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# Report on Census Content Research Study Disability Schedule November 2006



**Statistics South Africa**

Private Bag X44  
Pretoria  
0001  
South Africa

170 Andries Street  
Pretoria

User Information Service: (012) 310 8600  
Fax: (012) 310 8500  
Main Switchboard: (012) 310 8911  
Fax: (012) 322 3374

Website: [www.statssa.gov.za](http://www.statssa.gov.za)  
Email: [info@statssa.gov.za](mailto:info@statssa.gov.za)

## **Preface**

The research activities of the Component: Research and Methodology within the Population Census Inputs and Outputs division of Statistics South Africa are directed at Census 2011 and focus on the following four areas:

- Content research (the topics to be covered in the census and the effective formulation of questions)
- Research on the effects of layout and format of the census form.
- Measurement of respondents' perceptions and attitudes as well as level of satisfaction of stakeholders.
- Business process redesign, the piloting of operations and performance measurement

The strategic plan of the component, which is available at this site, lists the schedule of census research projects for the 2004/5 to 2010/11 financial years.

This research report relates to the Census Content Research project that was conducted in November 2006. The research investigated issues with regard to a schedule of questions on disability for the next census. The research was preceded by focus group discussions to inform the design of the questionnaire. The report that discusses the results of these focus group discussions, which were conducted by the Human Sciences Research Council in February/March 2006, is available at this site.

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# **1. Executive Summary**

## **1.1 Introduction and methodology**

Statistics South Africa is undertaking a series of testing procedures for various question schedules for Census 2011. One of these is on disability. The testing process started with a series of 26 focus group discussions after which the proposed set of questions were revised. The revised set uses wording that asks about difficulties people have in doing a series of eight activities, viz. seeing, hearing, walking, remembering, concentrating, self-care, communication and participating in community activities.

The second phase of the testing was a population based sample survey of 6000 households. The selected households were visited and a Household Questionnaire administered to the head of the household or most knowledgeable person. This questionnaire included the revised set and the household respondent gave a proxy response for each member of the household. The questionnaire also included the Census 2001 questions to allow for a comparison of the responses on the revised set and the Census 2001 questions. The household respondent also responded to a Living Standard Measure Questionnaire for the whole household.

An Adult Questionnaire was administered to every household member 15 years or older. This questionnaire included the revised set of questions, the question "Are you disabled?" and a series of extended questions also asking about difficulties that people have but on a more detailed range of activities.

The data was captured twice and inconsistencies checked. The data from the Household Questionnaire were weighted using Iterative Proportional Fitting. The analysis was undertaken using SAS. This report presents an overview of the following results:

- A comparison of the revised set of questions to the Census 2001 questions and to the 'Are you disabled?' question;
- A comparison of the proxy responses on the Household Questionnaire to the direct responses on the Adult Questionnaire; and
- An investigation of the influence of various independent variables on the responses given by the household respondents.

## **1.2 Results**

The revised set had four response options – 'No difficulty', 'Some difficulty', 'A lot of difficulty' and 'Unable to do'. The Census 2001 questions had only 'Yes/No' response options and 'Are you disabled?' question had three options – 'No', 'Yes' and 'Sometimes'. The results, unless specified, are for the age group 15 years and older.

### **1.2.1 Endorsement rates for the revised set**

The endorsement rates are for the weighted household data unless specified otherwise.

The revised set composite or overall score indicates that 67% of the South African population (all ages) is reported as having 'No difficulty' on any of the eight domains of functioning covered in the New Set. A further 20,24% have 'Some difficulty' doing one or more of the activities. Nearly 10% of the population (9,86%) have a lot of difficulty doing at least one of the activities and 2,48% are unable to do at least one of the activities.

The results indicate that there are major differences in the response rates for different age groups, income categories, educational achievements, employment status, and marital status. The older, poorer, less educated, unemployed and widowed or divorced respondents were the most likely to indicate having difficulties.

### **1.2.2 The revised set compared to the extended set questions – Adult Questionnaire**

In general, the extended set on the Adult Questionnaire generated responses that were more severe in terms of the difficulty than the revised set of questions that was also included on the Adult Questionnaire. For example, the response indicating 'A lot of difficulty' on the extended set often yielded responses of 'No difficulty' or 'Some difficulty' on the revised set of questions. This was the case across all the domains, except for 'some difficulty' in the domains of seeing and hearing. Some factors that could have caused this are the more precise reference in many of the extended questions (e.g. concentrating for 10 minutes) and the placement of the extended set of questions after the revised set, which could have had an influence on the person's frame of reference for answering the extended sets. The overall composite scores for the revised set and the extended questions only differed by 2%, with the extended set having the higher rate of difficulty.

### **1.2.3 The revised set compared to the Census 2001 questions**

The Census 2001 questions, as reported on the Household Questionnaire, yielded a rate of 12% of people having a 'serious disability'. This highlights the fact that this question identified predominantly people with more severe degrees of difficulty and missed out people with only some degree of difficulty. Census 2001 questions mostly identify people who see themselves or are seen by the household respondent as disabled. A logistic regression analysis indicated that age, sex, marital status and education level were all found to have an effect on the risk of a difference arising between the revised set of questions and the Census 2001 questions. For example, being older increased the risk of a difference, which reflects the fact that older people do not see themselves as disabled, but do report having difficulties. They would therefore, respond positively on the revised set and negatively on the Census 2001 questions.

### **1.2.4 The revised set compared to 'Are you disabled?'**

The results indicate a very good correspondence between the responses given on the revised set and 'Are you disabled?' but with a much lower endorsement for the latter question. This confirms the finding from the focus group study that being disabled (self-identified) entails having difficulties, but having difficulties does not entail being 'disabled' as identified by the respondent.

### **1.2.5 Comparison of the revised set responses on the Household Questionnaire to revised set responses on the Adult Questionnaire**

These results provide an indication of the proxy effect. The results reflect predominantly a good match, but with some degree of over-reporting by the proxy respondent where they perceive the difficulty being more than what the individual actually reports. There is also an under-reporting by the proxy respondent where they either do not note the problem or see it as being less severe than what the person reports in the direct interview. There were minimal differences between the composite scores for the proxy and direct responses. The findings indicated that using the proxy format of the Census probably will not significantly under-report the number of people with difficulty, but may exaggerate to some extent the degree of difficulty.

### **1.3 Conclusion**

The revised set identifies more people who have a difficulty in doing various activities than the Census 2001 questions, especially people with only 'Some difficulty'. The revised set also allows for different prevalence estimates to be calculated for different purposes. For example, to calculate the likely need for social assistance, only the responses indicating 'A lot of difficulty' with or 'Unable to do' one or more of the activities would be used.

Further research is required to determine the effectiveness of the revised set with children 14 years old and younger.

## 2. Background and Introduction

Statistics South Africa is undertaking a series of testing procedures for various question schedules for Census 2011. One of these is on disability. The testing process started with a series of 26 focus group discussions. The focus group study provided suggestions for revisions to the proposed census questions based on the Washington Group's short set of questions for Censuses.<sup>1</sup> The revisions were effected and the revised questions were tested in a nationally representative survey. The revised questions were as follows:

### Part 1: Functioning questions

1. Do you (or does the person) have difficulty in doing any of the following?

1 = No difficulty

4 = Unable to do

2 = Some difficulty

5 = Don't know

3 = A lot of difficulty

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

### Part 2: Use of assistive devices

2. Does the person use any of the following?

1 = Yes

2 = No

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

The rationale for using these questions was that they ask about difficulties people have rather than "disabilities". The response options also allowed for a range of responses without predetermining which level would be used as the cut-off point to determine the disability status of a person. This is an inclusive approach to determining functioning within a population. Further details on this approach can be found in the report on the focus group discussions.

The responses given on the survey questionnaires were all self- or proxy reported indications of difficulties people experience. They were not observed or measured levels of difficulty. The self- or proxy report of difficulty is the method used in the Census and was therefore replicated in the testing procedure. Further research is required to fully understand the nature of how people respond on these proposed questions in relation to their observed or measured health status.

This report presents the findings from the second phase of the testing which comprised of a nationally representative sample survey carried out in November 2006 by Statistics South Africa.

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<sup>11</sup> Testing a disability schedule for Census 2001: Summary Report on 26 focus groups; Presented to Statistics South Africa By Child, Youth, Family and Social Development, Human Sciences Research Council; Margie Schneider and Jacqui Couper; February 2007

### 3. Methodology

#### 3.1 Sampling frame and household and individual selection

The Master Sample of Statistics South Africa that is based on Census 2001 was used as a sampling frame. To ensure a higher probability of sampling households with disabled persons, the Master Sample Primary Sample Units (PSUs) were filtered for the 35<sup>th</sup> percentile and higher of percentage of the population measured as disabled in Census 2001. This left a total of 1510 PSUs. Of these, two in KwaZulu-Natal could not be covered due to unavoidable circumstances.

For each of the PSUs a total of four households with two replacements were selected. The two replacement dwelling units were used mostly to substitute for out-of-scope units, such as vacant structures, listing errors and demolished structures. In the case of non-response the field teams were expected to attempt to convert these into successful interviews, failing which, the replacement dwelling units were used.

No sub-sampling was done within the responding households. The respondents answered questions to a Household Questionnaire and all persons that were fifteen years and above were asked additional questions from an Adult Questionnaire. The respondent for the Household Questionnaire was the head of the household or any responsible adult.

A total of 6032 dwelling units were sampled. Data for 4705 dwelling units (78% of the sample) was collected.

**Table 1** shows the distribution of households with usable data and households whose data could be weighted by province.

**Table 1: Distribution of households with usable data and households whose data could be weighted**

Province	Sampled		Usable data		Weighted data	
	Dwelling Units		Households		Households	
Western Cape	668	11,1%	526	11,06%	437	11,17%
Eastern Cape	940	15,6%	470	9,88%	417	10,66%
Northern Cape	260	4,3%	231	4,85%	206	5,27%
Free State	568	9,4%	477	10,03%	408	10,43%
KwaZulu-Natal	1296	21,5%	1116	23,36%	864	22,09%
North-West	592	9,8%	514	10,80%	417	10,66%
Gauteng	584	9,7%	467	9,82%	360	9,20%
Mpumalanga	524	8,7%	434	9,12%	365	9,33%
Limpopo	600	9,9%	523	10,99%	437	11,17%
<b>Total</b>	<b>6032</b>	<b>100%</b>	<b>4758</b>	<b>100%</b>	<b>3911</b>	<b>100%</b>

**Table 2** shows the profiles of persons 15 years and older (Household Questionnaire) whose data was processed.

**Table 2: Profiles of persons 15 years and older for whom data was processed**

<b>Age</b>	<b>Usable data</b>		<b>Weighted data</b>	
15-24 years	3079	30,6%	8562565	29,7%
25-34 years	1945	19,3%	5503668	19,1%
35-59 years	3770	37,4%	11031564	38,3%
60+ years	1284	12,7%	3724671	12,9%
<b>Sex</b>	<b>Usable data</b>		<b>Weighted data</b>	
Male	4445	44,1%	12750985	44,2%
Female	5620	55,8%	16035065	55,6%
Missing	13	0,1%	36417	0,1%
<b>Relationship to head of household</b>	<b>Usable data</b>		<b>Weighted data</b>	
Don't know	9	0,1%	22129	0,1%
Close relation to head	9455	93,8%	27022537	93,8%
Other	596	5,9%	1734586	6,0%
<b>Marital status</b>	<b>Usable data</b>		<b>Weighted data</b>	
Don't know	13	0,1%	28680	0,1%
Married/Living together	3803	37,7%	11438026	39,7%
Never married	5094	50,5%	14031610	48,7%
Widower/widow	828	8,2%	2270180	7,9%
Separated/Divorced	337	3,3%	1045116	3,6%
Missing	3	0,0%	8855	0,0%
<b>Highest level of education</b>	<b>Usable data</b>		<b>Weighted data</b>	
Don't know	37	0,4%	100396	0,3%
No schooling/primary school	2720	27,0%	7005976	24,3%
Primary school completed/high school	4687	46,5%	12820225	44,5%
Matric (Grade 12)	1567	15,5%	5050362	17,5%
Tertiary	1053	10,4%	3814945	13,2%
Missing	14	0,1%	30563	0,1%
<b>Population group</b>	<b>Usable data</b>		<b>Weighted data</b>	
Black African	7723	76,6%	22411324	77,8%
Coloured	1339	13,3%	2512849	8,7%
Indian/Asian	215	2,1%	807035	2,8%
White	792	7,9%	3067951	10,6%
Missing	9	0,1%	23308	0,1%
<b>Employment status</b>	<b>Usable data</b>		<b>Weighted data</b>	
Employed	3466	34,4%	10546268	36,6%
Unemployed/Economically not active	6607	65,6%	18259156	63,4%
Missing	5	0,0%	17043	0,1%
<b>Marital status</b>	<b>Usable data</b>		<b>Weighted data</b>	
LSM 1 – 3	2819	28,0%	7310751	25,4%
LSM 4 – 6	5740	57,0%	14420313	50,0%
LSM 7 – 10	1519	15,1%	7091402	24,6%
<b>Geographic type</b>	<b>Usable data</b>		<b>Weighted data</b>	
Rural	4627	45,9%	12257154	42,5%
Urban	5451	54,1%	16565313	57,5%

Given the fact that the sample size was small and biased, with an over-sampling of dwelling units in tribal areas, **it was not the intention of this survey to derive national estimates of disability in South Africa.** Our intention was to collect enough data to study the effects of proxy response in the measurement of disability in censuses, the comparability of the revised set of disability questions with the schedule used in Census 2001 as well as the consistency and effectiveness of the revised set.

### 3.2 The survey instruments and data collection strategy

There were three questionnaires used in the survey: A Household Questionnaire, a Living Standard Measure (LSM) Questionnaire and an Adult Questionnaire.

<p><b>The Household Questionnaire</b></p>	<p>The respondent for this questionnaire was a responsible adult in the household, preferably the head of the household.</p> <p>The questionnaire was completed for persons who usually live in the household, as well as visitors who stayed the previous night.</p> <p>The following demographic, social and economic variables were recorded:</p> <ul style="list-style-type: none"> <li>Age</li> <li>Sex</li> <li>Relationship to the head of the household</li> <li>Marital status</li> <li>Level of education</li> <li>Population group</li> <li>Employment status</li> </ul> <p>This was followed by the revised schedule under the heading <b>General Health and Functioning</b>. Finally, the Census 2001 schedule for measuring disability under the heading <b>Disability</b> followed.</p> <p>The questionnaire was completed through an interview by preference.</p>
<p><b>The Living Standard Measure Questionnaire</b></p>	<p>The respondent for this questionnaire was a responsible adult in the household, preferably the head of the household.</p> <p>The schedule of questions corresponded to that which was developed by the South African Advertising Research Foundation and is used in the All Media and Products Surveys. This Living Standard Measure proved in previous census research surveys to be a useful variable in analysis.</p> <p>The questionnaire was completed after the Household Questionnaire, so refusals would not impact on the completion of the Household Questionnaire.</p> <p>The questionnaire was completed through an interview by preference.</p>
<p><b>The Adult Questionnaire</b></p>	<p>The respondent for this questionnaire was a person, 15 years or older, for whom information was recorded in the Household Questionnaire. The questionnaire was completed through an interview.</p> <p>The questionnaire began with the revised schedule under the heading <b>General Health and Functioning</b>.</p> <p>Several detailed questions then followed, to provide a comparison between responses given on a single question versus more detailed and specific questions on the same domain.</p> <p>Finally the respondent was asked to self-classify with regard to disability status and was asked about the receipt of government grants.</p>

The questionnaires were printed in English. A translation book was prepared to assist interviews in other official languages.

All households at a selected dwelling unit had to be covered. The fieldworkers were instructed to make up to three visits to cater for non-contacts.

Respondents to the Household Questionnaire had to be briefed on the aim of the research prior to the interview. They also had to be at that time informed of the need to interview persons for the Adult Questionnaire separately. It had to be stated that the objective of these interviews was to study the efficacy of a particular schedule. Persons eligible for the Adult Questionnaire therefore were not allowed to sit in on that interview. Details on the content of the Adult Questionnaire were not communicated at that stage.

The Adult Questionnaire was completed by means of direct interviews for all eligible persons after the completion of the Household Questionnaire and the Living Standard Measure Questionnaire. Fieldworkers were instructed to make up to two further re-visits to cater for non-contacts.

### 3.3 The Living Standard Measure

It has been demonstrated in previous research by Statistics South Africa that material welfare has a strong relationship with certain relevant measurement phenomena in census content and publicity research. The Living Standard Measure (LSM), which was developed by the South African Advertising Research Foundation (SAARF) and is used extensively in market research (specifically in AMPS<sup>2</sup>), served in this research as a measurement of material welfare.

The measure, which is based on a regression model, is calculated by finding the sum of the following weights for which the corresponding criterion is satisfied. **Table 3a** shows the weights that are used in the calculation of the Living Standard Measure.

**Table 3a: Weights used in the calculation of Living Standard Measure**

Criterion	Weight
Hot running water	0,158200
Fridge/freezer	0,152515
Microwave oven	0,126829
Flush toilet in house or on plot	0,142228
VCR/DVD in household	0,134488
Vacuum cleaner/floor polisher	0,135318
Washing machine	0,138930
Computer at home	0,132148
Electric stove	0,163219
TV set(s)	0,133830
Tumble dryer	0,117338
Telkom telephone	0,097140
Hi-fi or music centre	0,105378
Built-in kitchen sink	0,165505
Home security service	0,091632

<sup>2</sup> All Media and Products Survey, commissioned annually by SAARF

<b>Criterion</b>	<b>Weight</b>
Deep freezer	0,093849
Water in home or on stand	0,127671
M-Net and/or DSTV	0,126068
Dishwasher	0,119925
Electricity	0,128613
Sewing machine	0,090320
Live in Gauteng	0,056788
Live in Western Cape	0,079999
1 or more motor vehicles	0,155217
No domestic worker	-0,222360
No cellphone in household	-0,175180
Home is a traditional hut	-0,201080
None or only one radio	-0,158250
Living in a non-urban area outside of Gauteng or Western Cape	-0,093220

A constant of 1,340410 is added to the sum of the weights, and the LSM is obtained through reference to the following table (**Table 3b**). Thus the range of the LSM is identified by the total obtained after this constant has been added.

**Table 3b: Reference table for the determination of Living Standard Measure from the calculated total**

<b>Calculated total</b>	<b>Living Standard Measure</b>
0,00000 – 0,72100	LSM 1
0,72101 – 1,05300	LSM 2
1,05301 – 1,35600	LSM 3
1,35601 – 1,72600	LSM 4
1,72601 – 2,12700	LSM 5
2,12701 – 2,68500	LSM 6
2,68501 – 3,01000	LSM 7
3,01001 – 3,32400	LSM 8
3,32401 – 3,65000	LSM 9
3,65001+	LSM 10

For the purpose of this study LSM 1 to LSM 3, LSM 4 to LSM 6 and LSM 7 to LSM 10 were grouped together to form super-LSM groups. These groups may, respectively, be referred to as people with low material welfare, people with medium material welfare and people with higher material welfare.

### **3.4 Weighing of data**

The data were weighted to investigate the impact on estimates when biases in the sample are addressed. As indicated in **Section 3.1** the weighted data do not purport to be national estimates. Unless specifically stated otherwise, the statistics in this report refer to un-weighted data.

Iterative Proportional Fitting was chosen as a weighting method as:

- Cell weighting was problematic due to the biased sample frame and the relatively small sample size.
- The Living Standard Measure was a suitable variable to use in correction for this bias and cell values for this measure were not known; and

The following rims were chosen:

- Rim 1      Suitable combinations of population group and province that ensured sufficient sample points for effective weighting
- Rim 2      LSM 1– 6 and LSM 7+

The number of households estimated for mid-year 2006 and the LSM proportions of AMPS 2004 were used to derive universe numbers that were used in the weighting.

The estimates derived from the weighted data did not differ significantly from those derived from un-weighted data.

### **3.5 Analysis of data**

The analysis focused on the following areas of interest:

- The questions of the revised set in terms of :
  - Overall endorsement rates where all questions are considered (Household Questionnaire);
  - The effect on responses for the overall revised set of various factors such as age, sex, marital status, relationship to the head of household, employment status, education, income level and urban versus rural location (Household Questionnaire);
  - The endorsement rates for individual questions within the revised set (Household Questionnaire);
  - Comparison of responses on the revised set versus those on the extended set of questions (Adult Questionnaire).
- The responses on the revised set compared to those on the Census 2001 question and possible factors that explain differences between these two sets of questions (Household Questionnaire).
- The responses on the revised set compared to the question 'Are you disabled?' (Adult Questionnaire).
- Differences between proxy responses (Household Questionnaire) and direct responses (Adult Questionnaire) for the revised set.
- Endorsement rates for the second part (use of assistive devices) of the revised set compared to responses on the first part (difficulties in functioning) of the set.

## 4. Results

The results are presented according to the questions asked as described in **Section 2**. The data used are both weighted and un-weighted, depending on the context and the questionnaire used. The Household Questionnaire data was weighted and all results reporting on these data are weighted. The results reporting on the adult questionnaire are not weighted. The graphs and tables indicate whether the data is weighted or un-weighted. Weighted data is reported as a proportion of the population, whilst un-weighted data is reported as a proportion of the respondents.

In presenting the results the term disabled is used in two ways. Firstly, anyone reported as having ‘some difficulty’, ‘a lot of difficulty’ or being ‘unable to do’ for one or more of the revised set of functioning questions are referred to as being disabled for purposes of disability statistics. Secondly, the term ‘disabled’ is used in the Census 2001 question (on the Household Questionnaire) as well as in a question on the Adult Questionnaire (‘Are you disabled?’). What was measured in these cases was therefore whether a person identified him/herself or a member of their household as being ‘disabled’ in response to the use of that term. The differences in responses to the term ‘difficulty’ versus “disabled” are discussed in the report on the focus group discussions.

### 4.1 Revised set of questions

This section presents the results for the revised set of questions. The revised set comprised two parts: the first part asked about activity limitations (functioning) and the second part asked about use of assistive devices. The questions are set out in **Section 1** of this report.

The results are presented for the overall endorsement rates for each response category including all 8 questions, followed by endorsement rates for the individual questions.

The overall rates were calculated as follows:

<i>No disability</i>	Responses to all 8 of the questions on functioning indicated ‘no difficulty’
<i>Some difficulty</i>	Responses to one or more of the 8 questions indicated ‘some difficulty’
<i>A lot of difficulty</i>	Responses to one or more of the 8 questions indicated ‘a lot of difficulty’
<i>Unable to do</i>	Responses to one or more of the 8 questions indicated ‘unable to do’

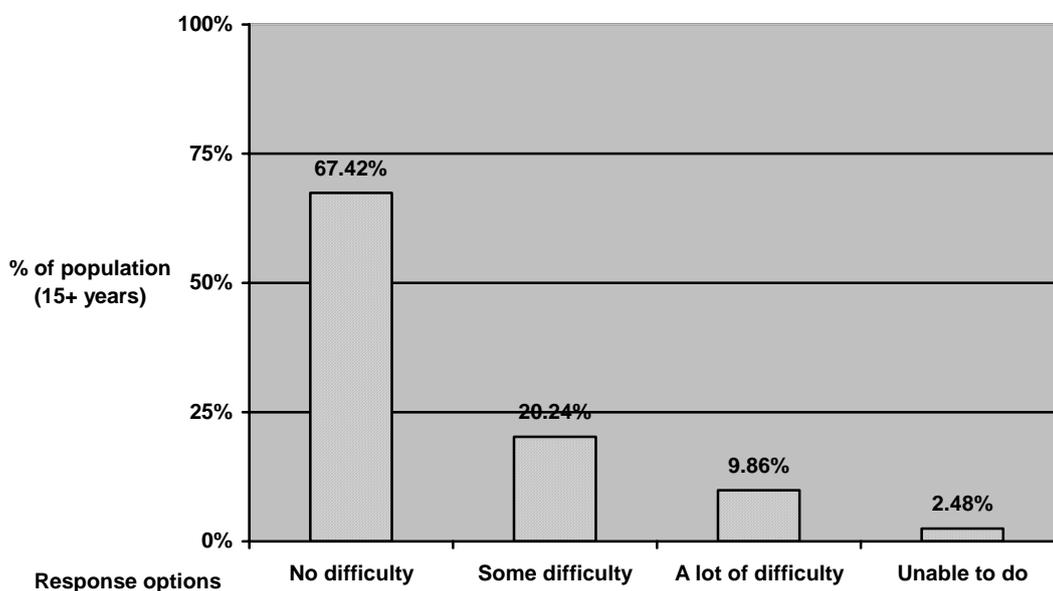
This means that the responses of ‘A lot of difficulty’ could have included some responses of ‘Some difficulty’ and those of ‘Unable to do’ could have included some responses of ‘Some difficulty’ and ‘A lot of difficulty’. However, each respondent was only counted once in one of the four response categories. The category in which a respondent was placed was determined by the most severe response option given on any one of the questions.

The same analysis was also undertaken for the 8 individual questions.

#### 4.1.1 Composite responses on the revised set for the Household Questionnaire (persons 15 years of age or older)

**Figure 1** presents composite results for the revised set, where all the questions were combined into one categorisation as described above. This is the composite or overall score. Over two-thirds (67,42%) of the South African population were reported by their household respondent as having no difficulties with any of the activities covered in the 8 questions asked in part 1 of the revised set. A further 20,24% had 'some difficulty' doing one or more of the activities. This percentage included people who indicated some difficulty participating in community activities, but this was probably for reasons other than a health condition (see **Figure 12** below). Nearly 10% of the population (9,86%) had a lot of difficulty doing at least one of the activities and 2,48% were unable to do at least one of the activities.

**Figure 1: Weighted response rates for the revised set (composite score for all 8 questions) for the 4 response options**

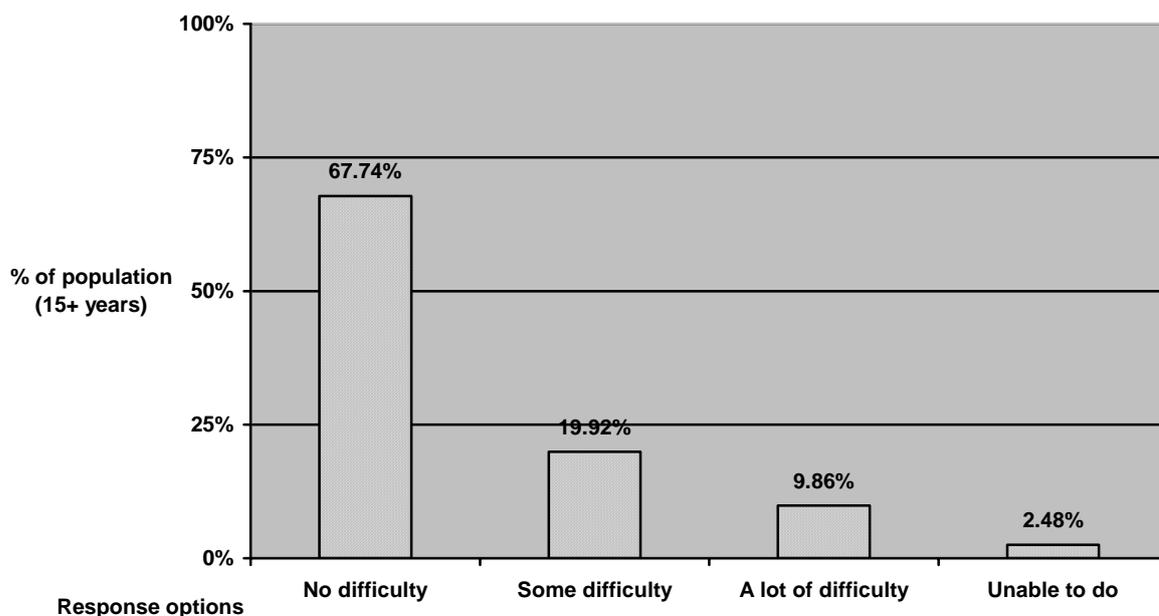


These results indicate a much higher population estimate for disability than previously obtained in South Africa and the reasons for this are discussed below in **Section 3.2**. This would imply that, if a more severe notion of disability is used ('A lot of difficulty' or 'Unable to do'), an estimated 12,34% of the South African population have a severe enough activity limitation (or disability) that probably warrants services of some form or another and/or provision of assistive devices. These people would most definitely need some form of environmental facilitators, such as accessible buildings, information in an accessible format and be affected by environmental barriers such as stigma and negative attitudes on disability.

However, the high response of ‘Some difficulty’ on the question on participating in community activities could have been difficulties people have arising from factors other than a health condition (as specified in the introductory phrase for the revised set of questions). For this reason, it was decided to recode these ‘Some difficulty’ responses as ‘no difficulty’. The estimates in **Figure 1** include the high responses on ‘Some difficulty’ for the last question on participating in community activities. When these ‘Some difficulty’ responses were coded as ‘No difficulty’ for the participation question and the composite estimate re-calculated the results did not change significantly. These revised estimates are presented in **Figure 2** below.

The responses for the participation question were analysed further to see whether they were made up of people who indicated “Some difficulty” only on that domain. The results indicate that few people fell into this category. Most people who indicated ‘Some difficulty’ in participating in community activities indicated ‘Some difficulty’ on at least one or more other activities as well. These results are discussed further below in **Section 4.1.D**.

**Figure 2: Weighted response rates for the revised set (all questions) with the ‘Some difficulty’ responses for participating in the community recoded as ‘no difficulty’**



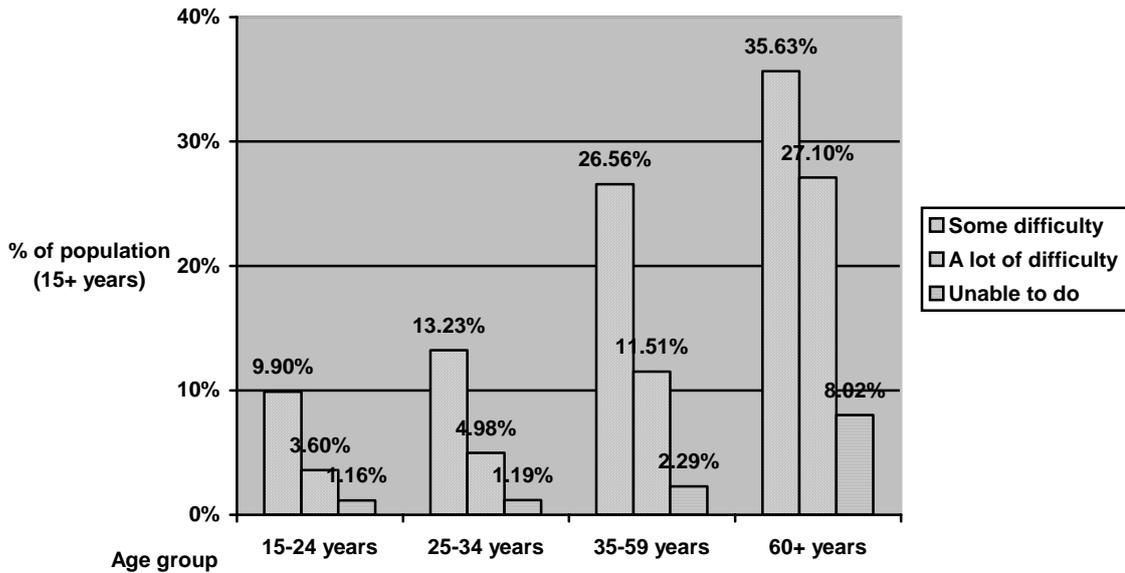
#### 4.1.2 Revised set in relation to various independent variables

This section analyses the household data in further detail. The response categories for the revised set of questions were analysed by various independent variables including age, sex, marital status, relationship, geographical location, population group, LSM status, education level and employment status of the respondents in the household. These responses were still those given by the household respondent about the members of the household, in other words, proxy responses.

#### 4.1.2.1 Age

**Figure 3** indicates that difficulties increase with increasing age. In the age group 60 + years more than 35% of the population had 'Some difficulty', while about 8% were 'Unable to do' one or more activities. The oldest age group (60+ years) showed a marked increase in the categories of 'A lot of difficulty' and 'Unable to do' compared to the other age groups. The youngest age group (15 – 24 years) showed the least difficulty in all response categories.

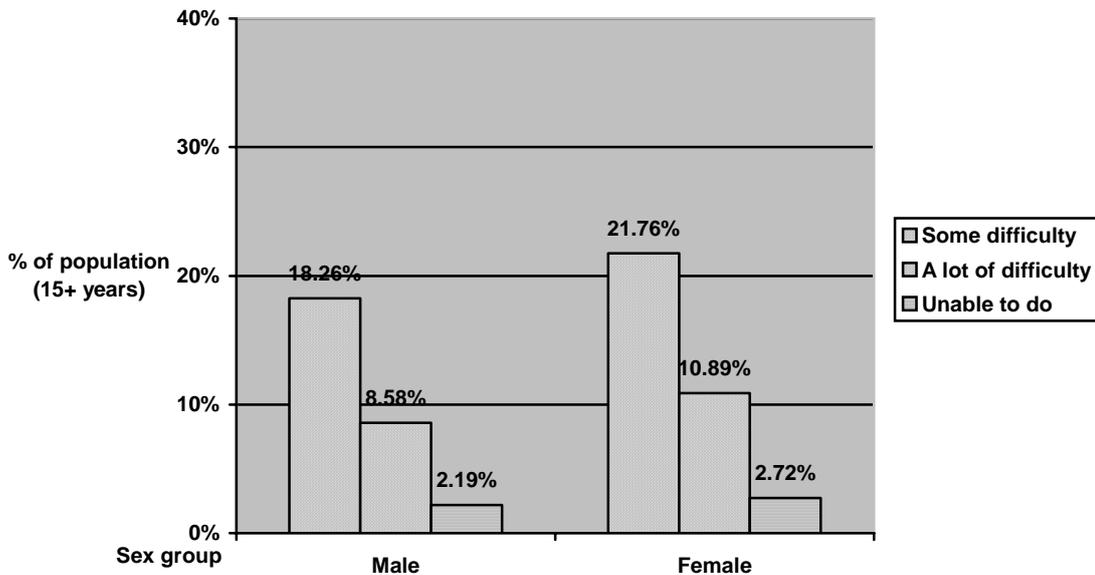
**Figure 3: Weighted responses on revised set by age**



#### 4.1.2.2 Sex

The results pertaining to the gender of the respondents are presented in **Figure 4**. The results show more women to have difficulties than men across all three response categories.

**Figure 4: Weighted responses on revised set by sex**



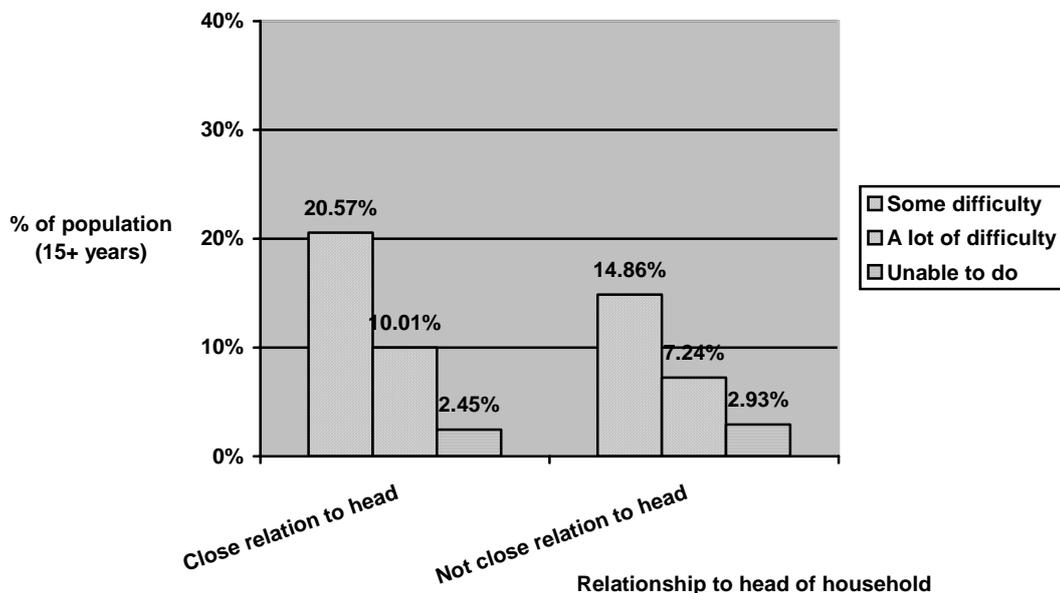
This is not an effect of proxy response – this pattern was valid for respondents as well as non-respondents to the Household Questionnaire.

### 4.1.2.3 Relationship to head of household

The relationship to the head of household was categorised into either 'close relationship' or 'other relationship'. A 'close relationship' was defined as one that includes spouses, siblings, parents, children, grandchildren or grandparents. 'Not close' relationships were defined to include all other types of relationships.

Responses provided by household respondents about their close relatives were more likely to indicate 'Some difficulty' (20,57% versus 14,86%) or 'A lot of difficulty' (10,01% versus 7,24%) than responses about those who did not have a 'close relationship'. This was the reverse for 'Unable to do', where those without a 'close relationship' were more likely to report that the person is unable to do one or more activities (2,45% for 'close relationship' and 2,93% for 'not close relationship').

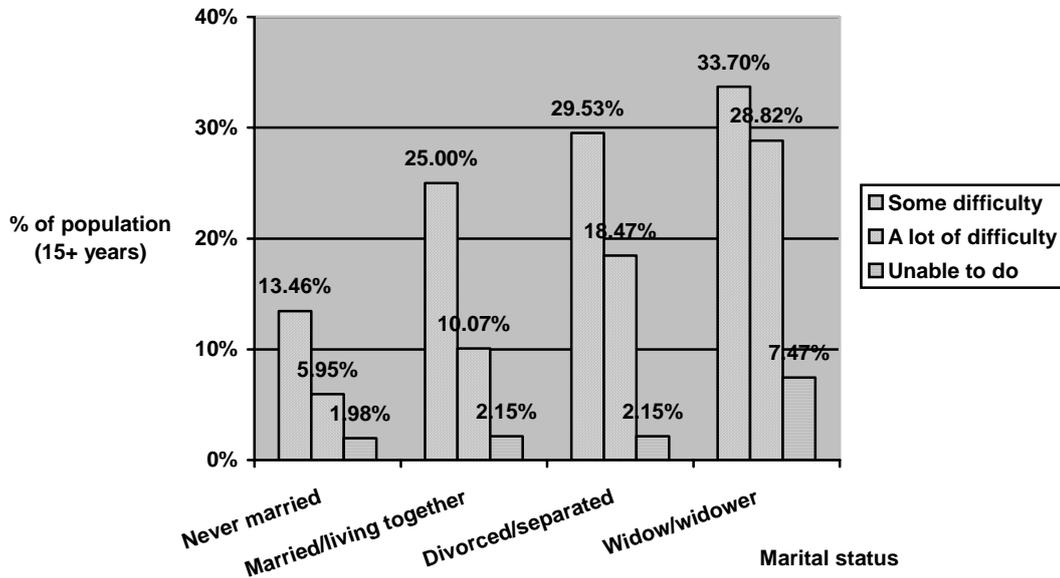
**Figure 5: Weighted responses on revised set by relationship to the head of the household**



#### 4.1.2.4 Marital status

Figure 6 presents responses on the revised set by marital status.

Figure 6: Weighted responses on revised set by marital status



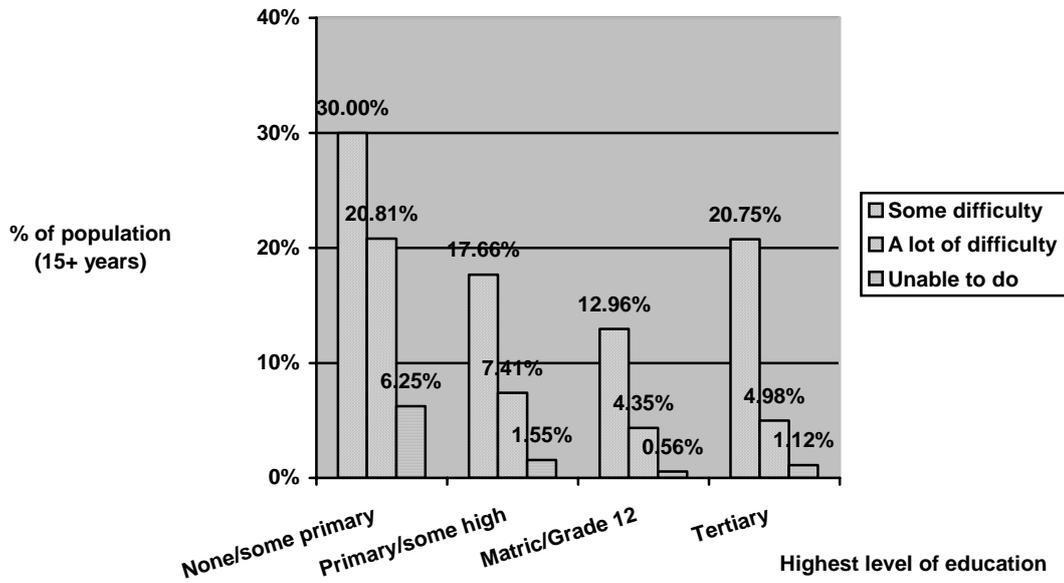
Marital status was categorised into 4 categories: Never married; Married or living together; Divorced or separated; and Widow/widower.

Of interest is the increasing identification of difficulty across all response categories, starting from never married and going through to widowhood. This effect is, of course, confounded by age, since persons never married tend to be younger than these groups.

#### 4.1.2.5 Highest level of education

Figure 7 indicates the responses by education level. Of note is the higher number of people with difficulties among the population with lower education. People with Matric (Grade 12) have the lowest rate of difficulties. The reason for the slight increase in difficulties for the group with tertiary education is not clear, but could be associated with these people also being older. The high number of people with difficulties in the group with no or less than primary school education can be attributed to two main reasons. The first is about low education levels being an outcome of disability, whilst the second sees disability as an outcome of low education. In terms of the former, people with disabilities tend to have lower educational achievement and so more severe disability is associated with low education levels. In terms of the latter, low education levels are associated with higher levels of poverty, poor access to services and lower levels of health. These all in turn can lead to disability (e.g. untreated injury can lead to permanent disability; lack of treatment for a chronic condition can lead to disability).

**Figure 7: Weighted responses on revised set by highest level of education**

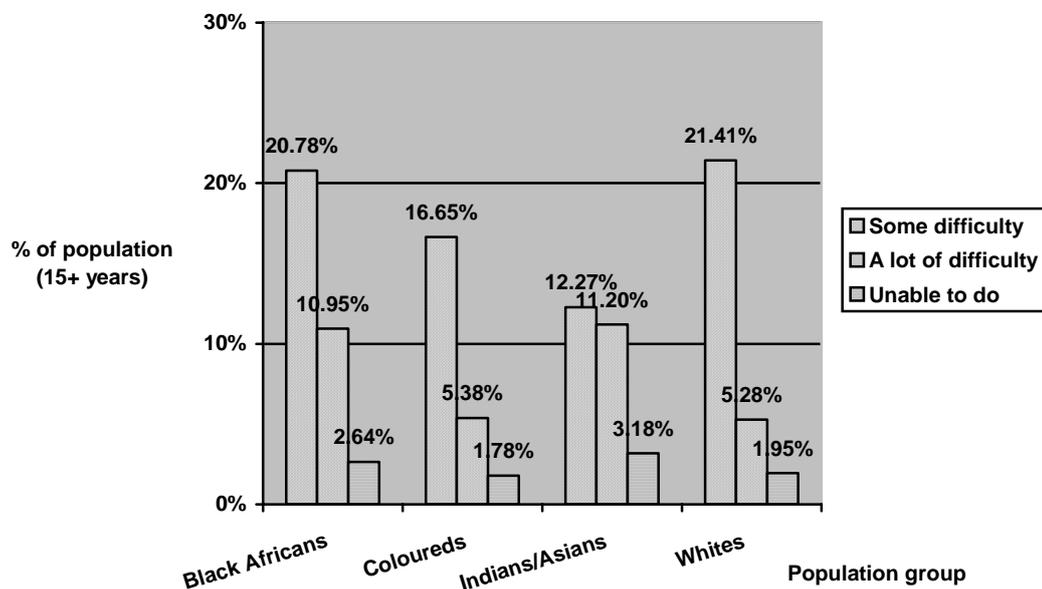


**4.1.2.6 Population group**

**Figure 8** shows the different prevalence rates for disability by population group. Black Africans have the highest prevalence of ‘A lot of difficulty’ (10,95%) and ‘Unable to do’ (2,64%). Indian/Asians have the lowest rate of ‘Some difficulty’ (12,27%) and almost the same levels of ‘A lot of difficulty’ (11,20%), indicating that with this population group a problem is probably more likely to be seen as resulting in ‘A lot of difficulty’ than in only ‘Some difficulty’.

As for other results, the effect of low education and low income levels are probably confounding factors in these results for population group, with Black Africans being most likely to have low education and low income levels.

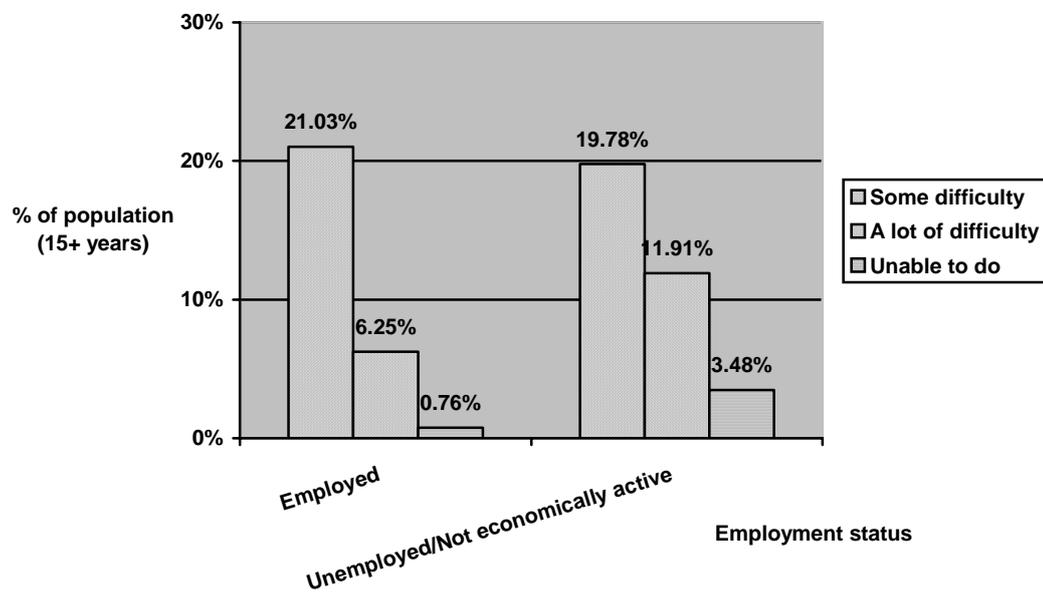
**Figure 8: Weighted responses on revised set by population group**



#### 4.1.2.7 Employment status

Employment status was calculated using employed versus unemployed and/or economically inactive. This is the broader definition of unemployment including people who are no longer looking for work. The results presented in **Figure 9** show big differences for the different categories of responses. Specifically, it can be seen that amongst unemployed or economically not active persons there was a higher proportion of persons with 'A lot of difficulty' or who were 'Unable to do'. This reflects the relatively low level of employment among people with more severe disabilities. This finding is consistent with other findings on employment levels for people with disabilities.<sup>3</sup>

**Figure 9: Weighted responses on revised set by employment status**

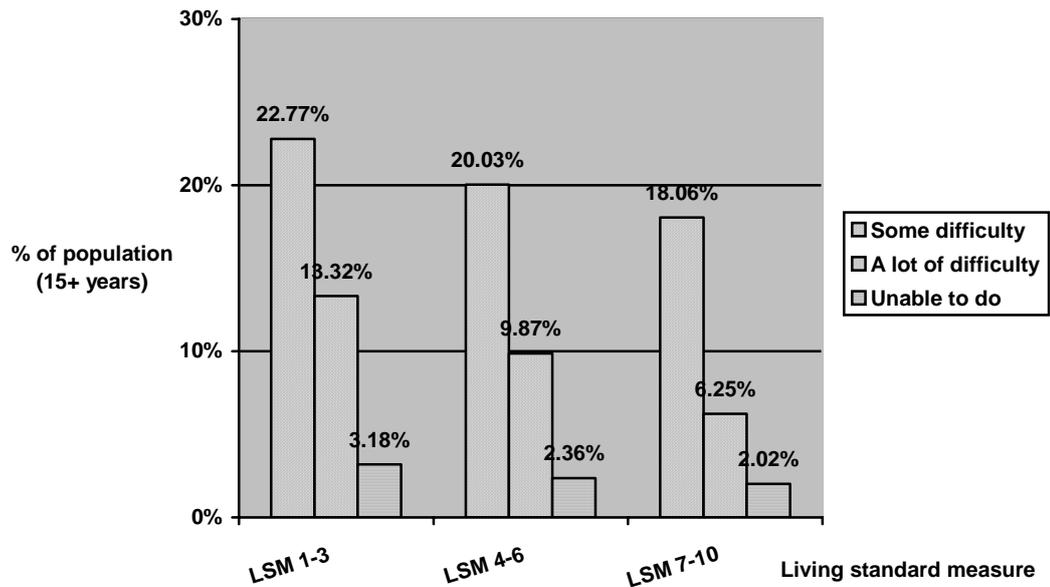


<sup>3</sup> Census 2001: Prevalence of disability in South Africa; Statistics South Africa; Report No. 03-02-44 (2001); Page 22

#### 4.1.2.8 Living Standard Measure

The Living Standard Measure for households was calculated from entries to the LSM Questionnaire. The 10 levels were collapsed into three categories: low for levels 1 to 3; middle for levels 4 to 6 and high for levels 7 – 10. The pattern that emerges from the results in **Figure 10** indicates that with the higher LSM levels there is a relatively lower prevalence of difficulties. Although, LSM is a household level variable, there is an effect of employment status on this pattern, as being employed would put one's household in a higher LSM level.

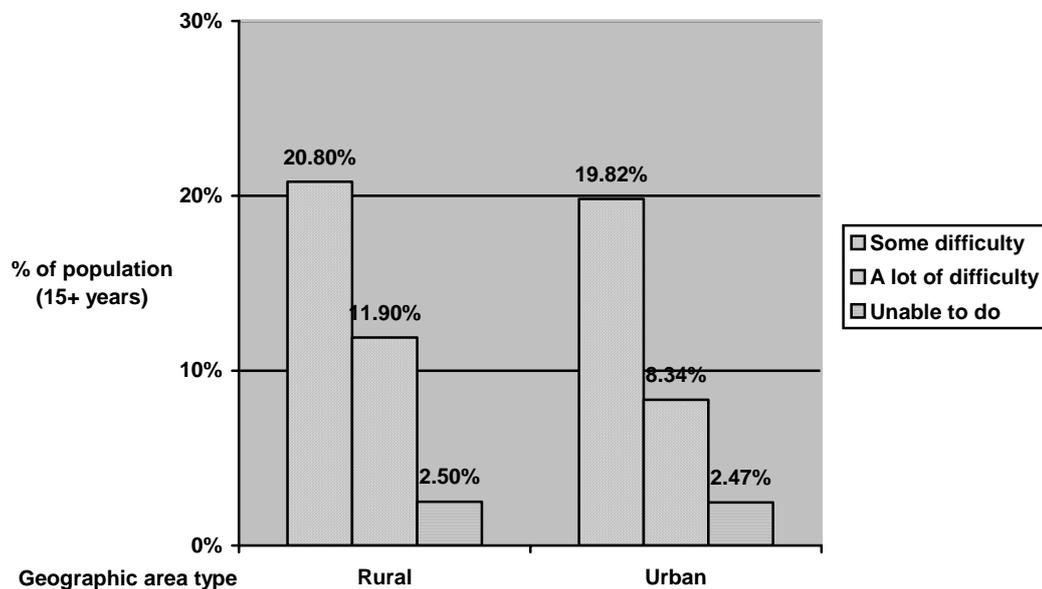
**Figure 10: Weighted responses on revised set by Living Standard Measure**



#### 4.1.2.9 Urban versus rural

Urban and rural classifications were based on the classifications of the areas in Census 96. **Figure 11** suggests that people with ‘Some difficulty’ are living in both urban and rural contexts with a higher proportion living in urban areas. People with ‘A lot of difficulty’ or who are ‘Unable to do’ are more likely to be living in rural areas. This can be explained in part by the lack of services in rural areas and the reality or perception that a problem is worse because of lack of services. For example, having a vision problem that can be corrected is more likely to be addressed and reported as only ‘Some difficulty’ or ‘No difficulty’ in urban areas than in rural areas. The lack of optometric services in rural areas might lead the person to experience ‘A lot of difficulty’ with the same degree of vision loss but no availability of glasses. There is no difference in terms of where people live who are ‘unable to do’ one or more activities.

**Figure 11: Weighted responses on revised set by geographic area type (urban versus rural)**



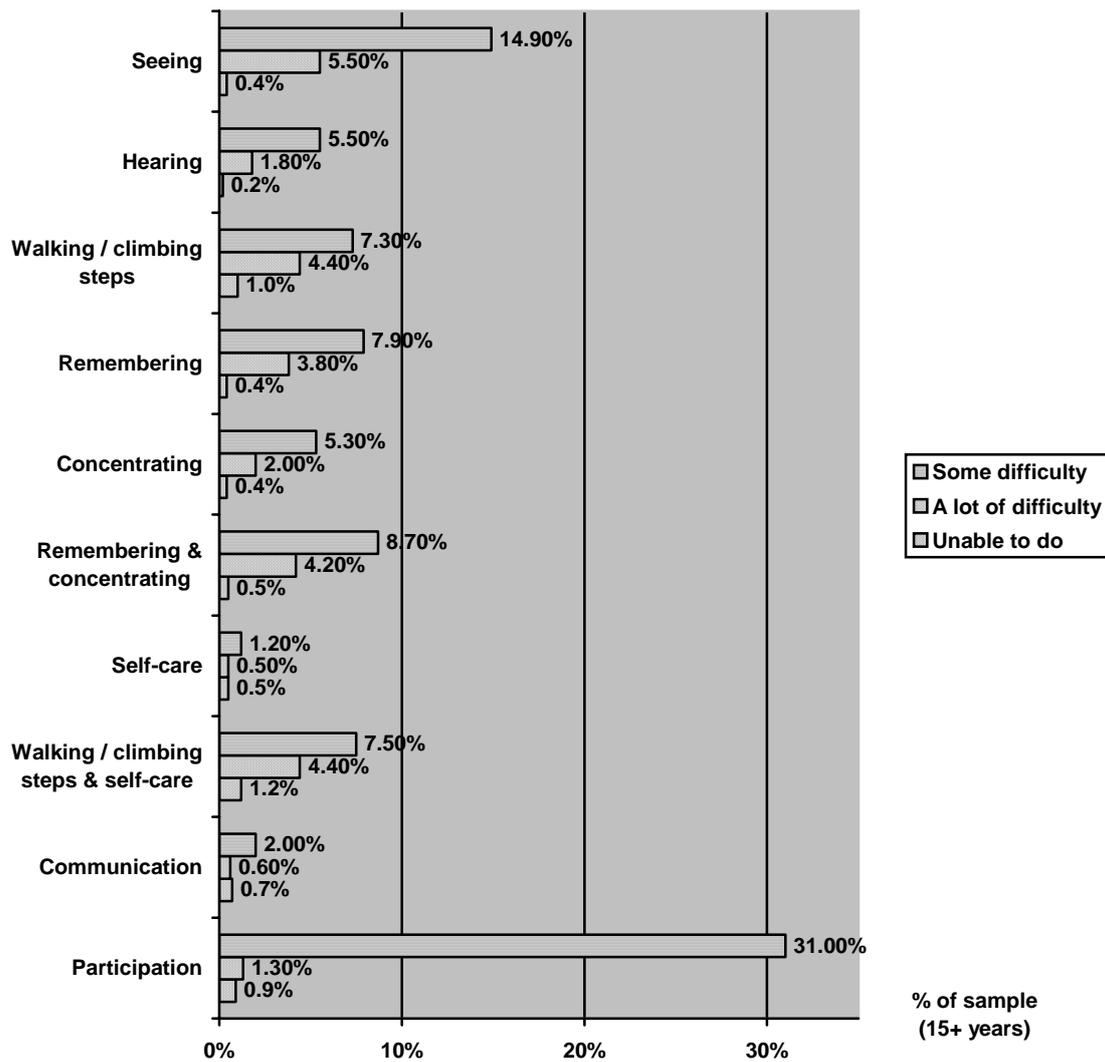
#### 4.1.2.10 Summary

The results presented in this section indicate that there are major differences in the response rates for different age groups, income categories, educational achievement, employment status, and marital status. The older, poorer, less educated, unemployed and widowed or divorced respondents were the most likely to indicate having difficulties. Some of these factors will be independent factors such as age and marital status. The other factors could be either independent or dependent variables. For example, low education and low living standard, as independent variables, could lead to a person becoming impaired and experiencing difficulties. On the other hand, these same factors, as dependent variables, could be the outcome of having difficulties because of poor access to quality education and loss of employment opportunities.

### 4.1.3 Individual questions of the revised set

Figure 12 presents the results for the individual questions. The most prevalent difficulties are those for the activities of seeing, walking and climbing steps and remembering. The least prevalent difficulties are for self care and communication.

Figure 12: Un-weighted responses on individual questions and combinations of revised set



The results indicate a high proportion of the total population reporting ‘Some difficulty’ seeing even with glasses and participating in community activities. The high responses for ‘some difficulty’ seeing could be explained as follows:

- A high awareness of difficulties in seeing as vision testing services and provision of glasses are generally relatively widespread;
- A person can notice with relative ease that he or she cannot see very well and therefore is able to report even mild difficulties (e.g. compared to a hearing difficulty);
- Some confusion with the phrase ‘even with glasses’ that might have been ignored by a number of respondents with their response being ‘without glasses’;
- The provision of eye glasses but with an inadequate or inappropriate prescription causing some difficulty even with glasses.

The high number of people who indicated ‘Some difficulty’ with participating in community activities could be explained by the nature of the question. The reference to ‘a health condition’ specified in the introductory phrase to the questions seems to have not been applied in this question. These responses are likely to be difficulties that people experience due to reasons other than a health condition.

However, when the overall composite estimate for all the questions together was analysed with the ‘Some difficulty’ on the participation question recoded as ‘No difficulty’, the estimates did not change significantly (less than 1%). This means that the people indicating ‘Some difficulty’ for community participation were also indicating some difficulties on other activities. A frequency analysis was done on the number of people who indicated ‘Some difficulty’ for community participation in relation to the number of other activities they also indicated having ‘Some difficulty’. This shows that only a few people responded as having ‘Some difficulty’ only to the participation question. Most indicated ‘Some difficulty’ also on one or more other activities. For the household questionnaire that was completed by proxy, ‘Some difficulty’ for participation was indicated for only 28% of the persons 15 years and older who had no other activity for which ‘Some difficulty’ was indicated. For the adult questionnaire, which was completed by direct interview, the figure drops to only 13%. This explains why the prevalence estimate did not change with the recoding for the community participation question.

**Table 4: Number of persons for whom ‘Some difficulty’ was indicated on one or more activities when ‘Some difficulty’ was indicated for the participation question**

Number of activities with ‘Some difficulty’ if ‘Some difficulty’ on participation	Household Questionnaire		Adult Questionnaire	
	Frequency	%	Frequency	%
1	50	28	17	13
2	25	14	13	10
3	31	18	18	14
4	25	14	25	20
5	21	12	12	10
6	10	6	11	9
7	8	5	14	11
8	7	4	17	13
<b>Totals</b>	<b>177</b>	<b>100</b>	<b>127</b>	<b>100</b>

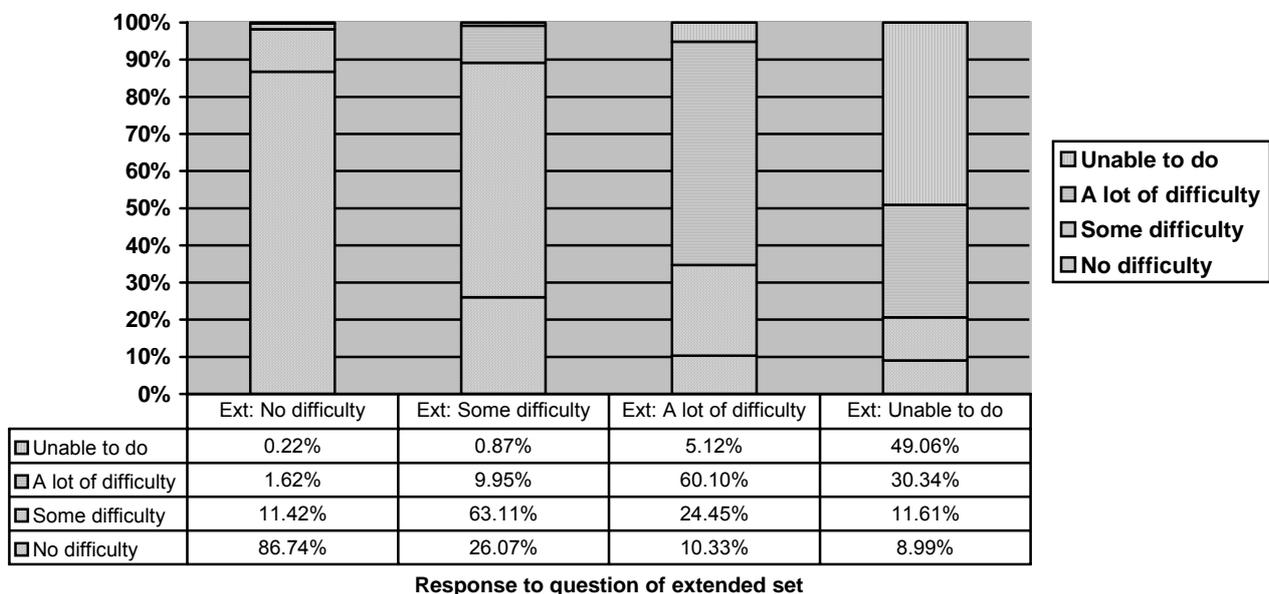
#### 4.1.4 Comparison of the revised set with composite responses on the extended set

The data analysed in this section are from the Adult Questionnaire. The overall composite response for the revised set of questions is compared to the overall composite response for the full extended set of questions. This is followed by the analysis of individual domains, comparing the responses on a single question in the revised set of questions to the related extended questions. For example, the question in the revised set on seeing is compared to the two questions on seeing in the extended set – one on far vision and one on near vision.

##### 4.1.4.1 Overall composite response on disability

Figure 13 shows that in general the responses provided on the revised set matched the composite responses on the extended set.

**Figure 13: Un-weighted responses for revised set and extended (Adult Questionnaire)**



The majority (86,74%) of the ‘No difficulty’ responses on the extended set were also ‘No difficulty’ responses on the revised set. Similarly, the majority (63,1%) of ‘Some difficulty’ responses on the extended set were also ‘Some difficulty’ on the revised set. Note, however, that only 49,06% of the ‘Unable to do’ responses on the extended set were the same on the revised set, with 30,34% of these being ‘A lot of difficulty’ on the revised set. This indicates that the responses were less severe on the revised set with less detailed or specific questions.

The prevalence estimate (the sum of ‘Some difficulty’, ‘A lot of difficulty’ and ‘Unable to do’) is 34,21% for the revised set and 36,02% for the extended set. If only the ‘A lot of difficulty’ and ‘Unable to do’ responses are considered, the prevalence estimate for the revised set measured 12,53% and for the extended set 12,07%. These figures are very close and indicate that the extended questions do not add much to the overall estimate. The difference of just over 2% between the responses for ‘Some difficulty’ between the revised set and the extended set could be attributed to the additional questions not subsumed under any of the revised set of questions such as learning and interpersonal interactions.

#### 4.1.4.2 The seeing domain

The questions asked in the extended set were whether the person has difficulty:

- Seeing and recognising a person he/she knows from 7 meters away (e.g. across a street) (with glasses if he/she wears them) and
- Seeing and recognising an object at arm's length (with glasses if he/she wears them).

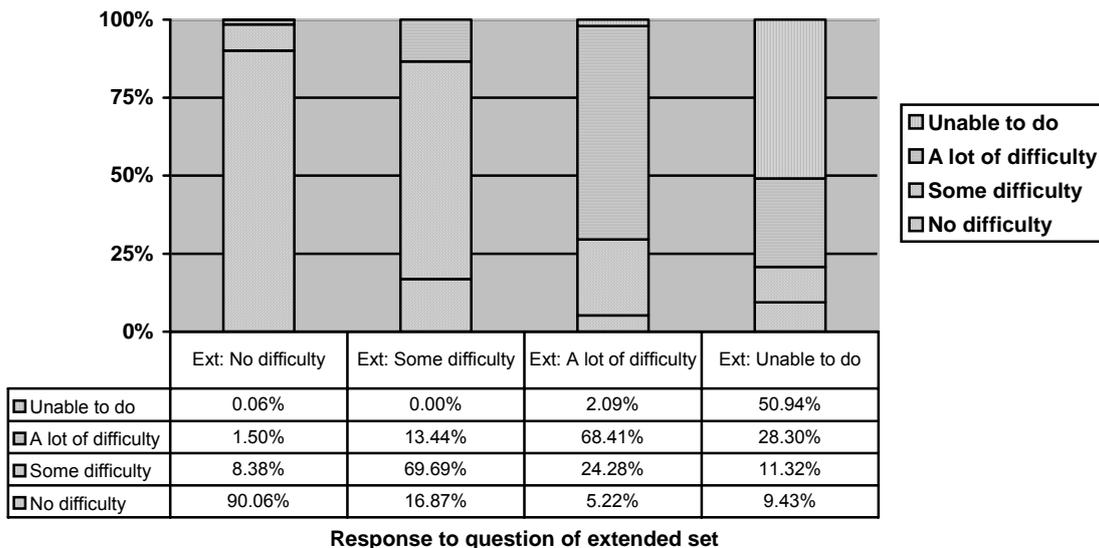
The extended set responses were analysed together to obtain the extended set response for seeing.

The revised set question on seeing would have elicited a response that took these two aspects of vision (far and near vision) into account.

The responses for seeing for the revised set and the extended set showed good correspondence for 'No difficulty'. (Refer to **Figure 14**.) There seems, however, to be some overlap between 'No difficulty' and 'Some difficulty' for the extended set, where 'Some difficulty' on the extended set elicited quite a number of 'No difficulty' responses on the revised set. For 'A lot of difficulty' there is a range of responses on the revised set from 'No difficulty' through to a few 'Unable to do'. The 'Unable to do' responses on the revised set did not correspond well with the 'Unable to do' on the extended set. Only 50,94% of the 'Unable to do' responses on the extended set was the same on the revised set, with 30,34% being given as 'A lot of difficulty' on the revised set.

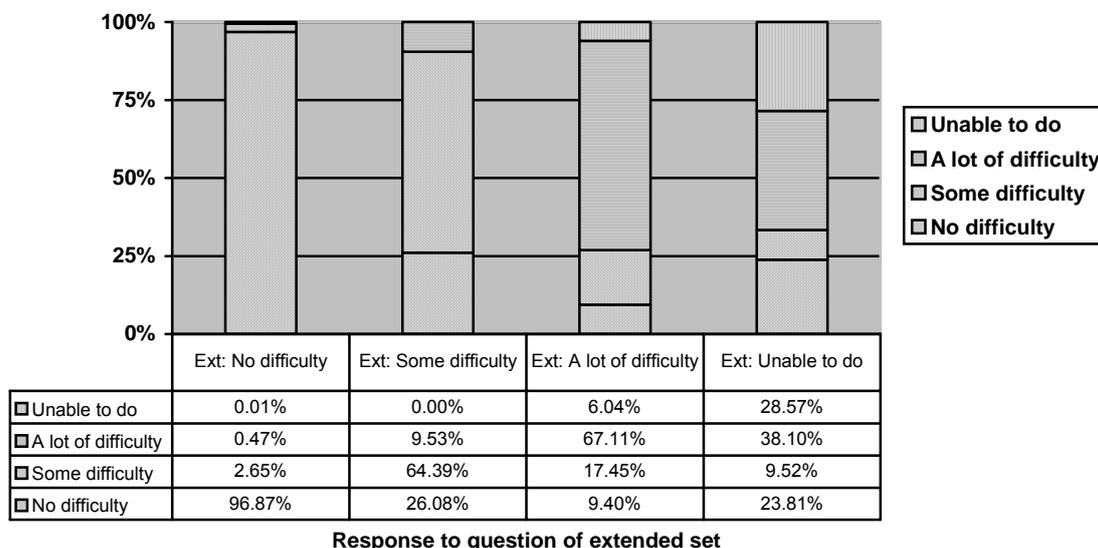
The prevalence estimate for difficulty seeing (the sum of 'Some difficulty', 'A lot of difficulty' and 'Unable to do') is 21,82% for the revised set and 15,63% for the extended set. If only the 'A lot of difficulty' and 'Unable to do' responses are considered, the prevalence estimate for the revised set measured 3,9% and for the extended set 5,69%. The revised set question on seeing identifies more people with 'some difficulty' seeing, but less people with more severe difficulties seeing.

**Figure 14: Un-weighted responses for revised set and extended set for the seeing domain (Adult Questionnaire)**



#### 4.1.4.3 The hearing domain

**Figure 15: Un-weighted responses for revised set and extended set for the hearing domain (Adult Questionnaire)**



**Response to question of extended set**

The extended questions asked about difficulty:

- Hearing someone talking on the other side of the room in a normal voice (with a hearing aid if the person wears one); and
- Hearing what is said in conversation with one other person in a quiet room (with a hearing aid if the person wears one).

These two questions asked about listening at a distance and in conversation.

The vast majority of the 'No difficulty' responses for the extended set were also 'No difficulty' for the revised set (96,87%). The 'Some difficulty' responses on the extended set were mostly 'No difficulty' (26,06%) or "Some difficulty" (64,39%) on the revised set. For the responses of "A lot of difficulty" on the extended set, the revised set had a range of responses with the majority being 'A lot of difficulty' (67,11%), but also 'Some difficulty' (17,45%), 'No difficulty' (9,4%) and a few 'Unable to do' (6,04%). The 'Unable to do' responses on the extended set were mostly given as 'Unable to do' (28,57%) or 'A lot of difficulty' (38,10%) on the revised set. There were, however, a large percentage of cases (23,8%, which represented 6 cases) where 'No difficulty' was indicated for the revised set.

The prevalence estimate for difficulty hearing (the sum of 'Some difficulty', 'A lot of difficulty' and 'Unable to do') is 7,96% for the revised set and 6.5% for the extended set. If only the 'A lot of difficulty' and 'Unable to do' responses are considered, the prevalence estimate for the revised set measured 2,2% and for the extended set 1,52%. This pattern is similar to that obtained for the domain of seeing.

#### 4.1.4.4 Domain of Mobility

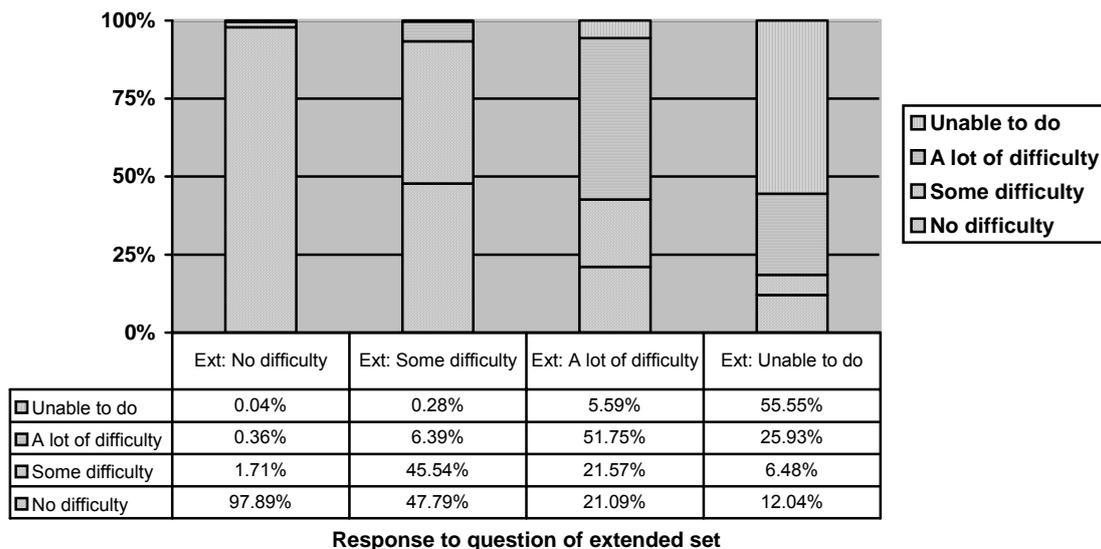
The questions asked in the extended set were difficulty in:

- Standing for long periods such as for 30 minutes; and
- Walking a long distance such as a kilometre (or equivalent).

The question about “standing for long periods” is a different activity to either walking or climbing stairs in the revised set and could account for some of the differences in responses.

**Figure 16** shows the comparison for the mobility domain. The responses for mobility for the revised set and the extended set corresponded for ‘No difficulty’. There was some overlap between ‘No difficulty’ and ‘Some difficulty’ for the extended set. For ‘Some difficulty’ on the extended set there were quite a number of ‘No difficulty’ responses on the revised set. ‘A lot of difficulty’ on the extended set showed a range of responses on the revised set, from ‘No difficulty’ through to a few ‘Unable to do’. The ‘Unable to do’ responses on the extended set did not correspond well with the ‘Unable to do’ on the extended set. Only 55,56% of the ‘Unable to do’ responses on the extended set was the same on the revised set, with 25,93% being ‘A lot of difficulty’ on the revised set.

**Figure 16: Un-weighted responses for revised set and extended set for the mobility domain (Adult Questionnaire)**



The prevalence estimate for mobility difficulties (the sum of ‘Some difficulty’, ‘A lot of difficulty’ and ‘Unable to do’) is 13,63% for the revised set and 19,31% for the extended set. If only the ‘A lot of difficulty’ and ‘Unable to do’ responses are considered, the prevalence estimate for the revised set measured 5,17% and for the extended set 6,57%. This indicates that the extended questions identify more people with mobility difficulties than the single revised set question.

#### 4.1.4.5 Domain of Cognition

For the domain of cognition, the revised set asked two separate questions – one on memory (remembering) and one on concentration.

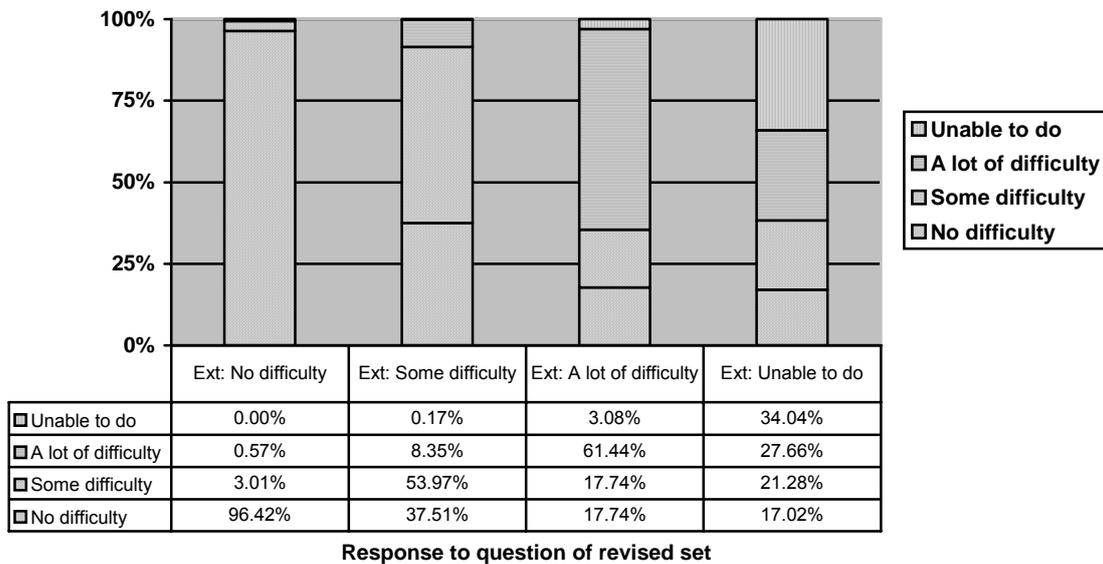
The extended set asked the following questions:

- Concentrate on doing something for 10 minutes;
- Remembering to do important things; and
- Learning a new task, such as learning how to get to a new place.

The extended set questions give more specific information about the context of the difficulty, such as ‘important tasks’ and ‘concentrating for 10 minutes’. The third question introduces the aspect of learning.

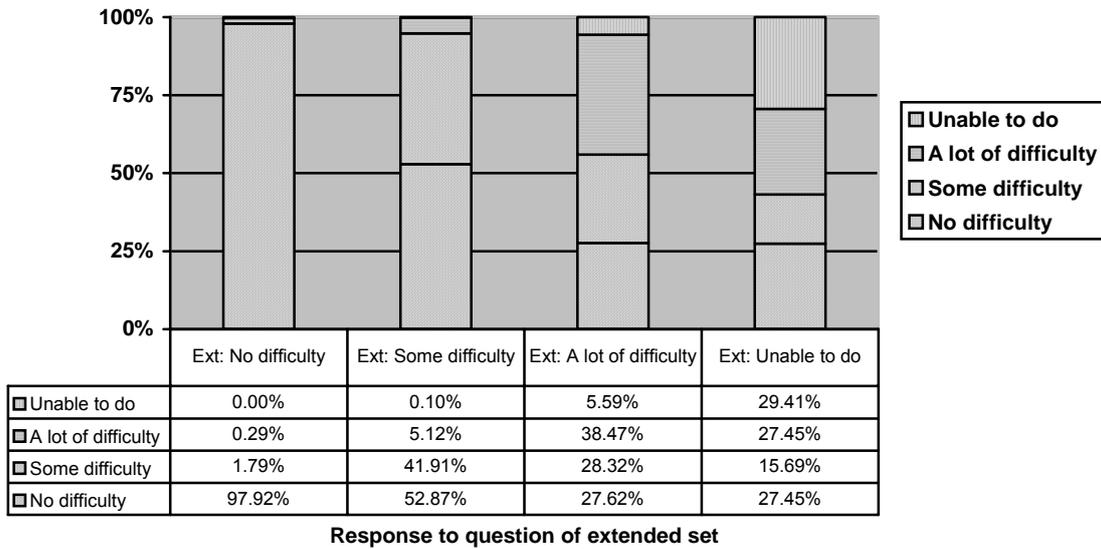
The analysis considered the revised set questions individually and combined. Remembering in the revised set was compared to remembering to do important things and learning of new tasks. Concentrating in the revised set was compared to concentrating for 10 minutes and learning of new tasks. The combined remembering and concentrating questions in the revised set were compared to the three extended questions together. These comparisons are presented in **Figures 17 – 19** below.

**Figure 17: Un-weighted responses for revised set and extended set for remembering in the cognitive domain (Adult Questionnaire)**

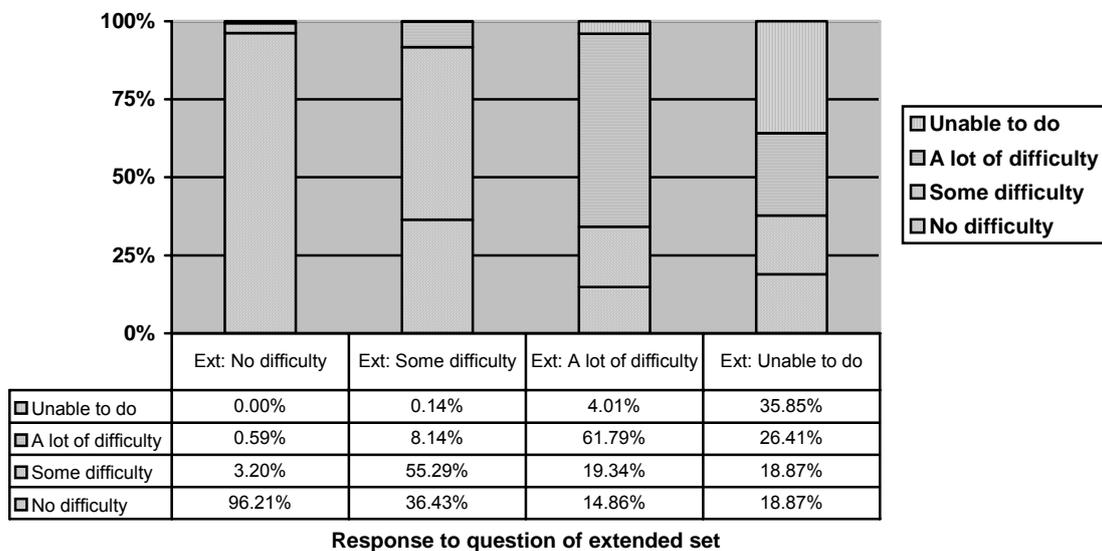


For all three comparisons the following remarks are valid. The responses for the revised set and the extended set corresponded for ‘No difficulty’ quite well. For ‘Some difficulty’ on the extended set there were a significant number of “No difficulty” responses on the revised set.

**Figure 18: Un-weighted responses for revised set and extended set for the concentrating in the cognitive domain (Adult Questionnaire)**



**Figure 19: Un-weighted responses for revised set and extended set for the remembering and concentrating combined (Adult Questionnaire)**



'A lot of difficulty' on the extended set showed a range of responses on the revised set, from 'No difficulty' through to a few 'Unable to do'. 'Unable to do' on the extended set did not show correlation with 'Unable to do' on the revised set.

The prevalence estimates for this domain are set out in the **table 5** below.

		Remembering %	Concentrating %	Remembering and concentrating %
<b>Sum of 'Some difficulty', 'A lot of difficulty' and 'Unable to do'</b>	Revised set	12,96	8,14	14,28
	Extended set	14,62	11,76	16,04
<b>Sum of 'A lot of difficulty' and 'Unable to do'</b>	Revised set	3,91	2,11	4,26
	Extended set	3,9	3,02	4,27

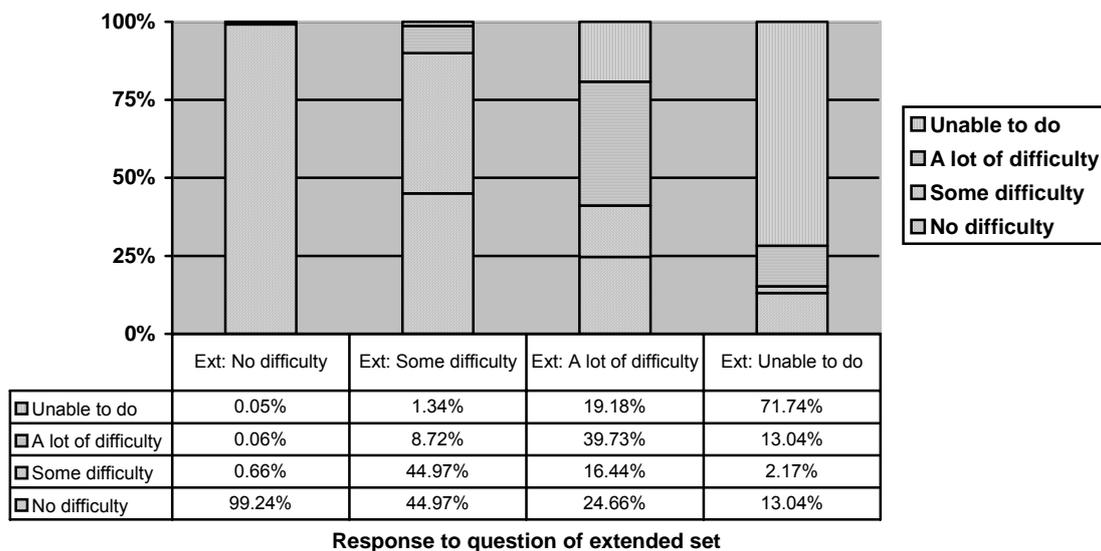
This initial analysis suggests that these questions work fairly well together and it might be possible to combine the remembering and concentrating questions in the final census schedule. In addition, the results indicate that including a question on learning could allow for people with cognitive difficulties to be identified.

#### 4.1.4.6 Domain of self-care

The extended questions were very similar to the revised set. The extended set asked about difficulty with:

- Washing one's whole body; and
- Getting dressed.

**Figure 20: Un-weighted responses for revised set and extended set for the self-care domain (Adult Questionnaire)**



The vast majority of the 'No difficulty' responses for the extended set were also 'No difficulty' for the revised set (99,24%). The 'Some difficulty' responses on the extended set were mostly 'No difficulty' (44,97%) or 'Some difficulty' (44,97%) on the revised set. For the responses of 'A lot of difficulty' on the extended set, the revised set had a range of responses. The response 'A lot of difficulty' was given by only 39,73% of the relevant persons, with 19,18% being 'Unable to do', 16,44% showing 'Some difficulty' and a large percentage (24,66%) showing 'No difficulty'. The 'Unable to do' responses on the extended set were mostly given as 'Unable to do' (71,74%) or 'A lot of difficulty' (13,04%) on the revised set. A further 13,04% of these, which represented 6 cases, indicated 'No difficulty' for the revised set.

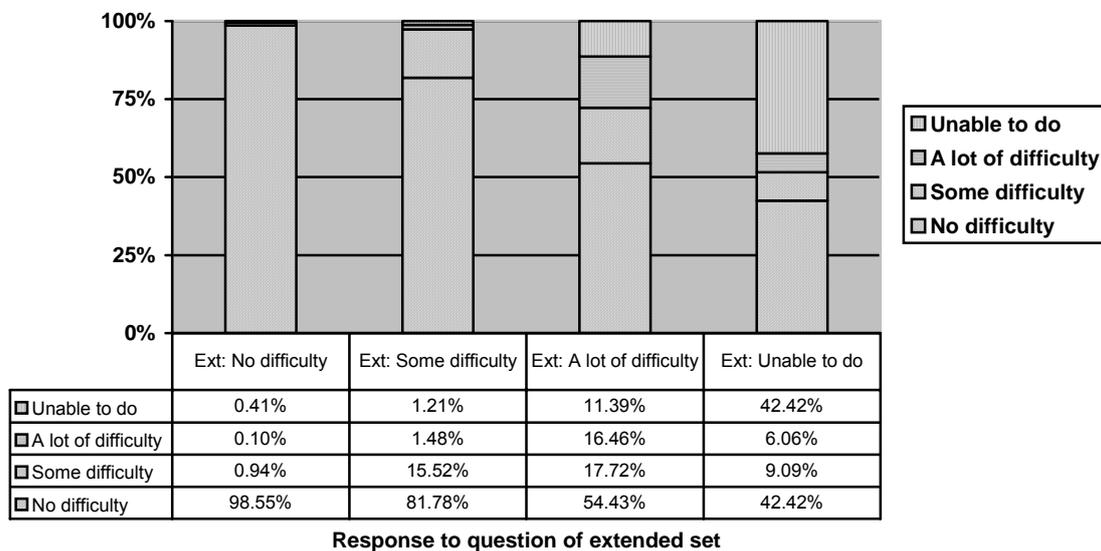
The prevalence estimate for self-care difficulties (the sum of 'Some difficulty', 'A lot of difficulty' and 'Unable to do') is 1,33% for the revised set and 1,36% for the extended set. If only the 'A lot of difficulty' and 'Unable to do' responses are considered, the prevalence estimate for the revised set measured 0,96% and for the extended set 1,06%.

#### 4.1.4.7 Domain of communication

The communication domain had three questions in the extended set:

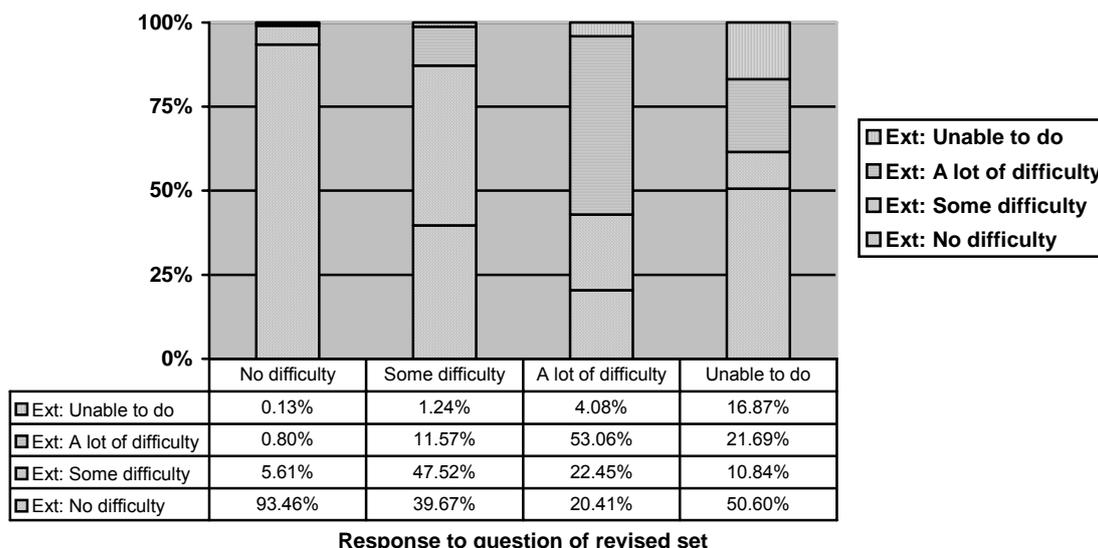
- Understanding others;
- Being understood; and
- Maintaining a conversation.

**Figure 21a: Un-weighted responses for revised set and extended set for the communication domain (Adult Questionnaire)**



The responses to the extended set of questions had a poor correspondence with the responses to the revised set for all three response categories that indicate a degree of difficulty. 'Some difficulty', 'A lot of difficulty' and 'Unable to do' responses on the extended set each generated all responses on the extended set from 'No difficulty' through to 'Unable to do'. Of particular concern is the lack of correspondence on the 'Unable to do' response. For this response on the extended set, the revised set had a large percentage (42,42%) as 'No difficulty', thus missing many people with communication difficulties.

**Figure 21b: Un-weighted responses for revised set and extended set for the communication domain (Adult Questionnaire)**



Refer to **Figure 21b** where the comparison is reversed. The majority of the 'Unable to do' responses on the revised set showed 'No difficulty' for the extended set. The question on the revised set includes mention of Sign language as a possible 'usual' language. This was included to allow Sign language users to say that they do not have any difficulty communicating in their usual language. However, this could have led some people to focus on that phrase and not on the whole question. They would thus have said that they were unable to communicate in Sign language. The extended questions did not mention Sign language and thus did not cause this confusion. However, this is merely a hypothesis that requires further testing.

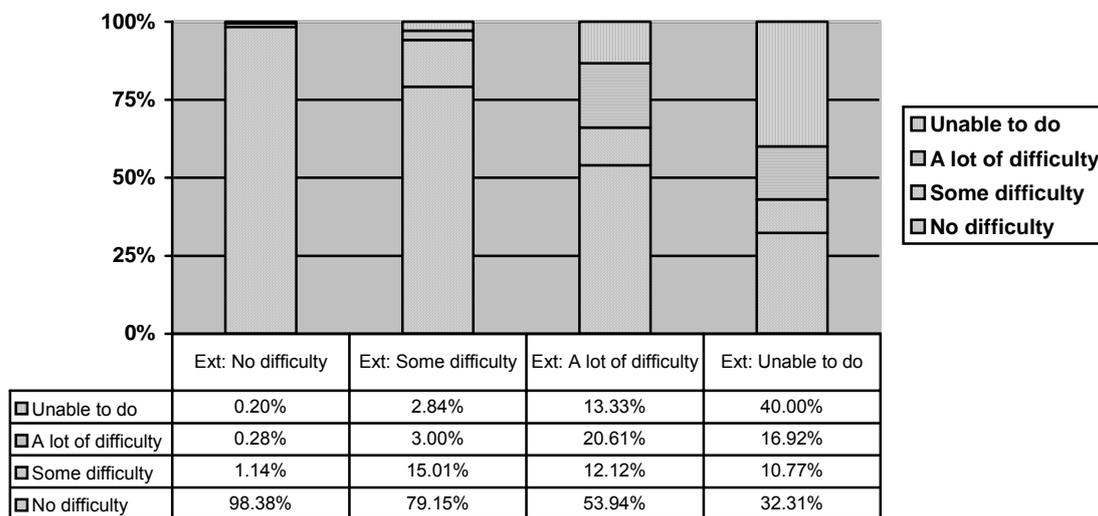
#### 4.1.4.8 Domain of participation

The two extended questions that were compared with the question of the revised set on participation asked about difficulties with:

- Taking care of one's household responsibilities; and
- In one's day-to-day work/schoolwork.

The domain relates to a person’s ability to participate in major life activities, although in the revised set and the extended set it referred to different contexts, namely the community versus the home and work/school environment respectively.

**Figure 22: Un-weighted responses for revised set and extended set for the participation domain (Adult Questionnaire)**



**Response to question of extended set**

The majority of the ‘No difficulty’ responses for the extended set were also ‘No difficulty’ for the revised set (98,38%). However, for the other response categories the correlation was not good. The “Some difficulty” responses on the extended set were mostly ‘No difficulty’ (79,15%) on the revised set. Even for the ‘A lot of difficulty’ and ‘Unable to do’ responses on the extended set large percentages of the responses on the revised set were ‘No difficulty’ (53,94% and 32,31% respectively).

The prevalence estimate for difficulties in participating in major life activities (the sum of ‘Some difficulty’, ‘A lot of difficulty’ and ‘Unable to do’) is 3,75% for the revised set and 7,73% for the extended set. If only the ‘A lot of difficulty’ and ‘Unable to do’ responses are considered, the prevalence estimate for the revised set measured 1,61% and for the extended set 2,06%.

These results suggest that community participation did not capture all the same people who had difficulties in taking care of household responsibilities or participating in work or school. The relationship between these questions warrants further investigation.

#### 4.1.4.9 Summary

The comparison of the revised set with the extended set of questions used only the data collected on the Adult Questionnaire.

In general, the single question responses seemed to correspond reasonably well with the responses for the related questions on the extended set. This was the case for all domains except for communication and participation. In the case of the communication domain it is possible that the use of the phrase 'including Sign language' could have lead some respondents in the revised set to say they were 'Unable to' communicate. This requires further investigation.

In general, the extended set generated responses that were more severe in terms of the difficulty than the revised set of questions. This was the case across all domains. Some possible factors that could have influenced these responses are the more precise reference in many of the extended questions (e.g. concentrating for 10 minutes) and the placement of the extended set questions after the revised set which could have had an influence on the person's frame of reference for answering the extended sets.

Further analyses should consider the relationship between the single question of the revised set and each related extended set question individually.

#### 4.2 Comparison of the revised set with the Census 2001 questions

The Census 2001 question was the following:

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

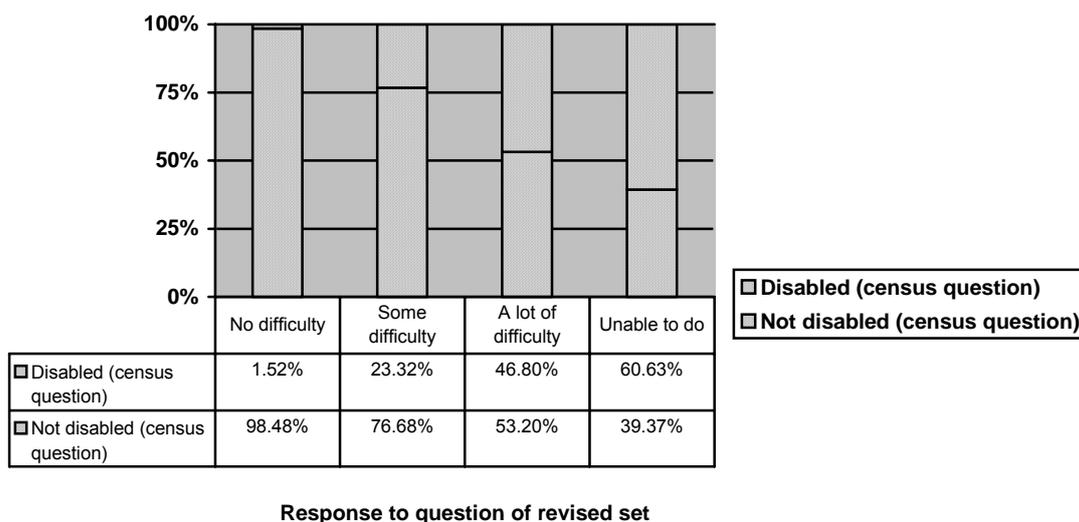
- 0: None
- 1: Sight (blind/severe visual limitation)
- 2: Hearing (deaf/profoundly hard of hearing)
- 3: Communication (speech impairment)
- 4: Physical (e.g. needs wheelchair, crutches or prosthesis; limb, hand usage limitations)
- 5: Intellectual (serious difficulties in learning)
- 6: Emotional (behavioural, psychological)

Of note in the Census 2001 question was the inclusion of the words 'serious disability that prevents participation' and the use of binary response options 'Yes' and 'No'. A person was classified as disabled if they said 'Yes' (dotted the appropriate box) to one or more of the impairment categories listed.

**Figure 23** compares the prevalence rates from the revised set with those from the Census 2001 question as asked in the Household Questionnaire.

The revised set measured a higher prevalence of disability than the Census 2001 question (33,24% if 'Some difficulty' is included and 13,25% if it is not included, versus 12,24% for the Census 2001 question). The 1,52% of the respondents for whom 'No difficulty' was indicated with regard to all the questions of the revised set, but for whom a status of disabled was allocated from the response to the Census 2001 question (refer to **Figure 23**) may be indicative of error in the field. This should be further investigated as there were 121 such cases.

**Figure 23: Un-weighted responses for revised set compared to the Census 2001 question (Household Questionnaire)**



Only 23,32% of people identified as having 'Some difficulty' on the revised set were identified as disabled using the Census 2001 question. Likewise, of those who experienced 'A lot of difficulty', 46,80% were also identified as being disabled using the Census 2001 question. Of the people for whom it was indicated that they were 'Unable to do' one or more activities (revised set), 60,63% were identified as disabled using the Census 2001 question. The major differences between the revised set and the Census 2001 lie at the mild end of the continuum of severity. These findings reinforce the conclusion that the Census 2001 question counted primarily people who had moderate to severe difficulties and who self-identified or were identified as 'disabled'.

The actual Census in 2001 identified 5% of the total population as being disabled. This figure applied to the whole population from birth to old age. The Census 2001 prevalence was re-calculated to provide a rate comparable to the one used in this study – i.e. for the population 15 years and older. The revised prevalence is 6,1% of the population 15 years and older. The weighted responses on the same Census 2001 question used in this survey identified 12,08% of the population 15 years and older as being disabled. The possible explanation for this is the nature of the survey (about difficulties and disabilities) and the placement of the Census 2001 question right at the end of the household questionnaire after the revised set of questions. This placement was used to avoid use of the word 'disability' before asking the revised set of questions, but it, together with the disability focus of the survey, could have sensitised household respondents to identifying disability in the Census 2001 question.

A logistic regression model was constructed to investigate relative risk respondents with specific characteristics to show a difference between disability statuses as derived from the revised set and the Census 2001 question.

Logistic regression is a special form of regression in which the dependent variable is a non-metric, dichotomous (binary) variable. The values of the discrete binary dependent variable are transformed into an S-shaped (logistic) curve representing the probability of an event. This probability is then used to estimate the odds ratio. This technique is especially appropriate when it is of interest to describe the odds of an outcome, or the odds of success faced by one group relative to another.

In the following model the odds ratios listed should be interpreted as the odds of success faced by that group relative to the relevant listed reference group (which were not used as an independent variable in the model) while controlling for other independent variables.

The model shown passed the goodness-of-fit test, had a sensible classification table and used data that was not weighted.

**Table 6: Model – Risk of difference in disability status: revised set versus Census 2001 question (Household Questionnaire)**

<b>Detail:</b>	Any of the following responses in the revised set for any of the entries taken as evidence of disabled status: 'Some difficulty' 'A lot of difficulty'; 'Unable to do'.			
<b>Definition of dichotomous variable:</b>	Difference in status → 1 No difference in status → 0			
<b>Respondent's Background</b>		<b>Odds Ratio</b>	<b>95% Confidence Interval</b>	
<b>Age</b>	25-34 years	1,4258690	1,2175780	1,6697940
	35-59 years	2,5852190	2,2198130	3,0107730
	50+ years	4,0412870	3,3347870	4,8974640
<b>Relationship to head</b>	Not close relation	0,8501157	0,6952966	1,0394080
<b>Sex</b>	Female	1,1356110	1,0062070	1,2816570
<b>Marital status</b>	Married/Living together	1,3502350	1,1227940	1,6237480
	Widow(er)	1,5753020	1,2434230	1,9957610
	Divorced/Separated	1,1038920	1,0054310	1,2119960
<b>Population group</b>	Black African	1,0066500	0,8252137	1,2279770
	Coloured	0,8665839	0,6919812	1,0852430
	Indian/Asian	0,8298592	0,5875480	1,1721020
<b>Level of Education</b>	No education/some primary	1,3129770	1,1030580	1,5628450
	Primary/some high school	1,1029040	0,9381902	1,2965370
	Grade 12	0,7881997	0,6530318	0,9513454
<b>Employment status</b>	Unemployed	1,0732500	0,9638922	1,1950150
<b>Living Standard Measure</b>	LSM 1-3	1,1331200	0,9708147	1,3225600
	LSM 4-6	1,1516420	1,0076280	1,3162380
<b>Reference groups:</b>	15-24 Years old Close relation to head of household Male Never married White Tertiary education Employed LSM 7+			
<b>Sample size</b>	11 947			

Significant differences in risk for a difference in disability status to arise were found for specific age, sex, marital status and education level groups relative to the relevant reference groups.

For age, the older groups all showed a higher risk relative to the 15-24 year old group. This can be explained in terms of how the two sets were structured. The use of the term 'disability' in the Census 2001 set would have resulted in few older people being identified as disabled. However, for the revised set the use of the term 'difficulties' allowed older people to be identified as having a difficulty without having to identify them as being 'disabled'. Difficulties in old age are seen as just that – difficulties arising from the normal process of ageing, and not as disability.

Women showed a higher risk of showing a difference between the two sets. The reasons for this are not clear and would need to be investigated further. The indications are that women are less likely to report being disabled (as per the Census 2001 question) but are more likely to report difficulties (as per the revised set). However, the fact that women survive longer in South Africa than men could be confusing the findings - this result for women, could in fact be related to older ages of women.

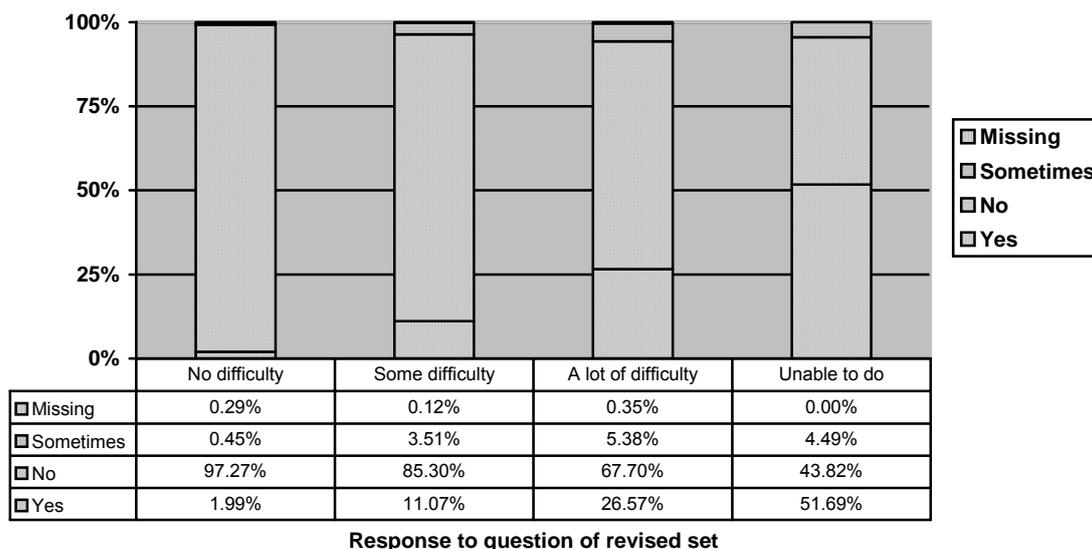
For marital status, the categories 'Married/Living together', 'Divorced/Separated' and 'Widow(er)' showed a higher risk for a difference between the two sets. Disabled people, in the traditional sense of the term disabled, have lower rates of marriage because of stigma associated with being disabled. These are also likely to be people who would identify themselves or be identified as being disabled and, hence, respond positively on the Census 2001 question as well as on the revised set. In a similar vein, a difficulty reported by a younger person (more likely to be 'never married') would more likely be seen as a disability than a difficulty.

With regard to highest level of educational level, the finding was that persons with no schooling or persons who completed only some primary schooling had a higher risk of showing a discrepancy than persons with a tertiary education. This could be due to the fact that lower education levels (as lower income levels) are associated with poorer health, and hence a higher likelihood of the reporting of difficulties. However, these difficulties might not be seen as disability and hence not reported by the Census 2001 question.

#### **4.3 Comparison of the revised set with the question "Are you disabled?"**

The use of the term 'disabled' was shown in the focus group study to inhibit people from responding that they have a lesser or greater extent of difficulty, merely because they do not identify with being disabled. We included the question 'Are you disabled?' at the end of the Adult Questionnaire to investigate the differences in responses on the revised set, that uses the term 'difficulty', to the question on being 'disabled'.

**Figure 24: Un-weighted responses to the revised set compared to "Are you disabled?" (Adult questionnaire)**



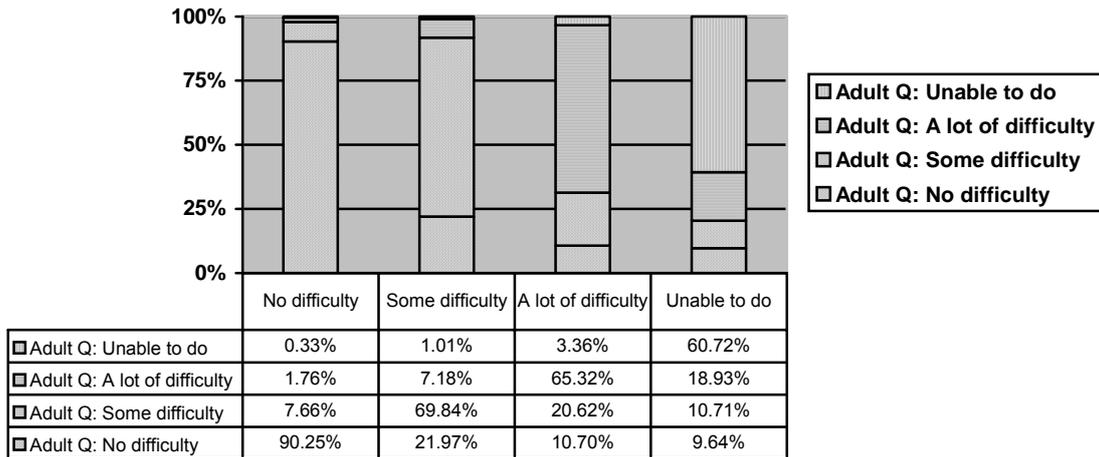
**Figure 24** shows that the percentage of respondents who said ‘Yes’ to ‘Are you disabled?’ increases with increasing severity of the difficulty on the revised set. Just over 50% of respondents who indicated that they were ‘Unable to do’ one or more activities also said that they were disabled. Very few respondents said that they were disabled ‘Sometimes’. These results highlight the need to move away from use of the terms ‘disability’ or ‘disabled’ in questions that aim at collecting statistics on population functioning. Their use not only provides a low count, but also confuses the issue as to the severity of the disability, as respondents who say ‘Yes’ have ‘Some difficulty’, ‘A lot of difficulty’ or are ‘Unable to do’ one or more activities. The revised set provides more detailed information on severity and can, thus, be used more effectively for policy planning.

The results indicate a very good correspondence between the responses given on the revised set and ‘Are you disabled?’, but show a much lower endorsement for the ‘Are you disabled?’ question. This confirms the finding from the focus group study that being disabled (self-identified) entails having difficulties, but having difficulties does not entail being ‘disabled’ as identified by the respondent.

#### 4.4 Investigation of proxy effect

In a census questions on disability and functioning are reported by the household respondent as proxy responses for the other household members. In order to test the effect of this proxy response, an Adult Questionnaire was administered directly to all household members who were 15 years or older. These responses were compared to those obtained for the same person on the Household Questionnaire.

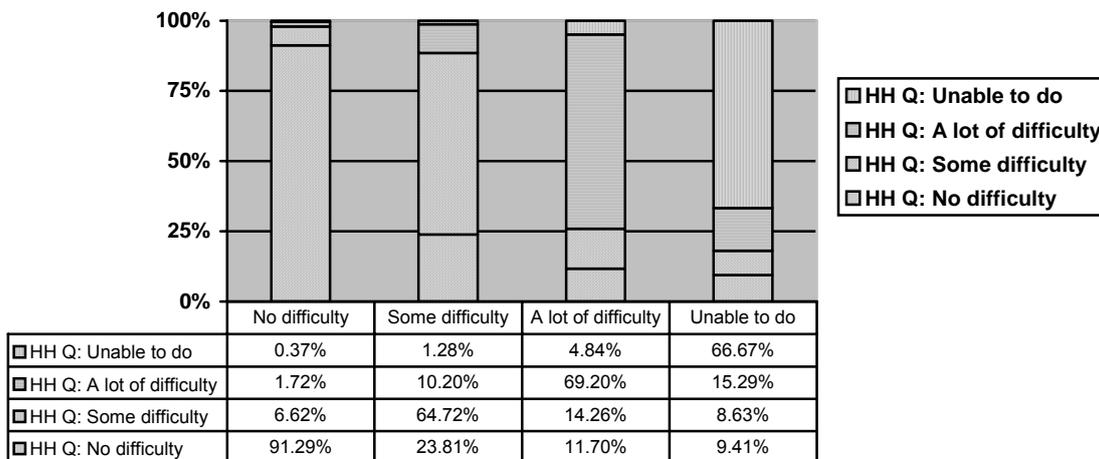
**Figure 25a: Un-weighted responses to revised set - Household Questionnaire (proxy) compared to Adult Questionnaire (direct)**



**Response to question of revised set on Household Questionnaire**

The results (refer to **Figures 25a** and **25b**) reflect a predominantly good match, with some degree of over-reporting by the proxy respondent where they perceive the difficulty being more than what the individual actually reports directly. To a far lesser extent, there is an under-reporting by the proxy respondent, where they either do not note the problem, or see it as being less severe than what the person reports in the direct interview.

**Figure 25b: Un-weighted responses to revised set - Household Questionnaire (proxy) compared to Adult Questionnaire (direct)**



**Response to question of revised set on Adult Questionnaire**

The reverse mapping of the direct response on the categories measured for the proxy response show a similar pattern, slightly more pronounced (for more severe responses on the proxy responses) where the direct response showed 'No difficulty' or 'Some difficulty' and slightly less where the direct response reported

a higher degree of severity than the proxy response. It is not possible to make statements about the net effect of proxy response from this data.

The prevalence estimate (the sum of 'Some difficulty', 'A lot of difficulty' and 'Unable to do') is 33,14% for the proxy responses and 33,89% for the direct responses. If only the 'A lot of difficulty' and 'Unable to do' responses are considered, the prevalence estimate for the proxy responses measured 13,21% and for the direct responses 12,38%. Thus the proxy effect does not seem to be a major one. It should be noted that the respondents answering the Adult Questionnaire only did so if they were able to respond for themselves. No 'proxy' Adult Questionnaires were administered.

#### **4.5 Frequency of use of assistive devices compared to responses on functioning questions**

The second part of the revised set comprised a question on the use of assistive devices, including the use of eye glasses, hearing aids, walking sticks or frames, wheelchairs, or chronic medication. This question was analysed only in relation to responses given for the questions on activities in the first part of the revised set. The analysis was done for both the Household and the Adult Questionnaires. The results are presented below in **Tables 7** and **8**. Note that in both tables the totals do not always add to 100% as missing responses have been omitted.

##### **4.5.1 Use of eye glasses**

The revised set question on seeing asked the respondent to report difficulties with seeing, even with glasses.

For the proxy respondents, 7,18% of those that reported 'No difficulty' in seeing, did in fact wear glasses. The percentages of respondents with a degree of difficulty who wear glasses are above 30% across the other three response categories. This suggests either that people ignored the phrase 'even with glasses', or had prescriptions that were not optimised and therefore remained with a degree of difficulty, even with glasses. The figures for the direct respondents were similar, except that proportionally more reported 'No difficulty' when using glasses, and fewer reported using glasses when they are 'Unable to see'.

**Table 7: Use of assistive devices for each of the related functioning questions (Household questionnaire)**

Response on revised set of functioning questions	Use of eye glasses (Seeing question)		Use of hearing aid (Hearing question)		Use of walking aid (Walking and climbing question)		Use of wheelchair (Walking and climbing Question)		Use of chronic medication (All questions)	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
<b>No difficulty</b>	7,18%	92,61%	0,23%	99,40%	0,41%	99,15%	0,17%	99,33%	5,00%	94,41%
<b>Some difficulty</b>	33,41%	66,25%	1,99%	97,71%	8,49%	91,17%	0,23%	99,08%	15,66%	83,71%
<b>A lot of difficulty</b>	38,44%	61,56%	6,88%	92,20%	21,41%	78,59%	1,53%	98,28%	25,65%	74,03%
<b>Unable to do</b>	30,77%	69,23%	18,18%	77,27%	20,06%	70,09%	20,51%	78,63%	25,40%	73,02%

**Table 8: Use of assistive devices for each of the related functioning questions (Adult questionnaire)**

Response on revised set of functioning questions	Use of eye glasses (Seeing question)		Use of hearing aid (Hearing question)		Use of walking aid (Walking and climbing question)		Use of wheelchair (Walking and climbing Question)		Use of chronic medication (All questions)	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
<b>No difficulty</b>	9,26%	90,71%	1,54%	98,44%	1,93%	98,05%	1,62%	98,36%	6,94%	93,00%
<b>Some difficulty</b>	31,63%	68,31%	1,81%	97,89%	8,91%	90,99%	0,64%	99,26%	16,27%	83,60%
<b>A lot of difficulty</b>	34,01%	65,99%	6,38%	5,91%	26,74%	73,26%	1,68%	98,32%	26,92%	73,08%
<b>Unable to do</b>	19,51%	80,49%	7,62%	92,38%	39,81%	60,19%	24,27%	75,73%	32,21%	67,42%

#### **4.5.2 Use of hearing aids**

There was generally a low usage of hearing aids, with direct respondents indicating a higher usage than the proxy respondents.

The revised set question on hearing was similar to the seeing one, where the person had to report difficulties, even with a hearing aid.

Proportionally less proxy respondents than direct respondents indicated 'No difficulty' with the use of a hearing aid, suggesting that the perception of having a difficulty is less for the direct respondents than for the proxy respondents. Similarly, at the other end, proxy respondents indicated the use of a hearing aid for a much higher percentage (18,18%) of people who are 'Unable to hear' than direct respondents who reported themselves 'Unable to hear' (7,62%). This probably reflected deaf or hard-of-hearing people who often have hearing aids, but do not necessarily wear them. The person may have a hearing aid, but it remains in the drawer, usually because it does not benefit the user.

#### **4.5.3 Use of walking stick or frame**

The question on walking and climbing stairs did not specify whether the person should respond taking into account use of a walking aid or not.

The proxy respondents reported that only 0,41% of household members who had 'No difficulty' did in fact use a walking aid, while nearly 2% of direct respondents with 'No difficulty' said they used a walking aid. This suggests that the direct respondents were more inclined to consider the difficulty they experience when using a walking aid than without. However, the percentages remain small. At the other end of the scale of difficulties, the direct respondents who were 'unable to walk or climb stairs' were twice as likely to report using a walking aid (39,81%) than the proxy respondents (20,06%) for the same degree of difficulty.

#### **4.5.4 Use of wheelchairs**

The percentages for the use of a wheelchair were similar for each response category for the proxy and direct respondents, with a slightly higher rate of use reported by the direct respondents who are 'unable to walk or climb stairs'. The use of a wheelchair usually implies quite severe difficulties and is usually used all the time, hence being more visible. This would lead to more correspondence between the reporting by proxy and direct respondents.

#### **4.5.5 Use of chronic medication**

Of note is the relatively high rate of chronic medication use (compared to use of other assistive devices) by respondents indicating 'No difficulty' and 'Some difficulty' on any of the activities. This is congruent with the notion that using chronic medication (e.g. treatment for asthma or diabetes) will usually avoid the person experiencing activity limitations that are severe. Proportionally more of the direct respondents who were 'Unable to do' one or more activities indicated use of chronic medication than the proxy respondents for the same category of severity. This suggests that chronic medication use is not as easily identified through proxy respondents.

## **5. Conclusions and further research**

The results of the survey have given some strong indications of how the revised set of questions functions. Further research and recommendations for revisions of the revised set are also proposed.

### **5.1 Conclusions**

Analysis of the survey data has shown that the revised set measured a much broader notion of disability than that measured by the Census 2001 question. The revised set counted the number of people with difficulties in doing a range of activities and did not focus only on people who self-identified or were identified by their household respondent as 'disabled'. The revised set also provided more detailed information on the different levels of severity, whilst the Census 2001 question only identified one level of severity, with this level being undetermined. The revised set provided a clearer measure of severity by the use of the four response options. Furthermore, the effect of age on the risk of showing a difference between responses on the revised set and the Census 2001 question indicates that older people are more willing to respond as having a difficulty, than as being "disabled".

The revised set resulted in a much higher estimate of disability than the Census 2001 question. The revised set also resulted in more than one estimate reflecting different degrees of difficulty. These different estimates can be used to provide estimates for different purposes. The estimate of people with high degree of difficulty ('A lot of difficulty' or 'Unable to do') reflects the number of people who are in need of services such as social assistance, welfare, health, reasonable accommodation at work and inclusive education, a facilitating social and attitudinal environment, and who are more likely to experience significant disadvantage due to their difficulty. The estimate of the population having any degree of difficulty (including a high percentage having only 'Some difficulty' on one or more activities), should be used to estimate population functioning for purposes of monitoring, for example, health prevention interventions and provision of curative health services. The estimate of people with 'Some difficulty' provides an indication of the number of people who are likely to benefit from some form of preventive and curative health care services and who do not require the services listed above for people with 'A lot of difficulty' or who are 'Unable to do' various activities. Thus, the use of the revised set requires good understanding on the part of data users as to the interpretation of the different estimates.

The context of the survey was one that could have influenced the high estimates obtained, even on the Census 2001 questions. The focus of the survey was disability and functioning and the majority of the questions asked related to these phenomena. This could have resulted in the respondents being more sensitive to their and their household members' difficulties than in a regular census which is not disability focused. Furthermore, the field managers and, through them, the actual supervisors and fieldworkers, were given some training on disability and how to interview people with different types of disability. This could have also further influenced the reporting of difficulties. The use of this type of sensitisation should be considered for any survey where questions on disability are included.

## **5.2 Recommendations and revisions**

The following revisions to the set of questions used in the survey are recommended:

- The questions on remembering and concentrating should be combined, as was underscored in the focus group study.
- Reference to 'Sign language' should be omitted in the question on communication.
- A participation question should be retained, but it must focus on household responsibilities and work/school in addition, or instead of, community participation;
- The use of a white cane or guide dog, and the use of Sign language should be included in the list of assistive devices used in the second part of the set.

## **5.3 Further research**

Further research, using the data collected in this survey may focus on:

- Analysis of the relationship between the single questions of the revised set and the relevant individual questions of the extended set;
- The application of stricter criteria for inclusion as 'disabled', specifically in relation to the response 'Some difficulty'. The analysis may include the calculation of estimates where only people with 'Some difficulty' on at least two or more activities from the revised set are counted as 'disabled';
- Further analysis of the effect of factors such as age of onset, duration and number of health conditions or impairments, etc., on the responses given to the revised set and the extended set, as well as on the proxy effect.

In addition to further analysis of the data collected, further research is also required on the effectiveness of the revised set for measuring disability amongst children 14 years or younger.