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*Ken Black:
Comparative analysis of censuses and surveys
as instruments to collect data on disability
- Australian experience*

Comparative analysis of censuses and surveys as instruments to collect data on disability - Australian experience

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**The following paper is an edited and condensed draft of
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1. Introduction

The World Health Organization (WHO) defines disability (prior to ICDH-2), in the context of health experience, as "any restriction or lack (resulting from impairment) of ability to perform an action in the manner or within the range considered normal for a human being" (World Health Organization 1980, p. 28). The Australian Bureau of Statistics (ABS) has conducted regular Special Supplementary Surveys (SSS) since 1981 which provide detailed information on disability consistent with the WHO definition. However these surveys cannot provide estimates for small geographical areas, the level at which disability services are often planned and delivered. In Australia therefore, as in many countries, there is a demand for a disability question to be included on the national census.

The ABS criteria for the inclusion of a topic in the Census of Population and Housing include:

- That the topic is of major national importance;
- That there is a need for data on the topic for small groups of the population and for small geographical areas; and
- The topic is suitable for collection via the census

It is broadly agreed that the disability topic meets the first two criteria. However, there have been concerns about its ability to meet the third criterion because of the complex nature of defining and identifying disability, the limited space available on the census form and the method of form completion (self-enumeration by any household member).

This report discusses the methods and results of the testing conducted by the ABS in November 1997 and September 1998 for the 2001 Census of Population and Housing. It also provides background information on the history of collecting disability data in Australia, the rationale for testing a census question on disability and the experience of overseas statistical agencies.

1.1 History of collecting disability data in Australia

The ABS has collected data on disability using both census and sample survey instruments. In response to the demand for handicap data, a question on handicap was included on the 1976 Census (see Appendix 1 for 1976 Census question). As shown in table 1, almost 30% of the people who reported a handicap in the census reported no handicap in exactly the same question in the post-enumeration survey. Over 50% of those who were identified in the post-enumeration survey as having a handicap, did not identify themselves in the census handicap question. Further evaluation indicated that the data obtained from the handicap question was unreliable. On the basis of these results, the disability and handicap topic was not included in later censuses.

Table 1—Summary of results from the 1976 Census(a)

Census handicap rate	3.5%
Survey handicap rate	5.9%
False negative rate (survey handicap, census no handicap) as a proportion of the survey handicap population	51.9%
False positive rate (survey no handicap, census handicap) as a proportion of the census handicap population	27.9%
Census to Survey Ratio (census handicap population divided by the survey handicap population)	0.6

(a) for information on the meanings of these terms see chapter 2 — census testing

In 1981, the International Year of Disabled Persons, the ABS conducted its first national survey on disability. Known as the Survey of Handicapped Persons, the collection identified people with a disability and addressed the nature and extent of their restrictions in activities of daily life, their use of aids, and their ongoing need for assistance, receipt of assistance and unmet need.

The survey also provided information on the characteristics of people restricted by disability, including their living conditions, work, education and recreation.

These topics continued to be the focus in the following surveys, the Survey of Disabled and Aged Persons in 1988 and the Survey of Disability, Ageing and Carers in 1993 and 1998 (disability criteria and related definitions for the 1998 survey can be found in Appendix 2). As information needs developed over time, in line with government policies and social attitudes, the population groups of interest expanded to include older people and carers, and some new topics emerged while others were seen as no longer relevant. For more information on the Survey of Disability, Ageing and Carers see Appendix 3. Further information is available in the publications *Disability, Ageing and Carers, Australia: Summary of Findings, 1998* (Cat. no. 4430.0), and *Disability, Ageing and Carers, Australia: User Guide, 1998* (Cat. no. 4431.0).

Since the 1993 Survey of Disability, Ageing and Carers, a shorter set of disability questions has been included as a module in other ABS surveys. These surveys include:

- Household Expenditure Survey 1993/4 and 1997/8;
- Time Use Survey 1992 and 1997;
- 1992 Survey of Training and Education;
- 1997 Education and Training Experience Survey. and
- the longitudinal Survey of Employment and Unemployment Patterns (1994–95, 1995–96, 1996–97).

Detailed analysis is currently being carried out by the ABS on these disability modules to determine their usefulness.

1.2 Demand for inclusion of disability in the census

The ABS national disability surveys provide a considerable amount of data on disability. The main limitation from a user perspective is that this information cannot be produced for small geographic areas or population groups from a sample survey.

Support services such as activity programs; living skills training and employment services for people with a disability; and home care or help for older people; are often organised and delivered at a local level. The demand for small area data is likely to rise as there is increasing emphasis being placed on regional planning of community services. Consequently there is a high level of demand for the census to provide information on the prevalence of disability in the Australian population which can be used in conjunction with the more detailed survey data. To compensate for lack of census data, small area predictors have been modelled using disability survey data and census population information. However, these do not reflect concentrations of people with disabilities because of special service provisions or risk factors in an area.

In addition, for adequate and sensitive delivery of personal services, information is needed at the small area level about people of different ages and diverse backgrounds. In particular there has been a call for more detailed information on the Indigenous disability population, which has not been successfully collected in existing disability or Indigenous collections.

In 1993, the disability survey used a sample size of about 17,000 households. Given the proportion of Indigenous people in the population and a sample of this size there should have been approximately

900 Indigenous respondents including about 175 with a disability. In fact because of the difficulties of disability identification in this population and the problem with Indigenous coverage, the numbers were considerably smaller than these expectations. The 1993 survey included 660 people who were Indigenous of whom 59 were identified as having a disability. Successful collection of information on disability in the census would provide more useful data on the Indigenous disability population.

There is public interest in the inclusion of disability on the census. [In the round of submissions regarding the content of the 1996 Census, 48 submissions out of around 280 submissions were received supporting the inclusion of disability.](#) Despite the number of submissions received, the ABS initially did not intend to include disability on the 1996 Census.

This decision was made in the light of the poor quality of the data collected in other censuses, e.g. in the United States of America, Canada, Great Britain and New Zealand (see Chapter 6 and Appendix 4 on overseas findings), as well as in the 1976 Australian Census. However, following further discussions on Census content and strong lobbying by a number of users, this decision was reconsidered.

It was finally agreed that the ABS should test a suitable question on disability in the 1993 census test. The quality of the data obtained would be measured by comparing the results with data collected through a personal interview follow-up survey (using the screening questions from the Disability, Ageing and Carers survey). Two disability questions relating to the need for assistance because of disability, for possible inclusion in the census, were tested in Melbourne in November 1993. These questions did not provide reliable results compatible with the follow-up survey. Because of the poor quality of data obtained during testing disability was not included in the 1996 Census (see Appendix 5 for details of the November 1993 testing for the 1996 Census).

Following the 1996 Census, 8 letters from government ministers were received regarding the exclusion of disability in 1996 and asking that it be considered in future censuses. In the last round of consultations about the content of the 2001 Census, the topic of disability attracted the largest number of submissions from users (31), with strong support for disability status to be collected in subsequent censuses

Considerable testing and revision of census disability questions for the 2001 Census again failed to produce reliable results that were consistent with the follow-up survey using the criteria of the Survey of Disability Ageing and Carers. As a result it was recommended that disability not be included as a topic in the 2001 Census.

As further background, the following two pages present some basic advantages and disadvantages of the census and survey approaches to data collection:

Population Censuses

<i>Advantages</i>	<i>Disadvantages</i>
<ol style="list-style-type: none"> 1. Data can be tabulated for small, local areas. 2. Prevalence rates can be calculated for small geographical areas because data are also gathered for the population at risk. 3. Detailed descriptive cross-tabulations are not subject to sampling errors. 4. If disability questions remain comparable, they can be useful for time series analysis of disability rates. 5. The numbers of people identified as having disabilities is usually large, and therefore more detailed cross-tabulations can be prepared, allowing for greater specificity and complexity in the analysis. 6. Can provide a useful sampling frame for research on people with disabilities who are otherwise difficult to find. 	<ol style="list-style-type: none"> 1. The subject matter is limited to basic socio-economic and demographic characteristics. Limited range and depth of interview are possible on the special situation of people with disabilities. 2. Data collection is infrequent i.e. usually every 5-10 years. The time between data collection and data dissemination can be considerable 3. The institutionalised population with disabilities may not be included in the census population or at least in the descriptive tabulations - i.e. sometimes only the non-institutionalised population is covered. 4. Potentially subject to high non-response rates and under-enumeration because of the complexity and sensitivity of the question. 5. It is very costly and time-consuming (<i>in a Census context</i>) to ask 80-90 percent of the total population a question that is likely to be answered negatively, in order to identify the 1-20 percent that has disabilities. 6. Given the massive task of training personnel, for a census operation, enumerators may be limited in the amount of training received on the subject of disability, which needs very specific guidelines.

Probability sample surveys

<i>Advantages</i>	<i>Disadvantages</i>
<ol style="list-style-type: none"> 1. There is much flexibility in the depth and range of topics that can be covered. Special probes can be used to ensure that people with disabilities are identified. 2. Relatively easy to initiate, given the availability of a sampling frame and a survey-taking infrastructure. 3. If comparability is built into the design and survey instrument, it can be useful in time-series analysis or as a comparison for census data. 4. There is greater control over the conditions of observation and the interview because of limited coverage geographically and a smaller number of interviews to be completed. 5. Design modifications may be tried in order to increase the power of the survey in locating people with disabilities - e.g. co-ordinating probability sample selection with the use of a census, registered population lists, stratification at the sampling stage or increasing sampling fraction. 6. There is greater opportunity for supervision of fieldwork and specialised field training and for careful pre-testing of detailed questions about impairment. 	<ol style="list-style-type: none"> 1. There is limited ability to analyse prevalence rates for many local areas, owing to the limited sample size and subsequent sampling errors associated with disaggregations for small areas. 2. Sample size is limited unless the survey is very large. Because less than 20 percent of any population is likely to be reported as having a disability, the size of the population with disabilities identified in any sampled population is likely to be especially small. 3. The coverage of the populations in unusual circumstances is typically very poor e.g. institutionalised persons, homeless persons and refugee or nomadic populations. 4. Time-series analysis of ad hoc surveys is subject to a great deal of uncertainty. 5. Detailed surveys require close supervision of fieldwork and special training for the field supervisors and interviewers about disability and related topics.

2. Census testing

The 2001 Census disability question testing used a different approach to previous tests, based on questions relating to difficulties experienced with everyday activities. Following discussions with the Census Consultative Group on Disability, testing was undertaken through a series of focus groups and two census tests, conducted in November 1997 and September 1998 (for details on the processes of the census tests and a copy of the questions see Appendix 6).

Conduct of census disability tests

1. A sample of census districts (a geographical area usually containing about 250 dwellings, designed for the purposes of a population census data collection) is selected. These districts might be chosen to increase the likely capture of the population of interest.
2. Census test forms are distributed to all households in the selected census districts.
3. The forms are completed by at least one member of the household for the whole household on the census test night.
4. Census test forms are collected.
5. Follow-up information (follow-up survey) is collected via personal interview from a responsible adult in respect of all persons in the household included on the census form (this may not be completed by the same person who completed the census test form).
6. Census form results and the personal interview results are then compared.

2.1 Indicators used to evaluate census disability tests

The primary measures the ABS uses to decide whether the disability questions tested are suitable for use in the census are how well and how consistently the populations identified as having or not having a disability match the populations that would be identified by the *Survey of Disability, Ageing and Carers*. Accordingly, the follow-up questionnaires were based on the initial screening questions in the *Survey of Disability, Ageing and Carers* (SSS16 in 1993, and SSS28 in 1998). These screen questions provide the benchmark.

The following constitutes a disability identification match:

Census response positive <-----> interview response positive
 Census response negative <-----> interview response negative

Two types of mismatch are identified:

False negative:

Census response negative -----> interview response positive
 Census response positive -----> interview response negative

False positive:

Identified on the Census	Identified in the follow-up survey	
	Disability	No disability
Disability	Matched disability (matched positive)	False positive
No disability	False negative	Matched non-disability (matched negative)

Table 2 provides definitions of the indicators used to evaluate the census disability tests. Some indicators are expressed as proportion of the survey or census disability populations, while others are a percentage of the total population for ease of understanding the overall effect.

Table 2—Indicators and results — the measures used to evaluate the census disability tests

Indicator	Definition	Formula	Purpose of the indicators
Matched disability (or matched positive)	people who were recorded with a disability in both the census and survey		To show how well the census questions capture the populations identified with a disability in the follow-up survey 100% represents a perfect match Rate of 80% considered acceptable
Matched disability rate	persons who were identified with a disability in both the census and survey as a proportion of the survey disability population	(matched disability / survey disability) *100	
Matched non-disability (or matched negative)	people who were recorded <i>without</i> a disability in both the census and survey		To show how well the census questions capture the non-disability populations identified in the follow-up survey 100% represents a perfect match Rate of 80% considered acceptable
Matched non-disability rate	persons who were identified <i>without</i> a disability in both the census and survey as a proportion of the survey non-disability population	(matched non-disability / survey non-disability) *100	
False positive	person who was identified with a disability in the census but not the follow-up survey		To show the accuracy of response of people answering the question in the census - those who incorrectly identified themselves with a disability 0% represents a perfect match Rate of 20% considered acceptable
False positive rate	persons who was identified with a disability in the census but not the follow-up survey as a proportion of the census disability population	(false positive / census disability) * 100	
False negative	person who was identified in the follow-up survey with disability but not in the census		To show the accuracy of response of people answering the question in the census - those who failed to correctly identify themselves with a disability 0% represents a perfect match Rate of 20% considered acceptable
False negative rate	persons who was identified in the follow-up survey with disability but not in the census as a proportion of the survey disability population	(false negative / survey disability) * 100	
Census disability	total people in the census population identified with a disability	(matched disability + false positives)	To show the percentage of the total population who were identified by the census questions with a disability

			Census disability rate = Survey disability rate represents a perfect match
Census disability rate	total people in the census population identified with a disability by the census question as a proportion of the total population	(census disability / total) * 100	

Table 2—Indicators and results — the measures used to evaluate the census disability tests *continued*

Indicator	Definition	Formula	Purpose of the indicators
Survey disability	total people in the survey population identified with disability	(matched disability + false negatives)	To show the percentage of people who were identified by the survey questions with a disability
Survey disability rate	total people identified in the follow-up survey with a disability as a proportion of the total population	(survey disability / total) * 100	
Overall match (total matched in the total population)	total number of respondents matched (matched disability plus matched no disability) as a proportion of total population	(matched disability + matched non-disability) / total * 100	To show how accurately the census responses matched with the survey responses for the whole population 100% represents a perfect match
Census to survey ratio	census disability population as a proportion of survey disability population	census disability population / survey disability population	To show the consistency between the census disability rate and the survey disability rate overall and for small population groups and geographical areas 1.0 represents a perfect match

2.2 Criteria for evaluating the census tests

Three different sets of criteria were selected to evaluate the census test results and determine if the results were good enough to consider inclusion in the census:

1. High rate of matched positives identified on the census test and the follow-up survey:
 - 80% of the survey identified population also identified on the census; and
 - 80% of the census identified population also identified on the survey.
2. A close relationship between the census disability rate and the follow-up survey disability rate [census to survey ratio =1 would be a perfect result],
3. A consistent census to survey ratio for small areas and small populations.

To produce an acceptable result and for the disability questions to be considered for inclusion in the census, one of the following combinations of the above criteria had to be met:

- Criterion 1 + Criterion 3: consider collecting disability in the census, may not be published to the public; or
- Criterion 2 + Criterion 3: consider collecting disability in the census, may not be published to the public; or **ideally**
- Criterion 1 + Criterion 2 + Criterion 3: collect disability in the census, publish results.

3. November 1997 Census test for the 2001 Census of Population and Housing

As agreed with the Census Consultative Group on Disability, a different approach for the 2001 Census was taken from that used in 1993 for the 1996 Census. [For the 2001 Census the criterion for disability was difficulty in performing a range of activities rather than the need for assistance, as in the 1993 Census test, which identified a narrower group](#) (see Appendix 6 for the development of the questions). After focus groups were conducted, a special census disability test was conducted in Victoria in November, 1997. Collection districts were selected from Melbourne and regional centres in areas known to have a higher proportion of people with disabilities. The filter question established a 'health' context for the activity question.

3.1 Aim

The aim of the November 1997 Census test was to test the feasibility of a question focusing on [difficulties with activities](#) for possible inclusion in the 2001 Census of Population and Housing.

3.2 Pre-testing of the questions using focus groups

Leading up to the November 1997 Census test, focus groups were commissioned to investigate the wording of the Census disability questions. Focus groups were designed to see how well the questions worked for relevant sub-populations, particularly whether these groups understood the disability questions and understood what was meant by disability (see Appendix 6 for a copy of the questions used in the focus group testing).

First wave of focus group testing

The first round of focus group testing for the 2001 Census disability questions took place in August 1997. A total of 59 people were given both sets of questions.

The focus groups consisted of:

- 2 general groups of people aged 15 to 59 years;
- People aged 60 years and over;
- People with an intellectual disability - with carers;
- People with an intellectual disability - independent; and
- People with a psychiatric disability.

Two versions were tested. The first question of version 1 asked if the persons had a physical or mental illness, health problem or disability that had lasted six months or more. The second questions asked if this long-term condition caused difficulty with or stopped them from doing a number of activities: physical activities; communicating in own language; learning, understanding or remembering things, any other difficulties or none of the above.

In version 2, the first question asked if the person found it impossible or difficult to do a number of activities: everyday activities; communication or socialising; learning, understanding or remembering things; any activity that people the same age could usually do; or none of the above. The second question asked what caused the difficulty: disability; long-term health condition (lasting 6 months or more); short term health condition; age; or other - please specify.

The results from the focus groups were not promising, with version 2 more prone to misinterpretation. Problems with correct answering of the questions were prominent for those with an intellectual disability, some older people and those where English was their second language. However, the result of this testing provided some useful recommendations to improve the census disability questions.

The recommendations were:

- Simplify version 1 so that only disability and health condition were identified and reverse their order;
- Separate some of the activities so that less words and fewer activities were combined;
- Change ordering of reasons for difficulty from least important to most important (short term illness first through to disability last);
- Add 'difficulty with language' to reasons for difficulty - use to filter difficulty because of English as a second language from difficulty because of a disability; and
- Exclude the word impossible and use the word 'difficulty'.

Second wave of focus group testing

The second round of focus group testing was undertaken in September/October 1997. A total of 65 people were involved. Focus groups were undertaken for:

Indigenous people;

People with intellectual and physical disabilities;

People with mental illnesses;

Aged people living in an institutional care setting;

Carers of people with disabilities;

Carers of aged people; and

General population.

Two more versions (versions 3 and 4) of the Census disability questions were tested and all participants completed both versions, with some completing version 3 first and others completing version 4 first. Version 3 of the Census disability questions placed the question on activity limitation first followed by the more direct question on disability while version 4 reversed the order. Participants also completed a private questionnaire to help assess their answers (the physically and intellectually disabled people were not required to complete this questionnaire), followed by an open-ended discussion on the strengths and weaknesses of the disability questions.

The focus groups found that both variants of the questions worked successfully. Version 3 was found to be a more reliable measure with participants preferring this question because it allowed the possibility of explaining more about the disability or health condition. Although the Indigenous population preferred version 4 of the questions, because it appeared to them to be less difficult to answer, the results for the Indigenous population were more successful on version 3.

The recommendation was that version 3 should be adapted in the light of the focus group testing findings for the November 1997 Census test.

3.3 Details of the 1997 Census test

In the two weeks from 21 November to 5 December, 1997, census forms were delivered to **around 2,600 households**, which were to be completed on 26 November 1997 (see Appendix 6 for a copy of the questions used in the November 1997 Census test). When the census form was collected, an interviewer conducted a follow-up survey in respect of all the persons in the household. There was a response rate of 78% which resulted in 5,406 respondents in the final sample.

3.4 Results of the 1997 test

Rate of Match

The disability questions tested in the November 1997 Census test performed better than those tested in 1993 with a match of 52% between the census and survey disability populations. There were, however, unacceptable levels of false negatives (48%), and to a lesser extent false positives (17%).

Table 3—Summary of results from the November 1997 test

Census disability rate	14.5%
Survey disability rate	23.1%
Matched disability rate (matched census disability as a proportion of the survey disability population)	52.0%
Matched non-disability rate (matched census non-disability as a proportion of the survey non-disability population)	96.7%
Matched disability (% of total)	12.0%
Matched non-disability (% of total)	74.4%
Total matched in test population (% of total)	86.4%
False negative rate (survey disability, census no disability) as a proportion of the survey disability population	48.0%
False positive rate (survey no disability, census disability) as a proportion of the census disability population	17.4%
Census to Survey Ratio (census handicap population divided by the survey handicap population)	0.6

Table 4— Census population groups by selected demographic characteristics, November 1997

	Matched disability	False positive	False negative	All persons	Total
	%	%	%	%	no.
Age					
0-14	8	11.1	11.2	21.4	1,139
15-59	45.4	45.9	53.9	60.7	3,234
60+	46.6	43	34.9	18	958
<i>All persons</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>5,331</i>
Sex					
Male	49.8	38.5	52	48.2	2,571
Female	50.2	61.5	48	51.8	2,760
<i>All persons</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>5,331</i>
Birthplace/self-assessed English proficiency					
Australia, NZ, UK, N. America, S. Africa	78.4	62.2	78	77.6	4,138
Europe, good English	7.2	9.6	9.2	6.9	370
Europe, English not good	4.7	7.4	5.4	2.7	143
North, East & South Asia, good English	1.6	6.7	2.5	5.4	289
North, East and South Asia, English not good	1.3	8.1	1.7	2.9	153
Middle East and N. Africa, good English	2	0.7	1.5	1.5	82
Middle East and N. Africa, English not good	2.7	4.4	0.8	0.8	41
Other countries, good English	1.4	0	0.3	1.6	87
Other countries, English not good	0.8	0.7	0.5	0.5	28
<i>All persons</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>5,331</i>
All persons (no.)	639	135	590	5,331	5,331

Table 4 shows the proportions of the populations within the total population and each of the census population groups (matched disability, false positive and false negative) for age, sex and birthplace/self-assessed English proficiency. The table shows that for each of these categories, the proportion of those identified as a matched disability, false positive or false negative do not align with the proportions of those for all persons.

For age, the census population groups are not expected to align with the total population. Disability is known to increase with age. People aged 60 years and over had a higher disability rate, 50% in the 1998 *Survey of Disability, Ageing and Carers*, than younger people (13%). The proportion, therefore, of those aged 60 and over in the matched disability group (47% of all of those who were identified with a disability in both the census and the survey) should be higher than their proportion of the total population (18%). In the 1997 census disability test, there was a 37% census disability rate (matched disability plus false positive), however, this group also had the highest rates of false positive and false negative identifications as shown in Table 5. Furthermore, there were significant differences in the census to survey ratio for age groups (Table 6).

For sex, no great difference would be anticipated, and the proportions in each population are generally closer. Males are less and females more likely to be false positives than their proportion in the total population suggests (Table 4) though the proportion of either sex classified as false positives was very small (Table 5).

Tables 4 and 5 show variations in the proportions for birthplace groups. Birthplace groups tend to have age differences reflecting the main period of arrival in Australia for that group. This would account for the higher disability rates among people of European or Middle Eastern birthplace, who arrived in Australia earlier, and have since aged. In addition, Australia's immigration policy includes stringent health checks for immigrants, so that more recent arrivals are likely to have low disability rates. Again, there were significant census to survey ratio differences for birthplace groups.

The sharp differences between those whose English is reported as good and those for whom it is not good might reflect how well they understood the form, or it might reflect higher disability rates associated with lower socioeconomic status (Table 5).

Table 5—Selected demographic characteristics by selected census population groups, November 1997

Matched disability	False positive	False negative	All persons	Total	Total
	%	%	%	%	no.
Age					
0-14	4.5	1.3	5.8	100	1,139
15-59	9	1.9	9.8	100	3,234
60+	31	6	21.5	100	958
<i>All persons</i>	12	2.5	11.1	100	5,331
Sex					
Male	12.4	2	11.9	100	2,571
Female	11.6	3	10.3	100	2,760
<i>All persons</i>	12	2.5	11.1	100	5,331
Birthplace/self-assessed English proficiency					
Australia, NZ, UK, N. America, S. Africa	12.1	2	11.1	100	4,138
Europe, good English	12.5	3.5	14.8	100	370
Europe, English not good	20.9	6.9	22.1	100	143
North, East & South Asia, good English	3.6	3.1	5.1	100	289
North, East and South Asia, English not good	5.4	7.1	6.5	100	153
Middle East and N. Africa, good English	16	1.2	11.1	100	82
Middle East and N. Africa, English not good	40.5	13.9	11.1	100	41
Other countries, good English	10.5	0	2.1	100	87
Other countries, English not good	19.2	3.5	11.1	100	28
<i>All persons</i>	12	2.5	11.1	100	5,331
All persons (no.)	639	135	590	5,331	5,331

Table 6—Selected census populations: Disability rates, November 1997

Census disability rate	Survey disability rate	Matched disability rate	Overall match	Census to Survey ratio	Total
	%	%	%	%	ratio
Age					
0-14	5.8	10.3	43.6	92.9	0.6
15-59	10.9	18.8	47.7	88.2	0.6
60+	37.2	52.6	59.1	72.4	0.7
<i>All persons</i>	14.5	23.1	52	86.4	0.6
Sex					
Male	14.4	24.3	50.9	86	0.6
Female	14.6	21.9	53.1	86.7	0.7
<i>All persons</i>	14.5	23.1	52	86.4	0.6
Birthplace/self-assessed English proficiency					
Australia, NZ, UK, N. America, S. Africa	14.1	23.2	52.1	86.9	0.6
Europe, good English	15.9	27	46	81.9	0.6
Europe, English not good	28	43.4	48.4	70.6	0.6
North,East & South Asia, good English	6.6	8.7	40	91.7	0.8
North,East and South Asia, English not good	12.4	11.8	44.4	86.3	1.1
Middle East and N. Africa, good English	17.1	26.8	59.1	87.8	0.6
Middle East and N. Africa, English not good	56.1	53.7	77.3	73.2	1
Other countries, good English	10.3	12.6	81.8	97.7	0.8
Other countries, English not good	21.4	28.6	62.5	85.7	0.7
<i>All persons</i>	14.5	23.1	52	86.4	0.6
All persons	14.5	23.1	52	86.4	0.6

Consistency for small areas and groups

For the November 1997 test, the matched disability rates for the collection districts varied from 38% to 60%, with the census to survey ratio ranging from 0.5 to 0.8.

The overall findings from the November 1997 census test were:

- Variations in the disability rate in different collection districts were similarly detected by both the census and the follow up survey. While there were notable differences in the disability rate in different collection districts, the census collection fairly consistently captured around 60% of the survey result, whether the survey rates were high or low.
- There was a less consistent relationship between the census and the follow-up survey across population groups than across collection districts.
- The census questions performed better for some disability groups than for others. They were particularly effective at identifying more severe mental illness, intellectual disability, stroke and physical restrictions particularly relating to mobility. These are the groups most likely to require service provision from Commonwealth and State programs and thus indications of their geographic locations would aid efficient program targeting.

Table 7—Census collection districts: Disability rates, November 1997

Collection District no.	Census disability rate	Survey disability rate	Matched disability rate	Census to survey ratio
	%	%	%	ratio
1	13.7	25.2	41.7	0.5
2	18.7	29.4	57.3	0.6
3	28.4	43.1	60.1	0.7
4	9.7	12.1	47.5	0.8
5	19.4	30.2	53.5	0.6
6	12.1	19	52.4	0.6
7	10.9	19.5	43.3	0.6
8	11.2	17.4	55.9	0.6
9	11.4	16	53.9	0.7
10	18.2	28.9	58.3	0.6
11	8.2	15.2	37.8	0.5
<i>All persons</i>	14.5	23.1	52	0.6

3.5 Conclusion

The disability question results from the November 1997 Census test did not satisfy the requirements for a successful test. The matched disability rate of 52% and the similar results for both the census and the follow-up survey within collection districts that varied across districts, provided some hope that the questions were measuring an identifiable subset of disability. However the high level of false negatives (48%) and the false positives (17%) were of concern.

This test had performed better than the previous attempts to measure disability in a census question, and some of the results were encouraging enough to justify a further test. The main problems were the high rate of false negatives, and the lack of consistency for small population groups. The Census Disability Advisory Group suggested that a scaled response might cut back the false negatives, and assist in identifying a more useful population, on the grounds that

- respondents would feel more comfortable answering 'a little' than 'yes' ; and
- the 'a lot' response might indicate a population with greater support need.

There was a further possibility that the census might be measuring an identifiable sub-group of the survey disability population.

4. September 1998 Census test for the 2001 Census of Population and Housing

Following the recommendations from the evaluation of the 1997 disability census test, the modified questions were tested in Adelaide in September 1998.

4.1 Aim

The second test was part of a full-scale census test of 20 collection districts. The aim of the disability part of this second test was to:

- evaluate whether a scale (none/a little/a lot), rather than a yes/no response, would decrease false negative responses and improve the match with disability status measured in the follow-up survey;
- measure whether disability identified by the census questions, or by the 'a lot' census responses, had a stable relationship with an identifiable subset of the disability population (as measured in the follow-up survey); and
- further test consistency for small population groups and small areas.

4.2 Details of the test

The September 1998 Test used a split sample to test two sets of questions. The two sets were:

- Form type 4 - Respondents were asked to indicate 'no' or 'yes' to whether they had difficulty with a range of several functions (e.g. hearing; living independently). The question was very similar to that used in the November 1997 test.
- Form type 5 - Respondents were asked to indicate whether they had 'none', 'a little' or 'a lot' of difficulty with the same seven functions (scaled response) (see Appendix 6 for the September 1998 form type 4 and form type 5 disability questions).

Response

Census responses were received from 4,536 dwellings of the 5,425 dwellings approached for the September census test (84% response rate) (Table 8). A total of 10,573 people completed the disability questions on the census forms. A follow-up survey was conducted with around half of the households where a census form had been collected.

Table 8—Response Rates, September 1998

Response	Form type 4		Form type 5		Total	
Responding dwellings						
Collected response	2278	(84.2%)	2258	(83.0%)	4536	(83.6%)
Non-responding dwellings						
Mail back	49	(1.8%)	46	(1.7%)	95	(1.8%)
Unoccupied dwellings	161	(6.0%)	169	(6.2%)	330	(6.1%)
Non-contacts	41	(1.5%)	50	(1.8%)	91	(1.7%)
Refusals	176	(6.5%)	197	(7.2%)	373	(6.9%)
Total	427	(15.8%)	462	(17.0%)	889	(16.4%)
Total dwellings	2705	(100.0%)	2720	(100.0%)	5425	(100.0%)

Follow-up interviews began once census collectors provided lists of the dwellings with completed census forms. Analysis was based on the population (5,695 people) that completed the follow-up survey.

The people in households where the follow-up survey was conducted had a similar demographic profile to the census test sample with a slight bias to households with older people, children, and people working part-time or not in the labour force, where there was a greater likelihood of making contact.

Composition

The difference between the age structure and the ethnic composition in the September 1998 test (conducted in South Australia) and the November 1997 Census test (conducted in Victoria), reflected differences in the population structure of the two States. A higher proportion of the 1998 South Australian test population were aged 60 years and over — 25.7%, compared with 19.0% in the 1997 Victorian test population. There was a correspondingly lower proportion of those aged 0 to 14 years in the 1998 test population.

The South Australian test had a higher proportion of people born in Europe and a lower proportion of people born in Asia, the Middle East and North Africa and other countries. The proportion of males and females was similar on both the 1997 and 1998 tests.

4.3 Results of September 1998 test

A range of different criteria for constructing disability were examined for both the census and the follow-up survey. The best result was the combination 23 (for more information see Appendices 7, 8 and 9). Combination 23 had a follow-up survey disability definition based on that used in the Survey of Disability, Ageing and Carers, 1998, and the most straightforward census disability definition. Form type 4 contained a 'yes' response, and form type 5 the responses 'a little' and 'a lot'. All the data included in this section is based on this census/survey match definition.

Table 9—Summary of results, September 1998(a)

	Form type 4 (yes/no response)	Form type 5 (scaled response)
Census disability rate	15.0%	22.4%
Survey disability rate	19.9%	21.7%
Matched disability rate (matched census disability as a proportion of the survey disability population)	52.1%	65.9%
Matched non-disability rate (matched census non-disability as a proportion of the survey non-disability population)	94.2%	89.7%
Matched disability (% of total)	10.4%	14.3%
Matched non-disability (% of total)	75.5%	70.2%
Total matched in test population (% of total)	85.8%	84.5%
False negative rate (survey disability, census no disability) as a proportion of the survey disability population	47.9%	34.1%
False positive rate (survey no disability, census disability) as a proportion of the census disability population	30.9%	36.0%
Census to Survey Ratio (census handicap population divided by the survey handicap population)	0.8	1.0

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

As suggested, the scaled response reduced the false negatives and led to a much higher matched disability rate (66%) (see Table 9). However, this was at the cost of a greatly increased false positive rate.

A closer correspondence between the census disability population and an identified subset of the survey population in consequence did not eventuate. Hopes for a consistent census to survey ratio were disappointed.

False Positives

The false positive rates in 1998 (31% for form type 4 and 36% for form type 5) were much higher than in the November 1997 test (17%).

However analysis of the false positive population does give some indications of factors contributing to the increase in false positives. The contributing factors are:

- The introduction of a scale in form type 5 made it easier to give false positive responses. Responses of 'a little' or 'a lot' were available. Where people were not sure whether the level of difficulty they have is high enough for a positive response, it was easier to answer 'a little' than an absolute 'yes'.
- A false positive response was more likely to be given for the older population and there was a higher proportion of older people in the 1998 South Australian Census test population (Table 10). For form type 4, almost 10% of those aged 60 years and over had a false positive response compared to 2% and 3% for 0 to 14 years and 15 to 59 years, respectively. For form type 5 the rate was 16% of those aged 60 years and over, compared to 3% for 0 to 14 years and 6% for 15 to 59 years.
- The percentage of people in the census test who were classified as a false positive or false negative varied between birthplace. For Form type 4, those from other European countries had a higher percentage of false positives, false negatives and matched positives. These higher percentages may be age-related rather than strictly related to birthplace. For form type 5, other European countries had a higher percentage of false negatives, those born in Northeast, Southeast and Southern Asian countries had a higher percentage of false positives and those born in other countries had a higher percentage of false negatives.
- A small number of people may have misinterpreted the census question on difficulties experienced and indicated all the areas where they had no difficulties, particularly for form type 4. Approximately 9% of the false positives in form type 4 (yes/no) had ticked all responses to the difficulties question and then indicated in the subsequent question that they had no difficulties. This figure was about 2% for the form type 5 (none/a little/a lot).

Table 10—False positives by age and sex, November 1997 and September 1998(a)

November 1997	November 1997		September 1998		September 1998	
			Form type 4		Form type 5	
	False positives	All persons	False positives	All persons	False positives	All persons
	%	%	%	%	%	%
Age						
0 to 14 years	11.2	21.4	7.6	16.7	5.2	16.1
15 to 59 years	53.9	60.7	42	59.2	39.8	56.7
60 years and over	34.9	18	50.4	24.2	55	27.3
<i>All persons</i>	100	100	100	100	100	100
Sex						
Males	52	48.2	51.1	47.5	51.9	48.2
Females	48	51.8	48.9	52.5	48.1	51.8
<i>All persons</i>	100	100	100	100	100	100

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

Around four in ten (38%) of the false positives had reported a disability or long term condition as the reason for experiencing difficulty. A similar proportion (38%) gave age as the reason for their difficulties. Most of the latter were aged 60 years or over. These are valid responses for disability and were found in comparable proportions among the matched positives.

It is difficult to establish a good rate of matched disability results using the census questions and an independent follow-up survey up to a month later. False positives may result from:

- a different person responding to the follow-up survey from the person(s) completing the census,
- varying responses at different times,
- varying response to self-enumeration of the census test and interview in the follow-up survey, and
- the different angle of approach in the survey (a wide group of restricting impairments) from the difficulty with specified activities used in the census questions.

False Negatives

Compared with the November 1997 false negative results (48%), false negatives from the September 1998 test were similar (48%) for form type 4 and lower (34%) for form type 5. Factors may have been:

- False negatives were lower in form type 5 (34%) compared to form type 4 (48%) in the September 1998 Census test. The Census test disability questions in form type 5 were designed to reduce the number of false negatives.
- There was a relationship between age and the recording of false negatives on the census test in 1998. For form type 5, 12% of the respondents aged 60 years and over gave false negatives, while 3% of respondents aged 0–14 years, and 7% of respondents aged 15–59 gave false negatives.
- Most of the people with false negatives in the September 1998 test (87%) indicated no difficulties in the first disability question in the census and also stated 'no difficulty' or did not respond in the second question, despite their positive responses to the follow-up survey. The majority of the

remaining few false negatives had reported a difficulty or reason for a difficulty in the census, but did not fully meet the census disability criteria (see Appendix 9). Possible changes to the census criteria to capture the remaining cases were identified but discarded, because they would have increased the false positives.

Consistency for small areas and groups

The scaled response of form type 5 showed greater consistency between the census and survey disability rates across census collection districts (CDs) than the yes/no option of form type 4 (Table 11). The greater consistency of ratio in form type 5 was not good enough, however, to warrant inclusion as a disability component in the 2001 Census, when the high rates of false negatives and false positives are taken into consideration. These results suggest that a scaled format of questions on disability within the census has some potential to identify the proportion of people with a disability within, and their distribution, across small areas. Such results might be useful in allocating funds to areas according to need, but the high variation in the results means that such a measure would not allow any useful identification of the characteristics of individuals who have been identified as having a disability.

Table 11—Census collection districts: Disability rates, September 1998(a)

Collection District no.	Form type 4 (yes/no)				Form type 5 (scaled response)			
	Census disability rate	Survey disability rate	Matched disability rate	Census to survey ratio	Census disability rate	Survey disability rate	Matched disability rate	Census to survey ratio
	%	%	%	ratio	%	%	%	ratio
1	18.3	15.7	38.9	1.2	18.8	20.8	60	0.9
2	23.4	17.9	50	1.3	23.1	19.9	71	1.2
3	29.7	35.2	65.6	0.8	21.2	17.2	76.5	1.2
4	8.6	16.5	47.8	0.5	28.7	23.1	68	1.2
5	15.7	19.3	56.3	0.8	26.4	24.5	61.5	1.1
6	23.1	22.3	59.3	1	30.5	27.7	66.7	1.1
7	22.4	21.5	78.3	1	25	24	64	1
8	14.6	15.2	52.2	1	28.4	26.4	69.2	1.1
9	10.9	13.6	33.3	0.8	23.6	18.9	79.2	1.3
10	8.6	14.8	52.8	0.6	18.5	18.1	65.9	1
11	15.1	21.4	53.7	0.7	27	22.7	77.4	1.2
12	13.9	22.9	47.8	0.6	19.8	26	62	0.8
13	13.5	21.2	55.6	0.6	20	21.9	54.3	0.9
14	11.3	18.1	48.6	0.6	13.6	19	45.7	0.7
15	14.8	26.2	39.6	0.6	25.2	29.7	65.2	0.8
16	8	16	41.7	0.5	13.8	16.3	61.5	0.8
17	11.4	17.1	60.6	0.7	22	19.9	70.3	1.1
18	12.9	12.9	66.7	1	23.4	22.6	64.3	1
19	15.4	26.8	40	0.6	23.1	18.8	70	1.2
20	24.1	25.3	66.7	1	16.7	13.9	60	1.2
<i>All persons</i>	<i>15</i>	<i>19.9</i>	<i>52.1</i>	<i>0.8</i>	<i>22.4</i>	<i>21.7</i>	<i>65.9</i>	<i>1</i>

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

Based on these results, it is recommended that any further testing on the inclusion of a disability component on the census use a scaled approach rather than the yes/no option.

Upon the recommendation of the Census Advisory Group, further analysis was carried out on small geographical areas for a different age split (0–64 years and 65 years and over) to determine if better small area disability data could be produced for relevant age groups. These ages correspond better with the scope of government support policy, disability services under 65, and aged care services at 65 and over.

Table 12 considers the better-performing form type 5 by an age split. The results of this analysis showed that the poor census/survey ratios found for small area data were less attributable to the 65 and over age group. This age group had a better result within census districts than for those aged 0 to 64 years, with a matched disability rate of 80% or more in 11 of the 20 census districts, and 70% or more in a further five. These results, however, continued to vary across the census districts with some areas producing poorer matches, and some with very good matches having poorer ratios because of a high level of false positives.

The younger age group had much poorer matched disability rates, with high rates of both false positives and negatives. Overall, both groups had a census/survey ratio within 10% of perfect, masking a level of variation between districts: the older group, however, had a more concentrated mode, with ten of the twenty districts having a ratio within 10% of 1, while for the younger group only 6 out of twenty were within this range.

Table 12—Census collection districts: Disability rates, September 1998(a)

Collection District no.	Form type 5, Age group 0-64	Survey disability rate	Form type 5, Age group 65 and over	Matched disability rate	Census to survey ratio	Form type 5 (scaled response)	Survey disability rate	Matched disability rate	Census to survey ratio
	%	%	%	%	ratio	%	%	%	ratio
1	14.2	18.1	56.5	0.8	0.8	52.9	41.2	71.4	1.3
2	12.8	8.8	54.5	1.5	1.5	64.5	64.5	80.0	1.0
3	8.1	10.8	62.5	0.8	0.8	60.0	36.0	88.9	1.7
4	10.6	12.1	50.0	0.9	0.9	57.1	40.5	76.5	1.4
5	13.9	8.3	66.7	1.7	1.7	52.9	58.8	60.0	0.9
6	20.8	21.7	56.5	1.0	1.0	60.0	45.7	81.3	1.3
7	14.8	18.5	53.3	0.8	0.8	60.9	43.5	80.0	1.4
8	13.8	12.8	58.3	1.1	1.1	53.7	50.0	74.1	1.1
9	20.4	12.9	83.3	1.6	1.6	32.4	35.3	75.0	0.9
10	15.1	14.2	67.7	1.1	1.1	48.0	52.0	61.5	0.9
11	17.1	16.0	69.0	1.1	1.1	61.5	46.2	87.5	1.3
12	14.5	21.5	54.1	0.7	0.7	65.0	65.0	84.6	1.0
13	8.9	13.7	41.2	0.6	0.6	58.3	50.0	66.7	1.2
14	9.4	15.0	29.2	0.6	0.6	41.7	45.8	81.8	0.9
15	13.4	21.0	56.0	0.6	0.6	63.9	58.3	76.2	1.1
16	11.4	11.4	62.5	1.0	1.0	30.0	50.0	60.0	0.6
17	10.8	9.2	50.0	1.2	1.2	48.2	44.6	80.0	1.1
18	6.8	11.4	30.0	0.6	0.6	63.9	50.0	83.3	1.3
19	15.4	11.2	50.0	1.4	1.4	88.2	82.4	92.9	1.1
20	11.5	9.8	33.3	1.2	1.2	45.5	36.4	100.0	1.3
<i>All persons</i>	13.5	14.6	54.8	0.9	0.9	55.9	48.9	78.2	1.1

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

One conclusion that can be drawn from this is that the census disability question may better identify the proportion of older people with a disability than those under 65 years in small areas. It is more important however, for a census disability question to correctly identify the geographical location of people in younger age groups with a disability for disability services planning and funding. There are much higher rates of disability among those in the older age groups, and therefore the concentration of older people in geographical regions can be used as a proxy to identify where funding and services for older people with disabilities are to be distributed. Any further work should focus on improving the measurement of younger people with disabilities across small geographical areas.

Small Population Groups

Table 13—Population groups: Disability rates, September 1998(a)

	Form type 4 (yes/no)				Form type 5 (scaled response)			
	Census disability rate	Survey disability rate	Matched disability rate	Census to survey ratio	Census disability rate	Survey disability rate	Matched disability rate	Census to survey ratio
	%	%	%	ratio	%	%	%	ratio
Age								
0 to 14 years	5.7	6.4	56.7	0.9	5.9	5.9	55.6	1
15 to 59 years	9.4	14.3	42.7	0.7	12.8	13.7	52	0.9
60 years and over	35.1	42.9	59.4	0.8	52	47.8	74.9	1.1
Sex								
Males	15.6	19.2	55.4	0.8	23.7	22	68.4	1.1
Females	14.4	20.5	49.3	0.7	21.1	21.5	63.4	1
Birthplace								
Australian, NZ, UK, N. America, S. Africa	12.9	17.4	53.3	0.7	20.2	19.1	64.9	1.1
Other European	27	33.9	50.7	0.8	35.5	37	69.5	1
Northeast, Southeast & Southern Asian	11.9	9.5	75.0	1.3	23.3	18.6	62.5	1.3
Middle East and N. Africa	9.1	9.1	100	1	20	20	100	1
Other countries	16.1	16.1	25	1	20.8	29.2	50	0.7
Not answered	12.1	33.3	27.3	0.4	18.8	22.9	63.6	0.8
<i>All persons</i>	<i>15</i>	<i>19.9</i>	<i>52.1</i>	<i>0.8</i>	<i>22.4</i>	<i>21.7</i>	<i>65.9</i>	<i>1</i>

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

- Form type 4 under-represented the disability rate for all age groups. Form type 5 was a better indicator, particularly for the age group 0 to 14 years. Although the rates and the ratio suggest a good match, they mask a high rate of false positives and false negatives which produce a much poorer match (Table 13).
- Consistent disability rates and ratios for different birthplace groups were not produced by either form type 4 or form type 5, although form type 5 was a better indicator for people from European and English speaking countries (Table 13).
- The census disability questions do not provide consistent census to survey ratios across the small population groups of age, sex and birthplace. This was particularly predominant for birthplace. This, coupled with the high false positives and false negatives, suggest that the census disability questions do not provide an adequate measure of disability. However, the scaled response of form type 5 performed better than the yes/no approach of form type 4 (Table 13).

Further analysis was carried out for disaggregations of age groups using the under 65 and the 65 and over split. The aim of this analysis was to test whether a disability question in the census may be reliable for certain age groups of special interest. Age was broken down into 0–14 years, 15–49 years, 50–64 years

and 65 and over. The 50–64 years group is of particular interest, as this is a group where male participation in the labour force has been declining for a number of years, and where the number of both males and females on the Disability Support Pension peaks (Table 14).

As expected, because of the association of disability with ageing, for both form type 4 and form type 5 the disability rate for 15–49 years (9% census disability rate for form type 5) was lower than for 15–59 years (13% census disability rate for form type 5), and the 65 and over age group had a disability rate higher (56% census disability rate for form type 5) than the 60 and over age group (52% census disability rate for form type 5) (Table 13).

On the more stable form type 5, the 50–64 age group performed better than the younger groups with a better match rate, lower false positives and negatives, and a perfect ratio. The 65 and over age group, however, had a much higher matched disability rate (Table 14).

Table 14—Variant age groups: Disability rates, September 1998(a)

	Matched disability rate	False positives	False negatives	Census disability rate	Survey disability rate	Census to survey ratio
	%	%	%	%	%	%
Age Groups						
Form type 4						
0-14	56.7	37	43.3	5.7	6.4	0.9
15-49	36.7	44	63.3	6.4	9.8	0.7
50-64	47.9	29.1	52.1	20.8	30.8	0.7
65 and over	62.7	25.6	37.3	39.3	46.6	0.8
<i>All persons</i>	<i>52.1</i>	<i>30.9</i>	<i>47.9</i>	<i>15</i>	<i>19.9</i>	<i>0.8</i>
Form type 5						
0-14	55.6	44.4	44.4	5.9	5.9	1
15-49	41.8	52.1	58.2	9.2	10.5	0.9
50-64	65.1	32.1	34.9	30.3	31.6	1
65 and over	78.2	31.5	21.8	55.9	48.9	1.1
<i>All persons</i>	<i>65.9</i>	<i>36</i>	<i>34.1</i>	<i>22.4</i>	<i>21.7</i>	<i>1</i>

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

The following tables indicate how well the two form types capture the sub-groups of the disability population identified in the follow-up survey. These tables do not take false positive responses into account.

Table 15—Level of restriction: Matched rate, September 1998(a)

	Form type 4	Form type 5
	Matched disability rate	Matched disability rate
	%	%
Populations		
Level of restriction		
Has severe/profound core activity restrictions	75.3	86
Has moderate core activity restrictions	56	71.7
Does not have moderate to profound core activity restriction	45	58.9
Has schooling or employment restrictions	62.3	71.2
Does not have schooling or employment restrictions (b)	25.5	39.5
Needs assistance with other everyday tasks	61.5	77.9
Does not need assistance with other everyday tasks but has difficulties	57.6	70.0
No difficulties in everyday activities (c)	40	54.9
<i>All persons with disability on survey</i>	<i>52.1</i>	<i>65.9</i>

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

(b) Only includes those persons aged between 5 and 64 years. All people outside of this age group were classified as not applicable.

(c) Only includes those persons aged 15 years and over. All people outside of this age group were classified as not applicable.

Both form types were more able to identify a higher level of restriction. Form type 5 produced a consistently better match than form type 4.

Table 16—Restricting impairment: Matched rate, September 1998(a)

	Form type 4	Form type 5
	Matched disability rate	Matched disability rate
	%	%
Populations		
Restricting impairment		
Has sight loss not corrected by glasses	51	72.5
Has hearing difficulties	72.5	78.5
Has loss of hearing: no aids or difficulty communicating	64.6	80.9
Has speech loss	73.7	71.4
Has difficulty breathing that restricts	65.3	81
Has chronic/recurring pain that restricts	59.2	73.6
Has blackouts, fits, loss of consciousness	36	57.7
Has difficulty learning/understanding	78.6	80.4
Has incomplete use of arms/fingers	60.7	77.2
Has difficulty gripping	62	73
Has incomplete use of legs/feet	69.9	82.9
Has a nervous/emotional condition	61.5	65.9
Restricted in physical activity	65.1	75.1
Has disfigurement/deformity	36	58.6
Needs help/supervision for mental illness	78.9	90.9
Has head injury, stroke or other brain damage	70.4	71.7
Receiving treatment for other long-term condition	56.8	72
Has other long-term condition	64.6	63.4
<i>All persons with disability on survey</i>	<i>52.1</i>	<i>65.9</i>

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

- For those people who were classified as having a disability in the follow-up survey, a greater percentage were identified through the Census questions for Form type 5 (scaled response) than for Form type 4 (yes/no response), 65.9% compared to 52.1% (Table 15).
- Only the disability types 'other long-term condition' and 'speech loss' produced a better result on Form type 4 than Form type 5, but the differences were small. Form type 5 is a better identifier of disability across most disability types.
- Hearing loss was well identified for people restricted by this impairment (79%) and those less restricted (81%); Form type 5 also produced a good match rate for people with more serious psychiatric disability (91%), intellectual disability (80%) and some types of physical impairment.
- Most of the other impairment types on Form type 5 had a match rate of over 70%. Only those with 'blackouts, fits, loss of consciousness', 'nervous/emotional condition', 'other long-term condition' and 'disfigurement/deformity', had a census to survey match under 70%.

Matched rates for census activity restrictions

Table 17—Activity restriction (Census): Matched disability rate and Census to survey ratio, September 1998(a)(b)

	Form type 4		Form type 5			
	Yes		A little	A lot		
	Matched disability rate(c) %	Census to survey ratio(d) ratio	Matched disability rate(c) %	Census to survey ratio(d) ratio	Matched disability rate(c) %	Census to survey ratio(d) ratio
Census question 18						
Activity restriction (using census test question)(e)						
Everyday activities						
i.e.eating, showering or dressing	98.4	1.6	93.3	1.1	97.9	1.1
Hearing	94.1	1.5	98.1	1.6	100	1.2
Learning, understanding, remembering	100.0	1.6	99.2	1.6	100.0	1.2
Reading or seeing even with glasses	89.6	1.5	89.9	1.4	94.3	1.2
Walking, kneeling or climbing stairs	94.4	1.3	94.9	1.4	96.2	1.1
Living independently	92	1.3	94.5	1.2	94.4	1.1
Doing other things people of the same age usually do (i.e. working, studying,etc.)	95.3	1.3	97.3	1.3	95.0	1.1

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

(b) Includes only those who answered 'yes' to each activity restriction, excludes those answer 'no' or 'not stated'.

(c) Those identified with a disability in both the census and the survey.

(d) Census disability as a proportion of the survey disability population. With 1.0 being the best census to survey ratio.

(e) Question 18 in the census: for form type 4 'Mark YES or NO for each of the following: Does the person have difficulty...'; for form type 5 'How much difficulty does the person have in:.'

Each person may have more than one activity restriction.

- The populations answering positively to each of the activity restrictions in census question 18 had very high matched disability rates, 90% to 100% in each form type (Table 16). This means that very few (up to 10%) of the people who had answered positively to a particular activity restriction but had not met all the criteria for a positive identification of disability in the census had been positively identified in the survey (i.e. they had been correctly disqualified from the census disability population).
- Most of the false negatives (see Table 10—48% in form type 4 and 34% in form type 5, respectively 10% and 7% of the total population responding to each form type) had either answered negatively or not answered the activity restriction question—they had positive identification in the survey, but had not provided a basis for positive identification in the census. The census question may be omitting an appropriate activity for identification.
- The census/survey ratio indicates the level of false positives in the population answering positively to activity restrictions. For the population with more severe restriction, those answering 'a lot', this overcount is within acceptable levels. The false positive levels for form type 4 and for the 'a little' response for form type 5 are much higher, although the latter performs better.

- For the Form type 5 population, the activities producing the highest overcount are 'hearing' and 'learning, understanding, remembering'. The inclusion of 'remembering' may lead to an over-response to difficulty in this activity [as it common for many people to consider they have poor memories](#)—further cognitive testing may be useful.

4.4 Conclusion

Form type 5 with the scaled response approach has shown a distinct improvement in decreasing false negatives compared with form type 4 and the earlier test. It performs well in capturing those with higher support needs, and has an improved capture rate for most impairments. It provides a very good census to survey ratio, and a reasonable consistency over small areas and some small populations. These good results, however, are offset by a higher false positive rate, and a still unacceptable rate of false negatives.

The analysis suggests some areas where further development and fine-tuning might improve the results, using Form type 5:

- possible new activity, or modified presentation of existing ones, to better capture disability for the younger age groups;
- cognitive testing on the wording of questions producing high census/survey ratios
 - to identify which elements of the activity group prompt undue identification; and
 - to consider whether qualifying the identified elements might lower this effect;
- further cognitive testing work with immigrants from Asian countries to understand why their false positive rates were high.

These attempts to match the results between the two census tests and survey results took no account of any response variance which might occur over time with repeated applications of either survey or census questions to the same set of respondents. No work has been done to quantify this variance. It is recommended that any future testing include measures of response variance.

5. Assessment of census tests against evaluation criteria

5.1 November 1997 test

Criterion 1: High rate (at least 80%) of matched positives identified on the census and the survey;

The results did not satisfy criterion 1.

Criterion 2: Close relationship between census disability rate and survey disability rate;

The results did not satisfy criterion 2.

Criterion 3: Consistent census to survey ratio for small areas and small populations;

The results did not satisfy criterion 3.

As no criteria were adequately met, none of the required combinations of criteria were satisfied. However, while the November 1997 Census test did not provide good enough results to warrant inclusion of disability questions in the 2001 Census, the results were promising enough to attempt another census test using modified questions.

5.2 September 1998 test—Form type 5

Criterion 1: High rate (at least 80%) of matched positives identified on the census and the survey;

- The overall matched disability rate was 66% for the survey disability population. This was higher than was found in form type 4 and in the 1997 test but does not meet the criterion of 80%.
- With a false positive rate of 36%, 64% of the census disability population were correctly identified, not meeting the 80% criterion.
- The overall matched non-disability rate was 90%. This meets the criterion, but is lower than the matched non-disability rates for form type 4 and the 1997 census test.
- The matched disability rates for collection districts for form type 5 ranged from 46% to 79%, with no areas achieving over the 80% range. However, the results across the collection districts was better than was found for form type 4 with most areas achieving around 60-70% matched disability rates.

The matched disability rates for form type 5 were consistently better than those produced for both form type 4 and the 1997 test, but they were not consistent enough amongst the different population groups and small areas to justify inclusion in the 2001 Census. For some population groups criterion 1 was met, while for other population groups this was not the case.

Criterion 2: Close relationship between census disability rate and survey disability rate;

- The overall census to survey ratio was 1.0. The disability rate for both the census and the survey was 22% which also corresponds with the South Australian disability rate reported in the *1998 Survey of Disability, Ageing and Carers*.

Form type 5 produced a much better result than for Form type 4 and the 1997 Census test. Form type 5 met criterion 2.

Criterion 3: Consistent census to survey ratio for small areas and small populations;

- Census to survey ratios for collection districts ranged from 0.7 to 1.3, with the bulk close to the perfect result of 1.0. This may be considered acceptable.

- The census to survey ratios for small population groups varied between 0.7 to 1.3, with birthplace being less consistent than the other population groups. Age and sex produced more consistent census to survey ratios within 10% of the optimum result.
- For the 'a little' responses to the census activity restriction question the census to survey ratios varied between 1.1 and 1.6 showing overcounting in the census. For the 'a lot' responses to the activity restriction question on the census, the census to survey ratio varied between 1.1 and 1.2, showing more consistent results than for the 'a little' responses. However, a large number of people identified with disability in the census had no or negative responses to the activity restriction questions.

Form type 5 produced more consistent census to survey ratios for small area data and small population groups than was found in form type 4 and the November 1997 Census test. However, although these ratios suggest that some consistent small level data on disability can be collected using the census, they do not overall meet criterion 3 for inclusion in the 2001 Census. Future testing may suggest ways to improve these results to an acceptable level.

	Evaluation Criteria		
	Criterion 1 (80% matched positives on census and survey)(a)	Criterion 2 (Close relationship between census and survey disability rates)	Criterion 3 (Consistent census to survey ratio for small population groups and areas)
Census test			
November 1997	×	×	×
September 1998—Form type 5*	×	✓	×

(a) this criterion plus one other criterion must be met

* criterion 1 and 3 were partially met for this census test

The results for form type 5 in the September 1998 test produced better results than for form type 4 and the November 1997 census test but did not meet the criteria for inclusion in the 2001 Census. The results provide some hope that scaled questions could be developed using the results from this test that may provide adequate results to include disability questions in a future census.

Attempting to find one or two questions that will produce a reliable measure of disability in a census is part of the wider problem of measuring disability. Disability covers a wide range of impairments, limitations and restrictions. The effects can vary for different people, and even for the same person at different times. There can be a reluctance to identify with particular types of disability, and this is likely to vary with time, and also with the collection methodology. People may be more prepared to respond to an interviewer than to write information down on a form. The different results from form type 4 and form type 5 show the effect of an apparently simple change in response categories. Disability measures are sensitive to context—surrounding questions may encourage or discourage a positive response.

6. Conclusion and considerations for further work

6.1 Conclusion

The ABS has made a considerable effort to design a census question set that would effectively measure disability in the census, particularly in the development period for the 2001 Census of Population and Housing. The results have not been sufficiently successful to justify inclusion of the disability topic in the 2001 census. The last variant tested, form type 5 with a scaled response, has problems with high false positive response rates specifically associated with the use of a scale, but has improved results against a number of the assessment criteria. If work is to continue on the same line of testing, then, form type 5 would be the appropriate starting point, however, given the extensive testing to date and the high false positives remaining, the benefits/gains of further testing may be small.

The experience of other countries indicates a similar lack of success in producing a good match between disability identification in a census and a follow-up survey, whether this be a repetition of the census question, or a more detailed survey question set. The best results reported have been from the UK census, measuring limiting long-term illness, a subset of disability. It is interesting that in recent testing, Canada's approach has been in a similar direction to Australia's—an initial question about difficulties with specified activities, with a scaled response, followed by a more direct question about disability or long-term health condition.

Whether to proceed with a census question where the validity of the results is doubtful becomes a matter of fitness for purpose. Where the primary purpose is to gain an enhanced sample for a survey, then a quite high level of false positive responses can be tolerated, as these will be corrected in the follow-up survey; a high level of false negatives would require a sampling of the 'no disability' population in the census as well. Where the results are to be disseminated and used directly to inform policy and planning decisions for small areas and small populations, as would be the case in Australia, an assured high quality of census data is required.

One of the difficulties the ABS has had with evaluating a census question is how well the results from a short question about activity limitation in a self enumerated form could be expected to match with an interviewer-based detailed set of restricting impairment questions. The ABS has used a disability module in other interviewer-based population surveys, with the same disability criteria as used for the disability survey but asked in a much more compressed way. The results for disability have been broadly stable across host surveys within a time band, but not comparable with the disability survey counts. This strongly indicates that taking the restricting impairment approach to a census question, with much less detail still, would not be effective at all. The results of form type 5 in achieving an optimum census/survey ratio with a fair level of consistency for areas (18 of the 20 collection districts had a ratio within 20% of optimum) and a little less for population groups (within 30% of optimum) suggest that the 'difficulty with activities' approach was a reasonable path to have followed for testing.

There are still substantial problems with the composition of the disability population identified in the census. The analysis has pointed to particular problem areas where further work may produce more acceptable results. While this outcome cannot be guaranteed, and may not even be probable, it justifies further testing and development of a census disability question, insofar as demand for the data continues to exist.

6.2 Recommendations

Further testing

If the pressure for a disability question on the census remains strong, further development could be considered. The recommended approaches could include:

1. Pre-testing

Some pre-testing should be done on how different population groups relate to basic disability words and concepts, particularly

- in the younger age groups; e.g. disability, difficulty with activities, relevant activities and meaningful names of activities;
- in the older age groups, for activities that produce high census/survey ratios; and
- immigrants from Asian countries, particularly East and South-east Asia.

2. Form question design

A multi-direction recommendation—

First:

Begin with form type 5 questions, which uses a scaled response, and asks about difficulties first; and Target some of the difficulties more clearly to a population aged under 65 years;

Second:

Closely follow the outcome of the 2001 UK Census and consider testing for the Australian Census a similar question on limiting long-term illness (although this may not meet the needs of disability planners, who have been key in pushing for the Census question for small area planning).

Third:

Target the 'severe and profound' disability population, which is the key population of interest to the majority of service planners and funders in Australia. Ask an initial question about need /receipt of help or assistance within the core activity areas of personal care, mobility and communication, followed by a question on the reason for the need - e.g 'disability or health condition lasting 6 months or more', 'old age', 'other'.

3. Census sample frame

If consideration is given to drawing the sample for the disability survey from the census-identified disability population, there are a number of issues to consider:

There may be legal, customary and practical barriers to this approach in Australia.

There would be loss of continuity with previous surveys - a major issue for key users of the data.

However, if it is possible, there are advantages, which relate to the purpose of a census question:

False positives will not be a serious problem, as they will be reclassified in the follow-up survey;

More time in the survey for specifically disability related questions; and

The link of actual records to the census may allow production of better and possibly more detailed small area data.

4. Testing response variance

Any future development should include testing of response variance - both in terms of the census question(s) being tested, and of the full survey as survey response variance has not yet been analysed.

Appendix 1— 1976 Census of Population and Housing — Census Disability question

1976 Census question

15. Is the person handicapped by a In his or her education..... **1**
SERIOUS long-term illness or
physical

or mental condition?

If yes, tick the appropriate boxes
for each
person to show types of
handicap.

If not handicapped tick box 8.

If no illnesses or conditions tick box 8.

In getting or holding a job..... **2**

In getting about alone..... **3**

In doing housework..... **4**

In sporting or recreational
activities..... **5**

In acts of daily living, e.g. dressing,
bathing..... **6**

In other
ways..... **7**

Not
handicapped..... **8**

Appendix 2 — Survey of Disability, Ageing and Carers 1998 disability criteria

<p>Disability A person has a disability if he/she has one of the following, that has lasted or is likely to last for 6 months or more:</p> <p>Loss of sight (not corrected by glasses); Loss of hearing (with difficulty communicating or use of aids); Loss of speech; Chronic or recurring pain that restricts everyday activities; Breathing difficulties that restricts everyday activities; Blackouts, fits or loss of consciousness; Difficulty learning or understanding; Incomplete use of arms or fingers; Difficulty gripping; Incomplete use of feet or legs; A nervous or emotional condition that restricts everyday activities; Restriction in physical activities or physical work; Disfigurement or deformity; Needing help or supervision because of a mental illness or condition; Head injury, stroke or other brain damage, with long-term effects that restrict everyday activities; Treatment for any other long-term condition, and still restricted in everyday activities; or Any other long-term condition that restricts everyday activities.</p>	<p>Specific restrictions are: Core activity restrictions; and/or Schooling or employment restrictions.</p> <p>Core activities are: <i>Self care</i> — bathing or showering, dressing, eating, using the toilet and managing incontinence.</p> <p><i>Mobility</i> — moving around at home and away from home, getting into or out of a bed or chair; and using public transport;</p> <p><i>Communication</i> — understanding and being understood by others: strangers, family and friends.</p> <p>Core activity restriction may be: <i>Profound</i> — unable to perform a core activity, or always needing assistance;</p> <p><i>Severe</i> — sometimes needing assistance to perform a core activity;</p> <p><i>Moderate</i> — not needing assistance, but having difficulty performing a core activity; and</p> <p><i>Mild</i> — having no difficulty performing a core activity, but using aids or equipment because of disability.</p>
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Appendix 3 — Measuring disability in ABS surveys

The Survey of Disability, Ageing and Carers (SDAC) is regularly conducted by the ABS. The survey collects a wide range of information on people with a disability:

- impairments and health conditions,
- severity of restriction,
- need for and receipt of assistance,
- use of aids and equipment, and
- living conditions and socioeconomic indicators in comparison with those without a disability.

To establish disability, the survey uses around fifty questions, with up to seventy further questions to establish severity of restriction. These surveys have been conducted in 1981, 1988, 1993 and 1998.

However Federal, State and local government departments and community and advocacy groups have identified unmet needs for information about people with disabilities:

- data for local areas;
- data for small populations;
- a greater level of detail about specific aspects of experience; and
- more regular updates of disability prevalence.

The first two needs would best be met by disability identification on the census, if that were possible. The third information need suggests the use of disability and severity of restriction identifiers (a disability module) on other relevant ABS surveys. The fourth need could be met in this way if the disability module were to give results comparable to the disability survey.

A number of ABS surveys contain a disability module. The disability module, developed after the 1993 Survey of Disability, Ageing and Carers, was used with some modifications in the 1993/94 Household Expenditure Survey, the 1992 and 1997 Time Use Surveys, the 1992/93 Survey of Training and Education, the 1997 Survey of Education and Training, and the Survey of Employment and Unemployment Patterns. A version updated to the 1998 disability survey was used for the 1998/99 Household Expenditure Survey.

The disability module uses the same criteria for disability and levels of restriction as the screening questions from the survey, with a much more limited number of questions and some prompt cards. It is an intermediate set of questions, larger than could be used on a census form, but much smaller than used for the disability survey.

The much smaller number of questions are likely to produce a higher disability rate, because of less emphasis on the qualifying filters, but a smaller severe/profound restriction population, because two questions with prompt cards (or rolling prompts in telephone interviewing) provide fewer triggers for identification than 70 questions.

Survey of Disability Ageing and Carers 1998

The 1998 Survey of Disability Ageing and Carers uses a broad restricting impairment approach to identify a population with disability. A responsible adult in each selected household is asked whether anyone in the household has any of seventeen impairments or restrictions (such as loss of sight or hearing, incomplete use of arms or legs, difficulty learning or understanding, or need for help or supervision in doing things because of mental illness), and about the health condition underlying the particular impairment. Ten activities are then examined for the extent to which a person is able to carry out typical daily activities. Severity of restriction is measured on the level of assistance needed, difficulty experienced or use of aids and equipment in performing specific tasks associated with daily living, in the areas of self care, mobility, (including the use of public transport), and communication. Two further areas where restricted participation is considered to disadvantage people with a disability are employment and

education.

Results

The 1998 SDAC found that 3.6 million people in Australia had a disability (19% of the total population). Of those, 87% (3.2 million) experienced specific restrictions in core activities (self care, mobility or communication), schooling or employment. The rate of disability increased with age, from 4% for children aged 0–4 years to 84% for those aged 85 years and over. A further 3.1 million had an impairment or long-term condition that did not restrict their everyday activities.

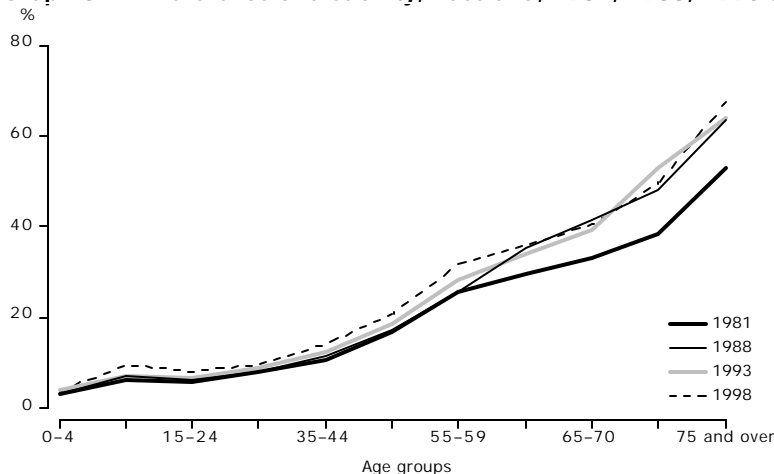
Three per cent of the population had a profound and three per cent a severe core activity restriction; the proportion with a moderate or mild core activity restriction was four per cent and six per cent respectively. While many of these were restricted in their participation in schooling and employment, a further two per cent of the population had a schooling or employment restriction only.

There has been a rise in the underlying disability rate since the first ABS disability survey in 1981. After adjusting for differences between surveys and in the age distribution of the population, the rate has increased from 15 % in 1981 to 19% in 1998. This underpins growth in the proportion with specific restrictions from 10% to 16 % in the same period. The greater part of the increase between 1993 and 1998 is for people with severe restrictions.

Prevalence patterns for disability by age groups show marked similarities across the four surveys (adjusted for comparability), apart from the major difference in 1981, the much lower reporting of disability by older people. With more focus on ageing in the 1988 survey, the rates among older people increased sharply. Higher rates among people aged 70 to 74 in 1993 were not repeated in 1998, but the higher concentration of people in the older part of the population aged 85 and over led to an increase in the disability rate for the highest age group.

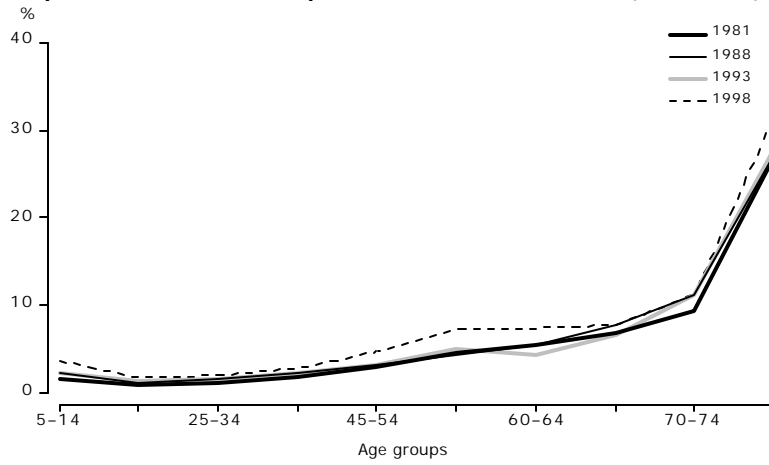
Other noticeable movements in 1998 are a slightly higher rate for most age groups under 60; particularly, a higher rate for children aged 5 to 14, mostly boys with Attention Deficit Hyperactive Disorders or with intellectual or developmental disorders, and an increased rate among people aged 45 to 59, building on increases for this group in 1993.

Graph 3.1—Prevalence of disability, Australia, 1981, 1988, 1993 and 1998(a)



(a) Adjusted for differences between the surveys

Graph 3.2—Prevalence of profound/severe restriction, Australia, 1981, 1988, 1993 and 1998(a)



(a) Adjusted for differences between the surveys

Examining the rates of profound/severe restriction, the differences in 1998 are more pronounced. It is clear that these differences are found in the same age groups as the rises in the disability rates, extending in the middle age groups to the 60-64 group. Further work is underway to understand these differences.

Appendix 5 — November 1993 Census Test

November 1993 test disability questions

11. Does the person have any physical, intellectual or sensory disability, brain injury or mental illness which has lasted, or is likely to last *for six months or more?*

If the person is less than five years old, leave blank.

Yes, has disability > **Go to 12**

No > **Go to 13**

12. *As a result of the above disability, does the person ever need, or receive, help or supervision with the following activities:*

Moving around at home or elsewhere (for example, getting out of bed, shopping, visiting people)

Yes, needs help or supervision moving around

Taking care of personal needs (for example, dressing, showering, toileting, or eating)

Yes, needs help or supervision with personal needs

Communicating verbally (for example, being understood or understanding others in the person's own language)

Yes, needs help or supervision communicating verbally

No, doesn't need help or supervision in these activities

Results of the November 1993 Census test

Aim

The aim of the disability question in the November 1993 Census test was to investigate whether a disability question could be developed for the 1996 Census that would provide consistent results across small areas and population groups.

Details of the 1993 test

Two disability questions were used. The first question was a filter question which detailed types of disability. The second question focused on need for assistance in activities of daily living as a result of disability, as this related well to the information needed by service providers

There were 29 different collection districts selected from various locations in Victoria for inclusion in the test, resulting in 2,316 dwellings. After loss and census under count due to unoccupied dwellings, refusals and interviewer non-contact, census forms were distributed to 1,644 households. The collection districts chosen were those predicted to have more than 10 per cent of their population with a severe handicap. From the 1,644 households involved in the census test and the follow-up survey, 2,576 persons were involved in the test. Analyses of the question results revealed that 96% of respondents gave complete answers to the census disability questions.

Results of 1993 test

Rate of Match

Table 5.1—Comparison of census test and follow-up survey results for November 1993 test

	Census			Total no.
	Severe handicap no.	No severe handicap no.	Question not answered no.	
Follow-up Results				
Severe handicap	68	93	17	178
No severe handicap	31	2,280	87	2,398
Total	99	2,373	104	2,576

The proportion of false negatives and false positives were substantial. Indeed the false negative rate was over 52%.

A further 10% of the persons categorised as having a severe handicap by the follow-up survey questions did not provide a codeable answer for the census questions on disability. In addition, 31% of those who would be categorised as having a severe handicap in the census did not have this information confirmed in the follow up survey (false positives). Thus only 38% of people who identified themselves as having a severe handicap according to the survey questions identified themselves the same way on the census form. Only 40% of the people who correctly identified themselves in the census forms gave the same answer in the census and the follow up survey about the type of restriction (personal care, mobility and communication) for which help was needed. The accuracy of the responses varied very little between the three types of restriction.

Consistency for small areas

The rate of census/survey match obtained from the answers to the disability questions varied enormously between CDs as did the rate of severe handicap. It was obvious from these results that there was little consistency in the ability to report disability on the census correctly; it was not possible to assume a constant level of under-reporting across all CDs (see Census Working paper 94/3; *Disability Census Test: November 1993* for more information).

Conclusion

It was recommended on the basis of the poor results of the census test that a disability question not be included on the 1996 Census.

Appendix 6 — Census test processes and census test and focus group questions

Census test processes

The Australian Bureau of Statistics used two slightly different processes in developing and testing disability questions in 1993 and 1997/8. The following processes were used:

	Testing for 1996 Census: November 1993	Testing for 2001 Census: November 1997 September 1998
Question Design	<p>The initial questions were designed by the Family and Community Statistics Section (known as the Welfare Section prior to 1999) of the ABS in the light of their experience in Disability and Ageing surveys.</p> <p>Extensive consultation was undertaken with users of disability data and with organisations representing people with disabilities. On the basis of these discussions, a number of modifications were made to the questions and a final question produced (see Appendix 2 for question design).</p> <p>Question directly measured disability, and used need for assistance criterion to measure severe handicap.</p>	<p>November 1997: Following discussions with the Census Consultative Group on Disability two versions of questions were suggested.</p> <p>September 1998: Based on a further meeting of the Census Consultative Group and consideration of the results of the November 1997 testing two form types were designed, one using yes/no answers, the other a 3 point scale (see Appendix 3 for question design).</p> <p>Question measured difficulty with activities, i.e. disabilities.</p>
Initial testing of Question design	<p>Some observational testing was undertaken in both Canberra and Melbourne.</p>	<p>November 1997: Questions were tested in two rounds of focus group testing in Sydney. Focus groups included younger and older age groups, people with intellectual and psychiatric disability, formal and informal carers and indigenous people.</p> <p>September 1998: For the second round of testing both sets of questions were modified in light of the experience from the first round.</p>
Census Test	<p>The Statistical Information Services Division selected a sample of collection districts (CDs) in Melbourne which were considered to have relatively high proportions of people with severe handicaps. Census forms containing the final disability questions, were distributed to all household in these areas. (A CD is a geographical area usually containing about 250 dwellings, designed for the purposes of population census data collection). The test involved 1,644 households.</p>	<p>The November 1997 test was a special test for the disability question involving 2,000 households. Because the population of interest represents about one fifth of the total population, collection districts were chosen that were likely to have a high prevalence of disability.</p> <p>The September 1998 test was a full scale census test which was to test all aspects of the census (including collection and delivery procedure, design of all questions) as well as the disability question. The test involved 5,425 households. A split sample was used to test the two sets of questions.</p>
Collection of follow up information	<p>Follow-up information was collected, via a personal interview, when the Census form was collected.</p>	<p>November 1997: follow up interview information was collected via a personal interview, when the census forms were collected</p> <p>September 1998: A computer assisted personal interview was conducted up to 2-3 weeks after the census forms were completed.</p>

**Question Design for 1997 focus groups, November 1997 census test
and September 1998 census test**

First round of focus groups — Version 1

<p>18 Does the person have a physical or mental illness, health problem or disability that has lasted six months or more.</p>	<p><input type="checkbox"/> No > Go to 20 <input type="checkbox"/> Yes</p>
<p>19 Does this long-term condition cause you difficulty with or stop you doing any of the following?</p> <p>Provide more than one answer if necessary</p>	<p><input type="checkbox"/> Physical activities (eg walking, kneeling, climbing stairs)</p> <p><input type="checkbox"/> Communicating in own language (eg talking, hearing)</p> <p><input type="checkbox"/> Learning, understanding or remembering things</p> <p><input type="checkbox"/> Any other difficulty - please specify</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><input type="checkbox"/> None of the above</p>

September 1998: First round of focus groups — Version 2

<p>18 Does the person find it impossible or difficult to do any of the following? Provide more than one answer if necessary</p>	<p><input type="checkbox"/> Everyday activities (such as eating, showering, dressing, moving around)</p> <p><input type="checkbox"/> Communicate or socialise with others</p> <p><input type="checkbox"/> Learn, understand or remember things</p> <p><input type="checkbox"/> Any activity that people the same age can usually do [or take part in] (eg work, school, shopping, reading, sport etc)</p> <p><input type="checkbox"/> None of the above > Go to 20</p>
<p>19 What causes the difficulty?</p>	<p><input type="checkbox"/> Disability</p> <p><input type="checkbox"/> Long term health condition (lasting 6 months or more)</p> <p><input type="checkbox"/> Short term health condition</p> <p><input type="checkbox"/> Age</p> <p><input type="checkbox"/> Other — please specify</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>

September 1998: Second round of focus groups — Version 3

For developing public policies and community-based programs, there is a need to measure the extent of disability existing in Australia

**17 Tick YES or NO for each of the following
Does the person...**

- | | | |
|---|------------------------------|-----------------------------|
| Have difficulty in doing everyday activities such as eating, showering or dressing? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty talking to or hearing other people? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty learning or remembering things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty reading or understanding things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty walking, kneeling or climbing stairs? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty living in independent housing without help from other people? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty doing any other things people of the same age generally do? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
-

18 What causes the difficulty shown in question 17 for the person?

- Short-term health condition
 - Long-term health condition
 - Disability
 - Age
 - Difficulty with English language
 - Other cause — please specify
-
-
-
- No difficulty
-

September 1998: Second round of focus groups — Version 4

For developing public policies and community-based programs, there is a need to measure the extent of disability existing in Australia

17	Does the person have a health problem that has lasted 6 months or more,	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Or		
	Does the person have a disability?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

18	Tick YES or NO for each of the following: Does the person...		
	Have difficulty in doing everyday activities such as eating, showering or dressing?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have difficulty talking to or hearing other people?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have difficulty learning or remembering things?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have difficulty reading or understanding things?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have difficulty walking, kneeling or climbing stairs?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have difficulty living in independent housing without help from other people?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have difficulty doing any other things people of the same age generally do?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

November 1997 test

For developing health policies and community-based programs, there is a need to measure the extent of disability existing in Australia

**14 For each of the following, tick YES or NO:
Does the person...**

- | | | |
|---|------------------------------|-----------------------------|
| Have difficulty in doing everyday activities such as eating, showering or dressing? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty talking to or hearing other people? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty learning or remembering things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty reading or understanding things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty walking, kneeling or climbing stairs? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty living in independent housing without help from other people? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have difficulty doing any other things people of the same age usually do? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

15 What causes the difficulty shown in question 14 for the person?

- Short-term health condition (lasting less than six months)
 - Long-term health condition
 - Disability
 - Age
 - Difficulty with English language
 - Other cause - please specify
-
-
-
- No difficulty

September 1998 test : Form type 4: Yes/no response

For developing health policies and community based programs, it is important to measure the extent of disability existing in Australia.

18 Mark YES or NO for each of the following:

Does the person have difficulty...

- | | | |
|--|------------------------------|-----------------------------|
| doing everyday activities such as eating, showering or dressing? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| hearing? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| learning, understanding or remembering things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| reading or seeing even with glasses? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| walking, kneeling or climbing stairs? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| living independently? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| doing any other things people of the same age usually do (for example working, studying, etc.) | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

19 What causes the difficulty shown in Q18 for the person?

- Short-term health condition (lasting less than six months)
 - Long-term health condition
 - Disability
 - Age
 - Difficulty with English language
 - Other cause - please specify
-
-
-
- No difficulty

September 1998 test : Form type 5: Scaled response

For developing health policies and community based programs, it is important to measure the extent of disability existing in Australia

18. How much difficulty does the person have in:	None	A little	A lot
doing everyday activities such as eating, showering or dressing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
learning, understanding or remembering things?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
reading or seeing even with glasses?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
walking, kneeling or climbing stairs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
living independently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
doing any other things people of the same age usually do (for example working, studying, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 19. What causes the difficulty shown in Q18 for the person?**
- Short-term health condition (lasting less than six months)
 - Long-term health condition
 - Disability
 - Age
 - Difficulty with English language
 - Other cause - please specify
-
-
-
- No difficulty

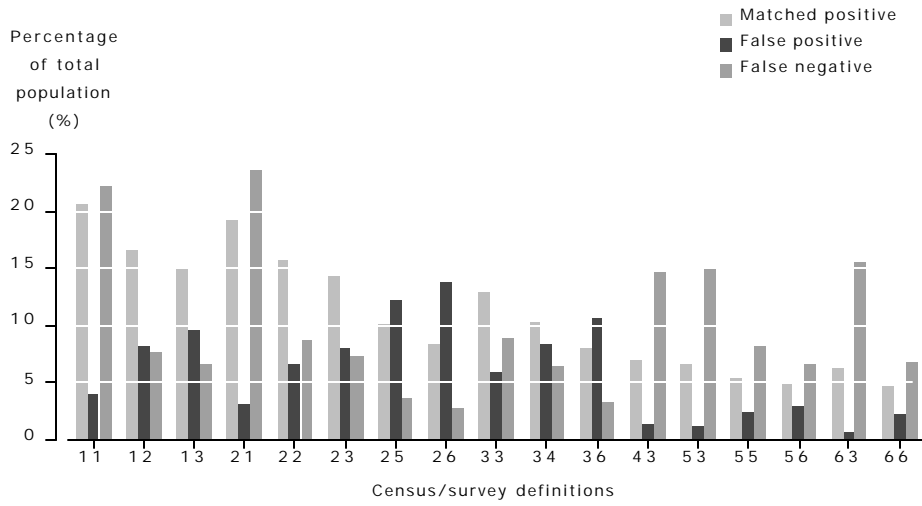
Appendix 7 — Efforts to improve the census/survey match

To investigate whether disability identified in the census had a relationship with a subset of the disability population and to investigate the high false positive rate, the data from the September 1998 test was analysed using a range of census and survey disability definitions. Six different sets of criteria were used to identify disability on the Census. Six different sets of criteria from the survey were used to try to identify what the Census was measuring. The broadest criteria set did not use a strict definition of disability. The groups from the survey were a long-term condition population, two definitions of disability, and subsets of disability with higher levels of difficulty or support need.

A numbering system was developed to identify the definition according to its census and survey criteria. The number 1 was selected to identify the broadest category of census disability or survey disability and the number 6 was used to identify the most restrictive categories. The definition number was developed with the census disability identification number displayed first and the survey disability identification number displayed second; for example the number 12 identifies that the broadest census classification was used (labelled as most comprehensive) and the second broadest survey classification was used (labelled as disability [with any hearing loss]) (see Appendices 8 and 9 for details about these classifications).

Fewer people were classified as having a disability under the more restrictive census definitions (see graph 1), resulting in lower false positive rates (the lowest rate was 10%) and higher false negative rates (up to 71%) than broader definitions. Likewise more restrictive survey disability definitions resulted in lower false negative definitions (down to 26%) and higher false positive rates (up to 62%) than broader definitions.

Graph 7.1—Results from different census and survey criteria – Form Type 5, September 1998



(a) The first digit indicates the census definition and the second digit indicates the survey definition. 1 is the broadest definition and 6 is the most restrictive definition. See census and survey criteria tested in Appendices 8 and 9.

Table 7.2—Results from different census criteria, September 1998, Form Type 4 and Form Type

5(bold)(a)

Census and Survey definition number	Matched positive no.	False positive no.	False negative no.	Matched negative no.	All persons no.
11	403	88	765	1,570	2,826
11	592	119	636	1,522	2,869
12	341	150	280	2,055	2,826
12	476	235	224	1,934	2,869
13	319	172	243	2,092	2,826
13	432	279	192	1,966	2,869
21	363	61	805	1,597	2,826
21	550	92	678	1,549	2,869
22	314	110	307	2,095	2,826
22	450	192	250	1,977	2,869
23 *	293	131	269	2,133	2,826
23 *	411	231	213	2,014	2,869
25	224	200	157	2,245	2,826
25	289	353	107	2,120	2,869
26	190	234	125	2,277	2,826
26	245	397	84	2,143	2,869
33	262	82	300	2,182	2,826
33	370	169	254	2,076	2,869
34	220	124	276	2,206	2,826
34	299	240	186	2,144	2,869
36	178	166	137	2,345	2,826
36	231	308	98	2,232	2,869
43	203	44	421	2,201	2,869
43	193	34	431	2,211	2,869
55	158	69	238	2,404	2,869
55	140	87	189	2,453	2,869
63	180	20	444	2,225	2,869
63	135	65	194	2,475	2,869

(a) See Appendices 8 and 9 for definitions of terms and census and survey definitions.

* indicates the match used for analysis. Analysis showed that this match provided the best results and was a best indicator of disability on the census and the follow-up survey.

Table 7.3—Results from different census criteria, September 1998, Form Type 4 and Form Type 5(bold)(a)

Census and survey definition number	False positive rate %	False negative rate %	Matched positive rate %	Matched disability rate %	Census to survey ratio
11	17.9	65.5	14.3	34.5	0.4
11	16.7	51.8	20.6	48.2	0.6
12	30.5	45.1	12.1	54.9	0.8
12	33.1	32	16.6	68	1
13	35	43.2	11.3	56.8	0.9
13	39.2	30.8	15.1	69.2	1.1
21	14.4	68.9	12.8	31.1	0.4
21	14.3	55.2	19.2	44.8	0.5
22	25.9	49.4	11.1	50.6	0.7
22	29.9	35.7	15.7	64.3	0.9
23 *	30.9	47.9	10.4	52.1	0.8
23 *	36	34.1	14.3	65.9	1
25	47.2	41.2	7.9	58.8	1.1
25	55	27	10.1	73	1.6
26	55.2	39.7	6.7	60.3	1.3
26	61.8	25.5	8.5	74.5	2
33	23.8	53.4	9.3	46.6	0.6
33	31.4	40.7	12.9	59.3	0.9
34	36	55.6	7.8	44.4	0.7
34	44.5	38.4	10.4	61.6	1.1
36	48.3	43.5	6.3	56.5	1.1
36	57.1	29.8	8.1	70.2	1.6
43	17.8	67.5	7.1	32.5	0.4
53	15	69.1	6.7	30.9	0.4
55	30.4	60.1	5.5	39.9	0.6
56	38.3	57.4	4.9	42.6	0.7
63	10	71.2	6.3	28.8	0.3
66	32.5	59	4.7	41	0.6

(a) See Appendices 8 and 9 for definitions of terms and census and survey definitions.

* indicates the match used for analysis. Analysis showed that this match provided the best results and was a best indicator of disability on the census and the follow-up survey.

To determine which census/survey definition would be the best approach to studying the results, a combination of indicators were used:

- 1 A balance of good match rate with low false positives and negatives;
- 2 Census rates similar to the survey rates;
- 3 Conceptual integrity of criteria; and
- 4 Consistency of criteria with those of the 1998 ABS disability survey.

The combination chosen was 23 as best matching the range of selection criteria. Other possible choices were 12, 13 and 22, performing as well or better on some criteria (see Appendices 8 and 9 for the more information about these classifications and how they vary from each other).

Table 7.4—Comparison of the best performing census criteria, September 1998, Form Type 4 and Form Type 5 (bold) as a percentage of total(a)

		Census disability rate/TOTAL	Survey disability rate/TOTAL	Matched positive /TOTAL	False positives /TOTAL	False negatives /TOTAL	Census to Survey	
		L	L	s				
		%	%	%	%	%	ratio	
Census/Survey definition	12	Form 4	17.4	22	12.1	5.3	9.9	0.8
		Form 5	24.8	24.4	16.6	8.2	7.8	1
	13	Form 4	17.4	19.9	11.3	6.1	8.6	0.9
		Form 5	24.8	21.7	15.1	9.7	6.7	1.1
	22	Form 4	15	22	11.1	3.9	10.9	0.7
		Form 5	22.4	24.4	15.7	6.7	8.7	0.9
	23	Form 4	15	19.9	10.4	4.6	9.5	0.8
		Form 5	22.4	21.7	14.3	8.1	7.4	1

(a) See Appendices 8 and 9 for definitions of terms and census and survey definitions.

In each case, form type 5 performed better. Considering form type 5 only, 23 has a lower matched positive rate than 12, 13 or 22. It has slightly lower error rates than 12, a better census to survey ratio than 22 and more compatible census and survey disability rates than 13. These definitions and the 23 definition were extensively compared on basic demographic aspects, geographical locations and sub-groups of restriction and impairment. It was found that 23 was an overall better measure than 22 and 13.

Both 12 and 13 use the broadest possible census definition, which strains the usual conceptual criteria of disability to improve the match—for instance, in certain circumstances, it includes short-term conditions. The '2' census definition is much more acceptable conceptually. A '1' census definition would have to produce much better results to be a preferred model.

The 23 combination was preferred to the 22 combination on the basis of a better census/survey ratio overall and a closer consistency of definition with the 1998 *Survey of Disability, Ageing and Carers*, excluding people with mild hearing loss.

Appendix 8 — September 1998 census test — Disability definitions

Disability definitions used to analyse data from the September 1998 Census test

Disability criteria

1. Most comprehensive

Disability is identified if:

- any response in Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'disability'. (1)
- any response in Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'long-term condition'. (2)
- any response in Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'age' and the person is aged 60 years or more. (3)
- there are 3 or more responses in Q18 and Q19 is 'short-term condition'. (4)
- there are zero 'yes', 'a little' or 'a lot' responses in Q18 but Q19 is 'disability'. (5)
- there are zero 'yes', 'a little' or 'a lot' responses in Q18 but Q19 is 'long-term condition'. (6)
- response to Q18B 'hearing' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and the person was born in Australia or an English speaking country and is aged 3 or more. (7)
- response to Q18B 'hearing' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and the person was born in a non-English speaking country but speaks English well, is aged 3 or more and - response to Q19 is not 'difficulty with English language'. (8)
- response to Q18A 'doing everyday activities such as eating, showering, or dressing' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and the person is aged 9 or more. (9)
- response to Q18C 'learning, understanding or remembering things' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and the person is aged 9 or more. (10)
- response to Q18E 'walking, kneeling or climbing stairs' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and the person is aged 60 or more. (11)
- response to Q18F 'doing any other things people of the same age usually do' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and the person is aged 3 or more. (12)
- response to Q18D 'reading or seeing even with glasses' or Q18E 'walking, kneeling or climbing stairs' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5), Q19 is 'age' and the person is aged more than 40. (13)
- response to Q18B 'hearing' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and the person is aged more than 40. (14)

No disability if:

- all responses in Q18 are 'no' (form type 4) or 'none' (form type 5); **and**
- Q19 is 'no difficulty' (20); **or**
- no response to Q19 (21); **or**
- no response to Q18 and Q19 is 'difficulty with English language' or 'no difficulty'. (22)
- response to Q18B, Q18C or Q18D is 'yes' (form type 4), 'a little' or 'a lot' (form type 5), and Q19 is 'difficulty with English language', and no other responses to Q19. (23)
- response to Q18C 'learning, understanding or remembering things' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'age' and the person is aged less than 8 years. (22)
- at least one response to Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5), and Q18G 'doing any other things people of the same age usually do' is 'no' (form type 4) or 'none' (form type 5), and the age of the person is less than 3 years, and Q19 is 'age'. (23)
- response to Q19 is 'age', no other responses to Q19, and person is aged less than 3 years. (26)
- any people not identified by any of the above statements were set to 'no disability'. (20)

2. Basic

Disability is identified if:

- any response in Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'disability'. (1)
- any response in Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'long-term condition'. (2)
- any response in Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'age' and the person is aged 60 years or more. (3)
- there are zero 'yes', 'a little' or 'a lot' responses in Q18 but Q19 is 'disability'. (5)
- response to Q18B 'hearing' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and the person was born in Australia or an English speaking country and is aged 3 or more. (7)
- response to Q18C 'learning, understanding or remembering things' is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and the person is aged 9 or more. (10)

No disability if:

- any people not identified by any of the above statements were set to 'no disability'. (20)

3. Reduced

Disability is identified if:

- any response in Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'disability'. (1)
- any response in Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'long-term condition'. (2)
- any response in Q18 is 'yes' (form type 4), 'a little' or 'a lot' (form type 5) and Q19 is 'age' and the person is aged 60 years or more. (3)
- there are zero 'yes', 'a little' or 'a lot' responses in Q18 but Q19 is 'disability'. (5)

No disability if:

- any people not identified by any of the above statements were set to 'no disability'. (20)

4. Comprehensive — severe

As for 1 (**Most comprehensive**), but only for form type 5, and using only 'a lot' responses to Q18.

5. Basic — severe

- As for 2 (**Basic**), but only for form type 5, and using only 'a lot' responses to Q18.

6. Reduced — severe

- As for 3 (**Reduced**), but only for form type 5, and using only 'a lot' responses to Q18.
- Q18 is the first question relating to disability on the census form and identifies difficulties that a person with disability might experience. Q19 seeks to clarify the reason for the difficulties identified in Q18.

Survey criteria

1. Any condition

A person has an **impairment or long-term condition** if he/she has one of the following, lasting six months or more:

- Loss of sight (not corrected by glasses);
- Loss of hearing;
- Loss of speech;
- Chronic or recurring pain;
- Breathing difficulties;
- Blackouts, fits or loss of consciousness;
- Difficulty learning or understanding;
- Incomplete use of arms or fingers;
- Difficulty gripping;
- Incomplete use of feet or legs;
- A nervous or emotional condition;
- Restriction in physical activities or physical work;
- Disfigurement or deformity;
- Needing help or supervision because of a mental illness or condition;
- Head injury, stroke or other brain damage;
- Treatment for any other long-term condition; or
- Any other long-term condition.

2. Disability (with any hearing loss)

A person has a **disability** if he/she has one of the following:

- Loss of sight (not corrected by glasses);
- Loss of hearing;
- Loss of speech;
- Chronic or recurring pain that restricts everyday activities;
- Breathing difficulties that restrict everyday activities;
- Blackouts, fits or loss of consciousness;
- Difficulty learning or understanding;
- Incomplete use of arms or fingers;
- Difficulty gripping;
- Incomplete use of feet or legs;
- A nervous or emotional condition that restricts everyday activities;
- Restriction in physical activities or physical work;
- Disfigurement or deformity;
- Needing help or supervision because of a mental illness or condition;
- Head injury, stroke or other brain damage, with long-term effects that restrict everyday activities;
- Treatment for any other long-term condition, and still restricted in everyday activities; or
- Any other long-term condition that restricts everyday activities.

3. Disability

A person has a **disability** if he/she has one of the following:

- Loss of sight (not corrected by glasses);
- Loss of hearing; with difficulty communicating or use of aids;
- Loss of speech;
- Chronic or recurring pain that restricts everyday activities;
- Breathing difficulties that restrict everyday activities;
- Blackouts, fits or loss of consciousness;
- Difficulty learning or understanding;
- Incomplete use of arms or fingers;
- Difficulty gripping;
- Incomplete use of feet or legs;
- A nervous or emotional condition that restricts everyday activities;
- Restriction in physical activities or physical work;
- Disfigurement or deformity;
- Needing help or supervision because of a mental illness or condition;
- Head injury, stroke or other brain damage, with long-term effects that restrict everyday activities;
- Treatment for any other long-term condition, and still restricted in everyday activities; or
- Any other long-term condition that restricts everyday activities.

4. Any condition and any activity restriction.

A person with an **impairment or long-term condition** (see **1: Any condition**) who **needed assistance, or had difficulty with:**

- Self care — bathing or showering, dressing, eating, using the toilet and managing incontinence; or
- Mobility — moving around at home and away from home, getting into or out of a bed or chair; and using public transport; or
- Communication — understanding and being understood by others: strangers, family and friends;

and/or

- Daily activities, such as health care, housework, home/garden maintenance, meal preparation, managing money/correspondence, and transport;

and/or

- Were restricted in schooling or employment.

5. Disability and any activity restriction

A person with a **disability** (see **3: Disability**) who **needed assistance, or had difficulty with self-care, mobility, communication, or a range of daily activities, or were restricted in schooling or employment** (see **4: Any condition and any activity restriction**).

6. Disability and severe activity restriction

A person with a **disability** (see **3: Disability**) who **needed assistance with self-care, mobility, communication, or a range of daily activities, or were restricted in schooling or employment** (see **4: Any condition and any activity restriction**).

Appendix 9 - Census and survey definitions for different census/survey match variables

<u>Variab le</u>	<u>Census definition</u>	<u>Survey definition</u>
11	1. Most comprehensive (positive response to disability, long-term health conditions or one of several specific combinations of difficulty and cause) (see Appendix 8 for details)	1. Any long-term health condition or impairment (see Appendix 8 for details)
12	1. Most comprehensive	2. Disability, with any hearing loss (for disability in the 1998 SDAC, the hearing loss criteria included only those who used a hearing aid or whose hearing loss made communication difficult) (see Appendix 8 for details)
13	1. Most comprehensive	3. Disability (positive response to a range of impairments, with some account taken of severity of hearing loss) (see Appendix 8 for details)
21	2. Basic (positive response to disability, difficulties due to long-term conditions or one of 3 specific criteria on old age, hearing and learning difficulties) (see Appendix 8 for details)	1. Any condition
22	2. Basic	2. Disability, with any hearing loss
23	2. Basic	3. Disability
25	2. Basic	5. Disability and any activity restriction (i.e. <u>needed assistance</u> , or <u>had difficulty with</u> self-care, mobility, communication, or a range of daily activities, or were restricted in schooling or employment) (see Appendix 8 for details)
26	2. Basic	6. Disability and severe activity restriction (i.e. <u>needed assistance with</u> self-care, mobility, communication, or a range of daily activities, or were restricted in schooling or employment) (see Appendix 8 for details)
33	3. Reduced (as for 2, with criteria for hearing and learning without reference to condition, removed) (see Appendix 8 for details)	3. Disability
34	3. Reduced	4. Any condition (as for 1) and any activity restriction (as in 5) (see Appendix 8 for details)
36	3. Reduced	6. Disability and severe activity restriction
43	4. Comprehensive — severe (as in 1, but for form type 5, using only 'a lot' responses to Q18) (see Appendix 8 for details)	3. Disability
53	5. Basic — severe (as in 2, but for form type 5, using only 'a lot' responses to Q18) (see Appendix 8 for details)	3. Disability
55	5. Basic — severe	5. Disability and any activity restriction
56	5. Basic — severe	6. Disability and severe activity restriction
63	6. Reduced — severe (as in 3, but for form type 5, using only 'a lot' responses to Q18) (see Appendix 8 for details)	3. Disability
66	6. Reduced — severe	6. Disability and severe activity restriction

Appendix 10 — Results of the September 1998 Census Test

Table 10.1—Census test September 1998: Form type 4 – Percentage of census population groups by selected demographic characteristics(a)

	Matched disability %	False positive %	False negative %	Matched non-disability %	All persons %	Total no.
Form Type 4						
Age						
0 to 14 years	5.8	7.6	4.8	20.2	16.7	471
15 to 59 years	34.8	42	50.9	64.6	59.2	1,672
60 years and over	59.4	50.4	44.2	15.2	24.2	683
<i>All persons</i>	100	100	100	100	100	2,826
Sex						
Males	48.8	51.1	42.8	47.7	47.5	1,343
Females	51.2	48.9	57.2	52.3	52.5	1,483
<i>All persons</i>	100	100	100	100	100	2,826
Birthplace						
Australia, NZ, UK, N. America, S. Africa	72.7	64.1	69.5	85.2	81.4	2,301
Other Europe	24.6	31.3	26	11.1	14.8	419
Northeast, Southeast & Southern Asia	1	1.5	0.4	1.7	1.5	42
Middle East and N. Africa	0.3	0	0	0.5	0.4	11
Other countries	0.3	2.3	1.1	0.6	0.7	20
Not answered	1	0.8	3	1	1.2	33
<i>All persons</i>	100	100	100	100	100	2,826
All persons (no.)	293	131	269	2,133	2,826	2,826

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

Table 10.2—Census test September 1998: Form type 4 – Percentage of selected demographic characteristics by selected census population groups(a)

	Matched disabilit y %	False positive %	False negative %	Matched non- disabilit y %	All persons %	Total no.
Form type 4						
Age						
0 to 14 years	3.6	2.1	2.8	91.5	100	471
15 to 59 years	6.1	3.3	8.2	82.4	100	1,672
60 years and over	25.5	9.7	17.4	47.4	100	683
<i>All persons</i>	<i>10.4</i>	<i>4.6</i>	<i>9.5</i>	<i>75.5</i>	<i>100</i>	<i>2,826</i>
Sex						
Males	10.6	5	8.6	75.8	100	1,343
Females	10.1	4.3	10.4	75.2	100	1,483
<i>All persons</i>	<i>10.4</i>	<i>4.6</i>	<i>9.5</i>	<i>75.5</i>	<i>100</i>	<i>2,826</i>
Birthplace						
Australian, NZ, UK, N. America, S. Africa	9.3	3.7	8.1	79	100	2,301
Other European	17.2	9.8	16.7	56.3	100	419
Northeast, Southeast & Southern Asian	7.1	4.8	2.4	85.7	100	42
Middle East and N. Africa	9.1	0	0	90.9	100	11
Other countries	5	15	15	65	100	20
Not answered	9.1	3	24.2	63.6	100	33
<i>All persons</i>	<i>10.4</i>	<i>4.6</i>	<i>9.5</i>	<i>75.5</i>	<i>100</i>	<i>2,826</i>
All persons (no.)	293	131	269	2,133	2,826	2,826

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

Table 10.3—Census test September 1998: Form type 5 – Percentage of census population groups by selected demographic characteristics(a)

	Matched disability %	False positive %	False negative %	Matched non-disability %	All persons %	Total no.
Form Type 5						
Age						
0 to 14 years	3.6	5.2	5.6	21	16.1	461
15 to 59 years	28.2	39.8	50.2	65.1	56.7	1,626
60 years and over	68.1	55	44.1	14	27.3	782
<i>All persons</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>2,869</i>
Sex						
Males	50.6	51.9	45.1	47.6	48.2	1,382
Females	49.4	48.1	54.9	52.4	51.8	1,487
<i>All persons</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>2,869</i>
Birthplace						
Australian, NZ, UK, N. America, S. Africa	70.6	79.2	73.7	85.2	81.8	2,346
Other European	25.5	17.3	21.6	10.8	14.2	408
Northeast, Southeast & Southern Asian	1.2	2.2	1.4	1.5	1.5	43
Middle East and N. Africa	0.2	0	0	0.2	0.2	5
Other countries	0.7	0.4	1.4	0.6	0.7	19
Not answered	1.7	0.9	1.9	1.7	1.7	48
<i>All persons</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>100</i>	<i>2,869</i>
All persons (no.)	411	231	213	2,014	2,869	2,869

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

Table 10.4—Census test September 1998: Form type 5 – Percentage of selected demographic characteristics by selected census population groups(a)

	Matched disability y %	False positive %	False negative %	Matched non- disability %	All persons %	Total no.
Form type 5						
Age						
0 to 14 years	3.3	2.6	2.6	91.5	100	461
15 to 59 years	7.1	5.7	6.6	80.6	100	1,626
60 years and over	35.8	16.2	12	35.9	100	782
<i>All persons</i>	<i>14.3</i>	<i>8.1</i>	<i>7.4</i>	<i>70.2</i>	<i>100</i>	<i>2,869</i>
Sex						
Males	15.1	8.7	6.9	69.3	100	1,382
Females	13.7	7.5	7.9	71	100	1,487
<i>All persons</i>	<i>14.3</i>	<i>8.1</i>	<i>7.4</i>	<i>70.2</i>	<i>100</i>	<i>2,869</i>
Birthplace						
Australian, NZ, UK, N. America, S. Africa	12.4	7.8	6.7	73.1	100	2,346
Other European	25.7	9.8	11.3	53.2	100	408
Northeast, Southeast & Southern Asian	11.6	11.6	7	69.8	100	43
Middle East and N. Africa	20	0	0	80	100	5
Other countries	15.8	5.3	15.8	63.2	100	19
Not answered	14.6	4.2	8.3	72.9	100	48
<i>All persons</i>	<i>14.3</i>	<i>8.1</i>	<i>7.4</i>	<i>70.2</i>	<i>100</i>	<i>2,869</i>
All persons (no.)	411	231	213	2,014	2,869	2,869

(a) Based on the definition 23 — see Appendices 7, 8 and 9 for more details.

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