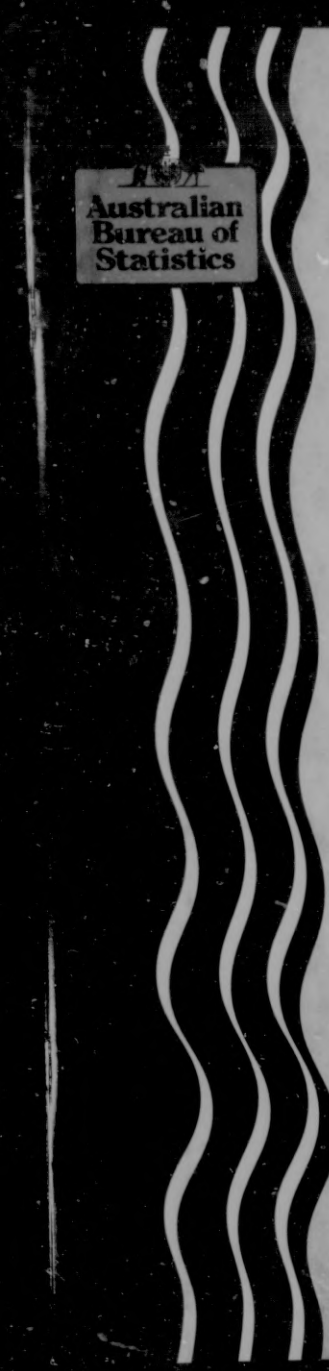



# DISABILITY, AGEING & CARERS

## User Guide

AUSTRALIA 1993

ABS Catalogue No. 4431.0

EMBARGOED UNTIL 11.30 A.M. 23 DECEMBER 1993

NEW ISSUE

# DISABILITY, AGEING AND CARERS AUSTRALIA, 1993

## USER GUIDE

IAN CASTLES
Australian Statistician

AUSTRALIAN BUREAU OF STATISTICS

CATALOGUE NO. 4431.0



Printed in Australia by ALAN LAW, Commonwealth Government Printer, Canberra

## CONTENTS



**APPENDIXES**



INQUIRIES

. *for further information about the Survey of Disability, Ageing and Carers, and the availability of unpublished statistics* contact the Information Officer on Canberra (06) 252 5315 or 252 7430.

. *for information about other ABS statistics and services* please refer to the back page of this publication.

## PREFACE

This publication contains details about the 1993 Survey of Disability, Ageing and Carers, its objectives and content, the concepts, methods and procedures used in the collection of data, and the derivation of estimates.

The purpose of the User Guide is to help users of the data to better understand the nature of the survey, its potential and its shortcomings, in meeting their data needs.

The introductory section gives a brief outline of the background and development of the 1993 Survey of Disability, Ageing and Carers. The second section provides an overview of the survey design, concepts and definitions and major areas of information collected. Following sections detail the survey methodology, operation and data content.

IAN CASTLES
**Australian Statistician**

**Australian Bureau of Statistics**
**Canberra ACT**
**December 1993**

# INTRODUCTION

The 1993 Survey of Disability, Ageing and Carers was conducted by the Australian Bureau of Statistics (ABS) in the period 7 February to 3 April 1993 as part of the Special Supplementary Survey program. This survey collected detailed information on persons with disabilities, those aged over 60 years and carers of these population groups. For comparison purposes, less detailed information was also collected on persons not in these populations.

About 18,000 households representing approximately 45,000 persons (or about 1 in every 400 persons in the Australian population) were selected at random for inclusion in the household component while about 700 institutions and 6,000 persons were randomly selected for the establishment component. After sample loss these totals were reduced to effective samples of approximately 16,000 households and 42,000 persons for the household component, and 600 institutions and approximately 5,000 persons for the establishment component.

## Background

Previous national surveys relating to disability were conducted by the ABS in 1981, *Handicapped Persons Survey*, and in 1988, *Disabled and Aged Persons Survey*. The 1993 Survey used concepts and definitions comparable to previous surveys but it complements rather than replicates, the 1981 and 1988 surveys.

Further detail relating to the main changes from the 1988 survey can be found in Section 2, *Overview of the survey - Main changes from the 1988 Survey of Disabled and Aged Persons*.

The 1993 survey was conducted as two separate components:

- a household component; and,
- an establishment component.

The household component was conducted using a personal interview based methodology, while the establishment component was conducted using a mail-based methodology. Discussion of the methodologies used and descriptions of the sample populations for each component are included in section 2 Survey design, with additional detail included in Appendix A.

The survey was conducted under the authority of the *Census and Statistics Act 1905*. The ABS sought the willing cooperation of households and establishments selected in the survey and the confidentiality of all information provided by respondents was guaranteed. Under its legislation the ABS cannot release identifiable information about households, establishments, or individuals.

**Survey Development**

Release of data from the 1988 Survey of Disabled and Aged Persons revealed substantial changes in the apparent extent of disability and handicap when compared with the 1981 Survey of Handicapped Persons, and this generated much debate among the user community. Although the reasons for the changes were not clear it was thought that some of the changes could be attributed to:

- differences in the methodologies used for each of the surveys;
- changes in community attitudes, perhaps influenced by the 1981 International Year of the Disabled;
- people with disabilities being more willing to report such conditions; and,
- the increased availability of aids for disabled people, as use of an aid is a determinant of mild handicap.

A decision to conduct the 1993 Survey of Disability, Ageing and Carers was made in September 1990.

The survey objectives were to obtain information on:

- the numbers and characteristics of:
  - persons with disabilities;
  - persons with a handicap;
  - persons aged 60 years or more; and,
  - principal carers of persons with disabilities or persons aged 60 years or more.

In relation to the identified population groups, the survey's content was to include data relating to:

- accommodation;
- education;
- employment;
- income;
- provision of care;
- care needs;
- identification of unmet need; and,
- identification of severity and area of handicap.

Development of the establishment component began in December 1991. The establishment component of the survey was conducted using a mail-based methodology, a departure from the interviewer method used for the 1988 Survey of Disabled and Aged Persons. The questionnaire used in this component mirrored the household component as much as possible, but excluded questions relating to education, income, housing, employment and transport. The range of

data collected in this component was smaller than in the household component as it was felt some areas could not be properly addressed through a mail based methodology or were perceived to be less relevant to persons in establishments.

The ABS made every effort to advise service providers, policy-planners, other relevant organisations and individuals that the survey was being developed. As the data specifications for the survey were being drafted, those who expressed an interest in the topic were approached for their comments. The ABS also received several submissions requesting specific issues be included. A series of meetings were organised to give users the opportunity to discuss their ideas with officers from the ABS. These meetings were held in Canberra, Sydney Melbourne and Brisbane.

From the user group meetings and submissions received, it became apparent that not all issues could be included in the survey. Therefore, in conjunction with the users, issues to be included were assessed against the following criteria:

- the importance of the issue as it related to disability, ageing or carers;
- the level of user interest in the issue;
- the existence of other data sources;
- respondent issues:
  - privacy and sensitivity;
  - respondent load concerns;
- methodological and operational issues; and,
- the relationship between issues in the survey.

In addition to assessing issues against these criteria, they were also reassessed during survey design tests. These tests were conducted first in Hobart in June 1991, then in Sydney in February 1992, and finally in Brisbane in August 1992. The testing principally reviewed:

- the effectiveness of the sampling procedures;
- the effectiveness of the interviewing procedures;
- whether the issues were addressed properly by the questions included;
- the correctness of classifications and coding frames; and,
- gauged respondent reaction to the survey.

The testing for the establishment component was designed to test the same areas but, as a mail-based methodology was used, only one test was conducted using an Australia wide sample. In addition, small scale testing and observational studies for this component were undertaken in the Canberra area.

During the entire development of the survey, and in addition to the user group meetings, the ABS consulted with a wide range of agencies with an interest in the survey and kept them informed of the progress and plans. All aspects of the survey were designed to conform to Information Privacy Principles in the *Privacy Act 1988*.

Details of the survey were tabled in Parliament, in November 1992, in accordance with section 6(3) of the *Australian Bureau of Statistics Act 1975*.

# OVERVIEW OF THE SURVEY

## CONCEPTS AND DEFINITIONS

All definitions for the survey were based on the definitions proposed by the World Health Organisation (WHO) in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) 1980.

**Disability**

The ICIDH definition for disability is as follows:

> *In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.*

It is difficult to put such a broad concept into operation. The approach adopted for this survey was to ask a series of screening questions on limitations, restrictions and impairments about each individual. These questions had been developed in the two previous surveys on the topic (1981, 1988), and in testing for this survey. Three additional screening questions (see section on *Main Changes from 1988 Survey of Disabled and Aged Persons* on page 9) were included for this survey because of concern that specific groups of people with disabilities were missed by the earlier surveys. It has been established that persons identified by one or more of these questions were within the concept of disability as commonly accepted by data users.

Persons with a disability were identified in the survey if they had one or more of the limitations, restrictions or impairments summarised below:

- loss of sight (even when wearing glasses or contact lenses);
- loss of hearing;
- speech difficulties in native languages;
- blackouts, fits, or loss of consciousness;
- slowness at learning or understanding;
- incomplete use of arms or fingers;
- difficulty gripping or holding things;
- incomplete use of feet or legs;
- treatment for nerves or an emotional condition;
- a restriction in physical activities or in doing physical work;
- a disfigurement or deformity.
- need for help or supervision due to a mental illness;
- long term effects of head injury, stroke or any other brain damage;
- treatment or medication for a long-term condition or ailment and still restricted;
- any other long-term condition resulting in a restriction;

Any definition of disability for this survey has to be stated in terms of the above.

Certain value judgements are implicit, for example, a person with loss of sight corrected by glasses is not included as having a disability, whereas a person with loss of hearing corrected by a hearing aid is included as having a disability.

For the purposes of this survey:

> ***disability*** *was defined as the presence of one or more of the above limitations, restrictions or impairments which had lasted, or was likely to last, for a period of 6 months or more.*

**Handicap**

For the purposes of this survey and in accordance with the definition and guidelines given by WHO:

> ***handicap*** *was identified if a person had a limitation or restriction in performing certain specific tasks associated with daily living, due to their disability.*

The limitation must be due to the disability as identified in the previous section and in relation to one or more of the specific tasks given in the areas of handicap as listed below:

- *Self-care*: showering, bathing, dressing, eating, toiletting, bladder or bowel control;
- *Mobility (profound/severe/moderate)*: moving away from the home/establishment, moving about the house/establishment, transferring between bed and chair.
  *Mobility (mild)*: limitation in walking 200 metres, walking up or down stairs or using public transport;
- *Verbal communication*: understanding or being understood by strangers/family/friends/staff in the person's native language;
- *Schooling*: unable to attend school, attended a special school, attended special classes in an ordinary school, needed time off from school or had difficulty at school because of a disabling condition. This information was collected for persons in households aged 5 to 14 years and those aged over 15 years and still attending school.
- *Employment*: permanently unable to work, restricted in the type of work could do, often needed time off work, restricted in the number of hours could work, would require an employer to make special arrangements, or limited in prospects of obtaining/keeping/changing jobs. This information was collected for persons in households aged 15 years and over, not attending school.

Persons aged less than 5 years with one or more disabilities were all regarded as being handicapped, but were not classified by area of handicap. This was due to difficulties inherent in determining whether the needs of the children aged less than 5 years were a function of their age or their disability.

**Severity of Handicap**

Four levels of severity (profound, severe, moderate and mild) were determined in the survey for each of the three areas of handicap: self-care, mobility and verbal communication. These levels were based on the person's ability to perform tasks relevant to these three areas and on the amount of help required. For each area of handicap, the levels of severity are as follows:

- *Profound handicap*: In households, profound handicap is defined as 'personal help or supervision always required'. In establishments, profound handicap is defined as 'occupant cannot perform tasks without help or supervision'.

- *Severe handicap*: In households, severe handicap is defined as 'personal help or supervision sometimes required'. In establishments, severe handicap was only determined for verbal communication.

- *Moderate handicap*: For both components, moderate handicap was defined as 'no personal help or supervision required, but the person has difficulty in performing one or more of the tasks'.

- *Mild handicap*: For both components, mild handicap was defined as 'no personal help or supervision required and no difficulty in performing any of the specified tasks, but the person uses an aid'. In addition, for the household component, any person having difficulty with walking 200 metres, walking up and down stairs, or picking up an object from the floor, was determined to have a mild handicap.

The highest level of severity in any one of the areas of self-care, mobility and verbal communication determines the severity of total handicap.

Severity of handicap was not determined for children aged less that 5 years due to the difficulties inherent in determining whether the needs of children aged less than 5 years were a function of their age or their disability. Additionally, severity of handicap was not determined for persons with only an employment or schooling limitation.

**Disability Without Handicap**

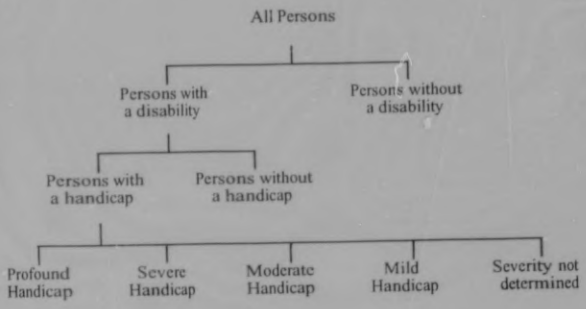
Persons with a disability but not identified as having a handicap must have stated that they had one of the broad limitations, restrictions or impairments as given for disability, but then stated that they were not restricted in any of the specific tasks given to identify persons with a handicap.

**Older Persons**

All persons aged 60 years or more were included in sections of the survey relating to older persons. This age range was chosen in 1988 as it reflected the legal retirement for women at that time. The age range was retained for the 1993 survey so that the majority of retired people would be included in the survey.

**Relationship Between Disability and Handicap**

The relationship between disability and handicap and severity of handicap is illustrated below.




**Main Changes from 1988 Survey of Disabled and Aged Persons**

As part of the development of the 1993 Survey of Disability, Ageing and Carers a complete review of the 1988 Survey of Disabled and Aged Persons was undertaken. The purpose of this review was to ascertain what could usefully be incorporated into the 1993 survey. From this review significant changes and additions were made.

The list of impairments used as screening questions was expanded to include:

- difficulty gripping and holding small objects;
- long term effects of head injury, stroke or any other brain damage;
- any other long-term condition resulting in a restriction.

These extensions were an attempt to reduce misunderstandings about types of

impairments and conditions to be included and to ensure that no one who came within the scope of the survey was unintentionally excluded.

The review, and subsequent consultation with potential users of the survey data, also resulted in new issues relating to disability and ageing being explored. The issues accepted for inclusion in the 1993 survey which were not present in the 1988 survey were identification of:

- print handicap;
- emergency arrangements used by people with disabilities and people aged 60 years or more; and,
- participation in community activities by people with disabilities and people aged 60 years or more.

The most significant development concerning the household component of the survey was the extension of the carers questions and the inclusion of the Carers Form. The information about carers and the effects of the caring role now forms a substantial part of the survey.

In 1988, both the household component and the establishment component were conducted using a personal-interview based methodology. In 1993 only the household component retained this methodology while the establishment component became mail-based.

## MAJOR AREAS OF INFORMATION COLLECTION

The household component of the survey was designed to collect information about people with a disability and people 60 years or more in the following areas:

- basic demographic characteristics such as age, sex, and marital status;
- education, employment, income and housing;
- long-term health conditions and cause of main disabling condition;
- difficulties experienced and help required in the areas of self-care (such as showering, dressing and eating), communication and mobility;
- help required with transport, household tasks etc;
- type of help required for specific tasks;
- types of aids needed to perform everyday tasks;

In addition information was collected on:

- carers of people with disabilities and people aged 60 years or more; and,
- the effect of the caring role on daily living.

Data were collected to enable government departments and community groups to plan for the future and develop relevant policies. Wherever possible, variables used standard ABS definitions and classifications to allow comparison with other sources of ABS data.

The data collected from the establishment component of the 1993 Disability Ageing and Carers Survey were a subset of the data collected from the household component of the survey. Information collected from the establishment component of the survey included details on:

- the main disabling condition;
- basic demographic characteristics;
- difficulties experienced and the provision of help for specific activities; and,
- the aids required and used for these activities.

Questions on these topics were comparable to the questions included in the household component of the survey with some minor modifications to make them more relevant to establishments.

Further detail relating to the data items of the survey can be found in Section 4, *Data Content*. A complete list of data items used in the survey is contained in the *Data Reference Package* (4432.0).

## SURVEY DESIGN

**Sample Selection**

*Private Dwelling Selection*

Private dwellings are defined as houses, flats, home units, garages, tents and other structures used as private places of residence at the time of the survey.

The sample of private dwellings for the 1993 Survey of Disability, Ageing and Carers was selected using a multi-stage sampling technique. This technique selects and sub-selects areas until the actual dwellings where people are to be interviewed are obtained. All sectors of the in-scope population were represented (see *Scope* p.13).

The sample was designed so that certain areas were randomly selected to represent each of the States and Territories. Dwellings were selected from these areas only.

To select the sample, each State or Territory was divided into geographic regions. Each region was then divided geographically, and smaller areas known as Census Collector's Districts (CDs) were selected. In each selected CD, one or two blocks were chosen to represent the whole Collector's District. All dwellings within each chosen block were used to select the actual dwelling sample.

*Special Dwelling Selection*

Special dwellings are defined as hotels, motels, boarding houses, educational and religious institutions, construction camps, caravan parks, etc.

Special dwellings (excluding the relevant Establishments below) in each State and Territory were listed and sampled directly from these lists. Each special dwelling was given a chance of selection proportional to the average number of persons it accommodated.

*Establishment Selection*

Establishments are defined as hospitals, nursing homes, hostels, retirement villages and other 'homes'.

Establishments were selected using a multi stage sampling technique. To identify the occupants to be included in the survey, all the occupants in the establishment were listed and then a random selection technique was applied.

Further detail on the sample selection procedures can be found in *Appendix A*.

**Sample Population**

The sample population for the household component of the survey was randomly selected to include approximately 42,000 persons from 18,000 households (representing 1 in every 400 persons in the Australian population).

Approximately 700 institutions and 6,000 persons were randomly selected for the establishment component. The sample design ensured that every person within each State and Territory was given an equal chance of selection. An allowance was made for sample loss resulting from the selection of vacant dwellings or through non-contact. These samples were considered sufficient to provide detailed information for each State and Territory, and total Australia, at an acceptable level of accuracy and reliability.

**Scope**

The 1993 Survey of Disability, Ageing and Carers covered rural and urban areas in all States and Territories of Australia, and included residents of private dwellings, special dwellings and establishments.

The survey included all persons except:

- overseas visitors, ie, people whose usual place of residence is outside Australia;
- members of non-Australian defence forces stationed in Australia and their dependents;
- non-Australian diplomats, non-Australian diplomatic staff and non-Australian members of their households; and,
- inmates of gaols and reformatories.

Note that hospitals, nursing homes, retirement villages and other homes were excluded from the special dwelling sample of the household component of the survey, but were included in the establishment component of the survey.

Temporary residents (other than those above) working or studying in Australia, and their dependents were included in the survey.

**Coverage**

Coverage rules were designed to ensure that, as far as possible, persons within the scope of the survey had only one chance of being selected. The household component and the establishment component of the survey each had their own coverage rules, outlined below.

*Household Component*
Usual residents of selected ***private dwellings*** were ***included*** in the household component of the survey if:

- they were staying at the selected dwelling on the night of the interview; or,
- were absent from the dwelling on the night of the interview, but were, or would be present at the dwelling during any part of the eight week enumeration period.

Usual residents of selected ***private dwellings*** were ***excluded*** from the household component of the survey if:

- they were absent from their private dwelling for the entire enumeration period.

Visitors, when located at selected private dwellings, were excluded on the expectation that most would have their chance of selection at their usual residence.

Residents of selected ***special dwellings*** were ***included*** in the special dwelling sample of the survey if:

- they did not usually live in a private dwelling and their usual residence was the selected special dwelling.

*Establishment Component*
Persons residing in establishments were included in the survey if they were expected to be a usual resident of the establishment during the enumeration period.

Persons who were not usual residents for the whole of the enumeration period were excluded from the establishment component.

**Methodology**

*Household component*
Trained ABS interviewers were used to collect data for the household component of the survey. Detailed personal interviews were conducted with:

- all persons with one or more disabilities;
- persons aged 60 years or more;
- carers of these two populations.

Basic socio-economic data were collected for other members of the household who were not included in the above populations.

Personal interviews with children aged 15 to 17 years with a disability were conducted with the consent of a parent or guardian.

Where the respondents were unable to answer the questions for themselves, or were less than 15 years of age, information was obtained via a proxy (ie, another person in the household who was able to answer for the respondent).

*Establishment component*

The establishment component was designed to collect data from persons with disabilities and persons aged 60 years or more, residing in establishments. A mail-based survey methodology was used which was directed to the administrators of the selected establishments. Instructions were provided to the administrators of the establishments on how to randomly select respondents from their list of occupants and on how to complete the forms.

Further detail relating to the changes in methodology can be found in Section 3, *Details of Methodology and Operation*.

## SURVEY OUTPUT AND DISSEMINATION

**Data Availability**

Results from the Survey of Disability, Ageing and Carers will be available in the form of:

- publications; and,
- tables produced on request to meet specific information requirements from the survey.

Consultancy services are also available to undertake statistical analysis of data collected.

The following, outlines the products and services which are proposed.

Information about the proposed products is contained in the *Catalogue of Publications and Products, Australia* (1101.0), and *Publications to be released in [year]* (1109.0). The ABS also issues, on Tuesdays and Fridays, a *Publications Advice* (1105.0) which lists publications to be released in the next few days. Publications and other standard products may be obtained by contacting Information Services at the ABS office in your State or Territory.

**Publications and Other Standard Releases**

*Disability, Ageing and Carers: Summary of Findings* (4430.0)
Expected release December 1993
Price $20.00

The Summary of Findings contains a selection of national estimates relating to disability and ageing in Australia. It also contains estimates of the number and demographic characteristics of persons with disabilities or handicaps, persons aged 60 years or more and carers. Information is also included relating to areas and levels of handicap and need for or receipt of help.

*Disability, Ageing and Carers: User Guide* (4431.0)
Expected release December 1993
Price $20.00

This publication.

*Disability, Ageing and Carers: Data Reference Package* (4432.0)
Expected release December 1993
Price $20.00

The package contains the forms used for both components of the Survey of Disability, Ageing and Carers. It also contains a complete list of the survey data items.

**Publication Program**

A series of specialised publications is planned to further analyse the information collected. Each publication will address an issue identified as being of significant interest to users. Topics will be finalised following analysis of the data from the survey, but it is envisaged that the following issues will be addressed.

- Employment: identifying aspirations and restrictions associated with disability and/or ageing and/or carers.
- Education: identifying restrictions associated with disability.
- Disabling conditions: identifying the areas most prevalent, the help required, and the source of that help.
- Carers: the numbers and characteristics of persons in the caring role.
- Carers: the effects of the caring role in relation to areas of everyday living.

Small publications relating to specific focus groups are being investigated. These may include topics such as:

- the need for, and help received by, those who are visually or hearing impaired, paraplegic, or brain injured;
- those involved in accidents;
- the transport needs of people with a disability.

**Related Publications**

These publications relate to the previous survey conducted in 1988.

*Carers of the Handicapped at home, Australia, 1988* (4122.0)
Released January 1990
Price $12.50

This publication presents data on the household composition and other characteristics of principal carers; characteristics of the main recipient of care; and help provided by, and support provided to, the principal carer.

*Disability and Handicap, Australia, 1988* (4120.0)
Released October 1990
Price $12.50

This publication presents data on persons with one or more disability showing household composition and other characteristics; disabling condition; type and severity of handicap; need for and receipt of help; use of aids; and income and

accommodation. Where relevant, tables covered persons with one or more disability living in households and establishments.

*Domestic Care of the Aged, Australia, 1988* (4120.0)
Released September 1992
Price $12.50

This publication presents data on persons aged 60 years or more, with or without a disability, showing household composition and other characteristics; their need for and receipt of help; and income and accommodation. A more extended range of age groups than those contained in *Disability and Handicap* is examined.

**Special Data Services**

*Special tabulations*
Special tabulations can be produced on request to meet individual user needs. Subject to stringent confidentiality and sampling variability constraints, the tabulations can be produced incorporating data items and populations to meet individual requirements.

Special tabulations can be made available in printed form or on floppy disk. Each request is costed individually and quotes are provided prior to completion.

The availability of the special tabulation service will coincide with the release of the initial publication (4430.0) in December 1993.

*PROTAB*
For users who have an expected on-going need for special tabulations, a software facility will be available which has been designed to assist in table specifications. This facility, called PROTAB, can be run from any IBM compatible microcomputer and has the following features:

- screen-based table facility;
- complete list of available data items;
- full details of the contents of each data item, including:
  - descriptions;
  - weighted counts of each value; and,
  - percentage distribution of values;
- immediate calculation of table cost and batch cost based on the number of cells requested and selected survey parameters; and,

- construction of a coded set of specifications for the required tables which can be transmitted to the ABS in printed form or on floppy disk.

The use of PROTAB enables the production of precise table specifications which will assist the ABS in servicing the table request promptly. PROTAB software for the Survey of Disability, Ageing and Carers is expected to be available in December 1993. The cost of the PROTAB software is available on application.

*Statistical Consultancy Services*

ABS offers a specialist statistical consultancy service to assist users with their statistical needs. This consultancy attracts a service charge. For further information, contact the Statistical Consultancy Service in the ABS office in your state.

# DETAILS OF SURVEY METHODOLOGY AND OPERATION

## QUESTIONNAIRES

Three questionnaires were developed for the Household Component of the 1993 Disability, Ageing and Carers Survey:

- the household form;
- the personal form; and,
- the carer's form.

Two questionnaires were developed for the Establishment Component:

- the contact information form; and,
- the establishment form.

### Design

Design of the questionnaires took into consideration the output requested by users as well as the basic core information required. Questions were then developed to obtain this data.

The factors taken into consideration in questionnaire design included:

- the length of individual questions;
- the types of questions asked;
- the wording of the questions;
- the number of subjects and overall length of the questionnaire;
- the sensitivity of topics;
- minimizing and simplifying any instructions;
- the logical sequence of the form; and,
- the physical design of the form.

For comparability reasons the majority of the questions asked in the 1993 Survey of Disability, Ageing and Carers were similar to those asked in the 1988 Survey.

### Testing

The questionnaire was fully field tested to:

- assess whether the information sought can be easily provided by respondents;
- ensure that there was minimum respondent concern about the sensitivity or privacy aspects of the information sought;
- ensure respondent and interviewer burden was minimised;
- assess the ordering of the topics with respect to the different target populations and the flow of the interview;
- check the mechanical accuracy (eg, question numbers, sequence

guides) of the questionnaire;
- ensure that the data collected meets user needs, eg, it was adequately addressing the data requirements of the survey;
- assess the adequacy and relevance of the response categories in the questionnaire;
- assess ability to process questionnaires and derive complex data items from the questions asked;
- determine the accuracy and completeness of supporting documentation, eg, interviewers instructions, supervisors instructions; and,
- assess whether estimated costs are within budget, through analysis of interview, edit and travel times of the interviewers.

**Information Recording**

Information was recorded in the questionnaires in a number of different ways.

- *Predetermined response categories*. This approach was used for recording answers where a limited range of responses were expected, or where the focus of interest was on a particular type or group of responses. Response categories were listed in the questionnaire and were expected to cover all given responses.

- *Classification and coding*. This method was used for the more sensitive and complex topics such as type of disabling condition, type of aids used, occupation, name and address of business, etc. Responses were recorded by interviewers 'as reported', for subsequent classification and coding by office staff.

- *Running prompt*. Questions were asked in the form of a 'running prompt' eg, predetermined response categories were read out to the respondent one at a time until the respondent indicated agreement to one of the categories or until all the predetermined categories were exhausted. If all categories were exhausted then a further category of 'other' could be marked and details recorded by the interviewer.

- *Prompt cards*. Printed lists of possible answers to the question were handed to the respondent who was asked to select the most relevant response. By listing a set of possible responses (either in the form of a prompt card or a running prompt question) the prompt served to clarify the question or to refresh the respondents' memory and at the same time, assist the respondent to select an appropriate response.

To ensure consistency of approach, interviewers were instructed to ask the interview questions exactly as written in the questionnaire. However, in certain areas of the questionnaire interviewers were asked to use indirect and neutral

- *Manipulation of data*: errors may have occurred during the various stages of computer processing involving the manipulation of raw data to produce the final survey data files.

A number of steps were taken to minimise errors at various stages of processing:

- *Coding*: detailed coding instructions were developed, and staff engaged in coding were trained in the various classifications and procedures used; a sample of forms were checked for coding accuracy and to identify any coding problems;

- *Computer editing*: edits were devised to ensure that logical

prompts at their discretion, eg, where the response given was inappropriate to the questions asked, or lacked sufficient detail necessary for classification and coding.

**Household Form**

This form was used to record basic demographic details (eg, age and marital status) and the details of the relationship between individuals in each household. The form included the screening questions designed to identify residents who had a condition which had lasted for six months or more, persons aged 60 years or more, or persons providing care outside the household. This information was obtained from any responsible adult within the household.

The form was also used to record:

- whether or not respondents met scope and coverage requirements;
- details of interviewer appointments; and,
- the response status of the household (eg, fully responding, non-response or sample loss).

A similar form (the Special Dwelling Form) was used for special dwellings in the sample in the same way as the household form.

**Personal Form**

Questions asked of each person varied according to whether the person was in one or more of the target populations of the survey.

All members of the household identified on the Household Form, except children aged less than 15 years without a disability, were asked a number of questions relating to demographic characteristics, employment status, education, housing and income.

Persons with a disability were asked questions to determine the presence and severity of handicap and questions relating to help and assistance needed and received for self care, mobility, verbal communication, health care, home help, home maintenance, meal preparation, financial management, and transport activities.

Persons aged 60 years or more without a disability were only asked questions about a need for or receipt of help for home help, home maintenance, meal preparation, financial management, and transport activities. Testing prior to the survey showed that very few older persons without a disability needed help with activities such as self-care, verbal communication, mobility or health care.

## RESPONSE RATES

**Household Component**

In total 17,820 private households and 1,601 special dwelling units were selected in the sample for the 1993 Survey of Disability, Ageing and Carers. As shown in Table 1 below, this reduced to an effective sample of 15,957 households and 378 special dwelling units after sample loss. The sample loss is of a similar level to that for other ABS surveys. The large sample loss for special dwellings was expected and is due to coverage rules.

From the effective sample of households, there were 42,215 persons in scope and coverage for the survey. Fully complete questionnaires were obtained from 97.6 percent of these persons. As Table 2 shows, non-response of all types was

Principal carers were asked questions relating to the help provided by them; the assistance they received with their caring role; and the effect on their lifestyle of their role as a carer.

For children aged less than five years with one or more disabilities, information was only obtained regarding their demographic characteristics. Data was not collected to determine the presence and severity of handicap, or the need for and receipt of help. This was due to difficulties inherent in deciding whether the needs of children aged less than five years of age were a function of their age or their disability.

For children aged 5-14 years with a disability, data about help needed and received were collected for the areas of self care, verbal communication, mobility and using public transport. Data were also collected on print handicap, community activities, education and aids used/needed. The other activities were not considered sufficiently relevant to those aged 5-14 years.

Further detail relating to data collected and targetted populations can be found in Section 4, *Data Content*.

**Carers Form**

The Carer's Questionnaire was provided to principal carers of persons with one or more disabilities and was self-enumerated, but was completed in the presence of the interviewer and returned to the interviewer in a sealed envelope. This approach was adopted in recognition of the potential sensitivity of the topics covered. Instructions to respondents on how to complete the form were contained on the form itself.

The Carer's Questionnaire contained questions relating to the effect of the caring role on people who care for a person with one or more disabilities.

**Contact Information Form**

The Contact Information Form (CIF) was sent to the administrators of the establishments selected, requesting the name of a contact officer and the number of occupants in the establishments. The information collected on the CIF was used to determine how the selections would be made. The survey questionnaires were then sent to the nominated contact officer.

**Establishment Form**

Instructions were provided to the nominated contact officer on how to randomly select occupants of their establishment. They were also instructed about applying coverage rules. An establishment questionnaire was then completed for each correctly identified occupant from the administrative records and knowledge of the occupants. ABS interviewers were not used for this questionnaire.

## INTERVIEWS AND INTERVIEWERS

### Interviews

Selected households were informed of their selection in the survey by mail and advised that an interviewer would call to arrange a suitable time to conduct the interviews. A guarantee of confidentiality, and a brochure providing information on the survey and the interview process were included with this primary approach letter.

At the initial interview a Household Form was completed with any responsible adult within the household. This form was used to record basic demographic characteristics and whether or not a person met scope and coverage requirements. A set of screening questions was used to identify those members of the household to be interviewed personally.

An interview was conducted with persons identified as having one or more disabilities, aged 60 years or more, or principal carers of persons living outside the household. Other adult members of the household were asked a short set of questions relating to employment, education, income and housing.

Principle carers of usual residents were identified by questions asked of persons with one or more disabilities during Personal Interview. Principle carers who were also usual residents were interviewed.

Children aged 15-17 years with one or more disabilities were interviewed with the consent of a parent or responsible adult. If consent was not given to interview the child personally, a parent or responsible adult was interviewed on their behalf (proxy interview).

If respondents were unable to answer for themselves because they were not well enough or because of their disability, or were less than 15 years of age with one or more disabilities, information about them was also obtained via proxy (ie, from another appropriate person in the household).

Where there were language problems (including sign language), another person in the household was asked to interpret if this was agreed to by the respondent, otherwise, arrangements were made to supply an interviewer who could speak the appropriate language, wherever possible.

Interviewers made appointments as necessary, in order to obtain personal interviews with appropriate respondents. In some cases appointments for call-backs were made by telephone, but all personal interviews were conducted face-to-face.

**Interviewers**

Interviewers for the household component of the 1993 Survey of Disability, Ageing and Carers were recruited from a list of trained interviewers with previous experience on ABS household surveys. Those selected to work on this survey underwent classroom and field training and were required to satisfactorily complete home study exercises. All phases of the training emphasized understanding the concepts of the survey, definitions and procedures in order to ensure that a standard approach was employed by all interviewers.

Each interviewer was supervised in the field and given an individual debriefing session during the interviewer's initial work load. Workloads averaged 20 to 25 dwellings in which interviews were to be conducted over a two week period. Each interviewer was responsible for a number of workloads.

## MEASURES TO MAXIMISE RESPONSE

In any sample survey responses should be obtained from all units selected; however, there will always be some non-response when people refuse to cooperate, cannot be contacted or are contacted but cannot be interviewed. It is important that response be maximized in order to reduce sampling variability and avoid bias.

Sampling variability is increased when the sample size decreases and bias can arise if people who fail to respond to the survey have different characteristics from those who did respond.

The ABS sought the willing cooperation of the households selected. Measures taken to encourage respondent cooperation and maximize response included:

- providing information to the households selected, by letter, explaining that their dwelling had been selected for the survey, the purposes of the survey, its official nature and the confidentiality of the information collected. This letter gave advance notice that an ABS interviewer would call, and provided an ABS contact number for more information, if required. An information brochure, specially designed for selected households was provided with the initial approach letter. This procedure could not be followed for a small number of households where the ABS did not have an adequate postal address;

- stressing the importance of participation in the survey by selected households. Each selected dwelling (and its residents) represented a number of others in that local area in that State and in Australia. The cooperation of those selected was important to ensure all households/persons were properly represented in the survey and so properly reflected in survey results;

- stressing the importance of the survey for planning and policy analysis, by Commonwealth and State Departments, and for organisations representing persons with disabilities, persons aged 60 years or more and carers;

- stressing the confidentiality of all information collected. This confidentiality of data is guaranteed by the *Census and Statistics Act 1905*; under provisions of this Act the ABS is prevented from releasing any identifiable information about individuals or households to any person, organisation or government authority.

Up to five calls were made to contact the occupants of each selected dwelling and to conduct the household component of the 1993 Survey of Disability, Ageing and Carers in those dwellings.

If any persons who were to be personally interviewed were absent from the dwelling when the interviewer called, arrangements were made to return and interview them. Interviewers made return visits as necessary in order to complete questionnaires for all persons within the scope and coverage of the survey. In some cases, individual members of the household were not subsequently available for interview, and these were classified as individual non-contacts. Respondents who refused to participate were usually followed-up later by letter and a subsequent visit by a supervisor. Completed questionnaires were obtained where possible.

Persons not included in the survey through non-contact or refusal were not replaced in the sample.

Similar encouragements, relating to the importance of the survey, were employed for the establishment component of the 1993 Survey of Disability, Ageing and Carers. Administrators of establishments who had not returned their questionnaires were sent two reminders and, where necessary, followed-up by telephone contact.

## DATA PROCESSING

A combination of clerical and computer-based systems were used to process the data obtained. These are outlined below.

### Clerical Editing

For the household component, clerical edits were initially applied by interviewers to ensure the completeness and consistency of the questionnaires before being returned to the ABS. Errors or omissions identified were not referred back to the respondent rather, the interviewer made note of any such problems and provided additional comment about individual questionnaires as appropriate when returning the questionnaires to an ABS office for processing.

All questionnaires were again checked on receipt in the ABS office to ensure interviewer workloads were fully accounted for and all questionnaires for each household and respondent were completed. Problems identified by interviewers were resolved by office staff, where possible, based on other information contained in the questionnaire, or on the comments provided by interviewers.

Establishment clerical editing allowed for respondents to be contacted to clarify information and redress ommissions.

### Clerical Coding

Clerical coding was undertaken on the following items:

- family relationship data;
- country of birth;
- main language spoken at home;
- long-term health conditions;
- underlying cause of the condition causing the most problems;
- aids used and needed;
- occupation; and,
- industry of employment.

An outline of each of the clerical coding tasks undertaken is provided below.

*Family relationship coding:*
All usual members of households in private dwellings were grouped into family units and classified according to their position within the family.

*Country of birth coding:*
Country of birth was classified according to the *Australian Standard Classification of Countries for Social Statistics* (1269.0). This classification is used for all country of birth data collected by ABS.

*Coding of the main language spoken at home:*
The classification separately identified fifty-seven languages. Languages not listed in the classification coding index were grouped together as 'Not elsewhere classified'.

*Coding of long-term health conditions:*
All reported health conditions that have lasted or are likely to last for six months or more were coded to a list of 160 selected conditions. The condition identified for coding was a current long-term illness, disease, impairment, or disorder representing a medical care problem. This classification was based on the *International Classification of Diseases 9th Revision (ICD9)*, but was modified to enable frequently reported conditions and alternative descriptions of the same condition to be easily coded. A list of the major categories of conditions is presented in *Disability, Ageing and Carers: Data Reference Package* (4432.0)

*Coding of underlying cause of the main condition:*
The ABS compiled a list of underlying causes that included both diseases and other causes such as age, accidents or effects of the environment. This was used to code the reported underlying cause of the main condition.

*Aids used and needed:*
Aids used and needed were coded using a list of aid codes compiled by the ABS. The code list was grouped into six broad areas, based on the primary function of the aid:

- self care;
- support and mobility;
- communication (hearing and conversation, sight and reading);
- medical care aids;
- other aids; and,
- car modifications.

*Coding of Occupation:*
Occupation was coded based on a description of the kind of work performed as reported by respondents and recorded by interviewers. Occupation was coded to the 4 digit (unit group) level of the *Australian Standard Classification of Occupations* (1222.0).

*Industry coding:*
Industry was coded based on information recorded describing the name and address of the respondent's employer/business and the kind of industry, business or service carried out at that address, and with reference to the ABS Register of

Businesses where possible. Industry was classified to the 3 digit (group) level of the *Australian Standard Industrial Classification, 1983 Edition* (1201.0).

Further clerical checks were performed on tabulated output data to ensure that the levels and distributions of data were consistent with that which might be expected.

**Computer Editing**

Following the clerical checks and coding outlined above, information was read via an optical mark recognition reader (OMR reader).

For each component an extensive range of appropriate computer edits were developed and applied to each record on the file to check that:

- logical sequences had been followed in the questionnaires;
- necessary items were present;
- specific values lay within valid ranges; and,
- relationships between items were within limits deemed acceptable for the purposes of this survey.

The edits were designed to detect errors which may have occurred and to identify cases which were sufficiently unusual or close to tolerance levels to warrant examination. Listings of all records involved were produced, which were then compared with the original questionnaires. Amendments were made to records on the computer file as required.

Following editing, information from the questionnaires was stored on the computer output file in the form of data items. In some cases, data items were taken directly from information recorded in individual survey questions; in others, data items were derived from answers to several questions.

## ESTIMATION PROCEDURES

Estimates obtained from the survey were derived using a ratio estimation procedure which ensured that the survey estimates conform to an independently estimated distribution of the total population by age, sex and area.

**Benchmarks**

The age-sex-area (capital city/rest of state) benchmarks used in estimation were based on population estimates, produced by the ABS.

**Weights**

The person level weights are broadly the ratio of the sample numbers in any age/sex/area group to the benchmark population for the corresponding area. Weights for income units, families and households are calculated as the average of the person weights in that unit (see appendix B for further details).

## DATA QUALITY

Although steps were taken to ensure that the results of the 1993 Survey of Disability, Ageing and Carers was as accurate as possible, there are certain factors which affect the reliability of the results and for which no adequate adjustments can be made. One such factor is known as sampling variability. Other factors are collectively referred to as non-sampling errors. These factors, which are discussed below, should be kept in mind in interpreting results of the survey.

### Sampling Variability

Since the estimates are based on information obtained from a sample of the population, they are subject to sampling variability (or sampling error), ie, they may differ from the figures that would have been obtained from an enumeration of the entire population. The size of the sampling error associated with a sample estimate depends on the following factors:

- *Sample design*: There are many different methods which could have been used to obtain a sample from which to collect data on the target groups. The final design attempted to make survey results as accurate as possible within cost and operational constraints;

- *Sample size*: The larger the sample on which the estimate is based, the smaller will be the sampling error;

- *Population variability*: Is the extent to which people differ on the particular characteristic being measured. This is referred to as the 'population variability' for that characteristic. The smaller the population variability of a particular characteristic, the more likely it is that the population will be well represented by the sample, and therefore the smaller the sampling error. Conversely, the more variable the characteristic, the greater the sampling error;

- *Measure of Sampling Variability*: One measure of sampling variability is the standard error. There are about two chances in three that a sample estimate will differ by less than one standard error from the figure that would have been obtained if all dwellings had been included in the survey, and about nineteen chances in twenty that the difference will be less than two standard errors. The relative standard error is the error expressed as a percentage of the estimate to which it relates.

Standard errors of estimates were computed using the split-halves method. A table of standard errors and relative standard errors will be provided in *Disability, Ageing and Carers: Summary of Findings* (4430.0).

Very small estimates may be subject to such high relative standard errors as to detract seriously from their value for most reasonable purposes. Only estimates with relative standard errors less than 25 percent are considered sufficiently reliable for most purposes.

Estimates with relative standard errors between 25 percent and 50 percent are preceded by the symbol *, and those with relative standard errors greater than 50 percent are preceded by **. This is a caution to indicate that they are subject to high relative standard errors.

**Non-sampling Error**

Non-sampling error can occur at any stage of the survey for reasons such as errors in response and reporting and can occur regardless of whether a sample or a complete enumeration of the population is taken. Non-sampling error can be grouped into two main types: systematic and variable.

Systematic error (called bias) makes survey results unrepresentative of the target population by systematically distorting the survey estimates.

Variable error can distort the results on any given occasion but tends to balance out on average.

Systematic and variable non-sampling error can arise from a number of different sources, for example:

- errors related to scope and coverage;
- response errors;
- bias due to non-response; or,
- errors in processing.

Each of these sources of error is discussed in the following paragraphs.

*Errors related to scope and coverage*
In some cases, persons may have been inadvertently included or excluded because of difficulties in applying the scope and coverage rules.

*Response Errors*
Response errors can arise from three main sources:

- questionnaire design and methodology;
- interviewing technique; and,
- interpretation by the respondent.

Individual questions and the overall questionnaire were thoroughly tested before being finalised for use in the survey. This was in order to overcome and minimise problems caused by: misleading or ambiguous questions; inadequate

or inconsistent definitions of terminology; or, by poor overall layout of the questionnaire.

Methods were employed to achieve and maintain uniform interviewing practices and a high level of accuracy in recording answers. These methods included: thorough training; regular supervision; and, checking of interviewers' work.

Non-uniformity of the interviewers themselves is a potential source of error in that the impression made upon respondents by personal characteristics of individual interviewers such as age, sex, appearance and manner, may influence the answers obtained.

Inaccurate reporting by the respondent may occur due to: misunderstanding of questions; inability to recall the required information; deliberate incorrect answering to protect personal integrity; or, lack of knowledge.

*Non-response bias*

Non-response bias may occur when people cannot or will not co-operate, or cannot be contacted.

Non-response can introduce a bias to the results obtained in that non-respondents may have different characteristics in relation to their health than those persons who responded to the survey. The magnitude of the bias depends on the extent of the differences and the level of non-response.

An examination of the demographic characteristics supplied on household forms indicates that any bias resulting from non-response of individuals was insignificant.

*Processing Errors*

Processing errors may occur at any stage between initial collection of the data and final compilation of statistics.

Specifically, in this survey, processing errors may have occurred at the following stages in the processing system:

- *Clerical checking and coding*: errors may have occurred during checking of questionnaires for completeness and during coding of various items by office processors;

- *Editing*: computer editing programs may have failed to detect errors which could reasonably have been corrected;

- *Manipulation of data*: errors may have occurred during the various stages of computer processing involving the manipulation of raw data to produce the final survey data files.

A number of steps were taken to minimise errors at various stages of processing:

- *Coding*: detailed coding instructions were developed, and staff engaged in coding were trained in the various classifications and procedures used; a sample of forms were checked for coding accuracy and to identify any coding problems;

- *Computer editing*: edits were devised to ensure that logical sequences were followed in the questionnaires, that necessary items were present and that specific values lay between certain ranges,

- *Data file checks*: at various stages during processing (such as after computer editing and subsequent amendments, weighting of the file and after derivation of new data items) tabulations were obtained from the data file showing the distribution of persons for different characteristics. These were used as checks on the contents of the data file, to identify unusual values which may have significantly affected estimates and illogical relationships not previously picked up by the edits; and,

- *Output editing*: tabulations were checked to locate unusual values and amendments made to the data, if necessary.

## RESPONSE RATES

### Household Component

In total 17,820 private households and 1,601 special dwelling units were selected in the sample for the 1993 Survey of Disability, Ageing and Carers. As shown in Table 1 below, this reduced to an effective sample of 15,957 households and 378 special dwelling units after sample loss. The sample loss is of a similar level to that for other ABS surveys. The large sample loss for special dwellings was expected and is due to coverage rules.

From the effective sample of households, there were 42,215 persons in scope and coverage for the survey. Fully complete questionnaires were obtained from 97.6 percent of these persons. As Table 2 shows, non-response of all types was relatively minor and the overall response rate is higher than for most ABS supplementary surveys. The item non-response on the main questionnaire referred to the income questions and is similar to other surveys for those questions.

Of the 1,393 carer's questionnaires issued, approximately 10 per cent were returned with one or more questions incomplete. This was due to the differing methodology for the carers questionnaire (ie, a self completion form).

TABLE 1: HOUSEHOLD TYPE BY SAMPLE STATUS AND AREA

| | PRIVATE DWELLING HOUSEHOLDS | | | |
|---|---|---|---|---|
| | *Metropolitan* | *Ex-Metropolitan* | *Total* | *Per cent* |
| Total sample | 11,326 | 6,494 | 17,820 | 100.0 |
| Sample loss(a) | | | | |
| Scope/coverage | 125 | 141 | 266 | 1.5 |
| Vacant dwellings | 514 | 719 | 1,233 | 6.9 |
| Other | 184 | 180 | 364 | 2.0 |
| Total sample loss | 823 | 1,040 | 1,863 | 10.5 |
| Effective sample | 10,503 | 5,454 | 15,957 | 89.5 |
| | SPECIAL DWELLING UNITS | | | |
| | *Metropolitan* | *Ex-Metropolitan* | *Total* | *Per cent* |
| Total sample | 565 | 1,036 | 1,601 | 100.0 |
| Sample loss(a) | | | | |
| Scope/coverage | 175 | 282 | 457 | 28.5 |
| Vacant dwellings | 200 | 504 | 704 | 44.0 |
| Other | 6 | 56 | 62 | 3.9 |
| Total sample loss | 381 | 842 | 1,223 | 76.4 |
| Effective sample | 184 | 194 | 378 | 23.6 |

(a) Those households where no questionnaires at all were obtained for reasons other than non-response eg all persons in the household were excluded on scope/coverage grounds; dwelling was vacant, demolished or converted to non-dwelling use.

TABLE 2: RESPONSE RATES, ALL PERSONAL SCHEDULES (HOUSEHOLD AND SPECIAL DWELLING UNITS)

| *Final Response* | *Number* | *Per cent* |
|---|---|---|
| Fully complete Questionnaires | 41,193 | 97.6 |
| Full Non Response | | |
| Refusal | 61 | 0.1 |
| Non-contact | 88 | 0.2 |
| Language Problems | 3 | 0.0 |
| Death/Illness | 3 | 0.0 |
| Item Non Response (main Questionnaire) | | |
| Refusal | 447 | 1.1 |
| Don't Know | 233 | 0.6 |
| Carer Not obtained | | |
| Refusal | 5 | 0.0 |
| Non-contact | 25 | 0.1 |
| Language Problems | 5 | 0.0 |
| Other Reasons | 9 | 0.0 |
| Carer Incomplete | 133 | 0.3 |
| Combination | 10 | 0.0 |
| Total | 42,215 | 100.0 |

**Establishment Component**

The original sample of establishments was 709. As explained earlier, a first phase mail contact was attempted to ascertain the current number of occupants of the sample establishments, as well as to check that the establishment were still in existence and were of the relevant type for the survey. It was established that 43 establishments either no longer existed, had been wrongly classified or for other reasons could be excluded from the sample.

For the remaining 666 establishments, instructions were given for the selection of a maximum of 7234 persons. Of these, 73 establishments with a planned total sample of 809 persons were excluded because of information about their closure, lack of contact, refusals or other reasons.

Forms were thus received for 593 establishments who had a planned total sample of 6,425 persons. Of this sample 4,816 were included on coverage rules. This was expected and the largest sample loss was in the general hospitals group where most occupants are short term and have usual residences elsewhere. A summary is given below in Table 3.

**TABLE 3: SAMPLE STATUS AND RESPONSE RATES**

| ESTABLISHMENTS | | |
|---|---|---|
| | *Number* | *Per cent* |
| Original Sample | 709 | 100.0 |
| 1st Stage Loss | 43 | 6.1 |
| 2nd Stage Loss | 73 | 10.3 |
| Final Sample | 593 | 83.6 |
| **PERSONS** | | |
| | *Number* | *Per cent* |
| In final sample | 6,425 | 100.0 |
| Coverage exclusions | 1,609 | 25.0 |
| Effective Sample | 4,816 | 75.0 |

## DATA CONTENT

## OVERVIEW

Descriptions of topics included in the 1993 Survey of Disability, Ageing and Carers are contained in this section. Details are provided on the definitions, data items and populations for each topic. Topics have been grouped under seven main headings listed below.

- Demographics and Socio-economic Characteristics:
  - Basic demographics
  - Education
  - Employment
  - Income
  - Housing
- Community activities
- Disability Identification
- Handicap Identification
- Aids:
  - Aids used
  - Aids needed
- Assistance:
  - Need for assistance
  - Receipt of assistance
  - Unmet need for assistance
- Carers

The survey design enables data for each topic to be cross-classified with other topics, for example, to examine primary disabling condition by severity of handicap.

## DEMOGRAPHIC AND SOCIO-ECONOMIC CHARACTERISTICS

### Basic Demographics

| *Main data items* | *Population* |
|---|---|
| Age<br>• in years at last birthday | All persons |
| Sex | All persons |
| Marital status | All persons |
| Ethnicity indicators<br>• Country of birth<br>- ASCCSS classification<br>• Country of birth of parents<br>- ASCCSS classification<br>• Language spoken at home<br>• Aboriginal/Torres Strait Islander origin | All persons |

### Education

| *Main data items* | *Population* |
|---|---|
| School attendance | Persons with a disability aged 5 years or more and persons without a disability aged 15 years or more |
| Schooling limitation<br>• unable to attend school<br>• attended a special school<br>• attended special classes in an ordinary school<br>• needed time off from school<br>• had difficulty at school because of a disabling condition. | Persons with a disability aged 5 years or more |
| Type of schooling attending/ attended | Persons with a disability aged 5 years or more and persons with a disability where condition became apparent before age left school |
| Difficulty experienced because of condition | Persons with a disability currently undertaking post-school study or who have previously obtained post-school qualifications and persons with a disability attending school |
| Post-school attendance<br>• highest qualifications achieved<br>• current study<br>• type of institution | Persons aged 15 years or more, not attending full-time school, currently undertaking relevant study, or who have previously obtained post-school qualifications |

**Employment**

Employment status for the purpose of this survey is the same as that defined in the Labour Force Survey. The labour force category to which a person is defined depends on their actual activity (ie, working, looking for work, etc).

| *Main data items* | *Population* |
|---|---|
| Labour force status<br>• Employed<br>• Unemployed<br>• Not in labour force | Persons aged 15 years or more not attending school |
| Industry of employment<br>• ASIC | Employed persons |
| Occupation of employment<br>• ASCO | Employed persons |
| Industry sector in which employed | Employed persons |
| Employment limitations<br>• Permanently unable to work<br>• Restricted in type of job because of condition(s)<br>• Restricted in number of hours can work because of condition(s) | Persons with a disability aged 15 years or more, not attending full-time education |

**Income**

| *Main data items* | *Population* |
|---|---|
| Source of personal income<br>• wages<br>• salary<br>• own business or partnership<br>• government pension or cash benefit<br>• investments<br>• other | All persons aged 15 years or more |
| Amount of current income from each source | All persons aged 15 years or more |
| Pensions or benefits received | Persons aged 15 years or more who report income from any Government Pension or Cash Benefit |

**Housing**

This section examines the existing housing arrangements and the housing needs of persons with a disability and of persons aged 60 years or more. Some data was also collected for persons not in these populations for comparison purposes.

| *Main data items* | *Population* |
|---|---|
| Description of dwelling | First person interviewed in the dwelling |
| Nature of occupancy | All persons |
| Whether person/family has had to move house because of condition or age | Persons with a disability aged 5 years or more and persons aged 60 years or more |

## COMMUNITY ACTIVITIES

This section is aimed at assessing whether respondents participate in activities outside the home and any restrictions they may face in doing so. It was intended to ascertain:

- whether respondents get out of the house as often as they would like;
- whether they have attended a variety of social functions: and,
- if they have access to, and are able to use, telecommunications.

| *Main data items* | *Population* |
|---|---|
| Person leaves their home as often as would like | Persons with a disability aged 5 years or more and persons aged 60 years or more |
| Main reason doesn't go out as often as would like | Persons with a disability aged 5 years or more and persons aged 60 years or more, who do not leave home as often as they would like |
| Main activities person has engaged in | Persons with a disability aged 5 years or more and persons aged 60 years or more |
| Who the person usually attends/ goes to activities with | Persons with a disability aged 5 years or more and persons aged 60 years or more, who have attended one or more activities |
| Whether person can operate telephone equipment | Persons with a disability aged 5 years or more and persons aged 60 years or more |
| Whether person has access to a telephone<br>• in own home<br>• outside own home, in close proximity | Persons with a disability aged 5 years or more and persons aged 60 years or more |

## DISABILITY IDENTIFICATION

The ABS definition of disability conforms as closely as possible to the World Health Organisation's (WHOs) definition as stated in the *International Classification of Impairment, Disabilities and Handicaps, 1980.*

For the purposes of this survey, disability was defined as the presence of one or more of the conditions, impairments or restrictions stated below which had lasted, or was likely to last, for a period of six months or more:

- loss of sight (even when wearing glasses or contact lenses);
- loss of hearing;
- speech difficulties in native languages;
- blackouts, fits, or loss of consciousness;
- slowness at learning or understanding;
- incomplete use of arms or fingers;
- difficulty gripping or holding things;
- incomplete use of feet or legs;
- treatment for nerves or an emotional condition;
- a restriction in physical activities or in doing physical work;
- a disfigurement or deformity.
- need for help or supervision due to a mental illness;
- long term effects of head injury, stroke or any other brain damage;
- treatment or medication for a long-term condition or ailment and still restricted;
- any other long-term condition resulting in a restriction;

| *Main data items* | *Population* |
|---|---|
| Presence of one of the above disabilities | All persons |
| Disabling condition<br>• condensed ICD9 3 digit code (See *Data Reference Package.*) | Persons with a disability aged 5 years or more |
| Main disabling condition | Persons with a disability aged 5 years or more |
| Cause of main condition<br>• eg, work, stress, disease, etc | Persons with a disability aged 5 years or more |
| Age when condition first became apparent | Persons with a disability aged 5 years or more other than cause 'present at birth' |
| Whether condition was likely to improve over the next two years | Persons with a disability aged 5 years or more |
| Disability status<br>• Handicap<br>• Disability without handicap<br>• No disability | All persons |

- a mental illness requiring help or supervision;
- treatment or medication for a long-term condition or ailment;
- any other long-term condition.

**Disability**

The International Classification of Impairments, Disabilities and Handicaps definition for disability is as follows:

> *In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.*

## HANDICAP IDENTIFICATION

For the purposes of this survey, handicap was identified if a person had a limitation or restriction in performing certain specific tasks associated with daily living, due to their disability. The limitation must be in relation to one or more of the following areas:

- self-care;
- mobility;
- verbal communication;
- employment; or,
- schooling.

Four levels of severity were determined for each of the three areas of handicap: self-care, mobility and verbal communication. These levels were based on the person's ability to perform tasks relevant to these three areas and on the amount of help required. For each area of handicap, the levels of severity are as follows:

- *profound handicap:* In households, profound handicap was defined as 'personal help or supervision always required'. In establishments, profound handicap is defined as 'occupant cannot perform tasks without help or supervision'.

- *severe handicap:* In households, severe handicap was defined as 'personal help or supervision sometimes required'. In establishments, severe handicap was only determined for verbal communication.

- *moderate handicap:* For both components, moderate handicap was defined as 'no personal help or supervision required, but the person has difficulty in performing one or more of the tasks'.

- *mild handicap:* For both components, mild handicap was defined as 'no personal help or supervision required and no difficulty in performing any of the specified tasks, but the person uses an aid'. In addition, for the household component, difficulty walking 200 metres, walking up and down stairs, or picking up an object from the floor, were included as a measure of mild handicap.

Persons aged less than 5 years with one or more disabilities were all regarded as being handicapped, but were not classified by area of handicap or severity or handicap. This was due to difficulties inherent in determining whether the needs of the children aged less than 5 years were a function of their age or their

Any definition of disability for this survey has to be stated in terms of the above. Certain value judgements are implicit, for example, a person with loss of sight corrected by glasses is not included as having a disability, whereas a person with loss of hearing corrected by a hearing aid is included as having a disability.

**Disability without handicap** Persons with a disability but not identified as having a handicap stated that they had one of the broad limitations, restrictions or impairments as given for disability, but then stated that they were not restricted in any of the specific tasks given to identify persons with a handicap.

**Employed person** Persons aged 15 years or more, who, in his or her main job during the enumeration period:

disability. Additionally, severity of handicap was not determined for persons with only an employment or schooling limitation.

| *Main data items* | *Population* |
|---|---|
| Self-care<br>• Showering/bathing<br>• Dressing<br>• Eating/feeding<br>• Toiletting<br>• Bladder/bowel control | Persons with a disability aged 5 years or more |
| Verbal communication<br>• Understanding strangers<br>• Understanding family/friends<br>• Being understood by strangers<br>• Being understood by family/ friends | Persons with a disability aged 5 years or more |
| Mobility<br>*Profound/Severe/Moderate*<br>• Moving about away from home<br>• Moving about home<br>• Transferring to and from a bed or chair<br>*Mild*<br>• Walking 200 metres<br>• Walking up and down stairs<br>• Ability to use public transport | Persons with a disability aged 5 years or more |
| Schooling and employment limitation are identified separately | |
| Handicap status<br>• Handicapped<br>• Disabled not handicapped<br>• Not disabled | All persons with a disability |
| Severity of Handicap<br>• Profound<br>• Severe<br>• Moderate<br>• Mild<br>• Not determined | All persons with a handicap |

- family or friends living outside the house, or neighbours, who receive money on a regular basis for providing care;

- other persons (excluding family, friends or neighbours as described in informal help) who provide care on a regular basis and who were not associated with any organisation.

**Handicap**

A handicap is identified as a limitation to perform certain tasks associated with daily living. The limitation must be due to a disability and in relation to one or more of the areas listed below.

- Self-care - difficulties in showering, bathing, dressing, eating, toiletting,

## AIDS

An aid is a device or appliance used by a person with one or more disabilities or a person aged 60 years or more to help with performing tasks. It is not help provided by a person or an organisation. Additionally, medicine, tablets, drugs and the instruments for administering them (eg, syringes, etc) are specifically excluded.

### Aids Used

Areas in which aids are used are divided into four major groups: self-care, mobility, communication and house modifications.

| *Main data items* | *Population* |
|---|---|
| Whether aids are used | Persons with a disability aged 5 years or more |
| Tasks for which aids used<br>• self care<br>- showering/bathing<br>- dressing<br>- eating/preparing food<br>• mobility<br>- moving about home<br>- moving about away from home<br>• communication<br>• house modifications<br>• other | Persons with a disability aged 5 years or more |
| Receipt of financial assistance to obtain aids currently used | Persons using aids |

### Aids Needed

Information is sought in relation to any additional aids which are needed.

| *Main data items* | *Population* |
|---|---|
| Any other aids needed | Persons with a disability aged 5 years or more |
| Main reason aid not obtained | Persons with a disability aged 5 years or more |
| Main aid needed | Persons with a disability aged 5 years or more, needing one or more aids |

| | |
|---|---|
| | need help. The source of help may be individuals, organisations or other bodies, but does not include help from the use of aids or appliances. |
| **Home help activity** | Home help activity covers tasks associated with household chores. |
| **Home maintenance activity** | Home maintenance activity covers tasks such as changing light bulbs and minor repairs to the home. |
| **Household** | A household consists of a person or people who consider themselves to form a separate household or who have common eating arrangements. Boarders who receive accommodation and meals with other people in the household are treated as part of that household. Lodgers who are provided with accommodation only are treated as separate households. |

## ASSISTANCE

### Need for Assistance

A person with a disability and/or a person aged 60 years or more is determined to have a need for help with an activity if that persons needs/received help or supervision to perform one or more specified tasks.

| *Main data items* | *Population* |
|---|---|
| Tasks for which assistance is needed<br>• self care<br>• verbal communication<br>• mobility<br>• health care | Persons with a disability aged 5 years or more |
| • home help<br>• home maintenance/gardening<br>• meal preparation<br>• transport | Persons with a disability aged 5 years or more and persons aged 60 years or more |
| Level of assistance needed<br>• always needs help<br>• sometimes needs help<br>• never needs help | Persons with a disability aged 5 years or more |

### Receipt of Assistance

Receipt of assistance relates only to persons with a disability and/or persons aged 60 years or more, who need help. The source of help may be individual people, organisations or other bodies, but does not include help from the use of aids or appliances. The assistance received must be due to the particular identified need(s) of persons with a disability or older persons.

| *Main data items* | *Population* |
|---|---|
| Tasks for which assistance is received<br>• self care<br>• verbal communication<br>• mobility<br>• health care | Persons with a disability aged 5 years or more |
| • home help<br>• home maintenance/gardening<br>• meal preparation<br>• transport | Persons with a disability aged 5 years or more and persons aged 60 years or more |
| Type of assistance received<br>• none<br>• informal<br>• formal<br>• informal and formal | Persons with a disability aged 5 years or more and persons aged 60 years or more |

| | |
|---|---|
| **Main disabling condition** | That condition identified by the person with multiple conditions as the one causing the most problems. Where only one condition is recorded, this is coded as the main disabling condition. |
| **Mobility activity** | Mobility activity relates to going places away from the home or establishment; moving about the house or establishment; and transferring to and from a bed or a chair. |
| **Mobility handicap**<br>- *Profound/Severe/Moderate* | A profound/severe/moderate mobility handicap relates to a person who has difficulties in:<br>• going places away from home/establishment;<br>• moving about the house/establishment; or, |

**Unmet Need for Assistance**

Unmet need for assistance exists where a need for help has been identified for one or more activities, but no help has been received or more help is needed with at least one activity in which a need exists.

| *Main data items* | *Population* |
|---|---|
| Tasks for which an unmet need was reported<br>• verbal communication<br>• mobility<br>• health care | Persons with a disability aged 5 years or more |
| • home help<br>• home maintenance/gardening<br>• meal preparation<br>• transport | Persons with a disability aged 5 years or more and persons aged 60 years or more |
| Whether more assistance is needed | Persons with a disability aged 5 years or more and persons aged 60 years or more |
| Main reason assistance is not received<br>• has not asked<br>• too busy<br>• need more help than family can provide<br>• no-one to help | Persons with a disability aged 5 years or more and persons aged 60 years or more |

**Provider of help**

A provider of help with an activity is a usual source of help nominated by persons with one or more disabilities and/or persons aged 60 years or more. Up to three sources of informal help and two sources of formal help could be nominated for each activity.

**Schooling limitation**

A schooling limitation relates to a person who:

- is unable to attend school;
- attended a special school;
- attended special classes in an ordinary school;
- needed time off from school; or,
- had difficulty at school because of a disabling condition.

This information was collected for persons in households aged 5 to 14 years and

summary is given below in Table 3.

## CARERS

A carer is a person, providing help on an ongoing basis, (ie, had provided help, or was likely to have been providing help, for 6 months or more), in one or more of a number of activities. Carers can be resident with the person cared for (UR carers) or not resident with the person cared for (Non-UR). If a carer is further identified as providing the most help for personal care, ie, self care, verbal communication or mobility and is aged 15 years or more, then they are classified as a principal carer.

| *Main data items* | *Population* |
|---|---|
| Relationship of carer to recipient | All main carers |
| Help usually provided for:<br>• self-care<br>• verbal communication<br>• mobility<br>• health care<br>• home help<br>• home maintenance/gardening<br>• meal preparation<br>• financial management/writing letters<br>• transport | All main carers of persons with a condition |
| Number of years carer has been in this caring role | All UR principal carers<br>All non-UR main carers |
| Whether carer has received any training,information or advice to help with the caring role | All UR principal carers<br>All non-UR main carers |
| Carers need for help to care for recipient | All principal carers |
| Respite care<br>• use of respite care<br>• types of respite care used | All principal carers |
| Effects of the caring role on:<br>• going out<br>• housework<br>• sleep<br>• financial situation<br>• friendships/relationships<br>• physical and emotional well-being | All principal carers |

# APPENDIXES

# APPENDIX A

**Sample Selection**

The Survey of Disability, Ageing and Carers covered both rural and urban areas in all States and Territories. Selection was made of private dwellings, special dwellings and establishments. For the purposes of this survey:

- private dwellings are defined as houses, flats, home units, garages, tents and other structures used as private places of residence at the time of the survey;
- special dwellings are defined as hotels, motels, boarding houses, educational and religious institutions, construction camps, caravan parks, etc; and,
- establishments are defined as hospitals, nursing homes, hostels, retirement villages and other 'homes'.

To enable a representative sample to be obtained for each component of the survey a multi-stage area sample was used, with the selection process varied for each type of dwelling.

*Selection of Private Dwellings*

Each State and Territory contains a number of Census Collector's Districts (CDs). Before any selection is made all CDs are allocated to mutually exclusive groups called strata. Within each stratum an independent sample is selected.

All persons within the selected dwellings, subject to scope and coverage rules, were included in the survey. The selection method ensured that dwellings had an equal chance of selection in every strata. In the ACT a proportionately larger sample of dwellings was selected.

These CDs were formed on a geographic basis containing around 250 dwellings. Each CD is likely to have similar socio-economic characteristics within it.

In metropolitan, major urban areas or high density population areas the sample was selected in three stages:

- a sample of CDs was selected from each stratum with probability proportional to the number of dwellings in each CD;
- each selected CD was divided into groups of dwellings or

blocks of a similar size, and one or two blocks were selected from each CD with probability proportional to the number of dwellings in the block;

- all the dwellings in a selected block were listed, and a systematic random sample of dwellings was selected. Dwellings selected were not contiguous with eight to 16 dwellings between each one selected.

In low density population areas each stratum was divided into units and one or two units selected with the probability of selection of units being proportional to the number of dwellings in each unit. Selection of dwellings was then conducted as for high density population areas. Effectively a sample was not selected from each Statistical Local Area (SLA), these SLAs being made up of CDs, but those selected were representative of neighbouring SLAs with similar characteristics.

*Selection of special dwellings*

The sample of special dwellings was selected separately from the sample of private dwellings to ensure they were adequately represented in the sample.

The sample of special dwellings was selected in two stages:

- special dwellings were initially selected with a probability proportional to the average occupancy of the special dwelling;

- an appropriate list of units (rooms, beds, etc) was prepared for each selected special dwelling and a systematic random sample of units selected. This selection method ensured that each unit in the special dwelling had an equal chance of selection.

*Selection of Establishments*

A sample frame for the selection of establishments was constructed by Statistical Support Section. The frame was constructed using establishments classified by type of establishment by Population Surveys Operations. Each type of establishment was stratified according to metropolitan/non metropolitan and size. (Size being determined by the occupancy potential of the establishment.)

The establishment sample was selected in two stages:

- selections were made according to type, and the selection ensured there was a representation of metropolitan and non metropolitan establishments by size;

- a list of occupants was prepared for each selected establishment and a systematic random sample of occupants selected. The listing ensured that each occupant in the establishment had an equal chance of selection.

## APPENDIX B

**Estimation Formulae**

State and national estimates were formed by producing estimates at State by part-of-State level and these were then summed to produce the estimates.

Weights used for this type of benchmark were derived from population benchmarks (N) showing number of persons in each State by part-of-State, cross-classified by age and sex. The weight ($w'$) of age (a), sex (s) and State by part-of-State (z) for a responding individual in the establishment component was determined using the formula:

$$w'_{zas} = \frac{N_{zas}}{[(c/f)n_{zas} + m_{zas}]}$$

where:

$N_{zas}$ = the number of persons of State by part-of-State (z), age group (a) and sex (s).

$n_{zas}$ = the number of respondents in State by part-of-State (z), age group (a) and sex (s) that are in households and special dwellings.

$m_{zas}$ = the number of respondents in State by part-of-State (z), age group (a) and sex (s) who are in establishments.

c = the cluster fraction for respondents in establishments.

f = the cluster fraction for respondents in households and special dwellings.

The weight (w) of age (a), sex (s) and State by part-of-State (z) for a responding individual in the household component was determined using the formula:

$$w_{zas} = \frac{N_{zas}}{[n_{zas} + (f/c)m_{zas}]}$$

The total State by part-of-State estimate for the variable x could then be obtained by:

$$X_z = \Sigma_a\Sigma_s(w'_{zas}\Sigma_i x'_{zasi} + w_{zas}\Sigma_i x_{zasi})$$

where:

$x'_{zasi}$ = the value of x for the $i^{th}$ individual respondent in State by part-of-State (z), age (a) and sex (s) for the establishment component.

$x_{zasi}$ = the value of x for the $i^{th}$ individual respondent in State by part-of-State (z), age (a) and sex (s) for the household component.

State and national estimates can then be obtained by adding the appropriate State by part-of-State estimates.

## GLOSSARY

**ARA** — Any responsible adult

**PD** — Private dwelling

**SD** — Special dwelling

**UR** — Usual resident

**Activity** — An activity comprises one or more tasks.

**Aid** — An aid is a device or appliance used by a person with one or more disabilities or a person aged 60 years or more to help with performing tasks. It is not help provided by a person or an organisation.

**Carers - all (UR)** — Carers are persons of any age, providing informal help (ie, help provided by family, friends or neighbours) for any of the following activities:

- self-care (eg, showering/bathing, dressing, eating feeding, toiletting, bladder/bowel control);
- mobility (eg, going away from home, moving about the house, transferring to and from bed or chair);
- verbal communication (eg, understanding someone known or unknown);
- health care (eg, taking medication/dressing wounds, footcare);
- home help (eg, washing, vacuuming, cleaning windows);
- home maintenance (eg, changing light globes, weeding the garden);
- meal preparation;
- financial management/writing letters;
- transport (eg, public transport, shopping, driving).

A recipient may have more than one carer and may identify up to three carers for each activity.

**Carer - Main (UR)** — A main carer of a UR is a person of any age who is identified by the care recipient as the person providing the most informal care for each of the above specified activities.

A recipient may have more than one main carer but can only have one main carer for each activity.

**Carer - Main (non-UR)** — A main carer of a non-UR is a person aged 15 years or more (identified by ARA as providing the most help) who later confirms that they provide the most informal help (unpaid) to a non-UR recipient for any of the following activities:

- mobility (eg, organising transport, driving, moving around the home, garden or away from home);
- verbal communication;
- supervising money matters;
- personal care (eg, washing, bathing, dressing, toiletting);
- teaching everyday living skills (eg, handling money, reading destination signs);
- meals (eg, preparing, cooking, feeding).

This list of activities differs from the list of activities used to identify carers of URs.

Only one main carer is identified for a non-UR.

**Carer - Principal (UR)**

A principal carer of a UR is a person aged 15 years or more providing the most informal care for the activities of **self-care, mobility or verbal communication**.

Principal carers are chosen (by the care recipient) from the main carers nominated for the activities of self-care, mobility or verbal communication. A recipient can identify only one as the principal carer.

**Carer - Principal (non-UR)**

To be identified as a principle carer of a non-UR, a main carer must be aged 15 years or more and be providing the most informal help for the activities of **self-care, mobility or verbal communication**.

**Coverage**

Coverage rules are designed to ensure that, as far as possible, persons remaining within the scope of the survey have one and only one chance of being selected.

**Disabling Condition**

A disabling condition is any condition, which had lasted or was likely to last for 6 months or more, and resulted in one or more of the limitations, restrictions or impairments listed below:

- loss of sight (even when wearing glasses or contact lenses);
- loss of hearing;
- speech difficulties in native languages;
- blackouts, fits, or loss of consciousness;
- slowness at learning or understanding;
- incomplete use of arms or fingers;
- difficulty gripping or holding small objects;
- incomplete use of feet or legs;
- treatment for nerves or an emotional condition;
- restriction in physical activities or in doing physical work;
- disfigurement or deformity;
- head injury, stroke or any other brain damage;

- a mental illness requiring help or supervision;
- treatment or medication for a long-term condition or ailment;
- any other long-term condition.

**Disability**

The International Classification of Impairments, Disabilities and Handicaps definition for disability is as follows:

> *In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.*

It is difficult to put such a broad concept into operation. The approach adopted for this survey was to ask a series of screening questions on limitations, restrictions and impairments about each individual. These questions had been developed in the two previous surveys on the topic (1981, 1988), and in testing for this survey. Three additional screening questions were included for this survey because of concern that specific groups of people with disabilities were missed by the earlier surveys. It has been established that persons identified by one or more of these questions were within the concept of disability as commonly accepted by data users.

For the purposes of this survey:

> ***disability** was defined as the presence of one or more of the below limitations, restrictions or impairments which had lasted, or was likely to last, for a period of 6 months or more.*

- loss of sight (even when wearing glasses or contact lenses);
- loss of hearing;
- speech difficulties in native languages;
- blackouts, fits, or loss of consciousness;
- slowness at learning or understanding;
- incomplete use of arms or fingers;
- difficulty gripping or holding small objects;
- incomplete use of feet or legs;
- treatment for nerves or an emotional condition;
- restriction in physical activities or in doing physical work;
- disfigurement or deformity;
- **long-term effects of** head injury, stroke or any other brain damage;
- a mental illness requiring help or supervision;
- treatment or medication for a long-term condition or ailment **and still restricted; and,**
- any other long-term condition **resulting in a restriction.**

Any definition of disability for this survey has to be stated in terms of the above. Certain value judgements are implicit, for example, a person with loss of sight corrected by glasses is not included as having a disability, whereas a person with loss of hearing corrected by a hearing aid is included as having a disability.

**Disability without handicap**

Persons with a disability but not identified as having a handicap stated that they had one of the broad limitations, restrictions or impairments as given for disability, but then stated that they were not restricted in any of the specific tasks given to identify persons with a handicap.

**Employed person**

Persons aged 15 years or more, who, in his or her main job during the enumeration period:

- worked for one hour or more for pay, profit, commission or payment in kind in a job, business, or on a farm (including employees, employers and self-employed persons);
- worked for one hour or more without pay in a family business or on a farm, (excluding persons undertaking other unpaid voluntary work); or,
- were employers, employees or self-employed persons or unpaid family helpers who had a job, business or farm, but were not at work.

**Employment limitation**

An employment limitation relates to a person who has any of the following limitations because of their conditions:

- is permanently unable to work;
- is restricted in the type of work can/could do;
- often needed time off work;
- is restricted in the number of hours can/could work;
- would require an employer to make special arrangements; or,
- is limited in prospects of obtaining/keeping/changing jobs.

This information was collected for persons in households aged 15 years or more not attending school. Retired persons were excluded.

**Establishments**

Establishments are defined for this survey as hospitals, nursing homes, hostels, retirement villages and other 'homes'.

**Formal help**

Formal help is help provided to persons with one or more disabilities or persons aged 60 years or more by:

- organisations or individuals representing such organisations (whether profit making or non-profit making, government or private);

- family or friends living outside the house, or neighbours, who receive money on a regular basis for providing care;

- other persons (excluding family, friends or neighbours as described in informal help) who provide care on a regular basis and who were not associated with any organisation.

**Handicap**

A handicap is identified as a limitation to perform certain tasks associated with daily living. The limitation must be due to a disability and in relation to one or more of the areas listed below.

- Self-care - difficulties in showering, bathing, dressing, eating, toiletting, bladder or bowel control;

- Mobility (profound/severe/moderate) - difficulties going places away from the home/establishment, moving about the house/establishment, transferring to and from a bed or chair.
  Mobility (mild) - limitation in walking 200 metres, walking up or down stairs or using public transport.

- Verbal communication - difficulties understanding or being understood by strangers/family/friends/staff in the person's native language;

- Schooling - limited in the ability to attend school or needing to attend a special school or special classes;

- Employment - limited in the ability to work, the type of work performed and other work problems such as the amount of time off required and special arrangements which need to be made.

Persons aged less than 5 years with one or more disabilities were all regarded as having a handicap, but were not classified by area of handicap. This was due to difficulties inherent in determining whether the needs of children aged less than 5 years were a function of their age or their disability.

**Health care activity**

Health care activity relates to footcare, taking medication and dressing wounds.

**Help needed**

A person with one or more disabilities is determined to have a need for help with an activity, if that person required help or supervision to do one or more specified tasks or, in some cases, would find the tasks(s) difficult to do alone. This person is considered to need help whether or not that help is actually received.

**Help received**

Help received with an activity relates only to persons with one or more disabilities and/or persons aged 60 years or more who have identified that they

need help. The source of help may be individuals, organisations or other bodies, but does not include help from the use of aids or appliances.

**Home help activity** — Home help activity covers tasks associated with household chores.

**Home maintenance activity** — Home maintenance activity covers tasks such as changing light bulbs and minor repairs to the home.

**Household** — A household consists of a person or people who consider themselves to form a separate household or who have common eating arrangements. Boarders who receive accommodation and meals with other people in the household are treated as part of that household. Lodgers who are provided with accommodation only are treated as separate households.

**Impairment** — Impairment is defined by the World Health Organisation as follows:

> *In the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.*

**Income unit** — Income unit relates to people in households only, and consists of:

- married couple income units - husband, wife (or de facto couple) and dependent children (if any);
- one parent income units - a parent and at least one dependent child; and,
- one person income units - all persons not included above.

**Informal help** — Informal help is help provided to persons with one or more disabilities and/or persons aged 60 years or more in households, by family, friends or neighbours. Generally, it is unpaid. All help provided by family or friends living in the same household as the person with a disability is regarded as informal, whether or not the provider is paid (see *formal help*).

**Living arrangement** — Living arrangement relates to the number of persons in a household, whether the person lives alone, with other family members or with other non-related persons. Living arrangements were not determined for persons in special dwellings or establishments.

**Main carer** — See *Carer - Main (UR)*
See *Carer - Main (non-UR)*

**Main disabling condition**

That condition identified by the person with multiple conditions as the one causing the most problems. Where only one condition is recorded, this is coded as the main disabling condition.

**Mobility activity**

Mobility activity relates to going places away from the home or establishment; moving about the house or establishment; and transferring to and from a bed or a chair.

**Mobility handicap**

*- Profound/Severe/Moderate*

A profound/severe/moderate mobility handicap relates to a person who has difficulties in:

- going places away from home/establishment;
- moving about the house/establishment; or,
- transferring to and from bed or chair.

*- Mild*

A mild mobility handicap relates to a person who has difficulties in:

- using public transport;
- walking 200 metres; or,
- walking up and down stairs.

**Occupant**

Occupant refers to all persons who usually reside in establishments. This includes persons in wards, hostels and self-care units which were part of the establishment, excluding staff.

**Older person**

Older person refers to persons aged 60 years or more.

**Participation rate**

The participation rate for any group is the number of persons in the labour force in that group (ie, employed plus unemployed) expressed as a percentage of the population aged 15 years and over in the same group.

**Personal affairs activity**

Personal affairs activity includes financial management and writing letters. Financial management covers day-to-day activities such as keeping track of expenses and paying bills. Writing letters includes drafting and writing correspondence.

**Personal care activities**

Personal care is the term used to describe the activities of self-care, verbal communication and mobility as an overall undertaking.

**Principal carer**

See *Carer - Principal (UR)*
See *Carer - Principal (non-UR)*

**Private dwelling**

Private dwellings are defined as houses, flats, home units, garages, tents and other structures used as private places of residence at the time of the survey.

**Provider of help**

A provider of help with an activity is a usual source of help nominated by persons with one or more disabilities and/or persons aged 60 years or more. Up to three sources of informal help and two sources of formal help could be nominated for each activity.

**Schooling limitation**

A schooling limitation relates to a person who:

- is unable to attend school;
- attended a special school;
- attended special classes in an ordinary school;
- needed time off from school; or,
- had difficulty at school because of a disabling condition.

This information was collected for persons in households aged 5 to 14 years and those aged 15 years or more still attending school.

**Scope**

The scope of any survey states the population to be covered by the survey, usually by giving the geographic areas or population groups to be excluded from the total resident population.

**Self-care activity**

Self-care activity relates to the essential tasks of showering and bathing; dressing; eating and feeding; toiletting; and bladder and bowel control.

**Self-care handicap**

A self-care handicap relates to difficulties in:

- showering and bathing;
- dressing;
- eating;
- toiletting; or,
- bladder or bowel control.

**Severity of handicap**

Four levels of severity (profound, severe, moderate and mild) were determined for each of the three areas of handicap: self-care, mobility and verbal communication. These levels were based on the person's ability to perform tasks relevant to these three areas and on the amount and type of help required. For each area of handicap, the levels of severity are as follows:

- profound handicap - personal help or supervision always required;
- severe handicap - personal help or supervision sometimes required ;
- moderate handicap - no personal help or supervision required, but the person has difficulty in performing one or more of the tasks;
- mild handicap - no personal help or supervision required and no difficulty in performing any of the tasks, but the person uses an aid, or has a mild mobility handicap or cannot easily pick up an object from the floor.

The highest level of severity in any one of the areas of self-care, mobility and verbal communication determines the severity of total handicap.

Severity of handicap in each area and in total was not determined for children aged less than 5 years due to difficulties inherent in determining whether the needs of the children aged less than 5 years were a function of their age or their disability. Additionally, severity was not determined for people with only an employment or schooling limitation.

**Special dwellings** Special dwellings are defined for this survey as hotels, motels, boarding houses, educational and religious institutions, construction camps, caravan parks, etc.

**Task** A task is a component of an activity. For example, self-care activity comprises the following tasks: showering/bathing, dressing, eating; toiletting; and bladder or bowel control.

**Transport activity** Transport activity relates to using public transport, shopping and driving.

**Type of residence** Type of residence refers to either a household or an establishment. Much of the data shown distinguishes between persons in these two types of residence as the survey was conducted in two components.

**Unemployed persons** Unemployed persons are those aged 15 years or more who were not employed during the enumeration period, but claimed to be looking for work. (This is a less precise definition than is used in the ABS monthly Labour Force Survey, where, to be classified as unemployed, persons must have taken active steps to find work and be available to start work if work is found.)

**Unemployment rate** The unemployment rate for any group is the number of unemployed persons expressed as a percentage of the labour force (ie, employed plus unemployed) in the same group.

**Unmet need** Unmet need relates only to persons with one or more disabilities and/or persons aged 60 years or more who need help. A person with one or more disabilities is considered to have an unmet need if:

- he/she requires help, but is not receiving it;
- he/she is receiving help, but the help is insufficient to satisfy the person's needs for a specific activity.

**Usual resident** A usual resident is a person who usually lives in that dwelling and regards it as his/her own or main home.

**Usual resident provider of help**

A usual resident provider of help is a person who usually lived in the same household as the person receiving help (see household). This person must have spent at least one night in the household during the enumeration period.

**Verbal communication activity**

Verbal communication activity relates to understanding speech and being understood when speaking in the person's native language.

**Verbal communication handicap**

A verbal communication handicap relates to difficulties understanding or being understood by strangers/family/friends/staff in the person's native language.

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