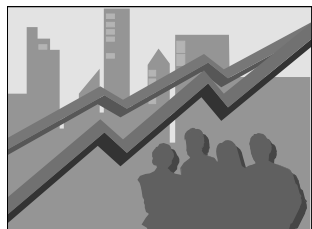




# **Working papers in Social and Labour statistics**

**Working Paper No. 2001/1**



## **ACCOUNTING FOR CHANGE IN DISABILITY AND SEVERE RESTRICTION, 1981–1998**

**Elisabeth Davis, Jaz Beer,  
Cassandra Gligora and Alison Thorn**

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## **P R E F A C E** .....

This paper is the first in a series of Social and Labour working papers designed to make the results of current ABS research available to interested parties.

Drawing on data from four disability surveys, this paper describes and explains changes in disability from 1981 to 1998, focussing primarily on the increased rate of people with severe restrictions.

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## SUMMARY OF FINDINGS .....

The results of the 1998 Survey of Disability, Ageing and Carers (SDAC) showed a relatively small increase in the number of people with a disability, but a larger than expected increase in the population with severe or profound restriction from their disability. This group had increased by 415,000 people, the severe and profound restriction rate rising almost 50% from 4% to 6%.

### PURPOSE OF PROJECT

The purpose of this project was twofold:

- to explore this increase—
  - Was there anything different about the way the survey was conducted that might produce an increase?
  - Was the increase diffused across the whole population, or concentrated in particular groups?
  - Was the assigned level of severity appropriate?
  - Was there any external evidence of a change in the level of disability, or in factors affecting the way people might respond?
- and, in the process,
- to compare the performance of the disability survey over time.

### METHOD

Several lines of investigation were developed:

- general survey issues, such as sampling, conduct and weighting;
- identifying the population groups where most of the change had occurred—
  - ◆ establishing whether there was more than a natural variance between different samples, i.e. was it significant at a 95% confidence level?
  - ◆ examining the literature for independent observation of characteristics of these groups;
- construct an underlying series adjusting the criteria for disability and severe restriction on a common basis between the surveys, and age standardising, to remove known changes;
- analyse identified population groups by other variables collected in the survey;
- assess the indirect effect of changes;
- measure the direct effects of change, compare the 1998 published results with:
  - ◆ 1998 survey data recoded in terms of 1993 disability and severe and profound restriction criteria; and
  - ◆ 1998 disability and 1993 severe and profound restriction criteria.

### RESULTS

#### Methodology

Sample design, weighting, and scope contributed little, if anything, to change; changes in other aspects of survey method appear to have had effects selectively, for specific population groups. The use of Computer Assisted Interviewing (CAI), a new disability

Methodology continued

criterion, the SF-12 international self-assessment instrument, and particular wording changes appear to have improved capture in certain areas, and are discussed in the paper for each of the identified groups. New disability criteria had a measurable direct effect; along with the other listed developments, they also had more indirect effects, discussed for each of the population groups.

Two rectification measures, assessment of severity for children under 5, and collecting sufficient information to distinguish moderate from severe restriction in cared accommodation, achieved their purpose and had a measurable effect.

Population groups

External effects

There is evidence of some independent developments in the community—greater diagnosis and awareness of particular types of conditions affecting children; increasing longevity of older people, particularly men; and a fairly high level of perception of work-related injury among people aged 45 to 64, especially those with musculoskeletal disorders. There appears in addition to be a continuing greater exposure to, acceptance of and openness about disability issues.

SUMMARY TABLE

.....	
<i>Contributors to change</i>	Percentage points
.....	
Population structure	0.3
Improved capture—direct	
Restricting chronic pain criterion/self-identification	0.2
Assessment of children under 5 years	0.2
Distinguishing severe from moderate restriction in cared accommodation	0.1
Other (include expanded communication criteria)	0.1
Total	0.6
Improved capture—indirect	
Children	0.1
Mid-age group	0.4
Older people	0.1
Total	0.6
Changes affecting respondents: increased awareness, willingness to respond, or activity restriction	0.5
<b>Total</b>	<b>2.0</b>
.....	

In Australia, some level of government-funded support for people with disabilities has been considered appropriate from early colonial times. Custodial institutionalisation was the dominant model, attitudes changing gradually with the rehabilitation of veterans after World War I. Over the next twenty years, disability-specific organisations such as the Crippled Children's Association were formed, often by parents, forming the basis of the advocacy groups that exist today. The forerunner of the Commonwealth Rehabilitation Service was formed in 1941. During the same period, some forms of income support were established, such as compensation for work or road injuries where another's negligence could be demonstrated (from the 1920s), and sickness benefits (in 1945) (Australian Institute of Health and Welfare 1993).

Interest in the prevalence and characteristics of disability in Australia continues to increase, as the ageing of the population makes disability a key issue for public policy. Disability increases markedly with ageing. More people are surviving to their late eighties and beyond and most will experience some kind of disability in their lifetime. As the population ages and the number of people requiring services because of disability increases, the cost to society of providing these services is also likely to increase. A considerable proportion, also, of those who retire early because of disability are likely to need income support for the rest of their lives. In 1997, 37% of males and 19% of females retiring from full-time work in the age group 45 to 64 gave the reason 'own ill health or injury' (ABS 1998b). The cost of sustaining community services with an ageing population was one of the arguments for broadening the tax base by the introduction of a goods and services tax.

A number of other concurrent trends are stimulating a demand for information by government agencies, academic researchers and advocacy groups. These include:

- Increasing awareness of human rights issues. With the human rights movements of the later 1960s onwards, people with disabilities, their families, friends and other supporters have become forceful advocates of their right to participate as fully as possible in the life of the community.
- Greater openness about disability, especially since the International Year of Disabled Persons in 1981.
- A shift in public policy towards 'normalisation' and the move away from institutional care, where possible.
- The introduction of comprehensive legislation for accommodation support, aged care and disability services, and against discrimination and barriers to access; penetration and outcomes therefore need to be measured. (See *Australia's Welfare 1993* (Australian Institute of Health and Welfare 1993) for an outline of legislation from 1985 to 1992, updated in later issues.)

At the same time, more people are surviving life-threatening events, such as premature birth, accidents and diseases, that may have ongoing effects that limit their activities and their social and economic participation. The impact is exacerbated by the changing structure of the population.



*The 'baby boomers' are the first generation to contain a substantial proportion of people with long standing disabilities. Advances in technology, medical care and community support mean that many people with a long standing disability who would once have died before reaching late adulthood are now having a life expectancy which approximates that of the general population. (Gething 1999, p.7)*

## MEASURING DISABILITY

Disability is a broad concept. The World Health Organisation (WHO) in its *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) (WHO 1980) created a framework for the consequences of disease, disorder or injury. It was to be separate from the etiology-based classification of diseases in the International Classification of Diseases (ICD), and attempted to introduce the interface between the impairments or limitations a person may have, and the restrictions placed on them by physical and social barriers to participation in the usual life of the community. The three dimensions of disablement—impairment, disability and handicap—were defined in a normative way, and were dependent on the perceptions of the particular society. This created the potential for new disability groups to emerge gradually into public awareness as requiring support (more recent examples in Australia are people with mental disorders, including dementia and behavioural disorders).

Impairment	Disability	Handicap
In the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function	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	In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age,

Source: WHO, *International Classification of Impairments, Disabilities and Handicaps*, 1980

In Australia, the term 'handicap' is perceived as pejorative, and no longer acceptable. Output from the 1998 disability survey has replaced the term 'handicap' with 'specific restriction', using the same criteria as the former 'handicap':

- Need for assistance, difficulty or the use of aids with the core activities of self care, mobility or communication; and
- Restricted participation in schooling (aged 5 to 20) or employment (aged 15 to 64).

In the 1981 and 1988 disability surveys, need for assistance with at least one specified self care, mobility or communication task constituted a 'severe' handicap. In the 1993 survey, further information was collected to distinguish those who always needed assistance with the task from those who only sometimes required assistance. Those who always needed assistance were classified as having a profound handicap, those who sometimes needed assistance a severe handicap. In this paper, the terms 'profound restriction' and 'severe restriction' replace the equivalent handicap terms.

MEASURING DISABILITY *continued*

These three dimensions provide a very broad definition of disability, including many different types of difficulties with everyday living. In a social policy context, the main interest is in people with severe levels of disability, as these are the people most in need of services. There is also an interest in the broader group, however, for two reasons:

- These are people already at risk of more severe restriction; knowing about the broader group assists with forecasting future service needs.
- More immediately, these are people whose lives can be made much more manageable by a different, integrated approach to the design of public infrastructure.

The needs of people with a disability are recognised in legislation with the *Disability Discrimination Act 1992* (Cwth) stipulating ease of access to buildings, public transport and other aspects of public life. This, along with the continuing growth of the disability population as a proportion of the total population, has heightened demand for more detailed information about characteristics of the wider disability group.

One difficulty in measuring disability, therefore, is in being sufficiently inclusive. A further difficulty is the subjective identification and the variable nature of many disabilities. The effects of a range of impairments on a person's ability to function may not be absolute. Personality, levels of energy and optimism contribute to a person's ability to cope with and overcome some obstacles sometimes, but these can be undermined by pain, exhaustion, depression, financial and family worries, experience of discrimination and even weather conditions. It is not clear that a person would answer survey questions designed to establish that he or she had a disability in the same way on different occasions, either legitimately (due to its episodic nature) or unintentionally (depending on how they felt at the time).

## HISTORY OF AUSTRALIAN BUREAU OF STATISTICS (ABS) COLLECTION OF DISABILITY INFORMATION

Data on the prevalence of disability, its consequent restrictions and their effects on the lives of those who have disabilities have been in demand in Australia for many years, by government agencies, researchers and advocacy groups. In the light of the need for small area and small population statistics, the ABS has explored the possibility of collecting disability information in the census. To date this has not been successful. A disability question on the 1976 Census was very poorly answered. Testing was undertaken for a disability question on the 1996 Census, without success. Extensive testing was carried out to try to develop a question for the 2001 Census, but again the quality of the results was not sufficient for inclusion of the question.

Several sample surveys have been carried out, however. In 1968 and 1974 the ABS conducted chronic illness surveys as supplementaries to the Monthly Population Survey. These surveys attempted to measure 'chronic limiting condition' by asking people whether any long-term conditions limited their activities in any way. Both surveys found that around 9% of Australians had limiting long-term conditions. In 1977–78, long-term illness and its effects was a topic in the Australian Health Survey, which found that approximately 10% of people had limiting long-term conditions (ABS 1982).

HISTORY OF AUSTRALIAN BUREAU OF STATISTICS (ABS) COLLECTION OF DISABILITY INFORMATION *continued*

The first ABS survey dedicated to disability was the Survey of Handicapped Persons in 1981, the International Year of Disabled Persons. Three further surveys have been conducted: the Survey of Disabled and Aged Persons in 1988 and Surveys of Disability, Ageing and Carers in 1993 and 1998. Respective disability and severe (including profound in 1993 and 1998) restriction rates as published for each survey are shown in table 1.1.

**1.1 DISABILITY AND SEVERE RESTRICTION , As published**

	Disability.....		Severe and profound restriction.....	
	'000	%	'000	%
1981	1,942.0	13.2	514.0	3.5
1988	2,543.1	15.6	657.5	4.0
1993	3,176.7	18.0	721.0	4.1
1998	3,610.3	19.3	1,135.9	6.1

Sources: ABS 1982, ABS 1990, ABS 1993, ABS 1999c.

APPROACH OF PAPER

With information from four surveys in hand, it is possible to do some useful analysis of disability in Australia, particularly accounting for the notable increase in the severe (includes profound) restriction rate in 1998. The criteria for disability and levels of restriction have evolved over this time, with a tension between preserving comparability and improving capture in areas with known deficiencies or to meet emerging requirements. Because of these changes, data in the table above are not directly comparable. The comparison analysis contained in this paper is carried out using a set of criteria common across the surveys. Age rates for the adjusted data are found in Appendix A. Criteria used for disability and for severe restriction for each of the surveys in this underlying comparison are listed in Appendix B. Unless otherwise stated, data in tables and graphs are from the ABS disability surveys.

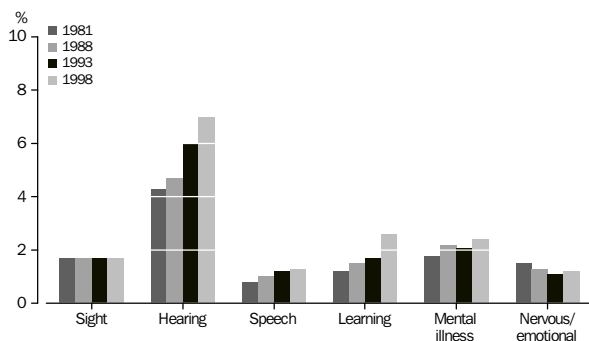
This paper sets out to analyse the changes in disability, particularly in severe restriction, from 1981, and developments in the collection of disability. It will cover the following areas:

- The underlying movements across the four surveys, particularly for severe restriction;
- Discussion of populations where significant differences have been identified;
- Changes to the 1993 and 1998 surveys and their impact on disability rates, both actual and underlying.

DISABILITY

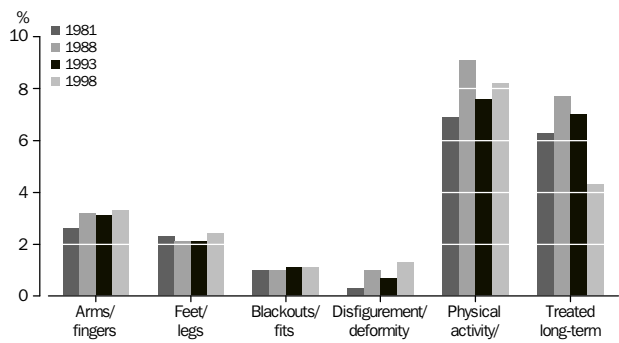
To identify people with a disability, a set of screening criteria is used, covering many aspects of disability. The aim is to spread a broad net, to capture physical, sensory, intellectual and psychological impairments. Some of these criteria capture only a small proportion of people, but they reflect important aspects of the whole disability field, and may be areas where the effect of the impairment is more severe. The following graphs show the relative contributions of the screening criteria common to the four surveys, and differences between surveys. The broad magnitude of the contribution of different criteria remains similar. However, there have been noticeable increases in hearing loss across all surveys, and intellectual/learning impairment particularly in 1998, with smaller increases in 1998 in mental illness requiring help or supervision and disfigurement or deformity. People may answer more than one of these, and so indicate more detail about their disability, or multiple disabilities.

2.1 DISABILITY CRITERIA(a), Sensory, intellectual, psychological



(a) Data adjusted for comparability across surveys.

2.2 DISABILITY CRITERIA(a), Physical and general



(a) Data adjusted for comparability across surveys.

In the underlying series, based on data that have been adjusted so that common criteria are used for disability, and then age standardised to the 1998 population, the overall disability rate for the four surveys are respectively 14.6%, 16.5%, 17.2% and 18.8%. Graph 2.3 shows age-specific disability rates, based on adjusted data for the three years 1988, 1993 and 1998.

The disability surveys conducted by the ABS have shown remarkably similar patterns of prevalence by age groups. Across the three surveys from 1988, there has been a rise in age-specific disability rates from children aged 0 to 4 years to children aged 5 to 14 years (more pronounced for boys), a decline for older teenagers, a slow rate of increase for adults under 50 years, then a relatively steady upward curve to older age. (The 1981 survey had similar rates to 1988 for the under-60s, but the reporting for older people dropped away. Later surveys focused more on capturing activity limitation among older people as well.) There tended to be a slight rise across most age groups under 60 in 1998. The age groups with significantly higher rates in 1998 will be examined more closely in the following chapter.

**Adjustments and age standardisation of comparison data: 1988 to 1998**

To compare data across the three surveys, common criteria for disability and severity of restriction were used to remove the effect of changes in methodology and coding. For example, people needing assistance with using the toilet or getting out of bed were included in the severe restriction population in 1993 and 1998, but not in the earlier years. For the purposes of this comparison, need for assistance using the toilet or getting out of bed were omitted from the criteria for severe restriction for all years. For disability, twelve screening questions reasonably comparable across the surveys were used. (See Appendix B for a full list of the common criteria used.) Severity of restriction rates were calculated for the population aged 5 years and over as this information was not collected for children under 5 prior to 1998.

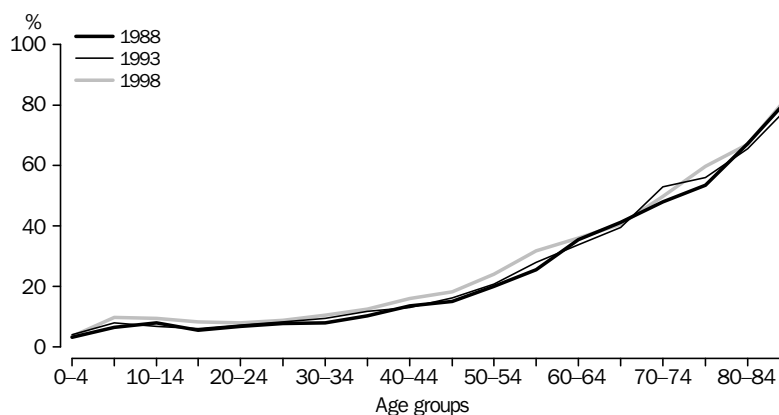
Several methodological effects could not be adjusted for. These were:

- The introduction of Computer Assisted Interviewing in 1998.
- A change in the coding of people in cared accommodation with severe and moderate restrictions in 1993 compared with the other years.
- A change in wording of one of the survey questions from 'Is anyone slow at learning or understanding' in 1993 to 'Does anyone have difficulty learning or understanding' in 1998.
- The effect of answering the new screen question on chronic pain: although excluded from the criteria for the underlying adjusted series, people admitted through other screen criteria had answered it.
- The use of an international instrument measuring health and well-being, after disability was established, but before the questions to establish severity of restriction.

The impact of these changes is discussed in Chapter 6: Recent developments.

Data have been age standardised to the 1998 population, disaggregated by sex and 5 year age groups (up to age 84, then 85 and over).

DISABILITY *continued*

**2.3 AGE-SPECIFIC DISABILITY RATES(a)**

(a) Data adjusted for comparability across surveys.

The rise in the disability rate for children corresponds with compulsory school age, and is likely to reflect both higher levels of diagnosis and the effect conditions such as intellectual disabilities, cerebral palsy and chronic asthma have on school performance. After the compulsory school age, while the effects may still be considerable on activities such as working, there is no consistent agency such as a school to keep track of these young people. If people modify their lifestyle to do the things they can readily do, a condition such as a learning difficulty may not appear to be such a problem, and may therefore be less commonly reported.

DISABILITY *continued*

Response rates to the 'slow at learning/understanding' screening questions peak in the 5 to 14 age group, then drop sharply away to rise again in older age. The higher rates for 1998, particularly after childhood, are likely to result from the change of question wording to 'difficulty learning or understanding', as a result of field test feedback about sensitivity. Consequently there has been a better capture of intellectual disability in young adults and dementia in people aged 75 and over.

The set of graphs on pages 8 and 9 compare patterns in the age prevalence of the various disability criteria common to the four surveys. Older people in the 1981 survey will be under-reported against most criteria. Otherwise, the prevalence patterns are very similar, except for:

- Increases in hearing loss between each survey;
- Higher rates of restriction in physical activity for people aged 60 to 74 in 1988, compared with the other three surveys; and
- A much lower rate across most age groups for restricting treated long-term condition in 1998, a direct result of a change in the question wording.

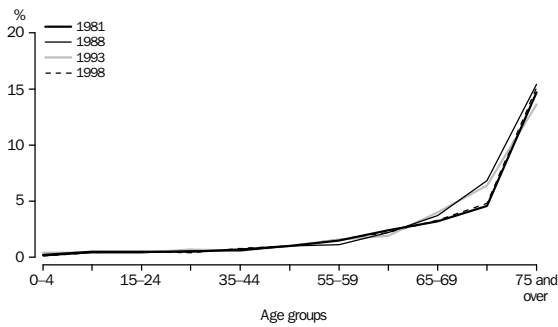
Closer analysis of the graphs reveals the following patterns and movements:

- Sight loss rates are unchanged;
- Hearing loss has risen substantially in each survey, with the point of increase being in young adulthood in the 1993 and 1998 surveys—increasing screening and detection may contribute to this apparent growth, as well as loud music and industrial noise.
- Speech problems echo intellectual and cognitive impairment, to which they are closely related, with an increasing peak for school-age children. Speech problems are also often a consequence of strokes, accounting for some of the increase in prevalence for those aged 70 and over.
- Arm, hand and finger limitation rates have remained very stable over time, with a steady upward trend by age and a marked increase to over 20% for the 75 and over age group. Limited use of legs or feet has also been fairly stable, increasing by age group to the 55 to 59 age group, then remaining around the 5% level in older age groups.
- The lower rate for treatment for a long-term condition that is still restricting is a direct result of a wording change in 1998 to 'any other' long-term condition; one of the new screening questions in 1998 designed to give more specific information about people in the general condition categories, breathing difficulty, has been included to compensate partially for the loss of those contributed only by this screen, but the overall response to this general criterion is affected by all the previous screening questions.

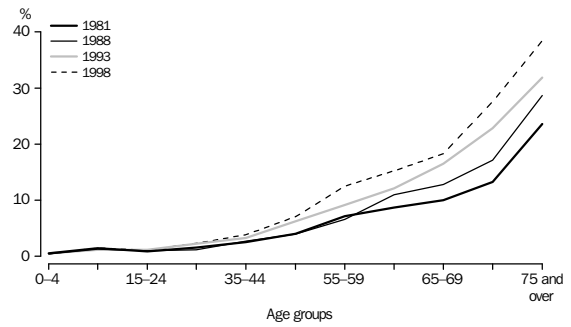
A noticeable feature in 1998 is the number of screening criteria that show a distinct rise at the 55 to 59 age group, either relative to other ages in 1998, or to other surveys. Hearing loss, slow at learning/understanding, treated for a nervous or emotional condition, limited use of arms and fingers, all show a peak at or rise to the 55 to 59 year age group. Restriction in physical activity shows very similar age rates across all surveys, rising to the 55 to 59 age group. Given the high levels of musculoskeletal disorders in the 1998 survey population, higher rates for this criterion might have been expected in 1998, but this was not the case.

2.4 PERSONS WITH A DISABILITY, Screening criteria rates

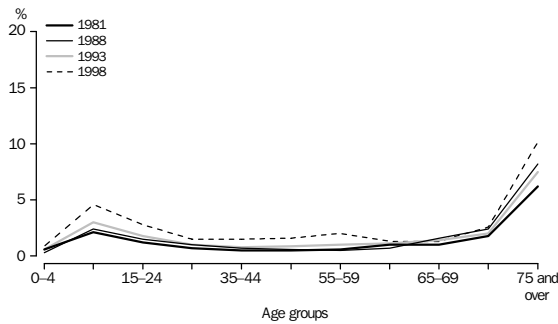
a. Sight loss



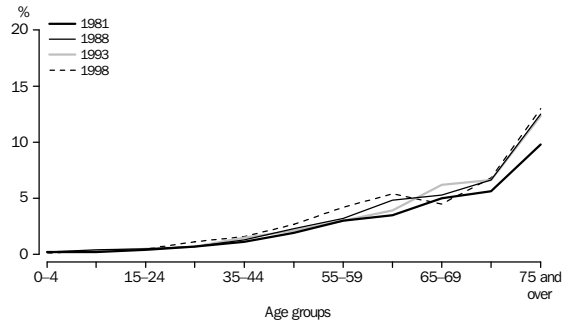
b. Hearing loss(a)



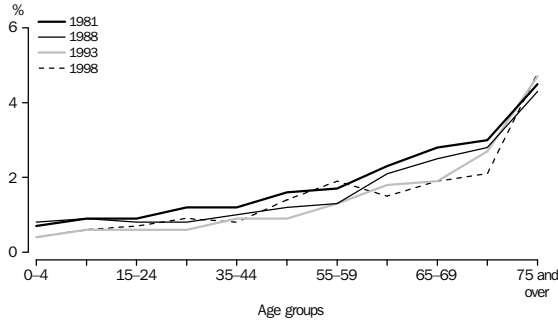
c. Slow at learning or understanding



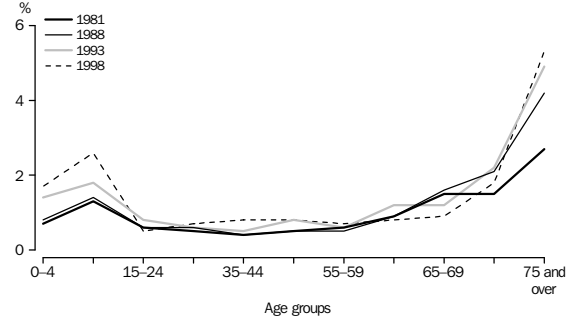
d. Mental illness needing supervision



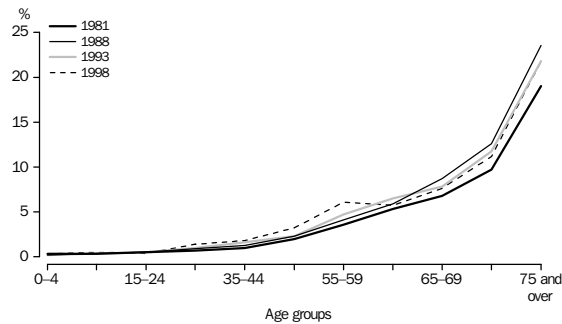
e. Treated for nervous/emotional condition(a)



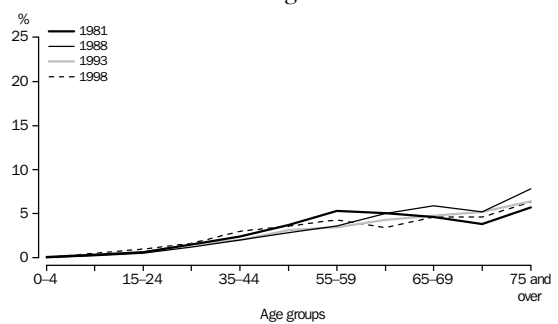
f. Speech problems



g. Limited use of arms or fingers



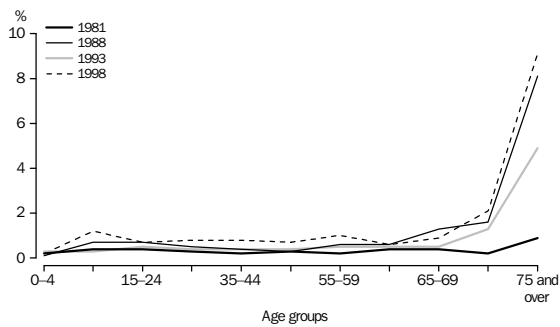
h. Limited use of feet or legs



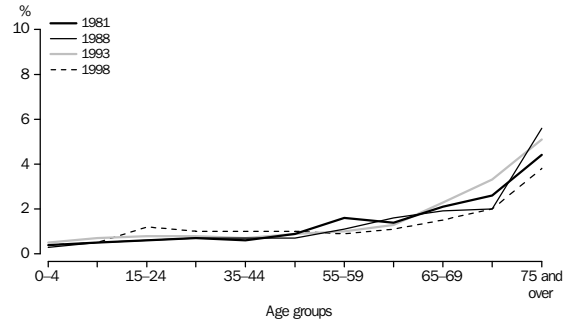
(a) Data adjusted for comparability across surveys

2.4 PERSONS WITH A DISABILITY, Screening criteria rates *continued*

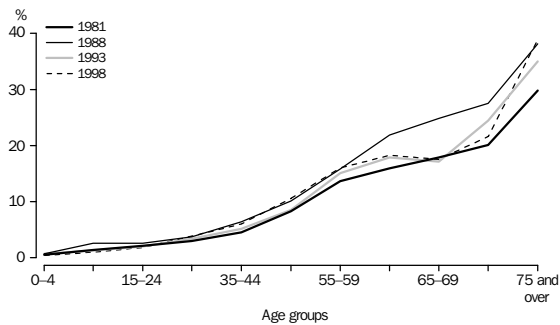
i. Disfigurement or deformity



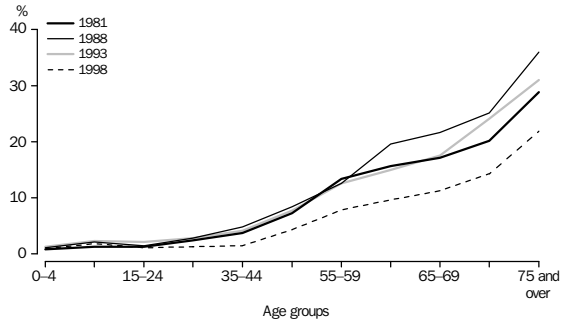
j. Loss of consciousness



k. Restricted in physical activity/work



l. Treated for long-term condition, still restricted(a)



(a) Data adjusted for comparability across surveys

SEVERITY OF RESTRICTION

Severity of restriction refers to whether a person needs help, has difficulty, or uses aids or equipment with communication, self care or mobility activities. The level of severity can be categorised as severe, moderate or mild. (In 1993 and 1998, severe restriction was further disaggregated into severe and profound restriction. In discussion of the adjusted series, which compares 1998 and 1993 with the earlier surveys, 'severe' includes both severe and profound; 'severe' is distinguished from 'profound' where the 1993 and 1998 surveys are the only ones being compared.) Data from the 1981 survey cannot readily be disaggregated for the older age groups on the same basis as later years, and are therefore excluded from some of this analysis.

This study focuses on the increase in the severe restriction rate between the 1998 and 1993 surveys. Table 1.1 shows a difference of two percentage points in data as published for each survey. In the adjusted and age standardised series, as shown in table 2.5, there is a difference of 1.1% of the population aged 5 and over, which is 1.0% of the total population. Half of the difference, therefore, is in the underlying series; the remaining one percentage point covers the contribution of differences from the earlier surveys not included in the adjusted series, and differences in the population structure.

Table 2.5 shows that the total specific restriction rate increased from 14.7% in 1988 to 16.1% in 1998, though dipping to 14.0% in 1993. The rise in 1998 was primarily due to increased rates of severe restriction (from 4.4% in 1993 to 5.5% in 1998) and mild restriction, which has increased steadily since 1988.



**2.5 ALL PERSONS AGED 5 YEARS AND OVER, Severity of restriction(a)**

	1988	1993	1998
<i>Severity of restriction</i>	%	%	%
Severe(b)	4.4	4.4	5.5
Moderate	3.9	2.4	2.9
Mild	4.8	5.6	5.9
Schooling/employment restriction only	1.7	1.6	1.7
<b>Total with specific restrictions</b>	<b>14.7</b>	<b>14.0</b>	<b>16.1</b>

(a) Data adjusted for comparability across surveys.

(b) Includes persons with profound restrictions in 1993 and 1998.

Although the moderate restriction rate increased slightly between 1993 and 1998, it fell considerably between 1988 and 1993. The residual schooling and employment restriction remained stable.

In 1998, on the basis of criteria common to all the disability surveys, with earlier surveys age standardised to 1998, just under a million people in Australia had a severe restriction because of their disability. This was close to 200,000 higher than in 1993 or 1988. These two surveys are very similar in their overall results: the 1993 survey, however, has higher numbers with severe restriction among younger people up to the 25 to 34 age group, while the 1988 survey has higher numbers in all but one of the other age groups. The 1998 survey has substantially larger numbers with severe restriction in most age groups under the age of 65, and in two of the five older age groups.

Over 80% of the difference between 1993 and 1998, and 75% of the difference between 1998 and 1988, is contributed by the 5 to 14, 45 to 64, 75 to 79 and 85 and over age groups (table 2.6). Graph 2.7, showing differences in numbers based on the adjusted series, but not age standardised, and graph 2.8 showing the age-specific rates are consistent with these findings.

Graph 2.7 below shows the substantial increases in numbers in the specified age groups before standardisation, underlying the overall rate increase. The number of people with a given characteristic in an age group is a combination of the size of the population in that age group, and the proportion with that characteristic within the group, that is, the age-specific rate. An increased rate in a smaller-sized group may have no impact on the overall severe restriction rate. Where increased rates are combined with increased numbers, the effects are magnified.

Age standardising removes the effect of changes in the population structure, so that other contributing factors can be examined. There is no doubt, however, that changes in population structure have contributed to the increase.

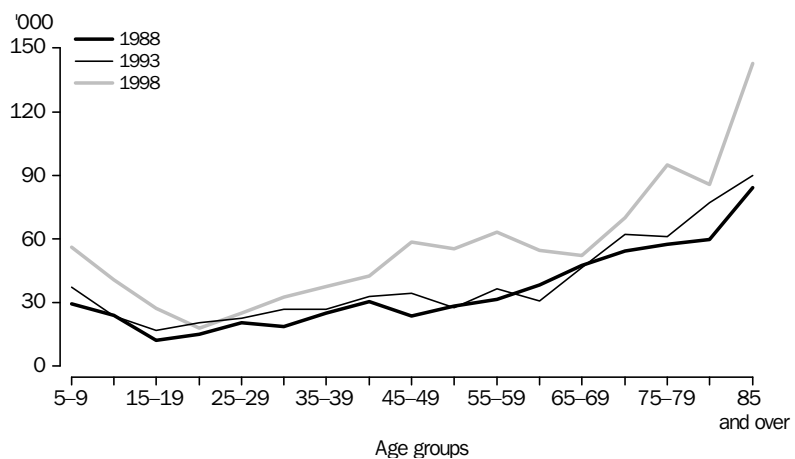
**2.6 ALL PERSONS AGED 5 YEARS AND OVER WITH SEVERE RESTRICTIONS(a), Differences between surveys by age(b)**

Age group	1998	1993	Difference from 1998	% of total difference	1988	Difference from 1998	% of total difference
	'000	'000	'000	%	'000	'000	%
5-14	96.8	62.9	33.9	17.1	57.7	39.1	20.4
15-24	45.3	36.4	8.9	4.5	27.4	17.8	9.3
25-34	57.8	50.2	7.6	3.8	42.0	15.7	8.2
35-44	80.1	64.5	15.6	7.9	66.5	13.6	7.1
45-54	113.8	74.4	39.5	19.9	76.9	37.0	19.2
55-64	117.7	73.7	44.0	22.2	75.6	42.1	21.9
65-69	52.3	46.3	6.0	3.0	52.7	-0.5	-0.2
70-74	69.9	69.0	0.9	0.4	69.2	0.6	0.3
75-79	94.9	71.3	23.6	11.9	75.7	19.2	10.0
80-84	85.7	85.6	0.1	0.0	85.0	0.7	0.4
85 and over	142.7	124.5	18.2	9.2	135.9	6.8	3.5
<b>Total</b>	<b>956.9</b>	<b>758.7</b>	<b>198.2</b>	<b>100.0</b>	<b>764.7</b>	<b>192.3</b>	<b>100.0</b>

(a) Includes persons with profound restrictions in 1993 and 1998.

(b) Data adjusted for comparability across surveys, and age standardised to the 1998 population.

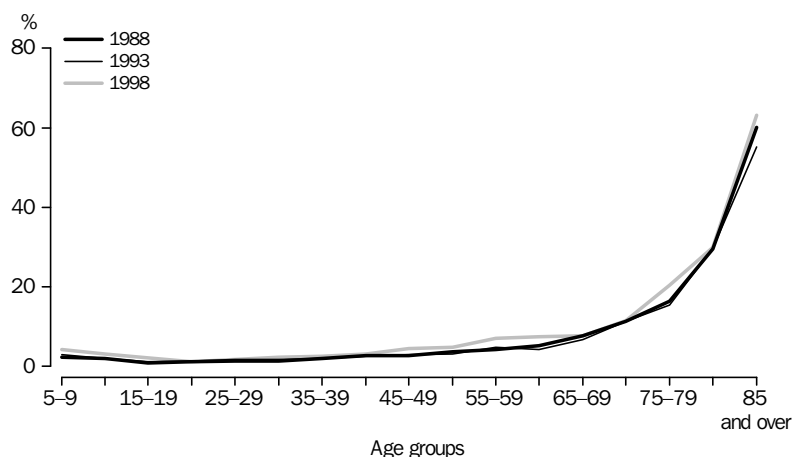
**2.7 PERSONS(a) WITH SEVERE RESTRICTIONS(b), Adjusted series, raw numbers(c)**



(a) Aged 5 years and over.

(b) Includes persons with profound restrictions in 1993 and 1998.

(c) Data adjusted for comparability across surveys, not age standardised.

**2.8 PERSONS(a) WITH SEVERE RESTRICTIONS(b), Adjusted series, age-specific rates(c)**

(a) Aged 5 years and over.

(b) Includes persons with profound restrictions in 1993 and 1998.

(c) Data adjusted for comparability across surveys.

Severe restriction is clearly age-related, declining through childhood to early adulthood, then slowly increasing with age up to the age of 70, when it increases sharply. Although results from the 1981 survey are not included here, age-specific severe restriction rates were very similar to the 1988 survey, including among the older population; it effectively captured older people who were experiencing need for assistance.

While the pattern of severe restriction was similar across all disability surveys, there were significant increases between 1998 and previous years for a number of age groups:

- Women aged 35 to 54 and 60 to 64 compared with 1993;
- Women aged 45 to 54 compared with 1988;
- Boys aged 5 to 14 compared with both previous years;
- Young men under 35 compared with 1988; and
- Men aged 45 to 64 and 75 to 79 compared with 1993 (omitting those aged 60 to 64 and adding those aged 85 and over compared with 1988).

Among the older population generally, there was little difference across surveys in the rates of people with severe restrictions. The slightly higher rate with each successive survey for the oldest group (aged 85 and over) is likely to relate to progressively higher concentrations of the very old within this age group. It is those age groups with significant increases relative to both previous surveys that require further explanation.

#### UNDERLYING CONDITIONS

Among children with severe restrictions, there was a significant increase in mental and behavioural disorders. This included a significant increase in intellectual and developmental disorders, mostly among boys; when these disorders are considered as a main condition, boys or girls separately were not significantly different from 1993, but there was a significant increase for boys from 1988. Another major contributing group was boys with Attention Deficit Hyperactivity Disorder (ADHD).

UNDERLYING CONDITIONS *continued*

For men aged 45 to 64 and women aged 45 to 54, restriction in physical activity or work was the most common disability criterion in 1998. Musculoskeletal disorders other than arthritis, particularly back problems and some soft tissue disorders, were the most common conditions, although there were increases in mental and behavioural conditions as well.

Among the 75 to 79 age group, there were significant increases in circulatory disorders. A screening question about head injury, stroke and brain damage with long-term effects was introduced in 1993; in 1998, the three components were separately identified, and stroke was directly coded in the circulatory conditions group. Some of this apparent increase, therefore, may be the result of more targeted capture in 1998.

## EXPLAINING THE MOVEMENTS

In addition to population change and changes in the survey, a number of factors are probably contributing to the increased rates of severe restriction, with different factors operating for different age groups. As the disability surveys rely on self-reporting of restrictions, changes in both actual and perceived disability may be contributing to the increase, as well as greater willingness to disclose information about disability and need for help. The following reasons for the apparent increase have been proposed and their contribution to the reported increase is discussed in the following chapters:

- Ageing of the population. Disability rates increase with age, therefore, as life expectancy increases, the disability rate can be expected to increase accordingly.
- Improved survival rates. Improvements in the care of some disorders, including certain intellectual disabilities, in recent years have led to more people with these disorders surviving to adulthood. Improved treatment of injuries and previously fatal diseases may have also contributed to increased disability rates.
- Improved survival rates of pre-term infants. Over the last thirty years, neonatal death rates have declined markedly due to improvements in the quality of care during pregnancy and labour, and in the postnatal period. Has this contributed to increased disability rates among children?
- Changes in attitude. People may be more willing to admit a need for help, particularly with personal tasks such as dressing, bathing and toileting. Similarly, people's expectations of ageing may have changed with people expecting healthy ageing and therefore regarding their limitations as disabilities rather than just a normal part of ageing.
- Increased awareness. With increased publicity of certain disabling conditions e.g. mental and behavioural disorders, people may be more inclined to seek help and be diagnosed with a disorder. Has this led to increased awareness of the limitations imposed by these conditions?

As various factors appear to have affected severe restriction rates for different age groups, three broad age groups will be examined separately: children aged 5 to 14, adults aged 15 to 64 and older people aged 65 and over. As severe restriction rates remained steady from 1988 to 1993, the following analysis will concentrate mainly on the recent increases which occurred in 1998.

**SEVERE RESTRICTION IN CHILDREN AGED 5 TO 14 YEARS .....**

The following table shows the underlying conditions of children with severe restrictions. The greatest increases occurred for children with mental and behavioural conditions, particularly boys.

Over the last thirty years, neonatal death rates have declined markedly due to improvements in the quality of care during pregnancy and labour, and in the postnatal period. While limited Australian data are available on the implications of these improvements, international research indicates that such improvements in care have led to normal survival rather than survival with disabilities (Henderson-Smart 1990, James 1988). It is unlikely, therefore, that this has contributed greatly to the increase in severe restriction rates.

This conclusion is supported by additional data from the disability surveys on the underlying conditions most prevalent in pre-term infants. The most common disorders in babies born at 24–26 weeks gestation are blindness and cerebral palsy, according to the Victorian Infant Collaborative Study Group (1995). Although the prevalence of eye diseases increased between 1993 and 1998 for children aged 5 to 14, the number of children with these disorders was quite small and not all of these children had disabilities, let alone severe restrictions. Over the same period, the number of children with cerebral palsy actually declined (see table 3.2).

**3.1 CHILDREN AGED 5–14 WITH SEVERE RESTRICTIONS(a), Main underlying condition**

	MALES.....			FEMALES.....		
	1988(b)	1993(b)	1998	1988(b)	1993(b)	1998
<i>Main condition</i>	'000	'000	'000	'000	'000	'000
<i>Physical conditions</i>	22.7	20.5	24.0	16.5	18.9	17.4
Nervous system conditions	*7.1	**1.9	*6.3	*5.4	*6.4	**2.1
Other physical conditions	15.6	18.6	17.7	11.1	12.5	15.3
<i>Mental and behavioural conditions</i>	13.2	18.1	42.0	*7.5	*5.5	13.4
Intellectual and developmental conditions	11.0	14.7	21.2	*6.8	*4.8	*8.0
Other mental and behavioural conditions	**2.2	*3.4	20.8	n.p.	n.p.	*5.4
<b>All conditions</b>	<b>36.0</b>	<b>38.6</b>	<b>66.0</b>	<b>24.0</b>	<b>24.4</b>	<b>30.8</b>

(a) Includes children with profound restrictions in 1993 and 1998.

(b) Age standardised to the 1998 population.

n.p. Not for publication

**3.2 CHILDREN AGED 5–14, Selected conditions**

	1993(a)	1998
Condition	'000	'000
Cerebral palsy	*8.2	*7.4
Eye diseases	*8.1	*9.5

(a) Age standardised to the 1998 population.

The increased rate of severe restriction among children was mainly due to an apparent increase in children with intellectual and developmental disorders and Attention Deficit Hyperactivity Disorder (ADHD). Between the 1993 and 1998 surveys, the rate of ADHD increased markedly, particularly among boys aged 5 to 14. The number with ADHD in 1998 (10,700) was greater than the total recorded with a mental disorder in 1993. (It is not possible to identify those with ADHD in the 1993 survey as it was not separately classified.)

An increase in prescriptions for the most commonly prescribed drugs for ADHD provides supporting evidence of an increase in the diagnosis of the disorder. These drugs, Dexamphetamine and Methylphenidate (Ritalin), are both well-established treatments.

Defined Daily Dose (DDD) per 1,000 per day indicates how many people per 1,000 of the population may in theory have received a standard dose daily. Between 1993 and 1998, the DDD per 1,000 population per day of Dexamphetamine increased from 0.115 to 0.431 (see table 3.3). Similarly, Methylphenidate increased from 0.161 to 0.469.

**3.3 DEFINED DAILY DOSE(a) OF SELECTED MEDICINES**

	1993	1994	1995	1996	1997	1998
Dexamphetamine	0.115	0.174	0.251	0.303	0.362	0.431
Methylphenidate (Ritalin)	0.161	0.239	0.326	0.391	0.413	0.469

(a) Per 1,000 population per day.

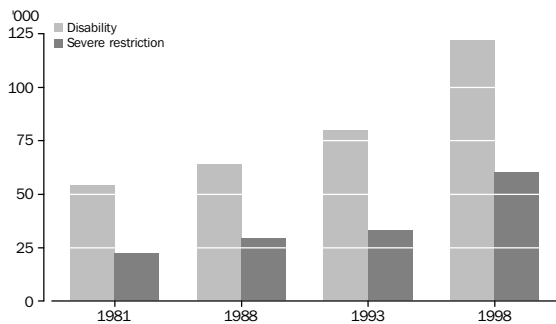
Source: Commonwealth Department of Health and Aged Care, *Australian Statistics on Medicines* (various years).

In one year alone (between 1997 and 1998), the number of scripts issued for Dexamphetamine and Methylphenidate combined, increased by 19% from 291,032 to 345,060 (Commonwealth Department of Health and Aged Care 1997 and 1998). Care should be taken in interpreting these figures, however, as these drugs can be used to treat other disorders such as narcolepsy, and other treatments are used for ADHD including other drugs, family therapy and behaviour modification techniques.

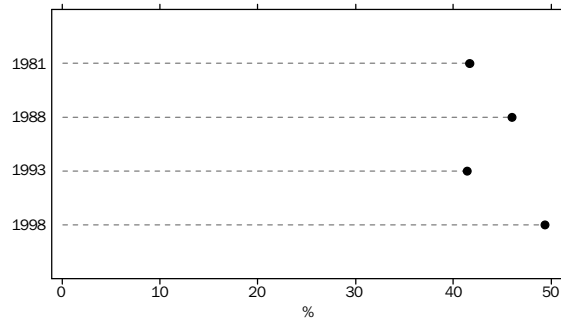
The significant increase in children with intellectual, developmental and behavioural conditions was, at least in part, due to improved capture into the disability population. The change from 'slow at learning or understanding' to 'difficulty learning or understanding' appears to have increased the positive response to this criterion across all age groups (see graph 3.4). This provided a greater pool of children who then went on to be asked questions to determine severity of restriction. Given this opportunity, 50% were classified with a severe restriction, a proportion very little higher than in 1988, although here, as in many instances, 1993 returned a lower result (see graph 3.5).

Before attributing undue effect to the change in wording, it is useful to look at the response to the speech problems criterion, where the wording was unchanged (see graphs 3.6 and 3.7). These questions were asked *before* the difficulty learning questions. While speech problems can arise because of hearing loss, there was no significant increase in hearing loss and the numbers were just over half of those with speech problems. Speech problems also relate to intellectual disorders and developmental delays. The movement patterns over the four years are so similar that they suggest an independent external contribution, either prevalence or reporting, in addition to the language change.

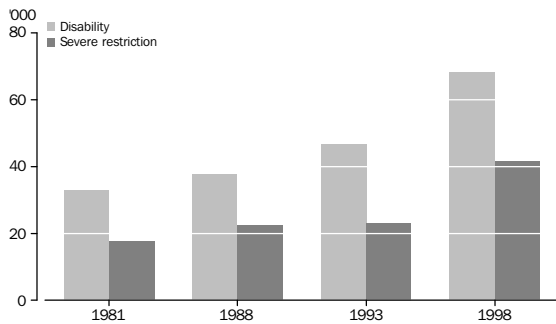
**3.4 CHILDREN AGED 5–14, Difficulty learning or understanding(a)—disability and severe restriction**



**3.5 CHILDREN AGED 5–14, Difficulty learning or understanding—severe restriction as a proportion of disability(a)**

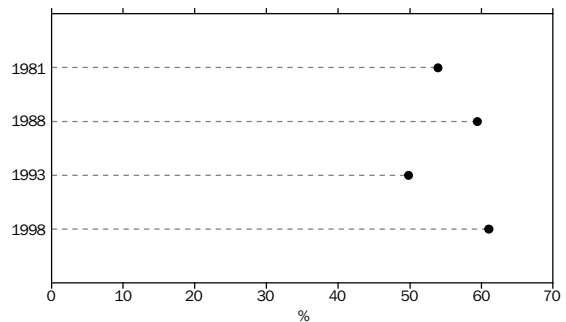


**3.6 CHILDREN AGED 5–14, Speech problems—disability and severe restriction(a)**



(a) Adjusted and age standardised series.

**3.7 CHILDREN AGED 5–14, Speech problems—severe restriction as a proportion of disability(a)**



(a) Adjusted and age standardised series.

## CONCLUSION

Both the modification of the learning and understanding screening question and early intervention policies have led to an increased capture of intellectual and developmental disorders in the 1998 survey. The number entering the disability population provided a larger base for the identification of severe restriction.

There are several possible reasons for the increased rate of ADHD found in the 1998 disability survey: actual increase of the condition, a greater level of awareness and diagnosis, the medicalisation of behaviour disorders, and the changed wording of the disability screening question about learning difficulty. Whether there is an actual change in prevalence cannot be known. The National Health and Medical Research Council noted in 1997 that, 'The apparently increasing prevalence of ADHD occurs in the context of raised awareness amongst parents, educators and health professionals of the adverse effects of learning and behavioural problems in children.' So the increase seems to be due, at least in part, to greater awareness and hence diagnosis of the disorder. Where parents understand the behavioural or learning problems of their children as a medical condition, it then becomes appropriate to report them in the disability survey, which operates within a health framework. It should be noted that classification to severe restriction depends on responses to a large number of further questions. While the 1998 disability survey identified 75,200 children with intellectual and developmental disorders, and 70,900 with behavioural disorders, living at home, around half of these children had a profound or severe restriction (48% and 50% respectively, on an unadjusted basis).

In the underlying adjusted and age standardised series, children aged 5 to 14 account for 0.2 percentage points out of the overall 1.0 percentage points difference between the 1998 and 1993 severe restriction rates.

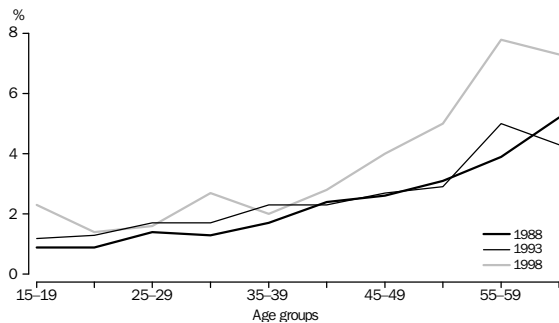


**SEVERE RESTRICTION IN ADULTS AGED 15 TO 64 YEARS** .....

For this age group, patterns of prevalence of severe restriction for men and women are broadly similar by respective survey (graphs 4.1 and 4.2). Men had slightly higher rates in 1993 than in 1988 in the younger age groups, and for the 55 to 59 age group, with substantial increases in 1998 in all but three age groups. The relationship between the surveys for women is less even, but there is some suggestion of the three surveys tracking particular age cohorts. The most noticeable feature for both men and women is the much higher severe restriction rate in the 1998 survey for those aged 45 to 64 years. The increase is significant for men in this age group, and for women aged 35 to 54 and 60 to 64 compared with 1993, and 45 to 54 compared with 1988. The effect of these increased rates on the total population rate in 1998 is magnified by the 'baby boomer' population increase in the 45 to 54 age group.

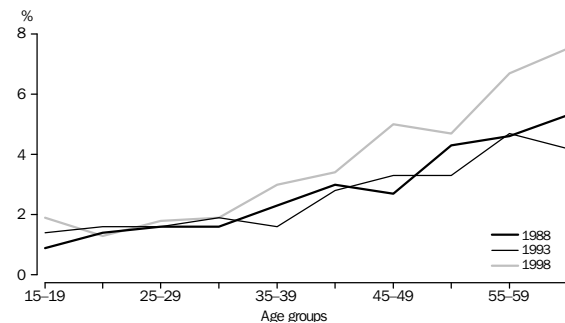
Almost all people with a severe restriction in the 15 to 64 age group live at home (rounds to 100%) (graphs 4.3 and 4.4). In cared accommodation, as a proportion of all people in the age group, there is a consistent decrease from 1988 for younger people, up to age 29 years, showing the effect of deinstitutionalising; community group houses are treated

**4.1 MALES AGED 15–64, Severe restriction rate(a)(b)**



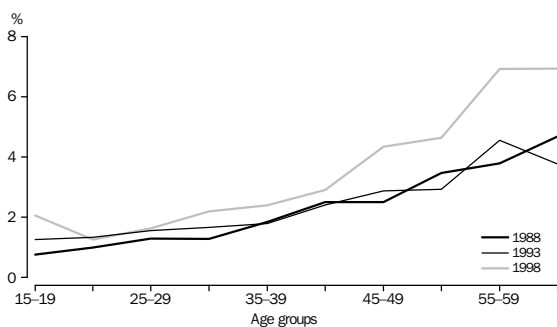
(a) Includes profound restriction in 1993 and 1998.  
 (b) Data adjusted for comparability across surveys.

**4.2 FEMALES AGED 15–64, Severe restriction rate(a)(b)**



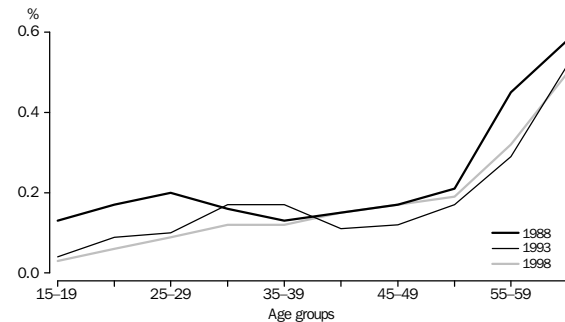
(a) Includes profound restriction in 1993 and 1998.  
 (b) Data adjusted for comparability across surveys.

**4.3 PERSONS AGED 15–64, Proportion with severe restriction living in households(a)(b)**



(a) Includes profound restriction in 1993 and 1998.  
 (b) Data adjusted for comparability across surveys.

**4.4 PERSONS AGED 15–64, Proportion with severe restriction living in cared accommodation(a)(b)**



(a) Includes profound restriction in 1993 and 1998.  
 (b) Data adjusted for comparability across surveys.

as part of the household population, and cannot be separately identified. The proportions of people aged 30 to 54 in cared accommodation are relatively stable across the surveys; they increase from the age of 55 years, but 1993 and 1998 are below the level for 1988.

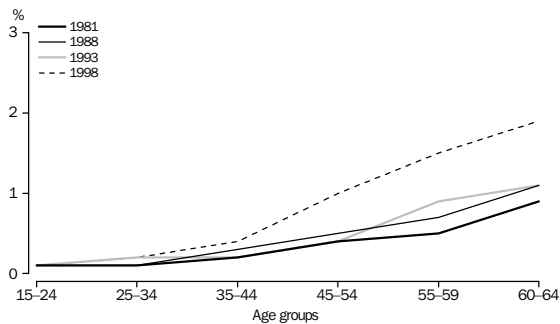
TYPE OF DISABILITY OR CONDITION

A number of the items in the 1998 survey can assist in understanding the populations with increased rates. Positive screening question responses, types of conditions, the restrictions they experience, self-assessed health and well-being status, among others, provide a picture of these groups, and some evaluation of their level of severity classification.

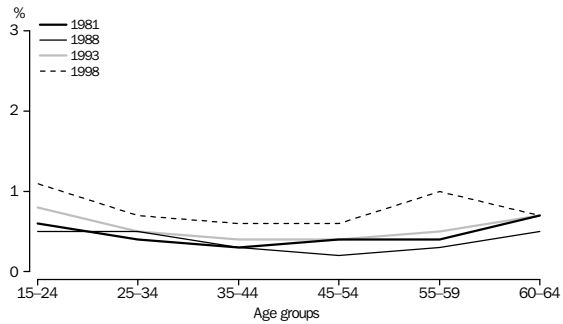
For six of the twelve screening criteria, age-specific severe restriction rates show no change over the surveys. For the remaining six (illustrated in the following graphs), there appear to be increases in 1998, but the rates are very low, the numbers in the age groups relatively small, and increases by particular age group not significant. 'Restriction in physical activity or physical work' (which showed no increase for disability), is the only screen question where there is an increase for some age groups—people in the 55 to 64 age groups, or aged 45 to 64 overall. Overall increases for the 15 to 64 age group, however, were significant for learning and understanding difficulties, for mental illness requiring help or supervision, for hearing loss and for limited use of hands and fingers.

4.5 ALL PERSONS AGED 15–64, Severe restriction rate(a) by selected screening criteria(b)

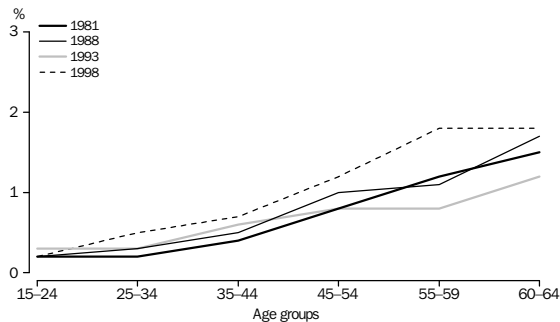
a. Hearing loss



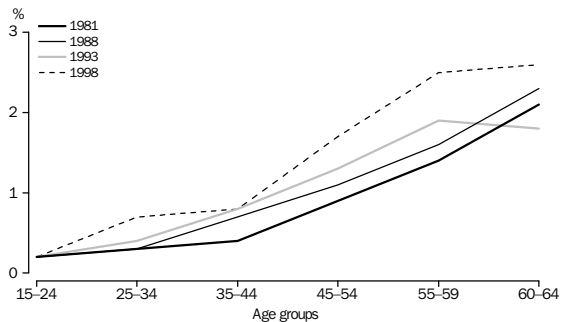
b. Slow at learning or understanding



c. Supervision needed for mental illness



d. Limited use of arms and fingers

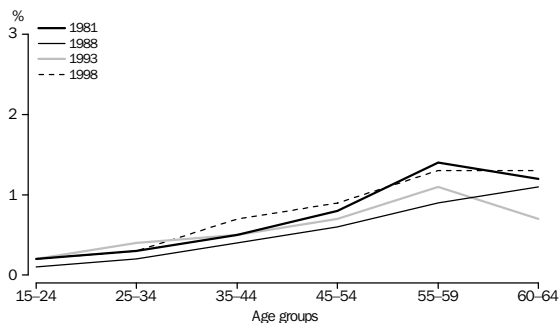


(a) Includes profound restriction in 1993 and 1998.

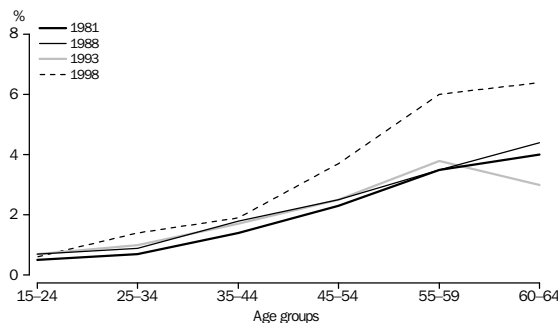
(b) Data adjusted for comparability across surveys.

4.5 ALL PERSONS AGED 15–64, Severe restriction rate(a) by selected screening criteria(b) *continued*

e. Limited use of feet and legs



f. Restriction in physical activity or physical work



(a) Includes profound restriction in 1993 and 1998.

(b) Data adjusted for comparability across surveys.

Consistent with the prominence of 'restriction in physical activity or physical work' is the increase in 1998 in the reporting of musculoskeletal conditions, particularly conditions other than arthritis (more than two and a half times for the 45 to 64 age group), both generally and as a main condition. The increase in the total population reporting these conditions, possibly as a result of the new pain criterion, required investigation.

As long-term conditions have also been collected every five years in the National Health Survey (NHS), it was possible to compare the results from the two surveys. The questions of interest were whether the NHS had recorded increases from the previous survey in 1989–90 and whether the greatly increased prevalence in the 45 to 64 age group would be within or close to that reported in the most recent NHS (1995).

Table 4.6 shows that the NHS actually recorded a decline in musculoskeletal disorders between 1989–90 and 1995; however the rates for 1995 were still considerably higher than those recorded in the 1998 disability survey. For the 45–64 age group the rates per 1,000 population were 389.9 and 293.3 respectively. For disorders other than arthritis in this group the rate is equivalent to the NHS, while arthritis still appears to be undercounted.

4.6 PERSONS LIVING IN PRIVATE DWELLINGS, Musculoskeletal disorders as a long-term condition—rate per 1,000 population, as reported

	25–45 years.....				45–64 years.....			
	NHS 89–90	SDAC 93	NHS 95	SDAC 98	NHS 89–90	SDAC 93	NHS 95	SDAC 98
Arthritis	57.4	25.6	82.0	28.7	216.4	138.6	280.1	153.7
Other musculoskeletal disorders	n.a.	33.7	137.3	111.0	n.a.	78.6	192.5	198.6
Total musculoskeletal disorders	269.6	54.5	193.6	129.0	430.2	192.9	389.9	293.3
Population ('000)	5,361.1	5,429.6	5,583.6	5,708.3	3,248.7	3,462.3	3,739.7	3 996.1

n.a. Not available

Sources: ABS, National Health Survey: Summary of results, Australia (Cat.no.4364.0) 1989–90 and 1995; unpublished 1989–90 and 1995 NHS data; and unpublished 1993 and 1998 SDAC data.

Health conditions *continued*

This is not unusual. Compared with the NHS, the disability surveys tend to undercount a number of long-term health conditions, probably because they are not the primary focus of the survey: they are collected as the cause of a disability or impairment, and may not be brought to mind unless they restrict activities. It would appear that musculoskeletal conditions other than arthritis (overwhelmingly back, neck and shoulder disorders) were perceived as restricting conditions in this age group in 1998, and arthritis less restricting.

Disability Support Pension—health conditions

Another source that may be compared with the disability survey for people aged 15 to 64 years is Centrelink data on recipients of the Disability Support Pension (DSP). The disability survey also identifies a population receiving the DSP. The survey identifies a smaller number than shown in the Centrelink data, 433,700 overall (21% of the disability population in this age group) compared with 544,100. In the Centrelink analysis by main

**4.7 DISABILITY SUPPORT PENSION RECIPIENTS AGED 15–64, Main condition**

	45–54 YEARS.....		55–64 YEARS.....		15–64 YEARS.....	
	Centrelink(a)	SDAC98	Centrelink(a)	SDAC98	Centrelink(a)	SDAC98
<i>Main condition</i>	%	%	%	%	%	%
Cancer/tumour	2.4	4.1	3.5	2.3	2.3	2.5
Circulatory system	6.0	6.2	13.1	14.2	6.7	7.9
Endocrine, immune system	2.4	3.8	1.7	4.1	2.3	2.8
Musculoskeletal (includes amputations)	40.6	40.6	53.1	44.8	36.6	35.3
<i>Total intellectual, nervous system and congenital disorders</i>	14.4	14.6	5.7	8.0	19.5	22.1
Intellectual/learning	6.3	1.4	0.6	0.5	11.0	5.2
Nervous system	4.1	9.8	2.7	5.2	3.7	10.9
Congenital abnormality	1.1	0.6	0.4	1.1	1.9	3.2
Acquired brain impairment	2.9	2.8	2.0	1.2	2.9	2.8
Psychological/psychiatric	24.3	16.8	10.7	6.1	22.7	14.4
Respiratory system	4.0	7.6	6.7	6.1	3.9	5.2
Sense organs	2.2	2.3	2.7	4.2	2.5	3.0
Visceral disorder	2.0	1.2	1.7	3.8	1.9	2.0
Other	1.7	2.8	1.1	6.4	1.6	4.8
<b>DSP recipients distributed by condition</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
	'000	'000	'000	'000	'000	'000
DSP recipients distributed by condition	130.9	123.7	143.2	163.5	435.9	433.7
Total DSP recipients	147.5	123.7	210.3	163.5	544.1	433.7

(a) Excludes people granted a Disability Support Pension prior to 12/11/1991.

Sources: Unpublished DSP data from Centrelink, Quarter 1, 1998; unpublished 1998 SDAC data.

Disability Support Pension—health conditions *continued*

health condition, however, there is a group of people granted the pension prior to 12 November 1991 not distributed by condition. The following comparison omits these people, the remaining population being similar in size to the survey population.

This type of comparison should be treated very cautiously: the Centrelink data comes from administrative records, and the primary condition is clinically assessed; in the disability survey (a large-scale sample population survey) reported receipt of the DSP, as well as conditions and assessment of main condition, rests on the awareness of the respondent. The information available about a condition affects the way it is classified. It is possible for the same people to be categorised differently in the two collections.

For example, in table 4.7 the disability survey includes Down's Syndrome in congenital abnormalities, and cerebral palsy in nervous system disorders. For DSP assessment, it *may* be that intellectual disability associated with these conditions or with brain damage is recorded as the primary condition. For this reason, a subtotal is provided for these four types of condition. A further concern is possible bias because of the undercount in the survey, and the undistributed people in the Centrelink data. There could also be up to three months difference in the collection period, allowing some slippage between age groups.

Notwithstanding these concerns, the distribution of main condition for the DSP population in the disability survey is consistent overall with the distribution in the Centrelink data, the poorest match being for psychological conditions. Musculoskeletal disorders align very closely overall, and in the 45 to 54 age group, but are somewhat lower for the disability survey in the 55 to 64 age group. This is further confirmation that the reporting of musculoskeletal disorders, and their selection as main conditions, are not overstated in the 1998 survey.

## POSSIBLE INFLUENCES

The improved capture of musculoskeletal conditions in the 1998 disability survey may have a number of causes. Most of the difference is present in the adjusted comparison series. People who entered the disability population through the restricting chronic pain question alone are excluded from this series. However, the question about chronic pain was answered by a high proportion of those who also met other physical criteria for disability, and are therefore included in the underlying series. It is likely that the addition of this particular question encouraged respondents to think about chronic pain and the medical conditions underlying it in a more focused way.

The new chronic pain criterion may also have indirectly affected responses to other screening questions and their causes, such as those on incomplete use of arms and fingers, feet and legs, and the physical restriction screen. The latter two show a slight increase on the 1993 age-specific rates for disability, but are the same as or below 1988 rates, for people aged 45 to 64. There is an increase in those reporting incomplete use of arms and fingers for people aged 45 to 59 years.

The increase in reporting of incomplete use of arms and fingers and musculoskeletal disorders, however, might simply reflect a wider experience of activity limitations arising from these conditions, perhaps relating to the types of equipment more commonly used

POSSIBLE INFLUENCES *continued*

now in manufacturing and clerical work. Once admitted to the disability population, a much higher proportion of the population with these characteristics were classified as having a severe restriction, as shown in the screening criteria graphs earlier in this chapter.

A further possible contributor to better capture of particular conditions might be the use of the Computer Assisted Interviewing instrument, with the capacity for coding to pick-lists and Computer Assisted Coding in the field, in the cases where descriptions matched. A smaller proportion of conditions overall were coded to 'dump' categories associated with the screening questions in 1998 than in 1993.

## APPROPRIATENESS OF CLASSIFICATION

The next issue is whether those with a severe restriction in the 45 to 64 age group have been appropriately classified. This section considers a range of disadvantages and difficulties people may have, to assess whether assignment to severe restriction is justified. The increase in the 1998 disability survey was in the severe, not the profound, restriction population. Unless otherwise indicated, the analysis refers to the severe restriction population living in households, in the 15 to 64 age group, using unadjusted data, and sometimes considering only those aged 45 to 64 as the location of significant increase.

## Labour force experience

The labour force participation rate was 19% for those with a profound restriction and 40% for those with a severe restriction, compared with 53% for everyone with a disability, and 80% for those without a disability (aged 15 to 64).

Over 90% of those with severe or profound restrictions had an employment restriction (difficulty finding or changing jobs, restricted in type of work, needing at least one day a week off work, needing special arrangements at work, or permanently unable to work) because of their condition.

## Income

Of people aged 15 to 64 with a severe or profound restriction, 37% received the Disability Support Pension, and constituted 42% of recipients; a further 26% received another type of pension.

## Need for assistance

People aged 45 to 64 with a severe restriction averaged a need for assistance with 1.9 core activity tasks, compared with 3.8 for people the same age with a profound restriction (table 4.8). The most common areas of need for those with a severe restriction were, in order, moving around away from home, dressing and getting out of bed or a chair, with a smaller proportion needing help moving around at home, and showering—that is, the tasks involving mobility and body disposition or flexibility.

**4.8 PERSONS AGED 45–64 WITH A SEVERE OR PROFOUND RESTRICTION LIVING IN HOUSEHOLDS, Need for assistance—1998**

Tasks for which assistance needed	SEVERITY OF RESTRICTION.....		
	Profound(a)	Severe(a)	Profound and severe
	%	%	%
Showering	54.9	17.7	26.0
Dressing	60.3	42.6	46.6
Eating	30.3	5.0	10.6
Toileting	22.6	4.3	8.4
Bladder/bowel control	19.1	6.1	9.0
Mobility away from home	82.2	45.8	53.9
Mobility around home	38.8	22.4	26.1
Bed/chair transfers	41.8	40.9	41.1
Understanding strangers	10.7	1.1	3.2
Understanding family/friends	4.1	0.7	1.5
Being understood by strangers	9.0	0.6	2.5
Being understood by family/friends	6.3	0.3	1.7
Average number of tasks	3.8	1.9	2.3

(a) People with a profound restriction *always* need help with at least one of these tasks; people with a severe restriction *sometimes* need help with one or more of these tasks.

SF-12

The 1998 disability survey included an international standard instrument, the SF-12, to measure self-assessed well-being. This is sometimes taken as a measure of disability in a population. Two scales are built from the responses to the 12 questions, a mental (MCS-12) and a physical (PCS-12) scale. An average score is close to 50, declining slightly by age for the physical scale score; lower scores indicate poorer well-being. Table 4.9 from the SF-12 manual shows mean results in the USA, as a guide to interpretation.

**4.9 MEAN MCS-12 AND PCS-12 SCORES, By age group**

(n=27,361)	Age groups.....			
	18–44	45–54	55–64	65 and over
MCS-12	48.4	50.1	52.9	53.7
PCS-12	52.5	51.0	49.4	45.5

Source: Ware et. al., 1995.

**4.10 PERSONS WITH SEVERE RESTRICTIONS(a) LIVING IN HOUSEHOLDS, MCS-12 and PCS-12 scores—1998**

Main condition	Age group.....					Total
	35-44	45-49	50-54	55-59	60-64	
AVERAGE MCS-12						
Arthritis	43.1	50.6	45.3	48.9	45.6	46.7
Other musculoskeletal conditions	42.0	45.6	47.3	43.8	49.0	45.0
Other physical conditions	47.4	45.6	43.4	47.0	48.0	46.2
Mental/behavioural disorders	33.1	28.9	32.6	37.6	38.2	33.3
<i>Total</i>	42.6	44.9	45.0	45.7	47.0	44.8
AVERAGE PCS-12						
Arthritis	34.0	33.6	29.8	28.8	27.9	30.5
Other musculoskeletal conditions	32.1	30.5	27.6	27.8	23.3	29.2
Other physical conditions	34.0	30.9	31.7	28.8	29.8	31.1
Mental/behavioural disorders	39.9	37.8	42.2	34.7	36.5	38.7
<i>Total</i>	33.9	31.5	30.1	28.8	28.1	30.8

(a) Excludes persons with profound restrictions.

SF-12 continued

Only those with a disability who were interviewed in person (not by proxy) were taken through the SF-12. Those who were not able to answer these questions are likely to be even more severely restricted.

The severity of limitation of the population with a physical main condition is confirmed by the physical scale (PCS-12), the lowest scores being for those with musculoskeletal disorders other than arthritis. The mental scale also returned results a little lower than average for those with a physical main condition. The severity classification of those with a mental/behavioural main condition in these age groups is unlikely to be challenged, but it is likewise confirmed on both the physical and mental scales (table 4.10).

**4.11 PERSONS WITH SEVERE RESTRICTIONS, Proportion who needed assistance or had difficulty with guidance tasks(a)**

Main condition	MALES.....				FEMALES.....			
	45-49	50-54	55-59	60-64	45-49	50-54	55-59	60-64
	%	%	%	%	%	%	%	%
Arthritis	9.5	32.8	52.1	36.7	25.0	26.0	46.4	53.9
Other musculoskeletal conditions	45.2	45.1	55.2	37.0	51.0	51.6	61.0	28.4
Other physical conditions	62.8	61.3	69.6	46.0	60.6	55.1	50.4	43.0
Mental disorders	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Unpublished unadjusted 1998 SDAC data.



Guidance tasks

It was expected that people with a mental/behavioural disorder would need assistance or have difficulty with guidance tasks, i.e. making decisions, coping with emotions and making and maintaining relationships. The proportion of people aged 45 to 64 with a severe restriction and a *physical* main condition who required guidance assistance because of their condition is revealing—their situation is more complex than first appears. Either they have more than one condition, or that condition creates a range of difficulties for them in their daily lives. The impact of coping difficulties is generally highest for the 55 to 59 age group, for men and women (table 4.11).

Persons not in the labour force: main activity

There is further evidence of an increase in the consciousness of restriction in this age group. The ABS regularly collects information on people who are not in the labour force. There has been an increase in the number (from 328,000 to 438,000) and proportion (from 8.9% to 12%) of these people citing 'own illness or injury' or 'own disability or handicap' as their main activity, between 1993 and 1998. The numbers are similar for men and women. The increase represents 0.5% of the total population, and 61% of this (0.3% of the total population) is contributed by people aged 45 to 64 (ABS 1994 and 1999d).

Number of conditions

As the number of health conditions increases, so does the likelihood of difficulty with everyday activities, and so of more severe restriction (although a person may be profoundly restricted by just one condition). Three-quarters of those aged 45 to 64 with a severe restriction had more than one health condition, and over half had more than two (table 4.12). This seems to be appropriate, and consistent with other levels of severity. The proportions of people with multiple conditions are consistent with the SF-12 and the guidance findings, and with the increased proportions of hearing loss, mental illness

**4.12 PERSONS AGED 45–64, Number of health conditions(a)**

.....

Number of health conditions	DISABILITY STATUS.....					
	Profound	Severe	Moderate	Mild	All with disability	No disability
	%	%	%	%	%	%
One	12.1	23.5	24.4	34.3	32.1	21.0
More than one	87.9	76.5	75.6	65.7	67.9	8.4
More than two	63.4	54.8	50.9	36.9	41.3	2.0
More than three	42.0	36.1	27.1	18.6	21.8	0.5
More than four	27.1	21.0	14.7	7.3	10.7	0.0
More than five	19.2	11.0	6.2	2.8	5.3	0.0
<b>All persons with conditions</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>29.3</b>

.....

(a) Unpublished unadjusted 1998 SDAC data.

Number of conditions *continued*

requiring supervision and intellectual impairment; together they present a picture of people with compound difficulties. The distribution of numbers of conditions by level of severity is very similar in the 1998 and 1993 surveys.

Effect of Disability Support Pension (DSP)

People who are eligible for the DSP must:

- Be 16 years or over;
- Have not reached Aged Pension age; and
- Meet the residential obligations for a government benefit.

Those who are permanently blind automatically qualify for DSP. Those who have a physical, intellectual or psychiatric impairment assessed at a certain level and a continuing inability to work qualify for DSP. Those who have a continuing impairment where they are unable to work or be retrained to work 30 hours or more a week within the next two years also qualify for the DSP.

Do DSP data support the level of severity classification in the disability survey? Does the need to protect access to the DSP influence respondents' answers to the disability survey, and thereby inflate the numbers with severe restriction? The eligibility criteria suggest the relationship between the severity classification and DSP receipt is more complex.

Table 4.13 shows that 15% of DSP recipients have a profound restriction, and 27% a severe restriction. Respondents are not likely to relate the questions establishing severe and profound restriction to the criteria for the DSP. The strongest association is with schooling/employment restrictions (93%), an umbrella group which may include people in all the restriction level groups as well as those with employment limitations only (quite a small group). Conversely, over half of the people with a profound restriction in the

**4.13 PERSONS AGED 15–64 LIVING IN HOUSEHOLDS, Severity group and receipt of Disability Support Pension—1988**

	<i>Profound</i>	<i>Severe</i>	<i>Moderate</i>	<i>Mild</i>	<i>Schooling/ employment restriction</i>	<i>Schooling/ employment restriction only</i>	<i>All with specific restriction</i>	<i>All with disability</i>	<i>No disability</i>	<i>All persons</i>
	%	%	%	%	%	%	%	%	%	%
SEVERITY GROUP AS PROPORTION OF DSP RECIPIENTS										
DSP recipients										
15–44	21.0	26.0	17.9	16.6	93.3	13.0	94.6	96.4	3.6	100.0
45–64	12.4	26.8	26.5	23.6	92.5	5.7	94.9	96.1	3.9	100.0
<b>Total</b>	<b>15.3</b>	<b>26.5</b>	<b>23.6</b>	<b>21.2</b>	<b>92.8</b>	<b>8.1</b>	<b>94.8</b>	<b>96.2</b>	<b>3.8</b>	<b>100.0</b>
DSP RECIPIENTS AS PROPORTION OF SEVERITY GROUP										
All persons										
15–44	47.6	25.2	17.2	9.1	19.9	10.8	17.0	14.6	0.1	1.7
45–64	58.1	36.0	29.1	21.1	33.6	15.5	28.3	25.0	0.4	7.1
<b>Total</b>	<b>52.7</b>	<b>31.5</b>	<b>24.7</b>	<b>15.6</b>	<b>27.3</b>	<b>12.6</b>	<b>23.2</b>	<b>20.2</b>	<b>0.2</b>	<b>3.5</b>

Source: Unpublished unadjusted 1998 SDAC data.

Effect of Disability Support Pension (DSP) *continued*

15 to 64 age group reported receiving DSP, and less than a third of people with severe restriction. There is no increase in the profound restriction rate in 1998. DSP receipt does not appear to have biased responses, and is spread across the levels of restriction.

## Other contributors

Overall, the level of severity assigned, and the numbers of people with other musculoskeletal conditions, do not appear to be overstated. What then can account for the increased number of people aged 45 to 64 with severe restrictions? There are two elements here, numbers and age-specific rates. There is a large population wave moving into the age where disability rates begin to increase sharply (45 to 54 years), and rates of severe restriction are moving gently upwards. This rising tendency combined with the size of the population will increase the numbers and the overall population rate with severe restriction. It is not just the numbers, however, but the actual age rates that have increased compared with the earlier surveys.

Most of the increase in this group relates to physical impairment, with a smaller contribution from intellectual and psychological impairment. The significant increase in condition type is in musculoskeletal disorders other than arthritis, although there is also a substantial, steady proportion with arthritis and with psychiatric disorders.

Over 70% of people with a severe restriction in the 45 to 64 age group were not employed. A number of sources were examined to see whether the severity of restriction might be work-related.

There is little evidence of increased workers' compensation claims because of these conditions. Mayhew (2000) points out, however, that there is a shift in employment in Australia to an increasing proportion of 'micro small businesses', self-employed workers and workers in owner-operated businesses; international and Australian studies have identified a much higher rate of work-related fatalities among self-employed and subcontracting workers (typically, more than double); some of the reasons are that:

- These businesses tend to be concentrated in high-risk industries;
- Industry data from non-insured workers are not collected; many of these workers are formally excluded from workers' compensation insurance cover, and very few take out non-compulsory insurance; thus insurance feedback does not inform practice; and
- These types of workers are under greater economic pressure, and tend to normalise familiar patterns of injury, rather than take remedial action.

Table 4.14 provides some support for this view. There was a higher proportion of people aged 15 to 64 employed in 1998, with an increase from 1993 in the proportion of people who were self-employed, owner-operators or family workers in the 45 to 64 age group. Among people with a severe restriction, the increase was much greater, and was found across the 15 to 64 age group. The numbers of self-employed or family-employed people with severe restriction were small, however, 8,000 for the 45 to 64 group and 26,000 for the 15 to 64 age group. Unfortunately, it is not possible to determine how many of those who were no longer employed had previously been self-employed.

**4.14 PERSONS AGED 15–64, LIVING IN HOUSEHOLDS, Employment status(a)**

	SEVERE RESTRICTION(b).....		ALL PERSONS.....	
	1993	1998	1993	1998
<i>Employment status</i>	%	%	%	%
.....				
45–64 YEARS				
Not applicable	83.3	71.1	40.3	24.7
Employee	13.0	22.1	47.1	60.5
Other status	3.7	6.8	12.6	14.8
Employer	1.2	0.7	3.5	4.7
Own account worker	2.5	5.1	8.9	9.6
Family worker	0.0	1.0	0.2	0.5
Total	100.0	100.0	100.0	100.0
.....				
15–64 YEARS				
Not applicable	75.7	73.1	35.7	30.7
Employee	20.7	20.2	55.2	59.8
Other status	3.6	6.7	9.2	9.5
Employer	1.3	1.2	2.6	3.0
Own account worker	2.3	4.5	6.3	5.9
Family worker	0.0	1.0	0.3	0.6
Total	100.0	100.0	100.0	100.0

(a) Data adjusted for comparability across surveys.

(b) Includes profound restriction in 1993 and 1998.

Respondents were asked about the cause of their main condition (table 4.15). For many people in the 45 to 64 age group with a severe restriction, their conditions began unobtrusively and developed slowly: a quarter of the group answered that they did not know how their condition began, or that the condition had just come on. Disease accounted for a further 13% of this population, and 16% cited a variety of other causes, including stress, family problems, allergies, and smoking.

The most common responses, though, were accidents and injuries, and work-related causes, 47% of the population. Of those reporting accident or injury, half were injured at work, so that work-related disorders affected 34% of this population overall.

For the 40% of the group who had other musculoskeletal disorders as a main condition, three-quarters cited accidents or injuries, or 'work, working conditions, overwork' as the cause. The workplace was the reported site of 60% of the accidents or injuries for this group, and the combination of work-related disorders and workplace accidents was the cause of the main condition for well over half (58%) of the other musculoskeletal conditions group.

## 4.15 PERSONS AGED 45–64(a) WITH SEVERE RESTRICTIONS, Cause of main condition—1998

Cause of main condition	MAIN CONDITION.....				Total
	Arthritis	Other musculoskeletal conditions	Other physical conditions	Mental disorders	
	%	%	%	%	%
Work-related	19.9	34.9	7.2	25.3	21.3
Accident or injury	18.9	39.2	17.4	5.0	25.7
At work	5.8	23.4	6.7	—	12.9
On the road	3.1	8.3	5.9	—	6.1
Disease, heredity	16.7	2.4	22.7	3.3	12.5
Just came on	21.3	9.4	18.7	7.5	14.7
Don't know	14.5	7.3	11.9	8.0	10.2
Other causes(b)	8.8	6.8	22.1	51.0	15.6
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
<b>Total ('000)</b>	<b>32.6</b>	<b>85.8</b>	<b>83.2</b>	<b>12.1</b>	<b>213.7</b>

(a) Living in households

(b) Includes stress, family problems, smoking etc.

Source: Unpublished unadjusted 1998 SDAC data.

## CONCLUSION

The information known from the 1998 survey about this group is consistent with information from a number of other sources. A wide range of internal evidence supports the accuracy of the classification to severe restriction. There are indications of increased disability in this age group from the rise in the number and proportions of DSP recipients, and in the number of people not in the labour force reporting their own illness/injury or disability as their main activity.

It is possible that the social, economic and workplace environments are contributing to an increase in the number of conditions and the difficulties people face. It is clear, for instance, that reporting of hearing loss continues to increase dramatically. More thorough measurement, or more frequent diagnosis, may be increasing reporting of many conditions. Public campaigns, for instance on mental illness, may make it easier or more acceptable to talk about these conditions.

There is evidence, however, that a major feature characterising this group, the increase in musculoskeletal disorders, represents better capture of the condition rather than picking up on actual change, and this may extend to level of severity as well. It is likely that the Computer Assisted Interview contributed to this result, by maintaining a momentum in a survey which requires frequent returns to earlier responses. It is very likely that the introduction of the pain question focused people more on their actual experience, and encouraged them to report things they may not otherwise have thought important

CONCLUSION *continued*

enough for a national survey. The specification of 'everyday' activities in the questions about restriction that were designed to filter people *out* of the disability population may have had the opposite effect.

Taking people through the SF-12 questions prior to the questions about core activity restrictions may have modified the context in a way that could sensitise people more to the questions asked. Analysis of the one question common to the SF-12 and the survey, however (ability to walk up and down stairs) indicated that respondents were able to take each question on its own terms, and could distinguish differences—the survey qualified the question by adding 'without a handrail', and many people modified their answer.

The 45 to 64 population with a severe restriction contributed 83,500 out of the 198,200 additional people, 0.45 percentage point out of the 1.0 percentage point of difference between the total 1998 and 1993 severe restriction rates, based on adjusted, age standardised data. The difference between the numbers with musculoskeletal disorders other than arthritis within this population in 1998 compared with 1993 probably constituted a high proportion of this, up to 0.39 percentage points. It is likely that a high proportion of the latter, perhaps around 0.35 percentage points, is better capture because of survey developments.

# CHAPTER 5

## SEVERE RESTRICTION IN OLDER PEOPLE AGED 65 YEARS AND OVER .....

### CONTRIBUTING FACTORS

#### Ageing population

Population ageing is one reason for the increase in the number of older people with severe restrictions from disabilities. People aged 65 and over constituted 11.6% of the general population in 1993, reaching 12.2% by 1998. The most rapid increases

### 5.1 DISTRIBUTION OF POPULATION AGED 65 AND OVER—1993 and 1998

Age group				TOTAL POPULATION RATE.....		
	June 1993 '000	June 1998 '000	Difference '000	June 1993 %	June 1998 %	% change
MALES						
65–69	330.0	334.3	4.3	1.9	1.8	-4.5
70–74	250.6	286.0	35.4	1.4	1.5	7.6
75–79	163.4	200.5	37.1	0.9	1.1	15.7
80–84	93.0	110.1	17.1	0.5	0.6	11.7
85 and over	50.1	68.3	18.2	0.3	0.4	28.5
Total 65 and over	887.2	999.2	112.0	5.0	5.3	6.2
<b>Total</b>	<b>8 795.5</b>	<b>9 313.9</b>	<b>524.4</b>	<b>49.8</b>	<b>49.8</b>	<b>0.0</b>
FEMALES						
65–69	355.6	348.7	-6.9	2.0	1.9	-7.5
70–74	303.5	329.9	26.4	1.7	1.8	2.5
75–79	230.2	267.9	37.7	1.3	1.4	9.7
80–84	158.0	180.0	22.0	0.9	1.0	7.4
85 and over	121.4	156.0	34.6	0.7	0.8	21.2
Total 65 and over	1 168.7	1 282.5	113.8	6.6	6.9	3.5
<b>Total</b>	<b>8 866.2</b>	<b>9 10.5</b>	<b>544.2</b>	<b>50.2</b>	<b>50.2</b>	<b>0.0</b>
ALL PERSONS						
65–69	685.6	683.0	-2.6	3.9	3.7	-6.0
70–74	554.2	615.9	61.8	3.1	3.3	4.8
75–79	393.7	468.4	74.8	2.2	2.5	12.2
80–84	251.0	290.1	39.1	1.4	1.6	9.0
85 and over	171.5	224.3	52.8	1.0	1.2	23.3
Total 65 & over	2 055.9	2 281.7	225.9	11.6	12.2	4.7
<b>Total</b>	<b>17 661.7</b>	<b>18,730.4</b>	<b>1 068.6</b>	<b>100.0</b>	<b>100.0</b>	<b>0.0</b>

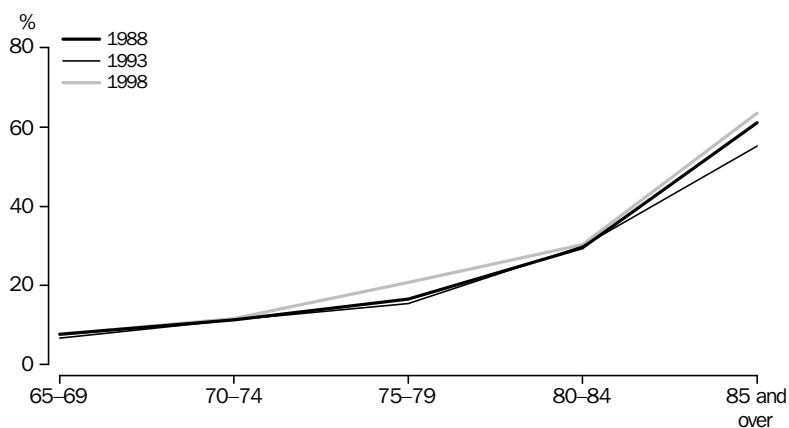
Sources: ABS 1997a and ABS 1998a.

Ageing population *continued*

were in the 75 to 79 age group (12%) and those aged 85 and over (23%), higher for men than women in both groups (table 5.1). The severe restriction rate is likely to continue to rise until the proportion of people becoming very old stabilises.

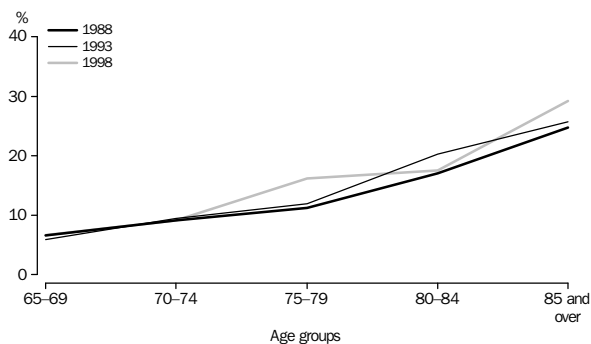
For three of the five age groups shown in the graph below, the rates of disability and severe restriction have remained very stable across the three surveys. The two groups with significant increases are the same two groups with the highest population growth, and in each case the increase in these rates is higher for men than for women. There is no significant difference in age-specific severe restriction rates from 1988 or 1993 for women. Men in the 75 to 79 age group had a significant increase in severe restriction in 1998, compared with both 1993 and 1988, and men in the oldest group compared with 1988 but not 1993.

**5.2 PERSONS AGED 65 AND OVER, Severe restriction rate(a)(b)**



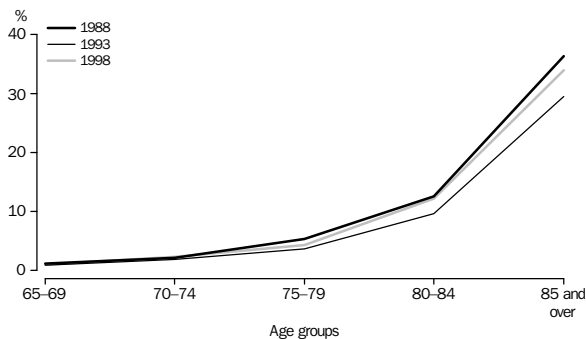
(a) Include persons with profound restrictions in 1993 and 1998.  
 (b) Data adjusted for comparability across surveys.

**5.3 PERSONS AGED 65 AND OVER, Proportion with severe restriction(a) living in households(b)**



(a) Includes persons with profound restrictions in 1993 and 1998.  
 (b) Data adjusted for comparability across surveys.

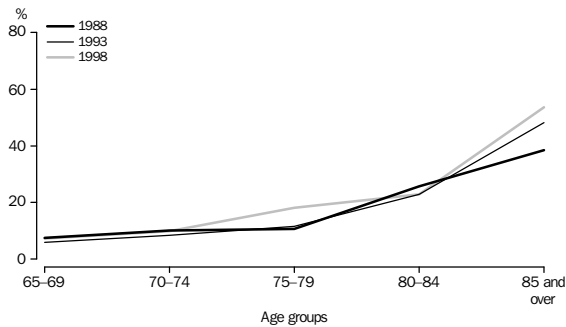
**5.4 PERSONS AGED 65 AND OVER, Proportion with severe restriction(a) living in cared accommodation(b)**



(a) Includes persons with profound restrictions in 1993 and 1998.  
 (b) Data adjusted for comparability across surveys.

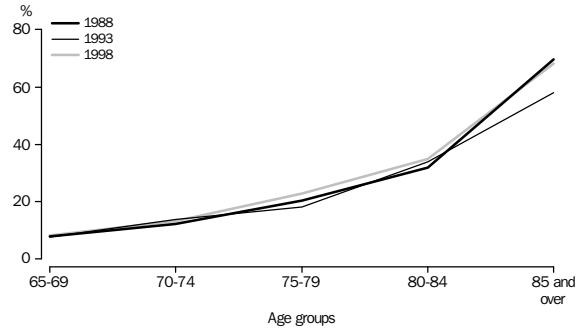


**5.5 MALES AGED 65 AND OVER, Severe restriction rate(a)(b)**



(a) Includes persons with profound restrictions in 1993 and 1998.  
 (b) Data adjusted for comparability across surveys.

**5.6 FEMALES AGED 65 AND OVER, Severe restriction rate(a)(b)**



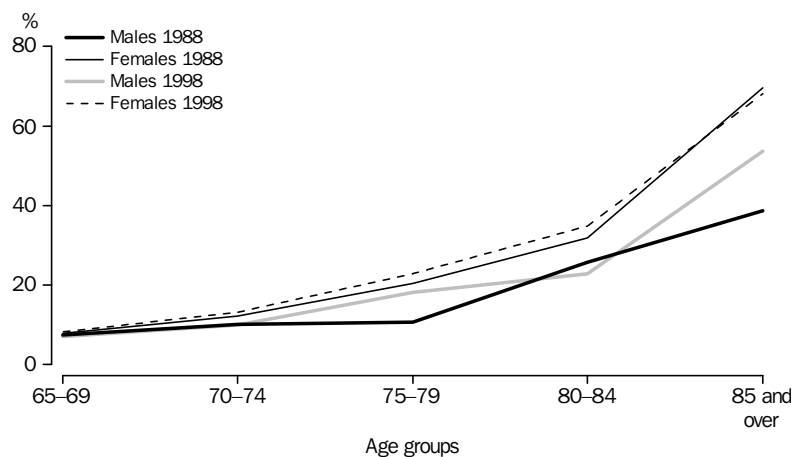
(a) Includes persons with profound restrictions in 1993 and 1998.  
 (b) Data adjusted for comparability across surveys.

Improved identification

Most of the increase in the population with severe restriction is found in people living in households, in the two age groups previously identified (graphs 5.3 and 5.4). In cared accommodation the rates for people aged 75 and over have risen, closer to 1988 than to 1993. Some of this is because information was not available in 1993 to distinguish severe from moderate restriction.

Men in later life have tended to have lower rates of severe restriction than women, but to die younger from events, such as heart attacks and strokes, that women were more likely to survive (two-thirds of people aged over 75 are women). Those men who lived into older age were more robust (graphs 5.5 and 5.6).

**5.7 PERSONS AGED 65 AND OVER, Severe restriction rate(a)(b)**



a) Includes persons with profound restrictions in 1998.  
 b) Data adjusted for comparability across surveys.

Improved survival rates

Both survival rates and consequent rates of restriction may now be changing for men, moving closer to the pattern for women. The median age at death for men has increased from 71.6 in 1988 to 74.5 in 1998 (ABS 1999a, p.16). Table 5.8 provides some evidence for this change in survival rates, and graph 5.7 for increasing severe restriction rates.

**5.8 RATIO OF WOMEN TO MEN, Persons aged 65 and over**

	1988	1993	1998
<i>Age group</i>	ratio	ratio	ratio
65–69	1.13	1.08	1.05
70–74	1.25	1.21	1.16
75–79	1.44	1.41	1.34
80–84	1.74	1.76	1.64
85 and over	2.64	2.29	2.27

Sources: ABS 1990, ABS 1993 and ABS 1999c.

**5.9 PERSONS AGED 75 AND OVER, Long-term circulatory diseases**

<i>Type of long-term circulatory disease</i>	1989-90.....		1995.....	
	'000	Rate(a)	'000	Rate(a)
Hypertension	183.8	267.1	317.6	393.6
Heart disease	81.8	118.9	117.1	145.1
Ill-defined signs and symptoms of heart disease	39.3	57.1	43.2	53.5
Stroke after effects	8.3	12.1	34.6	42.9
Other cerebrovascular disease	14.7	21.4	n.a.	n.a.
Varicose veins	36.4	52.9	96.2	119.2
Atherosclerosis(b)	6.4	9.3	..	..
Fluid problems(b)	20.1	29.2	..	..
Haemorrhoids	12.3	17.9	28.3	35.1
Other diseases of circulatory system	20.5	29.8	50.6	62.7
Total diseases of circulatory system(c)	332.1	482.6	479.6	594.3
<b>Total</b>	<b>688.1</b>	<b>1,000.0</b>	<b>807.0</b>	<b>1,000.0</b>

a) Per 1,000 population

b) Not separately available in 1995

c) Each person may have reported more than one type of illness and therefore components do not add to totals.

Source: ABS 1991 and ABS 1997b.

Improved survival rates *continued*

Taken with the higher median age at death, other ABS sources confirm a higher survival rate from circulatory disorders. A comparison of long-term conditions reported in the 1989–90 and 1995 National Health Surveys (table 5.9) shows that for the population aged 75 years and over, diseases of the circulatory system have increased from a rate of 482.6 per 1,000 population in 1989–90 to 594.3 per 1,000 population in 1995. Cause of death data (ABS 1999b) show that diseases of the circulatory system as an underlying cause of death have decreased for the population aged 75 years and over between 1989–90 and 1998. As a consequence of the increased life expectancy of men relative to women, there has been a reduction in the ratio of women to men in the population.

Health conditions

Men in the 75 to 79 age group have an interesting history. Born immediately after World War I, from 1919 to 1923 (and possibly during the influenza epidemic of 1919), they were children and young adolescents during the depression, of an age to fight in World War II, and possibly also in Korea. Their children may have fought in Viet Nam. In middle age, they had the advantage of new styles of food, with the rapid growth of Chinese and Italian restaurants, soon followed by other ethnic restaurants, health foods in the stores, and the whole emphasis in magazines on healthy cooking and exercise.

They were probably the first generation who commonly owned cars as young men, and for whom family and holiday travel was easy. Rapid increases in medical technology have become an accepted part of their lives, and access to medical

**5.10 PERSONS AGED 75–79 WITH SEVERE RESTRICTIONS(a), Main condition(b)**

	MALES.....			FEMALES.....			PERSONS.....		
	1988(c)	1993	1998	1988(c)	1993	1998	1988(c)	1993	1998
<i>Main condition</i>	%	%	%	%	%	%	%	%	%
Mental disorders	10.3	15.4	18.5	14.4	14.6	14.2	13.3	14.8	15.8
Physical conditions	90.8	84.6	81.5	86.2	85.5	85.8	87.5	85.2	84.2
Central nervous system	17.6	12.7	7.7	11.5	5.3	4.2	13.2	7.7	5.5
Eye	5.2	5.3	12.7	9.2	6.0	4.4	8.1	5.8	7.5
Circulatory	25.9	11.8	31.6	16.6	13.1	17.0	19.2	12.7	22.4
Respiratory	5.7	9.5	6.8	3.6	4.7	3.3	4.2	6.2	4.6
Musculoskeletal	18.2	23.6	10.1	32.6	38.7	40.2	28.5	33.7	29.0
Other	18.1	21.7	12.6	12.1	17.7	16.7	14.1	19.1	15.2
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
<b>Total ('000)</b>	<b>15.4</b>	<b>23.2</b>	<b>35.2</b>	<b>42.1</b>	<b>48.1</b>	<b>59.7</b>	<b>57.5</b>	<b>71.3</b>	<b>94.9</b>

(a) Includes persons with profound restrictions in 1993 and 1998.

(c) Certain disorders were coded to both mental and physical in 1988, so the total may be more than 100%.

(b) Age standardised to the 1998 population.

Health conditions *continued*

support through Medicare and health care cards have accompanied their ageing. Living longer, however, means an increasing number of men for whom the cost is severe restriction, a trade-off women have been experiencing for a longer time.

Has this led to different types of disorders presenting as the main condition of people with a severe restriction? This analysis is not straightforward, as it is only partly looking at prevalence, and partly at the respondent's choice of the condition that causes the most problems. Some differences in coding between years may also contribute to apparent change. The most obvious apparent inconsistency is in circulatory disorders, where the 1988 and 1998 proportions look relatively consistent, with a sharp drop in 1993, particularly for men (table 5.11). It may be that some were coded to conditions in the 'other' group in 1993, as the presenting condition (e.g. speech problems or incontinence rather than stroke). The lower than expected totals for 1993 (even allowing for the 1,200 in cared accommodation who should have been included) raises the possibility that people with circulatory main conditions were not captured as well in 1993, even though one new disability criterion was about stroke (combined with other brain injury) and another, 'any other restricting long-term condition', made specific reference to heart disease.

For both men and women, central nervous system disorders such as Parkinson's disease and epilepsy have been declining as a proportion of people with severe disorders. A smaller proportion of women are reporting eye disorders.

**5.11 PERSONS AGED 85 AND OVER WITH SEVERE RESTRICTIONS(a), Main condition(b)**

	MALES.....			FEMALES.....			PERSONS.....		
	1988	1993	1998	1988	1993	1998	1988	1993	1998
<i>Main condition</i>	%	%	%	%	%	%	%	%	%
Mental disorders	11.2	22.9	18.5	20.1	24.8	26.3	18.4	24.3	24.6
Physical conditions	90.0	77.1	81.5	82.8	75.2	73.7	84.2	75.7	75.4
Central nervous system	4.6	4.5	7.7	4.5	4.8	3.3	4.5	4.7	3.6
Eye	12.0	8.0	12.7	13.4	8.4	7.6	13.1	8.3	7.3
Circulatory	18.2	19.6	31.6	13.2	7.9	18.4	14.2	11.0	18.8
Respiratory	3.8	5.7	6.8	1.6	3.2	2.6	2.1	3.8	3.6
Musculoskeletal	20.9	16.8	10.1	26.0	30.5	28.2	25.0	26.8	26.6
Other	29.3	22.5	12.6	21.1	20.4	13.9	22.7	21.0	15.5
<b>Total</b>	<b>101.2</b>	<b>100.0</b>	<b>100.0</b>	<b>102.9</b>	<b>100.0</b>	<b>100.0</b>	<b>102.6</b>	<b>100.0</b>	<b>100.0</b>
<b>Total ('000)</b>	<b>26.6</b>	<b>33.2</b>	<b>35.2</b>	<b>109.2</b>	<b>91.2</b>	<b>106.0</b>	<b>135.9</b>	<b>124.5</b>	<b>142.7</b>

(a) Includes persons with profound restrictions in 1993 and 1998.

(b) Age standardised to the 1998 population.

(c) Certain disorders were coded as both mental and physical in 1988, so the total may be more than 100%.

Health conditions *continued*

Otherwise, for women musculoskeletal and circulatory disorders are rising, and other types of conditions are fairly stable. For men, mental disorders are increasing, with a shift to dementia.

Circulatory disorders, however, make the greatest contribution to the increase in severe restriction for men aged 75 to 79 in 1998. More than half of the 'other' category for men in 1993 consists of cancers, infectious disorders and diabetes, so even if there is some different coding practice, the combination would still be considerably lower than the proportion of men with circulatory disorders in 1988, and much lower than in 1998.

The 85 and over age group has no upper boundary, so, as the numbers of very old people increase, this will increase the severe restriction rate within the whole group. As the 85 and over age group of women is much larger and more stable, the effect will be seen more strongly for men, and has been shown in progressive increases in severe restriction in 1993 and 1998. The major change in men's main condition is the increase in circulatory disorders, and, compared with 1988, in mental disorders, mainly dementia.

## CONCLUSION

The effects of survey changes on severe restriction in the older population in 1998 appear to be selective, mostly affecting the 75 to 79 age group, unless they are masking declining rates in the other groups. The lower rate for 1993 for women aged 85 and over appears to relate to that survey, and is not significant; the higher rate for men in that age group appears to show a steady rise from 1988, and may be linked with an increasing survival rate over the ten years.

The modification of the learning and understanding screening question appears to have improved the capture of people with dementia. The specific question about strokes also probably led to increased reporting. Computer Assisted Interviewing is also likely to have contributed to better capture. There are increasing numbers of people entering the oldest age group, however, contributing to a likely increase in the actual prevalence in this group. It is likely that there is also an actual increase for men in the 75 to 79 age group. These two factors might account for half of the recorded increase among older people, and changes in survey procedures the other half.

Overall, in the underlying adjusted and age standardised series, the 75 to 79 age group and the 85 and over age group account for 0.23 percentage points out of the overall 1.06 percentage points difference between 1993 and 1998 data.

The task of collecting disability data is a challenging one and each ABS survey has built on the experience of previous surveys. Changes were made in the 1993 Survey of Disability, Ageing and Carers (SDAC) to improve capture of particular sub-groups, and to the 1998 survey to align it more closely with international classifications, take advantage of emerging technology and resolve difficulties encountered in the previous survey.

#### MODIFICATIONS AND ADDITIONS

##### Computer Assisted Interviewing (CAI)

The introduction of Computer Assisted Interviewing (CAI) in 1998 led to different logical organisation of the instrument and different in-field dynamics. There seems to be a general consensus throughout the literature on CAI that it has the potential to improve data quality. It has this potential because 'the process eliminates the need for interviewers to apply what is often complex sequencing so the appropriate questions are asked only of particular populations. In-field editing is involved, which enables data inconsistencies or errors to be resolved on the spot rather than during office editing' (White & McGovern 1999, p.6). Furthermore, there are indications that CAI may increase the accuracy of responses to sensitive questions (Tourangeau & Smith 1996, Baker et. al. 1995). The smoother flow of the interview may well encourage people to answer more readily, and may have contributed to improved capture of activity restriction. It is therefore possible that the introduction of CAI in 1998 contributed to an increase in rates of restriction.

A further advantage of the CAI method was the ability to capture relationships between the data items collected. In particular, in the 1998 SDAC, it was possible to keep the relationship between the restricting impairment screening question and the underlying health condition, allowing more targeted analysis.

##### Self-identification

Disability was identified in the previous three disability surveys by a responsible adult in the household. In 1998, 39% of the respondents in the household component of the survey were, as the selected responsible adult, answering for themselves. In 1998, persons aged 15 years and over, identified as having a long-term condition but no disability by a responsible adult, were given the opportunity to answer for themselves whether they were restricted in everyday activities by their condition. Of the 2,055 respondents asked, 254 (12%) gave a positive response. This added an estimate of 110,000 to the disability population (3%, or 0.6 % of the total population), mostly in the 15 to 64 age group. Once in the disability population, 85% proved to have a specific restriction, including 17% with a severe restriction. They added 0.1 percentage point to the total severe restriction population rate, and nothing to the profound restriction population rate.

### Response to demand for 'disability type'

An important variable in the analysis of service provision data is 'Disability Type', classifying recipients into broad disability groups such as physical, intellectual, sensory, psychological, and groups with multiple disabilities such as those with neurological disorders and acquired brain injury. In service provision collections, these categories are based on the underlying clinically-assessed health conditions, one or one group of which is selected as the primary disability. In the disability survey, respondents with one reported condition are defined as having that condition as their main disabling condition. Respondents with more than one condition are asked to nominate their main disabling condition, with the question 'Which of these condition(s) causes you the most problems?' A 'Disability Type' item can be built on all or main health conditions, 'Primary Disability Type' on main conditions.

It is difficult to determine whether a respondent's assessment of his/her main disabling condition would be comparable with a clinically-assessed primary disability, and whether it could be linked with their main activity limitation. The condition nominated might be the most immediately troublesome, rather than one that produced more systematic activity limitations. For example, someone may have severe arthritis restricting movement, and also have eye damage following shingles. The eye damage might have been reported as the main condition because it interfered with favourite activities, in the modified and accepted lifestyle that the arthritis allowed. Which one would a clinical assessment denote as primary?

A disability module has become widely used by the ABS in other population surveys. While collected in the SDAC, health conditions, and therefore a disability type item built on health conditions, are not available from the module. The module collects restricting impairments in the same way as the SDAC, however.

Restricting impairments, that is, the disability screening criteria, correspond readily with disability types: for example, sight and hearing problems are sensory disabilities; difficulty gripping and a restriction in physical activity or physical work are physical disabilities. A disability type item could be built on the screening questions in SDAC, and this indicator would also be available from the disability module in other collections.

The use of CAI in 1998 made it possible to preserve the relationship between a screening criterion and its underlying health condition. Respondents were asked in 1998 to nominate the restricting impairment that caused them the most problems. In the 1998 SDAC, where the relationship between the screening impairment and its main underlying condition was captured, respondents were asked which of these impairments caused them the most problems. Two possibilities emerged from this new variable:

- A 'Primary disability type' indicator; and
- The capacity to evaluate the main disabling condition, by comparing it with the condition producing the main restricting impairment.

### Additional screening questions

In 1993, three further screening questions were added in response to concern by stakeholders that important segments of the disability population, for example those with arthritis, dementia and acquired brain injury, were under-represented in the survey.

#### Additional screening questions *continued*

The additional 1993 criteria were difficulty gripping and holding things; head injury, stroke or other brain damage; and any other long-term restricting condition, with prompts for Alzheimer's disease and dementia, arthritis and heart disease. These questions added 0.6 percentage points to the disability population (ABS 1993).

Following the 1993 SDAC, an experimental disability type classification based on the screening questions was published in *Disability, Ageing and Carers, Disability and Disabling Conditions, Australia, 1993* (Cat. no. 4433.0). A major difficulty with this approach was the very large number of people, 12% of the disability population, who entered the disability population only through generic questions about restriction because of treated or other long-term conditions. As the most common diseases recorded in these other condition groups were respiratory, circulatory and musculoskeletal conditions, adding screening questions about chronic pain and breathing difficulties that restricted everyday activities would allow these people to be identified in a way that would enable a better disability type classification to be built on the screening questions. After consultation with major stakeholders, these screening questions were added to the 1998 SDAC. A further screening question designed to capture cognitive impairment and improve the data on people with dementia and Alzheimer's disease was tested, but not used, as the population it identified had been captured by existing screening questions.

#### Other screening question modifications

After feedback from field testing, certain changes were made to the wording of screening questions:

- 'Is anyone slow at learning or understanding' was modified to 'Does anyone have difficulty learning or understanding', after interviewers reported back on sensitivity. It was expected that this change would increase the positive response rate, but that the increase would be in the population with disability but without restriction. In fact, there was an increase in severe and profound restriction; this change resulted in a better capture of people with dementia and Alzheimer's disease, a more credible post-school-age representation of people with intellectual disability, and an increase in children with intellectual, developmental and behavioural disorders.
- In previous surveys, any hearing loss was treated as disability. There was discussion about whether people with hearing loss corrected by hearing aids or cochlea implants should be excluded, as were people whose eyesight problems were corrected by lenses. Expert advice, however, was that hearing loss could not be 'corrected' in the same way as problems of eye focus. A further consideration was the effect this change would have on mild restriction. At the same time, reporting of hearing loss was increasing dramatically, in the 1993 survey and again in the 1998 survey. Some of this could be attributed to more widespread measurement because of industrial deafness, and consequent knowledge about low levels of hearing loss, and might be an impairment rather than a disability. The final decision was to collect all hearing loss, but to accept aid use or experienced difficulty as a criterion for disability, where hearing loss was the only positive response.
- Filter questions about restriction were made more precise, from 'restricted in any way' to 'restriction in everyday activities'.



Other screening question modifications *continued*

- Questions about head injury, stroke and other brain damage were expanded to allow separate identification of the three elements, and distinguish 'acquired' brain injury.
- The question about treatment for a long-term condition was modified to treatment for any other long-term condition. This was not a successful change, as it has created problems for the underlying series. The older form, capturing all treated long-term conditions, should be used for future surveys.

## Health conditions coding

Health conditions reported in the 1998 survey were coded to the International Classification of Diseases (ICD-10), replacing the ICD-9 used for previous surveys. All chapters of the ICD-10 were used in the coding frame.

In the households component, many conditions were coded in-field using picklists, with a fallback to Computer Assisted Coding (CAC) and a write-in field as needed.

Interviewers were instructed to use the picklists and CAC lists only where there was a perfect match. Otherwise they should type in the name of the condition for post-field office coding.

## International classification

The development of the 1998 survey coincided with the redevelopment of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). In the new approach of Body Structure and Function, Activity and Participation, it became clearer that the ABS 'core activities'— self care, mobility and communication— aligned more closely with Activity than with Participation, as did the other seven activities collected in the SDAC (health care, housework, light property maintenance, meal preparation, transport, paperwork and guidance), while participation in schooling and employment aligned with Participation. Difficulty, need for assistance and use of aids were emerging as the qualifiers for the Activity dimension of the revised ICIDH. These had always been the qualifiers used in the ABS disability surveys, but there was some lack of consistency in the measures for different activities. The opportunity was taken in the development of the 1998 survey to collect further information to allow for a consistent set of data items across all ten activities, and for core activity tasks. These would all include:

- Always needs assistance;
- Sometimes needs assistance;
- Needs no assistance but has difficulty;
- Has no difficulty.

The effects of these changes were to:

- Allow a distinction between always and sometimes needing assistance and having difficulty communicating with family and friends (previously could only distinguish between 'could not at all' and 'had difficulty');
- Introduce difficulty with bed/chair transfers; and
- Introduce difficulty with toileting and with bladder/bowel control.

International classification *continued*

The opportunity was also taken to include people who did not do one or more of the three mobility tasks in the profound mobility restriction group. In practice, all of those who did not get up, or move around the house, were admitted to the profound restriction category through other core activities. Those who did not leave the house had presented a problem in previous surveys: surely someone who did not perform an activity at all was at least as restricted as someone who always needed assistance? However, it was difficult to disentangle how far this was a lifestyle choice rather than an effect of disability. In the 1998 survey, further questions were asked to establish why the person did not go out. Those who were restricted from going out by their conditions were then regarded as having a profound restriction, as they would need assistance if they *had* to leave their house—to go to hospital, for instance, or be evacuated in an emergency. The number of people not already classified to profound restriction through other activities is extremely small, and adds less than a hundredth of a percent of the total population to the profound population.

## Restriction—level of severity

Criteria for levels of restriction in the core activities in 1993 were generalised as:

- 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 (ABS 1993).

In 1998, having the capacity to apply these principles more consistently had some effect on the distribution of severe and profound restrictions, and on the extent of moderate restriction. An analysis of the effects of these changes for the actual 1998 results follows later in this chapter. See Appendix C for a detailed list of criteria for disability and severe restriction in the 1993 and 1998 surveys.

## Severe/moderate restriction in cared accommodation

For the first time in 1993, information from cared accommodation was collected via a mailback survey, which asked for less detailed information on the level of core activity restrictions than in the household component of the survey. It was not possible to distinguish between severe and moderate levels of restriction and consequently, all people in this group were conservatively categorised as having a moderate restriction. In 1998, additional information was collected, allowing people living in cared accommodation to be categorised to the appropriate level. The proportions of severe and moderate restriction found in the cared accommodation collection in 1998 can be applied to the relevant moderate population in 1993 to provide a better estimate of those in cared accommodation with severe restrictions. Applying this assumption increases the severe restriction population in 1993 by 9,400 people (age standardised), or 0.05% of the total population.

## New activity

In response to growing interest in people with a psychological disability, a new activity, guidance, was added to the 1998 disability survey. It covered need for assistance and difficulty in the areas of making decisions, creating and maintaining relationships, coping with moods and emotions and, for children, managing behaviour. Because of time constraints on the survey, receipt of assistance was not collected for this activity. Initially intended for people with intellectual and psychological disability, the questions were asked of all people with a disability, as some of them reflect the social frustrations that may be experienced by people with any type of disability.

## SF-12

The SF-12 is a multipurpose short-form generic measure of health status, a shorter, yet valid, alternative to the SF-36. It has two components: Physical Component Summary (PCS) and the Mental Component Summary (MCS). The SF-12 was included for the first time in the 1998 disability survey, to provide a self-assessment of health and well-being to compare with disability classifications. Analyses were carried out to see if the inclusion of SF-12 may have impacted on people's responses in the severe and profound restriction population. The SF-12 questions were placed after the screening questions, and therefore could not have affected the size of disability population, but they may have caused respondents to think more closely about the effect of their impairment, and therefore answer more positively in relation to the subsequent questions on restriction and the need for assistance.

## EFFECTS OF CHANGES ON DISABILITY POPULATIONS

The following method was used to identify and quantify the effect of changes in criteria for disability and levels of restriction between 1993 and 1998. Using 1998 data only:

- Use the 1993 disability definition:
  - exclude the chronic pain criterion from the disability definition;
  - retain restricting breathing difficulties, to compensate in part for the effect of 'other' in the 'treatment for other long-term conditions' question. (Analysis has indicated that the distribution of conditions for the 'breathing difficulty' only population is much closer to the 1993 'treatment for long-term conditions' only population than the 'pain only' distribution, and the combination contributes less to the disability population than the treated long-term condition screen in 1993 and previous surveys);
  - exclude the population identified with long-term health conditions but no disability in the screening procedure, but self-identified with disability in the personal interview;
  - include all those with hearing loss; and
  - use the 'treated for a nervous or emotional condition' response.
- Reproduce the 1993 criteria for profound, severe, moderate and mild restriction.
- Run one table with both disability and restriction adjusted.
- Run a further table with adjusted restriction, but unadjusted disability.
- Compare these with actual 1998 data. This should enable the maximum direct effect of the pain question to be quantified. (It is likely to overstate the difference, as the 'restricted by chronic pain only' population overlaps to some extent the 1993 concept of the 'treatment for long-term conditions' population).

## Results

Comparing actual 1998 data with 1998 data in 1993 terms, the disability population was 4.8% lower; the contribution from restricting chronic pain and the self-identified group to the disability population was more than offset by excluding mild hearing loss and nervous/emotional conditions. A higher proportion of the population defined with disability in 1998 terms had a severe or profound restriction (adding 0.6 percentage points with 1998 severity criteria, and 0.2 using 1993 severity criteria) (see tables 6.1, 6.2 and 6.3 on page 46).

### Contributions to increased severe and profound restriction rates

Because the following data are all from the 1998 survey, there is no change in the sample or the population structure contributing to the increases shown. The effect of a number of specific changes can therefore be measured.

#### 1. Addition of pain criterion

In the 1998 SDAC, a new disability criterion was added: whether restricted in everyday activities by chronic or recurrent pain. The difference between tables 6.2 and 6.3 shows the contribution of the pain criterion and the self-identified group. Between them, these changes directly account for up to 0.2 percentage points of the 3.2% of the population in 1998 with severe restrictions. The greatest impact was on the 45 to 64 year age group, accounting for 0.4 percentage points of the 5.3% with severe restrictions.

#### 2. Addition of 0 to 4 age group

In 1993, severity of restriction was not determined for the 0 to 4 age group. In 1998, there were 28,100 children aged 0 to 4 with a profound or severe restriction. This group accounts for 0.2 percentage points of the 6.1% of the total population with profound or severe restrictions, and 0.4 percentage points of the 3.0% of people aged 0 to 24 with profound or severe restrictions.

#### 3. Self-identified group

Those who had been identified by another person as having a long-term health condition but no disability were given the opportunity to say for themselves whether they were restricted by their condition. This group forms less than 3% of the disability population, adds 0.1 percentage point to the severe and profound restriction population overall, but has no significant effect on any age group.

#### 4. Moderate/severe coding change

Adjusting 1998 data to reflect the coding used for cared accommodation in 1993 results in a loss of 24,800 persons with severe restrictions, primarily in the older age groups. This change accounts for 0.1 percentage point of the 6.1% of the population with severe and profound restrictions in 1998.

#### 5. Change to communication criteria

The other major change to the restriction criteria affecting the severe and profound restriction group was for communication tasks. (See Appendix C: Criteria for Disability, and Profound and Severe Restriction, Actual 1993 and 1998 for more details.) One effect of this is a move from profound to severe and moderate, with the respective reclassification of those sometimes needing assistance and those not needing assistance but having difficulty communicating with family or friends.

### 6.1 DISABILITY, SEVERE RESTRICTION AND PROFOUND RESTRICTION RATES, As published—1998

<i>Age group</i>	<i>Profound</i> %	<i>Severe</i> %	<i>Profound and severe</i> %	<i>Disability</i> %
0–24	1.5	1.5	3.0	8.0
25–44	0.9	2.1	3.0	12.9
45–64	1.7	5.3	7.1	27.5
65–84	9.9	6.4	16.4	50.6
85 and over	51.7	13.2	64.9	84.2
<b>Total</b>	<b>2.9</b>	<b>3.2</b>	<b>6.1</b>	<b>19.4</b>

### 6.2 DISABILITY, SEVERE RESTRICTION AND PROFOUND RESTRICTION RATES, Using 1993 criteria for disability and restriction—1998

<i>Age group</i>	<i>Profound</i> %	<i>Severe</i> %	<i>Profound and severe</i> %	<i>Disability</i> %
0–24	1.7	0.6	2.3	8.2
25–44	0.9	1.9	2.8	13.6
45–64	1.7	4.9	6.6	28.8
65–84	9.9	5.4	15.3	54.2
85 and over	51.8	9.5	61.3	85.6
<b>Total</b>	<b>2.9</b>	<b>2.6</b>	<b>5.5</b>	<b>20.3</b>

### 6.3 DISABILITY, SEVERE RESTRICTION AND PROFOUND RESTRICTION RATES, Using 1993 criteria for restriction—1998

<i>Age group</i>	<i>Profound</i> %	<i>Severe</i> %	<i>Profound and severe</i> %	<i>Disability</i> %
0–24	1.7	0.7	2.3	8.0
25–44	0.9	2.0	2.9	12.9
45–64	1.7	5.3	7.0	27.5
65–84	10.0	5.6	15.6	50.6
85 and over	52.0	9.6	61.6	84.2
<b>Total</b>	<b>3.0</b>	<b>2.7</b>	<b>5.7</b>	<b>19.4</b>

Sources: 6.1, ABS 1999c; 6.2 and 6.3, unpublished data SDAC 1998.

Contributions to increased severe and profound restriction rates *continued*

5. Change to communication criteria *continued*

There is also a move in the opposite direction from moderate to severe for those who sometimes need assistance communicating with strangers. The remaining difference in the 'other' column of table 6.4 is largely due to changes in communication criteria.

**6.4 INCREASE TO PROFOUND AND SEVERE RESTRICTION RATE FROM 1993 TO 1998 CRITERIA, Contributing factors**

<i>Age group</i>	<i>Pain criterion</i>	<i>0-4 age group</i>	<i>Moderate/severe coding change</i>	<i>Other</i>	<i>Total</i>
	%	%	%	%	%
0-24	0.1	0.4	0.0	0.2	0.7
25-44	0.2	0.0	0.0	0.0	0.2
45-64	0.4	0.0	0.0	0.0	0.5
65-84	0.3	0.0	0.6	0.2	1.0
85 and over	0.3	0.0	4.4	-1.0	3.6
<b>Total</b>	<b>0.2</b>	<b>0.2</b>	<b>0.1</b>	<b>0.1</b>	<b>0.6</b>

The only age group for which the increases shown are significant is the 0 to 24 age group which is largely accounted for by the inclusion of the 0 to 4 year age group in those with severe and profound restrictions.

**OVERALL EFFECTS OF MODIFICATIONS AND ADDITIONS**

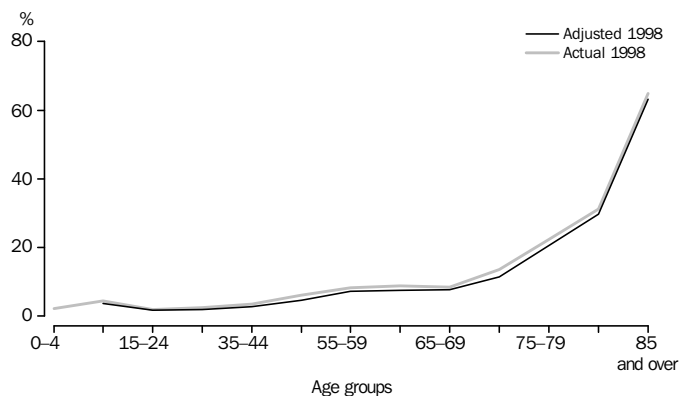
Some of the changes for the 1998 survey, such as CAI, the introduction of the chronic pain disability criterion and the wording 'difficulty learning and understanding' have contributed to the increase in severe and profound restriction shown, particularly for men, in the adjusted underlying trend series. These developments, however, appear to be more accurately capturing certain populations, such as people with intellectual and developmental disorders, musculoskeletal disorders and dementia. Many of these people have then responded to the questions establishing core activity restrictions in a way that increased the severe restriction rate. The severe categorisation appeared to be most problematic for the 45 to 64 age group. Extensive analysis of independent questions in the survey, however, supports the accuracy of the classification.

Other changes have been to correct inadequacy, as in enabling a more appropriate measure of severe restriction in cared accommodation, or to allow better analysis of children under 5 and the circumstances of their carers. These two modifications have added 0.35 percentage points to the severe restriction rate.

For severe and profound restriction, there is an overall difference in 1998 between the underlying adjusted rate (5.5% of the population aged 5 and over, 5.1% of all persons) and the actual rate (6.1%) of 1.0 percent of the total population, with no significant difference in any age group (see graph 6.5). Some of this difference comes from changes in 1993 (specific collection of acquired brain injury, improved collection of arthritis and some other long-term conditions, etc.), as well as 1998.

OVERALL EFFECTS OF MODIFICATIONS AND ADDITIONS *continued*

The changes itemised in table 6.4 on page 47 were not included in the underlying adjusted series. They therefore represent 0.6 percentage points out of the 1.0%. The difference in age rates between the as-reported and the underlying series is small (graph 6.5).

**6.5 SEVERE RESTRICTION RATE(a) ON UNDERLYING ADJUSTED AND ACTUAL BASIS**

(a) Includes persons with profound restrictions.

In the previous analysis, the earlier surveys were age standardised to negate the effect of population change. To gain a measure of the effect of the change in the population structure, the 1998 underlying adjusted series results were age standardised to 1993, reducing the underlying rate from 5.5% to 5.2%. Population changes contribute a minimum of 0.3 of a percentage point, a little higher when children under 5 and the others excluded from the underlying series are added in. In this way over 0.9 of a percentage point is accounted for.

## CONCLUSION

Between the reported rate of severe and profound restriction in the 1998 and the 1993 surveys, there is a difference of 2.0 percentage points. Of this, 1.1 percentage point is present in the adjusted, age-standardised series. Improved capture because of survey developments accounts for over half of the increase in the severe restriction rate of those excluded from the underlying series.

Improved capture may also account for up to 75% of the increase in the 45 to 64 age group in the underlying series, illustrated by the rate of musculoskeletal conditions. Among children aged 5 to 14 and people in the older age groups showing increases, there are methodological effects, but they are likely to be smaller, perhaps around half. With children, increased diagnosis, particularly of ADHD, and public awareness play a large part. For the older people, there are also changes to community attitudes, but actual increases appear to be a reasonable expectation for the two specified groups.

Put together, over half of the change in the underlying series and in the remainder is likely to have resulted from survey developments, contributing around 1.2 percentage points; around 0.3 percentage points is contributed by structural population change, and the remaining 0.5 percentage points by changes affecting respondents—increased awareness, increased willingness to respond, and/or increased activity restriction.

The rate of severe and profound restriction combined increased from 4.1% to 6.1% between 1993 and 1998, a difference of 414,900 people. When data are adjusted for comparability and changes in the age structure of the population are taken into account, there has been a continuing rise in the overall disability rate since 1988. However, the rate of severe restriction (including profound), was 4.4% in 1988 and 1993, increasing to 5.5% in 1998.

Recent improvements in the survey design and implementation account for some of the increase in severe restriction rate. Improved capture of this population due to a minor wording change (from 'slow at learning or understanding' to 'difficulty learning or understanding') clearly increased the base disability population who were then asked questions to ascertain severity of restriction. Exposure to a question about chronic pain, and possibly to the SF-12 self-assessment of well-being, appears to have focused respondents on the day-to-day effects of their conditions. An undercount of people with musculoskeletal conditions in 1993 also accentuates the increase recorded in the 1998 survey. The introduction of Computer Assisted Interviewing may also have encouraged more positive responses to questions regarding activity restrictions. Assessing the severity level of children under five years was in response to demand, and ensuring that severity levels could be assessed in cared accommodation was corrective action. Both of these were expected to add to the rate of severe restriction.

Changes in attitudes towards disability may also have contributed to the increase in the severe restriction rate. These include a greater openness in talking about difficulty and need for assistance. They also include developments in the diagnosis of behavioural disorders (e.g. ADHD), more clearly including them in a medical context. There is, in addition, some basis for considering that a real increase has taken place, particularly among certain groups of older men.

Around half of the difference between the 1998 estimate of severe restriction and earlier surveys is accounted for by population change (0.3 percentage points) and the combined effects of including young children, improving the measure of severity in cared accommodation, introducing a chronic pain criterion for disability, and the modification of communication criteria (0.6 percentage points). The remaining half of the difference was present in the adjusted underlying series using comparable criteria and removing the effect of change in the population structure.

Analysis of raw and underlying differences identified three groups of people as contributing most to the difference, and the reasons are different for each of the groups. Children, especially boys, and older people, especially older men, accounted for a third of the underlying difference, and people aged 45 to 64 for almost half. The remainder was distributed over other age groups, with little significant difference. The impact of changed criteria or wording appear to have been selective. The effects of Computer Assisted Interviewing were probably more systematic, providing an atmosphere in which fairly intimate questions could be answered more openly.



Among children, particularly boys, the change of wording to 'difficulty learning or understanding' appears to have encouraged more reporting of intellectual, developmental and behavioural conditions; on the other hand, the increase in those reporting speech problems suggests that even without this change there would have been a higher response from people with these conditions. The substantial increase in diagnosis of Attention Deficit Hyperactivity Disorder has contributed to the increase.

For the mid-age population (aged 45 to 64 years), the increase in musculoskeletal disorders other than arthritis (mainly back problems) correlates with an increase in the number of people reporting a need for assistance. It is likely that the chronic pain question had an influence on this group. Evidence from other collections indicates improved capture rather than actual change in the prevalence of these conditions, although the high rate of reported need for assistance with self care and mobility may also indicate that limitations from these conditions are being more widely experienced. A wide range of internal evidence confirmed the appropriateness of the severity classification.

For older people, particularly men, 'difficulty learning and understanding' appears to have improved the capture of people with dementia. Most of the increase in this group, though, came from people with circulatory conditions. This may also reflect better capture, perhaps because of a direct question about strokes and greater confidence inspired by computer-assisted interviewing. However, improved survival rates from previously fatal diseases, or events such as heart attacks and strokes, has also played an important part.

The results of this analysis will be considered when developing the next ABS Survey of Disability, Ageing and Carers, due to be run in 2003. While there will always be a need to respond to emerging disability issues, the primary focus of the 2003 survey will be to maintain comparability of the data over time, allowing actual changes in disability and core activity restriction rates to be more easily measured.

## REFERENCES .....

- Australian Bureau of Statistics (1982), *Handicapped Persons, Australia, 1981*, (Cat. No. 4343.0), Canberra.
- Australian Bureau of Statistics (1990), *Disability and Handicap, Australia, 1988*, (Cat. No. 4120.0), Canberra.
- Australian Bureau of Statistics (1991), *National Health Survey: Summary of Results, Australia, 1989-90*, (Cat. No. 4364.0), Canberra.
- Australian Bureau of Statistics (1993), *Disability, Ageing and Carers, Australia, Summary of Findings, 1993*, (Cat. No. 4430.0), Canberra.
- Australian Bureau of Statistics (1994), *Persons Not in the Labour Force, Australia, September 1993*, (Cat. No. 6220.0), Canberra.
- Australian Bureau of Statistics (1996), *Disability, Ageing and Carers, Australia, Disability and Disabling Conditions, 1993*, (Cat. No. 4433.0), Canberra.
- Australian Bureau of Statistics (1997a), *Australian Demographic Statistics, March 1997*, (Cat. No. 3101.0), Canberra.
- Australian Bureau of Statistics (1997b), *National Health Survey, Summary of Results, Australia, 1995*, (Cat. No. 4364.0), Canberra.
- Australian Bureau of Statistics (1998a), *Australian Demographic Statistics, June 1998*, (Cat. No. 3101.0), Canberra.
- Australian Bureau of Statistics (1998b), *Retirement and Retirement Intentions, Australia, 1997*, (Cat. No. 6238.0), Canberra.
- Australian Bureau of Statistics (1999a), *Deaths, 1998*, (Cat. No. 3302.0), Canberra.
- Australian Bureau of Statistics (1999b), *Causes of Death, 1998*, (Cat. No. 3303.0), Canberra.
- Australian Bureau of Statistics (1999c), *Disability, Ageing and Carers: Summary of Findings, Australia, 1998*, (Cat. No. 4430.0), Canberra.
- Australian Bureau of Statistics (1999d), *Persons Not in the Labour Force, Australia, September 1998*, (Cat. No. 6220.0), Canberra.
- Australian Institute of Health and Welfare 1993, *Australia's Welfare 1993: Services and Assistance*, Australian Government Publishing Service, Canberra.
- Baker, R., Bradburn, N. and Johnson, R. (1995), 'Computer-assisted personal interviewing: an experimental evaluation of data quality and cost', *Journal of Official Statistics*, vol. 11, no. 4, pp. 413-431.
- Commonwealth Department of Health and Aged Care, various years, *Australian Statistics on Medicines*.

## REFERENCES *continued* .....

- Council on the Ageing and the Committee for Economic Development of Australia 2000, 'Older Australians: a working future?' *Strategic Ageing*, vol. 10.
- Gething, L. (1999). *We're Growing Older, Too: Quality of Life and Service Provision Issues for People With Long Standing Disability who are Ageing*, Community Disability and Ageing Program, University of Sydney, Sydney.
- Henderson-Smart, D. (1990), 'Low birth weight babies', *Trends in Biomedical Regulation*, pp. 145–152.
- James, A. (1988), 'Why are we saving more premature babies?', *Australian Patient Management*, vol. 12, no. 9, pp. 165–72.
- Mayhew, C. (2000), 'OHS in Australian 'micro' small businesses: evidence from nine research studies', *Journal of Occupational Health and Safety, Australia and New Zealand*, vol. 16, no. 4, pp. 297–305.
- National Health and Medical Research Council 1997, *Attention Deficit Hyperactivity Disorder (ADHD)*, internet report, NHMRC.
- Tourangeau, R. and Smith, T. (1996), 'Asking sensitive questions. The impact of data collection mode, question format, and question context', *Public Opinion Quarterly*, vol. 60, pp. 275–304.
- Victorian Infant Collaborative Study Group (1995), report cited in *Australian Doctor*, 28 February 1997, p. 61.
- Ware, J.E., Kosinski, M. and Keller, S.D. (1995), *SF-12: How to Score the SF-12 Physical and Mental Health Summary Scales*, Second Edition, The Health Institute, New England Medical Center, Boston, MA.
- White, P. and McGovern, N. (1999), *The Future of Computer Assisted Interviewing (CAI) in ABS Household Surveys*, unpublished report.
- World Health Organisation (1980), *International Classification of Impairments, Disabilities, and Handicaps*, WHO, Geneva.
- World Health Organisation (2001), *International Classification of Functioning*, WHO, Geneva.

**APPENDIX A. ADJUSTED AND AGE STANDARDISED SERIES, 1988, 1993 AND 1998** .....

Age group	Males	Females	Persons	Males	Females	Persons
	'000	'000	'000	%	%	%
SEVERE RESTRICTION, 1988						
5-9	16.6	15.5	32.2	2.5	2.4	2.4
10-14	16.9	8.5	25.5	2.5	1.3	1.9
15-19	6.2	5.5	11.8	0.9	0.9	0.9
20-24	6.5	9.2	15.7	0.9	1.4	1.2
25-29	10.0	11.7	21.8	1.4	1.6	1.5
30-34	8.9	11.3	20.3	1.3	1.6	1.4
35-39	12.4	17.0	29.4	1.7	2.3	2.0
40-44	16.4	20.7	37.1	2.4	3.0	2.7
45-49	17.1	17.6	34.8	2.6	2.7	2.7
50-54	18.1	24.0	42.1	3.1	4.3	3.7
55-59	17.2	19.9	37.0	3.9	4.6	4.3
60-64	19.1	19.5	38.6	5.2	5.3	5.3
65-69	25.1	27.7	52.7	7.5	7.9	7.7
70-74	28.8	40.4	69.2	10.2	12.3	11.3
75-79	21.4	54.3	75.7	10.8	20.5	16.4
80-84	28.1	57.0	85.0	25.7	31.9	29.5
85 and over	26.6	109.2	135.9	38.6	69.6	60.1
<b>Total</b>	<b>295.4</b>	<b>469.2</b>	<b>764.7</b>	<b>3.4</b>	<b>5.4</b>	<b>4.4</b>

SEVERE RESTRICTION, 1993						
5-9	23.1	15.4	38.5	3.4	2.4	2.9
10-14	15.5	8.9	24.4	2.3	1.4	1.9
15-19	8.2	8.7	17.0	1.2	1.4	1.3
20-24	8.7	10.7	19.4	1.3	1.6	1.4
25-29	12.2	12.0	24.3	1.7	1.6	1.7
30-34	12.3	13.6	25.9	1.7	1.9	1.8
35-39	17.0	12.2	29.2	2.3	1.6	2.0
40-44	15.7	19.6	35.3	2.3	2.8	2.5
45-49	17.4	21.5	38.8	2.7	3.3	3.0
50-54	17.1	18.5	35.6	2.9	3.3	3.1
55-59	22.0	20.2	42.2	5.0	4.7	4.9
60-64	15.9	15.6	31.5	4.3	4.2	4.3
65-69	19.5	26.8	46.3	5.9	7.7	6.8
70-74	24.1	44.9	69.0	8.5	13.7	11.3
75-79	23.2	48.1	71.3	11.7	18.2	15.4
80-84	24.9	60.7	85.6	22.8	33.9	29.7
85 and over	33.2	91.2	124.5	48.1	58.1	55.1
<b>Total</b>	<b>310.0</b>	<b>448.7</b>	<b>758.7</b>	<b>3.6</b>	<b>5.1</b>	<b>4.4</b>

a) Age standardised to the 1998 benchmark population for the Survey of Disability, Ageing and Carers

ADJUSTED AND AGE STANDARDISED(a) SERIES, 1988, 1993 AND 1998 *continued*

Age group	Males	Females	Persons	Males	Females	Persons
	'000	'000	'000	%	%	%
SEVERE RESTRICTION, 1998						
5-9	37.1	19.1	56.2	5.5	3.0	4.3
10-14	28.9	11.7	40.6	4.3	1.8	3.1
15-19	15.2	12.1	27.3	2.3	1.9	2.1
20-24	9.5	8.5	18.0	1.4	1.3	1.3
25-29	11.9	13.3	25.2	1.6	1.8	1.7
30-34	18.8	13.7	32.6	2.7	1.9	2.3
35-39	15.0	22.6	37.5	2.0	3.0	2.5
40-44	19.1	23.5	42.6	2.8	3.4	3.1
45-49	26.4	32.2	58.6	4.0	5.0	4.5
50-54	28.9	26.3	55.2	5.0	4.7	4.8
55-59	34.6	28.5	63.0	7.8	6.7	7.2
60-64	26.9	27.8	54.6	7.3	7.5	7.4
65-69	23.8	28.4	52.3	7.2	8.2	7.7
70-74	28.0	41.9	69.9	9.8	12.7	11.4
75-79	35.2	59.7	94.9	17.8	22.6	20.5
80-84	24.4	61.4	85.7	22.3	34.3	29.8
85 and over	36.6	106.0	142.7	53.0	67.6	63.1
<b>Total</b>	<b>420.3</b>	<b>536.6</b>	<b>956.9</b>	<b>4.9</b>	<b>6.1</b>	<b>5.5</b>

(a) Age standardised to the 1998 benchmark population for the Survey of Disability, Ageing and Carers

ADJUSTED AND AGE STANDARDISED(a) SERIES, 1988, 1993 AND 1998 *continued*

Age group	Males	Females	Persons	Males	Females	Persons
	'000	'000	'000	%	%	%
DISABILITY, 1988						
0-4	26.1	16.6	42.7	4.0	2.7	3.3
5-9	50.6	36.8	87.5	7.5	5.7	6.6
10-14	63.1	43.8	106.9	9.4	6.9	8.2
15-19	38.9	33.9	72.8	5.8	5.3	5.6
20-24	50.7	42.6	93.4	7.3	6.4	6.9
25-29	62.6	54.0	116.5	8.5	7.4	8.0
30-34	61.3	52.8	114.1	8.7	7.5	8.1
35-39	76.4	76.6	152.9	10.3	10.3	10.3
40-44	99.1	89.7	188.8	14.3	12.8	13.6
45-49	99.2	95.5	194.7	15.2	14.8	15.0
50-54	118.8	111.6	230.5	20.4	19.9	20.2
55-59	127.9	94.2	222.1	28.9	22.0	25.5
60-64	159.2	102.6	261.8	43.5	27.9	35.6
65-69	157.5	125.3	282.8	47.3	35.9	41.3
70-74	144.3	151.1	295.4	50.8	45.9	48.1
75-79	104.9	143.0	247.9	53.0	54.1	53.6
80-84	74.0	119.6	193.7	67.8	66.9	67.2
85 and over	52.7	134.0	186.8	76.3	85.4	82.9
<b>Total</b>	<b>1,567.6</b>	<b>1,523.7</b>	<b>3,091.2</b>	<b>16.9</b>	<b>16.3</b>	<b>16.6</b>
DISABILITY, 1993						
0-4	29.4	23.6	53.0	4.5	3.8	4.1
5-9	64.8	40.6	105.4	9.6	6.3	8.0
10-14	57.6	32.6	90.2	8.6	5.1	6.9
15-19	38.2	41.3	79.5	5.7	6.5	6.1
20-24	52.8	45.6	98.3	7.6	6.8	7.2
25-29	62.6	60.0	122.5	8.5	8.2	8.4
30-34	74.4	61.9	136.4	10.6	8.8	9.7
35-39	90.9	84.1	175.1	12.2	11.3	11.8
40-44	99.3	81.8	181.1	14.3	11.7	13.0
45-49	116.8	95.3	212.1	17.9	14.7	16.3
50-54	136.7	101.9	238.7	23.5	18.2	20.9
55-59	136.8	108.6	245.4	30.9	25.4	28.2
60-64	152.3	96.5	248.8	41.6	26.2	33.9
65-69	146.6	122.8	269.4	44.0	35.2	39.5
70-74	165.4	159.9	325.3	58.3	48.6	53.1
75-79	117.9	142.1	260.0	59.6	53.7	56.2
80-84	79.9	109.9	189.8	73.2	61.5	65.9
85 and over	56.0	124.8	180.7	81.0	79.5	80.0
<b>Total</b>	<b>1,678.5</b>	<b>1,533.2</b>	<b>3,211.7</b>	<b>18.1</b>	<b>16.3</b>	<b>17.2</b>

(a) Age standardised to the 1998 benchmark population for the Survey of Disability, Ageing and Carers

ADJUSTED AND AGE STANDARDISED(a) SERIES, 1988, 1993 AND 1998 *continued*

Age group	Males	Females	Persons	Males	Females	Persons
	'000	'000	'000	%	%	%
DISABILITY, 1998						
0-4	31.3	15.6	47.0	4.8	2.5	3.7
5-9	81.1	49.1	130.2	12.0	7.6	9.9
10-14	85.1	39.5	124.6	12.7	6.2	9.5
15-19	60.8	48.3	109.1	9.0	7.6	8.3
20-24	63.1	46.2	109.3	9.1	6.9	8.0
25-29	67.7	63.2	130.9	9.2	8.6	8.9
30-34	86.5	63.9	150.4	12.3	9.0	10.6
35-39	105.3	81.9	187.2	14.2	11.0	12.6
40-44	113.7	109.2	222.9	16.4	15.6	16.0
45-49	118.4	118.7	237.1	18.1	18.4	18.3
50-54	157.1	117.6	274.7	27.0	20.9	24.0
55-59	152.5	123.7	276.2	34.5	28.9	31.7
60-64	157.6	106.5	264.1	43.1	28.9	36.0
65-69	151.1	125.2	276.4	45.4	35.9	40.5
70-74	156.6	148.3	304.9	55.2	45.1	49.8
75-79	128.8	147.8	276.6	65.1	55.9	59.8
80-84	73.0	120.1	193.1	66.9	67.2	67.0
85 and over	59.7	129.5	189.2	86.4	82.5	83.7
<b>Total</b>	<b>1,849.5</b>	<b>1,654.3</b>	<b>3,503.8</b>	<b>19.9</b>	<b>17.6</b>	<b>18.8</b>

(a) Age standardised to the 1998 benchmark population for the Survey of Disability, Ageing and Carers

**APPENDIX B. CRITERIA FOR ADJUSTED DISABILITY, AND PROFOUND AND SEVERE RESTRICTION, 1988, 1993 AND 1998**

.....

1988..... 1993..... 1998.....

.....

DISABILITY

Loss of sight, not corrected by glasses/contact lenses	Loss of sight, not corrected by glasses/contact lenses	Loss of sight, not corrected by glasses/contact lenses
Loss of hearing	Loss of hearing	Loss of hearing
Speech difficulties	Speech difficulties	Speech difficulties
Blackouts, fits or loss of consciousness	Blackouts, fits or loss of consciousness	Blackouts, fits or loss of consciousness
Slowness at learning or understanding	Slowness at learning or understanding	Difficulty learning or understanding
Limited use of arms/fingers	Limited use of arms/fingers	Limited use of arms/fingers
Limited use of legs/feet	Limited use of legs/feet	Limited use of legs/feet
Treated for nerves or an emotional condition	Treated for nerves or an emotional condition	Treated for a nervous or emotional condition
Condition that restricts physical activity/work	Restricted in physical activity or physical work	Restricted in physical activity or physical work
Disfigurement or deformity	Disfigurement or deformity	Disfigurement or deformity
Needs help/supervision doing things because of mental illness	Needs help/supervision doing things because of mental illness	Needs help/supervision doing things because of mental illness
Treated for long-term condition, still restricted	Treated for long-term condition, still restricted	Treated for other long-term condition, still restricted in everyday activities
		Shortness of breath or difficulty breathing, still restricted in everyday activities

SEVERE RESTRICTION

<b>Self care</b>	<i>Needs help with:</i> bathing/showering dressing eating	<i>Needs help with:</i> bathing/showering dressing eating	<i>Needs help with:</i> bathing/showering dressing eating
<b>Mobility</b>	<i>Needs help with:</i> going to/getting around a place away from home moving about the house	<i>Needs help with:</i> going to/getting around a place away from home moving about the house	<i>Needs help with:</i> going to/getting around a place away from home moving about the house
<b>Communication</b>	<i>Has difficulty:</i> understanding family/friends or staff being understood by family, friends or staff  <i>Cannot at all, or needs help:</i> understanding strangers being understood by strangers  Uses sign language	<i>Has difficulty:</i> understanding family/friends being understood by family/friends  <i>Cannot at all, or needs help:</i> understanding strangers being understood by strangers  Uses sign language	<i>Cannot at all, needs help or has difficulty:</i> understanding family/friends being understood by family/friends  <i>Cannot at all, or needs help:</i> understanding strangers being understood by strangers  Communicates more easily using sign language



**APPENDIX C. CRITERIA FOR DISABILITY, AND PROFOUND AND SEVERE RESTRICTION, ACTUAL 1993 AND 1998 .....**

1993..... 1998.....

DISABILITY—HOUSEHOLDS

Loss of sight, not corrected by glasses/ contact lenses	Loss of sight, not corrected by glasses/ contact lenses
Loss of hearing	Loss of hearing, with difficulty communicating or use of aids
Speech difficulties	Speech difficulties
Blackouts, fits or loss of consciousness	Blackouts, fits or loss of consciousness
Slowness at learning or understanding	Difficulty learning or understanding
Limited use of arms/fingers	Limited use of arms/fingers
Difficulty gripping	Difficulty gripping
Limited use of legs/feet	Limited use of legs/feet
Treated for nerves or an emotional condition	A nervous or emotional condition that restricts everyday activity
Restricted in physical activity or physical work	Restricted in physical activity or physical work
Disfigurement or deformity	Disfigurement or deformity
Needs help/supervision doing things because of mental illness	Needs help/supervision doing things because of mental illness
Head injury, stroke, other brain damage	Head injury, stroke, other acquired brain damage
Treated for long-term condition, still restricted	Treated for other long-term condition, still restricted in everyday activities
Any other restricting long-term condition	Any other long-term condition that restricts everyday activities
	Shortness of breath or difficulty breathing, that restricts everyday activities
	Chronic or recurring pain that restricts everyday activities

DISABILITY—CARED ACCOMMODATION

As above	As above, but no qualification on hearing loss
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PROFOUND RESTRICTION—HOUSEHOLDS AND CARED ACCOMMODATION

<b>Self care</b>	<i>Always needs help/supervision with:</i>	<i>Always needs help/supervision with:</i>
	bathing/showering	bathing/showering
	eating	eating
	dressing	dressing
	toileting	toileting
	bladder/bowel control	bladder/bowel control
<b>Mobility</b>	<i>Always needs help/supervision with:</i>	<i>Always needs help/supervision with:</i>
	moving about the house	moving about the house
		Does not get out of bed/move about the house
		Does not leave the house because of conditions

CRITERIA FOR DISABILITY, AND PROFOUND AND SEVERE RESTRICTION, ACTUAL 1993 AND 1998 *continued*

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1993..... 1998.....

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PROFOUND RESTRICTION—HOUSEHOLDS AND CARED ACCOMMODATION *continued*

<b>Communication</b>	<i>Has difficulty:</i>	<i>Always needs help:</i>
	understanding family/friends	understanding family/friends
	being understood by family/friends	being understood by family/friends
		understanding strangers
		being understood by strangers

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SEVERE RESTRICTION—HOUSEHOLDS

<b>Self care</b>	<i>Sometimes needs help/supervision with:</i>	<i>Sometimes needs help/supervision with:</i>
	bathing/showering	bathing/showering
	eating	eating
	dressing	dressing
	toileting	toileting
	bladder/bowel control	bladder/bowel control
<b>Mobility</b>	<i>Sometimes needs help/supervision with:</i>	<i>Sometimes needs help/supervision with:</i>
	going to/getting around a place away from home	going to/getting around a place away from home
	moving about the house	moving about the house
	getting out of bed or a chair	getting out of bed or a chair
<b>Communication</b>	<i>Always needs help:</i>	<i>Sometimes needs help:</i>
	understanding strangers	understanding family/friends
	being understood by strangers	being understood by family/friends
		understanding strangers
		being understood by strangers
		Communicates more easily in non-spoken ways (including sign language)

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SEVERE RESTRICTION—CARED ACCOMMODATION

<b>Self care</b>	Not applied—required information not available	<i>Sometimes needs help/supervision with:</i>
		bathing/showering
		eating
		dressing
		toileting
	bladder/bowel control	bladder/bowel control
<b>Mobility</b>	Not applied—required information not available	<i>Sometimes needs help/supervision with:</i>
		going to/getting around a place away from home
		moving about the house
		getting out of bed or a chair
<b>Communication</b>	<i>Always needs help:</i>	<i>Sometimes needs help:</i>
	understanding strangers	understanding family/friends
	being understood by strangers	being understood by family/friends
		understanding strangers
		being understood by strangers
		Communicates more easily in non-spoken ways (including sign language)

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