

Health Series
Number 10

**Disability and Ageing
in the ACT:
An Epidemiological
Review**

Carol Gilbert

Epidemiology Unit
Population Health Group
ACT Department of Health and Community Care

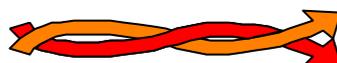
March 1997

ACKNOWLEDGEMENTS

This publication has drawn on the expertise and knowledge of several individuals and sections within the Department of Health and Community Care, the Australian Bureau of Statistics, and the Australian Institute of Health and Welfare.

The author is particularly grateful to colleagues in the Department of Health and Community Care including Dr Bruce Shadbolt, Dr Doris Zonta and the staff of the Epidemiology Section for their support, advice and patience; the Aged and Disability Policy Unit; ACT Community Care; and Public Affairs Section for publishing assistance. Also Dalma Jacobs and her staff at the Australian Bureau of Statistics for ACT analyses.

A special thank you to Kelli Mimis for her excellent cover design.



©Australian Capital Territory, Canberra 1997

ISSN 1325-1090

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced without written permission from the Director, Publications and Public Communication, Department of Urban Services, ACT Government, GPO Box 158, Canberra ACT 2601.

Published by Publications and Public Communication for the Department of Health and Community Care's Epidemiology and Population Health Section and printed by the Authority of Peter Bell, ACT Government Printer.

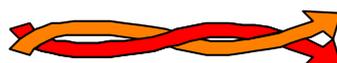
150 - 2/96 A4 (96/2832)

Suggested citation: Gilbert C, (1997), *Disability and Ageing in the ACT: An Epidemiological Review*, Epidemiology Unit, ACT Dept of Health and Community Care: Health Series No 10, ACT Government Printer, ACT

TABLE OF CONTENTS

1. INTRODUCTION	6
1.1 Definitions	6
1.2 The impact of disability on daily living	7
1.3 The cost of disability and aged care	8
1.4 The purpose of this publication	9
2. A PROFILE OF DISABILITY AND AGEING IN THE ACT	10
2.1 Age structure	10
2.2 Disability and handicap	11
2.2.1 Disability and handicap profile	11
2.2.2 Sex and age composition	13
2.2.3 Disabling conditions	17
2.2.4 Country of birth	21
2.2.5 Living arrangements	22
2.2.6 Employment	22
3 TYPES OF ASSISTANCE NEEDED	26
3.1 People aged 60 or more	28
4. CARERS	29
4.1 Restrictions on carers due to their caring roles, Australia 1993	31
4.2 Support for carers, Australia, 1993	32
5. ACT AND NATIONAL INITIATIVES	33
5.1 Commonwealth State Disability Agreement (CSDA)	33
5.2 ACT Goals and Targets	33
5.3 Quality of Life Project: Knowledge and attitudes towards disability	36
5.4 Data collection	39
5.5 ACT Government services	40
5.6 Community organisations	43
5.6 Advisory Committees	45
6. GLOSSARY	46
6.1 Survey of Disability, Ageing and Carers 1993	46
6.2 Levels of severity of handicap	46
<hr/>	
Disability and Ageing in the ACT	3

6.3 SHORT FORM 36 (SF-36)	46
6.4 Definitions	47
7. APPENDICES	48
7.1: Tables	48
7.2: Activity data for government services	52
7.3. Appendix C: Methodologies	56
7.3.1 Rates	56
7.3.2 Three year moving averages	56
7.4: Data limitations	57
7.4.1 Overall data	57
7.4.2 National Health Survey 1989-90	57
7.4.3 Disability, Ageing and Carers Surveys	57
8. REFERENCES	58
9. HEALTH SERIES PUBLICATIONS	58



Tables

Table 1 : Gross recurrent expenditure (\$) on welfare services, ACT and national average, 1990-94	8
Table 2: Prevalence of disability (%), Australia, 1981-93	12
Table 3: Prevalence of handicap and severe handicap (%), Australia, 1988-93	12
Table 4: Handicap & disability rates (per 1,000 population), ACT & Australia, 1993	13
Table 5: Recipients of various pensions, ACT, 1991-95	13
Table 6: General health & wellbeing mean scores, persons aged 18 or more, by category, by age, by sex, ACT, 1995	16
Table 7: Long-term conditions, rate per 1,000, by age, by sex, ACT 1989-90	20
Table 8: Long term conditions, rate, by type, by age, by sex, ACT, 1995-96	20
Table 9: Living arrangements, by disability status, by number, by age, ACT, 1993	22
Table 10: Employment status, persons aged 15-64 yrs in households, by number, by handicap & disability status, ACT, 1993	23
Table 11: Employment, by handicap & disability status, by age group, ACT, 1993	24
Table 12: Accommodation & employment service use, by special needs groups, ACT, NSW, Australia, 1995-96	25
Table 13: Main provider of assistance, by activity for which help was needed, ACT, 1993	26
Table 14: Activities for which help was needed & activities for which help was received, ACT, 1993	27
Table 15: People with a disability, in households, activities for which help was needed, by age, ACT, 1993	27
Table 16: Average length of stay, people 60 yrs or more, ACT hospitals, 1994-95	28
Table 17: Principal carers, aged 15 years or more, by age, by sex, ACT, 1993	30
Table 18: Main providers of assistance, by activities requiring help, ACT, 1993	30
Table 19: Affects of caring on principal carers' working lives, Australia, 1993	32
Table 20: Health goals and targets, disability or chronic condition, ACT	34
Table 21: Health goals, mental health, ACT	36
Table 22: Type of main disabling condition, by age, by sex, ACT, 1993	48
Table 23: Handicap and disability status, by age group, by sex, ACT, 1993	49



Figures

Figure 1: Estimated total population, by age groups, by sex, ACT & Australia, June 1995	11
Figure 2: Number & proportion of persons with a disability, with a handicap, ACT, 1993	12
Figure 3: Handicap & disability age-specific rates, by sex, ACT, 1993	14
Figure 4: Handicap & disability age-specific rates, ACT & Australia, 1993	15
Figure 5: Mean score profiles, SF-36, by disability status, ACT, 1994-95	16
Figure 6: Disabling conditions, ACT, 1993	17
Figure 7: Disabling conditions due to mental disorders, rate by age groups, by sex, ACT, 1993	18
Figure 8: Disabling conditions, physical, rates by age groups, by sex, ACT, 1993	19
Figure 9: Country of birth, population & persons with a disability, ACT, 1993	21
Figure 10: Responses to 'What factors do you think determine whether somebody has a disability?'	36
Figure 11: Responses to 'Which groups of people do you think are more likely to become disabled?'	37
Figure 12: Responses to 'Do you think that disability can be temporary?'	37
Figure 13: Responses to 'What do you think are the main causes of disability?'	38
Figure 14: Responses to 'What is your disability?'	39



Disability, Ageing and Carers in the ACT

1. Introduction

1.1 Definitions

The International Classification of Impairments, Disabilities and Handicaps (World Health Organisation) provides the definition of a disability as

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

The Commonwealth State Disability Services Agreement (CSDA) (Refer 5.1) defines the target group of disability services as ‘*people with disabilities that:*

- ◇ *are attributable to an intellectual, psychiatric, sensory or a physical impairment or a combination of such impairments; and*
- ◇ *are permanent or are likely to be permanent; and result in: substantially reduced capacity of the person or persons for communication, learning or mobility; and the need for on-going services;*
- ◇ *this includes a person or persons with a disability of a chronic episodic nature’.*

In terms of an operational definition, the Australian Institute of Health and Welfare (AIHW) uses the Australian Bureau of Statistics (ABS) definition which states that ‘*a person with a disability is one who has one or more of a number of health conditions which limit their ability to perform everyday activities and which last, or are likely to last, for six months or more*’ⁱⁱ.

For the purpose of this publication, disabilities and handicaps, are *long-term results of a health condition, impairment, disease or accident which impact on the quality of life of the person affected*. It is important to note that all people with disabilities are not necessarily handicapped. A handicapped person is defined as one whose disability limits to some degree, their ability to perform certain tasks such as self-care, mobility, verbal communication, schooling and employment.

Older persons refers to people aged 60 years or more, (both by the Australian Bureau of Statistics and in this publication).

Frames of reference include:

- ◇ Ageing is a *normal* process which does not inevitably result in mental deterioration, or thwart a person’s capacity to successfully cope with life’s challenges.
- ◇ Older people are much more heterogeneous than homogenous. Their abilities differ greatly.
- ◇ The onset, duration and level of any dysfunction for these, as for other people, is different for each individual.
- ◇ Older people do not change radically just because they are older. Personality remains fairly constant.ⁱⁱⁱ
- ◇ Older people are singled out for focus in this publication since there is a strong positive relationship between age and disablement.

In the 1993 Survey of Disability, Ageing and Carers, the Australian Bureau of Statistics defined carers as persons of any age, providing informal help (ie help provided by family, friends or neighbours) for any of the following activities:

- ◇ self-care (eg showering, dressing, eating, toileting)
- ◇ mobility (eg going away from home, moving about the house, transferring to a chair)
- ◇ verbal communication
- ◇ health care (eg taking medication, dressing wounds, foot care)
- ◇ home help (eg washing, vacuuming, cleaning)
- ◇ home maintenance (eg changing light globes, gardening)
- ◇ meal preparation
- ◇ financial management, writing letters
- ◇ transport (eg public transport, shopping, driving)

A main carer is anyone of any age who is identified by the care recipient as the person providing the most informal care for each of the above activities. A principal carer is defined as a person aged 15 years or more who is the main carer in the areas of self-care, mobility and/or verbal communication..

There is no agreed definition of severe mental illness although the US National Advisory Mental Health Council version as reported in the First National Mental Health Report.^{iv} can be used as a guide: it is *'defined through diagnosis, disability and duration and includes disorders with psychiatric symptoms such as schizophrenia, autism, major depression, panic disorder and obsessive compulsive disorder'*. With regard mental illness generally, there is even less agreement as to a definition. Mental health problems such as 'nerves' and 'tension' which are detailed in the National Health Survey and reported in this publication, are not generally defined as mental illness although they may, at some stage, be precursors to more serious problems.

1.2 The impact of disability on daily living

◆ People with disabilities:

People with disabilities have varying problems with daily living, depending on the nature and severity of their disability, and the availability of appropriate services to assist them. Their disability may limit participation in the mainstream education system or workforce, and/or recreation and sporting activities, and may impact on lifestyle opportunities and financial security. Many people with disabilities however, do not experience any, or only minor limitations to daily living activities.

The ACT Quality of Life Project 1994-95^v findings for disability status (refer 5.3) highlighted the relatively poorer health-related quality of life of those reporting disabilities. There were no significant differences between different levels of disability (mild through to profound) in the degree of psychological distress being experienced, although other parts of emotional life were poorer for people with disabilities than for those without disabilities. Furthermore, people with disabilities were found to have worse general health which suggests that they may live for a shorter period than those with no disabilities. However, since the sample surveyed was small, results should be treated with caution.

◆ *Carers of people with disabilities:*

Principal carers of people with disabilities may experience minor or major disruptions to their daily lives, depending on the magnitude of the caring role. Disruptions include disruptions to education and training, the inability to participate in the workforce on a full-time or even part-time basis with the resultant financial burdens, inability to go out or take holidays, inability to perform usual tasks such as housework and gardening. Such restrictions can impact on the social, emotional and financial well-being of carers. The Survey of Disability, Ageing and Carers 1993 examined the burdens of principal carer roles. Results are tabled in Section 4.

1.3 The cost of disability and aged care

Reliable data on the financial cost of welfare services for people with disabilities and those requiring aged care are not extensively available. Welfare expenditure in the public sector is the only area where reasonable estimates can be obtained.

◆ *The public sector:*

The Australian Institute of Health and Welfare (AIHW) estimated that the ACT expended \$24,693,000 (49.5% of total welfare budget) in 1992-93, and \$26,596,000 (50.1% of total welfare budget) in 1993-94, on these services. These figures include Commonwealth and Territory funding for such services as Home & Community Care, employment and accommodation services, but do not include expenditure on nursing homes, domiciliary nursing services, long-term housing assistance or public housing mortgage assistance.^{vi}

Total welfare expenditure per person (which includes costs of family and childcare, aged and disability services and other welfare services, but does not include expenditure on nursing homes, domiciliary nursing services, long-term housing assistance or public housing mortgage assistance) is outlined in Table 1 using current prices. It can be seen that the ACT allocates a similar amount to welfare services as the national average.

Table 1 : Gross recurrent expenditure (\$) on welfare services, ACT and national average, 1990-94

Year	ACT	National average
	\$	\$
1990-91	148	125
1991-92	137	141
1992-93	168	160
1993-94	175	172
Ave annual growth rate	9.7%	9.7%

NB expenditure includes Territory and Commonwealth Governments allocations at current prices.

Source: AIHW, *Welfare Services Expenditure*^{vii}

◆ *Voluntary work:*

A large proportion of welfare work in Australia is carried out by volunteers who are either members of recipients' families or social networks, or not-for-profit welfare organisations. It has been estimated that not-for-profit organisations account for over half of all welfare services provided. Since they are generally not paid in a cost recovery sense for their services, it is difficult to estimate the real costs of services. There are no 'market prices' calculated for this type of work. The Australian Bureau of Statistics has carried out a survey of the community services industry in 1996 and when available, results from it will give more comprehensive information as to the contribution of profit and not-for-profit welfare organisations in Australia.

It has been estimated that in 1994-95, 26.1 per cent of the ACT population over the age of 15 years (some 59,500 people in all) provided some form of voluntary work through an organisation or group. This was the highest percentage of all states and territories and considerably higher than the national average of 19 per cent. However, volunteers worked an average of 137.8 hours each during the twelve months to June 1995 compared to the national average of 164.4 hours. The ACT volunteer proportion for females was 28.4 per cent (of the total ACT female population) compared to 23.7 per cent (of the total ACT male population) for males.^{viii}

There were 8.2 million hours of voluntary work done in the ACT during 1995. Using the most conservative method of equating these hours to dollar values, volunteers have saved the ACT community at least \$114 million per year in foregone wages.^{ix}

1.4 The purpose of this publication

This publication aims to give as detailed an analysis as possible, given the data available, on the profile of disability and ageing in the ACT and how it compares to Australia as a whole. This will provide planners and interested bodies with as full a set of information as possible on which to base priorities for interventions to improve both current and future services in the ACT.

Since older persons are *more likely* to become incapacitated or disabled than younger persons, an emphasis on older people over 60 years of age is given. Research indicates that disability is independently associated with increasing age, not being married, less years of schooling, lower income and not being employed^x. It is important to note however, that older age or lower socio-economic status *does not* inherently mean a life living with disability. Most elderly persons are not disabled or handicapped and lead healthy and active lives with little or no assistance.

Many younger people with disabilities do not require formal services either, to assist them in their daily lives, but as their parents age or die, such assistance may be needed.

A section is included on family and community carers in recognition of the fact that the caring role is generally undertaken by family members, local friends and community groups. Their contributions are invaluable, often allowing the person being cared for the ability to stay in their own home and local environment, but sometimes putting difficult pressures on the carers' lives.

Since the next publication in the Health Series will be devoted entirely to an epidemiological profile of mental health in the ACT, the emphasis of this publication is not on disability caused by mental illness.

2. A profile of disability and ageing in the ACT

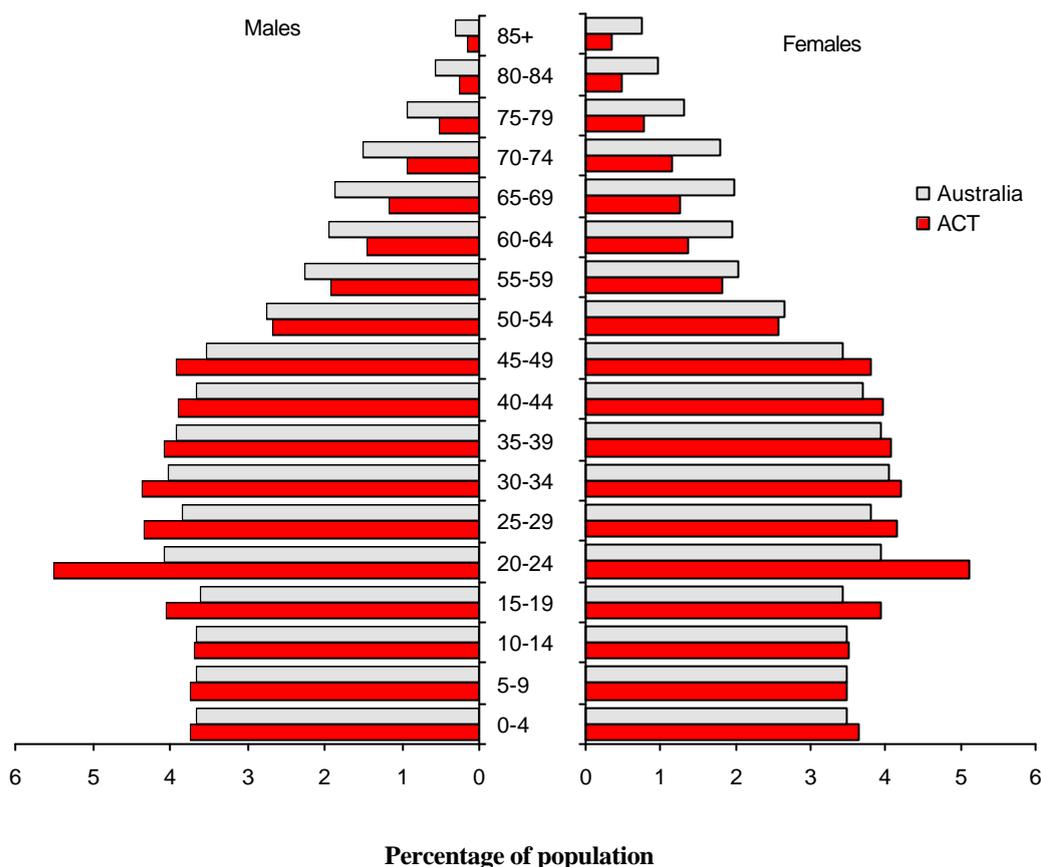
2.1 Age structure

The ageing of the Australian population is an on-going trend, especially in the oldest age group of 80 years and older. The annual rate of increase in size of this group is projected to be around 4 per cent compared to less than 2 per cent for people aged 65 and over, to the year 2006. Since those in the oldest group are more likely to have handicaps and need assistance, this rate of increase will impact on the demand for services in the near future. However, less than 10 per cent of people aged 65 to 69 years are profoundly or severely handicapped, and less than one per cent are resident in nursing homes or hostels. On the other hand, over half of people over 84 years are profoundly or severely handicapped and 31 per cent are in nursing homes or hostels.^{xi} Many older people have multiple handicaps. The prevalence of severe handicap in Australians 65 years and over has been found to be 32 per cent higher in females than in males.^{xii}

The ACT has a relatively young population compared to the national population (note in particular the percentage of the population of males and females at the 20 to 24 year age range in Figure 1). Since the prevalence of disability and handicap increases with age, it could be assumed that prevalence rates are lower in the ACT than for Australia generally. However, since the ACT's population (and that of Australia) are ageing, it is estimated that ACT (and Australian) rates will rise over time.

The following figure shows the composition of age groups by sex for the ACT and Australia in 1995, for the general population. It can be seen that females predominate in the oldest age groups (57% of all people 65 years or over increasing to 70% for those 85 and over), but males predominate slightly in younger age groups to age 64 years. This profile is similar to that of Australia as a whole.

Figure 1: Estimated total population, by age groups, by sex, ACT & Australia, June 1995



Source: ABS publication, June 1994 and Preliminary June 1995 *Estimated resident population by sex and age States and Territories*. Catalogue No. 3201.0

2.2 Disability and handicap

Information on the prevalence and incidence of disability and handicap is limited. The Australian Bureau of Statistics (ABS) does conduct regular surveys which give a reasonably sound basis for analysis, although the size of the ACT sub-sample has been smaller than would be desired. The most recent survey, titled the Survey of Disability, Ageing and Carers^{xiii} was conducted in 1993. (Refer 7.4.3) It is based on self-reported answers to questionnaires and is used extensively in the following analyses.

2.2.1 Disability and handicap profile

The reported prevalence of disability has increased substantially in Australia, especially in males, since the first ABS survey in 1981^{xiv}. This may be due to changing community perceptions of disability and handicap. Changing attitudes may have resulted in people being more aware of disabling conditions and/or more willing to report such conditions^{xv}. The increase in prevalence is demonstrated in the following table:

Table 2: Prevalence of disability (%), Australia, 1981-93

	1981	1988	1993
Males	14.8	16.9	18.0
Females	12.8	14.6	14.8
Total	13.8	15.8	16.4

Note: prevalence rates age-adjusted using the total Australian population as at 30 June 1991

Source: AIHW, derived from ABS *Disability, Ageing and Carers Survey 1993, Summary of Findings*, Cat. No. 4430.0

The prevalence of handicap has increased from 1981, but decreased slightly since 1988:

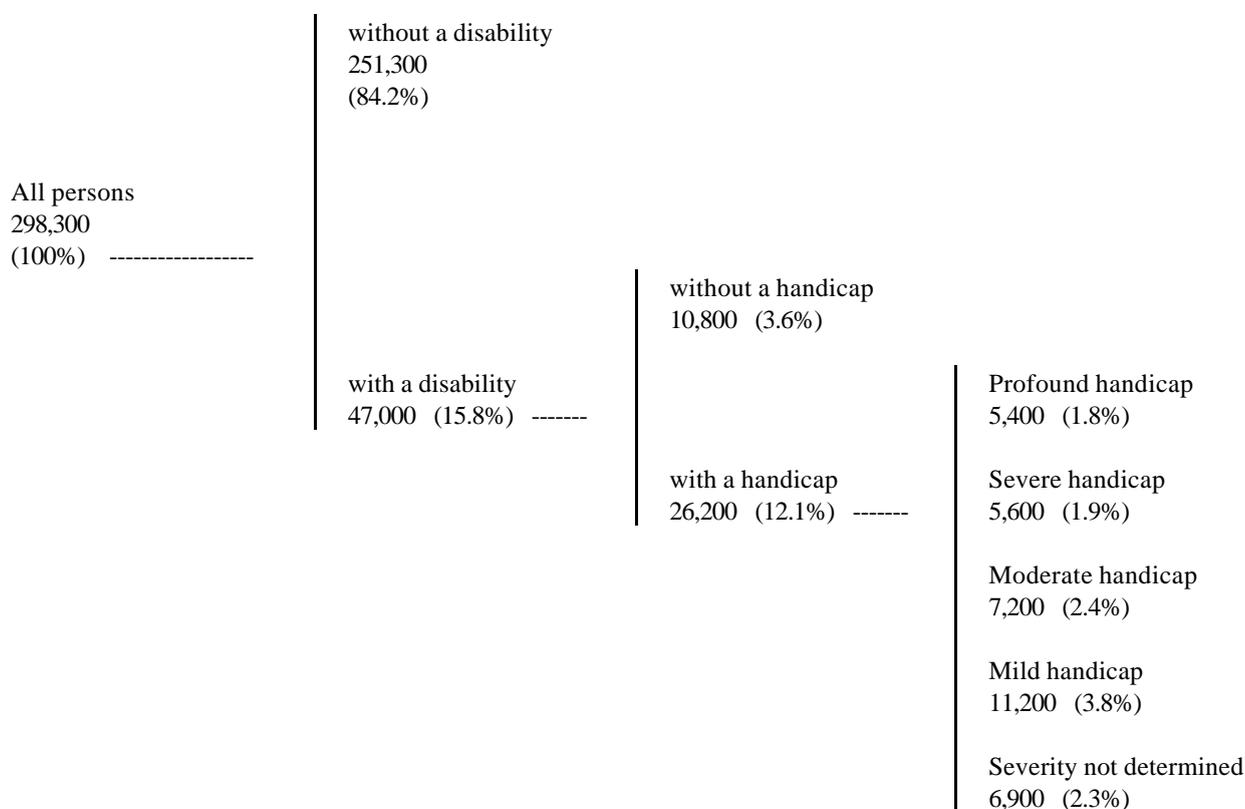
Table 3: Prevalence of handicap and severe handicap (%), Australia, 1988-93

	Handicap			Severe handicap		
	1981	1988	1993	1981	1988	1993
Males	9.4	13.8	13.5	3.5	3.5	3.5
Females	8.8	12.4	11.8	4.1	4.5	4.1
Total	9.2	13.1	12.7	3.8	4.1	3.9

Note: prevalence rates age-adjusted using the total Australian population as at 30 June 1991

Source: AIHW, derived from ABS *Disability, Ageing and Carers Survey 1993, Summary of Findings*, Cat. No. 4430.0

The prevalence of reported disability has increased over time in line with the national trend. The Survey of Disability, Ageing and Carers, 1993, estimated that there were 47,000 people in the ACT (15.8% of the ACT population) who had a disability. Of those, 36,200 people (or 12.1% of the ACT population) had a handicap. Nationally however, there were 18.0 per cent with a disability and 14.2 per cent with a handicap.

Figure 2: Number & proportion of persons with a disability, with a handicap, ACT, 1993

Note: For definitions of severity of handicap refer Glossary (6.2)

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished

Because of the strong relationship between age and disability, age standardised rates standardised to the national population at March 1993, were calculated. This removed any difference in age structures between each state and territory. Results are outlined below:

Table 4: Handicap & disability rates (per 1,000 population), ACT & Australia, 1993

	Handicap rate		Disability rate	
	Actual	Standardised	Actual	Standardised
ACT	121.3	148.8	157.6	187.8
Australia	141.8	141.8	180.2	180.2

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished

After standardisation, the ACT had a slightly higher, but statistically not significantly higher, rate for both disability and handicap.

2.2.2 Sex and age composition

Nationally, more males (18.4%) reported a disability than females (17.6%), in all age groups in 1993. The largest gender difference occurred in the 60-64 year age group where 43.2 per cent of males reported a disability compared to 29.6 per cent of females.

For all age groups in the ACT however, there was an equal distribution of males and females reporting a disability (15.7% compared to 15.9%). The age group where the largest difference occurred was the 60-64 years group where 43.9 per cent of females and 33.3 per cent of males reported a disability (a reversal of national percentages). The rates for disability and handicap increased considerably for those aged 45 and over for both males and females.

Data concerning the recipients of various social security pensions as outlined in the following table, give some indication of acute or chronic disability in the Territory.

Table 5: Recipients of various pensions, ACT, 1991-95

Type of pension	1991	1992	1993	1994	1995
Age pension	9 558	10 118	10 798	11 564	11 926
Wife's	190	204	236	249	279
Carer's	22	23	6	37	45
<i>Total</i>	9 770	10 345	11 040	11 850	12 250
Invalid/disability					
Support pension (a)	2 375	2 952	3 250	3 582	3 981
Wife's	496	556	614	689	721
Carer's	31	40	26	61	79
<i>Total</i>	2 902	3 548	3 890	4 332	4 781
Child disability allowance	808	1 040	1 174	1 410	1 553

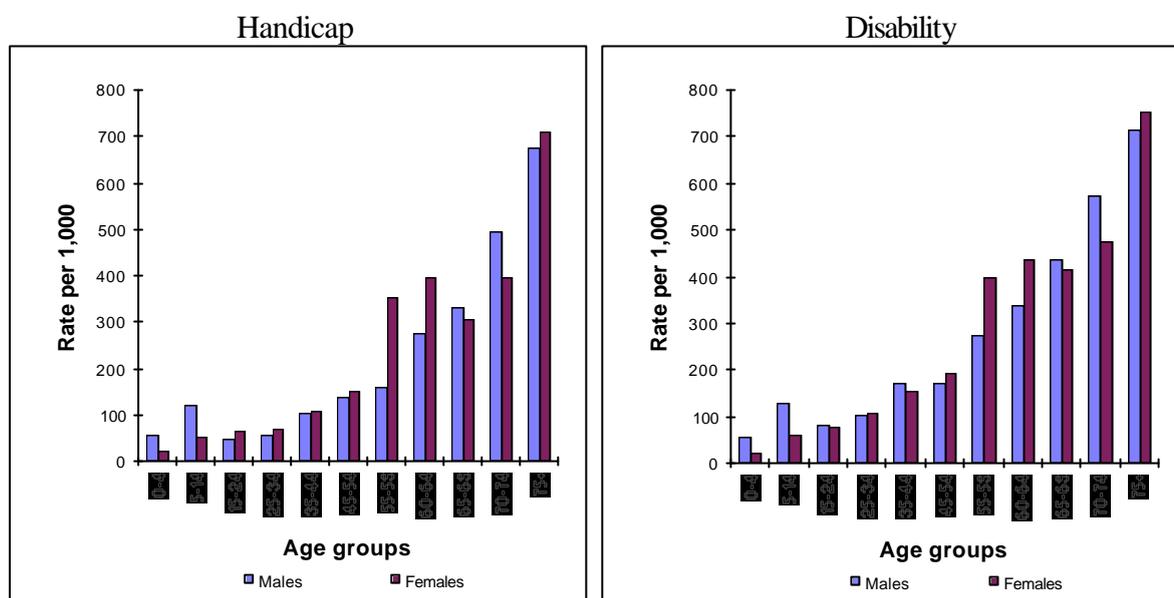
(a) Note: From 12 November 1991, Disability Support Pension replaced Invalid Pension & Sheltered Employment Allowance
Source: *ACT in Focus, 1996*^{vii}

There was an increase of over 10 per cent from 1994 to 1995 in the number of persons receiving the Disability Support Pension. There was a similar increase in 1992 and 1993, indicating a steady trend. Child Disability allowance payments increased by nearly 9 per cent (a reduction in percentage increases

on previous years) and the number of persons receiving the Aged Pension increased by over 3 per cent (also a reduction in percentage increase over previous years) from 1994 to 1995.

In terms of rates of handicap and disability by sex for age groups, the following figure shows rates per 1,000 persons in the ACT in 1993:

Figure 3: Handicap & disability age-specific rates, by sex, ACT, 1993



Note: Data at the 0-4 years age group is subject to high relative standard error

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, ABS, *Disability, Ageing and Carers, Australia, 1993*, Cat. No. 4430.0

Since approximately 77 per cent of people with a disability also have a handicap, those people are reflected in both of the above figures.

With a few exceptions, the disability and handicap rates become higher as age increases. The exceptions include: males aged 5-14 years (higher handicap rate than would be expected - discussed below and in Section 2.2.3), females aged 55-64 years who have a higher handicap rate than would be expected, and females aged 65-74 who have a lower handicap rate than would be expected. There are similar, but less obvious exceptions for disability rates for these groups. None of these differences are statistically significant, since the sampling variance and relative standard errors were high. As a consequence, there are no significant differences between the age groups.

In Australia generally, boys in the age group 0-14 years have a mental retardation and developmental delay rate (included in the 'other mental disorders category') of more than twice that of girls in the same age group. Overall, they have 40 per cent higher rates of disability, handicap, and severe handicap than girls.^{xvii} This is reflected in Figures 7 and 8 in Section 2.2.3 (age breakdowns).

Using the 0-4 years age group as the comparative benchmark, (refer Table 4 following) it can be seen that:

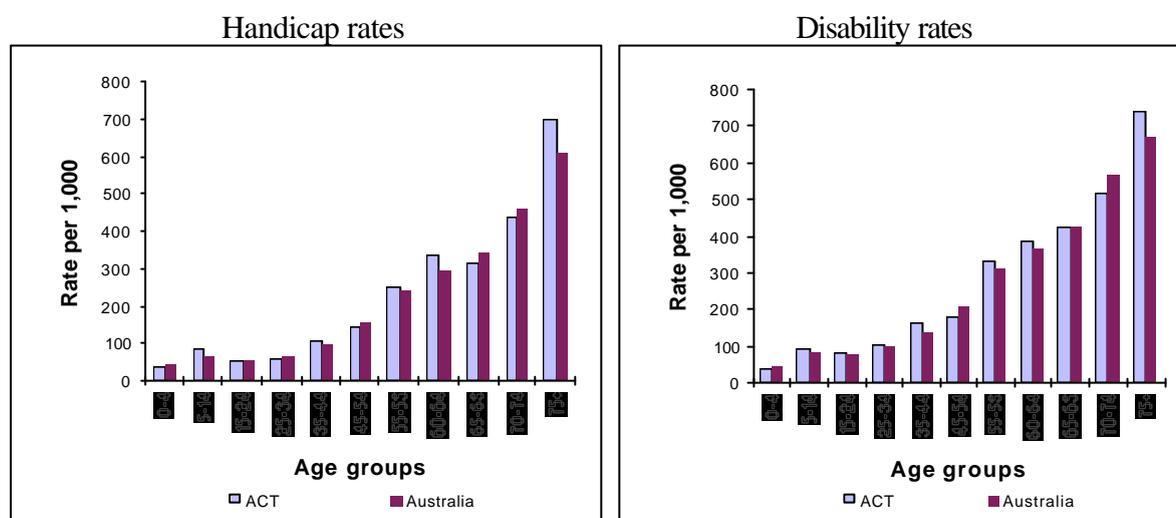
Handicap rates:

- The rate for ACT people aged 35-44 years is more than double that of children aged 0-4 years.
- The rate for ACT people aged 60-64 years is approximately eight times that of children aged 0-4 years.
- By age 75 years the ACT rate is approximately eighteen times that of children aged 0-4 years.

Disability rates:

Disability rates follow a similar pattern to that for handicap, since most persons in the ACT with a disability (77%) also have a handicap. If one compares the ACT disability and handicap rates with those of Australia, some interesting comparisons can be made:

Figure 4: Handicap & disability age-specific rates, ACT & Australia, 1993



Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished
ABS, *Disability, Ageing and Carers, Australia, 1993*, Cat. No. 4430.0

The overall trends as age increases is similar for both the ACT and Australia for rates of both handicap and disability. Particular differences appear to occur at the 5-14 age group and the over 75 years age group where the ACT rates for disability and handicap are higher than Australian rates; and the 45-54 and 65-74 year age groups where Australian rates are higher than for ACT. Since ACT rates are subject to considerable relative standard error and sampling variance however, it is difficult to make comparisons, so data should be treated with caution. Confidence intervals are large. It will be important to monitor ACT carefully in the future.

Some further indication of *possible* rates of disability can be ascertained from the preliminary results of the National Health Survey 1995-96 (refer 7.4.2). Questions were based on the SF-36 (refer Glossary 6.3) and self-reporting of respondents' perceptions of their general health status. Scores were between 0 and 100 with higher scores denoting better state of health. Results were as follows:

Table 6: General health & wellbeing mean scores, persons aged 18 or more, by category, by age, by sex, ACT, 1995

Category	Age groups					Total
	18-24	25-44	45-64	65-74	75+	
Physical functioning	90.5	90.0	83.8	68.8	54.1	86.1
Role limitations: physical	85.3	83.6	81.5	71.7	59.6	82.0
Bodily pain	76.7	77.9	76.7	73.6	70.6	76.9
General health	73.0	74.6	72.0	65.6	65.2	72.8
Vitality	65.5	64.3	65.2	67.5	59.5	64.8
Social functioning	84.9	85.6	85.0	87.4	80.8	85.3
Role limitations: emotional	80.8	83.8	84.0	83.8	67.7	82.9
Mental health	74.3	75.1	75.5	79.9	78.6	75.5

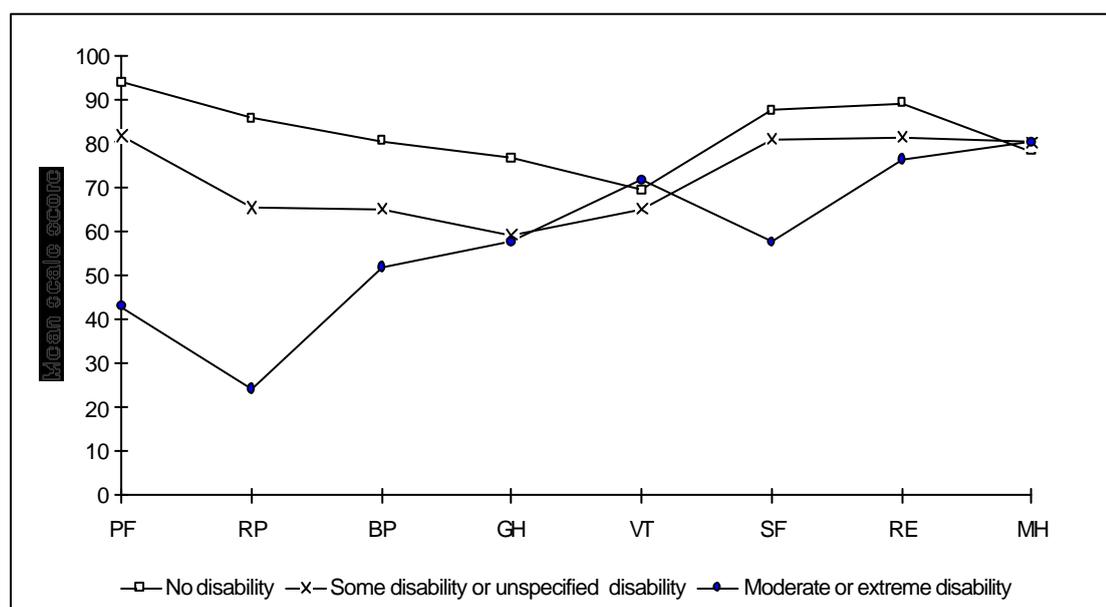
Source: National Health Survey, First Results, ACT tabulations, 1995, Catalogue No. 4392.0

It can be seen that mean scores in all categories except mental health decreased with age. This was particularly so with the category of physical functioning. Males had higher total scores than females with the exception of general health (males 72.2, females 73.4).

It is interesting to note that ACT mean scores were slightly better than national scores, with the exceptions of role limitations (emotional) which was identical, and mental health which was slightly lower (but not statistically significantly lower) than the national score. It should be acknowledged however, that low scores do not necessarily indicate disability, but could be interpreted as an *indicator* of disability risk.

The ACT Quality of Life Survey^{xviii} (Refer 5.3), also using the SF-36 forms, found that ‘for physical functioning and role-physical scales, respondents who had no disability scored significantly higher than those with some disability, who again scored significantly higher than those with moderate or extreme disability. For the bodily pain and general health scales, those with no disability had significantly better scores than the others. For the social functioning scale, those with moderate or extreme disability had significantly lower mean scores than the rest’.

Figure 5: Mean score profiles, SF-36, by disability status, ACT, 1994-95



Note: weighted data is used.

Source: Health Related Quality of Life in the ACT: 1994-95^{xix}

2.2.3 Disabling conditions

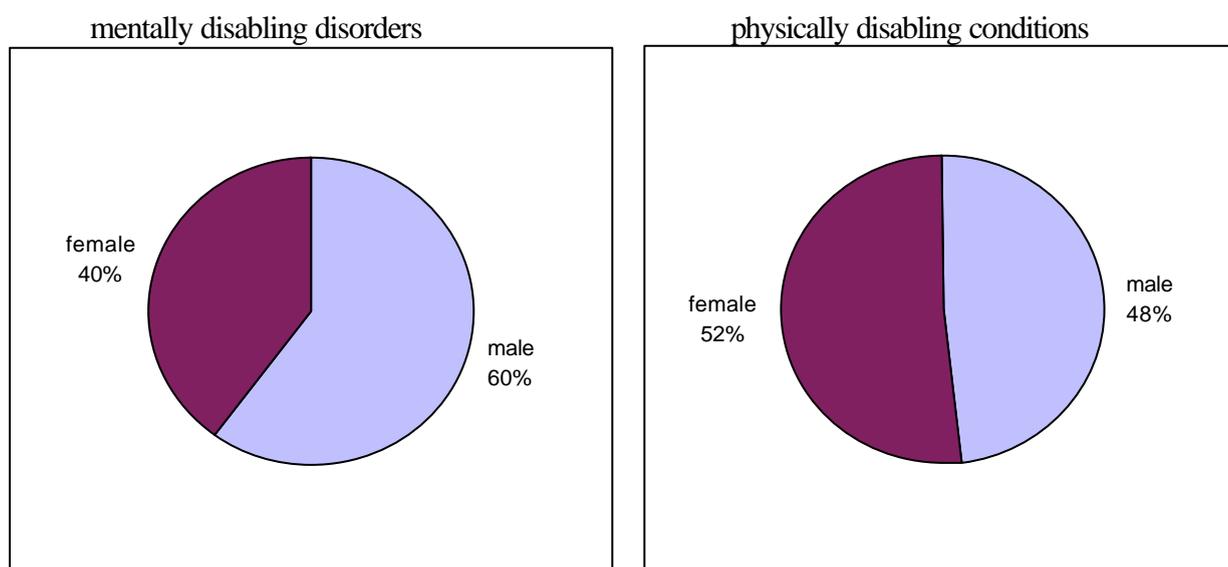
The World Health Organisation (1982) estimated that 15 per cent of all disability worldwide, was caused by injury. The proportion is particularly high for younger males: a British cohort study found that between 23 and 32 per cent of disabled males aged 23 years, were disabled as a result of injury. This percentage due to injury rose to between 30 and 50 per cent for those males disabled after 16 years of age. The study also noted that the risk of permanent disability after an accident increased with the number of accidents experienced.^{xx}

Older people are also at particular risk of injury and possible consequent disablement. Falls in the elderly, especially in females, account for the highest proportion of hospitalisations for injury and the third highest cause of death from injury in the ACT^{xxi}. Such falls are caused by a multitude of factors such as medical, environmental, psychological and social factors that interact with physiological age-related changes. Gait and balance abnormalities are significant predictors of falls^{xxii}.

Research into the relationship between disability and various musculoskeletal disorders suggests that inflammatory arthritis is the strongest determinant of all forms of disability. In one of many studies, osteoarthritis, especially of the hip and knee, was found to be the strongest determinant of both occasional and regular need for assistance, and chronic low back pain was a strong determinant of reduced working capacity in people aged 30 to 64 years. A low level of education and a low or very high body mass index also represented independent associations of all forms of disability^{xxiii}. Furthermore, in findings from the Ontario Health Survey, musculoskeletal disorders rank first in prevalence as the cause of chronic health problems and consultations with health professionals, and second for restricted activity days and use of prescription and non-prescription drugs. The impact of these disorders was greatest in people in the 65 and over age groups^{xxiv}. A German study into musculoskeletal symptoms in peri and post menopausal women found that current back, neck and joint pain was consistently higher in females than in males at all age groups and that the peak prevalence was in females aged 55 to 64 years^{xxv}.

The Disability, Ageing and Carers Survey 1993 found the following results with regard to the two categories of disabling conditions in the ACT (For estimated cases by category, refer Appendix 7.1):

Figure 6: Disabling conditions, ACT, 1993



Source: ABS, *Disability, Ageing and Carers Survey 1993*, Cat No. 4432.0

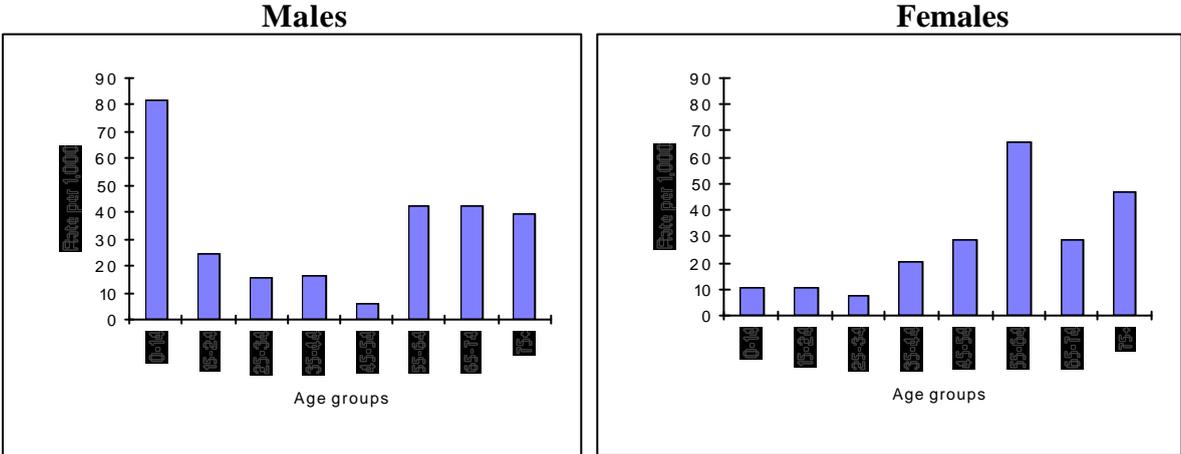
Males represented over half of all cases of mentally disabling disorders, but under half the cases of physically disabling conditions. The breakdown of reported prevalence rates by age group shows the peaks and profiles for males and females (refer Figures 7 and 8):

Mental disabling conditions

Research suggests that psychopathology is consistently associated with increased disability. Disability is most prominent among people with major depression, panic disorder, generalised anxiety and neurasthenia^{xxvi}.

Mental disorders are defined in two categories in the 1993 Survey: ‘senile and other psychosis’; and ‘other mental disorders’ which includes mental retardation, mental degeneration due to brain damage, slow learning and specific delays in development, neurotic disorders, personality disorders and other non-psychotic mental disorders.

Figure 7: Disabling conditions due to mental disorders, rate by age groups, by sex, ACT, 1993



Source: ABS, *Disability, Ageing and Carers Survey 1993*, Cat No. 4432.0

It is interesting to note the different age profiles for males and females (refer Figure 7). Male rates peak at a very young age, drop dramatically at age 15 years and return to a peak at age 55 and onwards. Females on the other hand, peak between 55 and 64 years, with high rates in all older age categories. Nevertheless, rates are quite small and are subject to high sampling variability, so should be treated with caution.

ACT males in the 0-14 years age group make up 46 per cent of all male mental disorders (unexpected). By contrast for Australia, the proportion is 27 per cent of all male mental disorders (also quite high). In fact, boys in the age group 0-14 years have a mental retardation and developmental delay rate (included in the ‘other mental disorders category’) of more than twice that of girls in the same age group. For females, 43 per cent of ACT cases occurred between 35 and 54 years.

One explanation for the high proportion of male incidence at the youngest age range may be that older males may not disclose mental disorders readily, thus skewing the rates. Females may be more likely to be frank about their disorders. In any event, the Australian Bureau of Statistics is testing modifications to the questionnaire for the next survey, to try and remove any impediments to disclosure (eg. questions posed in different ways, more related questions which could uncover any disorders or conditions without threatening the respondents). It will be important to monitor results of future surveys.

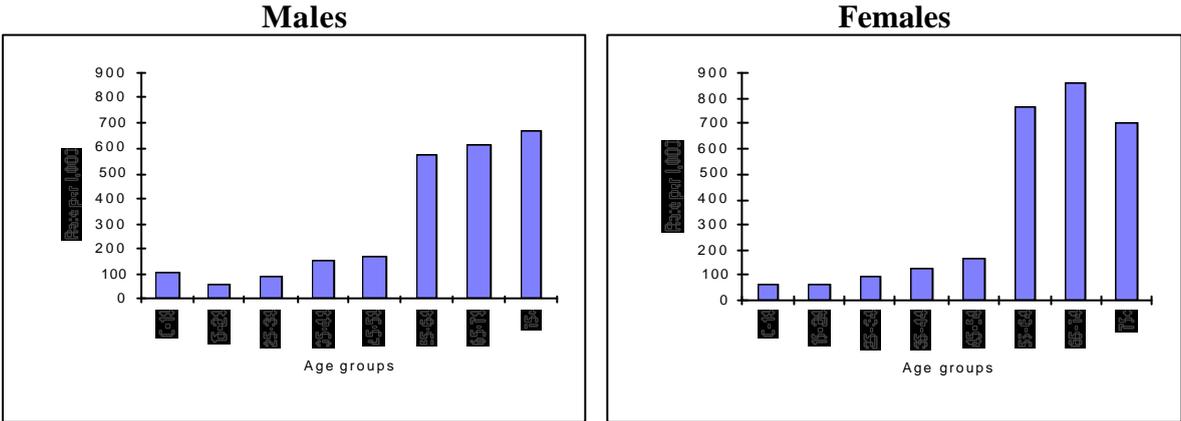
The standardised rate for mental disorders (standardised to the Australian population in March 1993) in the ACT was 2.3 per 1,000 males, 1.7 per 1,000 females and 1.9 per 1,000 persons. (This compares to an Australian rate of 2.0 per 1,000 persons).

It is generally recognised that, at some time in their lives one in five adult Australians and at least one in ten children and adolescents experience mental illness to a level which interferes with their lives. A report commissioned for the National Mental Health Strategy estimated that the prevalence of serious mental illness each year was about 3 per cent of Australians. Only about half of these are receiving treatment from either public mental health services, private psychiatrists or general practitioners.^{xxvii} Further information regarding the mental health profile in the ACT will be released in the Health Series shortly, in a publication titled *‘Mental Health in the ACT’*.

Physical disabling conditions

Male and female rates for physical disabling conditions are smoother and more homogeneous than for mental disabling conditions:

Figure 8: Disabling conditions, physical, rates by age groups, by sex, ACT, 1993



Source: ABS, *Disability, Ageing and Carers Survey 1993*, Cat No. 4432.0

Both males and females have high rates at age 55 years and older, as would be expected. The female rates for older people is considerably higher than for males (refer research at end of 2.2.3). Males have a higher rate in the 0 to 14 years age group. This may be due to risk taking behaviour and high involvement in contact sports.

The standardised rate for physical disabling conditions (standardised to the Australian population in March 1993) in the ACT was 15.9 per 1,000 males, 17.6 per 1,000 females and 16.8 per 1,000 persons. (This compares to an Australian rate of 16.0 per 1,000 persons).

The results of *National Health Surveys* give estimates of the incidence of conditions and diseases. Whilst the existence of conditions detailed may not result in disability or handicap, the results are useful to evaluate trends or possibilities. As an instance, British research suggests that people reporting rheumatic disorders have an estimated prevalence of disability of 82 per 1,000^{xxviii}. Arthritis (mainly osteoarthritis) was the most commonly reported cause (47 per 1,000), followed by back and neck disorders (25 per 1,000), soft tissue disorders (18 per 1,000) and rheumatoid arthritis (4 per 1,000).

It can be seen from Table 7 below, that the rate of having a disease of the musculoskeletal system and connective tissue increases to the age group of 65-74 years and then decreases. The decrease is probably due to the survivor effect. People with these conditions at old age are more likely to have died or be in a nursing home (not included in the Survey). The rate of mental disorder peaks at age 0-14 years and again at 45-64 years. ACT rates in the three categories were higher than national rates.

Table 7: Long-term conditions, rate per 1,000, by age, by sex, ACT 1989-90

	Age group						Persons		Total	
	0-14	15-24	25-44	45-64	65-74	75+	Males	Females	ACT	Aust
Diseases, musculoskeletal system & connective tissue	*32.9	228.5	313.2	458.2	830.9	679.2	268.3	295.5	281.8	258.0
Mental disorders	*46.9	*28.5	*8.5	*32.4	**	**	32.0	*12.6	22.4	21.8
'Other' disability	**	*17.9	*11.0	**	**	**	*7.9	*12.7	10.3	6.8

* Subject to sampling variability between 25% and 50% ** Subject to sampling variability too high for most practical purposes.
Source: ABS, National Health Survey 1989-90

Preliminary results from the 1995-96 Survey do not include long term conditions in the above categories. They will be released shortly, and it will be interesting to compare them with 1989-90 results. Preliminary results do however include some categories which assist in developing a profile of disability and handicap for the ACT. These are tabled below:

Table 8: Long term conditions, rate, by type, by age, by sex, ACT, 1995-96

Type	Age group						Males	Females	Total	
	under 5	5-14	15-24	25-44	45-64	65-74				75+
far-sighted	**	58.3	96.3	104.3	470.7	533.5	414.7	165.4	209.8	187.4
short-sighted	**	60.7	205.3	289.9	367.4	312.7	256.4	211.6	258.6	234.9
other sight	**	65.0	83.4	123.4	270.2	415.4	538.9	139.4	163.5	151.3
arthritis	**	**	22.8	73.1	214.3	442.9	400.3	80.3	121.5	100.7
deafness	**	23.5	43.9	70.9	134.4	275.6	438.0	100.4	69.4	85.0
back problems	**	6.7	49.2	89.7	91.4	60.8	*48.3	67.6	55.4	61.5

Note: rate per 1,000 population of same age or sex

* Subject to sampling variability between 25% and 50% ** Subject to sampling variability too high for most practical purposes

Source: ABS, *National Health Survey, First Results*, ACT, Cat. No. 4392.0

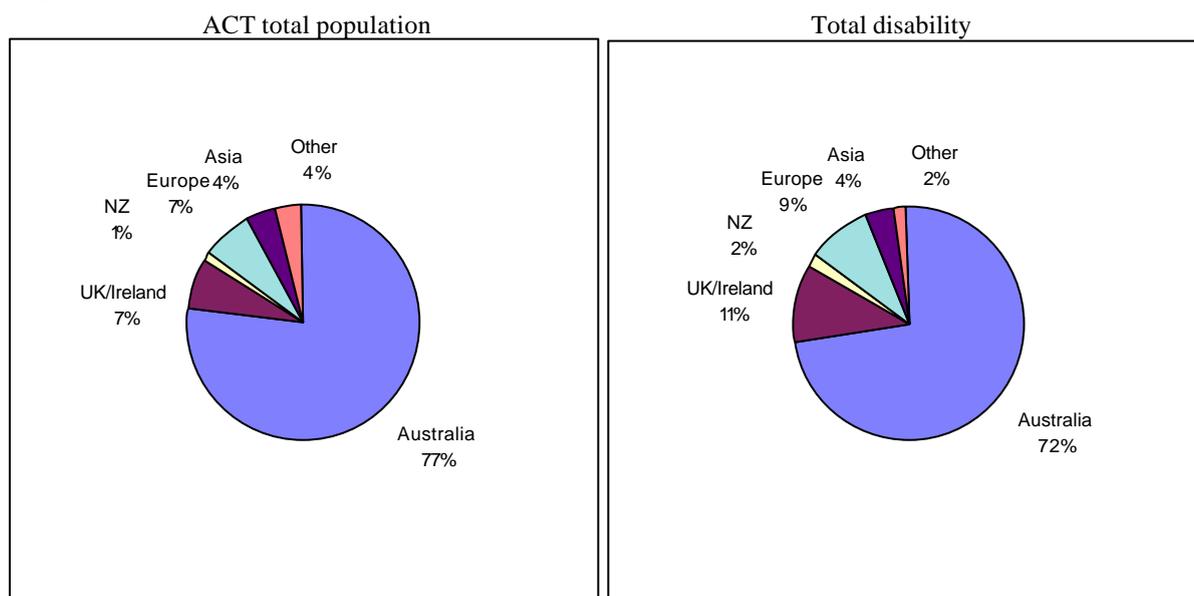
It can be seen that all categories outlined above have increasing rates as persons age to 74 years. In the 75 plus age group, far-sightedness, short-sightedness, arthritis and back problems actually decrease. With the exception of arthritis, this decrease also occurred in Australian rates for people 75 years and over. The ABS reports that the rate for the general category of musculoskeletal problems, which includes back problems and arthritis, rises for the 75 plus age group (unpublished data). The rises within the category are in the areas of osteoporosis, osteoarthritis and rheumatism. It could be concluded therefore, that people are reporting more specific conditions, rather than the general condition of 'back problems' or 'arthritis'. With regard to sight impairment, the questions asked included a prompt card on which was recorded a category titled 'age related sight problems'. Older people may have been prompted to use this category rather than a more specific one. Those nominating this category had their answer noted in the 'other sight' category. This would account for the high rate of 'other sight' problems at the 75+ age group. It would be useful to monitor future data to ascertain whether a trend emerges.

A five year follow up epidemiological study in the USA^{xxix}, researching the correlation between risk of disability for women and body mass index (BMI) found that high BMI is a strong predictor of long-term risk for mobility disability in older women and that this risk persists to a very old age. Paradoxically, it was found that there was also a risk associated with weight loss in women over 76 years of age.

2.2.4 Country of birth

From the 1993 figures below, it can be seen that people born in Australia living in the ACT represent 77 per cent of the population, but only 72 per cent of the population with disabilities. In contrast, people living in the ACT from the United Kingdom and Ireland represent 7 per cent of the population, but 11 per cent of the population with disabilities. European people also have a slightly higher proportion of disability than their population would have suggested. Two explanations for the difference may be the family reunion policy of the past where more older people (who are therefore more liable to have or develop disabilities) from those countries may have entered the ACT, or that people from those countries may undertake more risky employment (eg manual labour). However, the differences are not statistically significant. If the anomalies increase over time and become significant, it would be useful to investigate the reasons more thoroughly.

Figure 9: Country of birth, population & persons with a disability, ACT, 1993



Source: ABS, *Disability, Ageing and Carers Survey 1993*, Cat No. 4432.0

2.2.5 Living arrangements

Table 9 shows where people with and without disabilities live in the ACT. It can be seen that, as for people with no disabilities, most people with a disability, irrespective of age, live in households.

Table 9: Living arrangements, by disability status, by number, by age, ACT, 1993

Living arrangements	Age group (years)							Total
	0-24	25-34	35-44	45-54	55-64	65-75	75+	
DISABILITY								
Households								
lives alone	*400	*700	*700	*700	1200	1900	1600	7200
lives with other people	9200	4600	7200	5700	5400	4000	2700	38800
Total	9600	5300	7900	6400	6600	5800	4300	45900
Establishments								
hospital	**0	**100	**0	**0	**100	**100	**200	*600
retirement village	**	**	**	**	**	**	**	**200
other	**	**	**	**	**	**0	*300	*300
Total	**0	**100	**0	**0	**100	**200	*700	1100
Total with disability	9600	5300	7900	6400	6700	6000	5000	47000
NO DISABILITY								
Households								
lives alone	2800	2400	3000	1900	1400	1300	*700	13500
lives with other people	111900	43500	38200	27000	10500	5600	1000	237700
Total	114700	45900	41200	29000	11900	6800	1700	251200
Establishments								
hospital	**	**	**	**	**	**	**	**
retirement village	**	**	**	**	**	**	**0	**0
other	**	**	**	**	**	**0	**100	**100
Total	**	**	**	**	**	**0	**100	**100
Total with no disability	114700	45900	41200	29000	11900	6900	1800	251300
TOTAL								
Households								
lives alone	3200	3100	3800	2600	2600	3100	2300	20600
lives with other people	121100	48100	45300	32800	16000	9600	3700	276500
Total	124300	51200	49100	35400	18500	12700	6000	297100
Establishments								
hospital	**0	**100	**0	**0	**100	**100	**200	*600
retirement village	**	**	**	**	**0	**0	**200	**200
other	**	**	**	**	**	**100	*400	*400
Total	**0	**100	**0	**0	**100	**200	*800	1200
Total Persons	124300	51200	49100	35400	18600	12900	6800	298300

** Data subject to high relative standard error. * Subject to sampling variability between 25% and 50% NB All figures are rounded.

Source: ABS, *Disability, Ageing and Carers Survey 1993*, Cat No. 4432.0

2.2.6 Employment

Table 10 shows the employment status of persons aged 15-64 yrs in households, by handicap and disability status in the ACT in 1993.

Stated in percentages, it shows that:

- ◆ Of all people with a disability, but with no handicap, of usual employment age (15-64 years) in the ACT, 87.5 per cent were in the labour force and, of those, 93.5 per cent (almost 100% males, 85.7% females) were actually employed.
- ◆ Of all people with a disability and a handicap, of usual employment age (15-64 years) in the ACT, 61 per cent were in the labour force and, of those, 90.2 per cent (93.8% males, 88.4% females) were actually employed.
- ◆ This compares with people who do not have a disability or handicap of whom 93.3 per cent were in the labour force and of those, 79.7 per cent (93.3% males, 93.4% females) were actually employed.

It can be concluded that people with a disability, but no handicap, have a lower unemployment rate and a higher participation rate in the workforce than people with no disabilities. This may be due to the effect of supported employment schemes. In addition, since there is no distinction made between full and part-time employment and since many people with disabilities are more likely than those without a disability to be employed in a part-time capacity, this comparison should be treated with caution however.

Table 10: Employment status, persons aged 15-64 yrs in households, by number, by handicap & disability status, ACT, 1993

Severity of handicap & disability status	Employed	Unem - ployed	Total in labour force	Not in labour force	TOTAL	Unemploy- ment rate (%)	Participat'n rate (%)
PERSONS							
Handicap							
Profound	*400	**	*400	*900	1300	**	31.4
Severe	1600	**300	1800	1800	3600	14.1	50.2
Moderate	2400	*400	2700	1900	4600	13.8	59.6
Mild	5600	*500	6100	2100	8200	7.6	74.7
Not determined (a)	2100	*200	2200	190	4200	7.2	53.7
Total with handicap	12000	1300	13300	8500	21800	9.5	61.0
Disability w/out handicap	7200	*500	7700	1200	8800	6.2	86.5
No disability	134100	9600	143700	36600	180200	6.7	79.7
Total	153300	11300	164600	46300	210900	6.9	78.1

** Data subject to high relative standard error. * Subject to sampling variability between 25% and 50% NB All figures are rounded.

Note: Data in this table may differ from that reported in the Labour Force Survey due to differences in survey sample size, the scope rules applied & the complexity of the questions asked to determine labour force status.

(a) Comprises persons with a schooling or employment limitation only & persons whose limitation was 'does not use the toilet'.

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished

It is interesting to compare the above information with data provided in a publication, released in February 1997 by the Steering Committee for the Review of Commonwealth/State Service Provision^{xxx}. It states that the labour participation rate for ACT people with a disability, irrespective of whether they have a handicap, was 68.3 per cent (Australian rate of 54.9%), and that the proportion unemployed in that group was 8.3 per cent (Australian proportion of 17.8%), in 1993. These revised figures utilised both the ABS Survey of Disability, Ageing and Carers 1993 results and recent work done by Madden et al 1997^{xxxi}.

The following table shows age group participation in the workforce. It can be seen that, for all groups with and without disability or handicap, the major age groups of employment are 25 to 54 years. (When analysing participation by sex, this is uniformly accurate for males, but there are some anomalies

in female participation. Specifically, differences occur in females with handicap and females with a disability without a handicap, both of whom have a peak participation rate at the 15-24 year age group, but also high rates at 25-54 years). It is important to reiterate however, that numbers are small and there is high sample variability in this group. Apparent trends should be treated with caution.

Table 11: Employment, by handicap & disability status, by age group, ACT, 1993

age (years)	Employed	Unemploy- ed	Total in the labour force	Not in the labour force	Total	Unemploye d rate (%)	Particip- ation rate (%)
Handicap							
15-24	1600	**200	1800	1300	3100	9.4	57.5
25-34	1800	**100	1900	1100	3100	4.2	62.6
35-44	3400	**200	3600	1600	5200	6.6	69.6
45-54	3400	*500	3900	1200	5100	13.5	77.3
55-64	1800	**200	2000	3300	5300	11.9	38.1
Total	12000	1300	13300	8500	21800	9.5	61
Disability with out a handicap							
15-24	*900	**100	*900	*400	1300	8.6	69.9
25-34	1800	**200	2000	**200	2200	7.7	89.5
35-44	2500	**100	2600	**100	2700	3.2	94.6
45-54	1100	**200	1300	**100	1300	12.8	94.9
55-64	*900	**	*900	*300	1300	**	73.2
Total	7200	*500	7700	1200	8800	6.2	86.5
No disability							
15-24	26700	5000	31700	20600	52200	15.8	60.6
25-34	38100	2300	40400	5500	45900	5.8	88.1
35-44	36700	1000	37700	3500	41200	2.7	91.6
45-54	25900	1100	26900	2000	29000	4.0	92.9
55-64	6800	**200	6900	5000	11900	2.2	57.9
Total	134100	9600	143700	36600	180200	6.7	79.7
All persons							
15-24	29200	5200	34400	22300	56700	15.2	60.7
25-34	41800	2600	44300	6800	51200	5.8	86.6
35-44	42500	1300	43900	5200	49100	3.1	89.4
45-54	30400	1800	32100	3300	35400	5.5	90.8
55-64	9500	*400	9900	8700	18500	4.0	53.3
Total	153300	11300	164600	46300	210900	6.9	78.1

** Data subject to high relative standard error. * Subject to sampling variability between 25% and 50% NB All figures are rounded.

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished

There is no information available for special needs groups in the Survey of Disability, Ageing and Carers 1993, but some information has just been published by the Steering Committee for the Review of Commonwealth/State Service Provision^{xxxii} on recent findings by Madden et al 1997^{xxxiii} (refer Table 12). Generally, a larger proportion of Indigenous people with a disability used employment services than used accommodation services. Similarly for people from a non-English speaking background, but these people did not use either service extensively.

Table 12: Accommodation & employment service use, by special needs groups, ACT, NSW, Australia, 1995-96

	Unit	ACT	NSW	Australia
People from an Aboriginal or Torres Strait Islander Background				
Using accommodation services	per 1,000 Indigenous populat' n	1.3	1.4	1.7
Using employment services	per 1,000 Indigenous populat' n	4.2	3.1	2.7
People from a non-English speaking background				
Using accommodation services	per 1,000 NESB populat' n	0.14	0.20	0.23
Using employment services	per 1,000 NESB populat' n	0.59	0.56	0.67

Source: Madden et al, 1997



3 Types of assistance needed

Persons participating in the 1993 Disability, Ageing and Carers Survey identified daily functions with which they needed assistance. From responses, it was estimated that there were nearly 21,400 people having a disability and living in households in the ACT, who needed such assistance in some area(s). Of those, 16,800 received help in at least one area. The help was mainly provided informally and nearly half of that by spouse/partners. 13.1 per cent received help from a friend or neighbour. (Refer Table 13). Data should be treated with caution, due to the high standard errors and sampling variability.

Table 13: Main provider of assistance, by activity for which help was needed, ACT, 1993

	Self-care	Mobility	Verbal communication	Health care	Home help	Home maintenance	Meal preparation	Personal affairs	Transport	Total (a)
Informal help from										
spouse/partner	2200	2800	**100	1700	2600	5200	*400	1000	3200	8800
mother	1800	1500	*400	**200	**200	**200	**100	*500	1000	2500
father	**100	**	**	**	**	**	**	**200	**100	*400
daughter	1000	1000	**200	1000	1100	*600	*600	*800	1900	3000
son	**200	*300	**200	**100	*300	1600	**	*700	*700	1900
other relative	*300	*700	**200	**200	*400	1400	**200	**200	1000	2500
friend/neighbour	**200	*300	**	**200	*600	*800	**	**200	*700	2200
Formal help from										
home care/home help/										
council handyperson	**	**100	**	**	1200	*400	**	**	**100	1600
community/home	**200	*400	**	*300	**	**	**	**	**200	*900
nursing										
privately arranged help/										
commercially provided	**	**	**	**200	1100	*900	**	**	*300	2100
service										
Meals on Wheels (b)	-	-	-	-	-	-	-	-	-	-
voluntary community	**	**200	**	**	**100	**	**	**	**100	*300
assistance scheme										
physiotherapist	**	**	**	**	**	**	**	**	**	**
chiropodist/podiatrist	**	**	**	2100	**	**	**	**	**	2100
speech therapist (c)	-	-	**100		-	-	-	-	-	**100
other	**200	**100	**	**200	**	**200	**	**	**100	*700
no provider of assistance	**200	*500	*300	1100	1500	1100	**200	*600	*300	4600
Total	6400	8000	1400	7200	9000	12400	1600	4100	9700	21400

** Data subject to high relative standard error. * Subject to sampling variability between 25% and 50% NB All figures are rounded.

(a) Needs help with at least one activity. Total may be less than sum of components since persons may need help with more than one activity.

(b) Only applicable to help with meal preparation. (c) Only applicable to verbal communication handicap.

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished

As can be seen from Table 14, the main areas where assistance was needed were home maintenance (57.9% of people with a disability requiring help), transport (45.3% of whom 72.2% were female) and home help (42.1%). People with no disabilities or who had a disability, but no handicap, required little help however.

Table 14: Activities for which help was needed & activities for which help was received, ACT, 1993

	Disability			No Disability	TOTAL
	Handicap	No Handicap	Total		
Activities for which help was needed					
Self-care	6400	**	6400	-	6400
Mobility	8000	*	8000	-	8000
Verbal Communication	1400	**	1400	-	1400
Health care	7000	**200	7200	-	7200
Home help	8900	**200	9000	*600	9600
Home maintenance	12000	*400	12400	2000	14400
Meal preparation	1600	**	1600	**	1600
Personal affairs	3900	**200	4100	*400	4500
Transport	9400	*300	9700	1800	11500
<i>Total</i> needing any help at all	20500	*900	21400	3600	25000
Activities for which help was received					
Self-care	6100	**	6100	-	6100
Mobility	7500	**	7500	-	7500
Verbal Communication	1000	**	1000	-	1000
Health care	6100	**100	6100	-	6100
Home help	7600	**	7600	**200	7800
Home maintenance	11000	**200	11300	1900	13200
Meal preparation	1300	**	1300	**	1300
Personal affairs	3400	**200	3500	*400	3900
Transport	9000	300	9400	1700	11100
<i>Total</i> receiving any help at all	19200	*600	19800	3400	23200
Total	34400	10600	45000	229200	274300

** Data subject to high relative standard error. * Subject to sampling variability between 25% and 50% NB All figures are rounded.

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished

As people age, the need for assistance increases. Table 15 below shows the heavier demand for assistance of people aged 55 years and over. Only 1,500 people aged 15-24 years (7.0% of all those people with a disability needing help) required assistance, whereas 3,600 people aged 75 years or over (or 16.8% of all those people with a disability needing help) required assistance.

Table 15: People with a disability, in households, activities for which help was needed, by age, ACT, 1993

Activities for which help was needed	Age group (years)								Total
	0-14	15-24	25-34	35-44	45-54	55-64	65-74	75+	
Self-care	1600	*500	*500	*800	*500	*800	*900	*800	6400
Mobility	1600	*500	*600	1100	*500	*900	*900	1900	8000
Verbal communication	*700	**100	**	**	**100	**100	**200	**200	1400
Health care		**200	**200	*900	*700	1100	1700	2400	7200
Home help		*400	*600	1300	*900	200	1900	2000	900
Home maintenance		*500	*900	1700	1400	2300	2700	2900	12400
Meal preparation		**100	**	**	**100	**200	*400	*900	1600
Personal affairs		*600	*400	*500	*400	**200	*700	1300	4100
Transport	1100	*600	**200	*500	*900	1500	1900	2900	9700
Total (a)	2100	1500	1600	3100	2500	3600	3600	3600	21400

** Data subject to high relative standard error. * Subject to sampling variability between 25% and 50% NB All figures are rounded.

(a) Needs help with at least one activity. Total may be less than sum of components since persons may need help with more than one activity.

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished

3.1 People aged 60 or more

The 1993 Survey asked specific questions regarding home help, home maintenance, meal preparation, personal affairs and transport of all respondents aged 60 years or more. Of the 12,200 ACT people in this age group who needed help, 8,700 (71.3%) were estimated as having a disability. Of all those with a disability, 65.2 per cent reported needing help with one or more of the specified activities.

The activities requiring the most help were home maintenance (8,900 people: 2,000 of whom did not have a disability), transport (7,800 people: 1,800 of whom did not have a disability) and home help (over 4,000 with at least 430 having no disability).

Although females represented 53.9 per cent of all people aged 60 years or more, they accounted for 72.1 per cent of all persons needing help in that age group. Females accounted for 67.8 per cent of people with a disability who needed help and 80.6 per cent of people with no disability who required assistance. However, if you examine crude rates, males with a disability require assistance at the rate of 226 per 1,000 males, whereas females with a disability require assistance at the lower rate of 69 per 1,000 females. Females with disabilities most frequently required help with home maintenance while males with disabilities required the most help with transport.

Recent research done at the Australian National University^{xxxiv} involved interviewing people aged 70 years or more in Canberra or Queanbeyan. It was found that elderly people who needed help, did so because of physical disability more often than behavioural disability. Those with physical disability received more formal services and more assistance from health professionals than those with behavioural disability. Contact with general practitioners was high for both disabled and non-disabled people. Results concerning carers is cited in Section 4.

An analysis of hospital separations gives some indication of the profile of acute health needs of people, although it does not take into account other interventions such as those performed in outpatient or other hospital clinics, or by general practitioners. Although people 60 years or more only account for 9.8 per cent of the total ACT population, they accounted for 24.6 per cent of all ACT hospital separations. The major causes for hospitalisation were health status factors (classifications where no current injury or disease is occurring; includes such on-going treatments as chemotherapy and renal dialysis), circulatory disease, neoplasms, digestive problems, genitourinary problems and musculoskeletal disorders. Mental disorders only accounted for 1.2 per cent of hospital separations for this age group.

The following table gives details of average length of stay (ALOS) for selected age groups:

Table 16: Average length of stay, people 60 yrs or more, ACT hospitals, 1994-95

ALOS (days)	Age groups (years)				Total
	60-64	65-69	70-74	75+	
0	2339	2634	1798	909	7680
1	306	334	308	466	1414
2	272	302	277	435	1286
3	197	218	203	342	960
4-7	516	605	696	986	2803
8-14	409	540	645	999	2593
15-34	180	221	277	606	1284
35+	41	72	84	219	416
Total	4260	4926	4288	4962	18436

Source: ACT Hospital morbidity Data, 1994-95

It can be seen that over 41 per cent of separations are for hospital stays of less than one day duration. There is an increase in usage as age rises, although people in the 70-74 age group tend to stay less in

hospital for between 0 and 3 days than would have been expected, (but as expected for longer stays). People staying longer than 15 days have complex acute care needs, or are possibly waiting for nursing home or hostel placement. As age rises, people who are admitted to hospital tend to stay in for a longer duration (27% at age 60-64 years; 29% at age 64-69 years; 40% at age 70-74; and 57% at age 75+ years, stay in hospital for 4 or more days).



4. Carers

Although the role of a principal carer can be very rewarding, the demands of caring can be highly stressful and time consuming. They may also result in dramatic changes to lifestyle, health status and quality of life. Levels of participation in the workforce, time for recreation and pursuing friendships, and access to regular income can be severely limited, while weekly costs of living often rise (heating bills, extra wear and tear on clothing, higher laundry costs etc.). The caring role is often not the preferred career choice of a carer, and is usually achieved at great personal cost^{xxxv}. This remains the case where caring is the preferred choice.

The ACT-Queanbeyan study^{xxxvi} mentioned in Section 3.1 found that the role of carer was often stressful. This was particularly so for carers of people with physical disabilities, who had raised levels of anxiety and symptoms of depression. They were also found to have poorer self-rated health. An Italian study^{xxxvii} of parents of mentally retarded children and children with neurological impairments found that parents of disabled children had significantly higher levels of psychiatric symptoms and were more likely to meet criteria for depressive disorders than a matched control group of parents of children without disabilities.

The reducing availability of informal carers (refer Glossary for definition) is also an issue for concern. Social change over recent years has resulted in increased participation of women (the traditional carers) in the workforce, higher rates of family breakdown and divorce, increases in the number of single parent households and the ageing of a number of major immigrant groups.^{xxxviii} These and other social trends have impacted on the availability of informal assistance from family and friends and the availability of volunteers for the not-for-profit community organisations who have historically cared for people in need.

In 1993, there were 1.5 million people caring for another person in the same household in Australia (or one in every 5 households). Just over 6 per cent of these cared for more than one person. There were 1.4 million people who received care. It is interesting to note that 54 per cent of carers co-residing with recipients of care were male, generally caring for their partner.

In the ACT, there were an estimated 10,800 principal carers aged 15 years or more, which represents 4.7 per cent of the ACT population in that age group. Of these carers, 7,100 lived in the same household as the recipient(s). It should be noted that this estimate of number of carers is likely to be conservative, since many people who are in a caring role, often do not identify with that role^{xxxix}. It can be seen from Table 17 that in the ACT, females predominate in the caring role, since they represent 69.4 per cent of all principal carers, 91.9 per cent of carers of recipients who do not live in the carer's households, and 57.7 per cent of carers of recipients in their usual households (considerably

higher than the Australian proportion of 46%). Caution should be taken in analyses however, due to the high sampling variability of data.

There were an estimated 1,000+ carers (approximately 10% of all carers) aged more than 65 years. Of these, 63.6 per cent were female. There were 5,200 carers who were between the ages of 15 and 44 years (approximately 48% of all carers). Of these, 69.2 per cent were female.

The ACT percentages are generally similar to those of Australia.

Table 17: Principal carers, aged 15 years or more, by age, by sex, ACT, 1993

Carer	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total
carer of a usual resident of their household								
Males	*100	*300	*900	*700	*600	**200	**200	2900
Females	**200	1300	*900	*600	*600	*400	**100	4100
Persons	**200	1700	1800	1200	1200	700	300	7100
carer of a non-usual resident of their household								
Males	**	**100	**200	**100	**	**	**	*300
Females	**200	*400	*700	1500	*500	**100	**	3400
Persons	**200	*500	*800	1600	*500	**100	**	3700
All carers								
Males	**100	*400	1100	*700	*600	**200	**200	3300
Females	*400	1700	1500	2100	1100	*600	**100	7500
Persons	*500	2100	2600	2800	1700	*800	*300	10800

** Data subject to high relative standard error. * Subject to sampling variability between 25% and 50% NB All figures are rounded.

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished

The relationship of carers with recipients of assistance is outlined in Table 18. The main burden of care was on spouse/partners (41% of activities), daughters (14%), and mothers (12%).

Table 18: Main providers of assistance, by activities requiring help, ACT, 1993

Carer relationship	Total no. of activities requiring assistance	Main activities requiring assistance in priority order
Informal help from		
spouse/partner	8800	home maintenance, transport, mobility, home help
mother	2500	self-care, mobility
father	*400	numbers too small to analyse
daughter	3000	transport, home help, self-care, mobility
son	1900	home maintenance, personal affairs, transport
other relative	2500	home maintenance, transport, mobility
friend/neighbour	2200	home maintenance, transport
Total	21300	home maintenance, transport, mobility, self-care

* Subject to sampling variability between 25% and 50% NB All figures are rounded.

Source: Jacobs D, *Disability, Ageing & Carers, 1993, Summary of Findings, ACT*, ABS, unpublished

The Carers Association of Australia have reported that informal carers provide 74 per cent of all service needs of people who have a disability or who are frail aged^{x1}.

A study conducted in Canberra and Queanbeyan in 1992-93 involved a community survey of people aged 70 or more years with the aim to assess the reasons disabled people need care, the types of formal services they receive and the characteristics of their carers^{xli}. Findings included that, of those people requiring assistance, only 11 per cent identified their main carer as a formal service, with 89 per cent identifying a family member. With regard carers, it was found that wives, daughters and husbands made up the biggest categories of carers and about two thirds of carers were women. 35 per cent of carers were under 60 years of age. Family carers played an central role in maintaining people with disabilities in the community, but the role was often stressful. It was interesting to find that carers of people with physical disabilities were found to have significantly higher levels of anxiety and depression and rated their own health as worse, than carers of people with behavioural disabilities. There was also a significant difference in scores for depression, but not for anxiety, between the types of carers by relationship to the recipient. Wives of recipients (closely followed by husbands of recipients) had significantly more symptoms of depression than 'daughter' or 'other relative' carers.

4.1 Restrictions on carers due to their caring roles, Australia 1993

As mentioned in the introduction, carers experience varying levels of restrictions as a direct result of their caring roles. Particular problems arise when a carer cannot obtain respite assistance: Some provide care for their recipient seven days a week, with no respite and no holiday breaks.

Some of the main findings from the Disability, Ageing and Carers Survey 1993 were^{xlii}:

- ⇒ Inability to go out during the day or only able to go out if help was arranged or they were accompanied by the person for whom they cared: (17% of carers experienced such difficulty).
- ⇒ Inability to go on holiday (35% of carers took fewer holidays or could not go on holiday at all because of their caring roles).
- ⇒ Difficulties in managing time. This varied according to the needs of recipients.
- ⇒ Inability to participate in the workforce as fully as other people (60% compared to 78%).
- ⇒ Financial difficulties (52% of carers compared to 42% of all persons had a personal income of \$200 or less per week).
- ⇒ Difficulties in completing housework (33% of carers experienced difficulties in completing such tasks).
- ⇒ Sleeping patterns (42% of carers living in the same household as recipients had their sleep interrupted by their caring roles and 66% of these said this affected their daily activity).
- ⇒ Inability to keep in contact with existing friends (18% of carers had this difficulty).
- ⇒ Effect on relationship with partner, where the recipient of care was not the carer's partner (31% of relationships have been adversely affected by strain and a lack of time together).
- ⇒ Effect on relationship with recipient of care. The level of strain differed with the nature of the relationship. (20% of parents caring for a child, 18% of adult children caring for a parent, experienced strain in their relationships).
- ⇒ Stress-related illness, worry, depression, anger or lack of energy (carers of partners or children are more likely to experience these conditions more severely than other carers).

Source: ABS, *Disability, Ageing and Carers, Australia, 1993*, Cat. No. 4430.0

Table 19 outlines the effects on principal carers' working lives. A greater proportion of carers of parents work than other carers. However, 7 per cent of them had to reduce their working hours and 5 per cent had given up work totally in order to fulfil their caring roles.

Table 19: Affects of caring on principal carers' working lives, Australia, 1993

Effect on working life	Principal carers			All carers
	of partners	of parents	of children	
	%	%	%	%
Currently working	26.2	55.5	45.2	39.8
No change in work hours	22.8	48.4	34.2	34.0
Reduced hours for caring role	3.5	7.0	11.0	5.8
Not currently working	73.8	44.5	54.8	60.2
Worked prior to caring role	27.5	17.4	19.6	22.5
Gave up work for caring role	7.8	4.5	10.4	6.6
Did not work prior to caring role	46.3	27.1	35.2	37.7
Total	100.0	100.0	100.0	100.0

Source: Survey of Disability, Ageing and Carers (unpublished data) as reported in *Australian Social Trends*, 1996, ABS

Issues concerning employment include flexibility of working hours, ability to work part-time and assistance for past carers to return to the workforce. This has particular relevance to 'young carers' (15-45 years old) who, as mentioned, make up 48.1 per cent of all carers. If they are unable to work during the 'young' years, they are disadvantaged in terms of skill acquisition and retention, competitiveness at an older age, and in the accrual of employment benefits such as superannuation.

4.2 Support for carers, Australia, 1993

Support for carers found from the Disability, Ageing and Carers Survey 1993 varied, according to the ages and needs of recipients and carers. Some of the salient findings were:

- ⇒ Carers of a child were more likely to have received training for the caring role or belong to a support group than other carers.
- ⇒ Only 27 per cent of carers of partners received help with the caring role. Carers of other people such as parents or children, were twice as likely to have received assistance.
- ⇒ Respite care services were used by 12% of carers. Approximately one quarter of carers did not use these services because they were unaware that they existed, they were too expensive or they were unavailable in their area.
- ⇒ Carers of children or parents were twice as likely to use respite services than carers of partners.
- ⇒ Just over half of all carers did not receive any help with the caring role from family, friends or formal organisations.
- ⇒ Of the carers who were receiving help with their caring roles, female carers received the most help from their partners (35%), but most male carers (26%) received their highest proportion of assistance from formal organisations. Male carers were less likely to gain assistance from partners since their partners were more likely to be the recipients of care.

Source: ABS, *Disability, Ageing and Carers, Australia, 1993*, Cat. No. 4430.0

Section 5 contains an outline of Government and community services to assist carers in their caring roles.

Carers of people who have intellectual disability, acquired brain injury and dementia appear to be particularly disadvantaged in accessing services.^{xliii}

5. ACT and national initiatives

5.1 Commonwealth State Disability Agreement (CSDA)

The CSDA was initially signed in 1991 by all states, territories and the Commonwealth. It aimed to achieve greater coordination and integration among the elements of the government's disability services network, but excluded the important areas of Home and Community Care (HACC) and the Commonwealth Rehabilitation Service. It outlined agreed delineation of state and Commonwealth responsibilities in the areas of funding and delivery of services. Under the CSDA, the Commonwealth assumed responsibility for administering employment services and states and territories assumed responsibility for administering accommodation support, respite care, independent living training, recreation, information and print disability services.

Some of the achievements of the CSDA include the establishment of a national data collection, the CSDA Minimum Data Set and the introduction of a common set of service standards.

The current CSDA expires in 1997. As negotiations towards a future agreement progress, parties to the agreement hope that further advances in the development of uniform assessment criteria for entry into services, further clarification of funding bases, and an inclusion of the disability component of HACC services, will be incorporated.

5.2 ACT Goals and Targets

The ACT Department of Health and Community Care developed health goals and targets for, amongst other issues, people with a disability or chronic condition, and for mental health in 1994 after considerable deliberation and consultation with key stakeholders. The goals and targets are:

Table 20: Health goals and targets, disability or chronic condition, ACT

Goals	Identified Targets for Individual Goals
1. Reduce the occurrence of new and preventable disability.	<ul style="list-style-type: none"> i) Identify & implement health care strategies that aim to prevent birth defects; ii) Identify & implement health care strategies that aim to prevent premature births; iii) Continue to promote regular dietary calcium intake & physical activity from an early age, as a way of preventing osteoporosis in older women; iv) Ensure early diagnosis & intervention & provision of appropriate support services to reduce the impact of physical disability on children & young people; v) Improve referral procedures for definitive hearing assessment in children for whom there is a concern; vi) Ensure that adequate speech therapy services are available to all children who require them; vii) Develop & implement programs for health practitioners, childcare workers & teachers that promote greater awareness of deafness & encourage earlier detection; viii) Ensure that programs to reduce work-related injuries, including redesign of work practices & workplace furniture, are widely disseminated & implemented in workplaces.
2. Improve the health and quality of life of people with a disability or chronic condition (including people with chronic pain).	<ul style="list-style-type: none"> i) Develop group frameworks within which young people can develop individual social & life skills; ii) Ensure appropriately targeted programs & facilities that encourage people with a disability or musculoskeletal conditions to be physically active; iii) Consider strategies to reduce the prevalence of overweight & obesity amongst people with a disability; iv) ACT agencies to continue to participate in national initiatives aimed at raising community awareness & dispelling myths about people with a disability; v) Ensure that rehabilitation of people with a newly acquired disability or musculoskeletal condition also includes stress management & coping strategies for dealing with chronic pain & onset of disability; vi) Ensure that rehabilitation addresses the needs of children with musculoskeletal & neurological degenerative conditions; vii) Ensure that care & rehabilitation continues to be provided to young people with congenital disorders & acquired conditions who 'outgrow' paediatric services; <p>Ensure access to a range of pain management alternatives.</p>

3. Enhance the capacity of people with a disability or chronic condition to lead independent lives.

- i) Ensure that home help services are resourced to a level that meets the needs & demand of all referred clients;
- ii) Encourage the development of workplace early intervention programs for people with newly acquired back injuries;
- iii) Develop & enact legislation in support of workplace early intervention programs, in line with similar legislation in other states;
- iv) Educate health care workers & employers/managers to encourage early active exercise programs for workers with newly acquired back injuries;
- v) Ensure that people with a disability & their carers have affordable access to appropriate equipment, home modifications, & other aids required to maintain independence in the community;
- vi) Dept of Health & Community Care to advocate for necessary support & change to improve the functional status & independence of people with a disability (eg accommodation, transport etc);
- vii) ACT Govt agencies to consider the development of integrated community support systems for people with a disability, including psychiatric disability (eg flexible delivery of housing) that are appropriate to individual circumstances;
- viii) ACT Govt agencies to consider initiatives to increase the proportion of community services & infrastructure that have been designed or modified to enable physical access, particularly in relation to public buildings, accommodation & public transport;
- vix) ACT Govt agencies to consider strategies for cross-portfolio policy & program development on issues relating to people with a disability, which enables a focus on human rights & access perspectives.

4. Improve the quality of life of carers of persons with a disability of chronic illness.

- i) Develop more respite care options to support carers of people with a disability;
- ii) Develop a greater range of short-term & permanent accommodation options which cater to the special needs of younger people with a disability, as a matter of urgency;
- iii) Consider strategies in support of carers, that encourage them to take time out & look after their own needs;
- iv) Establish a mechanism whereby all people in need, including people with a disability & their carers, can access affordable home help, as well as a central point from which to obtain information about existing services;
- v) Ensure that carers & family members of people with a newly acquired disability receive prompt & early information about the full extent of the person's impairment & the associated implications for care provision.

Source: ACT Goals and Targets for the year 2000, ACT Govt printer, Canberra, 1994

Table 21: Health goals, mental health, ACT

1. Increase coordination across ACT mental health programs and services.
2. Implement the ACT Mental Health Services Strategic Plan.
3. Improve the mental and emotional well-being of all ACT residents.
4. Reduce the impact of moderate to severe mental illnesses and emotional/behavioural disturbances on affected individuals, their families and the community.

Source: ACT Goals and Targets for the year 2000, ACT Govt printer, Canberra, 1994

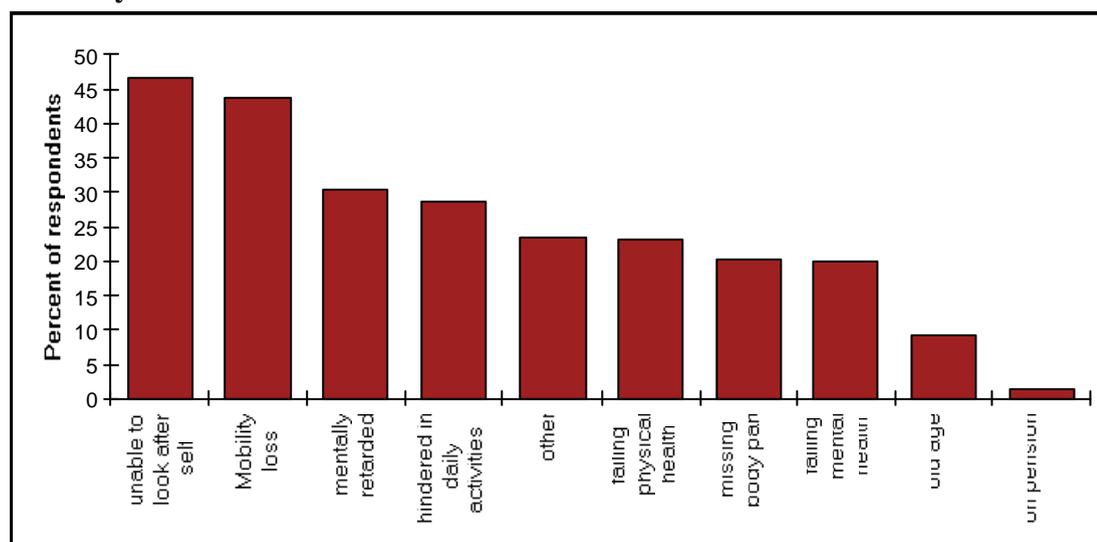
The Health Outcomes Reference Group has been established by the Department of Health and Community Care to consider strategies for the attainment of goals and targets.

5.3 Quality of Life Project: Knowledge and attitudes towards disability

The Quality of Life Project^{xliv} is a collaborative project between the Epidemiology Unit in the Department of Health and Community Care and the National Centre for Cultural Heritage at the University of Canberra. It has operated for two years and, to date, it has surveyed randomly selected ACT people, asking them to rate their health-related quality of life using the Medical Outcomes Study's Short Form 36 (SF-36). In its second year (1994-95), questions regarding attitudes and understanding of disability were posed. The results from the Survey are outlined below:

When asked to identify the factors (up to 3 choices) which determine whether somebody had a disability (see Figure 10), the most common choices were; "unable to look after oneself " (chosen by 47% of respondents), "mobility loss"(44%), "mentally retarded" (30%) and "hindered in daily activities"(29%). Interestingly there were some differences between age groups in the distribution of choices. Older people were more likely to choose "failing physical health" (52%) than were young (20%) or middle aged (24%) people. Conversely, older people (3%) were less likely to mention "failing mental health" than young (20%) or middle aged (22%) people. (Since people were offered three choices, the sum of percentages will add to more than 100).

Figure 10: Responses to 'What factors do you think determine whether somebody has a disability?'



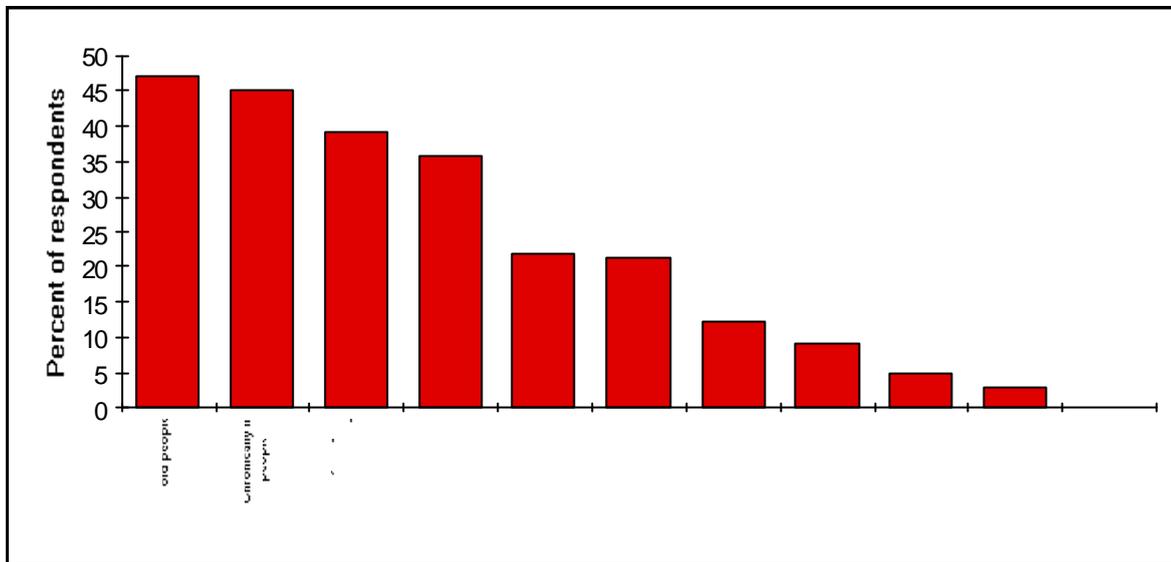
Note: up to 3 choices coded per respondent

Source: Quality of Life Project 1994 &1995 weighted data

When asked to identify which groups of people were more likely to become disabled (refer Figure 11), the most common choices were; "old people" (47% of respondents), "chronically ill people"(45%),

"young drunks/drug addicts", (39%) and "drunk drivers" (36%). Again there were differences between the age groups. More older people (71%) chose "young drunks /drug addicts" as one of their choices than did middle aged (38%) or young (37%) people. Whereas older people were less likely (35%) to choose "old people" than the young (43%) or the middle aged (60%).

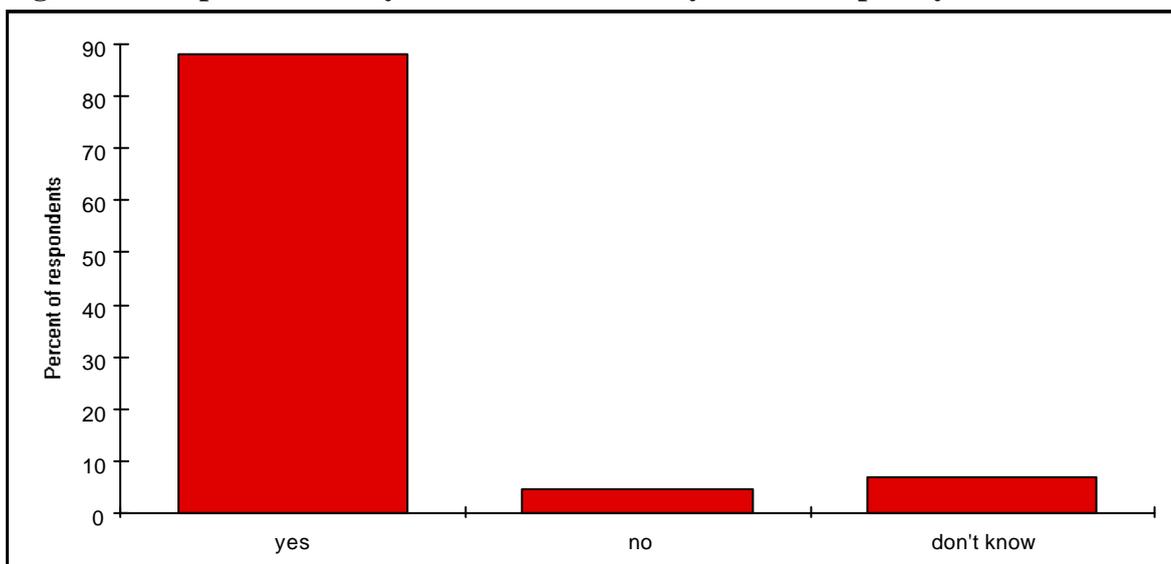
Figure 11: Responses to 'Which groups of people do you think are more likely to become disabled?'



Note: up to 3 choices coded per respondent
 Source: Quality of Life Project 1994 & 1995 weighted data

When asked about the temporary nature of disability, the majority of respondents (88%) thought that disability could be temporary, with only 5% of respondents disagreeing with this proposition. 7% didn't know (refer Figure 12).

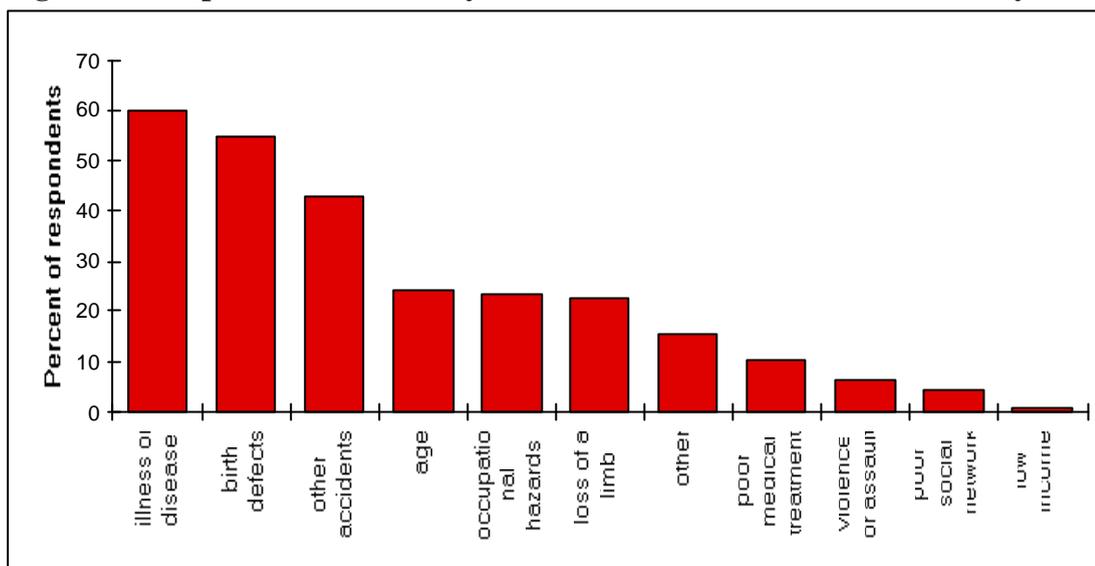
Figure 12: Responses to 'Do you think that disability can be temporary?'



Source: Quality of Life Project 1994 & 1995 weighted data

When asked to identify the main causes of disability (refer Figure 13), 60 % of respondents chose "illness/disease", 55% chose "birth defects", and 43% chose "other accidents". Less common choices were; "age" (24%), "occupational hazards" (23%), and "loss of a limb" (23%).

Figure 13: Responses to 'What do you think are the main causes of disability?'



Note: up to 3 choices coded per respondent
 Source: Quality of Life Project 1994 & 1995 weighted data

Responses to ‘What term would you prefer to use when referring to people living with a disability?’

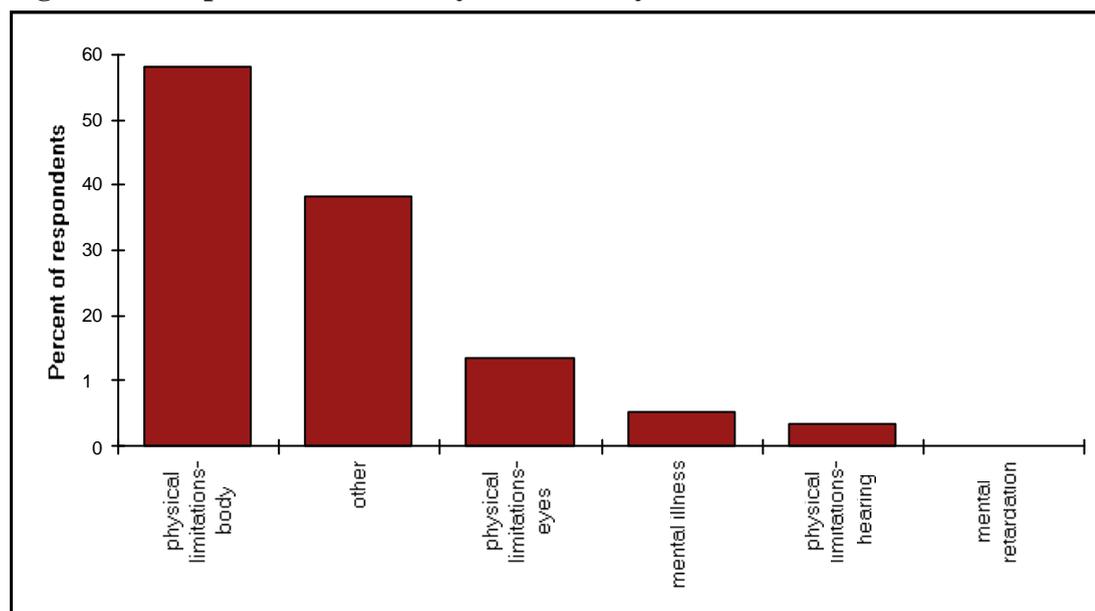
When asked to identify preferred terminology when referring to disabled people, the two choices most favoured were "disabled people" (chosen by 34% of respondents) and "people with a disability" (34%). The term "differently abled people" was not a popular choice (13%), while 20% chose the "other" option.

Responses to 'Reasons for degree of respondents' own disability?'

Of the 50 weighted cases who had a disability themselves, when asked to list up to 3 reasons for their degree of disability, 49% chose the "other" category as one of their choices. This indicates that the list of choices given to them was not sufficiently comprehensive or that the question may not have been clear enough. 31% chose "illness/disease", and 29% chose "had an accident" while 15% chose "can not do things".

When those with a disability were asked to identify what type of disability they had (Refer Figure 14), 58% selected "physical limitations - body not functioning", 38% selected "other", while 14% selected "physical limitations due to poor eye sight". Mental illness was selected by 5% of the respondents.

Figure 14: Responses to 'What is your disability?'



Note: up to 3 choices coded per respondent

Source: Quality of Life Project 1994 & 1995 weighted data

5.4 Data collection

The implementation of health goals and targets, and the maintenance of, and improvements to, service delivery will depend on the availability of base-line data on which to base evaluations of programs and interventions. Refinement and expansion of data collections have commenced in the ACT with the establishment of a new data banks in the emergency departments at The Canberra Hospital and Calvary Hospital. The data collection system has been installed and is compatible with the new NSW data system, thus allowing cross border comparisons. The system development was funded by the Commonwealth through the Ambulatory Care Reform Program and utilises the National Injury Surveillance data definitions and national emergency definitions which have recently been developed.

A computerised data base has been developed and is being piloted by the Department of Health and Community Care. Information on nature of disability, age (but not name), needs, services being accessed is being collated on people using the Home and Community Care (HACC) services. Analysis of data will assist in planning of future appropriate services.

The *National Health Survey* is also an excellent source of information (Refer 7.4). This will be particularly so for the 1995-96 survey, since the ACT had negotiated a larger ACT sample to ensure greater reliability.

Another excellent method for collecting data is the *ACT Care Continuum and Health Outcomes of Hospital Inpatients Project*. This is a two year innovative pilot project, funded by the Commonwealth Department of Health and Family Services, which commenced in early 1995 and is being undertaken by the Epidemiology Unit of the ACT Department of Health and Community Care in collaboration with The Australian National University. The project involves investigating approximately 7,000 inpatients and their experiences prior to admission, during their hospital stay and up to six months after discharge. Questions regarding formal and informal service utilisation, costs across the care continuum and how to

make better use of resources, and health outcomes including quality of life are being addressed. Data are collected through an interview questionnaire, a diary maintained by the patient and self-completion questionnaires complemented by existing data bases. The information collected will allow for the development of a profile of patient care and outcomes on which to base future planning for the enhancement of quality of care and relevance of health interventions.

Mental health

To date, it has not been possible to draw accurate conclusions regarding the mental health of ACT residents from national data. The larger sample of the ACT population surveyed in the 1995-96 National Health Survey will assist. In addition, the Commonwealth Department of Health and Family Services has commissioned a national mental health survey which is currently being developed for use in 1996/97 by the ABS. Results should be available by 1998. The ACT has commissioned the ABS to increase the ACT sample from 250 to over 400 households in order that sufficient data be obtained for accurate analysis. Another initiative which will assist, is a training project by Professor Scott Henderson and his team at the NHMRC Social Psychiatry Research Unit at the Australian National University. They are training personnel, including two from the ACT, to interview persons identified as having low prevalence psychosis and who are high-end users of mental health and other services. This is part of a national study of low prevalence psychosis which will utilise an international standardised survey tool to ensure national and international comparisons can be made. It is envisaged that some 250 subjects from the ACT will be interviewed and questioned on such issues as levels of personal dysfunction, medication, types of interventions and types of unmet needs. These initiatives will ensure a more accurate profile of mental illness in both the ACT and Australia generally.

Within the ACT Department of Health and Community Services, a data manager has been employed to address data requirements for mental health and enhance the Client Information System. Enhanced data on the prevalence of mental illness will now be available to assist with future planning of services.

The Epidemiology Unit is also preparing a publication titled *Mental Health in the ACT*, Health Series No. 11, which aims to draw together all available data on incidence and prevalence of mental illness in the ACT.

5.5 ACT Government services

Aged people and people with disabilities

Services which the ACT Government provides to aged people and people with disabilities include:

- ◇ The *Aged and Disability Policy and Planning Unit* in the Department of Health and Community Care, which has specific responsibility for developing policy directions and for strategic planning for the delivery of quality services in the areas of community-based aged care, services for people with disabilities, and associated community care services. It focuses on a broad strategic framework for service delivery and reform of the service system in these areas and has a major role in the development and implementation of quality assurance and quality improvement programs at both a systemic and service specific level. The Unit also provides advice on Commonwealth/State issues in the disability, aged care and community care areas, including specific program areas such as the Home and Community Care Program and the Disability Services Grants Program.

- ◇ The *Performance Management Unit* in the Department of Health and Community Care administers the *Home and Community Care (HACC) Grants Program* where funds have been provided for individualised support for clients with complex needs, enhancement of respite care services and to provide continuity of care for people being discharged from hospital into the community.

The Unit also administers the *ACT Disability Services Grants* program, which aim to support individuals to continue living in their homes in ways that improve their quality of life, enhance their independence and maximise their participation in community life. The program also offers funds for Individual Support Packages.

The target groups for services are frail and elderly people, people with disabilities and their carers. Grants for the above programs totalled \$12, 811,500 in 1995-96. 58 organisations were allocated funds with the aim of providing complementary health-related services that are not provided by Government.

In addition, the Unit administers the *ACT Taxi Subsidy Scheme* which assists frail and elderly people and people with disabilities to meet the cost of taxi fares where they are unable to access public transport.

- ◇ *Day Centres for Senior Adults* operate each week day from health centres around Canberra. They provide interesting activities and opportunities for social interaction for senior citizens and free time for those who normally care for them. Occupational therapists are available at the Centres to discuss individual needs and supervise activities.
- ◇ *ACT Community Care Disability Program* which provides a range of support services to increase the quality of life and inclusion of people with disabilities in the ACT community. It aims to provide individualised, needs based support which is determined through an individual planning process. It aims to work in co-operation with families, client personal networks and other service providers to achieve an integrated approach to support clients. Services offered include professional services (psychology, social work, speech pathology, occupational therapy, physiotherapy and recreational services), support and skills development in the home (eg cooking, taking medication, showering, recreation), support and skills development in the community (eg shopping, travelling, paying bills, sport), support with behaviour management in home and community settings, centre-based respite care, advice and referral relating to disability and disability services. One such service is;
 - * *the Independent Living Centre* which aims to assist people with disabilities to enhance their independence and quality of life by providing advice, assessment and information on daily living aids and equipment. It has a centre displaying a large range of equipment so that clients may try them before deciding on the best choice. A therapist is available for advice on the most suitable equipment for the individual and who can refer them to the suppliers of chosen equipment. A registered nurse is also available to offer advice on continence needs.

Mental health services

The ACT has little reliance on psychiatric hospitals since psychiatric services are all mainstreamed. There are no, and have never been any, psychiatric hospitals in the ACT.

- ◇ There is a 32 bed acute unit at The Canberra Hospital, a 20 bed general psychiatric unit at Calvary Hospital, one 40 bed and one 20 bed hostel and 2 group houses for people with mental illness. The Psychiatric Unit at The Canberra Hospital and the two hostels account for 40 per cent of the Departmental service budget, leaving 60 per cent for community regional initiatives (1994-95).^{xlv} Further attention needs to be given to making the proportions more equitable, but this is being addressed in planning for a five year strategic plan.
- ◇ The Mental Health and Drug Strategy Unit of the Department of Health and Community Care is developing a Strategic Services Plan which incorporates the five year strategic plan and which will be an overarching plan for the maintenance and development of mental health services (government and non-government) in the Territory.
- ◇ The ACT is the only state or territory to have all its public sector mental health services accredited with an appropriate independent accreditation body (Australian Council of Healthcare Standards).
- ◇ Clearly, the mental health of people is not solely dependent on clinical interventions. Health is determined by biological and medical conditions and/or pre-dispositions as well as environmental conditions such as the climate, socio-economic status, health education and knowledge, nutrition and access to adequate housing and services. The ACT Government therefore takes a global approach in its planning for quality mental health services. Interdepartmental liaison to ensure access to housing and transport and liaison with Commonwealth Government agencies such as Social Security are integral to its approach.
- ◇ Non-government (NGO), community and self-help organisations play a major role in enhancing the mental health of the Territory. In recognition of the crucial role of non-government involvement, the Department of Health and Community Care assists non-government organisations through a *grants process*. Grants specifically for mental health activities have been allocated to a number of community organisations. (Refer Section 5.5)
- ◇ *ACT Mental Health Services*, which is part of The Canberra Hospital, is involved with the overarching clinical care of people with mental illness and the implementation of preventative and educative strategies for reducing mental illness in the Territory. (Refer 7.2 for activity data). It embraces the use of multi-disciplinary teams based on a case management approach, early intervention and continuity of care leading to the rehabilitation of clients within mainstream services.

It operates in three components:

- * Community Mental Health which includes Forensic and Child and Adolescent Services and operates Adult Regional Services;
- * Psychiatric Rehabilitation Services; and
- * Psychiatric Inpatient Services.

Recent initiatives by the ACT Mental Health Services, in response to client changing needs include:

- * development of a five year strategic plan for 1993-98 to incorporate the responsibilities of utilising National Mental Health Strategy funds;
- * Community Mental Health Services attends psychiatric ward rounds at The Canberra Hospital and at Calvary to assist with discharge planning and continuity of care;
- * enhancement of the 24 hour crisis team, after hours crisis assessment team, and triage system;
- * A&NZ Mental Health Services Achievement Award winning innovative service model in Psychiatric Rehabilitation Service using clinical and non-clinical interventions to assist people live and participate in the community;
- * expansion of activities in the Psychiatric Rehabilitation Services to include neuro-cognitive training, development of life plans with clients to assist in rehabilitation and to encourage clients to be cognisant of their health (especially in monitoring their mental health) and sensitive vocational training including the establishment of a training coffee shop. The coffee shop venture is a joint program run by PRS and Canberra Schizophrenia Fellowship with training provided by the Commonwealth Employment Service;
- * trainee child psychiatrist position established in Child and Adolescent Services
- * various publications as a result of evaluations, research and initiatives, have been developed (eg. on the First Onset Psychosis Project, on dual diagnosis, on the Case Management Project);
- * enhancement of community based resources is being planned;
- * changes to program structure are being undertaken to include aged, adult, child and adolescent sections;
- * production of an Aboriginal and Torres Strait Islander health needs report detailing recommendations for action for the mental Health Services;
- * alterations to client data base to enhance accurate and relevant data collection.

5.6 Community organisations

There are a number of community organisations which aim to serve the needs of people with disabilities and/or who are aged. Many are funded or partially funded by ACT Government, some are self-funded. Some of the organisations include:

- ◇ *ACROD* (Australian Council for the Rehabilitation of the Disabled) which is the national peak council of disability providers, organisations and associations interested in disability services provision. Their Canberra office provides a forum for groups working in the field to develop a common voice for promoting issues associated with the provision of services for people with disabilities.
- ◇ *ACT Disability, Aged and Carer Advocacy Service (ADACAS)* , which aims to promote, protect, and defend the rights of people with disabilities, older people and their carers.
- ◇ *ACT Division of the Australian Red Cross* offers a diverse range of services, some of which are funded or partially funded by Government. Services include Meals on Wheels (using over 900 volunteers), Heavy Linen Laundry Service for people experiencing incontinence (Government funded), Homebound Service which provides trained volunteers to regularly visit people who are isolated and lonely, Telecross which provides a daily phone contact for elderly people living alone,

and Volunteer Grandparents who visit children with physical and/or intellectual disabilities who live away from home.

- ◇ *Arthritis Foundation of the ACT* which is a voluntary organisation with some ACT Government funding and which exists to help people with arthritis or other musculoskeletal conditions through general, specialist and telephone support services, self-management courses, information (newsletters, library etc), hydrotherapy sessions (at The Canberra Hospital) and social activities.
- ◇ *Carers Association of the ACT* which aims to promote, assist and enhance the well-being of carers in the ACT. It provides a range of services to carers, their families and friends including advocacy and lobbying, an information service (on lobbying, rights, entitlements and services), professional counselling, carer education and support programs, information via a library and newsletter, community education, regular group meetings, and policy and research development. They distribute free carer support kits to carers in the community.
- ◇ *Community Options* which aims to assist people who are frail aged, have a disability or have dementia, to remain living at home, with increased independence and quality of life. Activities include provision of case management and co-ordination of support services.
- ◇ *COTA ACT* (Council on the Ageing), which aims to represent the interests of older people in the ACT to Government. It provides information and advice to the ACT Government on the effects of policy on older people, develops and advocates policies that will improve the lives of older people and explains the impact of government policy to older people themselves and to the broader community. It administers the ACT Seniors Card and is actively engaged in negotiations with the states to extend benefits to ACT residents. Each year COTA produces an updated, comprehensive Directory of Services and is also responsible for co-ordinating events during Seniors Week. At present it is producing a paper on euthanasia, establishing a safety and security project (in conjunction with Australian Federal Police, Firefighter and Ambulance Services), and producing an Older Drivers Handbook (in conjunction with the NRMA).
- ◇ *Handyhelp ACT Inc.* which is a volunteer organisation. It arranges the provision of home maintenance activities (not requiring tradespersons) to maintain safety and security in the home for people without access to other support.
- ◇ *Home Help Service* (funded by Government) which assists people unable to do domestic tasks, is an initiative of Red Cross.
- ◇ *Mental Health Foundation* which is funded by government, seeks to improve the mental health services of the ACT and promote better community mental health through liaison with government and non-government organisations, conducting educational presentations in ACT schools on behalf of Mental Illness Education Australia, providing housing, respite and support services through its Friendship House program, and representing mental health interests on advisory bodies.
- ◇ *Radio One* which is a radio station for the print handicapped. It is administered by a not-for-profit organisation and relies heavily on volunteers and donations. The radio station broadcasts special interest, current affairs and information programs for people unable to see or understand the written word and other interested people.
- ◇ *Respite Care (ACT)* is funded by the ACT and Commonwealth Governments to offer a range of services including respite care at home for people with disabilities, frail aged people and their carers (by selecting support workers for times when the regular carer is absent, and providing 'back-up' support for care in the home which may include personal care), priority help for those people whose long-term caring arrangements could be at risk without access to relief care, and a personalised service of carefully selecting experienced support workers appropriate to the needs of the recipients. It also runs a free information service for frail aged people, people with disabilities, and their carers, titled 'Infolink', which provides information on assistance available in the ACT, costs involved, accessibility and where to obtain services. Its 'LeisureLink' program offers trained volunteer

‘friendly neighbours’ to people requiring home visits, companionship and assistance with outings. A feature of services offered is easy accessibility for people from non-English backgrounds.

- ◇ *Richmond Fellowship* aims to provide a range of supported accommodation and rehabilitation programs for younger adults with a psychiatric disability. It provides a residential program of transitional supported accommodation for people with a psychiatric disability in the ACT.
- ◇ *Technical Aid to the Disabled (ACT) Inc. (TADACT)* which is a voluntary organisation dedicated to designing and making special items for people with disabilities which are not commercially available. This assists people to live more comfortable and independent lifestyles.
- ◇ *TRANSACT* (Torture Rehabilitation & Network Service) is an organisation established by Amnesty volunteer workers to assist people who have experienced extreme trauma, assimilate into the community. One aspect of the organisation’s work is the provision of a mental health service for people across different cultural backgrounds. This work involves the training of health professionals in assisting patients with a torture or trauma background, provision of a counselling and advocacy service, an On-Arrival Health Review Program, an Early Assessment Program for Children at risk, and a formal English program to assist people unable to cope with the pressures of mainstream classes.

5.6 Advisory Committees

- ◇ *ACT Consumer Advisory Group* provides advice to the ACT Government on issues concerning mental health. (eg in 1995 they advised the Australian Federal Police on the management of people with a mental illness who come in contact with law enforcement).
- ◇ *ACT Disability Services Advisory Committee*, which is a forum for consumers to provide advice to Commonwealth and ACT Governments on the planning process through such mechanisms as regional consultations.
- ◇ *Home and Community Care (HACC) Advisory Committee*, which was established to facilitate the involvement of community organisations and service providers in the provision of advice to the Commonwealth and ACT Governments on such issues as accessibility and availability of appropriate services.



6. Glossary

6.1 Survey of Disability, Ageing and Carers 1993

This survey was the third in a series conducted by the ABS (Refer 7.4.3). It provides estimates of the numbers and main characteristics of persons with disabilities and/or handicaps, persons aged 60 years or more and carers. It was conducted in private and special dwellings, and establishments such as hospitals, hostels, retirement villages and nursing homes. The ACT sample of respondents numbered 3,777, which is a large enough sample on which to base valid analyses.

A person was identified as having a disability if they had one or more of a group of selected limitations, restrictions or impairments which had lasted, or would be likely to last, for six months or more. A person was identified as having a handicap if they had limitations in performing one or more selected tasks of daily living. Children aged less than 5 years with a disability were deemed to all have a handicap, but the area and severity of that handicap was not determined.

6.2 Levels of severity of handicap

In the Survey of Disability, Ageing and Carers 1993, the ABS defined the levels of severity of handicap as:

- *Profound*: always needing help from another person to perform one or more designated tasks
- *Severe*: sometimes needing help to perform the designated tasks
- *Moderate*: needing no help, but having difficulty performing one or more of the designated tasks
- *Mild*: needing no help with, and having no difficulty with any of the tasks, but uses an aid to perform one or more of the designated tasks, or has difficulty walking 200 metres, or walking up and down stairs, or in using public transport, or picking up an object from the floor
- *Not determined*: having a schooling or employment limitation only, or who are aged less than five years, or whose only limitation was 'did not use the toilet'.

6.3 Short Form 36 (SF-36)

The SF-36 was developed in 1988 by the RAND Corporation as part of its Medical Outcomes Study carried out in the USA. The SF-36 was 'constructed to yield a profile of scores that would be useful in understanding population differences in physical and mental health statuses, the burden of chronic disease, other medical conditions and the effect of treatments on general health status'^{xlvi}. It is hypothesised that the SF-36 has 2 major dimensions of health; Physical Health and Mental Health.

Additionally, the SF-36 was designed '... to achieve minimum standards of precision necessary for group comparisons across eight conceptual areas'. The subscales most sensitive to measuring physical health are;

- Physical function (PF)
- The impact of physical health on role performance (RP)
- Bodily pain (BP)
- General health perceptions (GH)

The subscales most sensitive to measuring mental health are;

- General mental health (MH)
- The impact of emotional health on role performance (RE)
- Social functioning (SF)
- Vitality (VT)

The subscales of PF, RP, BP, SF, and RE range from 0-100 with a score of 100 indicating better health status or absence of limitation or disabilities. The subscales of GH, VT, and MH are bipolar in nature with a range of 0 to 100. A score of 100 indicates when '... respondents report positive states and evaluate their health favorably'. For more detailed information, refer Health Series No. 9, *Health Related Quality of Life in the ACT: 1994-95*

6.4 Definitions

Age-sex standardisation - demographic technique for adjusting for the effects of age and sex between populations which allows comparisons between populations.⁴

Age-sex standardised ratio - The expected number of events is given by calculating the number of events which would have occurred if the rates for each age/sex group in a given population (the standard) were applied to the population of interest.³

Crude death rate is the number of deaths per 1,000 population (unless otherwise stipulated) in a given year.⁴

ICD-9 refers to the International Classification of Diseases, ninth revision as developed by the World Health Organisation. Details of disease classifications are at Appendix C.

Incidence refers to the number of instances of illness commencing, or of persons falling ill, during a given period in a specified population (ie the number of new cases which develop during a specified period of time).¹

Informal care/help is help provided to a person with a disability, or a person who is aged 60 and over, by family, friends or neighbours. It is generally unpaid help.

Labour force in employment refers to those persons employed and those unemployed seeking employment.

Median is a measure of central tendency. It refers to the point between the upper and lower halves of the set of measurements.¹

Mortality rate is the relative number of deaths, or death rate, as in a district or community.²

Morbidity rate is the proportion of sickness in a locality.²

Participation rate in employment of any group refers to the number of persons in the labour force (employed and unemployed) in that group expressed as a percentage of the total population in the same group.

Prevalence refers to the number of instances of a given disease or other condition in a given population at a designated time.¹

Separation (from hospital) refers to when a patient is discharged from hospital, transferred to another hospital or other health care accommodation, or dies in hospital following formal admission.⁴

Sex differentials are the differences in rates between males and females.¹

Standardised death rate is the overall death rate that would have prevailed in a standard population, in this case the 1991 Australian population, if it had experienced at each stage the death rates of the population being studied.⁴

Statistically significant infers that it can be concluded on the basis of statistical analysis, that it is highly probable at a particular level, usually at the 95 per cent level of confidence.

References

1. Last J, *A Dictionary of Epidemiology*, IEA, 1988
2. Delbridge A, Bernard JRL, *The Macquarie Concise Dictionary, 2nd Edition*, 1988, 1992
3. Glover J, Woollacott T. *A Social Health Atlas. ABS Catalogue No. 4385.0*, 1992.
4. Australian Bureau of Statistics definitions.
5. Ware JE et al. *SF-36 Health Survey. Manual and interpretation guide*. Boston: Health Institute, New England Medical Center, 1993

7. Appendices

7.1 Tables

Table 22: Type of main disabling condition, by age, by sex, ACT, 1993

Type of main disabling condition	Age Group (years)							Total	
	0-14	15-24	25-34	35-44	45-54	55-64	65-74		75+
MALES									
Mental disorders									
Mental psychoses	**100	**100	**0	**0	**100	**0	**0	**0	*400
Other disorders	1500	*700	*300	*400	**0	**200	**	**100	3100
<i>Total</i>	1600	*700	*400	*400	**100	**200	**0	**100	3500
Physical conditions									
Disorders of the eye & adnexa	**100	**100	**200	*300	**200	*100	*400	**100	1300
Disorders of the ear & mastoid process	*300	**300	*500	*700	*700	*800	*600	**200	4100
Nervous system diseases	*300	**300	**200	**200	**200	**	**0	**100	1300
Circulatory diseases	**	**100	**	**0	*300	**100	**200	**200	*900
Respiratory diseases	*500	**300	**300	**200	*400	**200	*600	*400	2900
Arthritis	**	**100	*400	**200	*300	*300	**100	**100	1600
Other musculoskeletal disorders	**200	*300	**00	*800	*600	*700	**200	**100	3100
Head injury/stroke/any other brain damage	**0	**0	**100	**100	**0	**	**0	**0	**200
All other diseases and conditions	*600	**200	*500	1100	*300	*500	*800	*600	4600
<i>Total</i>	200	1600	2300	3700	3100	2700	2900	1700	20000
TOTAL	3600	2300	2700	4200	3100	2900	2900	1800	23500
FEMALES									
Mental disorders									
Mental psychoses	**100	**	**0	**100	**100	**0	**0	**100	*400
Other disorders	**200	**300	**200	*400	*500	**200	**100	**0	1900
<i>Total</i>	**200	**300	**200	*500	*500	**300	**100	**200	2300
Physical conditions									
Disorders of the eye & adnexa	**100	**100	**	*400	**	**0	**100	**200	*800
Disorders of the ear & mastoid process	**	**200	*500	*400	*400	*300	**100	*300	2300
Nervous system diseases	**300	**200	**20	*500	*300	**200	**0	**100	1800
Circulatory diseases	**	**0	**0	**100	**100	**200	*600	1100	2200
Respiratory diseases	*	*400	**200	*400	**100	**100	**200	**0	1900
Arthritis	**	**100	**200	*500	*500	1200	1200	*600	4300
Other musculoskeletal disorders	**	*400	*600	*500	*600	*600	*300	**0	2900
Head injury/stroke/any other brain damage	**	**0	**0	**0	**	**100	**	**100	**200
All other diseases & conditions	*400	*600	*900	*500	*800	*800	*400	*500	4700
<i>Total</i>	1300	1900	2400	3300	2800	3500	3000	3000	21300
TOTAL	1500	2200	2700	3800	3300	3800	3100	3200	23600

Continued next page

Type of main disabling condition	Age Group (years)								Total
	0-14	15-24	25-34	35-44	45-54	55-64	65-74	75+	
PERSONS									
Mental disorders									
Mental psychoses	**100	**100	**100	**100	**100	**0	**0	**200	*800
Other disorders	1700	*900	*600	*800	*500	*400	**100	**100	500
Total with mental disorders	1800	1000	*600	*900	*600	*400	**100	**200	5800
Physical conditions									
Disorders of the eye & adnexa	**200	**200	**200	*700	**200	**100	*400	*300	2200
Disorders of the ear & mastoid process	*300	*400	1000	1100	1200	1100	*700	*500	6400
Nervous system diseases	*600	*500	*300	*800	*500	**200	**100	**200	3100
Circulatory diseases	**	**100	**0	**100	*500	*300	*800	1300	3100
Respiratory diseases	1100	700	*400	*600	*500	**200	*900	*400	4800
Arthritis	**	**200	*600	*700	*800	1600	1300	*800	5900
Other musculoskeletal disorders	**200	*700	*700	1400	1200	1300	*500	**100	6100
Head injury/stroke/any other brain damage	**0	**0	**100	**100	**0	**100	**0	**100	*400
All other diseases & conditions	1000	*700	1400	1600	1100	1300	1100	1100	9300
Total with physical conditions	3300	3500	4700	7000	5800	6200	5900	4800	41200
TOTAL	5100	4500	5300	7900	6400	6700	6000	5000	47000

** Data subject to high relative standard error. * Subject to sampling variability between 25% and 50%

Source: ABS, *Disability, Ageing and Carers, Australia, 1993*, Cat. No. 4430.0

Table 23: Handicap and disability status, by age group, by sex, ACT, 1993

age (years)	Employed	Unemploy-ed	Total in the labour force	Not in the labour force	Total	Unemployed rate (%)	Participation rate (%)
MALES							
Handicap							
15-24	*400	**	*400	*900	1400	**	32.4
25-34	*800	**	*800	*500	1400	**	61.7
35-44	1800	**	1800	*700	2500	**	70.9
45-54	1900	**200	2200	*300	2500	11.5	86.6
55-64	1000	**200	1200	*800	2000	14.1	58.6
Total	6000	*400	6400	3300	9700	6.5	65.7
Disability w/out a handicap							
15-24	*500	**100	*500	*400	*900	15.1	57.0
25-34	1300	**	1300	**	1300	**	100.0
35-44	1600	**	1600	**	1600	**	100.0
45-54	*700	**	*700	**	*700	**	100.0
55-64	*800	**	*800	**100	*900	**	89.8
Total	4800	**100	4800	*500	5300	1.7	90.8
No disability							
15-24	13700	2900	16600	10000	26600	17.3	62.4
25-34	20800	1400	22200	*900	23100	6.3	96.3
35-44	19700	*300	20000	**200	20200	1.6	99.2
45-54	14100	*600	14700	*300	15000	3.9	97.9
55-64	5000	**200	5100	1500	6600	2.9	77.6
Total	73400	5300	78700	12800	91500	6.8	86.0

Continued next page

age (years)	Employed	Unemploy-ed	Total in the labour force	Not in the labour force	Total	Unemployed rate (%)	Participation rate (%)
All persons							
15-24	14600	300	17600	11300	28900	16.8	60.8
25-34	22900	1400	24300	1400	25700	5.7	94.6
35-44	23100	*300	23400	*900	24300	1.4	96.3
45-54	16700	*800	17500	*700	18100	4.7	96.4
55-64	6800	*300	7100	2400	9500	4.5	74.7
Total	84100	5800	89900	16700	106600	6.5	84.4
FEMAL ES							
Handicap							
15-24	1200	**200	1400	*400	1800	12.4	77.0
25-34	1000	**100	1100	*600	1700	7.4	63.2
35-44	1600	**200	1800	*800	2700	1.3	68.3
45-54	1500	*300	1800	*800	2600	15.9	68.4
55-64	*800	**100	*900	2500	3300	8.8	25.8
Total	6100	*800	6900	5200	12100	12.2	57.2
Disability without a handicap							
15-24	*400	**	*400	**	*400	**	100.0
25-34	*600	**200	*700	**200	*900	21.3	75.4
35-44	*900	**100	*900	**100	1100	8.7	86.5
45-54	*400	**200	*600	**100	*700	26.6	90.0
55-64	**200	**	**200	**300	*400	**	37.6
Total	2400	*400	2800	*700	3500	14.1	80.1
No disability							
15-24	13000	2100	15100	10600	25600	14.1	58.8
25-34	17200	*900	18200	4600	22800	5.2	79.8
35-44	17000	*700	17700	3300	21000	4.0	84.3
45-54	11700	*500	12200	1700	14000	4.1	87.6
55-64	1800	**	1800	3500	5300	**	33.5
Total	60700	4300	65000	23700	88700	6.6	73.3
All persons							
15-24	14500	2300	16800	11000	27800	13.6	60.6
25-34	18800	1200	20000	5500	25400	5.9	78.5
35-44	19400	1000	20400	4300	24700	5.0	82.6
45-54	13700	*900	14600	2600	17300	6.5	84.8
55-64	2700	**100	2800	6300	9100	2.7	30.8
Total	69200	5500	74700	29600	104300	7.4	71.6
PERSON S							
Handicap							
15-24	1600	**200	1800	1300	3100	9.4	57.5
25-34	1800	**100	1900	1100	3100	4.2	62.6
35-44	3400	**200	3600	1600	5200	6.6	69.6
45-54	3400	*500	3900	1200	5100	13.5	77.3
55-64	1800	**200	2000	3300	5300	11.9	38.1
Total	12000	1300	13300	8500	21800	9.5	61
Disability without a handicap							
15-24	*900	**100	*900	*400	1300	8.6	69.9
25-34	1800	**200	2000	**200	2200	7.7	89.5
35-44	2500	**100	2600	**100	2700	3.2	94.6
45-54	1100	**200	1300	**100	1300	12.8	94.9
55-64	*900	**	*900	*300	1300	**	73.2
Total	7200	*500	7700	1200	8800	6.2	86.5

Continued next page

age (years)	Employed	Unemploy-ed	Total in the labour force	Not in the labour force	Total	Unemployed rate (%)	Participation rate (%)
No disability							
15-24	26700	5000	31700	20600	52200	15.8	60.6
25-34	38100	2300	40400	5500	45900	5.8	88.1
35-44	36700	1000	37700	3500	41200	2.7	91.6
45-54	25900	1100	26900	2000	29000	4.0	92.9
55-64	6800	**200	6900	5000	11900	2.2	57.9
Total	134100	9600	143700	36600	180200	6.7	79.7
All persons							
15-24	29200	5200	34400	22300	56700	15.2	60.7
25-34	41800	2600	44300	6800	51200	5.8	86.6
35-44	42500	1300	43900	5200	49100	3.1	89.4
45-54	30400	1800	32100	3300	35400	5.5	90.8
55-64	9500	*400	9900	8700	18500	4.0	53.3
Total	153300	11300	164600	46300	210900	6.9	78.1

** Data subject to high relative standard error.

* Subject to sampling variability between 25% and 50%

Source: ABS, *Disability, Ageing and Carers, Australia, 1993*, Cat. No. 4430.0



7.2 Activity data for government services

Activity data on service utilisation for ACT Government services is published in ACT Department of Health and Community Care Annual Reports. Data relevant to services for people with disabilities and aged persons is tabled below. It should be noted that some data (eg hospital statistics) will *include* usage by other people as well (eg people requiring short-term intervention who do not fit the definition of 'disabilities lasting longer than 6 months')

Jindalee Nursing Home

Upper Jindalee (a)	1994-95	1995-96
Admissions	30	22
Occupied Bed Days	28,699	22,482
Average occupancy	99.6	99.4
Lower Jindalee		
Admissions	27	8
Occupied Bed Days	13,221	12,450
Average occupancy	98.6	85.0

(a) Upper Jindalee privatised on 19 March 1996

Community Nursing

Occasions of Service	1994-95	1995-96
Domiciliary (Adult and Child)	83,716	80,102
Child Health	97,636	96,223
Palliative Care Program visits	9,128	11,297
Intellectual Disability Program occasions of service	19,418	20,429
Discharge Planner services	4,691	3,645
Early Discharge Program services	1,312	1,618
Health Promotion services	16,372	16,667

Disability Services (now Disability Program)

	1994-95	1995-96
Accommodation Support Services (Residential Services)		
Number of Clients	141	142
Professional and Therapy Services (Community Disability Services)		
Average number of clients per month (a)	215	124
Average number of new referrals per month (a)	34	27
Independent Living Centre (ILC)		
Number of people attending appointments (b)	1,691(1,378)	1,660
Number of appointments (including unbooked) (b)	871 (999)	874
Wednesday drop-in service (number of people)	811	982
Telephone Enquiry Service (number of enquiries) (b)	1,774(1,952)	2,104
Total number of people using the ILC	4,276	4,746
Respite Care Services		
Occupancy Rates		
- Birralea (c)	80%	76%
- Finnis Crescent	95%	95%

Taxi Subsidy Scheme

Number of registered members (d)	2,900	2,782
----------------------------------	-------	-------

(a) Variations largely reflect changes in the collection of statistics and the change of focus in the management of clients with challenging behaviours as part of the regionalisation of Disability Services.

(b) The figures identified in the brackets are statistics printed in the 1994-95 Annual Report. These were incorrectly reported as a result of a malfunction in the Centre's data collection system which was unknown at the time of printing.

(c) Occupancy rates decreased as some clients were unable to attend respite as prebooked. Due to the short notice given at times, some vacancies cannot be backfilled.

(d) Variation as a result of the review of the Taxi Subsidy Scheme and priority being given to clients with the highest need.

Woden Valley (now The Canberra Hospital) and Calvary Public Hospitals Inpatient Activity**Calvary Public Hospital Occasions of Service for Inpatients**

Includes Nursing Home Type Ward (20 Beds)

	1994-95	1995-96
Department		
Clinical Psychology	629	680
Occupational Therapy	6,851	6,321
Physiotherapy	8,687	8,960
Psychiatric	610	1,547
Social Work	11,668	8,785
Speech Pathology/Therapy	727	723
Total	50,496	53,845

The Canberra Hospital Occasions of Service for Inpatients

(excludes Detox. Unit (13 Beds) but includes Renal Satellite & Peritoneal Dialysis)

	1994-95	1995-96
Health Professional Services		
Neuropsychology	318	514
Occupational Therapy	3,663	3,743
Physiotherapy	34,230	38,002
Podiatry	362	207
Psychology	1,324	1,114
Social Work	12,802	16,510
Speech Pathology	1,959	2,629
Total	65,655	72,746

Woden Valley and Calvary Public Hospitals Occasions of Service for Inpatients

	1994-95	1995-96
Department		
Neuropsychology	318	514
Occupational Therapy	10,514	10,064
Physiotherapy	42,917	46,962
Podiatry	362	207
Psychology	1,953	1,794
Social Work	24,470	25,295
Speech Pathology/Therapy	2,686	3,352
Psychiatric	610	1,547

Calvary Public Hospital Outpatient Activity Statistics

	1994-95	1995-96
Department		
Clinical Psychology	734	1,374
Occupational Therapy	270	462
Physiotherapy	9,772	8,126
Psychiatric Day Care Hospital	1,528	2,470
Social Work	4,398	2,744
Speech Pathology/Therapy	21	54

The Canberra Hospital Outpatient Activity Statistics

	1994-95	1995-96
Department /Clinic		
Clinical Psychiatry	993	446
Neuro-Physiology	276	0
Neuro-Psychology	1,128	1,183
Neurology	794	781
Occupational Therapy	2,721	2,540
Physiotherapy	14,929	12,912
Podiatry	974	687
Psychology	3,795	3,211
Rehabilitation and Aged Care Services	14,914	12,023
Social Work	7,824	6,356
Social Work - CAR	2,675	3,127
Speech Therapy	853	984

Woden Valley and Calvary Public Hospitals Outpatient Activity Statistics

	1994-95	1995-96
Department /Clinic		
Clinical Psychiatry	993	446
Clinical Psychology	734	1,374
Neuro-Physiology	276	0
Neuro-Psychology	1,128	1,183
Neurology	794	781
Occupational Therapy	2,991	3,002
Physiotherapy	24,701	21,038
Podiatry	974	687
Psychiatric Day Care Hospital	1,528	2,470
Psychology	3,795	3,211
Rehabilitation and Aged Care Services	14,914	12,023
Social Work	12,222	9,100
Social Work - CAR	2,675	3,127
Speech Therapy	874	1,038

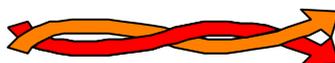
Mental Health Services

Service Type	1994-95	1995-96
24 Hour Crisis Service Community Mental Health		
Total number of contacts (a)	9,255	7,444
Number of contacts by point of contact		
Domiciliary	538	871
Office	3,683	3,596
Telephone	5,085	2,951
Number of contacts by shift		
Morning	3,243	2,846
Evening	3,385	3,031
Night	1,203	1,017
Community Mental Health Services (b)		
New referrals	3,303	3,092
Total number of contacts (c)	39,733	34,045
Psychiatric Unit		
Available beds	32	32
Admissions	873	899
Average length of stay	8.69	9.47
Average occupancy	93.8%	n/a
Hostels		
Available beds	60	60
Admissions	24	33
Average occupancy	98.3%	90.1%
Psychiatric Rehabilitation Services		
New Referrals	71	43
Total number of contacts	12,509	14,258

(a) Changes in Crisis team figures indicate a move from counting all telephone calls to counting occasions of service.

(b) Including Child and Adolescent and Forensic Services

(c) The changes in Community Mental Health reflect the reduction in staff due to recruitment difficulties, particularly in Child and Adolescent Services.



7.3 Appendix C: Methodologies

7.3.1 Rates

Rates per 100,000 are calculated as follows:

Rate = $N/P \cdot 100,000$ (where N = number of events and P= population at risk of experiencing the event).

7.3.2 Three year moving averages

The three year moving averages were calculated by taking the rate over three years.

$$\text{Rate } Y_2 = \frac{(N_1+N_2+N_3)}{(P_1+P_2+P_3)}$$

where N_i = number of events year i

where Y_i = year i

and P_i = population at risk year i

For end years the average of 2, rather than 3, years was taken.



7.4 Data limitations

7.4.1 Overall data

- Generally, data sets contain small numbers of occurrences of particular events. The smaller the numbers, the more likely there is to have inexplicable fluctuations in results. One extra death may alter mortality and morbidity statistics dramatically in a small area like the ACT. Where changes in pattern from year to year are noted, time series and moving averages are utilised to ensure a more reliable analysis;
- There is no supplementary morbidity collection for diseases that can be treated outside the hospital system. For example by a GP, specialist, outpatient clinics or emergency. Therefore there is a heavy reliance on survey data;
- Relying on available survey data means that some information is updated only after a number of years. Disease profiles may not be static with an everchanging ACT population and important information may be lost during the period where data is not collected.

7.4.2 National Health Survey 1989-90

The Australian Bureau of Statistics (ABS) 1989-90 National Health Survey collected data from approximately 54,000 people living throughout Australia. The sample was designed so that the states and territories could be separately analysed. However:

- Until the 1995-96 survey, the sample size of respondents was very small in the ACT. This resulted in fluctuations in results and reduced reliability of findings.
- When responses were broken down into sub-groups (eg people aged under 18), the sample became even smaller resulting in more inaccuracies.
- It should also be noted that the Survey utilises a self-reporting format. Results represent respondents' perceptions, not necessarily health professionals' findings. It also depends in part, on the literacy of the respondents and their ability to understand English.

The second Survey was conducted in the twelve months from January 1995 to January 1996. Preliminary results were released in late December 1996. Some 2,156 dwellings (or one in fifty dwellings) in the ACT were surveyed. This is an increase on the previous Survey and will allow for more relevant analysis. It should be noted however, that some sections of the survey were only administered to half of the sample. This includes sections on women's health, alcohol consumption and general health and well-being.

7.4.3 Disability, Ageing and Carers Surveys

The ABS conducts regular surveys which give a reasonably sound basis for analysis, although the size of the ACT sub-sample has been smaller than would be desired. They conducted a Survey of Handicapped Persons in 1981, followed by a Survey of Disabled and Aged Persons in 1988 which had comparable questions to the 1981 survey. The most recent survey, titled the Survey of Disability, Ageing and Carers was conducted in 1993. It contained a larger sample of ACT respondents from previous samples, on which to base analysis (3,777 people). The surveys are based on self-reported answers to questionnaires. It should therefore be noted that the results represent respondents' perceptions, not necessarily health professionals' findings. They also depend in part, on the literacy of the respondents and their ability to understand English. This may be particularly relevant to people with intellectual disabilities.

Tables used in this publication use 'rounded' numbers, so totals may not necessarily be accurate. There are also many asterisks highlighting the fact that numbers are so small as to result in high sampling variation or high relative standard error. Survey results should therefore be treated with caution.



8. References

- ⁱ AIH Welfare, 1995, *Australia's Welfare & Services Assistance 1996*, AGPS, Canberra
- ⁱⁱ Abraham B, d'Espaignet E, Stevenson C, *Australian Health Trends 1995*, AIHW, AGPS, Canberra
- ⁱⁱⁱ Lewis K, *Persons with disabilities and the Ageing Factor*, J. of Rehab, Oct-Dec 1989
- ^{iv} Dept. Human Services & Health, *First National Mental Health Report 1993*, AGPS, Canberra, 1994
- ^v Gannon D, Gordon C, Egloff B, Shadbolt B, *Health Related Quality of Life in the ACT: 1994-95*, Health Series No. 9, Epidemiology Unit, ACT Dept of Health & Community Care, Canberra, February 1997
- ^{vi} AIHW, *Welfare Services Expenditure*, Welfare Services Expenditure Bulletin, No. 2, July 1996
- ^{vii} Ibid
- ^{viii} ABS, *ACT in Focus, 1996, Canberra, AGPS, Cat. No. 1307.8*
- ^{ix} AIHW, *Australia's welfare 1995: services & assistance*, Canberra, AGPS, 1995
- ^x Bradley EM, Ibanez D, *Socio-economic risk factors & musculo-skeletal disability*, J of Rheumatology, 21(3):515-22, March, 1994
- ^{xi} Op cit (9)
- ^{xii} Mathers C, *Health Differentials among older Australians*, AIHW, Health Monitoring Series No. 2, AGPS, Canberra, 1994
- ^{xiii} ABS, *Disability, Ageing and Carers, Summary of findings ACT*, Cat. No. 4432
- ^{xiv} Op cit (2)
- ^{xv} Mathers C, *Health expectancies in Australia 1981 and 1988*, AIHW, AGPS, Canberra, 1991
- ^{xvi} Op cit (8)
- ^{xvii} Mathers C, *Health differentials among Australian children*, Health Monitoring Series No. 3, AIHW, 1995
- ^{xviii} Op cit (5)
- ^{xix} Op cit (5)
- ^{xx} Barker M, Power C, *Disability in young adults: the role of injuries*, J Epidem Comm Health, 47: 349-354, 1993
- ^{xxi} Gilbert C, Gordon C, *The Epidemiology of Injury in the ACT*, Epi Section, Dept of Health & Community Care, 1996
- ^{xxii} Cwikel J, Fried A, Galinsky D, Ring H, *Gait & activity in the elderly: implications for community falls-prevention & treatment programmes*, Disability & Rehabilitation Vol 17, No 6, 277-280, 1995
- ^{xxiii} Makela M, Heliavaara M, Sievers K, Knekt P, Maatela J, Aromaa A, *Musculoskeletal disorders as determinants of disability in Finns aged 30 years or more*, J of Clinical Epidemiology, 46(6):549-59, June, 1993
- ^{xxiv} Badley EM, Rasooly I, Webster GK, *Relative importance of musculoskeletal disorders as a cause of chronic health problems, disability, and health care utilisation: findings from the 1990 Ontario Health Survey*, J of Rheumatology, 21(3):505-14, March, 1994
- ^{xxv} Raspe A, Matthis C, et al, *Current musculoskeletal symptoms in peri & postmenopausal women: results of a multicenter population epidemiological study, The EVOS Study Group*, Sozial und Preventivmedizin, 39(6):379-86, 1994
- ^{xxvi} Ormel J, VonKorff M, Ustun TB, Pini S, Korten A, Oldehinkel T, *Common mental disorders & disability across cultures, Results from the WHO Collaborative Study on Psychological Problems in General Health Care*, JAMA, 272(22):1741-8, Dec 14, 1994
- ^{xxvii} Dept. Human Services & Health, *National Mental Health Report 1994*, AGPS, Canberra, 1995
- ^{xxviii} Bradley EM, Tennant A, *Impact of disablement due to rheumatic disorders in a British population: estimates of prevalence from the Calderdale Rheumatic Disablement Survey*, Annals of Rheumatic Diseases, 52(1):6-13, Jan 1993
- ^{xxix} Launer LJ, Harris T, Rumpel C, Madans J, *Body mass index, weight change, and risk of mobility disability in middle aged & older women, The epidemiological follow-up study of NHANES I*, JAMA, 271(14):1093-8, April 13, 1994
- ^{xxx} Steering Committee for the Review of Commonwealth/State Service Provision, *Report on Government Service Provision*, Vol 2, Commonwealth of Aust, 1997
- ^{xxxi} Madden R, Black K, Choi C, Wen K, Eckerman S, *Effective Indicators & Descriptors: First Results*, Welfare Division Working Paper No. 15, AIHW, Canberra, 1997
- ^{xxxii} Op cit (29)
- ^{xxxiii} Op cit (30)
- ^{xxxiv} Jorm AF, Henderson S, Scott R, Mackinnon AJ, Korten AE, Christensen H, *The disabled elderly living in the community: care received from family & formal services*, Med J of Aust, 158(6):383-5, 388, March 1993
- ^{xxxv} Carers Association of Aust., *Listen to the Carers! Report of the Nat. Carers Consultation to the International Year of the Family Council, Sept. 1994*
- ^{xxxvi} Op cit (33)

-
- ^{xxxvii} Carpiniello B, Piras A, Pariante CM, Carta MG, Rudas N, *Psychiatric morbidity & family burden among parents of disabled children*, Psychiatric Services, 46(9):940-42, Sept, 1995
- ^{xxxviii} Op cit (9)
- ^{xxxix} Dept of Health, *ACT Health Goals & Targets for the Year 2000*, Canberra, 1994
- ^{xl} Carers Association of Australia, *Fair Deal for Carers! Federal Election Campaign 1996*, Canberra, 1996
- ^{xli} Op cit (33)
- ^{xlii} Aust Bureau of Statistics, *Focus on Families: Caring for families: Support for persons who are older or have disabilities*, 1995, Catalogue No. 4423.0
- ^{xliii} Op cit (34)
- ^{xliv} Op cit (5)
- ^{xlv} Dept. Health & Family Services, *National Mental Health Report 1995*, AGPS, Canberra, 1996
- ^{xlv} Ware JE et al, *SF-36 Health Survey, Manual and Interpretation Guide*, Boston: Health Institute, new England Medical Centre, 1993

9. Health Series Publications

The Epidemiology Unit of the Department of Health and Community Care has developed an on-going health series of publications to inform health professionals, policy developers and the community on health status in the Territory. Information contained therein will assist in the development of appropriate policy and service delivery models, the evaluation of programs, and an understanding of how the ACT compares with Australia as a whole with regard health status.

- Number 1: *ACT's Health: A report on the health status of ACT residents*
Carol Gilbert, Ursula White, October 1995
- Number 2: *The Epidemiology of Injury in the ACT*
Carol Gilbert, Chris Gordon, February 1996
- Number 3: *Cancer in the Australian Capital Territory 1983-1992*
Norma Briscoe, April 1996
- Number 4: *The Epidemiology of Asthma in the ACT*
Carol Gilbert, April 1996
- Number 5: *The Epidemiology of Diabetes Mellitus in the ACT*
Carol Gilbert, Chris Gordon, July 1996
- Number 6: *Developing a Strategic Plan for Cancer Services in the ACT*
Kate Burns, June 1996
- Number 7: *The First Year of The Care Continuum and Health Outcomes Project*
Bruce Shadbolt, June 1996
- Number 8: *The Epidemiology of Cardiovascular Disease in the ACT*
Carol Gilbert, Ursula White, January 1997
- Number 9: *Health Related Quality of Life in the ACT: 1994-95*
Darren Gannon, Chris Gordon, Brian Egloff, Bruce Shadbolt, February 1997
- Number 10: *Disability and Ageing in the ACT: An Epidemiological Review*
Carol Gilbert, March 1997

