

Guardianship arrangements and demographic trends, 2010-2030

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The Victorian Law Reform Commission (VLRC) commissioned the Centre for Population and Urban Research to provide estimates of the numbers of Victorian residents likely to be experiencing cognitive impairment (CI) in 2020 and 2030.

The purpose of the study was to assess the numbers of persons with CI, who on this account would be unable to make their own financial and life management decisions. Persons who lack this capacity may potentially need guardianship arrangements to assist them with these management decisions. An additional purpose of the study was to assess the number of such persons who are likely to be in some form of residential care in an institution (such as a hospital or nursing home). The need for the latter assessment derives from the State's responsibility for persons who are living in non-home settings that receive government financial support. Should the VLRC wish to make recommendations to change guardianship laws, it needed information on the numbers of people who might be affected and who might potentially require state government assistance.

Rates of cognitive impairment

Cognitive impairment may arise from a range of conditions. The best known is the various forms of dementia, which include Alzheimer's disease. However other conditions can lead to CI, such as stroke and mental illness. The task was to identify the range of conditions that should be included as potentially leading to CI, then count the number of Victorian residents experiencing these conditions (by age and sex). Since not all persons identified would be unable to make financial and management decisions the next task was to assess the proportion, by age and sex, who would qualify as lacking this capacity (and thus meet the above definition of CI). The resulting counts of those cognitively impaired persons provide the numerator for calculations of the proportion of all Victorian residents as of 2003 by age and sex who are cognitively impaired. These proportions, when applied to the projected number of Victorian residents in 2020 and 2030 by age and sex will provide an estimate of the number of Victorian residents likely to be cognitively impaired by 2020 and 2030.

There is a substantial literature on dementia, some of which includes projections of the number of those likely to be experiencing the condition to 2030 and beyond. There is no parallel literature on the wider range of conditions, like stroke and mental illness that provides parallel estimates of their prevalence and the implications for cognitive functioning.

The only comprehensive survey that encompasses the full range of conditions potentially leading to CI is that provided by the 2003 Disability, Ageing and Carers (DAC) Australian survey¹. This involved a very large national sample of 41,200 persons. The survey included interviews of persons living in households and those in some form of residential care, including nursing homes or hospitals (subsequently referred to as cared accommodation). The purpose was to establish

the prevalence of a wide range of potentially disabling conditions and the extent of the disablement resulting from the condition.

For this study the following conditions identified in the DAC survey were included in this study: dementia, Alzheimer's disease, Parkinson's disease, multiple sclerosis, cerebral palsy, other diseases of the nervous system, stroke, head injury/acquired brain damage, complications/consequences of surgery and medical care n.e.c., schizophrenia, depression/mood affective diseases (excluding postnatal depression), mental retardation/intellectual disability, autism and related disorders (including Retts syndrome), intellectual and development disorders n.e.c., mental and behavioural disorders n.f.d., other mental and behavioural disorders and intellectual and development disorders. The numbers of persons experiencing each of these conditions were drawn from the DAC survey by state of residence and by age and sex.

As indicated, not all of those identified could be regarded as cognitively impaired. Most of the conditions in question, like dementia, are progressive. They involve various stages of mental and physical incapacity. The early stages after diagnosis do not usually involve CI (as defined above). The DAC classified the persons identified with the conditions listed into four stages; those experiencing profound limitation, severe limitation, moderate limitation and mild limitation. Profound limitation included those who always need help with a core activity task, and severe limitation included those who sometimes need help with any of the tasks related to the core activities of self-care, mobility and communication. This severe group included those who sometimes have difficulty understanding or being understood by family and friends. Those experiencing moderate or mild impairment were defined as those who need no help, but sometimes have difficulty with a core activity task, or may use aids and equipment to complete the task.ⁱⁱ

For the purposes of this study persons who were classified in the profound or severe disablement categories were regarded as likely to be experiencing CI. Just under half of those with the conditions included in the study were classified as in the profound or severe limitation categories. Among those suffering from profound or severe CI, about one in five were due to dementia and a similar proportion was due to stroke or acquired brain damage (see Table 1 for details).

The DAC survey has been criticised as undercounting the prevalence of dementia. This is because it relied on self-reported identification of conditions. This is thought to lead 'to severe under reporting due to an individual's limited capacity to recognize mild and moderate dementia, if it has not been formally diagnosed.'ⁱⁱⁱ Since in this study only those who were classified as experiencing profound or severe limitation were included, any undercounting of those in the early stages of dementia should not affect the numbers identified in the DAC survey as experiencing profound or severe limitation. Those with dementia who had reached this stage should have been evident to interviewers. Undercounting is likely to be much less of a problem for those in cared accommodation. For these persons the DAC interviewer communicated with expert staff in the care institution as well as those sampled for the survey.

Table 1: Persons with CI by major condition, 2003 (per cent)

Main condition	Number	per cent
Mental and behavioural disorders n.f.d	6365	1.9
Dementia	58,571	17.5
Schizophrenia	13,817	4.1
Depression/mood affective disorders excl. postnatal depression	32,907	9.8
Intellectual and development disorders n.e.c.	7363	2.2
Mental retardation/intellectual disability	31,558	9.4
Autism and related disorders (incl. Rett's syndrome)	20,690	6.2
Other mental and behavioural disorders	39,859	11.9
Parkinson's disease	15,561	4.7
Alzheimer's disease	8698	2.6
Multiple sclerosis	6824	2.0
Cerebral palsy	6285	1.9
other diseases of the nervous system	19,690	5.9
Stroke	49,494	14.8
Head injury/acquired brain damage	9689	2.9
Complications/consequences of surgery and medical care n.e.c.	6821	2.0
Total	334,191	100.0

Source: DAC Disability Survey, 2003

A further caution in regard to the DAC results concerns the classification of degree of incapacity. The Australian Institute of Health and Welfare (AIHW), in evaluating the DAC data indicates that the 'severe' category may include some who the AIHW would regard as suffering 'mild' disability. The AIHW defines 'mild' to include those whose dementia has a significant impact on daily activities, but are still able to undertake these activities.^{iv} The implication is that some of those defined in our study as cognitively impaired because they are included in the severe limitation category, may not in fact be cognitively impaired. The same qualification may apply to those with conditions other than dementia who the DAC survey classifies as severely impaired.

On the other hand our estimates of CI are likely to be far more accurate than estimates based on the numbers of persons diagnosed with any of the conditions included in our study. Such estimates cannot be used as indicators of CI. For example, in the case of dementia sufferers, Access Economics has prepared projections of the prevalence of dementia sufferers in each state for Alzheimer's Australia. These include persons at all stages of the disease, including the early stages where most sufferers would not yet be regarded as cognitively impaired as defined above.

The AIHW indicates that about 45 per cent of those clinically diagnosed with dementia fall into the categories equivalent to ‘profound’ impairment as defined by the DAC.^v

Proportion of the cognitively impaired in cared accommodation

The Australia Government has established a rigorous clinical assessment of all those currently seeking to enter Commonwealth subsidised age care facilities. Of those in such care who have had such an assessment, nearly half are classified as suffering from dementia and another 23 per cent suffering from ‘other mental illness’.^{vi} Useful as these statistics are, they do not help in identifying the proportion of all those with CI who are in cared accommodation.

Again, the DAC data are the only reliable source. In the DAC survey, persons were identified by their condition and by whether they lived with their household or in some form of cared accommodation, including nursing homes and hospitals. This data was used to calculate the proportion of the cognitively impaired for each condition who were living in a household or cared accommodation by age and sex. These proportions have been used as the basis for projections of the numbers of cognitively impaired persons who are likely to be in cared accommodation over the projection period. This was done by applying the current proportions in cared accommodation to the projections of those likely to be cognitively impaired by age and sex.

Findings

Projections of the numbers cognitively impaired

Table 2 shows the rates of cognitive impairment as defined above for Victoria and Australia in 2003. These rates have been applied to a projection of Victoria’s population, and the results are presented in Table 3. The rates for Australia have been used because they were considered to be more reliable than those detailed for Victoria. This is because of the much smaller sample size for Victoria relative to Australia.

Table 2: Rates of cognitive impairment for males and females in Victoria and Australia

Age group	Victoria		Australia	
	Males	Females	Males	Females
20–29 years	1.0	1.8	1.1	0.7
30–49 years	0.8	1.0	0.8	0.8
50–69 years	1.1	1.6	1.2	1.2
70–79 years	4.4	3.7	4.7	4.3
80–84 years	5.4	14.3	7.4	10.8
85+ years	19.0	23.0	13.1	21.8

Source: DAC survey, 2003, numbers identified as profoundly or severely incapacitated for conditions identified per hundred of the resident population

The Victorian population projection used derives from the series of projections prepared by the Australian Bureau of Statistics (ABS) and published in 2008.^{vii} Series B has been used, partly because we regard it as a plausible projection and partly because the 2008 Victorian Government projections for Victoria, published in *Victoria in Future* 'use very similar assumptions to the ABS Series B Projection'.^{viii} The assumptions used for the Victorian projection were that net overseas migration would be 47,700 per year (or 26.5 per cent of the total for Australia of 180,000 per year). The age and sex distribution of net migration to Victoria each year was assumed to match that of the actual numbers for the years 2005 to 2007. Net interstate migration was assumed to be -6,000 per year. The Total Fertility Rate for Victoria was assumed to be 1.73 throughout the projected period. As would be expected, the projection outcomes are very close to those detailed in *Victoria in Future*. Under the ABS projection used, Victoria's population grows from 5.4 million in 2010 to 6.2 million in 2020 and 6.9 million in 2030. As indicated, the CI rates by age and sex shown in Table 2 were applied to the total number of residents of Victoria projected to 2020 and 2030 by age and sex.

Only adults aged 20-plus are shown for the projection of those with CI shown in Table 3. The projection starts with 20–24-year-olds because there was no data for the years 18 or 19 in the ABS projection.

Table 3: Projections of cognitively-impaired residents of Victoria, males and females, for 2010, 2020 and 2030

Age group	2010		2020		2030	
	Males	Females	Males	Females	Males	Females
20–29 years	4414	2716	4797	2910	4998	3040
30–49 years	6140	6246	6844	6838	7640	7486
50–69 years	7066	7299	8328	8721	9097	9508
70–79 years	7078	7297	10,435	10,527	13,323	13,600
80–84 years	3622	7068	4489	8152	7205	12,788
85+ years	4633	14,801	6958	18,897	10,272	25,322
Total	32,953	45,426	41,852	56,045	52,536	71,744

Source: CPUR, 2010, cognitive impairment rates for Australia (Table 2) multiplied by the projected population of Victoria in 2020 and 2030.

Projections of the numbers of cognitively impaired in cared accommodation

As described above, in order to estimate the numbers of the cognitively impaired persons in Victoria who were in cared accommodation the data on place of residence provided in the DAC survey was utilised. Again, because of the sample size issue, Australian rather than Victorian rates were used. The results are shown in Table 4. As is evident, the share of those living in cared accommodation increases sharply with age.

This is an important finding because of the high incidence of cognitive impairment among older residents and because the number of persons aged 70 plus living in Victoria will increase sharply over the next two decades. This increase will be due to the ageing of the very large cohort of baby boomers who are about to enter the post-65 retirement age group.

Table 4: Proportion of profound and severe cognitive impairment cases in cared accommodation by age and sex, 2003

Age group	Australia	
	Males	Females
20–29 years	4.4	4.1
30–49 years	12.4	7.5
50–69 years	21.7	20.8
70–79 years	32.3	46.1
80–84 years	52.2	69.7
85+ years	82.5	77.3

Source: Australian Bureau of Statistics (ABS), 4431.0: Disability, Ageing and Carers, Australia

In order to compute the number of persons with CI who are likely to be in cared accommodation the proportions shown in Table 4 were then applied to the projection of Victorian residents likely to be cognitively impaired in 2020 and 2030 shown in Table 3. The results are shown in Table 5.

By 2030 the projection indicates that there will be a 71 per cent increase in the number of cognitively impaired females living in cared accommodation relative to 2010 and an 88 per cent increase in the number of males living in such accommodation. This is higher than the total increase in the numbers projected to be cognitively impaired shown in Table 3. The increase between 2010 and 2030 for these numbers was 58 per cent for females and 59 percent for males. The reason for this outcome is the relatively rapid growth in the numbers of persons in the retirement ages.

Table 5: Projections of cognitively-impaired persons in cared accommodation in Victoria by age and sex for 2010, 2020 and 2030

Age group	2010		2020		2030	
	Males	Females	Males	Females	Males	Females
20–29 years	192	111	209	118	218	124
30–49 years	759	466	846	510	944	558
50–69 years	1536	1518	1810	1813	1977	1977
70–79 years	2288	3364	3373	4854	4307	6271
80–84 years	1889	4925	2341	5680	3757	8911
85+ years	3822	11,443	5740	14,611	8474	19,578
Total	10,486	21,827	14,319	27,587	19,678	37,419

Source: CPUR, numbers of cognitively-impaired persons in Victoria in 2010, 2020 and 2030 multiplied by the estimated cared accommodation rate for Victoria in 2009

Implications for guardianship and administration cases

There is only a limited amount of information available to make any accurate estimate of the implications of the projections of persons with CI, shown in Table 3 for the likely number of guardianship and administration cases over the projection period.

In the case of the 1574 guardianship cases dealt with by the Office of the Public Advocate in 2009–10, the Office of the Public Advocate provides some information on the age distribution and major condition (such as dementia) of the caseload. These conditions mainly fall into the CI category. As to the age distribution, in 2009–10, 41 per cent of the case load was aged 80+.ix This is very close to the 38.4 per cent (calculated from Table 3) of our estimate of the share of cognitively impaired persons in Victoria in 2010 who were in the 80+ age group. This implies that at least for the guardianship group, the people included have similar characteristics to the total Victorian population (of 32,953 males and 45,426 females, or 78,379 in all) with CI in 2010 identified in Table 3.

Therefore it is reasonable to regard the share of our estimate of the number of the cognitively impaired in 2010 who are in guardianship as a guide to the likely numbers in guardianship in 2020 and 2030. This share was 2.01 per cent, that is 1574 out of the total estimate of those with CI in 2010 of 78,379. These numbers projected on this basis are provided in Table 6. On this analysis the guardianship caseload in Victoria is likely to increase from 1,574 in 2010 to some 1,958 in 2020 and 2,486 in 2030.

Table 6: projected number of guardianship cases in Victoria in 2020 and 2030

	2010	2020	2030
Number of cognitively impaired	78,379	97,897	124,280
Share in guardianship	2.01	2.01	2.01
Number in guardianship	1574	1958	2486

Source: Calculated from projections of those with CI shown in Table 3

In the case of the administration caseload, managed by the State Trustees, the 8,866 cases for which age and sex distribution data in 2009-10 are available suggest quite a different population (data provided by the VLRC). It is much younger than for the guardianship case load, with just 13 per cent aged 81 plus and a predominance of males relative to females (rather than the other way round as for the guardianship caseload). This implies that the pattern of conditions which contributed to persons becoming subject to the State Trustees jurisdiction is different from that of the guardianship caseload. The latter was much older, reflecting the high incidence of CI in the older age groups, particularly amongst females. It is therefore not advisable to use the projection of the numbers of cognitively impaired persons calculated in this study to make any projection of the likely caseload of the State Trustees.

ⁱ ABS, 4430.0.00.001, Basic confidentialised unit record file: Survey of disability, ageing and carers 2003 (reissue), 2005.

ⁱⁱ AIHW, *Dementia in Australia, national data analysis and development*, January 2007, p. 61

ⁱⁱⁱ Access Economics, *Keeping dementia front of mind: incidence and prevalence 2009–2050*, Alzheimer’s Australia, August 2009, p. 6

^{iv} AIHW, op cit, p. 61

^v AIHW, op cit, p. 61

^{vi} AIHW, *Residential aged care in Australia, 2007–08, A statistical overview*, June 2009, p. 130

^{vii} ABS, 3222.0, Population Projections, Australia, 2006 to 2010, .0, 2008

^{viii} Victorian Government, *Victoria in Future*, 2008, Victorian State Government Population and Household Projections 2006–2036, September 2009, p. 6

^{ix} Office of the Public Advocate, *Annual Report 2009–10*, p. 5