4 AIHW estimates of ABI in Australia

4.1 Approaches to estimating ABI incidence and prevalence

Data sources

There are several characteristics of ABI that make it particularly challenging to find reliable data relating to its impact at a community level. As ABI can arise from various different causes, result in a range of effects, and have various associated co-morbidities, there is no single common point of contact in the health or welfare system at which reliable data can be collected. In addition, certain types of ABI (e.g. alcohol-related brain injury) carry a level of stigma that may discourage individuals from identifying as having ABI.

The National Hospital Morbidity Database and the 1993 ABS Survey of Disability, Ageing and Carers are two major sources of national data that can be used to look at rates of ABI in Australia. Estimated rates of ABI-related hospitalisation based on the National Hospital Morbidity Database (1996–97) are presented in Section 4.2 and estimated rates of ABI-related disability based on the 1993 ABS disability survey data are presented in Section 4.3.

In this section some general features of hospital data, population survey data and other relevant data sources will be discussed and measures of hospitalisation rate (treated as indicative of incidence) and prevalence used in the remainder of the chapter will be outlined.

Hospital data

Hospital separations data are consistently collected throughout Australia and collated at the national level as the National Hospital Morbidity Database. The database is held by AIHW and summarised data are published regularly (AIHW 1998). Health conditions and external causes are coded according to the ICD–9–CM, and other information, such as sex, age, country of birth, Indigenous status, and length of stay, is recorded for each hospital episode.

These data can be useful for looking at rates of hospitalisation associated with some subgroups of ABI. It must be emphasised that rates of hospitalisation are not incidence rates, although incidence is one of the factors that affects rates of hospitalisation. Hospital data only provide information on people who are hospitalised—those treated outside the hospital system will not be captured by the data. People with certain types of ABI may not routinely come into contact with hospitals. This is particularly true for alcohol- and substance-related ABI (Marilyn Hage, ARBIAS, pers. comm.), stroke (Bonita et al. 1994), and possibly for certain types of degenerative diseases that result in ABI.

Hospital admission policies can influence rates of hospitalisation (Jennett 1996). Variation in hospitalisation rates between two regions, or over time, may reflect different admission policies rather than different incidence rates (Moller et al. 1996). Diagnosis coding practices can also differ between hospitals (although differences are unlikely to be great as coding practices are standardised throughout Australia).

Some people with newly incident cases of a condition may not attend a hospital in respect of that condition, while others may be hospitalised several times. Double counting is a feature of hospital data, as separations signify hospital episodes rather than individuals. Double counting of patients transferred between acute hospitals has been estimated to account for 2% of recorded admissions for head injury (Jennett 1996).

Perhaps the most significant limitation of hospital morbidity data from a disability and disability services perspective is that they do not provide any information on ongoing impairment, activity limitation or participation restriction resulting from brain injury (Honey 1995a). Reliable information on the proportion of people hospitalised with brain injury who experience long-term effects could potentially be used in conjunction with hospital data to provide a rough estimate of the 'incidence' of disability attributable to ABI.

Population surveys

Population surveys, such as the 1993 ABS Survey of Disability, Ageing and Carers, rely on self-reported information. Self-reported health and disability status is likely to reflect perceptions and expectations of health and activity, and these can vary between cultures and over time. An illustration of this is provided by surveys conducted by the ABS, in which Indigenous Australians tend to report similar or better health than other Australians. However, more 'objective' measures of health status, such as standardised mortality ratios and life expectancy, indicate that Indigenous people have substantially poorer health than other Australians (Mathers 1996).

Aspects of survey methodology can affect estimates of disability prevalence. A Dutch study found that seemingly minor differences in the wording of questions resulted in substantial differences in the estimated prevalence of disability in elderly people (Picavet & van den Bos 1996). It was also reported that prevalence estimates based on self-administered questionnaires tend to be substantially higher than estimates from interview-based surveys. The advantages and disadvantages of population surveys are discussed in a United Nations report on obtaining disability-related data from household surveys (UN 1988). An interesting point made in that report is that, although self-reported information may be unreliable in some respects, it is able to reflect those aspects of the disability experience most important to people with disabilities themselves, and perhaps less amenable to professional assessment.

The National Health Survey is a 5 yearly population survey conducted by the ABS that collects information on the health status of Australians. In the 1995 Survey, all conditions reported by survey respondents were coded using a classification based on the ICD–9. However, many of the ICD–9 codes were collapsed into broader groupings more appropriate for the type and quality of information collected in the Survey (ABS 1996c). Unfortunately, the broad groupings mean that National Health Survey data cannot be used to estimate the prevalence of ABI.

Other data sources

The Australian GP survey is a potential source of information about ABI. Data collection began in April 1998. Like hospital separations data, the GP survey provides information on 'encounters' (or 'visits') rather than individuals. Data collected include diagnoses, demographic information and management details (e.g. prescriptions, referrals).

Administrative data collected by service providers are a potential source of information on ABI. Client data can be valuable in providing detailed information on demographic factors and support needs for people accessing services (e.g. Ramsey & Hilson 1995). Data on recipients of services under the Commonwealth / State Disability Agreement, collected annually, could be used to estimate the number of people with ABI receiving specific service types. However, service data cannot be used to estimate the prevalence of specific disability groups in the community, and are therefore not within the scope of this paper.

Calculation of rates used

Measures used in this chapter are rates of hospitalisation (based on hospital data, and treated as indicative of incidence) and rates of prevalence (based on population survey data). As well as crude rates, indirectly standardised rates will be used to adjust for the different age and sex structures of sub-populations being compared.

An unstandardised rate is calculated by dividing the total number of cases observed in a population by the number of people in that population. However, populations vary in age structure—some populations have a greater proportion of older or younger people than other populations. This can affect the estimation of prevalence or incidence, because people in certain age groups are likely to be more or less ‘at risk of’ the occurrence under study (e.g. ABI-related disability) than people in other age groups. Therefore, a high overall prevalence rate of ABI-related disability may be due to high age-specific prevalence rates, or high representation within the population of age groups in which ABI-related disability is more prevalent, or a combination of both these factors.

The confounding effect of population age structure can be controlled for using methods of age standardisation. Age-standardised estimates allow more meaningful comparison of rates between different populations. Direct standardisation involves applying the age-specific rates of the study population to the age structure of a standard population. However, when the number of observations within the study population is small, age-specific rates may be unreliable. In such situations, an alternative is to use indirect standardisation.

Indirectly standardised rates for a study population are calculated using the ratio of the total number of cases observed in the study population *(O)* and the number that would be expected if the study population was subject to the age- and sex-specific rates of the standard population *(E)*. The expected number of cases in the study population is:

$$E = \sum_{x=1}^{g} m_x \lambda_x$$

where λ_x is the rate for group x in the standard population, m_x is the number of individuals in group x in the study population and g is the number of groups (Esteve et al. 1994). The ratio of the number of cases observed in the study population to the number expected *(O/E)* provides a measure of the relative risk of the study population compared with the standard population. For example, a ratio of less than one indicates that individuals in the study population are at a lower risk of the occurrence under study (e.g. ABI-related disability) than are individuals in the standard population. The ratio can be multiplied by the overall rate for the standard population to obtain the indirectly standardised rate for the study population.

In this paper, indirectly standardised rates are used to make comparisons between populations with different age and sex structures (e.g. between sub-populations defined by country of birth, Indigenous status, or place of residence). The standard population used in calculation is the total Australian population.

Standardised rates are used only for comparison between different populations. They do not reflect the actual prevalence of ABI-related disability, or the number of hospital separations associated with ABI, within a given sub-population. Therefore, unstandardised rates should be used for assessing the level of need or demand for health and disability services.

Confidence intervals can be calculated for both unstandardised rates and indirectly standardised rates, as described in Appendix 2. In the following sections of this paper, statistical tests of significance have not been conducted to examine differences between estimated rates. Instead, when there is no overlap between the 95% confidence intervals for two rates the rates are treated as significantly different.

4.2 Estimates from the National Hospital Morbidity Database 1996–97

The National Hospital Morbidity Database is a collection of confidentialised electronic summary records for patients admitted to Australian hospitals. It includes data from public acute and Department of Veterans' Affairs hospitals, public psychiatric hospitals, private acute and psychiatric hospitals, and private free-standing day hospital facilities. A small number of hospitals do not contribute to the collection. The database is held by the Australian Institute of Health and Welfare, and data are provided by State and Territory health authorities, and by the Department of Veterans' Affairs for the hospital it operates in New South Wales (AIHW 1998).

Each record in the database relates to a 'separation' (i.e. the discharge, transfer or death of a patient). Data on patients admitted in one year but separated in another are included in the database for the year in which they separated. Patients who separated more than once in a single year will have more than one record in the database. Each record provides basic information on the hospital (e.g. sector, jurisdiction), and more detailed information on the patient (e.g. age, sex, country of birth, Indigenous status), and the episode of care (e.g. admission and discharge dates, diagnoses, procedures carried out), with diagnoses and procedures classified and coded using the ICD–9–CM.

As outlined in Section 4.1, although data on separations can provide useful information about hospital services provided in respect of particular conditions, these data cannot strictly provide measures of incidence. Therefore, the rates presented later in this section should be thought of as rates of hospitalisation for ABI-related conditions, with some adjustments (as described below).

Identifying ABI-related separations

In using the Hospital Morbidity Database to look at rates of ABI-related hospital separations ICD–9–CM codes were used to identify traumatic brain injury and five other subgroups of ABI: stroke, anoxic brain injury, alcohol-related brain injury, brain injury arising early in life, and 'other' ABI (Table 4.1). Neurological diseases such as multiple sclerosis were not included, as these were grouped as 'neurological disability', a subgroup of physical disability, considered in a previous report in this series (Wen & Fortune 1999). A seventh grouping, the 'ABS group', comprises ICD–9–CM codes that are equivalent to the disabling condition categories of 'mental degeneration due to brain damage' and 'head injury / brain damage' in the 1993 ABS disability survey (see Section 4.3 below). This last group is used as a basis for comparing findings from the two data sources.

Table 4.1: ICD–9–CM codes used in analyses of the National Hospital Morbidity Database to identify hospital separations with diagnoses associated with various subgroups of acquired brain injury

ABI subgroup	ICD–9–code	Description
Traumatic brain injury	800	Fracture of vault of skull
	801	Fracture of base of skull
	803	Other and unqualified skull fractures
	804	Multiple fractures involving skull or face with other bones
	850	Concussion
	851	Cerebral laceration and contusion
	852	Subarachnoid, subdural and extradural haemorrhage, following injury
	853	Other and unspecified intracranial haemorrhage following injury
	854	Intracranial injury of other and unspecified nature
Stroke	430	Subarachnoid haemorrhage
	431	Intracerebral haemorrhage
	432	Other and unspecified intracranial haemorrhage
	433	Occlusion and stenosis of precerebral arteries
	434	Occlusion of cerebral arteries
	435[a]	Transient cerebral ischaemia
	436	Acute, but ill-defined, cerebrovascular disease
	437[a]	Other and ill-defined cerebrovascular disease
	438[a]	Late effects of cerebrovascular disease
Anoxic brain injury	348.1	Anoxic brain damage
	997.0	Central nervous system complications (anoxic brain damage or cerebral hypoxia during or resulting from a procedure)
Alcohol-related brain injury	291.1	Alcohol amnestic syndrome
	291.2	Other alcoholic dementia
Brain damage arising before birth, at birth, or during childhood	760.71	Foetal alcohol syndrome
	767.0	Birth trauma—subdural and cerebral haemorrhage
	768.5	Severe birth asphyxia
	768.6	Mild or moderate birth asphyxia
	768.9	Unspecified birth asphyxia in liveborn infant
	772.2	Foetal and neonatal haemorrhage—subarachnoid
	330	Cerebral degenerations usually manifest in childhood

(continued)

Table 4.1 (continued): ICD–9–CM codes used in analyses of the National Hospital Morbidity Database to identify hospital separations with diagnoses associated with various subgroups of acquired brain injury

ABI subgroup	ICD–9–code	Description
Other	290	Senile and presenile organic psychotic conditions
	294	Other organic psychotic conditions (chronic)
	310	Specific non-psychotic mental disorders due to organic brain damage
	331	Other cerebral degenerations (includes Alzheimer's disease)
ABS group(b)	TBI	ICD–9–CM codes 800, 801, 803, 804, 850–854
	Stroke	ICD–9–CM codes 430–434, 436
	310.9	Unspecified non-psychotic mental disorder following organic brain damage
	348.1	Anoxic brain damage
	997.0	Central nervous system complications (anoxic brain damage or cerebral hypoxia during or resulting from a procedure)

(a) These codes are included in the 'long' list for identifying stroke, but are excluded from the 'short' list.
(b) See Madden et al. (1995), Appendix D, for mapping of ICD–9 codes to ABS disabling condition categories.

Traumatic brain injury was identified using the 3-digit ICD–9–CM codes recommended by the Centers for Disease Control and Prevention in the USA (Thurman et al. 1995). These codes have been used in several published studies looking at the incidence of traumatic brain injury (see Section 2.2). The ICD–9–CM codes that make up the remaining subgroups flag conditions that may be associated with different subgroups of acquired brain injury.

For each separation record a number of diagnoses may be recorded. The diagnosis that is chiefly responsible for occasioning the patient's episode of care in hospital is identified as the principal diagnosis (AIHW 1997b). For each ABI subgroup, records containing the specified ICD–9–CM codes, either as the principal diagnosis or among the additional diagnoses, were retrieved from the database.

To minimise double counting, records for patients transferred to another acute hospital were excluded using the data item 'separation mode'. Further, as we are interested only in episodes of acute care, the data item 'episode type' was used to limit the analysis—only records for which the value of this data item was 'acute' or null were included. Null values were included because information on episode type was not collected in Tasmania and the Australian Capital Territory—excluding null values for episode type would have the effect of excluding all separations from hospitals in these jurisdictions.

This approach relies on the assumption that people admitted for an acute episode of care in one hospital and then transferred to a second acute hospital always receive acute care at the second hospital. However, there may be a number of cases in which a person transferred to a second acute hospital will be recorded as having an episode of rehabilitation or palliative care. In such cases the person will not be counted in the first or second instance, and will thus be lost to the analysis.

An alternative approach would have been to limit the analysis to episodes of acute care and also exclude separations for which the data item 'referral source' indicated that the patient had been transferred from another hospital (and thus, presumably, already included in the analysis). This approach would not be subject to the assumption explained above. However, it seems that the data item 'referral source' is not as reliable as the data item 'separation mode' (AIHW analysis of National Hospital Morbidity Database). Theoretically, the number of records in the database for which 'separation mode' indicates that the patient was transferred should roughly equal the number of records for which 'referral source' indicates that the patient has been transferred. In reality the former is substantially higher than the latter, indicating that in many instances when a patient is transferred from one hospital to another this is not documented by the receiving hospital. Therefore, it was decided that the data item 'separation mode' should be used to limit the analysis, although it is acknowledged that this might result in underestimation.

Hospital separations associated with acquired brain injury

For each ABI subgroup (see Table 4.1) information on hospital separations is presented, broken down by sex and age group. For traumatic brain injury the data are also broken down by country of birth, Indigenous status, and State or Territory of residence.

ABS population estimates for 31 December 1996 were used for the calculation of unstandardised and indirectly standardised rates (per 100,000 population per year) in most instances. However, for calculating rates broken down by country of birth and Indigenous status, population estimates for 30 June 1996 were used, as estimates for 31 December 1996 were not available for these populations.

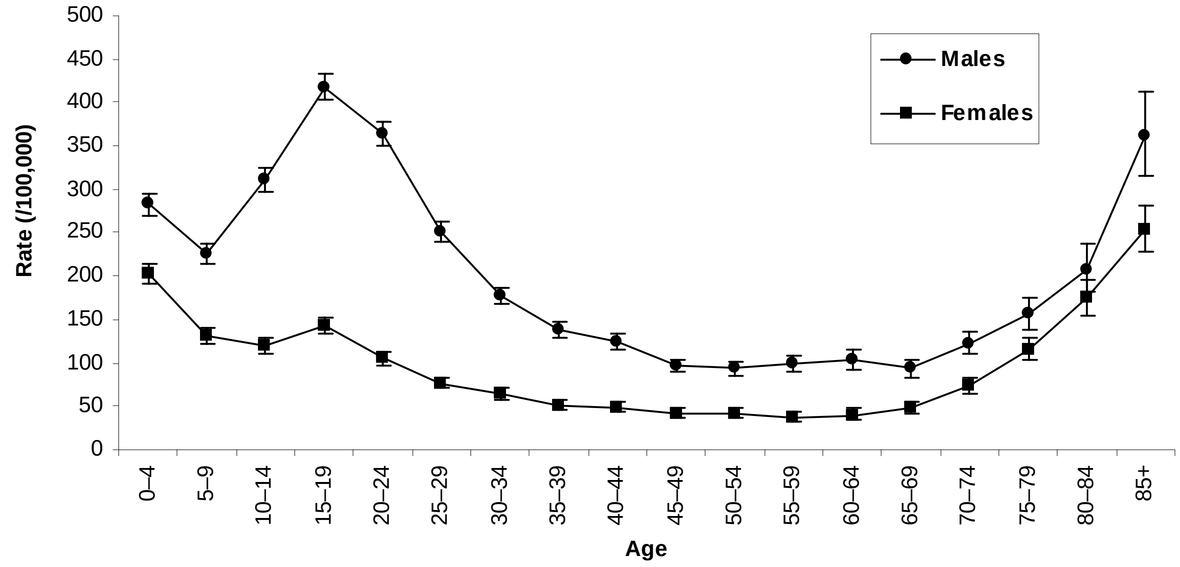
Traumatic brain injury

There were 27,437 hospital separations with a diagnosis of traumatic brain injury in the year 1996–97 (i.e. from July 1996 to June 1997), a rate of 149 per 100,000 population (Table 4.2). Almost 60% of separations were people of working age (i.e. aged 15–64). The highest age-specific rate was for people aged 15–19 (284 per 100,000) and the second highest rate was for children aged 0–4 (244 per 100,000). The lowest rate was for people aged 45–64 (69 per 100,000).

Table 4.2: Traumatic brain injury: hospital separations, by sex, by age, Australia 1996–97

	Males		Females		Persons	
Age	Number	Rate (/100,000)	Number	Rate (/100,000)	Number	Rate (/100,000)
0–4	1,883	283	1,279	203	3,162	244
5–14	3,612	269	1,602	125	5,214	199
15–19	2,754	418	896	143	3,650	284
20–29	4,359	307	1,264	90	5,623	199
30–44	3,133	147	1,181	55	4,314	101
45–64	1,924	97	783	41	2,707	69
65+	1,388	143	1,377	110	2,766	125
Total 0–64	17,665	216	7,005	87	24,670	152
Total 15–64	12,170	197	4,124	68	16,294	133
Total	**19,054**	**208**	**8,382**	**91**	**27,437**	**149**

Source: AIHW analysis of 1996–97 National Hospital Morbidity Database.



Source: Table A4.1.

Figure 4.1: Traumatic brain injury hospital separations, by sex and age, Australia 1996–97 (unstandardised rate per 100,000)

Almost 70% of traumatic brain injury separations were males, and males had higher rates than females in all age groups. The male to female rate ratio was highest for people aged 20 to 29 (3.4). The general pattern of separation rates with age was similar for males and females, with peaks in the age groups 0–4, 15–19 and 85-plus (Figure 4.1). However, for males the rate for the 15–19 age group was much higher than that for any other age group, whereas the rate for 15–19 year old females was lower than for the very young and very old.

Country of birth

Country of birth was grouped into three categories: Australia, 'other English-speaking countries', and 'non-English-speaking countries'. 'Other English-speaking countries' are the United Kingdom, Ireland, Canada, the United States of America, South Africa and New Zealand, according to the ABS standard classification of countries for social statistics[2] (ABS 1990:139).

Of all separations with a diagnosis of traumatic brain injury, 84% (23,051) were for people born in Australia, 6% (1,602) were for people born in 'non-English-speaking countries' and 5% (1,423) were for people born in 'other English-speaking countries' (Table 4.3). For 1,361 separations country of birth was inadequately described.

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[2] These are countries from which people migrating to Australia are likely to be English-speaking.

Table 4.3: Traumatic brain injury: hospital separations, by country of birth, by sex, by age, Australia 1996–97

	Country of birth								
	Australia		'Non-English-speaking'		'Other English-speaking' [(a)]		'Other'[(b)]	Total	
Age	Number	Rate (/100,000)	Number	Rate (/100,000)	Number	Rate (/100,000)	Number	Number	Rate (/100,000)
Males									
0–4	1,817	280	21	208	22	307	23	1,883	283
5–14	3,355	273	88	122	80	215	89	3,612	270
15–19	2,429	432	84	132	77	257	164	2,754	420
20–29	3,624	315	220	130	230	230	285	4,359	307
30–44	2,406	159	259	73	257	102	211	3,133	148
45–64	1,337	109	252	58	184	64	151	1,924	99
65+	959	151	194	103	132	97	103	1,388	145
Total 0–64	14,968	236	924	84	850	119	923	17,665	217
Total 15–64	9,796	220	815	80	748	112	811	12,170	198
Total	*15,927*	*229*	*1,118*	*87*	*982*	*116*	*1,027*	*19,054*	*209*
Females									
0–4	1,238	201	15	156	8	121	18	1,279	203
5–14	1,506	129	28	41	25	71	43	1,602	126
15–19	797	149	30	50	28	100	41	896	144
20–29	1,060	94	92	52	59	60	53	1,264	91
30–44	929	61	101	27	98	40	53	1,181	55
45–64	551	44	103	26	78	30	51	783	41
65+	1,042	118	115	58	145	92	75	1,377	111
Total 0–64	6,081	98	369	34	296	44	259	7,005	88
Total 15–64	3,337	76	326	32	263	42	198	4,124	68
Total	*7,123*	*101*	*484*	*38*	*441*	*53*	*334*	*8,382*	*91*
Persons									
0–4	3,055	242	36	183	30	218	41	3,162	244
5–14	4,861	202	116	82	105	145	132	5,214	199
15–19	3,226	294	114	92	105	181	205	3,650	285
20–29	4,684	206	312	91	289	146	338	5,623	200
30–44	3,335	110	360	49	355	71	264	4,314	101
45–64	1,888	77	355	43	262	48	202	2,707	70
65+	2,001	132	309	80	277	94	178	2,765	126
Total 0–64	21,049	168	1,293	59	1,146	83	1,182	24,670	153
Total 15–64	13,133	148	1,141	56	1,011	78	1,009	16,294	134
Total	**23,051**	**164**	**1,602**	**62**	**1,423**	**85**	**1,361**	**27,437**	**150**

(a) United Kingdom, Ireland, Canada, the United States of America, South Africa and New Zealand, according to the ABS standard classification of countries for social statistics. These are countries from which people migrating to Australia are likely to be English-speaking.

(b) Includes 'inadequately described',' born at sea', 'not elsewhere classified' and 'not stated'.

Source: AIHW analysis of 1996–97 National Hospital Morbidity Database.

Looking at unstandardised rates, people born in ‘non-English-speaking countries’ had the lowest rates of hospital separations with a diagnosis of traumatic brain injury (62 per 100,000), followed by people born in ‘other English-speaking countries’ (85 per 100,000), and people born in Australia had the highest rates (164 per 100,000). This pattern can also be seen in the age-specific rates (Table 4.3). The overall male to female rate ratio was similar for all three country of birth groups (around 2.2–2.3).

Indirectly standardised rates show that, when population age- and sex-structure is accounted for, separation rates for people born overseas were lower than the Australian average, both for people of all ages and for people aged under 65 (Table 4.4; Figure 4.2). However, the indirectly standardised rates were slightly higher than unstandardised rates. This indicates that the low unstandardised rates for people born overseas can be explained by a combination of low age-specific rates and population age structures different from that of the overall Australian population (Table A4.2). Both overseas-born populations had smaller proportions of people in the 0–4, 15–19 and 20–29 age groups than the national population. As rates of TBI-associated hospital separations are relatively high in these age groups, an under-representation of them in the population will tend to result in lower unstandardised rates. Indirectly standardised rates for people born in Australia were slightly above the Australian average.

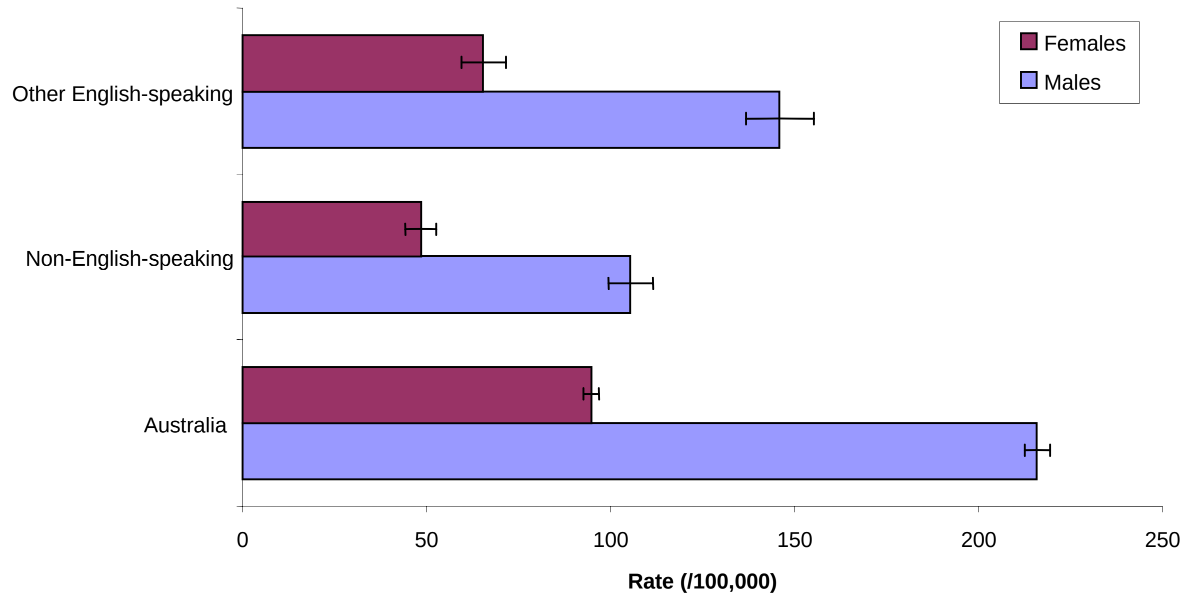
Table 4.4: Traumatic brain injury: hospital separations, by country of birth, by age and sex—standardised and unstandardised rates, Australia 1996–97

	Ages 0–64			All ages		
Country of birth	**Number**	**Unstandardised rate (/100,000)**	**Standardised rate (/100,000)[(a)]**	**Number**	**Unstandardised rate (/100,000)**	**Standardised rate (/100,000[(a)])**
Males						
Australia	14,968	236	224	15,927	229	216
‘Non-English-speaking’	924	84	102	1,118	87	105
‘Other English-speaking’ [(b)]	850	119	153	982	116	146
Total	*17,665*	*217*	*217*	*19,054*	*209*	*209*
Females						
Australia	6,081	98	91	7,123	101	95
‘Non-English-speaking’	369	34	45	484	38	48
‘Other English-speaking’ [(b)]	296	44	61	441	53	65
Total	*7,005*	*88*	*88*	*8,382*	*91*	*91*
Persons						
Australia	21,049	168	158	23,051	164	155
‘Non-English-speaking’	1,293	59	74	1,602	62	77
‘Other English-speaking’ [(b)]	1,146	83	108	1,423	85	106
Total	**24,670**	**153**	**153**	**27,437**	**150**	**150**

(a) Rates for males are age-standardised to the total Australian male population and rates for females to the total Australian female population. Rates for persons are age- and sex-standardised to the total Australian population.

(b) United Kingdom, Ireland, Canada, the United States of America, South Africa and New Zealand, according to the ABS standard classification of countries for social statistics. These are countries from which people migrating to Australia are likely to be English-speaking.

Source: AIHW analysis of 1996–97 National Hospital Morbidity Database.



Source: Table A4.4.

Figure 4.2: Traumatic brain injury hospital separations, by country of birth, by sex, Australia 1996–97 (rate per 100,000, standardised to the total Australian population, June 1996)

Indigenous status

Of all separations with a diagnosis of traumatic brain injury, 6% (1,582) were for people identified as Aboriginal or Torres Strait Islander and 92% (25,263) were for people identified as not Aboriginal or Torres Strait Islander (Table 4.5). For 590 separations (2%) Indigenous status was not recorded. It has been suggested that Indigenous status (or 'Aboriginality') is not always identified or recorded accurately, so data tend to be relatively unreliable (AIHW 1997b; Moller et al. 1996). Therefore, the Indigenous separation rate data presented here should be interpreted with care.

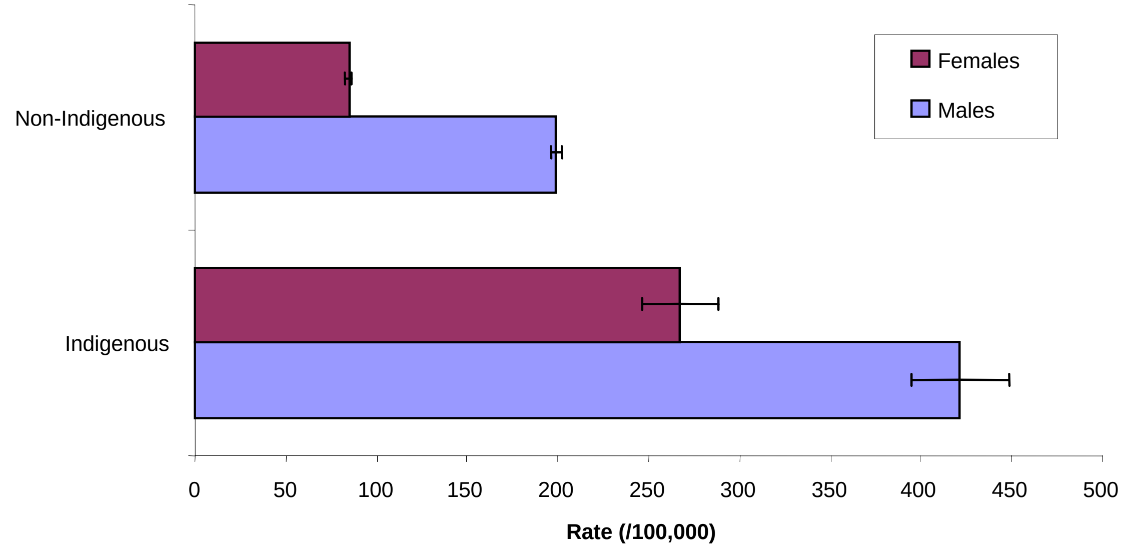
Indigenous Australians had much higher unstandardised rates of TBI-associated hospital separations (410 per 100,000) than non-Indigenous Australians (141 per 100,000) (Table 4.5). The biggest differences between the two groups, where rates for Indigenous Australians were several times those for non-Indigenous Australians, were for adults aged 20 to 64 years. The male to female rate ratio for Indigenous Australians was substantially lower (1.6) than for non-Indigenous Australians (2.4), suggesting that in the Indigenous population traumatic brain injury is not so heavily male-dominated as in the non-Indigenous population.

Indirectly standardised rates for Indigenous people were substantially higher than for non-Indigenous people (Table 4.6; Figure 4.3). Standardised rates were lower than unstandardised rates for Indigenous people, suggesting that while high unstandardised rates are largely due to high age-specific rates, there is a contributing effect of a population age structure very different to that of the total Australian population (Table A4.3).

Table 4.5: Traumatic brain injury: hospital separations, by Indigenous status, by sex and age, Australia 1996–97

	Indigenous		Non-Indigenous		Unknown	Total	
Age	**Number**	**Rate (/100,000)**	**Number**	**Rate (/100,000)**	**Number**	**Number**	**Rate (/100,000)**
Males							
0–4	113	400	1,750	275	20	1,883	283
5–14	145	287	3,395	263	72	3,612	270
15–19	106	554	2,566	403	82	2,754	420
20–29	255	747	4,013	290	91	4,359	307
30–44	240	687	2,830	135	63	3,133	148
45–64	89	464	1,789	93	46	1,924	99
65+	14	323	1,337	140	37	1,388	145
Total 0–64	948	509	16,343	205	374	17,665	217
Total 15–64	690	642	11,198	186	282	12,170	198
Total	*962*	*505*	*17,680*	*198*	*411*	*19,053*	*209*
Females							
0–4	83	304	1,178	195	18	1,279	203
5–14	73	151	1,502	122	27	1,602	126
15–19	50	265	823	136	23	896	144
20–29	181	500	1,062	78	21	1,264	91
30–44	172	449	991	47	18	1,181	55
45–64	54	261	704	37	25	783	41
65+	7	121	1,323	107	47	1,377	111
Total 0–64	613	323	6,260	81	132	7,005	88
Total 15–64	457	400	3,580	60	87	4,124	68
Total	*620*	*317*	*7,583*	*84*	*179*	*8,382*	*91*
Persons							
0–4	196	353	2,928	236	38	3,162	244
5–14	218	221	4,897	195	99	5,214	199
15–19	156	410	3,389	273	105	3,650	285
20–29	436	620	5,075	185	112	5,623	200
30–44	412	563	3,821	91	81	4,314	101
45–64	143	358	2,493	65	71	2,707	70
65+	21	208	2,660	121	84	2,765	126
Total 0–64	1,561	415	22,603	144	506	24,670	153
Total 15–64	1,147	518	14,778	123	369	16,294	134
Total	**1,582**	**410**	**25,263**	**141**	**590**	**27,435**	**150**

Source: AIHW analysis of 1996–97 National Hospital Morbidity Database.



Source: Table 4.6.

Figure 4.3: Traumatic brain injury hospital separations, by Indigenous status, by sex, Australia 1996–97 (rate per 100,000, standardised to the total Australian population, June 1996)

Table 4.6: Traumatic brain injury: hospital separations, by Indigenous status, by age—standardised and unstandardised rates, Australia 1996–97

	Ages 0–64			All ages		
Indigenous status	**Number**	**Unstandardised rate (/100,000)$^{)}$**	**Standardised rate (/100,000)$^{(a)}$**	**Number**	**Unstandardised rate (/100,000)**	**Standardised rate (/100,000)$^{(a)}$**
Males						
Indigenous	948	509	435	962	505	421
Non-Indigenous	16,343	205	206	17,680	198	199
Total	*17,665*	*217*	*217*	*19,053*	*209*	*209*
Females						
Indigenous	613	323	261	620	317	266
Non-Indigenous	6,260	81	81	7,583	84	85
Total	*7,005*	*88*	*88*	*8,382*	*91*	*91*
Persons						
Indigenous	1,561	415	352	1,582	410	343
Non-Indigenous	22,603	144	144	25,263	141	142
Total	**24,670**	**153**	**153**	**27,435**	**150**	**150**

(a) Rates for males are age-standardised to the total Australian male population and rates for females to the total Australian female population. Rates for persons are age- and sex-standardised to the total Australian population.

Source: AIHW analysis of 1996–97 National Hospital Morbidity Database.

In 1996–97, the age-standardised rate of all hospital separations for Indigenous Australians was 86% higher (531 / 1,000) than for the total Australian population (285 / 1,000) (AIHW 1998). Our analysis shows that for separations with a diagnosis of traumatic brain injury the difference was even greater—129% higher for Indigenous Australians (343 per 100,000) than for the total Australian population (150 per 100,000) (Table 4.6). As the identification of Indigenous origin is likely to have been incomplete, the difference in rates of hospitalisation between Indigenous and all Australians may have been even greater (AIHW 1998:60).

There is little published data on rates of ABI in the Indigenous population. Stanton et al. (1994) suggested, on the basis of their hospital-based study, that Aboriginal people were more likely than non-Aboriginal people to have ABI—Aboriginal people accounted for about 8% of the data base in that study, but made up only about 2% of the population in the study region. A study of hospital morbidity due to head injury in New Zealand found that rate of hospitalisation for Maoris (460 per 100,000) was much higher than for non-Maoris (204 per 100,000) (Caradoc-Davies & Dixon 1995).

States and Territories

For the analysis of rates of TBI-associated hospital separations by jurisdiction, the State or Territory of usual residence of the patient was used, rather than the State or Territory in which the person attended hospital. In most jurisdictions 98% or more of hospital separations were for people who were usual residents of that jurisdiction. However, for the Northern Territory and Australian Capital Territory, separations for people not usually resident in the jurisdiction accounted for 7% and 23%, respectively, of all separations (AIHW 1998:53, Table 5.9). As mentioned previously, variations in separation rates between regions may reflect different admission policies rather than real differences in incidence rates (Moller et al. 1996).

Unstandardised rates and numbers of TBI-associated hospital separations varied substantially between jurisdictions (Tables 4.7 and 4.8). The lowest rate was for Australian Capital Territory residents (72 per 100,000) and the highest rate was for Queensland residents (214 per 100,000). Rates were also high for South Australian and Western Australian residents.

Looking at age- and sex-specific rates, for Queensland residents rates were above the national average for both males and females in all age groups, but were markedly higher for both sexes in the 15–19 year age group. For South Australian residents the higher overall rate seems to be largely explained by higher rates for males below the age of 30.

For Australian Capital Territory residents the low overall rate is largely attributable to age-specific rates for males under age 45 being well below the national average. It is interesting that the characteristic ‘peak’ for males in late teenage and early adult years is virtually absent for Australian Capital Territory residents. However, it must be noted that the number of hospitalisations of Australian Capital Territory residents was small, so the standard errors associated with age-specific rates are relatively high. For Victorian residents rates were below the national average for both males and females in all age groups.

Indirectly standardised rates were not greatly different from unstandardised rates and showed a similar pattern between jurisdictions (Table 4.9; Figure 4.4).

Estimating incidence of disability from traumatic brain injury

Some authors have attempted to estimate the percentage of people with newly diagnosed cases of traumatic brain injury who will go on to experience long-term disability (e.g. Kraus 1987; Sorenson & Kraus 1991).

Table 4.7: Traumatic brain injury: hospital separations, by residence State or Territory, by sex and age, Australia 1996–97

Age	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Other Territories	Total
Males										
0–4	585	281	521	254	175	28	13	22	4	1,883
5–14	1,048	675	899	462	395	73	28	27	5	3,612
15–19	751	532	778	297	286	63	20	18	9	2,754
20–29	1,183	867	1,130	515	422	118	29	37	58	4,359
30–44	901	553	827	389	277	89	21	46	30	3,133
45–64	587	358	535	168	175	52	21	12	16	1,924
65+	438	307	322	122	141	33	12	2	11	1,388
Total 0–64	5,055	3,266	4,690	2,085	1,730	423	132	162	122	17,665
Total 15–64	3,422	2,310	3,270	1,369	1,160	322	91	113	113	12,170
Total	*5,493*	*3,574*	*5,012*	*2,207*	*1,871*	*456*	*144*	*164*	*133*	*19,054*
Females										
0–4	373	218	344	157	128	27	16	13	3	1,279
5–14	500	303	371	199	161	26	18	19	5	1,602
15–19	239	155	260	90	112	28	9	1	2	896
20–29	329	244	344	156	108	25	8	23	27	1,264
30–44	285	231	320	161	128	19	8	16	13	1,181
45–64	221	157	215	79	71	20	5	10	5	783
65+	404	302	339	111	156	44	15	2	4	1,377
Total 0–64	1,947	1,308	1,854	842	708	145	64	82	55	7,005
Total 15–64	1,074	787	1,139	486	419	92	30	50	47	4,124
Total	*2,351*	*1,610*	*2,193*	*953*	*864*	*189*	*79*	*84*	*59*	*8,382*
Persons										
0–4	958	499	865	411	303	55	29	35	7	3,162
5–14	1,548	978	1,270	661	556	99	46	46	10	5,214
15–19	990	687	1,038	387	398	91	29	19	11	3,650
20–29	1,512	1,111	1,474	671	530	143	37	60	85	5,623
30–44	1,186	784	1,147	550	405	108	29	62	43	4,314
45–64	808	515	750	247	246	72	26	22	21	2,707
65+	843	609	661	233	297	77	27	4	15	2,765
Total 0–64	7,002	4,574	6,544	2,927	2,438	568	196	244	177	24,670
Total 15–64	4,496	3,097	4,409	1,855	1,579	414	121	163	160	16,294
Total	**7,845**	**5,184**	**7,205**	**3,160**	**2,735**	**645**	**223**	**248**	**192**	**27,437**

Source: AIHW analysis of 1996–97 National Hospital Morbidity Database.

Table 4.8: Traumatic brain injury: hospital separations, by residence State or Territory, by sex and age, rate (per 100,000), Australia 1996–97

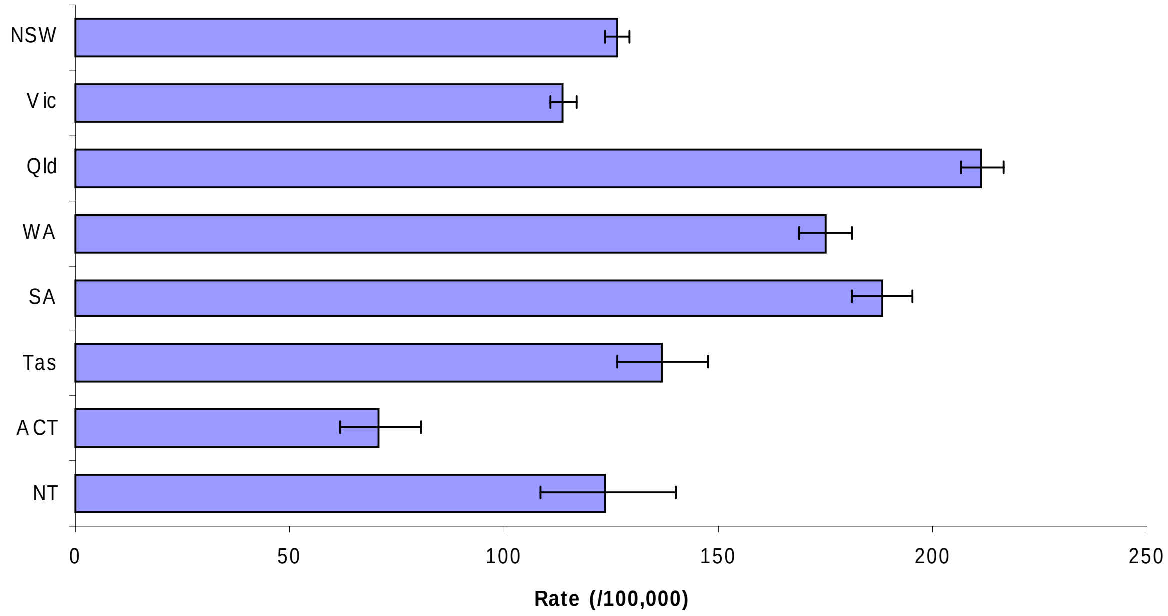
Age	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Males									
0–4	259	173	417	389	351	160	115	239	283
5–14	234	208	353	337	382	201	120	164	269
15–19	345	329	620	446	572	364	156	247	418
20–29	252	244	424	363	389	363	106	196	307
30–44	125	105	214	183	165	168	57	184	147
45–64	87	73	148	88	109	102	65	70	97
65+	128	124	191	149	157	125	122	65	143
Total 0–64	183	162	309	256	270	204	92	172	216
Total 15–64	164	151	287	224	238	209	84	165	197
Total	*177*	*158*	*297*	*246*	*256*	*195*	*94*	*169*	*208*
Females									
0–4	174	142	291	255	270	164	148	151	203
5–14	117	98	154	153	164	74	81	123	125
15–19	115	101	218	143	234	169	74	15	143
20–29	71	69	132	115	104	77	30	132	90
30–44	39	43	83	76	76	35	21	70	55
45–64	34	32	62	44	44	39	16	74	41
65+	90	93	163	108	132	128	117	69	110
Total 0–64	72	66	126	108	113	70	45	97	87
Total 15–64	52	51	102	82	87	60	27	83	68
Total	*75*	*69*	*130*	*108*	*116*	*79*	*51*	*96*	*91*
Persons									
0–4	217	158	356	324	312	162	131	196	244
5–14	177	155	256	247	276	139	101	144	199
15–19	233	218	424	299	407	269	116	137	284
20–29	161	157	279	242	249	220	68	165	199
30–44	82	74	148	130	120	101	39	130	101
45–64	61	53	106	67	76	71	41	71	69
65+	107	106	176	126	143	127	119	67	124
Total 0–64	128	114	219	183	192	137	69	137	152
Total 15–64	109	101	196	154	163	134	55	127	133
Total	**126**	**113**	**214**	**177**	**185**	**136**	**72**	**134**	**149**

Source: AIHW analysis of 1996–97 National Hospital Morbidity Database.

Table 4.9: Traumatic brain injury: hospital separations, by residence State or Territory, by age-standardised and unstandardised rates, Australia 1996–97

	Ages 0–64			All ages		
State or Territory	Number	Unstandardised rate (/100,000)	Standardised rate (/100,000)	Number	Unstandardised rate (/100,000)	Standardised rate (/100,000)
NSW	7,002	128	129	7,845	126	126
Vic	4,574	114	115	5,184	113	114
Qld	6,544	219	216	7,205	214	211
WA	2,927	183	181	3,160	177	175
SA	2,438	192	195	2,735	185	188
Tas	568	137	138	645	136	137
ACT	196	69	67	223	72	71
NT	244	137	127	248	134	124
Total	**24,670**	**152**	**152**	**27,437**	**149**	**149**

Source: AIHW analysis of 1996–97 National Hospital Morbidity Database.



Source: Table 4.9.

Figure 4.4: Traumatic brain injury hospital separations, by State or Territory, by sex, Australia 1996–97 (rate per 100,000, standardised to the total Australian population, June 1996)

The calculations used rely on assumptions about the proportions of mild, moderate and severe cases, and about the proportion of cases within each severity category that result in long-term disability.

Kraus (1987) reviewed several studies of incidence and concluded that, as a reasonable generalisation, 80% of hospitalised TBI cases were mild injuries, 10% were moderate and 10% severe. Of people discharged from hospital alive after a traumatic brain injury, 85.6% were mild injuries, 9.9% were moderate and 4.5% severe (these different proportions reflecting the higher in-hospital death rates associated with greater injury severity). Further, Kraus assumed that 10% of people with mild TBI, 33% with moderate TBI and 100% with severe TBI would go on to experience long-term disability. By multiplying and summing these proportions it is predicted that 16.4% of people with newly incident cases of traumatic brain injury who are discharged from hospital alive will experience long-term disability. Sorenson and Kraus used this approach to estimate the number of brain-injured individuals in a community likely to require some form of rehabilitation (Sorenson & Kraus 1991).

Our analysis of the National Hospital Morbidity Database indicates that, of the 27,437 hospital separations with a diagnosis of traumatic brain injury in the year 1996–97, 2.9% died in hospital. This is a lower proportion than is assumed in Kraus' formula (6.5%), perhaps because of the exclusion of transfers and non-acute episodes of care in our analysis. However, if we nonetheless follow Kraus' calculations, it may be predicted that for 4,368 of the separations identified (16.4% of the 26,636 discharged alive), the individual will go on to experience long-term disability—an annual rate of 24 per 100,000 total population.

The proportions of mild, moderate and severe cases used in Kraus' calculations are in line with those reported in a number of other studies (Kraus & Arsemanian 1989; Nell & Brown 1991; Tiret et al. 1990), though some studies have reported higher (Rimel et al. 1981) or lower (Servadei et al. 1988) proportions of severe cases. However, as Kraus points out, there are very few reliable data on the rates of disability that typically result from severe, moderate and mild brain injury. The assumption that 100% of people with severe brain injury would experience disability was based on a definition of disability that included people with 'good recovery' but 'minor residua'.

It is difficult to draw any conclusions about 'reasonable' estimates of disability rates based on the studies reviewed earlier in this paper (Section 3.2; Table 3.3). However, two studies that reported on outcome at discharge from hospital for people with ABI of all severity levels gave figures of 12% (San Diego) and 15% (South Australia) for the proportion of people needing ongoing care or rehabilitation (Kraus et al. 1984; Hillier et al. 1997). In the Swedish study, 15% of people assessed reported at least one in a list of disabilities that included limitations in self-care, occupation and leisure activities (Johansson et al. 1991). These proportions are not substantially below the 16.4% of Kraus' formula, so the rate of 24 per 100,000 might be considered a reasonable estimate if 'disability' is defined relatively broadly.

Three studies assessed outcome at discharge, across all severity levels, using the Glasgow Outcome Scale (GOS) (Fife et al. 1986; Kraus et al. 1984; Vazquez-Barquero et al. 1992). Three to five percent of cases resulted in moderate disability or worse—that is, moderate disability, severe disability or persistent vegetative state (see Section 2.4). At the milder end of this category, patients may have 'memory deficits or personality changes, varying degrees of hemiparesis, dysphasia or ataxia, post-traumatic epilepsy, or major cranial nerve deficits' (Jennett & Teasdale 1981). If 3% is applied to our Australian data, as a conservative estimate of the proportion of people hospitalised with TBI who go on to experience 'moderate disability or worse', then an annual rate of 4 per 100,000 total population is obtained (799 separations).

While this approach to estimating the ‘incidence’ rate of disability attributable to traumatic brain injury is interesting to consider, results must be treated with extreme caution. Not only do the estimates have the same limitations as the hospital separations data on which they are based, but they also rely on a series of assumptions that cannot easily be verified.

Acquired brain injury resulting from non-traumatic causes

Below, the number of hospital separations with diagnoses that are potentially associated with ABI are presented, divided into five subgroups—stroke, anoxic brain injury, alcohol-related brain injury, brain injury acquired at or shortly after birth, and ‘other’ ABI (Table 4.1). A final subgroup, the ‘ABS group’, is included for comparison with data from the ABS disability survey.

It should be noted that few of the ICD–9–CM codes used to define the ABI subgroups specify the presence of brain injury (Table 4.1). Also, not all people who have the conditions listed will attend a hospital, and not all records of a specific condition will be newly incident cases. Therefore, the data should be interpreted as indicative of the number of hospital separations potentially associated with ABI, and not as measures of ABI incidence.

Stroke

Two lists of ICD–9–CM codes were used to look at hospital separations associated with stroke—a ‘long’ list, including codes 430–438, and a ‘short’ list, including codes 430–434 and 436 (Table 4.1). The ‘long’ list includes transient cerebral ischaemia, non-acute, ill-defined cerebrovascular disease, and late effects of cerebrovascular disease. These three codes were thought less likely to indicate new, acute stroke events.

Using the ‘long’ list of ICD–9–CM codes 84,334 separations were identified. Rates were relatively low in people aged under 65 (107 per 100,000), but much higher in people aged 65 and over (3,018 per 100,000). In both these age groups rates were higher for males than for females (Table 4.10). (The figure of 51,854 hospitalisations for stroke in 1996–97, published by the AIHW in a report on heart, stroke and vascular diseases, was based on primary diagnosis only (AIHW 1999b)).

Using the ‘short’ list of ICD–9–CM codes 42,304 separations were identified—half the number identified using the ‘long’ list, though age and sex patterns were similar. This ‘short’ list may give a better indication of the number of people who experience an acute stroke event that may lead to ongoing disability (Table 4.10).

As a generalisation, about one-third of people who have a stroke will die within a year and a further one-third will have long-term disability (AIHW 1999b). If this ‘rule of thumb’ is applied to the 1996–97 hospital separations data about 14,100 of the 42,300 separations would be expected to result in disability—a rate of 77 per 100,000 total population.

As with the estimation of the incidence of disability from TBI (discussed above), this rough estimate of the rate of stroke hospitalisations leading to disability must be treated with extreme caution. It is subject to the same limitations as the hospital separations data on which it is based, and relies on assumptions that cannot easily be verified.

Anoxic brain injury

There were 3,503 separations with a diagnosis associated with anoxic brain injury in Australia in 1996–97 (Table 4.10). Of these, 66% had a diagnosis of anoxic brain damage or cerebral hypoxia during or resulting from a medical procedure (ICD–9–CM code 997.0). The overall rate of hospital separation associated with anoxic brain injury was 19 per 100,000 per year. For people aged under 65 the rate was very low (12 per 100,000). For people aged over 65 the rate was much higher (71 per 100,000), and higher for males than for females.

Alcohol-related brain injury

Of the 2,432 separations with diagnoses associated with alcohol-related brain injury, over half were in the 65-plus age group and nearly 80% were males (Table 4.10). Rates for both males and females aged under 65 were very low, but increased markedly in people aged over 65. It is likely that the overall rate of 13 per 100,000 is a severe underestimate, as it has been shown that only a minority of cases of alcohol-related brain injury are diagnosed prior to death (Harper 1983).

Brain injury arising early in life

There were 2,087 separations with a diagnosis associated with brain injury arising early in life (Table 4.10). Of these, 642 had a diagnosis of 'cerebral degenerations usually manifest in childhood' and the remaining 1,445 had diagnoses relating to conditions arising at or before birth. Children aged under one year accounted for 1,349 separations, and it is likely that most of these were newly incident cases. It is clear, however, that some of the separations identified were not newly incident cases, but relate to brain injuries in adults or older children that arose earlier in life. Rates were similar for males and females (around 11 per 100,000). As discussed above (Section 1.2), for the purpose of service provision, people with brain injury present from birth or early childhood are likely to be considered as having an intellectual disability, rather than an acquired brain injury.

Other brain injury

There were 59,160 separations with diagnoses relating to organic psychotic conditions, mental disorders due to organic brain damage, and other cerebral degenerative conditions ('other' acquired brain injury) (Table 4.10). The overall rate was very high—321 per 100,000. However, as discussed above, people with conditions that fall into this category may or may not be regarded as having ABI. Rates were relatively low for people aged under 65 but very high for people aged 65 and over. Rates were higher for males than for females among people aged under 65, but higher for females among people aged 65 and over and people of all ages.

ABS grouping

The 'ABS group' is made up of ICD–9–CM codes that are equivalent to the disabling condition categories of 'mental degeneration due to brain damage' and 'head injury / brain damage' in the 1993 ABS disability survey (see Section 4.3 below). The group includes ICD–9–CM codes for traumatic brain injury, stroke ('short' list, excluding codes 435, 437 and 438), anoxic brain injury and non-psychotic mental disorders following organic brain damage (Table 4.1). There were 74,595 separations identified, around 50% of which were for people aged 65 and over (Table 4.10). The overall rate was 405 per 100,000, with rates of 221 per 100,000 for people aged under 65 and 1,744 per 100,000 for people aged 65 and over. The much higher rate for people aged 65-plus is likely to be accounted for largely by high rates of stroke. Males had higher rates than females in both the under 65 and the 65-plus age groups.

Table 4.10: ABI subgroups: hospital separations, by sex, by age, Australia 1996–97

	Males		Females		Persons	
	Number	**Rate (/100,000)**	**Number**	**Rate (/100,000)**	**Number**	**Rate (/100,000)**
Stroke—'Long' list (ICD–9–CM 430–438)						
0–64	10,289	126	7,019	88	17,308	107
65+	34,450	3,557	32,572	2,600	67,024	3,018
Total	**44,741**	**488**	**39,591**	**428**	**84,334**	**458**
Stroke—'Short' list (ICD–9–CM 430–434, 436)						
0–64	5,587	68	3,440	43	9,027	56
65+	17,353	1,792	15,922	1,271	33,275	1,498
Total	**22,942**	**250**	**19,362**	**209**	**42,304**	**230**
Anoxic brain injury						
0–64	1,114	14	811	10	1,925	12
65+	884	91	694	55	1,578	71
Total	**1,998**	**22**	**1,505**	**16**	**3,503**	**19**
Alcohol-related brain injury						
0–64	913	11	200	2	1,113	7
65+	986	102	332	27	1,319	59
Total	**1,899**	**21**	**532**	**6**	**2,432**	**13**
Brain injury arising early in life						
0–64	1,110	14	945	12	2,056	13
65+	16	2	15	1	31	1
Total	**1,126**	**12**	**960**	**10**	**2,087**	**11**
'Other' ABI						
0–64	4,856	59	2,743	34	7,599	47
65+	20,951	2,163	30,607	2,444	51,560	2,321
Total	**25,807**	**282**	**33,350**	**360**	**59,160**	**321**
ABS grouping						
0–64	24,521	299	11,348	142	35,869	221
65+	20,105	2,076	18,617	1,486	38,723	1,744
Total	**44,626**	**487**	**29,965**	**324**	**74,595**	**405**

Source: AIHW analysis of 1996–97 National Hospital Morbidity Database.

4.3 Prevalence estimates from the 1993 ABS disability survey

A working definition of disability attributable to ABI

To look at the number of TBI-related hospital separations in the previous section we adopted the ‘uniform data systems’ case definition of TBI proposed by the Centers for Disease Control and Prevention in the USA (Thurman et al. 1995). There is no equivalent case definition that can be readily adopted as a basis for estimating the prevalence of ABI-related disability using the ABS disability survey data.

A working definition for this purpose should (i) be in line with the definition set out in the National Policy on Services for People with Acquired Brain Injury (Department of Human Services and Health 1994; Table 2.1), (ii) reflect the scope of the ABI disability group in the field and (iii) for practical reasons, be compatible with the 1993 ABS survey data. In practice it has proved difficult to develop a single working definition that meets these three criteria.

The National Policy definition sets out a non-exhaustive list of possible causes. Brain injury present at birth is not specifically included in the list, but nor is it specifically excluded (Table 2.1). The ABI disability group in Australia generally seems to be limited to brain injury acquired after birth (see other Australian definitions in Table 2.1). However, it is not possible to separately identify brain injury present at birth using the ABS disability survey data (except where brain injury is reported as ‘main disabling condition’—see below).

In this chapter we will prepare estimates of the prevalence of ABI-related disability using three approaches. The first is a ‘restrictive’ approach that focuses only on ‘main disabling conditions’, allowing the exclusion of brain injury present at birth. The second and third approaches are more ‘inclusive’, in that they are based on ‘all disabling conditions’ and include those present at birth.

We present estimates of the number of people with an ABI-related disability and different degrees of functional limitation (e.g. severe or profound handicap; reported activity limitation). In general, whether a working definition specifies a threshold level of severity will depend on what the definition is being used for. If it is being used to calculate prevalence of ABI-related disability for comparison with other disability groups then severity level should be the same for all disability groups being compared. Alternatively, the level of severity may be set to reflect service eligibility criteria.

Although the National Policy definition states that the effects of brain injury ‘may be temporary or permanent’, some minimum duration requirement is desirable if the aim is to identify people with long-term support needs as a result of brain injury. The durational requirement used in the 1993 ABS disability survey was 6 months. Jennett and Teasdale (1981) suggest that 6 months after injury is an appropriate time to assess outcome after TBI, citing studies showing that only about 10% of people progress to a better category of the Glasgow Outcome Scale between 6 and 12 months after injury. For stroke, about half of all recovery occurs in the first 2–3 weeks, but improvement can continue for at least 6 months, with some patients making appreciable recovery of independence between 6 and 12 months (Wade 1988). However, it is recognised that outcome, in terms of participation and social integration, can continue to change and improve over years, particularly in response to environmental factors such as social networks and support. Six months is adopted here for practical, data-related reasons.

Below, we outline some important aspects of the 1993 ABS disability survey data, explain our approaches to estimating the prevalence of ABI-related disability, and then present a range of estimates.

The ABS disability survey

The 1993 ABS Survey of Disability, Ageing and Carers is the main source of national data on disability and will be used to estimate the prevalence of ABI-related disability in Australia[3].

The survey covered both rural and urban areas in all States and Territories and gathered information on people living in households and establishments. The establishment sample included approximately 4,800 people in 700 establishments (e.g. hospitals, nursing homes, hostels). The household sample included about 42,000 people in 17,800 private dwellings and 1,600 special dwelling units.

Like any population sampling survey, the 1993 ABS disability survey is subject to sampling error. Estimates derived from the survey may differ from the figures that would have been obtained from an enumeration of the entire population. The size of the sampling error associated with an estimate depends on a number of factors such as sample design and sample size. As a general guide for the 1993 disability survey, national estimates of less than 8,000 have a relative standard error (RSE) greater than 25% and estimates of less than 1,900 have an RSE greater than 50% (ABS 1993b).

The ABS survey used a screening device to identify a broad spectrum of people potentially experiencing some level of disability. The screening device effectively consisted of 15 screening questions about disabling conditions, impairments, activity limitations and participation restrictions (Box 4.1). A person who responded positively to any of the screening questions was considered to have a disability and was asked further questions about activity limitations, participation restrictions and need for help.

One of the screening questions asked respondents if they had ‘ever suffered a head injury, stroke or any other brain damage’, and whether they had ‘long-term effects as a result of this’. Unfortunately, it is not possible from the survey data to separately identify people with long-term effects from head injury and people with long-term effects from stroke.

It is possible that the screening question might have failed to pick up some respondents with brain injury, for various reasons (Fay Rice, Head Injury Council of Australia, pers. comm.). For instance, some people may not know that they have brain injury, because the injury was not identified at the time and long-term effects only became evident later. Some people may not want to disclose that they have a brain injury, because of community prejudices, or may not consider that they have a disability. Also, some children have brain injury as a result of domestic violence, which is unlikely to be disclosed by the family, and the child may never have their brain injury correctly diagnosed.

The survey provides information on disabling conditions. A disabling condition was defined as any condition that had lasted or was likely to last for 6 months or more and resulted in one or more of the restrictions or limitations identified through the screening questions. Multiple disabling conditions could be reported. A person’s main disabling condition was

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[3] Data for the 1998 ABS Survey of Disability, Ageing and Carers were not available at the time of finalising this report.

the condition identified by the person as the one causing most problems. Where only one condition was reported, this was coded as the main disabling condition.

Two ABS disabling condition codes can be used for identifying people with ABI-related disability: ‘mental degeneration due to brain damage’ (equivalent to ICD–9–CM code 310.9), and ‘head injury / brain damage’ (including conditions coded to ICD–9–CM codes 348.1 and 997.0, plus responses to the screening question about ‘head injury, stroke or any other brain damage’) (c.f. ‘ABS group’, Table 4.1). If a person reported one of these as their main disabling condition it would be possible to use information on ‘general cause of main condition’ to determine whether the brain damage was present at birth or was due to a number of other specified causes. However, for conditions other than the main disabling condition no information about cause was recorded.

Box 4.1 Impairments, limitations and restrictions for disability identification

In the 1993 ABS disability survey people were identified as having a disability if they had one or more of the impairments, limitations or restrictions summarised below that had lasted, or was expected to last, for 6 months or more (ABS 1993b:6):

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

AIHW methods of prevalence estimation

Data from the 1993 ABS disability survey were analysed using three broad approaches for estimating the prevalence of ABI-related disability. The three approaches differ in terms of the way in which responses to the screening questions, reported disabling conditions, and information from questions later in the Survey on activity limitations are used to delineate the ABI group.

While the approaches differ in terms of their inclusiveness, all estimates are bounded by the definition of disability used in the ABS survey. A person was identified as having a disability if they reported one or more of the impairments or limitations listed in the screening questions that had lasted, or was expected to last, for 6 months or more (see Box 4.1).

Main disabling condition

Estimates of prevalence based on reported main disabling condition include people who answered positively to one or more of the 15 screening questions and reported an ABI-related condition as their main disabling condition. For people identified using this approach, their ABI-related disabling condition caused them more problems than any other disabling condition they may also have had.

People who did respond positively to the screening question on long-term effects of head injury, stroke or other brain damage but who reported some other condition as their main disabling condition are excluded using this approach.

Because people were asked about the time of onset of their main disabling condition it is possible to calculate the proportion of people with an ABI-related main disabling condition who had that condition since birth.

We also present estimates of the number of people identified using this approach who had a severe or profound handicap, meaning that they always or sometimes needed personal assistance or supervision with activities of daily living (self-care, mobility or verbal communication). The National Policy on Services for People with Acquired Brain Injury is primarily concerned with people who have severe or profound handicap as these are the people most likely to be consumers of ABI disability support services (Department of Human Services and Health 1994).

All disabling conditions

This is the most inclusive of the three approaches used. Estimates include people who responded positively to the screening question about long-term effects of head injury, stroke or other brain damage and/or reported an ABI-related condition, whether or not this was their main disabling condition (as set out in 'step one' below). It is not possible to determine the proportion of people who acquired brain injury at or before birth using this approach.

Again, we also present estimates of the number of people identified by this approach who had a severe or profound handicap.

All disabling conditions plus activity limitation

This approach is closely based on a method first introduced by Madden et al. (1995), and used to estimate the prevalence of physical disability in an earlier paper in this series (Wen & Fortune 1999). In previous publications it has been referred to as the 'AIHW method'. However, it is not intended that this approach should be seen as the 'best' way of estimating prevalence using the 1993 ABS disability survey data.

This approach uses a two-step process to identify people with an ABI-related disability. Step one selects people who reported long-term effects from head injury, stroke or other brain damage, or an ABI-related disabling condition. This group is then narrowed down in step two by applying a 'filter'—only people who reported limitations or restrictions in one or more activities of daily or social life are retained in the group. Step one is identical to the 'all disabling conditions' approach outlined above.

Step one

This step uses information from the screening questions and from responses to survey questions about disabling conditions.

A person is initially included in the ABI disability group if:

- a positive response was made by or for them to the screening question about long-term effects of head injury, stroke or other brain damage; and / or
- a positive response was made by or for them to one or more of the 15 screening questions **and** one or both of the ABI-related disabling conditions was reported.

The ABI-related disabling conditions were 'mental degeneration due to brain damage' and 'head injury / brain damage', which can be mapped to ICD–9–CM codes as set out in Table 4.1 ('ABS group') (Madden et al. 1995).

Step two

After step one, an activity limitation 'filter' is applied. Only people who reported any one or more of a list of activity limitations and participation restrictions (via their response to certain survey questions) remain in the ABI disability group (for the full list of questions see Appendix 3).

People in establishments were asked fewer questions than were people in households. Therefore, some people in establishments may have been excluded by the activity limitation 'filter' because of the less extensive set of questions. Similarly, questions about activity limitations and participation restrictions were not asked in respect of children aged 0–4, so children who satisfied the criteria of step one may have been excluded by the 'filter' in step two. Only children for whom a positive answer was given to the screening question about 'receiving treatment or medication for a long-term condition or ailment and still restricted' would pass through the activity limitation filter, as this question forms part of the 'filter' (Appendix 3).

It should also be noted that the survey questions about activity limitations and restrictions tended to focus on physical activities of daily living—there were few questions concerning cognitive abilities. Thus there is an emphasis on disability arising from physical impairment (Madden et al. 1995). People with acquired brain injury who have cognitive or psychosocial limitations, but do not have physical limitations, are likely to be excluded by the activity limitation filter.

The prevalence of ABI-related disability in Australia

The measures of prevalence used in the following sections include estimated numbers of people with an ABI-related disability, unstandardised estimates of prevalence rates and indirectly standardised prevalence rates.

Unstandardised prevalence rates are presented based on each of the three approaches outlined above. These estimates can be compared directly with estimates of the prevalence of physical disability reported by Wen and Fortune (1999), as the same three approaches were used in that paper. Estimates based on 'all disabling conditions' but including only people with a severe or profound handicap are comparable with the prevalence estimates for intellectual disability reported by Wen (1997).

For the comparison of prevalence rates between different population groups 95% confidence intervals were calculated, based on standard errors provided by the ABS (ABS 1993a). If there was no overlap between the 95% confidence intervals for two rates the rates were treated as significantly different.

Estimates at national level

Main disabling condition

Estimates of the prevalence of ABI-related disability based on reported ‘main disabling condition’ are presented in Table 4.11. These estimates include people who answered positively to any one or more of the 15 screening questions and had an ABI-related main disabling condition, as outlined above.

In 1993, there were 60,600 people, or 0.3% of the Australian population, with a disability who reported an ABI-related main disabling condition. Of these, 24,900 people, or 0.1% of the total Australian population aged 5 years and over, also had a severe or profound handicap, meaning that they always or sometimes needed personal assistance or supervision with activities of daily living (self-care, mobility or verbal communication) (Table 4.11). Handicap was not assessed for children aged under 5 years.

For people aged under 65 years, there were 40,600 people with a disability, or 0.3% of Australians in that age group, reporting an ABI-related main disabling condition. Of these, 12,500 people, or 0.1% of Australians aged 5 to 64 years, had a severe or profound handicap (Table 4.11).

For people of all ages with an ABI-related main disabling condition, 41% had a severe or profound handicap. This is a significantly higher percentage than for people with a physical main disabling condition, of whom 25% had a severe or profound handicap (Wen & Fortune 1999). It is not significantly higher than the 37% of people with an intellectual disability (based on main disabling condition) who also had a severe or profound handicap (Wen 1997).

Of the 60,600 people who reported an ABI-related main disabling condition, 40% (24,300) said the condition was caused by accident or injury, 15% (9,000) said it was caused by a stroke, and 7% (4,300) said the condition was present at birth or due to birth injury. It is likely that, from the perspective of service providers and representative groups, this last group of people would be considered to have intellectual disability rather than ABI.

Indeed, further analysis using the ABS confidentialised unit record file (a summarised version of the ABS disability survey data, providing less detail on some variables) suggested that, of the 4,300 people who said their condition was present at birth, approximately 80% would be identified as having an intellectual disability based on answers to screening questions and all reported disabling conditions.

The estimates presented in Tables 4.11 and 4.14 based on ‘main disabling condition’ include people with an ABI-related main disabling condition present at birth. As the estimates are subject to high rates of standard error the exclusion of this relatively small group of people would not make a significant difference to the estimates.

Table 4.11: People with a disability: ABI-related 'main disabling condition', by sex and age, Australia 1993 [(a)(b)]

	Males		Females		Persons	
Age	**('000)**	**(%)**	**('000)**	**(%)**	**('000)**	**(%)**
Severe and profound handicap						
5–14	**0.4	**0.0	**1.4	**0.1	**1.8	**0.1
15–19	**0.1	**0.0	**0.4	**0.1	**0.5	**0.0
20–29	**1.2	**0.1	**1.2	**0.1	*2.4	*0.1
30–44	*2.0	*0.1	**0.5	**0.0	*2.6	*0.1
45–64	*3.0	*0.2	*2.3	*0.1	*5.3	*0.2
65+	*4.6	*0.5	*7.8	*0.7	12.4	0.6
Total 5–64	*6.7	*0.1	*5.7	*0.1	12.5	0.1
Total 15–64	*6.3	*0.1	*4.3	*0.1	10.7	0.1
Total	**11.3**	**0.1**	**13.6**	**0.2**	**24.9**	**0.1**
Total with disability						
0–4	**1.2	**0.2	**0.0	**0.0	**1.2	**0.1
5–14	**0.4	**0.0	**1.7	**0.1	*2.1	*0.1
15–19	**1.7	**0.2	**0.7	**0.1	*2.4	*0.2
20–29	*4.1	*0.3	*3.5	*0.2	*7.5	*0.3
30–44	*6.6	*0.3	*5.4	*0.3	12.0	0.3
45–64	10.9	0.6	*4.5	*0.3	15.4	0.4
65+	8.5	1.0	11.5	1.0	20.0	1.0
Total 0–64	24.9	0.3	15.7	0.2	40.6	0.3
Total 15–64	23.3	0.4	14.0	0.2	37.3	0.3
Total	**33.4**	**0.4**	**27.2**	**0.3**	**60.6**	**0.3**

(a) Estimates include people with an ABI-related main disabling condition present at birth.

(b) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

All disabling conditions

Estimates of the prevalence of ABI-related disability based on reported 'all disabling conditions' are presented in Table 4.12. These estimates include people who responded positively to the question about long-term effects of head injury, stroke or other brain damage and/or reported an ABI-related disabling condition, whether or not this was their main disabling condition.

Based on this approach, there were 370,700 people, or 2.1% of the Australian population, with an ABI-related disability in 1993. Of these, 160,200 people, or 0.9% of the total Australian population aged 5 years and over, also had a severe or profound handicap (Table 4.12).

For people aged under 65 years, there were 211,500 people, or 1.4% of Australians in that age group, with an ABI-related disability based on reported 'all disabling conditions'. Of these, 74,800 people, or 0.5% of Australians aged 5 to 64 years, had a severe or profound handicap (Table 4.12).

For people of all ages with an ABI-related disability based on reported 'all disabling conditions', 43% had a severe or profound handicap. This is a significantly higher percentage than for people with a physical disability based on reported 'all disabling conditions', 26% of whom had a severe or profound handicap (Wen & Fortune 1999). Of people with an intellectual disability (based on 'all disabling conditions') 53% had a severe or profound handicap—a significantly higher percentage than for either physical disability or ABI-related disability (Wen 1997).

Table 4.12: People with a disability: ABI-related 'all disabling conditions', by disability status, by sex and age, Australia 1993[(a)]

	Males		Females		Persons	
Age	('000)	(%)	('000)	(%)	('000)	(%)
Severe and profound handicap						
5–14	*7.2	*0.6	*6.2	*0.5	13.4	0.5
15–19	**1.3	**0.2	*2.5	*0.4	*3.8	*0.3
20–29	*4.2	*0.3	*4.7	*0.3	8.9	0.3
30–44	9.2	0.4	*7.0	*0.3	16.2	0.4
45–64	18.9	1.1	13.6	0.8	32.4	0.9
65+	35.7	4.0	49.7	4.3	85.4	4.2
Total 5–64	40.9	0.5	33.9	0.4	74.8	0.5
Total 15–64	33.6	0.6	27.8	0.5	61.4	0.5
Total	**76.5**	**0.9**	**83.6**	**0.9**	**160.2**	**0.9**
Total with disability						
0–4	*2.6	*0.4	**1.5	**0.2	*4.1	*0.3
5–14	11.6	0.9	*6.9	*0.6	18.5	0.7
15–19	*5.2	*0.8	*4.7	*0.7	9.8	0.8
20–29	20.6	1.4	12.8	0.9	33.3	1.2
30–44	35.6	1.7	22.3	1.1	57.9	1.4
45–64	59.4	3.3	28.4	1.6	87.8	2.5
65+	82.4	9.3	76.8	6.6	159.2	7.8
Total 0–64	134.9	1.7	76.6	1.0	211.5	1.4
Total 15–64	120.7	2.0	68.1	1.2	188.8	1.6
Total	**217.3**	**2.5**	**153.4**	**1.7**	**370.7**	**2.1**

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

All disabling conditions plus activity limitation

In 1993, there were 338,700 people, or 1.9% of the Australian population, with an ABI-related disability, based on 'all disabling conditions plus activity limitation' (Table 4.13). There were 185,000 people aged under 65 years (1.2% of the population in that age group) with an ABI-related disability. For people of working age (15–64 years) there were 165,000 people, or 1.4% of people in that age group, with an ABI-related disability.

Table 4.13: People with a disability: ABI-related disability (all disabling conditions plus activity limitation), by sex and age, Australia 1993[(a)]

	Males		Females		Persons	
Age	**('000)**	**(%)**	**('000)**	**(%)**	**('000)**	**(%)**
0–4	**1.3	**0.2	**0.6	**0.1	*2.0	*0.2
5–14	11.1	0.8	*6.9	*0.6	18.0	0.7
15–19	*4.4	*0.7	*4.1	*0.6	8.6	0.7
20–29	13.0	0.9	11.2	0.8	24.2	0.9
30–44	32.4	1.6	19.4	0.9	51.8	1.3
45–64	55.1	3.1	25.4	1.5	80.5	2.3
65+	77.6	8.8	76.1	6.5	153.7	7.5
Total 0–64	117.3	1.5	67.7	0.9	185.0	1.2
Total 15–64	104.9	1.8	60.1	1.0	165.0	1.4
Total	**194.9**	**2.2**	**143.8**	**1.6**	**338.7**	**1.9**

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

Estimates of the prevalence of ABI-related disability using the three different approaches are summarised in Table 4.14. Prevalence estimates based on 'main disabling condition' are an order of magnitude lower than those obtained using the other two approaches. The two approaches that use information on 'all disabling conditions' plus responses to the screening question on 'long-term effects of head injury, stroke and other brain damage' produce estimates of similar magnitude. The 'activity limitation filter' reduces estimated prevalence by around 10%.

Prevalence estimates reported in the remainder of this section are calculated using the approach based on 'all disabling conditions' and applying the 'activity limitation filter'.

Age and sex patterns of prevalence

The prevalence of ABI-related disability increased with age for both males and females (Table 4.13; Figure 4.5). Rates for people aged over 65 were significantly higher than for younger age groups. The steep increase in prevalence in later years is likely to reflect a high prevalence of brain injury caused by stroke in older people.

The prevalence of ABI-related disability for people of all ages was higher among males (2.2%) than females (1.6%). Age-specific rates for males were higher than for females in all age groups, but were significantly higher only in later age groups (45–64, and over 65) (Table 4.13).

Table 4.14: Estimates of ABI-related disability based on different approaches—'main disabling condition', 'all disabling conditions' and 'all disabling conditions plus activity limitation'—Australia 1993 [(a)]

	Males		Females		Persons	
	('000)	(%)	('000)	(%)	('000)	(%)
Main disabling condition—severe and profound handicap [(b)]						
Total 5–64 years	*6.7	*0.1	*5.7	*0.1	12.5	0.1
Total all ages	*11.3*	*0.1*	*13.6*	*0.2*	*24.9*	*0.1*
Main disabling condition—total with disability [(b)]						
Total 0–64 years	24.9	0.3	15.7	0.2	40.6	0.3
Total all ages	*33.4*	*0.4*	*27.2*	*0.3*	*60.6*	*0.3*
All disabling conditions—severe and profound handicap						
Total 5–64 years	40.9	0.5	33.9	0.4	74.8	0.5
Total all ages	*76.5*	*0.9*	*83.6*	*0.9*	*160.2*	*0.9 (c)*
All disabling conditions—total with disability						
Total 0–64 years	134.9	1.7	76.6	1.0	211.5	1.4
Total all ages	*217.3*	*2.5*	*153.4*	*1.7*	*370.7*	*2.1*
All disabling conditions with activity limitation filter [(d)]						
Total 0–64 years	117.3	1.5	67.7	0.9	185.0	1.2
Total all ages	*194.9*	*2.2*	*143.8*	*1.6*	*338.7*	*1.9*

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Estimates include people with an ABI-related main disabling condition present at birth.

(c) This estimate is comparable with the AIHW 'best estimate' of the prevalence of intellectual disability (Wen 1997:xi).

(d) These estimates are comparable with estimates of physical disability prevalence obtained using the 'AIHW method' (Wen & Fortune 1999).

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

Country of birth

Country of birth was grouped into three categories: Australia, 'other English-speaking countries', and 'non-English-speaking countries'. 'Other English-speaking countries' were the United Kingdom, Ireland, Canada, the United States of America, South Africa and New Zealand, according to the ABS standard classification of countries for social statistics[4] (ABS 1990:139). About 39,000 people in the general population and 1,000 people with an ABI-related disability for whom birthplace was not recorded were excluded from the comparative analysis.

Of all people with an ABI-related disability (based on 'all disabling conditions plus activity limitation') 78% were born in Australia, 9% in 'other English-speaking countries' and 13% in 'non-English-speaking countries'. There was no significant difference in the prevalence of ABI-related disability (unstandardised rates) between people born in Australia, people born in 'other English-speaking countries' and people born in 'non-English-speaking countries' (Table 4.15).

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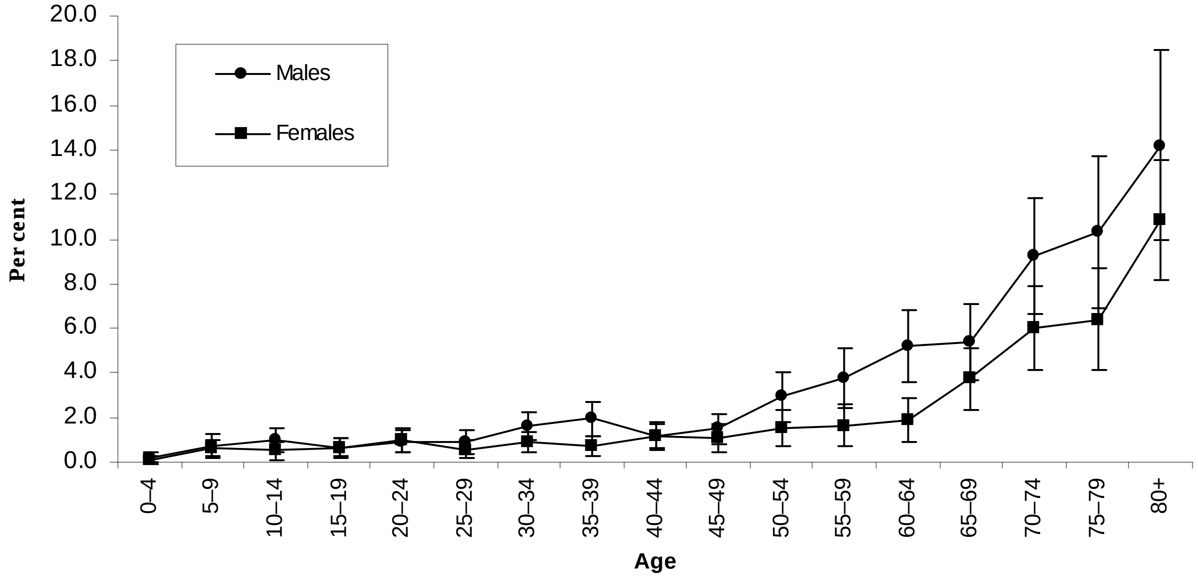
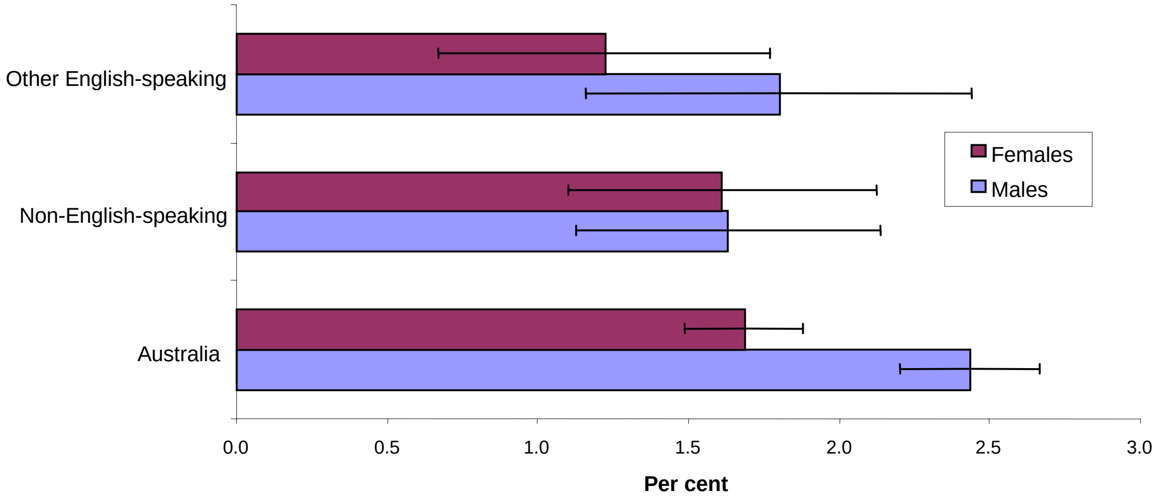
[4] These are countries from which people migrating to Australia are likely to be English-speaking.



Source: Table A4.5.

Figure 4.5: ABI-related disability, by sex and age, Australia 1993 (%, unstandardised)



Source: Table 4.15.

Figure 4.6: ABI-related disability, by country of birth, by sex, Australia 1993 (%, standardised to the total Australian population, March 1993)

Table 4.15: People with a disability: ABI-related disability (all disabling conditions plus activity limitation), by country of birth, by age and sex—standardised and unstandardised rates, Australia 1993 [(a)]

	0–64			All ages		
Country of birth	**Number ('000)**	**Unstandardised rate (/100,000)**	**Standardised rate (/100,000)**[(b)]	**Number ('000)**	**Unstandardised rate (/100,000)**	**Standardised rate (/100,000)**[(b)]
Males						
Australia	93.0	1.5	1.6	151.1	2.2	2.4
'Non-English-speaking'	10.5	1.6	1.3	19.4	2.4	1.8
'Other English-speaking' [(c)]	13.7	1.3	1.0	24.1	2.0	1.6
Total	*117.3*	*1.5*	*1.5*	*194.9*	*2.2*	*2.2*
Females						
Australia	55.9	0.9	1.0	111.5	1.6	1.7
'Non-English-speaking'	4.3	0.7	0.6	12.1	1.5	1.2
'Other English-speaking' [(c)]	7.5	0.8	0.6	19.5	1.7	1.6
Total	*67.7*	*0.9*	*0.9*	*143.8*	*1.6*	*1.6*
Persons						
Australia	148.9	1.2	1.3	262.6	1.9	2.1
'Non-English-speaking'	14.8	1.1	0.9	31.5	2.0	1.5
'Other English-speaking' [(c)]	21.2	1.1	0.8	43.6	1.9	1.6
Total	**185.0**	**1.2**	**1.2**	**338.7**	**1.9**	**1.9**

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Rates for males are age-standardised to the total Australian male population and rates for females to the total Australian female population. Rates for persons are age- and sex-standardised to the total Australian population.

(c) United Kingdom, Ireland, Canada, the United States of America, South Africa and New Zealand, according to the ABS standard classification of countries for social statistics. These are countries from which people migrating to Australia are likely to be English-speaking.

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

Indirectly standardised rates show some differences between people born in Australia and people born overseas (Table 4.15; Figure 4.6). However, the only significant difference was among people aged under 65, for whom people born in Australia had higher rates of ABI-related disability than people born in 'non-English-speaking countries' (1.3% and 0.8%, respectively).

Indigenous status

The 1993 ABS disability survey collected information about Indigenous status. However, for about 199,300 people in the general population and 49,400 people with an ABI-related disability Indigenous status was not stated or not known.

Unstandardised estimates indicate that, in 1993, 1.0% of the Indigenous population had an ABI-related disability—1.9% standardised to the total Australian population (Table 4.16; Figure 4.7). However, because of the very small sample size, the standard errors associated with the estimates are very high and it is not possible to detect whether prevalence rates for Indigenous people differ from those of non-Indigenous people. It is interesting that, of people for whom Indigenous status was not recorded, 24.8% had an ABI-related disability—a significantly higher rate than for either Indigenous or non-Indigenous people.

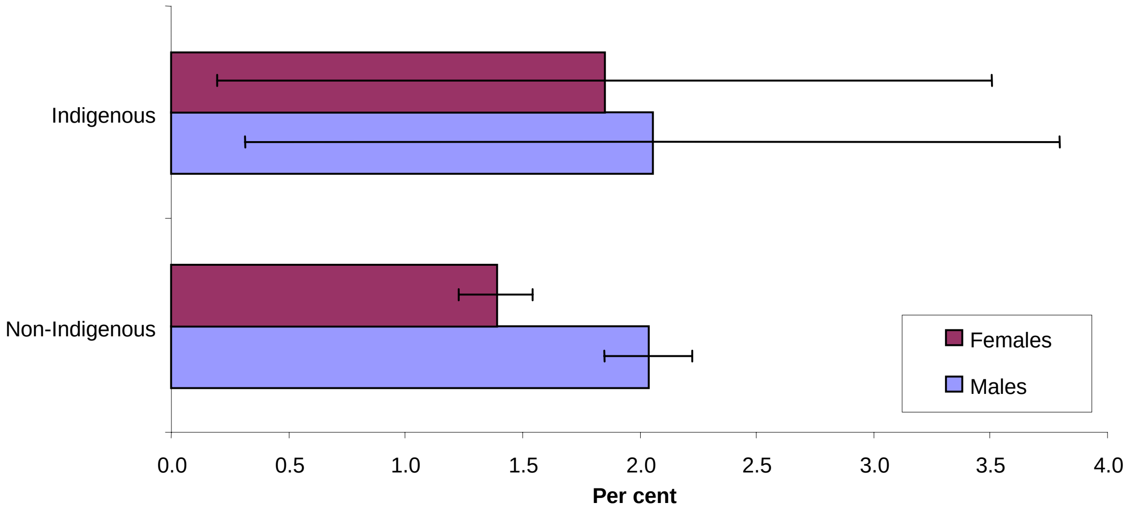
Table 4.16: People with a disability: ABI-related disability (all disabling conditions plus activity limitation), by Indigenous status, by age and sex standardised and unstandardised rates, Australia 1993[(a)]

	Ages 0–64			All ages		
Indigenous status	**Number ('000)**	**Unstandardised rate (/100,000)**	**Standardised rate (/100,000)[(b)]**	**Number ('000)**	**Unstandardised rate (/100,000)**	**Standardised rate (/100,000)[(b)]**
Males						
Indigenous	1.3	1.1	1.4	1.3	1.1	2.1
Non-Indigenous	109.5	1.4	1.5	172.9	2.2	2.0
Total	*117.3*	*1.5*	*1.5*	*194.9*	*2.2*	*2.2*
Females						
Indigenous	1.1	0.9	1.1	1.1	0.8	1.8
Non-Indigenous	61.6	0.8	0.8	114.0	1.3	1.4
Total	*67.7*	*0.9*	*0.9*	*143.8*	*1.6*	*1.6*
Persons						
Indigenous	*2.4	*1.0	*1.3	*2.4	*1.0	*1.9
Non-Indigenous	171.1	1.1	1.1	286.9	1.7	1.7
Total	**185.0**	**1.2**	**1.2**	**338.7**	**1.9**	**1.9**

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Rates for males are age-standardised to the total Australian male population and rates for females to the total Australian female population. Rates for persons are age- and sex-standardised to the total Australian population.

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.



Source: Table 4.16.

Figure 4.7: ABI-related disability, by Indigenous status, by sex, Australia 1993 (%, standardised to the total Australian population, March 1993)

Estimates for States and Territories

Unstandardised estimates of the prevalence of ABI-related disability in each State and Territory (based on 'all disabling conditions plus activity limitation') are given in Tables 4.17 and 4.18. Queensland was the only jurisdiction with a prevalence rate significantly higher than the national average, for people of all ages and for people aged under 65. Victoria had lower rates than Queensland and South Australia for people of all ages and people aged under 65. The Australian Capital Territory had lower rates than Queensland and South Australia for people of all ages.

Table 4.17: People with a disability: ABI-related disability (all disabling conditions plus activity limitation), by State or Territory, by age, Australia 1993 ('000)[(a)]

Age	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
0–4	**0.7	**0.0	**0.4	**0.3	**0.3	**0.0	**0.0	**0.2	*2.0
5–14	5.2	4.5	2.3	2.8	2.5	**0.3	0.3	**0.0	18.0
15–19	**1.3	**1.1	3.1	*1.2	1.3	**0.3	0.3	**0.0	8.6
20–29	7.6	3.6	8.0	1.8	1.9	*0.6	0.4	*0.4	24.2
30–44	15.6	11.5	11.8	4.1	5.7	0.9	1.0	1.1	51.8
45–64	30.1	14.2	18.5	6.9	7.1	1.6	1.2	1.1	80.5
65+	52.8	37.9	30.2	12.0	14.9	4.3	1.4	*0.3	153.7
Total 0–64	60.5	34.9	44.1	17.2	18.7	3.5	3.3	2.8	185.0
Total 15–64	54.5	30.3	41.3	14.0	15.9	3.3	3.0	2.6	165.0
Total	**113.3**	**72.7**	**74.3**	**29.2**	**33.6**	**7.8**	**4.7**	**3.1**	**338.7**

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

Table 4.18: People with a disability: ABI-related disability (all disabling conditions plus activity limitation), by State or Territory, by age, as a percentage of the population of that age and State or Territory, Australia 1993 [(a)]

Age	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
0–4	**0.2	**0.0	**0.2	**0.2	**0.3	**0.0	**0.0	**1.1	*0.2
5–14	0.6	0.7	0.5	1.1	1.2	**0.4	0.8	**0.0	0.7
15–19	**0.3	**0.3	1.3	*1.0	1.2	**0.9	1.2	**0.0	0.7
20–29	0.8	0.5	1.6	0.7	0.8	*0.8	0.7	*1.2	0.9
30–44	1.1	1.1	1.6	1.0	1.7	0.8	1.4	2.5	1.3
45–64	2.5	1.6	3.0	2.1	2.4	1.7	2.3	4.3	2.3
65+	7.2	7.1	8.9	7.1	7.6	7.4	7.1	*6.9	7.5
Total 0–64	1.1	0.9	1.6	1.1	1.5	0.9	1.2	1.7	1.2
Total 15–64	1.4	1.0	2.0	1.3	1.6	1.1	1.4	2.2	1.4
Total	**1.9**	**1.6**	**2.4**	**1.7**	**2.3**	**1.7**	**1.6**	**1.9**	**1.9**

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

The indirectly standardised rates show that when age structure is taken into account quite a different picture can emerge (Table 4.19). A high unstandardised prevalence rate may reflect high age-specific rates, or high representation within the population of age groups in which ABI-related disability is more prevalent, or a combination of both these factors. The prevalence of ABI-related disability tends to be higher for older age groups. Thus, for jurisdictions that have younger population age structures than the national population (i.e. higher representation of younger people in the total population), age-adjusted rates are likely to be higher than unstandardised rates. Likewise, for jurisdictions that have higher proportions of older people, age-adjusted rates are likely to be lower than unstandardised rates.

Table 4.19: People with a disability: ABI-related disability (all disabling conditions plus activity limitation), by State or Territory, by age—standardised and unstandardised rates, Australia 1993 (a)

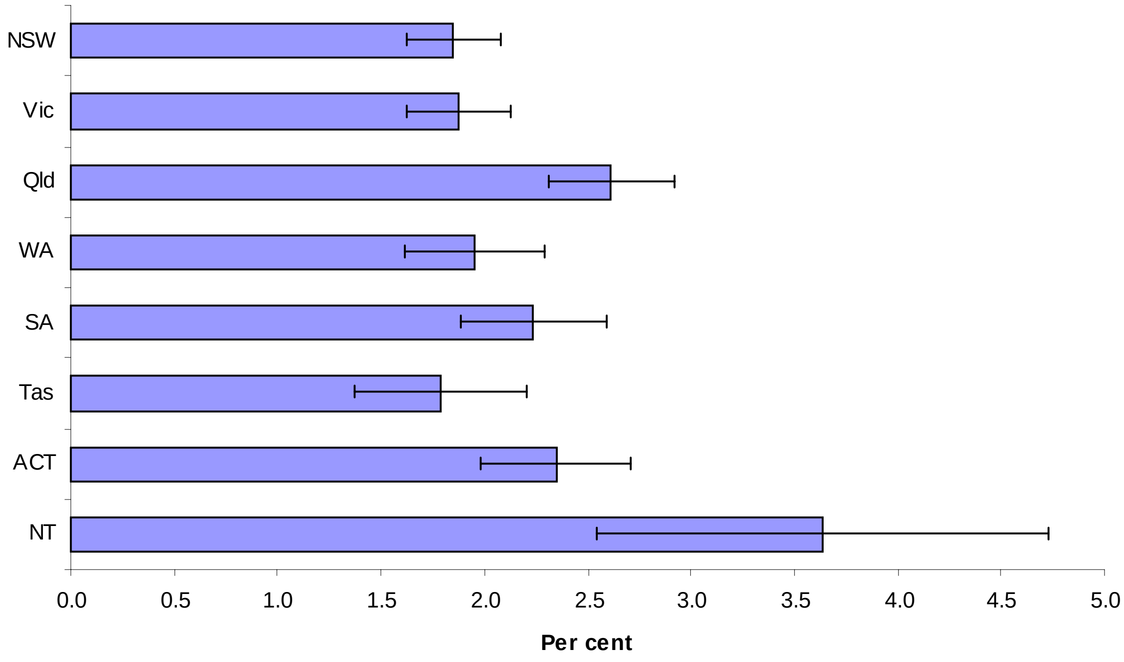
	Ages 0–64			All ages		
State or Territory	Number ('000)	Unstandardised rate (%)	Standardised rate (%)	Number ('000)	Unstandardised rate (%)	Standardised rate (%)
NSW	60.5	1.1	1.1	113.3	1.9	1.8
Vic	34.9	0.9	1.1	72.7	1.6	1.9
Qld	44.1	1.6	1.8	74.3	2.4	2.6
WA	17.2	1.1	1.2	29.2	1.7	2.0
SA	18.7	1.5	1.6	33.6	2.3	2.2
Tas	3.5	0.9	1.0	7.8	1.7	1.8
ACT	3.3	1.2	1.6	4.7	1.6	2.3
NT	2.8	1.7	2.5	3.1	1.9	3.6
Total	**185.0**	**1.2**	**1.2**	**338.7**	**1.9**	**1.9**

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

Looking at the indirectly standardised prevalence rates (Table 4.19), both for people of all ages (Figure 4.8) and people aged under 65, Queensland and the Northern Territory had rates significantly higher than the national average. For the Northern Territory and the Australian Capital Territory, standardised rates were substantially (though not significantly) higher than unstandardised rates. This reflects the fact that both Territories had very low proportions of older people in their populations. At a national level, the proportion of the population aged 65 and over was nearly twice and four times as high as in the Australian Capital Territory and Northern Territory, respectively (Table A4.5). Thus, in the unstandardised estimates, higher age-specific rates of ABI-related disability in the Territories were masked by young population age structures.

No jurisdictions had rates significantly below the national average. However, for people of all ages and for people aged under 65, New South Wales, Victoria and Tasmania had prevalence rates lower than those of Queensland and the Northern Territory. Western Australia had a prevalence rate lower than that of Queensland and the Northern Territory for people of all ages.



Source: Table 4.19.

Figure 4.8: ABI-related disability, by State or Territory, Australia 1993 (%, standardised to the total Australian population, March 1993)

Associated disabilities and impairments

Table 4.20 presents data on other impairments and disabilities reported by people with an ABI-related disability. The three approaches to prevalence estimation are used to estimate the number of people with ABI-related disability—main disabling condition, all disabling conditions and all disabling conditions plus activity limitation. The 'other' category includes all conditions that were not readily assigned to a particular disability group (groupings of impairments and disabling conditions were based primarily on AIHW 1997a: Table A1.2).

Based on 'all disabling conditions plus activity limitation', physical disabilities were the most common associated disability—77% of people aged under 65 and 84% of people of all ages with an ABI-related disability also had a physical disability. 'Other' disabilities were the next most common associated disability, followed by intellectual and psychiatric disabilities. Hearing impairments were relatively more frequent among people of all ages than among people aged under 65 with an ABI-related disability.

Similar patterns of associated impairments and disabilities were obtained using all three approaches to estimation. However, the proportion of people with hearing, speech and physical disabilities was substantially lower using estimates of ABI-related disability based on 'main disabling condition' than when either of the other approaches was used (Table 4.20).

Table 4.20: **People with a disability: ABI-related disability (calculated using 'main disabling condition', 'all disabling conditions' and 'all disabling conditions plus activity limitation'), by age, by other reported disabilities, Australia 1993** [(a)]

Other reported disabilities	Main disabling condition ('000)	Main disabling condition (%)	All disabling conditions ('000)	All disabling conditions (%)	AIHW method ('000)	AIHW method (%)
Ages 0–64						
Intellectual	10.4	25.7	60.8	28.8	58.8	31.8
Psychiatric	9.4	23.1	55.0	26.0	53.0	28.7
Vision	*3.7	*9.1	27.7	13.1	25.2	13.7
Hearing	*5.0	*12.4	42.7	20.2	35.9	19.4
Speech	*8.0	*19.7	37.1	17.5	35.3	19.1
Physical	23.7	58.2	157.6	74.5	142.6	77.1
Other	23.2	57.1	132.0	62.4	126.6	68.5
Total ABI group	**40.6**	**100.0**	**211.5**	**100.0**	**185.0**	**100.0**
All ages						
Intellectual	13.4	22.1	96.1	25.9	94.1	27.8
Psychiatric	14.3	23.7	103.0	27.8	100.5	29.7
Vision	*6.7	*11.0	67.0	18.1	64.4	19.0
Hearing	9.3	15.4	110.9	29.9	100.2	29.6
Speech	12.2	20.1	70.1	18.9	67.8	20.0
Physical	41.5	68.5	302.2	81.5	283.9	83.8
Other	38.9	64.2	252.9	68.2	245.8	72.6
Total ABI group	**60.6**	**100.0**	**370.7**	**100.0**	**338.7**	**100.0**

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

4.4 Discussion

In this chapter we have presented data on rates of hospitalisation in Australia in 1996–97 for conditions potentially associated with different subgroups of ABI. We have also presented estimates of the prevalence of ABI-related disability, using the 1993 ABS Survey of Disability, Ageing and Carers.

Three approaches were used to estimate the prevalence of ABI-related disability using the ABS data. Prevalence estimates differed depending on the approach used. The lowest estimates were obtained using the approach based on reported main disabling condition only (Table 4.14). Using the approach based on 'all disabling conditions plus activity limitation' there were an estimated 338,700 Australians (1.9% of the total population) with an ABI-related disability in 1993. This figure can be compared with the estimated 2,099,600 people (11.9% of Australians) with a physical disability, identified using the same approach (Wen & Fortune 1999).

There were 160,200 people (0.9% of the total population) who reported an ABI-related disabling condition and had a severe or profound handicap, meaning that they always or sometimes needed personal assistance or supervision with activities of daily living (self-care, mobility or verbal communication) (Table 4.14). This figure can be compared with the 620,400 people, or 3.8% of Australians, who reported one or more physical impairments or disabling conditions and had a severe or profound handicap (Wen & Fortune 1999), and with the AIHW estimate of intellectual disability prevalence—178,000 or 1.0% of the Australian population—which included only those people with a severe or profound handicap (Wen 1997).

Analysis of the National Hospital Morbidity Database indicated that, of the ABI subgroups examined, stroke, traumatic brain injury and 'other' brain injury (which included degenerative conditions) accounted for the greatest number of hospital separations in 1996–97 (Tables 4.2 and 4.10). There were much lower rates of hospitalisation for anoxic brain injury, alcohol-related brain injury and brain damage present at birth or arising early in childhood (Table 4.10). This does not necessarily mean that these latter subgroups of ABI are insignificant in comparison with stroke, traumatic brain injury and ABI caused by degenerative conditions. As discussed previously, rates of hospitalisation must be distinguished from incidence (Sections 4.1 and 4.2), and it is likely that some subgroups of ABI are not readily identified in the hospital system.

Comparing the two data sources

It is necessary to make some comment about how estimates of the prevalence of ABI-related disability and estimates of rates of hospitalisation associated with ABI might relate to each other. For this purpose we looked at the number of hospital separations with ICD–9–CM diagnosis codes equivalent to the ABI-related disabling condition categories in the ABS disability survey (i.e. 'mental degeneration due to brain damage' and 'head injury / brain damage'—see 'ABS group', Table 4.1).

In 1996–97 there were 74,600 hospital separations with diagnoses coded to ICD–9–CM codes in the 'ABS group'. If each of these separations related to a different individual (i.e. there was no double-counting), and all individuals went on to experience some long-term disability, it would take about 5 years (with the same rates of hospitalisation for these conditions) to accumulate the estimated 338,700 people with an ABI-related disability identified using the 1993 ABS survey data (based on 'all disabling conditions plus activity limitation'). This scenario, however, does not take into account mortality, or the likelihood that a percentage of the individuals counted in 1996–97 have been hospitalised for a similar condition in a previous year, or will be hospitalised again in a subsequent year (e.g. for a repeat stroke).

Also, it is likely that only a percentage of people hospitalised will go on to experience long-term disability. ICD–9–CM codes associated with traumatic brain injury and stroke accounted for over 90% of the 74,600 'ABS group' hospital separations. In Section 4.1 we discussed the estimation of the 'incidence' of disability from traumatic brain injury and stroke.

Based on a formula developed by Kraus (1987) it might be predicted that about 4,400 of the 27,400 separations with a diagnosis of traumatic brain injury would go on to experience long-term disability. A more conservative prediction, based on three studies that used the Glasgow Outcome Scale to assess disability, is that only about 800 of the 27,400 separations would lead to disability. Similarly, the 'incidence' of disability due to stroke could be estimated at 14,100 of the 42,300 separations identified from the hospital data (Section 4.1).

A conservative estimate of the number of people acquiring an ABI-related disability would therefore be 14,900 per year (800 from TBI plus 14,400 from stroke). It would take about 23 years to accumulate the estimated 338,700 people with an ABI-related disability identified using the 1993 ABS survey data. Again, this does not take into account mortality and repeat admissions, and it does not include disability due to other subgroups of ABI within the ‘ABS group’ (e.g. anoxic brain damage).

However, this is really no more than speculation. It must be concluded that, without better information, it is very difficult to relate data from the National Hospital Morbidity Database and data from the ABS disability survey in any meaningful way.

The two data sources are very different, not only in terms of the data items collected and the methodology used for data collection (e.g. population-based vs hospital-based, self-report vs professional medical assessment), but also in terms of their focus and purpose. The National Hospital Morbidity Database is a source of disease-focused epidemiological data and can be used for addressing questions about cause and prevention, and demand for acute care services. The ABS survey provides data on the prevalence and distribution of disability, and can be used to look at the broader experiences of people with disabilities (e.g. socioeconomic factors such as source and level of income, education and employment status), and to assess the need for different types of long-term support services.

For the individual, these two levels of focus reflect different aspects of their experience, or perhaps different temporal phases in their contact with health-related services. A person may first have contact with acute care services and later seek access to disability support services (perhaps also continuing to access acute care services).

From a societal perspective these two levels of focus are also related. Individuals move through the health and welfare services network, and policy initiatives in one area (e.g. prevention campaigns, provision of rehabilitation) may affect levels of demand at other points in the network. Therefore, to gain a better understanding of the needs of people with ABI, the level of demand for services, and the factors that affect patterns in demand for different types of services, it seems desirable to develop means of relating disease-oriented and disability-oriented data sources.

Information that might help to link data from the National Hospital Morbidity Database and the ABS disability survey for the purpose of looking at rates of ABI in Australia would be likely to include:

- rates of hospital readmission for a single injury / event;
- the proportion of people hospitalised for different ABI-related conditions who go on to experience disability (e.g. using follow-up studies or data linkage techniques);
- rates of repeat hospitalisation, due to recurrence of conditions (e.g. recurrent head injury or repeat stroke); and
- mortality rates for people with different types of ABI of different ages.

The Research Centre for Injury Studies at Flinders University (which incorporates the National Injury Surveillance Unit, a collaborating unit of AIHW) has been examining a range of issues relating to the availability, quality and utilisation of data on traumatic brain injury (Peter O’Connor, pers. comm.). There is clearly a need for more work in this area, and greater cooperation at the national level.

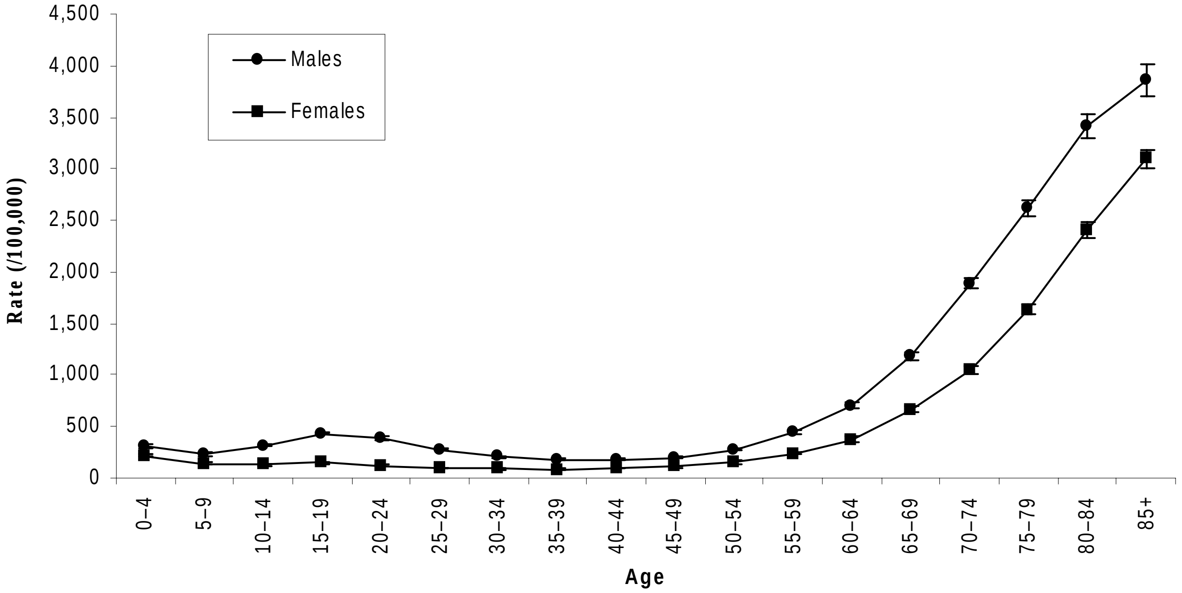
Age and sex patterns

Based on our analysis of the 1996–97 National Hospital Morbidity Database, about 70% of the 27,437 hospital separations with a TBI-related diagnosis were for males. For males, rates of hospitalisation for TBI-related conditions peaked in the late teenage years and early twenties, but were also high in early childhood and very old age. For females, the very young and the very old had the highest rates. There was a peak in the late teenage years, but it was much less pronounced than for males (Figure 4.1).

These patterns are consistent with those found in many other hospital-based TBI incidence studies. Commonly males account for around 70% of TBI cases identified (e.g. Fife et al. 1984; Hillier et al. 1997; Kraus et al. 1984; Tate et al. 1998). Males in late adolescence and early adulthood are usually over-represented—for instance, Tate et al. (1998) found that males aged 15–24 represented 7% of the resident population of the region, but accounted for 26% of head injuries identified. Many studies have also identified the three 'peaks' in incidence rate, occurring in early childhood, late adolescence / early adulthood and old age (e.g. Fife et al. 1986; Kraus et al. 1984).

Many of the studies reviewed in Section 3.1 have looked at the different causes of TBI, and at relationships between cause and age and sex (e.g. Hillier et al. 1997; Kraus et al. 1984; Tate et al. 1998). This type of information is valuable for designing and effectively targeting prevention programs. However, because the emphasis of this paper is on the incidence and prevalence of disability attributable to ABI we have not investigated issues of cause.

The two ABI subgroups that accounted for the greatest number of hospital separations were stroke and 'other' ABI (including degenerative conditions, such as Alzheimer's disease)



Source: Table A4.7.

Figure 4.9: 'ABS group' hospital separations (see Table 4.1), by sex and age, Australia 1996–97 (rate per 100,000)

(Table 4.10). For both these groups rates of hospitalisation were relatively low for younger age groups, but increased steeply for people aged over 65. For stroke, males had markedly higher rates of hospitalisation, particularly among people aged over 65, while for 'other' ABI rates were higher for females than for males.

Many of the studies of stroke incidence reviewed in Section 3.4 found patterns of age- and sex-specific incidence rates similar to those we have found (e.g. Bonita et al. 1994; Giroud et al. 1989; Sarti et al. 1994). For instance, Anderson et al. (1993) found that rates of incidence rose steeply with each 10-year age group, and that males predominated in all age groups beyond 35 years, with the greatest difference occurring in the age group 55–64 years.

The 1993 ABS disability survey data revealed an increase in the prevalence of ABI-related disability with age (Table 4.13). For males, prevalence increased slowly up to about age 50, and then increased more steeply in later age groups. For females the pattern was similar, but the steeper increase in prevalence began around age 60—later than for males (Figure 4.5). The overall prevalence rate for males (2.2%) was higher than for females (1.6%), although age-specific rates were significantly higher for males only in the later age groups (45–64 and over 65).

Data from the Canadian Health and Activity Limitation Survey on the prevalence of TBI-related disability showed that the overall rate for males was approximately double that for females (Steger Moscato et al. 1994). Prevalence rates were highest in age groups 45–54 and 55–64. Similarly, Wang et al. (1986) found that the prevalence of brain injury due to head trauma was substantially higher for males than for females, and that age-specific rates increased steadily to peak in the age groups 40–49 and 50–59, before decreasing in later age groups.

This pattern in age-specific rates for TBI-related disability is quite different to the pattern for ABI-related disability found using the 1993 ABS survey data. This is likely to be because the ABS data include brain injury caused by stroke, which becomes highly prevalent in the later adult years. Data from the South Australian Survey of Disability Prevalence (South Australian Health Commission 1998) are more readily comparable with the ABS data in that the definition of 'brain injury' covers brain injury due to a number of causes, including stroke. The survey found that the prevalence of brain injury was higher for males than females, and higher for people aged over 60 than for people in younger age groups—similar to our findings from the ABS survey data.

Making specific comparisons of age and sex patterns between the two data sources presented in this paper is difficult as it is not possible to break down the ABS disability survey data by ABI subgroup[5]. Figure 4.9 shows age- and sex-specific rates of hospitalisations with ICD–9–CM diagnosis codes in the 'ABS group' (see Table 4.1). A slight increase in rates for males can be seen around the 15–19 year age group, reflecting high rates of TBI-related hospitalisation. However, rates do not begin to rise markedly until much later age groups. These increased rates of ABI-related hospitalisation in later life are due mainly to increased stroke incidence, with a small contribution from higher rates of TBI in older people. Rates for males appear to increase more steeply than rates for females between ages 50 and 69.

Figures 4.5 (prevalence of ABI-related disability) and 4.9 ('ABS group' hospital separations) have roughly similar shapes—both are dominated by steeply increasing rates in older

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[5] Data from the 1998 ABS Survey of Disability, Ageing and Carers are expected to enable the separate identification of people with disability resulting from stroke and people with disability resulting from other types of brain damage.

people. The high incidence rate of TBI in males in early adulthood is not clearly reflected in the disability data, where it might be expected to show up as an increase in prevalence in the 20–30 year age group (Figure 4.5). The increase in prevalence of ABI-related disability in later age groups is likely to reflect higher incidence rates of stroke later in life, as well as an accumulation of people with long-term disability from traumatic and other subgroups of brain injury acquired earlier in life. The steeper increase in prevalence began later for females than for males, a pattern consistent with the initially steeper increase for males in rates of hospitalisation (Figure 4.9).

Other demographic patterns

Country of birth

For both males and females, people born in Australia had the highest rates of TBI-associated hospitalisation, followed by people born in ‘other English-speaking countries’ and then people born in ‘non-English-speaking countries’ (Table 4.4; Figure 4.2). This same pattern was evident for ABI-related disability in males, although high standard errors associated with small sample sizes mean that it is not possible to establish whether the differences between groups are significant. For females, people born in ‘other English-speaking countries’ appeared to have the lowest rates of ABI-related disability although, again, the estimates have very high standard errors (Table 4.14; Figure 4.6).

Rates of TBI-associated hospitalisation were much lower for females than for males in the three country-of-birth groups. This pattern was reflected in the estimates of ABI-related disability prevalence for people born in Australia and ‘other English-speaking countries’. However, for people born in ‘non-English-speaking countries’ rates for males and females were very similar.

Because ABI-related disability as identified by the ABS survey includes TBI, stroke and other types of brain injury, demographic patterns in the prevalence of ABI-related disability should not necessarily be expected to mirror demographic patterns in the rate of hospitalisation for TBI-related conditions. While people born outside Australia may be at lower risk of sustaining a traumatic brain injury, as the hospital data suggest (perhaps due to certain cultural factors), they may not be at lower risk of acquiring other types of brain injury.

Indigenous status

Rates of TBI-associated hospitalisation were much higher for Indigenous people than for non-Indigenous people, and proportionately more so for females than for males (Table 4.6; Figure 4.3). This pattern was not nearly as clear from the Disability Survey data—the high standard errors associated with estimates for Indigenous people make it impossible to draw any conclusions about relative prevalence rates of ABI-related disability (Table 4.15; Figure 4.7).

Jurisdictions

South Australia, Western Australia and Queensland had the highest rates of TBI-associated hospitalisation, and the Australian Capital Territory had the lowest rate (Table 4.9; Figure 4.4). The same pattern was not evident in the disability data (Table 4.19; Figure 4.8). Again, because of high standard error rates, it is difficult to make comparisons between jurisdictions. Queensland and the Northern Territory were the only jurisdictions with prevalence rates of ABI-related disability above the national average.

4.5 Conclusion

This is the final report in the series examining the definition and prevalence of particular disability groups. The series has addressed intellectual disability, physical disability and acquired brain injury, and estimates of prevalence have been based on the 1993 ABS Survey of Disability, Ageing and Carers.

This review of definitions of ABI and estimates of its incidence and prevalence overseas and in Australia has shown that there is a great deal of uncertainty surrounding the field. Definitions have been developed separately for specific applications by epidemiologists, medical professionals, researchers, service providers, representative organisations and others. Estimates of incidence and prevalence vary accordingly.

Data sources currently available within Australia can cast some light on the impact of ABI at the community level. However, the various sources all have certain limitations and cannot readily be related to one another to build up a complete picture of ABI in Australia. Better data are needed for a more definite assessment of the number of people with disability resulting from ABI in Australia. This would provide a firm basis for developing better information on the needs of people with ABI, the level of demand for services, and the factors that affect patterns in demand for different types of services.

As a first step towards improving the quality of data on ABI, clearer and more consistent definitions should be developed. In Australia the National Policy on Services for People with Acquired Brain Injury may provide a good basis for the development of a set of operational guidelines. Ideally, such guidelines should provide a means of bridging the gap between disease-oriented and disability-oriented data sources, and should address all subgroups of ABI.