Summary

Introduction

This report critically reviews:

- definitions of acquired brain injury (ABI);
- existing estimates of incidence of ABI and prevalence of disability attributable to ABI in Australia and overseas; and
- data sources and approaches to estimating incidence and prevalence.

Newly derived estimates of rates of hospitalisation associated with ABI (treated as indicative of incidence rates) and the prevalence of disability attributable to ABI in Australia are also presented. 'Incidence' is the number of new cases of a condition diagnosed or reported during a specified time period (usually one year). 'Prevalence' is the total number of cases of a condition within a population at a given point in time.

This report is the third in a series looking at the definition and prevalence of different disability groups in Australia.

ABI as a disability group

A disability group is 'a broad categorisation of disabilities in terms of the underlying impairment, condition or cause' (AIHW 1999a). Disability groups tend to include people with a disability who are considered—by themselves, society, and / or service providers—to have similar characteristics and related needs, often arising from a similar cause, impairment or disabling condition.

ABI is recognised as a disability group in Australia. This reflects the fact that people living with ABI maintain that their needs and experiences are different from those of people living with other types of disability. In 1994 the Commonwealth and State governments agreed on a National Policy on Services for People with Acquired Brain Injury (Department of Human Services and Health 1994).

It is difficult to define the scope of the ABI group. ABI can result from a variety of causes and lead to a range of types of disability. Individuals with ABI-related disability often have impairments in more than one area (e.g. physical, cognitive and psychosocial). There is scope for overlap between ABI and other disability groups. For instance, disability resulting from some degenerative neurological diseases may be regarded as ABI or as neurological disability. Brain injury acquired at birth or very early in life is sometimes included in the scope of ABI, but more often included within the intellectual disability group.

Definitions

Clear, consistent definitions provide a basis for collecting and presenting reliable, comparable data. Definitions of ABI vary markedly among the studies reviewed, reflecting the different purposes for which they are intended. To assist in comparing definitions five key 'elements' are identified: (i) specification of whether actual injury to the brain has

occurred (as opposed to head injury only); (ii) cause (and the related issue of whether brain injury present at birth is included); (iii) the presence of specific symptoms during the critical stage (e.g. loss of consciousness); (iv) functional effects; and (v) the duration of functional effects.

Definitions used in policy, legislative and administrative contexts

In this group of definitions the presence of actual injury to the brain is usually specified in the definition, as is the nature of functional effects (usually impairments and / or activity limitations), and often the duration of functional effects. Cause also tends to be specified, by an exhaustive statement of causes included, an inclusive list of possible causes, and / or a list of causes that are excluded.

The National Policy on Services for People with Acquired Brain Injury provides a definition that is quite broad:

> Acquired brain injury is injury to the brain which results in deterioration in cognitive, physical, emotional or independent functioning. ABI can occur as a result of trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological diseases or stroke. These impairments to cognitive abilities or physical functioning may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment. (Department of Human Services and Health 1994)

The National Policy is primarily concerned with people who have 'severe or profound disability'—that is, people who always or sometimes need personal assistance or supervision with activities of daily living. The National Policy definition has been used in some broad studies of brain injury in Australia.

Definitions associated with disability support services are typically more specific about the severity and duration of disability resulting from ABI, reflecting service eligibility criteria. For instance, the Commonwealth / State Disability Agreement, which relates to a range of disability support services nationally, uses a definition of disability that includes only disability that is likely to be permanent, and results in 'substantially reduced capacity' in certain areas, 'requiring ongoing or episodic support'.

Definitions used in studies of ABI incidence

Most studies of ABI incidence are based on hospital data and focus on morbidity and mortality, rather than disability. The operational definitions used tend not to make reference to the nature or duration of ongoing, post-critical functional limitations resulting from brain injury—information on long-term effects is usually not readily available. In many studies 'cause' is implicitly or explicitly limited to 'trauma' or 'injury'.

Typically, definitions focus on diagnoses and symptoms associated with brain injury. In many hospitals, both in Australia and overseas, diagnoses are classified and coded using the World Health Organization's International Classification of Diseases (ICD). Often, ICD diagnosis codes are used to identify potential cases from a coded summary database, then individual medical records are examined for uncoded information on symptoms.

The specific diagnosis codes and symptoms used to identify cases vary, which makes it difficult to validly compare estimates of ABI hospitalisation rates from different studies. In 1995 the National Center for Injury Prevention and Control (USA) produced guidelines for the surveillance of central nervous system injury, to facilitate the collection of comparable epidemiological data. The guidelines provide a 'clinical case definition' of traumatic brain

injury (TBI) for use with uncoded data and a 'uniform data systems case definition' (a list of ICD–9 codes).

Definitions of ABI used in disability prevalence studies

The prevalence of disability attributable to ABI is most commonly estimated using self-report data from population disability surveys. In definitions used to identify disability attributable to ABI, actual injury to the brain (as opposed to 'head injury') is generally either specified or strongly implied by the fact that there must be evidence of long-term functional effects associated with head injury. While the presence of functional effects is usually required, definitions tend to vary in terms of the degree to which the nature and duration of functional effects is specified. In some cases the definition is limited to ABI caused by head trauma, and in some cases brain injury present at birth is excluded.

Existing estimates

Estimates of the incidence of ABI

Most estimates of the incidence of ABI are based on hospital separations data. While rates of hospitalisation may be indicative of incidence, they are not equivalent to incidence rates. Many factors, such as hospital admissions policies and rates of readmission for a single injury, can cause variation in rates of hospitalisation independently of any variation in incidence rates.

Differences between estimates from different studies may reflect both real variations in the rate of brain injury between regions and over time, and differences in methodology. A range of estimates of the incidence of ABI overseas and in Australia are reviewed. Most of the estimates focus primarily on TBI. Study methodologies vary in terms of:

- whether data were from a single hospital or from multiple hospitals in a region;
- methods of identifying cases of brain injury;
- whether principal diagnoses or all diagnoses were used to identify cases of ABI from coded summary data sources;
- the population age range included;
- whether or not deaths before hospital admission and / or in hospital were included in the estimate of brain injury incidence; and
- whether or not non-residents (i.e. people who reside outside the study area) and repeat admissions were included.

Of 15 estimates of ABI incidence from overseas studies, 13 were based on hospital data. These estimates ranged from 91 to 372 per 100,000 population. The 11 Australian incidence estimates reviewed ranged from 57 to 377 per 100,000 population.

If we consider only those estimates that are based on hospital data and apply to the total population, and we exclude estimates based on data from a single hospital (as they may be more susceptible to local variations in demographic factors such as socioeconomic status), a narrower range of estimates is obtained. Applying these criteria gives a range of 100 to 270 per 100,000 per year for estimates of incidence overseas and 100 to 377 per 100,000 per year for estimates of incidence in Australia.

Even narrowing the range of estimates considered in this way there remains considerable methodological variation among the studies, and the range of estimates remains broad.

The proportion of incident cases leading to disability

Several studies have provided estimates of the proportions of people who suffer acquired brain injury (mostly traumatic) who go on to experience longer-term problems. The studies reviewed varied considerably in terms of definitions and methodologies used.

Of the studies that included ABI of all severity levels, measures of the proportion of people suffering adverse outcomes ranged from 3% with moderate disability or worse, measured using the Glasgow Outcome Scale one year after injury, to 40% with residual difficulties on discharge from hospital. Studies focusing only on people with severe brain injury generally produced higher estimates of the proportion of people suffering adverse outcomes.

Estimates of the prevalence of disability attributable to ABI

There are relatively few existing estimates of the prevalence of long-term disability attributable to ABI, either in Australia or overseas.

The five overseas prevalence estimates reviewed ranged from 62 to 783 per 100,000. This variation is likely in part to reflect different definitions and methodologies. However, it is possible that real rates of prevalence differ markedly between the countries represented, due to factors such as different levels of interpersonal violence and differences in occupational health and safety and traffic safety standards.

Nine estimates of the prevalence of ABI-related disability in Australia were reviewed—some relating to particular States or Territories and some to Australia as a whole (Table S1). The estimates ranged from 134 to 1,920 per 100,000. Six estimates were based on data from the 1993 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers. However, even though they were based on a single data source, different operational definitions used meant that these estimates were not all directly comparable.

Table S1: Australian estimates of prevalence rates of disability attributable to ABI [(a)]

Rate (/100,000)	Jurisdiction	Data sources and methods
294	Vic, 1993	1993 ABS Survey of Disability, Ageing and Carers. Criteria for inclusion unclear.
240–290	Vic	Based on a 'realistic interpretation' of estimates derived from various data sources
1,696	WA, 1991	Hospital admissions data used to determine incidence, then demographic model of WA population used to calculate prevalence based on incidence
161	WA, 1993	1993 ABS Survey of Disability, Ageing and Carers, based on ABI reported as main disabling condition
400	WA, 1993	1993 ABS Survey of Disability, Ageing and Carers, based on ABI reported as main disabling condition
1,740	SA, 1996–97	South Australian Survey of Disability Prevalence—telephone survey
134	ACT, 1993	1993 ABS Survey of Disability, Ageing and Carers, based on ABI reported as main disabling condition
1,400	Australia, 1993	1993 ABS Survey of Disability, Ageing and Carers, based on positive response to screening question about long-term effects of head injury, stroke or other brain damage
1,920	Australia, 1993	1993 ABS Survey of Disability, Ageing and Carers, based on positive response screening question, ABI reported as disabling condition, and reported restrictions and limitations

(a) See Table 3.5 for sources and notes.

Non-traumatic ABI

Estimates of the incidence and prevalence of non-traumatic brain injury are less easily found in the literature than estimates relating to traumatic brain injury (TBI). Some other causes of ABI are briefly reviewed.

Stroke is a cause of ABI that most commonly affects people in later life. Incidence estimates of 'first ever' stroke in developed countries relating to people of all ages tend to be around 160–200 per 100,000 per year. Estimates of the prevalence of disability attributable to stroke are relatively few. Overseas estimates reviewed range from 173–623 per 100,000. However, the definition of disability and the age groups to which the estimates apply vary. A Victorian study produced an estimate of 200 per 100,000 for people aged over 25.

Alcohol-related brain injury (ARBI) is an important cause of ABI-related disability, particularly in the middle-adult years. Estimates of the incidence and prevalence of ARBI are particularly difficult to obtain because of underdiagnosis, and the estimates that are available are difficult to compare because of different methodologies and different study populations. Autopsy studies in Australia have produced estimates of the prevalence of Wernicke–Korsakoff syndrome (a type of alcohol-related brain injury associated with thiamine malnutrition) of around 2% for the adult population.

AIHW estimates of ABI in Australia

New estimates of rates of hospitalisation associated with ABI and the prevalence of ABI-related disability are presented. The measures used 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 are used to adjust for the different age and sex structures of sub-populations being compared.

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.

ICD–9–CM codes were used to identify separations with a diagnosis associated with TBI and five other subgroups of ABI: stroke, anoxic brain injury, alcohol-related brain injury, brain injury arising early in life, and 'other' ABI (including degenerative conditions such as Alzheimer's disease) (see Table 4.1). Records containing the specified ICD–9–CM codes, either as the principal diagnosis or among the additional diagnoses, were retrieved from the database. The analysis was limited to separations relating to episodes of acute care. To minimise double counting, records for patients transferred to another acute hospital were excluded.

Traumatic brain injury

There were 27,437 hospital separations with a diagnosis of TBI in the year 1996–97 (i.e. from July 1996 to June 1997), a rate of 149 per 100,000 population (Table S2). Almost 60% of separations were for 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).

Almost 70% of TBI separations were males, and males had higher rates than females in all age groups. The general age pattern of separation rates was similar for males and females, with peaks in the age groups 0–4, 15–19 and 85-plus.

Standardised rates of TBI-associated hospitalisation were substantially lower for people born overseas (77 per 100,000 for people born in 'non-English-speaking countries' and 106 per 100,000 for people born in 'other English-speaking countries'[1]) than for people born in Australia (155 per 100,000). Standardised rates for Indigenous people (343 per 100,000) were substantially higher than for non-Indigenous people (142 per 100,000).

Standardised rates of TBI-associated hospital separations varied substantially between jurisdictions (Table S2). The highest rate was for Queensland residents (211 per 100,000) and the lowest for Australian Capital Territory residents (71 per 100,000).

Table S2: Traumatic brain injury: hospital separations, by residence State or Territory, Australia 1996–97

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number	7,845	5,184	7,205	3,160	2,735	645	223	248	27,437
Standardised rate (/100,000)	126	114	211	175	188	137	71	124	149

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

Non-traumatic ABI

Of the other ABI subgroups examined, stroke and 'other' brain injury (which included degenerative conditions) accounted for the greatest number of hospital separations in 1996–97 (Table S3). 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. This does not necessarily mean that these latter subgroups of ABI are insignificant in comparison with stroke, TBI and ABI caused by degenerative conditions. It is likely that some subgroups of ABI are not readily identified in the hospital system.

Table S3: ABI subgroups: hospital separations, by sex, by age, Australia 1996–97

	Males		Females		Persons	
	Number	(/100,000)	Number	(/100,000)	Number	(/100,000)
Stroke	27,738	303	23,779	257	51,517	280
Anoxic brain injury	1,998	22	1,505	16	3,503	19
Alcohol-related brain injury	2,121	23	592	6	2,714	15
Brain injury arising early in life	1,341	15	1,109	12	2,451	13
'Other' ABI	29,068	317	37,610	406	66,680	362

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

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

Prevalence estimates from the 1993 ABS disability survey

The 1993 ABS Survey of Disability, Ageing and Carers is used in this report to estimate the prevalence of ABI-related disability in Australia. The Survey used a screening device, consisting of 15 screening questions, to identify a broad spectrum of people potentially experiencing some level of disability. 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'.

The survey also provides information on disabling conditions. Multiple disabling conditions could be reported. A person's main disabling condition was the condition identified as the one causing most problems. Survey respondents were also asked questions about activity limitations, participation restrictions and need for assistance.

Prevalence of ABI-related disability

Three broad approaches were used to estimate the prevalence of ABI-related disability using the ABS data (Table S4). The lowest estimates were obtained using an approach based on reported main disabling condition only: 60,600 people, or 0.3% of the total population.

Using an approach based on 'all disabling conditions plus activity limitation' an estimated 338,700 Australians (1.9% of the total population) had 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).

Table S4: Estimates of ABI-related disability using different approaches to estimation, Australia 1993

	Males		Females		Persons	
	('000)	(%)	('000)	(%)	('000)	(%)
Main disabling condition—severe or profound handicap						
Ages ≥ 5	11.3	0.1	13.6	0.2	24.9	0.1
Main disabling condition—total with disability						
Total	33.4	0.4	27.2	0.3	60.6	0.3
All disabling conditions—severe or profound handicap						
Ages ≥ 5	**76.5**	**0.9**	**83.6**	**0.9**	**160.2**	**0.9**
All disabling conditions—total with disability						
All ages	**217.3**	**2.5**	**153.4**	**1.7**	**370.7**	**2.1**
All disabling conditions with activity limitation filter						
All ages	194.9	2.2	143.8	1.6	338.7	1.9

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

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). 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).

The prevalence of ABI-related disability increased with age for both males and females. The steep increase in later years is likely to reflect a high incidence of brain injury caused by stroke in older people. The prevalence of ABI-related disability, using the approach based on 'all disabling conditions plus activity limitation', was substantially higher among males (2.2%) than females (1.6%).

High standard errors associated with survey estimates make it difficult to draw firm conclusions about differences in the prevalence of ABI-related disability between people born in Australia and people born overseas, and between Indigenous and non-Indigenous Australians.

Prevalence varied between jurisdictions. Using indirectly standardised rates ('all disabling conditions plus activity limitation') Queensland (2.6%) and the Northern Territory (3.6%) had rates significantly higher than the national average (1.9%). No jurisdictions had rates significantly below the national average.

Conclusion

This review of definitions of ABI and estimates of its incidence and prevalence overseas and in Australia has shown that there has been a good deal of uncertainty in 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.

As a first step towards reducing the uncertainty, 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 that would in turn provide a basis for the collection of relatable and comparable data on the incidence and prevalence of ABI. In particular, it is necessary to develop means of relating disease-oriented and disability-oriented data sources in order 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.