The definition, incidence and prevalence of acquired brain injury in Australia

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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.

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Abbreviations

ABI	acquired brain injury
ABS	Australian Bureau of Statistics
ADL	activities of daily living
AIHW	Australian Institute of Health and Welfare
ARBI	alcohol-related brain injury
BIOC	Brain Injuries Options Coordination (South Australia)
FIM	Functional Independence Measure
FIM+FAM	Functional Assessment Measure
GCS	Glasgow Coma Scale
GOS	Glasgow Outcome Scale
HICOA	Head Injury Council of Australia
ICD	International Classification of Diseases
ICIDH	International Classification of Impairments, Disabilities and Handicaps
MICHI	Ministerial Implementation Committee of Head Injury (Victoria)
TBI	traumatic brain injury
WHO	World Health Organisation
WKS	Wernicke–Korsakoff syndrome

1 Introduction

Acquired brain injury (ABI) can result from a number of causes, including head trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological disease and stroke. It can cause physical, cognitive, psychosocial, and sensory impairments, which may lead to restrictions in various areas of life.

ABI is recognised as a disability group in Australia. 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). People living with disability resulting from ABI have characteristic support needs that differ from those of people with other types of disability. In particular, because of the acquired nature of ABI and the wide range of impairments that can result, individuals who sustain ABI, and their families and friends, may need to find strategies for coping with changes in lifestyle and expectations.

The impact of ABI at the community level is also quite substantial. ABI, particularly traumatic brain injury, commonly affects people in early adulthood, and survivors may not have substantially reduced life expectancy. Therefore, people with ongoing support needs as a result of ABI commonly live for 20 to 40 years after injury (Jennett et al. 1981). Around Australia there are a number of organisations that represent the interests of people living with ABI.

It is widely recognised that there is a lack of data concerning the prevalence and pattern of disability attributable to ABI. This makes it difficult to assess the level of need for appropriate support services (HICOA 1998; Health Department Victoria et al. 1991). There is also confusion surrounding the terminology used in connection with ABI. Good information on disability at the population level is dependent on consistent definitions that can provide a sound underpinning for statistical data. Common terms also provide a basis for more effective communication, which in turn promotes understanding of people's needs, allowing those needs to be more effectively addressed (Madden & Hogan 1997).

This paper is the third in a series of reports on the definition and prevalence of different disability groups in Australia. The first report in the series focused on intellectual disability (Wen 1997), and the second on physical disability (Wen & Fortune 1999).

Objectives of the report

In this report we set out to critically review:

- definitions of 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.

Structure of the report

In the remainder of this chapter we review a number of terms commonly used in connection with ABI, some of the issues that face people with ABI and the delimitation of ABI as a disability group.

Chapter 2 provides a review of definitions of ABI used in policy and administrative contexts, and operational definitions used as a basis for data collection and the estimation of incidence and prevalence rates. Approaches to measuring severity of injury and outcome are also discussed.

In Chapter 3 we review international and Australian estimates of incidence and prevalence. The relationship, at a population level, between the epidemiology of brain injury and rates of disability attributable to brain injury is explored.

National estimates of the rates of hospitalisation associated with ABI and the prevalence of disability attributable to ABI, based on the National Hospital Morbidity Database and the 1993 ABS Survey of Disability, Ageing and Carers, are presented in Chapter 4.

1.1 ABI—an overview

Terminology

A number of synonymous and related terms are commonly encountered in the literature on ABI—notably 'acquired brain damage', 'acquired brain injury', 'head injury', and 'traumatic brain injury'. '(Acquired) brain damage', and '(acquired) brain injury' are usually treated as synonyms, to mean acquired damage to the brain. However, in some cases the word 'injury' is taken to imply that the brain has been damaged by some external force. It could be argued, then, that 'acquired brain damage' has greater intuitive appeal as a term for describing damage to the brain regardless of cause.

'Traumatic brain injury' (TBI) is acquired brain injury caused by a traumatic event—e.g. a blow to the head. TBI is the most prominent subgroup of ABI, and is often the main or sole focus of studies of incidence based on hospital data. Sometimes the term 'acquired brain injury' or 'brain injury' is used even though the subject of the study is solely TBI.

'Head injury' means an injury to the cranium caused by some external force, whether or not brain injury results. 'Head injury' and 'brain injury' are overlapping classifications in that 'head injury' may or may not lead to 'brain injury', and 'brain injury' may or may not be due to 'head injury' (Kraus 1987). Often the term 'head injury' is used to mean physical trauma to the head that is likely to be associated with brain injury (e.g. in studies based on hospital data, where the presence of actual brain injury cannot be ascertained). In some discussions a clear distinction is made between 'head injury' and 'brain injury' (e.g. Health Department Victoria et al. 1991), while in other instances the two terms are treated as synonyms (e.g. Cuff & Donald 1987).

As the term 'acquired brain injury' (ABI) seems to be most widely used in the field we will use ABI as an umbrella term throughout this paper to cover all acquired damage to the brain, regardless of cause. The term 'head injury' will be used to mean injury to the head where brain damage is likely but cannot be ascertained.

As has been discussed in a previous paper in this series (Wen & Fortune 1999), terminology used in relation to disability generally is in a transitional phase. In this paper 'impairment' will be used to mean 'a loss or abnormality of body structure or of a physiological or

psychological function', as it is defined in the draft ICIDH–2 (see Section 2.3). 'Disability' will be used as an umbrella term meaning negative experience in any one or more of the draft ICIDH–2 dimensions—i.e. an impairment, activity limitation or participation restriction. (See Appendix 1 for definitions of terms used frequently throughout this paper.)

Damage to the brain

Damage to the structure or function of the brain can lead to a wide range of impairments of varying degrees of severity. Acquired brain injury may result from many different causes, including trauma, such as a blow to the head or a sudden arrest of movement ('acceleration / deceleration' injury), disruption to the supply of oxygen to the brain, stroke, tumours, infection (e.g. meningitis), poisoning and substance abuse, and degenerative neurological diseases.

The nature of damage and parts of the brain affected can vary with the cause. In some cases damage is diffuse and widespread. For instance, in 'acceleration / deceleration' injuries, such as those often sustained in motor vehicle accidents, nerve fibres and blood vessels throughout the brain can be torn by shearing stresses. Prolonged alcohol abuse tends to cause diffuse neuronal damage. In other cases damage is focal. In traumatic brain injury specific parts of the brain may be impacted against the skull and bruised or torn. Stroke also tends to cause localised damage in the brain (Jennett et al. 1981).

In recent decades the development of technologies such as computerised tomography (CT) and magnetic resonance imaging (MRI) have provided new insights into brain injury. These technologies are now used routinely as diagnostic tools and have confirmed that there is often structural brain damage even in people whose injuries appear to be mild (Jenkins et al. 1986). In some incidence studies results of CT scan and MRI are used to confirm cases of brain injury or to assess severity (e.g. Kraus et al. 1984; Servadei et al. 1988). The ability to detect injury to the brain that might previously have been overlooked means that more people are likely to receive appropriate post-injury support.

The nature and severity of damage to the brain, along with other medical, social and personal factors, influence the nature and severity of resulting disability. The brain is of central importance in every aspect of physical, cognitive, sensory, behavioural and social functioning. While people with only one type of impairment (e.g. mental or physical) may be able to develop compensatory adaptations, people with more than one type of impairment are less able to do this (Jennett & Bond 1975). The wide range of types of disability that can result from ABI means that people with ABI have very diverse support needs.

Disabilities and service needs

The focus of this paper is on the incidence and prevalence of ABI. However, in order to provide a context for this focus it is necessary to outline briefly some aspects of the disabilities experienced by people with ABI and issues that face them in the community.

The effects of acquired brain injury are complex, and individuals are affected differently. Brain injury may lead to physical, sensory, cognitive and psychosocial / emotional disabilities, often in combination (Kendall 1991). A follow-up study of people with traumatic brain injury found that the most frequently reported ongoing problems, several years post-injury, were poor memory, irritability, loss of temper, headaches, and difficulty concentrating (Tennant et al. 1995). ABI is sometimes referred to as the 'hidden' disability, because individuals can appear 'normal' but experience cognitive or emotional disabilities.

Emotional and social difficulties, including aggression, depression, mood swings and disinhibition, can be particularly challenging for individuals and their families—close relationships may be affected by changes in personality and behaviour caused by the brain injury.

The ultimate goal for a person with ABI is often to be a participating and valued member of their family and community. However, re-entering the community can be very challenging. The person may find themselves disconnected from their social circle and unable to return to work. Negative community attitudes and a widespread lack of understanding of ABI increase the difficulties they face.

People with ABI may need support to help them build relationships and establish social networks, achieve independence and autonomy in day-to-day life, access community resources and services, build confidence and self-esteem, develop skills, and find work. Successful community integration is likely to depend on long-term access to appropriate specialist and generic services.

In recent years specialised brain injury services have been established around Australia in response to community demand and in recognition of the unique needs of people with ABI. A study conducted in 1995, that looked at barriers preventing people with ABI accessing appropriate services, identified 48 organisations across Australia specifically funded to provide services for people with brain injury (Ramsey & Hilson 1995). However, a literature review conducted as part of that study revealed that people with ABI generally had insufficient access to services in a range of areas, including rehabilitation, accommodation and respite. Factors that made it difficult for people with ABI to access services included: absence of appropriate services; means testing, which may exclude people eligible for a compensation payment in respect of their brain injury; lack of funding and resources; lack of awareness of appropriate services; inaccessibility, due to physical factors or other factors including communication barriers; and lack of understanding of the needs of people with ABI on the part of service staff (Ramsey & Hilson 1995).

Views expressed in an ABI consumer focus group, concerning changes being made to employment assistance under Centrelink, included that service staff need to have an understanding of the differences between ABI and other disabilities. A poor understanding of ABI may reduce the likelihood of the person being given a suitable work placement and receiving appropriate support. There was also a concern that assessment instruments, such as work ability tables, designed for people with other types of disability are unlikely to pick up the kind of difficulties experienced by people with ABI (Headway Victoria 1998).

1.2 ABI as a disability group

Disabilities are often categorised into ‘disability groups’. The concept of ‘disability group’ was first formally introduced in the Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS) Data Guide for the 1997 collection. The Data Guide defines disability group as ‘a broad categorisation of disabilities in terms of the underlying impairment, condition or cause’ (AIHW 1999a). From a data perspective, it is necessary to clearly delineate a disability group before questions of incidence and prevalence can sensibly be discussed in relation to that group.

Groupings reflect common usage in the disability field, rather than a universally agreed classification of disabilities. Existing ‘groups’ in Australia (e.g. intellectual, physical and ABI) 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 (unpublished agenda paper of CSDA MDS annual network meeting 1998).

ABI as a disability group is not easily defined. As discussed above, ABI may result from a variety of causes and people with ABI may experience a wide range of impairments and activity limitations. Nonetheless, ABI is recognised as a disability group in the field because people living with ABI maintain that their needs and experiences are different from those of people living with other types of disability (e.g. physical or intellectual) (HICOA 1998).

In the USA traumatic brain injury is singled out in legislation as a disability group worthy of special recognition. In the explanatory notes for the Traumatic Brain Injury Act (1996, USA) it is stated that 'because of the serious consequences of TBI and the failure of human services systems and educational programs to meet their needs properly, people with TBI want to be identified as people with brain injuries, not to be labelled as having some other disability. This is extremely important if appropriate services are to be developed and targeted and prevention efforts are to be conducted'. The Individuals with Disabilities Education Act defines the term 'child with a disability' as a child with any of a list of stated impairments and disabilities including 'traumatic brain injury' (20 USCA § 1400 (West Supp. 1998)).

In Australia in 1994 the National Policy on Services for People with Acquired Brain Injury was developed as 'a statement by Commonwealth, State and Territory Governments on the future direction of service provision and support for people with Acquired Brain Injury' in response to 'growing concern about the impact of ABI in the community' and 'issues raised by people with ABI and their families and carers, the organisations which represent them, and government and non-government service agencies' (Department of Human Services and Health 1994). The scope of ABI as laid out in the policy encompasses ABI resulting from trauma, alcohol abuse, hypoxia, tumour, stroke and infection.

However, the limits of ABI as a disability group are not clearly defined, and there is scope for overlap with other disability groups. For instance, disability resulting from some degenerative neurological diseases may be regarded as ABI or as neurological disability (often treated as a subgroup within physical disability—Wen & Fortune 1999). Decisions on this point, for the purpose of service delivery, may need to be made on a case by case basis (Geraldine Jones, Brain Injuries Options Coordination, pers. comm.).

People with brain injury acquired before, during or shortly after birth are not usually included within the group by service providers or representative organisations in Australia (Geraldine Jones, Fay Rice, pers. comm.)—this is perhaps because change in life circumstances and identity are important characteristics of ABI. People with brain injury from birth are more likely to be included in the intellectual disability group. However, common definitions of intellectual disability—which usually involve low intellectual functioning and onset before age 18—may encompass many people with brain injury acquired during childhood or teenage years (see Wen 1997).

2 Defining acquired brain injury

Clear, consistent definitions provide a basis for collecting reliable, comparable data. In the absence of consistency it can be difficult to know whether rates of ABI really differ between regions or over time, or whether different estimates merely reflect different operational definitions.

Many of the definitions discussed later in this chapter are used as a basis for estimating the incidence or prevalence of ABI. Both measures may be useful in measuring the impact of ABI at a community level, or assessing the need for services associated with ABI. However, when talking about 'incidence' and 'prevalence' it is important to distinguish between acquired brain injury as an event, or a critical episode, and disability attributable to ABI.

Incidence can be defined as the number of new cases of a condition diagnosed or reported during a specified time period (usually one year) (Pol & Thomas 1992). Most studies that look at the 'incidence' of ABI include all brain injury events, regardless of whether or not they lead to long-term disability. This provides information that is useful for monitoring trends in ABI-related morbidity and assessing demand for critical care services.

In some studies information on long-term outcome is collected, allowing an estimation of the 'incidence' of disability. The incidence of disability resulting from ABI is likely to reflect a mix of factors—the incidence of ABI in the population, the proportion of mild, moderate and severe cases, and the effectiveness of critical care and rehabilitation care services.

Prevalence is the total number of cases of a health condition within a population at a particular point in time (Pol & Thomas 1992). Most studies aimed at calculating the prevalence of ABI are actually interested in the number of people with ongoing disability from brain injury. This information is useful in assessing the need for appropriate disability support services.

Definitions of acquired brain injury (and other related terms) used in policy or administrative contexts, and in incidence studies and population surveys, are discussed in the remainder of this chapter.

Comparing definitions of ABI

Five 'elements' that commonly appear in definitions of ABI and related terms are:

(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 (at the body, person or society level); and

(v) the duration of functional effects.

The elements included in a particular definition will vary depending on the purpose for which the definition has been developed. In Tables 2.2, 2.3 and 2.5, following, definitions of ABI used for different purposes are broken down according to these five elements.

2.1 Definitions used in policy, legislative and administrative contexts

Two definitions from the USA and eight from Australia are given in Table 2.1. In Table 2.2 they are decomposed according to the five elements listed above. Typically the presence of actual injury to the brain is specified. Usually cause is also specified, by an exhaustive statement of causes included, an inclusive list of possible causes, and / or a list of causes that are not included. Only two of the definitions, both relating specifically to traumatic brain injury, mention immediate symptoms (Cuff & Donald 1987; Health Department Victoria et al. 1991). All the definitions contain some statement as to the nature of functional effects, and all but three mention duration (Table 2.2). Below, the definitions are discussed in detail.

USA definitions

Both definitions from the USA explicitly exclude brain injury caused by congenital or degenerative disorders or birth trauma (Table 2.1).

The official definition of the Brain Injury Association (USA) was developed (a) to provide a basis for the establishment of brain injury registries in all states, and (b) to be used by both lay and professional advocates in the development of services. It was not intended as an exclusive statement of the population served by the Brain Injury Association (Brain Injury Association 1997). It is a broad definition in that it includes brain injury resulting from a range of causes and is not very specific as to the nature, severity or duration of functional effects.

The definition given in the Traumatic Brain Injury Act of 1996 covers brain injury resulting from externally inflicted trauma or anoxia. The legislative history of the Act states that the injury should result in 'significant impairment' to functional abilities but, again, no durational requirement is specified. The purpose of the Act is primarily to provide for research aimed at reducing the incidence and impact of TBI, and projects aimed at improving service provision. Therefore, the definition was probably not intended as a basis for identifying individuals with TBI.

Australian definitions

The National Policy on Services for People with Acquired Brain Injury states that 'for definitional purposes, people with ABI are distinguished from people with congenital intellectual disability or a psychiatric disorder although there is some overlap'. The definition provided is quite broad, covering traumatic and non-traumatic ABI resulting from a range of causes and leading to impaired functioning which may be temporary or permanent and cause partial or total disability (Table 2.1). Elsewhere in the document it is stated that the National Policy on ABI is concerned with people who have severe or profound disability (according to the severity classification used by the ABS disability survey)—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 (e.g. Backhouse 1997).

A data research project was undertaken by the Ministerial Implementation Committee on Head Injury (MICHI) in Victoria to 'improve the data available for planning health, community and education services for people with acquired brain damage'. MICHI recommended the adoption of a set of definitions very similar to those set out in the

Table 2.1: Administrative, legislative and policy definitions of ABI (or related terms)

Source	Type	Definition
USA definitions		
Traumatic Brain Injury Act of 1996 (Pub L No 104–166, Stat 1445; HR No 104–652, 1135)	Legislation	Traumatic brain injury is defined as 'an acquired injury to the brain. Such term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include brain injuries caused by anoxia due to near drowning'. In the legislative history of the Act, traumatic brain injury is defined as 'brain damage from some externally inflicted trauma to the head that results in significant impairment to an individual's physical, psychosocial, and/or cognitive functional abilities'.
Brain Injury Association (USA) Brain Injury Association (1997)	Advocacy	'Acquired brain injury: injury to the brain which is not hereditary, congenital or degenerative.' The injury commonly results in a change in neuronal activity which affects the physical integrity, the metabolic activity or the functional ability of the cell. Causes include external forces applied to head and/or neck, anoxic/hypoxic injury, intracranial surgery, vascular disruption, infectious diseases, intracranial neoplasms, metabolic disorder, seizure disorders and toxic exposure. Brain injuries that are congenital or induced by birth trauma are not included. An acquired brain injury may result in mild, moderate, or severe impairments in one or more areas.
Australian definitions		
National Policy on Services for People with Acquired Brain Injury Department of Human Services and Health (1994)	Policy document	'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.' In addition to this general definition, six types of acquired brain injury are defined (i.e. brain injury related to trauma, alcohol, hypoxia, infection, tumour and stroke).
Cuff & Donald (1987)	Service planning and administration	'Injury to the brain may be called "severe head injury" or "severe brain injury"; it signifies loss of consciousness sufficient to cause some permanent deficit in function.' 'Brain injury is a form of acquired brain damage', caused by trauma.
'Head injury impact' project Health Department Victoria et al. (1991)	Service planning and administration	'Brain damage can be caused by stroke (cerebrovascular accident, CVA), brain tumour, infection, alcohol and drug abuse, AIDS, oxygen reduction, Alzheimer's Disease, or head injury (trauma).' Head injury: 'a history of a blow to the head and concussion or altered consciousness after relevant injury'. Brain injury: 'physical damage to or functional impairment of the brain which may result from head injury…and which may be manifested in disability'.

(continued)

Table 2.1 (continued): Administrative, legislative and policy definitions of ABI-related terms

Source	Type	Definition
Australian definitions		
Stanton et al. (1994)	Service planning and administration	Acquired brain injury: 'neurological impairment which is acquired after birth', distinguished from congenital brain damage or degenerative or genetically predisposed conditions. Causes include trauma, stroke, tumours, epilepsy and substance abuse.
Ministerial Implementation Committee on Head Injury (MICHI) Honey (1995a)	Service planning and administration	The Committee proposed a set of definitions very similar to those given in the National Policy on Services for People with Acquired Brain Injury: '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 may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment.' In addition to this general definition, five types of acquired brain injury are defined (i.e. brain injury related to trauma, alcohol, hypoxia, infection and tumour). Within each of these definitions it is stated that brain injury 'can also result in the disturbance of behavioural or emotional functioning'.
Rice (1994)	Service planning and administration	'Acquired brain injury refers to those instances where an individual sustains damage to the brain some time after birth. This can occur from "traumatic" or "non-traumatic" causes. The former describes those circumstances where an individual receives a blow to the head or where the head is forced to move rapidly forward or backward and sustains loss of consciousness…Alcohol and drug abuse, poisoning, near drowning, infection and disease, haemorrhage and tumour are some of the causes of non-traumatic brain injury.'
Commonwealth/State Disability Agreement (AIHW 1999a; Department of Health and Family Services 1998)	Service planning and administration	ABI: Characteristically, multiple disabilities arising from damage to the brain acquired after birth. Results in deterioration in cognitive, physical, emotional or independent functioning. Can be as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological disease etc. 'People with disabilities' means people with a disability which is likely to be permanent and results in substantially reduced capacity in self-care/management, mobility or communication, requiring ongoing or episodic support.
Brain Injuries Options Co-ordination, South Australia (BIOC) (Geraldine Jones, BIOC, pers. comm.)	Service planning and administration	BIOC adopts the definition of disability in the *Disability Services Act 1993* (SA), which covers people with a disability '(b) that is, or is likely to be, permanent; and is the result of the person having (i) a reduced capacity for social interaction, communication, learning, mobility, decision making or self-care; and (ii) a need for continuing support services'. The disability must be a result of brain injury acquired after birth. This includes brain injury due to aneurism, CVA, tumour, neurosurgery, anoxia, hypoxia, etc. It does not include brain injury due to degenerative diseases such as multiple sclerosis, Parkinson's, etc., but does include degeneration of unknown aetiology.

National Policy (Honey 1995a). Again, the definition of acquired brain injury contains no stated duration or severity requirement. However, in the report it is stated that the focus of the project was 'those forms of ABI which result in functional disability at a level sufficient to require long-term service provision'.

Most of the Australian definitions in Table 2.1 include brain injury resulting from a wide variety of causes. The definition of brain injury used by Cuff and Donald (1987) is limited to traumatic causes. Cuff and Donald state that 'brain injury' is a form of 'acquired brain damage', and that 'brain damage' may be acquired (e.g. due to injury, alcohol, stroke, encephalitis, tumour or senile dementia), or congenital (e.g. from congenital disorders, infections acquired in the womb, or foetal alcohol syndrome). The 'Head Injury Impact' Project also focused on 'brain injury' resulting from 'head injury', though a more inclusive definition of 'brain damage' was also given (Table 2.1).

Apart from Cuff and Donald (1987), all the definitions explicitly include stroke as a cause of ABI. Stanton et al. (1994) excluded stroke from their operational definition because the study was focused on people within the age range 16–65, for whom stroke is relatively uncommon. Four of the Australian definitions in Table 2.1 explicitly exclude congenital brain injury (Stanton et al. 1994; Rice 1994; AIHW 1994; Jones, BIOC, pers. comm.).

The definitions vary in the degree to which they specify the type, severity and duration of functional effects resulting from brain injury (Table 2.2). The National Policy and MICHI definitions envisage functional effects in a wide range of areas—cognitive, physical, emotional or independent functioning—that may be either temporary or permanent. Other definitions are non-specific about the types of effects that may result, for instance 'some permanent deficit in function' (Cuff & Donald 1987), 'physical damage to or functional impairment of the brain…which may be manifested in disability' (Health Department Victoria 1991). Other definitions do not incorporate the notion of ongoing functional impairment at all (e.g. Stanton et al. 1994; Rice 1994).

Definitions associated with disability support services are typically more specific about the severity and duration of disability resulting from ABI, reflecting service eligibility criteria. The Commonwealth / State Disability Agreement (CSDA), which relates to disability support services nationally, uses a definition of disability that is relatively narrow, including only people with disability that is likely to be permanent, and results in 'substantially reduced capacity' in certain areas, 'requiring ongoing or episodic support'. Likewise, the definition used by Brain Injuries Options Coordination (South Australia) to assess eligibility for services requires that a person have a disability that 'is, or is likely to be, permanent', and results in a 'reduced capacity' in specific areas and a 'need for continuing support services'.

2.2 Definitions used in studies of ABI incidence

There are very few studies that genuinely collect data on the 'incidence' of ABI. Most studies based on hospital data use rates of hospitalisation (admissions or separations) as indicative of incidence. However, for reasons outlined later in this report (Sections 4.1 and 4.2), rates of hospitalisation may not give a true reflection of incidence rates. This is so even if the focus of the study is solely TBI, for which most new cases might be expected to result in some hospital contact.

Most studies of ABI incidence 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

Table 2.2: Administrative, legislative and policy definitions of ABI (or related terms)—elements of definition [(a)]

Source	Country	Injury to brain	Cause	Immediate symptoms	Nature of functional effects	Duration of functional effects
Traumatic Brain Injury Act of 1996 (Pub L No 104–166, Stat 1445; HR No 104–652, 1135)	USA	'Injury to the brain'	Externally inflicted trauma to the head; excludes congenital or degenerative disorders and birth trauma; includes anoxia due to near drowning		Significant impairment to physical, psychosocial, and/or cognitive functional abilities	
Brain Injury Association (USA) (Brain Injury Association 1997)	USA	'Injury to the brain'	Range of possible causes given; not hereditary, congenital or degenerative		Mild, moderate or severe impairment in one or more areas	
National Policy on Services for People with Acquired Brain Injury Department of Human Services and Health (1994)	Australia	'Injury to the brain'	List of causes (not exclusive): trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological diseases or stroke		Deterioration in functioning, causing partial or total disability or psychosocial maladjustment	May be temporary or permanent
Cuff & Donald (1987)	Australia	'Injury to the brain'	Injury	Significantly affects consciousness	Deficit in function	Permanent deficit
'Head injury impact' project Health Department Victoria et al. (1991)	Australia	'Physical damage to or functional impairment of the brain'	May result from head injury—a blow to the head	Concussion/altered consciousness	May manifest in disability	
Stanton et al. (1994)	Australia	'Neurological impairment'	Congenital, degenerative conditions and genetic predisposition excluded			

Table 2.2 (continued): Administrative, legislative and policy definitions of ABI-related terms—elements of definition [(a)]

Source	Country	Injury to brain	Cause	Immediate symptoms	Functional effects	Duration of functional effects
Ministerial Implementation Committee on Head Injury (Victoria) Honey (1995a)	Australia	'Injury to the brain'	List of causes (not exclusive)		Deterioration in functioning causing partial or total disability or psychosocial maladjustment	
Rice (1994)	Australia	'Damage to the brain'	Traumatic or non-traumatic; 'some time after birth'			
Commonwealth/State Disability Agreement (AIHW 1999a; Department of Health and Family Services 1998)	Australia	'Damage to the brain'	List of causes (not exclusive); 'acquired after birth'		Deterioration in functioning, resulting in substantially reduced capacity in certain activities and need for ongoing support	Likely to be permanent
Brain Injuries Options Co-ordination, South Australia (BIOC) (Geraldine Jones, pers. comm.)	Australia	Brain injury	Certain degenerative diseases excluded; acquired after birth		Substantially reduced capacity in certain activities and need for ongoing support	Is, or is likely to be, permanent

(a) See Table 2.1 for definitions in full. Also refer to Chapter 2 introduction for explanation of the five 'elements' used to compare definitions of ABI (appearing as column headings in this table).

effects is not generally readily available. Typically, definitions focus on diagnoses and symptoms associated with brain injury. In many hospitals, both in Australia and overseas, diagnoses are routinely classified and coded using the International Classification of Diseases.

The International Classification of Diseases (ICD)

The World Health Organization's International Classification of Diseases (ICD) provides a detailed and internationally recognised system for describing the nature and cause of morbidity and mortality. The 9th Revision of the ICD (ICD–9) provides a system of 3- and 4-digit codes grouped into chapters. It is designed for 'the classification of morbidity and mortality information for statistical purposes, and for the indexing of hospital records…for data storage and retrieval' (National Coding Centre 1995).

A clinical modification of the classification, the ICD–9–CM, has been developed to provide a means of classifying morbidity data more precisely, in a way more appropriate for use by clinicians and other medical practitioners. The ICD–9–CM retains the sequence and content of the 3- and 4-digit codes of the ICD–9. However, a fifth digit is added to many of the existing codes and additional 4-digit codes are added in some instances to provide greater detail. An Australian version of the ICD–9–CM was developed by the National Coding Centre and became effective in 1995 (National Coding Centre 1995). Australian hospital data currently available in the National Hospital Morbidity Database use this ICD–9–CM classification to code diagnoses.

The ICD–9 or ICD–9–CM is often used in studies of ABI incidence for identifying cases of head injury or brain injury in hospital databases (Sorenson & Kraus 1991). Thus it forms the basis of the operational definitions used in many studies. The ICD–9 and ICD–9–CM also contain a supplementary classification of external causes of injury and poisoning, to be used in conjunction with the diagnosis codes contained in the main body of the classification. These 'E-codes' 'permit the classification of environmental events, circumstances, and conditions as the cause of injury, poisoning, and other adverse effects' (National Coding Centre 1995), and can therefore be used to record cause in cases of traumatic brain injury.

Operational definitions used in incidence studies

In Table 2.3 operational definitions used in ABI incidence studies overseas and in Australia are decomposed according to three of the five 'elements' identified at the beginning of Section 2. There was no requirement as to the nature or duration of functional effects in any of the incidence definitions reviewed.

Operational definitions of ABI in incidence studies often make reference to 'head injury' or the presence of specific diagnoses, rather than 'brain injury'. This probably reflects the difficulty of unequivocally determining the presence of brain injury during the critical phase of care.

Definitions are often based around a list of selected ICD codes. During a hospital episode an individual may have several diagnoses recorded. Under some definitions people are identified if one of the selected codes appears anywhere among their diagnoses (e.g. Hillier et al. 1997). In other studies only the principal diagnosis is considered (e.g. Selecki et al. 1981; Tate et al. 1998). In Australia, the 'principal diagnosis' is 'the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of care in hospital' (AIHW 1997b). A person admitted to hospital with brain injury after a car crash or fall may

have an associated injury (e.g. abdominal injury) recorded as their principal diagnosis. Therefore, an estimate of incidence based on principal diagnoses only is likely to be lower than an estimate using the same data based on all recorded diagnoses.

Depending on the specific diagnosis codes used in the definition, some of the people identified may not actually have brain injury. For instance, ICD codes for skull fracture are often used to identify cases of ABI, but skull fracture is not always accompanied by brain injury. Thus there is a danger of overestimating ABI incidence. To minimise this problem some studies use a shorter list of diagnosis codes, including only those most likely to indicate brain injury (e.g. codes for skull fracture with cerebral laceration and contusion—van Balen et al. 1996).

In other studies a more inclusive list of diagnosis codes (sometimes termed 'case-finding codes') is used to identify possible cases, which are then individually confirmed by checking for specific symptoms commonly associated with brain injury (e.g. Tate et al. 1998). Often, ICD diagnosis codes will be used to identify potential cases from a coded summary database, then individual medical records will be examined for uncoded information on symptoms such as altered consciousness, post-traumatic or retrograde amnesia, abnormal findings in neurological tests, seizures, headaches, vomiting and cerebrospinal fluid rhinorrhea (Anderson et al. 1980; Hillier et al. 1997).

Where coded hospital data are not available, an operational definition based solely on uncoded information documented in individual patient records can be used (e.g. Thurman et al. 1995; Tate et al. 1998). However, checking individual records is resource intensive and not usually a viable approach in very large studies.

In incidence study definitions the 'cause' of brain injury is often explicitly limited to 'trauma' or 'injury'. In many cases it is effectively limited by virtue of the specific ICD codes or symptoms used to identify brain injury. Three of the definitions given in Table 2.3 explicitly exclude brain injury due to birth trauma and other specified causes (Kalsbeek et al. 1980; Kraus et al. 1984; Stanton et al. 1994).

The National Center for Injury Prevention and Control is part of the Centers for Disease Control and Prevention (CDC) in the USA. In 1995 the Center produced guidelines for the surveillance of central nervous system injury, to facilitate the collection of comparable epidemiological data across the USA and thus further prevention and control efforts (Thurman et al. 1995). The guidelines provide definitions, data items, and methods for designing and implementing surveillance plans and analysing data. Both a 'clinical case definition' (for uncoded data) and a 'uniform data systems case definition' (a list of ICD–9 codes—see Table 2.4) are given. Under the clinical case definition TBI is defined either

- as an occurrence of injury to the head that is documented in a medical record, with one or more of the following conditions attributed to head injury: observed or self-reported decreased level of consciousness; amnesia; skull fracture; objective neurological or neuropsychological abnormality; diagnosed intracranial lesion, or
- as an occurrence of death resulting from trauma, with head injury listed on the death certificate, autopsy report, or medical examiner's report in the sequence of conditions that resulted in death. (Thurman et al. 1995)

The CDC definitions are used in a number of state-based traumatic brain injury and spinal cord injury surveillance programs throughout the USA (Thurman et al. 1995). The CDC uniform data systems case definition has recently been adopted by the Research Centre for Injury Studies in Australia in its work on traumatic brain injury (Peter O'Connor, pers. comm.).

Table 2.3: Definitions of ABI (or related terms) used in studies of incidence—elements of definition [(a)]

Source	Country	Injury to brain	Cause	Immediate symptoms
Wang et al. (1986)	China	Diagnosed 'brain injury'	Head trauma	Episode of unconsciousness; post-traumatic amnesia; evidence of focal brain dysfunction
Tiret et al. (1990)	France	Contusions, lacerations, skull fractures or brain injuries	Physical injury caused by external (mechanical) force	Loss of consciousness
Nestvold et al. (1988)	Norway	Head injury	Trauma to face, head or neck	Unconsciousness, retrograde or post-traumatic amnesia, skull or neck fracture, or trauma with headache, nausea or vomiting
van Balen et al. (1996)	Netherlands	Selected ICD–9 codes in primary or secondary diagnosis		
Caradoc-Davies & Dixon (1995)	New Zealand	Selected ICD–9 codes		
Brown & Nell (1991)	South Africa	'Cerebral laceration or contusion'; selected ICD–9 codes	Trauma	List of symptoms used if only 'case-finding' ICD diagnosis codes were recorded in coded summary data [(b)]
Vazquez-Barquero et al. (1992)	Spain	Head injury		Loss of consciousness; skull fracture; objective neurological findings attributed to head injury
Johansson et al. (1991)	Sweden	Selected ICD–9 codes		
Johnson & Gleave (1987)	UK	Diagnosed 'head injury'		

(continued)

Table 2.3 (continued): Definitions of ABI (or related terms) used in studies of incidence—elements of definition [a]

Source	Country	Injury to brain	Cause	Immediate symptoms
Kalsbeek et al. (1980) (see also Anderson et al. 1980)	USA	Selected ICD–8 codes	Caused by external (mechanical) force. Birth trauma excluded	List of symptoms used if only 'case-finding' ICD diagnosis codes were recorded in coded summary data [b]
Cooper et al. (1983)	USA	Selected ICD–9 codes	Traumatic injury to the head	Loss of consciousness >10 min; skull fracture; post-traumatic seizure; neurologic findings
Kraus et al. (1984)	USA	Diagnosed 'brain injury' (ICD–9 codes used for case-finding; hospital records checked in detail to verify diagnosis of brain injury)	Acute mechanical energy exchange; birth injury, infection, chronic degenerative processes and stroke excluded	
Fife et al. (1986)	USA	ICD–9 codes associated with 'head injuries likely to involve brain injuries'		
Fife (1987)	USA	Skull fracture or damage to cranial contents (assigned to specific ICD–9 codes)	Injury	Resulting in physician visit or at least one day of 'disability'
Guidelines for central nervous system injury surveillance—uniform data systems case definition (Thurman et al. 1995)	USA	Selected ICD–9 codes		
Guidelines for central nervous system injury surveillance—clinical case definition (Thurman et al. 1995)	USA		Injury to the head; excludes injury to face, eye, ear, or scalp, birth trauma, primary anoxic, inflammatory, infectious, toxic or metabolic encephalopathies, cancer, and ischaemic and haemorrhagic stroke	Decreased level of consciousness; amnesia; skull fracture; objective neurological or neuropsychological abnormality; or diagnosed intracranial lesion

(continued)

Table 2.3 (continued): Definitions of ABI (or related terms) used in studies of incidence—elements of definition [(a)]

Source	Country	Injury to brain	Cause	Immediate symptoms
Selecki et al. (1981)	Australia	Selected ICD–8 codes in primary diagnosis	Some diagnosis codes included only if selected external cause codes also recorded	
Tate et al. (1998)	Australia	Selected ICD–9 codes in principal diagnosis or history of head trauma ascertained from hospital records		'Definitive period of alteration of the conscious state'
Honey (1995a)	Australia	Selected ICD–9 codes		
Badcock (1988)	Australia	Diagnosed 'head injury'		
Stanton et al. (1994)	Australia	'Neurological impairment'	Excludes congenital brain damage, acquired foetal infection or toxicity, damage due to degeneration or genetic predisposition, and stroke	
Hillier et al. (1997)	Australia	Selected ICD–9 codes in primary or secondary diagnoses	Trauma to the head	Any of a specified list of symptoms

(a) There was no requirement as to the nature or duration of functional effects in any of the incidence definitions reviewed, so these 'elements' are not included in this table. Refer to Chapter 2 introduction for explanation of the five 'elements' used to compare definitions of ABI (appearing as column headings in this table).
(b) Two lists of ICD codes were used—'included' codes, indicative of direct injury to the brain, and 'case finding' codes, suggesting the possibility of injury to the brain. If an 'included' ICD code was recorded the case was included without further investigation. If only a 'case finding' code was recorded the medical record for the patient was checked and the case was included only if specified symptoms associated with brain injury were noted.

Scope of ICD codes used to define ABI

The ICD codes used to identify ABI in a range of studies are given in Table 2.4 (numbers quoted in the text here refer to the 'key to studies' at the bottom of Table 2.4). In the case of the US National Health Interview Survey (8) and the Australian ABS Survey of Disability, Ageing and Carers (10) the answers given to survey questions were assigned to appropriate ICD codes. In some studies referenced in Table 2.4 ICD codes were used as the sole basis for identifying cases of brain injury from coded summary data. In others ICD codes were used to identify possible cases, which were then included or excluded on the basis of more detailed information contained in individual medical records.

There are two core groups of 3-digit ICD codes used to identify traumatic brain injury (shaded in Table 2.4): those indicating skull fracture (800, 801, 803, 804), and those indicating concussion or intracranial injury (850–854). For these codes (excluding 850) the duration of loss of consciousness can be recorded as a fifth digit (National Coding Centre 1995).

Codes 850–854 are included in all studies in Table 2.4 except that of van Balen et al. (1996) (1), in which only concussion and cerebral laceration and contusion are included. Most studies also included the skull fracture codes. Brown and Nell (1991) (3) included codes 800–804 as 'case finding' codes, among other codes (e.g. cranial nerve injuries, traumatic complications and nervous system or endocrine system diseases). In their study, individuals with a diagnosis coded within this wider range were included only if certain symptoms were also recorded. Van Balen et al. (1996) (1) used a very conservative approach, selecting specific 4-digit skull fracture codes which specified cerebral contusion, to avoid an overestimation of incidence by including cases of skull fracture without brain injury. However, the choice of codes is curious, as 850 (concussion) is likely to include some people with very mild brain injury, whereas more severe cases of brain injury, possibly with substantial loss of consciousness recorded in the fifth digit, may well be coded to some of the skull fracture and intracranial injury codes not included in the study.

Two studies referenced in Table 2.4 included 'late effects' codes (Kraus et al. 1984; Tate et al. 1998) (6,13). These codes are used to indicate instances in which past injury is the cause of a condition itself classifiable to another code. Thus 'late effects' codes are more likely to identify people who have had a brain injury at some time in the past rather than people with newly incident cases of brain injury. Of the other codes listed, some are arguably more likely to be associated with brain injury than others, and the choice of codes will depend largely on the focus and objectives of a particular study.

Differences in the range of ICD codes used to identify people with ABI effectively mean that some operational definitions are broader than others. This is likely to affect the estimation of incidence rates, and must be considered when comparing incidence estimates from different studies.

2.3 Definitions used in disability prevalence studies

The prevalence of disability attributable to ABI is most commonly estimated using data from population disability surveys. Usually estimates are based on self-reported information provided in response to a set of questions designed to identify people with a disability. The International Classification of Impairments, Disabilities and Handicaps (WHO 1980) is often used as a conceptual framework in the design and interpretation of disability surveys.

Table 2.4: ICD–9 codes used in operational definitions

		Study (see key below for references)												
Code	**Description**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**
293.0	Acute delirium			x										
293.1	Subacute delirium			x										
294.0	Amnestic syndrome			x										
310	Specific nonpsychotic mental disorders due to organic brain damage			x										x
310.9	Unspecified nonpsychotic mental disorder following organic brain damage										x			
348.1	Anoxic brain damage										x	x		
800	Fracture of vault of skull		x			x	x	x	x	x	x	x	x	x
800.1	Closed with cerebral laceration and contusion	x												
800.6	Open with cerebral laceration and contusion	x												
801	Fracture of base of skull		x			x	x	x	x	x	x	x	x	x
801.1	Closed with cerebral laceration and contusion	x												
801.6	Open with cerebral laceration and contusion	x												
802	Fracture of face bones						x				x			
803	Other and unqualified skull fractures		x			x	x	x	x	x	x	x	x	x
803.1	Closed with cerebral laceration and contusion	x												
803.6	Open with cerebral laceration and contusion	x												
804	Multiple fractures involving skull or face with other bones		x			x	x	x		x	x	x	x	x
804.1	Closed with cerebral laceration and contusion	x												
804.6	Open with cerebral laceration and contusion	x												
805	Fracture of vertebral column without mention of spinal cord injury					x								
806	Fracture of vertebral column with spinal cord injury					x								

(continued)

Table 2.4 (continued): ICD–9 codes used in operational definitions

		Study (see key below for references)												
Code	**Description**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**
850	Concussion	x	x	x	x	x	x	x	x	x	x	x	x	x
851	Cerebral laceration and contusion	x	x	x	x	x	x	x	x	x	x	x	x	x
852	Subarachnoid, subdural and extradural haemorrhage following injury		x	x	x	x	x	x	x	x	x	x	x	x
853	Other and unspecified intracranial haemorrhage, following injury		x	x	x	x	x	x	x	x	x	x	x	x
854	Intracranial injury of other and unspecified nature		x	x	x	x	x	x	x	x	x	x	x	x
873	Open wound of head						x							
905.0	Late effects of fracture of skull and face bones						x							x
907.0	Late effect of intracranial injury without mention of skull fracture													x
997.0	Central nervous system complications										x			

Key to studies: 1. van Balen et al. (1996); 2. Caradoc-Davies & Dixon (1995); 3. Brown & Nell (1991); 4. Johansson et al. (1991); 5. Cooper et al. (1983); 6. Kraus et al. (1984); 7. Fife et al. (1986); 8. Fife (1987); 9. Thurman et al. (1995); 10. Madden et al. (1995); 11. Hillier et al. (1997); 12. Honey (1995a); 13. Tate et al. (1998).

The International Classification of Impairments, Disabilities and Handicaps (ICIDH)

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) is an internationally recognised classification system for disabilities (WHO 1980, 1997). It was designed to be complementary to the ICD, which focuses on diagnosis and procedure. While the ICIDH is not as widely used as the ICD as a basis for data collection, it is widely recognised as providing a sound conceptual framework for the consideration of disability (Chamie 1995). The classification describes disability in terms of three dimensions—impairment, disability, and handicap—each of which is related to a person's 'health experience'.

Impairment is defined as 'any loss or abnormality of psychological, physiological or anatomical structure or function', and is concerned with the functioning of individual parts of the body. Disability is defined as 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being', and relates to functioning at the level of the person. Handicap reflects the interaction between impairment or disability and environmental factors (i.e. the physical and social characteristics of a person's environment). It is defined as 'a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual' (WHO 1980).

The ICIDH is currently under review and the new draft ICIDH–2 is being trialed in several countries. One of the changes in the draft ICIDH–2 is that the terms 'disability' and 'handicap' have been replaced by the more neutral terms 'activity' and 'participation' (see Appendix 1 for definitions). The relationship between impairment, activity limitation, and participation restriction is complex, and mediated by factors operating in the external environment (for discussion see Madden & Hogan 1997).

Operational definitions used in prevalence studies

Operational definitions used in studies that look at the prevalence of disability attributable to ABI can be viewed in terms of the five 'elements' introduced at the beginning of Section 2 (Table 2.5). The term 'disability' is used here as an umbrella term, to mean negative experience in any one or more of the draft ICIDH–2 dimensions (i.e. an impairment, activity limitation, or participation restriction).

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 (Table 2.5). This is in contrast with definitions used in incidence studies (Table 2.3).

The first three studies in Table 2.5 were restricted to traumatic brain injury. The US National Head and Spinal Cord Injury Survey (Kalsbeek et al. 1980) was aimed at determining the frequency and economic costs of injury to the head and spinal cord (excluding that due to birth trauma), and was based on information from hospital records.

The 1993 Australian Disability Survey definition includes brain injury 'present at birth, or arising later' (ABS 1996b), reflecting the wording of the screening question used to identify ABI. The question asked people whether they had 'ever suffered a head injury, stroke or any

other brain damage'. The Canadian Health and Activity Limitation Survey only included brain injury acquired 'after birth'.

Some requirement as to the presence of functional effects is common to all the prevalence studies listed in Table 2.5, except that reported by Wang et al. (1986). For the National Head and Spinal Cord Injury Survey (Anderson et al. 1980) the requirement that a person 'received treatment or health care services associated with head injury in the past 6 months' has been included in the 'functional effects' column of Table 2.5 because the ongoing use of services might suggest that the person has continuing problems.

The US National Head and Spinal Cord Injury Survey provided an estimate of the 'frequency' rather than 'prevalence' of head injury. The estimate included people who were hospitalised for head injury during 1974 (whether or not they had ongoing problems as a result) and people who had been hospitalised for head injury during the period 1970–73, were still alive at follow-up in 1974 and were not deemed to have 'recovered'. Recovery was defined as not having received treatment or services associated with head injury from any provider of health care within the past 6 months. The authors acknowledged that this definition was likely to exclude some people with ongoing disability who were not continuing to access health services (Anderson et al. 1980).

The term 'functional effects' as used in Table 2.5 includes both impairment and activity limitation, as defined in the draft ICIDH–2. Some definitions are quite specific about the nature of functional effects (e.g. 'substantial behavioural change and / or significant memory loss', 'ongoing problems with ability to remember or learn'), while others are broader (e.g. 'long-term effects'). Given the wide array of impairments and activity limitations that can result from ABI, definitions that specify only a few specific types of impairments or activity limitations may result in underestimation of the prevalence of disability attributable to ABI.

The definitions used in the 1993 Australian Disability Survey and the Canadian Health and Activity Limitation Survey were the only two which included a durational requirement (i.e. effects that had lasted or were expected to last for at least 6 months). The South Australian Survey of Disability Prevalence included people who had ever experienced injury to the brain resulting in substantial behavioural change and / or significant memory loss. This suggests that even people who had no ongoing problems at the time of the survey may have been included.

2.4 Measures of severity and outcome

Measures of initial severity of brain injury usually relate specifically to traumatic brain injury. Some measure of severity is useful in the management of brain injury in the acute stages. Measures of severity are also used in studies of ABI, to define the study group or to assess outcome against initial severity. In combination with other factors, initial severity can be used as a predictor of outcome.

Measures of outcome after brain injury can be used to describe a person's level of disability or need for assistance. Outcome is often measured to assess the effectiveness of rehabilitation (i.e. to look at improvement over time). At a population level information about outcome after brain injury can be used to estimate the number of people in the community needing certain levels of support services.

Table 2.5: Definitions of ABI (or related terms) used in prevalence studies—elements of definition [(a)]

Source	Country	Injury to brain	Cause	Immediate symptoms	Nature of functional effects	Duration of functional effects
Wang et al. (1986)	China	Diagnosed 'brain injury'	Head trauma	Episode of unconsciousness; post-traumatic amnesia; past or present evidence of focal brain dysfunction		
Community disability survey, Scotland Bryden (1989)	UK	Disability or handicap caused by 'head injury'	Head injury		Disabled or handicapped in own or family's eyes	
National Head and Spinal Cord Injury Survey Kalsbeek et al. (1980); Anderson et al. (1980)	USA	ICD–8 codes associated with head or brain injury	External (mechanical) force. Birth trauma excluded	List of symptoms used if only 'case-finding' ICD diagnosis codes were recorded in coded summary data [(b)]	Received treatment or health care services associated with head injury within past 6 months	
Canadian Health and Activity Limitation Survey Statistics Canada (1991)	Canada	'Injury to the brain'	Not present at birth		Ongoing problems with ability to remember or learn	Has lasted or is expected to last for at least 6 months
ABS Survey of Disability, Ageing and Carers ABS (1996a)	Australia	'Head injury, stroke, or any other damage to the brain'			'Long-term effects'	Has lasted or is expected to last for at least 6 months
SA Survey of Disability Prevalence South Australian Health Commission (1998)	Australia	'Injury to the brain'	List of causes (not exclusive), including blow to the head, drowning or asphyxiation, stroke or illness		Substantial behavioural change and/or significant memory loss	'Reported ever experiencing'

(a) Refer to Chapter 2 introduction for explanation of the five 'elements' used to compare definitions of ABI (appearing as column headings in this table).
(b) Two lists of ICD codes were used—'included' codes, indicative of direct injury to the brain, and 'case finding' codes, suggesting the possibility of injury to the brain. If an 'included' ICD code was recorded the case was included without further investigation. If only a 'case finding' code was recorded the medical record for the patient was checked and the case was included only if specified symptoms associated with brain injury were noted.

Severity of brain injury

In investigating the incidence of traumatic brain injury the use of severity measures, that can be simply and reliably applied, aids the comparison of data from different sources. There are various approaches to measuring the severity of injury.

The Glasgow Coma Scale

The Glasgow Coma Scale (GCS) was initially proposed by Teasdale and Jennett (1974), as a tool for assessing the depth and duration of impaired consciousness and coma. Altered consciousness is an expression of dysfunction in the brain as a whole, and is an important indicator for gauging deterioration or improvement during the acute phase after head injury, and for predicting outcome. The GCS uses indicators—motor responsiveness, verbal performance and eye opening response—as independent measures of level of consciousness. The three measures are commonly combined to give a GCS 'score'. While this approach was not recommended by the original authors (Jennett 1976) it has become an internationally accepted standard for assessing depth of coma. A GCS score, ranging between 3 (no response to any stimulation) and 15 (no abnormalities in the three performance criteria), is routinely recorded for brain injury patients in many hospitals. In studies of ABI the GCS score is commonly used (either alone or in combination with other criteria) to define mild, moderate and severe brain injury.

The limitations of the GCS have been discussed by a number of authors. One criticism is that response in the three areas may be unreliable because of factors unrelated to brain injury. For instance, facial swelling may restrict eye opening, and response may be affected by alcohol or by drugs administered to reduce intracranial swelling (Kraus 1987; Sorenson & Kraus 1991). Using the GCS for comparison between studies can be problematic without standardisation of the time after injury at which the assessment is made. A person's state of consciousness may change substantially over a period of hours following injury, so time of assessment is quite important (Brown & Nell 1991; Hall & Johnston 1994; Kraus 1987). Also, loss of consciousness may not always correlate strongly with injury severity—where damage to the brain is localised there may be focal neurological dysfunction without loss of consciousness (Jennett 1976; Kraus 1987).

For these and other reasons, some authors have questioned the use of the GCS alone as a measure of severity. In some studies it has been used in conjunction with other indicators, such as length of hospital stay and neurological findings, to give a more reliable indication of severity (Kraus & Arsemanian 1989).

Other measures of severity of injury

Post-traumatic amnesia can be defined as the period between injury and the return of continuous memory (Brown & Nell 1991). It is generally considered a fairly good surrogate measure for severity (Jennett 1976; Levin 1989; but c.f. Levin 1989). Post-traumatic amnesia typically lasts four times as long as loss of consciousness (Guthkelch 1979, cited in Brown & Nell 1991).

Length of stay in hospital is commonly used as a measure of severity in hospital-based incidence studies. However, length of stay can be affected by factors other than severity of injury (Tennant et al. 1995). For instance, the presence of other injuries may result in a longer hospital stay. Also, elderly people and those who are injured far from home may tend to stay in hospital longer (Jennett 1996).

Hospital admission is an implicit criterion for defining the lower limit of severity in many studies of ABI incidence (Jennett 1976). The National Health Interview Surveys in the USA revealed that only 16% of people who had head injuries that resulted in at least a day of disability or a physician visit were hospitalised (Fife 1987).

Outcome

The measurement of outcome after brain injury is challenging, as individuals may have a complex array of enduring problems that affect their lives in various, often subtle ways. Some of the more common sequelae, such as problems with initiative or motivation, are particularly difficult to assess (Krefting et al. 1992).

There are many approaches to measuring outcome. Some approaches focus primarily on basic functioning at the level of the body, corresponding to the draft ICIDH–2 Impairment dimension. Other approaches look at the person's ability to do more complex activities independently, and to participate in various spheres of community life, corresponding to the Activity and Participation dimensions of the draft ICIDH–2 (see Appendix 1).

The Glasgow Outcome Scale

The Glasgow Outcome Scale (GOS) was developed to describe the severity of persisting disability after brain injury, and to complement the Glasgow Coma Scale to provide the basis for a predictive system specifically relevant to brain injury (Jennett & Bond 1975). The GOS is used to assess overall social outcome on the basis of a structured interview which concentrates on social and personal functioning, without the need for neurological or psychological evaluation. The scale consists of five exclusive categories: (i) death, (ii) persistent vegetative state, (iii) severe disability (conscious but dependent for daily support), (iv) moderate disability (disabled but independent), and (v) good recovery (people in this category may have minor neurological and psychological deficits) (Jennett & Bond 1975; Jennett et al. 1981).

Other measures of outcome

Some hospital-based incidence studies use destination on discharge (e.g. home, inpatient rehabilitation) as an indication of whether individuals have ongoing problems, beyond the initial period of critical care (e.g. Fife et al. 1986; Hillier et al. 1997; Kraus et al. 1984). However, destination may be influenced by factors other than a person's need for support or rehabilitation, such as hospital policy, the accessibility of appropriate rehabilitation care, the person's financial situation and the level of support available from family members. In addition, it is possible that some patients discharged to rehabilitation facilities may have been referred for injuries other than ABI.

Tate et al. (1989a) used an impairment-based approach to measure outcome at an average of 6 years post-injury—neurophysical and neuropsychological functioning were clinically assessed. People were also assessed against the GOS and there was good correlation between outcome as measured by the impairment classification and GOS category (Tate et al. 1989a).

Some studies have used various measures of participation to assess outcome. For instance, Tennant et al. (1995) used ability to occupy time, utilising the ICIDH concept of Occupation Handicap (WHO 1980). This measure was compared with the GOS. While 86% of people assessed had achieved a 'good recovery' on the GOS, only 64% were able to occupy their time (defined as being in full- or part-time employment, education or homemaking). Stilwell

et al. (1998) developed a ‘community outcome scale’, to measure aspects of outcome that depend on community response, in terms of minimising barriers and the impact of particular problems, rather than solely on impairments and activity limitations caused by the brain injury. This scale was also developed utilising concepts from the ICIDH Handicap dimension. Return to work has also been used as a measure of outcome (Asikainen et al. 1996; Johnson & Gleave 1987).

The Functional Independence Measure (FIM) is an outcome measurement instrument that was developed for use in rehabilitation practice. The FIM consists of 18 items, corresponding with daily activities, against which an individual may be scored. An expanded version of the FIM, the Functional Assessment Measure (FIM+FAM), was developed specifically for assessing rehabilitation outcomes of people with acquired brain injury. The FIM+FAM consists of the 18 FIM items, plus an additional 12 items that emphasise cognitive, communicative and psychosocial function. The activities covered by the FIM+FAM can be divided into five groups: self-care, mobility, communication, cognitive function and psychosocial (Hall & Johnston 1994; McPherson et al. 1996).

3 Review of existing estimates

3.1 Incidence

Problems arise when trying to compare incidence estimates from different studies, as operational definitions and study methodologies can affect estimates. Differences between estimates may reflect both real variations in the rate of brain injury between regions and over time, and differences in methodology.

Existing estimates of the incidence of ABI are presented in Table 3.1 (overseas estimates) and Table 3.2 (Australian estimates). Most studies use rates of hospitalisation as indicative of incidence (although factors other than incidence affect hospitalisation rates). Among hospital-based studies, operational definitions and methodologies can differ in terms of:

- whether data were from a single hospital or from multiple hospitals in a region—this is likely to affect sample size, catchment area, and the heterogeneity of the sample in terms of demographic and socioeconomic factors;
- methods of identifying cases of brain injury—both the source of data (e.g. coded summary data; individual medical records containing uncoded information), and the medical criteria used (e.g. specific diagnoses; symptoms);
- 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.

Important aspects of study methodology are summarised in Tables 3.1 and 3.2, where this information is provided in the published sources (see also Table 2.3 for more detailed analysis of operational definitions). Most of the estimates reviewed in this section relate to traumatic brain injury, rather than ABI more broadly.

Overseas estimates

Table 3.1 presents 15 estimates of ABI incidence overseas. All are expressed as number of incident cases of head / brain injury per 100,000 per year. The earliest estimate of incidence is for Minnesota, USA, during the decade 1965–1974, and the most recent is for Colorado in the 1990s.

Table 3.1: Overseas estimates of annual ABI incidence rates [a]

Rate (/100,000)	Study location and data collection period	Data sources and methods	Criteria for inclusion[b]	Population	Source
55	China 1982	Population survey, with review of available medical records	History of head trauma with loss of consciousness, post-traumatic amnesia, or clinical evidence of subsequent focal brain dysfunction. Deaths included	People living in households in six large cities	Wang et al. (1986)
281	Aquitaine, France 1986	Hospital admissions and death certificates—used sample approach rather than census	Contusion, laceration, skull fracture, or brain injury, and/or loss of consciousness following injury caused by external mechanical force. Residents of Aquitaine. Pre-hospital deaths included	Total population	Tiret et al. (1990)
372	Ravenna, Italy 1984–85	Hospital admissions—single hospital servicing study area	Examination by neurologist revealed indication of head injury (including loss of consciousness or post-traumatic amnesia). Non-residents included	Total population	Servadei et al. (1988)
228	New Zealand 1988	Hospital discharge data (all public hospitals)—excluding deaths	ICD–9 codes. Only people alive at discharge included. Transfers excluded	Total population	Caradoc-Davies & Dixon (1995)
236	Akershus County, Norway 1974	Hospital admissions and pre-hospital deaths	Trauma to face, head or neck with skull or neck fracture, or specified symptoms. Pre-hospital deaths included where head injury recorded (whether or not recorded as cause of death)	Total population	Nestvold et al. (1988)
316	Johannesburg, South Africa 1986–87	Hospital admissions—used sample approach rather than census	'Included' ICD–9 code, or 'case–finding' ICD–9 code with clinical symptoms of brain injury. Resident of Johannesburg. Only first admissions included	Age 15 and over	Nell & Brown (1991)
91	Cantabria, Spain 1988	Hospital admissions—single hospital servicing study area	Loss of consciousness, skull fracture or neurological findings attributable to head injury. Resident of Cantabria. Contacted hospital within 24 hours of injury	Total population	Vazquez-Barquero et al. (1992)

(continued)

Table 3.1 (continued): Overseas estimates of annual ABI incidence rates [a]

Rate (/100,000)	Study location and data collection period	Data sources and methods	Criteria for inclusion[b]	Population	Source
249	Umea district, Sweden 1984–85	Hospital admissions and pre-hospital deaths	Physician or autopsy diagnosed traumatic brain injury—implied symptoms of impaired brain function due to trauma. Surveyed ICD codes listed. Repeat brain injuries within study period excluded. Pre-hospital deaths included	16–60	Johansson et al. (1991)
160	Cambridge, UK 1982	Hospital admissions	Admissions with diagnosis of head injury	Total population	Johnson & Gleave (1987)
270 (males) 116 (females)	Olmsted County, Minnesota, USA 1965–74	Hospital admissions, emergency room visits, out-patient examinations, home visits, and death certificates (i.e. any medical attention)	Concussion with loss of consciousness, post-traumatic amnesia, neurologic signs of brain injury, and skull fracture (with or without altered consciousness). Pre-hospital deaths included	Total population (age-adjusted to 1970 USA population)	Annegers et al. (1980)
200	USA 1974	Sample survey of hospital data	'Included' ICD–8 code, or 'case–finding' ICD–8 code with clinical symptoms of brain injury	Total population	Kalsbeek et al. (1980) see also Anderson et al. (1980)
249	Bronx, New York, USA 1980–81	Hospital admissions, emergency room attendances, and Medical Examiner's reports—sample of hospitals serving the area	Loss of consciousness >10 min, skull fracture, post-traumatic seizure, or neurological findings attributable to head injury (ICD–9 codes used for some hospitals). Resident of Bronx. Identified within 24 hours of injury. Only first admissions included. Pre-hospital deaths included	Total population	Cooper et al. (1983)
152	Rhode Island, USA 1979–80	Hospital admissions— all hospitals in Rhode Island	ICD–9 codes	Total population	Fife et al. (1986)
160	San Diego, USA 1981	Hospital admissions—all hospitals in San Diego	ICD–9 codes used to flag cases, but only people with physician-diagnosed brain injury included	Total population	Kraus et al. (1984)
101	Colorado, USA 1990s	Traumatic Brain Injury Surveillance System. Hospital admission or death due to TBI	Skull fracture or intracranial injury	Total population	Brooks et al. (1997)

(a) See Table 2.3 for more detailed information on operational definitions used in incidence studies.
(b) Unless otherwise indicated it is assumed, based on information provided in the cited sources, that all estimates include deaths before discharge from hospital, but not deaths prior to admission.

Only two of the estimates were not based on hospital data. The lowest estimate (55, China 1982) was based on a population survey in six large cities, and the definition used was quite narrow, requiring clinical evidence of focal brain dysfunction. The estimates of brain injury incidence in Minnesota included all people who had 'head injury with evidence of presumed brain involvement', identified from hospital admissions, emergency room visits, out-patient examinations, home visits and death certificates. Although information was gathered from a wide range of sources, the overall estimate (which would lie somewhere between the reported 119 for females and 274 for males), is well within the range of estimates obtained from hospital data only (see Table 3.1).

Overseas estimates based on hospital data range from 91 to 372. It is difficult to assess the likely effect of definitional and methodological differences on the estimates obtained. Presumably studies that look at a number of hospitals, rather than a single hospital, and use a census rather than a sample approach to data collection, produce more reliable and representative data. Variation in the age structure of populations that use given hospitals is likely to be reflected in rates of hospitalisation for ABI (Moen & Batey 1986). Thus studies that combine data from a number of hospitals produce estimates that are effectively averaged across differences in demographic factors.

Many studies use a list of ICD codes to identify cases of brain injury. Some lists are longer and more inclusive than others (see Table 2.4). However, the extent to which the inclusion or exclusion of specific ICD codes will affect estimated incidence will depend on the distribution of cases between codes, and on hospital coding practices. Some codes may be used very infrequently, so their inclusion or exclusion will have little effect on the estimates arrived at. Unless the number of separations for each diagnosis code is reported it is difficult to assess the magnitude of the effect of including or excluding specific codes.

It has been argued that definitions that identify cases of brain injury solely on the basis of diagnosis codes recorded in summary data can lead to over-estimation of incidence (Willer et al. 1990). However, the extent of overestimation will depend on the particular codes used, and coding practice.

Estimates in Table 3.1 for New Zealand in 1988, the USA in 1974, Rhode Island in 1979–80, and Johannesburg in 1986–87 were based on operational definitions that used diagnosis codes to identify cases from coded summary data—these estimates range from 152 to 316. Estimates based on operational definitions that are arguably more rigorous, in that they require the presence of specific symptoms to identify brain injury (Minnesota 1965–74, Cantabria 1988, New York 1980–81, Ravenna 1984–85, Aquitaine 1986, Akershus County 1974 and Rhode Island 1981), range from 91 to 372.

Thus, based on the studies reported in Table 3.1, there does not seem to be any general tendency for what appear to be more restrictive definitions to produce lower estimates. This does not suggest that differences in operational definitions are not important in influencing estimates. Rather, there is such variation, due to other methodological differences and real differences in incidence rates, that any effect cannot be clearly detected.

Only two estimates in Table 3.1 are restricted to certain age groups within the population. The estimate for Johannesburg in 1986–87 (316) is for the population aged 15 and over, and the estimate for Umea District in 1984–85 (249) is for people aged 16 to 60. Both these estimates are relatively high. The effect of excluding certain age groups from the calculation of overall incidence rate will depend on age-specific rates of incidence, and the age structure of the population.

Some estimates include people who have died before hospital admission, where brain injury has been recorded in the coroner's report. These people may account for a substantial

proportion of all brain injuries (e.g. 12%, Kraus et al. 1984; 17%, Willer, cited in Honey 1995a; 3.8%, Selecki et al. 1981). People who die in hospital tend to make up a smaller proportion of the overall estimate (e.g. 7%, Willer, cited in Honey 1995a; 6%, Kraus et al. 1984; 2.3%, Selecki et al. 1981), but this group is more commonly included in estimates of incidence. It is important to consider deaths due to brain injury when discussing the overall impact of brain injury in a society. However, from a disability perspective, we are interested in those people who survive the critical phase and return to the community.

Australian estimates

Table 3.2 presents 11 estimates of incidence of brain injury in Australia. The estimates are all expressed as number of incident cases of head / brain injury per 100,000 per year. They range from 57 to 377—similar to the range for overseas estimates reported in Table 3.1 (55–372). Nine of the estimates are based on hospital admissions data but, as for the overseas estimates, operational definitions and methodologies differ substantially between studies.

The estimate of 160 for New South Wales in 1990 (Lyle et al. 1990) was derived by direct application of the incidence rate reported for San Diego (USA) in 1981 (see Table 3.1, Kraus et al. 1984). The objective of Lyle et al. (1990) was to predict the extent of brain injury in New South Wales by applying severity and outcome rates obtained in the San Diego study, as comparable local data were not available. The authors based their work on the assumption that brain injury rates in New South Wales and San Diego were similar. This assumption was supported by a detailed comparison of data collected by Selecki et al. (1981) in New South Wales with data from San Diego.

The estimate of 128 for Victoria in 1992 was derived using a formula developed by Willer (cited in Honey 1995a), based on the Canadian Health and Activity Limitation Survey. The methods by which the formula was devised are not reported by Honey (1995a).

Caution must be exercised if estimates and formulae based on studies conducted elsewhere are to be used to answer questions about rates of brain injury in Australia. Estimates can be affected by a range of factors, as well as differences in operational definitions and study methodology, including population sex and age structure and socioeconomic and cultural factors (such as levels of interpersonal violence), geography, traffic safety policy, and hospital admission practices. These factors are likely to differ between countries, and between regions within countries. Lyle et al. (1990) stated in their paper that 'reliance on these estimates for service development should be seen only as a short-term solution…Access to local information is essential for aetiological research, evaluation and monitoring'.

Of the nine estimates based on hospital data, six apply to the total population. The estimates for Victoria of 116 in 1987–88 and 104 in 1990 are limited to people aged 0–65, and the estimate of 57 for Western Australia in 1988–92 applies only to people aged 16–65. It is difficult to know what effect these restrictions have on the overall estimate.

The very low Western Australian estimate was based on a definition of brain injury that included traumatic head injury, ruptured aneurysm, neoplasms / tumour, post-infectious brain damage and anoxia. However, people were excluded if they did not stay in hospital for more than a day, were not resident in Western Australia or died in hospital, and 'duplicate' records were removed. These factors might partially explain the low estimate, particularly the exclusion of people who did not stay in hospital for more than a day. A high

Table 3.2: Australian estimates of annual ABI incidence rates [a]

Rate (/100,000)	Study location and data collection period	Data sources and methods	Criteria for inclusion[b]	Population	Source
377	NSW 1977	Admissions to all public hospitals in 1977, plus 50% sample of private hospitals in the first 6 months of 1978	Principal diagnosis only. List of ICD–8 codes all included, plus list of ICD–8 codes to be included if accompanying external cause code indicates trauma	Total population	Selecki et al. (1981)
100	NSW, North Coast Health Region 1988	Admissions to all 22 hospitals in the region	ICD–9 codes used to flag cases of possible brain injury in some hospitals. Diagnosis of brain injury, defined as documentation of a definitive period of alteration of the conscious state. Transfers excluded	Total population	Tate et al. (1998)
160	NSW 1990	Incidence rate for San Diego, 1981 (based on hospital admissions) applied to NSW without adjustment	ICD–9 codes used to flag cases, but only people with physician-diagnosed brain injury included	Total population	Lyle et al. (1990) Kraus et al. (1984)
116[c]	Vic 1987–88	Admissions to public hospitals—Patient Reporting System	Recorded as due to head injury	Age under 65	Health Department Victoria et al. (1991)
104	Vic 1990	Victorian Inpatient MDS (admissions to all public hospitals)	ICD–9–CM codes associated with head injury	Age 0–65	Honey (1995a)
128	Vic 1992	Formula developed from results of 1986 Canadian Health and Activity Limitation Survey applied to 1992 Victorian population data	Unclear whether or not pre-hospital deaths included	Total population	Willer, cited in Honey (1995a:29)

(continued)

Table 3.2 (continued): Australian estimates of annual ABI incidence rates [a]

Rate (/100,000)	Study location and data collection period	Data sources and methods	Criteria for inclusion[b]	Population	Source
200–300	Qld	Hospital admissions	No details given	Total population	Queensland Department of Family Services and Aboriginal and Islander Affairs (1994)
57[d]	WA 1988–92	Hospital admissions	List of conditions (specific ICD–9 codes not given); length of stay >1 day; of WA origin; duplicates removed. Only people alive at discharge included	Age 16–65	Stanton et al. (1994)
250	SA (one metropolitan region) 1984	Admission through accident and emergency department of one major hospital	Problem presented or diagnosis given indicated head injury. Deaths after admission included	Total population	Badcock (1988)
322	SA 1987	Hospital separations, all public and private hospitals in SA	Records flagged by ICD–9 codes, then a subset checked in detail against a clinical definition involving certain critical symptoms. Unclear whether deaths after admission included	Total population	Hillier et al. (1997)
232[e]	ACT 1977	Hospital admissions		Total population	Selecki et al. (1981)

(a) See Table 2.3 for more detailed information on operational definitions used in incidence studies.
(b) Unless otherwise indicated, it is assumed, based on information provided in the cited sources, that all estimates include deaths before discharge from hospital, but not deaths prior to admission.
(c) This figure was calculated using the annual number of incident cases (4,970) published in the source and ABS population data for Victoria as at 30 June 1988.
(d) This figure was calculated using the annual number of incident cases (600) and the population data provided in the source.
(e) This figure was calculated using information in the source on the number of ACT residents hospitalised for head injury (495) and ABS population data for the ACT as at 30 June 1977.

proportion of people who are admitted to hospital with head injury are discharged after one day. For example, in the hospital-based study of Selecki et al. (1981) 46% of patients admitted with head injury remained in hospital for one day or less.

For several of the hospital-based estimates there is little information on the 'criteria for inclusion' used. The three studies for which ICD–9 codes were specified (Hillier et al. 1997; Honey 1995a; Tate et al. 1998) differ slightly in the range of codes selected (Table 2.4). All three included codes for skull fracture (800, 801, 803 and 804) and intracranial injury (850–854). In addition, Hillier et al. (1997) included anoxic brain damage, and Tate et al. (1998) included non-psychotic mental disorders due to organic brain damage and 'late effects' of fracture of the skull and face bones and intracranial injury. Selecki et al. (1981) used a short list of ICD–8 codes (including birth trauma), plus an additional longer list of codes that were included if an accompanying external cause code indicating trauma was recorded. In practice, this definition is likely to have been quite broad, which might explain the high incidence estimate obtained for New South Wales (377) (although the estimate of 232 for the Australian Capital Territory, based on the same operational definition, was not so high). It should be noted that Selecki et al. (1981) and Tate et al. (1998) only included people for whom one of the selected ICD codes was recorded as principal diagnosis.

The 1990 Victorian study (Honey 1995a) included all records identified by the listed ICD codes. In the South Australian study, individual medical records for a sub-sample of cases identified using the ICD codes were checked against a 'clinical definition'. This required subjects to have been admitted to hospital with 'a presenting history of trauma to the head' resulting in any of a number of specified symptoms or conditions (Hillier et al. 1997). All records reviewed conformed to the clinical definition, so the overall estimate was effectively based on ICD–9 codes alone. In the North Coast study, records identified by the ICD diagnosis codes were excluded if there was no mention of 'a definitive period of alteration of the conscious state'. In contrast to the South Australian study, 846 of the 1,259 cases identified by ICD–9 codes were excluded because they did not meet this criterion. Had the clinical definition not been applied in the New South Wales North Coast study the estimate of 'incidence' would have been similar to that produced by the South Australian study.

Can we identify a 'reasonable range' for incidence estimates?

Having reviewed a number of estimated 'incidence' rates it is necessary to make some comment as to what might be considered a 'reasonable' estimate or range of estimates.

Looking first at the overseas estimates reviewed (Table 3.1), two were from studies based on non-hospital data (Wang et al. 1986; Annegers et al. 1980) and, because of the very different methodologies they used, it is difficult to make a meaningful comparison between these and the estimates based on hospital data.

However, methodologies also varied among the hospital-based studies. Two of the hospital-based studies were restricted to certain age groups (Nell & Brown 1991; Johansson et al. 1991). Given the very different levels of risk of brain injury (particularly TBI) associated with different age groups, these two studies will be excluded for the purpose of deciding on a 'reasonable' estimate for the total population.

Of the remaining estimates, those based on data from a single hospital might, in general, be less reliable as indicators of incidence for a variety of reasons, such as differences in demographic factors (e.g. socioeconomic status), admission policies and coding practices. Estimates based on data from a number of hospitals in a region are likely to be more reliable because they average across these differences.

Focusing on studies that used data from a number of hospitals, estimates ranged from 101 to 281 per 100,000 per year. Though operational definitions varied slightly between these studies, all were framed fairly narrowly to identify cases of head injury / traumatic brain injury. Two of the estimates (Cooper et al. 1983; Tiret et al. 1990) included deaths prior to hospitalisation. Exclusion of pre-hospital deaths would have reduced these estimates to about 270 per 100,000 in the case of the French study (Tiret et al. 1990) and 228 per 100,000 in the case of the New York study (Cooper et al. 1983).

Thus, based on overseas studies, a 'reasonable' estimate of the rate of hospitalisation due to traumatic brain injury would seem to lie within the range of 100 to 270 per 100,000 per year.

Similar reasoning can be followed to arrive at a 'reasonable' range of estimates based on Australian studies (Table 3.2). Excluding estimates not based on Australian hospital data (Lyle et al. 1990; Willer, cited in Honey 1995a), restricted to certain age groups (Health Department Victoria et al. 1991; Honey 1995a; Stanton et al. 1994) or based on data from a single hospital (Badcock 1988), the range of estimates is between 100 and 377 per 100,000 per year. Only one of these estimates is under 200 per 100,000 (Tate et al. 1998). This range of estimates is likely to be too broad for many applications.

Cumulative incidence

Annegers et al. (1980) estimated a lifetime cumulative incidence for traumatic brain injury (to age 75) of 20% for males and 8% for females. However, this is an inflated estimate of individual risk, because it was based on annual incidence rates and there was no adjustment for the fact that an individual may experience repeat brain injury events. In fact, the study found that people who had experienced one head injury were at increased risk of repeat head injury. Of the 3,587 head injury episodes in that study, 7% were not the first head injury experienced by the individual. It was calculated that, after one head injury a person was at three times the risk of a subsequent head injury, and after a second head injury this increased to eight times the risk of the general population. However, medical staff might be more likely to use technology such as CT scan or MRI to investigate a potential brain injury in a person who has a history of brain injury, leading to a greater proportion of subsequent brain injuries being confirmed and recorded.

3.2 Proportion of incident cases leading to long-term disability

If we have reliable information on the proportion of people who go on to experience long-term disability as a result of their brain injury, incidence data can potentially be used to calculate the number of people in the community needing ongoing support. However, studies that look at incidence rates of brain injury, and related incidence rates of resulting impairment or disability, are quite rare (van Balen et al. 1996).

Table 3.3 lists several studies that have provided estimates of the proportions of people who have brain injuries (mostly TBI) who go on to experience longer-term problems. The studies vary in terms of the definition of ABI used, what severity levels of ABI are included in the sample, time elapsed between injury and follow-up assessment, sample size, age groups considered, and measure of outcome. The proportions, as presented in Table 3.3, are calculated as a percentage of the sample of survivors assessed. In many of the studies more than one measure of outcome is used. As the outcome categories are generally not mutually exclusive, percentages should not be summed.

The first six studies presented in Table 3.3 included all new cases of head / brain injury, regardless of severity, admitted to a certain hospital (or hospitals) within a specified period. Three of these six only provide information collected at discharge from hospital. This information is of limited use in predicting the proportion of people who will experience long-term disability, as significant improvement commonly occurs in the first few months after brain injury (Jennett & Teasdale 1981).

What stands out looking at these first six studies is the variation in terms of how and when 'outcome' was measured. Some studies used more than one measure, producing quite different estimates of the proportion of people with ongoing problems or needs.

Kraus et al. (1984) used three measures of 'outcome' at discharge. They reported that 12% of people discharged alive were in need of ongoing care (primary care, rehabilitation, outpatient or home care). Using the Glasgow Outcome Scale, 5% of patients had moderate or severe disability or were in a persistent vegetative state. Seven per cent of patients had physician-diagnosed neurologic deficit or limitation.

Hillier et al. (1997) reported that 40% of people hospitalised for ABI had 'residual difficulties' on discharge, most commonly physical difficulties (experienced by 23% of people) and headaches (experienced by 21%). Eight percent of people needed some sort of physical assistance, particularly with mobility.

Five studies presented data on outcome for people who had 'severe' ABI (Cuff & Donald 1987; Johansson et al. 1991; Johnson & Gleave 1987; Tate et al. 1989a, b; Tennant et al. 1995). However, the definition of 'severe' differed between studies. Tennant et al. (1995) found that 16% of people experienced disability of moderate or greater severity (GOS). Taking an alternative approach to assessing outcome, based on the 1980 ICIDH concept of Occupational Handicap (WHO 1980), they found that 36% of people were unable to occupy their time in employment, education or homemaking. Ability to occupy time may be a useful measure of quality of life.

The last three studies in Table 3.3 deal with moderate brain injury (Rimel et al. 1982) and minor brain injury (Powell et al. 1996; Rimel et al. 1981). The two definitions of minor brain injury are very similar, and the follow-up time was 3 months after discharge in all three studies. In both studies of minor brain injury persistent symptoms were reported for around 85% of people. Powell et al. (1996) reported that the most common symptoms were headache (experienced by 46% of people) and tiredness (37% of people). Rimel et al. (1981) reported that 78% of people with minor ABI experienced persistent headaches and 59% had memory deficits. Of people with moderate ABI, 93% experienced headaches, 90% had memory deficits, and 87% had difficulties with activities of daily living (Rimel et al. 1982).

The three studies also looked at the percentage of people who were unemployed 3 months after discharge. A large proportion of people with moderate ABI who had been employed before injury were unemployed. The difference in the percentage of people unemployed in the two studies of minor brain injury (Powell et al. 1996; Rimel et al. 1981) might be explained by demographic differences between the two samples. Rimel et al. (1982) observed that factors such as education and socioeconomic status can significantly influence outcome after minor brain injury, while these factors are less important in determining outcome after moderate or severe brain injury, as their influence is overwhelmed by the severity of the injury itself.

Table 3.3: Estimates of the proportion of people who suffer adverse outcomes as a result of ABI [(a)]

Region and date	Measure of outcome[(b)(c)]	Proportion with specified outcome	Level of severity[(d)]	Time of assessment (relative to time of injury)	Sample size	Source
Rhode Island, USA, 1979–80	Discharged to chronic care institution:	4%	All levels	At discharge	2,870	Fife et al. (1986)
San Diego, USA, 1981	GOS moderate disability or worse:	5%	All levels	At discharge	2,972	Kraus et al. (1984)
	Need for continuing care/rehab on discharge:	12%				
	Neurologic deficits or disability:	7%				
South Australia, 1987	Discharge to rehab. care:	15%	All levels	At discharge	177	Hillier et al. (1997)
	Residual difficulties on discharge:	40%				
Cantabria, Spain, 1988	GOS moderate disability or worse:	3%	All levels	1 year	477	Vazquez-Barquero et al. (1992)
Umea, Sweden, 1984–85	Self-reported impairment:	35%	All levels	1.5–3 years	162 (aged 16–60)	Johansson et al. (1991)
	Self-reported disability:	15%				
Ravenna, Italy, 1984–85	GOS moderate disability or worse:	4%	All levels	3 months	370	Servadei et al. (1988)

(continued)

Table 3.3 (continued): Estimates of the proportion of people who suffer adverse outcomes as a result of ABI [(a)]

Region and date	Measure of outcome[(b)(c)]	Proportion with specified outcome	Level of severity[(d)]	Time of assessment (relative to time of injury)	Sample size	Source
Cambridge, UK, 1980–82	Unemployable:	19%	Severe: post-traumatic amnesia >24 hours	Min. 2 years	68	Johnson & Gleave (1987)
North West Region, UK, 1974–83	GOS moderate disability or worse:	16%	Severe: length of stay in neurosurgery > 1 week	2–13 years	176 (aged 16–50)	Tennant et al. (1995)
	Unable to occupy time:	36%				
Canton St Gallen, Switzerland, 1987	GOS moderate disability or worse:	33%	Severe: intracranial lesions detected by CT scan	3 years	45	Annoni et al. (1992)
	Capacity for work reduced:	55%				
Western Metropolitan Health Region of Sydney	GOS moderate disability or worse:	48%	Severe: sufficient severity to necessitate inpatient rehabilitation after acute medical management	3–10 years (average 6 years)	87 (aged 15–45 at admission)	Tate et al. (1989a) Tate et al. (1989b)
	Neurophysical and/or neuro-psychological Impairment:	91%				
	'Substantially limited' or 'poor' psychosocial outcome:	76%				
NSW	GOS moderate and severe disability:	30%	Severe	?	?	Cuff & Donald (1987)

(continued)

Table 3.3 (continued): Estimates of the proportion of people who suffer adverse outcomes as a result of ABI [(a)]

Region and date	Measure of outcome[(b)(c)]	Proportion with specified outcome	Level of severity[(d)]	Time of assessment (relative to time of injury)	Sample size	Source
Virginia, USA, 1977–79	GOS moderate disability or worse: Persistent symptoms: Unemployed (% of those employed before injury):	22% 84% 34%	Minor: loss of consciousness ≤20 minutes, GCS ∫13 and length of stay ≤48 hours	3 months	424	Rimel et al. (1981) Rimel et al. (1982)
Virginia, USA, 1977–79	GOS moderate disability or worse: Persistent symptoms: Unemployed (% of those employed before injury):	61% 96% 69%	Moderate: GCS 9–12	3 months	170	Rimel et al. (1982)
Berkshire, UK, 1992–93	Persisting symptoms: Not returned to work:	86% 5%	Minor: loss of consciousness ≤20 minutes, GCS ∫13, post-traumatic amnesia ≤24 hours, and no complications	3 months	46	Powell et al. (1996)

(a) The definitions of head/brain injury used in many of these studies can be found in Table 2.3.
(b) GOS=Glasgow Outcome Scale.
(c) In many of the studies more than one measure of outcome is used. As the outcome categories are not mutually exclusive, percentages should not be summed,
(d) GCS=Glasgow Coma Scale.

The Glasgow Outcome Scale (GOS) is used as a measure of outcome in a number of the studies cited. An outcome of 'moderate disability or worse' includes moderate disability, severe disability and persistent vegetative state (see Section 2.4). If assessment is made soon after injury many patients might be expected to recover sufficiently over subsequent months to reach a better outcome category on the scale. Assessments made a year or more after injury are more likely to reflect the ultimate level of long-term disability that will be experienced (Jennett & Teasdale 1981).

The three studies that used the GOS to assess people with all levels of initial injury severity gave similar estimates of the proportion of people with moderate disability or worse (3–5%), although the time at which assessment was made varied between studies (Kraus et al. 1984; Servadei et al. 1988; Vazquez-Barquero et al. 1992). Studies that include all levels of injury severity might be more readily comparable with one another than studies that focus on brain injuries of a particular severity. Differing definitions of severity level can add an extra source of variation.

The studies focusing on severe brain injury produced varying estimates of the proportion of people with moderate disability or worse, ranging from 16% to 48% (Annoni et al. 1992; Cuff & Donald 1987; Tate et al. 1989b; Tennant et al. 1995). Surprisingly, in the study reported by Rimel et al. (1981, 1982), 22% of people with mild brain injury and 61% of people with moderate brain injury had moderate disability or worse at the 3 month follow-up. These proportions are substantially higher than those reported for samples that included brain injury of all severities, and even some of the studies looking at severe injury only. These differences suggest that, even using a widely accepted scale for assessing outcome (the GCS) it can be difficult to make valid comparisons between studies.

3.3 Prevalence

There are relatively few existing estimates of the prevalence of long-term disability attributable to ABI, either in Australia or overseas. Information about the incidence of ABI is sometimes used, in conjunction with other information, to calculate prevalence estimates. However, such estimates usually rely on a series of assumptions that are not easily verified. Also, these estimates are subject to the same limitations as the incidence data on which they are based. Prevalence estimates based on population surveys may be more reliable indicators of real prevalence rates. However, operational definitions and methodologies vary between surveys so, as with estimates of incidence, caution should be exercised when comparing estimates from different studies.

Overseas estimates

Table 3.4 presents five overseas estimates of the prevalence of disability attributable to ABI, varying between 62 and 783 per 100,000. Three of the estimates are based on population surveys, and are limited to people living in households. However, the survey methodologies and operational definitions used vary.

The 1983 estimate for China (783) was based on a door-to-door survey in six large cities. People who gave responses indicating unconsciousness following head injury or past or present evidence of focal brain dysfunction resulting from head injury were asked to be examined by a neurosurgeon, who gave a diagnosis based on examination and review of

Table 3.4: Overseas estimates of prevalence rates of disability attributable to ABI [(a)]

Rate (/100,000)	Study location and data collection period	Data sources and methods	Criteria for inclusion	Population	Source
783	China 1983	Population survey, with review of available medical records	History of head trauma with loss of consciousness, post-traumatic amnesia, or clinical evidence of subsequent focal brain dysfunction	People living in households in six large cities	Wang et al. (1986)
62	Canada 1986	Health and Activity Limitation Survey—survey of individuals with disability identified through census question	Limited in normal daily activity; ongoing problems with ability to remember and learn due to injury to brain acquired after birth	People living in households, age 15 and over	Steger Moscato et al. (1994)
100	UK 1982	Population survey	Disabled or handicapped in own or family's eyes; disability caused by head injury	People living in households	Bryden (1989)
100	UK 1988	Cited in a report by the Medical Disability Society	Disabled survivors of brain injury	Total population (unclear in source)	Tennant et al. (1995)
439	USA 1974	Sample survey of hospital data 1970–74, with patient follow-up in 1974	People first hospitalised for head injury during 1970–74 and still alive in 1974 and having received health services treatment related to head injury during last 6 months of 1973 or during 1974[(b)]	Total population	Kalsbeek et al. (1980) (see also Anderson et al. 1980)

(a) See Table 2.5 for more detailed information on operational definitions used in prevalence studies.
(b) The US National Head and Spinal Cord Injury Survey provided an estimate of the 'frequency'. The count included people who were hospitalised for head injury during 1974 (whether or not they suffered ongoing problems as a result) and people who had been hospitalised for head injury during the period 1970–73, were still alive at follow-up in 1974 and were not deemed to have 'recovered'. Recovery was defined as not having received treatment or services associated with head injury from any provider of health care within the past 6 months. The rate was obtained by dividing this count by the average population of the USA in 1974.

available medical records. The operational definition used may have included people who once had a brain injury, but who did not have ongoing sequelae (Wang et al. 1986).

In the Canadian Survey people were initially identified as having a disability through a question in the Canadian census about whether they were limited in 'normal daily living'. The follow-up Health and Activity Limitation Survey then identified people as having ABI if they reported 'ongoing problems with ability to remember and learn', due to injury to the brain acquired after birth. It seems that brain injury due to stroke, disease (e.g. brain tumour, Alzheimer's disease), ageing or developmental delay was excluded (Dawson & Chipman 1995). This fairly narrow definition may in part explain the low estimate. Also, the estimate did not include people with ABI living in establishments. The fact that the estimate was limited to people aged 15 and over should not have resulted in a lower rate, as the prevalence of disability attributable to TBI tends to be highest in the middle adult years (Steger Moscato et al. 1994).

The 1982 estimate for the UK was based on a household population survey carried out in a particularly socioeconomically disadvantaged region in Scotland. The survey identified people with a disability or handicap caused by head injury and was therefore, presumably, limited to traumatic brain injury. Disability or handicap was identified by the question: 'Is there anyone living here whose everyday life is affected by illness, disability or injury, either physical or mental, or by problems due to age (e.g. arthritis, rheumatism or heart trouble), injury, or defect of sight, hearing or mobility?' (Bryden 1989).

The National Head and Spinal Cord Injury Survey in the USA (Kalsbeek et al. 1980) used a very different approach to estimating the 'frequency' of head injury. The data were taken from a sample of hospital records drawn from a sample of hospitals throughout the contiguous United States. The estimate included all people hospitalised for head injury during 1974, plus people who had been hospitalised for head injury during the period 1970–73, were still alive at follow-up in 1974 and were not deemed to have 'recovered'. Recovery was defined as not having received treatment or services associated with head injury from any provider of health care within the past 6 months. Thus, people with ongoing disability who were not accessing health services would have been excluded. People with disability due to a head injury sustained prior to 1970 were also not included. These factors would tend to lead to an underestimate. However, people hospitalised in 1974 were included regardless of whether they experienced ongoing problems as a result of head injury. This would tend to lead to an overestimate, if the rate was considered as a measure of prevalence.

Given the very different definitions and methodologies used it is difficult to draw any conclusions about how 'reasonable' the various estimates presented in Table 3.4 might be. It is likely that real rates of prevalence differ between the countries represented, due to factors such as different levels of interpersonal violence, traffic safety standards, and the quality and availability of acute care and rehabilitation.

Australian estimates

Table 3.5 presents nine existing estimates of ABI prevalence within Australia. Methodologies vary, with six of the estimates based on data from the 1993 ABS disability survey. Four of the estimates (Western Australia 1991, South Australia 1996–97 and the two estimates for Australia 1993) are markedly higher than any of the overseas estimates presented in Table 3.4.

The first estimate of prevalence for the whole of Australia based on the 1993 ABS disability survey includes all people who answered positively to the screening question about long-

term effects of head injury, stroke or other brain damage (ABS 1996b). The second, slightly higher, estimate for Australia (Madden et al. 1995) was arrived at by identifying people who answered positively to the screening question on long-term effects of head injury, stroke or other brain damage and / or reported an ABI-related disabling condition, and reported a limitation, restriction or need for help. (This method is equivalent to the approach based on 'all disabling conditions plus activity limitation' explained in Section 4.3.)

Estimates for Western Australia and the Australian Capital Territory based on the ABS disability survey include only people who reported head injury, stroke or other brain damage as their main disabling condition. People who had long-term effects of head injury, stroke or other brain damage, but reported some other condition as their 'main disabling condition' were not included in these estimates. It should also be noted that these estimates are based on small sample sizes and are subject to relative standard errors of between 25% and 50%.

The Western Australian estimate of 1,696 per 100,000 (Stanton et al. 1994) included only people aged between 16 and 65 and was obtained using a population modelling approach and incidence rates based on hospital data. While it is not perfectly clear from the information published, it would seem to be an estimate of the number of people in the community who have had a brain injury at some point, whether or not they have ongoing disability as a result.

The other two estimates for Western Australia are based on the 1993 ABS disability survey. Rook (1994) stated that 2,700 people in Western Australia with a disability had a main disabling condition of 'head injury / stroke / any other brain damage' (Rook 1994:9). Applying ABS population figures for Western Australia in 1993 gives a rate of 161 per 100,000. This is substantially lower than the '0.4% of all Western Australians' who reported ABI as the main cause of their disability (Alessandri et al. 1996:9). Without further information on the methodology used it is not possible to explain the difference between these two estimates.

The estimate of the prevalence of disability attributable to ABI obtained using data from the South Australian Survey of Disability Prevalence was 1,740 per 100,000. Both the South Australian Survey and the 1993 ABS Survey of Disability, Ageing and Carers used fairly broad definitions, in that ABI was not limited to brain injury resulting from particular causes, and stroke was explicitly included in both surveys. The South Australian Survey definition was perhaps narrower, as it specified brain injury 'resulting in a substantial behavioural change and / or significant memory loss', while the ABS survey did not specify the type of 'long-term effects'. However, the ABS survey did specify that 'long-term effects' meant effects that had lasted or were expected to last 6 months or more, while the South Australian survey definition did not impose a minimum duration requirement. The South Australian estimate is limited to people living in households, while the estimates based on the ABS survey data also include people living in establishments.

3.4 Non-traumatic ABI

Most of the estimates reviewed above, particularly the estimates of incidence, focus primarily on traumatic brain injury. Estimates of the incidence and prevalence of other subgroups of ABI are less easily found in the literature. Below, we briefly review definitions and existing incidence and prevalence estimates for two subgroups of ABI—stroke and alcohol-related brain injury—and mention some other causes of ABI.

Table 3.5: Australian estimates of prevalence rates of disability attributable to ABI

Rate (/100,000)	Study location and data collection period	Data sources and methods	Criteria for inclusion	Population	Source
294[(a)]	Vic 1993	1993 ABS Survey of Disability, Ageing and Carers	Unclear from information published in source	Total population	Honey (1995a)
240–290	Vic	Based on a 'realistic interpretation' of estimates derived from various data sources	Long-term moderate or severe disability	Aged under 65 (unclear in source)	Health Department Victoria et al. (1991)
1,696[(b)]	WA 1991	Hospital admissions data used to determine incidence, then demographic model of WA population used to calculate prevalence based on incidence	List of conditions; alive on discharge; length of stay >1 day; of WA origin	Age 16–65	Stanton et al. (1994)
161[(c)]	WA 1993	1993 ABS Survey of Disability, Ageing and Carers	People with a disability (as defined in the survey) who reported ABI as their main disabling condition	Total population	Rook (1994)
400	WA 1993	1993 ABS Survey of Disability, Ageing and Carers	People with a disability (as defined in the survey) who reported ABI as their main disabling condition	Total population	Alessandri et al. (1996)

(continued)

Table 3.5 (continued): Australian estimates of prevalence rates of disability attributable to ABI

Rate (/100,000)	Study location and data collection period	Data sources and methods	Criteria for inclusion	Population	Source
1,740	SA 1996–97	South Australian Survey of Disability Prevalence—telephone survey	Brain injury caused by e.g. drowning, asphyxiation, stroke or illness resulting in a substantial behavioural change and/or significant memory loss	People living in households	South Australian Health Commission (1998)
134[(d)]	ACT 1993	1993 ABS Survey of Disability, Ageing and Carers	People with a disability (as defined in the survey) who reported ABI as their main disabling condition	Total population	Gilbert (1997)
1,400	Australia 1993	1993 ABS Survey of Disability, Ageing and Carers	People with a disability (as defined in the survey) who gave a positive response to the screening question on long-term effects of head injury, stroke, or any other brain damage	Total population	Australian Bureau of Statistics (ABS) (1996a)
1,920[(e)]	Australia 1993	1993 ABS Survey of Disability, Ageing and Carers	AIHW method: disability (as defined in the survey), plus positive response to relevant screening question and/or reported relevant ICD code, plus 'filter' based on restrictions and limitations	Total population	Madden et al. (1995)

(a) This figure was calculated using the estimated number of people (13,100) published in the source and ABS population data for Victoria as at March 1993.
(b) This figure was calculated using the estimated number of people (17,843) and population data for WA in 991 published in the source.
(c) This figure was calculated using the estimated number of people (2,700) published in the source and ABS population data for WA as at March 1993.
(d) This figure was calculated using the estimated number of people (400) published in the source and ABS population data for the ACT as at March 1993.
(e) This figure was calculated using the estimated number of people (338,469) published in the source and ABS population data for Australia as at March 1993.

Stroke

Stroke is the second most common cause of death in Australia, after coronary heart disease, and is an important cause of disability (AIHW 1999b). While stroke is a cause of death and disability in people of all ages, it occurs most commonly in the later years of life. In older people disability tends to result from multiple causes. Therefore, it can be difficult to distinguish disability caused by stroke from disability caused by other conditions, both in individuals and in epidemiological studies (Campbell et al. 1994).

Definitions

The definition of stroke used by the World Health Organization (WHO) is 'sudden onset of clinical signs of focal or global disturbance of cerebral function lasting more than 24 hours (except in cases of sudden death or if the development of symptoms is interrupted by a surgical intervention) with no apparent cause other than vascular' (The WHO Monica Project 1990, cited in Sarti et al. 1994). Many studies of stroke epidemiology have used the WHO definition, or definitions based closely on it (e.g. Christie 1982; Wolfe et al. 1993).

Table 3.6: ICD–9 diagnosis codes for cerebrovascular conditions

3-digit code	Description
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	Transient cerebral ischaemia
436	Acute, but ill-defined, cerebrovascular disease
437	Other and ill-defined cerebrovascular disease
438	Late effects of cerebrovascular disease

Source: National Coding Centre (1995)

In some studies ICD–9 codes are used to identify stroke in coded hospital morbidity and mortality data (see Table 3.6). However, the range of codes included differs between studies. Codes 430–438 cover all cerebrovascular disease and its after-effects (Bennett et al. 1994), but a smaller subset can be used to identify acute 'stroke' events. An Australian study looking at rehabilitation after stroke used ICD–9 codes 430–436, excluding 437 and 438 (Shah et al. 1991). Tuomilehto et al. (1993) defined stroke using ICD–9 codes 430–434, and 436, excluding 435, 437 and 438. A transient ischaemic attack (TIA—included within code 435) is an episode of acute neurological deficit that resolves completely within 24 hours (Toole 1994), and therefore does not come within the WHO definition of stroke. However, mild but definite cognitive deficits have been documented in some TIA patients (Toole 1994).

Epidemiology of stroke and stroke-related disability

Incidence

Incidence of stroke can be affected by the age, sex and race mix of a population. Estimates of incidence can also vary depending on whether only first-ever-in-a-lifetime strokes or all strokes are counted, whether transient ischaemic attacks are included, and what diagnostic criteria are used (US Department of Health and Human Services 1995).

Estimates of stroke incidence based solely on hospital admissions are likely to be underestimates, as not all people who have a stroke are admitted to hospital (Bonita et al. 1984). The Perth Community Stroke Study found that 20% of all stroke events were managed entirely outside hospital, and that the likelihood of being admitted to hospital after a stroke decreased with increasing age (Anderson et al. 1993). In developed countries hospital admission may reflect a person's living arrangements and the extent to which help is available to them at home, as well as the severity of their stroke (Poungvarin 1998). Many studies, therefore, use information from a variety of sources (e.g. GPs, hospitals, nursing homes, health centres) so that the majority of stroke events occurring within a community are identified.

In Table 3.7 overseas and Australian estimates of stroke incidence rates are given. In all cases where it was specified, the working definition of stroke used was the WHO definition, or a definition based closely on it. However, methodology and the population age range considered differed between studies, so comparisons should be made with caution.

In addition to the estimates presented in Table 3.7, Aho et al. (1980) presented estimates of stroke incidence for 14 countries, based on a study coordinated by the WHO in which data were collected in the early 1970s through registers set up at local hospitals or health centres. Age-standardised estimates of incidence (all attacks) ranged from 189 per 100,000 per year in Sri Lanka to 1,344 per 100,000 in Japan. Warlow (1998), in a review of stroke epidemiology, gave an annual incidence estimate of 200 per 100,000 first-ever-in-a-lifetime strokes, based on studies in 'various white populations'. In general, first-ever strokes account for 70–80% of all stroke events (Anderson et al. 1993; Bonita et al. 1984, 1994; Sarti et al. 1994).

Of the three Australian estimates, the Melbourne figure of 380 per 100,000 is the highest for incidence for all stroke events (Christie 1981). However, the Melbourne study included only people aged over 25, while the Sydney and Perth studies included people of all ages (Fisher et al. 1979; Anderson et al. 1993). Including people aged 25 and under would be expected to produce a lower overall estimate, as few cases of stroke are likely to occur in this age group—their inclusion will increase the denominator without a proportionate increase in the numerator. The three studies also differed in terms of the number of data sources used (GPs, hospitals, nursing homes, etc.), which may also have contributed to differences in estimated incidence.

In both the Melbourne and Perth studies data were collected over a period of 18 months. As some studies have found that stroke incidence varies with season (e.g. Giroud et al. 1989), collecting data over periods that are not multiples of 12 months may bias annual incidence rates.

Several studies have revealed substantially higher rates of stroke in men than in women (Anderson et al. 1993). Data from the Finland study indicated a male to female rate ratio of around 1.8 for both 'first-ever' and all strokes (Sarti et al. 1994). Aho et al. (1980) reported male to female rate ratios for first-ever stroke ranging from 1.0 in Israel to 2.0 in Japan. In

Table 3.7: Overseas and Australian estimates of stroke incidence

Incidence (/100,000 per year)		Study location and data collection period	Data sources and methodology	Early mortality	Population	Source
All strokes	**First ever**					
Overseas estimates						
346 (m) 193 (f)	269 (m) 154 (f)	Finland 1983–85	Data collected from hospital admission/discharge diagnoses and death certificates	30% (m) 26% (f) (4 weeks, % all strokes)	People aged 25–74	Sarti et al. (1994)
326 (m) 180 (f)	252 (m) 143 (f)	Finland 1987–89	Data collected from hospital admission/discharge diagnoses and death certificates	21% (m) 24% (f) (4 weeks, % all strokes)	People aged 25–74	Sarti et al. (1994)
145		Dijon, France 1985–87	Stroke registry of Dijon—data from hospitals and GPs	12.5%—first week 21.5%—first month 30%—first year	Total population	Giroud et al. (1989)
224	170	New Zealand, 1981	Data collected from hospitals, GPs, death certificates, rest homes, locum and emergency services	33.5% (1 month) 43.5% (6 months) 48.5% (1 year) (% of first events during study period)	People aged 15 and over	Bonita et al. (1984)
195	142	New Zealand, 1991	Data collected from GPs, hospital medical staff, private physicians and supervisors of hostels and nursing homes	All strokes: 24% at 4 weeks	Age-standardised to world population aged $\geq$ 15	Bonita et al. 1994
	330	Taiwan, 1990	Population study, with annual follow-up over 4 years. Stroke confirmed by physician	17.3% (1 month, % first strokes)	People aged > 35	Hu et al. (1992)

(continued)

Table 3.7 (continued): Overseas and Australian estimates of stroke incidence

Incidence (/100,000 per year)		Study location and data collection period	Data sources and methodology	Early mortality	Population	Source
All strokes	**First ever**					
	160	Oxfordshire, UK 1981–86	Data collected from GPs and hospitals, and patients were assessed by neurosurgeon to confirm stroke	19% (1 month) 31% (1 year)	Total population	Bamford et al. (1990), Bamford et al. (1988)
	6.3 (age <45) 35 (age 45–54) 149 (age 55–64) 397 (age 65–74)	England 1989–90	Data collected from GPs, district nursing and rehab services, hospital admissions and death certificates	26% (3 weeks, % first strokes)	People aged under 75	Wolfe et al. (1993)
	200		Review of incidence rates in white populations	20% (1 month, % first strokes)	Total population	Warlow (1998)
Australian estimates						
380		Melbourne, Victoria 1978–79 (18 months)	Data collected from GPs, hospitals and ambulance calls	24% (3 weeks, % all strokes)	People aged over 25	Christie (1981)
205	160	Sydney, NSW 1979–80	Data collected from GPs and hospital records	33% (12 weeks, % all strokes)	Total population	Fisher et al. (1979)
258	178	Perth, WA 1989–90 (18 months)	Data collected from GPs, hospital medical staff, private physicians and supervisors of hostels and nursing homes	All strokes: 24% at 4 weeks 39% at 1 year First ever strokes: 23% at 4 weeks 36% at 1 year	Total population	Anderson et al. (1993)

Australia, while men have higher rates of stroke, greater numbers of women are affected by stroke because more women than men live into old age (AIHW 1999b).

Stroke incidence rates also increase dramatically with age (Aho et al. 1980; Bamford et al. 1988; Bonita et al. 1994; Giroud et al. 1989; Wolfe et al. 1993). A projection study conducted by the National Health and Medical Research Council (NHMRC) in 1996 suggested that, '[a]ssuming stable incidence rates and patterns of care, the changing age / sex structure of the population is expected to result in a 69% increase in the number of new cases of stroke per year' (National Stroke Foundation 1997).

Prevalence

Prevalence of stroke survivors in a community depends on rates of incidence and mortality. As with ABI generally, a distinction must be drawn between the prevalence of people who have ever had a stroke, and the prevalence of people who have some ongoing disability resulting from stroke. Measuring the prevalence of stroke-related disability is difficult because co-morbidities, such as osteoarthritis and dementia, are common in older people and make it difficult to establish the extent to which stroke contributes to the overall level of disability (Warlow 1998).

Estimates of the prevalence of people who have ever experienced a stroke vary considerably (Table 3.8). Again, this may partly reflect the different age ranges to which the estimates apply. The estimate range for India (90–222 per 100,000) is substantially lower than the others given in Table 3.8. The estimate for Taiwan (1,642) is substantially higher, but it relates to an older population (people aged over 35) than any of the other estimates. The estimates reported by Wade (1988) for the UK indicate that 50% of people in the community who have ever had a stroke have 'significant problems' as a result. The New Zealand study found that slightly over half of all people who have ever had a stroke make an 'incomplete recovery', and about 20% require assistance in at least one area of self-care (Bonita et al. 1997). The data also indicated that, among stroke survivors, more women (27%) were dependent on others for self-care activities than men (16%) (Bonita et al. 1997).

The three Australian prevalence estimates fall within the range of the overseas estimates presented. The estimate of 990 per 100,000 was based on the 1995 National Health Survey, a 5 yearly population survey that collects self-reported information on the health status of Australians. The National Health Survey does not provide information on people living in establishments (i.e. nursing homes, etc.). The estimate covers all health conditions coded to ICD–9 codes 430–438, including 435 (transient cerebral ischaemia)—a more inclusive definition than those used in most of the other studies presented in Table 3.8.

The Victorian estimate was from a community-based stroke study in which people who had a stroke were followed up at intervals for two years. Survival rates over the 2 year period were used to calculate the estimated community prevalence of 792 per 100,000. This, along with information about disability experienced by survivors, was used to produce an estimate of the prevalence of disability attributable to stroke—slightly over 200 per 100,000. Disability was defined as 'not being independent in all [activities of daily living] and / or not being able to walk at least 100 metres unaided' (Christie 1981).

The Perth estimate of 1,200 per 100,000 was based on the Perth Community Stroke Study. Methods of estimation were not detailed in the source (NHMRC 1997).

Table 3.8: Overseas and Australian estimates of the prevalence of stroke and disability attributable to stroke

Prevalence (/100,000)					
Ever had stroke	**Disability**	**Location and date**	**Data sources and methodology**	**Population**	**Source**
Overseas estimates					
820	623	Finland, 1973–76	Follow-up examination—part of prospective population study (only stroke treated in hospitals, health centres and homes for the elderly detected)	People aged 20 and over	Aho et al. (1986)
90–222		India	Not specified	Total population	Cited in Poungvarin (1998)
833	461 (incomplete recovery) 173 (ADL[(a)] disability)	Auckland, New Zealand, 1992	Estimates derived from two population-based incidence studies (1981–82 and 1991–92) using an actuarial model	People aged ≥ 15	Bonita et al. (1997)
1,642	540 (ADL[(a)])	Taiwan, 1986	Population-based study	People aged >35	Hu et al. (1989)
690		Bangkok, Thailand	Population survey with professional medical examination to confirm stroke	People aged >20	Viriyavejakul et al. (1983)

(continued)

Table 3.8 (continued): Overseas and Australian estimates of the prevalence of stroke and disability attributable to stroke

Prevalence (/100,000)					
Ever had stroke	**Disability**	**Location and date**	**Data sources and methodology**	**Population**	**Source**
Overseas estimates (continued)					
831		UK, 1985	Office of Population Censuses and Surveys disability survey data	Total population	Clark & Opit (1994)
600	300	UK	Not specified	Total population	Wade (1988)
Australian estimates					
792	200	Victoria, 1979	Incidence data collected from GPs, hospitals and ambulance calls. Follow-up of patients at intervals to 2 years post-stroke used to calculate prevalence	People aged >25	Christie (1981)
1,200		Perth, 1990	Based on Perth Community Stroke Study—methods not detailed in source	Total population	NHMRC (1997)
990		Australia, 1995	National Health Survey—stroke and other cerebrovascular disease reported by respondents and classified and coded by ABS as ICD–9 codes 430–438	People aged 25 and over	AIHW analysis of 1995 National Health Survey data

(a) ADL = activities of daily living.

Alcohol-related brain injury

Alcohol-related brain injury (ARBI) is 'physical injury sustained by a part or parts of the brain, as a result of excessive consumption of alcohol' (ARBIAS 1996). Although reliable estimates of the incidence and prevalence of ARBI are particularly difficult to obtain, there is some evidence to suggest that rates of ARBI are higher in Australia than in other comparable countries (Connelly 1993; Harper et al. 1989). ARBI is recognised to be a major cause of ABI-related disability, particularly in the middle-adult years (Honey 1995b).

As well as being a primary cause of ABI, alcohol can be a risk factor for traumatic brain injury (TBI). The association of alcohol with TBI (particularly due to road accidents) has been well documented (Kraus 1987). Rimel et al. (1981, 1982) found that the proportion of brain-injured patients who had positive blood alcohol levels at admission to hospital increased with injury severity—43% of patients with mild injury, 73% of patients with moderate injury, and 84% of patients with severe injury. Mean blood alcohol level also increased with injury severity.

Intoxication can interfere with diagnosis and severity assessment after TBI, as alcohol tends to depress consciousness, as measured using the Glasgow Coma Scale (Kraus 1987). This may hamper physicians in prescribing appropriate management for brain-injured patients during the critical phase of care. There is also a suggestion that alcohol abuse can result in more severe damage and poorer outcome in the event of TBI (Levin 1989; R nty et al. 1993).

Characteristics of ARBI

The mechanisms by which excessive alcohol consumption brings about brain damage are likely to be several, and are not yet properly understood. Both the direct neurotoxic effect of alcohol and thiamine (Vitamin B1) malnutrition that commonly accompanies alcoholism are thought to contribute to alcohol-related brain damage (Tuck & Jackson 1991). Some types of neurological damage caused by alcohol abuse seem to be at least partially reversible (Oscar-Berman et al. 1997).

In its 'Guide to general practitioners and health professionals', the ARBI services and support organisation ARBIAS identifies six disorders commonly associated with ARBI: cerebellar atrophy, peripheral neuropathy, hepatic encephalopathy, frontal lobe dysfunction, Wernicke's encephalopathy and Korsakoff's amnestic syndrome (ARBIAS 1996). Wernicke's encephalopathy, an acute neurological illness caused by severe thiamine deficiency, and Korsakoff's amnestic syndrome, a chronic disorder of cognitive function, seem to be associated conditions, though the relationship between them is not fully understood. The term 'Wernicke–Korsakoff syndrome' (WKS) is frequently used in the literature, though its specific meaning is somewhat unclear.

ARBI is similar to other forms of ABI in terms of the types of impairment that commonly result (Honey 1995b). Alcoholics tend to exhibit fairly circumscribed patterns of cognitive deficit, rather than global impairment. Characteristic types of impairment include disturbances of executive function (e.g. difficulties with planning, problem solving), memory impairment, disorders of awareness (e.g. denial, lack of motivation), and emotional problems (e.g. confusion and anger) (ARBIAS 1996).

Estimates of incidence and prevalence

Obtaining estimates of the proportion of the population affected by ARBI is especially challenging because of underdiagnosis. The particular stigma attached to ARBI may affect the willingness of individuals to identify as having ARBI. Also, relatively few cases of ARBI are treated in the acute care system, and there is no other common point for collection of data. Even when individuals do come into contact with the health care system their condition may not be recognised, as diagnosis involves comprehensive neuropsychological and neurological assessment—there is no easily administered screening tool (Honey 1995b). The earliest signs of cognitive impairment are subtle and doctors are unlikely to suspect brain damage until it is well established (Tuck & Jackson 1991).

However, hospital-based studies have been used to obtain estimates of incidence and / or prevalence. Table 3.9 presents some estimates of rates of ARBI in Australia and overseas. The methods used for obtaining estimates vary between studies. Other estimates not reported here are referred to in the sources cited.

Overseas estimates

Thompson et al. (1988) estimated the proportion of the population of England and Wales affected by alcohol-related brain injury at 2% (Table 3.9). This figure was based on evidence from previous studies that about 50% of heavy drinkers showed signs of cognitive impairment, and that 4% of the adult population of England and Wales were heavy drinkers (Thomson et al. 1988).

Victor and Laureno (1978) provided two estimates of the prevalence of Wernicke–Korsakoff syndrome in the USA based on hospital admissions—cases were identified by the presence of a combination of characteristic clinical symptoms (e.g. ataxia of gait, mental confusion). The estimates of 130 per 100,000 (Boston) and 50 per 100,000 (Massachusetts) represent the proportion of all hospital admissions. The estimates of 2,200 per 100,000 (for Wernicke's encephalopathy) and 4,100 per 100,000 (for cerebellar atrophy) are proportions of all autopsies conducted at a major hospital in Cleveland over a 13 ½ year period.

The estimates of 800 per 100,000 for Wernicke's encephalopathy and 1,700 per 100,000 for cerebellar atrophy in Norway also represent the proportion of all autopsies conducted (Torvik et al. 1982). The authors noted that alcohol consumption in Norway is considerably lower than in most other western countries.

Australian estimates

In a retrospective study of medical records in 17 public general hospitals in Sydney between 1978 and 1993, cases of Wernicke's encephalopathy, Korsakoff's psychosis, and WKS were identified using ICD–9 codes and specified diagnostic criteria. A total of 1,267 cases were identified, including 10 non-alcoholic patients with WKS. Over the 16-year period, rates of WKS (calculated as a proportion of all hospital admissions) decreased from about 32 per 100,000 in 1978 to 23 per 100,000 in 1993. Thiamine enrichment of bread flour (mandatory in Australia since 1991) and a decrease in national alcohol consumption were discussed as possible contributors to the decrease (Ma & Truswell 1995).

Gold et al. (1986) conducted a 12-month hospital surveillance program in an inner urban area of Sydney. They produced an estimate for the 'attack rate' (presumably meaning 'incidence') of cerebral alcohol syndrome of 38 per 100,000 per year. Cerebral alcohol syndrome was used as a blanket term to mean 'the spectrum of cognitive dysfunction associated with chronic alcohol abuse'.

Table 3.9: Estimates of the proportion of the population affected by ARBI, overseas and in Australia

Rate (per 100,000)	Location, date and population	Data sources and methods	Source
Overseas			
2,000	England and Wales 1980s (adult population)	Information on the prevalence of cognitive impairment in alcoholics combined with information on the proportion of adults who drink heavily	Thomson et al. (1988)
130	USA	Admissions to single major general hospital with Wernicke–Korsakoff syndrome	cited in Victor & Laureno (1978)
50	USA	Admissions to single major general hospital with Wernicke–Korsakoff syndrome	cited in Victor & Laureno (1978)
Autopsy studies (calculated as proportion of autopsies performed)			
800 (Wernicke's encephalopathy) 1,700 (cerebellar atrophy)	Oslo, Norway 1975–79	Autopsies from hospitals in the Oslo area	Torvik et al. 1982
2,200 (Wernicke's encephalopathy) 4,100 (cerebellar degeneration)	USA, 1963–76	Post-mortem material from single major general hospital	Victor & Laureno (1978)
Australia			
38 ('cerebral alcohol syndrome')	NSW, 1981 (age >15)	Condition identified in hospitalised patients, confirmed by neuropsychological screening. Rates calculated as proportion of population aged >15	Gold et al. (1986)
23 (Wernicke's encephalopathy and/or Korsakoff's psychosis)	NSW, 1993	Condition identified through hospital records. Rates calculated as proportion of all admissions	Ma & Truswell (1995)
Autopsy studies (calculated as proportion of autopsies performed)			
2,800 (Wernicke's encephalopathy)	WA, 1973–81 (age > 20)	Autopsy study (131 cases identified)—forensic and hospital autopsies	Harper (1983)
2,100 (Wernicke–Korsakoff syndrome)	NSW, ? (age >15))	Autopsy study (6 cases identified)—forensic and hospital autopsies	Harper et al. (1989)
1,100 (Wernicke–Korsakoff syndrome)	NSW, 1996–97 (age >15)	Autopsy study (25 cases identified)—forensic autopsies only	Harper et al. (1998)

The remaining three Australian estimates presented are based on autopsy studies. A study of 4,677 brains of patients aged over 20 between 1973 and 1981 in Western Australia revealed 2.8% (2,800 per 100,000) with Wernicke's encephalopathy. This 2.8% was described as 'incidence'. The rate was substantially higher among coroners' necropsies (4.7%) than among necropsies performed at the Royal Perth Hospital (1.7%). For the combined sample, incidence was highest for people aged in their fifties, and 75% of the cases identified were in males. A review of medical records indicated that in at least 90% of the cases alcoholism was the cause. Only 20% of the cases had been clinically diagnosed (Harper 1983).

Two similar autopsy studies were conducted in Sydney (Harper et al. 1989; Harper et al. 1998). In these, the rates obtained were reported as 'prevalence' rather than 'incidence'—probably a more accurate description. In the 1996–97 study, based on autopsies from the New South Wales Institute of Forensic Medicine, 25 cases of WKS were identified among the 2,212 brains examined—a prevalence of 1.1% (Harper et al. 1998). This rate was compared with the rate of 4.7% for coroners' necropsies from the 1973–81 Western Australian study (no comparison with the previous New South Wales study was made, possibly because of the small sample size in that study). The authors suggested that the significant reduction in prevalence might have been due to the fortification of bread flour with thiamine.

Because of the different methodologies used, a direct comparison of estimates from clinical studies and autopsy studies is not appropriate. As well as different approaches to the identification of ARBI cases, rates were calculated in quite different ways. In the three autopsy studies rates of WKS were calculated as a proportion of all autopsies. The two clinical studies used very different approaches to calculating rates—Ma and Truswell (1995) reported WKS as a proportion of all hospital admissions, while Gold et al. (1986) used the population of the study area as the denominator. Thus the populations being considered in these various studies were at very different levels of risk for WKS.

Nonetheless, it is somewhat surprising that the two clinical studies produced rates so similar in magnitude, and so much lower than the rates from the autopsy studies. One explanation for this may be the high level of under-diagnosis of Wernicke–Korsakoff syndrome in living patients (Harper 1983). Also, the clinical studies included a cross-section of people at different stages of life. Many people included may not have had ARBI at the time of the study, but may have developed it in later life. In contrast, the autopsy studies included only people at the end of life, and thus provide what is essentially a cumulative prevalence estimate, or a measure of the lifetime 'risk' of acquiring ARBI.

Other causes of ABI

Neurological diseases such as multiple sclerosis can cause ABI, although, as mentioned in Section 2.1, disability resulting from such causes may be grouped as neurological disability rather than ABI. Jacobson et al. (1997) used incidence and prevalence rates from numerous studies conducted in western countries and published between 1965 and 1995 to estimate the population burden of multiple sclerosis. They calculated a pooled (weighted mean) prevalence rate of 58.3 per 100,000, and a pooled (weighted mean) incidence rate of 3.2 per 100,000. Their review suggested that there had been an increase in the prevalence of multiple sclerosis over the 30-year period.

McLeod et al. (1994) reported results of a 1981 study looking at the prevalence of multiple sclerosis in Australia. Age-standardised prevalence varied markedly across Australia between 11.8 per 100,000 in tropical Queensland and 75.6 per 100,000 in Hobart—these results supported a previously noted increase in prevalence with increasing latitude. Females were two to three times more likely to have multiple sclerosis than males. The

authors did not report on levels of disability. In Australia age of onset for multiple sclerosis is generally between 20 and 50 years, and the mean duration of the disease (from onset to death) is more than 25 years (Hammond et al. 1988).

Diseases such as dementia (e.g. Alzheimer's disease) and Parkinson's disease are important causes of ABI, particularly in older people. It would seem that stroke survivors are at particularly high risk of developing dementia. Results from an Italian population survey found dementia present in about 8% of people aged 65 years or over. However, dementia was much more common in people who had a history of stroke (30%) than in people who had never had a stroke (6%) (Prencipe et al. 1997). Similarly, a survey of people aged 75 years and older in Stockholm found that rates of dementia were three times higher among people with a history of stroke (Zhu et al. 1998). Given its high prevalence in older people dementia is a substantial contributor to the overall impact of ABI.

Volatile substance abuse is another cause of brain injury, particularly among young people. Substances inhaled include petrol, glue and other hydrocarbon products such as liquid correction fluid. Petrol sniffing is recognised as an important cause of sickness and death in some Aboriginal communities in Australia (Brady 1992). Goodheart and Dunne (1994) conducted a study of 25 patients admitted to the Royal Perth Hospital between 1984 and 1991 with a diagnosis of intentional petrol sniffing. Eight of the 20 'chronic' petrol sniffers died while in hospital. Results of neuropathological examination of these eight patients showed abnormalities in all cases. Of the survivors, only one was functionally independent at discharge. While the short-term effects of inhalation may be attributable to several constituents of petrol, the long-term effects are thought to be largely a result of organic lead poisoning. The 11 patients with particularly high blood lead levels had very poor outcomes—eight died in hospital and the remaining three were left with moderate to severe handicap.

There are other important causes of ABI which we are, unfortunately, unable to review here, due to space limitations and the general lack of information available in the published literature. Honey (1995a) has reviewed data available on ABI caused by tumour, hypoxia and infection, and has discussed some of the difficulties associated with gathering data on these subgroups of ABI.

3.5 Summary of estimates reviewed

Most of the estimates of ABI incidence and prevalence reviewed in this chapter relate to traumatic brain injury. Though some estimates of rates of other types of ABI are available in the literature, differences in definition and methodology make it impossible to construct a picture of the overall impact of ABI in Australia or overseas. Even for TBI, on which numerous studies have been conducted, it is very difficult to put forward a 'best estimate' for incidence or prevalence.

Hospital separation data, while they do not provide information on incidence as such, are collected in a systematic manner across Australia. These data may provide a reasonable basis for monitoring the level and demographic pattern of demand for acute care services associated with traumatic brain injury, and perhaps other ABI subgroups. There is patchy information on the proportion of people who experience a traumatic brain injury or stroke who go on to have long-term disabilities. However, definitional problems are compounded here by questions about when and how to measure 'outcome' and what constitutes disability.

The 1993 ABS Survey of Disability, Ageing and Carers is the most commonly used source of data for estimating the prevalence of ABI, although estimates vary depending on the operational definition employed (e.g. whether 'main disabling condition' or 'all disabling conditions' is used—Table 3.5). Despite its limitations (discussed further in Section 4.3) the ABS survey is the best source of disability prevalence data currently available in Australia.

More detailed information about the nature and level of support needed by people with ABI, at the population level, is likely to rely on first establishing reliable estimates of incidence and prevalence.

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.

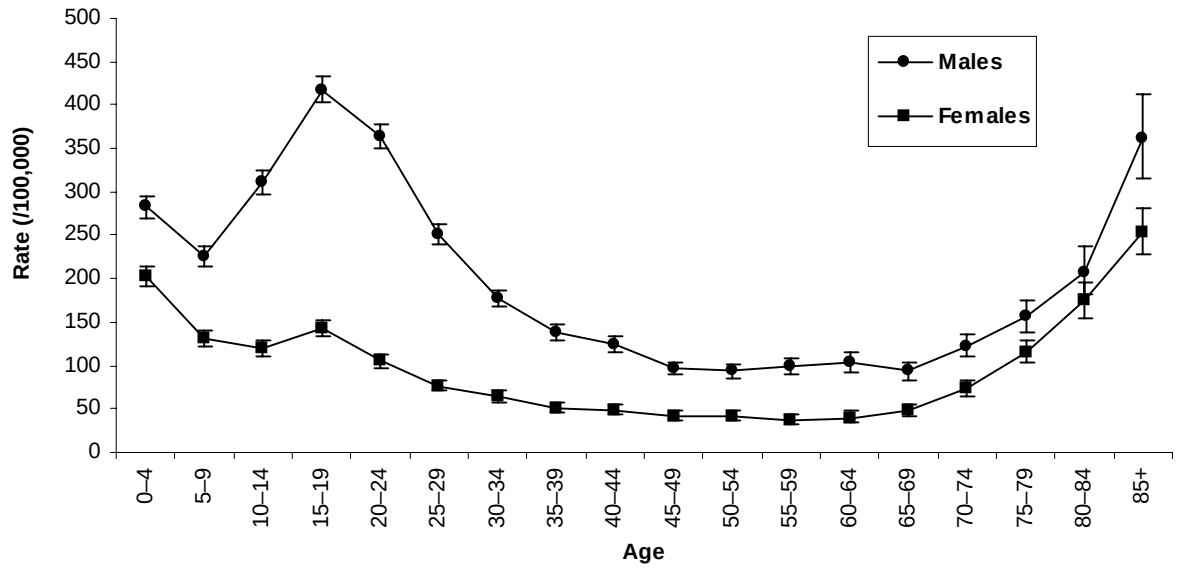
Traumatic brain injury

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.

[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).

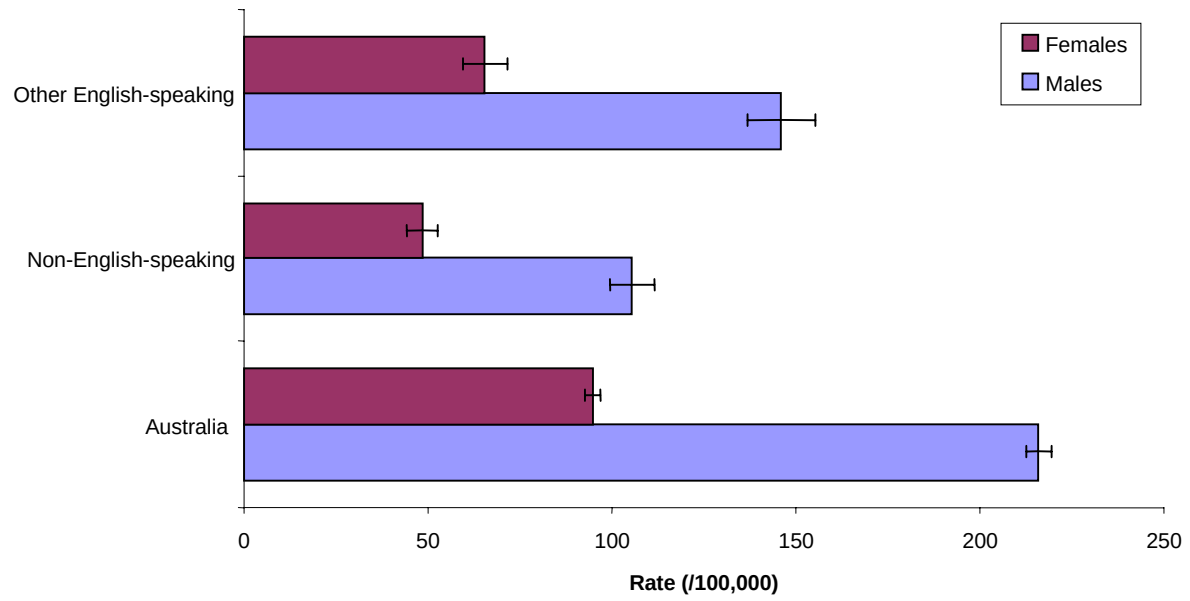
Indirectly standardised rates show that, when population age- and sex-structure is accounted for, separation rates for people born overseas were lower than the Australian average, both for people of all ages and for people aged under 65 (Table 4.4; Figure 4.2). However, the indirectly standardised rates 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.

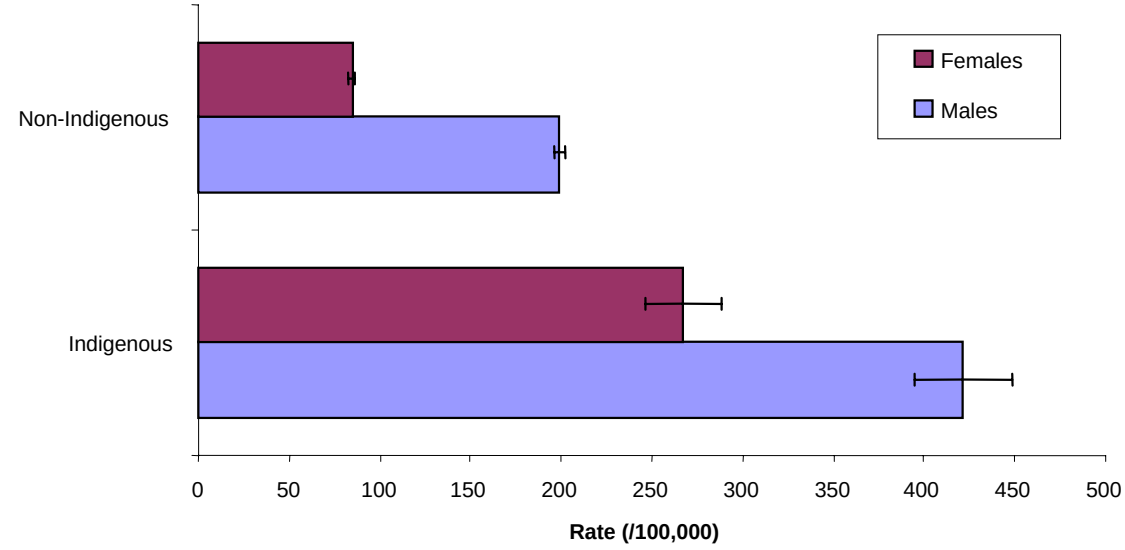
Indigenous Australians had much higher unstandardised rates of TBI-associated hospital separations (410 per 100,000) than non-Indigenous Australians (141 per 100,000) (Table 4.5). The biggest differences between the two groups, where rates for Indigenous Australians were several times those for non-Indigenous 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

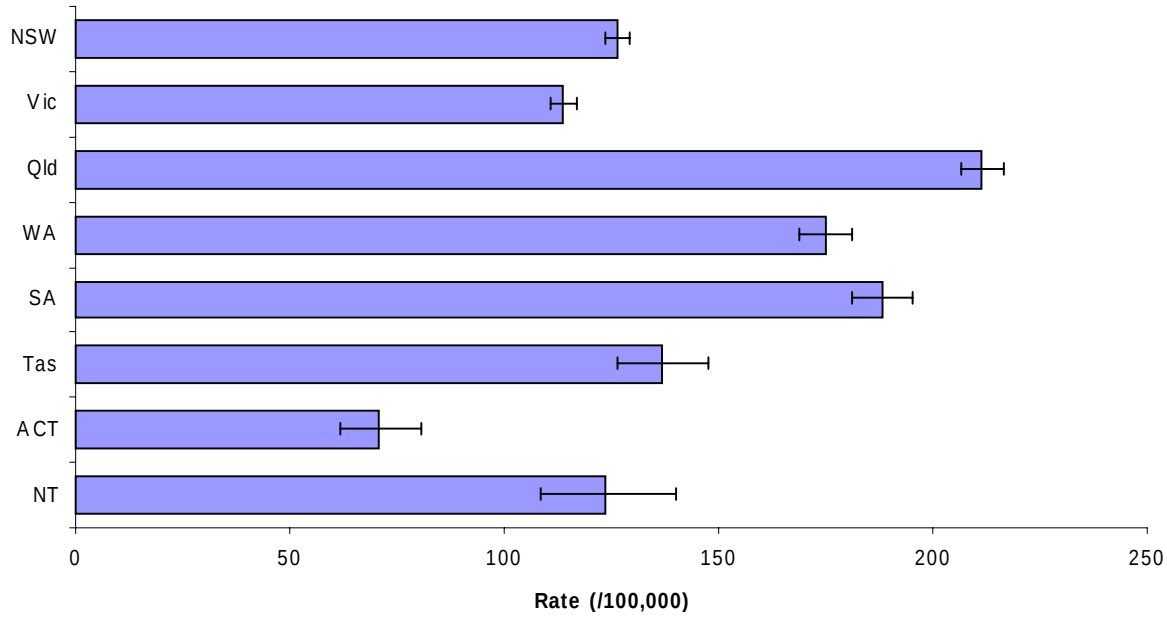
Age	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Males									
0–4	259	173	417	389	351	160	115	239	283
5–14	234	208	353	337	382	201	120	164	269
15–19	345	329	620	446	572	364	156	247	418
20–29	252	244	424	363	389	363	106	196	307
30–44	125	105	214	183	165	168	57	184	147
45–64	87	73	148	88	109	102	65	70	97
65+	128	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

[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).

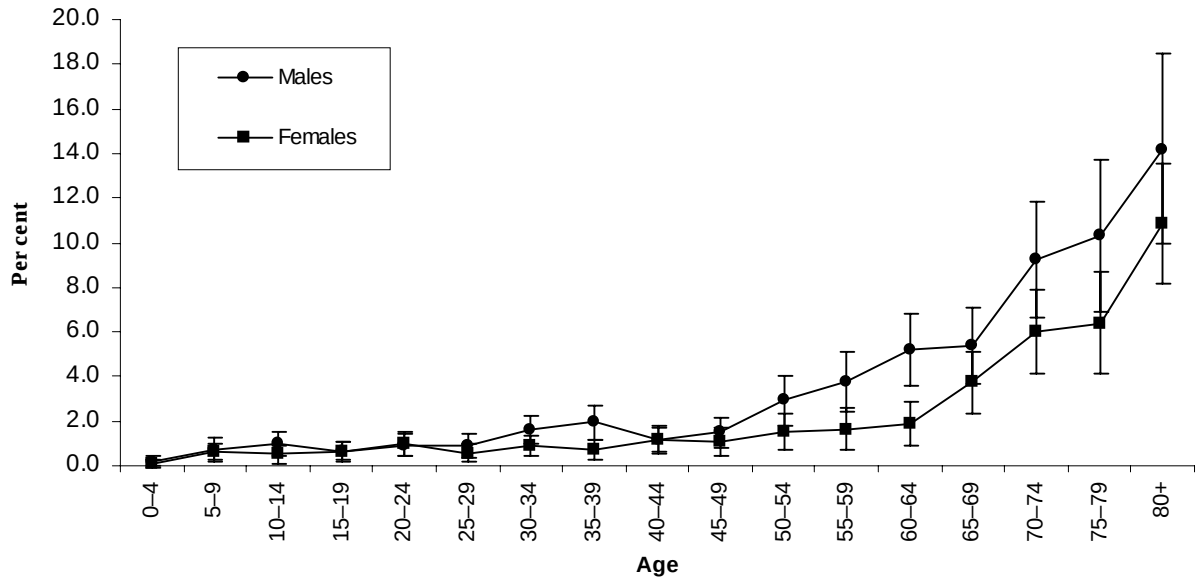
Source: AIHW analysis of 1993 ABS Survey of Disability, Ageing and Carers data.

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.

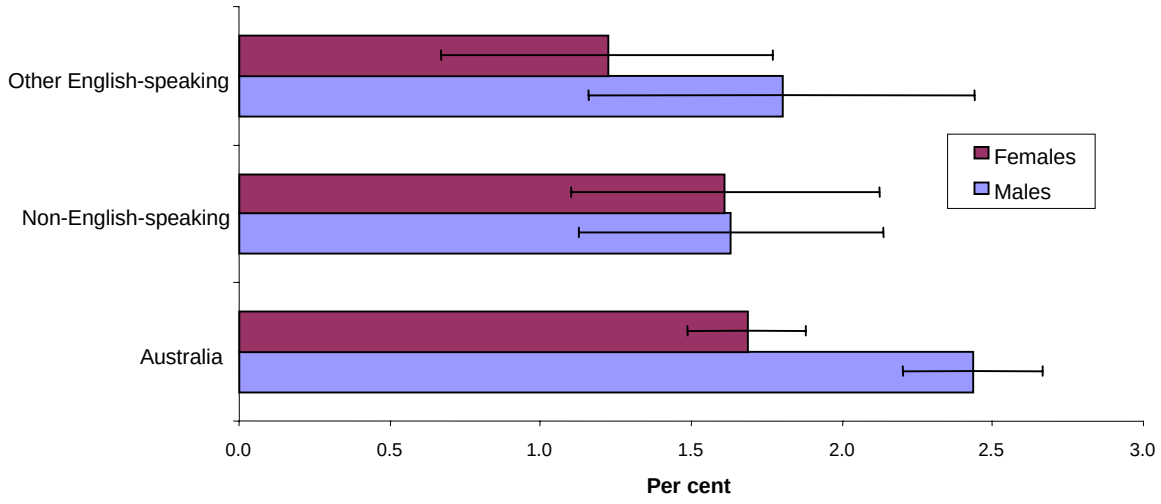
Of all people with an ABI-related disability (based on 'all disabling conditions plus activity limitation') 78% were born in Australia, 9% in 'other English-speaking countries' and 13% in 'non-English-speaking countries'. There was no significant difference in the prevalence of ABI-related disability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

[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)]

Country of birth	0–64			All ages		
	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.

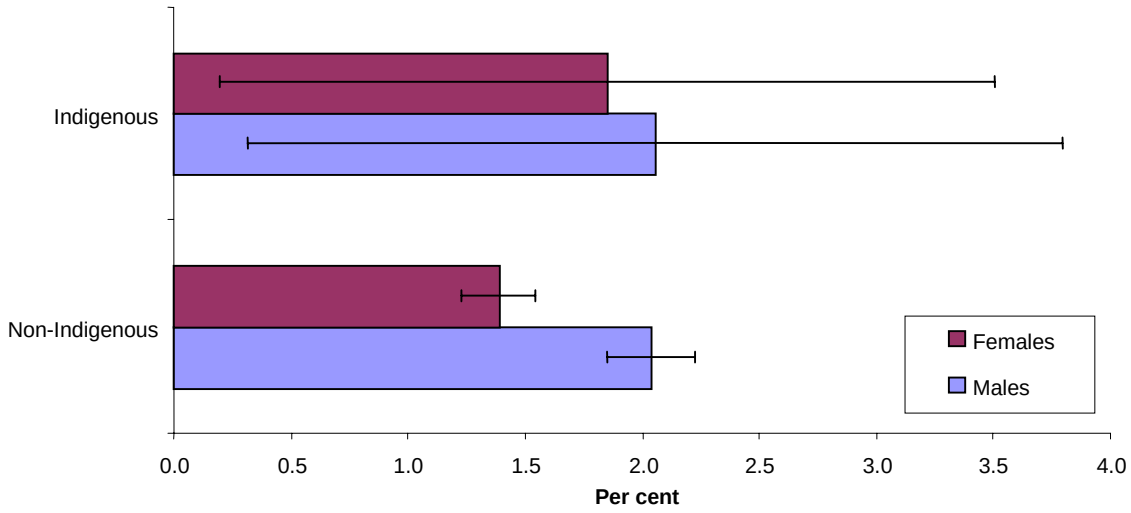
Unstandardised estimates indicate that, in 1993, 1.0% of the Indigenous population had an ABI-related disability—1.9% standardised to the total Australian population (Table 4.16; Figure 4.7). However, because of the very small sample size, the standard errors associated with the estimates are very high 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)]

Indigenous status	Ages 0–64			All ages		
	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)

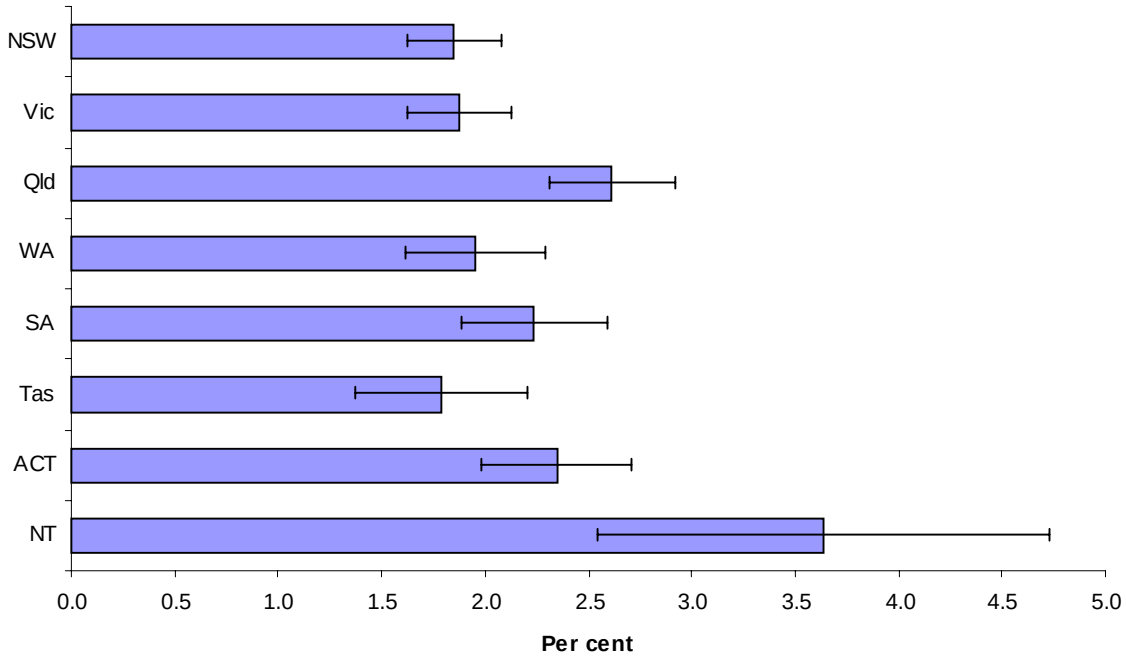
	Ages 0–64			All ages		
State or Territory	Number ('000)	Unstandardised rate (%)	Standardised rate (%)	Number ('000)	Unstandardised rate (%)	Standardised rate (%)
NSW	60.5	1.1	1.1	113.3	1.9	1.8
Vic	34.9	0.9	1.1	72.7	1.6	1.9
Qld	44.1	1.6	1.8	74.3	2.4	2.6
WA	17.2	1.1	1.2	29.2	1.7	2.0
SA	18.7	1.5	1.6	33.6	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		All disabling conditions		AIHW method	
	('000)	(%)	('000)	(%)	('000)	(%)
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

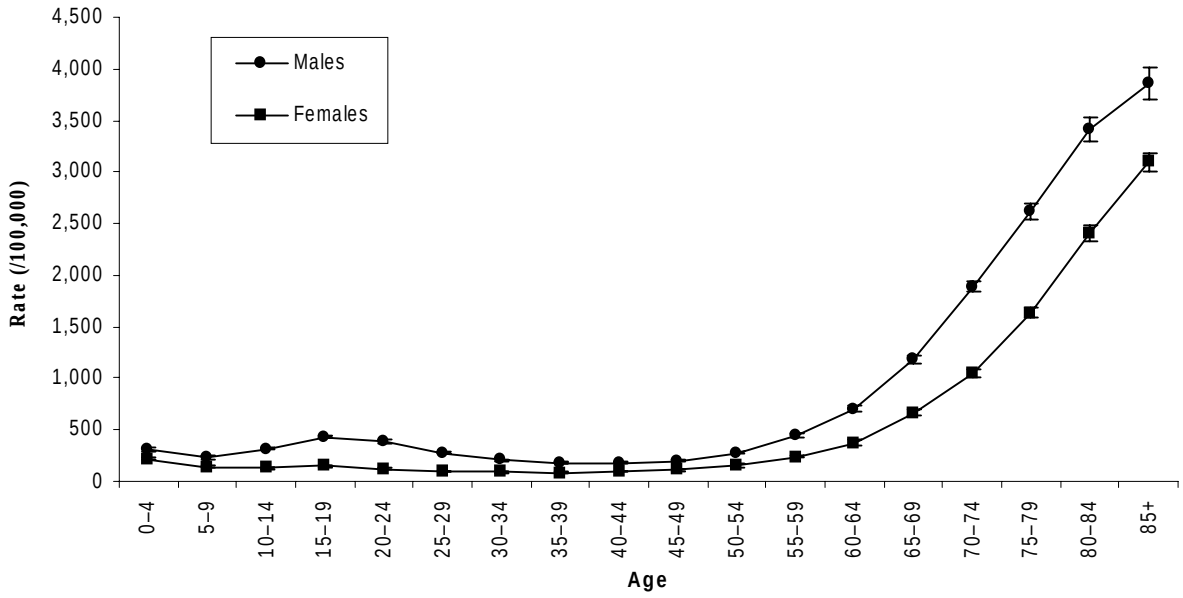
Based on our analysis of the 1996–97 National Hospital Morbidity Database, about 70% of the 27,437 hospital separations with a TBI-related diagnosis were for males. For males, rates of hospitalisation for TBI-related conditions peaked in the late teenage years and early twenties, but were also high in 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

[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.

Appendix 1: Table of terms

The following table sets out definitions for terms that are used frequently throughout this paper. Definitions of the dimensions of the 1980 ICIDH and draft ICIDH–2 are also given (the terminology of the draft ICIDH–2 is used in this publication). The table is based on one presented in a previous paper in the current series on the definition and prevalence of disability groups (Wen & Fortune 1999).

Term	Working definition
Acquired brain injury	An umbrella term covering all acquired damage to the brain, regardless of cause.
Head injury	Injury to the head where brain damage is likely but cannot be ascertained.
Disability	An umbrella term meaning negative experience in any one or more of the draft ICIDH–2 dimensions (i.e. an impairment, activity limitation or participation restriction).
Disabling condition	A disease, disorder or event that leads to impairment, activity limitation or participation restriction. In the context of the 1993 ABS Survey of Disability, Ageing and Carers, a disabling condition is a disease, disorder or event that has lasted or is likely to last for six months or more, or has produced a long-term effect, resulting in one or more of the limitations, restrictions or impairments used to identify disability (ABS 1996a).
Functional (ability or limitation)	Relating to functioning at the body, the person or the society level (depending on the context in which it is used). In the context of functional assessment measures 'functional limitation' generally means a limitation of functioning at the person level (i.e. equivalent to activity limitation). It is also commonly used at the body level to mean impairment of body parts and organ systems.
Draft ICIDH–2 dimensions	
Impairment	(In the context of health condition) A loss or abnormality of body structure or of a physiological or psychological function.
Activity	(In the context of health condition) The nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.
Participation	(In the context of health condition) The extent of a person's involvement in life situations in relationship to Impairments, Activities, health conditions and Contextual factors. Participation may be restricted in nature, duration and quality.
Context	Includes the features, aspects and attributes of, or objects, structures, human-made organisations, service provision and agencies in, the physical, social and attitudinal environment in which people live and conduct their lives.
1980 ICIDH dimensions	
Impairment	(In the context of health experience) Any loss or abnormality of psychological, physiological or anatomical structure or function.
Disability	(In the context of health experience) Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
Handicap	(In the context of health experience) A disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Appendix 2: Calculation of confidence intervals for estimates

Whether they are based on survey (sample) data or registry (census) data, estimated rates are subject to random variation. It is necessary to use some measure of the precision of estimated rates, in order to know how much confidence may be placed in them.

Below we describe the methods used in this paper for calculating lower (μ_0) and upper (μ_1) 95% confidence limits for estimated rates. Different approaches are used for calculating confidence intervals for estimates based on the ABS disability survey and estimates based on the National Hospital Morbidity Database.

Confidence intervals for ABS disability survey estimates

The ABS has provided a table of standard errors for a range of sizes of survey estimate. These are used as a basis for calculating 95% confidence intervals for indirectly standardised prevalence rates based on survey data.

Indirectly standardised prevalence rates are calculated using the method described in Section 4.1.

To calculate upper and lower confidence limits for an indirectly standardised rate, the rate is multiplied by the total population of the study group (e.g. the total number of people born in 'non-English-speaking countries') to obtain the theoretical number of 'cases' that would give rise to such a rate in that population. The relative standard error (RSE) for an estimate of this size is calculated (using linear interpolation) from the table provided by the ABS. This RSE is used to calculate 95% confidence limits for the indirectly standardised rate (ISR), as follows:

$$[\mu_0;\mu_1] = ISR \pm 1.96(RSE \times ISR)$$

Confidence limits for estimates based on hospital morbidity data

The method used for calculating confidence limits for estimates based on the National Hospital Morbidity Database is taken from Esteve et al. (1994:65). The method can be applied to both unstandardised and indirectly standardised rates.

It is assumed that the sole source of variability in an estimated rate is the numerator, which is the number of 'cases' (e.g. hospital episodes) observed in the study population of interest (Esteve et al. 1994:20, 63). Therefore, upper and lower confidence limits for the observed number of cases can be used to calculate upper and lower confidence limits for the corresponding unstandardised and indirectly standardised rates.

Confidence limits for the number of observed cases (O) are calculated as follows:

$$[\mu_0;\mu_1] = \left[\left(\frac{Z_{\alpha/2}}{2} - \sqrt{O}\right)^2; \left(\frac{Z_{\alpha/2}}{2} + \sqrt{O+1}\right)^2\right]$$

For a 95% confidence interval, $Z_{\alpha/2}$ is 1.96.

To calculate lower and upper confidence limits for rates, μ_0 and μ_1 (respectively) are substituted for *O* in the following equations for calculating unstandardised and indirectly standardised rates.

$$\text{Unstandardised rate} = \frac{O}{M}$$

$$\text{Indirectly standardised rate} = \left[\frac{O}{\sum_{x=1}^{g} m_x \lambda_x}\right] \times \text{Std rate}$$

Where *M* is the total number of people in the study population, m_x is the number of individuals in age-sex group *x* in the study population, $\bullet_x$ is the rate for group *x* in the standard population, and 'Std rate' is the overall rate for the standard population.

Appendix 3: 1993 ABS disability survey questions on limitations, restrictions and need for assistance

Note: these questions were only asked for the household component of the survey.

Question number	Question wording	Population who could be asked depending on survey sequencing
Q41=1	Do you ever have difficulty showering or bathing without help or supervision?	All aged 5+ with a disability (except those with 'hearing loss' only)
Q43=1	Do you ever have difficulty dressing without help or supervision, for example doing up shoe laces, buttons or zips?	As above
Q45=1	Do you ever have difficulty eating a meal without help or supervision?	As above
Q47A=1	Do you have any difficulty controlling your bladder?	As above
Q47B=1	Do you have any difficulty controlling your bowel?	As above
Q49=1	If shaded box marked for any 'personal care' task (Q40–Q48)	As above
Q61=3	Do you ever need help or supervision when going to, or getting around, a place away from home?	As above
Q62=1	Do you ever find it difficult to go somewhere away from home without help or supervision?	As above
Q63=3	Do you ever need help to move about the house because of your condition?	As above
Q64=1	Do you ever find it difficult to move about the house without help or supervision?	As above
Q66=1	If shaded box marked for any 'mobility' task (Q61–65)	As above
Q95=1	If shaded box marked for any 'communication' task (Q89–Q93)	All aged 5+ with a disability
Q111=1	If '1' in Q106 (having difficulty holding a book or magazine, or turning the pages) or '1' in Q109 (having difficulty reading normal print)	All aged 10+ with a disability
Q132=2	Aids used (Questions 113–130 relate to aids and equipment)	All aged 5+ with a disability
Q139=1, Q142=1	Changes made or needed to dwelling	As above
Q148=1	If shaded box marked for any 'health care' task (Q146 & Q147)	All aged 15+ with a disability
Q161=1 or 2	What makes it difficult for you to do these tasks (household chores) by yourself? What would prevent you from doing these tasks (household chores) by yourself?	All aged 15+ with a disability, and all persons aged 60+
Q167=1 or 2	What makes it difficult for you to do these household chores by yourself?	As above

(continued)

Question number	Question wording	Population who could be asked depending on survey sequencing
Q174=1 or 2	What makes it difficult for you to do these tasks (home maintenance) by yourself? What would prevent you from doing these tasks (home maintenance) by yourself?	As above
Q180=1or 2	What makes it difficult for you to do these household chores by yourself?	As above
Q187=1 or 2	What makes it difficult for you to do these tasks (meal preparation) by yourself? What would prevent you from doing these tasks (meal preparation) by yourself?	As above
Q193=1 or 2	What makes it difficult to prepare meals by yourself?	As above
Q198=1	If shaded box marked in Q196 or Q197 (financial management, writing letters)	As above
Q209=2	Is there any form of public transport that you could use?	All aged 5+ with a disability
Q210/212=1	Do you ever need help or supervision when using (the) public transport (that you can use)?	All aged 5+ with a disability/all persons aged 60+
Q211/213=1	(Does/do) your condition(s) make it at all difficult for you to use (the) public transport (that you can use)?	All aged 5+ with a disability/all persons aged 60+
Q223=1	As a result of your (age/condition(s)), is it difficult for you to get out of a car parked in a standard width parking space?	All aged 5+ with a disability and all persons aged 60+
Q239=2	If the other (person/people) in this household had to go away for a few days would you be able to look after yourself?	All aged 15+ with a disability and all persons aged 60+
Q242=1	Would you find it difficult to look after yourself?	As above
Q252=2	Are you able to use a standard telephone?	All aged 5+ with a disability and all persons aged 60+
Q258=1	Is the reason does not attend school because of condition(s)?	All aged 5–14 with a disability
Q268=1	On average, do you need at least one day a week off from (specify institution in Q261) because of your condition(s)?	All aged 5+ with a disability, attending education other than school
Q269=1	Do you have any difficulty at (specify institution in Q261)because of your condition(s)?	As above
Q273=1	Do you go to special school because of your condition(s)?	All aged 5+ with a disability who attend school
Q274=1	Do you have to attend special classes because of your condition(s)?	As above
Q275=1	On average, do you need at least one day a week off from school because of your condition(s)?	As above
Q276=1	Do you have any difficulty at school because of your condition(s)?	As above
Q293=1	(Does/do) your condition(s) prevent you from undertaking (further) study?	All aged 15+ with a disability, not currently studying

(continued)

Question number	Question wording	Population who could be asked depending on survey sequencing
Q295=3	Does...currently work in a job, business or farm?	All aged 15+ with a disability
Q318=1	(Does/do) your condition(s) restrict the type of hours you can work?	All aged 15+ with a disability, who currently work
Q319=1	(Does/do) your condition(s) restrict the number of hours you can work?	As above
Q322=1	On average, do you need at least one day a week off from work because of your condition(s)?	As above
Q324=1	Was it necessary for your employer to provide any equipment, or make any arrangements for you, because of your condition(s)?	As above
Q328=1	(Does/do) your condition(s) make you permanently unable to work?	All aged 15+ with a disability, who are not currently working
Q341=1	Would your condition(s) restrict the type of job you could do?	As above
Q342=1	On average, would you need at least one day a week off from work because of your condition(s)?	As above
Q343=1	Would your condition(s) restrict the number of hours you could work?	As above

Note: The screening question relating to the use of long-term treatment or medication also forms part of the 'activity limitation filter' used in the 'all disabling conditions plus activity limitation' approach to estimating the prevalence of ABI-related disability (Section 4.3).

Source: Madden et al. 1995, Appendix B.

Appendix 4: Additional data tables

Table A4.1: 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	1,874	281	1,275	202	3,149	243
5–9	1,518	226	835	131	2,353	179
10–14	2,088	311	764	119	2,852	218
15–19	2,735	415	888	142	3,623	282
20–24	2,524	360	709	104	3,233	234
25–29	1,786	248	543	76	2,329	162
30–34	1,248	174	459	64	1,707	119
35–39	1,003	137	379	52	1,382	94
40–44	839	123	337	49	1,176	86
45–49	622	95	268	42	890	69
50–54	494	92	211	41	705	67
55–59	411	96	154	37	565	67
60–64	357	100	145	40	502	70
65–69	309	92	166	47	475	69
70–74	332	119	233	71	565	93
75–79	275	149	273	109	548	126
80–84	204	191	289	163	493	174
85+	211	341	351	242	563	272
Total	**18,830**	**206**	**8,279**	**89**	**27,110**	**147**

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

Table A4.2: Population: country of birth, by sex and age, Australia, 30 June 1996

	Australia		Non-English-speaking		Other English-speaking [(a)]		Total	
Age	**Number**	**%**	**Number**	**%**	**Number**	**%**	**Number**	**%**
Males								
0–4	648,360	9.3	10,083	0.8	7,168	0.8	665,611	7.3
5–14	1,230,174	17.7	72,069	5.6	37,235	4.4	1,339,478	14.7
15–19	561,628	8.1	63,807	4.9	29,910	3.5	655,345	7.2
20–29	1,150,477	16.5	168,982	13.1	99,901	11.8	1,419,360	15.6
30–44	1,516,905	21.8	354,627	27.5	251,990	29.7	2,123,522	23.3
45–64	1,223,999	17.6	433,723	33.6	287,718	33.9	1,945,440	21.4
65+	635,578	9.1	187,802	14.5	135,919	16.0	959,299	10.5
Total	*6,967,121*	*100.0*	*1,291,093*	*100.0*	*849,841*	*100.0*	*9,108,055*	*100.0*
Females								
0–4	615,218	8.7	9,612	0.7	6,608	0.8	631,438	6.9
5–14	1,170,991	16.5	68,540	5.3	35,257	4.3	1,274,788	13.9
15–19	536,140	7.6	59,533	4.6	28,101	3.4	623,774	6.8
20–29	1,122,103	15.8	175,755	13.6	97,663	11.8	1,395,521	15.2
30–44	1,510,852	21.3	376,404	29.2	244,813	29.5	2,132,069	23.2
45–64	1,243,734	17.6	399,525	31.0	258,053	31.1	1,901,312	20.7
65+	885,902	12.5	199,622	15.5	158,233	19.1	1,243,757	13.5
Total	*7,084,940*	*100.0*	*1,288,991*	*100.0*	*828,728*	*100.0*	*9,202,659*	*100.0*
Persons								
0–4	1,263,578	9.0	19,695	0.8	13,776	0.8	1,297,049	7.1
5–14	2,401,165	17.1	140,609	5.4	72,492	4.3	2,614,266	14.3
15–19	1,097,768	7.8	123,340	4.8	58,011	3.5	1,279,119	7.0
20–29	2,272,580	16.2	344,737	13.4	197,564	11.8	2,814,881	15.4
30–44	3,027,757	21.5	731,031	28.3	496,803	29.6	4,255,591	23.2
45–64	2,467,733	17.6	833,248	32.3	545,771	32.5	3,846,752	21.0
65+	1,521,480	10.8	387,424	15.0	294,152	17.5	2,203,056	12.0
Total	**14,052,061**	**100.0**	**2,580,084**	**100.0**	**1,678,569**	**100.0**	**18,310,714**	**100.0**

(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.

Source: ABS population estimates.

Table A4.3: Population age structure: Indigenous status, by sex and age, Australia, 30 June 1996

	Indigenous		Non-Indigenous		Total	
Age	**Number**	**%**	**Number**	**%**	**Number**	**%**
Males						
0–4	28,263	14.8	637,348	7.1	665,611	7.3
5–14	50,461	26.5	1,289,017	14.5	1,339,478	14.7
15–19	19,141	10.0	636,204	7.1	655,345	7.2
20–29	34,155	17.9	1,385,205	15.5	1,419,360	15.6
30–44	34,930	18.3	2,088,592	23.4	2,123,522	23.3
45–64	19,184	10.1	1,926,256	21.6	1,945,440	21.4
65+	4,334	2.3	954,965	10.7	959,299	10.5
Total	*190,468*	*100.0*	*8,917,587*	*100.0*	*9,108,055*	*100.0*
Females						
0–4	27,318	14.0	604,120	6.7	631,438	6.9
5–14	48,347	24.7	1,226,441	13.6	1,274,788	13.9
15–19	18,873	9.6	604,901	6.7	623,774	6.8
20–29	36,223	18.5	1,359,298	15.1	1,395,521	15.2
30–44	38,309	19.6	2,093,760	23.2	2,132,069	23.2
45–64	20,727	10.6	1,880,585	20.9	1,901,312	20.7
65+	5,784	3.0	1,237,973	13.7	1,243,757	13.5
Total	*195,581*	*100.0*	*9,007,078*	*100.0*	*9,202,659*	*100.0*
Persons						
0–4	55,581	14.4	1,241,468	6.9	1,297,049	7.1
5–14	98,808	25.6	2,515,458	14.0	2,614,266	14.3
15–19	38,014	9.8	1,241,105	6.9	1,279,119	7.0
20–29	70,378	18.2	2,744,503	15.3	2,814,881	15.4
30–44	73,239	19.0	4,182,352	23.3	4,255,591	23.2
45–64	39,911	10.3	3,806,841	21.2	3,846,752	21.0
65+	10,118	2.6	2,192,938	12.2	2,203,056	12.0
Total	**386,049**	**100.0**	**17,924,665**	**100.0**	**18,310,714**	**100.0**

Source: ABS population estimates.

Table A4.4: People with a disability: ABI-related disability (all disabling conditions plus activity limitation), by age and sex, Australia 1993

	Males		Females		Persons	
Age	**Number**	**%**	**Number**	**%**	**Number**	**%**
0–4	**1.3	**0.2	**0.6	**0.1	*2.0	*0.2
5–9	*4.9	*0.7	*3.6	*0.6	8.5	0.7
10–14	*6.2	*1.0	*3.3	*0.5	9.5	0.8
15–19	*4.4	*0.7	*4.1	*0.6	8.6	0.7
20–24	*6.8	*0.9	*7.2	*1.0	14.0	1.0
25–29	*6.2	*0.9	*3.9	*0.6	10.2	0.7
30–34	11.7	1.6	*6.5	*0.9	18.2	1.2
35–39	13.2	1.9	*5.1	*0.7	18.3	1.3
40–44	*7.5	*1.1	*7.8	*1.2	15.3	1.2
45–49	8.7	1.5	*6.1	*1.1	14.8	1.3
50–54	13.3	2.9	*6.6	*1.5	19.9	2.2
55–59	14.4	3.8	*6.1	*1.6	20.5	2.7
60–64	18.6	5.2	*6.7	*1.9	25.3	3.5
65–69	17.6	5.4	13.2	3.7	30.9	4.5
70–74	22.8	9.2	18.0	6.0	40.8	7.4
75–79	16.9	10.3	14.8	6.4	31.6	8.0
80–84	20.3	14.2	30.1	10.8	50.4	12.0
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.

Table A4.5: Population: States and Territories, by sex and age, Australia 1993

	States and Territories								
Age	**NSW**	**Vic**	**Qld**	**WA**	**SA**	**Tas**	**ACT**	**NT**	**Australia**
Male									
0–4	225,793	164,971	117,658	64,653	50,937	17,920	11,735	8,586	662,253
5–19	656,347	487,326	362,929	196,334	155,489	54,930	36,211	22,160	1,971,726
20–64	1,788,839	1,331,996	919,085	505,608	434,663	136,126	93,379	54,332	5,264,028
65+	312,648	225,980	151,127	73,638	83,634	24,833	8,471	2,478	882,809
Total	*2,983,627*	*2,210,273*	*1,550,799*	*840,233*	*724,723*	*233,809*	*149,796*	*87,556*	*8,780,816*
Female									
0–4	215,018	156,772	111,351	61,456	47,762	17,132	11,095	8,258	628,844
5–19	624,649	463,037	342,342	185,472	147,586	52,471	34,604	20,673	1,870,834
20–64	1,759,029	1,327,146	900,312	490,755	428,872	135,522	91,625	49,398	5,182,659
65+	417,564	304,207	190,203	94,618	111,111	32,580	11,215	2,402	1,163,900
Total	*3,016,260*	*2,251,162*	*1,544,208*	*832,301*	*735,331*	*237,705*	*148,539*	*80,731*	*8,846,237*
Persons									
0–4	440,811	321,743	229,009	126,109	98,699	35,052	22,830	16,844	1,291,097
5–19	1,280,996	950,363	705,271	381,806	303,075	107,401	70,815	42,833	3,842,560
20–64	3,547,868	2,659,142	1,819,397	996,363	863,535	271,648	185,004	103,730	10,446,687
65+	730,212	530,187	341,330	168,256	194,745	57,413	19,686	4,880	2,046,709
Total	**5,999,887**	**4,461,435**	**3,095,007**	**1,672,534**	**1,460,054**	**471,514**	**298,335**	**168,287**	**17,627,053**

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

Table A4.6: Population age structure: States and Territories, by sex and age, Australia 1993

	States and Territories								
Age	**NSW**	**Vic**	**Qld**	**WA**	**SA**	**Tas**	**ACT**	**NT**	**Australia**
Male									
0–4	7.6	7.5	7.6	7.7	7.0	7.7	7.8	9.8	7.5
5–19	22.0	22.0	23.4	23.4	21.5	23.5	24.2	25.3	22.5
20–64	60.0	60.3	59.3	60.2	60.0	58.2	62.3	62.1	59.9
65+	10.5	10.2	9.7	8.8	11.5	10.6	5.7	2.8	10.1
Total	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*
Female									
0–4	7.1	7.0	7.2	7.4	6.5	7.2	7.5	10.2	7.1
5–19	20.7	20.6	22.2	22.3	20.1	22.1	23.3	25.6	21.1
20–64	58.3	59.0	58.3	59.0	58.3	57.0	61.7	61.2	58.6
65+	13.8	13.5	12.3	11.4	15.1	13.7	7.6	3.0	13.2
Total	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*
Persons									
0–4	7.3	7.2	7.4	7.5	6.8	7.4	7.7	10.0	7.3
5–19	21.4	21.3	22.8	22.8	20.8	22.8	23.7	25.5	21.8
20–64	59.1	59.6	58.8	59.6	59.1	57.6	62.0	61.6	59.3
65+	12.2	11.9	11.0	10.1	13.3	12.2	6.6	2.9	11.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

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

Table A4.7: 'ABS group' hospital separations (see Table 4.1), by sex and age, Australia 1996–97

	Males		Females		Persons	
Age	**Number**	**Rate (/100,000)**	**Number**	**Rate (/100,000)**	**Number**	**Rate (/100,000)**
0–4	2,065	310	1,370	217	3,435	265
5–9	1,560	232	903	141	2,463	188
10–14	2,138	318	823	129	2,961	226
15–19	2,861	434	942	150	3,803	296
20–24	2,690	384	806	118	3,496	253
25–29	1,993	277	687	96	2,680	186
30–34	1,471	205	651	90	2,122	148
35–39	1,305	178	622	85	1,927	131
40–44	1,223	179	677	99	1,900	139
45–49	1,284	197	701	110	1,985	154
50–54	1,499	279	806	156	2,305	219
55–59	1,932	453	999	241	2,931	349
60–64	2,500	700	1,361	378	3,861	538
65–69	3,996	1,186	2,345	664	6,341	919
70–74	5,258	1,889	3,450	1,053	8,708	1,437
75–79	4,823	2,615	4,079	1,635	8,902	2,051
80–84	3,641	3,410	4,262	2,403	7,903	2,781
85+	2,387	3,854	4,481	3,095	6,869	3,323
Total	**44,626**	**487**	**29,965**	**324**	**74,592**	**405**

Note: see Table 4.1.

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

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