# 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'.<br>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)<br>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<br>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.'<br>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.'<br>'Brain injury is a form of acquired brain damage', caused by trauma. |
| 'Head injury impact' project<br>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).'<br>Head injury: 'a history of a blow to the head and concussion or altered consciousness after relevant injury'.<br>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)<br>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:<br>'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.'<br>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<br>(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.<br>'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)<br>(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'.<br>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<br>(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)<br>(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<br>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<br>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)<br>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<br>(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)<br>(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<br>(Thurman et al. 1995) | USA | Selected ICD–9 codes | | |
| Guidelines for central nervous system injury surveillance—clinical case definition<br>(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<br>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<br>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<br>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<br>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<br>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).