



Disability in Australia: acquired brain injury

Summary

Acquired brain injury (ABI) refers to any damage to the brain that occurred after birth. Common causes of ABI include accidents, stroke, lack of oxygen and degenerative neurological disease. ABI-related disability can affect cognitive, physical, emotional and independent functioning.

This bulletin provides data on the prevalence of ABI in Australia, and includes details of the support needs of, and services received by, people with ABI-related disability. It updates key analyses published previously (AIHW: Fortune and Wen 1999; AIHW 2003).

Based on analyses of the Australian Bureau of Statistics' (ABS) 2003 Survey of Disability, Ageing and Carers:

- ABI is common: around 1 in 45 Australians (432,700 people) had ABI with activity limitations or participation restrictions due to disability. Almost three-quarters of these people were aged less than 65 years
- about 20,000 children aged under 15 years had ABI
- people with ABI tended to have complex disability. They reported more disability groups and more health conditions than the average person with disability
- ABI prevalence rates increased with age. People aged 65 years or over were more than twice as likely as those aged under 65 years to have ABI with activity limitations or participation restrictions
- prevalence rates were higher for males than females at all ages

(summary continued overleaf)

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- ♦ ABI was the main disabling condition reported by about 27,300 people aged under 65 years. A traffic injury was the main cause for more than half (55%) of these people
- ♦ more than one in three people with ABI aged under 65 years needed help with cognitive and/or emotional tasks.

ABI caused by a traumatic event, such as a traffic accident or blow to the head, is referred to as traumatic brain injury. According to hospital records:

- ♦ there were almost 21,800 hospital stays relating to traumatic brain injury in 2004–05
- ♦ the age-standardised hospitalisation rate for traumatic brain injury was more than twice as high for males as females
- ♦ between 1999–2000 and 2004–05, the age-standardised rate of traumatic brain injury hospitalisations among children aged less than 15 years fell by more than one-fifth.

In 2004–05, almost 12,000 people with ABI used specialist disability services funded under the Commonwealth State/Territory Disability Agreement (CSTDA). These service users accounted for about 6% of CSTDA-funded disability service users.

Background

This bulletin presents the most recent available national data on people with acquired brain injury (ABI) in Australia. ABI is a term used to describe disability arising from any damage to the brain acquired after birth, regardless of cause. Brain injury acquired at birth is sometimes also included in the scope of ABI. The term ‘traumatic brain injury’ (TBI) refers to acquired brain injury caused by a traumatic event such as a traffic accident or a blow to the head.

The National community services data dictionary, version 4 defines ABI as:

multiple disabilities arising from damage to the brain acquired after birth. It results in deterioration in cognitive, physical, emotional or independent functioning. It can be as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological disease etc. (AIHW 2006a)

Three data sources are used in this bulletin:

- ♦ the 2003 ABS Survey of Disability, Ageing and Carers—data on the number of people with an ABI-related disability in Australia, including information on age, sex, associated disabilities, needs for assistance, living arrangements, and whether people have an informal carer (See Box 1 for information on survey concepts and terms.)
- ♦ the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS)—data on people with ABI who use CSTDA-funded disability services
- ♦ the National Hospital Morbidity Database—data on numbers of hospital stays for which a diagnosis of traumatic brain injury has been recorded.

In Australia, people with brain injury acquired before, during or shortly after birth are more likely to be classified into the intellectual disability group by service providers or representative organisations. (See p.10 of this bulletin and AIHW 1999; Fortune & Wen and AIHW 2003 for further information on the definition of ABI.)

The consequences of ABI are complex, and individuals are affected differently (AIHW: Fortune & Wen 1999). Physical problems commonly reported by people with ABI include headaches, fatigue, seizures, poor balance, visual and hearing disturbances, chronic pain and paralysis. Many people with ABI experience cognitive problems, including poor memory and concentration, reduced ability to plan and problem solve and inflexible thinking, and psychosocial/emotional problems, such as depression, emotional instability, irritability, and impulsive or inappropriate behaviour (BIAQ 2007).

ABI is often referred to as a 'hidden disability' because it is not always obvious, especially among people who have mild or moderate physical disability. However, it can result in significant restrictions on an individual's ability to participate fully in education, employment and other aspects of life. Relationships with families, friends and carers can also be affected by personality and behavioural changes. The complex and diverse needs of people with ABI can create challenges for disability support services as well as the general service system.

In part due to its complex nature, ABI-related disability is the subject of a number of policies at different levels of government. For example:

- ♦ ABI is recognised as a major disability group in the Commonwealth State/Territory Disability Agreement (FaCSIA 2003; AIHW 2004).
- ♦ In 2001 the Victorian Government developed the Acquired Brain Injury Strategic Plan, setting the future direction of policy and service development for people with ABI (DHS 2001). One outcome of the strategic plan has been the development of a protocol to enhance service delivery and coordination to people with ABI who have a mental illness (DHS 2004).
- ♦ In 2006, the Council of Australian Governments (COAG) announced a 5-year, \$244 million program aimed at providing more appropriate accommodation options for young people with disability living in nursing homes. Many of these people have ABI-related disability (Winkler, Farnworth and Sloan 2006).

In addition, the high prevalence of ABI among people in custody raises issues related to prisoner health and treatment of people with ABI-related disability by the criminal justice system. For example, the 2001 NSW Inmate Health Survey found that 39% of women and 45% of men surveyed had sustained a head injury at some time in the past that resulted in unconsciousness or blacking out (Butler & Milner 2003). Of those people who had suffered a head injury, 41% of women and 23% of men continued to suffer side effects such as memory loss, anxiety or depression, poor concentration and personality changes.

This bulletin presents data on the prevalence of ABI in Australia, and its common causes, as well as information on needs for assistance and services received by people with ABI-related disability. It also examines the geographical distribution of ABI, hospitalisations due to traumatic brain injury, and ABI-related disability among older people. The possible effects of ABI on families and carers is acknowledged, but not analysed in this publication.

Box 1: ABS disability survey concepts and terms

The ABS Survey of Disability, Ageing and Carers provides a broad range of information on people with disability. In the survey, a person is identified as having disability if they report having at least one of 17 limitations, restrictions or impairments, which has lasted or is likely to last for at least 6 months. People with ABI-related disability can be identified by a positive response to the ABI-specific screening questions about any long-term effects of head injury or any other kind of brain damage that interfere with doing everyday activities and/or a positive response to any of the 17 screening questions, plus one or more reported disabling conditions related to head injury or brain damage. This information was obtained through personal interview where possible, although proxy interviews were conducted in some cases (children and people whose disability prevented them from giving a personal interview).

Activity limitations and participation restrictions

People who were identified as having disability were asked questions about whether they had difficulty or needed assistance in 10 activity areas—property maintenance, cognitive/emotional activities, health care, transport, mobility, housework, paperwork, self-care, meal preparation, and communication—and whether they were restricted in schooling, employment or social life as a result of their disability. In this bulletin, a positive response to any of these questions has been used to identify people with ABI and some activity limitations or participation restrictions.

Core activity limitation

For ABS survey purposes, the three 'core activity' areas are:

- self-care—bathing or showering, dressing, eating, using the toilet, and bladder or bowel control
- mobility—getting into or out of a bed or chair, moving around at home and going to or getting around a place away from home
- communication—understanding and being understood by others: strangers, family and friends.

Four levels of core activity limitation are determined as follows:

- profound—always needs assistance from another person to perform a core activity
- severe—sometimes needs assistance from another person to perform a core activity, or has difficulty understanding or being understood by family or friends, or can communicate more easily using sign language or other non-spoken forms of communication
- moderate—does not need assistance, but has difficulty performing a core activity
- mild—has no difficulty performing a core activity but uses aids or equipment because of disability; or cannot perform the activities of easily walking 200 metres, walking up and down stairs without a handrail, easily bending to pick up an object from the floor, and using public transport; or has difficulty using public transport.

A person's overall level of core activity limitation is recorded as the highest level of limitation the person reports in any of the core activity areas.

Disabling conditions

A disabling condition is a disease, disorder or event that leads to an impairment or restriction that has lasted or is likely to last for at least 6 months.

Main disabling condition

If multiple conditions are reported in the survey, then the main disabling condition is the one reported as causing the most problems. If only one disabling condition is reported, this is recorded as the main disabling condition.

Sources: ABS 2004; AIHW 2005.

ABI in the Australian population

Prevalence

No single number can be quoted as 'the prevalence' of ABI in Australia. Different prevalence estimates may be obtained from the ABS disability survey data for different purposes (Table 1). In 2003:

- ♦ around 438,300 people had ABI with disability
- ♦ about 432,700 people had ABI and some activity limitations or participation restrictions—2.2% of the population. Almost three-quarters of these, or 311,800 people, were aged under 65 years
- ♦ almost 157,500 people had ABI and a severe or profound core activity limitation—0.8% of the population. Close to two-thirds of these, or 99,900 people, were aged under 65 years.
- ♦ of those people with activity limitations or participation restrictions, 28,700 nominated ABI as their main condition—0.1% of the population. Almost all (27,300) were aged under 65 years.

Of those 28,700 people whose main condition was ABI:

- ♦ almost three-quarters were males
- ♦ prevalence was highest among young adults—slightly less than half were between 15 and 34 years old.

Focusing on the 311,800 people with ABI and some activity limitations or participation restrictions who were aged under 65 years:

- ♦ more than two-thirds (68%) were male
- ♦ the overall prevalence rate was 1.8% of the population in this age group
- ♦ prevalence increased with age—almost half were aged between 45 and 64 years
- ♦ about 20,000 were children under the age of 15 years.

Age and sex distribution of prevalence rates

Among those people aged under 65 years with ABI who had activity limitations or participation restrictions (Table 1 and Figure 1):

- ♦ prevalence rates increased rapidly with age, from 0.5% of people aged 0–14 years to 3.5% of those aged 55–64 years
- ♦ prevalence rates were higher for males than females at all ages.

Among those aged under 65 with ABI who had severe or profound core activity limitations:

- ♦ prevalence rates increased gradually with age, from 0.3% of people aged 0–14 years to 1.0% of those aged 55–64 years
- ♦ the prevalence rate was slightly higher for males than females until the age group 55–64 years, when the rates were roughly the same.

A number of causes of ABI are strongly associated with age. In addition, older people with ABI often have age-related health conditions in addition to their brain injury. Therefore this bulletin will primarily focus on the 311,800 people aged under 65 years who have ABI along with some activity limitations or participation restrictions. Data on ABI among people aged 65 years or over are presented in Box 4.

Table 1: Prevalence of ABI, by disability status and age group, 2003

Age group (years)	ABI with activity limitations or participation restrictions		ABI with severe or profound core activity limitations		ABI as main disabling condition	
	'000	Per cent ^(a)	'000	Per cent ^(a)	'000	Per cent ^(a)
0–14	20.1	0.5	12.9	0.3	*3.0	*0.1
15–24	38.0	1.4	*9.5	*0.3	*7.0	*0.3
25–34	49.2	1.7	16.0	0.6	*6.2	*0.2
35–44	59.3	2.0	20.4	0.7	*5.3	*0.2
45–54	75.0	2.8	21.8	0.8	*4.2	*0.2
55–64	70.3	3.5	19.3	1.0	**1.6	**0.1
Total <65	311.8	1.8	99.9	0.6	27.3	0.2
65 or over	120.9	4.7	57.5	2.3	**1.4	**0.1
Total	432.7	2.2	157.5	0.8	28.7	0.1

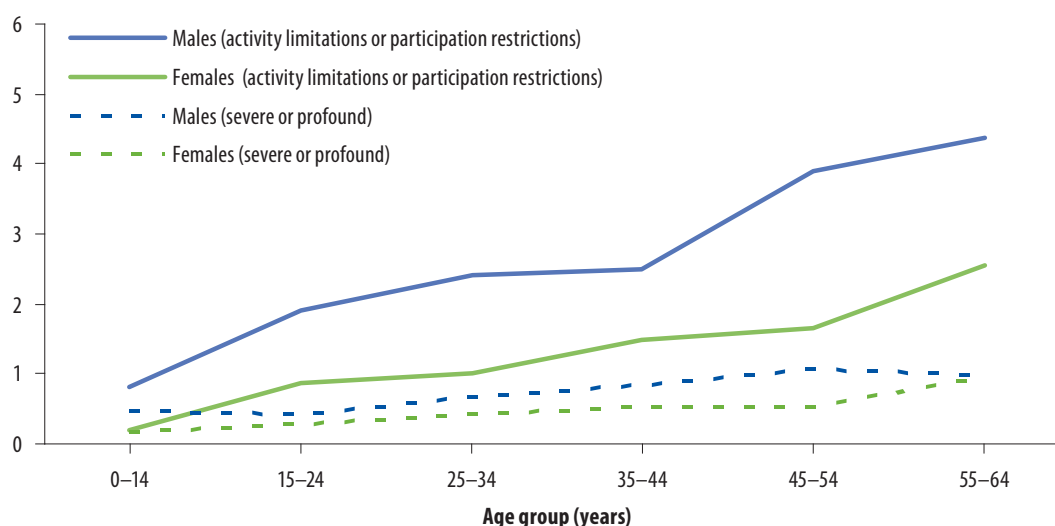
(a) Percentage of the population in each age group

Notes

1. Estimates marked with * have an associated relative standard error (RSE) between 25% and 50% and should be interpreted with caution.
2. Estimates marked with ** have an associated relative standard error (RSE) greater than 50% and are considered too unreliable for general use.
3. See Box 1 for information on survey concepts and definitions.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Per cent

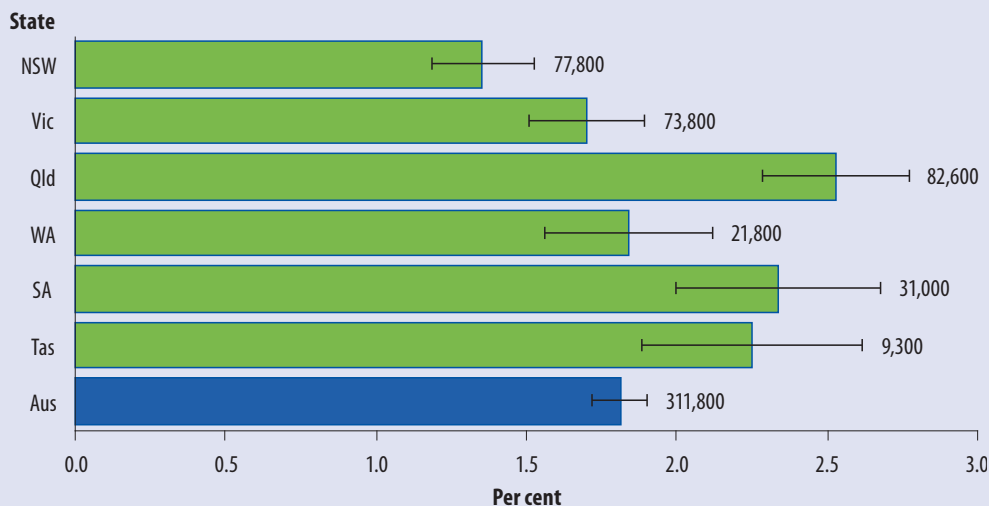


Source: Table A1.

Figure 1: Age- and sex-specific prevalence rates of ABI, by disability status, 2003 (per cent)

Box 2: ABI prevalence rates across Australia

- The ABI prevalence rate for people aged under 65 years in Queensland (2.5%) was significantly higher than the Australian average (1.8%), even after accounting for differences due to age and sex. The rate in New South Wales (1.4%) was significantly lower than the Australian average.
- Estimated numbers of people with ABI in the Northern Territory (2,600) and Australian Capital Territory (3,300) are too small to allow reliable comparison of prevalence rates.
- In 2003, 41% of people aged under 65 years with ABI lived outside major cities, compared with 38% of all people with disability and 34% of the Australian population in this age group.
- The age- and sex-standardised ABI prevalence rate for people living outside major cities (2.2%) was significantly higher than for people living in major cities (1.6%).



Notes

1. Based on all people with ABI and activity limitations or participation restrictions.
2. The number of people in each jurisdiction with ABI is shown at the right of each bar.
3. The estimated prevalence in Tasmania has a relative standard error between 25% and 50% and should be interpreted with caution.

Source: Table A2.

Figure 2: Age- and sex-standardised prevalence of ABI among people aged under 65 years, by state, 2003 (per cent)

Cause of ABI and age at onset

Information about cause and age at onset is only available for people who nominated ABI as their 'main condition'—that is, the one causing them the most problems. In the survey, some people with ABI may report 'head injury/acquired brain damage' as their main condition, while others report a condition related to their ABI, or an unrelated condition. For example, many people with ABI reported back problems and depression/mood affective disorders as their main condition. Data about age at onset of main condition were not collected for people living in cared accommodation.

In 2003, there were 27,300 people aged under 65 years with ABI and activity limitations or participation restrictions who said that 'head injury/acquired brain damage' was their main condition. Of these:

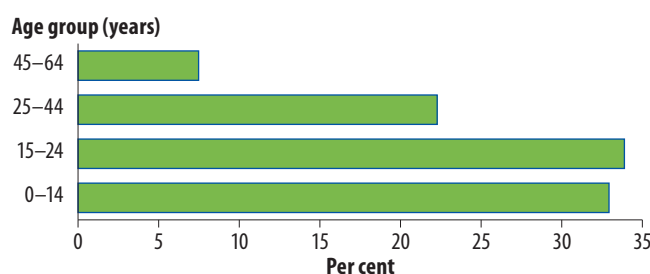
- More than nine in ten (25,100 people) said their ABI was caused by accident or injury. This includes 15,000 (55%) who said the accident or injury occurred on a street, road or highway (Table 2).
- Two-thirds (18,300 people) said that they acquired their brain injury when they were aged under 25 years (Figure 3).

Table 2: Cause of main condition, people aged under 65 years with main condition ABI, 2003

	'000	Per cent
Accident or injury	25.1	91.9
On a street, road or highway	15.0	54.9
At home	*4.4	*16.1
Other cause/don't know	*2.2	*8.1
Total	27.3	100.0

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.



Note: Age of onset data were not collected for people living in cared accommodation (3% of all people aged under 65 years with main condition ABI).

Source: Table A3.

Figure 3: Age at onset of ABI, persons aged under 65 years with main condition ABI, 2003 (per cent)

Disabilities and health conditions associated with ABI

People with ABI often have multiple disabilities. The survey data can be used to group people's reported disabilities into broad groups, to provide information on patterns of associated disabilities (Figure 4).

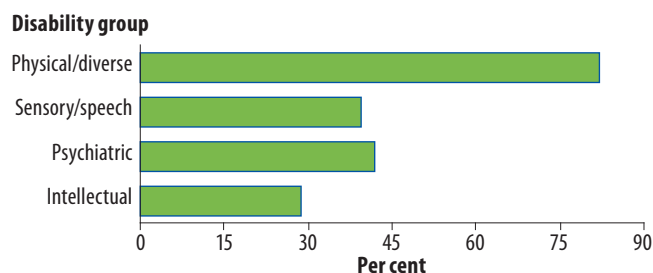
Of people aged under 65 with ABI:

- four out of five had disability in the physical/diverse group (a broad grouping that includes conditions such as neurological conditions, cardiovascular and respiratory conditions, cerebral palsy, and arthritis)
- around 42% had psychiatric disability, 39% had a sensory/speech disability, and 29% had an intellectual disability.

In many cases, the associated disabilities people reported in the survey are likely to be related in some way to the person's ABI, though this will not always be the case.

Compared with all people with disability, those with ABI tend to report more disability groups and more health conditions:

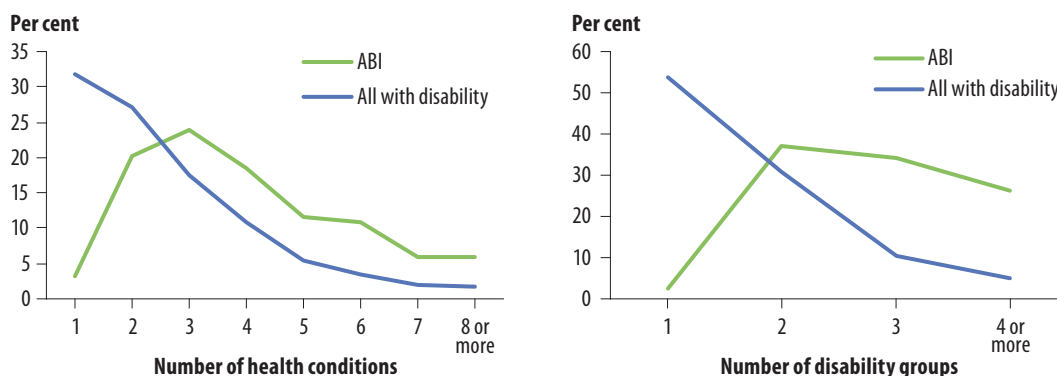
- More than one in four (26%) people with ABI reported four or more disability groups, compared with one in eighteen (5%) of all people with disability (Figure 5).
- More than one in three (34%) people with ABI reported 5 or more health conditions, compared with about one in eight (13%) of all people with disability (Figure 5).
- People with ABI reported an average of 2.9 disability groups and 4.1 health conditions, compared with an average 1.7 disability groups and 2.6 health conditions for all people with disability.
- Some of the health conditions commonly reported by people with ABI were back problems (reported by 32%), arthritis (26%), hearing problems (22%) and depression (15%).



Note: Based on people with ABI and activity limitations or participation restrictions.

Source: Table A6.

Figure 4: Other disability groups reported by people with ABI aged under 65 years



Note: Based on people with activity limitations or participation restrictions.

Source: Table A7.

Figure 5: Number of disability groups and health conditions, people with ABI and all people with disability, aged under 65 years, 2003

Box 3: Hospitalisations for traumatic brain injury

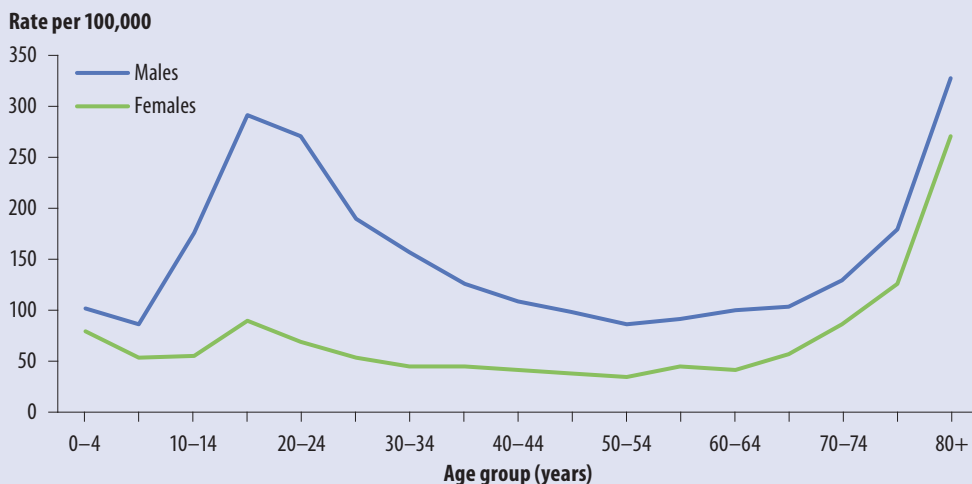
It is not possible to use hospital data to say how many new incidences of traumatic brain injury (TBI) there are in a given year because:

1. not all people who suffer a traumatic brain injury are hospitalised
2. people who are hospitalised more than once for their TBI will be counted more than once.

However, patterns of incidence can be estimated. In particular, over-counting can be reduced somewhat by excluding records where the patient was transferred to another acute hospital.

In 2004–05 there were almost 21,800 hospital stays for which a diagnosis associated with TBI was recorded as either the principal or an additional diagnosis (Table A5)—a rate of 107 TBI-related hospital stays per 100,000 people in the population. Of these hospital stays:

- males accounted for more than two-thirds (69%)—males were more likely to be hospitalised than females, at all ages (Figure 6). The age-standardised hospitalisation rate was 150 per 100,000 for males and 65 per 100,000 for females
- there was a strong peak in TBI-related hospitalisation rates for males between the ages of 15 and 24 years—almost 300 hospital stays per 100,000 people
- rates of TBI-related hospitalisation rose steeply beyond the age of 75 years for both sexes.



Source: Table A4.

Figure 6: Traumatic brain injury-related hospital stays, 2004–05

Between 1999–2000 and 2004–05 the overall rate of hospitalisations related to TBI remained steady at around 107–108 stays per 100,000 people per year. However, there were notable trends within different age groups over this 5-year period:

- Among children aged less than 15 years, the age-standardised hospitalisation rate fell by more than one-fifth, from 120 to 93 per 100,000. In absolute terms, there were around 1,000 fewer TBI-related hospitalisations of children aged 0–14 years in 2004–05 than 1999–2000.
- There was a 15% increase in the age-standardised hospitalisation rate among people aged 45–64 years, from 58 to 66 per 100,000 (almost 800 more hospitalisations in 2004–05 than 1999–2000).
- The age-standardised hospitalisation rate among people aged 65 years or over rose by almost one-third, from 118 to 153 per 100,000 population, accounting for 1,400 more hospitalisations. The rate increase was greater among females (36%) than males (24%).

Living arrangements and carers

- In 2003, 30,700 people with ABI lived in cared accommodation, almost all (97%) of whom had a severe or profound core activity limitation.
- Of people aged under 65 years with ABI, 97% (303,200 people) lived in households and 3% (8,700 people) lived in cared accommodation. About 8% of people aged under 65 who had ABI with a severe or profound core activity limitation lived in cared accommodation.
- Of people aged 65 years or over with ABI, 82% (98,800 people) lived in households and 18% (22,100 people) lived in cared accommodation. About 38% of people aged 65 years or over who had ABI and a severe or profound core activity limitation lived in cared accommodation.
- There were 56,200 people with ABI living in households with a co-resident primary carer. A primary carer is the person who provides the most informal help to someone with disability. About two-thirds of people with co-resident primary carers were aged less than 65 years.
- More than one in four (26%, or 14,500 people) co-resident primary carers of people with ABI were themselves aged 65 years or over.

Need for assistance

The ABS Survey of Disability, Ageing and Carers provides information on need for assistance across 10 'life domains'—the three core activities (mobility, self-care and communication) plus seven 'non-core activities' (Table 3). This section will focus on people living in households only, because information about non-core activities is not available for people living in cared accommodation.

The area with which people with ABI most commonly required assistance was cognitive and emotional tasks—over 100,000 people, or more than one-third of all people with ABI aged under 65 years, reported needing help in this area. Compared with people with disability generally, people with ABI were more likely to need assistance with mobility, self-care, cognitive and emotional tasks, paperwork, transport, health care and meal preparation.

Almost 30% of people with ABI aged under 65 years living in households needed help with at least one core activity, and 4% needed help with all three core activities (Table 3). In comparison, 26% of people with disability generally needed help with at least one core activity, and 2% needed help in all three areas.

Of the 90,000 people with ABI aged under 65 years living in households who needed help with core activities, 43% needed help at least once per day, including 12% who needed help more than five times per day (Table 4). In comparison, higher proportions of people with intellectual, sensory/speech and psychiatric disability needed daily assistance with core activities.

Putting this information on need for assistance together with the data on numbers of associated conditions and disability groups suggests that, compared with other types

of disability, people with ABI do not necessarily have higher support needs in the core activities of daily living, or require a greater intensity of assistance with these activities. However, they may have more complex or diverse needs for support and assistance, particularly in life areas related to independent living.

Table 3: Need for help with activities, people with ABI and all people with disability^(a) living in households, aged under 65 years, 2003

	Acquired brain injury		All with disability	
	'000	Per cent	'000	Per cent
Core activities				
Mobility ^(b)	72.5	23.9	466.6	18.9
Self-care ^(b)	51.3	16.9	318.6	12.9
Communication	20.5	6.8	167.3	6.8
Any core activity ^(b)	90.0	29.7	641.5	25.9
All three core activities	11.7	3.9	57.6	2.3
Non-core activities				
Cognitive/emotional tasks ^(b)	107.8	35.6	635.8	25.7
Property maintenance	85.1	28.1	658.6	26.6
Transport ^(b)	77.0	25.4	426.9	17.3
Health care ^(b)	75.1	24.8	496.6	20.1
Paperwork ^(b)	62.1	20.5	223.1	9.0
Housework	62.1	20.5	477.6	19.3
Meal preparation ^(b)	31.5	10.4	143.6	5.8
Total aged under 65 years living in households	303.2	100.0	2,473.4	100.0

Notes

(a) Based on people with activity limitations and participation restrictions.

(b) Differences in percentages between people with ABI and all people with disability are statistically significant.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 4: Highest frequency of need for assistance with core activities, people aged under 65 years living in households who need help with core activities, by disability group, 2003

Disability group	>5 times a day		1–5 times a day		<once per day	
	'000	Per cent	'000	Per cent	'000	Per cent
Intellectual	35.7	17.9	81.6	41.0	81.8	41.1
Sensory/speech	34.5	14.9	82.3	35.6	114.8	49.5
Psychiatric	30.8	11.8	87.4	33.4	143.4	54.8
ABI	10.4	11.5	28.1	31.2	51.6	57.3
Physical/diverse	35.5	7.2	141.3	28.6	316.6	64.2

Note: Based on people with activity limitations and participation restrictions.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Assistance received

The survey asked people whether their needs for help with different activities were met (Table 5). The following data relate to people with activity limitations or participation restrictions who were aged under 65 years.

- Most people with ABI had their self-care and personal health care needs fully met—more than 80% reported having their needs fully met in these areas.
- The highest levels of unmet need were associated with self-care and property maintenance. More than 10% of people with ABI who needed help in these areas didn't receive any.
- The apparent discrepancy in met and unmet need for self-care is related to the low percentage of people reporting partly met self-care needs. That is, while a relatively large group of people with ABI received no assistance with self-care (13% of those who needed help), those that did receive help usually received enough to fully meet their needs.
- Almost one in three (32%) people with ABI who needed assistance with cognitive or emotional tasks received some help, but needed more.
- Lower proportions of people with ABI than with disability generally had their needs fully met in the areas of mobility, property maintenance, transport and meal preparation, while higher proportions had their communication needs fully met. However, these differences were not statistically significant.

Table 5: Extent to which need for assistance is met, people with ABI and all people with disability aged under 65 years living in households, by area of need for assistance, 2003 (per cent of those needing assistance in each area)

	Acquired brain injury			All with disability		
	Fully	Partly	Not at all	Fully	Partly	Not at all
Core activities						
Mobility	77.3	20.4	**2.3	82.3	12.8	4.8
Self-care	82.8	4.7	*12.5	86.3	4.1	9.6
Communication	79.0	*20.0	**1.0	66.3	30.7	*3.0
Non-core activities						
Cognitive/emotional support	63.0	31.7	*5.3	61.8	33.0	5.2
Property maintenance	68.6	20.3	*11.0	73.6	20.3	6.1
Transport	77.8	13.5	*8.7	82.3	9.9	7.7
Health care	80.6	*12.7	*6.7	80.3	13.1	6.6
Paperwork	78.2	17.4	*4.4	78.9	14.7	6.3
Housework	73.8	20.3	*5.9	74.0	19.4	6.6
Meal preparation	76.8	*23.2	—	86.7	10.8	*2.5

Notes

1. Based on people with activity limitations or participation restrictions.

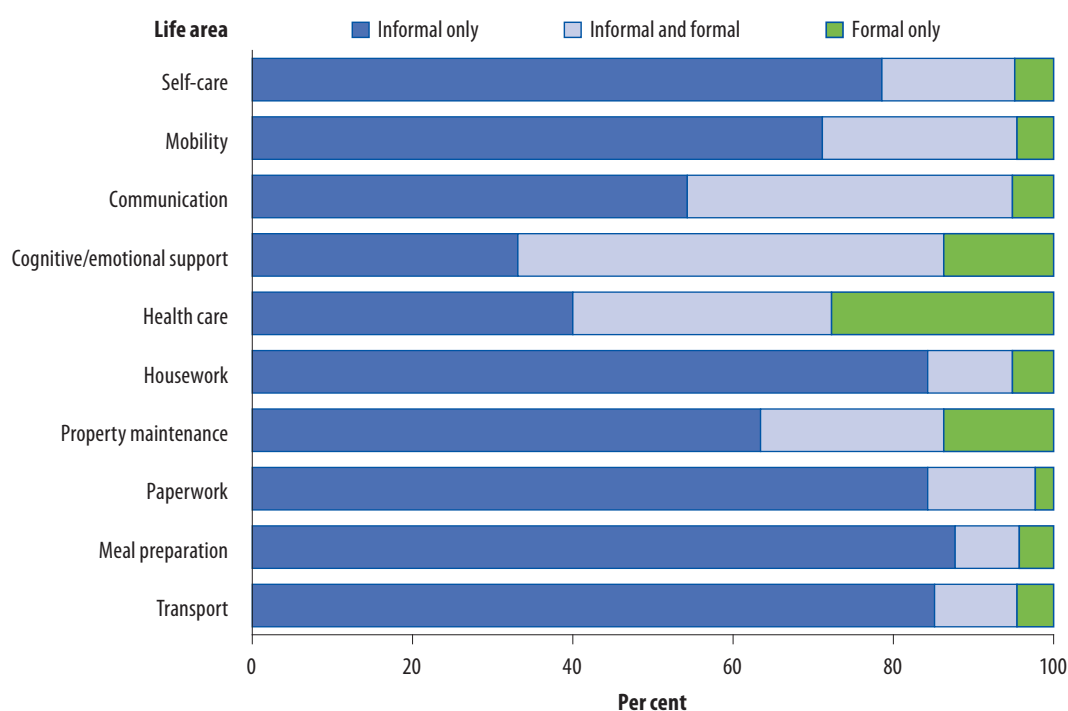
2. Estimates marked with * have an associated relative standard error (RSE) between 25% and 50% and should be interpreted accordingly.

3. Estimates marked with ** have an associated relative standard error (RSE) greater than 50% and are considered too unreliable for general use.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

The following relates to those people with ABI who did receive some assistance (Figure 7).

- More than 80% received informal assistance only with meal preparation, transport, paperwork and housework.
- They were most likely to receive formal assistance, with or without additional informal help, in the areas of health care and cognitive or emotional tasks. Still, more than one-third who received help in these areas used informal sources only.
- They were more likely to receive only formal help for health care than any other life area.
- They were more likely to receive assistance from formal sources for non-core activities than core activities. Half (52%) accessed a mix of formal and informal sources for non-core activities while 12% used formal sources only. In comparison, one-quarter (27%) received help with core activities from a mix of formal and informal sources, and 5% used formal sources only (Table A8).



Note: Based on people with activity limitations or participation restrictions.

Source: Table A8.

Figure 7: Sources of assistance in different life areas, people with ABI aged under 65 years living in households who received assistance, 2003

Box 4: ABI among older people

ABI can result from a number of different causes. Many of these rapidly increase in prevalence among older people. For example, stroke, Parkinson's disease, dementia including Alzheimer's disease, neurodegenerative conditions, alcohol-related brain injury, and falls are all somewhat age-related causes of ABI. Very few people (1,400) aged 65 years or over reported ABI as their main disabling condition, possibly because they had other significant health conditions that they saw as causing more problems. Therefore, among older people, ABI is usually one of several health conditions associated with disability. Because of these factors, people with ABI aged 65 years or over may be considered separately from younger people with ABI.

Among people aged 65 years or over in 2003:

- There were 120,900 people who had ABI and some activity limitations or participation restrictions—4.7% of the population in this age group, which is more than twice the rate for people aged under 65 years.
- About 57,500 people had ABI and severe or profound core activity limitations—2.3% of the population in this age group, or almost four times the under 65 years rate.
- The prevalence rate of ABI with activity limitations and participation restrictions increased with age, from 4.1% of all people aged 65–74 years to 8.5% of the population aged 85 years or over. The prevalence rate of ABI with severe or profound core activity limitations rose from 1.4% of the population aged 65–74 years to 6.2% of all people aged 85 years or over (Table A1).
- Males aged 65–74 years and 75–84 years were more likely to have ABI and activity limitations or participation restrictions than females in the same age groups. Among people aged 85 years or over there was no significant difference in ABI prevalence rates between the sexes. Rates of ABI with severe or profound core activity limitations were not significantly different between males and females at any age above 65 years (Table A1).
- There were no significant differences in the age- and sex-standardised prevalence rate of ABI across states and territories, or between people living in major cities and people living outside major cities.
- People aged 65 years or over with ABI had more disability groups than people of the same age with disability generally—an average of 3.2 compared with 1.9. Similarly, older people with ABI had an average 5.2 health conditions, compared with 3.8 for all older people with disability.
- Almost all (96%) people with ABI aged 65 years or over had physical/diverse disability, and more than two-thirds (68%) had sensory/speech disability. These rates are higher than among younger people with ABI (Figure 5). Psychiatric and intellectual disability were more common among people aged under 65 years.
- Some of the most common health conditions experienced by people aged 65 years or over with ABI were hearing problems (54%), arthritis (44%) and hypertension (40%). About one in five (20%) older people with ABI had experienced a stroke, and one in eight (12%) had dementia.
- People with ABI aged 65 years or over living in households were significantly more likely to need assistance with cognitive and emotional tasks than older people with disability generally (19% compared with 12%). It is important to note that these data exclude older people living in cared accommodation, who largely have higher support needs than people living in the community.

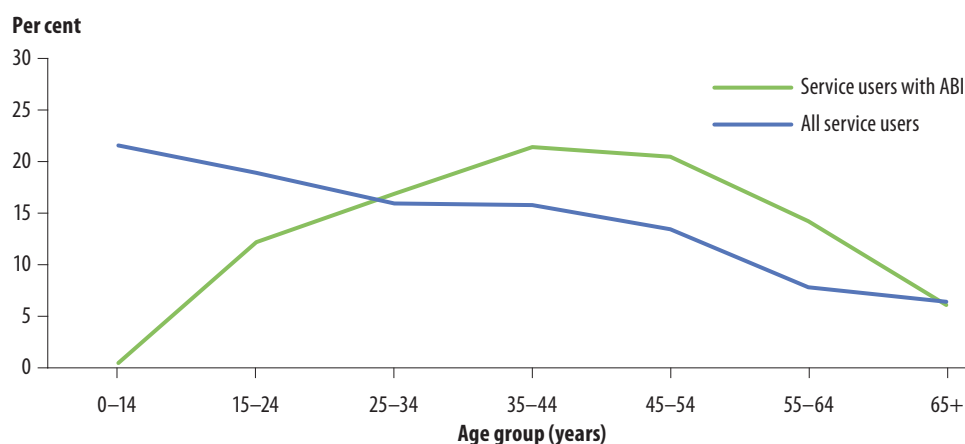
CSTDA-funded service users with ABI

The Commonwealth State/Territory Disability Agreement (CSTDA) funds services targeted at people with an ongoing need for support in everyday activities. The services aim to 'maximise the opportunity for people with disabilities to participate socially and economically in the community' (CSTDA 2003:12). The 2002–07 Agreement specifies that disability experienced by a CSTDA service user should be manifest before the age of 65 years. In practice, services generally do not place upper age restrictions on their clients. However, many people with age-related causes of ABI (such as stroke and dementia) may receive services through the aged care system rather than through CSTDA-funded agencies.

Demographic profile

In 2004–05, 11,866 people recorded as having ABI used CSTDA-funded disability services.

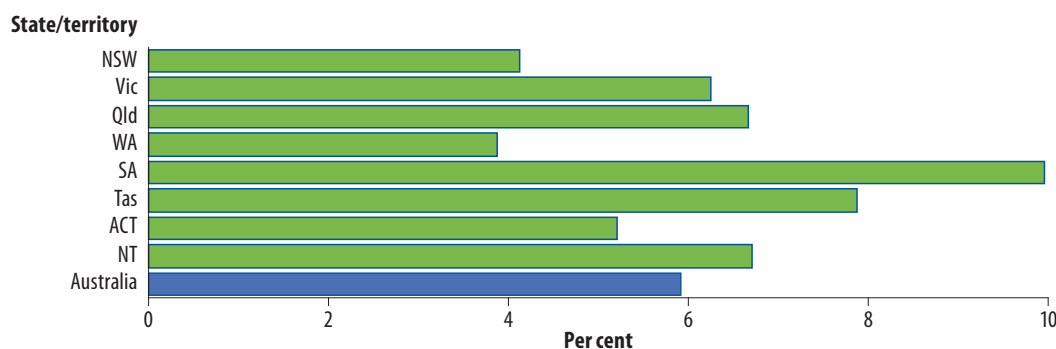
- People with ABI accounted for 6% of all CSTDA service users.
- People with ABI accounted for 7% of CSTDA service users who always or sometimes needed help with activities of daily living.
- More than two-thirds (68%) of service users with ABI were male, compared with 56% of CSTDA service users overall.
- The age distribution of service users with ABI was older than for service users generally (Figure 8). Only 13% of people with ABI were aged under 25 years, compared with 41% of all service users. A large proportion of CSTDA service users access community support, which includes programs with a focus on children and youth, such as early intervention and therapy support. Also, about half of all CSTDA service users have intellectual, learning or early developmental disability, which are more prevalent among children and young people than older adults.
- About half (51%) of service users with ABI had a carer, compared with 42% of CSTDA service users generally.
- More than half (52%) lived with their family, 25% lived with other people, and 19% lived alone. About 4% of service users with ABI did not state their living arrangements.
- Almost two-thirds (64%) of service users with ABI lived in major cities, 22% lived in inner regional areas, 10% in outer regional areas, 2% in rural areas and 1% in remote areas. This is typical of the distribution of CSTDA service users generally (AIHW 2006b).
- People with ABI made up a relatively high proportion of all service users in South Australia (10%) and Tasmania (8%). In contrast, 4% of service users in New South Wales and Western Australia had ABI (Figure 9).



Note: 'Service users with ABI' includes ABI as either a primary or other significant disability group.

Source: Table A9.

Figure 8: CSTDA-funded service users with ABI and all service users, by age group, 2004–05 (per cent)



Notes

1. Includes ABI as either a primary or other significant disability group.

2. Per cent of all service users with ABI in each state or territory

Source: Table A10.

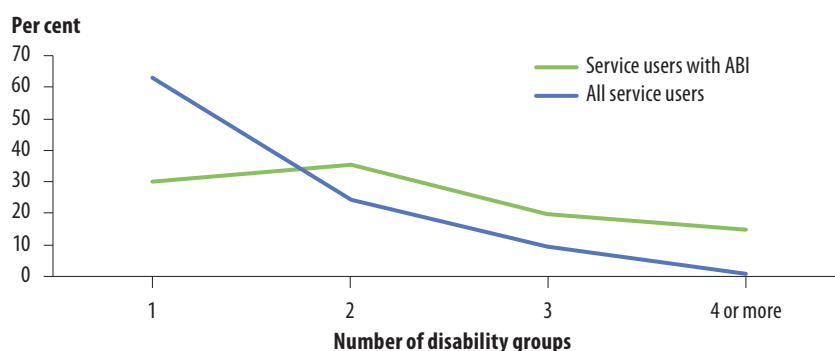
Figure 9: CSTDA service users with ABI by state/territory of residence, 2004–05 (per cent)

Associated disabilities of CSTDA service users with ABI

The CSTDA NMDS collects data on the disability group(s) of service users. Each individual reports a primary disability (equivalent to the 'main condition' in the population survey), and may also report other significant disabilities. Disabilities are categorised into four broad groups: physical/diverse, intellectual/learning, sensory/speech and psychiatric. In this bulletin, ABI was singled out as a separate broad disability group, in order to enable comparisons with the population data. The following relate to service users in 2004–05.

- ♦ People with ABI who used CSTDA services had an average of 2.2 disability groups. The average for all service users was 1.4 disability groups.

- ♦ Almost 15% of service users with ABI had 4 or more disability groups, compared with only 1% of service users generally (Figure 10).
- ♦ About two-thirds (68% or 8,017 people) of CSTDA service users with ABI said that this was their primary disability. Of these, 55% (4,437 people) had other significant disability groups.
- ♦ The disabilities most commonly associated with ABI among CSTDA service users were in the physical/diverse category. Half of all service users with ABI reported physical/diverse disability, compared with 33% of service users generally.
- ♦ Service users with ABI were more likely than the average service user to report sensory/ speech and psychiatric disability, but were less likely to have intellectual/ learning disability (Figure 11).
- ♦ These data show that, as for the broader population, specialist disability service users with ABI have more complex or diverse disability than service users generally.

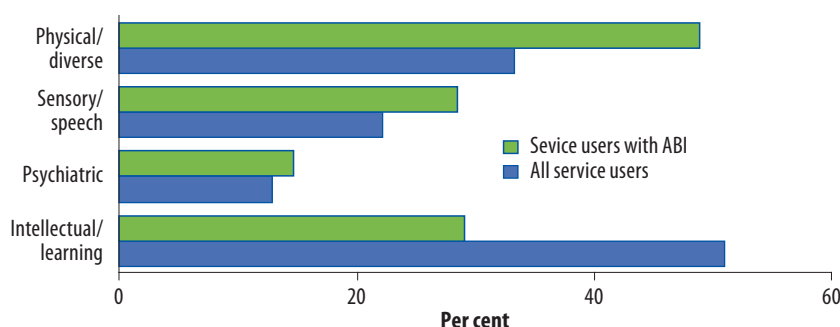


Notes

1. Excludes people for whom the number of disability groups was not stated or not known.
2. 'Service users with ABI' includes ABI as either a primary or other significant disability group.

Source: Table A11.

Figure 10: Number of disability groups, CSTDA service users with ABI and all service users, 2004–05 (per cent)



Note: 'Service users with ABI' includes ABI as either a primary or other significant disability group.

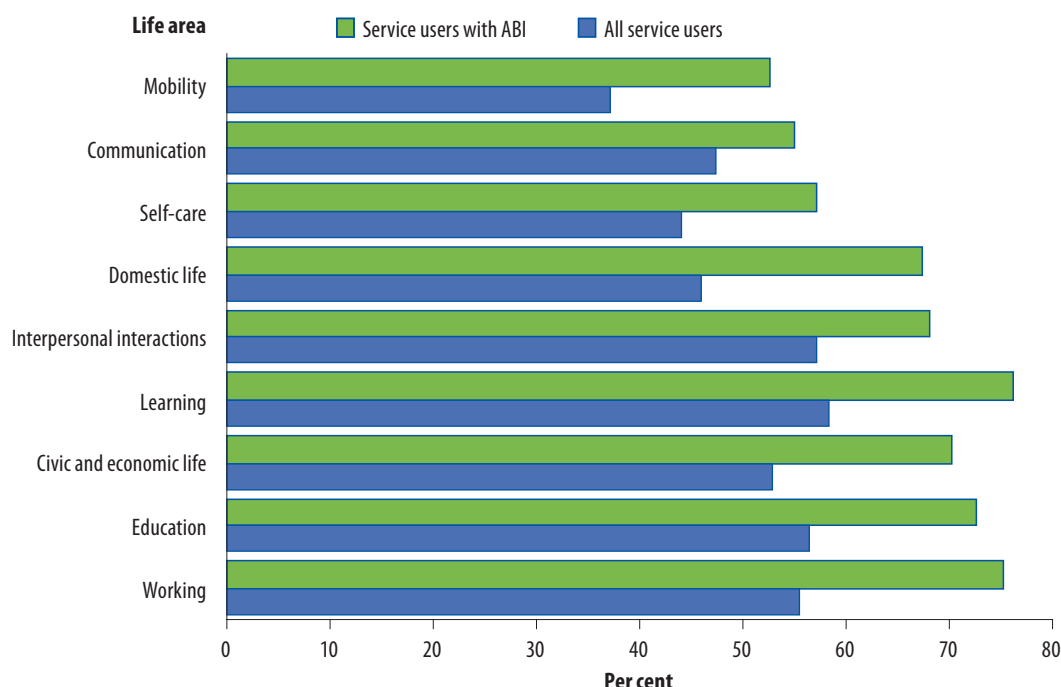
Source: Table A12.

Figure 11: Other disability groups reported by CSTDA service users with ABI and all service users, 2004–05 (per cent)

Need for assistance

The CSTDA NMDS collection includes data on the support needs of service users in nine life areas (Figure 12). Service users with ABI:

- were most likely to need help with activities related to learning and working—more than three-quarters of service users with ABI needed assistance in these areas
- were less likely to need help with activities of daily living (mobility, communication and self-care) than other life areas
- were more likely than service users generally to need support in each of the nine life areas.



Notes

1. Percentage of each group who sometimes or always need assistance with, or are unable to do, tasks related to each life area.
2. Not stated/not collected responses are excluded.
3. 'Service users with ABI' includes ABI as either a primary or other significant disability group.
3. The full name for the life area 'interpersonal interactions' is 'interpersonal interactions and relationships'.
4. The full name for the life area 'learning' is 'learning, applying knowledge and general tasks and demands'.

Source: Table A13.

Figure 12: Need for assistance with different life areas, CSTDA service users with ABI and all service users, 2004–05 (per cent)

Service use

- People with ABI tend to have complex patterns of service usage. CSTDA service users with ABI were more likely to use multiple service types, groups or outlets than service users generally (Table 6).

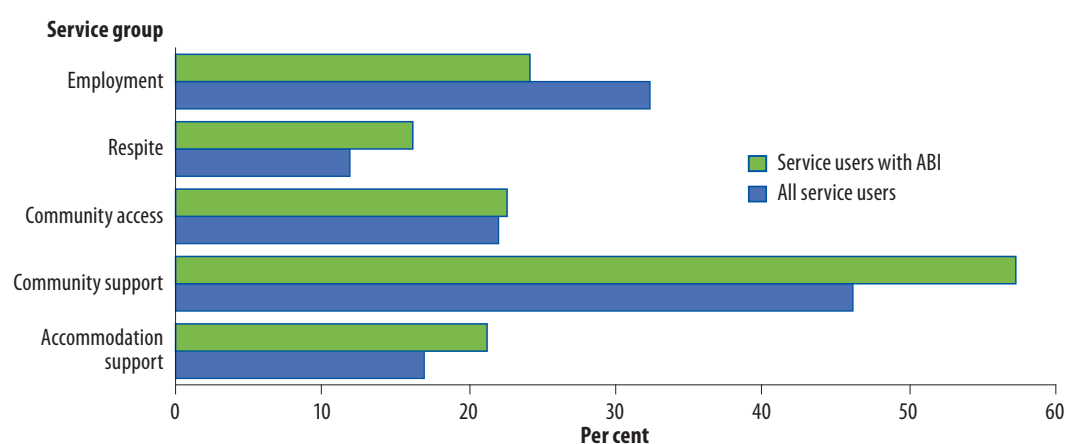
Table 6: Multiple service use, CSTDA service users with ABI and all service users, 2004–05 (per cent)

	Service users with ABI	All service users
Using more than one service type	34.9	26.5
Using more than one service group	30.1	21.6
Using more than one service outlet	38.7	29.1

Note: 'Service users with ABI' includes ABI as either a primary or other significant disability group.

Source: AIHW analysis of Commonwealth State/Territory Disability Agreement National Minimum Data Set.

- ✦ Of the different service groups funded under the CSTDA, people with ABI were most likely to access community support — a group of services that help people with disability live in a non-institutional setting (Figure 13). This includes such services such as early intervention, therapy and case management.
- ✦ People with ABI were more likely than service users generally to access community support, respite and accommodation support.
- ✦ People with ABI were less likely than service users generally to access disability employment services.
- ✦ Of the specific service types provided by CSTDA-funded agencies, people with ABI were most likely to use case management (Table 7).
- ✦ More than one in ten service users with ABI accessed open employment, individual therapy support, learning and life skills development, and in-home accommodation support.



Note: 'Service users with ABI' includes ABI as either a primary or other significant disability group.

Source: Table A14.

Figure 13: Service groups accessed, CSTDA service users with ABI and all service users, 2004–05 (per cent)

Table 7: Service types accessed by service users with ABI and all service users, 2004–05

	Service users with ABI		All service users	
	Number	Per cent	Number.	Per cent
Case management, local coordination & development	4,823	40.6	42,614	21.3
Open employment services	1,938	16.3	43,831	21.9
Therapy support for individuals	1,686	14.2	29,111	14.5
Learning and life skills development	1,650	13.9	25,111	12.5
In-home accommodation support	1,231	10.4	16,055	8.0
Flexible/combination respite	917	7.7	11,103	5.5
Other community access & day programs	847	7.1	13,212	6.6
Supported employment services	836	7.0	18,615	9.3
Centre-based respite/respite homes	706	5.9	11,011	5.5
Group homes	678	5.7	10,722	5.3

Notes

1. 'Service users with ABI' includes ABI as either a primary or other significant disability group.
2. Only the 10 service types most commonly used by service users with ABI are listed.
3. Columns show the percentage of service users (with ABI/all service users) who accessed a given service type. Individuals may use more than one service type.

Source: AIHW analysis of Commonwealth State/Territory Disability Agreement National Minimum Data Set.

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Appendix

Table A1: ABI prevalence rates by disability severity, sex and age group, 2003 (per cent)^(a)

Age group (years)	ABI with activity limitations or participation restrictions			ABI with severe or profound core activity limitations		
	Males	Females	Persons	Males	Females	Persons
0–14	0.8	*0.2	0.5	*0.5	*0.2	0.3
15–24	1.9	0.9	1.4	*0.4	*0.3	*0.3
25–34	2.4	1.0	1.7	*0.7	*0.4	0.6
35–44	2.5	1.5	2.0	0.8	*0.5	0.7
45–54	3.9	1.7	2.8	1.1	*0.5	0.8
55–64	4.4	2.6	3.5	*1.0	*0.9	1.0
Total under 65	2.4	1.2	1.8	0.7	0.4	0.6
65–74	5.6	2.7	4.1	1.8	*1.1	1.4
75–84	6.4	3.1	4.6	2.8	*1.9	2.3
85 or over	*10.4	7.7	8.5	*4.6	6.9	6.2
Total 65 or over	6.2	3.5	4.7	2.3	2.2	2.3
Total	2.9	1.5	2.2	0.9	0.7	0.8
Total number ('000)	282.5	150.3	432.7	88.6	68.8	157.5

(a) Percentage of the population in each age group.

Note: Estimates marked * have a relative standard error of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A2: Age- and sex-standardised prevalence of ABI among people aged under 65 years, by state/territory of residence, 2003

State/territory	'000	Per cent ^(a)	95% confidence interval
New South Wales	77.8	1.4	1.1–1.6
Victoria	73.8	1.7	1.4–2.0
Queensland	82.6	2.5	2.1–3.0
Western Australia	21.8	1.8	1.3–2.4
South Australia	31.0	2.3	1.7–3.0
Tasmania	9.3	2.2	1.1–3.4
Australian Capital Territory	*3.3	*1.1	0.2–2.0
Northern Territory	*2.6	*1.8	0.2–3.5
Australia	311.8	1.8	1.6–2.0

(a) Percentage of the population in each jurisdiction.

Note: Estimates marked * have a relative standard error between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A3: Age at onset of ABI, persons aged under 65 years with main condition ABI, 2003 (per cent)

Age group (years)	'000	Per cent
0–14	*9.0	*33.0
15–24	*9.3	*33.9
25–44	*6.1	*22.2
45–64	*2.1	*7.5
Total	26.4	96.6

Notes

1. Age of onset data were not collected for people living in establishments (3% of all people aged under 65 years with main condition ABI).
2. Estimates marked * have a relative standard error between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A4: Traumatic brain injury-related hospital stays, by age group and sex, 2004–05

Age group	Males		Females		Persons	
	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)
0–4	661	102	490	80	1,151	91
5–9	582	86	345	53	927	70
10–14	1,254	176	376	56	1,630	117
15–19	2,054	291	598	89	2,652	192
20–24	1,951	270	476	69	2,427	172
25–29	1,308	190	362	54	1,670	123
30–34	1,179	156	343	45	1,522	100
35–39	920	126	325	44	1,245	85
40–44	838	109	316	41	1,154	75
45–49	703	98	276	38	979	68
50–54	568	86	232	35	800	60
55–59	565	92	268	44	833	68
60–64	466	100	188	41	654	71
65–69	388	103	218	57	606	80
70–74	389	129	281	86	670	107
75–79	448	180	381	126	829	151
80 or over	837	327	1,190	270	2,027	291
Not reported	1	—	1	—	2	—
Total^(b)	15,112	150	6,666	65	21,778	107

(a) Rate per 100,000 population.

(b) Total is age-standardised to the Australian population at 30 June 2001.

Notes

1. Traumatic brain injury-related diagnoses may be either the principal or an additional diagnosis.
2. A hospital stay refers to a single separation, where a separation is the process by which an episode of care for an admitted patient ceases. Analysis excluded separations where the patient was transferred to an (other) acute hospital. Care type = 'acute care' or 'unknown/not specified'.

Source: AIHW analysis of National Hospital Morbidity Database.

Table A5: ICD-10-AM codes used to identify traumatic brain injury-related hospital stays

ICD-10-AM code	Description
S02.0	Fracture of vault of skull
S02.1	Fracture of base of skull
S02.8	Fractures of other skull and facial bones
S02.7	Multiple fractures involving skull and facial bones
S06.0	Concussive injury
S06.2	Diffuse brain injury
S06.3	Focal brain injury
S06.4	Epidural haemorrhage
S06.5	Traumatic subdural haemorrhage
S06.6	Traumatic subarachnoid haemorrhage
S06.8	Other intracranial injuries
S06.9	Intracranial injury, unspecified
S09.7	Multiple injuries of the head
T06.0	Injuries of the head and cranial nerves with injuries of nerve and spinal cord at neck level

Notes

1. Data on traumatic brain injury-related hospital stays were extracted from the National Hospital Morbidity Database.
2. Traumatic brain injury-related diagnoses may be either the principal or an additional diagnosis.
3. Analysis excluded separations where the patient was transferred to an (other) acute hospital.

Source: NCCH 2004.

Table A6: Other disability groups reported by people with ABI aged under 65 years, 2003

	Per cent
Physical/diverse	82.1
Sensory/speech	39.4
Psychiatric	42.0
Intellectual	28.8

Note: Based on people with ABI and activity limitations or participation restrictions.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A7: Number of disability groups and health conditions, people with ABI and all people with disability, aged under 65 years, 2003 (per cent)

	People with ABI	All people with disability
Number of disability groups		
1	2.5	53.7
2	36.9	30.8
3	34.3	10.6
4 or more	26.4	4.8
Number of health conditions		
1	3.2	31.8
2	20.3	27.2
3	23.8	17.5
4	18.5	10.8
5	11.7	5.5
6	10.8	3.4
7	5.8	2.0
8 or more	5.9	1.8

Note: Based on people with activity limitations or participation restrictions.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A8: Sources of assistance in different life areas, people with ABI aged under 65 years living in households who received assistance, 2003 (per cent)

	Informal only	Formal only	Formal and informal
Self-care	78.6	4.8	16.6
Mobility	71.0	4.5	24.5
Communication	54.4	5.2	40.3
Any core activity	67.9	5.0	27.1
Cognitive/emotional support	33.1	13.9	53.1
Health care	40.0	27.6	32.4
Housework	84.3	5.1	10.6
Property maintenance	63.6	13.7	22.7
Paperwork	84.3	2.2	13.5
Meal preparation	87.8	4.2	8.0
Transport	85.1	4.5	10.4
Any non-core activity	35.4	12.4	52.2

Note: Based on people with activity limitations or participation restrictions.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A9: CSTDA-funded service users by age, service users with ABI and all service users, 2004–05 (per cent)

Age (years)	Service users with ABI	All service users
0–14	0.5	21.6
15–24	12.2	18.9
25–34	16.9	15.9
35–44	21.5	15.8
45–54	20.5	13.4
55–64	14.2	7.8
65 or over	6.1	6.5

Note: 'Service users with ABI' includes ABI as either a primary or other significant disability group.

Source: AIHW analysis of Commonwealth State/Territory Disability Agreement National Minimum Data Set.

Table A10: CSTDA-funded service users with ABI^(a) by state or territory of residence, 2004–05 (per cent)^(b)

State/Territory	Per cent
New South Wales	4.1
Victoria	6.2
Queensland	6.7
Western Australia	3.9
South Australia	10.0
Tasmania	7.9
Australian Capital Territory	5.2
Northern Territory	6.7
Australia	5.9

(a) ABI as either a primary or other significant disability group.

(b) Per cent of all service users with ABI in each jurisdiction.

Source: AIHW analysis of Commonwealth State/Territory Disability Agreement National Minimum Data Set.

Table A11: Number of disability groups, CSTDA service users with ABI and all service users, 2004–05 (per cent)

	Service users with ABI	All service users
1	30.2	62.9
2	35.4	24.5
3	19.6	9.7
4 or more	14.8	0.9

Notes

1. Excludes people for whom the number of disability groups was not stated or not known.
2. 'Service users with ABI' includes ABI as either a primary or other significant disability group.

Source: AIHW analysis of Commonwealth State/Territory Disability Agreement National Minimum Data Set.

Table A12: Other disability groups reported by CSTDA service users with ABI and all service users, 2004–05 (per cent)

	Service users with ABI	All service users
Physical/diverse	48.9	33.3
Sensory/speech	28.4	22.2
Psychiatric	14.8	12.9
Intellectual/learning	29.2	50.9

Note: 'Service users with ABI' includes ABI as either a primary or other significant disability group.

Source: AIHW analysis of Commonwealth State/Territory Disability Agreement National Minimum Data Set.

Table A13: Need for assistance with different life areas, CTSDA service users with ABI and all service users, 2004–05 (per cent)

	Service users with ABI	All service users
Mobility	52.6	37.1
Communication	55.1	47.3
Self-care	57.3	43.9
Domestic life	67.4	46.0
Interpersonal interactions	68.0	57.2
Learning	76.2	58.4
Civic and economic life	70.1	52.8
Education	72.7	56.5
Working	75.3	55.5

Notes

1. Percentage of each population who sometimes or always need assistance with, or are unable to do, tasks related to each life area.
2. Not stated/not collected responses are excluded.
3. 'Service users with ABI' includes ABI as either a primary or other significant disability group.
3. The full name for the life area 'interpersonal interactions' is 'interpersonal interactions and relationships'.
4. The full name for the life area 'learning' is 'learning, applying knowledge and general tasks and demands'.

Source: AIHW analysis of Commonwealth State/Territory Disability Agreement National Minimum Data Set.

Table A14: Service groups accessed, CTSDA service users with ABI and all service users, 2004–05 (per cent)

	Service users with ABI	All service users
Accommodation support	21.1	16.9
Community support	57.3	46.2
Community access	22.7	22.0
Respite	16.1	11.9
Employment	24.1	32.3

Note: 'Service users with ABI' includes ABI as either a primary or other significant disability group.

Source: AIHW analysis of Commonwealth State/Territory Disability Agreement National Minimum Data Set.

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