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Disability in Australia: intellectual disability

Summary

This bulletin analyses the patterns of transitions by people with intellectual disability into and out of school education and their needs for services and assistance. It also presents an overview of prevalence of intellectual disability, associated disabilities and conditions, causes and age at onset of main disabling conditions, and geographic location in Australia.

Over half a million Australians have intellectual disability and a majority (61%) of those people have a severe or profound limitation in 'core' activities of daily living. People with intellectual disability are a major group of users of disability support services in Australia (AIHW 2005, 2007a).

People with intellectual disability encounter special challenges that are different from people with other types of disabilities in a number of important aspects. For example, they have difficulty learning and applying knowledge and in decision making. They may have difficulty identifying and choosing options at key life transition points. They often have difficulty adjusting to changed circumstances and unfamiliar environments and therefore need high support during times of change (Western Australia Ministerial Advisory Council on Disability 2006). Two important life transition points are from home to school and from school to adult life—work, post-school study and participation in meaningful activities.

(summary continued overleaf)

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What the data reveal

In 2003, 588,700 people (3% of the population) had intellectual disability. Most were aged under 65 years (436,200). It is common for people with intellectual disability to have other types of disability, the most common being psychiatric disability.

Almost 60% of people with intellectual disability have severe communication limitations. This distinguishes intellectual disability from other major disability groups for which severe limitations are more concentrated in self-care and mobility. People with intellectual disability are also highly likely to have severe limitations in all three core activities of daily living—self-care, mobility and communication.

However, need for help with core activities may not fully reflect the level of support that an individual with intellectual disability requires to participate in society. Even though they may function relatively well in the familiar routines of self-care and domestic life, and be independently mobile, people with intellectual disability often have considerable difficulty in managing emotions and relating to other people. It is therefore important to also consider the level of support that is needed in non-core activity areas, especially making friendships, maintaining relationships and interacting with others.

If we consider need for support among people with intellectual disability in this broader context, the data reveal interesting findings on the extent to which needs are being met. Across a range of specific activities for which need for assistance was measured in 2003, the two areas with the lowest levels of fully met need for assistance were cognition/emotion (38% of people with intellectual disability had partially met or fully unmet needs) and communication (36%) (Figure 11).

School students with intellectual disability typically need additional support at school in order to learn and successfully participate in the school environment. This is reflected in their lower rate of participation in ordinary classes, compared to students with other disabilities. In 2003, 45% of students with intellectual disability attended ordinary school classes, compared to 95% of students with physical or diverse disability. For this group of students, learning and social difficulties were far more common problems than other sorts of problems that people with disabilities often encounter, such as participating in sport or physical access barriers (Table 7).

Most school students aged 5–9 years in 2003 with intellectual disability and severe or profound limitation started school life in an ordinary class and remained in ordinary classes for at least five years. Some, however, moved between different school environments. The most common transition was to start off in an ordinary class, then move to a special class or special school (a move made by 29% of a 5-year age cohort of students with severe disability, Figure 7). Around 28% of school students with intellectual disability in 2003 did not receive additional educational support for their disability (Table 8).

On finishing school, people with intellectual disability are far less likely to move into post-secondary education or the labour force than their age peers without disability. In 2003, the labour force participation rate of those aged in their 20s was around 60% and

between 34% and 46% for those aged in their 30s, well below the 85% participation by young adults without disability. Transitions out of the labour force were common at ages 30–34 years and onwards, possibly highlighting difficulties for people with intellectual disability in maintaining employment and a need for those who do leave a job to find alternative means of social participation.

Population baseline estimates of unmet demand show that a substantial number of people with intellectual disability need employment and community access services, or alternative sources of support (for example, informal care) to participate in employment and community life (see 'Population baseline estimates of unmet demand for services among people with intellectual disability').

Other statistical findings

Prevalence of intellectual disability and associated disabilities

- About 351,000 people with intellectual disability had a severe or profound core activity limitation (1.8% of the total population), of whom 215,100 were aged under 65 years (1.2% of the under-65 population).
- The escalating prevalence rates for people aged 75 years and over are associated with dementia-related conditions (AIHW 2006).
- Psychiatric disability is commonly associated with intellectual disability—in 2003, 57% of people aged under 65 years with intellectual disability also had psychiatric disability.
- Speech problems were the most common problems reported by people with intellectual disability in 2003 (24%).

Transition from home to school—participation in education

- In 2003, 82,400 (45%) school students with intellectual disability were attending an ordinary class, while 70,200 (38%) were attending a special class and 31,500 (17%) were attending a special school.
- About 101,700 school students with intellectual disability who had severe or profound schooling restrictions were either in a special class or a special school.
- An estimated 68,900 people aged under 20 years with intellectual disability had severe or profound limitations/restrictions with both core activity and schooling, of whom 64,600 were attending school—54%(34,700) in special classes and 45% (28,800) in special schools. These people had more difficulties at school and higher and more complex needs for support than other students with intellectual disability.
- In 2003, there were high proportions of school students with intellectual disability who had difficulties in learning (66%), fitting in socially (41%) and communicating (31%). These difficulties were far more common than difficulty participating in physical activity and physical access problems.

- The most common types of assistance received by students with intellectual disability were special tuition (54%), a counsellor or disability support person (28%) and a special assessment procedure (22%).
- An estimated 28% of students with intellectual disability did not receive special support at school.

Transition from school to adult life

Analyses of age cohorts between 1998 and 2003 for young adults with intellectual disability show that:

- the proportion who participated in post-school study was very low—about 9% of those who turned 20–24 years in 2003 and less than 5% of those who turned 25 years or over
- they were much less likely to successfully transfer into the labour force than their age peers without disability
- considering people with intellectual disability aged 25–34 years in 1998, labour force participation rates dropped considerably over the five years to 2003; the falling labour force participation rates were not explained by increased participation in post-school study or disability day activity programs
- people aged 15–64 years with intellectual disability, compared with people without disability of the same age, were less likely to complete Year 12 studies, participate in tertiary education, participate in the labour force, to be employed working full-time, or work in the government sector
- they were more likely to be unemployed, have never married, rely on a government pension or allowance as their main source of cash income, and were less likely to be wage or salary earners.

Need and unmet demand for services and assistance

- Among the 202,600 people aged under 65 years with intellectual disability and severe or profound core activity limitation living in households, 102,200 people needed help with self-care, 138,400 with mobility and 115,800 with communication.
- The proportion of people with intellectual disability who needed help with communication was 57%. By contrast, the corresponding proportions of people with other disabilities (and no intellectual disability) were considerably lower: physical/diverse (3%), acquired brain injury (6%), psychiatric (8%) and sensory/speech (25%) disabilities.
- Overall, of the 335,000 people aged under 65 years with intellectual disability living in households who needed help with either core or other activities, just half (166,800) had their support needs fully met. Of the 198,500 people who needed help with a core activity, 128,600 (65%) had their support needs fully met.
- For specific activities, the proportion having their support needs fully met was lowest for cognition or emotional support (62%) and communication (64%).

- Depending on the purposes and focus of different service programs, population baseline estimates of unmet demand for employment services among people with intellectual disability ranged from 1,400 people (most conservative) to 17,700 people (least conservative) in 2003 (see 'Population baseline estimates of unmet demand for services among people with intellectual disability').
- The population baseline estimates of unmet demand for community access services ranged from 1,400 people (most conservative) to 10,300 people (least conservative) in 2003 (see 'Population baseline estimates of unmet demand for services among people with intellectual disability').

People with intellectual disability accounted for the majority of people aged under 65 years who had unmet demand for accommodation and respite services (22,800 out of 26,700).

Introduction

Intellectual disability is a major disability in the Australian population, especially among children and young adults. It is also the most common primary disability reported by users of services funded by the Commonwealth State/Territory Disability Agreement (CSTDA), reflecting the priority given to this group and the origins of many disability services in Australia.

Disability can be described in relation to several aspects of life experience: as an impairment in body function and structure, as a limitation in activities; or as a restriction in participation (involvement in 'life situations' such as work and social interaction). These life experiences are affected by environmental factors such as the built and social environment, opportunities, services and assistance provided, or barriers (WHO 2001).

Over the past two decades, new approaches have broadened the concept of disability to place increased emphasis on functional and environmental considerations and less emphasis on individual deficiency. These new approaches avoid sole reliance on IQ scores to define intellectual disability and rate its severity. For example, the two most recent editions of the manual of the American Association on Mental Retardation (AAMR) introduced a new concept of 'intensities of needed supports' to replace the formal classifications of severity using IQ scores. This approach to measuring severity is more functionally relevant and oriented to service provision and outcomes (Luckasson et al. 1992, 2002). Need for support is now used to differentiate mild from severe intellectual disability, in addition to measures of IQ scores and functional ability in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) (WHO 1992). Thus, by viewing intellectual disability through a wider lens, the impact of environment and support in reducing the effect of intellectual impairment can be better measured and addressed.

The key criteria for defining intellectual disability are: significant impairment in intellectual functioning; difficulties in adaptive behaviour; and manifestation in the

developmental period (Luckasson et al. 1992, 2002). The AAMR definition requires that the impairments and disability manifest before age 18. However, the ICD-10 does not specify an age threshold to define intellectual disability. Instead, the ICD–10 definition refers to 'impairment of skills manifested during the developmental period' (WHO 1992).

People with intellectual disability are a diverse group. They vary considerably in the nature and extent of their intellectual impairments and functional limitations, the origin of their disability, their personal background and social environment. Some people have genetic disorders that impact severely on their intellectual, social and other functional abilities. Others with mild intellectual impairment may develop adequate living skills and are able to lead relatively independent adult lives, but are nevertheless disadvantaged in society.

This bulletin contains three strands of analysis. The first is an overview of the number of people with intellectual disability, including other associated disabilities; health conditions; main disabling conditions and age at onset; and geographic location. The other strands focus on outcomes of participation in major life areas for children and young adults with an intellectual disability, their needs for disability services and any remaining unmet demand (expressed need). The focus is on people aged under 65 years. This largely excludes people with impairments of intellectual function caused by dementia and other age-related conditions.

Main data sources and definitions

The main data sources are the 1998 and 2003 Survey of Disability, Ageing and Carers (SDAC) conducted by the Australian Bureau of Statistics (ABS). This bulletin uses SDAC terminology for some key concepts of disability and activity limitation (see Technical appendix).

'Intellectual disability' is identified in this analysis as follows, using data from the SDAC. A person is initially included in the intellectual disability group if a positive response was made by or for them to the survey question about:

- having a difficulty learning or understanding things; and/or
- having one or more intellectual impairments or disabling conditions and one or more of 17 impairments, activity limitations or participation restrictions that have lasted, or are likely to last, for at least 6 months and that restrict everyday activities (see more details in Technical appendix).

A 'severe or profound core activity limitation' is defined as sometimes or always requiring personal assistance or supervision with self-care, mobility or communication. In this bulletin, a 'severe or profound core activity limitation' is sometimes abbreviated to 'a severe or profound limitation'.

Prevalence and patterns of intellectual disability

Prevalence

Prevalence estimates vary with the scope and level of disabilities under consideration. In 2003:

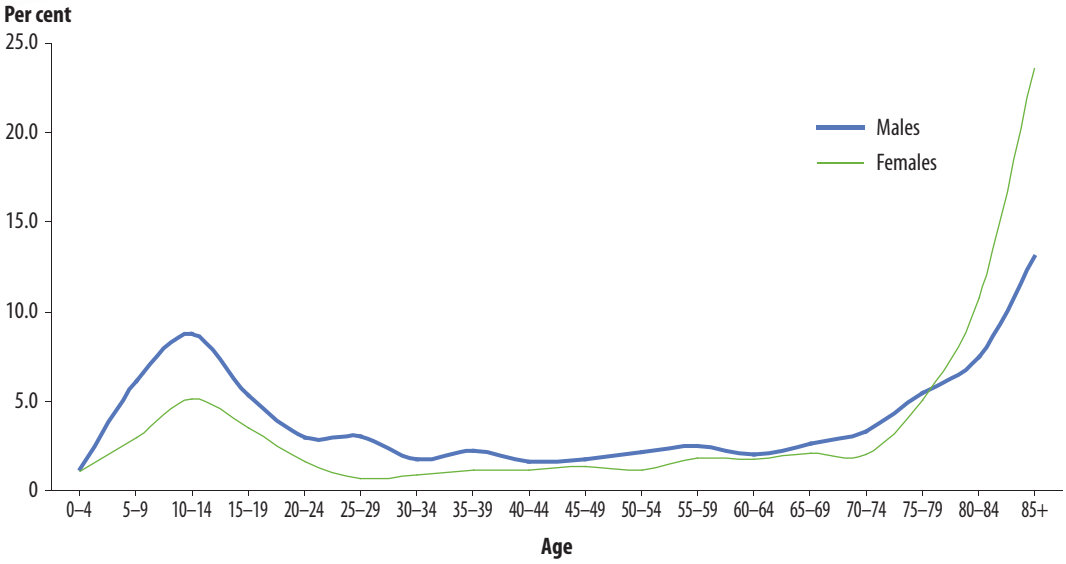
- approximately 588,700 people, or 3% of Australians, had intellectual disability (based on all disabling conditions reported in the survey; Table 1).
- 436,200 people with intellectual disability were aged under 65 years (2.5% of that population), 152, 500 were aged 65 years or older (6.1%).
- around 351,000 people with intellectual disability had a severe or profound limitation (1.8% of the total population), of whom 215,100 were aged under 65 years (1.2% of the under-65 population)
- for an estimated 165,700 people (0.8% of Australians), intellectual impairment was their main disabling condition and almost all were aged under 65 years. This estimate is slightly lower than the estimate from the 1998 SDAC (212,700 people, 1.1%) due to data coding errors in the 2003 SDAC confidentialised unit record file (see details in Technical appendix)
- the overall prevalence rate for males was higher than for females. The sex difference increased with age up to 10–14 years and then reduced substantially (Figure 1)
- the higher prevalence among people aged 75 years or over, especially for women, is associated with dementia-related conditions (discussed further in next section).

Table 1: Prevalence of intellectual disability by age group, 2003

	'000			Per cent		
Age group (years)	All disabling conditions	All disabling conditions plus severe or profound core activity limitation	Main disabling condition	All disabling conditions	All disabling conditions plus severe or profound core activity limitation	Main disabling condition
0–4	13.9	13.0	*2.8	1.1	1.1	*0.2
5–14	152.8	87.8	82.2	5.8	3.3	3.1
15–19	59.8	24.1	32.0	4.4	1.8	2.4
20–29	60.2	25.1	23.4	2.1	0.9	0.8
30–44	65.1	29.1	14.8	1.5	0.6	0.3
45–64	84.4	35.9	*7.6	1.8	0.8	*0.2
65+	152.5	135.9	*3.0	6.1	5.4	*0.1
Total	**588.7**	**351.0**	**165.7**	**3.0**	**1.8**	**0.8**
Total 0–64	***436.2***	***215.1***	***162.7***	***2.5***	***1.2***	***0.9***
Total 15–64	***269.5***	***114.2***	***77.8***	***2.0***	***0.9***	***0.6***
Total 65–84	***95.1***	***79.5***	***2.8***	***4.3***	***3.6***	***0.1***
85+	***57.4***	***56.5***	****0.2***	***20.2***	***19.9***	****0.1***

* Estimates marked with * have an associated relative standard error of between 25% and 50% and should be used with caution.
** Estimates marked with ** have an associated relative standard error of 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.



Source: Table A1.

Figure 1: Age- and sex-specific prevalence rates of intellectual disability, 2003

Prevalence excluding ADHD, autism and dementia

Learning disability is a subcategory of intellectual disability. It would be desirable to separate learning disability from intellectual disability in the estimation of prevalence, since some people with a learning disability may have no impairment in intellectual functioning. However, it is difficult to do so because of the survey data limitations. People with an intellectual disability are more likely to have learning difficulties, and intellectual disability and learning disability may occur together (American Psychiatric Association 1994).

The change of wording in the key screening question for identifying intellectual disability, from 'slow at learning or understanding' (1993 SDAC) to 'difficulty in learning or understanding' (1998 and 2003 SDAC), may have encouraged reporting of intellectual disability, in particular among males (Figure 2). The sharp increase in positive responses to this screening question in 1998 and 2003 was notable for children aged 10–14 years and people aged 75 years and over. These people were more likely to be associated with Attention Deficit Hyperactivity Disorder (ADHD), autism or dementia-related conditions.

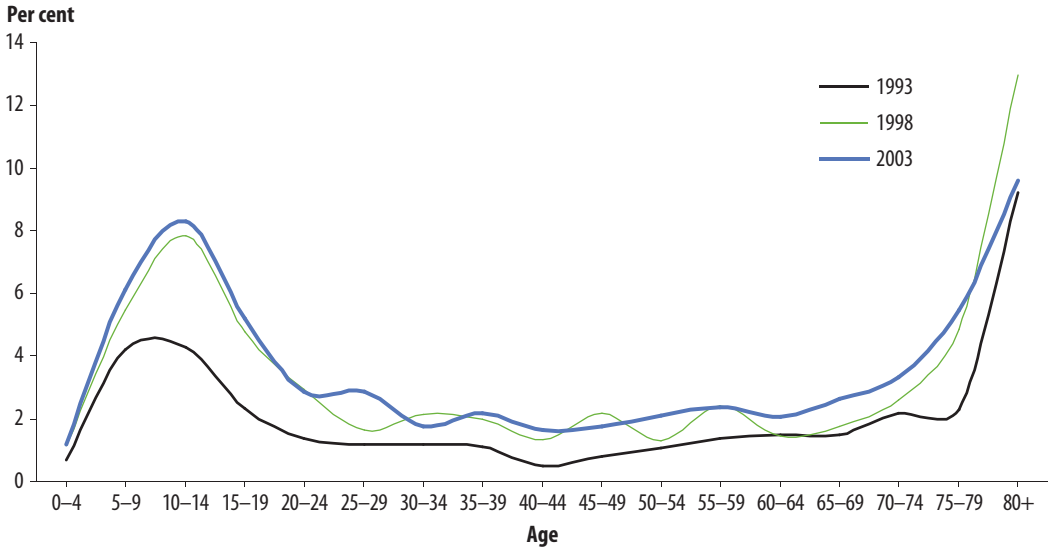
- Among people aged under 65 years, rates were markedly higher for school-age children than for the adult population, peaking at the age group of 10-14 years. This peak is far less pronounced when ADHD and autism-related conditions are excluded (Figure 3).
- For people aged 65 years or over, rates increase with age, with a peak rate of 20% for those aged 85 years and over. This includes a large proportion of people with intellectual impairments associated with dementia (AIHW 2006).
- Excluding dementia-related conditions, the prevalence of intellectual disability among people aged 85 years or over reduces from 20% to 5.7%, and the overall rate for all ages was 2.6%(505,700 people) in 2003. Therefore, dementia-related conditions account for most intellectual disability in the older population.

- Excluding both dementia and ADHD-related conditions, the overall rate in 2003 was 2.2% (430,400 people).

The general pattern of a markedly high rate among children of school age and a lower rate in the adult population is consistent with the estimates from both Australian regional studies and other international studies (AIHW: Wen 1997; Kiely 1987; McLaren & Bryson 1987; Roeleveld et al. 1997). This pattern may largely reflect different efforts in case ascertainment. The lower prevalence rates for children under age 5 years probably reflect the underestimation due to difficulties in case identification among children at preschool ages. The high rates for children of school age demonstrate the role of the education system in case identification of intellectual disability.

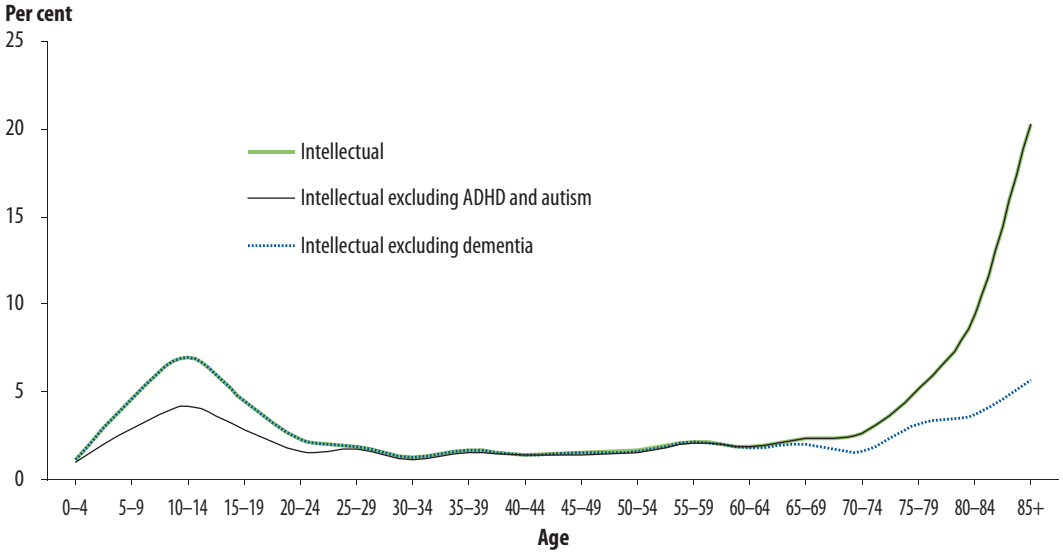
The lower rates for people of post-school ages may be, to some extent, related to a change in survey collection method—from parent reporting for children under 15 years of age to self-reporting for those aged 15 years or over (with parental permission for those aged 15 to 17 years). The lower rates for the adult population may be partly due to the ability of adults with mild intellectual disability to adapt to the demands of society with the passage of time. The differentials in mortality between people with intellectual disability and the general population may also account, to some extent, for the lower prevalence among the adult population (Baird & Sadovnick 1988).

Estimated prevalence rates of mild intellectual disability vary substantially between different studies and among different populations (AIHW: Wen 1997; Leonard & Wen 2002). The presence of mild intellectual disability is more likely as a consequence of both polygenetic and social and environmental influences (Holland & Jacobson 2001). It has been suggested that the smaller variations in prevalence rates of severe intellectual disability indicate that the aetiological process of severe intellectual disability is not influenced greatly by external factors (Roeleveld et al. 1997).



Source: AIHW analysis of 1993, 1998 and 2003 ABS Survey of Disability, Ageing and Carers confidentialised unit record files.

Figure 2: Males reporting slowness (1993) or difficulty (1998, 2003) with learning or understanding by age, 1993, 1998 and 2003

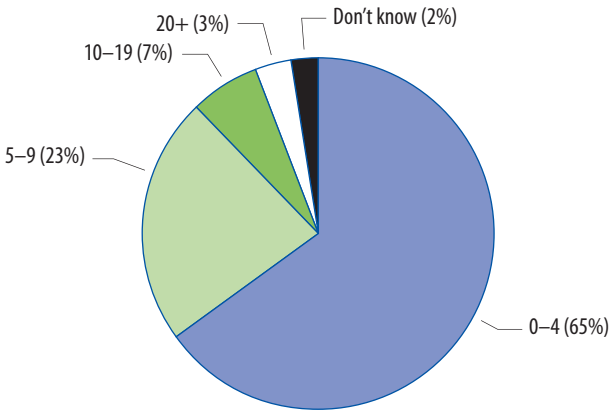


Source: Table A1.

Figure 3: Prevalence rates of intellectual disability: including and excluding ADHD, autism and dementia, 2003

Reported causes and age at onset of main disabling conditions

In the SDAC, only people living in households were asked when their disabling conditions first occurred, and this question related only to their main disabling condition. A great majority (95%) of people with an intellectual disability (main disabling condition relating to intellectual impairment) acquired that condition before age 20 years (Figure 4), including 65% of people for whom intellectual disability was identified before age 5 years.



Source: Table A2.

Figure 4: People in households reporting an intellectual disability (main condition): age when condition identified (per cent), 2003

The SDAC also collected information about what people with disability considered to be the cause of their main disabling condition.

- Almost one quarter (22%) of people with an intellectual disability (main disabling condition relating to intellectual impairment) did not know the cause of their intellectual disability, of whom 71% were aged under 15 years (Table 2; AIHW analysis of ABS 2003 SDAC confidentialised unit record file).
- Genetic disorders are the most common known causes of intellectual disability. About 54% of people with a known cause identified their main condition as being present at birth (Table 2). This pattern is consistent with findings from both overseas and other Australian studies (AIHW 2003).
- About 17% of people considered disease, illness or hereditary disorder as the main cause. About 19% reported that their intellectual disability 'just came on', of whom 55% were aged under 15 years (Table 2; AIHW analysis of ABS 2003 SDAC confidentialised unit record file).

Table 2: People with intellectual disability (based on main disabling condition): by reported causes, 2003

	No. ('000)	Per cent	Per cent of known causes
Present at birth	70.1	42.3	53.9
Just came on	24.5	14.8	18.8
Disease or illness or hereditary disorders	22.3	13.4	17.1
Other causes	13.2	7.9	10.1
Total known causes	*130.0*	*78.5*	*100.0*
Don't know	35.7	21.5	..
Total	**165.7**	**100.0**	..

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

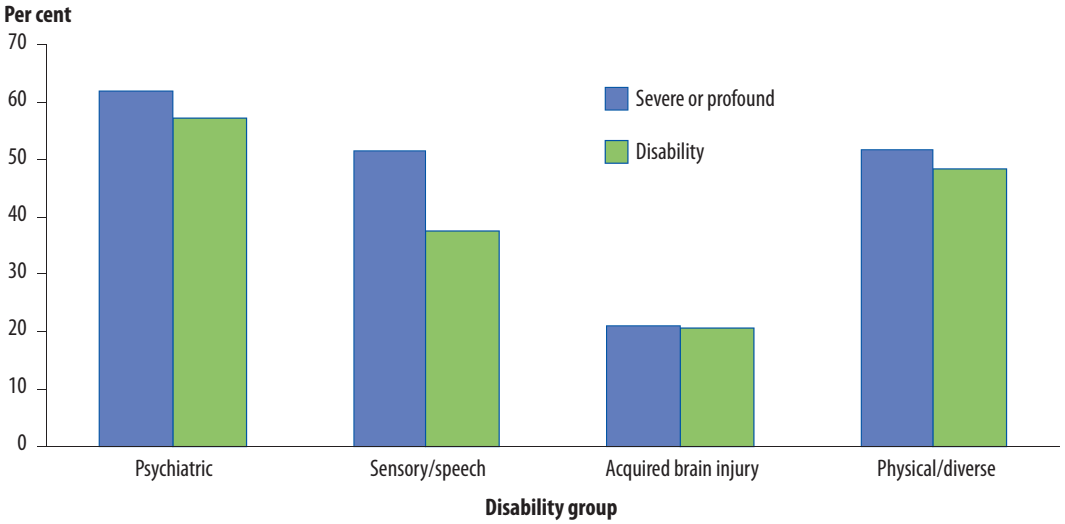
The rest of this bulletin focuses on people aged under 65 years with intellectual disability, based on all disabling conditions. Information about people ageing with an intellectual disability and disabilities associated with dementia can be found in other AIHW reports (AIHW 2000, 2006; AIHW: Hales et al. 2006).

Other associated disabilities and disabling conditions

- Many people with intellectual disability have multiple impairments or disabilities. Among people aged under 65 years, psychiatric disability was the most commonly associated disability in 2003—57% of people with intellectual disability in this age group also experienced psychiatric disability (Figure 5). About 62% of people with intellectual disability and a severe or profound limitation also had psychiatric disability.
- Just under 50% of those with intellectual disability also had physical/diverse disability.
- Sensory/speech and physical/diverse disabilities were reported by more than half of people with intellectual disability and a severe or profound limitation (Figure 5).
- The top five other health conditions were: speech problems (24%), ADHD (17%), asthma (15%), hearing disorders (14%) and back problems (12%).

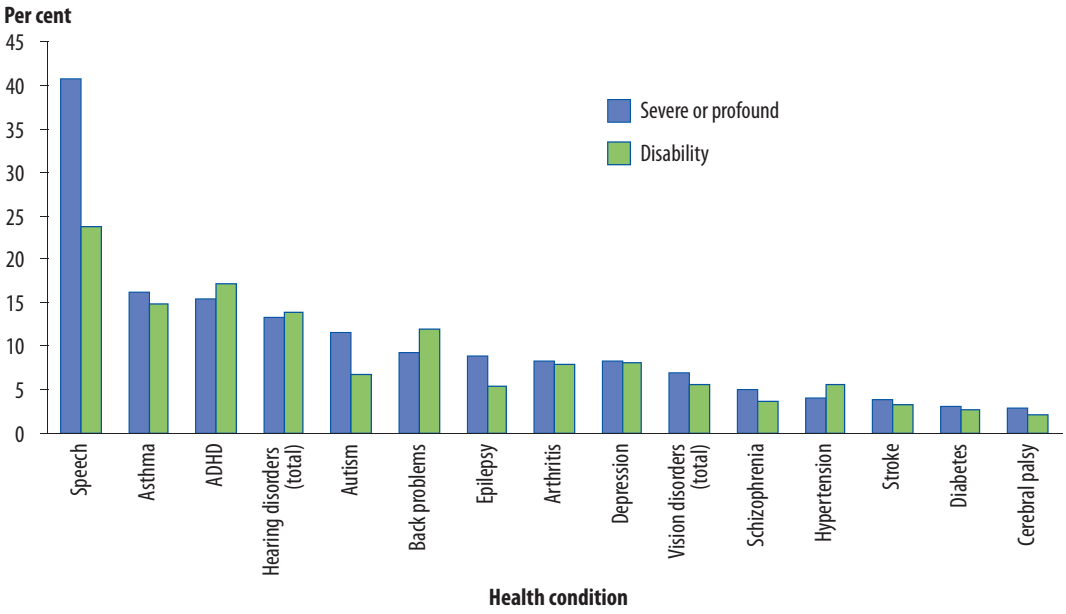
- Speech problems were far more common among people who also had a severe or profound limitation (41%). Autism (12%) was the fifth most common condition within this group (Figure 6).

The high prevalence of psychiatric disability and speech problems among people with intellectual disability is associated with the high proportion of people in this group who have difficulty communicating and fitting in socially. These disabilities may mean that people often have difficulty adjusting to changed circumstances and unfamiliar environments. These restrictions affect their participation in education and employment (see discussions in later sections).



Source: Table A3.

Figure 5: People aged under 65 years with intellectual disability: presence of other disabilities, 2003



Source: Table A4.

Figure 6: People aged under 65 years with intellectual disability: selected health conditions, 2003

Place of residence, accessibility and remoteness

- A total of 105,600 people with intellectual disability and a severe or profound limitation were living in some form of care accommodation (for example, aged care facilities or hostels for people with disability). Of these, 12,500 (12%) were aged under 65 years, and 93,100 (88%) were aged 65 years or over (AIHW analysis of ABS 2003 SDAC confidentialised unit record file).
- Estimated numbers of people with intellectual disability per jurisdiction ranged from 168,800 people in New South Wales to 6,300 people in the Australian Capital Territory (Table 3).
- The 2003 age-standardised prevalence rates for jurisdictions are not significantly different from the national average. Variations in the estimated numbers are mainly due to differences in population sizes, and age and sex profiles.
- A majority (about 65%) of people with intellectual disability lived in major cities of Australia, and about a quarter lived in inner regional Australia. Differences in the prevalence rates across remoteness groups are not statistically significant (Table 4).

Table 3: Prevalence of intellectual disability: state or territory of usual residence, 2003

	NSW	Vic	Qld	WA	SA	Tas	ACT	Australia[a]
0–64 years								
Total with intellectual disability ('000)	123.5	99.0	104.4	53.1	39.6	*9.7	*4.9	436.2
Total rate of intellectual disability[b]	**2.2**	**2.3**	**3.2**	**3.0**	**3.0**	***2.4**	***1.7**	**2.5**
Intellectual disability with severe or profound limitation('000)	51.5	55.5	56.8	23.6	20.3	*4.0	*2.4	215.1
Rates of intellectual disability with severe or profound limitation[b]	0.9	1.3	1.7	1.4	1.6	*1.0	*0.8	1.2
Total population ('000)	**5,740.2**	**4,348.4**	**3,267.2**	**1,730.1**	**1,299.9**	**406.6**	**289.6**	**17,222.5**
All ages								
Total with intellectual disability ('000)	168.8	143.6	132.5	68.4	52.6	14.4	*6.3	588.7
Total rate of intellectual disability[b]	**2.6**	**2.9**	**3.6**	**3.6**	**3.3**	**3.0**	***2.1**	**3.0**
Intellectual disability with severe or profound limitation('000)	94.8	94.0	81.4	36.1	32.2	*7.9	*3.4	351.0
Rates of intellectual disability with severe or profound limitation[b]	1.4	1.9	2.2	1.9	2.0	*1.6	*1.2	1.8
Total population ('000)	**6,597.8**	**4,999.3**	**3,712.6**	**1,947.7**	**1,523.8**	**472.9**	**318.7**	**19,719.3**

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.
(a) Estimates for Northern Territory (NT) were included in total Australia. The survey sample in the NT was reduced to a level such that the NT records contributed appropriately to national estimates but could not support reliable estimates for the NT (ABS 2004:58).
(b) Rates (per cent) have been adjusted using the age- and sex-specific rates for the Australian estimated resident population as at 30 June 2003.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 4: Prevalence of intellectual disability by remoteness[a], 2003

	0–64 years			All ages		
	No.('000)	Prev. rate[b]	Per cent of total	No.('000)	Prev. rate[b]	Per cent of total
Total with intellectual disability						
Major Cities	285.9	2.5	65.5	384.9	2.9	65.4
Inner Regional	97.8	2.6	22.4	132.8	3.0	22.6
Other areas[c]	52.6	2.7	12.0	71.0	3.1	12.1
Total	**436.2**	**2.5**	**100.0**	**588.7**	**3.0**	**100.0**
Intellectual with severe or profound limitation						
Major Cities	131.3	1.2	61.1	222.9	1.7	63.5
Inner Regional	57.4	1.5	26.7	86.7	1.9	24.7
Other areas[c]	26.4	1.3	12.3	41.4	1.7	11.8
Total	**215.1**	**1.2**	**100.0**	**351.0**	**1.8**	**100.0**

(a) The delimitation criteria for remoteness are based on Accessibility/Remoteness Index of Australia (ARIA). ARIA measures the remoteness of a point based on the physical road distance to the nearest Urban Centre in each of five size classes. For more information on how ARIA is defined see the Information Paper ABS views on remoteness. 2001 (Cat.no. 1244).
(b) Rates have been adjusted using the age- and sex-specific rates for the Australian estimated resident population as at 30 June 2003.
(c) This category combines Outer Regional, Remote and Very Remote areas.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Transition from home to school—participation in education

Education participation and levels of limitation and restriction

Children with intellectual disability face challenges in transition to school when they reach school age (Dyke et al. 2007). They may attend 'special' schools, or 'ordinary' classes in mainstream schools that offer special or support education, or 'special' classes in mainstream schools that address their specific education needs. In the SDAC, a school-age person has a severe or profound schooling restriction if the person is unable to attend school, attends a special school or a special class in an ordinary school, has a signing interpreter, or receives special tuition or assistance from a counsellor or disability support person.

- In 2003, 82,400 (45%) school-age students (5–20 years) with intellectual disability were attending an ordinary class, while 70,200 (38%) were attending a special class and 31,500 (17%) were attending a special school (Table 5).
- Less than half (45%) of students with intellectual disability were attending an ordinary class, compared with 95% of students with no intellectual disability but psychiatric, acquired brain injury or physical /diverse disability, and 77% of those with sensory/speech disability.
- Most students (101,700 or about 90%) attending a special school/class had intellectual disability (Table 6).

- About 101,700 (97%) school students with intellectual disability who had severe or profound schooling restrictions were either in a special class or a special school (Table 6).
- An estimated 68,900 people aged under 20 years with intellectual disability had severe or profound limitations/restrictions with both core activities and schooling (Table 6). Of these, 64,600 were attending school. Almost all those attending school were either in a special class (54%) or a special school (45%).

Table 5: People with disability attending school by types of school/class by disability groups (per cent), 2003

		Other disability groups[(a)]			
	Intellectual	Psychiatric	Sensory/ speech	Acquired brain injury	Physical/ diverse
Ordinary school class	44.8	95.0	77.2	94.6	95.0
Ordinary school (special class)	38.1	**2.7	*16.4	**5.4	*4.0
Special school	17.1	**2.3	*6.4	—	**1.0
Total attending school	100.0	100.0	100.0	100.0	100.0
Total attending school ('000)	**184.2**	**17.0**	**51.7**	**12.1**	**101.5**

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.
** Estimates have an associated relative standard error of greater than 50% and are considered too unreliable for general use.
— Nil or rounded to zero (include null cells).
(a) People with disabilities other than intellectual disability.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 6: Students with intellectual disability attending school by type of school attending by level of core activity limitation and schooling restriction, 2003 (per cent)

	Ordinary school class	Ordinary school– special class	Special school	Total (per cent)	Total '000
Level of core activity limitation					
Profound or severe	37.4	33.7	28.9	**100.0**	**103.0**
Moderate or mild	47.6	47.5	**4.8	**100.0**	**36.3**
Schooling restriction only	51.6	48.4	—	**100.0**	**37.8**
Disability no core activity limitation or schooling restriction	*100.0	—	—	**100.0**	***7.2**
Level of schooling restriction					
Profound or severe	3.3	66.7	29.9	**100.0**	**105.3**
Moderate or mild	100.0	—	—	**100.0**	**64.3**
No schooling restriction	100.0	—	—	**100.0**	**14.6**
Profound or severe core activity limitation and schooling restriction	1.6	53.8	44.6	**100.0**	**64.6**
Total attending school ('000)	**82.4**	**70.2**	**31.5**	**184.2**	
Total attending school (per cent)	**44.8**	**38.1**	**17.1**	**100.0**	

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.
** Estimates have an associated relative standard error of greater than 50% and are considered too unreliable for general use.
— Nil or rounded to zero (includes null cells).
Note: A total of 68,900 people aged under 20 years with intellectual disability had severe or profound limitations/restrictions with both core activities and schooling. Of these, 4,300 people (6.3%) were not attending school.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Types of difficulty and support or special arrangements in school

- School students with intellectual disability commonly experienced learning difficulties (66%), difficulty fitting in socially (41%) and communication problems (31%) (Table 7). For this group of students these problems are far more common than difficulty participating in sport (12%) or other issues such as physical access (4%).
- The most common types of assistance received by students with intellectual disability were special tuition (54%), a counsellor or disability support person (28%) and a special assessment procedure (22%) (Table 8).
- The 68,900 students with intellectual disability who had severe or profound limitations/restrictions with both core activities and schooling tended to have more difficulties at school than students with intellectual disability in general or those with physical/diverse disability but no intellectual disability (Table 7). They also had high and complex needs for support and special arrangements (Table 8).
- An estimated 51,000 (28%) school students with intellectual disability did not receive special support at school.

Table 7: People with intellectual disability currently attending school: types of difficulty experienced at school, 2003

	Intellectual and severe or profound core activity limitation and schooling restriction		Total intellectual disability		Physical/diverse disability but no intellectual disability	
	'000	Per cent	'000	Per cent	'000	Per cent
Learning difficulties	44.9	65.2	121.1	65.8	*6.0	*5.9
Fitting in socially	39.1	56.8	75.1	40.8	*8.7	*8.6
Communication difficulties	33.6	48.8	56.2	30.5	*4.8	*4.7
Intellectual difficulties	24.5	35.6	33.7	18.3	**1.2	**1.2
Sports participation	15.6	22.7	22.8	12.4	18.9	18.6
Difficulty sitting	*7.9	*11.5	19.1	10.4	*4.4	*4.3
Hearing or sight problems	*6.5	*9.5	*9.2	*5.0	*4.1	*4.0
Needs time off school because of condition[(s)]	*4.5	*6.6	*8.2	*4.4	13.8	13.6
Other, including access difficulties	*2.8	*4.1	*8.0	*4.4	13.5	13.3
Total attending school[(a)]	**68.9**		**184.2**		**101.5**	

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.
** Estimates have an associated relative standard error of greater than 50% and are considered too unreliable for general use.
(a) A total of 68,900 people aged under 20 years with intellectual disability had severe or profound limitations/restrictions with both core activities and schooling. Of these, 4,300 people (6.3%) were not attending school. Total may not be the sum of components since students may experience more than one type of difficulty or restriction.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 8: People with intellectual disability currently attending school: types of support or special arrangements at school, 2003

	Severe or profound core activity limitation and schooling restriction		Total intellectual disability	
	'000	Per cent	'000	Per cent
Special tuition	46.7	67.8	98.5	53.5
Counsellor or disability support person	22.5	32.6	52.1	28.3
Special assessment procedure	22.8	33.1	40.5	22.0
Special equipment (including computer)	13.2	19.2	17.9	9.7
Special access or transport arrangements	13.6	19.8	15.4	8.4
Other support	*3.2	*4.6	13.1	7.1
No support received	*9.0	*13.1	51.0	27.7
Total attending school[(a)]	**68.9**	**100.0**	**184.2**	**100.0**

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.

(a) A total of 68,900 people aged under 20 years with intellectual disability had severe or profound limitations/restrictions with both core activities and schooling. Of these, 4,300 people (6.3%) were not attending school. Total may not be the sum of components since students may experience more than one type of difficulty or restriction.

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

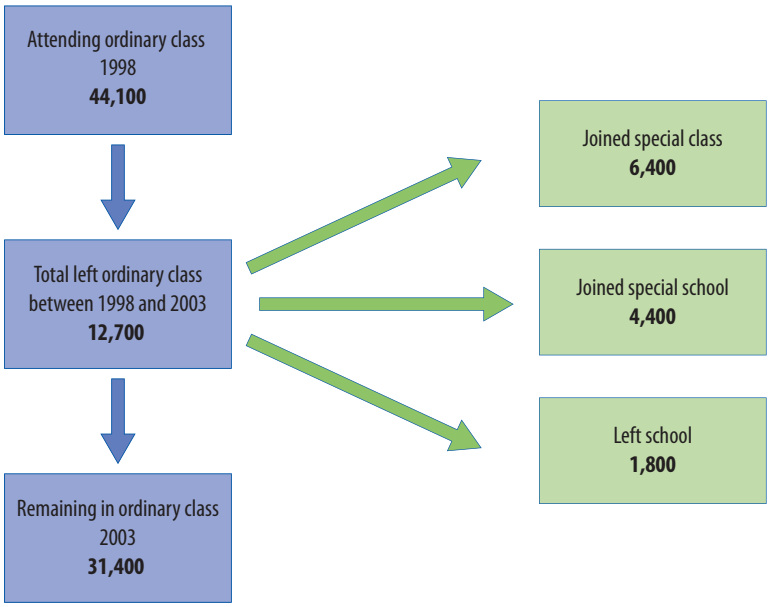
Transition between special and mainstream class environments

Since integration of students with disability into the mainstream school environment is now a general policy of most state and territory governments, many school-age children with a severe or profound core activity limitation and/or schooling restriction are encouraged to start school in an ordinary class. What are the placement outcomes for these students? Do they remain in an ordinary class for the longer term?

In the absence of longitudinal data, it is possible to use data from a sequence of cross-sectional surveys to construct 'synthetic age cohorts'. For example, comparisons can be made between students with a severe or profound core activity limitation aged 5–9 years (as represented by the 1998 SDAC) and those aged 10–14 years (as represented by the 2003 SDAC). Such comparisons can illustrate changes in type of school/class attending among students of this age cohort between 1998 and 2003 as they move through a statistically constructed life-cycle, assuming no radical changes in education policy and practice.

The age cohort analysis shows that in 1998, about 44,100 students aged 5–9 years with a severe or profound core activity limitation were attending ordinary classes. By 2003, most (31,400) remained in ordinary classes. But 12,700 (29%) students in this cohort (aged 10–14 years in 2003) had either transferred to special classes (6,400) or special schools (4,400), or had left school (1,800) (Figure 7).

The high retention of students with a severe or profound core activity limitation in an ordinary class may reflect the effects of inclusion policy programs and supports. The transition of some 12,700 students may reflect their high and complex needs for assistance, as well as some service gaps. It has been suggested that there is a lack of knowledge among teachers relating to educating students with special needs in some ordinary classes; teachers take on substantial additional workloads and classes are not necessarily reduced in size to accommodate special needs students (Dyke et al. 2007).



Note: This is a follow-up of a synthetic age cohort of students aged 5–9 years in the 1998 SDAC and 10–14 years in the 2003 SDAC. It is restricted to students of this age cohort who had a severe or profound limitation and were attending an ordinary class in 1998.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Figure 7: Age cohort changes in attending an ordinary class, 1998 and 2003

Transition from school to adult life

A successful transition from school to adult life is essential for young people with a disability. Just as this is a major life transition for people without disability, people with intellectual disability leave school to commence on the next stage of their life journey: post-school study; employment; and meaningful social activities. Particular challenges for people with intellectual disability may include: leaving a safe and familiar environment; forming new social relationships (leaving old friends); and possibly losing supports provided during the school years.

Analysis of transitions among four synthetic age cohorts of people with intellectual disability within the age range of 15 to 34 years in 1998 and 20 to 39 years in 2003 (Figure 8) shows that:

- the proportion of people who moved into post-secondary school study was very low—about 9% of those who turned 20–24 years in 2003 and less than 5% of those who turned 25 years or over (Table 9)
- they were much less likely to move into the labour force than people of the same ages without disability. The labour force participation rate was only about 60% for those in their 20s in 2003, 34% and 46% for those aged 30–34 years and 35–39 years

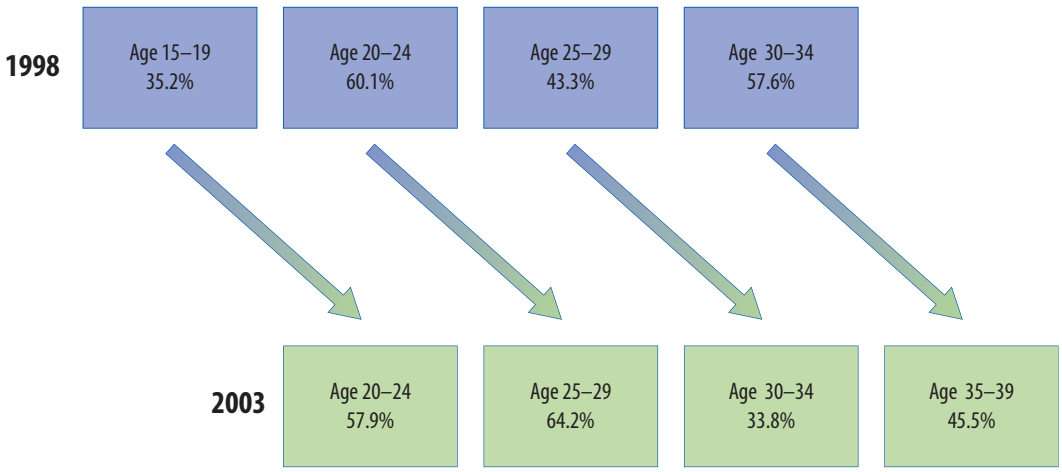
respectively, compared with 83% or more for people without disability of these same ages (Figure 9, Table 9)

- labour force participation rates dropped considerably between 1998 and 2003 for people with intellectual disability aged 25–29 years and 30–34 years (in 1998), and this decline was not explained by a compensating increased participation in post-secondary school study or disability day activity programs (Figure 8, Table 9)
- for people with disability in general, over 70% of those in their early 20s transferred into employment or were seeking a job; about 65% of those aged 25 years or older transferred into the labour force (Table 9).

It is noteworthy that the labour force participation rate for people with intellectual disability aged 30–34 in 2003 was considerably lower (34%) than the rate (58%) for those aged 30–34 in 1998.

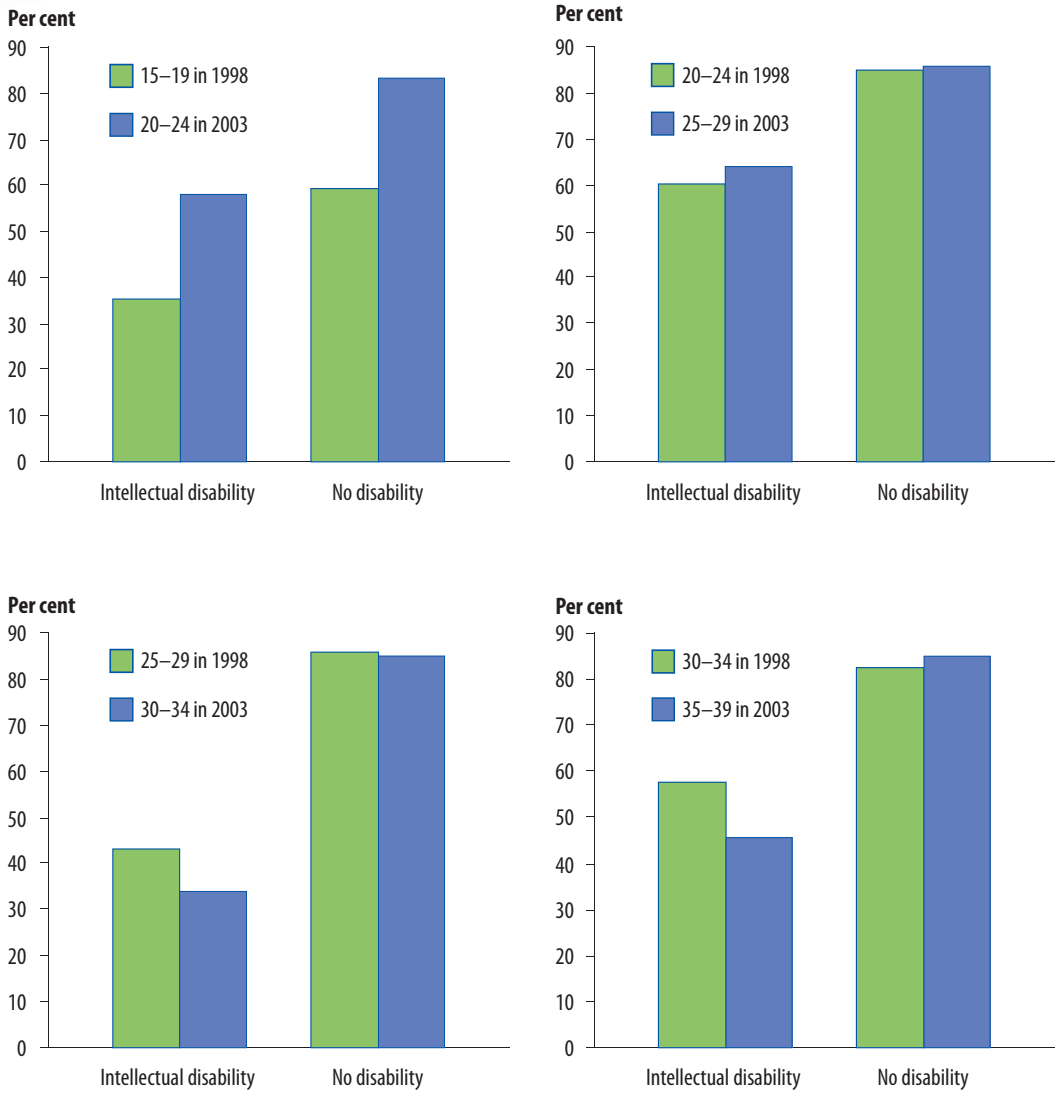
Overall, while people with intellectual disability have high participation in school education, their participation in the labour force is significantly lower than that of people without disability. Many factors may affect their participation in employment, for example, difficulty in obtaining open employment opportunities; lack of training in skills needed to succeed in the work environment; lack of employer awareness of the needs of people with disabilities or willingness to accommodate those needs in the workplace.

It has been suggested that key factors affecting the successful transition from school to employment for young people with disability are: the provision of information and support during later school years; supportive employment environments and staff; and individuals, families and employers working together towards clear goals (Western Australia Ministerial Advisory Council on Disability 2006).



Source: Table 9.

Figure 8: People with intellectual disability: labour force participation rates (per cent) for four synthetic age cohorts of 15 to 34 years in 1998 and 20 to 39 years in 2003.



Source: Table 9.

Figure 9: Age cohort changes in labour force participation rates, 1998 and 2003

Table 9: Young people (aged 15–39) with intellectual disability living in households: transition from school to adult life, synthetic age cohort changes between 1998 and 2003

	Synthetic age cohorts							
	15–19	20–24	20–24	25–29	25–29	30–34	30–34	35–39
	1998	2003	1998	2003	1998	2003	1998	2003
	Per cent of total people in that age cohort							
Employed	27.8	44.7	36.5	49.9	28.6	32.5	51.1	39.7
Unemployed	*7.4	*13.2	*23.6	*14.3	*14.7	*1.2	**6.6	**5.9
Not in the labour force	64.8	42.1	39.9	35.8	56.7	66.2	42.4	54.5
Studying	65.4	*9.4	*19.0	**4.7	**7.9	**2.9	—	**4.6
Not studying	34.6	90.6	81.0	95.3	92.1	97.1	100.0	95.4
Attending disability day activity	*15.3	*17.0	**7.5	*21.6	*23.4	*16.7	*19.5	**4.0
Does not attend	84.7	83.0	92.5	78.4	76.6	83.3	80.5	96.0
	Labour force participation rate (per cent)							
With intellectual disability	35.2	57.9	60.1	64.2	43.3	*33.8	57.6	45.5
Total with disability	47.9	72.5	77.2	67.2	65.4	65.4	64.2	65.6
Total without disability	59.2	83.3	85.1	85.9	85.8	85.1	82.7	85.0
Total ('000)	**44.6**	**33.1**	**31.1**	**25.8**	**20.0**	**18.8**	**21.9**	**22.6**

* Estimates marked with * have an associated relative standard error of between 25% and 50% and should be used with caution.
** Estimates marked with ** have an associated relative standard error of greater than 50% and are considered too unreliable for general use.
— Nil or rounded to zero (includes null cells).
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Outcomes of transition—people aged 15–64 years with intellectual disability

What are the outcomes of transition in major social and economic life areas for people aged 15–64 years with intellectual disability? What are the factors affecting their full participation in major life areas? In comparison to people without disability of the same ages in 2003 they were (Table 10):

- less likely to complete Year 12 studies (19% versus 49%) and participate in tertiary education (6% versus 12%)
- less likely to participate in the labour force (43% versus 81%) and to be employed working full-time (19% versus 54%), or in the government sector (2% versus 13%).
- more likely to be unemployed (unemployment rate 17% versus 5%)
- more likely to rely on a government pension or allowance as their main source of cash income (57% versus 14%) and less likely to be wage or salary earners (23% versus 63%)
- more likely to have never married (67% versus 39%).

Table 10: People aged 15–64 with intellectual disability: education, employment, income and marital status, 2003

	Intellectual disability		No disability	
	'000	Per cent	'000	Per cent
Whether completed Year 12				
Completed Year 12 or equivalent	49.3	19.2	5,495.2	49.4
Didn't complete Year 12 or equivalent	207.2	80.8	5,638.0	50.6
Current educational institution attended				
Higher Education	*4.2	*1.6	851.7	7.6
TAFE	12.1	4.7	482.5	4.3
Business college or industry skills centre	—	—	93.6	0.8
Other, including Secondary School	*3.7	*1.4	159.5	1.4
Not studying	236.6	92.2	9,546.0	85.7
Labour force status				
Employed working full-time	47.6	18.6	6,046.1	54.3
Employed working part-time	44.0	17.2	2,484.1	22.3
Unemployed looking for full-time work	*9.9	*3.9	296.5	2.7
Unemployed looking for part-time work	*9.4	*3.7	151.7	1.4
Not in the labour force	145.5	56.7	2,154.9	19.4
Total in the labour force	***111.0***	***43.3***	***8,978.3***	***80.6***
Total employed	***91.6***	***35.7***	***8,530.2***	***76.6***
Unemployment rate		***17.4***		***5.0***
Sector of employment				
Government	85.3	*2.1	1495.9	13.4
Private/Not known	86.3	33.7	7034.2	63.2
Main source of cash income				
Wages or salary (including from own incorporated business)	57.9	22.6	6,971.4	62.6
Any Government pension or allowance	146.4	57.1	1,506.9	13.5
Other sources	13.1	5.1	1,404.2	12.6
Not stated[(a)]	39.2	15.3	1,250.6	11.6
Registered marital status				
Married	44.0	17.1	5,724.9	51.4
Separated/Divorced/Widowed	42.0	16.4	1,122.0	10.1
Never married	170.6	66.5	4,286.0	38.5
Total	**256.5**	**100.0**	**11,133.2**	**100.0**

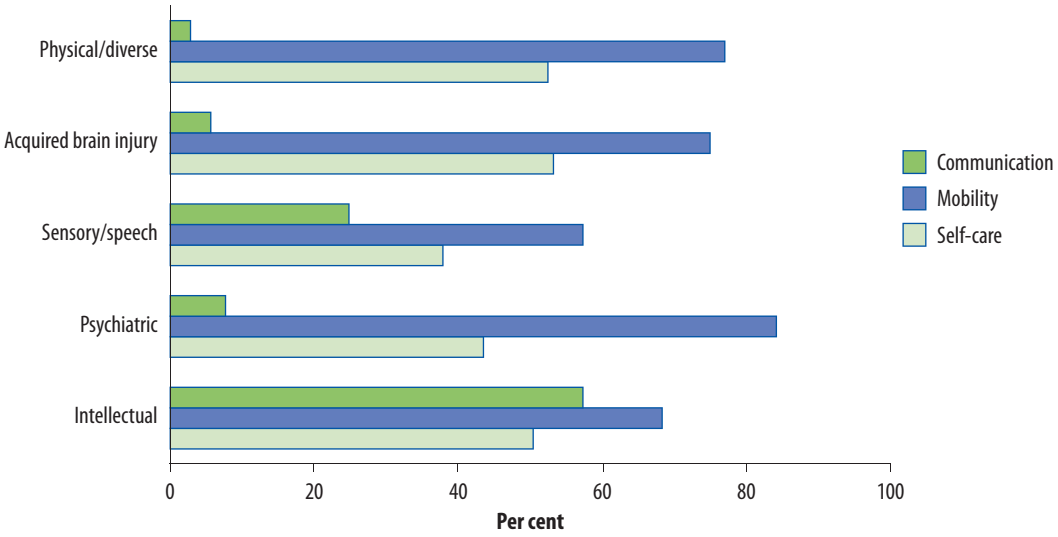
* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.
— Nil or rounded to zero (includes null cells).
(a) Includes people who report no source of income or main source of income not known.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Needs and unmet demand for services and assistance

Need for help with core activities

Over half of people aged under 65 years with intellectual disability and a severe or profound limitation needed help with self-care (51%), mobility (68%) or communication (57%) (Figure 10).

The proportion of people with intellectual disability who needed help with communication was markedly higher (57%) than for people without intellectual disability but with physical/diverse (3%), acquired brain injury (6%), psychiatric (8%) or sensory/speech (25%) disability.



Note: This is a comparison of people with intellectual disability and people with other disabilities but no intellectual disability, based on all disabling conditions.

Source: Table A5.

Figure 10: People aged under 65 years with a severe or profound core activity limitation living in households: needs for help with core activities by disability groups, 2003

Are needs for services and assistance being met?

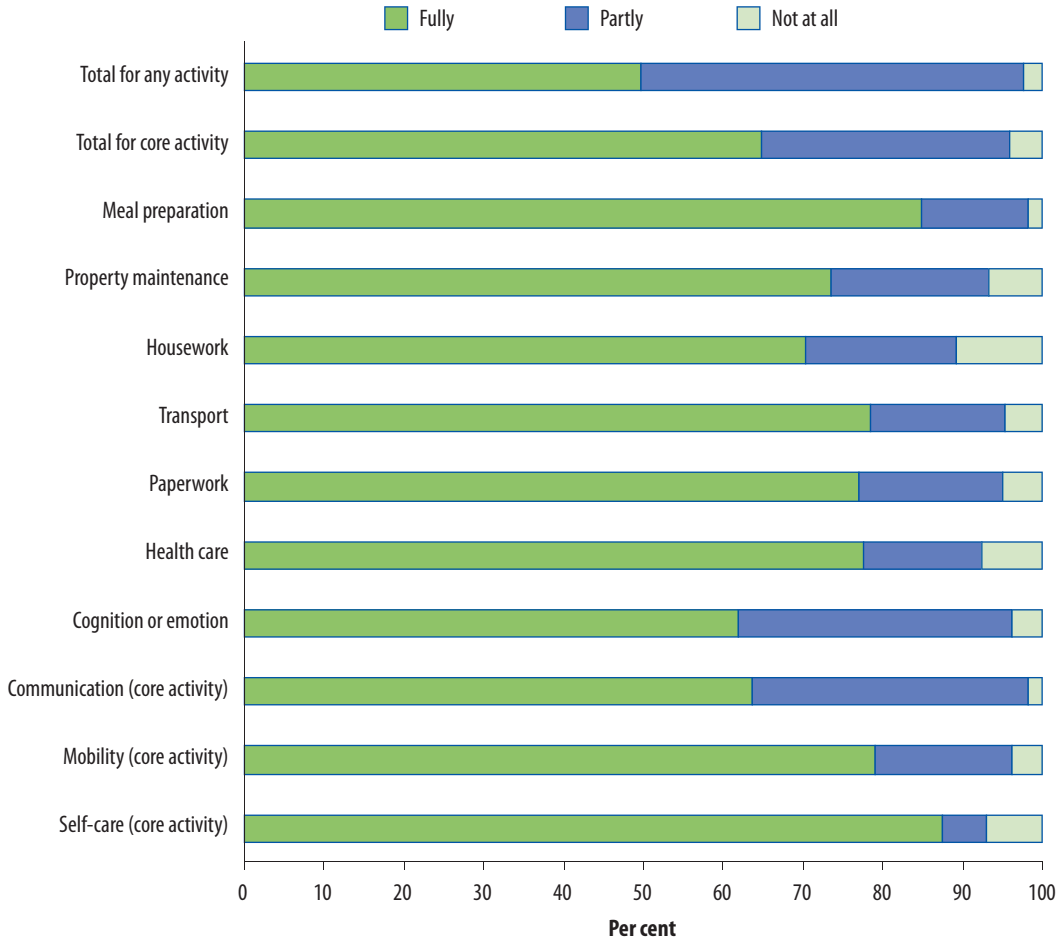
Overall, of the 335,000 people aged under 65 years with intellectual disability living in households who needed help with core or other activities, just half (166,800) had their needs fully met and 160,500 (48%) had their needs only partly met (Figure 11; Table A4). Of the 198,500 people who needed help with a core activity, 128,600 (65%) had their needs fully met and 62,000 (31%) had their needs partly met.

For specific activities, the proportion having their needs fully met was lowest for cognition or emotion (62%) and communication (64%).

It is noteworthy that the overall proportion with needs fully met across all activities is lower than the proportion with needs fully met for some specific activities. The data

relating to the overall extent to which need for support was met (the top two bars in Figure 11) summarise the survey responses relating to grouped activity areas (any activity or core activity). For example, a person who needs help with all three core activities is counted as having their overall needs fully met only if needs are fully met in each one of the three core activities.

The variation seen between specific activities could be due to two main reasons. First, some services or assistance may be provided more readily or consistently than others. Second, the limitations and support needs of people with intellectual disability are complex, and people might find it difficult to navigate a complex system of support services.



Source: Table A6.

Figure 11: People aged under 65 years with intellectual disability living in households, extent to which need for assistance was met for various activities, 2003

Population baseline estimates of unmet demand for services among people with intellectual disability

Disability employment services provide assistance to people with disability in obtaining and/or retaining paid employment in the open employment market, or provide employment opportunities and assistance to people with disability to work in specialised and supported work environments. These services focus on people who are in the labour force and those who are not in the labour force but could work with special assistance (AIHW 2007a).

Under the Commonwealth State/Territory Disability Agreement (CSTDA), community access services (predominantly day activity programs) are designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence. People who do not attend school, and who are not employed full-time, mainly use these services.

People with intellectual disability may also receive assistance from mainstream or general services, that is, services not specifically designed for people with disability but which are able to address needs such as employment or community access support.

In this section, 'unmet demand' is considered to be the expressed need for a service or assistance, where the person reports not receiving the service, or receiving an inadequate amount of service (AIHW 2007b). Previous AIHW demand studies have focused on all people with disability. The key concepts and approaches of the AIHW studies, including how they were developed and agreed upon with National Disability Administrators, were discussed in detail in earlier reports (AIHW: Madden et al. 1996; AHIW 1997, 2002, 2007b). A main feature of previous approaches was that, although they provided estimates relating to a range of levels of support needs, effort was concentrated on producing robust estimates of people with high support needs in order to provide reliable, 'conservative' estimates.

Estimates of unmet demand for services in this bulletin focus on people with intellectual disability. In the light of the specific functional limitations of people with intellectual disability in cognition, emotion and communication, this section modifies the approach of previous AIHW demand studies to construct a range of baseline estimates of unmet demand for employment and community access services.

The modified approach used here ensures that the unmet demand for support with employment and social participation can be identified for those people with intellectual disability who have low frequency of need or no need for help with core activities but who have limitations or need for help with cognition or emotion. Cognition and emotion are vital for successful participation in employment and social activities.

Among users of the CSTDA-funded services in 2005–06 for whom information about support needs was available, over 40% did not need help with activities of daily living (core

activities) (AIHW 2007a). The users of CSTDA-funded employment services are much more likely to need support with education, work and leisure activities than activities of daily living. This supports the idea that the population baseline estimates of unmet demand for employment services be based on needs other than the activities of daily living (AIHW 2002:143).

According to the different purposes and focuses of various service programs, the modified approach also aims to provide additional estimates of unmet demand. Together with earlier estimates, these place the estimated number of people with intellectual disability and unmet demand for services and assistance within a range from more to less conservative. Sensitivity analysis in the 2002 AIHW demand study indicated that a relaxation of criteria relating to high frequency of need for support with core activities or the number of core activities in which support is needed substantially increases the baseline estimates (AIHW 2002:151). If the purpose is to estimate unmet demand for services for people with intellectual disability who had high support needs for core activities, then a more conservative approach is appropriate, for example, estimates of unmet demand for accommodation support and respite services (see next section). If the purpose is to estimate unmet demand for support with employment or community activities (that is, not core activities), then a less conservative approach seems more appropriate. To meet this type of support need, specialist services, mainstream services and informal carers, where available, may all have a role in the provision of support.

The main modifications to the conventional methods of estimation are:

- provide a range of estimates according to the level and intensity of support needs with core activities (activities of daily living), according to different purposes of estimation
- start with all people with intellectual disability rather than restrict estimates to those who also had a severe or profound core activity limitation
- relax the criteria relating to high frequency of need for help with core activities that were used to produce conservative estimates.

Figure 12 illustrates the current status of participation in employment and social activities for people aged 15–64 years with intellectual disability, and a step-by-step process of estimating need for disability employment and community access services.

Employment services: population baseline estimates of unmet demand

- In 2003, there were 256,500 people aged 15–64 with intellectual disability living in households, of whom 91,600 were employed. Of these employed people, 6,700 were also attending disability day activity programs. Some of these people may have been receiving employment services.
- A total of 19,300 people were unemployed, of whom 17,100 were not attending day activity programs.

- About 145,500 people were not in the labour force (not looking for a job), of whom 6,300 stated that they could work with special assistance. Of these 6,300 people, about 1,100 reported that their main reason for not looking for a job was their own illness or disability, including 600 people who were not attending day activity programs.

A least conservative estimate (high-end of the range) is that, in 2003, 17,700 people needed employment services. These people were either unemployed, or could work with special assistance but were not looking for a job due to their own illness or disability, and they were not attending disability day activity programs. Of these 17,700 people, 65% had psychiatric disability and 45% had physical/diverse disability.

Included in the 17,700 people were 5,100 (29%) who had a severe or profound limitation, including 1,400 people who needed at least daily support with any core activity. This number of 1,400 people is a conservative estimate (low-end of the range) based on the conventional methods of earlier AIHW demand studies.

Two other sub-groups of people who were not in the labour force include:

- 79,300 people who could not work for various reasons, of whom 63,000 were not attending disability day activity programs
- 59,900 people who did not state whether they could work or not but were not in the labour force for different reasons, of whom 46,600 were not attending day activity programs.

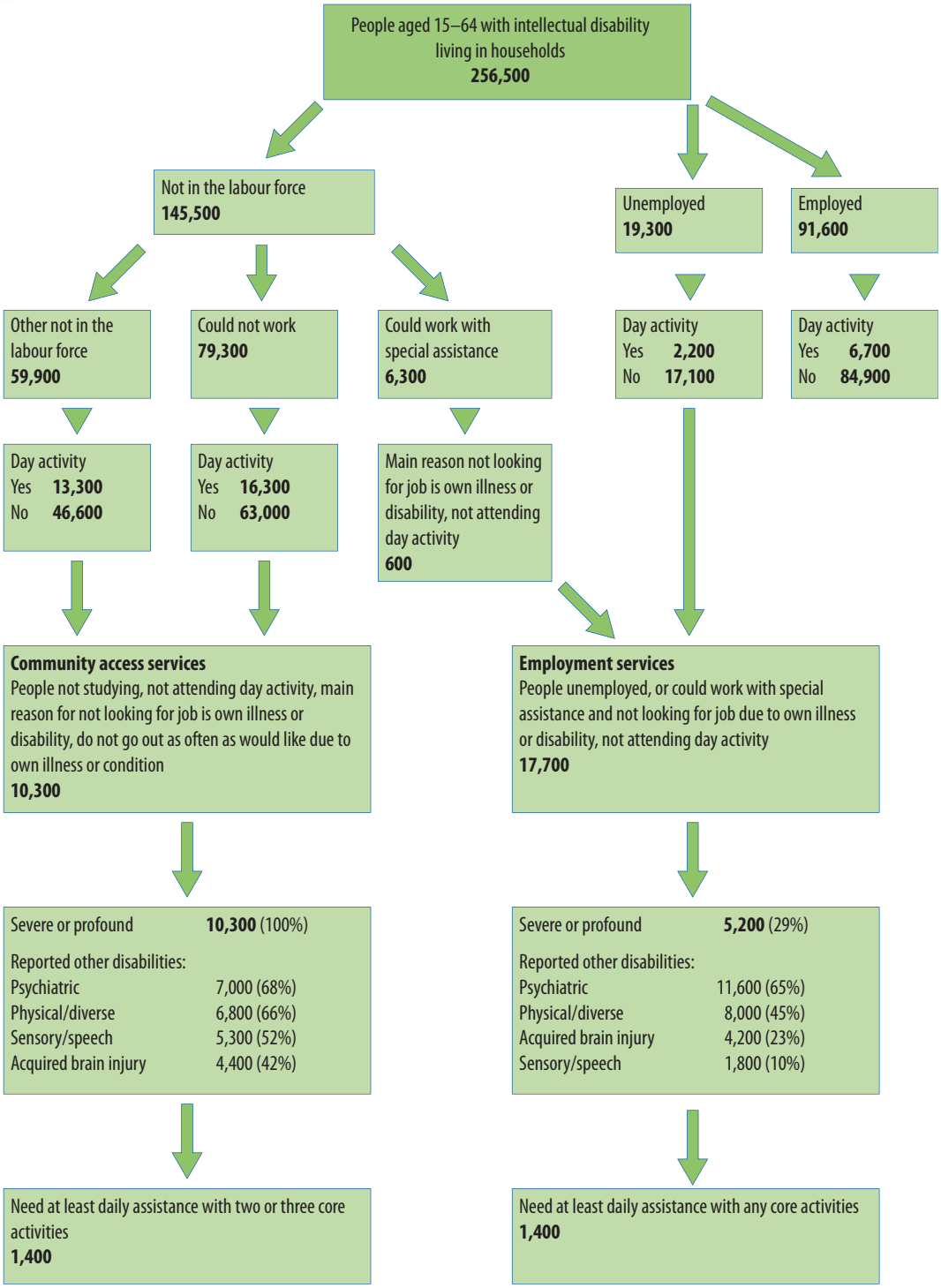
Community access services: population baseline estimates of unmet demand

A least conservative (high-end) estimate is that, in 2003, 10,300 people needed community access services. These people were not studying or attending a day activity program; their main reason for not looking for a job was their illness or disability, and they could not go out as often as they would like because of their condition. All the 10,300 people had a severe or profound limitation, including 1,400 people who needed at least daily help with two or three core activities. This number of 1,400 people is the conservative (low-end) estimate based on the conventional methods of earlier AIHW demand studies.

These estimates exclude 29,600 people who were attending a day activity program and 99,300 people who were either studying, or whose main reasons for not looking for a job or not going out as often as they like was unrelated to disability.

About 68% of the 10,300 people with unmet demand for community access services also had psychiatric disability; 66% had physical/diverse disability; 52% had sensory/speech disability; and 42% had acquired brain injury in addition to intellectual disability.

Unmet demand for services can possibly be met by a range of services, not only specialist disability services but also generic services.



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

Figure 12: People with intellectual disability aged 15–64 in households: population baseline estimates of need for disability employment and community access services, 2003

Population baseline estimates of unmet demand for accommodation and respite services among people with intellectual disability

Accommodation support services provide accommodation for people with disability and services that provide the support needed to enable people with disability to remain in their existing accommodation or move to a more suitable or appropriate accommodation. Respite services provide a short-term and time-limited break for families and other voluntary caregivers of people with disability (AIHW 2007a).

This section replicates previous estimates of unmet demand for accommodation and respite services (AIHW 2007b), restricted to people with intellectual disability. The estimates calculated here refer to population baseline estimates in 2003, not adjusted to 2005 to account for population growth and increased supply of CSTDA services between 2003 and 2005.

In 2003, there was a household population of 661,400 people aged under 65 years with a severe or profound limitation. The population baseline estimate of unmet demand resulted in a total of 26,700 people with unmet demand for accommodation and/or respite services (AIHW 2007b). This is a conservative estimate that includes people with high support needs and unmet demand for services with core activities who:

- need assistance with one core activity at least 3 to 5 times a day; or
- need assistance with two core activities, at least twice daily for one of those; or
- need assistance with three core activities, at least once daily for one of those; and
- stated at least one of the reasons for unmet demand as 'no service was available', 'unable to arrange a service', 'service costs too much', or 'service does not provide sufficient hours'.

In 2003, of the total 26,700 people with unmet demand for accommodation and respite services, 22,800 (85%) were people with intellectual disability, based on all reported disabling conditions (Table 11).

A large proportion of people with intellectual disability in this group had multiple disabilities of various combinations:

- 16,500 (62%) sensory/speech disability
- 13,700 (51%) psychiatric disability
- 13,400 (50%) physical/diverse disability
- 12,300 (46%) psychiatric and sensory/speech disability
- 10,700 (40%) sensory/speech and physical/diverse disability.

Table 11: People aged under 65 years with a severe or profound core activity limitation in households: population baseline estimates of unmet demand for accommodation and respite services, by disability groups, 2003

	Unmet demand for accommodation and respite services					
	Service availability[a]	Cost/hours[b]	Total	Service availability[a]	Cost/hours[b]	Total
Disability groups[c]	('000)			Per cent		
Intellectual	11.2	11.6	22.8	93.8	78.7	85.4
Psychiatric	*8.1	*8.1	16.2	*68.1	*54.6	60.5
Sensory/speech	*9.0	11.0	20.0	*75.6	74.6	75.0
Acquired brain injury	*2.2	**2.0	*4.2	*18.7	**13.7	*15.9
Physical/diverse	*7.1	*8.3	15.3	*59.4	*55.8	57.4
Multiple disabilities						
Intellectual & psychiatric	*7.4	*6.3	13.7	*61.8	*42.6	51.1
Intellectual & sensory/speech	*8.3	*8.3	16.5	*69.4	*56.0	61.9
Intellectual & physical/diverse	*6.3	*7.1	13.4	*53.1	*47.7	50.1
Intellectual & acquired brain injury	**1.5	**1.5	*2.9	**12.4	**9.9	*11.0
Intellectual & psychiatric & sensory/speech	*6.2	*6.1	12.3	*52.2	*41.5	46.2
Intellectual & psychiatric & physical/diverse	*3.9	*4.4	*8.3	*32.7	*30.0	*31.1
Intellectual & sensory/speech & physical/ diverse	*5.0	*5.7	10.7	*41.8	*38.4	39.9
Total disability	**11.9**	**14.8**	**26.7**	**100.0**	**100.0**	**100.0**

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.
** Estimates have an associated relative standard error of greater than 50% and are considered too unreliable for general use.
(a) No service available, or unable to arrange service.
(b) Service costs too much or does not provide sufficient hours.
(c) Based on all reported disabling conditions.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

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Technical appendix

Concepts and terms of the ABS Survey of Disability, Ageing and Carers

Disability

For ABS survey purposes, a person has disability if he/she has at least one of 17 limitations, restrictions or impairments that has lasted or is likely to last for at least 6 months and that restricts everyday activities. People with disability, so defined, are asked further questions about core activity limitations and schooling/employment restrictions. Those reporting a core activity limitation or schooling/employment restriction are the population with disability and a specific limitation or restriction. The remainder are the population with disability and no specific limitations (ABS 2004).

Core activity

People identified as having disability are asked about their need for assistance with core activities of self-care, mobility, and communication.

Core activities comprise the following tasks:

- 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.

Core activity limitations

Four levels of core activity limitation are based on whether a person needs personal assistance with, has difficulty with, or uses aids or equipment for any of the core activities. A person's overall level of core activity limitation is determined by the highest level of limitation the person experiences in any of the core activity areas. The four levels of core activity limitation are:

- 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 easily walk 200 metres, walk up and down stairs without a handrail, easily bend to pick up an object from the floor, or use public transport; or has difficulty or needs help using public transport.

In this bulletin, a 'severe or profound core activity limitation' is sometimes referred to as 'severe or profound limitation'.

Schooling or employment restriction

The survey identified two other life areas in which people may experience restrictions or difficulty due to disability, referred to as non-core restrictions. Schooling restrictions are applicable to people aged 5–20 years and employment restrictions are limited to persons aged 15–64 years living in households.

Disabling condition

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

Method of prevalence estimates of intellectual disability

All the estimates start with the base 'disability' population defined by the SDAC. The most inclusive approach is based on **all disabling conditions** reported by the respondents. A person is initially included in the intellectual disability group if:

- a positive response was made by or for them to the screening question about having 'difficulty learning or understanding things'; and/ or
- a positive response was made by or for them to one of 17 screening questions and one or more intellectual impairments or disabling conditions was reported.

The approach using data on **all disabling conditions plus a severe or profound core activity limitation** relies on multidimensional survey information. The estimates from the previous approach are now narrowed down by applying a 'filter'—only people who have reported a severe or profound core activity limitation are retained in the group.

Estimates based on **main disabling condition** related to conditions that were reported by the survey respondents as causing the most problems.

In the 2003 SDAC confidentialised unit record file, Down syndrome, 'developmental learning disorders' and 'other developmental disorders' were grouped with a variety of other conditions under 'other mental and behavioural disorders'—a catch-all category that cannot be broken down further to the lower level categories and is included in the psychiatric disability categories. The inclusion of these intellectual/learning conditions in this catch-all category has resulted in an increase in the estimated prevalence of psychiatric disability, and a decrease in the estimated prevalence of intellectual disability, based on the main disabling condition.

Learning disability is a subcategory of intellectual disability. It would be desirable to separate learning disability from intellectual disability in the estimation of prevalence, since some people with a learning disability may have no impairment in intellectual functioning. However, it is difficult to do so because of the survey data limitations. People with an intellectual disability are more likely to have learning difficulties, and intellectual disability and learning disability may occur together (American Psychiatric Association 1994).

Impairment of intellectual function may occur at any age beyond the developmental period through an acquired physical trauma or central nervous system deterioration. If this happens, the condition is more properly classified as dementia (Grossman 1983).

In this bulletin, the criterion of age 18 as the cut-off point for manifestation of intellectual disability is not used in the prevalence estimation. However, analyses focus on people aged under 65 years. This largely excludes people with impairments of intellectual function caused by dementia and other age-related conditions.

Using data of the 2003 SDAC, the disabling conditions included in the estimates of intellectual disability are:

- intellectual and developmental disorders n.e.c.
- mental retardation/intellectual disability
- autism and related disorders (including Rett's syndrome and Asperger's syndrome)
- attention deficit disorder/hyperactivity.

Appendix tables

Table A1: Age-specific prevalence rates of intellectual disability, including and excluding ADHD, autism and dementia, 2003

Age group (years)	Males	Females	Persons	Excluding ADHD	Excluding ADHD and autism	Excluding dementia	Excluding ADHD and dementia
0–4	*1.2	*1.1	1.1	1.1	1.0	1.1	1.1
5–9	6.2	3.0	4.6	3.4	2.9	4.6	3.4
10–14	8.8	5.1	7.0	4.8	4.2	7.0	4.8
15–19	5.3	3.5	4.4	3.1	2.9	4.4	3.1
20–24	3.0	1.6	2.3	1.9	1.6	2.3	1.9
25–29	3.0	*0.7	1.9	1.8	1.8	1.9	1.8
30–34	1.8	*0.9	1.3	1.2	1.2	1.3	1.2
35–39	2.2	*1.1	1.7	1.6	1.5	1.7	1.6
40–44	1.6	*1.2	1.4	1.4	1.4	1.4	1.4
45–49	1.8	*1.4	1.6	1.5	1.5	1.6	1.5
50–54	2.1	*1.2	1.7	1.6	1.6	1.7	1.6
55–59	2.5	1.8	2.2	2.1	2.1	2.1	2.1
60–64	*2.0	*1.8	1.9	1.9	1.9	1.8	1.8
65–69	*2.6	*2.1	2.4	2.4	2.4	2.0	2.0
70–74	*3.3	*2.1	2.6	2.6	2.6	1.6	1.6
75–79	5.5	5.1	5.2	5.2	5.2	3.2	3.2
80–84	7.5	10.8	9.4	9.4	9.4	3.8	3.8
85+	13.1	23.6	20.2	20.2	20.2	5.7	5.7
Total	**3.4**	**2.6**	**3.0**	**2.6**	**2.5**	**2.6**	**2.2**
Total No.(000')	**333.6**	**255.1**	**588.7**	**513.4**	**488.7**	**505.7**	**430.4**

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A2: People with an intellectual disability living in households, based on main disabling condition: age at onset of main disabling condition, 2003

Age at onset	'000	Per cent
0–4	105.3	65.0
5–9	36.9	22.8
10–19	10.7	6.6
20+	*5.3	*3.3
Don't know	*3.7	*2.3
Total	162.0	100.0

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.

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

Table A3: People aged under 65 years with intellectual disability: presence of other types of disability, 2003

	Psychiatric	Sensory/speech	Acquired brain injury	Physical/diverse	Total with intellectual disability[(a)]
			Per cent of total with intellectual disability		
All people with intellectual disability	57.1	37.6	20.6	48.3	100.0
Intellectual and severe or profound limitation	61.9	51.6	21.0	51.7	49.3
			'000		
All people with intellectual disability	249.2	163.8	89.9	210.8	436.2
Intellectual and severe or profound limitation	133.1	110.9	45.1	111.2	215.1

Total number of people with intellectual disability is less than the sum of disability groups since people may have multiple disabilities.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A4: People aged under 65 years with intellectual disability: selected health conditions, 2003 (per cent)

Selected long-term health conditions	Intellectual and severe or profound limitation	All people with intellectual disability
Speech problems	40.7	23.7
Asthma	16.2	14.9
ADHD	15.5	17.2
Hearing disorders (total)	13.3	13.8
Autism	11.5	6.8
Back problems	9.3	12.0
Epilepsy	9.0	5.4
Arthritis	8.3	8.0
Depression	8.3	8.1
Vision disorders (total)	6.9	5.7
Schizophrenia	4.9	3.6
Hypertension	*4.1	5.6
Stroke	*4.0	3.3
Diabetes	*3.1	2.7
Cerebral palsy	*3.0	*2.1
Migraine	*2.6	3.7
Hearing (noise-induced)	*2.5	3.9
Osteoporosis	*2.3	*1.2
Heart diseases	*1.6	2.7
Cancer	*1.2	*1.0
Paralysis	*1.1	*0.7
Total intellectual disability ('000)	**215.1**	**436.2**

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A5: People aged under 65 years with a severe or profound core activity limitation living in households: needs for help with core activities by disability groups, 2003

		Other disabilities[a]			
	Intellectual	Psychiatric	Sensory/ speech	Acquired brain injury	Physical/ diverse
			'000		
Self-care	102.2	61.9	53.7	28.7	209.1
Mobility	138.4	119.9	81.2	40.5	306.4
Communication	115.8	11.0	35.1	*3.0	11.5
Total	**202.6**	**142.4**	**142.1**	**54.0**	**398.1**
			Per cent		
Self-care	50.5	43.5	37.8	53.2	52.5
Mobility	68.3	84.2	57.2	74.9	77.0
Communication	57.2	7.7	24.7	*5.5	2.9

* Estimates have an associated relative standard error of between 25% and 50% and should be used with caution.
(a) People with disabilities other than intellectual disability.
Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table A6: People aged under 65 years with intellectual disability living in households: extent to which need for assistance met for various activities, 2003

	Extent to which need for assistance was met			
	Fully	Partly	Not at all	Total
	'000			
Self-care	89.3	5.9	7.0	102.2
Mobility	109.5	23.7	5.2	138.4
Communication	73.7	40.3	1.9	115.8
Cognition or emotion	156.1	86.7	9.4	252.2
Health care	100.7	19.2	9.9	129.7
Paperwork	99.2	22.9	6.5	128.6
Transport	60.4	12.9	3.7	77.0
Housework	41.5	11.2	6.3	59.0
Property maintenance	50.4	13.6	4.5	68.5
Meal preparation	38.9	6.2	0.8	45.9
Total core activity[(a)]	**128.6**	**62.0**	**7.9**	**198.5**
Total for any activity[(b)]	**166.8**	**160.5**	**7.7**	**335.0**
	Per cent			
Self-care	87.4	5.7	6.9	100.0
Mobility	79.1	17.1	3.7	100.0
Communication	63.6	34.8	1.6	100.0
Cognition or emotion	61.9	34.4	3.7	100.0
Health care	77.6	14.8	7.6	100.0
Paperwork	77.1	17.8	5.1	100.0
Transport	78.4	16.8	4.8	100.0
Housework	70.3	19.0	10.7	100.0
Property maintenance	73.6	19.9	6.6	100.0
Meal preparation	84.7	13.5	1.7	100.0
Total core activity[(a)]	**64.8**	**31.2**	**4.0**	**100.0**
Total for any activity[(b)]	**49.8**	**47.9**	**2.3**	**100.0**

(a) Includes people who need help with at least 1 core activity.
(b) Include people who need help with at least 1 of the 10 activities.
Sources: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

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Any enquiries or comments on this publication should be directed to:

Dr Xingyan Wen
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Phone (02) 6244 1177
Email xingyan.wen@aihw.gov.au

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