

14 People ageing with an early onset disability

This chapter presents data on age at onset of main condition for people ageing with a disability and looks at relationships between main condition and age at onset.

For the purposes of the analyses in this section, early onset disability is defined as disability where the age at onset of main condition was 17 years or less, and late onset disability is defined as disability where the age at onset of main condition was 65 years or more.

14.1 Age at onset of disability

Although no direct question about age at onset of disability was asked in the ABS disability surveys, information about age at onset of main condition was collected. The survey respondent was asked how old he/she was when it was first found that he/she had the condition.

In the 1998 survey, a person's main condition was defined as 'a long-term condition identified by a person as the one causing the most problems'. Where a person reported only one long-term condition, this was recorded as their main long-term condition. A long-term condition is defined as 'a disease or disorder that has lasted or is likely to last for at least six months; or a disease, disorder or event (e.g. stroke, poisoning, accident etc.) which produces an impairment or restriction which has lasted or is likely to last for at least six months' (ABS 1999: 69).

When interpreting data on age at onset from the ABS disability surveys, some data limitations need to be considered.

The time between onset of a condition and the development of disability may vary depending on the nature of the condition and other factors. In the analysis presented in this report, age at onset of main condition is used as a proxy for age at onset of disability. However, a person with multiple long-term conditions may have been experiencing disability caused by another condition prior to the onset of their main condition. It is possible that a person with an early onset disability who has learned to cope with that disability very well might find a recently acquired condition more disabling because they have had less time to adjust to it. In this case, the person might report the more recently acquired condition as their main condition. In the following discussion of the ABS disability data, 'age at onset of disability' means 'age at onset of main condition', treated as indicative of age at onset of disability.

Information about age at onset of main condition was only collected among people living in households. In 1998, among people with a disability living in households, 29,900 people (0.9%) reported that they did not know their age at onset of their main condition (Table 14.1). For people with a severe or profound core activity restriction, 11,300 people (1.2%) did not know their age at onset of their main condition (Table 14.2).

Because the ABS disability survey data are cross-sectional (i.e. represent a snapshot at a point in time) they cannot provide information on the overall distribution of age at onset of main condition. Longitudinal data would be more useful in this regard, as they could give a more complete picture of disability experience in the population. However, there are no

such data available in Australia. The ABS disability survey data provide information on respondents' life experience up to the date of the survey. Cross-sectional data cannot provide disability information on young people who have no disability at the time of the survey, but who may acquire a disability later in life, or people with a disability who died before the survey date. Therefore, percentage distribution patterns of age at onset do not reflect the probability of acquiring disability in particular age groups.

Despite these caveats, the information on age at onset of main condition is useful for disability service planning. It can be used to provide some indication of the proportion of people with an early onset disability, as against the proportion who acquire a disability later in life, within particular age groups. For instance, when considering clients with a disability aged between 45 and 64, it may be relevant to know what percentage have an early onset disability, as these people may have different support needs from people with a recently acquired disability. These issues will be explored further in Chapter 18 (implications for support services).

14.2 Distribution of age at onset by current age

Table 14.1 shows the distribution of age at onset by current age (i.e. age of the respondent at the time of the survey) for people with a disability living in households. Table 14.2 shows the distribution of age at onset by current age for people with a severe or profound core activity restriction living in households. In this section we focus particularly on two age groups—people aged between 45 and 64 years, and people aged 65 years and over. In the following discussion, people who did not know their age at onset of their main condition are excluded from calculations.

Table 14.1: People with a disability living in households: age at onset of disability by age ('000), Australia, 1998^(a)

Age	Age at onset								Not known	Total	Total excluding not known
	0–14	15–29	30–44	45–59	60–64	65–69	70–75	75+			
0–14	295.0								**0.7	295.7	295.0
15–29	195.1	174.3							**0.9	370.3	369.4
30–44	110.0	232.0	245.9						*7.9	595.9	587.9
45–59	74.0	130.2	316.7	296.9					*3.3	821.0	817.7
60–64	16.6	21.3	56.8	145.9	38.4				*3.5	282.5	279.0
65–69	12.6	19.6	39.2	103.1	54.8	34.0			**2.7	266.0	263.3
70–74	12.1	27.9	28.2	71.3	45.0	58.1	39.3		**2.6	284.5	282.0
75+	16.6	31.4	43.1	58.1	51.9	55.6	88.8	156.2	*8.4	510.2	501.7
Total	732.0	636.7	729.8	675.3	190.2	147.7	128.1	156.2	29.9	3,426.0	3,396.1

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Table 14.2: People with a severe or profound core activity restriction living in households: age at onset of disability by age ('000), Australia, 1998^(a)

Age	Age at onset								Not known	Total	Total excluding not known
	0–14	15–29	30–44	45–59	60–64	65–69	70–75	75+			
0–14	143.6									143.6	143.6
15–29	44.3	35.2							**0.6	80.1	80.1
30–44	28.8	50.0	55.0						**2.4	136.2	133.8
45–59	19.1	37.2	84.6	72.0					**1.4	214.3	212.9
60–64	*5.4	*4.3	12.7	29.2	9.5				**0.6	61.7	61.1
65–69	*3.2	*2.8	*5.5	18.8	10.2	*8.9			**1.3	50.6	49.4
70–74	**2.2	*5.6	9.6	16.5	10.3	13.0	10.3		**1.0	68.6	67.5
75+	*6.0	*8.8	18.2	19.1	18.5	24.2	33.9	73.8	*4.0	206.4	202.4
Total	252.6	144.0	185.6	155.7	48.4	46.1	44.1	73.8	11.3	961.6	950.3

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

For people aged between 45 and 64 years, 11.0% of those with a severe or profound core activity restriction first experienced disability before the age of 18 years, and 48.6% between the ages of 18 and 44 years. Of all people with a disability aged between 45 and 64 years, 10.3% first experienced disability before the age of 18 years, and 45.9% between the ages of 18 and 44 years (Figure 14.1 and Table 14.3).

Among people aged 65 years and over, only 4.1% of people with a severe or profound core activity restriction and 4.8% of people with a disability first experienced disability before the age of 18 years. Some 51.4% of people with a severe or profound core activity restriction and 41.3% of all people with a disability had a late onset disability (i.e. first experienced at age 65 or over) (Figure 14.2 and Table 14.3). Clearly, it is not possible for people aged 45–64 to report an age at onset of 65 or over, and this in large part explains the different percentage distributions of age at onset between the 45–64 and the 65 or over age groups.

14.3 Age at onset of disability by main condition

This section looks at how patterns of age at onset differ with main condition groups, for people aged 45 to 64 and people aged 65 or over. Six broad main condition groups are used—intellectual, psychiatric, vision, hearing, acquired brain injury and physical/other. Table A14.1 shows which conditions fall within each of the broad groupings.

In making comparisons between main condition groups it is important to note that the proportions of people living in cared accommodation vary substantially between different main condition groups. Since the question about age at onset of main condition was not asked among people living in cared accommodation, this could affect the percentage distributions of age at onset.

Overall, 5% of people with a disability and 17% of people with a severe or profound core activity restriction were living in cared accommodation. However, the proportion living in cared accommodation was much higher in some main condition groups (e.g. psychiatric, intellectual and other mental) and lower in others (e.g. vision, hearing).

Table 14.3: People with a disability living in households: distribution of age at onset of disability by age, Australia, 1998^(a)

	Age at onset				Total ^(a)
	0–17	18–44	45–64	65+	
Age 45–64					
Severe or profound core activity restriction					
Number ('000)	30.2	133.1	110.7	—	274.1
%	11.0	48.6	40.4	—	100.0
All with disability					
Number ('000)	112.5	503.0	481.2	—	1,096.7
%	10.3	45.9	43.9	—	100.0
Age 65 or over					
Severe or profound core activity restriction					
Number ('000)	13.0	48.9	93.4	164.0	319.3
%	4.1	15.3	29.2	51.4	100.0
All with disability					
Number ('000)	49.9	180.9	384.3	432.0	1,047.0
%	4.8	17.3	36.7	41.3	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

— Nil or rounded to zero.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

For condition groups such as intellectual and other mental disorders that have higher rates of early onset and higher risk of institutionalisation for those affected (see Tables A14.2, A14.3, A14.4 and A14.5), the exclusion of people living in cared accommodation may result in an underestimation of the proportion with an early onset disability. Likewise, for conditions that are more common in older age groups and possibly associated with institutional living, the proportion of people with a late onset disability may be underestimated.

People aged between 45 and 64 years

Of people with a disability aged between 45 and 64 years, the main condition group with the highest rate of early onset was intellectual—63.3% of people aged 45–64 with an intellectual main condition reported an age at onset of under 18 years (Table 14.4). The main condition groups physical/other and psychiatric had the lowest rates of early onset (8.3% and 10.6%, respectively). The groups of vision and physical/other had relatively high rates of onset between ages 45 and 64. For the main condition groups psychiatric, hearing, and acquired brain injury, the highest rates of onset were in the age group 18–44 years.

Of people with a disability aged between 45 and 64 years who reported onset before age 18, 67.2% had a main condition in the group physical/other, and 14.3% had a hearing-related main condition. Of those who reported onset between ages 45 and 64, 85.9% had a main condition in the group physical/other, 6.2% had a psychiatric main condition and 5.5% had a hearing-related main condition (Table 14.4).

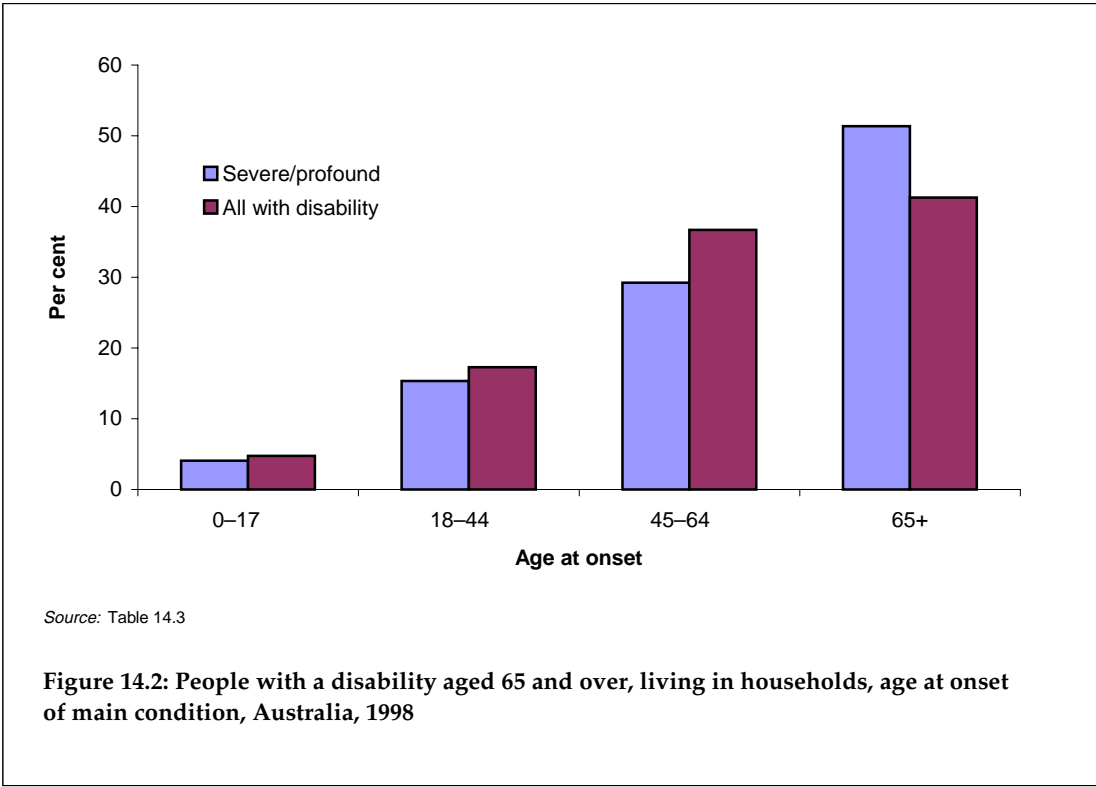
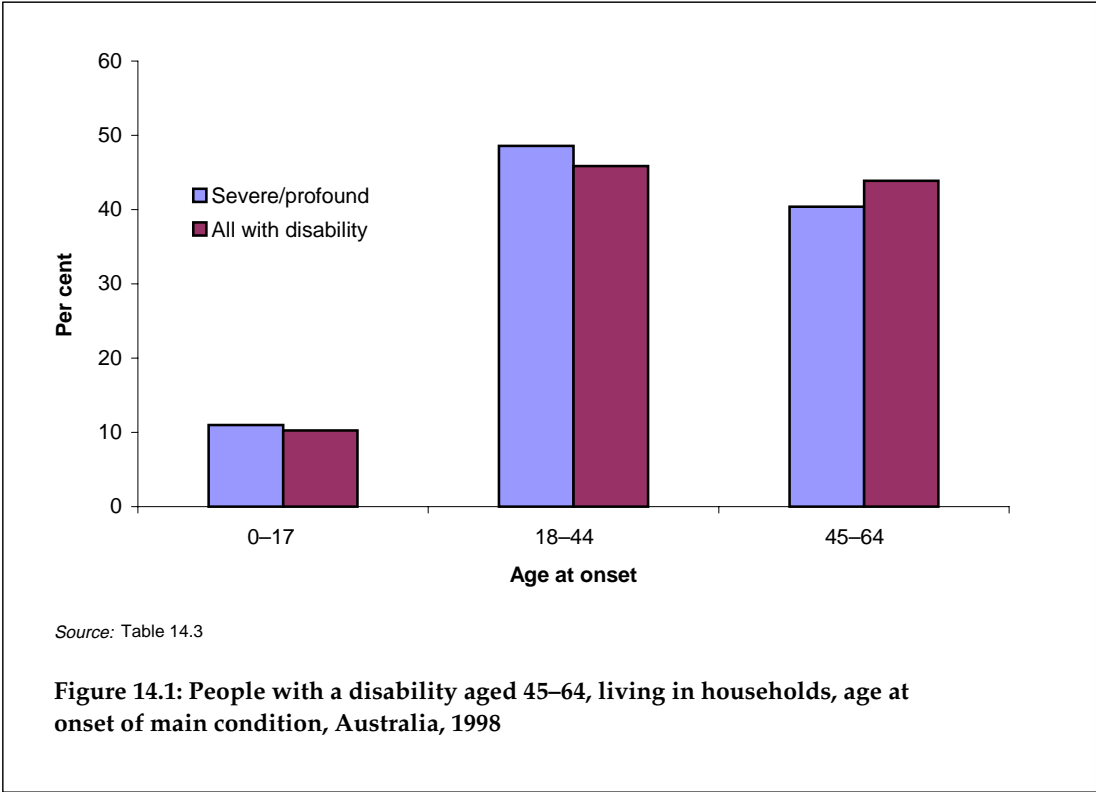


Table 14.4: People with a disability aged 45–64 living in households: distribution of age at onset of disability by main condition, by age, Australia, 1998^(a)

	Age at onset			Total ^(b)
	0–17	18–44	45–64	
	Number ('000)			
Intellectual	*7.6	*4.0	**0.4	11.9
Psychiatric	*7.9	36.7	30.0	74.7
Vision	*2.9	*4.9	*8.0	15.8
Hearing	16.1	39.3	26.5	82.1
Acquired brain injury	**2.5	*6.1	*2.8	11.4
Physical/other	75.6	412.0	413.4	907.6
Total	112.5	503.0	481.2	1,103.5
	Per cent (sum horizontally)			
Intellectual	63.3	*33.4	**3.3	100.0
Psychiatric	*10.6	49.2	40.2	100.0
Vision	*18.1	*31.1	50.8	100.0
Hearing	19.7	47.8	32.3	100.0
Acquired brain injury	*21.7	53.7	*24.6	100.0
Physical/other	8.3	45.4	45.6	100.0
Total	10.2	45.6	43.6	100.0
	Per cent (sum vertically)			
Intellectual	*6.7	*0.8	**0.1	1.1
Psychiatric	*7.0	7.3	6.2	6.8
Vision	*2.5	*1.0	*1.7	1.4
Hearing	14.3	7.8	5.5	7.5
Acquired brain injury	**2.2	*1.2	*0.6	1.0
Physical/other	67.2	81.9	85.9	82.2
Total	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

For people aged 45–64 with a severe or profound core activity restriction, intellectual was, again, the main condition group with the highest rate of early onset (Table 14.5). In comparison with all people with a disability (Table 14.4), rates of later onset (i.e. age 45–64) were substantially lower in the psychiatric, vision and hearing groups. That is, in these groups, greater severity of activity restriction may be associated with earlier onset of disability. However, it should be noted that many of the estimates in Tables 14.4 and 14.5 are small and have very high relative standard errors, which limits the confidence with which comparisons can be made.

Table 14.5: People with a severe or profound core activity restriction aged 45–64 living in households: distribution of age at onset of disability by main condition, by age, Australia, 1998^(a)

	Age at onset			Total ^(b)
	0–17	18–44	45–64	
	Number ('000)			
Intellectual	*3.4	**1.3	**0.4	*5.1
Psychiatric	*3.8	10.2	*6.0	20.0
Vision	**0.7	**1.4	**0.3	**2.5
Hearing	**1.1	*3.0	**1.0	*5.1
Acquired brain injury	**1.6	**1.9	**0.8	*4.3
Physical/other	19.5	115.4	102.3	237.1
Total	30.2	133.1	110.7	274.1
	Per cent (sum horizontally)			
Intellectual	*66.9	**25.2	**7.8	100.0
Psychiatric	*19.1	51.0	*29.9	100.0
Vision	**30.3	**55.7	**14.1	100.0
Hearing	**21.9	*58.5	**19.6	100.0
Acquired brain injury	**37.9	*44.1	**18.0	100.0
Physical/other	8.2	48.7	43.1	100.0
Total	11.0	48.6	40.4	100.0
	Per cent (sum vertically)			
Intellectual	*11.3	**1.0	**0.4	*1.9
Psychiatric	*12.6	7.7	*5.4	7.3
Vision	**2.5	**1.0	**0.3	**0.9
Hearing	**3.7	*2.3	**0.9	*1.9
Acquired brain injury	**5.4	**1.4	**0.7	*1.6
Physical/other	64.6	86.7	92.3	86.5
Total	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Of people with a severe or profound core activity restriction aged between 45 and 64 years who reported onset before age 18, 64.6% had a main condition in the group physical/other, 12.6% had a psychiatric main condition and 11.3% had an intellectual main condition. This pattern is somewhat different from that for all people with a disability aged 45–64 who reported onset before age 18 (Table 14.4). Of people with a severe or profound core activity restriction aged between 45 and 64 who reported onset between ages 45 and 64, 92.3% had a main condition in the group physical/other (Table 14.5).

For people aged between 45 and 64 with a disability, 0.6% (6,800 people) reported that they did not know their age at onset of their main condition (Table A14.2). Most people who did not know their age at onset had a main condition in the group physical/other (97.3%), and the remainder had a hearing-related main condition (2.7%). For people aged 45–64 with a severe or profound core activity restriction, 0.7% (2,000 people) did not know their age at onset of their main condition (Table A14.3). All of these people had a main condition in the group physical/other.

The proportion of people living in cared accommodation also varied between main condition groups. For people aged 45–64 with a disability, 1.1% lived in cared accommodation. However, the proportion was much higher for people with an intellectual main condition (22.6%), and was also relatively high for people with acquired brain injury and psychiatric main conditions (3.4% and 3.1%, respectively) (Table A14.2). For people aged 45–64 with a severe or profound core activity restriction, 3.9% lived in cared accommodation (Table A14.3). Again, the proportion was higher for some main condition groups, particularly intellectual (39.2%) and psychiatric (8.9%). As noted above, this variation needs to be taken into account when comparing the percentage distributions of age at onset between main condition groups, as the question about age at onset of main condition was not asked of people living in cared accommodation.

People aged 65 or over

Of people with a disability aged 65 or over, only 3,000 reported an intellectual main condition (Table 14.6). The number was even lower for people with severe and profound core activity restrictions (Table 14.7). Because these estimates are so small, and correspondingly have very high relative standard errors, it is not possible to make comments about the distribution of age at onset for people aged 65 or over with an intellectual main condition.

For the main condition groups physical/other, hearing and vision, there tended to be higher rates of onset later in life (i.e. in the age groups 45–64 and 65+). For the psychiatric main condition group, there was a more even spread of onset through the adult years. The patterns for people with severe or profound core activity restrictions were similar to those for disability generally, although the estimates are smaller still, so it is difficult to make valid comparisons between main condition groups.

Of people aged 65 or over with a disability, 1.1% (13,600 people) reported that they did not know their age at onset of their main condition (Table A14.4). For people with a severe or profound core activity restriction the rate was similar—1.3% or 6,300 people (Table A14.5).

The proportion of people with a disability living in cared accommodation was much higher for people aged 65 or over than for people aged between 45 and 64. Of people aged 65 or over, 13.2% (161,900) of all people with a disability and 32.2% (154,800) of people with a severe or profound core activity restriction lived in cared accommodation (Tables A14.4 and A14.5). People who reported an intellectual or psychiatric main condition were much more likely to be living in cared accommodation than people in other main condition groups. For people aged 65 or over with a severe or profound core activity restriction, 91.5% of those with an intellectual main condition and 78.6% of those with a psychiatric main condition were living in cared accommodation.

Table 14.6: People with a disability aged 65 or over living in households: distribution of age at onset of disability by main condition, by age, Australia, 1998^(a)

	Age at onset				Total ^(b)
	0–17	18–44	45–64	65+	
	Number ('000)				
Intellectual	**0.5	**0.8	**0.5	**1.1	*3.0
Psychiatric	*3.2	*7.4	*7.4	*7.8	25.8
Vision	*4.6	*5.2	14.5	43.3	67.6
Hearing	10.4	22.0	41.2	40.5	114.2
Acquired brain injury	—	**1.0	**2.2	—	*3.2
Physical/other	31.2	144.5	318.3	339.2	833.2
Total	49.9	180.9	384.3	432.0	1,047.0
	Per cent (sum horizontally)				
Intellectual ^(c)	—	—	—	—	—
Psychiatric	*12.5	*28.5	28.7	30.3	100.0
Vision	*6.7	*7.7	21.5	64.1	100.0
Hearing	9.1	19.3	36.1	35.5	100.0
Acquired brain injury ^(c)	—	—	—	—	—
Physical/other	3.7	17.3	38.2	40.7	100.0
Total	4.8	17.3	36.7	41.3	100.0
	Per cent (sum vertically)				
Intellectual	**1.1	**0.4	**0.1	**0.3	*0.3
Psychiatric	*6.5	*4.1	*1.9	*1.8	2.5
Vision	*9.2	*2.9	3.8	10.0	6.5
Hearing	20.8	12.2	10.7	9.4	10.9
Acquired brain injury	—	**0.5	**0.6	—	*0.3
Physical/other	62.5	79.9	82.8	78.5	79.6
Total	100.0	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

(c) Estimates for intellectual and acquired brain injury main condition groups were too small to allow percentage breakdown by age at onset.
— Nil or rounded to zero.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Table 14.7: People with a severe or profound core activity restriction aged 65 or over living in households: distribution of age at onset of disability by main condition, by age, Australia, 1998^(a)

	Age at onset				Total ^(b)
	0–17	18–44	45–64	65+	
	Number ('000)				
Intellectual	—	—	—	**0.4	**0.4
Psychiatric	**1.2	*3.1	*3.1	*6.3	13.6
Vision	**1.9	**1.3	*6.0	19.1	28.3
Hearing	**0.8	**0.7	**2.5	*6.1	10.0
Acquired brain injury	—	**0.6	**1.3	—	**1.8
Physical/other	*9.0	43.3	80.6	132.2	265.1
Total	13.0	48.9	93.4	164.0	319.3
	Per cent (sum horizontally)				
Intellectual ^(c)	—	—	—	—	—
Psychiatric	**9.1	*22.4	*22.5	46.0	100.0
Vision	**6.9	**4.6	*21.2	67.4	100.0
Hearing	**7.9	**7.1	*24.6	60.4	100.0
Acquired brain injury ^(c)	—	—	—	—	—
Physical/other	*3.4	16.4	30.4	49.9	100.0
Total	4.1	15.3	29.2	51.4	100.0
	Per cent (sum vertically)				
Intellectual	—	—	—	**0.2	**0.1
Psychiatric	**9.5	*6.2	*3.3	*3.8	4.3
Vision	**15.0	**2.6	*6.4	11.7	8.9
Hearing	**6.1	**1.4	**2.6	*3.7	3.1
Acquired brain injury	—	**1.1	**1.4	—	**0.6
Physical/other	69.4	88.6	86.3	80.6	83.0
Total	100.0	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

(c) Estimates for intellectual and acquired brain injury main condition groups were too small to allow percentage breakdown by age at onset.

— Nil or rounded to zero.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

14.4 Summary

- The 1998 ABS disability survey provides information on age at onset of main condition, which can be treated as indicative of age at onset of disability. Information about age at onset was not collected among people living in cared accommodation.
- Among people living in households, 0.9% of people with a disability and 1.2% of people with severe or profound core activity restriction did not know their age at onset of their main condition.

People aged between 45 and 64 years

- 10.3% (112,500) of all those with a disability and 11.0% (30,200) of those with a severe or profound core activity restriction had an early onset disability (before age 18);
- 45.9% (503,000) of those with a disability and 48.6% (133,100) of those with a severe or profound core activity restriction reported an age at onset of between 18 and 44 years.
- The main condition group with the highest rate of early onset was intellectual—63.3% of people with a disability and an intellectual main condition reported an age at onset of under 18 years.
- The main condition groups physical/other and psychiatric had the lowest rates of early onset (8.3% and 10.6%, respectively, for all people with a disability aged 45–64).
- Of people with a severe or profound core activity restriction who reported onset before age 18, 64.6% had a main condition in the group physical/other, 12.6% had a psychiatric main condition and 11.3% had an intellectual main condition.
- Of people with a severe or profound core activity restriction, 3.9% (11,200) lived in cared accommodation. However, the proportion was much higher for the main condition groups intellectual (39.2%) and psychiatric (8.9%). This variation needs to be taken into account when comparing the percentage distributions of age at onset between main condition groups.

People aged 65 or over

- Only 4.8% (49,900) of people with a disability and 4.1% (13,000) of people with severe or profound core activity restriction first experienced disability before the age of 18 years.
- 41.3% (432,000) of people with a disability and 51.4% (164,000) of people with a severe or profound core activity restriction had a late onset disability (age 65 or over).
- 13.2% (161,900) of all people with a disability and 32.2% (154,800) of people with a severe or profound core activity restriction lived in cared accommodation.
- People with an intellectual or psychiatric main condition were much more likely to be living in cared accommodation. For people with a severe or profound core activity restriction, 91.5% (4,400) of those with an intellectual main condition and 78.6% (55,200) of those with a psychiatric main condition were living in cared accommodation.