



Highlights

Chapter 1—Introduction

- What is known about children with disabilities in Australia, in terms of their characteristics, and the needs and circumstances of them and their families? What is known about the services, benefits and assistance provided to them? This report uses a range of information sources to explore these questions and presents for the first time, an overview of this important group in Australia.

Chapter 2—Concepts and definitions

- This report focuses on children aged 0–14 years of age.
- Disability is conceptualised as a multi-dimensional concept, relating to a child’s health conditions, their body functions and structures, the activities they do, the life areas in which they participate and the environmental factors that affect all of these experiences. This report therefore highlights information that relates to all of these facets of disability, including, for example, information about health conditions such as Attention Deficit Hyperactivity Disorder, participation of children in mainstream education, and the presence of environmental factors such as family support and formal services.
- Wherever possible, analysis is broken down to the level of five disability groups – intellectual/learning disability, psychiatric disability, sensory/speech disability, physical/diverse disability and acquired brain injury.

Chapter 3—The prevalence of disability in children

- This report draws on two main groups of children: children with a disability, and children with a severe or profound core activity restriction (‘severe disability’). The latter group of children are those who require assistance with one or more activities of daily living (i.e. self-care, mobility or communication). This could mean, for example, they need help to change their clothes or shower, to get out of bed or move around their bedroom, or talk to a family member.
- In 1998, about 296,400 children, or 7.6% of children aged 0–14 years, were estimated to have a disability. Of these, about 144,300, or 3.7% of children aged 0–14 years, had a severe or profound core activity restriction (‘severe disability’).
- Almost twice as many boys as girls had a disability (192,800 or 9.6% of boys compared to 103,600 or 5.4% of girls). This sex difference also applies when we consider the pattern for children with a severe disability (97,400 or 4.9% of boys compared to 47,000 or 2.5% of girls).
- Of the 296,400 children with a disability, 144,100 children (or 3.7% of the population aged 0–14 years) were estimated to have a physical/diverse disability, either as a main disabling condition or an associated disabling condition. The next most common disability group among children was intellectual/learning disability (143,000 children or 3.7% of the population of this age), followed by sensory/speech disability (119,900 or 3.1%), psychiatric disability (43,600 or 1.1%) and disability related to acquired brain injury (12,700 or 0.3%) (Table S1).

Table S1: Children aged 0–14 years with a disability by disability group and level of restriction, 1998^(a)

	Disability		Severe or profound core activity restriction	
	'000	% of population aged 0–14 years	'000	% of population aged 0–14 years
Intellectual/learning	143.0	3.7	83.0	2.1
Psychiatric	43.6	1.1	37.0	0.9
Sensory/speech	119.9	3.1	77.6	2.0
Physical/diverse	144.1	3.7	69.2	1.8
ABI	12.7	0.3	11.4	0.3
Total	296.4	7.6	144.3	3.7

(a) Table S1 provides estimates based on *all disabling conditions* reported for each child aged 0–14 years. This means that children may appear in more than one disability group and that totals in each disability group do not add to the total number of children with disabilities. Estimates based on the *main disabling condition* reported for each child aged 0–14 years or the condition causing the child the most problem are discussed Section 3.2.

- The rate of intellectual/learning disability among boys is 2.6 times that for girls (5.2% compared to 2.0%) while the rate of physical/diverse disability for boys is 1.4 times that for girls (4.2% compared to 3.1%).
- The likelihood of having a severe disability (i.e. severe or profound core activity restriction) varies across disability groups, with a much higher probability among children with an acquired brain injury (90%) or psychiatric disability (85%) compared to the other disability groups (48% among children with a physical/diverse disability, 58% among children with an intellectual/learning disability and 65% for children with a sensory/speech disability).
- The great majority of children with disabilities were born in Australia. The rate of disability was higher amongst children living outside capital cities.
- Between 1981 and 1998 there appears to have been an upward trend in the reported prevalence of disability and severe disability among children aged 0–14 years. However, most of this increase occurred between 1993 and 1998 and is largely associated with methodological changes between the two ABS surveys. It is also possible that the increase in reported prevalence reflects, for example, a reduction in the stigma associated with disability, increased awareness of particular health conditions (e.g. ADHD), increased provision of services to meet the needs of children with disabilities and their families, and/or an increase in the underlying prevalence of childhood disability. These contributing factors cannot be disentangled using existing data sources.

Chapter 4—Families and carers

- The trend in Australia away from institutional care towards in-home care has been accompanied by children with disabilities tending to live at home with their families; in 1998, almost all children aged 0–14 years with disabilities lived in a household; less than 1% lived in cared accommodation.
- There is a strong association between childhood disability and low family income, based on research conducted in Australia, the United Kingdom and the United States.

- The financial costs associated with having a child with a disability can be especially marked, and more keenly felt, by families already living on low incomes. In some families, having a child with a disability may be linked to cycles or more sustained periods of dependence on government benefits, and in some cases, poverty.
- A more equivocal picture of the family effects of childhood disability is drawn from the current literature. Families of children with disabilities undergo a range of experiences and emotions associated with caregiving, none of which are necessarily unique to these families. However, there is evidence that some family members, especially mothers, experience more stress and a change to their wellbeing than families who do not have children with disabilities. Time and emotional commitments associated with raising a child with high support needs are usual sources of this stress.
- Mothers and fathers hence benefit significantly, both financially and emotionally, from receiving additional informal and formal support. While access to formal support services is crucial to parents, mothers have also described emotional support as possibly the most important influential coping factor.
- In 1998, primary carers of Australian children with a disability were mostly mothers (85% of all primary carers), followed by fathers (10%).
- Over half of these carers spent more than 40 hours a week engaged directly in the care of a resident child with a disability.
- Around 53% of primary carers felt they needed more support, particularly in relation to financial assistance and respite care.

Chapter 5—Services, assistance and other care arrangements

- Formal services available to children with disabilities and their families in Australia include a range of income support benefits, respite care, therapy and early child intervention, aids and equipment services, housing and crisis accommodation services, and child protection.
- Most carers of children with disabilities receive the Carer Allowance as their main ‘disability-related’ support payment, with a smaller proportion receiving the Carer Payment.
- CSTDA-funded support services are a primary source of formal support for children with disabilities in Australia. Nineteen per cent, or 29,563, of all service users receiving CSTDA-funded support services between 1 January and 30 June 2003 were children with disabilities aged 0–14 years. Community support, including services such as therapy support, early childhood intervention and behaviour/specialist intervention, was the most common support service received, followed by respite services.
- Additional forms of formal support can be sourced from programs such as HACC (Home and Community Care). In 2002–03, 2.1%, or 12,679, of all clients receiving HACC services were aged under 15 years.
- Children with disabilities tend to visit health care professionals more often than other children but actual access to health care services may be more limited.
- Mainstreaming of children with disabilities within the education system has increased substantially in Australia. In 2002, 81% of children with disabilities attending government schools and 91% of children with disabilities attending non-government schools attended

mainstream rather than special schools. Support for children, however, was more commonly provided in 1998 in special schools (82% of all children with a disability attending received support services) or special classes (82% of all children with a disability) compared with mainstream classes (17% of all children with a disability).

- Participation of children with disabilities in mainstream child care facilities is encouraged, with child-care services entitled to receive additional funding and services to care for children with disabilities. However, while children with disabilities made up 1–4% of children in each of the formal child care service settings, 14% of children cared for in an in-home setting had a disability.
- Around 40% of children with disabilities aged 0–14 years in 1998 used aids and equipment; almost half of these children relied on medical aids.
- Processes are in place to assist children with disabilities and their families to find accommodation within public and community housing, and to provide alternative care arrangements for children at risk of harm or of entering the juvenile justice system. There is also a range of valuable data collections relating to adoptions, child protection and juvenile justice, however little or no data are currently collected to provide statistical information on the numbers and characteristics of children with disabilities accessing these services.

Chapter 6—Data sources, data gaps and future directions

- This chapter provides a brief overview of the main data collections used in preparing this report, before describing in less detail a number of collections that were considered for analysis but not used, along with the reasons these sources were not used. This chapter therefore provides a valuable resource for others interested in statistics about children in general, or in statistics about children with disabilities.
- Australia is in the relatively privileged position of having a wealth of existing data sources that capture, in various formats and levels of detail, parts of the picture about the experiences of children with disabilities and their families. With relatively minor additions and improvements to these existing data sources, and more collaborative use or linkage of existing data sources, it is possible that substantial gains could be made in our ability to identify and describe this group and therefore assist them and their families.

