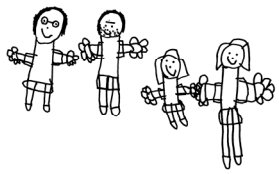
1 Introduction



1.1 Purpose of the report

Children represent our future. Promoting their development and wellbeing is widely accepted as an essential investment, as well as a moral obligation because of their vulnerability. This report sets out to piece together what we know about one group of children, those with disabilities, who are potentially a particularly vulnerable group, both in childhood and later in their adult lives. Throughout the report we seek to answer a number of important questions, including: How many children in Australia live with disability? What do we know about them, their disability and the experiences of their families? What do we know about the environment these children and their families live in and the services they access? Do we know anything about trends over time in the number of children with disability?

The purpose of this report is to detail what is currently known about children with disability in Australia. The report consists of two broad parts—the first part presents a basic profile of children with disabilities, and their families, in Australia, examining their needs and circumstances; the second part constructs a picture of the services, benefits and assistance provided to children with disabilities.

For a number of reasons, it is a complex task to describe this group of children and the special needs they and their families face. Disability exists on a continuum which means that 'children with disabilities' are not a single, easily identifiable group. Whether or not a child is described as having a disability may vary across different contexts. Thus while most children with activity limitations associated with Down syndrome will be considered to have a disability in all circumstances, children who experience limitations associated with health conditions such as Attention Deficit Hyperactivity Disorder (ADHD) or asthma may not. The multidimensional nature of disability is discussed further in Chapter 2.

In addition to conceptual and definitional problems, research, practice and policy relating to children have often been conducted in 'silos' (e.g. Prior 2002), meaning that information about children with disability is often difficult to find and synthesise into a meaningful picture. This report presents a broad range of information about this important group of children and their families, drawing on a number of data and information sources. We take a multidimensional view of childhood disability, examining both health and disability of children, characteristics of and effects on families in which a child with disability lives, and government and non-government service provision across a range of portfolios.

1.2 Structure of the report

The structure of the report is as follows:

- This introductory chapter provides context to the report, including a brief discussion of the historical policies and practices relating to and attitudes towards children with disabilities.

- Chapter 2 outlines key definitions and a conceptual framework for the report.
- Chapter 3 provides information about the prevalence of disability among Australian children.
- Chapter 4 describes the characteristics of families in which a child with disability lives, including some discussion of what is known about the effects of childhood disability on these families, and particularly the primary carer. This chapter also includes a discussion about the costs of disability and the related issue of family poverty and its relationship to childhood disability.
- Chapter 5 describes a range of formal supports such as specialist disability support services, health, education and housing, and benefits such as income support, which affect the ability of children with disabilities and their families to thrive and develop to their full potential.
- Chapter 6 focuses on data issues, including details of the data sources used throughout the report, data gaps identified during the process of developing the report, and future developments that may lead to improved data availability in the future.

This report thus begins by focusing on the child and moves attention out to the family and then to formal services and benefits which assist the child and their family. The International Classification of Functioning, Disability and Health (ICF) is used as a framework to organise the information included throughout this report (for more information on the ICF, see Chapter 2 and the following web sites <www.aihw.gov.au/disability/icf> and <www3.who.int/icf/icftemplate.cfm>).

1.3 Historical context

In the first half of the 20th century, Australian children with disabilities were largely an invisible population. Living conditions were variable and children had few opportunities to mix with other, non-disabled children. This period, however, saw some improvements, specifically in the education of children with disabilities. A government endorsement of education as an entitlement for all led the way for the establishment of 'special' schools. These schools catered for children with sensory, intellectual or physical disabilities and were run by private charities, with backing from state governments.

The 1960s and 1970s proved to be a turning point for reshaping public opinion on disability and people with disabilities (see AIHW 1993 for a more extensive review of the history of disability policy and services in Australia). Central to this transformation was the human rights movement and the theory of normalisation, which promoted independence and participation for people with disabilities. Increasing nationwide and worldwide adoption of these principles saw Australia become a signatory to the 1971 United Nations Declaration on the Rights of Mentally Disabled Persons and the 1975 United Nations Declaration on the Rights of Disabled Persons, both of which declared the right of people with disabilities to be given access to opportunities available to all other citizens. For children with disabilities in Australia, this call for inclusiveness mostly manifested itself in new directions in schooling. Scholars had argued that children educated in special schools developed 'institutionalised' and 'dependent' behaviours and recommended greater integration of children with disabilities into mainstream schools. State governments responded by establishing special educational units within mainstream school settings.

Focus on the circumstances and rights of people with disabilities continued into the 1980s and 1990s. The United Nations declared 1981 as the International Year of Disabled Persons, observed in Australia with an appeal to 'Break down the Barriers', and 1982–93 as the United Nations Decade of Disabled Persons. Integration was the major principle defining the reformist movement, with an emphasis on maximising services available to people with disabilities so they could continue or be given the opportunity to live, receive education and work in the wider community.

The rights of people with disability were formally recognised in the Disability Discrimination Act, which was passed by the Commonwealth Parliament in 1992. This Act makes discrimination on the grounds of disability unlawful, and provides for the removal of discrimination in legislation and in service provision and for the resolution of issues arising under it. The Act was followed in 1994 by the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, developed to focus worldwide attention on the need for equal rights and opportunities for persons with disabilities.

The rights and interests of people with disabilities, their families and their carers have received additional support with the increase in the number and breadth of peak bodies, advocacy and support organisations operating in Australia. The National Council on Intellectual Disability (NCID) and the Australian Council for the Rehabilitation of the Disabled (now simply ACROD), established in the 1950s and 1960s respectively, have since been joined by organisations such as Carers Australia, Australian Association of the Deaf, Blind Citizens Australia, Brain Injury Australia, Deafness Forum of Australia, National Ethnic Disability Alliance, and Physical Disability Council of Australia. These organisations work with the disability sector and state, territory and Federal governments to protect the rights of people with disabilities and their carers, promote public awareness, improve access to appropriate services, and enable greater participation in the community. Representatives from these and other organisations are now involved in the Australian Federation of Disability Organisations, which was recently established as a national peak body funded by the Australian government to represent people with disability across Australia.

For children with disabilities, this recognition of protecting rights and enhancing opportunities meant an improvement in access to and availability of services, the introduction of income support for their carers, and more mainstreaming of education. One consequential and significant outcome was deinstitutionalisation. Australia in the last 20–30 years has seen a clear trend away from institutional care for people with disabilities toward in-home and community care. This process of deinstitutionalisation, or rather non-institutionalisation, has tended to be more about people with disabilities, particularly children and younger people, staying in the community rather than moving out of institutions. In 1981, an average of 15.9 people under the age of 30 and with a severe disability lived in cared accommodation for every 100 living in households. By 1993 this ratio had fallen to 3.1 for every 100 (AIHW 1997:336). With regard to children, the proportion aged 0–14 years with a severe disability living in cared accommodation declined from 9% (3,500 children) to 0.4% (500 children[1]) (Table 1.1). Most of this change occurred in the 1980s.

With almost all children with a disability now living in households, provision of care became increasingly the domain of family care givers, with different levels of assistance from more formal sources of care. Responses to improve integration and the services needed to maximise this integration led to the establishment of the Commonwealth Disability Services

[1] This figure has an associated relative standard error (RSE) of 50% or more and should be interpreted accordingly.

Act (DSA) in 1986 and the Commonwealth/State Disability Agreement (CSDA) in 1991, the latter outlining government responsibility in the provision of disability services. The CSDA, now CSTDA, was re-signed in 1998 and 2003, giving the Commonwealth (Australian Government) responsibility for the planning, policy development and management of employment services, and the states and territories responsibility for all other specialist services, including accommodation support, community support and respite. In the period 1 January to 30 June 2003, around 29,600 children with a disability aged 0–14 years received CSTDA services (see Table 5.2 in Chapter 5 for the type of CSTDA services received).

Table 1.1: Children aged 0–14 years with a severe or profound core activity restriction: accommodation type, Australia, 1981–1998[(a)]

	1981		1988		1993		1998	
	'000	%	'000	%	'000	%	'000	%
Children 0–14 living in households	38.0	91.5	54.3	98.2	69.6	98.4	117.8	99.6
Children 0–14 living in cared accommodation	*3.5	8.5	**1.0	1.8	**1.1	1.6	**0.5	0.4
Total ('000)	**41.5**	**100.0**	**55.3**	**100.0**	**70.7**	**100.0**	**118.2**	**100.0**

(a) Substantial changes made to the ABS survey methodology appear to have resulted in greater identification of the number of people with disability, especially severe or profound core activity restriction, compared with the 1993 survey (ABS: Davis et al. 2001; AIHW 2001a). The 2003 SDAC, which largely retained the 1998 questions, found that there was no significant increase in the rate of disability among children aged 0–14 years between 1998 and 2003, or in the rate of profound or severe core activity restriction among children of this age (ABS 2004).

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

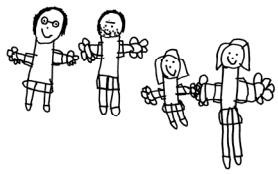
Source: AIHW 1999: Table 4.8.

Additional services that became available to children with disabilities and their families in this period included other community-based forms of care, such as Home and Community Care (HACC) services, respite care, and government and non-government funded aids and equipment schemes, providing aids based on eligibility criteria.

Income support also became tailored, to some extent, to assist carers of children with disabilities. The Carer Allowance, including Carer Allowance (Child), was established in 1999, and a 1997–98 Federal Budget extension of the Carer Payment allowed caregivers of children under 16 years of age with a profound disability to be eligible for the Carer Payment benefit.

Children's education in the 1980s and 1990s became progressively more mainstreamed than it was in the decades before, with fewer children being educated in special schools. Between 1976 and 1993, the number of children with a disability attending special schools dropped from 25,200 to under 18,000, although the trend between 1993 and 1998 is less clear, partly due to the absence of consistent nationwide data (Dempsey et al. 2002). This decline was associated with further implementation of special classes within mainstream educational settings and inclusion of children with disabilities into mainstream classes. In 2002, over 80% of children with a disability were being educated in a mainstream school (see Table 5.5).

2 Concepts and definitions



2.1 Children

This report focuses on children aged 0–14 years. This age group is used in much of the relevant research and corresponds to one of the standard definitions used by the Australian Bureau of Statistics (ABS). The ABS definition relates to the concept of dependency, assuming that all children under the age of 15 years are dependent on their parents or caregivers for income, housing, food and other necessities. At 15 years of age children are legally able to gain employment and, in most Australian states, leave school if they wish (ABS: Webster 1998). The concept of dependency is more complicated in relation to many children with disability, who may remain in some way dependent on their parents or caregivers for many more years or throughout their life. However, all families have expectations about the life areas in which their children and they themselves should be participating at certain stages of their family life cycle. The selected age range allows some analysis of the important transitions to formal child care and school but excludes discussion of the transition from school to employment or other day time activities and the transition to intimate adult relationships including marriage.

For many other purposes, children are regarded as all people under the age of 18 years. This is the age of majority in Australia, when young people are given civic responsibilities and are able to vote, marry without parental consent and purchase alcohol. This is also the definition adopted by the United Nations in the 1990 Convention on the Rights of the Child. In this report, adolescents or youth aged 15–18 years are generally excluded from analysis.

2.2 Disability

The conceptualisation and classification of disability

The International Classification of Functioning, Disability and Health (ICF) is used in this report as a framework for conceptualising disability. This report uses the ICF framework to assist in organising an array of data in which the concept of 'disability' is often operationalised in different ways.

The ICF describes disability as a multi-dimensional concept, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and the factors in their environment that affect these experiences (WHO 2001). The conceptual framework of the ICF has three components: body functions and structures, activities and participation, and environmental factors (see Figure 2.1). These components are defined 'in the context of health'. That is, the framework excludes situations that are not health related, such as participation restrictions due solely to socioeconomic or religious factors (WHO 2001).

The ICF provides a classification structure within each component, which is useful in terms of organising information on the various domains of the disability experience. For example:

- the body functions and structures components each consist of eight domains, including mental functions, voice and speech functions, structures of the nervous system and structures related to the digestive, metabolic and endocrine systems;
- the activities and participation component consists of nine domains, including self-care, mobility, communication, learning and applying knowledge and interpersonal interactions and relationships; and
- the environmental factors component consists of five domains including products and technology, natural environment and human-made changes to the environment, and services, systems and policies (AIHW 2003a; WHO 2001).

The first two components—body functions and structures, activities and participation—can be used in two ways. They can be used to describe neutral or positive aspects of health states, summarised with the umbrella term 'functioning'. They can also be used to describe problems (impairments, activity limitations or participation restrictions), which are summarised under the umbrella term 'disability'. Impairments are 'problems in body function or structure such as a significant deviation or loss' of hearing or vision. Activity limitations are 'difficulties an individual may have in executing activities' such as learning to read. Participation restrictions are 'problems an individual may experience in involvement in life situations' such as attending school or participating in recreation (WHO 2001).

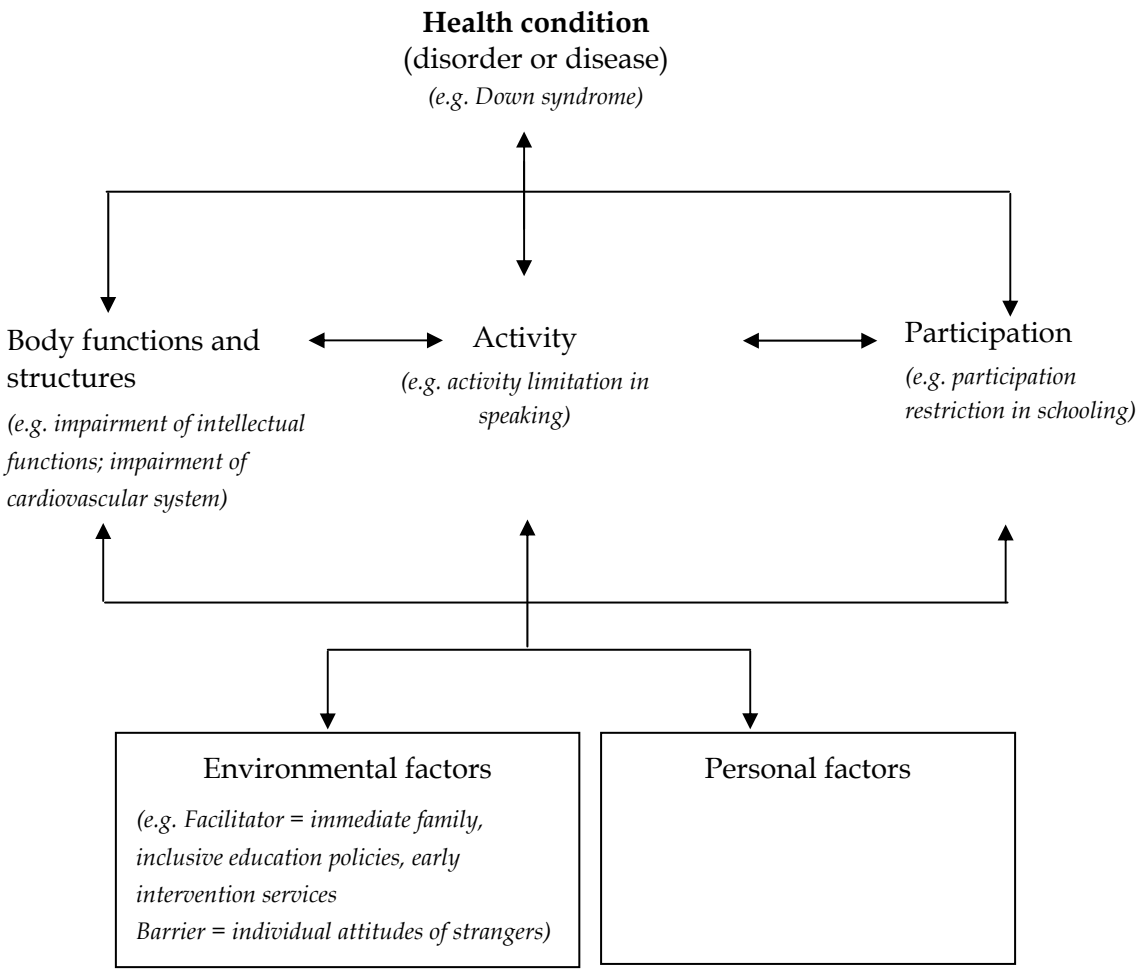
Personal factors, like environmental factors, are contextual factors but they are not classified in, and beyond the scope, of the ICF. Personal factors relate to the individual, for example, their age, gender and socioeconomic status.

The italicised text in Figure 2.1 provides examples of the type of information that might be collected under each of the ICF components. The example case refers to the type of information that might be used to describe the experience of a child with Down syndrome.

The *International Statistical Classification of Diseases and Related Health Problems 10th Revision* (ICD-10) (WHO 1992) is the primary international classification used to define and classify diseases and disorders. The ICD-10 has been used widely as a framework and coding system to classify health conditions, including those related to disability (AIHW 2003b).

It is important to note that the ICF framework does not describe a 'process' of disability in terms of causal links between health condition, impairment, activity limitation and participation restriction. Rather, it is considered that information about diagnosis or health condition together with information about functioning provide a more meaningful picture of the health status of a population (WHO 2001).

In this report, information about health condition, functioning and disability (including impairment, activity limitation and participation restriction as well as associated need for assistance), environmental and personal factors, will be drawn together in an attempt to describe the experience of children with disabilities and their families, living in Australia today.



Source: WHO 2001.

Figure 2.1: Interactions between components of the International Classification of Disability and Health—example of Down syndrome and possible related disabilities

Operational definitions of disability

In practice, the multi-dimensional concept of disability is operationalised in various ways to meet different purposes. Definitions often focus on different components of the ICF framework (e.g. impairment, activity limitation, participation restriction) and on different domains within each component. For example, in determining eligibility for income support payments, assessment tools tend to focus predominantly on health conditions and activity limitations. Eligibility requirements for disability support services often relate to the activity limitations and participation restrictions in the context of environmental factors currently available to an individual (e.g. assistance provided by family members). Both types of tools will usually include some attempt to measure the severity and duration of the impairment, activity limitation or participation restriction.

Population surveys tend to describe disability in terms of a broad range of ICF components, including health condition, impairment, activity limitations and participation restrictions

and environmental factors. Population surveys may vary in terms of question wording and the way data are collected (e.g. telephone interview, self-completed questionnaire). They may also vary in terms of their screening devices—the set of questions, based on the operational definition of disability, that identify people who may have a disability and 'screen' them into the detailed 'disability' section of a survey. Such screening questions, as with the operationalisation of 'disability' more generally, can substantially affect estimates of disability prevalence (AIHW 2003b). Care is therefore often needed when interpreting data about disability.

As noted in the introduction to this report, children with disability are not a uniquely identifiable group. This is largely because different operational definitions of disability mean that some children are considered to have a disability in one context or data collection and not in another. The ICF provides a framework which enables us to understand and 'locate' the different groups of children included in the various service programs and data collections. To illustrate:

- The ABS population survey covers the ICF model fairly well, including questions regarding health conditions, impairments and activity limitations, together with information on carers and more limited information on participation restrictions and environmental factors. All of these ICF components feed into AIHW estimates of prevalence of disability (see Chapter 3).
- Disability support services provide personal assistance to people with disabilities, including respite to them and their carers; the information in related data collections focuses on activity limitations, in particular assistance needed.
- Income support services, in relation to children with disabilities, are effectively providing income replacement to parents who must take additional time to look after their children. Again, the focus is on the support of the child's needs in their daily lives (i.e. activity limitation and participation restriction).
- Health-focused analyses tend to focus on health conditions often associated with disability, such as cerebral palsy and Down syndrome. Frequently the concern is with prevention and the analytical focus is therefore on 'causal pathways' rather than on related disability in the form of impairments, activity limitations and participation restrictions.

Disability groups

In Australia, disability groups, such as 'intellectual disability' and 'physical disability', provide a broad categorisation of disabilities based not only on underlying health conditions and impairments, but also on activity limitations and participation restrictions. These groupings are generally recognised in the disability field and in legislative and administrative contexts in Australia (AIHW 2003b). Disability groups are not an attempt to classify people but rather to categorise the experience of people across various domains of functioning and disability (AIHW 2003b).

Box 2.1: Disability groups

Intellectual/learning disability *is associated with impairment of intellectual functions with limitations in a range of daily activities and with restriction in participation in various life areas. Supports may be needed throughout life, the level of support tending to be consistent over a period of time but may change in association with changes in life circumstances.*

Psychiatric disability *is associated with clinically recognisable symptoms and behaviour patterns frequently associated with distress that may impair personal functioning in normal social activity. Impairments of global or specific mental functions may be experienced, with associated activity limitations and participation restrictions in various areas. Supports needed may vary in range, and may be required with intermittent intensity during the course of the condition. Changes in level of support tend to be related to changes in the extent of impairment, or in the environment.*

Sensory/speech disability *is associated with impairment of the eye, ear and related structures and of speech, structures and functions. Extent of impairment and activity limitation may remain consistent for long periods. Activity limitations may occur in various areas, for instance communication and mobility. Availability of a specific range of environmental factors will affect the level of disability experienced by people in this grouping. Once in place, the level of support tends to be relatively consistent.*

Physical/diverse disability *is associated with the presence of an impairment, which may have diverse effects within and among individuals, including effects on physical activities such as mobility. The range and extent of activity limitation and participation restriction will vary with the extent of impairment as well as with environmental factors. Environmental adjustments and support needs are related to areas of activity limitation and participation restriction, and may be required for long periods. Levels of support may vary with both life changes and extent of impairment.*

Acquired brain injury *is the term used to describe multiple disabilities arising from damage to the brain acquired after birth. It can occur as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological disease, etc. Effects include deterioration in cognitive, physical, emotional or independent functioning. For national and international data comparison purposes, acquired brain injury is often included as a subcategory in the broad category of physical/diverse disability.*

Source: AIHW 2003b.

Wherever possible, this report provides information in terms of the disability groups described in Box 2.1.[2] Further information is also provided throughout the report about particular health conditions that are usually or always associated with long-term disability (e.g. Down syndrome, generally associated with intellectual disability, and cystic fibrosis, generally associated with physical disability).

It is important to note that many children experience health conditions that are related to more than one disability group. Furthermore, there is often an overlap between disability groups, such as a reported association between intellectual and psychiatric disability (for children, see Borthwick-Duffy 1994; Tonge et al. 1996). Throughout this report, unless otherwise stated, the experience of these children is recorded under all of the disability groups they experience.

It should also be noted that the prevalence estimates presented in this report for each of the disability groups described above will not necessarily relate to estimates derived for other purposes and using other methodologies. For example, the prevalence of intellectual/learning disability, as estimated using population data, is based on a range of survey questions which relate to whether the person has difficulty in learning or

[2] These groups are further described in the *National Community Services Data Dictionary Version 3* (AIHW 2004a) and the report *Disability Prevalence and Trends* (AIHW 2003b).

understanding, whether this difficulty is associated with restrictions in everyday activities, which health conditions are associated with the difficulty etc. These questions thus relate to a range of ICF components (health conditions, impairments, activity limitations) and will not relate directly to estimates of intellectual disability based solely on, for example, an impairment measure such as the intelligence quotient (IQ) rating of less than 70–75.

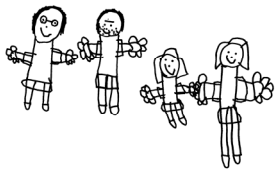
2.3 Information sources

As stated in the previous chapter, this report was undertaken to provide a comprehensive picture of children with disabilities in Australia. To ensure completeness and balance, information was sourced from a range of resources and assembled, for the first time, to describe Australian children with disabilities, their experiences, and the experiences of their families.

To do so, a list of key Australian data collections was first collated and, where possible, these collections were investigated as primary sources of information. These collections are outlined and described in Chapter 6, which also discusses gaps in the data relating to children with disabilities. Many of the data collections relevant to this topic have been analysed previously and reported on by the AIHW and its collaborating centres; however, the report also includes original analyses where no published data were available or further enquiry was considered warranted.

A literature review was then undertaken, as well as searches of relevant government, non-government and research organisations' web sites. These references were used to provide detail in areas such as family characteristics and effects where Australian data were lacking, as well as context for the report as a whole.

3 The prevalence of disability in children



3.1 Introduction

This chapter firstly presents broad prevalence estimates of childhood disability based on Australian population data (Section 3.2), before presenting more detailed estimates of the prevalence of the five disability groups described in Chapter 2 (intellectual/learning disability, psychiatric disability, sensory/speech disability, physical/diverse disability and acquired brain injury) (Section 3.3). Section 3.4 outlines what is known about some of the significant diseases and health conditions associated with childhood disability. Section 3.5 then discusses available information on the prevalence of childhood disability among different population sub-groups, specifically Aboriginal and Torres Strait Islander children, children from different cultural and linguistic backgrounds, and children living in different geographic locations. Section 3.6 presents a brief discussion of trends over time in the prevalence of childhood disability in Australia.

3.2 Prevalence of childhood disability in Australia

The main data source for estimating the prevalence of disability in Australia is the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), conducted in 1981, 1988, 1993 and 1998.[3] The AIHW has undertaken extensive analysis of this survey in the past and this report draws on and expands those previous analyses. Further details of the ABS survey and AIHW analysis of the survey are included in Chapter 6 on data sources.

The 1998 Survey of Disability, Ageing and Carers defines 'disability' as the presence of one or more of 17 limitations, restrictions or impairments which restrict everyday activities (Box 3.1). When a survey respondent states that they experience one or more of the 17 listed items, they are 'screened' into the full survey. They are then asked to provide details about health conditions they may have, how much personal assistance they require with specified tasks, whether this assistance is provided formally or informally, and whether they use aids or equipment for specified tasks. The key terms used in describing the ABS survey results are detailed in Table 3.1.

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[3] The ABS conducted a Survey of Disability, Ageing and Carers in 2003. While summary data from this survey were available at the time of finalising this report, the detailed Confidentialised Unit Record File (CURF), required to repeat the analysis presented elsewhere in this report for 2003, was not. ABS analysis of the 2003 SDAC suggests that there has been no significant change in the rate of disability among children aged 0–14 years between 1998 and 2003, or in the rate of severe or profound core activity restriction among children of this age (ABS 2004).

Box 3.1: Areas of limitation, restriction or impairment identified by the ABS

Affirmative responses to any of the following categories, where the limitation, restriction or impairment has lasted or was likely to last for six months or more 'screen' the person into the ABS survey:

- *loss of sight, not corrected by glasses or contact lenses;*
- *loss of hearing, with difficulty communicating or use of aids;*
- *loss of speech;*
- *chronic or recurring pain that restricts everyday activities;*
- *shortness of breath or breathing difficulties that restrict everyday activities;*
- *blackouts, fits, or loss of consciousness;*
- *difficulty learning or understanding;*
- *incomplete use of arms or fingers;*
- *difficulty gripping or holding things;*
- *incomplete use of feet or legs;*
- *a nervous or emotional condition that restricts everyday activities;*
- *restriction in physical activities or physical work;*
- *disfigurement or deformity;*
- *head injury, stroke or any other brain damage with long-term effects that restrict everyday activities;*
- *needing help or supervision because of a mental illness or condition;*
- *treatment or medication for any other long-term condition or ailment and still restricted;*
- *any other long-term condition that restricts everyday activities.*

This list thus creates the implicit definition of disability for the ABS 1998 Survey of Disability, Ageing and Carers (ABS 1999).

In terms of the ICF framework outlined in Chapter 2, the ABS survey thus 'screens' people into the disability section of the survey by a number of questions that predominantly relate to the ICF concepts of impairment and health condition. Once into the disability section of the survey, respondents are asked to report on all relevant activity limitations and participation restrictions,[4] as well as a number of environmental factors that they presently have access to or would like access to. In 1998, 594,000 children aged 0–14 years were reported as having a health condition, of whom 296,400 reported impairments of body functions and/or structures, 245,200 reported activity limitations and 188,700 reported participation restrictions (AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file).

It is important to recognise that the estimates derived from population survey data will not necessarily align with other estimates (e.g. those from epidemiological studies). This is for a number of reasons, including different methodologies and different purposes, as discussed in Chapter 2. Two examples are estimates of intellectual and psychiatric disability.

Estimates of intellectual disability derived from the SDAC include people with a learning disability. The structure of the screening and health condition questions prevents separating these two groups into those with an intellectual disability and those with a learning disability. Furthermore, health conditions such as autism and ADHD, which are often

[4] The ABS survey term 'activity restriction' relates to both the ICF concepts of activity limitation and participation restriction. When discussing ABS data in this report, ABS terminology is used.

Table 3.1: Key terms from the ABS Survey of Disability, Ageing and Carers, 1998

Terms	Working definition
Disabling condition	A disabling condition is 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.) that leads to an impairment or restriction that has lasted or is likely to last at least six months.
Main disabling condition	If only one disabling condition is reported in the survey, this is recorded as the main disabling condition. If multiple conditions are reported, then the main disabling condition is the one identified as causing the most problems.
All disabling conditions	All disabling conditions reported by or for a person.
Activity	An activity comprises one or more tasks in daily life. In the 1998 disability survey tasks have been grouped into ten activities: self-care, mobility, communication, health care, housework, meal preparation, paperwork, property maintenance, transport and guidance.
Core activities	Core activities are self-care, mobility and communication.
Profound core activity restriction	A profound core activity restriction refers to a person who is unable to do, or always needs help with, a core activity task.
Severe core activity restriction	A severe core activity restriction refers to a person who sometimes needs help with a core activity task; 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 core activity restriction	The person needs no help but has difficulty with a core activity task.
Mild core activity restriction	• The person needs no help and has no difficulty with any of the core activity tasks, but uses aids and equipment; or • cannot easily walk 200 metres; or • cannot walk up and down stairs without a handrail; or • cannot easily bend to pick up an object from the floor; or • cannot use public transport; or • can use public transport but needs help or supervision; or • needs no help or supervision but has difficulty using public transport.
Activity limitations	Activity limitations refers to a person being unable to do, or has a need for assistance, or has difficulty with, at least one of the ten activities; or uses aids and equipment; or has changes made to the home environment because of his/her health condition(s).
Participation restrictions	Participation restriction refers to a person being restricted in schooling, employment or social and community participation because of his/her disability.
Schooling restriction	A schooling restriction is determined for persons aged 5–20 years who have one or more disabilities if, because of their disability, they: are unable to attend school; attend a special school; attend special classes at an ordinary school; need at least one day a week off school on average; have difficulty at school.

Note: A full list of survey questions on activity limitations and participation restrictions is presented in Appendix 2 of AIHW 2003b.

Source: ABS 1999; AIHW 2003b.

included in psychological studies, are considered an intellectual disability here. Prevalence estimates of intellectual disability often vary and this variation depends on a range of factors including operational definitions of intellectual disability, measurement, survey methodology and methods of data collection. For a concise review of these issues, see AIHW: Wen 1997 and AIHW 2003b.

Conversely, estimates of psychiatric disability from the SDAC tend to be lower compared with estimates from surveys focusing specifically on mental health, such as the 1998 Survey of Mental Health and Wellbeing (Child and Adolescent Component). In this report, using

AIHW analysis of the SDAC, we present estimates of the prevalence of 'psychiatric disability' as 1.3% among boys aged 0–14 years and 0.6% for girls of this age (based on all disabling conditions). The Survey of Mental Health and Wellbeing (Child and Adolescent Component) estimates the prevalence of 'mental health problems', finding that, for example, 4.1% of boys aged 4–12 years and 2.9% of girls aged 4–12 years are anxious or depressed (Sawyer et al. 2000). These differences are understandable given that the SDAC was not specifically designed to monitor psychological wellbeing among children and young people, and also because it focuses on a broad range of health conditions associated with disabilities but not those health conditions where no disability is involved.

The methodology used here has been designed for consistency with the national and international disability groups specified in the National Community Services Data Dictionary V3 (AIHW 2004a) and to enable comparison with estimates for the population overall (as in AIHW 2003b).

Level of restriction

In 1998, there were an estimated 3,905,600 children aged 0–14 years living in Australia, of whom 296,400 (or 7.6% of children aged 0–14 years) had a disability (Table 3.2, Figure 3.1). The rate of disability among children is lower than for the population overall, where 19.3% (or 3,610,300 from 18,660,600 people) have a disability (ABS 1999). While children aged 0–14 years make up 20.9% of the Australian population, they account for only 8.2% of the population with a disability.

Of the 296,400 children with a disability, 252,800 experienced specific restrictions. Of these, 206,300 experienced core activity restrictions (i.e. in the areas of self-care, mobility or communication) and 175,200 experienced schooling restrictions (Figure 3.1, Table 3.2).

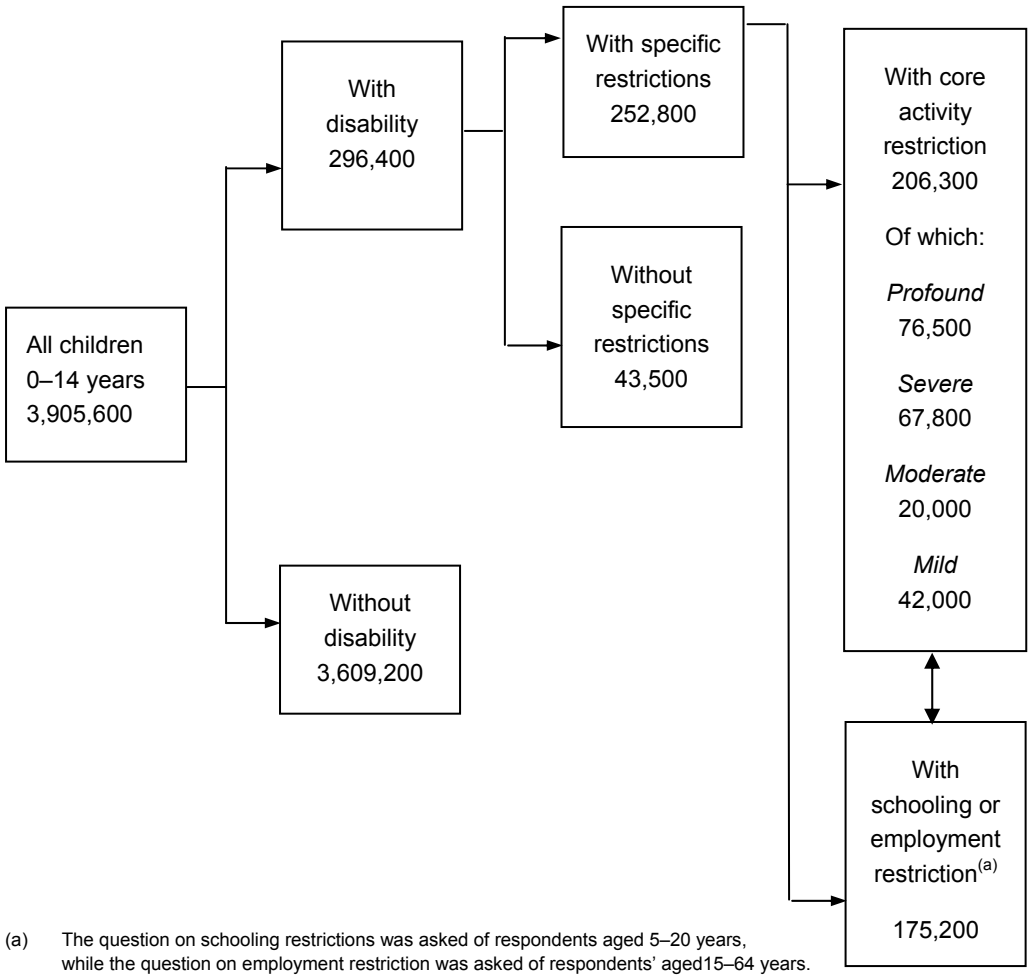
The level of core activity restriction experienced by a child provides a broad understanding of the level of support they are reported as needing in areas known as activities of daily living (i.e. self-care, mobility or communication). The estimated number of people with a severe or profound core activity restriction is generally accepted as a broad indicator of potential need for disability support services in Australia. That is, this is the broad target group for specialist disability support services, although not all of these people will necessarily need services (and some with moderate restrictions will). Throughout this report, the term 'severe disability' is used interchangeably with 'severe or profound core activity restriction'.

In 1998, there were an estimated 144,300 children aged 0–14 years (or 3.7% of children aged 0–14 years) with a severe or profound core activity restriction (severe disability). In more detail, in 1998 there were:

- 76,500 children aged 0–14 years (2.0% of children of this age) with a profound level of core activity restriction, meaning that they were unable to do, or always needed help with, one or more core activity;
- 67,800 children in this age group (1.7% of children of this age) with a severe level of core activity restriction, meaning that they sometimes needed help with a core activity task, or had difficulty understanding or being understood by family or friends, or could communicate more easily using sign language or other non-spoken forms of communication;

- 20,000 children in this age group (0.5% of children of this age) with a moderate level of core activity restriction meaning they did not need assistance but had difficulty performing a core activity; and
- 42,000 children in this age group (1.1% of children of this age) with a mild level of core activity restriction, broadly meaning they had no difficulty performing a core activity but used aids or equipment because of disability (Table 3.2).

In addition, there were 175,200 children aged 0–14 years with a schooling or employment restriction. Of these, 128,700 also had a mild, moderate, severe or profound core activity restriction, while 46,500 had a schooling restriction only.



(a) The question on schooling restrictions was asked of respondents aged 5–20 years, while the question on employment restriction was asked of respondents' aged15–64 years. This figure includes 46,500 children aged 0–14 years with a schooling restriction only.

Note: Numbers are rounded to the nearest hundred.

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

Figure 3.1: Children aged 0–14 years by disability status, Australia, 1998

Table 3.2: Disability status by sex and age, Australia, 1998

	Profound core activity restriction	Severe core activity restriction	Moderate core activity restriction	Mild core activity restriction	Schooling or employment restriction only	All with specific restriction	All without specific restriction	All with disability	Total
					('000)				
Boys									
0–4	*8.5	11.8	**1.6	. .	. .	22.0	8.3	30.3	655.9
5–9	24.7	19.4	*5.1	14.7	8.9	72.9	*5.2	78.1	677.8
10–14	15.3	17.7	*6.5	15.3	17.8	72.6	11.8	84.4	666.9
Total 0–14	*48.5*	*48.9*	*13.2*	*30.1*	*26.7*	*167.5*	*25.3*	*192.8*	*2,000.6*
Girls									
0–4	*5.8	**1.4	**2.0	. .	. .	9.2	*7.8	17.1	623.5
5–9	16.0	*8.9	*3.1	*6.3	*8.8	43.0	*4.9	47.9	642.0
10–14	*6.2	*8.6	**1.7	*5.6	11.0	33.0	*5.5	38.6	639.5
Total 0–14	*28.0*	*18.9*	*6.8*	*11.9*	*19.7*	*85.3*	*18.3*	*103.6*	*1,905.0*
Children									
0–4	14.4	13.2	*3.6	. .	. .	31.2	16.1	47.3	1,279.4
5–9	40.7	28.3	*8.2	21.1	17.7	115.9	10.1	126.0	1,319.8
10–14	21.5	26.3	*8.2	21.0	28.8	105.7	17.4	123.0	1,306.5
Total 0–14	*76.5*	*67.8*	*20.0*	*42.0*	*46.5*	*252.8*	*43.5*	*296.4*	*3,905.6*
					%				
Boys									
0–4	*1.3	1.8	**0.2	. .	. .	3.4	1.3	4.6	100.0
5–9	3.6	2.9	*0.8	2.2	1.3	10.8	*0.8	11.5	100.0
10–14	2.3	2.7	*1.0	2.3	2.7	10.9	1.8	12.7	100.0
Total 0–14	*2.4*	*2.4*	*0.7*	*1.5*	*1.3*	*8.4*	*1.3*	*9.6*	*100.0*
Girls									
0–4	*0.9	**0.2	**0.3	. .	. .	1.5	*1.3	2.7	100.0
5–9	2.5	*1.4	*0.5	*1.0	*1.4	6.7	*0.8	7.5	100.0
10–14	*1.0	*1.3	**0.3	*0.9	1.7	5.2	*0.9	6.0	100.0
Total 0–14	*1.5*	*1.0*	*0.4*	*0.6*	*1.0*	*4.5*	*1.0*	*5.4*	*100.0*
Children									
0–4	1.1	1.0	*0.3	. .	. .	2.4	1.3	3.7	100.0
5–9	3.1	2.1	*0.6	1.6	1.3	8.8	0.8	9.5	100.0
10–14	1.6	2.0	*0.6	1.6	2.2	8.1	1.3	9.4	100.0
Total 0–14	*2.0*	*1.7*	*0.5*	*1.1*	*1.2*	*6.5*	*1.1*	*7.6*	*100.0*

. . Not applicable

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

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

Sex patterns

There are sex differentials in the prevalence of disability among children. In 1998, there were almost twice as many boys aged 0–14 years with a disability as girls (192,800 boys compared to 103,600 girls). Even though there are slightly more boys than girls aged 0–14 years in the Australian population, the prevalence rate of disability for boys was also almost twice the rate for girls (9.6% compared to 5.4%).

The sex difference persists when we consider the pattern for children with severe disability (97,400 boys compared to 47,000 girls) (Table 3.2). Put another way, about one in ten boys (9.6%) aged 0–14 years were estimated to have a disability and nearly one in twenty (4.9%) a severe disability, with rates roughly half this level for girls (5.4% and 2.5% respectively).

Age patterns

The prevalence of core activity restriction (in terms of numbers and rates) in 1998 tended to be lowest in the 0–4 years age group and highest among 5–9 year olds. This pattern is particularly pronounced among the group of children with profound core activity restrictions. This may relate to the increased identification of activity restrictions upon school entry, the availability of assistance, and may suggest that some issues resolve or become less prominent in the minds of parents, children and/or teachers as children age. It may also relate to the complexity of asking and answering questions about activity limitations among children aged 0–4 years, who, regardless of disability, are likely to need assistance in many activity areas due to their age (see Box 6.1 for more detail about question wording in the SDAC).

The pattern or distribution of core activity restriction among children with disability is quite different than for the population overall with a disability. As previously noted, 3.7% of children aged 0–14 years have a severe or profound core activity restriction compared to 6.1% of the population overall (and 1.6% of children aged 0–14 have moderate or mild core activity restrictions compared to 9.0% of the population overall). Among children aged 0–14 years with a disability, there are relatively more children aged 0–14 years with severe or profound core activity restriction (144,300 or 49% of children with a disability) than moderate or mild core activity restriction (62,000 or 21% of all children with a disability). However, this is not the case when we consider Australians of all ages, where relatively fewer people have a severe or profound core activity restriction (1,135,900 or 31% of all people with a disability) than moderate or mild core activity restriction (1,692,100 or 47% of all people with a disability) (ABS 1999; Appendix Table A2.1).

There are a number of possible explanations for the different pattern in level of restriction among children compared to the population overall. First, as outlined above, it is possible severe or profound core activity restrictions are more likely to be reported among children because of the difficulty in estimating need for assistance among children aged 0–4 years and the way that support needs are identified among children aged 5–9 years upon school entry.

Second, the relatively large proportion of children with disability who experience severe or profound core activity restriction might relate to their increased likelihood of reporting communication restrictions. Communication, self-care and mobility are the three core activities in the ABS Survey of Disability, Ageing and Carers. If a child always or sometimes needs assistance with any one of these three areas then they are considered to have a severe or profound core activity restriction. About one-fifth (17.8%) of all people with a disability living in households and nearly one-third (30.1%) of people with a severe or profound core

activity restriction living in households experienced a communication restriction (AIHW 2003c). These proportions are much higher for children, where 39.1% of children with a disability have a communication restriction and 69.4% of children with a severe or profound core activity restriction have a communication restriction (Table A2.2). This could mean that children with disability are much more likely than the population overall with a disability to experience a communication restriction but it could also point to a possible issue with the survey methodology, whereby the question wording makes it more likely that communication restrictions will be reported for children. For example, it should be noted that the majority of children identified as having a communication restriction (65,500 or 45.4% of all children of this age with a severe or profound core activity restriction) had a severe communication restriction, which means they had responded positively to the survey questions about having difficulty understanding or being understood by family or friends, or about whether the child can communicate more easily using sign language or non-spoken communication (see Chapter 6 for more details about the ABS survey methodology).

3.3 Prevalence of disability groups

The AIHW developed prevalence estimates for each of the five major recognised disability groups: intellectual/learning, psychiatric, sensory/speech, physical/diverse and acquired brain injury (AIHW 2003b). A description of each of the sets of prevalence estimates is included in Box 3.2 (these groups are defined in Box 2.1). These estimates were based on the 1998 ABS SDAC. For a more detailed discussion of how the estimates were generated for each disability group see the report *Disability Prevalence and Trends in Australia* (AIHW 2003b).

Table 3.3 presents prevalence estimates for each disability group for boys and girls. The top panel of the table 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. The bottom panel of Table 3.3 presents estimates based on the *main disabling condition* reported for each child aged 0–14 years, or the condition causing the child the most problem. When using estimates based on *main disabling condition*, people who reported a physical disabling condition as their main disabling condition are only included in the physical/diverse disability group, even if they also report, for example, intellectual or sensory disabling conditions. The *main disabling condition* approach means that the numbers in each disability group are mutually exclusive and the sum of each disability group adds to the total number of children with a disability.

Unless otherwise stated, prevalence estimates in this chapter are based on the *all disabling conditions* estimation methodology.

Level of restriction

All disabling conditions

In 1998, 144,100 children aged 0–14 years (or 3.7% of the population of this age) 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 3.3).

This pattern varies somewhat when we consider only children aged 0–14 years with a severe disability. Among this group of children the most common disability group is intellectual/learning (83,000 children or 2.1% of the population of this age), followed by sensory/speech disability (77,600 or 2.0%), then physical/diverse disability (69,200 or 1.8%), psychiatric disability (37,000 or 0.9%) and acquired brain injury (11,400 or 0.3%) (Table 3.3).

Box 3.2: Prevalence estimates for disability groups

The AIHW has developed four sets of prevalence estimates for each of the five disability groups.

These are estimates based on:

1. *main disabling condition;*
2. *all disabling conditions;*
3. *all disabling conditions plus activity limitations and participation restrictions; and*
4. *main/all disabling conditions plus a severe or profound core activity restriction.*

The key terms relating to each of these approaches are listed in Table 3.1.

Estimates based on reported main disabling condition *relate to conditions that were identified by survey respondents as causing the most problems. For example, where people are identified as having a physical disability, this means the physical disabling conditions caused them more problems than any other disabling conditions they may also have had. In this approach, people are excluded from the estimate of physical disability unless they reported physical disabling conditions as their main disabling condition (for the full list of groupings of impairments and disabling conditions see Appendix 1 in AIHW 2003b). Such estimates are useful for some purposes because the estimates of different disability groups are mutually exclusive. This means that the numbers in each disability group sum to give the total number of people with a disability, as defined by the 1998 ABS disability survey (AIHW 2003b).*

The estimates based on all disabling conditions *are the most inclusive of the four types of estimates, including all reported disabling conditions, whether or not these were reported as main disabling conditions. This approach prevents the underestimation that results using the* main disabling conditions *and enables the disability experiences of people with multiple disabling conditions to be recorded. When this approach is used the numbers in each disability group do not sum to give the total number of people with a disability (AIHW 2003b).*

The approach using data on all disabling conditions and activity limitations and participation restrictions *draws in multi-dimensional information from the survey on impairment, disabling conditions, activity limitations, participation restrictions, and need for assistance with daily activities (AIHW 2003b). This approach initially includes people who reported one or more disabling conditions relating to each of the five disability groups (whether or not these were reported as main disabling conditions). The estimates are then narrowed down to only include people who reported limitations or restrictions in one or more activities of daily or social life (for a full list of survey questions on limitations and restrictions see Appendix 2 in AIHW 2003b).*

The approach using data on all disabling conditions and a severe or profound core activity restriction *is similar to the previous approach except that an additional and more exclusive 'filter' is used. Only people who reported a severe or profound core activity restriction, meaning that they sometimes or always needed personal assistance or supervision with activities of daily life (self-care, mobility and communication), are included in these estimates. This corresponds quite closely to the 'target population' of specialist disability services provided throughout Australia under the Commonwealth State/Territory Disability Agreement (see Chapter 5 for more on CSTDA services). The estimated number of people with a severe or profound core activity restriction is generally accepted as a broad indicator of potential need for disability support services in Australia (AIHW 2003b).*

Source: AIHW 2003b.

Table 3.3: Children aged 0–14 years with a disability: type of disabling condition by level of restriction and sex, as a percentage of the Australian population of that sex and age, 1998

	Boys		Girls		Children	
	('000)	%	('000)	%	('000)	%
All disabling conditions						
Intellectual/learning	104.6	5.2	38.5	2.0	143.0	3.7
Psychiatric	30.4	1.5	13.2	0.7	43.6	1.1
Sensory/speech	80.0	4.0	39.9	2.1	119.9	3.1
Physical/diverse	84.7	4.2	59.5	3.1	144.1	3.7
ABI	9.3	0.5	*3.4	0.2	12.7	0.3
Total	**192.8**	**9.6**	**103.6**	**5.4**	**296.4**	**7.6**
All disabling conditions and severe or profound core activity restriction						
Intellectual/learning	58.7	2.9	24.3	1.3	83.0	2.1
Psychiatric	25.8	1.3	11.2	0.6	37.0	0.9
Sensory/speech	54.1	2.7	23.5	1.2	77.6	2.0
Physical/diverse	42.9	2.1	26.2	1.4	69.2	1.8
ABI	*8.3	0.4	*3.1	0.2	11.4	0.3
Total	**97.4**	**4.9**	**46.9**	**2.5**	**144.3**	**3.7**
Main disabling condition						
Intellectual/learning	87.1	4.4	25.7	1.3	112.9	2.9
Psychiatric	5.1	0.3	3.1	0.2	8.2	0.2
Sensory/speech	32.9	1.6	19.4	1.0	52.3	1.3
Physical/diverse	66.6	3.3	54.3	2.9	120.9	3.1
ABI	1.0	0.0	1.0	0.1	2.1	0.1
Total	**192.8**	**9.6**	**103.6**	**5.4**	**296.4**	**7.6**
Main disabling condition and severe or profound core activity restriction						
Intellectual/learning	45.9	2.3	14.6	0.8	60.4	1.5
Psychiatric	3.4	0.2	2.1	0.1	5.4	0.1
Sensory/speech	15.3	0.8	7.2	0.4	22.6	0.6
Physical/diverse	32.3	1.6	22.3	1.2	54.6	1.4
ABI	0.5	0.0	0.8	0.0	1.3	0.0
Total	**97.4**	**4.9**	**46.9**	**2.5**	**144.3**	**3.7**

Notes

1. Row totals may not be the sum of components when all disabling conditions are considered.
2. Estimates marked with a * have an associated relative standard error (RSE) of between 25% and 50% or more. These estimates should be interpreted accordingly.

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

Main disabling condition

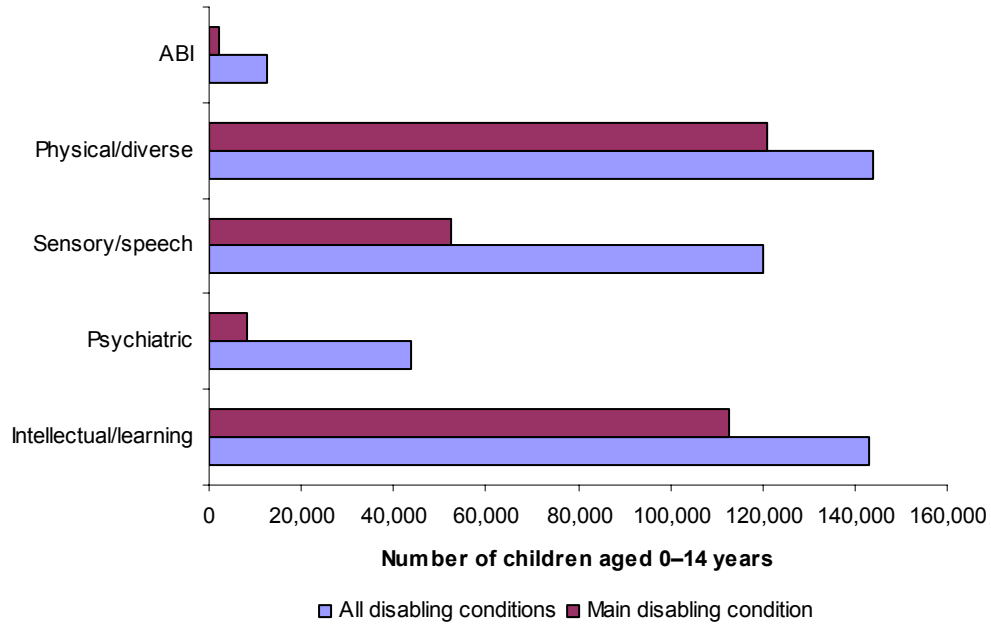
Many children experience a range of health conditions, impairments, activity and participation restrictions, and thus appear in more than one disability group. On average, children aged 0–14 years with a disability experience 1.6 disabling conditions each (AIHW unpublished analysis of 1998 ABS SDAC).

When we consider main disabling condition only, an estimated 120,900 children aged 0–14 years (3.1% of the population of this age) have a physical/diverse disability, 112,900 children (2.9%) have an intellectual/learning disability, 52,300 (1.2%) a sensory/speech disability, 8,200 (0.2%) a psychiatric disability, and 2,100 (0.1%) an acquired brain injury (Table 3.3). When we consider only those children with a severe or profound main disabling condition, the largest number of children have an intellectual/learning disability (60,400 children or 1.5% of the population of this age), followed by 54,600 children (1.4%) with a physical/diverse disability, 22,600 (0.6%) with a sensory/speech disability, 5,400 (0.1%) a psychiatric disability and 1,300 (less than 0.1%) with an acquired brain injury (Table 3.3).

Figure 3.2 shows the number of children estimated to have disabling conditions associated with each of the five disability groups. The darker bars show the number of children according to their main disabling condition only, where physical/diverse is the most common disability group, followed by intellectual/learning, sensory/speech, psychiatric and then ABI. The lighter bars show the number of children who have disabling conditions associated with each of the disability groups, either as their main disabling condition or another disabling condition. The pattern across disability groups remains the same, with the largest numbers of children experiencing main or other disabling conditions associated with physical/diverse and intellectual/learning disability.

The figure provides an illustration of a number of important points. It shows that many children with disabilities have multiple disabling conditions. To the extent that many of these disabling conditions require formal and/or informal support, this figure also illustrates the importance of considering not only main disabling condition but other disabling conditions when estimating the numbers in the population who may require assistance.

The figure also reveals that it is particularly important to consider all disabling conditions in the case of some disability groups. In the case of intellectual/learning disability and physical/diverse disability, the prevalence estimates based on all disabling conditions are around 20–25% higher than those based on main disabling condition. For example, while 112,900 children are estimated to have a main disabling condition associated with intellectual/learning disability, a further 30,100 (143,000 minus 112,900, or a further 26%) have another condition, which they do not consider to be their main disabling condition, that is associated with intellectual/learning disability. In the case of sensory/speech disability, psychiatric disability and ABI, however, the increase in numbers varies much more markedly when we consider all disabling conditions. For example, while 8,200 children have a main disabling condition associated with psychiatric disability, a further 35,400 report health conditions, which they do not consider to be their main disabling condition, that are associated with psychiatric disability.



Source: Table 3.2.

Figure 3.2: Main disabling conditions and all disabling conditions, children aged 0–14 years, 1998

The above patterns are also likely to be a reflection of the finding that children with intellectual/learning disability are more likely to also have associated health conditions, for example, relating to the psychiatric or sensory/speech disability groups (see, for example, US Public Health Service 2002).

Sex patterns

Sex differences in disability are particularly pronounced in relation to intellectual/learning disability, where the rate among boys aged 0–14 years is 2.6 times that for girls (5.2% compared to 2.0%). The prevalence rate of physical/diverse disability amongst similarly aged boys, however, is not quite as marked, around 1.4 times that for girls (4.2% compared to 3.1%) (Table 3.3).

There is a slight reduction in the differences between the sexes across disability groups when we consider only those children with a severe disability. For example, the rate of severe intellectual/learning disability among boys is 2.2 times that for girls.

Boys aged 0–14 years with a disability were much more likely than girls to have an intellectual/learning disability (45% compared to 26%) and much less likely to have a physical/diverse disability (35% compared to 54%) as their main disabling condition (Table 3.3). This pattern applies whether we consider children with disability or children with a disability and a severe disability (Table 3.3). This could relate to health conditions, such as ADHD, that are more commonly observed in boys and often associated with lower levels of restriction (see discussion in Section 3.5 on trends in disability).

Age patterns

Overall, 3.7% of children in 1998 aged 0–14 years were estimated to have an intellectual/learning disability (Table 3.4). Breaking this age group into five year age groups reveals that this percentage is higher among children aged 5–9 years (4.4%) and 10–14 years (5.7%), than among the youngest age group (Table 3.4). Higher rates of disability among children aged 5–9 and 10–14 years, compared to those in the 0–4 year age group, were found for each of the disability groups.

A similar pattern is also found for children with a severe disability, with one exception. While the largest number of children with a severe or profound core activity restriction and a sensory/speech disability were still in the 5–9 year age group (39,400 children or 3.0% of the population of this age), slightly more children were identified in the 0–4 year age group (20,000 or 1.6% of the population of this age) than the 10–14 year age group (18,200 children or 1.4%).

The overall pattern described above may partly reflect the difficulties in case identification in infancy and early childhood and the probability that some health conditions and associated disability are more likely to be identified once children enter formal education (e.g. ADHD, autistic spectrum disorders). In the case of sensory/speech disability, particularly that associated with severe or profound core activity restriction, it is possible that infant and early childhood screening programs make early detection of serious hearing, vision and speech difficulties more likely.

Prevalence of disability groups among children differs somewhat from that in the population as a whole, where people were far more likely to have a disabling condition (either as a main or other disabling condition) associated with physical/diverse disability (16.2% of the total population compared to 3.7% of children), sensory/speech disability (7.5% compared to 3.1%), psychiatric disability (4.1% compared to 1.1%) and disability associated with acquired brain injury (1.1% compared to 0.3%) but less likely to have an intellectual/learning disability (2.7% compared to 3.6%) (AIHW 2003b; Table A2.3). This pattern also applies when considering only people with a severe or profound level of core activity restriction but with less exaggerated differences. For example, 2.1% of children aged 0–14 years had an intellectual/learning disability with a severe or profound core activity restriction compared to 1.6% of the population overall, and 1.8% of children aged 0–14 years had a physical/diverse disability with a severe or profound core activity restriction compared to 5.2% of the population overall (Table A2.3).

Table 3.4: Children with a disability: type of disabling condition by level of restriction, as a percentage of the Australian population of the same age (0–4, 5–9, 10–14 years), 1998

	All disabling conditions		All disabling conditions and activity limitations and participation restrictions		All disabling conditions and severe or profound core activity restrictions	
	'000	%	'000	%	'000	%
Intellectual/learning						
0–4	11.4	0.9	11.4	0.9	10.6	0.8
5–9	57.5	4.4	57.1	4.3	40.3	3.1
10–14	74.1	5.7	72.7	5.6	32.1	2.5
0–14	*143.0*	*3.7*	*141.2*	*3.6*	*83.0*	*2.1*
Psychiatric						
0–4	**3.7	0.3	**3.7	0.3	**2.9	0.2
5–9	19.4	1.5	19.4	1.5	17.3	1.3
10–14	20.5	1.6	20.5	1.6	16.8	1.3
0–14	*43.6*	*1.1*	*43.6*	*1.1*	*37.0*	*0.9*
Sensory/speech						
0–4	24.2	1.9	21.6	1.7	20.0	1.6
5–9	61.2	4.6	56.5	4.3	39.4	3.0
10–14	34.5	2.6	30.4	2.3	18.2	1.4
0–14	*119.9*	*3.1*	*108.5*	*2.8*	*77.6*	*2.0*
Physical/diverse						
0–4	28.6	2.2	23.4	1.8	13.1	1.0
5–9	59.6	4.5	57.5	4.4	34.1	2.6
10–14	56.0	4.3	51.8	4.0	22.0	1.7
0–14	*144.1*	*3.7*	*132.6*	*3.4*	*69.2*	*1.8*
ABI						
0–4	**2.0	0.2	**2.0	0.2	**2.0	0.2
5–9	*5.7	0.4	*5.7	0.4	*5.7	0.4
10–14	*5.0	0.4	*4.5	0.3	*3.7	0.3
0–14	*12.7*	*0.3*	*12.2*	*0.3*	*11.4*	*0.3*

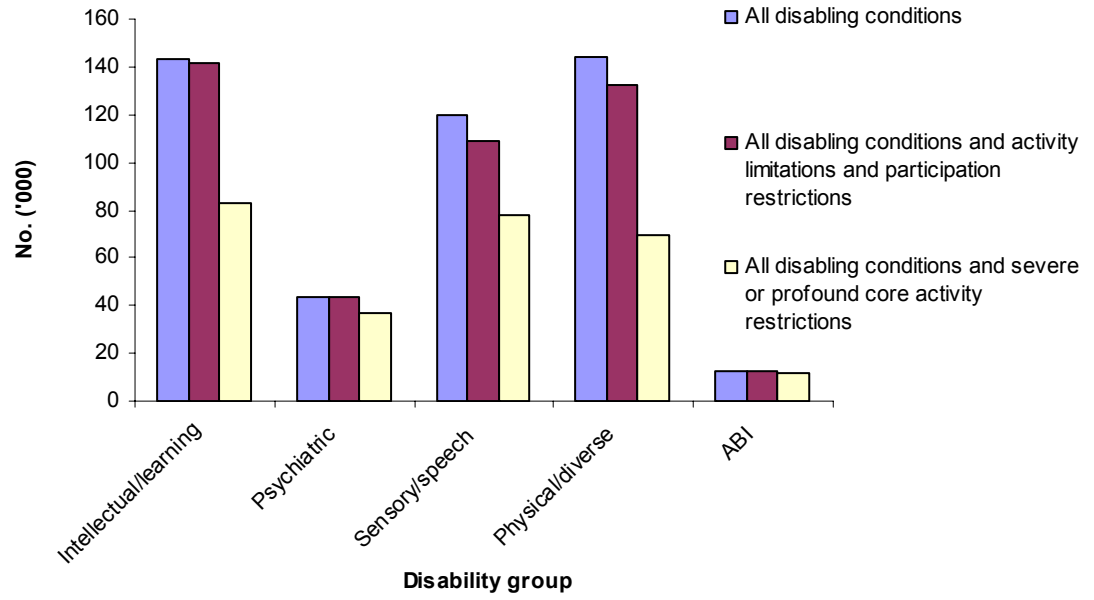
Notes

1. The 'all disabling conditions' approach used to generate these estimates means that the numbers in each disability group do not add to the total number of children with a disability.
2. Estimates marked with a * have an associated relative standard error (RSE) of between 25% and 50%. Estimates marked with a ** have an associated relative standard error (RSE) of 50% or more. These estimates should be interpreted accordingly.

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

Severe restriction

The likelihood of having a severe or profound core activity restriction (and associated high levels of need for assistance) varied across disability groups, with a much higher probability among children with an acquired brain injury or psychiatric disability compared to the other disability groups. Nearly all children (90%) who were identified as having an acquired brain injury (as a main or associated disabling condition) had severe or profound core activity restrictions (11,400 of 12,700 children) (Table 3.4). Similarly, most children with a psychiatric disability had severe or profound core activity restrictions (37,000 of 43,600 or 85%). In contrast, about half the children (69,200 of 144,100 or 48%) identified as having a physical/diverse disability, about three-fifths of children with intellectual/learning disability (58% or 83,000 of 143,000) and about two-thirds of children with sensory/speech disability (65% or 77,600 of 119,900) experienced severe or profound core activity restrictions (Table 3.4 and Figure 3.3).



Source: Table 3.4.

Figure 3.3: Children aged 0–14 years with a disability: type of disabling condition by level of restriction, 1998 ('000)

3.4 Some significant diseases and health conditions associated with disability

According to the ICF framework, disability exists in the context of a health condition. Childhood disability is associated with a wide range of health conditions and diseases (e.g. Down syndrome, ADHD, asthma, depression).

Population data

Using population data it is possible to examine some of the most common health conditions associated with each of the five disability groups: intellectual/learning, psychiatric, sensory/speech, physical/diverse and acquired brain injury. In interpreting the following data it should be noted that individuals may report any number of health conditions in the main data source.

Intellectual/learning disability was associated with a range of diseases or health conditions, some of which are separately identified in the 1998 ABS disability survey.[5] On the basis of all reported disabling conditions among children aged 0–14 years with an intellectual/learning disability in 1998 it is possible to estimate that:

- about 42,700 (1.1% of the population of this age and 29.9% of children this age with an intellectual/learning disability) reported ADHD;
- about 10,700 (0.3% of the population of this age and 7.5% of children this age with an intellectual/learning disability) reported autism and related disorders.

Boys were far more likely to experience these health conditions than girls. For example, ADHD was reported in relation to 36,400 boys compared to 6,400 girls and a developmental learning disorder was reported in relation to about 8,400 boys compared to about 4,000 girls.[6]

Of the 119,900 children aged 0–14 years with a sensory/speech disability:

- about 89,000 (2.3% of the population of this age, or 74.2% of children this age with a sensory/speech disability) reported health conditions such as speech impediment or speech difficulties, associated with speech disability;
- about 31,000 (0.8% of the population of this age, or 25.8% of children this age with a sensory/speech disability) reported health conditions such as congenital hearing loss or noise-induced hearing loss, associated with hearing disability; and
- about 13,800 (0.4% of the population of this age, or 11.5% of children this age with a sensory/speech disability) reported health conditions including cataracts and retinal disorders, associated with vision disability.

Boys aged 0–14 years were more likely than girls of the same age to experience all forms of sensory disability, particularly speech disability (62,300 boys compared to 26,700 girls). About 16,200 boys reported health conditions associated with hearing disability (compared to 14,000 girls) and about 5,300 boys reported health conditions associated with vision disability (compared to 3,500 girls[7]) (AIHW unpublished analysis of the 1998 ABS SDAC).

Physical/diverse disability is associated with a large number of diseases or health conditions. Some of the most common conditions reported in relation to children aged

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[5] Many specific diseases or conditions associated with intellectual/learning disability were not separately identified in the 1998 ABS Survey of Disability, Ageing and Carers, but rather included under headings such as 'intellectual and developmental disorders not further defined'.

[6] The estimated figures of 6,400 girls aged 0–14 years with ADHD, 8,400 boys aged 0–14 years with a developmental learning disorder and 4,000 girls aged 0–14 years with a developmental learning disorder have associated relative standard errors of between 25% and 50% and should be interpreted accordingly.

[7] The estimated figure of 3,500 girls aged 0–14 years with vision disability has an associated relative standard error of between 25% and 50% and should be interpreted accordingly.

0–14 years in 1998 are highlighted in Table 3.5. On the basis of all reported health conditions, approximately:

- 80,900 children aged 0–14 years reported asthma (2.1% of children this age and 56.2% of children this age with a physical/diverse disability);
- 33,300 children aged 0–14 years reported heart disease (0.9% of children this age and 23.1% of children this age with a physical/diverse disability);
- 14,200 children aged 0–14 years reported epilepsy (0.4% of children this age and 9.8% of children this age with a physical/diverse disability); and
- 9,600 children aged 0–14 years reported cerebral palsy (0.2% of children this age and 6.7% of children this age with a physical/diverse disability).

Table 3.5: Selected health conditions associated with physical disability, children aged 0–14 years, number and percentage of all children aged 0–14 years, 1998 ('000)

	Asthma		Heart disease[(a)]		Epilepsy		Cerebral palsy	
	'000	%	'000	%	'000	%	'000	%
Boys	50.8	2.5	19.9	1.0	*7.5	*0.4	*5.3	*0.3
Girls	30.1	1.6	13.4	0.7	*6.6	*0.3	*4.4	*0.2
Children	80.9	2.1	33.3	0.9	14.2	0.4	9.6	0.2

(a) Heart disease includes two ABS categories (heart disease not further defined and other heart disease) and excludes angina, myocardial infarction (heart attack), hypertension, stroke and other diseases of the circulatory system.

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

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

All of these health conditions were relatively more common in boys compared to girls, especially asthma (50,838 boys compared to 30,095 girls) and heart disease (19,898 boys compared to 13,400 girls).

Data are not presented for health conditions associated with psychiatric disability and acquired brain injury, as the relative standard error associated with the population estimates is greater than 50%.

Birth defects data

A proportion of health conditions among children with disabilities may be identified prenatally, at birth or in the first years of life. The more serious of these health conditions are likely to be reported as birth defects to state-based registers and subsequently included in national statistics about birth defects. Birth defects are anatomical defects, chromosomal abnormalities or other genetic diseases that are present at birth. Birth defects remain a significant public health problem in Australia as they often result in disabilities and are a major reason for hospitalisation in infancy and childhood and a leading cause of infant mortality (AIHW NPSU: Birch et al. 2004:vi). Data about a small selection of birth defects are presented in Table 3.6 for births and terminations of pregnancy occurring in 2001, with birth defects notified by 31 December 2002 (in Victoria, Western Australia and South Australia).

Two measures are presented, birth prevalence and total prevalence. Birth prevalence refers to the prevalence of birth defects among babies born in 2001. It includes live births and stillbirths. Total prevalence includes terminations of pregnancy with birth defects as well as

stillbirths and livebirths. This measure is useful for evaluating the effectiveness of primary prevention and prenatal screening strategies over time (Owen et al. 2000).

In 2001, the estimated birth prevalence of neural tube defects was 0.6 per 1,000 births. The estimated total prevalence was markedly higher at 1.4 per 1,000 births. Of the neural tube defects, spina bifida had the highest birth prevalence (0.4 per 1,000 births). Spina bifida and anencephalus had the highest total prevalence (0.6 per 1,000 births respectively).

The Victorian, Western Australian and South Australian birth defects registers have all reported a decline in the prevalence of neural tube defects of 35–45% since 1996. Prior to this, the rate was steady at about 1.6–2.0 per 1,000 births (Bower 2003). This decline has been associated with increased peri-conceptional folic acid intake, through the fortification of selected foods and through health promotion campaigns aimed at encouraging women to take folate supplements before and during early pregnancy (Owen et al. 2000; Chan et al. 2001; Bower et al. 2002).

Table 3.6: Estimated total prevalence of selected birth defects (including terminations of pregnancy), Victoria, Western Australia and South Australia, 2001[a]

		Birth prevalence (live births and stillbirths)[b]		Total prevalence (live births, stillbirths and terminations of pregnancy)[b]	
ICD-9-BPA code[c]	Birth defect	Number of birth defects	Rate per 1,000 births	Number of birth defects	Rate per 1,000 births
Neural tube defects					
740.00–742.09	Neural tube defects	58	0.6	142	1.4
740.00–740.29[d]	Anencephalus	9	0.1	61	0.6
741.00–741.99	Spina bifida	39	0.4	66	0.6
742.00–742.09	Encephalocoele	10	0.1	15	0.1
Down syndrome					
758.00–758.09	Down syndrome	119	1.1	266	2.5

(a) Data for Victoria, Western Australia and South Australia are included. Births and terminations of pregnancy occurring in 2001 with birth defects notified by 31 December 2002 are included.

(b) Numerator: Prevalence (births)—live births and stillbirths ≥20 weeks gestation or ≥400 g birthweight with the specified birth defect. Prevalence (births and terminations of pregnancy)—live births and stillbirths ≥20 weeks gestation or ≥400 g birthweight and terminations of pregnancy <20 weeks gestation or <400 g birthweight with the specified birth defect.

Denominator: live births and stillbirths ≥20 weeks gestation or ≥400 g birthweight.

(c) Classified using the British Paediatric Association Classification of Diseases.

(d) Includes 740.1 Craniorachischisis and 740.20–740.29 Iniencephaly.

Source: AIHW NPSU 2004.

In 2001, the estimated birth prevalence for Down syndrome was 1.1 per 1,000 births, with the estimated total prevalence markedly higher at 2.5 per 1,000 births.

There is a large amount of literature relating to risk factors or causal pathways to specific birth anomalies. These include, either on their own or in combination, genetic causes, maternal infections, illnesses, environmental substances such as mercury, teratogenic agents taken by the mother (drugs or chemicals), and nutritional deficiencies, such as a lack of folate. Advanced maternal age, multiple pregnancies, low birthweight, and some forms of assisted conception have also been linked to an increased likelihood of some types of birth anomalies. This literature is outside the scope of this report. However, it is worth noting that the causes of most birth anomalies are still unknown (AIHW NPSU: Hurst T et al. 1997).

3.5 Characteristics of children with disabilities

What is known about the prevalence of disability among different population groups in Australia? Does the overall prevalence of disability vary according to the ethnic background of children? Does the prevalence of certain disability groups or health conditions differ among children according to Indigenous status or geographic location? While there is a lack of information in this area, this section presents a brief summary from the literature of what is known about disability in Indigenous children, children of different cultural backgrounds and children in regional and rural settings compared to other children.

Indigenous profile

Very little is known about the rate at which Aboriginal and Torres Strait Islander children experience disabilities. In present sample surveys such as the 1998 ABS Survey of Disability, Ageing and Carers, Indigenous people are not identified. The inclusion of an item on disability status in the National Aboriginal and Torres Strait Islander Social Survey will enable a profile of the prevalence of disability amongst Indigenous people; however, the survey is restricted to people aged 15 years and over so no population estimates will be available about the health conditions and disability of children. Plans for a Longitudinal Study of Indigenous Children (LSIC) will assist in future determinations of childhood disability prevalence amongst Indigenous children.

Bower et al. (1989) compared the prevalence of congenital malformations in Aboriginal and non-Aboriginal infants born in Western Australia from 1980 to 1987. They found that total malformation rates were similar in the two groups but that there were significant differences in some particular congenital malformations. Aboriginal infants were more likely than non-Aboriginal infants to have microcephaly, several types of congenital heart defect, cleft lip with or without cleft palate and talipes. A number of malformations were less common in Aboriginal infants, namely pyloric stenosis, hypospadias and undescended testes.

More recent data on Aboriginal childhood disability are available from the Western Australian Aboriginal Child Health Survey, conducted in 2001 and 2002 by the Telethon Institute for Child Health Research. This survey focused on developmental and environmental factors to describe the prevalence of commonly occurring medical conditions and disabilities, adverse health behaviours (e.g. smoking, substance abuse) and other psychosocial problems (e.g. school leaving, juvenile offending), the impact of common health and mental health problems, and access and use of health care, education, housing, juvenile justice and social services of Aboriginal children living in different regions of Western Australia. A total of 5,289 children aged 0–17 years were surveyed with data collected, depending on information sought, from primary and secondary carers.

The prevalence of disability amongst Aboriginal children aged 4–17 years was determined using questions on activity limitation and sensory/speech impairment (Zubrick et al. 2004). An estimated 1.7% of Aboriginal children living in Western Australia were reported to need some sort of physical help when eating, dressing, bathing and/or going to the toilet. While difficulties with mobility could not be determined due to the small number of positive responses, limitation in vigorous activity such as sports was experienced by 4.1% of Aboriginal children. Sensory and speech impairment was investigated in more detail. Of the children aged 4–17 years surveyed:

- 8.1% did not have 'normal' vision in both eyes. This rate fell from 11.3% in the Perth metropolitan area to 3.1% in areas of 'extreme' relative isolation.
- 6.8% did not have 'normal' hearing in both ears. Of these children, 49% were deaf or partially unable to hear in one ear only and 24% were deaf or partially unable to hear in both ears.
- 9.8% had trouble saying certain sounds. Amongst children aged 4–11 years, this difficulty was more pronounced in boys (16.5%) than girls (9.9%).
- 8.5% had a speech impairment which prevented other people readily understanding them when they spoke (Zubrick et al. 2004).

For a discussion on the conceptualisation of disability by Indigenous people in the Northern Territory, see Senior 2000.

Cultural and linguistic profile

Given the scarcity of data about the prevalence of childhood disability overall, it is not surprising that information about disability among children from various cultural and linguistic backgrounds is also rare. The conceptualisation of disability and the readiness to approach formal services differs across different cultural and ethnic groups.

The health screening of potential migrants to Australia, combined with the known tendency for migrants to be in good health when deciding to migrate, probably has the effect of lowering their prevalence of disability (AIHW: Black & Eckerman 1997). Disability types likely to arise from conditions at birth, or the early developmental period, would therefore be expected to be less frequent for the overseas-born population. As a result it is likely that the prevalence of disability amongst overseas-born children living in Australia is correspondingly low.

Population data from 1998 for children aged 0–14 years shows almost all children with a disability were born in Australia (99%). Somewhat less, but still the majority, of child consumers receiving CSTDA-funded services between 1 January and 30 June 2003 were also born in Australia (87%) (Table 3.7). A considerably smaller proportion of children were born in EP1[8] (or English Proficiency 1) countries, which include Canada, Ireland, New Zealand, South Africa, United Kingdom and USA, with even less from other English Proficiency Groups. EP1 countries are those where immigrants score 98% or higher on the English Proficiency Index, and from where there is an immigrant population of 10,000 or more.

[8] The 1996 *Classification of Countries into English Proficiency Groups* places every country into one of four groups based on the relative English Proficiency (EP) of recent arrivals to Australia from the 1996 census data. An 'English Proficiency Index', a standard tool developed by the Bureau of Immigration, Multicultural and Population Research, was used to construct each of the EP groups (see DIMA 1999).

Table 3.7: Children aged 0–14 years receiving CSTDA-funded services, by English Proficiency Group, 1 January to 30 June 2003

English Proficiency Group	No.	%
Australia	25,719	87.0
EP Group 1	284	1.0
EP Group 2	155	0.5
EP Group 3	178	0.6
EP Group 4	79	0.3
Not stated or not specified	3,148	10.6
Total	**29,563**	**100.0**

Note: English Proficiency Groups 1–4 are defined as follows:

a) EP Group 1 includes those countries with immigrants that scored 98% or higher on the EP Index and had an immigrant population of 10,000 or more.

b) EP Group 2 includes those countries with a 'high' level of English Proficiency (80–98%, or above 98% but with an immigrant population of less than 10,000).

c) EP Group 3 includes those countries with a 'moderate' level of English Proficiency (a rating of more than 50% but less than 80% on the EP index).

d) EP Group 4 includes those countries with a 'low' level of English Proficiency (a rating on the EP Index of less than 50%).

Source: AIHW analysis of 2003 CSTDA National Minimum Data Set (unpublished data).

Geographic profile

The relationship between geographic location and disability is complex and interrelated with other factors such as socioeconomic status, access to transport and services such as health and education. The estimated prevalence of disability and activity restriction for children aged 0–14 years according to geographic location is presented in Table 3.8. In 1998, the overall disability rate was higher for children who lived in the 'balance of the state' compared to those who lived in capital cities (82.1 per 1,000 compared with 71.2 per 1,000). Children who lived in the 'balance of the state' also experienced higher rates of core activity restriction than children living in capital cities (69.3 compared with 61.0 per 1,000 children). These patterns applied to both boys and girls.

Table 3.8: Children aged 0–14 years with a disability, by sex, area of residence and specific core activity restriction status, 1998 (rate per 1,000 population)

	Total with specific core activity restriction		Total without specific core activity restriction		Total with disability	
Sex	Capital city	Balance of states/ territories	Capital city	Balance of states/ territories	Capital city	Balance of states/ territories
Boys	79.1	89.4	11.5	14.5	90.6	103.9
Girls	42.1	48.1	8.8	11.0	50.9	59.0
Children	61.0	69.3	10.2	12.8	71.2	82.1

Source: Adapted from Table 5.2, AIHW: Al-Yaman et al. 2002.

Bradbury et al. (2001) used the ABS Survey of Disability, Ageing and Carers 1998 and the ABS Index of Relative Socio-Economic Disadvantage (IRSED) to examine the characteristics of geographic locations where adults (aged 15–64 years) with disability live in Australia. They found that the percentage of adults with disability fell as the geographic location became more socioeconomically advantaged.[9] That is, people with disability were more likely to live in locations which were relatively disadvantaged. Bradbury et al. (2001) applied another ABS geographic indicator to the SDAC population, namely whether people's households are in a capital city or the 'balance of the state'. They found that people living in capital cities were less likely to experience disability than people living in the 'balance of the state'. In subsequent multi-variate analysis it was found that this relationship related to the fact that regions outside capital cities are more likely to be disadvantaged.

3.6 Trends in childhood disability

Trends in the prevalence of disability, including childhood disability, are of great interest to Australian families, researchers, policy makers and service providers. Information about changing patterns of childhood disability provide clues about possible causal factors for specific health conditions and associated disabilities, thereby suggesting positive preventive measures for possible introduction. Further, only with reliable data is it possible for government and non-government agencies to plan provision of appropriate services and assistance for children with disabilities and their families, both now and into the future. Before commencing the main body of this section, we start with a brief outline of the current issues relating to trends in the prevalence of childhood disability (e.g. emerging health conditions such as ADHD, growing understanding of the genetic basis of an increasing number of health conditions) and then highlight a number of technical or foundation concepts relevant to discussing estimates of prevalence over time.

Current issues relating to the prevalence of childhood disability

Current issues relating to the prevalence of childhood disability include: the emergence of new and changing patterns in health conditions associated with disability; the implications of rapid developments in genetic science and technology; and improvements in obstetric and perinatal care and associated medical technological support, which have prolonged the life of children who would have previously died.

Recent evidence, although not always conclusive, suggests that specific health conditions associated with disability are on the increase amongst Australian children. The last five years have seen an increase in reports in the media, and the published literature, about, for example, possible 'epidemics' of ADHD and autism, possible relationships between environmental exposures and health conditions associated with disability (e.g. the MMR

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[9] Bradbury et al. (2001) applied the Australian Bureau of Statistics' Index of Relative Socio-Economic Disadvantage (IRSED) to each household in the ABS Survey of Disability, Ageing and Carers 1998. The IRSED is based on attributes such as low income, low educational attainment, high unemployment and jobs in relatively unskilled occupations, in each Census collector's district in Australia. It is considered to be an indicator of the characteristics of a locality, with higher IRSED values indicating more favourable outcomes or less disadvantage.

vaccination and autism[10]) as well as considerably more interest in environmental factors affecting the lives of children with disabilities (e.g. highly publicised cases where children with disabilities are denied access to a particular school). While there is a lot of interest in disability and increasing interest in the social context of disability, there is often insufficient data to fully support claims.

Some chronic diseases and risk factors associated with disability may be on the increase. For example, there is a general acceptance that there was a rise in the proportion of children with asthma in the 1980s and early 1990s (ACAM 2003), although more recent surveys, in Melbourne (Robertson et al. 2004) and Belmont, New South Wales (Toelle et al. 2004), have found no further increase since that time. Current estimates for children show the prevalence estimate of asthma to be around 14–16% (ACAM 2003). The incidence of diabetes is also rising amongst children. For example, between 1983 and the period 2000–02, the incidence of Type 1 diabetes rose from 12.3 per 100,000 to 19–20 per 100,000 (AIHW 2004b; Glatthaar et al. 1988).

Risk factors are an additional issue, and a prominent risk factor gaining significant attention is the increase in the number of overweight and obese children in Australia (see, for example, Magarey et al. 2001). One study, which compared rates of overweight and obesity for children in 1969, 1985 and 1997 found the prevalence of overweight to have risen by 60–70% and obesity to have trebled, with most of this increase occurring between 1985 and 1997 (Booth et al. 2003). The potential for long-term health issues, and hence experience of disability, for overweight and obese children is still being investigated and will only be fully realised when these children reach adulthood. Nonetheless, there are strong suggestions that overweight and obese children are doubly at risk of being overweight or obese as adults, and developing coronary heart disease and other adult comorbidities (Must 1996). Some of these health conditions have already been detected in obese children, for example, early signs of atherosclerosis in obese Western Australian children as young as six years (Watts et al. 2004).

Conversely, the advent of immunisation programs targeting specific diseases has seen a decline in other health conditions associated with disability. Such programs have resulted, for example, in the eradication of polio (Roche & Spencer 2002) and, more recently, a reduction in the occurrence of rubella (Sullivan et al. 1999), particularly since the introduction of the MMR vaccination schedule (McIntyre et al. 2000; McIntyre et al. 2002). Similarly, the introduction of health campaigns promoting the peri-conceptional intake of folic acid has been associated with a decline in the incidence of neural tube defects (Bower 2003). If childhood disability, or specific childhood disabilities related to health conditions, is increasing (or declining) this has implications for the continuation and extension of appropriate services.

Changes to obstetric and perinatal care, and technological improvements, associated with increased survival rates for babies have meant that babies who in the past may not have been expected to live, often do so now. This is particularly apparent for low (<2,500 g) and very low (<1,500 g) birth weight babies. Since such babies are often more likely to have or develop disabilities, this potentially means that more babies born with severe anomalies are surviving to childhood, and sometimes into adulthood. On the other hand, advancements in genetic testing, both of the embryo and foetus, mean parents not only have the option to find out whether their child has a genetic disorder, but to selectively terminate the pregnancy if they

[10] The absence of any significant association between autism and the MMR vaccine has since been found in a number of large epidemiological studies (see, for example, Taylor et al. 1999; Kaye et al. 2001).

wish to do so. Both forms of intervention raise serious ethical issues, on the rights of the child and of the parents, and the perception of disability in the current world (see a brief review in AIHW 2003d).

Measuring the prevalence of childhood disability over time

Given the varying ways in which the concept of disability can be defined and operationalised, it is a very complex task to compare the prevalence of childhood disability, both over time and in different countries or locations. This section focuses predominantly on Australian population data to explore what is known about trends in childhood disability and associated health conditions over time. The complicated task of fully exploring international literature about overall trends in childhood disability is not attempted in this report. Further, while there is a lot of interest in causes of or risk factors for health conditions likely to be associated with disability, this report does not attempt to explore this area.

At any point in time, the underlying prevalence of disability is determined by the combined effect of a range of factors. These include past and recent incidence, remission rates for diseases, rehabilitation rates, age at onset of disability and survival rates of people with disability and of the general population (AIHW 2003b: Chapter 8.1). A host of environmental factors also influence the extent to which health conditions, impairments, activity limitations or participation restrictions are experienced by individuals as disability. For example, changes to legislation relating to transport or building codes can diminish or eliminate activity limitations and participation restrictions often associated with physical disability, and changes in social attitudes towards people with certain health conditions (e.g. HIV/AIDS) can prevent participation restriction and associated disability. A discussion of the environmental factors possibly influencing the prevalence or severity of childhood disability is included in Chapter 4 on children and their families and carers and Chapter 5 on services and assistance.

In addition to factors affecting the underlying prevalence of disability, there are factors that may influence the reported prevalence of disability, even when the underlying prevalence rates may not have changed. These factors include changes in community perceptions and awareness of disability and certain health conditions, economic incentives surrounding the reporting of disability and health conditions, and changes in survey methodology. These factors are most likely to affect the prevalence rates of mild and moderate disability, rather than more severe disability (AIHW 2003b: Chapter 8.1).

Australian population data

This section draws on population data from the Australian Bureau of Statistics disability surveys conducted in 1981, 1988, 1993 and 1998.[11] The reported prevalence of disability among children aged 0–14 years was relatively stable across the 1981, 1988 and 1993 surveys, before increasing between 1993 and 1998 (Table 3.9, Figure 3.4).

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[11] While summary data from the 2003 Survey of Disability, Ageing and Carers (SDAC) were available at the time of finalising this report, the detailed Confidentialised Unit Record File (CURF), required to repeat the analysis presented elsewhere in this report, was not. The 2003 SDAC, which largely retained the 1998 questions, found that there was no significant increase in the rate of disability among children aged 0–14 years between 1998 and 2003, or in the rate of profound or severe core activity restriction among children of this age (ABS 2004).

Table 3.9: Children aged 0–14 years with a disability by disability status, for 1981, 1988, 1993 and 1998, age-standardised prevalence rates[a]

	Severe/profound core activity restriction[b]	All with specific restrictions[b]	Total with disability
	5–14 years	5–14 years	0–14 years
	Age-standardised prevalence rates		
Boys			
1981	2.0	5.0	6.2
1988	2.5	7.2	7.0
1993	2.7	7.3	7.6
1998	4.9	10.6	9.8
Girls			
1981	1.2	3.0	4.2
1988	1.9	5.1	5.1
1993	1.8	4.5	5.1
1998	2.4	5.7	5.5
Children			
1981	1.6	4.0	5.2
1988	2.2	6.2	6.1
1993	2.3	5.9	6.4
1998	3.7	8.2	7.7

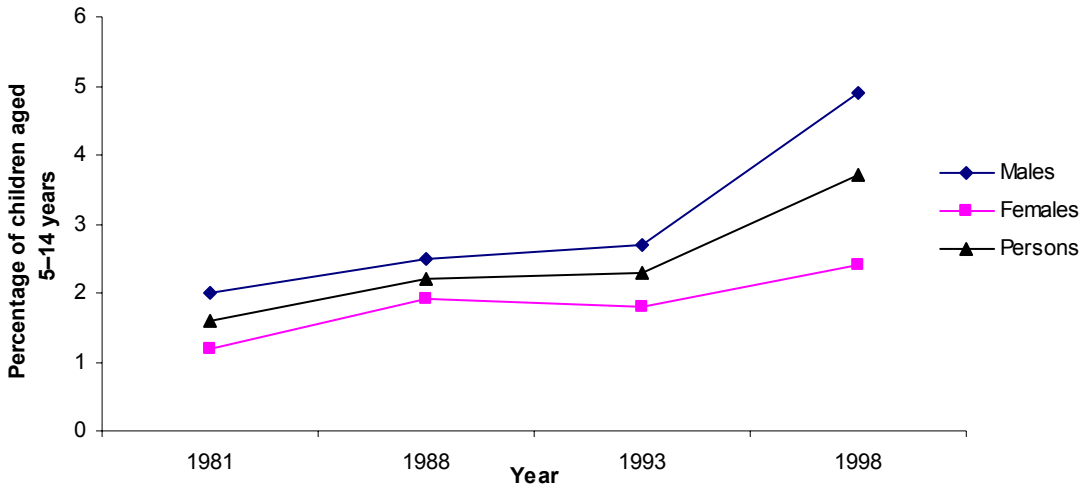
(a) Disability data were re-derived using criteria common to the four surveys. Rates are age-standardised to the estimated resident population for March 1998.

(b) Only children aged 5 years and over are included. Information on severity of core activity restriction among children aged under 5 years was collected in the 1998 survey but not in the previous surveys. For comparative purposes, information on activity restrictions among children under 5 years is not included in the data presented here, and children aged under 5 years have been excluded from the total population used as the denominator to calculate the prevalence rates.

Source: AIHW 2000a: Tables 12.1 and A13.1–3.

Between 1993 and 1998, the reported rate of disability among children aged 0–14 years increased from 6.4% to 7.7%. The reported rate of disability increased more markedly for boys (from 7.6% to 9.8%) than for girls (from 5.1% to 5.5%). Between 1993 and 1998, the rate of severe or profound core activity restriction among children aged 5–14 years increased from 2.3% to 3.7% overall—for boys the rate of severe or profound core activity restriction increased from 2.7% to 4.9% and for girls from 1.8% to 2.4%.

The most likely factor contributing to this increase is the substantial changes made to the 1998 ABS SDAC, which appear to have resulted in greater identification of the number of people with a disability, especially with a severe or profound core activity restriction, compared with the 1993 survey (ABS: Davis et al. 2001; AIHW 2001a). In particular, there was a change of wording in the survey screening question, from 'slow at learning or understanding' (1993 survey) to 'difficulty learning or understanding' (1998 survey), which may have encouraged reporting of intellectual disability, in particular among boys. There was a sharp increase in positive response rates to this screening question for boys in each of the age groups within the 0–14 year age group (AIHW 2003b: Table A8.3).



Sources: AIHW 2000a: Table 12.1; AIHW analysis of unpublished data tables from the ABS 1981, 1988, 1993 and 1998 disability surveys.

Figure 3.4: Prevalence rate of severe and profound core activity restriction for children aged 5–14 years, various years (percentage of children aged 5–14 years)

Table 3.9 presents re-derived prevalence estimates prepared by the AIHW for the four surveys (1981, 1988, 1993 and 1998), using only criteria common to all surveys, however some variation remains across the surveys, particularly in relation to survey design and interview methods. While it is not possible to control for these factors post hoc, summary data from the 2003 SDAC tend to confirm that the increase in disability prevalence rates between 1993 and 1998 was the result of these methodological changes. The 2003 SDAC, which largely retained the 1998 questions, found that there was no significant increase in the rate of disability among children aged 0–14 years between 1998 and 2003, or in the rate of severe disability among children of this age (ABS 2004).

With the above provisos in mind, what do we know about the characteristics of children with disability over time? Table 3.10 shows the number of children with a severe or profound core activity restriction in terms of the activity areas in which they were reported to need support. Among this group of children, there were increases in the numbers who needed assistance with all activities of daily living (i.e. self-care, mobility and communication) between 1993 and 1998. However, the increase was most notable in the case of communication restriction, which rose from 26,400 to 69,900, an increase of 164%. As previously discussed, this increase is likely to relate largely to changes in survey question wording between the 1993 and 1998 surveys.

Table 3.10: Children aged 5–14 years with a severe or profound core activity restriction living in households: activity type with which assistance needed, 1993–1998[(a)] ('000)

Activity	1993	1998[(b)]	Change in number between 1993 and 1998[(b)]	% change in number of children needing assistance between 1993–1998[(b)]
Self-care	47.7	70.1	22.3	46.8
Mobility	43.1	61.4	18.3	42.4
Communication	26.4	69.9	43.4	164.3

(a) The age group for this table is restricted to children 5–14 years because children aged 0–4 years were not included in the 1993 survey.

(b) For comparative purposes, 1998 data were re-derived using the 1993 operational definition of disability.

Source: AIHW 2000a: Table 15.8.

Table 3.11 outlines the types of education setting for children with disability over time. A higher percentage of people aged 5–20 years with a disability were attending school in 1998 than in 1981 (AIHW 2001a:311). In 1998, 7.1% of the Australian population aged 5–20 years attending school had a disability, compared to 5.3% of the population in 1993, 5.2% in 1988 and 4.2% in 1981 (Table 3.11). This trend is evident regardless of the level of core activity restriction.

Trends in the prevalence of health conditions associated with disability

Specific health conditions

There is much speculation that certain health conditions are increasing or decreasing, or that medical technologies and practices are implicated in other increases or decreases in disability prevalence. In preparing this report, a considerable amount of research was undertaken in relation to trends over time in specific health conditions associated with childhood disability (e.g. autism, asthma, cerebral palsy). The number of health conditions of interest, in combination with the complexity in synthesising the various information sources, methodologies and diagnostic criteria that appeared throughout the literature, led to a decision to exclude the majority of this information from the final report. This type of synthesis would contribute to the Australian literature on childhood disability.

Nevertheless, using population data it was possible to examine trends over time in a number of 'disabling conditions'. This information is presented below.

Disabling conditions

An analysis of the disabling conditions reported by children aged 0–14 years with a disability shows that, while there have been minor changes in some health conditions between specific survey years, there are generally no obvious trends over time in the prevalence of health conditions associated with childhood disability. The reported prevalence of intellectual disabling conditions among children aged 0–14 years was stable at around 1.1–1.2% in the 1980s before increasing slightly to 1.7% in the 1993 ABS survey and then more markedly to 3.6% in the 1998 ABS survey (Table 3.12 and see AIHW 2003b: Table 8.4) [12]. This is consistent with other analysis presented in the report about the broader intellectual/learning disability group, and is likely to be the result of methodological changes in the 1998 SDAC.

In addition to the possible influence of the 1998 ABS SDAC methodological changes, it is possible that a number of factors may be contributing to the increase in reported prevalence of intellectual disabling conditions. A notable disabling condition within the 'intellectual/learning' disability group in 1998 was ADHD. In 1998, about 42,700 children aged 0–14 years with a disability (1.1% of children aged 0–14 years) reported ADHD, either as a main disabling condition or an associated disabling condition. Of these, 38,700 considered ADHD as their main disabling condition. This means that ADHD was the condition identified as causing the most problems for 13% of all children aged 0–14 years with a disability and 27% of all children aged 0–14 years with an intellectual disability. While ADHD was not separately classified in the 1993 survey, it is likely that this condition is contributing to an increase in reported intellectual disability in this age group.

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[12] Estimates for each of the disability groups (intellectual/learning, psychiatric, sensory/speech, physical/diverse and acquired brain injury) have not been generated by the AIHW for the 1981 and 1988 ABS surveys and it is therefore not possible to examine changes across all surveys in terms of the disability groups. See Section 2.2 for definitions of these disability groups.

Table 3.11: Children and youth aged 5–20 years with a disability, school attendance by type of school and class, by disability status, as a percentage of the Australian population of that age, 1981–1998[(a)]

Type of school/class	Core activity restriction			Schooling or employment restriction only	Total with specific restrictions	Total with a disability
	Severe	Moderate	Mild			
Ordinary school class						
1981	0.5	0.2	0.2	0.6	1.5	3.1
1988	0.8	0.5	0.9	0.9	3.0	4.0
1993	0.8	0.2	0.5	0.8	2.3	3.6
1998	1.8	0.4	0.6	0.8	3.5	n.a.
Ordinary school (special class)						
1981	0.2	*0.1	0.0	0.3	0.6	0.6
1988	0.3	*0.1	*0.1	0.3	0.8	0.8
1993	0.6	*0.1	*0.1	0.5	1.4	1.4
1998	0.8	*0.1	*0.1	0.6	1.6	n.a.
Special school						
1981	0.3	0.0	0.0	0.1	0.4	0.4
1988	0.4	0.0	0.0	0.1	0.5	0.5
1993	0.3	0.0	0.0	0.0	0.3	0.3
1998	0.5	0.0	0.0	0.0	0.6	n.a.
Total attending school						
1981	1.0	0.3	0.3	0.9	2.5	4.2
1988	1.5	0.6	1.0	1.2	4.3	5.2
1993	1.8	0.4	0.6	1.3	4.0	5.3
1998	3.1	0.5	0.7	1.3	5.7	7.1
Not attending school						
1981	0.2	*0.1	*0.1	0.1	0.6	1.5
1988	0.3	*0.2	0.3	0.3	1.1	1.4
1993	0.5	*0.1	0.3	0.3	1.2	1.6
1998	0.6	*0.1	0.4	0.3	1.5	2.1
Total						
1981	1.2	0.4	0.4	1.1	3.1	5.7
1988	1.7	0.8	1.3	1.6	5.3	6.7
1993	2.2	0.5	0.9	1.6	5.2	7.0
1998	3.7	0.6	1.1	1.6	7.1	9.2

n.a. Not available

(a) The percentages have been age standardised using the age and sex distributions of the Australian estimated resident population for March 1998 for comparative purposes. The estimates for the 1993 and 1998 disability survey data were made using definitions as close as possible to the definitions of the 1981 and 1988 disability surveys.

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

Source: AIHW 2001a: Table 7.24.

Table 3.12: Children aged 0–14 years with a disability: prevalence rates (%) of all reported disabling conditions by type of condition, Australia, 1981, 1988, 1993 and 1998

Disabling condition	1981	1988	1993	1998
Psychiatric	0.4	0.4	0.4	0.3
Intellectual	1.1	1.2	1.7	3.6
Diseases of eye	0.4	0.3	0.3	0.2
Diseases of ear	1.1	1.0	1.0	1.1
Nervous system diseases	0.8	0.9	0.7	0.6
Circulatory diseases	0.2	0.1	0.1	0.2
Respiratory diseases	0.8	1.7	2.1	2.2
Musculoskeletal disorders	0.5	0.4	0.3	0.2
All other diseases and conditions	1.2	1.7	2.5	2.0

Notes

1. Percentages have been standardised using the age and sex structures of the estimated resident population at March 1998. The estimates from the previous three surveys were adjusted to show the prevalence rates that would have been expected in the 1981, 1988 and 1993 populations, if those populations had the same age and sex structure as the 1998 population.
2. The 1993 and 1998 data were adjusted to the 1981 and 1988 definition of disability.

Sources: AIHW analysis of ABS 1993 and 1998 Surveys of Disability, Ageing and Carers confidentialised unit record files; ABS 1981 Survey of Handicapped Persons unpublished data table; ABS 1988 Survey of Disabled and Aged Persons unpublished data table.

An increase in prescriptions for the most commonly prescribed drugs to treat ADHD suggests an increase in the diagnosis of the disorder (ABS: Davis et al. 2001; AIHW 2001a). While Ritalin (methylphenidate) is the most commonly known of the drugs prescribed to treat ADHD, dexamphetamine is the most prescribed, possibly because it attracts a pharmaceutical benefit rebate. Prescription rates for dexamphetamine have increased significantly in the period 1992–2003 (Table 3.13). For some states and territories, this rise has been especially high. A recent review of dexamphetamine prescriptions for the period 1999–2000 estimated that prescription rates were especially high in Western Australia, where the number of prescriptions per 1,000 head of population was 43.2, followed by Tasmania (16.3 per 1,000) (Mackey & Kopras 2001). Both higher levels of diagnosis and heightened awareness among parents, educators and health professionals may also have contributed to the increase in reported ADHD.

More generally, the high ADHD prevalence rates for children of school age may partly reflect the impact of the educational system on the identification of disability. Some 'intellectual' disabling conditions are not identified until children reach school and the impact on school performance is highlighted. It is possible that over time educators have become more aware of, or have had increased incentives to identify, intellectual or specific learning difficulties among their students.

Table 3.13: Dexamphetamine prescription items requested under the Pharmaceutical Benefits Scheme (PBS), by state and territory, 1992–2003

	No. of prescriptions								
	NSW	Vic	Qld	SA	WA	Tas	ACT	NT	Aust
1992	4,369	1,080	1,809	1,241	2,040	138	146	36	10,859
1993	9,019	2,422	3,618	3,127	5,610	257	302	98	24,453
1994	17,224	4,982	6,052	5,262	11,334	810	689	232	46,585
1995	29,195	9,787	9,860	7,828	18,451	1,847	1,267	620	78,855
1996	39,698	14,948	14,947	12,369	28,976	2,760	1,687	675	116,060
1997	46,590	19,445	20,046	15,798	38,982	4,252	1,828	669	147,610
1998	52,783	25,225	23,214	18,125	49,821	5,314	2,024	662	177,168
1999	58,769	30,329	26,972	19,485	60,355	6,877	2,353	854	205,994
2000	62,688	33,116	31,186	18,185	68,729	8,299	2,883	758	225,844
2001	61,272	33,463	34,010	18,983	75,017	9,058	2,967	777	235,547
2002	62,571	32,839	35,831	19,028	81,695	9,244	3,125	729	245,062
2003	61,211	32,323	36,233	19,514	86,780	8,756	3,166	707	248,690
Total	**515,605**	**244,648**	**249,301**	**162,225**	**541,121**	**58,946**	**22,965**	**6,925**	**1,801,736**

Source: Pharmaceutical Benefits Scheme Item Statistics <http://www.hic.gov.au/providers/health_statistics/statistical_reporting/pbs.htm>.

A range of other factors could be affecting the change over time in reported prevalence of intellectual disabling conditions and these are not explored in depth here. However, it should be noted that there is some evidence to suggest that the reported prevalence of autistic spectrum disorders has been rising. For example, some Western Australian epidemiological evidence suggests that the prevalence rates of autistic spectrum disorders have increased over time (from 3–6 per 10,000 children born in Western Australia between 1980–93 compared to 10–13 per 10,000 children in 1989–92). The researchers attribute this increase as most likely due to changing diagnostic methods and increased awareness (Bower et al. 2000).

Finally, while there are no obvious trends over time in the other disabling health conditions selected in Table 3.12, it is possible that changes have occurred in the composition of each of the disabling condition categories. As previously noted, a more detailed exploration of changes over time in the prevalence of the component health conditions (e.g. cerebral palsy, depression, anxiety, vision impairment), using epidemiological and other sources, was beyond the scope of this report.

Australian administrative data sources

Compared to population data, administrative data collections have some limitations in terms of establishing trends over time. First, administrative data sources provide an indication of changes over time in the level of service provision to children with disabilities, rather than changes in the underlying prevalence of childhood disability. Second, administrative data relating to income support or disability support services include information about a sub-set of people with disability, namely those who are eligible for benefits or services, and such eligibility criteria may change over time. Given these limitations, what do administrative data sources tell us about changes over time in service provision to children with disabilities and their carers?

Disability-related carer payments

Carers of children with disability may be eligible for Carer Allowance (Child) and/or Carer Payment, administered by the Australian Government (see Chapter 5). In the last decade there has been a fairly steady increase in the number of people receiving these payments (Table 3.14). For example, people in receipt of Carer Allowance (Child) have increased by around 70% from 69,693 in 1994 to 115,404 in 2002.

Table 3.14: Recipients of disability-related carer payments and allowances, June 1994–June 2002

	1994	1995	1996	1997	1998	1999	2000	2001	2002
Carer Allowance (Child)[(a)]	69,693	78,898	90,644	95,520	90,830	100,452	116,955	111,691	115,404
Carer Payment (DSP)[(b)]	9,450	10,633	13,483	15,735	18,556	21,392	24,500	28,171	34,963
Carer Payment (AP)[(c)]	7,441	8,324	9,500	10,954	11,740	13,407	15,346	18,097	20,227
Carer Payment (other)	808	1,141	2,054	2,869	3,683	5,271	7,704	10,922	12,070

(a) Excluded from these counts in 2002: 2,216 received both Carer Allowance (Adult) and Carer Allowance (Child) and 11,708 received Carer Allowance (Child) Health Care Card only. Excluded from these counts in 2003: 2,744 received both Carer Allowance (Adult) and Carer Allowance (Child) and 11,749 received Carer Allowance (Child) Health Care Card only.

(b) DSP = Disability Support Pension.

(c) AP = Adult Pension.

Sources: AIHW 2001a; FaCS 2002, 2003c; FaCS unpublished data.

While it is possible that the increase in payments reflects an increase in the prevalence of childhood disability, the following factors are also likely to have influenced the increase over time:

- a reduction in access to other forms of income support, such as widow pensions and Parenting Payment;
- greater public awareness of these two payments;
- the increase in numbers of people with disabilities and medical conditions being cared for at home rather than in institutional settings;
- the liberalisation of the qualification criteria for Carer Payment; and
- broader targeting of Carer Allowance (FaCS 2002).

Services funded under the Commonwealth State/Territory Disability Agreement

A wide range of specialist disability support services, such as accommodation support, community support, community access and respite services, are funded under the Commonwealth State/Territory Disability Agreement (CSTDA) (see Section 5.3 for further information about these services). CSTDA-funded services are designed for people who need ongoing support with everyday life activities. From 1995, information about disability support services has been collected by all CSTDA-funded agencies according to an agreed national minimum data set. The data presented in Table 3.15 relate to all consumers seen by CSTDA-funded agencies on selected snapshot days in 1999 to 2002. [13]

The CSTDA data show that each year around 8,000 children aged 0–14 years are assisted on the snapshot day. Children of this age have consistently made up about 13% of the total

[13] Between 2000 and 2003, the CSDA Minimum Data Set was redeveloped into the new full-year Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS). The first data, for January 2003–June 2003, are published in AIHW 2004c.

Table 3.15: Consumers of CSTDA-funded services, 0–14 years, 1999–2002

Age group (years)	1999	2000	2001	2002
0–4	2,665	2,879	2,840	2,711
5–14	5,354	5,466	5,499	5,405
0–14	8,019	8,345	8,339	8,116
Total (all ages)	62,752	62,341	63,830	65,809

Note: The number of consumers is estimated using a statistical linkage key to account for individuals who received more than one service on the snapshot day.

Sources: AIHW 2000b, 2001b, 2002a, 2003e.

CSTDA population (which is generally people under 65 years of age). While the number of consumers seen on the snapshot day has increased overall by nearly 3,000 people over the 1999–2002 period, the number of children aged 0–14 years increased by less than 40 between 1999 and 2002 (i.e. less than a 2% increase). It should be noted that snapshot data may not reflect the actual trends for all consumers of disability services, especially for the categories used by children.

Conclusion

Between 1981 and 1998 there appeared to have been an upward trend in the reported prevalence of disability among children aged 0–14 years. However, most of this increase occurred between 1993 and 1998 and was largely associated with methodological changes between these two surveys. The overall prevalence may have increased over time for a number of reasons. For example, it is possible that people may have been more likely to report childhood disability over time as a result of reduced stigma associated with disability, increased awareness of particular health conditions (e.g. ADHD) and increased provision of services to meet the needs of children with disabilities and their families. It is also possible that the underlying prevalence of childhood disability is increasing. These contributing factors cannot be disentangled using existing data sources.

The 2003 SDAC data suggest that the increase in reported prevalence between the 1993 and 1998 surveys was largely the result of methodological changes. The 2003 survey, which largely retained the questions from the 1998 survey, found that there was no significant increase in the rate of disability among children aged 0–14 years between 1998 and 2003, or in the rate of severe or profound core activity restriction among children of this age (ABS 2004).

Our attempts to systematically review the literature on specific conditions likely to be associated with disability revealed the complexity and size of the task to be done. On the advice of our referees, the attempt was abandoned after considerable work. This is itself revealing: the medical literature does not provide meta-analysis of this very interesting question—are such health conditions increasing or decreasing in prevalence? This lack of authoritative information does not prevent much public speculation about such changes.