Review of trends in disabilities among children and adolescents

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FRASER MUSTARD CENTRE

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Executive Summary

Background

The prevalence of disability among children and adolescents in Australia, as well as trends in prevalence, are difficult to discern. According to the Australian Bureau of Statistics (ABS) 2018 Survey of Disability, Ageing, and Carers (SDAC) 9.6% of children and adolescents aged 5-14 years were reported to have a disability[1]. However, disability prevalence varies across data sources, presenting a challenge to the planning and allocation of resources and supports. This is a difficulty faced by the education sector in particular, tasked with providing ongoing, high quality support for children and adolescents with a disability, despite limited evidence regarding levels of need.

Against this background, the aim of this review was to provide the South Australian Department for Education with a synthesis of high quality evidence on the population prevalence of various disabilities among school-aged children. Ten chapters, one focused on each of the disabilities listed below, present information compiled from a review of the scientific evidence.

1. Attention deficit hyperactivity disorder
2. Autism spectrum disorder
3. Global developmental delay
4. Dyslexia
5. Intellectual disability
6. Generalised anxiety disorder
7. Speech disorders
8. Language disorders
9. Major depressive disorder
10. Fetal alcohol spectrum disorder

Chapters include information on disability definition, presentation characteristics, diagnosis, and onset and progression, followed by descriptions of prevalence among children and adolescents overall as well as by a range of demographic characteristics and level of severity. Trends in prevalence over time are described according to available evidence, both in Australia and internationally. Information regarding common comorbidities and help seeking behaviours were also explored to better understand complex needs and service use among children and adolescents. Finally, factors associated with the prevalence of each disability and trends in these factors were identified.

In this summary we discuss findings relative to two key internal data sources used by the Department for Education to guide understanding of disability prevalence and provision of supports, namely:

- The **Inclusive Education Support program (IESP)** is a functional needs-based funding model for students with a disability in South Australia. Data are collected annually, providing the Department with an understanding of the prevalence of different types of disabilities among students in government primary and secondary schools. Eligibility for the IESP is based on clinical diagnosis or assessment reports. Eligibility criteria are aligned with the national disability legislation and guidelines, and focus on a child's needs rather than their disability diagnosis or label. This approach seeks to recognise all disabilities and learning difficulties, including mental health, trauma, complex behaviours and complex health care needs.

[1] Disability according to the ABS SDAC is defined as any limitation, restriction or impairment, which restricts everyday activities and has lasted, or is likely to last, for at least six months.

- The **Nationally Consistent Collection of Data (NCCD)** is an annual collection of information on students with disability, conducted in schools across Australia. Data collected are based on the professional judgement of teachers and school teams, regarding the adjustments provided for students as part of day-to-day teaching practice. Adjustments, either supplementary, substantial, or extensive, are actions taken to enable a student with disability to access and participate in education on the same basis as other students. For a student to be included in the NCCD, schools need to have evidence that adjustments have been provided for a minimum period of 10 weeks in the 12 months prior to the census day.

In doing so, we seek to identify how disability prevalence as reported in the scientific literature aligns with that of internal Department data sources. Additionally, investigation of trends in the factors associated with disability prevalence help to highlight potential drivers that may lead to shifts in prevalence in future. Lastly, we highlight gaps in the available evidence on disability among school-aged children that emerged as a result of the review. Together, findings will help to inform the Department's future planning and provision of supports for students with disability.

Summary of findings

Prevalence

The IESP data reported that overall prevalence of disability among students in South Australia was 10.8% in 2019, which is slightly higher than the ABS SDAC population estimate of 9.6% among children and adolescents aged 0-14 years in 2018. When exploring prevalence of individual disabilities, there were both similarities and differences between prevalence reported by the IESP data versus that observed in the scientific literature. However, IESP data are not collected for some of the disabilities in this review and so prevalence across data sources could not be compared in these instances.

Prevalence of Autism Spectrum Disorder (ASD; see Chapter 2) is described as an example. Australian research reported prevalence of ASD to be 2.1% among children aged 0-14 years as reported by the ABS SDAC, 2.3% among children aged 4-6 years as reported by the Australian Early Development Census (AEDC), and 1.5% among children aged 6-7 years and 2.4% among children aged 10-11 years as reported by the Longitudinal Study of Australian Children (LSAC). Internationally, based on systematic reviews and meta-analyses, prevalence of ASD among children and adolescents in high-income countries was estimated to be around 1-1.5%. In contrast, IESP data reported that 3.5% of primary and secondary school students in South Australia had an ASD diagnosis.

It is important to highlight that prevalence can vary due to a range of methodological factors, including diagnostic criteria employed, data collection procedures, and sample characteristics. For example, the SDAC employed the International Classification of Diseases: 10th Revision (ICD-10) to classify disability, which uses subtypes in the diagnosis of ASD (i.e. Rett Syndrome and Asperger Syndrome) as opposed to a continuous spectrum of ASD as defined most recently by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). The IESP prevalence of ASD is based on diagnosis using either fourth or fifth editions of the DSM. In terms of data collection, the SDAC asked respondents to identify if anyone in their household had social, emotional, behavioural, learning, or mental health difficulties; and if 'yes' the respondent was asked to identify the condition/s the individual is experiencing, including ASD. The IESP relies on teacher knowledge of, as well as diagnostic

and functional evidence, of a student's ASD. Finally, differences in sample characteristics should also be considered when comparing results. The SDAC is designed to provide nationally representative estimates, while the IESP is focused on students from government schools in South Australia.

Evidently, such methodological variability is testament to the challenge of accurately determining the prevalence of disability such as ASD at the population level.

In contrast, prevalence of Global Developmental Delay (GDD; see Chapter 3) as reported by the IESP data was more aligned to that observed in the scientific literature. Data collected via the AEDC reported that 0.4% of children who were in their first year of school (i.e. 4-6 years) had GDD. According to the SDAC, 0.5% of children aged 0-5 years in Australia were estimated to have some form of developmental disorder, inclusive of GDD. Internationally, research has estimated that GDD affects between 1-3% of children aged 0-5 years in Canada, the US and the UK. Similarly, data collected through the IESP reported that 0.5% of students in South Australia had a GDD diagnosis.

Similarities in prevalence figures for some disabilities but differences in prevalence rates reported between IESP and the scientific literature for others, highlights potential inconsistencies in the ways some disabilities are being defined/assessed/measured across sources. This is discussed further below in terms of how this applies to investigation trends in prevalence over time.

Trends in prevalence

Overall, review findings indicate that while prevalence of some disabilities has increased (e.g. ASD, Fetal Alcohol Spectrum Disorder) or remained stable over time (e.g. Attention Deficit Hyperactivity Disorder, Generalised Anxiety Disorder), the trends in prevalence of many disabilities cannot be determined with the evidence available. This is due to a range of factors, such as lack of high quality prevalence information, as well as changes to diagnostic criteria over time, terminology and definitions used, and public awareness of disability over time.

In cases where there is evidence of increased prevalence over time, as researchers themselves have identified, it is difficult to determine what is driving these trends. Specifically, are increases in prevalence driven by shifts in 'external' factors, such as diagnostic criteria and public awareness, or are they a result of true increases in prevalence of disability? The former suggests that there have always been a certain proportion of individuals in the community with a disability who are only now getting an appropriate diagnosis, while the latter suggests an increase in population prevalence due to greater exposure to risk factors. Evidence collected from this review suggests it is more likely the former, with increased prevalence a result of changes in diagnostic criteria and public awareness.

We highlight this using ASD (see Chapter 2) as an example again as the evidence available makes it possible to do so. Prevalence of ASD in Australia has increased by more than four times within the last 15 years (as indicated by SDAC and AEDC data), but there is evidence that this is partly due to broader diagnostic criteria, increased awareness of ASD, and an increase in relevant services, rather than a large increase of ASD in the population. For instance, research in Western Australia was able to demonstrate that increased prevalence corresponded with changes in diagnostic criteria (i.e. broadening age of onset), as well as the availability and funding of services. Other research argues

that these factors have also led to more children and adolescents with milder disability being identified and diagnosed, as stigma around disability has decreased and thus help-seeking increased.

Associated factors

The majority of disabilities are influenced by genes but a range of environmental factors have been identified to increase risk of disability. Therefore, trends in these risk factors are important to consider when investigating the drivers of increased prevalence. This review highlighted the most common factors associated with disabilities of focus were perinatal risk factors (e.g. preterm birth and low birth weight), maternal smoking and alcohol use, and maternal age. In South Australia specifically, evidence indicates increases in perinatal risk factors as well as maternal age over the last 20 years. Childhood abuse and neglect was also identified as a significant risk factor for mental health disorders in particular, including Major Depressive Disorder and Generalised Anxiety Disorder. Evidence suggests child maltreatment has been increasing in South Australia over the last 30 years, based on the proportion of children to have received notifications to the child protection system over time. The true prevalence of child maltreatment is difficult to determine, however child protection notifications offer a useful indicator for determining if maltreatment is increasing. Lastly, screen use during childhood was identified as an emerging factor associated with the prevalence of disability, including Attention Deficit Hyperactivity Disorder. Although there is clear evidence of increased screen use among children over time, evidence around how this contributes to disability is lacking.

Overall, increases in environmental risk factors associated with disability may contribute to increased prevalence now and in years to come. This will be important for the Department to consider in future planning of resources and supports. However, as is a common theme throughout this review, evidence of increased disability prevalence as a result of increased exposure to risk factors is not available.

Impact on children and adolescents and help-seeking behaviours

Despite the fact that about 1 in 10 young people are reported to have a disability, there is a lack of evidence regarding severity of impact on individuals. The 2013-14 Australian Child and Adolescent Survey of Mental Health and Wellbeing (Young Minds Matter; YMM) reported on the prevalence, severity, and impact of mental health disorders (e.g. Major Depressive Disorder, Generalised Anxiety Disorder) in children and adolescents aged 4-17 years in Australia. This included severity of impact of disorders on school or work, family, friends and social activities, as well as impact on self, as reported by young people and their parents. Although this provides valuable insight into the impacts of living with disability, it does not provide clinical classification of levels of severity and associated impacts and impairments, according to a health professional. Indeed, this review revealed that the latter is severely lacking from the evidence base, which is essential for the planning and provision of appropriate supports in an education setting. With recent clinical definitions and diagnoses embracing a spectrum/continuum model of disability, this raises challenges for how severity and impact of disability is measured and recorded for both research and service provision purposes.

The review also highlighted a lack of evidence regarding co-occurring disability, or young people with complex needs. Prevalence figures for comorbid conditions were largely unavailable or varied, however there was a general consensus that children and adolescents with disability often have co-occurring disabilities and/or health conditions. The majority of this evidence was based on specific

population sub-groups, such as young people with an Aboriginal and/or Torres Strait Islander background or individuals in the criminal justice system. Information regarding complex needs among the general population of children and adolescents is an important area for future research.

Further, the interplay between severity of disability, complex needs, and help-seeking behaviours among young people and their families remains unclear. Again, the YMM collected information on trends in service use among children and adolescents with a mental health disorder. Figures reported provide evidence of an increase in service use between 1998 and 2013-14. Although increased service use may suggest an increase in help-seeking, the evidence required to explore how service use and help-seeking behaviours may be driving trends in prevalence is not available.

Support and levels of adjustment

In light of the above, provision of supports in schools for children and adolescents with disability is understandably complex. The NCCD collects data on students with disability who require adjustments as part of day-to-day teaching practice to access and participate in education on the same basis as other students. Levels of adjustment for students are based on teacher judgments of student needs.

Data collected through the NCCD shows that in South Australian government schools, 17.3%[2] of students received some level adjustment due to disability in 2018. This is relative to 14.8% of students receiving adjustment across all school sectors in South Australia, and 12.9% of students for all students in all schools across Australia. More specifically, 10.9% of students were eligible for supplementary, 3.8% for substantial, and 2.6% for extensive adjustments.

- Students are provided adjustments that are **supplementary** to the strategies and resources already available for all students within the school. This might include adapted or additional instruction, planned health, personal care and/or safety support, and adjustments to enable access to learning such as specialised technology or support to ensure access to facilities.
- Students with disability who have more **substantial** support needs are provided with essential adjustments and considerable adult assistance. This might include additional support or individualised instruction in a highly structured manner, planned health, personal care and/or safety support or intervention, and adjustments to enable access to learning such as specialised equipment or modification to school environments to ensure access to facilities.
- Students with disability and very high support needs are provided with **extensive** targeted measures and sustained levels of intensive support. These adjustments are highly individualised, comprehensive and ongoing.

Overall, the percentage of students in South Australian government schools receiving some level of adjustment is greater than disability prevalence as indicated by the scientific literature as well as the IESP data collected internally by the Department. Important to note, however, is that IESP data only captures information on certain disabilities, which may contribute to these differences.

[2] This figure is exclusive of students for whom support is provided within quality differentiated teaching practices (QDTP), that is, students are supported through adjustments through usual processes without drawing on additional resources.

Conclusion

The prevalence of disability among children and adolescents varies between sources, in part due to methodological differences in data collection. Although trends in prevalence for many disabilities cannot be determined with the evidence currently available, increased prevalence observed for some disabilities is likely attributable to changes in diagnostic criteria and increased public awareness over time, rather than a true increase in population prevalence. There is a clear lack of evidence available regarding impacts of disabilities and therefore complex needs among children and adolescents, as well as help-seeking behaviours, and how all of these factors may be having an influence on trends in disability prevalence. Internal data used by the South Australian Department for Education indicates that more than 1 in 6 children require supports to enable them to participate in education on the same basis as other students. This figure is higher than overall disability prevalence observed in the scientific literature, which is likely a reflection of the approach for support, based on the professional judgements of teachers and schools, that seeks to recognise all disabilities and learning difficulties, including mental health, trauma, complex behaviours and complex health care needs.

More broadly, findings from this review align with South Australian evidence from various sources, all of which highlight the need for universal monitoring of children's health and development from birth to preschool age. Coupled with increases in the number of students requiring support for disability, South Australia is the only jurisdiction that has observed a steady increase in the percentage of children who are developmentally vulnerable at school entry over time. Monitoring in the years before school, ideally a nationally or internationally consistent approach, would strengthen evidence around the prevalence of disability among young children, informing provision of supports and enabling identification of disability at an age where there is the greatest opportunity for early intervention.

1. Attention Deficit/Hyperactivity Disorder

Key findings

Findings presented in this chapter demonstrate that Attention Deficit/Hyperactivity Disorder (ADHD) is one of the most common disabilities among children and adolescents. The 2018 Survey of Disability, Aging and Carers (SDAC) reported ADHD was found to effect around 1 in 6 children and adolescents with a disability (53,800, 15.0%), which equates to 1.2% aged 0-14 years in Australia. Across data sources, prevalence of ADHD in males was typically at least double than that in females. Further, evidence shows that prevalence of ADHD is higher among children and adolescents from disadvantaged backgrounds, with increases in household income, parental education and employment associated with a decrease in prevalence. The key factors associated with the prevalence of ADHD are genetic, environmental, and/or pre- and perinatal factors. While genetics and heritability have been described to account for 60-90% of ADHD cases, this leaves 10-40% influenced by environmental factors. After taking into account varied methodologies and diagnostic criteria, evidence suggests that the global prevalence of ADHD has remained stable over the last 30 years.

1.1 Background

1.1.1 Definition

As described by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [DSM-5; 1], ADHD is characterised by a persistent pattern of inattention and/or hyperactivity/impulsivity that interferes with functioning or development.

1.1.2 Presentation/key characteristics

Symptoms of ADHD fall into two key categories:

Inattention:

- Difficulty paying attention to details e.g. makes careless mistakes in schoolwork
- Difficulty remaining focused in class, conversations, or reading
- Avoiding tasks that take continuous mental effort
- Difficulty following through on instructions (i.e. a tendency to start but not finish tasks)
- Difficulty organising tasks/activities, belongings, or time
- Easily distracted or daydreams
- Losing/misplacing belongings
- Does not appear to listen when spoken to
- Forgetful with everyday tasks, such as chores and appointments

Hyperactivity and impulsivity:

- Fidgeting and squirming
- Running or climbing in situations where it is inappropriate
- Talking non-stop
- Interrupting conversations, games or activities or using people's things without permission
- Blurting out an answer before a question has been finished

- Having difficulty playing quietly
- Having difficulty waiting their turn
- Leaving the seat in class or in other situations where sitting is expected
- Being constantly on the go as if "driven by a motor" (e.g. unable to be still)

1.1.3 Diagnosis

ADHD is diagnosed by a specialist paediatrician or psychiatrist, after referral from a doctor, using strict criteria based on the DSM-5. Each of the following criteria must be met:

- Several inattentive or hyperactive-impulsive symptoms (as described above) were present before the age of 12 years, specifically:
  - 6 or more symptoms of **inattention** for children up to 16 years, symptoms are inappropriate for developmental level and have been present for at least 6 months; and/or
  - 6 or more symptoms of **hyperactivity-impulsivity** for children up to 16 years, symptoms are inappropriate for developmental level and have been present for at least 6 months
- Several symptoms are present in two or more settings (e.g. at home and school)
- Symptoms cause significant impairment, at school, home, or socially
- Symptoms are not better explained by another mental health disorder

Based on the type of symptoms experienced, three presentations of ADHD can be diagnosed as described below. These are not fixed, however, and children and adolescents may experience different symptoms and presentations of ADHD over time.

- **Predominantly Inattentive:** 6 or more symptoms of inattention, but not hyperactivity-impulsivity, were present for the past 6 months.
- **Predominantly Hyperactive-Impulsive:** 6 or more symptoms of hyperactivity-impulsivity, but not inattention, were present for the past 6 months.
- **Combined:** 6 or more symptoms of inattention and 6 or more symptoms of hyperactivity-impulsivity were present for the past 6 months.

The DSM-5 also outlines criteria for specifying severity of the disorder:

- **Mild:** Few, if any, symptoms in excess of those required to make the diagnosis are present, with symptoms resulting in minor functional impairments.
- **Moderate:** Symptoms or functional impairment between "mild" and "severe" are present.
- **Severe:** Many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present, or the symptoms result in marked impairment in functioning.

1.1.4 Onset and progression

Onset of ADHD is typically considered to occur as a young child, with the average age of diagnosis being around 6 to 8 years, however changes in diagnostic criteria over time have revealed uncertainty on the topic. Onset of ADHD was previously considered to begin before a child reached 7 years [1, 2]. More recently, the DSM-5 has increased the age of onset to before 12 years [3]. Prevalence is higher in children and adolescents than adults, which has led researchers to believe that ADHD does not

always persist into adulthood. There is evidence to suggest it may persist into adulthood for around 65% of cases [4]. Considering ADHD is viewed as a neurodevelopment disorder, whether it can appear de novo in adults is a topic of ongoing debate [3].

1.1.5 Treatment

While there are no curative treatments, ADHD is typically managed by a combination of pharmacological and non-pharmacological interventions, dependent on level of impairment and presence of comorbidities. For milder cases, young children, or for those who do not respond positively to medication, non-pharmacological treatments could include dietary adjustments (e.g. excluding artificial additives), behavioural interventions (e.g. parent training), and neurocognitive therapies (e.g. memory training) [4]. While behavioural interventions are the most widely used approach, there is evidence that they may work best alongside medication rather than as a sole form of management [4]. Pharmacological treatments include use of stimulants (amphetamine and methylphenidate) or non-stimulants (atomoxetine, guanfacine and clonidine), depending on the individual [5]. However, due to possible side effects and questions around efficacy, exploration of how best to manage ADHD is ongoing [3].

1.2 Prevalence

To describe the prevalence of ADHD among children and adolescents in Australia, three key data sources were used.

The **2018 ABS Survey of Disability, Aging and Carers (SDAC)** is a national survey designed to provide reliable estimates of the prevalence of different disabilities in Australia. In 2018, a multi-stage area sampling approach was used to identify a random sample of 31,000 Australian households. This sample included a number of exclusions, including households in very remote areas. A total of 27,573 households were contactable and invited to participate in the survey and data were available for analyses for approximately 21,983 households (79.7% response rate). Respondents were asked are a series of questions to identify if anyone in their household had social, emotional, behavioural, learning, or mental health difficulties; and if 'yes' the respondent was asked to identify the condition/s the individual is experiencing, including ADHD. Survey responses were used to estimate total population prevalence of ADHD, with sub-group analysis presented by age, gender, and a range of sociodemographic variables. Previous surveys conducted (2003, 2009, 2012, 2015) can be used to explore the trends in prevalence over time.

The **2013-14 Australian Child and Adolescent Survey of Mental Health and Wellbeing** (Young Minds Matter; YMM) sought to estimate the prevalence, severity, and impact of mental health disorders in children and adolescents in Australia. The survey aimed to collect information from a random sample of 5,500 families with children and adolescents aged 4-17 years across Australia, with the exception of very remote areas. An additional random sample of 800 families with adolescents aged 16-17 was included to enable estimates specific to this age group. Area based sampling was used and where there were more than one child in a household, one child was selected at random. In total, 6,310 parents responded (55% response rate) and 2,967 (89%) children and adolescents aged 11-17 years in those households for whom their parents had given permission also completed a questionnaire. Parents completed the Diagnostic Interview Schedule for Children Version 4 (DISC-4), a validated tool

for identifying mental health disorders (including ADHD) according to criteria specified in the DSM-4. The survey was previously conducted in 1998, enabling exploration of prevalence over time.

The **2018 Australian Early Development Census (AEDC)** is a national census of children's early development and readiness for school, completed by teachers for children in their first year of full time school (i.e. when children are aged 4-6 years, with the majority of children 5 years old). The census aims to collect information on all children across Australia in their first year of full time school, with a participation rate of 96.4% or 308,953 children, through information collected from 17,508 teachers across 7,507 schools, achieved in the 2018 census. As part of the census, teachers were asked if children had a special needs status; if 'yes', they then selected from a number of medical diagnoses that qualify the child to have special needs, including ADHD. The AEDC is conducted triennially and information collected in 2009, 2012, and 2015 can be used to compare prevalence rates over time.

1.2.1 Overall prevalence[3]

The SDAC reported ADHD to be one of the most common disabilities among children and adolescents aged 0-14 years. Specifically, ADHD was found to effect around 1 in 6 children with a disability (53,800, 15.0%), which equates to 1.2% aged 0-14 years in Australia. YMM found that 7.4% (298,000) of children and adolescents aged 4-17 years had ADHD. Data collected via the AEDC indicated that 0.3% (1,024) of children in their first year of school across Australia had ADHD.

Differences in prevalence rates are likely to be influenced by differences in the age range of children and adolescents included in each data source (see Section 1.2.3). Primarily, however, differences in prevalence are likely to reflect differences in methodology including samples, survey respondents (i.e. caregiver versus teacher) as well as how ADHD was determined (see Section 1.2 above). Considerably higher prevalence identified through YMM might suggest that a larger proportion of children and adolescents experience symptoms of ADHD that would qualify for diagnosis, compared to the proportion of the population who have received an ADHD diagnosis.

Internationally, systematic reviews and meta-analyses have estimated global prevalence of ADHD to be between 2-7% [6]. Polanczyk and colleagues combined studies that included cases diagnosed using the DSM or International Classification of Disease (ICD) criteria and found worldwide prevalence among 0-18 year olds to be around 5%, concluding that differences in prevalence rates were a reflection of differing methodology and diagnostic criteria [7]. While there are studies from the US that report prevalence rates as high as 10% [8], research in the UK estimated national prevalence among children aged 6-8 years to be 1.4%, based on caregiver reports of professional diagnosis and extrapolated to the national population [9].

[3] The Inclusive Education Support program (IESP), an annual collection of information from schools on students with disability, is used to provide the Department with an understanding of the prevalence of disability among students in primary and secondary schools in South Australia. The IESP, however, does not collect information on prevalence of ADHD in particular. Therefore prevalence rates presented throughout this chapter are not able to be compared to internal Department data sources.

1.2.2 Prevalence by gender

Although prevalence rates differ depending on the data source used, across all sources, prevalence of ADHD in males was typically at least double than that in females. However, it is unclear whether this is due to true differences in prevalence between genders, or if ADHD is more likely to go undetected in females and is not formally diagnosed at the rate it is in females [6].

The SDAC reported prevalence of ADHD among males aged 0-14 years was 1.8%, compared to 0.5% among females. YMM reported a prevalence of 10.4% among males aged 4-17 years, compared to 4.3% for females. Data collected via the AEDC indicated that 0.5% of males in their first year of full time school had ADHD, compared to 0.1% of females.

1.2.3 Prevalence by age

The SDAC reported prevalence of ADHD to be highest in children aged 5-9 years (1.7%), followed by 10-14 years (1.6%), and 0-4 years (0.2%). YMM reported higher prevalence of ADHD among children aged 4-11 years (8.2%), relative to those aged 12-17 (6.3%). This was attributed to lower prevalence among adolescent females compared with those aged 4-11 years (2.7% versus 5.4%, respectively), while prevalence in males was around 10% across both age groups. Prevalence by age according to AEDC data are not reported as the majority of children included in data collection were aged 5 years.

1.2.4 Prevalence by other socio-demographic characteristics

YMM also reported prevalence of ADHD across a range of other socio-demographic factors, including family type, household income, parent education and labour force status, area of residence and level of family functioning (Table 1). Overall, prevalence of ADHD was highest among children and adolescents aged 4-17 years who did not live with their original family (i.e. their biological, adoptive or foster parents); were from a household in the lowest income bracket; had parents/carers with low educational attainment or those not in the labour force; and those with poor family functioning.

Table 1. Prevalence of ADHD by socio-demographic characteristics as reported by YMM

	% of children and adolescents
Family type	
Families with two parents/carers	6.5
Original family	5.7
Step family	7.9
Blended family	13.4
Families with one parent/carer	11.1
Household income	
$130,000+ per year	5.2
> $52,000 and < $130,000 per year	6.6
< $52,000 per year	11.7
Parental education	
Bachelor degree or higher	5.4
Diploma or certificate III/IV	8.6
Year 11 or 12	8.0
Year 10 or below	11.7
Parental labour force status	
Both parents/carers employed	5.8
One parent/carer employed, one parent/carer unemployed	7.0
Both parents/carers unemployed	15.6
Sole parent/carer employed	7.7
Sole parent/carer unemployed	15.3
Family functioning	
Very good	5.6
Good	7.8
Fair	12.3
Poor	18.1

Neither the SDAC nor YMM included information on the prevalence of ADHD in children and adolescents with an Aboriginal and/or Torres Strait Islander background. It was reported that measurement of mental health and wellbeing in Aboriginal children would require a more culturally appropriate survey [10]. The AEDC collected information for children with an Aboriginal and/or Torres Strait Islander background, however. This was often done in conjunction with a cultural consultant who was able to contribute additional knowledge of children's cultural context to support teachers in completing the census. The AEDC found an ADHD prevalence rate of 0.9% among children with an Aboriginal and/or Torres Strait Islander background, and 0.3% among children who did not have an Aboriginal background.

1.2.5 Prevalence by level of severity/impairment

None of the data sources collected information on the prevalence of different severities of ADHD, as defined by the DSM-5. While different presentations of ADHD are not indicative of levels of severity, YMM reported prevalence of each sub-type as follows; inattentive was the most common (3.4%), followed by combined type (2.8%) and hyperactive type (1.2%). This contrasts with other reviews of ADHD which have cited combined type as the most prevalent [4].

In children and adolescents with ADHD, severity of impact on school or work, family, friends and social activities, and impact on self (i.e. level of distress caused by symptoms) was reported in YMM. Around 1 in 10 (10.3%) children and adolescents reported experiencing severe impact on at least one of these domains, around 1 in 4 reported moderate impact (23.4%), and 65.7% reported mild impact. The highest levels of impairment were related to school, work and family domains. Children and adolescents reported that friends and social activities were the least impacted, with 40.9% experiencing no impact in this domain as a result of ADHD.

1.2.6 Trends in prevalence over time

Tables 2-4 present ADHD prevalence over time, as measured by the SDAC, YMM, and AEDC. The SDAC shows that overall prevalence decreased between 2003 and 2009, but increased in 2018 back to the rate it was in 2003 (1.2%; Figure 1). Prevalence rates by age show an increase in ADHD among children aged 5-9 years, and a decrease among those aged 10-14 years over time. In contrast, YMM found prevalence slightly decreased over time, with the largest decrease in children aged 6-11 years. Finally, prevalence of ADHD as measured by the AEDC was shown to maintain over time.

Table 2. Prevalence of ADHD as measured by the SDAC over time

	2003 n (%)	2009 n (%)	2012 n (%)	2015 n (%)	2018 n (%)
Overall					
0-4 years	–	900 (0.1)	–	–	2,600 (0.2)
5-9 years	15,700 (1.2)	14,800 (1.1)	11,700 (0.8)	21,900 (1.5)	27,400 (1.7)
10-14 years	28,900 (2.2)	20,300 (1.5)	19,200 (1.4)	21,400 (1.5)	24,300 (1.6)
All ages	45,000 (1.2)	35,000 (0.8)	31,300 (0.7)	41,100 (0.9)	53,800 (1.2)
Males					
0-4 years	–	900 (0.1)	–	–	2,600 (0.3)
5-9 years	12,700 (1.9)	13,500 (2.0)	10,300 (1.4)	18,100 (2.3)	21,900 (2.7)
10-14 years	21,700 (3.2)	14,600 (2.0)	13,300 (1.9)	18,300 (2.5)	19,900 (2.6)
All ages	35,700 (1.8)	29,600 (1.4)	22,300 (1.0)	33,000 (1.4)	42,700 (1.8)
Females					
0-4 years	–	–	–	–	0 (0.0)
5-9 years	4,100 (0.7)	1,600 (0.2)	4,800 (0.7)	3,600 (0.5)	7,600 (1.0)
10-14 years	6,500 (1.0)	5,700 (0.8)	4,000 (0.6)	4,000 (0.6)	6,000 (0.8)
All ages	7,800 (0.4)	5,700 (0.3)	8,100 (0.4)	7,900 (0.4)	11,500 (0.5)

Note. Subgroup prevalence estimates are subject to large standard errors and should be taken with caution. Prevalence could not be estimated for children aged 0-4 years in some instances due to small cell size.

Figure 1. Prevalence of ADHD as measured by the SDAC over time

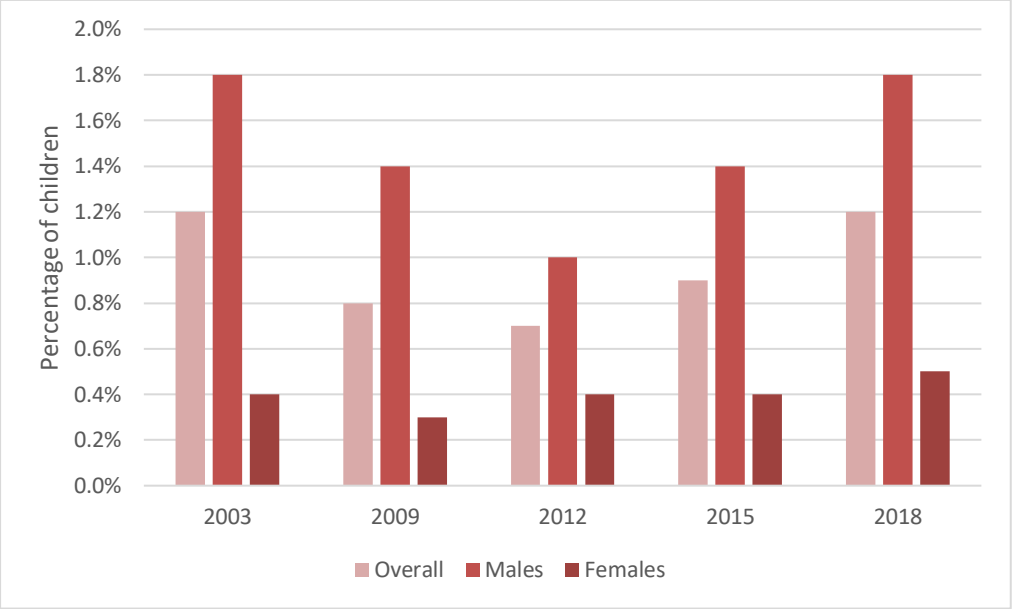

Table 3. Prevalence of ADHD as measured by YMM over time

	1998 %	2013-14 %
Overall		
6-11 years	12.6	9.2
12-17 years	7.1	6.3
All ages	9.8	7.8
Males		
6-11 years	16.7	12.3
12-17 years	10.9	9.8
All ages	13.8	11.0
Females		
6-11 years	8.3	5.9
12-17 years	3.1	2.7
All ages	5.7	4.3

Note. Data are presented for children aged 6-17 years only (i.e. 4-5 years are excluded) to enable valid comparisons with previous data. Population estimates are not provided for the 1998 collection so we are able to present percentages only.

Table 4. Prevalence of ADHD as measured by the AEDC over time

	2015 n (%)	2018 n (%)
Overall	757 (0.3)	1,024 (0.3)
Male	604 (0.4)	843 (0.5)
Female	153 (0.1)	181 (0.1)

Note. Although the AEDC was also conducted in 2009 and 2012, ADHD was only included in the previous two censuses. Prevalence by age is not presented as the majority of children included in the AEDC are aged 5 years.

Since the first version of the diagnostic criteria for ADHD in the 1980s, increased awareness of the disability led to increased research globally and consequently varying rates of prevalence [4, 7]. This heterogeneity, and high prevalence rates in countries such as the US, has led many people to believe ADHD to be a product of western values and technologies.

Importantly, several changes in diagnostic criteria may have contributed to shifts in prevalence over time. The fifth edition of the DSM was introduced in 2013. In this edition, the age of onset was increased from 7 to 12 years of age, as a result of evidence that differences in age of diagnosis did not result in cases differing clinically (e.g. severity, outcome, or treatment response) [1]. At this time, dual diagnosis of ADHD and Autism Spectrum Disorder was also introduced, which had been prohibited in previous editions. As described by Faraone and colleagues, such diagnostic changes could contribute to the sense that ADHD prevalence is on the rise [4].

However, recent systematic reviews and meta-analyses argue that, after taking into account varied methodologies and diagnostic criteria, the global prevalence of ADHD has remained stable over the last 30 years [4, 7, 11, 12].

1.3 Complex needs

Children and adolescents with ADHD may experience additional disabilities or mental health difficulties, the presence of which lead to more severe impairment and require more support. Multiple or complex needs also make diagnosis difficult as symptoms overlap and can be hard to differentiate.

1.3.1 Prevalence of comorbidities

In Australia, Efron and colleagues [2, 5] explored comorbidities among a sample of 190 children aged 4-9 years who were referred to an ADHD assessment clinic for diagnosis throughout 2004-14. Of the 132 children diagnosed with ADHD, 76.5% had one or more comorbidities. In order of prevalence, these were; oppositional defiant disorder (53.0%), anxiety disorder (23.5%), learning disability (15.9%), language disorder (14.4%), mood disorder (5.3%), autism spectrum disorder (3.8%), intellectual disability (3.8%), conduct disorder (2.3%), and developmental coordination disorder (0.8%). The authors highlighted the importance of differential diagnoses of comorbidities to ensure that appropriate interventions can be offered.

Other research has shown that children with ADHD experience a number of health-related impairments, which together, have a negative effect on functioning and quality of life. For instance, Sciberras and colleagues explored health-related impairments among children aged 6-8 years in an Australian community, both with (n=177) and without ADHD (n=212) [13]. Results showed that

children with ADHD were more likely to experience other mental health disorders (e.g. separation anxiety disorder, generalized anxiety disorder, major depression, oppositional defiant disorder, and conduct disorder) or autism spectrum disorder, relative to their non-ADHD peers. Presence of ADHD in combination with mental health challenges increased the risk of sleep problems and a higher BMI, compared to that of children without ADHD. Other studies in Australia have also shown that ADHD and mental health and/or psychiatric comorbidities are associated with poorer quality of life and functioning in children [14, 15].

1.3.2 Help seeking behaviours as a possible driver of complex needs

Help seeking behaviours for mental health disorders, including ADHD, may be influenced by a range of factors, such as perceived need, parental and personal beliefs, cultural attitudes, as well as services available. YMM collected information on service use among children and adolescents, as well as the perceived need of and barriers to receiving mental health care.

About half (50.7%) of all children and adolescents aged 4-17 years with ADHD were reported to have accessed health or school services for emotional or behavioural issues in the past 12 months. Health service use (e.g. general practitioner, psychologist, social worker, counsellor) was highest among children and adolescents aged 4-17 years who reported their ADHD had a severe impact on their lives (88.1%), followed by those who experienced moderate (72.0%) and mild impact (37.0%). Similarly, school service use (e.g. individual or group counselling, special classes, school nurse) was highest among those who reported severe impacts as a result of ADHD (70.6%), followed by children and adolescents who moderate (56.5%) and mild impacts (24.9%). About 1 in 6 children and adolescents aged 4-17 years with ADHD reported taking medication for emotional or behavioural problems within the past two weeks. This was considerably higher among the older age group of children (i.e. 21.5% of those aged 12-17 years vs 14.3% among children aged 4-11 years).

Although not specific to ADHD, service use (including health, school, online and telephone services) among children and adolescents aged 4-17 years with a mental health disorder (i.e. including, but not limited to ADHD) varied by a range of demographic factors. For instance; service use was higher among those in the lowest income bracket (61.9%), those with the least educated parent/carer (year 10 or below; 62.2%), relative to those in the highest income bracket (50.6%) and those with a more educated parent/carer (diploma or certificate 56.3%; bachelor degree or higher 55.5%).

Information on service use is not directly comparable between the 2013-14 YMM and previous data collection in 1998. In 1998, parents were asked about use of services in the past 6 months, while in YMM they were asked about use of services in the past 12 months. Further, the service use module was re-developed for YMM based on the current health care environment and thus the types of services included in both surveys differed. In order to provide comparison of service use between 1998 and 2013-14, health and school services common across both surveys were identified.

Among children and adolescents aged 6-17 years with either major depressive disorder, ADHD or conduct disorder, 31.2% had used services in the six months prior to the 1998 survey, while 68.3% had used services in the 12 months prior to the 2013-14 survey. There was a greater apparent change in use of school services for emotional or behavioural problems. In the six months prior to the 1998 survey 19.2% of children or adolescents with one of the three mental disorders common to both

surveys had used a school service, while 54.0% of children or adolescents had used a school service in the 12 months prior to the 2013-14 survey. While differences in questions and time period make comparisons difficult, authors highlight that the increase in use of services is unlikely to be attributable to changes in methodology alone. Overall, authors conclude that the data suggest there has been a significant increase in service use by children and adolescents with mental disorders in Australia between 1998 and 2013-14 [16].

1.4 Associated factorsFactors associated with prevalence of disability

The key factors associated with the prevalence of ADHD are genetic, environmental, and/or pre- and perinatal factors. While genetics and heritability have been described to account for 60-90% of ADHD cases, this leaves 10-40% influenced by environmental factors [3]. ADHD is believed to be mostly multifactorial in its aetiology, and caused by complex interactions of the above elements [4, 17].

Research has demonstrated a high heritability of ADHD and that molecular genetics play a key part in its causation [4, 17]. This can make identifying environmental factors difficult as genes confound parent-level variables as well as presence of ADHD, and thus the contribution of environmental factors alone cannot be determined. For example, genes linked to ADHD may influence certain behavioural patterns that have been linked with ADHD, such as maternal smoking during pregnancy [4]. Other prenatal and perinatal factors that may increase risk of ADHD include alcohol use, premature birth, low birthweight, and exposure to certain environmental toxins including polychlorinated biphenyls, organophosphate pesticides, zinc, and lead [4, 18, 19].

Sociodemographic factors are also associated with the prevalence of ADHD, such as low household income [10], which is supported by prevalence figures reported above. Faraone and colleagues argue this does not necessarily support the conclusion that a low socioeconomic status increases risk of ADHD because the disorder has high heritability (i.e. runs in families) and can lead to poorer education outcomes, in turn leading to an over-representation of socioeconomic disadvantage among families affected by ADHD [4]. However, a study in the US found that low socioeconomic status increased the risk of ADHD in children after accounting for parental diagnosis of ADHD, suggesting that, in children without genetic predispositions, low socioeconomic status and environments of adversity still have a significant influence on prevalence [20].

Finally, recent research synthesising international evidence for the relationship between a variety of sedentary behaviours and mental health in school-aged children has demonstrated a positive relationship between screen time and hyperactivity and inattention (i.e. not ADHD per se, but the symptoms that children with ADHD present) [21].

1.4.2 Trends in associated factors over time

Overall, trends in the factors associated with ADHD are varied, with some factors increasing, others decreasing, and some maintaining over time. As described in Section 1.2.6 however, evidence suggests the global prevalence of ADHD has remained stable over the last 30 years. In Australia, the reported prevalence of ADHD has followed similar trends, with increased awareness and screening for ADHD likely contributing to any increases in prevalence [22].

There has been little change in the proportion of babies born with a low birthweight or pre-term in Australia between 2007 and 2017 [23]. In South Australia specifically, however, as reported by the Pregnancy Outcome Unit which undertakes statewide monitoring of pregnancy characteristics and outcomes, the percentage of low birthweight babies (<2,500g) increased slightly from 6.8% in 2001 to 7.3% in 2017, while the percentage of very low birthweight babies (<1,500g) remained stable (1.6%) during this period [24]. The proportion of babies born preterm (<37 weeks gestation) in South Australia has also increased slightly between 2001-2017, from 8.1% to 9.6% [24]. In contrast, there have been reductions in smoking and alcohol consumption during pregnancy in Australia over time. The proportion of women who reported smoking at any time during pregnancy in Australia has fallen from 13.7% in 2010 to 9.9% in 2017 [23]. In South Australia specifically, the proportion of women who reported smoking during pregnancy decreased from 13.5% in 2010 to 8.5% in 2017 [24]. Similarly, according to the National Drug Strategy Household Survey, the proportion of women in Australia abstaining from drinking alcohol while pregnant increased from 40% in 2007 to 56% in 2016 [25].

Increased exposure to screen time among children in Australia has been highlighted in recent years, with children aged 7-9 years spending on average 3-9 hours per day engaging in screen-based media [26]. In South Australia specifically, Bell and colleagues found that only 17% of children aged 5-12 years met the recommended amount of screen time of less than 2 hours a day [27]. Currently however, there is little evidence to suggest that screen use above or below what is specified in such guidelines is or is not harmful to development.

1.5 Quality of prevalence evidence The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) is a checklist of items that should be included in all reports of observational studies [28]. As an indicator of quality, we have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

- **2018 SDAC:** the most comprehensive national survey of disability among people of all ages in Australia, the SDAC relies on the accurate self-report of conditions (including ADHD) and in 2018, achieved a household response rate of about 80%. A common issue discussed however, is the reliability of prevalence estimates when disaggregated due to sample size. For example, when breaking down data according to age, gender, and socioeconomic status, high relative standard of error rates (as noted in the footnote of Table 2), mean estimates in some categories should be used with caution or are considered too unreliable for most purposes.
- **2013-14 YMM:** the largest national survey exploring the mental health of children and adolescents in Australia, YMM has strength in that it uses the DISC-4 to assess ADHD based on DSM-4 criteria (i.e. identification of conditions does not rely on parent- or self-report). Participant exclusion criteria (young people living in very remote areas, with an Aboriginal or Torres Strait Islander background, and experiencing homelessness or living in institutional care; all sub-populations that are likely to experience greater mental health concerns) and a low household response rate (55%), however, might hinder confidence in the accuracy of ADHD population prevalence estimates.
- **2018 AEDC:** of all data sources used in this chapter, the AEDC is the only true “census” as it seeks to collect information for all children in their first year of school across Australia. Population

estimates do not need to be calculated because actual population prevalence is collected. Important to note, however, is that prevalence of ADHD as reported by the AEDC is reliant upon teacher knowledge of children's diagnosis of ADHD.

1.6 Information sources

To identify relevant evidence beyond that presented in the surveys above (i.e. comorbidities and factors associated with the prevalence of ADHD), databases (namely, Embase, PubMed, PsychInfo, and Web of Science) were searched using key terms: child/ren, adolescent/s, Attention Deficit Hyperactivity Disorder, ADHD, prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including the Lancet, International Journal of Epidemiology, Nature Reviews, and Pediatrics.

2. Autism Spectrum Disorder

Key findings

Findings presented in this chapter demonstrate that Autism Spectrum Disorder (ASD) is one of the most common disabilities among children and adolescents. The 2018 Survey of Disability, Aging and Carers (SDAC) reported autism and related disorders was found to effect around 1 in 4 children with a disability (95,800, 26.8%), which equates to 2.1% aged 0-14 years in Australia. Further, evidence demonstrates that prevalence of ASD is more than three times higher in males compared to females, and is more prevalent in children and adolescents from socioeconomically disadvantaged backgrounds. While the aetiology of ASD is not fully understood, it is believed to be highly heritable (estimates from the international literature range from about 50-95%) and the result of complex genetic and environmental interactions. The main environmental risk factors for ASD include pre- and perinatal factors, maternal dietary and lifestyle factors, alcohol and smoking, and environmental chemicals. Prevalence of ASD in Australia has increased by more than four times within the last 15 years. Changes to diagnostic criteria and increased public awareness have contributed to increases in ASD prevalence over time, but it is difficult to determine the extent to which these factors have increased prevalence, compared to increases of true prevalence in the community.

2.1 Background

2.1.1 Definition

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [DSM-5; 1], describes ASD as the presence of two main difficulties; social communication, and restricted, repetitive behaviour or interests.

2.1.2 Presentation and key characteristics

Symptoms of ASD among children and adolescents fall into two key categories.

Difficulties in social communication:

- Deficits in social-emotional reciprocity (e.g. an abnormal social approach and failure in back-and-forth conversation; little sharing of interests, emotions, or affect; failure to initiate or respond to social interactions).
- Deficits in non-verbal communicative behaviours used for social interaction (e.g. poorly integrated verbal and non-verbal communication; abnormalities in eye contact and body language or deficits in understanding and use of gestures; lack of facial expressions and non-verbal communication).
- Deficits in developing, maintaining, and understanding relationships (e.g. difficulties adjusting behaviour to suit various social contexts; difficulties in sharing imaginative play or in making friends; absence of interest in peers).

Restricted, repetitive behaviour or interests:

- Stereotyped (i.e. aimless) or repetitive motor movements, use of objects, or speech (e.g. simple motor stereotypies, lining up toys or flipping objects, echolalia; that is, repeating others' words and/or sentences, idiosyncratic phrases).

- Insistence on sameness, inflexible adherence to routines, or ritualised patterns (e.g. extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to travel same route or eat same food every day).
- Highly restricted, fixated interests that are abnormal in intensity or focus (e.g. preoccupation with unusual objects, excessively circumscribed or perseverative interest).
- Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g. indifference to pain, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

2.1.3 Diagnosis

ASD is diagnosed by professionals, such as paediatricians and psychiatrists, using the DSM-5 diagnostic criteria and diagnostic assessments. Each of the following criteria must be met:

- Have difficulties in all social communication items, and at least two items from the restricted, repetitive behaviour or interests category.
- Have had symptoms from early childhood, even if symptoms do not limit functioning until later in childhood.
- Symptoms cause significant impairment, at school, home, or socially.
- Symptoms are not better explained by another mental health disorder.

Diagnosis of ASD is made after a multidisciplinary diagnostic assessment, where professionals observe the child/adolescent interacting with others, interview caregivers, and review developmental history.

Former subtypes used in the DSM-4, such as Asperger Syndrome, are being phased out. Rather, the DSM-5 includes a severity ranking to reflect the spectrum of autism and differences in levels of functioning. Rankings can be given separately for social and non-social difficulties (i.e. repetitive behaviours) as an individual may be high functioning in social communication but low functioning in non-social behaviours and vice-versa. Examples of severity levels are provided below.

Level 1: Requiring support

- Without supports in place, deficits in social communication cause noticeable impairments. May have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engage in communication but whose back-and-forth conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.
- Inflexibility of behaviour causes significant interference with functioning in one or more contexts.

Level 2: Requiring substantial support

- Marked deficits in verbal and non-verbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others.
- Inflexibility of behaviour, difficulty coping with change, or other restricted/repetitive behaviours appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts.

Level 3: Requiring very substantial support

- Severe deficits in verbal and non-verbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions; and minimal response to social overtures from others.
- Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours markedly interfere with functioning in all spheres.

ASD diagnosis also requires specification of whether the diagnosis is accompanied by an intellectual and/or language impairment. Sometimes, those with ASD and an intellectual disability might be referred to as 'low-functioning', while those without an intellectual disability might be considered 'high-functioning', but this is often seen as too reductionist as it does not provide enough information on how a person's functioning or experiences may be impacted by ASD.

2.1.4 Onset and progression

ASD is considered to be a developmental condition that is often identified early, at around 2 years of age, with diagnosis occurring on average around 4 years of age. It is a lifelong condition but there is evidence that children who are diagnosed earlier, before or around the age of 4, are more likely to benefit from early interventions and support which may improve symptom severity later in life. International research indicates that children receiving later diagnoses are those more likely to present with no language delays, be female, of ethnic minorities, culturally and linguistically diverse or low socioeconomic backgrounds [29].

ASD's impact on functioning may be exacerbated during adolescence, when social communication difficulties can make interactions with peers difficult, or during the transition into young adulthood if routines and levels of independence change. Since the 1990s, the neurodiversity movement has had an influence on how ASD is perceived, highlighting that how one person grows up with autism may be very different from another's experience. There is evidence to suggest that there are a small proportion of autistic children who achieve an 'optimal outcome' in adulthood, where symptoms have reduced so much that they no longer meet the diagnostic criteria for autism [30]. This is more likely in children who were diagnosed early and able to receive early intensive treatments or interventions. Of course, the idea of an 'optimal outcome' may be refuted by those questioning who decides what is 'optimal' but it does provide useful information on how ASD may change over time and the interventions that may be able to alleviate stress for families.

2.1.5 Treatment

As with many other developmental conditions, there is no 'cure' and opinions on the value of aiming to 'cure' autism are varied. Management and support for children and adolescents with ASD varies depending on the severity of symptoms and level of functioning. Seeking different levels of support and treatment may be a very personal and individual process for parents and caregivers that involves accepting their child's identity whilst still acknowledging there are some symptoms it would be helpful to improve (e.g. those that may cause harm). Many interventions are related to skills and behaviours, focusing on supporting parents/caregivers and children to engage with others and helping children with the particular challenges that they face. Some children and adolescents with co-occurring conditions, such as ADHD, may also be treated using medication.

2.2 Prevalence

To describe the prevalence of ASD among children and adolescents in Australia, three key data sources were used.

The **2018 ABS Survey of Disability, Aging and Carers (SDAC)** is a national survey designed to provide reliable estimates of the prevalence of different disabilities in Australia. In 2018, a multi-stage area sampling approach was used to identify a random sample of 31,000 Australian households. This sample included a number of exclusions, including households in very remote areas. A total of 27,573 households were contactable and invited to participate in the survey and data were available for analyses for approximately 21,983 households (79.7% response rate). Respondents were asked are a series of questions to identify if anyone in their household had social, emotional, behavioural, learning, or mental health difficulties; and if 'yes' the respondent was asked to identify the condition/s the individual is experiencing, including ASD. Survey responses were used to estimate total population prevalence of ASD, with sub-group analysis presented by age, gender, and a range of sociodemographic variables. Previous surveys conducted (2003, 2009, 2012, 2015) can be used to explore the trends in prevalence over time.

The **2018 Australian Early Development Census (AEDC)** is a national census of children's early development, completed by teachers for children in their first year of full time school (i.e. when children are aged 4-6 years, with the majority of children 5 years old). The census aims to collect information on all children across Australia in their first year of full time school, with a participation rate of 96.4% (308,953), through information collected from 17,508 teachers across 7,507 schools, achieved in the 2018 census. As part of the census, teachers were asked if children had a special needs status; if 'yes', they then selected from a number of medical diagnoses that qualify the child to have special needs, including autism, ASD and Asperger Syndrome. The AEDC is conducted triennially and information collected in 2009, 2012, and 2015 can be used to compare prevalence rates over time.

Two studies using data from the **Longitudinal Study of Australian Children (LSAC)** were included to provide further information on ASD in the Australian context. Sampled first by postcode and then by the Australian Medicare database, LSAC cohorts are described to be representative of the population of children in Australia. However, there is evidence to suggest that the LSAC under-represents disadvantaged families in the population. The B (5,107 children, born 2003-2004) and K (4,983 children, born 1999-2000) cohorts were recruited in 2004. Prevalence of ASD was reported twice: when children were 6-7 years, and then again at 10-11 years [31, 32]. In interviews, parents were asked if their child had any ongoing conditions, from which they could select 'autism, Asperger's, or other autism spectrum' as a response. Parents were also asked about the severity of their child's condition (mild/moderate/severe).

The Inclusive Education Support program (IESP) is a functional needs-based funding model for students with a disability in South Australia. Data are collected annually, providing the Department with an understanding of the prevalence of different types of disabilities among students in primary and secondary schools. Eligibility for the IESP is based on clinical diagnosis or referrals from speech-language pathologists. Eligibility criteria are aligned with the national disability legislation and guidelines, and focus on a child's needs rather than their disability diagnosis or label. This approach is

designed to recognise all disabilities and learning difficulties, including mental health, trauma, complex behaviours and complex health care needs.

2.2.1 Overall prevalence

ASD is one of the most common disabilities among children and adolescents. In children aged 0-14, the SDAC estimated that 'autism and related disorders' accounted for 26.8% (95,800) of children with a disability, and that prevalence in the population was 2.1% among the same age group. According to data collected via the AEDC, the prevalence of ASD among children aged 4-6 years was 2.3% (7,161). LSAC data indicated prevalence of ASD among children aged 6-7 years ranged from 1.5% (58 children, K cohort) to 2.5% (107 children, B cohort). Prevalence of ASD for the same cohorts, aged 10-11 years, ranged from 2.4% (78-92 children, K cohort) to 3.9% (117-145 children, B cohort) [32]. The sample sizes are reported as a range due to missing data across outcomes of interest.

Data collected through the IESP reported that 3.5% (6,166) of primary and secondary school students in South Australia had an ASD diagnosis (inclusive of Asperger Syndrome).

Internationally, based on systematic reviews and meta-analyses, prevalence of ASD among children and adolescents in high income countries is estimated to be around 1-1.5% [33-35]. However, reports from the US typically indicate higher prevalence. For example, using results from the US National Health Interview Survey, Xu and colleagues [36] estimated prevalence of ASD among children and adolescents aged 3–17 years in 2016 to be nearly 2.8%. ASD prevalence in the UK is considered to be more aligned with the global estimate of 1-1.5% [37]. Prevalence estimates can vary depending on the sources of data used (e.g. administrative data and population surveys) and a recent study indicated that ASD as measured by parent and teacher reports can lead to overestimates of prevalence [37].

Some points should be noted when considering these prevalence figures. The SDAC groups ASD together with conditions previously described as subtypes of ASD (Rett Syndrome and Asperger Syndrome). It also uses the International Classification of Diseases: 10th Revision (ICD-10), which still uses subtypes in the diagnosis of ASD, to classify disabilities. The ICD-11, which will come into use in 2022, mirrors the DSM-5 in that it will favour a continuous spectrum of ASD. This should be kept in mind when considering the SDAC prevalence estimates, and how they might change in the future. The AEDC collects information separately for autism, ASD, and Asperger Syndrome, and the prevalence figure above relates to children who were reported to have at least one of these conditions.

2.2.2 Prevalence by gender

ASD prevalence was more than three times higher in males compared to females. The SDAC reported prevalence of ASD among males aged 0-14 years was 3.1%, compared to 0.9% among females. Similarly, 3.6% of males in their first year of full time school were reported to have ASD, compared to 1.0% of females as captured by the AEDC. Lastly, although separate prevalence rates for males and females were not provided, around 80% of children with ASD in both LSAC cohorts were male.

An international meta-analysis of the proportion of males and females with ASD found that, although males are more likely to have ASD, there may exist a diagnostic gender bias, with females who meet diagnostic criteria for ASD less likely to be diagnosed than males [38].

2.2.3 Prevalence by age

As reported by the SDAC, prevalence of ASD was highest in the 5-9 year age group (2.9%), followed by 10-14 year olds (2.7%) and 0-4 year olds (0.7%). The 2.3% prevalence rate from the AEDC data relates to children, mostly aged 5 years, in their first year of full time schooling. Prevalence according to LSAC data ranged from 1.5-2.5% when cohorts were aged 6-7 years, and 2.4-3.9% at 10-11 years.

2.2.4 Prevalence by other socio-demographic characteristics

Data from the SDAC and AEDC, presented in Tables 5 and 6, show prevalence of ASD is higher among children from socioeconomically disadvantaged backgrounds[4], families with one parent, and children with an Aboriginal and/or Torres Strait background.

Using LSAC data, Randall and colleagues [31] found that children aged 6-7 years with ASD were more likely to live in single parent families, but other characteristics between children with and without ASD (e.g. socioeconomic status, maternal and paternal age) were relatively similar. In contrast, the later LSAC study of children aged 10-11 years found that children with ASD experienced greater socioeconomic disadvantage [32].

Table 5. Prevalence of ASD by socio-demographic characteristics as reported by SDAC

	n (%) of children and adolescents
Socio-Economic Indexes for Areas (SEIFA)	
Quintile 1 (most disadvantaged)	23,000 (2.8)
Quintile 2	15,000 (1.7)
Quintile 3	21,100 (2.3)
Quintile 4	20,700 (2.0)
Quintile 5 (least disadvantaged)	15,000 (1.5)
Family type	
One parent family	32,600 (4.1)
Couple parent family	65,000 (1.7)

[4] Socio-Economic Indexes for Areas (SEIFA) is a set of measures derived from ABS census information that summarise different aspects of socioeconomic conditions in an area. Each geographical area in Australia is given a SEIFA score that ranks the disadvantage of an area, compared with other areas across the country. Quintile 1 represents the most socioeconomically disadvantaged areas, while Quintile 5 represents the least disadvantaged areas.

Table 6. Prevalence of ASD by socio-demographic characteristics as reported by AEDC

	n (%) of children
Socio-Economic Indexes for Areas (SEIFA)	
Quintile 1 (most disadvantaged)	1,683 (2.6)
Quintile 2	1,536 (2.6)
Quintile 3	1,534 (2.4)
Quintile 4	1,316 (2.1)
Quintile 5 (least disadvantaged)	1,092 (1.8)
Aboriginal and/or Torres Strait Islander background	
Yes	514 (2.7)
No	6,642 (2.3)

A recent review of ASD among people with an Aboriginal and/or Torres Strait Islander background found that while prevalence rates are similar between people with and without an Aboriginal background, those with an Aboriginal and/or Torres Strait Islander background may experience higher instances of undiagnosed or misdiagnosed ASD, compared to the non-Aboriginal population [39]. This reflects reduced access to diagnostic services and in some communities, differences in cultural values surrounding individuals with a disability [39].

In the international literature there have been reports of higher ASD prevalence among socioeconomically advantaged populations, despite the burden of disability and disease usually being highest among the socioeconomically disadvantaged. While it is possible there are mechanisms through which children from advantaged backgrounds are more vulnerable to ASD, evidence suggests these differences can be attributed to access to services as well as measurement bias. For example, in Sweden, a country with free universal healthcare and routine developmental screening, ASD was found to be associated with lower income and having parents that worked manual occupations [40]. In contrast, a study from the US found a positive association between ASD diagnosis and a more advantaged socioeconomic background [41].

2.2.5 Prevalence by level of severity/impairment

None of the data sources reported on the prevalence of different severities of ASD, as defined by the DSM-5. However, using LSAC data on children aged 6-7 years, Randall and colleagues [31] reported that the majority of cases of ASD were 'mild' (64%, B cohort; 50%, K cohort), as defined by parents, while the remainder of children were reported to have either moderate or severe ASD (percentages in each category were not reported). The majority of all children with ASD, regardless of severity, were reported to have problems with social interaction (91-93% of children in B and K cohorts, respectively, with moderate-severe ASD and 80-88% of children in each cohort with mild ASD).

The SDAC collects data on the level of limitations due to disability in three core areas; communication, mobility, and self-care. These levels of limitations are defined as:

- Mild: no need for help and no difficulty, but uses aids or has limitations;
- Moderate: no need for help but has difficulty;
- Severe: needs help sometimes or has difficulty with a core activity; and

- Profound: greatest need for help, that is, always needs help with at least one core activity.

Limitations experienced by children and adolescents aged 0-14 years with ASD are shown in Table 7. For those who experienced limitations, most responses indicated either severe or profound limitations across all three areas.

Table 7. Level of limitation among children and adolescents with ASD as reported by the SDAC

		% of children and adolescents
Communication		
	No limitation	34.8
	Mild	-
	Moderate	4.4
	Severe	37.0
	Profound	23.9
Mobility		
	No limitation	13.0
	Mild	22.9
	Moderate	1.0
	Severe	25.6
	Profound	37.5
Self-care		
	No limitation	41.1
	Mild	-
	Moderate	2.2
	Severe	17.1
	Profound	39.5

Note. Response rates could not be estimated in some instances due to small cell size e.g. responses of 'mild' limitations.

2.2.6 Trends in prevalence over time

Tables 8 and 9 demonstrate shifts in ASD prevalence over time according to SDAC and AEDC data. Reports of ASD as reported by the SDAC have increased by more than four times over the last 15 years, from 0.5% in 2003, to 2.1% in 2018. Prevalence has increased steadily with each new wave of data (Figure 2), which has been consistent across age groups as well as genders. Similarly, prevalence of ASD according to the AEDC increased from 1.9% to 2.3% between 2015 and 2018, with increases over time similar for both males and females. As reported in Section 2.2.1, prevalence of ASD was higher among children in the LSAC B cohort (2.5%) relative to the K cohort (1.5%). Authors suggested that the increased prevalence of ASD among children in the B cohort, those born more recently, may be due to increasing identification of children with milder ASD [32].

Table 8. Prevalence of ASD as measured by the SDAC over time

	2003 n (%)	2009 n (%)	2012 n (%)	2015 n (%)	2018 n (%)
Overall					
0-4 years	–	2,300 (0.2)	4,100 (0.3)	2,800 (0.2)	10,800 (0.7)
5-9 years	7,800 (0.6)	17,400 (1.3)	32,500 (2.3)	37,400 (2.5)	45,700 (2.9)
10-14 years	10,900 (0.8)	15,900 (1.1)	28,300 (2.0)	36,800 (2.6)	41,100 (2.7)
All ages	18,800 (0.5)	37,600 (0.9)	64,300 (1.5)	80,100 (1.8)	97,600 (2.1)
Males					
0-4 years	–	900 (0.1)	2,000 (0.3)	1,500 (0.2)	6,800 (0.9)
5-9 years	6,500 (1.0)	14,400 (2.1)	27,900 (3.9)	30,200 (3.9)	33,500 (4.1)
10-14 years	8,200 (1.2)	14,500 (2.0)	21,800 (3.1)	28,400 (3.9)	33,800 (4.4)
All ages	15, 000 (0.8)	30,400 (1.4)	48,500 (2.2)	62,000 (2.7)	74,100 (3.1)
Females					
0-4 years	–	1,400 (0.2)	1,400 (0.2)	–	2,000 (0.3)
5-9 years	3,100 (0.5)	4,600 (0.7)	4,900 (0.7)	8,600 (1.2)	12,100 (1.6)
10-14 years	1,900 (0.3)	1,900 (0.3)	6,900 (1.0)	6,600 (1.0)	6,100 (0.8)
All ages	3,800 (0.2)	5,900 (0.3)	13,900 (0.7)	17,700 (0.8)	20,200 (0.9)

Note. Subgroup prevalence estimates are subject to large standard errors and should be taken with caution. Prevalence could not be estimated for children aged 0-4 years in some instances due to small cell size.

Figure 2. Prevalence of ASD as measured by the SDAC over time

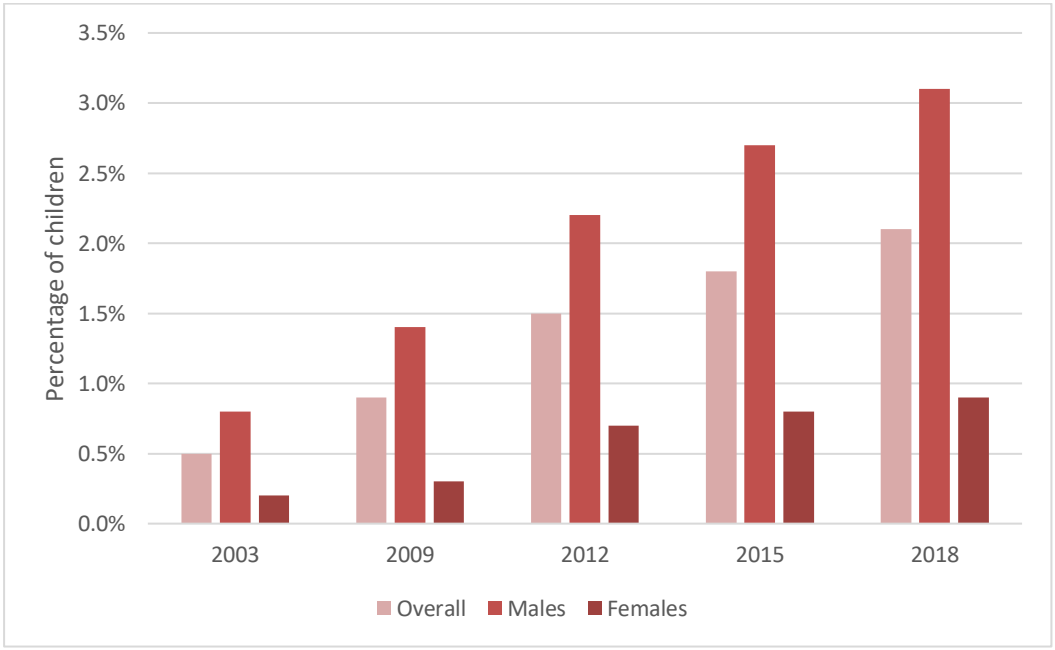

Table 9. Prevalence of ASD as measured by the AEDC over time

	2015 n (%)	2018 n (%)
Overall	5,868 (1.9)	7,161 (2.3)
Male	4,726 (3.1)	5,657 (3.6)
Female	1,142 (0.8)	1,504 (1.0)

Note. Although the AEDC was also conducted in 2009 and 2012, ASD was only included in the previous two censuses. Prevalence by age is not presented as the majority of children included in the AEDC are aged 5 years.

This evidence is aligned with information collected via the IESP in schools, which indicates a steady annual increase in the prevalence of ASD among children and adolescents in South Australia over time, from 0.6% (931 children) in 2009, to 3.5% (6,166 children) in 2019.

Historically, ASD prevalence rates have increased over time but there is evidence that this is partly due to broader diagnostic criteria, increased awareness of ASD, and an increase in relevant services, rather than a large increase of ASD in the community [33]. Indeed, a recent review argued that true prevalence of ASD in high-income countries has remained reasonably stable since 1990 [42]. Comparison of trends in Australian prevalence rates with changes in diagnostic criteria is explored in further detail below.

A study of ASD diagnoses in Western Australia reported that a prevalence increase of 11.9% per annum between 1983 and 1999 corresponded with changes in diagnostic criteria (i.e. broadening age of onset in 1987), as well as the availability and funding of services, especially for children under 5 years [43]. More recently, introduction of the DSM-5 in 2013 has had an impact on rates of ASD diagnosed. Changes in the DSM-5 included using a single category of ASD, rather than subtypes such as Asperger Syndrome, as well as the number of domains and items required for diagnosis. Previously, the DSM-4 for autism was divided into three domains of impairment: (i) social interaction; (ii) communication; and (iii) repetitive behaviour or restricted interest. Diagnosis required that an individual met at least six criteria altogether, including two from the social domain and one each from the communication and repetitive behaviour domains [44]. Now there are only two domains of impairment as described in Section 2.1.2: social communication and restricted, repetitive patterns of behaviour, interests, or activities, however all items in the social communication domain are required to be present for diagnosis [44].

Research that utilised data for more than 32,000 children aged under 7 years who were registered with Helping Children with Autism in Australia, showed that prevalence of autism increased from 2010 to 2013, and plateaued to 2015 [45]. Stricter DSM-5 criteria may have slowed the rate of diagnoses post-2013, and this had been predicted by previous research [44]. This is reflected in the SDAC data to an extent, with the increase from 2012-2015 not as large as that between 2009-2012, however drivers of the increase in prevalence in 2018 are unclear [45]. Overall, evidence indicates that changes in diagnostic criteria, along with increased awareness and screening, have influenced trends in prevalence, but it is difficult to distinguish between this effect and true increases in community prevalence.

2.3 Complex needs

Many children and adolescents diagnosed with ASD have additional disabilities and/or health conditions that can impact their day to day activities, as well as quality of life. These include other neurodevelopmental disorders, intellectual disability, and developmental delays.

2.3.1 Prevalence of comorbidities

According to a 2018 report from the National Disability Insurance Scheme (NDIS) on participants of all ages and with a primary disability of ASD, 36% had at least one secondary disability. Specifically, 15.3% had an intellectual disability, 10.6% a psychosocial disability, 7.3% a sensory or speech disability, 5.2% a neurobiological condition, 2.3% a physical disability, 1.7% global developmental delay, and 1.5% developmental delay [46]. Some individuals fall into more than one of these groups, with multiple comorbidities.

In the international literature, reports of intellectual disability alongside ASD in children vary from 11-65% [29]. In a review of ASD's changing epidemiology, Lyall and colleagues [34] write that intellectual disability is currently estimated to occur in around 30% of people with ASD compared to historical estimates of around 70%. Attention deficits are considered to occur in around 30-40% of ASD cases, with ADHD specifically estimated to occur in 28% [29, 34]. Anxiety and depression are also common among those with ASD, and may increase during adolescence. Speech and language delays are estimated to occur in 87% of three year olds with ASD [29]. Epilepsy may affect around 8.6% of people with ASD, particularly if they have an intellectual disability or are female [29]. Other comorbidities include tics (9%), sleeping problems (25-40%), restricted and rigid food choices (42-61%), obesity (23%), and gastrointestinal problems (47%) [29, 47].

2.3.2 Help seeking behaviours

Data from the SDAC were used to describe service use and need among children and adolescents aged 0-14 years with ASD. Examples of formal services include nurses, speech therapists, psychologists, teacher's aides, and government and non-government services. Table 10 shows that few children and adolescents received regular assistance, with 38.3% not receiving any assistance. While 34.8% of children and adolescents reported they did not need more formal assistance, for others, unmet needs were due to service cost or availability (Table 11).

Table 10. Frequency of service use for communication, self-care, and/or cognitive or emotional tasks, according to the SDAC, in children and adolescents with ASD

	% of children and adolescents
Does not receive any assistance	38.3
Less than once a year month but at least once a year	1.4
1 to 3 times a month	14.9
Once a week	16.3
2 to 6 times a week	6.9
Once a day	2.6
Twice a day	9.5
3 to 5 times a day	4.6
6 or more times a day	5.6

Table 11. Main reason for unmet need for formal assistance with communication, self-care, and/or cognitive or emotional tasks, according to the SDAC, in children and adolescents with ASD

	% of children and adolescents
Does not know if needs more formal assistance	4.4
Does not need more formal assistance	34.8
Service doesn't provide sufficient hours	3.6
Service costs too much	9.2
Not eligible for service	1.3
No services available	2.9
Unable to arrange service	2.5
Did not know of service	2.1
Other reason	39.2

The NDIS is also included as a formal service in the SDAC and includes a range of services to support children and adolescents with ASD. The NDIS lists an ASD of level 2 or 3 (as defined by the DSM-5) as a condition likely to be eligible for support, while those with milder forms (i.e. level 1) may have to provide more information to determine eligibility. Children under the age of 7 years can access the NDIS via the Early Childhood Early Intervention pathway, which provides early intervention for children with a developmental delay or disability. ASD is the largest primary disability category in the NDIS, making up 29% of NDIS participants [46].

2.4 Associated factors

2.4.1 Factors associated with prevalence of disability

Aside from changes in diagnostic criteria, factors associated with the prevalence of ASD include genetic and environmental risk factors. While the aetiology of ASD is not fully understood, it is believed to be highly heritable and the result of complex genetic and environmental interactions. In European and US studies, heritability estimates range from about 50-95% [34].

The main environmental risk factors for ASD studied are pre- and perinatal factors, maternal dietary and lifestyle factors, alcohol and smoking, and environmental chemicals. Pre- and perinatal factors found to increase the risk of ASD include: maternal age over 40 years and paternal age over 50 years; short pregnancy intervals (i.e. less than 24 months); maternal weight gain and hypertension; infection during pregnancy, and medications (e.g. antidepressants) [34]. In terms of maternal dietary and lifestyle factors, folic acid supplementation may reduce the risk of ASD. Higher levels of other nutrients such as B12, vitamin D, and iron have shown decreases in risk, but this evidence is inconsistent and requires more rigorously designed studies to infer better associations [34]. There is little evidence showing that alcohol and smoking, while increasing adverse neonatal outcomes in general, increase the risk of ASD specifically [34]. Prenatal exposure to environmental chemicals in the form of air pollution has been shown to increase the risk of ASD, and exposure to endocrine disrupting chemicals that may interfere with neurodevelopment and immune system activity could be associated with ASD [34].

Engagement with technology (i.e. screen devices, social media, gaming) is considered to be a possible associated factor for developmental disorders such as ASD and ASD-like symptoms. A US cohort study of 2,152 children, enrolled at birth, found that increased screen media use at 12 months was associated with increased ASD-like symptoms at 24 months, but not with an ASD diagnosis itself [48]. A recent review of the literature was not able to draw conclusions as to whether screen media use increased risk of ASD, but they did find that children and adolescents with ASD were exposed to more screen time than their typically developing peers and that exposure started at a younger age [49]. The long-term effects of early exposure to technology and screen media is not understood at this stage, in regards to ASD as well as more broadly. Overall, the evidence suggests screen use may exacerbate ASD symptoms, particularly if there is a trade-off between screen media use and protective factors for symptom severity, such as time spent engaging with parents and others [49].

2.4.2 Trends in associated factors over time

Despite rising ASD prevalence, the factors driving increases are unclear and trends in possible risk factors are varied. There has been little change in the proportion of babies born with a low birthweight or pre-term in Australia between 2007 and 2017 [23]. In South Australia specifically, however, as reported by the Pregnancy Outcome Unit which undertakes statewide monitoring of pregnancy characteristics and outcomes, the percentage of low birthweight babies (<2,500g) increased slightly from 6.8% in 2001 to 7.3% in 2017, while the percentage of very low birthweight babies (<1,500g) remained stable (1.6%) during this period [24]. The proportion of babies born preterm (<37 weeks gestation) in South Australia also increased slightly between 2001-2017, from 8.1% to 9.6% [24].

Average maternal age may be a contributing factor as it has increased across Australia from an average of 29.9 years in 2007 to 31.4 years in 2018 [23, 50]. Paternal age, on the other hand, has only increased on average from 33.1 to 33.5 [50]. In South Australia, maternal age has also increased over time, with 32.0% of women who gave birth in 2001 aged 30-34 years and 13.6% aged 35-39 years, compared to 35.9% aged 30-34 years and 18.0% aged 35-39 years in 2017 [24].

Other potential risk factors, such as maternal smoking and alcohol consumption, have decreased overtime. In Australia, 9.9% of women reported smoking at any time during their pregnancy in 2017,

down from 13.7% in 2010 [23]. In South Australia specifically, the proportion of women who reported smoking during pregnancy has decreased from 13.5% in 2010 to 8.5% in 2017 [24]. According to the National Drug Strategy Household Survey, 56% of women in Australia reported abstaining from alcohol during pregnancy, up from 40% in 2007 [25].

Screen time has increased among children and adolescents in recent years and presents a unique exposure in comparison to previous generations. In South Australia specifically, Bell and colleagues found that only 17% of children aged 5-12 years met the recommended amount of screen time of less than 2 hours a day [27]. Currently however, there is little evidence to suggest that screen use above or below what is specified in such guidelines is or is not harmful to development.

Changes in diagnostic criteria, public awareness, and access to services have had a major impact on trends in prevalence rates. As discussed in Section 2.2.6, some argue that most increases in prevalence can be linked with these factors [22].

2.5 Quality of prevalence evidence

The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) is a checklist of items that should be included in all reports of observational studies [28]. As an indicator of quality, we have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

- **2018 SDAC:** the most comprehensive national survey of disability among people of all ages in Australia, the SDAC relies on the accurate self-report of conditions (including ASD) and in 2018, achieved a household response rate of about 80%. A common issue discussed however, is the reliability of prevalence estimates when disaggregated due to sample size. For example, when breaking down data according to age, gender, and socioeconomic status, high relative standard of error rates (as noted in the footnote of Table 8), mean estimates in some categories should be used with caution or are considered too unreliable for most purposes.
- **2018 AEDC:** of all data sources used in this chapter, the AEDC is the only true “census” as it seeks to collect information for all children in their first year of school across Australia. Population estimates do not need to be calculated because actual population prevalence is collected. Important to note, however, is that prevalence of ASD as reported by the AEDC is reliant upon teacher knowledge of children’s diagnosis of ASD.
- **LSAC:** a national longitudinal study that has followed cohorts of children through adolescence and into early adulthood, the LSAC relies on the accurate report of diagnosed conditions (including ASD) by children’s caregivers. Importantly, although LSAC cohorts are described to be representative of the population of young people in Australia, there is evidence (i.e. developmental vulnerability as measured by the AEDC in LSAC cohorts vs the overall population) to suggest that the LSAC under-represents disadvantaged families in the population. This might be attributable to participant exclusions as well as the sampling frame.

2.6 Information sources

To identify relevant evidence beyond that presented in the surveys above (i.e. comorbidities and factors associated with the prevalence of ASD), databases (namely, Embase, PubMed, PsychInfo, and Web of Science) were searched using key terms: child/ren, adolescent/s, Autism/ASD/Autism Spectrum Disorder, prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including the Lancet, International Journal of Epidemiology, and JAMA Pediatrics.

3. Global Developmental Delay

Key findings

Evidence regarding the prevalence of Global Developmental Delay (GDD) is limited, both in Australia and internationally. This might be attributable to the fact that GDD has only recently been included in the Diagnostic and Statistical Manual of Mental Disorders, but also because GDD is viewed as a temporary diagnosis typically limited to children below 5 years of age, with many children often going on to meet diagnosis criteria for intellectual disability once they reach school age. Available evidence shows that prevalence of GDD in Australia is around 0.5%, and that prevalence is higher among males, as well as children from socioeconomically disadvantaged backgrounds. Though the aetiology of GDD is not fully understood, international evidence demonstrates genetic conditions to be the most common identified cause of GDD, accounting for as much as 47% of diagnoses. A variety of environmental risk factors have also been associated with prevalence of GDD, including pre-and perinatal, as well as maternal lifestyle factors. Overall, better quality evidence on the prevalence of GDD among children in Australia, associated factors, as well as comorbidities experienced by children with a GDD diagnosis, is required to better understand supports required.

3.1 Background

3.1.1 Definition

As described by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), GDD is characterised by a significant delay in two or more developmental domains, including: fine and gross motor skills, speech and language, cognition, social, as well as activities of daily living [1].

The term GDD was introduced in the DSM-5 in 2013, but had emerged in the literature prior to this, as delays across a variety of developmental domains [51]. Thus when terms such as 'developmental delay', 'developmental disability' or 'intellectual disability' are used in earlier literature, they might refer to conditions including GDD as well as GDD-like symptoms, or children with developmental delays that impair function but have not been formally diagnosed as per the DSM-5 criteria (see section 3.1.3 below). With this in mind, some prevalence figures relating to the broader category of 'developmental delays' have been included in this chapter.

3.1.2 Presentation and key characteristics

Characteristics that signify delay at specific ages (i.e. the stages at which children would have typically mastered a particular developmental milestone) include those listed below. In addition, loss of any previously acquired skills in any domain at any age, signifies the need for developmental assessment. Typically, children with GDD exhibit delays across most areas of development [52]. It should be acknowledged that these descriptions are based on a medical model of disability, which may be at odds with social models of disability and more nuanced presentations that caregivers might observe in their children [53].

- **Gross/fine motor:** lack of steady head control (4 months); lack of proto-declarative gestures (e.g. showing, reaching, waving; 15 months); inability to walk (18 months).

- **Speech/language:** lack of babbling consonant sounds and/or reciprocal vocalizations (9 months); lack of single words (15 months); lack of spoken language/gesture combinations (18 months); failure to use 10-25 single words (24 months); failure to speak in two word sentences (26 months); failure to speak in three word sentences; unintelligible speech (36 months).
- **Cognition:** lack of fixation (2 months); lack of visual tracking (4 months); failure to turn to sound or noise (6 months); failure to follow a simple command without a gesture (18 months).
- **Social/personal:** failure to respond to name (12 months).
- **Activities of daily living:** lack of simple pretend play (18 months).

3.1.3 Diagnosis

GDD is diagnosed after evaluation by a medical professional has taken place. This will often include a developmental assessment, physical examination, family history checks, as well as genetic testing to search for underlying aetiology. Significant delay, as per the DSM-5 definition of GDD, is performance two or more standard deviations below the mean on age-appropriate, standardised tests, in at least two of the developmental domains described earlier: fine and gross motor skills, speech and language, cognition, social, as well as activities of daily living.

GDD diagnosis is reserved for children under 5 years of age, who are not able to undergo assessment of intellectual functioning reliably. Children with GDD are often re-assessed when they are older, and at this stage many children meet diagnostic criteria for an intellectual disability. In this way, GDD and intellectual disability are closely aligned.

3.1.4 Onset and progression

Delays in development can be evident from infancy. For many children diagnosed with GDD, parental concerns begin with speech delays (the most common developmental delay) from around 12-24 months as described in Section 3.1.2. GDD is not typically a progressive condition and so does not worsen over time. GDD is, to an extent, viewed as a temporary diagnosis limited to children below 5 years of age, and with early identification and ongoing management some children catch up to their peers. However, many children go on to meet diagnosis criteria for Intellectual Disability once they reach school age [54].

3.1.5 Treatment

The aetiology of a child's GDD diagnosis will often help to guide management of the condition, as different aetiologies will have different implications for treatment, prognosis, as well as identification and management of associated conditions. Management of GDD focuses on individualised rehabilitation and education plans, delivered in collaboration with families and carers. Typically a multidisciplinary approach is taken considering many children with GDD experience delays across a number of domains. This might include a social worker, occupational therapist, physiotherapist, speech language pathologist, psychiatrist, developmental paediatrician, and neurologist – all of which will be dependent on the delays a child experiences.

Evidence has shown that early diagnosis and ongoing management of GDD, due to evidence of brain plasticity in the early years, is critical in order to provide children with the best opportunity to avoid future diagnosis of intellectual disabilities later in life [54].

3.2 Prevalence

Our search highlighted that there exists little of evidence of GDD prevalence among children in Australia. Therefore, one data source was used to investigate the prevalence of GDD, and another was used to report prevalence of developmental delay more broadly among children in Australia.

The **2018 Australian Early Development Census (AEDC)** is a national census of children's early development and readiness for school, completed by teachers for children in their first year of full time school (i.e. when children are aged 4-6 years, with the majority of children 5 years old). The census aims to collect information on all children across Australia in their first year of full time school, with a participation rate of 96.4% or 308,953 children, through information collected from 17,508 teachers across 7,507 schools, achieved in the 2018 census. As part of the census, teachers were asked if children had a special needs status; if 'yes', they then selected from a number of medical diagnoses that qualify the child to have special needs, including GDD. The AEDC is conducted triennially and information collected in 2009, 2012, and 2015 can be used to compare prevalence rates over time.

The **2018 ABS Survey of Disability, Aging and Carers (SDAC)** is a national survey designed to provide reliable estimates of the prevalence of different disabilities in Australia. In 2018, a multi-stage area sampling approach was used to identify a random sample of 31,000 Australian households. This sample included a number of exclusions, including households in very remote areas. A total of 27,573 households were contactable and invited to participate in the survey and data were available for analyses for approximately 21,983 households (79.7% response rate). Respondents were asked are a series of questions to identify if anyone in their household had social, emotional, behavioural, learning, or mental health difficulties; and if 'yes' the respondent was asked to identify the condition/s the individual is experiencing, including 'intellectual and developmental disorder' and 'other developmental/learning disorders'. Survey responses were used to estimate population prevalence of developmental disorders, with sub-group analysis presented by gender and sociodemographic variables. Previous surveys (2003, 2009, 2012, 2015) can be used to explore prevalence over time.

The Inclusive Education Support program (IESP) is a functional needs-based funding model for students with a disability in South Australia. Data are collected annually, providing the Department with an understanding of the prevalence of different types of disabilities among students in primary and secondary schools. Eligibility for the IESP is based on clinical diagnosis or referrals from speech-language pathologists. Eligibility criteria are aligned with the national disability legislation and guidelines, and focus on a child's needs rather than their disability diagnosis or label. This approach is designed to recognise all disabilities and learning difficulties, including mental health, trauma, complex behaviours and complex health care needs.

3.2.1 Overall prevalence

Data collected via the AEDC reported that 0.4% (1,230) of children who were in their first year of school had GDD. According to the SDAC, 0.5% (19,100) of children aged 0-5 years in Australia were estimated to have some form of developmental disorder. Similarly, data collected through the IESP reported that 0.5% (852) of students in South Australia had a GDD diagnosis.

Internationally, research has estimated that GDD affects between 1-3% of children aged 0-5 years in Canada and the US [52]. This was consistent with more recent evidence of the prevalence of GDD among children aged below 5 years in the UK [55].

3.2.2 Prevalence by gender

The AEDC reported higher GDD prevalence among males (0.5%) (849) compared to females (0.3%) (381). Similarly, the SDAC reported 0.6% (12,700) of males aged 0-5 years to have a developmental disorder, compared to a lower prevalence of 0.2% (3,900) among females.

3.2.3 Prevalence by age

Prevalence by age according to AEDC data are not reported as the majority of children included in data collection were aged 5 years (as children are all in their first year of school). Similarly, as GDD diagnosis is reserved for children aged below 5 years only, developmental disorder prevalence as measured by the SDAC has been reported for the 0-5 age group only (see Section 3.2.1).

3.2.4 Prevalence by other socio-demographic characteristics

Data collected via the AEDC presented in Table 12 below shows that prevalence of GDD is higher among children from socioeconomically disadvantaged backgrounds[5] and children with an Aboriginal and/or Torres Strait background. This is aligned with evidence from an Australian longitudinal cohort study conducted in the early 90s (n=8,556), which found that socioeconomic disadvantage at pregnancy (as measured by extended periods of financial difficulties, as well as education and income) was positively associated with developmental delays among children at 5 years of age. Specifically, the most disadvantaged mothers were about 4 times more likely to have a child with developmental delay, compared to those less disadvantaged [56].

Although the SDAC typically reports on the prevalence of disabilities by a variety of socio-demographic factors, disaggregation of the prevalence of developmental disorders among children aged 0-5 years was not possible due to small numbers of children in these groups.

[5] Socio-Economic Indexes for Areas (SEIFA) is a set of measures derived from ABS census information that summarise different aspects of socioeconomic conditions in an area. Each geographical area in Australia is given a SEIFA score that ranks the disadvantage of an area, compared with other areas across the country. Quintile 1 represents the most socioeconomically disadvantaged areas, while Quintile 5 represents the least disadvantaged areas.

Table 12. Prevalence of GDD by socio-demographic characteristics as reported by AEDC

	2018 n (%)
Socio-Economic Indexes for Areas (SEIFA)	
Quintile 1 (Most disadvantaged)	401 (0.6)
Quintile 2	252 (0.4)
Quintile 3	231 (0.4)
Quintile 4	191 (0.3)
Quintile 5 (Least disadvantaged)	147 (0.2)
Aboriginal and/or Torres Strait Islander background	
Yes	170 (0.9)
No	1,055 (0.4)

3.2.5 Trends in prevalence over time

Prevalence of GDD as measured by the AEDC maintained stable between 2015 and 2018 (Table 13). Arabiat and colleagues used SDAC data to explore trends in prevalence of childhood disabilities over time. Results showed that the prevalence of intellectual disabilities decreased by half a percentage between 2003 (4.2%) to 2012 (3.7%), and then increased again in 2015 (4.3%) [22]. In contrast, the IESP indicates an increase in the prevalence of GDD among children in South Australian schools over the past decade, from 0.2% (359 children) in 2009, to 0.5% (852 children) in 2019.

Earlier reports of intellectual disability and developmental delay among children in Australia, which as described, may be proxy measures for GDD and GDD-like conditions, show prevalence rates higher than that reported by the AEDC. In 1998, 0.9% of 0-4 year olds were reported to have an intellectual disability, which increased to 1.0% in 2003 [57, 58]. Similarly, research by Najman and colleagues described earlier estimated that 2-4% of children in Australia may have a developmental delay at age 5, depending on sociodemographic characteristics [56]. Importantly however, these higher prevalence rates are inclusive of all conditions considered to fit within the broader category of intellectual and/or developmental disability.

Table 13. Prevalence of GDD as measured by the AEDC over time

	2015 n (%)	2018 n (%)
Overall	1,307 (0.4)	1,230 (0.4)
Male	916 (0.6)	849 (0.5)
Female	391 (0.3)	381 (0.2)

Note. Although the AEDC was also conducted in 2009 and 2012, GDD was only included in the previous two censuses. Prevalence by age is not presented as the majority of children included in the AEDC are aged 5 years.

3.3 Complex needs

Children with GDD, and intellectual disabilities more broadly, may experience additional disabilities, including mental and physical health difficulties, the presence of which lead to more severe impairment and require more support.

3.3.1 Prevalence of comorbidities

Research exploring comorbidities of GDD specifically, both in Australia and internationally, is scarce. However, there is evidence to show that children with a GDD diagnosis are more likely to experience iron deficiency and related conditions, compared to children in the general population. Research in Australia explored the prevalence of and risk factors for iron deficiency in children aged 2-5 years (n=122) with GDD. Results showed that prevalence of iron deficiency among children with GDD was 10.9%, compared to 2.8% among the wider population of children aged 2-5 years [59].

Considering the links between GDD and later intellectual disability, we also explored additional conditions experienced by young people with an intellectual disability.

Evidence, both in Australia and internationally, has demonstrated that young people with an intellectual disability are far more likely to experience mental health difficulties, compared to the general population. Emerson and colleagues [60] used data from the Longitudinal Study of Australian Children (LSAC) to examine the prevalence of mental health problems in children with an intellectual disability or borderline intellectual functioning, among a cohort of 4,337 children aged 4-5 years and then again at 6-7 years. Results showed that children identified to have an intellectual disability or borderline intellectual functioning at age 4-5 had significantly higher rates of mental health concerns (as measured by parent completion of the Strengths and Difficulties Questionnaire) at age 6-7, after controlling for socioeconomic disadvantage. This evidence is supported by a large scale international systematic review and meta-analysis (n=6,151) of intellectual disability and mental health problems among young people ranging in age from 4-18 years [61]. Results demonstrated that between 38-49% of children with an intellectual disability showed psychiatric symptoms (dependant on the measurement tool used). Of those with a diagnosed psychiatric disorder, the most prevalent conditions were attention deficit/hyperactivity disorder, conduct disorder, and anxiety disorders.

Data reported by the National Disability Insurance Scheme (NDIS) has also highlighted that intellectual disability often co-occurs with Autism Spectrum Disorder (ASD) [62]. Specifically, among people of all ages with ASD, 15.3% were reported to also have an intellectual disability.

Research has also demonstrated links between intellectual disability and overweight and obesity. An Australian cross-sectional study of 261 adolescents aged 13-18 years with an intellectual disability showed that overweight and obesity was considerable more prevalent among participants (22.0% of males and 23.1% of females were obese; 21.4% of males and 26.7% of females were overweight) when compared to the wider population [63].

3.3.2 Help seeking behaviours

The NDIS reported on information regarding individuals who first entered the scheme in 2016-17 and 2017-18. This provided insight into the proportions of children diagnosed with GDD or developmental delay who had accessed specialist services (e.g. speech pathology and occupational therapy), and how effective these services were deemed to be. The prevalence of children from birth to school entry age with GDD or developmental delay who had accessed specialist services in 2018 was 67%. This was a 21% increase from children who entered the NDIS one year prior in 2016-17, indicating an increase in service use among children with a GDD or developmental delay diagnosis [46].

3.4 Associated factors

3.4.1 Factors associated with prevalence of disability

While the aetiology of GDD is not fully understood and many children with GDD will not have a definitive etiologic diagnosis, as with many developmental disorders, the condition is believed to be highly heritable. A review of etiologic categories of GDD across countries reported that genetic conditions are the most common identified cause of GDD, accounting for as much as 47% of diagnoses [64]. In addition, a variety of environmental risk factors have been associated with the prevalence of GDD including pre- and perinatal factors (including perinatal asphyxia, intrauterine growth restriction, infection during pregnancy, pre-term birth), as well as maternal lifestyle factors (including use of prescription medications, smoking, alcohol consumption or use of illicit drugs) [65, 66].

Evidence suggests that psychosocial factors also serve as risk factors for GDD, including low parental education as well as particular cultural values or expectations, both of which may be related to deprivation of stimulation and responsivity that is essential to children's early development [64].

Further, research by Thomaidis and colleagues [67] in Europe (n=142) has suggested that, while there are several genetic and environmental factors associated with GDD, pre-term birth and intrauterine growth restriction are associated with more severe developmental delay, suggesting these factors were the most important predictors of GDD in this particular cohort of children.

3.4.2 Trends in associated factors over time

One of the key factors associated with GDD, pre-term birth, has remained stable in Australia between 2007 and 2017 [23]. However, the proportion of babies born preterm (<37 weeks gestation) in South Australia has increased slightly between 2001 and 2017, from 8.1% to 9.6%, as reported by the Pregnancy Outcome Unit which undertakes statewide monitoring of pregnancy characteristics and outcomes [24]. Over the same time period in South Australia, the percentage of low birthweight babies (<2,500g) has increased slightly from 6.8% to 7.3% and for very low birthweight babies (<1,500g), has remained stable at 1.6% [24].

Although not associated with GDD per se, advanced maternal age is linked with an increased risk of a variety of adverse perinatal outcomes including pre-term birth [68]. Average maternal age in Australia has increased over time, from an average of 29.9 years in 2007 to 31.4 years in 2018 [23, 50]. In South Australia specifically, maternal age has also increased over time, with 32.0% of women who gave birth in 2001 aged 30-34 years and 13.6% aged 35-39 years, compared to 35.9% aged 30-34 years and 18.0% aged 35-39 years in 2017 [24].

Other potential risk factors, such as maternal smoking and alcohol consumption, have decreased overtime. In Australia, 9.9% of women reported smoking at any time during their pregnancy in 2017, down from 13.7% in 2010 [23]. In South Australia specifically, the proportion of women who reported smoking during pregnancy has decreased from 13.5% in 2010 to 8.5% in 2017 [24]. According to the National Drug Strategy Household Survey, 56% of women in Australia reported abstaining from alcohol during pregnancy, up from 40% in 2007 [25].

3.5 Quality of prevalence evidence

The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) is a checklist of items that should be included in all reports of observational studies [28]. As an indicator of quality, we have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

- **2018 AEDC:** the AEDC is a true "census" as it seeks to collect information for all children in their first year of school across Australia. Population estimates do not need to be calculated because actual population prevalence is collected. Important to note, however, is that prevalence of GDD as reported by the AEDC is reliant upon teacher knowledge of children's diagnosis of GDD.
- **2018 SDAC:** the most comprehensive national survey of disability among people of all ages in Australia, the SDAC relies on the accurate self-report of conditions and in 2018, achieved a household response rate of about 80%. A common issue discussed however, is the reliability of prevalence estimates when disaggregated due to sample size. For example, when breaking down data according to age, gender, and socioeconomic status, high relative standard of error rates, mean estimates in some categories should be used with caution or are considered too unreliable for most purposes.

3.6 Information sources

To identify relevant evidence beyond that presented in the surveys above (i.e. comorbidities and factors associated with the prevalence of GDD), databases (namely, Embase, PubMed, Google Scholar, and Web of Science) were searched using key terms: child/ren, adolescent/s, Global Developmental Delay/GDD, developmental delay/disability, intellectual disability, prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including the Archives of Disease in Childhood and the Australian and New Zealand Journal of Psychiatry.

4. Dyslexia

Key findings

Evidence regarding the prevalence of dyslexia among children and adolescents is limited internationally. According to Australian research, recognition and knowledge of dyslexia among teachers is lacking. This may be a reflection of the absence of a consistent definition of dyslexia, in addition to the lack of recognition of dyslexia as a disability in Australia. Most recently, the 2018 Survey of Disability, Aging and Carers (SDAC) estimated the prevalence of dyslexia among children and adolescents aged 0-14[6] years to be 0.1%, however international estimates are considerably higher and vary markedly from 4-20%. Evidence outside Australia has indicated an overrepresentation of males with dyslexia, relative to that of females, with a ratio ranging from approximately 2:1 to 3:1. A variety of genetic and environmental factors have been associated with dyslexia and reading difficulties more broadly, including pre-and perinatal factors, as well as electronic device use in childhood. Overall, better quality evidence on the prevalence of dyslexia among young people in Australia, as well as associated environmental factors, is required to better understand the supports required.

4.1 Background

4.1.1 Definition

As described by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), dyslexia is a term used to refer to a pattern of learning difficulties characterised by problems with accurate or fluent word recognition, decoding, and spelling [1].

4.1.2 Presentation/key characteristics

Individuals with dyslexia experience difficulties with spelling, written expression and/or word reading. Symptoms may also be expressed behaviourally, such as a reluctance to engage in learning or oppositional behaviour. While dyslexia presents as a reading difficulty, theory proposes this difficulty is due to a specific disorder in auditory and phonological processing [69, 70]. However, difficulties in spatial crowding (identifying a target letter or word in a text) and spatial attention (selectively attending to and processing visual information), leading to impairments in orthographic development (the ability to use the visual system to form, store and recall words) have also been proposed as underlying mechanisms dyslexia [71, 72].

4.1.3 Diagnosis

The DSM-5 classifies dyslexia under the broad category of Specific Learning Disorder [1]. To meet diagnostic criteria for Specific Learning Disorder an individual must experience difficulties learning and using academic skills as indicated by the presence of at least one of the following symptoms:

- Inaccurate or slow and effortful word reading
- Difficulty understanding the meaning of what is read

[6] See Section 4.2.1 SDAC prevalence figures are for the 0-14 age range and could not be disaggregated further due to small numbers. However, it is important to note that, as per DSM diagnostic criteria, dyslexia can only be diagnosed once formal learning starts (i.e. from 5 years of age onward).

- Difficulties with spelling
- Difficulties with written expression
- Difficulties mastering number sense, number facts, or calculation
- Difficulties with mathematical reasoning

Additionally, an individual's reading level must be substantially and quantifiably below that of peers their age, and difficulties must persist despite targeted support in the last six months. If these difficulties are better accounted for by an intellectual disability, sensory disorder, or other neurological disorder, a diagnosis of Specific Learning Disorder is not appropriate [1].

Based on the impairments experienced, three categories of Specific Learning Disorder can be diagnosed. More than one domain may be impaired and therefore, more than one category can be included in the diagnosis.

- **Impairment in reading** (dyslexia): word reading accuracy, reading rate or fluency, reading comprehension.
- **Impairment in mathematics** (dyscalculia): number sense, memorisation of arithmetic facts, accurate or fluent calculation, accurate math reasoning.
- **Impairment in written expression**: spelling accuracy, grammar and punctuation accuracy, clarity or organization of written expression.

An individual must meet the criteria for Specific Learning Disorder with impairment in reading by the presence of impairments in word reading accuracy, reading rate or fluency and reading comprehension to meet the criteria for what is commonly termed dyslexia.

The DSM-5 also outlines criteria for specifying the severity of Specific Learning Disorder:

- **Mild:** Some difficulties learning skills in one or two academic domains, but of mild enough severity that the individual may be able to compensate or function well when provided with appropriate accommodation or support services, especially during the school years.
- **Moderate:** Marked difficulties learning skills in one or more academic domains, so that the individual is unlikely to become proficient without some intervals of intensive and specialised teaching during the school years. Some accommodations or supportive services may be needed to complete activities accurately and efficiently.
- **Severe:** Severe difficulties learning skills, affecting several academic domains, so that the individual is unlikely to learn those skills without ongoing intensive individualised and specialised teaching for most of the school years. Even with an array of appropriate accommodations or services at home, at school, or in the workplace, the individual may not be able to complete all activities efficiently.

A clinician, typically a psychologist, will conduct a comprehensive assessment to determine a diagnosis of dyslexia [73]. A battery of cognitive assessments and tests of achievement are used and results are considered together with information gathered from the individual, their family and other relevant sources (e.g. school, work). Specific Learning Disorder can only be diagnosed once formal education starts (i.e. typically when children are aged 5 years onward) but can be diagnosed at any point afterward providing there is evidence of onset during early schooling years.

4.1.4 Onset and progression

Onset, recognition and diagnosis of dyslexia often occur during the primary school years when formal learning of reading, spelling and writing typically begins. Precursors can occur prior to school, but are typically not fully manifested until the demands for the affected skills exceed an individual's abilities.

Difficulties associated with dyslexia typically persist into adulthood, however the course and expression are variable and dependent on a number of factors such as the range and severity of difficulties experienced, comorbidities, and available support systems. The DSM-5 highlights the following possible progression of dyslexia symptoms at different stages of schooling:

- Preschool aged children may have difficulty remembering names of letters or days of the week, recognising letters in or writing their name. They may have difficulty breaking down spoken words into syllables, recognising words that thyme, connecting letters with their sounds, and may be unable to recognise phonemes.
- In primary school aged children, dyslexia may present in difficulty learning letter-sound correspondence, fluent word decoding or spelling. Reading aloud may be slow, inaccurate and effortful, and children may continue to have problems recognising and manipulating phonemes, be unable to read common one-syllable words, and make reading errors that indicate difficulty in connecting sounds and letters.
- Middle school aged children with dyslexia may mispronounce or skip parts of long, multi-syllable words, may confuse words that sound alike, have trouble completing homework or tests on time, and they may have poor spelling and written work compared to peers.
- Adolescents may have mastered word decoding but reading may remain slow and effortful, with trouble pronouncing multi-syllable words and in reading comprehensions and written expression. They may avoid both leisure and work-related activities that require reading or writing or use alternative approaches to access print.

4.1.5 Treatment

Treatment typically relies on the involvement of teachers who use specific educational approaches and targeted techniques to aid in supporting the skills that children with dyslexia have difficulties with. This often involves direct instruction in reading, spelling and phonological training, with intervention most effective when provided in a one-to-one or small group setting [69, 74]. Assistive technology such as speech to text software is also a common strategy employed to assist the functioning of individuals with dyslexia. Early intervention has been highlighted to be key to addressing and reducing the impairment of symptoms associated with dyslexia.

4.2 Prevalence

To describe the prevalence of dyslexia among children and adolescents in Australia, two key data sources were available.

The **2018 Australian Early Development Census (AEDC)** is a national census of children's early development and readiness for school, completed by teachers for children in their first year of full time school (i.e. when children are aged 4-6 years, with the majority of children 5 years old). The census aims to collect information on all children across Australia in their first year of full time school, with a participation rate of 96.4% or 308,953 children, through information collected from 17,508

teachers across 7,507 schools, achieved in the 2018 census. As part of the census, teachers were asked if children had a special needs status; if 'yes', they then selected from a number of medical diagnoses that qualify the child to have special needs, including dyslexia. The AEDC is conducted triennially and information collected in 2009, 2012, and 2015 can be used to compare prevalence rates over time.

The **2018 ABS Survey of Disability, Aging and Carers (SDAC)** is a national survey designed to provide reliable estimates of the prevalence of different disabilities in Australia. In 2018, a multi-stage area sampling approach was used to identify a random sample of 31,000 Australian households. This sample included a number of exclusions, including households in very remote areas. A total of 27,573 households were contactable and invited to participate in the survey and data were available for analyses for approximately 21,983 households (79.7% response rate). Respondents were asked are a series of questions to identify if anyone in their household had social, emotional, behavioural, learning, or mental health difficulties; and if 'yes' the respondent was asked to identify the condition/s the individual is experiencing, including 'reading disorder/dyslexia' (herein referred to as dyslexia). Survey responses were used to estimate population prevalence of dyslexia, and previous surveys conducted (2003, 2009, 2012, 2015) used to explore the trends in prevalence over time.

Beyond these survey data, a number of research studies have explored the prevalence of dyslexia among children and adolescents. Due to limited evidence in Australia, this chapter makes reference to these research studies to provide more information on the prevalence of dyslexia globally.

4.2.1 Overall prevalence[7]

According to the SDAC, the prevalence of dyslexia among children and adolescents aged 0-14 years is 0.1% (2,000). It is important to highlight that, as per DSM criteria, dyslexia can only be diagnosed once formal learning starts. However, SDAC prevalence figures could not be disaggregated further by age due to small numbers, and thus are only able to be reported for the broader 0-14 age range.

Data collected via the AEDC reported that very few children (<0.01%) were identified by teachers as having been diagnosed with dyslexia. This may be partly attributable to the method and timing of the AEDC collection; completed by teachers toward the beginning of the year when children first commenced school. At this stage, reading difficulties may not yet have become apparent. Further, diagnostic criteria requires difficulties remain present after receiving a targeted intervention. Therefore, the first year of school may be when recognition of reading difficulties begins, however diagnosis may not occur until later in a child's schooling. In addition, researchers report that the recognition of Specific Learning Disorder and knowledge of dyslexia among Australian teachers is lacking, which may be a reflection of the lack of a consistent definition of dyslexia, in addition to the lack of recognition of dyslexia as a disability in Australia [75, 76].

Indeed, the absence of a consistent definition of dyslexia has resulted in a lack of prevalence evidence globally. An international review exploring the prevalence of Specific Learning Disorder (including

[7] The Inclusive Education Support program (IESP), an annual collection of information from schools on students with disability, is used to provide the Department with an understanding of the prevalence of disability among students in primary and secondary schools in South Australia. The IESP, however, does not collect information on prevalence of dyslexia in particular. Therefore prevalence rates presented throughout this chapter are not able to be compared to internal Department data sources.

dyslexia) reported prevalence rates ranging from 1-20% [77]. This large variation in prevalence estimates is likely a reflection of global inconsistencies in diagnostic criteria, assessment procedures, language characteristics and definitions. This large variation is also seen in research focused largely in China, Hong Kong, Brazil and Germany, with prevalence rates of dyslexia or reading disabilities reported to range from approximately 4-20% [78-83].

4.2.2 Prevalence by gender

Due to small sub-group numbers, the prevalence of dyslexia by gender was not reported in either the SDAC or the AEDC. Earlier longitudinal research in Australia explored the prevalence of reading disability among a cohort of grade two children (n=1,205, aged 7-8 years), which showed no gender differences in the prevalence of reading disability (i.e. more than one standard deviation below the sample mean on a directly assessed word knowledge test) [84].

According to the international literature, however, there is an overrepresentation of males with dyslexia, relative to that of females. The male to female prevalence ratio among children in China and Hong Kong has been reported to range from approximately 2:1 to 3:1 [78, 83]. Further, a summary of the evidence of gender differences in dyslexia from four epidemiological studies in New Zealand and the UK reported that overall, dyslexia in children is more frequent among males than females [85].

4.2.3 Prevalence by age

Again, small sub-group numbers in the SDAC did not allow for the reporting of dyslexia prevalence by age. Further, prevalence by age according to AEDC data were not reported as the majority of children included in data collection were aged 5 years (as children were all in their first year of school).

However, a longitudinal study on the health of male children, adolescents and adults in Australia (n=15,988) reported prevalence of dyslexia to be higher among younger males; specifically, 4.3% among males aged 10-14 years compared to 1.7% among those aged 15-17 years [86]. This is also reflected in the international evidence. For instance, research in China (n=5,063, aged 7-13 years) explored the prevalence of dyslexia among children in grades 3-6, with prevalence rates ranging from 4.1% for children in grade 3, to 2.7% for children in grade 6 [78].

4.2.4 Prevalence by other socio-demographic characteristics

While evidence of the prevalence of dyslexia by other socio-demographic characteristics in Australia is particularly scarce, earlier longitudinal research (n=1,205) by Prior and colleagues [84] demonstrated that a child's socioeconomic background may contribute to the successful management of reading difficulties. Specifically, of the children who were classified to have a reading disability in grade 2, improvements in reading abilities two years later were seen among children from a higher socioeconomic background. However, it is important to note that these findings are based on a small sample of children identified to have a reading disability (n=36). Despite this, findings are aligned with the broader literature on access to services across the socioeconomic gradient, and developmental trajectories of children from more versus less disadvantaged backgrounds.

International research has also identified a relationship between socioeconomic background and the prevalence of reading difficulties among children, however, much of this research has been conducted

with small sample sizes and has not focused on dyslexia as defined in this chapter. For instance, in France, maternal education and neighbourhood socioeconomic status were associated with the prevalence of reading impairment in a sample of 150 grade two children [87].

4.2.5 Prevalence by level of severity/impairment

None of the data sources collected information on the prevalence of different severities of dyslexia, and our search of the scientific literature revealed no evidence on the prevalence of dyslexia by severity as defined by the DSM-5.

Research in Hong Kong sought to understand the proportion of children experiencing different levels of reading and writing difficulty among a sample of 690 children aged 6-10 years [83]. Using composite literacy scores, results showed 6.2% of children were classified into the mild severity group, 2.2% in the moderate severity group, and 1.3% in the severe group.

4.2.6 Trends in prevalence over time

According to the SDAC, prevalence of dyslexia among children and adolescents aged 0-14 years remained stable between 2015 (2,400; 0.1%) and 2018 (2,000; 0.1%). Although AEDC prevalence figures were too low to report (<0.01%), this remained consistent across 2015 and 2018 collections.

Earlier longitudinal research in Australia explored the prevalence of reading disability among grade two children (n=1,205, aged 7-8 years). Reading ability was directly assessed via a word knowledge test, with 16% of children scoring more than one standard deviation below the sample mean, classified to have a reading disability [84]. Internationally, research in the US has explored trends in prevalence of Specific Learning Disorder more broadly. Using K-12 (i.e. age 6-21 years) enrolment figures throughout 1995-2012 across the country, authors reported that prevalence of Specific Learning Disorder showed an overall ascending (up until around 1999-2001) and then descending pattern [88].

Importantly, changes in diagnostic criteria over time may have contributed to trends in the prevalence of dyslexia. Specifically, changes to the DSM-5 in 2013, included the introduction of an overarching category of Specific Learning Disorder under which “specifiers” are used to provide a description of symptoms in the domains of reading, writing and arithmetic, and the elimination of the IQ-achievement discrepancy criterion used for diagnosis. Al-Yagon and colleagues investigated the potential impact of these changes across a range of countries, with results indicating diagnostic changes were likely to increase prevalence [77]. Further, Fortes and colleagues assessed whether these changes in diagnostic criteria would impact the prevalence of dyslexia in a sample of 1,618 children in Brazil [80]. They found that 7.5% met DSM-5 criteria for Specific Learning Disorders with reading impairment (i.e. dyslexia), compared to 4.3% who met DSM-4 criteria.

4.3 Complex needs

Children and adolescents with dyslexia may experience additional learning disabilities as well as mental health difficulties, which can lead to more severe impairment and require more support.

4.3.1 Prevalence of comorbidities

Evidence regarding dyslexia and comorbidities in the Australian context is scarce, however international literature highlights attention deficit/hyperactivity disorder (ADHD), other sub-types of Specific Learning Disorder, as well as anxiety as common comorbidities. Research among young people aged 8-18 years in the US has highlighted that individuals with dyslexia are more likely to meet diagnostic criteria for ADHD, compared to those without dyslexia [89]. The same researchers demonstrated that dyslexia has a stronger association with symptoms of inattention, rather than symptoms of hyperactivity [90]. Further, Germano and colleagues [91] reviewed studies conducted between 1990 and 2010, with results showing that between 18-45% of children with ADHD also experienced dyslexia. Authors described the large discrepancy in prevalence rates across studies to be a reflection of the differing definitions and assessment methods used to determine dyslexia.

Dyslexia has also been reported to occur alongside other types of Specific Learning Disorder. For example, research in Germany assessing comorbidity of learning disorders among children in grades 3-4 (n=1,633) reported that comorbid learning disorders were more common than isolated learning disorders. Specifically, 58% of children with dyslexia had an additional learning disorder, compared to 42% of children with dyslexia only. The most prevalent combination of sub-types of Specific Learning Disorder were reading and spelling difficulties [79].

Children and adolescents with learning disabilities more broadly have also been found to be more likely to experience anxiety related symptoms. In Canada, research using a national sample (n=36,984, aged 15-44 years) demonstrated that 20.4% of adolescents aged 15-21 with a learning disability also had a diagnosed anxiety disorder, compared to 9.7% of those without a learning disability [92]. A review of the international literature also found that school-aged students with a learning disability had higher mean scores on measures of anxiety, compared to those without a learning disability [93].

4.3.2 Help seeking behaviours as a possible driver of complex needs

Evidence regarding help seeking behaviours of children and adolescents with a dyslexia diagnosis is difficult to find because targeted supports and intervention are typically provided by schools and teachers, rather than specific organisations, health professionals, or health services. Dyslexia has only recently been recognised as a disability in Australia, indeed it has been argued that Australia is behind other countries in the provision of appropriate funding and supports for individuals with dyslexia and Specific Learning Disorder more broadly [75, 76].

4.4 Associated factors

4.4.1 Factors associated with prevalence of dyslexia

Both genetic and environmental factors have been identified to be associated with dyslexia. Dyslexia is considered to be moderately heritable, with a number of genes (particularly those that act on pathways that are involved in the development of the nervous system) identified as potentially playing a role in the development of dyslexia [69, 94, 95]. A review highlighted that research into the biological basis of dyslexia has increased in recent years and as a result, more candidate genes have being identified, along with increasing support for associations between previously identified genes [95].

A number of environmental factors are associated with dyslexia. As described in Section 4.2.4, socioeconomic status, parental education, and the pre-literacy environment play a role in reading ability and may contribute to development of dyslexia [96-98]. In addition, time spent on electronic devices has been identified as a risk factor for the development of dyslexia in China [99]. Specifically, a cross-sectional investigation among 5,063 children in grades 3-6 found that total time spent on electronic devices (limited to computer and television use) was positively associated with dyslexia.

Factors in the pre- and perinatal periods have also been identified to be related to the development of reading ability. Specifically, longitudinal research was conducted in Australia among children born at a hospital in New South Wales either extremely pre-term (less than 28 weeks gestation) or extremely low birth weight (less than 1000g) between 1985-1990 (n=82). At age 8, 27% of children were below their grade level in reading. Further, compared to matched controls, extremely premature children without a diagnosed disability were more likely to be reported by teachers as falling below grade level in reading (48% versus 13%) [100]. Further, research in Italy assessed the effect of interactions between genes and environment (i.e. epigenetics mechanisms) on dyslexia and found that maternal smoking during pregnancy and low birth weight both had an effect on a child's susceptibility to dyslexia [97].

4.4.2 Trends in associated factors over time

Time spent using electronic devices appears to have increased in recent years. In 2015 children aged between 4-5 years in Australia averaged more than two hours of screen time per day [101], while children aged between 7-9 years spent on average 3-9 hours a day engaging in screen-based media use [26]. In South Australia specifically, Bell and colleagues found that only 17% of children met the recommended amount of less than 2 hours of screen time daily [27]. Currently however, there is little evidence to suggest that screen use above or below what is specified in such guidelines is or is not harmful to children's development.

There has been little change in the proportion of babies born with a low birthweight or pre-term in Australia between 2007 and 2017 [23]. In South Australia specifically, however, as reported by the Pregnancy Outcome Unit which undertakes statewide monitoring of pregnancy characteristics and outcomes, the percentage of low birthweight babies (<2,500g) increased slightly from 6.8% in 2001 to 7.3% in 2017, while the percentage of very low birthweight babies (<1,500g) remained stable (1.6%) during this period [24]. The proportion of babies born preterm (<37 weeks gestation) in South Australia also increased slightly between 2001-2017, from 8.1% to 9.6% [24].

In contrast, maternal smoking during pregnancy, another key risk factor for dyslexia, has decreased over time in Australia, with the proportion of women who reported smoking at any time during pregnancy falling form 13.7% in 2010 to 9.9% in 2017 [23]. In South Australia specifically, the proportion of women who reported smoking during pregnancy has decreased from 13.5% in 2010 to 8.5% in 2017 [24].

4.5 Quality of prevalence evidence

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have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

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- **2018 SDAC:** the most comprehensive national survey of disability among people of all ages in Australia, the SDAC relies on the accurate self-report of conditions and in 2018, achieved a household response rate of about 80%. A common issue discussed however, is the reliability of prevalence estimates when disaggregated due to sample size. However, due to small sub-group numbers, disaggregated prevalence estimates are not presented in this chapter.

4.6 Information sources

To identify relevant evidence beyond that presented in the surveys above databases (namely, Embase, PubMed, Google Scholar, and Web of Science) were searched using key terms: child/ren, adolescent/s, specific learning disorder, specific reading disorder, dyslexia, prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including JAMA, the International Journal of Epidemiology, and the Journal of Child Psychology and Psychiatry.

5. Intellectual Disability

Key findings

The prevalence of intellectual disability among children and adolescents in Australia varies across data sources, from 0.3% to 1.7%. Internationally, there is consensus that approximately 1% of the population have an intellectual disability. Evidence across sources demonstrates that intellectual disability is more prevalent among males than females, however this gender gap is not as pronounced as that of other developmental disorders such as autism or attention deficit/hyperactivity disorder. Further, children and adolescents from the most socioeconomically disadvantaged backgrounds have more than five times the risk of having an intellectual disability, compared to those living in the least disadvantaged areas. The aetiology of intellectual disability is complex, however other disabilities such as Down syndrome are often identified as the cause of moderate to severe intellectual disability. Recent Australian research has demonstrated increased risk of intellectual disability as a result of maternal alcohol use disorder and assisted reproductive technology. Trends in the prevalence of intellectual disability also differ across data sources. While some have reported small increases in prevalence in recent decades, largely due to an increase in mild and moderate cases of intellectual disability, others have demonstrated that recent changes in diagnostic criteria may lead to a decrease in prevalence in more recent years.

5.1 Background

5.1.1 Definition

According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), intellectual disability is an impairment of general mental abilities that impacts social, conceptual, and/or practical domains of adaptive functioning [1]. The term intellectual disability, as used in this chapter, refers to the diagnosed condition but it can also be used to describe one of the four broad categories of disability (i.e. intellectual, physical, or sensory disability, and mental health conditions).

5.1.2 Presentation and key characteristics

The DSM-5 describes adaptive functioning to consist of three domains that reflect everyday tasks that individuals with intellectual disability may have difficulty coping with or need support in:

- Conceptual: skills in language, reading, writing, math, reasoning, knowledge, and memory.
- Social: empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- Practical: self-management in areas such as personal care, job responsibilities, money management, recreation, and organising school and work tasks.

5.1.3 Diagnosis

Diagnosis of intellectual disability, according to the DSM-5, requires the satisfaction of three criteria:

- Deficits in intellectual functioning – which might include reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience – confirmed by clinical evaluation and individualised standard IQ testing;

- Deficits in adaptive functioning in at least one domain – conceptual, social, or practical – that significantly hamper conforming to developmental and sociocultural standards for the individual's independence and ability to meet their social responsibility; and
- The onset of these deficits during childhood.

In the DSM-5 introduced in 2013, severity of impairment relies on a combination of clinically assessed adaptive functioning deficits and IQ scores, in contrast to the DSM-4 which relied on IQ scores alone. The American Psychiatric Association states that by removing IQ test scores from the diagnostic criteria, but still including them in the text description of intellectual disability, the DSM-5 ensures that they are not overemphasised as the defining factor of a person's overall ability, without adequately considering functioning levels [1]. Despite these changes to the DSM, IQ scores are commonly used in the academic literature to describe severity of intellectual disability. In general, intellectual disability is considered to be approximately two standard deviations or more below the population average, which is equivalent to an IQ score of around 70 or below.

Severity of intellectual disability can be classified as mild, moderate, severe, or profound. Individuals with mild intellectual disability may be able to acquire basic reading, writing, and maths skills and may need intermittent support with daily tasks as an adult. Moderate intellectual disability reflects an IQ approximately three to four standard deviations below the mean (i.e. an IQ of between 35 and 55) [102]. Individuals with moderate intellectual disability require substantial ongoing support as adults with daily tasks and employment. Individuals with severe intellectual disability may have an IQ that falls between 20 and 40. In addition to severe deficits in intellectual functioning, individuals may also have motor impairments and other associated conditions that further limit intellectual and adaptive functioning. Individuals with severe intellectual disability are care-dependant, and require support in daily living activities. Profound intellectual disability reflects an IQ less than 20-25 and is associated with other impairments such as motor and sensory disorders that further limit acquisition and use of motor, adaptive or social skills. Individuals with profound intellectual disability require high intensity, pervasive support across all domains.

5.1.4 Onset and progression

Age and characteristics of onset vary and are dependent on the cause and severity of intellectual disability. Typically, more severe intellectual disability that is the result of genetic conditions, is associated with earlier diagnosis [102]. For example, severe or profound intellectual disability may be recognised at 2-3 years of age. Mild to moderate intellectual disability among children under 5 years – an age at which IQ testing is not deemed reliable – may be initially diagnosed as global developmental delay. If symptoms of developmental delay persist beyond the age of 5, or have not improved through early intervention, then children can undergo the appropriate diagnostic testing and may go on to be diagnosed with intellectual disability.

Depending on cause, intellectual disability may be stable and non-progressive or it may increase in severity with time. Increased severity over time tends to be associated with an underlying genetic cause that may be degenerative in nature (e.g. Rett syndrome). Severity may also change with age, with other conditions and health behaviours emerging throughout the life course and impacting

intellectual and adaptive functioning. Similar to other developmental disorders, early identification and intervention may improve outcomes and increase adaptive skills.

5.1.5 Treatment

Treatment and management of intellectual disability tend to fall under three categories:

- Treatments that address or mitigate any underlying cause;
- Treatments addressing comorbid physical and mental health disorders to improve functioning and quality of life, which may include targeted pharmacological treatments; and
- Early behavioural and cognitive interventions, which could include special education and psychosocial supports.

Children and adolescents with an intellectual disability, along with their family and/or caregivers, often receive support from multidisciplinary teams, the extent of which is dependent upon individual circumstances and level of impairment.

5.2 Prevalence

Our search highlighted that there exists little of evidence of intellectual disability prevalence among young people in Australia. To describe the prevalence of intellectual disability among children and adolescents in Australia, one key data source was available[8].

The **2018 ABS Survey of Disability, Aging and Carers (SDAC)** is a national survey designed to provide reliable estimates of the prevalence of different disabilities in Australia. A multi-stage area sampling approach was used to identify a random sample of 31,000 Australian households. This sample included a number of exclusions, including households in very remote areas. A total of 27,573 households were contactable and invited to participate in the survey and data were available for analyses for approximately 21,983 households (79.7% response rate). Respondents were asked a series of questions to identify if anyone in their household had social, emotional, behavioural, learning, or mental health difficulties; and if 'yes' the respondent was asked to identify the condition/s the individual experienced, including 'mental retardation/intellectual disability[9]' (herein referred to as intellectual disability) or 'intellectual and developmental disorders, not elsewhere classified'. Survey responses were used to estimate total population prevalence of intellectual disability and intellectual and developmental disorders, with sub-group analysis presented by age, gender, and sociodemographic characteristics. Previous surveys are used to explore prevalence over time.

Beyond these survey data, a number of research studies have explored the prevalence of intellectual disability among children and adolescents in Australia using linked administrative data. Most of this research has been conducted in Western Australia using the Disability Services Commission as the key source of intellectual disability cases, as well as cases identified through education departments (government, catholic, and independent) [103-107]. Due to limited evidence of the prevalence of intellectual disability in Australia, this chapter relies on the findings of these research studies.

[8] The Australian Early Development Census (AEDC), although a key data source used in other chapters, does not collect information regarding intellectual disability and so has not been included in this chapter.
[9] Intellectual disability was previously termed 'mental retardation' in earlier editions of the DSM.

In this chapter, we draw comparisons between prevalence information from these sources, with that of Department for Education internal data. Specifically, the 2019 Inclusive Education Support program (IESP), an annual collection of information from schools on students with disability, is used to provide the Department with an understanding of the prevalence of disability among students in primary and secondary schools in South Australia. Previous collections from 2009 onward are used to explore prevalence over time.

5.2.1 Overall prevalence

According to the SDAC, 0.3% (12,800) of children aged 0-14 years were reported to have an intellectual disability, while prevalence in the broader intellectual and developmental disorders category was 0.9% (39,900) among 0-14 year olds. Data linkage studies have been used to identify the prevalence of intellectual disability in Western Australia, and reports range from 1.4% among those born between 1983-1992, to 1.7% among those born between 1983-2010 [105, 107]. Data linkage of health services in New South Wales identified 92,542 individuals with an intellectual disability, which equates to around 1.1% of the state's population [108].

Data collected through the IESP reported that 1.5% (2,589) of primary and secondary school students in South Australia met criteria for intellectual disability.

International estimates of the prevalence of intellectual disability among the total population are around 1% [102, 109]. A meta-analysis of 52 population-based studies including low, middle, and high income countries found that around 1% of the population have an intellectual disability [109]. In studies focused on intellectual disability among children and adolescents, prevalence estimates were higher (1.8%), than studies that also included adults (0.5%) [109].

5.2.2 Prevalence by gender

Similar to other developmental disorders, males are at a higher risk of intellectual disability, with the prevalence ratio between males and females estimated to be around 2:1 [102]. This is reflected in the SDAC, with prevalence of intellectual disability estimated to be 0.4% (8,600) among males and 0.2% (5,400) among females aged 0-14 years. Among those with intellectual disability in research in Western Australia, 65.0% were male and 35.1% were female [107].

Table 14. Prevalence of intellectual disability by gender as reported by SDAC

	n (%) of children and adolescents
Intellectual disability	
Male	8,600 (0.4)
Female	5,400 (0.2)
Total	12,800 (0.3)
Intellectual and developmental disorders	
Male	24,100 (1.0)
Female	14,300 (0.6)
Total	39,900 (0.9)

Note. Subgroup prevalence estimates are subject to large standard errors and should be taken with caution, which is also why prevalence estimates for males and females do not sum to the total prevalence estimate.

5.2.3 Prevalence by age

Prevalence of intellectual disability, as reported by the SDAC, increases with age. As demonstrated in Table 15, prevalence among children and adolescents aged 10-14 years was more than three times that of prevalence among children aged 5-9 years.

Table 15. Prevalence of intellectual disability by age as reported by SDAC

	n (%) of children and adolescents
Intellectual disability	
0-4 years	-
5-9 years	3,000 (0.2)
10-14 years	8,700 (0.6)
All ages	12,800 (0.3)
Intellectual and developmental disorders	
0-4 years	5,500 (0.4)
5-9 years	11,900 (0.7)
10-14 years	22,700 (1.5)
All ages	39,900 (0.9)

Note. Prevalence could not be estimated for intellectual disability among children aged 0-4 years due to small cell size. Subgroup prevalence estimates are subject to large standard errors and should be taken with caution, which is also why prevalence estimates for age groups do not sum to the total prevalence estimate.

5.2.4 Prevalence by other socio-demographic characteristics

Data from the SDAC, presented in Table 16, shows that the prevalence of intellectual disability is higher among children living in a one parent family, compared to those living in couple parent families.

Table 16. Prevalence of intellectual disability by family type as reported by SDAC

	n (%) of children and adolescents
Intellectual disability	
One parent family	7,000 (0.9)
Couple parent family	5,400 (0.1)
Intellectual and developmental disorders	
One parent family	15,600 (2.0)
Couple parent family	22,500 (0.6)

Associations between intellectual disability and sociodemographic characteristics in Australia and internationally, as reported in the academic literature, are described below.

In Western Australia, a research study with 2,871 children with a diagnosed intellectual disability and 236,964 children without a diagnosed intellectual disability explored a range of sociodemographic risk factors [104]. Children born fourth or later, or children of single mothers, teenage mothers, or mothers with an Aboriginal and/or Torres Strait Islander background, were at an increased risk of mild or moderate intellectual disability. Further, children of mothers in the most socioeconomically

disadvantaged areas (as measured by SEIFA[10]) had more than five times the risk of mild or moderate intellectual disability, compared to those in the least disadvantaged areas.

Data linkage research showed children with an Aboriginal and/or Torres Strait Islander background had 2.5 times greater risk of intellectual disability, compared to children without an Aboriginal background [107]. According to the 2002 National Aboriginal and Torres Strait Islander Social Survey, prevalence of intellectual disability among those over 15 years was as high as 7% [110]. However, there are concerns regarding the cultural appropriateness of some psychometric instruments used to test cognitive ability in children with an Aboriginal and/or Torres Strait Islander background [111].

5.2.5 Prevalence by level of severity/impairment

Among a population-based sample born between 1983-2010 (n=10,361) in Western Australia, the prevalence of mild or moderate intellectual disability was 1.5%, while that of severe intellectual disability was 0.1% [107]. Similarly, Leonard and colleagues [105] reported 1.1% of children born between 1983-1992 had mild or moderate intellectual disability, while 0.1% had a severe intellectual disability. Across the lifespan (i.e. children and adolescents as well as adults), mild intellectual disability is most common and accounts for about 85% of individuals who have an intellectual disability diagnosis [102, 109]. Moderate intellectual disability accounts for 10%, severe intellectual disability accounts for around 4%, and profound intellectual disability occurs in around 1% of cases [102, 109].

5.2.6 Trends in prevalence over time

According to the SDAC, the prevalence of intellectual disability has followed a slight downward trend since 2003, as demonstrated in Tables 17 and 18. This pattern is evident across both males and females, as well as different age groups of children and adolescents.

In contrast, information collected via the IESP in schools indicates the prevalence of intellectual disability among children and adolescents in South Australia increased slightly from 1.3% (2,123 children) in 2009, to 1.5% (2,589 children) in 2019. Similarly, Bourke and colleagues [107] found that the prevalence of intellectual disability in Western Australia increased over a 10 year period from 1.4% to 1.7%. This was largely due to an increase in mild and moderate cases of intellectual disability.

[10] Socio-Economic Indexes for Areas (SEIFA) is a set of measures derived from ABS census information that summarise different aspects of socioeconomic conditions in an area. Each geographical area in Australia is given a SEIFA score that ranks the disadvantage of an area, compared with other areas across the country. Quintile 1 represents the most socioeconomically disadvantaged areas, while Quintile 5 represents the least disadvantaged areas.

Table 17. Prevalence of intellectual disability as measured by the SDAC over time

	2003 n (%)	2009 n (%)	2012 n (%)	2015 n (%)	2018 n (%)
Overall					
0-4 years	1,700 (0.1)	2,000 (0.1)	-	-	-
5-9 years	3,900 (0.3)	3,900 (0.7)	5,300 (0.4)	-	3,000 (0.2)
10-14 years	13,700 (1.0)	5,300 (0.4)	7,500 (0.5)	-	8,700 (0.6)
All ages	19,300 (0.5)	16,800 (0.4)	14,300 (0.3)	14,600 (0.3)	12,800 (0.3)
Males					
0-4 years	–	1,100 (0.2)	-	-	-
5-9 years	3,900 (0.6)	6,500 (0.9)	3,200 (0.4)	-	2,300 (0.3)
10-14 years	8,100 (1.2)	3,900 (0.5)	5,800 (0.8)	-	4,600 (0.6)
All ages	12,100 (0.6)	11,700 (0.6)	9,000 (0.4)	8,500 (0.4)	8,600 (0.4)
Females					
0-4 years	1,700 (0.3)	900 (0.1)	-	–	-
5-9 years	-	2,800 (0.4)	2,100 (0.3)	-	2,000 (0.3)
10-14 years	5,600 (0.9)	1,400 (0.2)	2,300 (0.3)	-	5,000 (0.7)
All ages	7,300 (0.4)	5,100 (0.3)	4,400 (0.2)	4,000 (0.2)	5,400 (0.2)

Note. Subgroup prevalence estimates are subject to large standard errors and should be taken with caution. Prevalence could not be estimated in some instances due to small cell size.

Figure 3. Prevalence of intellectual disability as measured by the SDAC over time

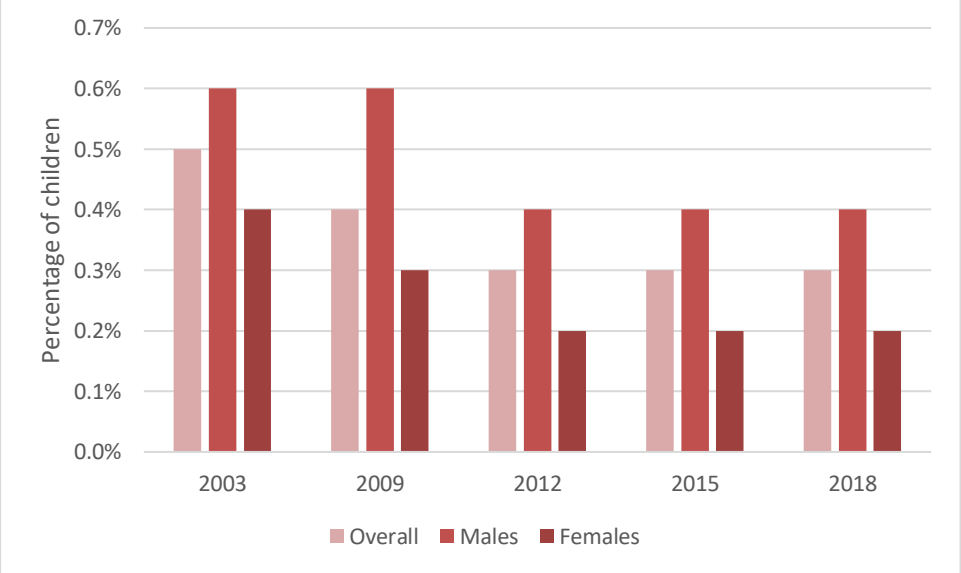


Table 18. Prevalence of broader intellectual and developmental disorders as measured by the SDAC over time

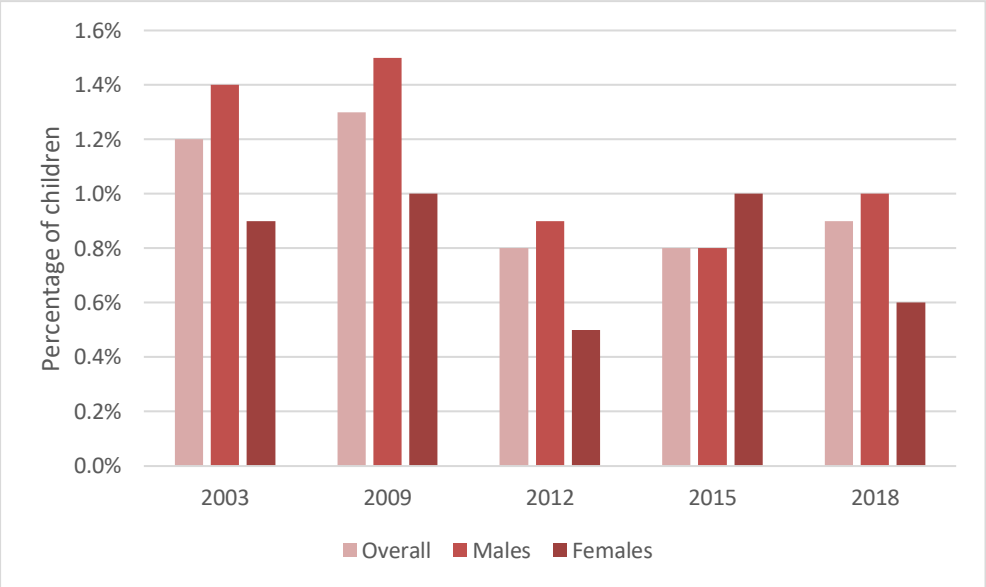
	2003 n (%)	2009 n (%)	2012 n (%)	2015 n (%)	2018 n (%)
Overall					
0-4 years	3,300 (0.3)	4,200 (0.3)	-	-	5,000 (0.4)
5-9 years	15,000 (1.2)	28,200 (2.1)	14,500 (1.0)	-	11,900 (0.7)
10-14 years	27,400 (2.1)	19,500 (1.4)	19,200 (1.4)	-	22,700 (1.5)
All ages	45,700 (1.2)	51,900 (1.3)	32,300 (0.8)	37,600 (0.8)	39,900 (0.9)
Males					
0-4 years	1,600 (0.3)	3,200 (0.4)	-	-	2,800 (0.4)
5-9 years	10,600 (1.6)	18,900 (2.7)	7,100 (1.0)	-	6,800 (0.8)
10-14 years	16,200 (2.4)	9,800 (1.4)	11,700 (1.6)	-	12,300 (1.6)
All ages	28,000 (1.4)	31,900 (1.5)	19,800 (0.9)	22,300 (0.8)	24,100 (1.0)
Females					
0-4 years	1,700 (0.3)	1,000 (0.1)	-	–	1,500 (0.2)
5-9 years	4,800 (0.8)	9,300 (1.4)	5,800 (0.8)	-	1,700 (0.2)
10-14 years	11,200 (1.7)	9,700 (1.4)	4,700 (0.7)	-	11,100 (1.5)
All ages	17,700 (0.9)	20,000 (1.0)	11,200 (0.5)	14,000 (1.0)	14,300 (0.6)

Note. Subgroup prevalence estimates are subject to large standard errors and should be taken with caution. Prevalence could not be estimated in some instances due to small cell size.

Internationally, in high-income countries, the prevalence of intellectual disability is currently estimated to be around 1% [109]. Due to changing diagnostic criteria, terminology, and measurement tools, there are challenges to exploring trends in prevalence over time. A review of intellectual disability prevalence studies from high-income countries in the late 1980s estimated that the overall prevalence of severe learning difficulty (i.e. IQ below 50, now considered to reflect moderate intellectual disability) among children aged 0-14 years was approximately 4%, which is higher than current estimates [112].

Changes to diagnostic criteria may be contributing to a decrease in prevalence more recently. Previously, diagnosis of intellectual disability according to the DSM-4 required impairments in two or more adaptive 'skill areas' (i.e. communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety) rather than at least one impairment in an adaptive functioning 'domain' (i.e. conceptual, practical, and social), as is used in the DSM-5 [113]. The DSM-5 also changed how severity is determined; now on the basis of adaptive functioning rather than IQ test scores as in the previous edition of the DSM. In the US, Papazoglou and colleagues examined if these diagnostic criteria changes would impact the prevalence of intellectual disability [113]. It was hypothesised that requiring one impairment in a broader domain, rather than two narrower, more specific skill sets, would be more challenging for physicians to discern and could make diagnosis more difficult. They found that 9% fewer children met diagnostic criteria for intellectual disability according to the DSM-5, compared to DSM-4, which could have an impact on trends in the prevalence of intellectual disability over time.

Figure 4. Prevalence of broader intellectual and developmental disorders as measured by the SDAC over time



5.3 Complex needs

Intellectual disability is commonly diagnosed alongside additional disabilities and/or health conditions. Due to the high prevalence of comorbidity and subsequent effects on quality of life, intellectually disabled children and adolescents are at increased risk of developing mental health conditions, such as depression and anxiety [114]. This impacts supports needed and services used.

5.3.1 Prevalence of comorbidities

Most research on the prevalence of intellectual disability and comorbidity in Australia has been conducted in Western Australia using linked administrative data. Using linked data for two cohorts (born 1950-64 aged 23-37 years; born 1965-79 aged 38-52 years) from the Western Australia population-based psychiatric and intellectual disorder registers (n=245,749), research found that 31.7% of individuals with an intellectual disability also had a psychiatric disorder [115].

This is reflected in the international literature, with the prevalence of mental health conditions among those with intellectual disability reported to be 4-5 times higher compared to those without an intellectual disability [114]. Specifically, a diagnosis of intellectual disability is associated with an increased risk of being diagnosed with autism spectrum disorder, depression, attention deficit/hyperactivity disorder, cerebral palsy, epilepsy, and schizophrenia [114]. Intellectual disability can also be caused by other conditions that prohibit children from reaching developmental milestones, such as Down syndrome and fragile X syndrome. Children with profound intellectual disability may also experience other impairments, such as motor and sensory disorders, that further limit acquisition and use of motor, adaptive, or social skills [102, 114].

There is little literature on comorbidities among young people with intellectual disability, which may be the result of comorbid conditions occurring later in life as well as diagnostic overshadowing (i.e.

comorbidities are mistaken for symptoms of intellectual disability and go unrecognised), which often means mental health issues and other conditions take longer to diagnose [116].

5.3.2 Help seeking behaviours

Service use and help seeking behaviours among children and adolescents with intellectual disability, as well as their families and caregivers, will differ depending on the severity of impairment experienced. In Australia, those with moderate or more severe intellectual disability are likely to be eligible for support through the National Disability Insurance Scheme (NDIS), making up 23.3% of individuals across the whole scheme and 12.3% of those aged 0-14 years old [62].

Despite the high prevalence of mental health disorders among individuals with intellectual disability, rates of service use do not reflect this overrepresentation, compared to the general population. Whittle and colleagues reviewed the literature to identify key barriers and enablers to accessing mental health services for people with an intellectual disability in Australia [117]. Although not focused on children and adolescents specifically, barriers to service use included lack of service availability, organisational barriers (e.g. referral process and delivery), misidentification of mental health disorders, and having milder intellectual disability [117]. Innovative service delivery that takes into account the needs of individuals with intellectual disability enabled service use, as did referral pathways, and capacity building and training of staff.

5.4 Associated factors

5.4.1 Factors associated with prevalence of disability

As the aetiology of intellectual disability is complex and often unclear, there are many associated factors that might influence prevalence. Conditions such as fragile X syndrome, Down syndrome, and Rett syndrome (in females) are often the cause of moderate to severe intellectual disability [102]. Approximately 15% of cases of intellectual disability identified in Western Australia were reported to be caused by Down syndrome [106].

Exposure to certain environmental factors can also increase the risk of intellectual disability, including; toxic substances, prenatal iodine deficiency, radiation, brain injury, and child and maternal infections. Data from a prospective, birth cohort study of 26,108 children in the US reported risk factors for intellectual disability in children to include: “advanced paternal/maternal age, prematurity, foetal distress, […] primary/repeat caesarean sections, low birth weight, [and] congenital infection” [118]. In Finland, research explored if two cohorts of children (born 1996, n=12,058; born 1985-6, n=9,432) had similar risk factors for intellectual disability [119]. Socioeconomic disadvantage and maternal multiparty were identified as key indicators across cohorts, and maternal obesity emerged as a new risk factor in the cohort born more recently.

There is evidence that maternal alcohol use disorder could be the leading risk factor for intellectual disability with no identified genetic origin. Research using linked data from Western Australia (n=8,526) compared cohorts of mothers with and without an alcohol related diagnosis, with results demonstrating that at least 3.8% of intellectual disability cases could be avoided by preventing maternal alcohol use disorder [103].

More recently, Hansen and colleagues used linked data on a cohort of births between 1994-2002 (n=210,627) in Western Australia to investigate if children conceived using assisted reproductive technology (ART) have a higher risk of intellectual disability, compared with children not conceived using ART [120]. After adjusting for a range of confounding factors including child gender, maternal age, parity, year of birth, and birth delivery mode, results showed a small increased risk of intellectual disability among children conceived using ART. Further, the risk for severe intellectual disability was more than doubled among children born very preterm (i.e. <32 weeks gestation), and after intracytoplasmic sperm injection treatments (an in vitro treatment variation). The link between ART, adverse birth outcomes, and development in general has also been made in the literature [121, 122].

5.4.2 Trends in associated factors over time

As intellectual disability has a range of causes which can increase risk cumulatively, tracing the influence of various factors and their trends back in time is challenging. Information on trends also differs between studies and locations. For example, in the UK, between 1985 and 2004 the prevalence of Down syndrome pregnancies, a common cause of intellectual disability, saw an overall increase in prevalence, while live-birth prevalence remained stable [123]. Evidence from Western Australia, however, shows that the rate of Down syndrome live-births decreased after screening was introduced in 1994, due to increased terminations [124]. In both countries, the increase in Down syndrome pregnancies occurred in conjunction with increases in maternal and paternal age [23, 50, 123].

The prenatal environment also impacts birth and childhood outcomes and can increase risk of intellectual disability. In Australia, maternal obesity has increased with around 50% of women who become pregnant overweight or obese [23, 125]. Prenatal iodine deficiency may be less common nowadays due to increases in fortified food, however there is evidence that many women are still deficient during pregnancy [126, 127]. Evidence suggests that maternal alcohol consumption has decreased over time, with more women reporting abstaining from alcohol during pregnancy. According to the National Drug Strategy Household Survey, 56% of women in Australia reported abstaining from alcohol during pregnancy, up from 40% in 2007 [25]. While abstaining from drinking during pregnancy may be decreasing on average, it is unclear how the prevalence of maternal alcohol use disorder has changed over time, particularly among at-risk sub-populations of women [103, 128, 129].

In Australia, ART treatments have been increasing steadily over the past 40 years and around 4.3% of children are now conceived through ART [120]. In a recent report on ART use in Australia and New Zealand, the National Perinatal Epidemiology and Statistics Unit demonstrate that rates of ART use continue to increase. In 2017 there were 82,215 initiated ART cycles in Australia and New Zealand, a 1.4% increase from that in 2016 [130]. Trends towards delayed childbearing, falling sperm counts, and increasing obesity suggest that ART treatments will continue to rise [120].

Finally, low birth weight has remained relatively stable in Australia between 2007 and 2017, as has the proportion of babies born pre-term [23]. In South Australia specifically, however, as reported by the Pregnancy Outcome Unit which undertakes statewide monitoring of pregnancy characteristics and outcomes, the percentage of low birthweight babies (<2,500g) increased slightly from 6.8% in 2001 to 7.3% in 2017, while the percentage of very low birthweight babies (<1,500g) remained stable (1.6%)

during this period [24]. The proportion of babies born preterm (<37 weeks gestation) in South Australia also increased slightly between 2001-2017, from 8.1% to 9.6% [24].

5.5 Quality of prevalence evidence

The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) is a checklist of items that should be included in all reports of observational studies [28]. As an indicator of quality, we have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

2018 SDAC: the most comprehensive national survey of disability among people of all ages in Australia, the SDAC relies on the accurate self-report of conditions (including intellectual disability) and in 2018, achieved a household response rate of about 80%. A common issue discussed however, is the reliability of prevalence estimates when disaggregated due to sample size. For example, when breaking down data according to age, gender, and socioeconomic status, high relative standard of error rates (as noted in the footnote of Tables 17 and 18), mean estimates in some categories should be used with caution or are considered too unreliable for most purposes.

5.6 Information sources

To identify relevant evidence beyond that presented in the SDAC, databases (namely, Embase, PubMed, PsychInfo, and Web of Science) were searched using key terms: child/ren, adolescent/s, intellectual disability/intellectual disorder, prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including the BMJ Open, American Journal of Epidemiology, and Pediatrics.

6. Generalised Anxiety Disorder

Key findings

The 2013-14 Australian Child and Adolescent Survey of Mental Health and Wellbeing reported that 2.2% of children and adolescents aged 4-17 years had a generalised anxiety disorder. Prevalence was slightly higher among females, with gender disparities increasing with age, which is consistent with the international literature. Prevalence was also higher among children and adolescents who did not live with their original family (i.e. their biological, adoptive or foster parents); were from a household in the lowest income bracket; had parents/carers with low educational attainment or those not in the labour force; and those with poor family functioning. Due to a lack of available data, trends in prevalence of generalised anxiety disorder over time in Australia could not be described. However, the international literature suggests that generalised anxiety disorder, and anxiety disorders in general, have remained relatively stable over the past 20 years. Genetic and family environment factors are associated with risk of generalised anxiety disorder, but trends in these factors are difficult to measure. One of the most substantial risks that has been measured over time is child maltreatment, which could account for 20-30% of anxiety disorder incidence. Evidence suggests child maltreatment has been increasing in South Australia, based on the number of child protection notifications and substantiations.

6.1 Background

6.1.1 Definition

Generalised anxiety disorder, described as anxiety and worry that is excessive and persistent, is a condition included in the wider classification of 'anxiety disorders' according to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), which also consists of social anxiety disorder, separation anxiety disorder, specific phobia, selective mutism, panic disorder, and agoraphobia [1]. Generalised, separation, and social anxiety disorders are often referred to – and studied – together as 'anxiety disorders' because of high rates of comorbidity [131]. Where possible, however, this chapter will focus specifically on generalised anxiety disorder.

6.1.2 Presentation and key characteristics

Those with generalised anxiety disorder experience debilitating pathological worry, which may also be paired with physical symptoms. Key characteristics include feelings of restlessness, being easily fatigued, difficulty concentrating, irritability, as well as muscle tension and sleep disturbance. Below we describe the presentation of generalised anxiety disorder per diagnostic criteria.

6.1.3 Diagnosis

According to the DSM-5, the diagnostic criteria for generalised anxiety disorder includes:

- Excessive anxiety and worry (i.e. apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities (such as work/school performance).
- The individual finds it difficult to control the worry.

- In children, the anxiety and worry are associated with at least one of the following six symptoms (in adults, at least three symptoms) with at least some symptoms having been present for more days than not for the past 6 months:
    - Restlessness or feeling keyed up or on edge
    - Being easily fatigued
    - Difficulty concentrating or mind going blank
    - Irritability
    - Muscle tension
    - Sleep disturbance (difficulty falling or staying asleep, or restless, unsatisfying sleep)
- The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- The disturbance is not attributable to the physiological effects of a substance (e.g. medication) or another medical condition (e.g. hyperthyroidism).
- The disturbance is not better explained by another mental health disorder.

The severity of generalised anxiety disorder in adults may be determined using self-report measures, such as the Generalized Anxiety Disorder 7-item (GAD-7) Scale or The Severity Measure for Generalized Anxiety Disorder—Adult, which is a 10-item scale. Both measures are used to determine the frequency of an individual's symptoms, with experiencing more symptoms more often indicative of increased severity. Based on responses individuals may have none, mild, moderate, severe, or extreme generalised anxiety disorder. Such measures may sometimes be used to determine disorder severity in adolescents, and for children clinicians may make judgments on severity based on similar principles [132, 133].

6.1.4 Onset and progression

The average age of onset of broad anxiety disorders is 6 years old, though diagnosis of anxiety disorder may not always be present throughout the life course (i.e. diagnosis is not fixed) [131]. Anxiety disorders often precede the onset of other psychiatric conditions, such as depression, conduct disorder, and substance abuse disorder, and individuals with a previous diagnosis are more vulnerable to reoccurring periods of anxiety [131].

6.1.5 Treatment

Psychotherapy is the most common treatment for anxiety disorders, specifically cognitive behavioural therapy [131]. Cognitive behavioural therapy can include a range of techniques such as psychoeducation, relaxation training, cognitive restructuring, and exposure practice, all of which seek to mitigate excessive anxiety and worry. A combination of psychotherapy and medications has also been shown to be effective for children and adolescents experiencing generalised anxiety disorder [131, 134].

6.2 Prevalence

To describe the prevalence of generalised anxiety disorder among children and adolescents in Australia, two key data sources were used, as described below.

The **2013-14 Australian Child and Adolescent Survey of Mental Health and Wellbeing** (Young Minds Matter; YMM) sought to estimate the prevalence, severity, and impact of mental health disorders among children and adolescents in Australia. The survey aimed to collect information from a random sample of 5,500 families with children and adolescents aged 4-17 years across Australia, with the exception of very remote areas. An additional random sample of 800 families with adolescents aged 16-17 was included to enable estimates specific to this age group. Area based sampling was used and where there were more than one child in a household, one child was selected at random. In total, 6,310 parents responded (55% response rate) and 2,967 (89%) children and adolescents aged 11-17 years in those households for whom their parents had given permission also completed a questionnaire. Parents completed the Diagnostic Interview Schedule for Children Version 4 (DISC-4), a validated tool for identifying mental health disorders (including generalised anxiety disorder) according to criteria specified in the DSM-4. The survey was previously conducted in 1998, enabling exploration of prevalence over time.

The **2018 Australian Early Development Census (AEDC)** is a national census of children's early development, completed by teachers for children in their first year of full time school (i.e. when children are aged 4-6 years, with the majority of children 5 years old). The census aims to collect information on all children across Australia in their first year of full time school, with a participation rate of 96.4% or 308,953 children, through information collected from 17,508 teachers across 7,507 schools, achieved in the 2018 census. As part of the census, teachers were asked if children had a special needs status; if 'yes', they then selected from a number of medical diagnoses that qualify the child to have special needs, including anxiety. The AEDC is conducted triennially and information collected in 2009, 2012, and 2015 can be used to compare prevalence rates over time.

In this chapter, we draw comparisons between prevalence information from these sources, with that of Department for Education internal data. Specifically, the 2019 Inclusive Education Support program (IESP), an annual collection of information from schools on students with disability, is used to provide the Department with an understanding of the prevalence of disability among students in primary and secondary schools in South Australia. Previous collections from 2009 onward are used to explore prevalence over time.

6.2.1 Overall prevalence

The prevalence of generalised anxiety disorder among 4–17 year olds as reported by the YMM was 2.2% (n=143). Relative to other anxiety disorders measured in the YMM, generalised anxiety disorder was one of the least common; more prevalent than obsessive-compulsive disorder (0.8%), but less prevalent than social phobia (2.3%) and separation anxiety (4.3%). Overall, 6.9% of 4-17 year olds had any anxiety disorder(s). In the AEDC data, very few children (<0.1%) were reported to have been diagnosed with an anxiety disorder. This is likely because onset typically occurs a little later than school entry, with the prevalence of generalised anxiety disorder greater among older children and adolescents (see Section 6.2.3 below).

Although not specific to anxiety disorders, data collected through the IESP reports on students classified to exhibit complex social/emotional behaviour. This is described to include students who have a disorder, illness, condition or developmental trauma that affects their thought processes,

perception of reality, emotions or judgement, or results in concerning behaviour(s). IESP data reported that 1.2% (2,100) of primary and secondary school students in South Australia met criteria for complex social/emotional behaviour.

Internationally, prevalence of generalised anxiety disorder in other high-income countries is quite varied [131]. For example, prevalence among adolescents in the US (n=10,148, 13-17 years) was reported to be 1.1%, however authors highlighted a low response rate and exclusion criteria (those who had left school early, were homeless, or were non-English speakers) to be limitations to this estimate [135]. Another US study, using diagnostic interviews based on the DSM-4 among a sample of 3,042 participants aged 8-15 years, reported a prevalence rate of 0.7% [136]. A higher prevalence rate of 5.8% was identified in research among a slightly older, but smaller US sample (n=906, 13-19 years) [137]. In the UK, findings from the 1999 British Child and Adolescent Mental Health Survey (n=10,438, 5-15 years) reported prevalence of generalised anxiety disorder to be 0.7% [138]. The 2017 British Child and Adolescent Mental Health Survey (n=9,117, 2-19 years) reported a prevalence rate of 1.5% [139].

6.2.2 Prevalence by gender

Survey responses from the YMM, described in Table 19, demonstrate that the prevalence of generalised anxiety disorder among children and adolescents aged 4-17 years was slightly higher among females (2.3%) relative to males (2.0%). This gender difference becomes greater when comparing prevalence among older children and adolescents only, however, with 3.4% of females and 2.3% of males aged 12–17 years meeting diagnostic criteria for generalised anxiety disorder.

Similarly, international research indicates that anxiety disorders tend to be more prevalent among females. In the US, prevalence rates are greater in females compared with males (3% vs. 1.5%), with many studies reporting up to two-fold differences between genders [136].

Table 19. Prevalence of generalised anxiety disorder as measured by the YMM

	% of children and adolescents
Overall	
6-11 years	1.7
12-17 years	2.9
All ages	2.2
Males	
6-11 years	1.8
12-17 years	2.3
All ages	2.0
Females	
6-11 years	1.5
12-17 years	3.4
All ages	2.3

6.2.3 Prevalence by age

The prevalence of generalised anxiety disorder, according to the YMM, increased with age and was 1.7% among children 4–11 years, and 2.9% among those aged 12-17 years (see Table 19).

Higher prevalence rates among adolescents, compared to younger children, was also commonly observed in the international literature [131, 140]. In the US, Bittner and colleagues (n=908) reported a prevalence rate of 1.8% among children aged 9-13 years, and a rate of 4.0% among adolescents aged 13-19 years [137].

6.2.4 Prevalence by other socio-demographic characteristics

The YMM also reported prevalence of generalised anxiety disorder across a range of other socio-demographic factors, including family type, household income, parent/carer education and labour force status, area of residence, and level of family functioning (Table 20). Overall, prevalence was highest among children and adolescents who did not live with their original family (i.e. their biological, adoptive or foster parents); were from a household in the lowest income bracket; had parents/carers with low educational attainment or those not in the labour force; and those who reported poor family functioning. Longitudinal research among adolescents (n=816) in Queensland also reported a negative association between anxiety disorder and socioeconomic status (i.e. caregiver income) [141].

Table 20. Prevalence of generalised anxiety disorder by socio-demographic characteristics as reported by YMM

	% of children and adolescents
Family type	
Families with two parents/carers	1.8
Original family	1.4
Step family	2.9
Blended family	4.1
Families with one parent/carer	3.8
Household income	
$130,000+ per year	1.8
> $52,000 and < $130,000 per year	1.7
< $52,000 per year	3.2
Parental education	
Bachelor degree or higher	1.5
Diploma or certificate III/IV	2.6
Year 11 or 12	2.5
Year 10 or below	3.1
Parental labour force status	
Both parents/carers employed	1.6
One parent/carer employed, one parent/carer unemployed	1.8
Sole parent/carer employed	3.4
Sole parent/carer unemployed	3.7

Family functioning		
	Very good	1.7
	Good	2.0
	Fair	3.7
	Poor	5.7
Area of residence		
	Greater capital cities	2.1
	Rest of state	2.3

YMM did not include information on the prevalence of anxiety disorders in children and adolescents with an Aboriginal and/or Torres Strait Islander background. It was reported that measurement of mental health and wellbeing in Aboriginal children requires a more culturally appropriate survey [10]. However, a recent meta-analysis, including 17 studies with primarily adult samples ranging in size from 146 to 40,333, reported no difference in prevalence of anxiety disorders among Indigenous and non-Indigenous populations in Australia and New Zealand [142].

6.2.5 Prevalence by level of severity/impairment

Information on the prevalence of different severities of generalised anxiety disorder as described in Section 6.1.3 was not available. In children and adolescents with generalised anxiety disorder, however, severity of impact on school or work, family, friends and social activities, and impact on self (i.e. level of distress caused by symptoms) was reported in the YMM (Table 21). Children and adolescents reported experiencing impacts across all four domains, with almost 1 in 3 experiencing severe impacts on at least one of these domains. Further, while 16.7% reported no impacts on friends and social activities, close to half of children and adolescents with a generalised anxiety disorder diagnosis reported moderate impacts in the same domain.

Table 21. Self-reported severity of impact among 4-17 year-olds (as reported by YMM)

	School/work %	Friends %	Family %	Self %	Overall severity %
None	14.3	16.7	10.9	3.8	-
Mild	23.4	18.7	25.4	28.1	38.1
Moderate	28.5	43.4	32.8	38.2	30.7
Severe	29.4	21.2	30.9	30.0	31.1

Note. Percentages in school/work column do not sum to 100 as 4.4% of participants did not go to school/work.

6.2.6 Trends in prevalence over time

The previous YMM survey, conducted in 1998, did not include generalised anxiety disorder, and so trends over time could not be described using this data. Recently, however, survey authors reported that the prevalence of all mental health disorders appeared stable between the two surveys; 12.5% in 1998 and 11.1% in 2013-14 [143]. Similarly, the IESP began collecting information on students with complex social/emotional behaviour in 2019, and so trends in prevalence cannot be reported.

Generalised anxiety disorder in children was formerly diagnosed as overanxious disorder (which would later change to a diagnosis of generalised anxiety disorder, if symptoms persisted into adulthood) [137, 144]. This change was made to the DSM-4 in 1994, making it difficult to determine trends in prevalence rates over time [137]. There are concerns that the DSM-4, and the diagnosis of generalised anxiety rather than overanxious disorder, has led to undiagnosed cases of severe anxiety among children and lower prevalence rates [137, 144]. No changes were made to the DSM-5 in relation to generalised anxiety disorder, however, and thus recent trends in general anxiety disorder are unlikely to be the result of changing diagnostic criteria.

A recent international systematic review found no evidence of an increase in anxiety disorders between 1990 and 2010, with the point prevalence being 3.8% and 4.0%, respectively [145]. The authors argued that perceived increases in prevalence are likely the result of greater public awareness and tendencies to use the term 'anxiety' where it does not actually represent a clinical disorder. Publications of research on childhood anxiety disorders have increased over the last 25 years, which is an indication of how interest in this area has grown and influenced public awareness [145-147].

6.3 Complex needs

Individuals with anxiety disorders often experience comorbid health conditions, which can impact the severity of impairment as well as the need for support and services.

6.3.1 Prevalence of comorbidities

The YMM survey reveals a high level of comorbidity among young people with generalised anxiety disorder, including social anxiety disorder (39.7%), separation anxiety (38.0%), and attention deficit/hyperactivity disorder (36.9%). Comorbid major depressive disorder was particularly high, with 41.1% of children and adolescents age 4–17 years with generalised anxiety disorder also experiencing major depressive disorder [148]. This is consistent with research in other countries. In the US 48% of children aged 9-13 years with generalised anxiety disorder were reported to have at least one other anxiety disorder [137], and in Iran, 58% of children and adolescents aged 6-18 years with generalised anxiety disorder had been diagnosed with another psychiatric disorder e.g. neurodevelopment, eating, and mood disorders [149].

As mentioned in Section 6.1.4, anxiety disorders may transform and lead onto other conditions, such as separation anxiety as a child, generalised anxiety as an adolescent, and depression as an adult [131, 137, 144]. For example, longitudinal research in the US (n=906, aged 9-13 years and 19 years at follow up) found that generalised anxiety disorder in childhood predicted conduct disorder in adolescence [137].

6.3.2 Help seeking behaviours

Help seeking behaviours for mental health disorders, including generalised anxiety disorder, may be influenced by a range of factors, such as perceived need, parental and personal beliefs, cultural attitudes, as well as services available. YMM collected information on service use among children and adolescents, as well as the perceived need for and barriers to receiving mental health care.

According to the YMM, 70.9% of children and adolescents with generalised anxiety disorder reported receiving assistance from a professional at school or a health service about an emotional or behavioural problem in the previous 12 months [148]. The proportion of those with any anxiety disorder receiving assistance from mental health professionals only was 55.9%, and 68.0% for generalised anxiety disorder specifically, indicating that the majority of services accessed involved a mental health service rather than other health or educational services.

Service use (including health, school, online and telephone services) among children and adolescents aged 4-17 years with any mental health disorder varied by a range of demographic factors in the YMM. For instance; service use was higher among those in the lowest income bracket (61.9%), those with the least educated parent/carer (year 10 or below; 62.2%), relative to those in the highest income bracket (50.6%) and those with a more educated parent/carer (diploma or certificate 56.3%; bachelor degree or higher 55.5%). Also, those with comorbid anxiety disorders (79.9%) were more likely to receive assistance than those with a single anxiety disorder (54.5%). Among those with comorbid anxieties, younger students aged 4-11 years (52.9%) were less likely to be receiving professional assistance than their older peers aged 12-17 years (72.4%) [148].

According to the Australian National Health Survey of Mental Health and Wellbeing, the proportion of those with a mental health disorder receiving some form of mental health service did not change significantly from 1997 to 2007: 32.6% and 34.9%, respectively [150]. While this was a survey of the adult population in Australia, this indicates trends in help seeking among the general population have remained stable over time [150, 151].

6.4 Associated factors

6.4.1 Factors associated with prevalence of disability

Research on the aetiology of anxiety disorders, including generalised anxiety disorder, has focused on complex theoretical models to explain how symptoms of anxiety in children develop, progress, and are maintained. More so than other disabilities, anxiety disorders are often thought to arise from complex interactions of parenting and family environment factors, along with other factors, such as genetics, prenatal stress, maternal alcohol consumption and foetal development. These factors and possible trends in associated factors are described below.

There is evidence that genetics plays a significant role in the risk of generalised anxiety disorder [146]. Twin studies have shown the heritability of general anxiety disorder could be between 19-30% among adults in the US (n = 1,030) and around 30% according to a review of anxiety disorders in children and adolescents [152, 153].

Environmental factors related to anxiety disorders include prenatal stress, family environment, insecure attachment, and negative life events [146, 154]. Cognitive biases towards situations, which are interpreted as threatening, play a role in the development and maintenance of anxiety disorders [146]. The temperament trait of behavioural inhibition in infants and children (a consistent tendency of children to display fear and withdrawal in unfamiliar situations) is also associated with the later development of anxiety disorders [137, 146].

In Australia, McClure and colleagues [141] analysed longitudinal data (n=816, aged 15 years), with results indicating maternal (but not paternal) anxiety disorder predicted anxiety disorders in children. Children of mothers with a history of anxiety disorder were more than two times more likely to have an anxiety disorder, which was consistent for males and females, compared to children of mothers who did not have an anxiety disorder. Adolescents' perception of parenting behaviour (i.e. whether they were controlling or rejecting) did not mediate this relationship. However, while maternal anxiety disorder did not predict, nor was mediated by, maternal 'psychological control' behaviour, it did predict child anxiety disorders. These findings demonstrate the complex relationship between genetic and family environmental factors that may influence anxiety disorders in children. Research on anxiety in parents and children has also drawn attention to the issue of temporality when determining a causal relationships between parenting styles and child anxiety disorders. That is, the possibility that parents react with controlling parenting behaviours in response to signs of anxious behaviour in children, rather than the former causing the latter [141].

Using longitudinal data on 2,224 women who delivered a baby in Western Australia in 1995/6, O'Leary and colleagues found that alcohol exposure during pregnancy increased the odds of scoring in the clinical range for anxiety and depression in children at ages 2, 5, and 8 years, especially at moderate to high levels of alcohol consumption during the first trimester of pregnancy [128].

Finally, there is evidence to suggest that child maltreatment may double the risk of anxiety disorders among children and adolescents, as well as other comorbid mental health conditions [155-157]. Using meta-analyses, Moore and colleagues [158] estimated that 20.9% of anxiety disorders in males and 30.6% in females was attributable to the four types of child maltreatment; sexual abuse, physical abuse, emotional abuse, and/or neglect.

6.4.2 Trends in associated factors over time

There is a lack of strong evidence in regards to different parenting styles and how they may have changed over time. Trifan and colleagues [159] examined whether parenting practices in Sweden have become less authoritarian (i.e. consisting of harsh parenting practices, strictness, punitive parenting, and constraining the expression of negative emotions in children) over the past 50 years. Results showed that parenting practices have become less authoritarian and more egalitarian among the youngest cohorts. While controlling parenting may contribute to anxiety symptoms in children, it is unclear whether less controlling but more acquiescent parenting carries similar risks, although through different mechanisms. As highlighted by Muris and Broeren [146], the avoidance of unfamiliar situations or stimuli that appear threatening, rather than a confronting and overcoming approach, may increase the risk of children developing specific thought patterns and maintaining cognitive biases that in turn increase risk of anxiety disorders.

There have been reductions in alcohol consumption during pregnancy in Australia over time. According to the National Drug Strategy Household Survey, the proportion of women in Australia abstaining from drinking alcohol while pregnant increased from 40% in 2007 to 56% in 2016 [25].

Australia has seen an increase in the early involvement of child protection, with annual incidence rates of notifications and substantiations doubling between 2001 and 2008 [160]. Analysis of longitudinal data on children born in South Australia shows that the prevalence of receiving at least one child

protection notification before 3 years of age has increased among those born in 1991 (4.0%), 1998 (7.5%), and 2002 (11.2%) [161, 162]. More recently, research has shown that around 1 in 4 children in South Australia will have a Department of Child Protection notification by the age of 10 [163]. The true prevalence of child maltreatment is difficult to determine, however child protection notifications offer a useful indicator for determining if maltreatment is increasing.

6.5 Quality of prevalence evidence

The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) is a checklist of items that should be included in all reports of observational studies [28]. As an indicator of quality, we have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

- **2013-14 YMM:** the largest national survey exploring the mental health of children and adolescents in Australia, YMM has strength in that it uses the DISC-4 to assess generalised anxiety disorder based on DSM-4 criteria (i.e. identification of conditions does not rely on parent- or self-report). Participant exclusion criteria (young people living in very remote areas, with an Aboriginal or Torres Strait Islander background, and experiencing homelessness or living in institutional care; all sub-populations that are likely to experience greater mental health concerns) and a low household response rate (55%), however, might hinder confidence in the accuracy of generalised anxiety disorder population prevalence estimates.
- **2018 AEDC:** of all data sources used in this chapter, the AEDC is the only true "census" as it seeks to collect information for all children in their first year of school across Australia. Population estimates do not need to be calculated because actual population prevalence is collected. Important to note, however, is that prevalence of general anxiety disorder as reported by the AEDC is reliant upon teacher knowledge of children's diagnosis of general anxiety disorder. Further, onset of general anxiety disorder typically occurs a little later than school entry, and both of these factors might have contributed to prevalence rates too low to report.

6.6 Information sources

To identify relevant evidence beyond that presented in the surveys above (i.e. comorbidities and factors associated with the prevalence of generalised anxiety disorder), databases (namely, Embase, PubMed, PsychInfo, and Web of Science) were searched using key terms: child/ren, adolescent/s, generalised anxiety disorder, prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including Pediatrics, PLOS Medicine, and the American Journal of Public Health.

7. Speech Sound Disorder

Key findings

Speech sound disorder (SSD), commonly referred to as speech disorders, impairments, or delay, describes difficulty talking and producing speech sounds in children. Australian data sources report markedly different prevalence rates of speech disorders. The 2018 Survey of Disability, Aging and Carers (SDAC) reported prevalence of 0.6% among children and adolescents aged 0-14 years, while the 2018 Australian Early Development Census (AEDC) reported that 13.4% of children in their first year of school had a speech impairment. Prevalence among males is typically double that observed among females; higher among younger children (i.e. 5-9 years); as well as among children living in socioeconomically disadvantaged areas. According to the SDAC, prevalence has remained relatively stable over the past 15 years, however the AEDC indicates prevalence has increased between 2009 and 2018. Researchers argue that use of varying definitions and classification systems make it difficult to measure and study speech disorders empirically, particularly when investigating prevalence over time. Uncertainty around prevalence figures, coupled with the notion that figures provide limited value in the context of speech-language development (i.e. because the majority of children overcome speech difficulties by 7-8 years) has led researchers and professionals to stress the importance of providing rich speech and language environments for all children, regardless of prevalence.

7.1 Background

7.1.1 Definition

Speech Sound Disorder (SSD) is a persistent difficulty with speech sound production that interferes with speech intelligibility or prevents verbal communication of messages, and is included in the wider category of Communication Disorders in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) [1]. SSD is the focus of this chapter as it captures, with clear diagnostic criteria, what is generally referred to when describing difficulty talking and producing speech sounds among children. However, the terms speech impairment, speech impediment, speech delay, or speech disorders, are often used interchangeably to describe SSD and SSD-like presentations in the literature.

7.1.2 Presentation and key characteristics

SSD encompasses difficulties with articulation and phonological skills beyond age-expected norms [164]. Children with SSD experience deficits in the production of individual speech sounds, or sequences of speech sounds, caused by inadequate planning, control, or coordination of the structures of the oral mechanism [165, 166]. Presentations of SSD include:

- **Omissions/deletions**: certain sounds are omitted or deleted (e.g. "cu" for "cup")
- **Substitutions**: one or more sounds are substituted, which may result in loss of phonemic contrast (e.g. "wabbit" for "rabbit")
- **Additions**: one or more extra sounds are added into a word (e.g. "buhlack" for "black")
- **Distortions**: sounds are altered or changed (e.g. a lateral "s")
- **Syllable-level errors**: weak syllables are deleted (e.g. "tephone" for "telephone")

7.1.3 Diagnosis

According to the DSM-5, four criteria must be met for a diagnosis of SSD:

- Persistent difficulty with speech sound production that interferes with speech intelligibility or prevents verbal communication of messages.
- The disturbance causes limitations in effective communication that interfere with social participation, academic achievement, or occupational performance, individually or in any combination.
- Onset of symptoms is in the early developmental period.
- The difficulties are not attributable to congenital or acquired conditions, such as cerebral palsy, cleft palate, deafness or hearing loss, traumatic brain injury, or other medical or neurological conditions.

SSD and speech disorders more broadly are diagnosed by a speech-language pathologist. There are a range of classifications and diagnostic criteria that can be used to diagnose speech disorders in addition to that of the DSM, such as the Speech Disorders Classification System (SDCS) and the Goldman-Fristoe Test of Articulation. For example, some studies use classifications of Speech Delay, as determined through using the SDCS, to represent SSD, highlighting the complexity of the classification of speech disorders found in the literature [167, 168]. Further, the severity of speech disorders are often based on a clinician's qualitative judgement, and it appears there is a lack of consensus within speech-language pathology on the optimal approach to determining severity.

7.1.4 Onset and progression

While the onset of SSD and speech disorders often occurs during the early developmental period and are typically predicted by difficulties speaking at 24 months of age [169], an international review of population estimates of speech disorders suggests that most children with a speech disorder will be diagnosed by 6 years of age [170]. The majority of children with speech disorders are able to overcome difficulties with speech therapy (see Section 7.1.5 below) by 7-8 years of age. However, more severe speech deficits may persist into adolescence and adulthood [170, 171].

7.1.5 Treatment

Treatment of SSD usually consists of consultations with speech-language pathologists, which can occur in clinical settings or in environments familiar to the child (e.g. home or childcare) [172]. These sessions focus on motor production of speech sounds (articulation approaches) and linguistic aspects of speech production (phonological approaches). This could include the practicing of specific speech sounds to construct words and sentences and/or phonological awareness training based on activities to promote age appropriate knowledge of phonological rules [173]. Frequent one-to-one sessions (2-3 times a week) have been identified as the most appropriate intervention model for children with SSD [174].

7.2 Prevalence

To describe the prevalence of speech disorders among children and adolescents in Australia, two key data sources were used, as described below. These data sources use terms broader than SSD (i.e. speech impediment and speech impairment; herein referred to as speech disorder). However, as

described earlier in Section 7.1.1, terms used to describe speech disorders overlap and are often used interchangeably. To complement this evidence, we also describe prevalence of SSD specifically, from the academic literature in Australia and internationally.

The **2018 ABS Survey of Disability, Aging and Carers (SDAC)** is a national survey designed to provide reliable estimates of the prevalence of different disabilities in Australia. In 2018, a multi-stage area sampling approach was used to identify a random sample of 31,000 Australian households. This sample included a number of exclusions, including households in very remote areas. A total of 27,573 households were contactable and invited to participate in the survey and data were available for analyses for approximately 21,983 households (79.7% response rate). Respondents were asked are a series of questions to identify if anyone in their household had social, emotional, behavioural, learning, or mental health difficulties; and if 'yes' the respondent was asked to identify the condition/s the individual is experiencing, including 'speech impediment'. Survey responses were used to estimate total population prevalence of speech impediments, with sub-group analysis presented by age, gender, and a range of sociodemographic variables. Previous surveys conducted (2003, 2009, 2012, 2015) can be used to explore the trends in prevalence over time.

The **2018 Australian Early Development Census (AEDC)** is a national census of children's early development and readiness for school, completed by teachers for children in their first year of full time school (i.e. when children are aged 4-6 years, with the majority of children 5 years old). The census aims to collect information on all children across Australia in their first year of full time school, with a participation rate of 96.4% or 308,953 children, through information collected from 17,508 teachers across 7,507 schools, achieved in the 2018 census. As part of the census, teachers were asked if children had a number of conditions/impairments/problems, including speech impairment. The AEDC is conducted triennially and information collected in 2009, 2012, and 2015 can be used to compare prevalence rates over time.

In this chapter, we draw comparisons between prevalence information from these sources, with that of Department for Education internal data. Specifically, the 2019 Inclusive Education Support program (IESP), an annual collection of information from schools on students with disability, is used to provide the Department with an understanding of the prevalence of disability among students in primary and secondary schools in South Australia. Previous collections from 2009 onward are used to explore prevalence over time.

7.2.1 Overall prevalence

According to the SDAC, prevalence of speech disorders among children aged 0-14 years was 0.6% (26,000), while the AEDC reported a prevalence rate of 13.4% (41,327) for children in their first year of school. Marked differences in prevalence rates may be a reflection of a number factors. First, as described in Section 7.2.3, the prevalence of speech disorders decreases with age and so we might expect prevalence to be higher among a cohort of children in the first year of school as in the AEDC, compared to those aged 0-14 years. Secondly, AEDC figures are dependent on teacher-reported speech abilities, while the SDAC relies on caregiver report. It is likely teachers have a better understanding of speech development and therefore greater capacity to identify children experiencing speech difficulties, relative to parents. It is important to also reiterate that

inconsistencies in definitions and classifications of speech disorders are likely to be a key factor driving differences in prevalence estimates across different data sources.

Although not specific to speech disorders alone, data collected through the IESP reports on two categories of students with speech and/or language difficulties. Students under the age of 7 years can be classified as having communication difficulties, which includes a language and/or speech disorder, and have been participating in interventions to remediate difficulties. Students older than 7 years can be classified to have speech/language difficulties, including difficulties understanding spoken language as well as with oral expression. In 2019, IESP data reported that 0.1% (216) students aged below 7 years in South Australia met criteria for communication difficulties, and 3.3% (5,872) of students aged 7 years or older met criteria for speech/language difficulties.

Similarly, research in Australia depicts that prevalence of speech disorders are heterogeneous, dependent upon definitions, sample characteristics, and measures used. A study (n=1,494, aged 4 years) using the Goldman-Fristoe Test of Articulation to identify SSD reported a prevalence rate of 3.4% [164]. Another study (n=10,425) reported that 1.1% of primary school students were identified by trained teachers and speech pathologists to have SSD [175]. The 1995 Australian Health Survey (n=12,388, aged 0-14 years) collected information on speech disorders more broadly, reporting a prevalence rate of 1.7% [176]. In this survey, children who had difficulty talking, producing speech sounds, or who stuttered in face-to-face interviews were identified to have a speech disorder. Data from the Longitudinal Study of Australian Children (LSAC) was used to determine the prevalence of speech and language impairment by parent-report, teacher-report, and direct assessment among 4,983 children aged 4-5 years) [177]. In relation to how a child talked and made speech, 11.8% of parents were 'concerned', and 6.7% of children were identified by teachers as 'much less competent' than others in their expressive language ability [177].

In the UK, data from the Avon Longitudinal Study of Parents and Children (n=7,391) estimated that the prevalence of SSD among children aged 8 years was 3.6% [169]. In the US, the 2012 National Health Interview Survey reported that 5.0% of children aged 3-17 years had speech sound problems [178]. Research in the US exploring speech disorders more broadly, reported similar prevalence. For example, Shriberg and colleagues estimated the prevalence of speech delay to be 3.8% among a sample of 1,328 children aged 6 years [179].

Differences in the prevalence of speech disorders across sources are often be attributed to different samples, settings, study designs, definitions, and measurements [175]. Researchers have also acknowledged that speech concepts are complex, with varying classification systems and cut-off points, which have proven difficult to measure and study empirically [168, 171]. In a paper reviewing the study of speech and language disorders and the use of population health data, authors argued that prevalence estimates from existing sources in the US, UK, and Australia "do not capture the condition in a reliable, uniform, or systematically valid manner, which poses a barrier to population level ascertainment of the condition" [p. 1289; 170]. To illustrate this further, the first international systematic review of speech and language delay reported a prevalence range of 2.3% to 24.6% [171].

Uncertainty around prevalence figures, coupled with the notion that figures provide limited value in the context of speech-language development (i.e. because the majority of children overcome speech

difficulties by 7-8 years; Section 7.1.4), has led researchers and professionals to stress the importance of providing rich speech and language environments for all children, regardless of prevalence [180].

7.2.2 Prevalence by gender

In both the SDAC and AEDC data sources, the prevalence of speech disorders was higher among males compared to females. In the SDAC, 0.7% of males had a speech disorder, compared to 0.5% of females. In the AEDC, 17.3% of males had a speech disorder, compared to 9.3% of females.

Similarly, according to the 1995 Australian Health Survey, which included 12,388 children aged 0-14 years, prevalence of speech disorders among males was 2.4%, and females 0.9% [176]. A male to female ratio of 2.85:1 was found by McKinnon and colleagues [175] in their sample of 10,425 primary school students in Australia. Ratios identified in US research were lower, with speech disorders from 1.5 [179] and 1.8 times [181] more prevalent among males. Further, male gender was commonly reported as a predictor of speech disorders in research from Australia [176, 182], the UK [169], and the US [181].

7.2.3 Prevalence by age

The prevalence of speech disorders decreases with age. In the SDAC, prevalence was 0.3% among children aged 0-4 years, 1.0% among those aged 5-9 years, and 0.2% among 10-14 year olds. The 13.4% prevalence rate from the AEDC data relates to children, mostly aged 5 years, in their first year of full time schooling. Data from the 1995 Australian Health Survey (n=12,388, aged 0-14 years) reported peak prevalence for males at age 5 (6.5%), and for females at age 3-4 years (1.8%) [176].

Similarly, an international review of speech disorder prevalence highlighted that prevalence tends to be higher in children and decreases among adolescents [170]. This is aligned with Section 7.1.4 that describes that the majority of children are able to overcome speech difficulties by age 7-8 years.

7.2.4 Prevalence by other socio-demographic characteristics

According to the SDAC and AEDC, prevalence of speech disorders were higher among children from lower socioeconomic backgrounds, one parent families, and children with an Aboriginal and/or Torres Strait Islander background.

Data from the SDAC and AEDC both showed that speech disorders were more prevalent in children from lower socioeconomic backgrounds[11] (Tables 22 and 23), however this pattern was more pronounced in AEDC data. Among children in their first year of school, 17.8% of those living in the most disadvantaged areas of Australia were reported to have a speech disorder, compared to 10.0% among children living in the least disadvantaged areas. Family type was reported in the SDAC, which showed a slightly higher prevalence among children from one parent families, compared to couple

[11] Socioeconomic background has been measured using the Socio-Economic Indexes for Areas (SEIFA), which is a set of measures derived from ABS census information that summarise different aspects of socioeconomic conditions in an area. Each geographical area in Australia is given a SEIFA score that ranks the disadvantage of an area, compared with other areas across the country. Quintile 1 represents the most socioeconomically disadvantaged areas, while Quintile 5 represents the least disadvantaged areas.

parent families. In the AEDC, prevalence of speech disorders among children with an Aboriginal and/or Torres Strait Islander background was almost double that of non-Aboriginal children.

Maternal education has also been identified to be related to SSD among children. In an Australian longitudinal cohort study, the Early Language in Victoria Study (ELVS) [164], low maternal education was associated with a higher probability of having SSD among a sample of 1,494 children aged 4 years. The Avon Longitudinal Study of Parents and Children (n=7,391) in the UK demonstrated similar findings, with maternal vocabulary associated with prevalence of SSD at 8 years [169]. US research has also shown low maternal education to be associated with speech and language skills more broadly [183, 184].

Table 22. Prevalence of speech disorders by socio-demographic characteristics as reported by SDAC

	n (%) of children and adolescents
Socio-Economic Indexes for Areas (SEIFA)	
Quintile 1 (most disadvantaged)	5,500 (0.7)
Quintile 2	10,300 (1.1)
Quintile 3	5,900 (0.6)
Quintile 4	3,500 (0.3)
Quintile 5 (least disadvantaged)	3,600 (0.4)
Family type	
One parent family	6,700 (0.8)
Couple parent family	21,200 (0.6)

Table 23. Prevalence of speech disorders by socio-demographic characteristics as reported by AEDC

	n (%) of children
Socio-Economic Indexes for Areas (SEIFA)	
Quintile 1 (most disadvantaged)	11,278 (17.8)
Quintile 2	8,882 (15.1)
Quintile 3	8,021 (12.8)
Quintile 4	6,955 (11.3)
Quintile 5 (least disadvantaged)	6,188 (10.0)
Aboriginal and/or Torres Strait Islander background	
Yes	4,372 (23.3)
No	36,919 (12.8)

7.2.5 Prevalence by level of severity/impairment

Severity of speech disorders is often based on qualitative judgments made by clinicians. Severity exists along a spectrum from mild to severe, but there appears no standard approach used to determine levels of impairment among children with SSD. Severity may be indicated by scores on a standardised test, or the number of speech errors a child makes, depending on the assessment measures and cut-offs used. However, in the academic literature these levels of severity were rarely compared or clearly described. This is likely the result of the heterogeneity and complexity of speech disorders and their impact on children, and a difficulty in determining comparable levels of severity or impairment [185].

7.2.6 Trends in prevalence over time

Tables 24 and 25 describe trends in the prevalence of speech disorders over time. Overall, data from the SDAC show that prevalence has remained relatively stable between 2003 and 2018. When disaggregated by gender, prevalence over time has decreased among males, but increased slightly among females. In contrast, AEDC data indicate prevalence has almost doubled between 2009 and 2018, increasing from 7.4% to 13.4%. It should be noted, however, that there were changes to response options in the AEDC between 2012 and 2015 that coincide with this increase in prevalence[12].

Table 24. Prevalence of speech disorders as measured by the SDAC over time

	2003 n (%)	2009 n (%)	2012 n (%)	2015 n (%)	2018 n (%)
Overall					
0-4 years	3,000 (0.2)	6,400 (0.5)	4,100 (0.3)	6,700 (0.4)	5,300 (0.3)
5-9 years	15,100 (1.2)	14,200 (1.2)	11,200 (0.8)	12,900 (0.9)	15,300 (1.0)
10-14 years	8,000 (0.6)	6,300 (0.5)	8,400 (0.6)	5,100 (0.4)	3,600 (0.2)
All ages	26,200 (0.7)	26,900 (0.6)	25,400 (0.6)	28,500 (0.6)	26,000 (0.6)
Males					
0-4 years	3,000 (0.5)	3,200 (0.4)	-	7,000 (0.9)	3,200 (0.4)
5-9 years	12,000 (1.8)	11,600 (1.7)	-	10,200 (1.3)	9,200 (1.1)
10-14 years	4,500 (0.7)	4,700 (0.7)	-	5,100 (0.7)	2,100 (0.3)
All ages	19,500 (1.0)	19,600 (0.9)	18,300 (0.8)	21,700 (1.0)	17,100 (0.7)
Females					
0-4 years	-	3,100 (0.5)	-	900 (0.1)	3,000 (0.4)
5-9 years	3,200 (0.5)	2,600 (0.4)	-	6,200 (0.9)	4,200 (0.5)
10-14 years	3,500 (0.5)	1,500 (0.2)	-	-	2,000 (0.3)
All ages	6,700 (0.4)	7,300 (0.4)	8,000 (0.4)	7,900 (0.4)	11,500 (0.5)

Note. Subgroup prevalence estimates are subject to large standard errors and should be taken with caution. Prevalence could not be estimated for children in some instances due to small cell size.

Figure 5. Prevalence of speech disorders as measured by the SDAC over time

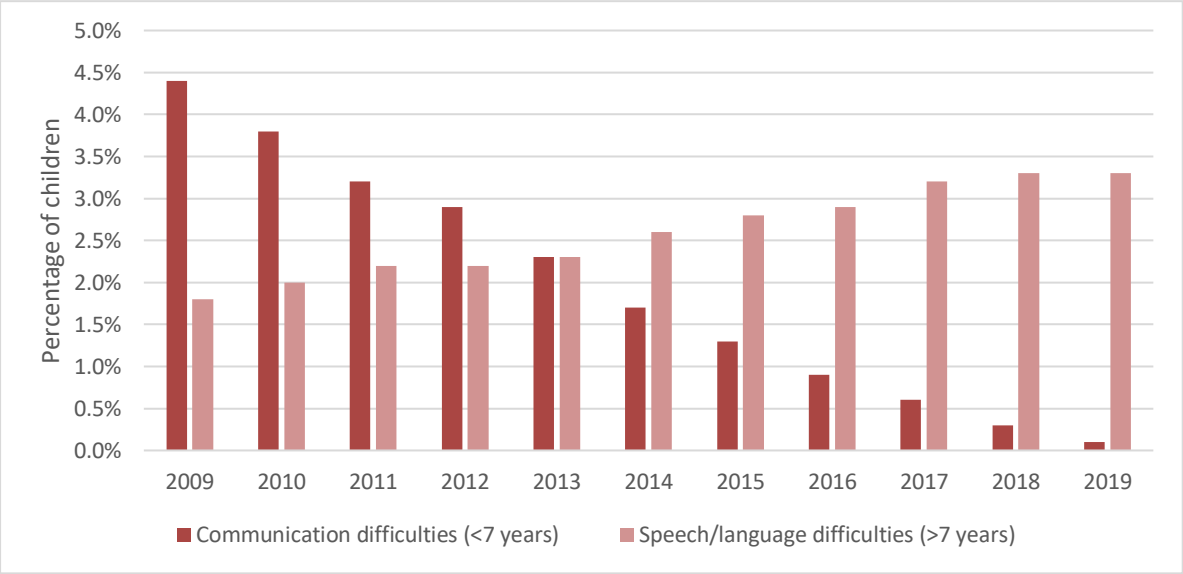
[12] In 2009 and 2012 AEDC collections, there was one response option ('yes') for whether a child had a speech impairment. From 2015 onward, there were two response options ('yes – affects learning' or 'yes – does not affect learning'). Prevalence presented in this chapter from 2015 onward have combined both 'yes' response options to allow comparability over time.

Table 25. Prevalence of speech impairment as measured by the AEDC over time

	2009 n (%)	2012 n (%)	2015 n (%)	2018 n (%)
Overall	19,169 (7.4)	23,923 (8.3)	40,267 (13.4)	41,327 (13.4)
Male	13,134 (9.9)	16,165 (10.9)	26,663 (17.3)	27,422 (17.3)
Female	6,035 (4.8)	7,758 (5.5)	13,604 (9.3)	13,905 (9.3)

Information collected via the IESP in schools indicated that 4.4% (7,368) of students aged below 7 years in South Australia met criteria for communication difficulties in 2009, which has decreased to 0.1% (216) in 2019. In contrast, the proportion of students aged 7 or older that met criteria for speech/language difficulties increased from 1.8% (3,007) in 2009, to 3.3% (5,872) in 2019. This 'swap' in prevalence figures across the different classifications (as presented in Figure 6) could be a result of changes in how speech and language difficulties have been measured/classified over time, or it may also reflect true changes in prevalence of speech difficulties among children in South Australia.

Figure 6. Prevalence of speech disorders as measured by the IESP over time



International evidence typically indicates prevalence estimates of speech disorders have increased over time. In the US, findings from the National Survey of Children with Special Health Care Needs show that prevalence of speech and language disorders have increased from 3.2% in 2005-06 to 5.0% in 2009-10 [170]. The National Survey of Children's Health also showed an increase from 3.8% in 2007 to 4.8% in 2011 [170]. Both US surveys included representative samples to estimate population prevalence, the former surveying 370,000 households and the latter including 90,000 children. To measure speech and language disorders, caregivers were asked about concerns for their child's speech or whether they had been advised by a clinician that their child had speech problems.

Classifications of speech disorders have changed over time, making it difficult to determine trends in prevalence. Each of the three most recent versions of the DSM have included changes to how communication and speech disorders are classified. As described earlier, the DSM-5 includes SSD as a type of Communication Disorder. In the DSM-4, this disorder was referred to as Phonological Disorder

and was a type of Expressive Language Disorder and Mixed Receptive-Expressive Language Disorder, while in earlier versions, it had been called Developmental Articulation Disorder [186].

7.3 Complex needs

Children with SSD and speech disorders more broadly often experience comorbid conditions beyond other language disorders, such as autism and intellectual disabilities. Severe impairments in functioning as a result of comorbid conditions can impact a child's quality of life and increase the need to access services [187, 188].

7.3.1 Prevalence of comorbidities

Findings from ELVS (n=1,494; aged 4 years) showed that, of the children with SSD, 40.8% had comorbid language disorder, and 20.8% had poor pre-literacy skills [164]. In the 1995 Australian Health Survey (n=12,388, aged 0-14 years), 25.8% of children with a speech disorder had a developmental delay or intellectual impairment [176]. The same survey also found that 87.4% of boys and 91.7% of girls with a speech disorder had at least one other heath condition (e.g. asthma, mental health disorder, otitis media, eczema, allergies), while this proportion was smaller for children who did not have a speech disorder: 72.0% and 72.5%, respectively [176].

Internationally, US research (n=1,328, aged 6 years) demonstrated that approximately 11-15% of children with speech delay had a comorbid language disorder [179]. Also in the US, data from across health and educational services (n=26,315) was used to identify children aged 8 years, born in 1994, with communication disorders more broadly (n=1,667) [181]. Among children identified with a communication disorder, the prevalence of intellectual disability and autism was 4.0% and 3.7%, respectively. Otitis media and hearing impairments have also been commonly reported alongside speech disorders due to impaired hearing being a possible aetiological factor [169, 184, 189].

7.3.2 Help seeking behaviours

In the context of Australia's universal child health services, referral to a speech-language pathologist often comes from Child and Family Health Nurses [190]. Despite strong referral systems in place, evidence suggests both over- and under-servicing for speech and language difficulties occurs. For example, among families in ELVS, 44.9% of children with a communication impairment had received help from a professional, and an additional 7% of children that did not meet the criteria for communication impairment had received help from a professional [191].

Ruggero and colleagues [172] used an online survey of 154 families, with 192 children, to investigate paediatric speech-language pathology service delivery in Australia. The most common disorders among children accessing these services were language disorders (40%), followed by childhood apraxia of speech (35%); and articulation or phonological disorder (21%); and auditory processing disorder (10%); or literacy impairment or dyslexia (11%). Childhood apraxia of speech can be considered a cause of SSD and articulation or phonological disorders are forms of SSD. In general, a quarter of children waited over 6 months to receive an initial assessment and once using the services, many attended sessions less often than the 2 to 3 times per week that is recommended for children with SSD [172, 174]. Parents often reported that they would like more frequent and longer sessions,

and advocated for greater service availability. Researchers found that most children attended private practices (40%) or community health services (30%), followed by school services (11%).

7.4 Associated factors

7.4.1 Factors associated with prevalence of disability

SSD may be the result of an underlying motor/neurological, structural, or sensory/perceptual cause (e.g. cleft palate, cerebral palsy, childhood apraxia of speech), and in some cases may have no known cause. Some of the main factors found to be associated with SSD are: low socioeconomic status, otitis media, and family history of speech-language disorders [166, 181, 184, 192].

As described in Section 7.2.4, low socioeconomic status and maternal education have been associated with greater prevalence of SSD among children, both in research in Australia as well as internationally.

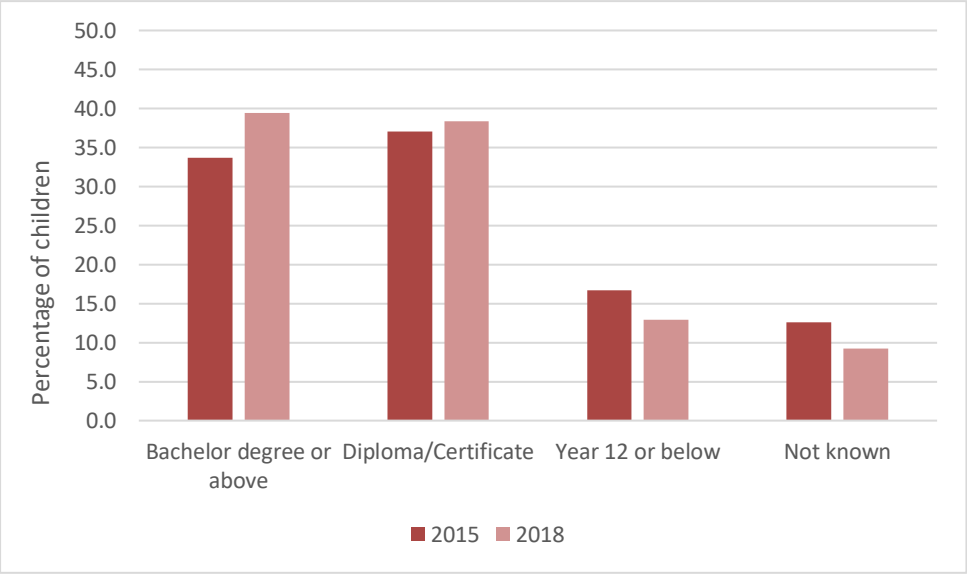
Other research in the US has explored a broader range of factors related to speech delay of unknown origin, among a sample of 100 children aged 3 years who had been identified to have speech delay from a larger sample (n=639) [184]. The variables explored included: gender, family history of communication disorder, maternal education, socioeconomic status, ethnicity, and prolonged otitis media. Results indicated that, low maternal education, low socioeconomic status, and family history of communication disorder were associated with the highest increased odds for speech delay. Despite otitis media commonly being reported alongside speech disorders, this study found no increased odds of speech delay in relation to the percentage of days reported with otitis media [184, 189, 192].

7.4.2 Trends in associated factors over time

Trends in the true prevalence of conditions such as intellectual disability and autism spectrum disorder, which may contribute to speech disorders in childhood, like speech disorders themselves, are difficult to ascertain [33, 42, 181]. Some conditions have increased (e.g. autism spectrum disorder) and some have decreased (e.g. cerebral palsy) over time [33, 193]. Methodological differences between studies over time and increased public awareness may be largely contributing to increases in certain disabilities, which would not necessarily lead to increases in associated conditions.

Trends in parental education, a factor commonly reported to be associated with SSD and speech disorders more broadly, was explored using AEDC data. Specifically, we used information regarding highest parental education (i.e. maternal or paternal education), which was collected in 2015 and 2018 cycles of the AEDC. Across Australia, the proportion of children of parents with a bachelor degree or above increased from 39.2% in 2015 to 43.6% in 2018. Figure 7 shows that, in South Australia specifically, the proportion of children of parents with a bachelor degree or above increased from 33.7% in 2015 to 39.5% in 2018. The proportion of children in South Australia of parents who completed a high school education only, decreased from 16.7% in 2015 to 12.9% in 2018.

Figure 7. Highest parental education among children in South Australia between 2015-2018, as reported by the AEDC



7.5 Quality of prevalence evidence

The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) is a checklist of items that should be included in all reports of observational studies [28]. As an indicator of quality, we have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

- **2018 SDAC:** the most comprehensive national survey of disability among people of all ages in Australia, the SDAC relies on the accurate self-report of conditions (including speech impediment) and in 2018, achieved a household response rate of about 80%. A common issue discussed however, is the reliability of prevalence estimates when disaggregated due to sample size. For example, when breaking down data according to age, gender, and socioeconomic status, high relative standard of error rates (as noted in the footnote of Table 24), mean estimates in some categories should be used with caution or are considered too unreliable for most purposes.
- **2018 AEDC:** of all data sources used in this chapter, the AEDC is the only true "census" as it seeks to collect information for all children in their first year of school across Australia. Population estimates do not need to be calculated because actual population prevalence is collected. Important to note, however, is that prevalence of speech impairment as reported by the AEDC is reliant upon teacher's knowledge and judgment of children's speech impairments.

7.6 Information sources

To identify relevant evidence beyond that presented in the surveys above (i.e. comorbidities and factors associated with the prevalence of speech disorders), databases (namely, Embase, PubMed, PsychInfo, and Web of Science) were searched using key terms: child/ren, adolescent/s, speech disorder/speech delay/speech sound disorders etc, prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify

relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including the Journal of Abnormal Child Psychology, Child Development, and the Journal of Paediatrics and Child Health.

8. Language Disorder

Key findings

This chapter highlights that the prevalence of language disorder varies considerably depending on the definition, measurement and/or assessment criteria employed. In Australia, the Early Language in Victoria Study reported that 17.2% of children aged 4 years met criteria for language disorder, while data from the Australian Early Development Census (AEDC) reported the prevalence of speech/language impairment among children in their first year of school was 13.4%. Prevalence among males is typically double that observed among females; decreases with age; and is higher among children living in socioeconomically disadvantaged areas. There is evidence that language difficulties are highly heritable, and family history of speech and language problems have been associated with increased prevalence of language disorder. Further, low maternal education and perinatal complications, such as low birth weight, have been identified as associated factors. Data from the AEDC suggests that the prevalence of language disorder has increased over time, almost doubling between 2009 and 2018. However, it is important to note that changes to the instrument's response options coincide with this increase in prevalence. This mirrors international evidence, in that different terminology and assessment criteria make it difficult to measure and study language disorder empirically, particularly when investigating prevalence over time.

8.1 Background

8.1.1 Definition

Language disorder represents a significant impairment in the acquisition and use of language. While language disorder can be secondary to other conditions, such as autism spectrum disorder, intellectual disability, attention deficit hyperactivity disorder, and traumatic brain injury, this chapter focuses on idiopathic language disorder (i.e. of unknown origin). This is captured in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) as Language Disorder, which is included in the wider category of Communication Disorders [1].

8.1.2 Presentation and key characteristics

Presentation of language disorder varies between individuals, but common symptoms relate to four domains of language; phonology, syntax and morphology, semantics, and pragmatics. These domains are dynamic and represent the complex system of language acquisition, use, and understanding [194]. Examples of deficits in each domain include:

- **Phonology**: tendency to vocalise less and use less varied or mature syllable structures than children of the same age.
- **Syntax and morphology**: late acquisition of word combinations, difficulty identifying and correcting grammatical errors, and difficulty identifying parts of speech.
- **Semantics**: difficulty understanding new words, comprehending and using synonyms and antonyms, multiple-meaning words, and figurative language, and paraphrasing information.
- **Pragmatics**: difficulty initiating play with peers, and initiating and sustaining conversations.

8.1.3 Diagnosis

According to the DSM-5 [1], the below four criteria must be met for a diagnosis of language disorder:

- Persistent difficulty using language in different manners (speaking, writing, using sign language, or other) due to deficits in understanding or production that include: reduced vocabulary, limited sentence structure, or impairments in discourse.
- Language capacity is significantly below what is expected at the individual's age, which may result in hindered communication, social participation, and academic achievement.
- Onset of symptoms is in the early developmental period.
- Difficulties are not result of a sensory impairment, motor dysfunction, or another medical condition, and cannot be attributed to intellectual disability or global developmental delay.

Speech- language therapists diagnose language disorders, and language skills are measured using scales and tests, such as the Peabody Vocabulary Test III or the Reynell Developmental Language Scales. Many children under 3 years of age are identified as late talkers using these measures, however, evidence shows that approximately 50-70% of late talkers will catch up to their peers around 3 years of age [195, 196]. Therefore language impairment around this age does not necessarily indicate language disorder. As a result, language disorder is more reliably identified from 4 years onward [197, 198]. Although the DSM-5 does not specify criteria for varying levels of severity of language disorder, this is typically determined by a clinician's qualitative judgement.

8.1.4 Onset and progression

While diagnosis of language disorder is most reliable from 4 years of age onward, as described above, onset of language disorder is considered to occur around 2 years of age when deficits in language skills first become apparent. As children enter school, language disorders may also progress to encompass difficulties with written language and communication, as well as reading skills [194]. The progression of language disorders will vary between individuals and also depend on the cause and severity of the disorder. For example, the progression of language disorders due to cerebral palsy may differ from that of idiopathic language disorders [199].

8.1.5 Treatment

Treatment of language disorder is tailored according to severity of disorder and profile of language skills. Interventions for language disorder will also differ depending on age, with therapy for younger children focusing on basic language acquisition and for older children, developing skills to navigate the demands of school. According to the Treatment Resource Manual for Speech-Language Pathology [200], effective treatment for language disorder, regardless of age and severity, should focus on:

- Teaching strategies for facilitating communication, rather than teaching isolated behaviours.
- Being dynamic in nature and include ongoing assessment of the child's progress.
- Individualised treatment based on the nature of a child's deficits and individual learning style.
- Setting realistic goals to promote a child's knowledge, one step at a time.

Milder language impairment, that would not meet criteria for a language disorder diagnosis, can hinder learning and development throughout childhood and adolescence. Therefore it should also be

noted that, along with these interventions, speech-language researchers and professionals stress the importance of providing rich language environments for all children.

8.2 Prevalence

To describe the prevalence of language disorder among children and adolescents in Australia, three key data source were used, as described below.

It is important to highlight the different terms used within speech-language pathology research and the lack of consensus over which labels to use [201, 202]. Most research in this area focuses on language impairment and delay, which may or may not indicate language disorder. The broad criteria used for language impairment in some research studies makes identifying the prevalence of language disorder difficult. Further, some research refers to the term Developmental Language Disorder (DLD)[13], which is equivalent to language disorder as described by the DSM-5 in Section 8.1.1. Throughout this chapter we refer to language impairment, DLD, and language disorder, dependent upon data source.

The **Early Language in Victoria Study** (ELVS) is a longitudinal cohort study based in six local government areas (LGAs) in Victoria that recruited 1,910 infants in 2003-4 through the Maternal and Child Health Service. LGAs were selected to ensure there were two LGAs representing each tertile of the Socio-Economic Indexes for Areas (SEIFA)[14]. The research referred to in this chapter draws on parent-reported data collected at 8, 12, and 24 months, and language outcomes measured at 4 years [203]. At 4 years of age (n=1,596), children were assessed to determine diagnosis of DLD (determined by scores on the Clinical Evaluation of Language Fundamentals-Preschool, Second Edition; CELF-P and the Kaufman Brief Intelligence Test, Second Edition; K-BIT2).

The **2018 Australian Early Development Census (AEDC)** is a national census of children's early development and readiness for school, completed by teachers for children in their first year of full time school (i.e. when children are aged 4-6 years, with the majority of children 5 years old). The census aims to collect information on all children across Australia in their first year of full time school, with a participation rate of 96.4% or 308,953 children, through information collected from 17,508 teachers across 7,507 schools, achieved in the 2018 census. As part of the census, teachers were asked if children had a number of conditions/impairments/problems, including speech/language impairment. The AEDC is conducted triennially and information collected in 2009, 2012, and 2015 can be used to compare prevalence rates over time.

The **Longitudinal Study of Australian Children (LSAC)** was included to provide further information on the prevalence of language impairment among children in Australia [177]. Sampled first by postcode and then by the Australian Medicare database, LSAC cohorts are described to be representative of the population of children in Australia. However, there is evidence to suggest that the LSAC under-

[13] Developmental Language Disorder replaced what was previously referred to as Specific Language Impairment (SLI). Although presentation of DLD and SLI are not identical, it is generally acknowledged that individuals with an SLI diagnosis will also satisfy criteria for diagnosis of DLD. As such, we refer to DLD throughout this chapter.

[14] The Socio-Economic Indexes for Areas (SEIFA) is a set of measures derived from ABS census information that summarise different aspects of socioeconomic conditions in an area. Each geographical area in Australia is given a SEIFA score that ranks the disadvantage of an area, compared with other areas across the country.

represents disadvantaged families in the population. The B (5,107 children, born 2003-2004) and K (4,983 children, born 1999-2000) cohorts were recruited in 2004. Language impairment was measured at ages 4-5 using parent and teacher interviews. Parents were asked 'do you have any concerns about how your child talks and makes speech sounds?' and 'do you have any concerns about how you child understands what you say to him/her?'. Teachers were asked to rate children's expressive and receptive language skills in comparison to other students. Direct assessment included the use of the Adapted Peabody Picture Vocabulary Test – III (PPVT – III), with a cut off-of more than one standard deviation below the mean indicating receptive language impairment.

In this chapter, we draw comparisons between prevalence information from these sources, with that of Department for Education internal data. Specifically, the 2019 Inclusive Education Support program (IESP), an annual collection of information from schools on students with disability, is used to provide the Department with an understanding of the prevalence of disability among students in primary and secondary schools in South Australia. Previous collections from 2009 onward are used to explore prevalence over time.

8.2.1 Overall prevalence

ELVS reported that 17.2% (251) of 4 year olds met criteria for DLD [203]. According to the AEDC, the prevalence of speech/language impairment among children in their first year of school was 13.4% (41,327). The LSAC reported that, in relation to how their child understood language, 4.4% of parents were 'concerned'. Further, 6.7% of children were identified by teachers as 'much less competent' than others in their expressive language ability, and 4.0% in their receptive language skills [177]. Direct assessment indicated language impairment among 13.0% of children in LSAC cohorts [177]. Overall, these prevalence figures are quite varied, however it is important to highlight that each data source captures language difficulties among children and adolescents in different ways.

Although not specific to language disorder alone, data collected through the IESP reports on two categories of students with speech and/or language difficulties. Students under the age of 7 years can be classified as having communication difficulties, which includes a speech and/or language disorder, and have been participating in interventions to remediate difficulties. Students older than 7 years can be classified to have speech/language difficulties, including difficulties understanding spoken language as well as with oral expression. In 2019, IESP data reported that 0.1% (216) students aged below 7 years in South Australia met criteria for communication difficulties, and 3.3% (5,872) of students aged 7 years or older met criteria for speech/language difficulties.

Prevalence of language disorder as reported in the international literature tends to be lower than that reported by research in Australia. A systematic review of studies that included children aged up to 16 years found that the prevalence of language impairment was around 7.4% [171]. Another international review, which focused on surveys that used cut-off scores from standardised tests to identify language disorder, found that 3-6% of children had a language disorder upon school entry [197]. Research among a survey sample in the US (n=7,218 children; aged 5 years) reported a 7.4% prevalence rate of DLD [204]. A UK population-based survey (n=12,398; aged 4-5 years) estimated that the prevalence of language disorder was 9.9%, of which 7.6% was idiopathic and 2.3% was associated with another condition [205]. Language disorder was identified in this study using a combination of

DSM-5 criteria, the Strengths and Difficulties Questionnaire, and the Children's Communication Checklist-Short.

8.2.2 Prevalence by gender

Findings from ELVS demonstrated that prevalence of DLD among males was around double that of females [203, 206]. This was consistent with the AEDC data, in which 17.3% of males were reported to have a speech/language disorder, compared to 9.3% of females. International research, however, has reported smaller male-to-female ratios. In the US, prevalence of DLD was 8% among males and 6% among females, indicating a ratio of 1.3:1 [204]. Similarly, a population-based survey of language disorder in the UK reported a prevalence ratio of 1.2:1, with greater prevalence among males [205].

8.2.3 Prevalence by age

Much of the available evidence regarding early language skills is focused on children at school entry. This allows for more reliable measurement of language skills and diagnosis of language disorder, relative to exploring these skills in younger children. As described in Section 8.1.3, prevalence of language impairment tends to decline between 2-3 years of age. Further, international evidence suggests that prevalence of language disorder continues to decrease with age [171]. This could be due to spontaneous recovery (i.e. catching up to peers), as well as a combination of successful targeted and environmental interventions [177]. Nonetheless, many children who no longer meet the diagnostic criteria for language disorder continue to have language difficulties and lower literacy skills later in life highlighting the need to provide ongoing support [207].

8.2.4 Prevalence by other socio-demographic characteristics

According to ELVS, AEDC, and LSAC data, prevalence of both language impairment and disorder was higher among children from low-socioeconomic backgrounds, specifically those of less educated mothers [203, 208]. The AEDC indicated that, among children in their first year of school, 17.8% of children living in the most disadvantaged areas of Australia were reported to have a speech/language impairment, compared to 10.0% among children living in the least disadvantaged areas (Table 26). Prevalence of speech/language impairment was also reported by teachers to be higher among children with an Aboriginal and/or Torres Strait Islander background.

Table 26. Prevalence of speech/language impairment by socio-demographic characteristics as reported by AEDC

	n (%)
Socio-Economic Indexes for Areas (SEIFA)	
Quintile 1 (most disadvantaged)	11,278 (17.8)
Quintile 2	8,882 (15.1)
Quintile 3	8,021 (12.8)
Quintile 4	6,955 (11.3)
Quintile 5 (least disadvantaged)	6,188 (10.0)
Aboriginal and/or Torres Strait Islander background	
Yes	4,372 (23.3)
No	36,919 (12.8)

8.2.5 Prevalence by level of severity/impairment

Severity of language disorder exists along a spectrum from mild to severe. Severity may be indicated by scores on a standardised test, but this depends on the assessment measures and cut-offs used. Severity of language disorder was rarely a focus, or clearly described in the literature. However, Norbury and colleagues [205] observed that children whose language disorder was the result of a medical condition and/or intellectual disability experienced more severe deficits, relative to children with an idiopathic language disorder. Using a combination of DSM-5 criteria, the Strengths and Difficulties Questionnaire, and the Children's Communication Checklist-Short to identify language disorder, the authors concluded that upon school entry around 6% of children experienced language disorder severe enough to affect their academic progress [205].

8.2.6 Trends in prevalence over time

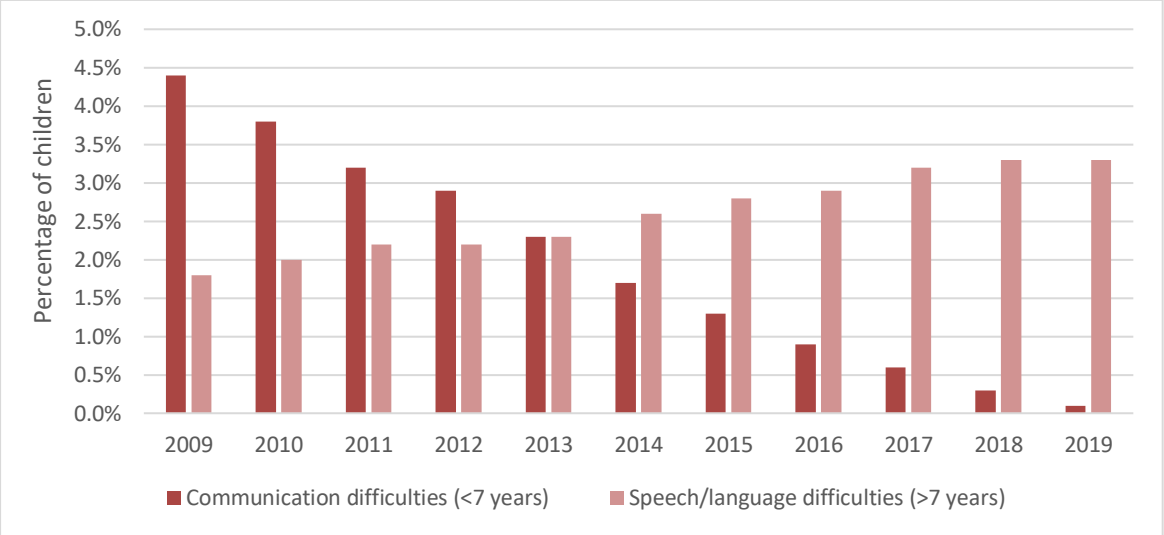
AEDC data indicated prevalence of speech/language impairment has almost doubled between 2009 and 2018, increasing from 7.4% to 13.4%. It should be noted, however, that there were changes to response options in the AEDC between 2012 and 2015 that coincide with this increase in prevalence. Specifically, in 2009 and 2012 AEDC collections, there was one response option ('yes') for whether a child had a speech/language impairment. From 2015 onward, there were two response options ('yes – affects learning' or 'yes – does not affect learning'). Prevalence presented in this chapter from 2015 onward have combined both 'yes' response options to allow comparability over time.

Table 27. Prevalence of speech/language impairment as measured by the AEDC over time

	2009 n (%)	2012 n (%)	2015 n (%)	2018 n (%)
Overall	19,169 (7.4)	23,923 (8.3)	40,267 (13.4)	41,327 (13.4)
Male	13,134 (9.9)	16,165 (10.9)	26,663 (17.3)	27,422 (17.3)
Female	6,035 (4.8)	7,758 (5.5)	13,604 (9.3)	13,905 (9.3)

Information collected via the IESP in schools indicated that 4.4% (7,368) of students aged below 7 years in South Australia met criteria for communication difficulties in 2009, which has decreased to 0.1% (216) in 2019. In contrast, the proportion of students aged 7 or older that met criteria for speech/language difficulties increased from 1.8% (3,007) in 2009, to 3.3% (5,872) in 2019. This 'swap' in prevalence figures across the different classifications (as presented in Figure 8) could be a result of changes in how speech and language difficulties have been measured/classified over time, or it may also reflect true changes in prevalence of speech difficulties among children in South Australia.

Figure 8. Prevalence of speech/language disorders as measured by the IESP over time



Internationally, trends in the prevalence of language disorder are difficult to determine due to lack of evidence, varied terminology, and changes to diagnostic criteria [171, 202]. For example, Weindrich and colleagues [209] investigated the prevalence of language disorder according to varying cut-offs among a longitudinal cohort (n=320; aged 4-5 years) of children in Germany. Prevalence was 2.2% using strict criteria, but three times higher when assessment criteria were broadened [209]. Further, the prevalence of language disorder in the literature may apply to idiopathic language disorder and/or language disorder secondary to other conditions, which may impact prevalence rates and have different implications for policy and service provision [170, 201, 202].

International research on speech and language disorders more broadly shows increases in prevalence over time. In the US, findings from the National Survey of Children with Special Health Care Needs show that prevalence of speech and language disorders increased from 3.2% in 2005-06 to 5.0% in 2009-10 [170]. The National Survey of Children's Health also showed an increase from 3.8% in 2007 to 4.8% in 2011 [170]. Both US surveys included representative samples to estimate population prevalence, the former surveying 370,000 households and the latter including 90,000 children. To measure speech and language disorders, caregivers reported concerns for their child's language skills or if they had received clinician advice that their child had speech and language problems.

8.3 Complex needs

Language disorders may be the result of comorbid conditions, such as autism and intellectual disabilities, but idiopathic language disorders can often co-occur with other health conditions. Severe impairment in functioning as a result of comorbid conditions can impact a child's quality of life and increase the need to access services [187, 188].

8.3.1 Prevalence of comorbidities

The prevalence of co-occurring language and speech disorders is high [164]. According to a systematic review, the prevalence of combined language and speech impairment ranged from 2.3% to 6.7% [171]. Evidence also shows that children with comorbid speech and language disorders are more likely to

have conditions such as attention deficit/hyperactivity disorder, anxiety, and conduct disorder [167, 181]. For example, a Swedish cohort study (n=2,359; aged 3 years) found that 61% of children with severe DLD had a comorbidity upon school entry, such as neurodevelopmental disorder or intellectual disability [210]. However, in examples such as this, it is unclear if this reflects idiopathic language disorder, or language disorder due to other conditions (e.g. intellectual disability).

8.3.2 Help seeking behaviours

In the context of Australia's universal child health services, referral to a speech-language pathologist often comes from Child and Family Health Nurses [190]. Despite strong referral systems in place, evidence suggests both over- and under-servicing for speech and language difficulties occurs. For example, among families in ELVS, 44.9% of children with a communication impairment (which encompasses language, speech, and fluency) had received help from a professional, and an additional 7% of children that did not meet the criteria for impairment had received help [191].

Ruggero and colleagues [172] conducted an online survey of 154 families (with 192 children aged 0-18 years) accessing speech-language pathology services in Australia, and found that the most common disorder among children accessing these services was language disorder (40%). Parents often reported that they would like more frequent and longer sessions, and advocated for greater service availability. Researchers found that, of all children accessing services, most attended private practices (40%) or community health services (30%), followed by school services (11%).

Finally, data from a longitudinal Australian study of 14,500 children aged 5-18 years in NSW schools showed that communication disorders (encompassing language, speech, and fluency) were the second most common reason for needing learning support [211]. At waves 1 and 2 (two years apart), support for communication disorder (13.0%; 12.4%) was less common than specific learning difficulty (17.9%; 19.1%), but more common than behavioural/emotional difficulty (8.2%; 6.1%).

Although there is evidence supporting the benefit of screening and treatments for speech and language impairments, taken together with the lack of evidence for treatment impact and the sensitivity of diagnostics the relevance of screening children for language delay and/or disorder prior to the age of 4 years is questionable.

8.4 Associated factors

8.4.1 Factors associated with prevalence of disability

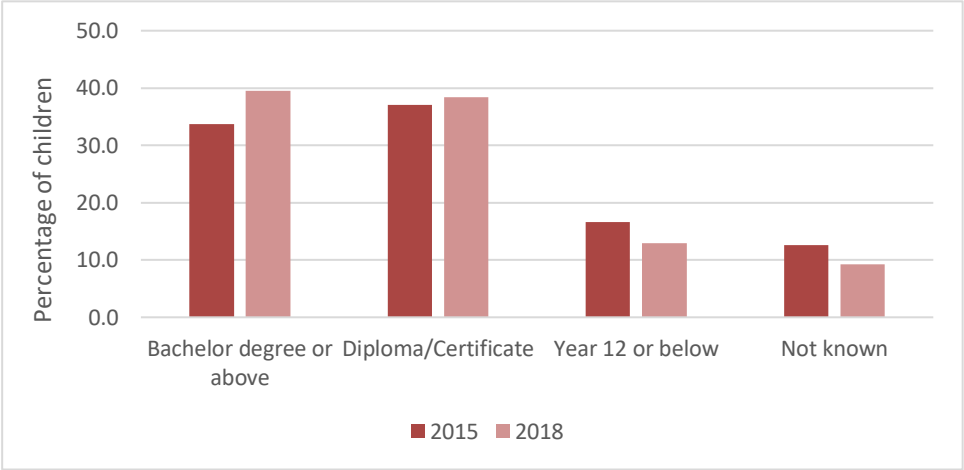
Language disorder may be the result of other conditions, such as intellectual disability or cerebral palsy, but language disorder that is a primary disability has unknown origins [199, 212]. Among children with idiopathic language disorders, low socioeconomic status and maternal education have been identified as associated factors as described in Section 8.2.4 [183, 203, 213, 214]. Family history of speech and language problems have also been associated with increased prevalence, and there is evidence that language difficulties are highly heritable [203, 215, 216]. Perinatal complications, like premature birth and low birth weight, have also been identified as risk factors for language disorder [206, 214, 217].

8.4.2 Trends in associated factors over time

Trends in parental education were explored using AEDC data. Specifically, we used information regarding highest parental education (i.e. maternal or paternal education), which was collected in 2015 and 2018 cycles of the AEDC. Across Australia, the proportion of children with parents who had a bachelor degree or above increased from 39.2% in 2015 to 43.6% in 2018. Figure 9 shows that, in South Australia specifically, the proportion of children of parents with a bachelor degree or above increased from 33.7% in 2015 to 39.5% in 2018. The proportion of children in South Australia of parents who completed a high school education only, decreased from 16.7% in 2015 to 12.9% in 2018.

Exploring trends in perinatal complications highlights that there has been little change in the proportion of babies born with a low birthweight or pre-term in Australia between 2007 and 2017 [23]. In South Australia specifically, however, the percentage of low birthweight babies (<2,500g) increased slightly from 6.8% in 2001 to 7.3% in 2017, while the percentage of very low birthweight babies (<1,500g) remained stable (1.6%) during this period [24]. The proportion of babies born preterm (<37 weeks gestation) in South Australia also increased slightly between 2001-2017, from 8.1% to 9.6% [24].

Figure 9. Highest parental education among children in South Australia between 2015-2018, as reported by the AEDC



8.5 Quality of prevalence evidence

The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) is a checklist of items that should be included in all reports of observational studies [28]. As an indicator of quality, we have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

- **ELVS:** is a longitudinal cohort study that aims to explore language development from infancy to adolescence. In 2003-4, 1,910 infants were recruited through the Victorian Maternal and Child Health Service. This is a relatively small sample compared to the other sources of evidence used in this chapter, however sampling of LGAs according to different socioeconomic backgrounds (i.e.

across all SEIFA tertiles) sought to ensure that children from across the socioeconomic spectrum were included. A strength of this study is that it used direct assessment, in combination with both parent and teacher report, to identify children with language disorder.

- **AEDC:** of all data sources used in this chapter, the AEDC is the only true "census" as it seeks to collect information for all children in their first year of school across Australia. Population estimates do not need to be calculated because actual population prevalence is collected. Important to note, however, is that prevalence of language impairment as reported by the AEDC is reliant upon teacher's knowledge and judgment of children's speech/language impairments.
- **LSAC:** a national longitudinal study that has followed cohorts of children through adolescence and into early adulthood, the LSAC typically relies on parent and teacher reports of children's language abilities. Importantly, although LSAC cohorts are described to be representative of the population of young people in Australia, there is evidence (i.e. developmental vulnerability as measured by the AEDC in LSAC cohorts vs the overall population) to suggest that the LSAC under-represents disadvantaged families in the population. This might be attributable to participant exclusions as well as the sampling frame.

8.6 Information sources

To identify relevant evidence beyond that presented in the surveys above (i.e. comorbidities and factors associated with the prevalence of speech disorders), databases (namely, Embase, PubMed, PsychInfo, and Web of Science) were searched using key terms: child/ren, adolescent/s, language disorder/language delay/specific language impairment etc, prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including the Journal of Child Psychology and Psychiatry, Child Development, and Pediatrics.

9. Major Depressive Disorder

Key findings

The prevalence of Major Depressive Disorder (MDD) among children and adolescents aged 4-17 years in Australia, as reported by the 2013-14 Australian Child and Adolescent Survey of Mental Health and Wellbeing, was 2.8%. Prevalence of MDD increases with age and onset typically coincides with that of puberty. Across data sources, prevalence of MDD in females was typically double than that in males. Further, evidence shows that prevalence of MDD is higher among children and adolescents from disadvantaged backgrounds, with increases in household income, parental education and employment associated with a decrease in prevalence. While genetics contribute to around 35-50% of MDD cases, environmental factors play a key role in the burden of MDD among children and adolescents. Experiences of childhood adversities in particular, including maltreatment as well as bullying, have been identified as factors associated with MDD. The heterogeneity of prevalence figures, likely a result of different methodologies and measurements used between studies, makes determining trends over time difficult. While some data sources indicate that prevalence of MDD has remained stable over the past 20-30 years, there is also evidence of increased prevalence over time, observed among females in particular. Further, although the dispensing of antidepressant medication has increased over time, trends in prevalence cannot be deduced from this information alone.

9.1 Background

9.1.1 Definition

Major Depressive Disorder (MDD), sometimes referred to as clinical depression, is described in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) as a depressed or irritable mood and loss of interest or pleasure [1]. In individuals with MDD, these symptoms are severe enough to cause persistent interference with daily functioning.

9.1.2 Presentation and key characteristics

The key characteristics and symptoms of MDD, as described in the DSM-5 include:

- **Depressed mood** (which may present as irritable mood in children and adolescents)
- **Loss of interest or pleasure** in almost all activities
- **Significant unintentional weight loss/gain** or decrease/increase in appetite (in children, failure to make expected weight gains)
- **Sleep disturbance** (i.e. insomnia or hypersomnia)
- **Psychomotor changes** (i.e. agitation) severe enough to be observable by others
- **Tiredness, fatigue, or low energy**, or decreased efficiency in completing routine tasks
- **A sense of worthlessness** or excessive, inappropriate, or delusional guilt (not merely self-reproach or guilt about being sick)
- **Impaired ability to think, concentrate, or make decisions**
- **Recurrent thoughts of death** (not just fear of dying), suicidal ideation, or suicide attempts

9.1.3 Diagnosis

MDD diagnosis, according to the DSM-5, requires five or more of the above symptoms to be present for a minimum of two weeks [1]. At least one of the symptoms must be depressed mood (or an irritable mood in children and adolescents) or loss of interest/pleasure. These symptoms can be based on self-report or on observations made by others. Additional criteria required for diagnosis include:

- Symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- Symptoms are not due to the direct physiological effects of a substance (e.g. drug abuse, a prescribed medication's side effects) or a medical condition (e.g. hypothyroidism).
- The individual has never experienced a manic or hypomanic episode.
- Symptoms are not better explained by schizophrenia spectrum or other psychotic disorders.

Levels of severity of MDD are not described in the DSM-5 but more symptoms typically indicate increased severity, based on clinical judgements or the use of assessment scales such as the Hamilton Depression Rating Scale. Alternatively, some studies may apply their own criteria for severity.

9.1.4 Onset and progression

Onset and progression of MDD is highly variable between individuals. Generally, the risk of MDD onset is highest from mid-to-late adolescence to early 40s [218]. Among children and adolescents specifically, onset typically occurs between 11 and 14 years old [219]. Approximately 40% of individuals will begin recovery within 3 months of symptom onset, and around 80% within a year [220]. Risk of MDD reoccurrence is described to be highest during the first month post-recovery, and then decreases as the period of remission increases [220]. MDD is highly recurrent, especially among individuals who experience onset in childhood or adolescence [221]. The average length of an MDD episode in children and adolescents is around 7-9 months [222]. While most children and adolescents will remit from a formal diagnosis of MDD, depressive symptoms that are not severe enough to require a diagnosis may remain for some time and increase the risk of reoccurrence.

9.1.5 Treatment

Treatment of MDD often relies on a combination of psychotherapy, psychopharmacology, and behavioural interventions [218]. Management of more severe MDD may require treatments such as cognitive behavioural therapy and medications, while milder episodes might be treated with psychotherapy and behavioural changes (i.e. implementing protective factors such as adequate sleep, exercise, and diet) [220, 223]. The use of psychotropic medications to treat MDD in Australia has increased over time. Between 2009 and 2012, the largest increase (from 16.1% to 35.5%) in the dispensing of antidepressant medication was for children aged 10-14 years [224]. Preventive approaches to MDD are also important considering the high prevalence and risk of reoccurrence among children and adolescents. For instance, research suggests universal school-based interventions (e.g. training of teachers by psychologists to deliver intervention material in class) may be an effective way to improve outcomes and reduce the burden of MDD in later life [225].

9.2 Prevalence

To describe the prevalence of MDD among children and adolescents in Australia, two key data sources were used.

The **2013-14 Australian Child and Adolescent Survey of Mental Health and Wellbeing** (Young Minds Matter; YMM) sought to estimate the prevalence, severity, and impact of mental health disorders in children and adolescents in Australia. The survey aimed to collect information from a random sample of 5,500 families with children and adolescents aged 4-17 years across Australia, with the exception of very remote areas. An additional random sample of 800 families with adolescents aged 16-17 was included to enable estimates specific to this age group. Area based sampling was used and where there were more than one child in a household, one child was selected at random. In total, 6,310 parents responded (55% response rate) and 2,967 (89%) children and adolescents aged 11-17 years in those households for whom their parents had given permission also completed a questionnaire. Parents completed the Diagnostic Interview Schedule for Children Version 4 (DISC-4), a validated tool for identifying mental health disorders (including MDD) according to criteria specified in the DSM-4[15]. The survey was previously conducted in 1998, enabling exploration of prevalence over time.

The **2018 ABS Survey of Disability, Aging and Carers (SDAC)** is a national survey designed to provide reliable estimates of the prevalence of different disabilities in Australia. In 2018, a multi-stage area sampling approach was used to identify a random sample of 31,000 Australian households. This sample included a number of exclusions, including households in very remote areas. A total of 27,573 households were contactable and invited to participate in the survey and data were available for analyses for approximately 21,983 households (79.7% response rate). Respondents were asked a series of questions to identify if anyone in their household had social, emotional, behavioural, learning, or mental health difficulties; and if 'yes' the respondent was asked to identify the condition/s the individual is experiencing, including depression/mood affective disorders[16]. Survey responses were used to estimate total population prevalence of depression/mood affective disorders. Previous surveys conducted (2003, 2009, 2012, 2015) are used to explore the trends in prevalence over time.

In this chapter, we draw comparisons between prevalence information from these sources, with that of Department for Education internal data. Specifically, the 2019 Inclusive Education Support program (IESP), an annual collection of information from schools on students with disability, is used to provide the Department with an understanding of the prevalence of disability among students in primary and secondary schools in South Australia. Previous collections from 2009 onward are used to explore prevalence over time.

[15] Diagnostic criteria in the DSM-4 is consistent with descriptions given above, in Section 9.1, using the DSM-5.

[16] Depression/mood affective disorders captures MDD as well as bipolar disorder.

9.2.1 Overall prevalence

Prevalence of MDD as reported by the YMM was 2.8% (112,000) among children and adolescents aged 4-17 year olds. Prevalence according to the SDAC was lower; 0.1% (4,600) of children and adolescents aged 0-14 years[17] were reported to have depression/mood affective disorder.

Although not specific to MDD, data collected through the IESP reports on students classified to exhibit complex social/emotional behaviour. This is described to include students who have a disorder, illness, condition or developmental trauma that affects their thought processes, perception of reality, emotions or judgement, or results in concerning behaviour(s). IESP data reported that 1.2% (2,100) of primary and secondary school students in South Australia met criteria for complex social/emotional behaviour. It is possible this captures MDD because of the changes in behaviour and judgments exhibited by children and adolescents with MDD (i.e. impaired ability to think, concentrate, or make decisions, and irritable behaviour). However, this would also capture other conditions that may affect students similarly, such as attention deficit/hyperactivity disorder or oppositional defiant disorder.

Internationally, prevalence of MDD is similar to that reported by the YMM. In the US, findings from the 2001-04 National Health and Nutrition Examination Survey (n=3,042; aged 8-15 years) reported a prevalence estimate of 2.7% [136]. More recently, MDD in the 2016 US National Survey of Children's Health (n=43,283; aged 3-17 years) was reported to be 3.2% [226]. In the UK, 0.7% of 5-15 year olds were reported to have MDD in the 1999 British Child and Mental Health Survey (n=10,438) [227].

9.2.2 Prevalence by gender

According to the YMM, prevalence of MDD was higher among females (3.1%; 61,300), compared to males (2.5%; 50,900). Low overall prevalence figures in the SDAC meant depression/mood affective disorder prevalence by gender was not reported, and therefore could not be compared (see Table 31).

Gender differences in MDD prevalence increase with age, as highlighted in the international literature. The female-to-male MDD prevalence ratio among adolescents is commonly reported to be around 2:1 [136, 222, 228]. For instance, the US 2001-04 National Health and Nutrition Examination Survey (n=3,042; aged 8-15 years) reported MDD prevalence to be 3.2% among females and 1.6% among males [136].

9.2.3 Prevalence by age

In the YMM, prevalence of MDD was 5 times higher among 12-17 year olds (5.0%) relative to children aged 4-11 years (1.1%). This is consistent with other research that demonstrates increased prevalence of MDD around the onset of puberty, continuing into late adolescence [227]. Again, low prevalence as reported by the SDAC meant estimates could not be reported across age groups.

9.2.4 Prevalence by other socio-demographic characteristics

The YMM also reported prevalence of MDD across a range of other socio-demographic factors, including family type, household income, parent education and labour force status, area of residence and level of family functioning (Table 28). Overall, prevalence of MDD was highest among children and

[17] Onset of MDD among children and adolescents typically occurs at 11-14 years. However, SDAC prevalence figures could not be disaggregated further by age due to small numbers, and thus are reported for the broader 0-14 age range.

adolescents who did not live with their original family (i.e. their biological, adoptive or foster parents); were from a household in the lowest income bracket; had parents/carers with low educational attainment or those not in the labour force; and those reported to have poor family functioning.

9.2.5 Prevalence by level of severity/impairment

Information on the prevalence of severity of MDD as described in Section 9.1.3 was not available. However, YMM reported on the impact of MDD on child and adolescent functioning in relation to school and/or work, friends, family, and self (Table 29). Approximately a third of respondents reported they experienced severe impacts of MDD on school/work, while 40.3% experienced severe impact on self. The majority of children reported moderate impacts on friends and family. Almost half of children and adolescents with MDD reported the overall impact of MDD to be severe (42.8%). This was the highest proportion of respondents to report severe impacts when compared to other mental health disorders captured in the YMM, such as generalised anxiety disorder (31.1%).

Table 28. Prevalence of MDD by socio-demographic characteristics as reported by YMM

	%
Family type	
Families with two parents/carers	2.1
Original family	1.7
Step family	4.7
Blended family	3.5
Families with one parent/carer	5.5
Household income	
$130,000+ per year	1.8
> $52,000 and < $130,000 per year	2.7
< $52,000 per year	3.8
Parental education	
Bachelor degree or higher	2.1
Diploma or certificate III/IV	3.0
Year 11 or 12	4.1
Year 10 or below	3.5
Parental labour force status	
Both parents/carers employed	1.8
One parent/carer employed, one parent/carer unemployed	2.4
Both parents/carers unemployed	4.9
Sole parent/carer employed	4.6
Sole parent/carer unemployed	6.9
Family functioning	
Very good	2.1
Good	3.0
Fair	4.1
Poor	7.7

Table 29. Impact of MDD on domains of functioning according to YMM

	School/work (%)	Friends (%)	Family (%)	Self (%)	Overall severity (%)
Severity					
None	9.6	14.4	8.4	np	
Mild	17.3	19.1	30.6	np	21.4
Moderate	34.1	43.1	33.5	37.5	35.8
Severe	34.4	23.4	27.4	40.3	42.8
Does not go to school or work	4.8				

Note: np - not available for publication because of small cell size, but included in totals where applicable.

9.2.6 Trends in prevalence over time

While the SDAC has demonstrated stable prevalence of depression/mood affective disorder over time, the YMM indicates an increased in the prevalence of MDD. Table 30 shows that prevalence of MDD has increased from 2.2% in 1998 to 3.6% in 2013-14. This increase has not been consistent across age ranges, however. While prevalence among children aged 6-11 years has remained stable, prevalence among those aged 12-17 years has almost doubled; from 3.1% to 5.8% among females and from 2.7% to 4.3% among males. The gap in MDD prevalence by gender has also increased over this time, reflecting a greater increase of MDD in females compared to males.

Table 30. Prevalence of MDD as measured by YMM over time

	1998 %	2013-14 %
Overall		
6-11 years	1.4	1.4
12-17 years	2.9	5.0
All ages	2.1	3.2
Males		
6-11 years	1.4	1.2
12-17 years	2.7	4.3
All ages	2.1	2.8
Females		
6-11 years	1.3	1.6
12-17 years	3.1	5.8
All ages	2.2	3.6

Note. Data are presented for children aged 6-17 years only (i.e. 4-5 years are excluded) to enable valid comparisons with previous data. Population estimates are not provided for the 1998 collection so we are able to present percentages only.

Table 31. Prevalence of depression/mood affective disorder as measured by the SDAC over time

	2003 n (%)	2009 n (%)	2012 n (%)	2015 n (%)	2018 n (%)
Overall	3,300 (0.1)	3,600 (0.1)	1,600 (0.04)	7,100 (0.2)	4,600 (0.1)
Males	3,300 (0.2)	2,900 (0.1)	800 (0.04)	3,800 (0.2)	2,000 (0.1)
Females	-	700 (0.03)	600 (0.03)	3,600 (0.2)	-

Note. Prevalence estimates are subject to large standard errors and should be taken with caution.

Other Australian research suggests that overall prevalence of MDD has remained stable over time. In the 1998 National Survey of Mental Health and Wellbeing (n=1,340), prevalence of MDD among 13-17 year olds was 5.2% [229]. MDD was measured in adolescents using the Centre for Epidemiological Studies Depression Scale (CES-D). The Parent- and/or carer-reported prevalence was 4.8%, and measured using the Diagnostic Interview Schedule for Children Version 4 (DISC-4). These prevalence figures are similar to those observed more recently in the 2013-14 YMM. There is also evidence that MDD among the adult population of Australia has remained stable over the last 30 years, despite increased provision of treatment and antidepressants [230].

An international review of papers published between 1986-96 found that prevalence of MDD among children and adolescents had increased and that onset appeared to be occurring at earlier ages [222]. Authors argued that this was likely driven by increases in milder, rather than more severe MDD. In this study, previously published prevalence figures cited ranged between 0.4% and 2.5% in children and between 0.4% and 8.3% in adolescents. The heterogeneity of prevalence figures, likely a result of different methodologies and measurements used between studies, makes determining trends over time difficult. According to the US National Survey on Drug Use and Health, prevalence of major depressive episodes among adolescents increased from 8.7% in 2005 to 11.3% in 2014 [231]. Data such as this, from repeated national surveys with consistent methodology, enables a comparison of trends. In contrast, prevalence of MDD among adolescents in Canada from 2000-2014 has remained stable. Using data from nationally representative surveys, Wiens and colleagues found that prevalence among 12-19 year olds has remained stable (around 5.5%) throughout this 15 year period [232].

9.3 Complex needs

Children and adolescents with MDD are more likely to have other mental health conditions, which can impact their functional abilities and increase the amount of support required. The presence of comorbid conditions may also significantly impact quality of life.

9.3.1 Prevalence of comorbidities

Comorbidity of MDD and other mental health conditions is common. In the YMM, over half of children and adolescents with MDD also had an anxiety disorder (i.e. generalised anxiety disorder, separation anxiety disorder, social phobia, and obsessive compulsive disorder). The total prevalence of comorbid MDD and anxiety disorders among all children and adolescents was 1.6%.

Similarly, international research suggests that MDD and other mental health conditions are highly comorbid. For instance, the British Child and Mental Health Survey reported that approximately 3 in 4 children with MDD also had anxiety [227]. Other research reported that 40-70% of children and adolescents with MDD may have another mental health condition, while 20-50% may have two or more additional mental health conditions [222]. MDD in children and adolescents most frequently occurs alongside anxiety disorder and conduct disorder [222, 233].

9.3.2 Help seeking behaviours

YMM also collected information on service use among children and adolescents, as well as the perceived need of and barriers to receiving mental health care.

Out of all children and adolescents aged 4-17 years with MDD, 79.6% were reported to have accessed health or school services for emotional or behavioural issues in the past 12 months. Health service use (e.g. general practitioner, psychologist, social worker, counsellor) was highest among children and adolescents who reported their MDD had a severe impact on their lives (86.4%), followed by those who experienced moderate (77.8%) and mild impact (57.1%). Similarly, school service use (e.g. individual or group counselling, special classes, school nurse) was highest among those who reported severe impacts as a result of MDD (72.1%), followed by children and adolescents who had moderate (63.0%) and mild impacts (40.2%). About 1 in 5 children and adolescents with MDD reported taking medication for emotional or behavioural problems within the past two weeks.

Although not specific to MDD, service use (including health, school, online and telephone services) among children and adolescents with a mental health disorder (i.e. including, but not limited to MDD) varied by a range of demographic factors. For instance; service use was higher among those in the lowest income bracket (61.9%), those with the least educated parent/carer (year 10 or below; 62.2%), relative to those in the highest income bracket (50.6%) and those with a more educated parent/carer (diploma or certificate 56.3%; bachelor degree or higher 55.5%).

Researchers also reported a significant increase in service use by children and adolescents with mental health disorders in Australia between 1998 and 2013-14 [16]. Among children and adolescents with MDD, attention deficit/hyperactivity disorder or conduct disorder, 31.2% had used services in the six months prior to the 2013-14 survey, compared with 19.2% in the 1998 survey. The service use survey module was re-developed for the 2013-14 YMM based on the current health care environment and thus the types of services included in both surveys differed. However, authors argued that trends in these figures reflect true increases in service use among children and adolescents over time.

9.4 Associated factors

9.4.1 Factors associated with prevalence of disability

The prevalence of MDD is driven by complex interactions between genetic, epigenetic, and environmental factors. Genetics may contribute to 35-50% of MDD, with high heritability observed in family and twin studies [218, 222]. Childhood adversities, including abuse and neglect, and bullying, are reported to be the key environmental factors that contribute to the burden of MDD among children and adolescents [234]. Other emerging risk factors have also been identified, including internet and social media use, and crises (e.g. extreme weather events due to climate change) [235-238].

Childhood adversity is known to increase risk of MDD in adulthood, but until recently the relationship between these factors and onset of MDD in children and adolescents was unclear. Recent research shows that there may be differences between adult-onset and youth-onset MDD, with some risk factors contributing to earlier onset more than others [234]. For instance, US research demonstrated that low socioeconomic status, family disruption, and residential instability were associated with onset of MDD before 14 years of age [221]. This study included a cohort of 1,089 children who were followed up between the ages of 18 and 39. A cohort study in New Zealand that followed 998 individuals from birth to 26 years of age explored the difference in risks between youth-onset and adult-onset of MDD [239]. They found that those in the youth-onset group experienced greater

childhood risk factors (e.g. adverse developmental outcomes, parental characteristics, and/or family circumstances), while those with adult-onset typically did not experience different risks from those who never had MDD. Finally, a meta-analysis explored the association between MDD and childhood adversity including sexual abuse, physical abuse, poverty, physical illness/injury, death of a family member, domestic violence, natural disaster, and emotional abuse. Findings from across 62 articles showed that individuals who experienced adversity during childhood were 2.5 times more likely to develop MDD before 18 years of age, compared to children who did not experience these adversities [234]. Of all childhood adversities, sexual, emotional, and/or physical abuse were strongly associated with MDD. Sexual abuse during childhood was found to have the largest effect on depression and suicide attempts among adolescents, compared to those with no history of abuse, in a random sample of 776 children aged 1-10 years who were followed to adulthood in the US [240].

An emerging factor associated with MDD and depressive symptoms more broadly is internet and social media use [237, 238]. Social media was associated with depression, anxiety, and psychological distress among adolescents in a systematic review of 13 studies, however limitations in study design and methods were noted [241]. Social media use among children and adolescents may be associated with MDD in part through cyberbullying [242, 243]. Data from the 2017-18 Health Behaviour in School-Aged Children Study across 42 countries (n=180,919; aged 11-15 years) found that social media use was associated with an increased risk of cyberbullying victimisation [243]. Evidence of the association between 'traditional' bullying victimisation (i.e. in person) and depression is more established. For example, a meta-analysis of 28 longitudinal studies found that children who experienced bullying were twice as likely to develop depression compared to those who had not been bullied [244]. Further, according to a systematic review of 22 longitudinal studies in Australia, bullying victimisation during childhood and adolescence accounted for 10.8% of the burden of MDD [245].

Another area of research that is gaining attention is the study of mental health disorders during crises, specifically the COVID-19 pandemic [246-248]. COVID-19 is likely to impact child and adolescent wellbeing, with one possible pathway being the family environment. Specifically, financial insecurity, caregiving burdens, and confinement-related stress could have long term negative impacts on the mental health of populations [249]. So far, this research is largely based on conceptual frameworks, and impacts on the prevalence of mental health of populations more broadly may not appear for some time. Other crises in the past, such as economic crises [250, 251] or natural disasters [235, 236] have had adverse effects on the mental health of children and adolescents. Evidently, such crises may affect the mental health of children and adolescents through increased exposure to childhood adversity.

9.4.2 Trends in associated factors over time

There is a paucity of Australian research on trends in childhood adversity over time. However, findings from the Longitudinal Study of Australian Children (LSAC) showed that early exposure to adversity was high among children born in 1999-2000 and 2003-4. Among a sample of 5,107 children, 52.8% had experienced two or more adversities by 10-11 years of age [252]. Adversities measured in the LSAC included legal problems; family violence; household mental illness; household substance abuse; harsh parenting; parental separation/divorce; unsafe neighbourhood; family member death; and bullying.

As described above, child maltreatment has a strong relationship with prevalence of MDD. The true prevalence of child maltreatment is difficult to determine but child protection notifications can offer a useful indicator for determining trends in maltreatment, given that the legislative mandatory reporting requirements remain stable over time. Australia has seen an increase in the early involvement of child protection, with annual incidence rates of notifications and substantiations doubling between 2001 and 2008 [160]. Analysis of longitudinal data on children born in South Australia shows that the prevalence of receiving at least one child protection notification before 3 years of age has increased among those born in 1991 (4.0%), 1998 (7.5%), and 2002 (11.2%) [161, 162]. More recently, research has shown that around 1 in 4 children in South Australia will have a Department of Child Protection notification by the age of 10 [163].

Research on comparable studies of bullying over time suggests that the global prevalence of in-person bullying may be decreasing, but that rates of cyber bullying are increasing [253, 254]. In Australia, a meta-analysis of 46 studies estimated the lifetime prevalence of bullying victimisation to be around 25.1%, which was still higher than cyberbullying victimisation (7.0%) [242].

In an increasingly connected and globalised world the risk of pandemics, natural disasters due to climate change, and global economic crises is increasing [255]. In Australia, hotter and drier summers will increase risk of bush fires [256], and children's mental health is predicted to be impacted primarily by increases in extreme weather events caused by climate change [236]. Further, research acknowledges that it is likely the most vulnerable groups that will experience a disproportionate burden of climate change, as they have other economic and natural crises in the past [257].

9.5 Quality of prevalence evidence

The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) is a checklist of items that should be included in all reports of observational studies [28]. As an indicator of quality, we have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

- **2018 SDAC:** the most comprehensive national survey of disability among people of all ages in Australia, the SDAC relies on the accurate self-report of conditions (including depressive/mood disorder) and in 2018, achieved a household response rate of about 80%. A common issue discussed however, is the reliability of prevalence estimates when disaggregated due to sample size. For example, when breaking down data according to age, gender, and socioeconomic status, high relative standard of error rates (as noted in the footnote of Table 31), mean estimates in some categories should be used with caution or are considered too unreliable for most purposes.

- **2013-14 YMM:** the largest national survey exploring the mental health of children and adolescents in Australia, YMM has strength in that it uses the DISC-4 to assess MDD based on DSM-4 criteria (i.e. identification of conditions does not rely on parent- or self-report). Participant exclusion criteria (young people living in very remote areas, with an Aboriginal or Torres Strait Islander background, and experiencing homelessness or living in institutional care; all sub-populations that are likely to experience greater mental health concerns) and a low household response rate (55%), however, might hinder confidence in the accuracy of MDD population prevalence estimates.

9.6 Information sources

To identify relevant evidence beyond that presented in the surveys above (i.e. comorbidities and factors associated with the prevalence of MDD), databases (namely, Embase, PubMed, PsychInfo, and Web of Science) were searched using key terms: child/ren, adolescent/s, Major Depressive Disorder/MDD etc., prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including the Lancet, Pediatrics, and the Australian & New Zealand Journal of Psychiatry.

10. Fetal Alcohol Spectrum Disorder

Key findings

This chapter demonstrates that the prevalence of fetal alcohol spectrum disorder (FASD) in Australia varies across data sources, and are often considered underestimates of the true prevalence in the community. According to the Australian Early Development Census (AEDC), the prevalence of FASD among children in their first year of school was 0.03%. Prevalence among males was double that for females, however this conclusion was not supported by other data sources both in Australia and internationally. The prevalence of FASD, as reported in the AEDC, was also higher among children from low socioeconomic backgrounds and children of Aboriginal and/or Torres Strait Islander background. Although onset begins in utero, only children with fetal alcohol syndrome (i.e. the most severe form of FASD) are likely to be diagnosed at birth. Prevalence of FASD increases with age, indicating increased rates of diagnosis as children age and symptoms become more apparent. Data from the AEDC indicates that prevalence of FASD has remained stable between 2015 and 2018, however evidence spanning longer time periods have reported increased prevalence over time. Evidence in Australia indicates that alcohol consumption during pregnancy, the cause of FASD, has decreased over time. However, maternal age, which is associated with increased alcohol consumption during pregnancy, has increased both in Australia and South Australia specifically, over time.

10.1 Background

10.1.1 Definition

Fetal alcohol spectrum disorder (FASD) refers to a range of symptoms and conditions associated with foetal exposure to alcohol including physical, cognitive, behavioural and emotional difficulties [258]. Unlike other disabilities included in this review, FASD is not included in the Diagnostic and Statistical Manual of Mental Disorders. Information on the presentation and diagnosis of FASD described in this chapter is sourced from the Australian Guide to the Diagnosis of FASD Report, commissioned by the Australian Government, to provide consistent diagnostic criteria to clinicians across Australia [258].

10.1.2 Presentation and key characteristics

Individuals with FASD may experience a range of physical, cognitive, behavioural, and emotional difficulties as a result of changes to the central nervous system in utero [258]. These can be described as neurodevelopmental domains and include:

- **Brain structure/neurology:** abnormal head circumference, structural brain abnormalities, significant neurological diagnoses otherwise unexplained
- **Motor skills:** difficulties with balance and coordination
- **Cognition:** presence of intellectual disability, impaired verbal and non-verbal reasoning skills
- **Language:** impaired expressive and receptive language skills
- **Academic achievement:** impaired literacy and numeracy skills and associated outcomes
- **Memory:** impaired overall, verbal, and/or visual memory
- **Attention:** difficulties with concentration, task focus, and work organisation
- **Executive function, including impulse control and hyperactivity:** problem solving, planning, and cognitive flexibility

- **Affect regulation:** mood and affective disorders
- **Adaptive behaviour, social skills or social communication:** life skills, how individuals cope with everyday tasks

Additionally, exposure to alcohol during pregnancy can change an infant's facial structures. Key physical characteristics of FASD include a short palpebral fissure (narrow eye openings), smooth philtrum (smooth area between the lip and the nose), and thin upper lip.

10.1.3 Diagnosis

FASD diagnosis is made by a multidisciplinary team of clinicians and requires prenatal alcohol exposure and severe impairment in three or more domains of central nervous system structure or function [258]. These are captured in the neurodevelopmental domains described above. Further, there are two sub-categories of FASD relating to the presence of sentinel facial features:

- FASD with three sentinel facial features
- FASD with less than three sentinel facial features

FASD with three sentinel facial features, or fetal alcohol syndrome, represents the most severe form of the disorder. Diagnosis of fetal alcohol syndrome at birth is possible because of the apparent changes to facial structure in utero. Without the presence of three sentinel facial features, diagnosis of FASD is more complex and may require a range of diagnostic assessments [258].

10.1.4 Onset and progression

Onset of FASD occurs in utero as alcohol passes through the placenta and affects the development of the fetus [259]. FASD exists on a spectrum and progression can vary greatly. Individuals with FASD will experience at least three impairments in the neurodevelopmental domains, as described above, but the amount and type of domains will differ across individuals [258]. Progression also depends on the severity as individuals with fetal alcohol syndrome may experience greater motor and cognitive impairments at an early age, while those with FASD might not experience impairments until school entry, when social and communication difficulties may become more apparent [260].

10.1.5 Treatment

Treatment of FASD consists of care from a multidisciplinary team, depending on the symptoms experienced, to support the child and family. This may include support from across health, social and education sectors, including neurologists, physiotherapists, speech-language pathologists, social workers, and special education teachers [259]. Treatment may also include interventions targeting specific areas, such as improving attention and/or self-regulation in childhood [261]. Prevention is also a key aspect of FASD research and policy. This includes policies and education surrounding alcohol consumption, such as clear labelling and guidelines. There are also interventions available for women during the course of their pregnancy to help reduce or abstain from alcohol. These may include motivational interviewing or referral to drug and alcohol support services [262].

10.2 Prevalence

To describe the prevalence of FASD among children and adolescents in Australia, one key data source was available.

The **2018 Australian Early Development Census (AEDC)** is a national census of children's early development and readiness for school, completed by teachers for children in their first year of full time school (i.e. when children are aged 4-6 years, with the majority of children 5 years old). The census aims to collect information on all children across Australia in their first year of full time school, with a participation rate of 96.4% or 308,953 children, through information collected from 17,508 teachers across 7,507 schools, achieved in the 2018 census. As part of the census, teachers were asked if children had a special needs status; if 'yes', they then selected from a number of medical diagnoses that qualify the child to have special needs, including FASD. The AEDC is conducted triennially and information collected in 2009, 2012, and 2015 can be used to compare prevalence rates over time.

As only one key data source was available, a range of research conducted in Australia and internationally has also been used to describe estimates of FASD prevalence and how this differs by age, gender, severity, and sociodemographic characteristics.

10.2.1 Overall prevalence[18]

In the AEDC, the national prevalence of FASD was 0.03% (n=83) among children in their first year of school. Similarly, a study using data from the Western Australian Register of Developmental Anomalies between 1980 to 2010, identified the birth prevalence of FASD to be 0.03% (n=210) [263]. According to Australian research, the prevalence of FASD in the general population (i.e. versus birth cohorts) is currently unknown [261, 264]. Researchers argue that estimates tend to be unreliable, due to using passive data collection methods (e.g. surveillance based studies) and relying on self-reported alcohol intake, and thus likely underestimate the true prevalence in the population.

Global prevalence of FASD is estimated to be around 7.7 per 1,000 population, or 0.8% [265]. This was based on a meta-analysis of 24 studies spanning 187 countries, including children and adolescents aged 0-16 years. The highest prevalence rates were observed in South Africa (11.1%), Croatia (5.3%), and Ireland (4.8%). Prevalence of FASD among children and adolescents in the World Health Organisation (WHO) Western Pacific Region, which includes Australia, was similar to the global average at 0.7%. Similar prevalence rates were found in another meta-analysis of global prevalence estimates, in which Australia again had a considerably lower prevalence of FASD compared to other countries [266]. In a meta-analysis of the prevalence of FASD in the US and Canada, the pooled prevalence rates were 1.5% and 0.5%, respectively [267].

[18] The Inclusive Education Support program (IESP), an annual collection of information from schools on students with disability, is used to provide the Department with an understanding of the prevalence of disability among students in primary and secondary schools in South Australia. The IESP, however, does not collect information on prevalence of FASD in particular. Therefore prevalence rates presented throughout this chapter are not able to be compared to internal Department data sources.

10.2.2 Prevalence by gender

According to the AEDC data, FASD prevalence was twice as high among males (0.04%), compared to that among females (0.02%). This contrasts with reports of prevalence in the academic literature, in both Australia and internationally, that found no difference in prevalence according to gender. For instance, in a study using data from the Western Australian Register of Developmental Anomalies between 1980 to 2010, 54.9% of infants with FASD were male [263]. Similarly, research in the US (n=196; aged 6-7 years) and Canada (n=2,555; aged 7-9 years) reported that the proportion of males with FASD among samples of children was 51.8% and 52.4%, respectively [268, 269].

10.2.3 Prevalence by age

The AEDC collects information for children in their first year of school, most of whom are 5 years of age, thus prevalence of FASD could not be described across age groups using this data source. Despite onset occurring in utero, research suggests that prevalence increases as children grow older. As described in Section 10.1.3, this is likely a reflection of complex diagnosis processes, as well as criteria for diagnosis becoming more apparent with age [263, 265].

10.2.4 Prevalence by other socio-demographic characteristics

The prevalence of FASD as reported by the AEDC was four times higher among children who lived in the most socioeconomically disadvantaged areas, compared to those living in the least disadvantaged areas. Prevalence among children with an Aboriginal and/or Torres Strait Islander background was also considerably higher as reported by teachers (see Table 32).

Table 32. Prevalence of FASD by socio-demographic characteristics as reported by the AEDC

	n (%)
Socio-Economic Indexes for Areas (SEIFA)	
Quintile 1 (most disadvantaged)	29 (0.05)
Quintile 2	22 (0.04)
Quintile 3	13 (0.02)
Quintile 4	14 (0.02)
Quintile 5 (least disadvantaged)	5 (0.01)
Aboriginal and/or Torres Strait Islander background	
Yes	44 (0.23)
No	39 (0.01)

A range of research has focused on the prevalence of FASD among Indigenous populations, both in Australia and internationally. In the Northern Territory, the prevalence of fetal alcohol syndrome among children with an Aboriginal and/or Torres Strait Islander background born between 1990-2000 was estimated to be between 1.9 and 4.7 per 1000 (i.e. 0.2% to 0.5%) [270]. In Western Australia, one study of FASD among school-aged children across 45 very remote Aboriginal communities found that prevalence was 19.4% [271]. International evidence indicates the prevalence of FASD among Indigenous populations tended to be lower than that reported in Australia. For example, in Canada the prevalence of FASD among Indigenous populations was 8.7%, and US research reported prevalence of 1.5% [267].

Australian research has also explored FASD prevalence among young people in the criminal justice system. For instance, research in Western Australia explored prevalence of FASD among 10-17 year olds in youth detention, with 36.4% (n=36) of participants met criteria for FASD diagnosis [272].

10.2.5 Prevalence by level of severity/impairment

FASD is more prevalent than fetal alcohol syndrome (i.e. the most severe form of the condition) with some studies reporting a five to seven fold difference. Data from the Australian Paediatric Surveillance Unit was used to investigate the national prevalence of fetal alcohol syndrome between 2001 and 2004. Over this time, 92 cases were identified, or 0.1 per 1,000 live births [273]. According to a review of FASD and fetal alcohol syndrome in Australia, birth prevalence rates of fetal alcohol syndrome were reported to be between 0.01 and 0.68 per 1,000 live births [274].

Greater prevalence of fetal alcohol spectrum was also observed in international research [267, 268, 275, 276]. For instance, a meta-analysis of global prevalence among children and adolescents aged 0-16 years, estimated the prevalence of fetal alcohol syndrome in the WHO Western Pacific Region to be 0.1%, while the prevalence of FASD was 0.7% [275]. In the US, prevalence of fetal alcohol syndrome among children aged 6-7 years was estimated to range from 0.6 to 0.9% (relative to prevalence of FASD estimated to be from 2.4 to 4.8%) [268].

10.2.6 Trends in prevalence over time

According to the AEDC data, the prevalence of FASD remained stable between 2015 and 2018. In contrast, other research spanning longer time periods indicated increases in prevalence, both in Australia and internationally. For instance, in Western Australia, notifications of FASD to the Register of Developmental Anomalies increased from 0.2 per 1,000 births in 1980-89 to 0.4 per 1,000 births in 2000-10 [263]. Among children with an Aboriginal and/or Torres Strait Islander background specifically, prevalence increased from 2.6 to 6.1 per 1,000 births. Similarly, US research reported that the prevalence of FASD among 6-7 year olds in 2010-11 was considerably higher than estimates measured between 1977-1990; 3.6% versus 1.0%, respectively [268, 277].

10.3 Complex needs

Children with FASD experience a range of difficulties across multiple domains, such as physical, cognitive, behavioural and emotional development. Due to the complex nature of FASD, comorbidity is common and in many ways inherent to the condition itself. The complexity of FASD can impact the quality of life of individuals and their families as well as impact how they seek and use services.

10.3.1 Prevalence of comorbidities

Our search highlighted that evidence regarding the prevalence of FASD and comorbidities in Australia is limited. An international meta-analysis (127 studies) indicated that the four most common comorbid conditions among individuals with FASD were abnormal functioning of the nervous system, conduct disorder, language disorder, and chronic serous otitis media [278]. Between 50-91% of individuals with FASD had at least one of these conditions. In another meta-analysis of comorbid mental health disorders specifically, 50.2% of those with FASD had attention deficit/hyperactivity disorder, 23.0% had an intellectual disorder, 19.9% had a learning disorder, and 16.3% had oppositional defiant

disorder [i.e. conduct disorder; 279]. This study used samples across varying age ranges, which included adults, but the mean age was approximately 10 years. As these disabilities are generally considered to be presentations of FASD, it should be noted that some may not consider them to be comorbidities.

10.3.2 Help seeking behaviours

Service use for FASD is often considered to be below required levels due to a range of factors, including lack of awareness and stigma [274]. Lack of awareness among clinicians specifically can lead to underdiagnoses, and children with FASD and their families do not receive the support required. Many researchers have argued that the prevalence of FASD reported in Australia, as described in Section 10.2.1, underestimates the true community prevalence. Research conducted by the Telethon Kids Institute in Australia demonstrated that a high proportion of young people in the criminal justice system met criteria for diagnosis of FASD or a similar neurodevelopmental disorder, but many have not had a formal diagnosis [280]. Researchers have argued that there is a lack of assessments and support for individuals with FASD in the Australian health system, and this increases risk of entering services like out-of-home care or the criminal justice system [271, 281].

10.4 Associated factors

10.4.1 Factors associated with prevalence of disability

Any alcohol consumption during pregnancy can increase risk of harm to the fetus. A meta-analysis of global FASD prevalence found that 1 in 13 women who consumed alcohol during pregnancy gave birth to a child with FASD [265]. A meta-analysis of studies of alcohol consumption during pregnancy and fetal alcohol syndrome prevalence estimated this figure to be 1 in 67 women [276]. Using global estimates of alcohol consumption during pregnancy, this study also found that 0.2% of children born every year would have fetal alcohol syndrome [276]. Furthermore, there are particular alcohol consumption habits that are more likely to increase the risk of FASD. This includes binge drinking and/or drinking regularly over the course of the pregnancy [282]. In a South African case control study (n=62) it was found that mothers who had children with fetal alcohol syndrome consumed an average of 6.6 standard drinks (an amount that is considered to be binge drinking) on two occasions weekly [283].

Environmental risk factors that can increase risk of maternal alcohol consumption and therefore FASD, include low socio-economic status, heavy drinking culture (e.g. among family and/or wider social groups), social isolation, and lack of awareness of FASD and the impact of maternal alcohol consumption on the developing fetus more broadly [282, 284]. Factors associated with low socioeconomic status in general, such as overcrowded housing and limited access to training, employment and health services, have been found to increase the risk of alcohol misuse [262]. In the 2007 National Drug Strategy Household Survey, older age was associated with increased risk of alcohol consumption during pregnancy after adjustment for possible confounders (e.g. educational attainment, marital status, tobacco use, employment status, and psychological distress) [285]. This is consistent with research in remote communities in Western Australia (n=489) that found that, among the 20% of women who drank alcohol while pregnant, most were 35-39 years old [286].

10.4.2 Trends in associated factors over time

Overall, trends in alcohol consumption among pregnant women appear to be decreasing [287]. The most recent 2019 National Drug Strategy Household Survey found that the proportion of women who drank alcohol while pregnant decreased from 60% in 2007 to 35% in 2019 [288]. Among women who did report consuming any alcohol while pregnant in 2019, 90% drank once a month or less and generally consumed 1-2 standard drinks on the day they did drink. While overall drinking during pregnancy appears to be declining, risky alcohol use may not be [103, 128, 129]. The overall summary of the National Drug Strategy Household Survey concluded that, despite more people lowering their alcohol intake for health reasons, the proportion of people drinking at risky levels has not changed over time [288]. However, it is unclear to what extent this includes women who consume alcohol while pregnant.

Average maternal age, which is associated with increased alcohol consumption during pregnancy, has increased across Australia from an average of 29.9 years in 2007 to 31.4 years in 2018 [23, 50]. In South Australia specifically, 32.0% of women who gave birth in 2001 were aged 30-34 years and 13.6% were aged 35-39 years, compared to 35.9% aged 30-34 years and 18.0% aged 35-39 years in 2017 [24].

10.5 Quality of prevalence evidence

The STROBE (Strengthening the Reporting of Observational studies in Epidemiology) is a checklist of items that should be included in all reports of observational studies [28]. As an indicator of quality, we have applied this checklist to the evidence we have used to inform this report. Exploring if the data sources reported against the STROBE criteria help to determine the strengths, weaknesses, and generalisability of prevalence rates provided. A summary is provided below.

- **2018 AEDC:** the AEDC is a true "census" as it seeks to collect information for all children in their first year of school across Australia. Thus, population estimates do not need to be calculated because actual population prevalence is collected. Important to note, however, is that prevalence of FASD as reported by the AEDC is reliant upon teacher knowledge of children's diagnosis of FASD. Researchers have argued that, in Australia, health professionals are often unaware of the diagnostic criteria of FASD. It is important to reflect on this when interpreting teacher-reported prevalence of the disorder [258].

10.6 Information sources

To identify relevant evidence beyond that presented in the surveys above (i.e. comorbidities and factors associated with the prevalence of FASD), databases (namely, Embase, PubMed, PsychInfo, and Web of Science) were searched using key terms: child/ren, adolescent/s, fetal alcohol spectrum disorder/fetal alcohol syndrome, prevalence, epidemiology, comorbity/ies, predicts/or, and Australia. This search was repeated and broadened by omitting Australia to identify relevant international literature. Both searches were limited to articles published in English in 1990 onward, and reference lists were scanned for additional relevant articles. All articles included in this chapter are peer reviewed academic journal articles, the majority having been published in high quality scientific journals including The Lancet, BMJ Open, and Pediatrics.

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About the Fraser Mustard Centre

Working together to improve the development, education, health and wellbeing of young Australians, the Telethon Kids Institute and the South Australian Department for Education have joined forces in a unique approach to research translation. The Fraser Mustard Centre collaboration aims to:

- Improve and promote the health and wellbeing of all children and young people in South Australia through the unique application of multidisciplinary research
- Help shift focus from the historical delineation between health and education services to an integrated approach with a focus on child development
- Build capacity amongst public sector staff and academic researchers to design, undertake and use research to improve the environments in which children live and the service systems which support families
- Attract funding for shared priorities for research that leads to improved developmental, education, health and wellbeing outcomes for children

The Fraser Mustard Centre brings forward-thinking policy makers and world class child health researchers. It reflects a shared view of policies and outcomes for children and young people. The Centre is a unique collaboration between two organisations passionate about making a difference.

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A COLLABORATION BETWEEN

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