

ASD and DLD diagnoses after 6 years old

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Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters they are to call the TAPS line for advice. The Research Team are unable to ensure that the information listed below provides an accurate & up to date snapshot of these matters

Research questions:

1. What are the types of later life developmental disorder diagnoses?
2. What is the incidence of diagnoses for Autism Spectrum Disorder (ASD) and Developmental Language Disorder (DLD) that occur after the age of 6?
3. What is the incidence of diagnosis for ASD for age groups:
 - 0-6
 - 7-15
 - 16 and above?
4. What is the impact of a later diagnosis on the functional capacity and severity of symptoms of people diagnosed with ASD or developmental delay?
5. Are there triggers or acute events that precipitate diagnoses?
6. What is the impact of the resolution of an acute event on functional capacity regardless of diagnosis?
7. Are there therapies / treatments / protocols designed for people with later in life diagnoses?
8. What is the impact on prevalence of changes to ASD criteria between DSM-IV and DSM-5?

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2. Summary

Researchers continue to improve early identification methods targeting developmental disorders. This can reduce the waiting time for children to be diagnosed and for intervention to begin. In some cases, children do not receive an accurate diagnosis until later childhood or adolescence. Some are not diagnosed until adulthood. This paper focusses on the incidence and impact of diagnosing Autism Spectrum Disorder (ASD) and Developmental Language Disorder (DLD) after the age of 6.

There is limited information directly answering the research questions for an Australian context. I have gathered information relevant to the research questions which may approximate answers.

Issues related to overall prevalence of ASD have been investigated in another TAB research paper, [RES 222 ASD diagnoses](#).

Types of later life developmental disorder diagnoses

Neurodevelopmental disorders (NDD) are a subset of developmental disorders defined by the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5). They are one of the most common classifications of childhood diagnoses and clinicians aim to diagnose the child as early as possible. Personal, clinical, social and environmental factors can delay diagnosis.

Incidence of later life diagnoses

No reliable and comprehensive estimates were found for incidence of later diagnoses of ASD and DLD nationally or across all age groups. There is evidence that later diagnoses of DLD are common in people with a history of involvement with youth justice and child protection. Internationally, the latest systematic review finds the mean age for first diagnosis of ASD is 60.48 months (5 years). However, the best data for Australia suggests mean age of first diagnosis is 6 years for children diagnosed before the age of 13. This is likely to be considerably higher if older age groups are incorporated into the estimate.

Events leading to later life diagnoses

There is evidence suggesting personal, social and environmental factors can predict whether someone will receive a later diagnosis of ASD. However, there is very little evidence describing events that precipitate a diagnosis. One study suggests adults choose to begin the assessment process due to encouragement by parents or spouses, difficulties with social interaction or mental health issues.

Outcomes for people with later life diagnoses

There is evidence establishing the effectiveness of early intervention for people with ASD. There is less evidence establishing the adverse outcomes for people with later diagnoses though existing evidence does support the correlation of reduced functional capacity and increased comorbid conditions in people with later diagnoses. People with missed diagnoses of DLD are overrepresented in the youth justice and child protection systems.

Supports for people with later life diagnoses

All interventions should be age-appropriate and targeted at the person's developmental stage. For older people this may mean interventions targeted at achieving life-stage outcomes such as employment and independent living. For people with ASD this may also mean accounting for the likelihood of comorbid conditions.

Prevalence of ASD after DSM-5

Refer to [RES 222 ASD diagnoses](#) for further information. The restriction of DSM-5 diagnostic criteria for ASD has contributed to a reduction in the number of ASD diagnoses even as the prevalence of ASD continues to rise. The rise in prevalence should be attributed to factors other than the change in diagnostic criteria in the DSM-5.

3. Diagnosing developmental disabilities later in life

The DSM-5 defines a group of NDDs which begin to manifest early in life and usually before the child enters school. NDDs can be global (affecting general intelligence or social skills) or specific (affecting specific aspects of learning or control of executive function) (DSM-5, 2013, p.31). They include intellectual disabilities, communication disorders, ASD, attention deficit hyperactivity disorder, specific learning disorder and motor disorders (including movement and coordination disorders and tic disorders) (p.xiv-xv).

Diagnosis of NDD is one of the most common types of diagnoses among children. Among NDDs the most common are learning disorders (8%), DLD (7%), ASD (2%) and ADHD (2%) (Micai et al, 2020, p.183). Behavioural signs are often observable within the first year of a child's life and some indications are known prior to the child's birth. For example, if the child has a sibling or other family member with a diagnosis of NDD it increases the risk that they will also have an NDD (Micai, 2020).

There are several factors that may delay a diagnosis. For example, it may be hard to determine if a child has social communication deficits until they are in situations which demand more sophisticated social behaviour. NDDs are often co-occurring, which introduces the risk of one diagnosis overshadowing other potential conditions and leading to later or missed diagnoses. Diagnoses can be a lengthy and costly process, which may delay the diagnosis itself or discourage some parents from beginning the process at all (Valentine et al, 2020; Micai et al, 2020).

4. Developmental Language Disorder

Many children show significantly slowed language development before the age of three. However, most of these children catch up to their peers after the age of three allowing them to perform within normal limits on linguistic tasks. Children who do not catch up may be diagnosed with DLD (Sansavini et al, 2021, p.2). DLD is the recommended label for language disorders that are not associated with a specific cause (e.g. autism, down syndrome). The term Specific language impairment (SLI) has also been used but the applications differ slightly (McGregor, 2020, pp.39-40). Prevalence of DLD among children is roughly 7% (Walker & Haddock, 2020, p.2; Ebbels et al, 2016, p.2). A report from the Deeble Institute of Health Policy states that prevalence among children in Australia may be as high as 17%, with higher rates in children from disadvantaged backgrounds (Walker & Haddock, 2020, p.2). This estimate is unreliable. The authors admit the estimate is based on minimal data and they do not offer an age range for the estimate.

I could not locate information on incidence of diagnoses by age. However, a 2021 review of systematic reviews suggests that the optimal screening time for DLD is between 2 and 3 years, with a diagnosis expected around 4 years (Sansavini et al, 2021, p.2). However, evidence is mixed with earlier screening increasing risk of false positives and later screening increasing risk of negative consequences for the child (p.20).

There is some evidence that DLD is often missed entirely or misdiagnosed in childhood (McGregor et al, 2020, p.40). A 2013 Australian study of 1607 children found only 45% of children with communication problems received any help before the age of 5 and only 33% received speech therapy (Skeat et al, 2014, p.219; Walker & Haddock, 2020, p.4). This does not differentiate communication problems from DLD specifically and so we can't straightforwardly conclude that most children with DLD are undiagnosed. It should also be noted that this study was prior to NDIS making early intervention available to more families.

A more recent Australian study of young people leaving 'out of home' care found that mean language scores were 2 standard deviations below the average. This level of deficit is often used as an indication of DLD. Despite this only a single participant in the study had a diagnosis relating to language difficulties (Snow et al, 2020, p.155). In another study of 44 young people leaving 'out of home' care between 16 and 26 years of age, Clegg et al found that over 60% met criteria for DLD and yet none had a diagnosis (Clegg et al, 2021, p.2). Results are similar in a youth justice setting (Snow et al, 2020, p.153; Clegg et al, 2021, p.2) with Winstanley et al finding 60% of their sample of youth offenders having met criteria for DLD despite no previous diagnoses (2021, p.399). These findings point to a high rate of unidentified DLD in young people with involvement of child protection or justice and is consistent with findings of previous studies that children from disadvantaged backgrounds are more likely to experience language difficulties (Walker & Haddock, 2020). Because the sample sizes of the studies were small and the populations unrepresentative, it is not possible to use them to reliably estimate prevalence of undiagnosed adolescents or young adults.

According to Walker and Haddock, research into the long-term effects of language impairment in an Australian context is limited. However:

International longitudinal studies have found that children with language disorders who do not receive intervention achieve lower levels of education and are subsequently at higher risk of lower wages and reliance on welfare and of higher levels of redundancy, under-employment and workplace conflict (2020, p.3).

As of 2016, most studies into the effectiveness of generalised intervention for symptoms of DLD in school-age children (i.e. children over early intervention age) found no significant effect. Results were more positive if the treatment group did not have receptive language difficulties, which are more likely to persist and more difficult to treat. Some positive results for receptive language skills were found if the interventions were targeted at specific areas, e.g. receptive vocabulary, word finding, comprehension of specific grammatical structures, etc. (Ebbels et al, 2016 pp.2-3). Ebbels et al found significant improvement on receptive and expressive language skills in primary and secondary aged students with DLD receiving 1:1 speech and language therapy (2016, pp.8-9).

Sansavini et al note the consensus in the literature on the importance of early intervention and diagnosis of DLD (Sansavini et al, 2021, p.14.). A 2021 systematic review of treatment studies found some evidence for the effectiveness of early intervention on some areas of language development. Early intervention effects last in the medium term for developing phonological skills but results of intervention targeting general language skills is mixed (Rinaldi, 2021, pp.18-19). For example, an Australian study by Wake et al compared the effect of home-based therapy sessions on children with language disorders with typically developing children. After 2 years they found language abilities for children in the treatment group normalised though they could not discern a significant effect of therapy sessions on most aspects of language development, including receptive and expressive language. Some effect was discerned for phonological awareness with a possible effect on reading ability (Wake et al, 2015, p.843).

5. Later diagnoses and autism

5.1 Age of first diagnosis

I was able to find only one study using Australian data that tracks age of first diagnosis for cohorts over 12 years old (Atherton et al, 2021) but this study was based on only 200 people. I am unable to give a good account of incidence of first diagnosis for the age groups requested.

Two systematic reviews have tracked age at first autism diagnosis between 1990 and 2019. Daniels and Mandell (2014) reviewed 42 papers published between 1990 and 2012. They provide a wide mean age range for first diagnosis at between 38 and 120 months. Van t' Hof et al (2021) analysed data from 56 studies and found a mean age for first diagnosis of 60.48 months (5 years) with a mean age range of between 30.9 months and 234.57 months (2021, p.862). The ranges provided by these reviews are significantly affected by age of participants in the studies reviewed. Many studies included only children, some studies included only older people. Daniels and Mandell use data from 12 countries. Van t' Hof et al use data from 40 countries. Both reviews include a single study from Australia (Daniels & Mandell, 2014, p.14-17; Van t' Hof, 2021, p.867).

International data indicates that age of diagnosis is decreasing (Daniels & Mandell, 2014, p.6; Sheldrick et al, 2017; Hanley et al, 2021). This contrasts with a recent UK-based study that found mean age of diagnosis rose from 9.6 years in 1998 to 14.5 years in 2018 (Russell et al, 2021, p.3). This might be explained by the fact that the Russell et al considered the entire UK population with an ASD diagnosis whereas the 2015 and 2021 systematic reviews included mostly studies of children. It may also be explained by regional differences in early intervention (Daniels & Mandell, 2014, p.10).

I have located 4 studies based on Australian data which discuss age of first diagnosis for ASD. Nassar et al was included in the Daniels and Mandell systematic review and focused on West Australian children between 2 and 8 years old. They found the mean age of first diagnosis decreasing from 4 years to 3 years throughout the 1990s (Nassar et al, 2009, p.1245). A study from Bent et al was included in the Van t' Hof systematic review and focused on children under 7 years. They found a mean age of first diagnosis of 49 months (Bent et al, 2015, p.318). May and Williams (2018) was not included in any of the reviews and looked at children under 13 years. Atherton et al was not included in any of the reviews and looked at 200 adults with ASD between 18 and 57 years.

According to May and Williams, the average age of diagnosis of children aged 0-12 years old is 6 years. The average is slightly higher in female children at 6.22 years. This estimate is based on Medicare data tracking first diagnosis item numbers from 2008 until 2016 and considers 73,463 children. The most frequent age of diagnosis is 5 until the year 2015/2016 when it lowers to 4 (May & Williams, 2018, p.5). In line with Russell et al (2021), May and Williams find that the rate of increase of older children being diagnosed is higher than the rate of increase for children under 5 (2018, pp.4-5). While this study underestimates total

prevalence due to limitations in the data, it likely captures most diagnoses occurring in this age range (p.2).

Based on a rough estimate obtained from a study by May and Williams (2018, p.4), for Australians diagnosed with ASD under the age of 12, 49% were diagnosed under the age of 6 and 51% were diagnosed between 6 and 12 years old. However, these shares will be significantly different when considering all those diagnosed with ASD in adolescence and adulthood. The average age of first diagnosis is bound to be higher than 6 when considering the entire population of Australians with ASD. This indicates that the average age of first diagnosis is above the early intervention age (>6) (Goodwin et al, 2018, p.2). This would be consistent with studies of other national populations. Atherton et al found the average age of diagnosis for their adult cohort was 15 for males and 21 for females (Atherton et al, 2021, p.4).

5.2 Reasons for later diagnosis

The rate of older people being diagnosed with autism is increasing. This appears to be true for adults (Russell et al, 2021, p.6) and older children (May & Williams, 2018, pp.4-5). Avlund et al. (2021) identify reasons that children may not receive an ASD diagnosis until later childhood or adolescence including:

- symptoms of other developmental disorder overshadow social impairments
- diagnostic threshold may not be met until it is clearer that the social demands on the child exceed their abilities
- the autistic symptoms may be expressed differently in early and later childhood
- socio-economic factors may influence the support a child receives (Avlund et al., 2021; Parikh et al, 2018).

A Melbourne based study also identifies limitations on resources as a primary reason that people do not receive a diagnosis until adolescence. They also note that symptoms being missed by the school system or primary care physician may result in missed diagnosis (Aggarwal & Angus, 2015, p.4).

International trends confirm that children are more likely to be diagnosed earlier if they have more severe autistic symptoms and more likely to be diagnosed later if they have milder autistic symptoms (Daniels & Mandell, 2014, p.7; Sheldrick et al, 2017 p.8; May & Williams, 2018, p.1; Parikh et al. 2018, p.6; Hanley et al, 2021, p.5; Avlund et al, 2021, pp.3849-3850). There is also some evidence to suggest that more severe symptoms can delay a diagnosis of autism if they are interpreted as symptoms of intellectual disability (Avlund et al, 2021, p.3851). A 2021 study by Atherton et al contrasts with the prevailing opinion, suggesting that people diagnosed later do not present differently but diagnoses may be missed due to environmental factors (Atherton et al, 2021, p.6). However, their results are also compatible with a worsening of symptoms over time in adults lacking proper diagnosis.

Barriers to adult autism diagnosis may include the following:

- there are few adult diagnostic screening tools
- difficulty remembering or recovering early developmental history
- limited understanding of adult autism in health professionals
- specialist multi-disciplinary team is often needed
- it requires significant time and effort from the patient
- symptoms of other conditions may mask autistic symptoms
- misdiagnosis or camouflaging of symptoms (Rødgaard et al, 2021, p.5; Scattoni et al, 2021, p.4130; Adamou et al, 2021, pp.1-2; Lai & Baron-Cohen, 2015; Legg et al, 2022, p.1).

There is mixed evidence to support these ideas. Rødgaard et al find that misdiagnosis or overshadowing of other childhood diagnoses may account for some of the reason autism diagnoses are missed. However, only 31% of males and 39% of females had childhood diagnoses at all, meaning that misdiagnosis or overshadowing cannot explain why diagnoses was not given in childhood for most later diagnosed people (2021, p.2).

A 2020 scoping review notes that factors prompting adult diagnosis include encouragement by parents or spouse, difficulties with social interaction or mental health issues (Huang et al, 2020).

5.3 Outcomes for people with later diagnoses

I could find only a single study that investigates quality of life for people diagnosed with autism later in life. Atherton et al found that people diagnosed earlier scored better on quality-of-life measures than people diagnosed later. Increasing age of diagnosis was correlated with increased social anxiety, social avoidance, and a lack of social support (2021, p.6).

Strong evidence suggests early intervention supports for children with ASD are effective in improving outcomes (Avlund et al, 2021, p.3843; Whitehouse et al, 2020; Productivity Commission, 2017; Clark et al, 2017, p.2; Zwaigenbaum et al, 2015, p.6; Estes et al. 2015). When children are diagnosed earlier, they have more access to services and interventions when their brains are most malleable. This means they can acquire skills from a younger age and build on these skills through their school years (Clark et al, 2017, pp.1-2).

Clark et al (2017) compared two groups of 7–9-year-olds with earlier or later diagnosis. The first group received diagnoses at 24 months. The second group received diagnoses between 3 and 5 years old. Those children diagnosed later received interventions later, received significantly less overall intervention, were slightly less likely to attend mainstream schooling, received more support at school age, had lower cognitive and language ability and were more likely to have an intellectual disability. These findings support the idea of improved outcomes for people diagnosed earlier and reduced functional capacity for people diagnosed later.

However, considering the ages of the comparison groups, this study may not reflect the outcomes for people diagnosed after early intervention age (<6 years). On the other hand, the underlying theory behind the effect is that earlier intervention works by making use of younger children's more malleable brains (Clark et al, 2017, pp.1-2; Anderson et al, 2014, p.8). If this is true then we may predict a similar trend for people diagnosed after early intervention age. As we found in [4.1 Later diagnosis of autism](#), this prediction is complicated by confounding factors such as multiple diagnoses for people with ASD, which may mean that they receive interventions targeting autistic symptoms even without a diagnosis of ASD.

Adults with autism typically have multiple diagnoses (Pelicano et al, 2020; Keller et al, 2020; Lai & Baron-Cohen, 2014). Adults with autism have an increased risk of depressive disorders, anxiety disorders, obsessive-compulsive disorder, attention deficit hyperactivity disorder, and personality disorders:

- more than 50% show increased depressive symptoms or depressive disorder
- as many as 66% report suicidal thoughts
- more than 50% may be diagnosed with anxiety disorders
- up to 40% may be diagnosed with attention deficit hyperactivity disorder
- up to 30% may be diagnosed with obsessive-compulsive disorder (Lai & Baron-Cohen, 2014, pp.1018-1019).

This information does not specify age of first diagnosis. However, there is evidence to suggest that later diagnosed people are more likely to have additional diagnoses (Daniels & Mandell, 2014; Goodwin et al, 2018; Pelicano et al, 2020; Rødgaard et al, 2021). A study of school age children by Goodwin et al notes that of people diagnosed between 5 and 18 years old, 58% had a psychiatric diagnosis. Of people diagnosed before 5 years old, only 29% had an additional diagnosis (Goodwin et al, 2018, p.4). In a small qualitative study of late diagnosed adults with autism, Pelicano et al note that of 28 participants in the study, 16 had at least one other psychiatric diagnosis and only 4 did not have any other medical condition (Pelicano et al, 2020, pp.21-23).

5.4 Supporting people with later life diagnoses

There is little research of the post-diagnostic needs of adults with ASD (Scatoni, 2021, p.2). Adults diagnosed with autism later in life have complex reactions and family, friends and clinicians supporting them should be aware of the potentially life-changing consequences of an adult diagnosis. In particular, later diagnosed adults and their caregivers report frustration with lack of post-diagnostic support (Legg et al, 2022, p.2; Scatoni et al, 2021, p.4142).

The UK's National Institute for Health and Care Excellence (NICE) has developed a series of clinical guidelines for people with autism. They recommend supports should be tailored to the person's age and developmental level ([NICE, 2021a](#), para. 1.3.1). However the

recommendations for support do not differ substantially for adults and young people except regarding their relative levels of autonomy and stages of life. For example, supported employment programmes ([NICE, 2021b](#), paras. 1.4.11-12) or residential care programmes (paras. 1.8.11-14) could be considered for adults with autism.

Considering the increased risk of co-morbid diagnoses as described in [5.1 Outcomes for people with autism](#), an increased focus on physical and mental health may be warranted. A 2020 systematic review by Benvenides et al found both cognitive behavioural therapy and mindfulness techniques had an emerging body of evidence as strategies for improving the health outcomes of older adults with autism. However, there is evidence that both strategies are also useful for children with autism (Benvenides et al, 2020, p.1351).

5.5 Effect of DSM-5 on ASD prevalence

For more information please refer to [RES 222 ASD diagnoses](#).

A 2019 systematic review investigated the effect of the changes to ASD diagnostic criteria between the DSM-IV-TR and the DSM-5. They found that approximately 1 in 5 people who would have received a diagnosis in DSM-IV-TR would not have received a diagnosis in the DSM-5. Further, only 28.8% of those who no longer meet ASD criteria would go on to meet diagnostic criteria for Social Communication Disorder (SCD) (Kulage et al, 2019, p.19). This means roughly 14% of people who met diagnostic criteria under DSM-IV no longer meet criteria for ASD or SCD. It is unclear what proportion of those people would go on to meet diagnostic criteria for other conditions and what proportion would remain below threshold for any DSM-5 diagnosis. According to this review, DSM-5 is contributing to a reduction in ASD diagnoses while the overall prevalence estimates continue to rise.

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7. Version control

Version	Amended by	Brief Description of Change	Status	Date
1.0	AHR908	Research paper on later life diagnoses for ASD and DLD	Final	15/02/2022