Submission: Community Affairs ADHD inquiry

Dear Senate Standing Committee on Community Affairs,

Thank you for the timely inquiry and the opportunity to make a submission.

I was diagnosed with ADHD as an adult in early 2022. Kid #1 was diagnosed in mid-2022. Kid #2 is in the process. Kid #3 isn't old enough to be diagnosed, but they are remarkably similar to Kid #1, so I expect Kid #3 to be diagnosed in due course.

Personally, I think having ADHD is great. Can you imagine being neurotypical? I'd be so bored I'd have to slit my wrists. At the same time, having ADHD is only great because I know that I have it. When you don't know, all you do is fail at being neurotypical. That's why, in my view, people with undiagnosed ADHD have such a high rate of mental health concerns. Those mental health concerns are, often, a symptom of undiagnosed ADHD rather than a comorbidity.

I am providing this submission because there are obvious and gaping holes in how ADHD is dealt with in Australia. Given I have direct recent lived experience of almost everything in the terms of reference, I hope my submission is of assistance.

I have organised my thoughts under the terms of reference.

Other introductory points:

- You will likely receive submissions from people who think ADHD is made up, or not serious, or similar. Please ignore them. Don't publish their submissions. Don't even accept their submissions as correspondence. Their input should not be given any weight, let alone a national platform.
- I can 'only' contribute lived experience. To the extent my submission exceeds the limits of what my lived experience qualifies me to say, I defer to the submissions of those with professional qualifications and expertise.

(a) adequacy of access to ADHD diagnosis

Cost

1. It is inaccessibly expensive. See the Australian ADHD Professionals Association's (AADPA) Clinical Practice Guideline (CPG) 7.1.5.

Children

- For children, the minimum requirements are approximately a cumulative minimum of 2 hours with a paediatrician (~\$1,000) and various assessments with a psychologist (\$1,500-3,000).
 - 2.1. This is only for diagnosis. It does not include post-diagnosis appointments to consider and review medication.
- 3. The paediatrician receives Medicare rebates in some circumstances (see below 'any other related matters'). The Medicare rebates are less than half the fee.
- 4. By default, psychological assessment does not receive any rebate. Some psychologists are set up such that they can claim a Medicare rebate *if* the child has a mental health treatment plan (MHTP). Even then, the total maximum rebate is ~\$390, being a third or less of the fee.
- 5. Private health extras insurance is worthless. That is true as a general proposition. It is specifically true for psychosocial assessments (ADHD or otherwise): it's less than what the Medicare rebate is (if the psychologist will use Medicare), and you cannot claim both the private health rebate and the Medicare rebate.
- Further, one will not even reach the extended Medicare safety net, which requires ~\$2,400 in out-of-pocket *Medicare* expenses. The paediatrician out-of-pocket cost counts (~\$600). The psychosocial assessments generally do not.
- 7. As a result, the minimum out of pocket cost for a child to receive an ADHD diagnosis is approximately \$1,700 (\$400 paediatrician, \$1,100 psychologist), with the mean more likely around \$2,700 (\$400 paediatrician, \$2,300 psychologist).
- 8. To put that in perspective, as at November 2022, average full-time weekly after-tax earnings are \$1,367. This makes the cost of an ADHD diagnosis at least 1.24x average weekly take-home pay, and more likely 1.98x.
- 9. Consequently, an ADHD diagnosis is simply unaffordable for any child that does not have both parents working full time. Even then, an ADHD diagnosis is the cost of a whole week's take-home pay for an average 2-income household.
- 10. Put another way, well under half of all children with ADHD have parents that can afford for the ADHD to be diagnosed.

Adults

- 11. My experience is that the cost for adults is slightly less, insofar as, a psychiatrist will generally undertake all the required assessments and therefore all assessments will receive a Medicare rebate.
- 12. At the same time, this requires a minimum cumulative 4 hours with a psychiatrist at a cost of ~\$2,100 before Medicare rebates. The Medicare rebate is barely 30%, making the out-of-pocket cost ~\$1,450.

13. As above, this is still more than a week's average full-time take-home pay. Affordable for some adults, but not most.

Geography

- 14. This is not my personal experience, because I am a city kid through and through.
- 15. Nonetheless, where one lives also has a significant impact on access.
- 16. I note the AADPA's CPG valid but substantial requirements for an ADHD diagnosis (see recommendation 2.1.2).
- 17. The idea that anyone living somewhere other than what I will call a 'Major Major Urban' area has physical access to the professionals required for an ADHD diagnosis is laughable (see ABS' ASGS: <u>https://www.abs.gov.au/statistics/statistical-geography/frequently-asked-questions</u>).

Quality of assessment

- 18. AADPA's CPG 2.1.4 notes that an ADHD diagnosis should not be made solely on rating scales. What it doesn't say is that, in my experience, rating scales are the price of entry: if the rating scale doesn't indicate ADHD, then the paediatrician won't move onto the 'full clinical and psychosocial assessment' required by 2.1.2.
- 19. This gives rating scales a disproportionate impact on the likelihood of obtaining an ADHD diagnosis. Bad rating scales will mean lots of false negatives.
- 20. What seems to be the primary rating scale is the 'NICHQ Vanderbilt Assessment Scale'.
- 21. The Vanderbilt is a bad scale.
- 22. The Vanderbilt does not seem to have been relevantly updated for some time. It is designed to diagnose boys who bounce off the walls at school (hyperactive ADHD). It more or less totally disregards any indications of inattentive ADHD (which are internal rather than external).
- 23. As a result, children with inattentive type ADHD have even less access to an ADHD diagnosis than their combined or hyperactive type peers.

(b) adequacy of access to supports after an ADHD assessment

- 24. This term of reference is difficult to respond to. One cannot rate the adequacy of supports that don't exist.
- 25. Put another way: with the exception of medication (discussed below), there are no supports for ADHD after diagnosis. None.

School

26. See AADPA CPG 7.2.

- 27. Some relevant context:
 - 27.1. ADHD, however so named, came into being as a diagnosis in the 1700s. This seems to be as a result of the industrial revolution. Agrarian society was suitable for children with ADHD. Most of each day was spent outside, in nature, doing exercise, and focusing on things that required immediate attention (such as: getting enough food to eat that day).
 - 27.2. Then the industrial revolution came along, with factories, clock-watching, rules, and a general societal expectation to constantly do things that aren't actually very interesting.
 - 27.3. To occupy the children while the adults were at work in a factory, we invented education factories. These are now known as 'schools'.
 - 27.4. If one set out to create an education system with the sole aim of making it as detrimental to people with ADHD as possible, you would find they had created schools and the current education system.
 - 27.5. Children with ADHD unsurprisingly couldn't cope in this system of detrimental education factories, and suddenly stood out as 'not normal'. Hence ADHD as a diagnosis came into being.
- 28. Given that society has designed schools to be detrimental for children with ADHD, it would be reasonable for society provide the support necessary for children with ADHD and their teachers to succeed at school.
- 29. No support is provided at school for children with ADHD.
- 30. Children with ADHD don't 'qualify' for any support. Moreover, this lack of support is as much to the detriment of their peers: children with ADHD require much more of their teacher's time and energy for successful 'behaviour management'. This is true for hyperactive type (bouncing off walls). It is also true, if less obvious, for inattentive type: for example, Kid #2 struggles to focus enough to go with the flow of the class without direct teacher assistance to Kid #2, the whole class would be continually late (to eating lunch, to library, to assembly, etc.).
- 31. Conversely, other children with seemingly equivalent disabilities qualify for support, despite having a much more minimal impact on the classroom.
- 32. This doesn't make sense. Even with a class of only neurotypical non-disabled children, teachers already spend most of their day on behaviour management. If extra behaviour management is required, how are teachers meant to teach, and otherwise provide for the needs of their class, without extra support? And how are children with ADHD meant to succeed, when despite their best attempts, they spend most of the day with their classmates and teacher being frustrated with them because they don't have the support they need?

33. Altogether, a child with ADHD should automatically attract additional support in a school context. As it stands, they get nothing.

Parking

- 34. There is a nationally coordinated scheme for disability parking permits.
- 35. Understandably, disability parking permits relate to mobility. The eligibility criteria relate to one's (in)ability to walk safely. Hence, being permitted to park in spaces that are physically closer to a destination.
- 36. In addition, disability parking permits generally entitle the holder to park for more than the signposted time, and/or, to park for free.
- 37. Successfully getting to a destination on time, parking lawfully, and getting back to the car on time, is a process extremely high on executive function. It has nearly 20 steps / points of failure.
- 38. ADHD does not cause mobility issues. People with ADHD don't need access to mobility parking spaces.
- 39. ADHD includes executive function differences. People with ADHD do need a reprieve from the executive function demands of parking. Parking fines are a particularly aggressive form of the 'ADHD tax' (<u>https://www.youtube.com/watch?v=2UFyO8Hf4LI</u>).
- 40. The Australian disability parking permit scheme should be split into 'mobility' and 'executive function', with an executive function permit entitling people with ADHD and other executive function differences to the non-mobility aspects of the current disability parking permit.

(c) the availability, training and attitudes of treating practitioners, including workforce development options for increasing access to ADHD assessment and support services

Availability

41. Availability is close to non-existent, even in a major major urban area.

Paediatrician

- 42. For example, in May the paediatrician's practice allocated the next available initial appointment, which was the following March. In January, it became apparent that appointment was on a public holiday. The paediatrician's office said 'oh sorry, we'll have to move you to the next available appointment', which was in May.
- 43. That's only one example, which suggests a minimum wait time of 5 months, and more likely 10-12 months. I understand waiting a year is not uncommon.

- 44. Further, paediatricians won't book an appointment unless the child is already 6 years old. So even though children can be diagnosed from 6 years old, in practice, the minimum age is nearly 7 years old.
- 45. And, all of this is *after* you've got a referral from the GP. Getting a referral is not altogether too difficult (although it is a waste of everyone's time and money), but a few extra weeks makes a difference.
- 46. Plus, a parent only learns the above after they've been through the system. At the start, one doesn't know how urgent it is. 'Oh yes, I should book with the GP' takes a few weeks to get onto it. Then a few more to book the paediatrician. Three additional months wait.
- 47. And, you can't do it concurrently the paediatrician won't book an appointment until you've got the GP referral.

Psychiatrist

- 48. The psychiatrist is similar. They tend to be booked out at least 6 months in advance. And that's just for an ordinary appointment. Plus, that is by telehealth if you want to see a psychiatrist, and you're willing to see any psychiatrist anywhere in the country, it's a wait of 6 months or more.
- 49. None of which is likely new information to you and it offers no solutions. The point is only: it's quite dire. The best I can suggest: tell the education factories to churn out more paediatricians and psychiatrists.

Attitude

- 50. In my experience, the paediatrician and psychiatrist have a great attitude. Helpful, appropriate, etc.
- 51. GPs are a mixed bag at best. I've been seeing my GP for years, and she is good, and has dealt with a variety of health concerns. She gave me a referral for the psychiatrist without issue (apparently some GPs decide you don't have ADHD and refuse).
- 52. Even so, her understanding of what ADHD means in day-to-day life is negligible. For example, I usually need an attendance certificate for appointments with her (whether for myself or a child). I perpetually forgot to ask during the appointment (see: ADHD, executive function difference), and call/email her reception afterwards to ask for one (at her convenience, not ASAP).
- 53. The GP was getting frustrated by this and in one appointment lectured me about it. I said words to the effect 'yes, I'm sorry, it's because ADHD. It's hard to remember to ask for a certificate and I haven't figured out a system to help.' She said words to the effect 'rubbish, you're in the middle of [successful tertiary study], it's not ADHD. Next time, if you don't ask in the appointment, I won't provide a certificate'.

54. While I'm sympathetic to her frustration, the flat contradiction that it wasn't ADHD was staggering. It lowered my trust in her. It was a garden variety breach of AADPA CPG 2.1.8, and the impact was profound (see also 'any other related matters').

(d) impact of gender bias, support services, and research

Diagnosing

- 55. See above my comments about the Vanderbilt.
- 56. Assessment tools geared toward boys who bounce off walls exclude women and girls at a higher rate than men and boys, because women and girls are more likely to have inattentive type ADHD.
- 57. Even though I have ADHD, and Kid #1 (a boy, hyperactive) has ADHD, and I knew all about ADHD and that it is strongly genetic, it didn't occur to me that Kid #2 (a girl, inattentive) might have ADHD. It was only because Kid #2's kindergarten teacher knew about this family context (they had taught Kid #1 the immediately prior year), and had several decades' teaching experience, that the kindergarten teacher suggested Kid #2 be assessed.
- 58. Kid #2 owes her kindergarten teacher a great debt that Kid #2 will probably never appreciate, because Kid #2's life could've turned out very differently. Even if Kid #2 was eventually diagnosed, figuring that out in kindergarten instead of Year 3 or 6 or 10 is hugely consequential.
- 59. Despite Kid #2 being picked up for ADHD against the odds, the Vanderbilt then got in the way. Kid #2's diagnosis is forthcoming, but it will have taken a year longer than required, because Kid #2 initially failed to pay the price of entry ('passing' the Vanderbilt).

Post-diagnosis support / medication

- 60. See below my comments on medication.
- 61. Women and girls with ADHD are less likely to be diagnosed at all, and when they are, it's generally later. As a result, more women are diagnosed after age 18, and therefore women disproportionately do not receive methylphenidate on the PBS.

(e) access to and cost of ADHD medication, including Medicare and Pharmaceutical Benefits Scheme coverage and options to improve access to ADHD medications

PBS

62. Methylphenidate should be on the PBS for adults. It's a no-brainer. Don't think about it: before you've finished reading this sentence, send a runner to the Health Minister's office and tell them to list methylphenidate on the PBS.

- 63. I raised this issue with my local MP in December 2022, who wrote to the Health Minister requesting methylphenidate be included on the PBS for adults. At the time of writing, the Health Minister has not replied.
- 64. Methylphenidate and dexamphetamine, in their various forms, are the 2 primary medications to support ADHD. There is no medical controversy about their use in children or adults: they are well-researched, safe, and effective.
- 65. Whether methylphenidate or dexamphetamine is more effective for a person is only determinable on a case-by-case basis. Both children and adults can safely and effectively use both, or a combination.
- 66. If you are diagnosed with ADHD before 18, both methylphenidate and dexamphetamine will be subsidised by the PBS forevermore.
- 67. If you are diagnosed with ADHD after 18, only dexamphetamine will be subsidised by the PBS.
- 68. There is no medical, scientific, policy, or rational basis to subsidise methylphenidate based on when a person received their diagnosis.
- 69. It is outright age discrimination: distinguishing on the basis of age when age is not relevant.
- 70. As set out above, it is indirect sex discrimination.
- 71. I am reminded every time I go to the pharmacy that 'the system' failed me as a child, because Kid #1's medication costs \$30 and my medication (which is the same) costs ~\$60. Why should I have to pay more now, because before I was 18, not a single adult of any sort even suggested ADHD be considered? Put another way: why should I forevermore suffer financial consequences of decisions I am not, and could not possibly have been, responsible for?
- 72. If methylphenidate is not listed on the PBS for adults in 2023, it will be a clear demonstration of the Committee's impotence.

Cost

73. If it's on the PBS it's fine. If it's not, it's expensive. Back of the envelope: \$2.50-\$5/day, or \$900-\$1,800/year. Not usually enough to reach the PBS threshold, but hardly insignificant, especially given the other economic costs of ADHD (see below).

Quality

- 74. If I understand correctly, Medication dispensed under the PBS is largely required to be the generic version.
- 75. The adequacy of generic medicine versus brand names is a question to be answered by someone with bona fide directly relevant qualifications.

- 76. Nonetheless, to the extent relevant, my understanding is that generic medicine does not need to be anything close to an exact copy of the brand. The generic medicine has the same amount of the same active ingredient, but that's about it.
- 77. I willingly assume that brand name medicines are more expensive because big pharma spends a lot of money on marketing, monopolises the market, and generally does its best to extract as much money as possible from vulnerable people so their shareholders can buy a second boat.
- 78. Even so, it is still partly the case that brand name medicine, at least sometimes, is of better quality. Sometimes this is for convenience and medically irrelevant: for example, brand name paracetamol tablets covered in sugar so they're easy to swallow, versus generic paracetamol that tastes awful. Other times, though, because fancy biochemistry I don't understand, the branded medicine is medically more effective.
- 79. Which is a long way of saying the PBS should dispense brand name medicine unless and until the generic medicine is independently proven to be as clinically effective. My understanding is that meeting the requirements required to permit a generic medicine to be sold does not equal independent proof that the generic medicine is as clinically effective as the brand name.
- 80. And: ADHD medications don't come in enough doses. Especially long-acting. If 30mg is not enough and 40mg is too much, why can't I get 35mg?

Over-regulated

- 81. ADHD medications are highly scheduled. This makes them administratively difficult to deal with.
- 82. My understanding is the scheduling relates to illicit use, not inherent danger. That is: ADHD medications have a street value, but are not inherently addictive or destructive. Compare opiates, which have a street value, and are prone to addiction and overdose etc.
- 83. People with ADHD should not have their lives made more difficult because some people illegally trade ADHD medication. This is especially the case given ADHD contains an executive function difference: the more rules and regulations that ADHD medications have, the more harm that people with ADHD are subject to.

84. Various complaints:

- 84.1. E-Scripts don't tell you the repeat date
- 84.2. You can't get more than one repeat at a time
- 84.3. Divorced parents can't get a second repeat they must forever count out pills, hand them over, and otherwise have to engage with each other
 - 84.3.1. I note that in the circumstances of some divorces, it is actively harmful to require one or both of the parents to interact with each other
- 84.4. The rules are different in each jurisdiction (see below).

Access

- 85. In my experience, paediatricians and psychiatrists have a 'set and forget' approach to ADHD medications (albeit unintentionally).
- 86. That is, they work toward figuring out what is the appropriate long-acting dose. Once figured out, that's it.
- 87. They don't inherently try both methylphenidate and dexamphetamine to see which is better.
- 88. They don't seem to consider a mix of long- and short-acting, on the same day, as being a dosage that should be considered.
- 89. This is despite the fact that for someone to know which ADHD medication schedule works best, they need to have tried all combinations. Including long-acting, short-acting, a combination of both, and in both methylphenidate, dexamphetamine, or a combination of both.

(f) the role of the National Disability Insurance Scheme in supporting people with ADHD, with particular emphasis on the scheme's responsibility to recognise ADHD as a primary disability 90. See AADPA CPG 7.1.2.

- 91. The NDIA does grant access to the NDIS with ADHD as a primary disability. It's in their publicly available data. From memory, as at September 2022 there are about 200 NDIS plans with ADHD as the primary disability.
- 92. However, NDIA actively refuse to disclose any information about this. They don't provide guidance as to how they decide when ADHD is or isn't a primary disability.
- 93. It looks like NDIA know ADHD meets the statutory criteria for being a primary disability. But they don't want to admit that, otherwise they'll have to grant more NDIS plans. Especially in circumstances where NDIA already face public criticism for the cost of the scheme.
- 94. That is, ADHD is actively excluded from the NDIS, despite meeting the statutory criteria. Solely because NDIA are embarrassed about paying out, for example, \$600 for a shower chair that costs \$150 (not once, but several hundred thousand times over).
- 95. I note that:
 - 95.1. As per the Deloitte report (attached), the wellbeing cost to a person with ADHD per year is nearly \$10,000.
 - 95.2. As defined in the Disability Discrimination Act 1992 (Cth), ADHD is a disability

- 95.3. Refusing to believe or meaningfully action requests from people with ADHD directly contributes to secondary symptoms such as anxiety and depression.
- 96. Consequently, my view is that ADHD clearly meets the NDIS criteria, and that NDIA are at best showing a reckless disregard for people with ADHD by refusing to 'list' ADHD on the NDIS.

(g) the adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people with ADHD at all life stages

- 97. See above on schools. Government services, whatever level, are not adequate in a school context. It is not possible for them to be adequate when they don't exist.
- 98. The rules for prescribing ADHD medication are different in every jurisdiction (see AADPA CPG 7.1.2). Some can prescribe by telehealth, some can't. Some will accept out-of-state prescriptions; some won't. Some require the script to be dispensed at one named pharmacy; others it's like a normal script.
- 99. Unfortunately, it is unlikely in my lifetime that the states will be abolished, leaving one national government and local governments (sort of like turning local governments into territories, so there are only 2 levels of government, but the Commonwealth is able to ensure national consistency).
- 100. Nonetheless, the situation with scripts for ADHD medication is a shambles. Vertical fiscal imbalance exists for a reason: please take away the states' pocket money until they get their act together. If they can do it to amend the *Act of Settlement 1701* (see *Succession to the Crown Acts 2013* (Qld, NSW, Tas, Vic) *2014* (SA) *2015* (WA, Cth), in particular Cth s 10, Sch 1) to undo male primogeniture for the throne, they can do it for something that is actually relevant to the lives of Australians.
- 101. Noting that ADHD scripts should be liberally regulated. The end result of this interstate cooperation should be that:
 - 101.1. any psychiatrist in any (Australian) jurisdiction can prescribe ADHD medication
 - 101.2. the psychiatrist in any jurisdiction can prescribe to a patient in any jurisdiction
 - 101.3. prescribing can be done either in person or by telehealth
 - 101.4. any pharmacy can dispense ADHD medication from any ADHD medication script.

(h) the adequacy of Commonwealth funding allocated to ADHD research

- 102. In my view there should be more research on the difference between ADHD having comorbidities and secondary symptoms.
 - 102.1. Comorbidities: ADHD *and* anxiety, *and* depression, etc., all existing as underlying causes in one person

- 102.2. Secondary symptoms: ADHD and anxiety *symptoms*, depression *symptoms*, etc., where ADHD is the only underlying cause and treating the ADHD resolves the other symptoms.
- 103. The medical community too readily assumes that people with ADHD have comorbidities, but sometimes it's just secondary symptoms (AADPA CPG 2.2.1). Instead, I think, it should be assumed that they are secondary symptoms until they are verified as their own underlying cause.
- 104. Put another way, giving someone with undiagnosed ADHD anxiety meds will help a little bit but won't resolve the underlying clause.

(i) the social and economic cost of failing to provide adequate and appropriate ADHD services

105. See above on parking fines and the 'ADHD tax'.

- 106. See attached Deloitte's 2019 report on the social and economic costs of ADHD in Australia.
- 107. The social (wellbeing) cost per person with ADHD per year is approximately \$9,324.
- 108. The economic cost per person with ADHD per year is approximately \$15,747.
- 109. Further:
 - 109.1. The health system cost of ADHD is 6% of the total economic cost of ADHD to the community
 - 109.2. Productivity losses are 81% of the total economic cost of ADHD to the community.
- 110. This suggests that more healthcare spending on ADHD will have a high return on investment. This is especially true for healthcare spending on ADHD before adulthood (see Chart ii in the attached), as most of the economic cost is employment related lost productivity from ages 20-35.

(j) the viability of recommendations from the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD

- 111. 1.1.1 (prisoners). As per 1.2.2, and contrary to 1.2.4, some population subgroups should have universal screening. In particular, as identified in 6.1., anyone who is imprisoned. I cannot agree with 6.1 strongly enough. To flesh it out:
 - 111.1. The research I have read* indicates at least 20% and potentially up to 50% of the prison population have undiagnosed ADHD.
 - 111.2. ADHD symptoms include impulse control, high risk tolerance, short-term thinking (time blindness), and a desperate search for any activity that provides

dopamine (junk food and risky sex won't get you imprisoned, but drugs, dangerous driving, and crime in general certainly will).

- 111.3. By the time imprisonment has occurred, the idea that someone with undiagnosed ADHD can get themselves out of their life of crime is laughable. It will almost never occur without support and treatment.
- 111.4. Recidivism rates often receive media attention. Think about that for a minute. If 20-50% of prisoners have undiagnosed ADHD, that suggests that recidivism rates are 20-50% higher than they need to be, purely on the basis of undiagnosed ADHD.
- 111.5. And it's usually the poor or vulnerable undiagnosed children that grow up into the prison system. Middle-class white kids with undiagnosed ADHD just look like they're failing to adult and not achieving their potential. If every kid with undiagnosed ADHD was diverted from the prison system, I'm going to brashly speculate that it would disproportionately be Aboriginal and Torres Strait Islander and other non-white children that benefited.
- 111.6. The only caveat is that ADHD and trauma can look very similar. When screening the prison population, care needs to be taken to ensure the correct diagnosis is reached (whether one or both of ADHD and trauma).

*True to ADHD form, I am writing this at the last minute. If you'd like the research, let me know, and I'll track it down.

- 112. 1.1.1 (ODD). I am not convinced ODD is a real diagnosis distinguishable from ADHD and/or another underlying condition. The underlying cause of ODD is adults failing to meet the needs of children (such as by ADHD diagnosis and treatment), being annoyed these children won't do what they're bloody told (how can the children do what they're told, their needs aren't met), and labelling the children as 'defiant' so they (the adults) don't have to blame themselves for the manifest breach of their duty of care toward the children.
 - 112.1. That is, ODD should be struck out of the DSM.
 - 112.2. Conduct disorder is different: it requires an element of maliciousness that children with ODD and/or ADHD don't usually have.
- 113. 1.2.2 As above, the questionnaires involved should cover inattentive and hyperactive ADHD. They should not include the Vanderbilt.
- 114. 2.1 The CPG recommended diagnosis process is agreeable, subject to comments above (it's expensive, questionnaires should not be the price of entry, etc.). 2.1.8 is especially important.
- 115. 2.2 See above comments under (h) on further ADHD research.
- 116. 4.1.1 In no context have I ever heard any medical practitioner 'offer strategies about diet and physical activity levels' that amounts to more than 'Did you know proper diet and exercise is good for you? You should improve your diet and do more exercise'.
 - 116.1. Thanks, Captain Obvious. Eating junk food is bad? How insightful of you. A decade of medical study and training is clearly required to give that advice, because I definitely couldn't've figured it out myself!

- 116.2. Put another way, unless the offered strategy has time, money, or other resources attached to it, medical practitioners should be very careful to avoid being patronising.
- 116.3. As against 2.3.2 no medical practitioner has ever suggested I should explore if a government benefit applies. That would actually be helpful.
- 117. 4.2 See my comments on 4.1.1. Everything in the list in 4.2 is only helpful if it comes with funding, or is covered by personal leave, or both.
- 118. 5.1.2 'Educational and employment circumstances' are not relevant to the decision to start ADHD medication. They can be relevant to the type and dose of ADHD medication.
- 119. 5.1.7 See my comments on comorbidity and secondary symptoms (under (h) further research). Without more, anxiety et al should be assumed to be a secondary ADHD symptom. Only if the ADHD medication and strategies have negligible impact should anxiety et al be considered as an underlying cause.
- 120. 5.2 See my comments above. In practice, paediatricians won't assess children under 6 years old.
- 121. 5.3 and 5.4. See my comments under (e), in particular, the sub-heading 'access'. The CPG in 5.3 are expressly detrimental in several respects:
 - 121.1. 5.3.3 recommends that another medication should only be trialled if the first one is ineffective. This is wrong. Methylphenidate and dexamphetamine should be trialled in everyone diagnosed with ADHD by default, especially if diagnosed as an adult.
 - 121.1.1. For example, introduce methylphenidate, and find the most effective type and dosage. Trial the 'equivalent' dexamphetamine type and dosage, with adjustments as required. Then, use the one the person with ADHD says was better.
 - 121.2. 5.6.7 Using a combination of long- and short-acting is an afterthought at the end. This should be a compulsory consideration (as against compulsory trial it doesn't have to be tried, but it should be thought about).
- 122. 5.8.1 'Remembering to organise repeat prescriptions and collect medication' is something that anyone, especially people with ADHD, can struggle to do. At the same time, see my comments above under 'over-regulated'. Before blaming people with executive function differences for failing at an executive function task that is outside their control, consideration should be given to the executive function task being administered by the government in a way that requires less executive function.
- 123. 7.1.2 One thousand times yes. See my comments under (j) and (f).
- 124. 7.3.3. One thousand times one thousand times yes.

(k) international best practice for ADHD diagnosis, support services, practitioner education and cost

125. Do not do what the Americans do without independent verification that what the Americans do is effective and worthwhile. Most problematic attitudes and approaches to ADHD in Australia come from America.

(I) any other related matters

- 126. Medicare is a nightmare:
 - 126.1. It is necessary to have conversations with the paediatrician about the child without the child present. Children with ADHD generally can't be left unsupervised in the waiting room. Medicare rebates are not available for appointments or phone calls with the paediatrician. So if you want to provide the necessary information to the paediatrician, you have to spend hundreds of dollars, or not provide it.
 - 126.2. The system of GP gate-keeping is a manifest failure. I have GP appointments a lot, whether for myself or my children. Very rarely do those appointments relate to actually being sick. They almost all relate to getting a piece of paper (literally GPs are not aware it's the 21st century) that permits me or my children to see a medical practitioner that might actually help.
 - 126.2.1. Telehealth is generally not permitted by Medicare which makes these appointments a logistical nightmare, usually missing some amount of work or school.
 - 126.2.2. Children are often not needed at these GP appointments at all. They're not being examined or having their temperature taken. Yet Medicare insists I take them out of school and sit them in a GP's office to qualify for the Medicare rebate.
 - 126.2.3. There is a national GP shortage. Perhaps if GPs were relieved from practicing paperwork, they would practice more medicine.
 - 126.2.4. There is a national GP shortage. Perhaps if they were incentivised to use administration systems, processes, and procedures from this century, the productivity improvements would be so significant we wouldn't actually need more GPs.
 - 126.3. All children under 14 should automatically qualify for the extended Medicare safety net. Supposedly it takes a village to raise a child perhaps the village could contribute some of the funds involved.
 - 126.3.1. Even on a self-centred, individualistic, and purely economic basis: prevention is better than cure. Giving all children under 14 the extended Medicare safety net would ultimately save the Commonwealth money.
- 127. ADHD is not a disorder. Stop calling it that. A disability is not a disorder. You don't say someone with quadriplegia has a neck disorder. Disorder is a term that exists because society decided to order itself a particular way, and then blame the people they didn't account for in that decision, for not fitting in (see above on the industrial revolution).

128. Leaving aside the 'disorder' part, ADHD needs an accurate name. Can we please get on with changing it? I don't care what the Americans put in their DSM – since at least 3 March 1986, we're our own country and we can make our own decisions.

Recommendations

I recommend:

- I. All children under the age of 14 automatically qualify for the extended Medicare safety net.
- II. That any psychological assessment required to assess ADHD be included in the Medicare Benefits Schedule.
- III. That all ADHD-related appointments that do not require a physical assessment of any kind (such as height and weight) be available by telehealth, if the person being assessed does not live in a major urban area.
- IV. That with immediate effect, the Vanderbilt ceases to be a permissible assessment tool.
- V. That medical practitioners be obliged to obtain more evidence than a questionnaire before discontinuing an ADHD assessment.
- VI. That any primary school teacher with at least one student with ADHD in their class be entitled to a full-time learning support assistant.
- VII. That any primary school teacher with at least 4 students with ADHD in their class be entitled to full-time learning support assistant at a ratio of 1 learning support assistant : 3 students with ADHD, rounded up (that is, 4 students with ADHD entitles the teacher to 2 learning support assistants).
- VIII. That ADHD and other executive function differences entitle a person to the nonmobility features of a disability parking permit.
- IX. That paediatricians and psychiatrists be required to take bookings without a GP referral, if a non-refundable deposit is paid against the first appointment's fee.
- X. That with immediate effect, methylphenidate and dexamphetamine in their various forms be included on the PBS for anyone with an ADHD diagnosis.
- XI. That by default, the PBS supplies brand-name methylphenidate and PBS.

- XII. That the various limitations on ADHD medication scripts be changed, such that people with ADHD can collect at least 2 repeats at a time.
- XIII. That the e-script system be amended so it advises when the next repeat date is.
- XIV. That AADPA's recommendations regarding ADHD scripts be implemented. Namely, nationally uniform rules where any paediatrician/psychiatrist can prescribe in and to any jurisdiction for dispensing in any jurisdiction.
- XV. That ADHD be listed on the NDIS.
- XVI. That the Commonwealth specifically refund research into the prevalence of ADHD comorbidities versus secondary symptoms.
- XVII. That prisoners be universally screened for ADHD at no cost to themselves.
- XVIII. That prisoners with ADHD receive fully funded ADHD treatment at no cost to themselves:
 - a. If imprisoned before age 21, until they turn 21; and/or
 - b. If imprisoned after age 21, until 12 months since they were last imprisoned
 - c. ('imprisoned' includes any incarceration, such as remand, weekend detention, etc.).
- XIX. That ODD be struck out of the DSM as a diagnosis.
- XX. That the AADPA CPGs, and/or other relevant rules, require paediatricians and psychiatrists to:
 - a. Trial both methylphenidate and dexamphetamine, unless there is a specific reason not to
 - b. Advise their patients (and/or their patient's guardian(s)) that a concurrent combination of long- and short-acting medication is an option they can trial.
- XXI. That all items on the MBS are claimable via telehealth, unless the item inherently requires in-person attendance.
- XXII. That the MBS include an item (X) whereby if any other item (Y) is being claimed against a person under 18, the treating practitioner for that other item (Y), can claim the first item (X) when consulting the patient's parents/guardians, without the patient present, and including by telehealth.

- XXIII. That the requirement for a referral from a GP be abolished (in general, for everything).
- XXIV. That GPs be incentivised to lower the executive function required to use their services. In particular, that GPs promptly transition to digital technologies for any aspect of their practice that presently requires or uses physical pieces of paper.
- XXV. That with immediate effect, ADHD cease to be referred to as a 'disorder'.
- XXVI. That ADHD is replaced with an accurate name, regardless of what the DSM says.

Thank you for considering my submission.

CBUDD

Christopher Budd

9 June 2023

Attachment 1



Alicia Payne MP

MEMBER FOR CANBERRA

The Hon. Mark Butler MP Minister for Health and Aged Care Parliament House Canberra ACT 2600

fork

Dear Minister Butler,

I write on behalf of my constituent Christopher Budd, who has been in contact with me regarding Methylphenidate (Ritalin), a medicine he would like to see placed onto the PBS.

Methylphenidate is a medication used to assist patients who have been diagnosed with ADHD, a neurodevelopmental disorder. This medication has been used to treat ADHD for many years and is available through the PBS if the patient's diagnosis was made before they were 18.

Christopher makes the point that this cut off is arbitrary and has no medical, scientific, policy or rational basis. It could also be construed as age discrimination. On top of this, given the nature of ADHD being harder to identify in girls and women, diagnosis tends to be delayed and thus women are more likely than men to have passed the cut-off age and lose the benefits of the PBS.

I would like to request your assistance in reviewing the PBS arrangements for Methylphenidate with a view to making this important medication more readily available to all Australians diagnosed with ADHD.

Thank you for your consideration of this matter.

Kind regards,

Alicia Payne MP Member for Canberra

13/12/2022

Deloitte.



The social and economic costs of ADHD in Australia

Report prepared for the Australian ADHD Professionals Association July 2019

Deloitte Access Economics

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Acknowledgements

Deloitte Access Economics acknowledges and thanks the Australian ADHD Professionals Association (AADPA) for commissioning this report and providing expert input and guidance throughout the project. AADPA received funding from the Australian Government under the Department of Health Mental Health program.

Glossary

i

ABODS	Australian Burden of Disease Study		
ABS	Australian Bureau of Statistics		
ADHD	attention deficit hyperactivity disorder		
AIC	Australian Institute of Criminology		
AIHW	Australian Institute of Health and Welfare		
AWE	average weekly earnings		
DALY	disability adjusted life year		
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4th Edition		
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition		
ER	emergency room		
GBD	Global Burden of Disease		
GP	general practitioner		
HKD	hyperkinetic disorder		
IEP	Individualised Educational Plans		
MBS	Medicare Benefits Schedule		
MRR	mortality rate ratio		
NCCD	Nationally Consistent Collection of Data on School Students with Disability		
NDI	National Death Index		
NHIS	National Health Interview Survey		
NHMRC	National Health and Medical Research Council		
ODD	oppositional defiant disorder		
PAF	population attributable fraction		
PBS	Pharmaceutical Benefits Scheme		
SSG	student support group		
VSL(Y)	value of a statistical life (year)		
YLD	year of healthy life lost due to disability		
YLL	year of life lost due to premature death		
YMM	Young Minds Matter		

Executive summary

Key findings

- ADHD affects approximately 281,200 children and adolescents (aged 0-19) and 533,300 adults (aged 20+) in Australia.
- The total cost of ADHD in Australia in 2019 is \$20.42 billion, which includes financial costs of \$12.83 billion and wellbeing losses of \$7.59 billion. Productivity losses due to ADHD are substantial (\$10.19 billion).

Background

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder that affects over 800,000 people in Australia today. ADHD is characterised by symptoms of inattention, impulsivity, and in some cases excessive levels of hyperactivity. Diagnosis is provided once symptoms are deemed by a specialist clinician to meet the diagnostic criteria. There is no one single known cause of ADHD; it is a syndrome that arises from an interaction of genetic, social and environmental factors. Despite the uncertainty of the cause of ADHD and the variation in the reported prevalence, it is clear that in Australia today, the social and economic cost of ADHD is large.

Prevalence

The reported prevalence of ADHD in Australia varies widely depending on the method used to assess the syndrome. There is some disagreement in the community over whether ADHD is under or over-diagnosed. Despite this, it is recognised as the most common neurodevelopmental disorder in children and adolescents. Prevalence estimates, both domestically and internationally vary considerably, however it is noted that higher income countries tend to have higher prevalence rates of ADHD.

In Australia, the prevalence of ADHD in children (under 14 years of age) was estimated to be 4.2%, and for adults (between 18 and 44 years of age) prevalence was estimated at 4.0%. Prevalence for adults over the age of 45 drops significantly, to 1.8%. Prevalence is higher for males than it is for females (a ratio of 2-3:1), with ADHD highest during childhood and declining with age. Prevalence of ADHD in children aged up to 14 years is 5.8% and 2.3% in males and females respectively; meaning a total of 197,400 children (14 years and younger) have ADHD. A breakdown of estimated prevalence by age and gender is shown in Chart i.

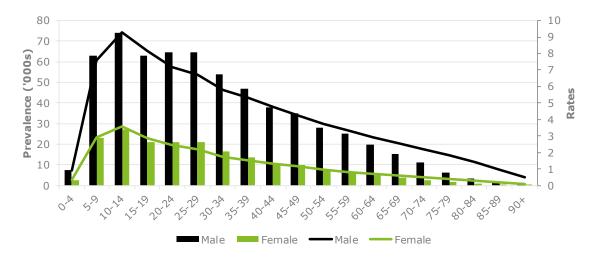


Chart i Estimated prevalence of ADHD, by age and gender, 2019

Source: Deloitte Access Economics analysis based on GBD (2017) and Ebejer et al (2012).

Social and economic costs of ADHD

The total social and economic costs of ADHD in 2019 were estimated to be \$20.42 billion. Per person with ADHD, the cost is \$25,071.

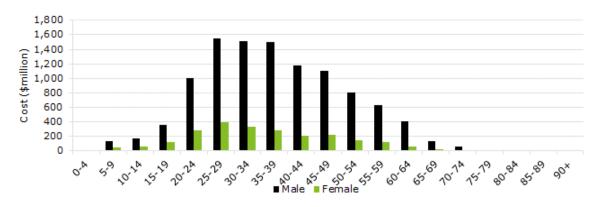
Table i Total costs of ADHD in 2019, by component

Loss of wellbeing	7.59	9,324	
Total economic costs	12.83	15,747	
Deadweight loss ¹	1.41	1,730	
Crime and justice	0.31	377	
Education	0.11	130	
Other financial costs	1.82	2,238	
Productivity costs	10.19	12,509	
Health system costs	0.81	1,000	
Cost component	Total (\$bn)	Per person (\$)	

Source: Deloitte Access Economics calculations. Note: components may not sum due to rounding.

Chart ii depicts the cost of ADHD by age and gender. Costs are concentrated in earlier to middle aged years due to the distribution of ADHD prevalence and the fact that people in their prime working years incur higher productivity costs as a result of ADHD.

Chart ii Financial costs of ADHD in 2019, by age and gender

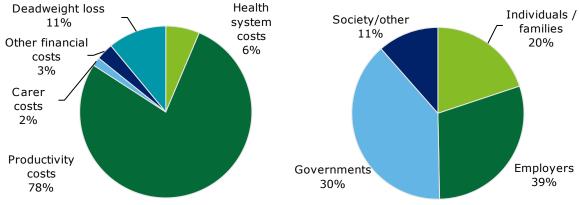


Source: Deloitte Access Economics.

Productivity costs make up 81% of total financial costs, which is followed by deadweight losses (11%), health system costs (6%), and other costs including educational and crime and justice costs (3%) (Chart iii). Employers were estimated to bear the largest share of financial costs (39%) followed by governments (30%), individuals and their families (20%) and society and other payers (11%).

¹ Deadweight losses are costs associated with the act of taxation, which create distortions and inefficiencies in the economy. Imposing taxes on a market reduces the efficiency of resource allocation within that market because it changes the price of those goods or services being taxed. For example, an increase in income tax rates will increase the relative price of work compared to leisure and therefore create a disincentive to work. Similarly businesses may be discouraged from operating in Australia if company tax rates were too high.





Source: Deloitte Access Economics.

Wellbeing costs

In addition to imposing significant financial costs, ADHD results in suffering that leads to a significant loss of wellbeing for those affected. Wellbeing costs total \$7.59 billion in 2019. Per person, the wellbeing cost of ADHD is \$9,324 per person in 2019.

Future directions

This report has found ADHD imposes significant economic and wellbeing costs on the Australian population. ADHD can have lifelong impacts, including on educational achievement, occupational attainment, and the increased likelihood of crime and interaction with the criminal justice system. These impacts place significant pressure on Australian society and its institutions.

As such, there is a continued need to raise awareness of the socioeconomic burden of ADHD in Australia and educate and inform key stakeholders including individuals, education systems, workplaces, and society in an attempt to reduce the burden and lifelong impact that ADHD may have. There are likely substantial opportunities for targeted policy interventions to help mitigate this costly condition.

Deloitte Access Economics

1 Background

Deloitte Access Economics was commissioned by the Australian ADHD Professionals Association (AADPA) to quantify the economic burden of attention deficit hyperactivity disorder (ADHD) in Australia.

The AADPA is a not-for-profit organisation that aims to provide a unified professional perspective on the causes, diagnosis, management and treatment of ADHD.

This report has been structured in the following manner:

- **Chapter 1** describes the condition and discusses the approach taken to estimate the costs of ADHD.
- **Chapter 2** presents prevalence estimates for ADHD.
- **Chapter 3** estimates the costs of ADHD to the health system by type of cost, and by payer.
- **Chapter 4** discusses the productivity costs due to ADHD.
- **Chapter 5** outlines other financial costs that arise from ADHD, including education and justice costs, and the costs of crime due to ADHD.
- **Chapter 6** estimates the burden of disease due to ADHD.
- **Chapter 7** summarises the total costs of ADHD.

1.1 What is ADHD?

ADHD is a mental health disorder and recognised as the most common of the neurodevelopmental disorders that usually start in childhood. ADHD is defined by age-inappropriate levels of inattention, impulsivity and hyperactivity.² Onset is classically in early childhood and is the most prevalent mental disorder of childhood and adolescence.³ While ADHD prevalence decreases with age, ADHD often persists and remains relatively common in adults (chapter 2). There is also evidence that ADHD can present for the first time in adolescence or adulthood for some people.⁴ Whilst these individuals would not meet the age of onset criterion in formal diagnostic tools their problems and impairments are similar to those with persistent ADHD with earlier onset. The prevalence of ADHD is higher in males than in females.

ADHD is typically separated into three presentations:

- **Hyperactive-impulsive presentation**: behaviours can include not being able to remain seated in a classroom, being unable to play or take part in leisure activities quietly, talking excessively, trouble waiting his/her turn and often interrupting or intruding on others.
- **Inattentive presentation:** behaviours can include not being able to focus on details, not following through on instructions and not seeming to listen when spoken to directly.
- **Combined presentation:** meeting the criteria for both hyperactive-impulsive and inattentive types.

The contribution of hyperactivity, impulsivity and inattention to an individual's presentation of ADHD varies from person to person and often changes across their lifespan.

² Erskine, H. E., Norman, R. E., Ferrari, A. J., Chan, G. C., Copeland, W. E., Whiteford, H. A., & Scott, J. G. (2016). Long-term outcomes of attention-deficit/hyperactivity disorder and conduct disorder: a systematic review and meta-analysis. Journal of the American Academy of Child & Adolescent Psychiatry, 55(10), 841-850.

³ Lawrence, D., Johnson, S., Hafekost, J., Boterhoven de Haan, K., Sawyer, M., Ainley, J., & Zubrick, S. R. (2015). The mental health of children and adolescents: report on the second Australian child and adolescent survey of mental health and wellbeing. *Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing*. Department of Health, Canberra.

⁴ Agnew-Blais, J. C., Polanczyk, G. V., Danese, A., Wertz, J., Moffitt, T. E., & Arseneault, L. (2016). Evaluation of the persistence, remission, and emergence of attention-deficit/hyperactivity disorder in young adulthood. JAMA Psychiatry, 73(7), 713-720.

1.2 Diagnosis of ADHD

ADHD is typically diagnosed by a paediatrician, psychiatrist or psychologist.⁵ Given there is no reliable biological test for ADHD, the assessment process involves a comprehensive evaluation of information gathered from a number of sources (e.g. the individual, parents, spouses, teachers, other family members). A full assessment includes: clinical examination; clinical interviews; assessment of familial and educational needs; and assessment tools and rating scales.

Formal diagnosis is made when the nature, frequency and duration of the patient's symptoms fulfil the criteria set out in one of two medical classification systems: the *Diagnostic and Statistical Manual of Mental Disorders,* 5th Edition⁶ (DSM-5⁷) or the International Statistical Classification of *Diseases and Related Health Problems,* 11th revision⁸ (ICD-11). In the DSM-5, six or more symptoms (five symptoms for adults) of inattention and/or hyperactivity and impulsivity must be present for at least 6 months, and the symptoms must be inappropriate for the individual's developmental level.⁹ Symptoms may include: often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g. loses focus, side-tracked); or often leaves seat in situations when remaining seated is expected.

For the DSM-5 there are a number of further criteria where the practitioner must be satisfied, including that the symptoms:

- were present before the individual was 12 years old
- are present in multiple settings (such as at home and school or work)
- are not better explained by another disorder
- clearly interfere with quality of life and functioning.

The DSM-5 was introduced in 2013, replacing the previous DSM-IV which included revisions to the diagnostic criteria for ADHD which aim at better identifying ADHD symptoms across the lifespan. These revisions include:

- additional examples of how symptoms may manifest in adolescence and adulthood
- a reduction from six to five in the minimum number of symptoms in either symptom domain required for older adolescents and adults
- change from onset of symptoms and impairments before age 7 to onset of symptoms before age 12
- change from evidence of impairment to evidence of symptoms in two or more settings
- autism spectrum disorder is no longer an exclusionary diagnosis.¹⁰

In summary, under DSM-5 adolescents and adults are more likely to receive an ADHD diagnosis than under DSM-IV due to the expansion of the age of symptom onset and reduction in the number of symptoms required for ADHD diagnosis in older adolescents and adults. Therefore

⁵ Australian Psychological Society. (January 2019). ADHD in Children. Retrieved from https://www.psychology.org.au/for-the-public/Psychology-topics/ADHD-in-children.

⁶ American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. 2013. ⁷ The DSM-5 was introduced in 2013, replacing the DSM-IV, including revisions to the diagnostic criteria for ADHD. While the specific criteria have not been fundamentally changed, they have been augmented with specific examples of possible symptom presentation in children, adolescents, and adults. The DSM-5 revisions include modifications to each of the ADHD diagnostic criteria, largely to provide examples of how ADHD may present in adults and to change the age of onset criterion from age 7 to age 12. The scope of some symptoms was also revised (e.g. to describe a general impact on functioning rather than a clinically relevant impact on functioning). Source: Epstein, J. N., and Loren, R.E. (2013). Changes in the Definition of ADHD in DSM-5: Subtle but Important. *Neuropsychiatry (London)*, Oct 1; 3(5): 455–458.

⁸ World Health Organization. The ICD-11 Classification of Mental and Behavioural Disorders. Available at: <u>https://icd.who.int/browse11/l-m/en</u> Accessed April 2019. The ICD-11 was introduced in June 2018 and will formally replace the previous ICD-10 in May 2019. The ICD-11 will be more comparable to the DSM-5 than the ICD-10. Studies that have used the ICD-10 will be describing a more severely affected group.

⁹ Center for Disease Control. (December 2018). Attention-Deficit/Hyperactivity Disorder (ADHD) – Symptoms and Diagnosis. Retrieved from https://www.cdc.gov/ncbddd/adhd/diagnosis.html.

¹⁰ Epstein, J. N., and Loren, R.E. (2013). Changes in the Definition of ADHD in DSM-5: Subtle but Important. *Neuropsychiatry* (London), Oct 1; 3(5): 455–458.

studies using DSM-IV may underestimate the prevalence of ADHD especially for adolescents and adults compared with the DSM-5 criteria.

The ICD-10 classified ADHD as hyperkinetic disorder (HKD), which was defined as a persistent and severe impairment of psychological development, characterised by early onset; a combination of overactive, poorly modulated behaviour with marked inattention and lack of persistent task involvement; and pervasiveness over situations and persistence over time of these behavioural characteristics. As such this defined a more severely affected group than either DSM-IV or DSM-5. The recently published ICD-11 has included a classification for ADHD that is more similar to the DSM-5 definition and it is therefore anticipated that the cases defined by the two systems will also be more alike.¹¹

The ICD and DSM systems are both widely used and accepted, although in Australia, most of the research and clinical practice of psychiatry is based on the DSM-5. As such, this report largely focuses on the DSM-5 (or earlier versions).

1.3 Risk factors and comorbidities of ADHD

Like many complex neurodevelopmental syndromes, ADHD is a highly heritable disorder involving multiple genes each with a small effect.¹² In addition to genetic factors, there are environmental risk factors for childhood symptoms of ADHD including maternal smoking and low birth weight.¹³ Children with ADHD often have increased difficulties with reading, motor performance, emotional regulation and social interaction.¹⁴ ADHD is associated with social, criminal and financial problems in adolescence and adulthood. Higher rates of academic failure, self-esteem problems, relationship difficulties, low socioeconomic status, injuries and accidents, substance abuse and interactions with the justice system are just some of those noted in the literature.¹⁵

Prevalence of ADHD in children and adolescents is associated with a range of socio-demographic characteristics. These include: 16

- The prevalence of ADHD is lowest in children and adolescents living in original or intact families with two parents. The prevalence of ADHD is, on average, twice as high in children and adolescents from single parent or carer families.
- The prevalence of ADHD is positively correlated with households of lower socioeconomic status.
- Children and adolescents from families with the highest level of education of a parent or carer have the lowest prevalence of ADHD. The prevalence of ADHD is twice as high in children and adolescents from families with the lowest level of parent or carer education compared to the highest level of parent or carer education.
- The prevalence of ADHD in children and adolescents with both parents or carers not in employment is twice as high as children or adolescents in families where one parent or carer is employed.

¹¹ World Health Organization. The ICD-11 Classification of Mental and Behavioural Disorders. Available at: <u>https://icd.who.int/browse11/l-m/en</u> Accessed April 2019.

¹² Demontis, D., Walters, R. K., Martin, J., Mattheisen, M., Als, T. D., Agerbo, E., ... & Cerrato, F. (2019). Discovery of the first genome-wide significant risk loci for attention deficit/hyperactivity disorder. *Nature genetics*, *51*(1), 63.

genetics, 51(1), 63.. ¹³ Sciberras, E., Mulraney, M., Silva, D. & Coghill, D. (2017). Prenatal Risk Factors and the Etiology of ADHD-Review of Existing Evidence. Curr Psychiatry Rep 19, 1.

¹⁴ Ebejer, J. L., Medland, S. E., Van Der Werf, J., Gondro, C., Henders, A. K., Lynskey, M., ... & Duffy, D. L. (2012). Attention deficit hyperactivity disorder in Australian adults: prevalence, persistence, conduct problems and disadvantage. *PLoS One*, 7(10), e47404.

¹⁵ Le, H. H., Hodgkins, P., Postma, M. J., Kahle, J., Sikirica, V., Setyawan, J., ... & Doshi, J. A. (2014). Economic impact of childhood/adolescent ADHD in a European setting: the Netherlands as a reference case. *European child & adolescent psychiatry*, 23(7), 587-598.

¹⁶ Lawrence, D., Johnson, S., Hafekost, J., Boterhoven de Haan, K., Sawyer, M., Ainley, J., & Zubrick, S. R. (2015). The mental health of children and adolescents: report on the second Australian child and adolescent survey of mental health and wellbeing. *Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing*. Department of Health, Canberra.

Overall, prevalence of ADHD in Australia is higher in children and adolescents living in families with lower levels of income, education and employment and with poorer family functioning.¹⁷

ADHD is often comorbid with one or more disorders. Around 65% of those with ADHD also have another disorder.¹⁸ Oppositional defiant disorder (ODD) is the most common comorbidity in children with ADHD, with reported rates ranging between 40% and 60%.¹⁹ Other common comorbidities in children with ADHD include learning disabilities (46% of children with ADHD, compared with 5% of children without ADHD), conduct disorder (27%, compared with 2%), anxiety (18%, compared with 2%), depression (14%, compared with 1%), and speech problems (12%, compared with 3%).²⁰ It has also been found that 28% of those diagnosed with autism spectrum disorder are also diagnosed with ADHD.²¹

1.4 Treatment and interventions of ADHD

Multimodal therapy is recommended for the treatment of ADHD in all age groups. Specific best practice treatment guidelines differ slightly by age. Psychoeducation and basic environmental manipulations is recommended as treatment for all age groups. Where this treatment is not enough, medication is recommended as a first line treatment with parent training offered to those children and adolescents with additional oppositional behaviours.²²

Both children and adults with ADHD tend to exhibit fewer symptoms after treatment with stimulant class medications, although treatment of very young children (under 6 years of age) with medication should only be used when there are severe functional disturbances which are unresponsive to behavioural interventions and educational support.²³ Evidence suggests stimulant treatments generally have strong effects on ADHD symptoms, while psychosocial interventions produce improvements in academic and organisational domains.²⁴

There is strong evidence that treatment of ADHD produces tangible short-term benefits, and some evidence suggests that people with ADHD who receive treatment have improved long-term outcomes compared to people with ADHD who do not receive treatment.²⁵ However, the current literature is not sufficient to fully attribute the effects of treatment characteristics (such as combinations, dosage, frequency and intensity), to the prevention of negative long-term outcomes in adulthood.²⁶

¹⁷ Ibid.

¹⁸ Holden, S. E., Jenkins-Jones, S., Poole, C. D., Morgan, C. L., Coghill, D., & Currie, C. J. (2013). The prevalence and incidence, resource use and financial costs of treating people with attention deficit/hyperactivity disorder (ADHD) in the United Kingdom (1998 to 2010). Child and adolescent psychiatry and mental health, 7(1), 34.

¹⁹ Banaschewski T., Rohde L.A. Phenomenology. In: Banaschewski T., Zuddas A., Asherson P., Buitelaar J., Coghill D., Danckaerts M., et al., editors. ADHD and Hyperkinetic Disorder. 2nd ed. Oxford: Oxford University Press; 2015. p. 5 -17.

²⁰ Larson, K., Russ, S. A., Kahn, R. S., & Halfon, N. (2011). Patterns of comorbidity, functioning, and service use for US children with ADHD, 2007. Pediatrics, 127;462.

²¹ Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(8), 921-929.

derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(8), 921-929. ²² National Institute for Health and Care Excellence (NICE). (2018). NICE guideline [NG87] Attention deficit hyperactivity disorder: diagnosis and management. <u>https://www.nice.org.uk/guidance/ng87</u>

²³ Subcommittee on Attention-Deficit/Hyperactivity Disorder. (2011). ADHD: clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. Pediatrics.

²⁴ Chan, E., Fogler, J. M., & Hammerness, P. G. (2016). Treatment of attention-deficit/hyperactivity disorder in adolescents: a systematic review. Journal of the American Medical Association, 315(18), 1997-2008.

²⁵ The main outcome variables studied were academic, antisocial behaviour, driving, non-medicinal drug use and addiction, obesity, occupation, services use, self-esteem and social function. Shaw, M., Hodgkins, P., Caci, H., Young, S., Kahle, J., Woods, A. G., & Arnold, L. E. (2012). A systematic review and analysis of long-term outcomes in attention deficit hyperactivity disorder: effects of treatment and non-treatment. BMC medicine, 10(1), 99.

²⁶ Chan, E., Fogler, J. M., & Hammerness, P. G. (2016). Treatment of attention-deficit/hyperactivity disorder in adolescents: a systematic review. Journal of the American Medical Association, 315(18), 1997-2008.

1.5 Estimating the costs of ADHD in Australia

This section describes the approach taken to estimate the costs of ADHD in Australia, and outlines some of the key economic terms, how costs are borne by members of society, and some of the underlying methodology presented throughout the following chapters. Specific methodologies for each of the costs associated with ADHD are outlined further in the chapter where they are discussed.

The costs of ADHD in Australia were estimated for the financial year 2018-19 (referred to as 2019) using a prevalence approach to cost estimation. A prevalence approach measures the number of people with ADHD at a point in time, and estimates the costs incurred due to ADHD for a given year (e.g. 2019). The costs from remitted cases (i.e. people who have had ADHD in the past, but no longer do) are generally excluded using this approach, although discussion has been included for some of the costs remitted cases incur throughout the report.

The broad types of costs associated with ADHD included in this report are:²⁷

- **financial costs to the Australian health system**, which include the costs of running hospitals and residential aged care facilities, GP and specialist services reimbursed through Medicare and private funds, the cost of pharmaceuticals and of over-the-counter medications, allied health services (in particular psychologists), research and other health system expenditures (such as health administration).
- **productivity costs,** which include reduced workforce participation, reduced productivity at work, loss of future earnings due to premature mortality, and the value of informal care (lost income of carers of children with ADHD).
- **other costs,** which include costs of government services, including education and the justice system, and the brought forward funeral costs due to premature mortality.
- **transfer costs,** which comprise the deadweight losses, or reduced economic efficiency, associated with the need to raise additional taxation to fund provision of government services.
- **wellbeing costs,** which are the costs associated with reduced quality of life and impaired functioning, and premature death²⁸ that result from ADHD. Wellbeing costs are measured in terms of the years of life, or healthy life, lost using the burden of disease methodology.

The costs of ADHD are borne by different individuals or sectors of society. Understanding how the costs are shared helps to make informed policy and healthcare decisions regarding interventions. While people with ADHD are most severely affected by the condition, other family members and society also face costs as a result of ADHD.

From the employer's perspective, work loss or absenteeism can lead to costs such as higher wages (i.e. accessing skilled replacement short-term labour) or alternatively lost production, idle assets and other non-wage costs. Employers might also face costs such as rehiring and retraining due to premature mortality.

Australian governments typically bear costs associated with the health system and other government services such as education and justice (noting there are also out of pocket expenditures and other payers). The analysis in this report shows the first round impacts on government and employers. No second round or longer term dynamic impacts are modelled (i.e. changes in wages or labour market outcomes associated with the economic burden of ADHD).

Any future costs ascribed to ADHD for the year 2019 were estimated in net present value terms to reflect the value of utility today rather than in the future. Taking inflation, risk and positive time

²⁷ Cost of illness methodology would typically include administrative costs and other financial costs associated with government and non-government programs such as respite programs, community palliative care, and any out-of-pocket expenses – e.g. formal care, and transport and accommodation costs associated with receiving treatment. These costs were excluded from the scope of the report as the costs are likely relatively minor.
²⁸ Some mortality due to ADHD occurs through other pathways, for example accidents due to ADHD.

preference into consideration, a real discount rate of 3% is traditionally used in discounting healthy life, and is also used in discounting other cost streams in this report, for consistency.²⁹

It is possible to estimate each of these costs using a top down or bottom up approach. The top down approach provides the total costs of a program element (e.g. the health system) due to a condition. A bottom up approach involves estimating the number of cases incurring each cost item, and multiplying the number of cases by the average cost of each item. A bottom up approach was used to estimate most of the costs of ADHD in this report.

A top down approach using national datasets can be more desirable to ensure that the sum of parts is not greater than the whole, although these data are typically difficult to obtain for people with ADHD as there are a range of confounding factors.

In attributing productivity costs to ADHD, controlling for confounding factors is important. For example, children with ADHD are more likely to come from lower socioeconomic status backgrounds than children without ADHD.³⁰ Lower socioeconomic status in childhood is also correlated with a range of poor health outcomes in adulthood.³¹ Similarly, children and adults with ADHD may have a number of comorbidities (section 1.3), which may contribute to worse employment outcomes or increased health costs.

²⁹ Generally, the minimum option that one can adopt in discounting expected healthy life streams is to set values on the basis of a risk free assessment about the future that assumes future flows would be similar to the almost certain flows attaching to a long-term Government bond. Another factor to consider is inflation (price increases), so that a real rather than nominal discount rate is used. If there is no positive time preference, the real long term government bond yield indicates that individuals will be indifferent between having something now and in the future. In general, however, people prefer immediacy, and there are different levels of risk and different rates of price increases across different cost streams.

³⁰ Kvist, A.P., Nielsen, H.S. and Simonsen, M., (2013). The importance of children's ADHD for parents' relationship stability and labor supply. *Social Science & Medicine*, *88*, pp.30-38.

³¹ Cohen, S., Janicki-Deverts, D., Chen, E. and Matthews, K.A., (2010). Childhood socioeconomic status and adult health. *Annals of the New York Academy of Sciences*, *1186*(1), pp.37-55.

2 Epidemiology

There is much research on the prevalence of ADHD, with varying global and regional estimates.³² The variation is due to different methods used to assess ADHD which can vary from the method of reporting symptoms (teacher versus parent versus both), measures (diagnostic versus symptom measures) and other factors.

Due to the differences in measurement of ADHD, prevalence estimates around the world range from as little as 1% up to 20%.³³ Due to the varying estimates of worldwide prevalence, a targeted literature review was undertaken to identify literature relevant to Australia, for the purpose of determining childhood, adolescent and adult prevalence of ADHD in Australia. The literature was then applied to demographic data to model the number of people with ADHD in Australia for 2019.

Estimates of prevalence in children (0 to 14 years) and adults (15 years and over) have been separated in this report due to the differing methods used, quality of evidence available, and different definitions used in the DSM-5 (e.g. only five symptoms for adults, rather than six for children). 2019 prevalence rates in children and adults are discussed in section 2.1 and 2.2 respectively.

Key findings

- The most recent results from the Global Burden of Disease study show that the prevalence of ADHD in Australia is 4.1% in children aged 0-14 years.
- ADHD is more likely to persist into adulthood in Australia than in comparable countries. Based on a local persistence study, 3.0% of Australian adults (15+) have ADHD. Males are more likely to have ADHD (4.9%) than females (1.5%).
- There are an estimated 814,500 people with ADHD in Australia in 2019.
- ADHD was estimated to cause 64 deaths in 2019, based on the findings of a cohort study conducted in Denmark.

2.1 Prevalence in children (0 to 14 years)

International estimates of ADHD prevalence in children vary, often explained by different analytical methodologies employed, such as the use of differing diagnostic criteria.³⁴ The Global Burden of Disease (GBD) study, which provides an estimate for prevalence of ADHD in Australia in 2017 was ultimately used as the source of prevalence in this report for children rather than the recent Young Minds Matter (YMM) survey. The rationale and methods used are discussed further below.

The YMM survey is an interview of 6,000 Australian families, which looked at the emotional and behavioural development of children and young people aged between 4 and 17 years.³⁵ The YMM

deficit/hyperactivity disorder: a systematic review and meta-analysis. *Pediatrics*, 135(4), e994-e1001. ³³ Polanczyk, G., De Lima, M. S., Horta, B. L., Biederman, J., & Rohde, L. A. (2007). The worldwide prevalence of ADHD: a systematic review and metaregression analysis. *American journal of psychiatry*, 164(6), 942-948. ³⁴ Polanczyk, G. V., Willcutt, E. G., Salum, G. A., Kieling, C., & Rohde, L. A. (2014). ADHD prevalence estimates across three decades: an updated systematic review and meta-regression analysis. *International journal of epidemiology*, 43(2), 434-442.

³⁵ Lawrence D, Johnson S, Hafekost J, Boterhoven De Haan K, Sawyer M, Ainley J,

Zubrick SR (2015) The Mental Health of Children and Adolescents. *Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing*. Department of Health, Canberra.

³² Thomas, R., Sanders, S., Doust, J., Beller, E., & Glasziou, P. (2015). Prevalence of attention-

survey uses face-to-face diagnostic interviews with parents and carers of 4 to 17 year olds and a self-report questionnaire. 36

The YMM survey found that ADHD was the most common mental disorder in Australian children and adolescents, followed by anxiety disorders, major depressive disorder and conduct disorder. Reported prevalence of ADHD in Australian children may range between 2.4% and 7.4%.^{37,38,39} As noted by Sibley et al (2016),⁴⁰ surveys that employ parent interviews, often yield higher prevalence and persistence rates than studies employing alternate reporting methods.

Given the uncertainty around parent-reported prevalence of ADHD, prevalence rates were sourced from the GBD study rather than relying on one single Australian survey. The GBD study pools results from a range of studies, controls for study quality, and ensures that each study was representative of the general population rather than a special population (e.g. prison inmates). Thus, the GBD estimates address potential sources of bias in sample and methodological techniques.

To calculate prevalence in 2019, prevalence rates of ADHD in male and female children (0 to 14 years) from the GBD study were applied to the 2019 population. Approximately 197,400 children aged 0 to 14 years had ADHD in 2019.

Age	1	Male	Fe	emale
	Rate (%)	Estimate ('000)	Rate (%)	Estimate ('000)
0-4	0.9	7.3	0.3	2.6
4-9	7.6	63.1	2.9	23.1
10-14	9.3	74.1	3.6	27.2
0-14	5.8	144.4	2.3	53.0

Table 2.1 Childhood prevalence estimate, 2019

Source: GBD (2017) and Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

2.2 Adult prevalence and persistence (15 years and above)

Worldwide prevalence of ADHD (all ages) is estimated to be between 2% and 5%⁴¹. Calculating prevalence of ADHD in adolescent and adult populations is more complex than childhood prevalence due to the limited evidence in Australia. Furthermore, for literature available, estimates vary considerably due to methodological differences.⁴²

Zubrick S. R. (2015). The Mental Health of Children and Adolescents. *Report on the second Australian*

Child and Adolescent Survey of Mental Health and Wellbeing. Department of Health, Canberra..

³⁹ Gomez, R., Harvey, J., Quick, C., Scharer, I., & Harris, G. (1999). DSM-IV AD/HD: confirmatory factor models, prevalence, and gender and age differences based on parent and teacher ratings of Australian primary school children. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, 40(2), 265-274... ⁴⁰ Sibley, M. H. Swanson, J. M. Arrold, J. E. Hochtman, J. T. Owons, E. R. Stabli, A. Abikoff, H. Hijnshaw,

³⁶ The YMM questionnaire was based on specific diagnostic modules from the Diagnostic Interview Schedule for Children Version IV (DISC-IV) and a specifically developed module to determine impact on functioning. The YMM study aligned the responses to the interview with the DSM-IV criteria.

³⁷ Lawrence D., Johnson S., Hafekost J., Boterhoven De Haan K., Sawyer M., Ainley J.,

³⁸ Graetz, B. W., Sawyer, M. G., Hazell, P. L., Arney, F., & Baghurst, P. (2001). Validity of DSM-IV ADHD subtypes in a nationally representative sample of Australian children and adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry*, 40(12), 1410-1417.

⁴⁰ Sibley, M. H., Swanson, J. M., Arnold, L. E., Hechtman, L. T., Owens, E. B., Stehli, A., Abikoff, H., Hinshaw, S. P., Molina, B., Mitchell, J. T., Jensen, P. S., Howard, A. L., Lakes, K. D., Pelham, W. E., MTA Cooperative Group (2016). Defining ADHD symptom persistence in adulthood: optimizing sensitivity and specificity. *Journal of child psychology and psychiatry, and allied disciplines*, 58(6), 655-662.

⁴¹ Polyzoi, M., Ahnemark, E., Medin, E., & Ginsberg, Y. (2018). Estimated prevalence and incidence of diagnosed ADHD and health care utilization in adults in Sweden - a longitudinal population-based register study. *Neuropsychiatric disease and treatment*, 14, 1149-1161. doi:10.2147/NDT.S155838

⁴² Sibley, M. H., Swanson, J. M., Arnold, L. E., Hechtman, L. T., Owens, E. B., Stehli, A., Abikoff, H., Hinshaw, S. P., Molina, B., Mitchell, J. T., Jensen, P. S., Howard, A. L., Lakes, K. D., Pelham, W. E., MTA Cooperative

Although prevalence of ADHD is widely thought to decrease with age, estimates still suggest that it is one of the most common adult psychiatric disorders.⁴³ A summary of international prevalence estimates in adulthood is provided in Table 2.2. Prevalence estimates typically vary from close to 2% up to 5%.

Study	Country and setting	Age range	Prevalence estimate
Bitter et al (2010)	Survey of 3,529 adult patients presenting to primary care in Hungary.	18-60	2.5% based on full DSM-IV criteria.
Bunting et al (2013)	Nationally representative household survey of 4,340 adults in Northern Ireland.	18+	1.3% based on DSM-IV criteria.
Ebejer et al (2012)	Survey of 3,795 participants on the Australian Twin Registry (and family members).	21-49	1.1% based on full DSM-IV criteria, increasing to 2.3% and 2.7% when relaxing age of onset and problem symptoms criteria.
Fayyad et al (2007)	Survey of 11,422 participants across ten countries in the Americas, Europe and the Middle East.	18-44	3.4% based on DSM-IV. Prevalence rates in lower income countries were lower (1.9%) compared with higher income countries (4.2%).
De Zwaan et al (2012)	Survey of 1,655 adults in Germany.	18-64	4.7% based on DSM-IV criteria.
Kessler et al (2006)			4.4% based on DSM-IV criteria.
Simon et al (2009)	Systematic review and meta-regression of six studies in multiple countries.	17-84	2.5% pooled prevalence based on DSM- IV.
Weighted average			2.8%

Table 2.2 Summary of prevalence of ADHD in adults in international settings

Source: as noted in table.

Given the variation in adult prevalence rates across studies, and noting that higher income countries tend to have higher prevalence rates, an Australian study was used to estimate the persistence of ADHD into adulthood.

As with prevalence estimates, persistence of ADHD (the rate at which that the condition continues into adulthood) varies widely in the literature, depending on the study design. Some of the main drivers of variation include the definition of ADHD and methodological considerations (e.g. structured interviews versus rating scales, self-reported versus parent/other-reported information).⁴⁴ Caye et al (2016) reported that persistence of ADHD into adulthood ranges from

Group (2016). Defining ADHD symptom persistence in adulthood: optimizing sensitivity and specificity. Journal of child psychology and psychiatry, and allied disciplines, 58(6), 655-662.

⁴³ Das, D., Cherbuin, N., Butterworth, P., Anstey, K. J., & Easteal, S. (2012). A population-based study of attention deficit/hyperactivity disorder symptoms and associated impairment in middle-aged adults. *PloS one*, 7(2), e31500.

⁴⁴ Sibley, M. H., Swanson, J. M., Arnold, L. E., Hechtman, L. T., Owens, E. B., Stehli, A., Abikoff, H., Hinshaw, S. P., Molina, B., Mitchell, J. T., Jensen, P. S., Howard, A. L., Lakes, K. D., Pelham, W. E., MTA Cooperative Group (2016). Defining ADHD symptom persistence in adulthood: optimizing sensitivity and specificity. Journal of child psychology and psychiatry, and allied disciplines, 58(6), 655-662.

11% to 75%.⁴⁵ Selected international studies on persistence rates are provided in Appendix Table A.1.

In calculating the number of people with ADHD in 2019, we have used the average persistence rates reported in an Australian based study by Ebejer et al (2012). Ebejer et al (2012) provided persistence rates in a sample from the Australian Twin Registry (ATR), which included 1,369 men and 2,426 women.⁴⁶

Ebejer et al (2012) calculated persistence from the age of 14 onwards, for three non-exclusive diagnostic definitions of ADHD respectively: (i) full DSM-IV criteria; (ii) excluding the age 7 onset criterion (no age criterion); (iii) participant experienced difficulties due to ADHD symptoms (problem symptoms).⁴⁷ The average rates of persistence were 55.3% (full DSM-IV criteria), 50.3% (no age criterion), and 40.2% (problem symptoms), meaning persistence of ADHD is more likely when the full diagnostic criteria are met.⁴⁸ To estimate prevalence, we have taken an average of persistence rates for each of the diagnostic definitions, for each age and gender group. The average decline in prevalence with a one unit increase in age was calculated and then extrapolated to estimate further decline in prevalence for older age groups.⁴⁹ The persistence rates were then applied to prevalence at age 14 from the GBD study to estimate the decline in prevalence rates with age. Chart 2.1 shows the estimated prevalence rates based on this approach, along with prevalence rates from other selected studies.

The final prevalence rates and number of people estimated to have ADHD in 2019, using the methods described above, are shown in Table 2.3. The overall prevalence in 2019, including children, adolescents and adults was estimated to be 3.2%, representing 814,500 Australians. This estimate is higher than the 2017 GBD study, which estimated the prevalence of ADHD at 2.0%. However, the higher rate is not unexpected given that adult prevalence rates are likely to increase with the changes to the DSM-5 diagnostic criteria, which supports adopting a higher prevalence estimate in Australia.⁵⁰ Moreover, the estimates are still within the expected range of approximately 2% to 5% in adults and are in line with the estimates calculated for high-income countries.⁵¹

⁴⁵ Caye, A., Spadini, A. V., Karam, R. G., Grevet, E. H., Rovaris, D. L., Bau, C. H. D., ..., Kieling, C. (2016). Predictors of persistence of ADHD into adulthood: A systematic review of the literature and metaanalysis. European Child & Adolescent Psychiatry, 25(11), 1151-1159. Retrieved from https://doi.org/10.1007/s00787-016-0831-8.

⁴⁶ There are still some limitations to the study design employed by Ebejer et al (2012). For example, the persistence rates are subject to recall bias as it is a retrospective study. Similarly, it is difficult to accurately measure changes in ADHD symptoms over time. However, as noted by Caye et al (2016), there are no prospective, population-based studies that address the issue of persistence rates of ADHD into adulthood. As such, it is unlikely that any studies that present better estimates of persistence. As such, we have used Ebejer et al (2012) to estimate adult prevalence of ADHD due to its applicability to the Australian population. Ebejer, J. L., Medland, S. E., Van Der Werf, J., Gondro, C., Henders, A. K., Lynskey, M., ... & Duffy, D. L. (2012). Attention deficit hyperactivity disorder in Australian adults: prevalence, persistence, conduct problems and disadvantage. *PLoS One*, 7(10), e47404.

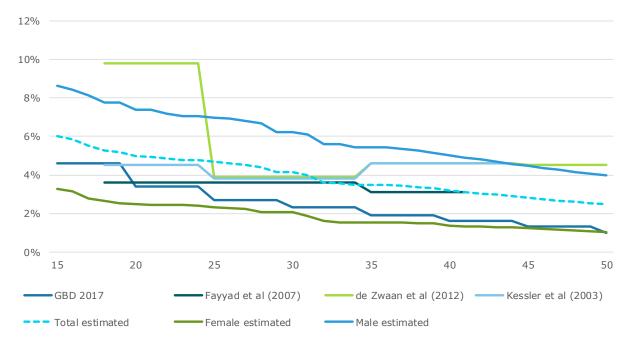
⁴⁷ Being a retrospective study, the results are vulnerable to an increased recall bias by participants. The study is also limited by the use of computer assisted telephone interviews, and the inability for symptoms to be accurately measured across time. However as noted by Caye et al (2016), there are no prospective, population-based studies that address the issue of persistence rates of ADHD into adulthood; meaning there are no studies that present better alternatives for persistence for the purposes of this report.

⁴⁸ Ebejer, J. L., Medland, S. E., Van Der Werf, J., Gondro, C., Henders, A. K., Lynskey, M., ... & Duffy, D. L. (2012). Attention Deficit Hyperactivity Disorder in Australian Adults: Prevalence, Persistence, Conduct Problems and Disadvantage. *PLoS ONE* 7(10): e47404.

⁴⁹ The compound annual growth rate (CAGR) method was used to determine the average reduction on persistence. This was calculated from the age of 14, to the last age of each category and applied to each subsequent age.

⁵⁰ Epstein, J. N., and Loren, R.E. (2013). Changes in the Definition of ADHD in DSM-5: Subtle but Important. *Neuropsychiatry (London),* Oct 1; 3(5): 455–458.

⁵¹ Fayyad, J., Sampson, N. A., Hwang, I., Adamowski, T., Aguilar-Gaxiola, S., Al-Hamzawi, A., ... & Gureje, O. (2017). The descriptive epidemiology of DSM-IV adult ADHD in the world health organization world mental health surveys. *ADHD Attention Deficit and Hyperactivity Disorders*, *9*(1), 47-65.





Source: as noted; and Deloitte Access Economics analysis based on GBD (2017) and Ebejer et al (2012).

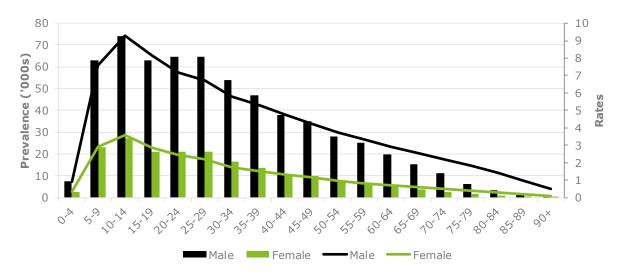


Chart 2.2 Estimated prevalence of ADHD, by age and gender, 2019

Source: Deloitte Access Economics analysis based on GBD (2017) and Ebejer et al (2012).

Age	Prev	valence (%)		Preva	alence (`000)	
	Male	Female	Total	Male	Female	Total
0-4	0.9	0.3	0.6	7.3	2.6	9.9
5-9	7.6	2.9	5.3	63.1	23.1	86.2
10-14	9.3	3.6	6.5	74.1	27.2	101.3
15-19	8.1	2.9	5.6	62.8	21.0	83.8
20-24	7.2	2.4	4.9	64.7	20.8	85.5
25-29	6.7	2.2	4.5	64.6	20.9	85.4
30-34	5.8	1.7	3.7	54.0	16.5	70.5
35-39	5.3	1.5	3.4	47.1	13.5	60.6
40-44	4.8	1.3	3.0	37.9	10.5	48.4
45-49	4.2	1.1	2.7	34.9	9.7	44.7
50-54	3.8	1.0	2.3	28.2	7.5	35.7
55-59	3.3	0.8	2.0	25.1	6.4	31.5
60-64	2.9	0.7	1.8	19.7	4.9	24.6
65-69	2.5	0.6	1.5	15.1	3.6	18.7
70-74	2.2	0.5	1.3	11.3	2.5	13.8
75-79	1.8	0.4	1.1	6.3	1.5	7.8
80-84	1.4	0.3	0.8	3.2	0.8	4.0
85-89	1.0	0.2	0.5	1.2	0.4	1.6
90+	0.5	0.1	0.2	0.3	0.1	0.5
Total	4.9	1.5	3.2	620.9	193.6	814.5

Table 2.3 Estimated prevalence of ADHD (rates and thousands of people with ADHD), 2019

Source: GBD (2017) and Deloitte Access Economics analysis based on GBD (2017) and Ebejer et al (2012).

2.3 Mortality due to ADHD

There is restricted evidence to indicate an increased mortality rate due to ADHD, however a limited number of studies have determined that the odds of dying are significantly higher among people who reported an ADHD diagnosis at one point in their life, when compared to a controlled sample with no history of ADHD diagnosis. Two studies, the first a Danish based prospective study of almost 2 million individuals⁵² and the second, a US study using data linkages from the 2007 National Health Interview Survey (NHIS) and the National Death Index (NDI)⁵³ both identify a statistically significant negative association between ADHD diagnosis and mortality. These studies provide some of the first evidence suggesting a causal link between ADHD and mortality outcomes.

Dalsgaard et al (2015) found that a diagnosis of ADHD significantly increased mortality rates, even when adjusted for comorbidities. The study found that people who had been diagnosed with ADHD had an all-cause mortality rate of 5.85 per 10,000 person-years compared with 2.21 per 10,000 person-years in controls, corresponding to a twofold increased mortality rate ratio (MRR). Women had higher mortality (3.01:1) than men (1.93:1). The increased mortality in individuals with ADHD was mainly driven by deaths from unnatural causes, with accidents being the most common cause of death. Even when adjusting for potential confounding from other conditions (e.g. the interaction

⁵² Dalsgaard, S., Østergaard, S. D., Leckman, J. F., Mortensen, P. B., & Pedersen, M. G. (2015). Mortality in children, adolescents, and adults with attention deficit hyperactivity disorder: a nationwide cohort study. *The Lancet, 385*(9983), 2190-2196.

⁵³ London, A. S., & Landes, S. D. (2016). Attention deficit hyperactivity disorder and adult mortality. *Preventive medicine*, 90, 8-10.

between conduct disorder and ADHD), ADHD was significantly associated with increased mortality, with a MRR of 1.5:1.

In the US study by London and Landes (2016), ADHD was found to be associated with significantly higher odds of dying for adults, and results suggested that accidents may be an underlying cause of death more often for people with ADHD than those without (13.2% versus 4.3%). However, it was noted that accidents only account for a proportion of the reported deaths amongst this cohort, with other causes of death, not linked to ADHD or accidents, still contributing to overall death rates.

No Australian specific estimates of increased mortality are available. However, the Dalsgaard et al (2015) study provides a reliable fully adjusted⁵⁴ MRR to use in our calculations for the purpose of this report.

The MRR (1.5:1) was applied to general population mortality rates in Australia to estimate the mortality due to ADHD. The Dalsgaard study only considers the risk of mortality from ADHD until 30 years of age, so it was conservatively assumed that there is no increased risk of mortality for adults who are older than this.

Overall, it was estimated that there were 64 deaths due to ADHD in 2019 in Australia. Approximately 85% of these deaths were in males, and most were between the ages of 15 to 29, reflecting the increased rate of accidents and injuries in this cohort.

10	2	12
17	2	19
18	3	21
	17	4 1 10 2 17 2

Table 2.4 Mortality attributed to ADHD in 2019

Source: Dalsgaard et al (2015) and Deloitte Access Economics analysis.

⁵⁴ Fully adjusted for age, calendar year, sex, parental history of psychiatric disorders, maternal and paternal age at time of delivery, parental education and parental employment status.

3 Health system costs

Health system costs comprise the costs of running hospitals, general practitioner (GP) and specialist services funded through Medicare and patient contributions, the cost of prescribed and over-the-counter pharmaceuticals, allied health services, research, residential aged care services, and `other' costs such as health administration.

Health system costs in Australia are primarily paid for by governments, with individuals and their families contributing through out-of-pocket payments. Private health insurers and other payers (e.g. worker's compensation) also pay for some health services.

The following sections provide an overview of the health system costs due to ADHD in Australia for 2019. Due to data limitations, it was only possible to estimate health system costs for a subset of all health expenditures. Specifically, data were available to estimate hospital, GP, specialist and psychologist service costs using a bottom up approach. However, no suitable bottom up data on the costs of allied health other than psychologists were identified for inclusion in the report.

Consequently, the health system costs presented here largely relate to government expenditure (hospitals, MBS, PBS and research-related). Future research could continue to focus on the out of pocket costs (e.g. for allied health services and complementary and alternative therapies) for individuals with ADHD and their families.

Key findings

- The total health system costs due to ADHD were estimated to be \$814.5 million in 2019, or \$1,000 per person with ADHD.
- Almost all health system costs were incurred within hospitals (\$361.1 million) or in out-of-hospital care (\$361.9 million), which represents 89% of all costs to the health system.
- Governments bore more than 80% of the estimated health system costs, noting it was not possible to estimate costs for a range of allied health services.

3.1 Hospital

To estimate the hospital costs attributable to ADHD in Australia in 2019, the average number of annual hospital visits attributed to ADHD was multiplied by the average cost per visit. This was then multiplied by prevalence to estimate the total annual hospital costs attributable to ADHD in Australia.

Children with ADHD have been shown to be more likely to experience injuries due to accidents than children without ADHD. This is likely because of their tendencies toward impulsive, overactive behaviour.⁵⁵ One study has estimated the incidence and cost of accidents among individuals with ADHD using an administrative database. Analyses were conducted for the whole population, adults alone, children under age 12, and adolescents aged 12 to 18 years. ADHD patients in all age groups were more likely than a matched control group to have at least one accident claim: children, 28% compared with 18%; adolescents, 32% compared with 23%; and adults, 38% compared with 18%.⁵⁶

⁵⁵ Matza, L. S., Paramore, C., & Prasad, M. (2005). A review of the economic burden of ADHD. *Cost Effectiveness and Resource Allocation*, 3:5.

⁵⁶ Swensen, A., Birnbaum, H. G., Hamadi, R. B., Greenberg, P., Cremieux, P. Y., & Secnik, K. (2004). Incidence and costs of accidents among attention-deficit/hyperactivity disorder patients. *Journal of Adolescent Health*, 35(4), 346-e1.

One study found that compared with controls, children under 4 years with ADHD had a greater mean number of visits to the emergency room (0.23 compared with 0.16).⁵⁷ The difference of 0.07 additional emergency room visits was used to estimate the average number of annual hospital visits attributed to ADHD for children.

Adults with ADHD were also found to have higher hospital use, compared with control groups in a US study. Results reveal a higher prevalence of visits to the emergency room (ER) among individuals diagnosed with ADHD (14.34% compared with 10.26%), as well as a significantly greater mean number of visits to the ER for those sent to the ER (1.56 compared with 1.33). This difference of 0.23 was used to estimate the average number of annual hospital visits attributed to ADHD for adults in Australia.⁵⁸ The ADHD cohort were also significantly more likely to be admitted as inpatients (6.71% compared with 4.09%) and, among those hospitalised, the ADHD cohort had significantly more admissions (1.44 compared with 1.22).⁵⁹ The UK study by Holden et al (2013) also found additional hospital admissions for the adult ADHD cohort compared with a control group (0.2 compared with 0.1).⁶⁰ Given the comparability between hospital admissions and emergency department visits, no additional costs were assigned to emergency department visits.

People with ADHD usually present to hospital for injury or poison, respiratory disease, ear disease and neurological conditions.⁶¹ With the exception of injury or poisoning, these are likely to be comorbidities that are commonly associated with ADHD.⁶² The average cost per hospital visit was calculated using a weighted average of the total actual cost for DRGs X60A (injuries with catastrophic or severe complications), X62A (poisoning/toxic effects of drugs and other substances with catastrophic or severe complications) and X64A (other injury, poisoning and toxic effect diagnosis with catastrophic or severe complications), weighted according to the number of separations. The 2014-15 cost values were updated to 2019 dollars using Australian Institute of Health and Welfare (AIHW) health expenditure inflation, which was estimated to be \$2,537 per hospital admission, on average.⁶³

Cost type	Average cost per visit (\$)	Average number of annual visits	Average cost per patient (\$)	Prevalence	Estimated annual cost (\$m)
Admissions (child)	2,537	0.07	178	281,187	49.9
Admissions (adult)	2,537	0.23	583	533,329	311.2
Total					361.1

Table 3.1 Hospital costs attributable to ADHD

Source: Deloitte Access Economics analysis.

⁶⁰ Holden, S. E., Jenkins-Jones, S., Poole, C. D., Morgan, C. L., Coghill, D., & Currie, C. J. (2013). The prevalence and incidence, resource use and financial costs of treating people with attention deficit/hyperactivity disorder (ADHD) in the United Kingdom (1998 to 2010). *Child and adolescent psychiatry*

⁵⁷ Chan, E., Zhan, C., & Homer, C. J. (2002). Health care use and costs for children with attentiondeficit/hyperactivity disorder. *Arch Paediatric Adolescent Medicine*, 156:504-511.

⁵⁸ No robust Australian evidence comparing hospital admission in Australian adults compared to controls was identified in the literature review. However, these estimates are comparable to results from the National Health Survey in Australia (Australian Bureau of Statistics, 2016), where results show that a sample of Australians with ADHD were admitted to hospital an additional 0.2 times compared to matched controls (not adjusted for confounding factors).

⁵⁹ Secnik, K., Swensen, A., & Lage, M. J. (2005). Comorbidities and Costs of Adult Patients Diagnosed with Attention-Deficit Hyperactivity Disorder. *Pharmacoeconomics*, 23 (1): 93-102.

and mental health, 7(1), 34. ⁶¹ Silva, D., Colvin, L., Hagemann, E., Stanley, F., & Bower, C. (2014). Children diagnosed with attention deficit disorder and their hospitalisations: population data linkage study. European Child & Adolescent Psychiatry, 23, 1043–1050.

⁶² Chan, E., Zhan, C., & Homer, C. J. (2002). Health care use and costs for children with attentiondeficit/hyperactivity disorder. *Arch Paediatric Adolescent Medicine*, 156:504-511.

⁶³ Independent Hospital Pricing Authority, National Hospital Cost Data Collection, Public Hospitals Cost Report, Round 20 (Financial year 2015-16) https://www.ihpa.gov.au/publications/national-hospital-cost-datacollection-public-hospitals-cost-report-round-20-0

3.2 Out-of-hospital health costs

For people with ADHD, out-of-hospital health costs may include visits to a/an:

- GP
- specialist (paediatrician, psychiatrist)
- allied health clinician (occupational therapist, psychologist)
- complementary and alternative medicine provider.

To estimate the out-of-hospital health costs attributable to ADHD in Australia in 2019, the average number of annual out-of-hospital visits attributed to ADHD was multiplied by the average cost per visit. The average annual cost per patient was then multiplied by prevalence to estimate the total annual out-of-hospital costs attributable to ADHD in Australia.

Out-of-hospital costs related to ADHD were estimated for GPs, specialists and some allied health services (e.g. psychologists) in section 3.2.1. However, due to evidence considerations it was not possible to estimate costs for complementary and alternative medicine services (other allied health services). The evidence for these other allied health services is discussed in section 3.2.2.

3.2.1 GP, specialist and psychologist costs

A UK study of clinically diagnosed children (aged 6 to 17 years) and adults with ADHD found that people with ADHD have a greater number of primary care appointments and specialist attendances compared with a control group. Over the first five years following diagnosis, children had 4.2 more primary care appointments and 2.2 more specialist attendances per year on average. For adults, the group with ADHD had 8.1 more primary care appointments and 2.4 more specialist attendances per year on average.⁶⁴ These values were used to estimate the average number of annual GP and specialist attendances attributed to ADHD for children and adults in Australia.⁶⁵

These estimates of average annual GP and specialist attendances attributed to ADHD are consistent with other, related studies. For example, an Australian study of children with ADHD by Sciberras et al (2013) found they have higher MBS costs compared with children without ADHD, and these costs appear to increase with age.⁶⁶ Similarly, a US study found that children with ADHD had 9.9 times more specialist mental health visits (1.35 per year compared with 0.14 per year), 3.4 times more pharmacy fills (11.25 per year compared with 3.30 per year), and 1.6 times more primary care visits (3.84 per year compared with 2.36 per year) than children without ADHD.⁶⁷ In a US study of adults, the ADHD cohort were also more likely to access out-of-hospital health services. Specifically, compared with control individuals, adults diagnosed with ADHD were significantly more likely to visit a psychiatrist (27.53% compared with 2.22%) or a psychologist (16.03% compared with 51.20%), and among those who visited a GP, the ADHD cohort had significantly more visits (7.18 compared with 5.00).⁶⁸

The use of allied health and complementary and alternative medicine treatments for children and adults with ADHD is discussed separately in Section 3.2.2.

⁶⁵ No robust Australian evidence comparing GP and specialist attendances in Australian children or adults compared to controls was identified in the literature review. However, these estimates are comparable to results from the National Health Survey in Australia (Australian Bureau of Statistics, 2016), where results show that a sample of Australians with ADHD attended an average annual additional 1.62 GP consultations and 1.92 specialist consultations compared to matched controls (not adjusted for confounding factors).

 ⁶⁴ Holden, S. E., Jenkins-Jones, S., Poole, C. D., Morgan, C. L., Coghill, D., & Currie, C. J. (2013). The prevalence and incidence, resource use and financial costs of treating people with attention deficit/hyperactivity disorder (ADHD) in the United Kingdom (1998 to 2010). *Child and adolescent psychiatry and mental health*, 7(1), 34.
 ⁶⁵ No robust Australian evidence comparing GP and specialist attendances in Australian children or adults

⁶⁶ Sciberras, E., Lucas, N., Efron, D., Gold, L., Hiscock, H., & Nicholson, J. M. (2017). Health Care Costs Associated With Parent-Reported ADHD: A Longitudinal Australian Population–Based Study. *Journal of attention disorders*, 21(13), 1063-1072.

⁶⁷ Guevara, J., Lozano, P., Wickizer, T., Mell, L., & Gephart, H. (2001). Utilization and cost of health care services for children with attention-deficit/hyperactivity disorder. *Pediatrics*, 108(1), 71-78.

⁶⁸ Secnik, K., Swensen, A., & Lage, M. J. (2005). Comorbidities and costs of adult patients diagnosed with attention-deficit hyperactivity disorder. *Pharmacoeconomics*, 23(1), 93-102.

The average cost of a GP service for adults was calculated based on Medicare Statistics data to be \$35.82. The average cost was derived using the total benefits provided for GP attendances (\$7.8 billion), the number of GP services (155 million), the proportion of services which were bulk billed (86.1%), and the average out of pocket cost (\$37.39).⁶⁹ The average cost per consultation was estimated to be \$55.52 in 2019 terms. However, patients may present to GPs with more than one problem, and therefore the entire cost is not directly attributable to ADHD. The average cost (\$55.52) was divided by the average number of problems (1.55) based on Britt et al's (2016) report into General Practice Activity in Australia.⁷⁰ The average cost of a specialist attendance for children and adults was estimated using the MBS fee for general specialist attendances (\$86.85).⁷¹

Cost type	Average cost per consultation (\$)	Average number of annual visits	Average annual cost, per patient (\$)	Prevalence (cases)	Total annual cost (\$m)
Child				281,187	
GP	35.8	4.2	150		42.3
Specialist	86.8	2.2	191		53.7
Total					96.0
Adult				533,329	
GP	35.8	8.1	290		154.7
Specialist	86.8	2.4	208		111.2
Total					265.9
Total					361.9

Table 3.2 Core out-of-hospital health costs attributable to ADHD

Source: Deloitte Access Economics analysis.

3.2.2 Other allied health services

People with ADHD and their families may use allied health services (such as parent skills training, cognitive and behavioural therapy, education psychology or occupational therapy), and complementary and alternative medicine therapies (such as diet modification or naturopathy) as part of their treatment. In standard medical practice, families often receive advice on the behavioural management of their child with ADHD and are often referred to a psychologist for ongoing management. Children with ADHD often have mild fine-motor difficulties and may also be referred to an occupational therapist. There is also reported use of other complementary and alternative therapies reported in the Australian setting including: diet modification, naturopathy, chiropractic therapy, aromatherapy, kinesiology, and acupuncture.⁷² In addition to a medical practitioner, the source of referral for an allied health or complementary and alternative medicine therapy also includes family and friends, private allergy centres and school teachers.⁷³

There is some evidence from the USA and Europe that indicates children and adolescents with ADHD use a range of therapies for treatment. A 2018 study of children and adolescents with ADHD

https://www.myhealthycommunities.gov.au/our-reports/out-of-pocket-spending/august-2018

⁷⁰ Britt et al estimate an average number of problems of 1.55, total services were divided by this amount.
⁷¹ MBS online, Item 104: professional attendances,

http://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=104&qt=item

⁶⁹ Formula: (Benefits+(Services×(1-Bulk billed rate/100)×Out of pocket cost). Sources: Annual Medicare Statistics 2018 http://www.health.gov.au/internet/main/publishing.nsf/Content/Annual-Medicare-Statistics; AIHW Patients' out-of-pocket spending on Medicare services, 2016–17

 ⁷² Stubberfield, T. G., Wray, J. A., & Parry, T. S. (1999). Utilization of alternative therapies in attention-deficit hyperactivity disorder. *Journal of paediatrics and child health*, 35(5), 450-453.
 ⁷³ Ibid.

in the USA found that 20% had used cognitive behavioural therapy.⁷⁴ Similarly, a study of preschoolers with ADHD in the USA found they are much more likely to use occupational therapy, physical therapy, speech therapy, and special education than those without. It would be expected this cohort would have high non-pharmacological treatment utilisation given medication is not the recommended first line treatment for that age group.⁷⁵ These results are consistent with the European studies that indicate children and adolescents with ADHD are more likely to use behavioural therapies than a control cohort.⁷⁶ However, these studies do not report on the average health service utilisation for these treatments and it is unclear whether the results are transferable to the Australian healthcare setting.

There are a small number of Australian based studies that estimate the proportion of children and adolescents with ADHD using allied health and complementary and alternative medicine therapies. Taken together, these studies indicate at least one third of children and adolescents with ADHD in Australia use a form of allied health or complementary and alternative medicine therapy.⁷⁷ No studies were identified in Australian settings that explore the service utilisation of these therapies. In Australia, the Royal Australian College of GPs and National Health and Medical Research Council (NHMRC) guidelines recommend allied health and behavioural therapies as part of the treatment of ADHD. However, the guidelines do not specify a recommended number of sessions, instead leaving it up to the treating clinician to recommend based on the characteristics of each case.

The AIHW⁷⁸ provides the only recent estimate of allied health costs due to ADHD in Australia, finding that the allied health costs were \$12.8 million in 2015-16. The AIHW used data collected from the Bettering the Evaluation and Care of Health program, better known as BEACH, to estimate this cost component. To do this, the AIHW allocates costs for GP-referred health services (including allied health) based on the recorded diagnosis. Costs due to ADHD may be understated using this approach as the underlying data require GPs to record ADHD as the diagnosis (that is, GPs must identify and diagnose ADHD during each encounter). As GPs are not the primary treatment provider for ADHD in Australia, ADHD would not be routinely considered during consultations, which can lead to lower costs due to under-diagnosis.

As there are no bottom up sources, and due to the uncertainty over the average service utilisation of allied health and complementary and alternative therapies used by people with ADHD in Australia, this has been excluded from the heath system cost estimates. However, as indicated from the limited number of studies in an Australian setting, this could constitute approximately one third of ADHD patients. This would also contribute to additional health system costs. Allied health treatments are eligible for a Medicare rebate in Australia, although they may incur an additional out-of-pocket co-payment. Complementary and alternative medicine treatment options

⁷⁷ Concannon, Pe., and Tang, YP. (2005). Management of attention deficit hyperactivity disorder: A parental perspective. *Journal of Paediatric and Child Health*, 41, 625–630. Leggett, C., and Hotham, E. (2011). Treatment experiences of children and adolescents with attention-deficit/hyperactivity disorder. *Journal of Paediatric and Child Health*, 47, 512–517. Sinha, D., and Efron, D. (2005). Complementary and alternative medicine use in children with attention deficit hyperactivity disorder. *Journal of Paediatric and Child Health*, 41, 23–26. Stubberfield, T. G., Wray, J. A., & Parry, T. S. (1999). Utilization of alternative therapies in attention-deficit hyperactivity disorder. *Journal of Paediatric and Child Health*, 41, 23–26.

 ⁷⁴ Danielson, M. L., Visser, S. N., Chronis-Tuscano, A., & DuPaul, G. J. (2018). A national description of treatment among United States children and adolescents with attention-deficit/hyperactivity disorder. *The Journal of pediatrics*, 192, 240-246.
 ⁷⁵ Marks, D. J., Mlodnicka, A., Bernstein, M., Chacko, A., Rose, S., & Halperin, J. M. (2008). Profiles of service

⁷⁵ Marks, D. J., Mlodnicka, A., Bernstein, M., Chacko, A., Rose, S., & Halperin, J. M. (2008). Profiles of service utilization and the resultant economic impact in preschoolers with attention deficit/hyperactivity disorder. *Journal of pediatric psychology*, 34(6), 681-689.

⁷⁶ De Ridder, A., and De Graeve, D. (2006). Healthcare Use, Social Burden and Costs of Children With and Without ADHD in Flanders, Belgium. *Clinical Drug Investigation*. Volume 26, Issue 2, pp 75–90. Kohlboeck, G., Romanos, M., Teuner, C. M., Holle, R., Tiesler, C. M., Hoffmann, B., ... & Bauer, C. P. (2014). Healthcare use and costs associated with children's behavior problems. European child & adolescent psychiatry, 23(8), 701-714.

⁷⁸ Australian Institute of Health and Welfare (AIHW). (2019). Disease expenditure in Australia, retrieved from https://www.aihw.gov.au/reports/health-welfare-expenditure/disease-expenditure-australia/contents/summary, accessed June 2019.

are not covered by Medicare in Australia and would constitute an out-of-pocket cost for people with ADHD and their families.

3.3 **Pharmaceuticals**

A 2018 study of 13 countries across Australia, Asia, North America and Europe found that while prevalence of ADHD medication use among children and adults varies across countries, this has increased over time in all countries and regions.⁷⁹ The core pharmacotherapy options for treatment of ADHD are methylphenidate (e.g. Ritalin 10), methylphenidate extended release (e.g. Concerta and Ritalin LA), dexamphetamine (e.g. Dexamfetamine), atomoxetine (e.g. Strattera), lisdexamfetamine (e.g. Vyvanse) and extended release guanfacine (e.g. Intuniv). These medications are rarely prescribed for other conditions, except narcolepsy which has a prevalence in Australia of approximately 0.05%.⁸⁰ Due to this small prevalence in comparison with the prevalence of ADHD, we have not controlled for this in the pharmaceutical cost estimates. With the exception of dexamphetamine, these medications are prescribed for both adults and children. Standard dosage is one tablet per day with the dosage strength dependent on the age of the patient. An Australian study of children with ADHD found that core ADHD medication costs increase with age.81

A top down approach was used to measure the costs of ADHD pharmacotherapy treatment options using Pharmaceutical Benefits Schedule (PBS) data, which is a measure of total expenditure.⁸² Total pharmaceutical expenditure for ADHD prescriptions is outlined in Table 3.3. Extended release guanfacine (e.g. Intuniv) was listed on the PBS in September 2018 for the treatment of ADHD.⁸³ The first six months of PBS data that is available at the time of reporting indicates approximately 16,000 services for extended release guanfacine.⁸⁴ For this reason, extended release guanfacine has been excluded from the cost calculations.

Drug type	Government expenditure by drug type (\$m)	Patient contribution (\$m)	Total cost (\$m)	Cost per script (\$)
Methylphenidate	25.4	13.8	39.2	50
Dexamphetamine	4.0	6.0	10.0	33
Atomoxetine	6.6	1.0	7.6	131
Lisdexamfetamine	28.1	5.8	33.8	117
Total annual cost	64.1	26.6	90.6	-

Table 3.3 Core ADHD medications costs FY2019

Source: Deloitte Access Economic analysis of PBS Item Reports.85

3.4 Research

Research expenditure is included within health system estimates as, in the absence of ADHD, there would not be a need for any research into the condition. To estimate health research expenditure

⁸⁰ https://www.snoreaustralia.com.au/narcolepsy.php

⁸¹ Sciberras, E., Lucas, N., Efron, D., Gold, L., Hiscock, H., & Nicholson, J. M. (2017). Health Care Costs Associated With Parent-Reported ADHD: A Longitudinal Australian Population-Based Study. Journal of attention disorders, 21(13), 1063-1072.

⁸² PBS Item Reports 2014 to 2018, retrieved from

⁷⁹ Raman, S. R., Man, K. K., Bahmanyar, S., Berard, A., Bilder, S., Boukhris, & Karlstad, Ø. (2018). Trends in attention-deficit hyperactivity disorder medication use: a retrospective observational study using populationbased databases. The Lancet Psychiatry, 5(10), 824-835.

http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp

⁸³ Minister for Health (September 2018). Media release.

http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2018-hunt114.htm ⁸⁴ PBS Item Reports 2018, retrieved from

http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp_accessed 3 April 2019. ⁸⁵ PBS Item Reports 2014 to 2018, retrieved from

http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp_accessed 3 April 2019.

on ADHD in Australia in 2019, this report utilised the NHMRC grants database. The database outlines all NHMRC research grant funding between 2000 and 2015 and provides a description of the projects and key outcomes achieved.⁸⁶

It was estimated that the NHMRC provided a total of \$14.2 million in research funding towards ADHD from 2000 to 2015. This was based on a keyword search, for the terms listed below. Following the keyword search, grant descriptions were reviewed to ensure the funding was for ADHD.

- ADHD
- attention deficit disorder
- attention deficit hyperactivity disorder
- hyperactivity

Expenditure associated with research for ADHD in 2019 dollars (adjusted using the Consumer Price Index) is \$15.7 million. Taking an average across the periods, the equivalent annual funding allocated to ADHD research in 2019 was estimated to be \$820,000.

3.5 Summary of health system costs

The health system costs presented in this report largely relate to government expenditure (hospitals, MBS, PBS and research-related). Overall, the total health system cost of ADHD was estimated to be \$814.5 million in Australia in 2019, which is \$1,000 per Australian with ADHD, although it likely exceeds this amount as it was only possible to estimate health system costs for a subset of all health expenditures due to data limitations. For example, no suitable data on the costs of allied health were identified for inclusion in the report.

The AIHW⁸⁷ recently estimated that ADHD cost the Australian health system approximately \$130 million in 2015-16 using both top down and bottom up approaches to estimate costs:⁸⁸ the AIHW estimated total expenditure across the health system and then allocated this expenditure to health conditions based on service use data. These estimates are substantially lower than those presented here, largely due to methodological differences and challenges in assigning health costs to any one health condition. The AIHW's approach uses a range of techniques and data sources to allocate health expenditure to more than 200 health conditions, including injuries. Where the sum of expenditure on all conditions exceeds total health expenditure, the AIHW scales expenditure down. It is possible for health expenditure due to any one condition to be higher as a result and it largely depends on how conditions are defined and allocated across datasets. For example, it is not likely that injury costs are attributed to ADHD using such an approach as ADHD may not be recorded as a diagnosis and it does not complicate the costs of care in hospital per se.

Furthermore, health system costs in our report have largely been estimated by comparing costs for children and adults with ADHD to matched control groups, after adjusting for confounding factors. These differences in average costs were then multiplied by prevalence to estimate total costs (a bottom up approach, as outlined in section 1.5). Some top down data sources have also been used, such as for estimating pharmaceutical expenditure.⁸⁹ The major advantage of estimating costs bottom up using matched control groups for any particular condition is that costs are associated with individual people, rather than episodes of care. As such, the estimates

https://www.nhmrc.gov.au/grants-funding/research-funding-statistics-and-data.

⁸⁶ National Health and Medical Research Council (NHMRC). (2017). NHMRC Research Funding – Disease/disorders or health condition based data collections. Retrieved from

⁸⁷ Australian Institute of Health and Welfare (AIHW). (2019). Disease expenditure in Australia, retrieved from <u>https://www.aihw.gov.au/reports/health-welfare-expenditure/disease-expenditure-</u>

australia/contents/summary, accessed June 2019. ⁸⁸ As outlined in section 1.5, a top down approach provides the total costs of a program element (e.g. hospital costs) due to a condition. A bottom up approach involves estimating the number of cases incurring each cost item, and multiplying the number of cases by the average cost of each item. A bottom up approach was used to estimate most health system costs of ADHD in this report.

⁸⁹ Pharmaceutical expenditure has been estimated using medications listed for use in treating ADHD. The costs in the AIHW disease expenditure database and this report are reasonably comparable when accounting for the growth in lisdexamfetamine, which was only listed on the PBS during 2015-16.

presented here attribute expenditure for other reasons to the underlying condition. For example, an Australian study has found that children under 4 years of age with ADHD are 73% more likely to be admitted for injury and poisoning (where the injury or poisoning is the principal reason for admission) compared to matched controls.⁹⁰ These costs are attributed to the underlying ADHD in our study, rather than to the consequent injury.

Moreover, GP and specialist costs in our study were also estimated using a bottom up approach where the underlying study estimated incremental service use for people with ADHD compared to matched controls. The AIHW report used data from the Bettering the Evaluation and Care of Health program, better known as BEACH, to estimate these cost components. As outlined in section 3.2.2, costs due to ADHD may be understated using this approach as GPs are not the primary treatment provider for ADHD in Australia. Consequently, ADHD would not be routinely considering during consultations, although again, it may be an underlying reason for the encounter and subsequent costs.

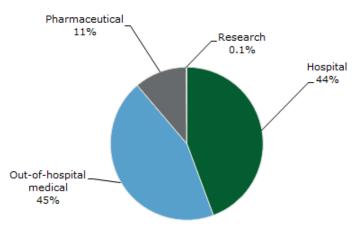
Category	Annual cost (\$m)	Proportion of total cost %	Per person with ADHD (\$)
Hospital	361.1	44.3	443
Out-of-hospital	361.9	44.4	444
Pharmaceuticals	90.7	11.1	111
Research	0.8	0.1	1
Total	814.5	100.0	1,000

Table 3.4 Total health system expenditure 2019

Source: Deloitte Access Economics analysis.

The largest component of health expenditure was hospital and out-of-hospital services which combined were estimated to account for the majority (89%) of health system costs associated with ADHD in Australia in 2019. This was followed by pharmaceuticals (11%) and research (0.1%), as shown in Table 3.4 and Chart 3.1.

Chart 3.1 Health system costs by sector (% of total)



Source: Deloitte Access Economics analysis.

⁹⁰ Silva, D., Colvin, L., Hagemann, E., Stanley, F., & Bower, C. (2014). Children diagnosed with attention deficit disorder and their hospitalisations: population data linkage study. European Child & Adolescent Psychiatry, 23, 1043–1050.

Health system costs in Australia are financed through a split of public funds (federal and state and territory governments) and private funds (out-of-pocket and private health insurance). Funding is administered through a number of different programs and jurisdictions. This includes the Commonwealth's Medicare Benefits Schedule (MBS), which provides full or partial rebates under a fee-for-service model, and the National Health Reform Agreement, which provides activity based funding for free treatment in public hospitals. There is also a substantial component of private funding which includes private health insurance and out-of-pocket costs.

While noting that it wasn't possible to estimate costs related to allied health services, governments bore a considerable proportion (more than 80%) of the estimated health system costs of ADHD. Individuals and their families bore approximately 10% and other payers (e.g. private health insurers) bore the rest of the included costs.

4 Productivity costs

ADHD has a negative impact on the individual's ability to function and to engage in work or schooling. The productivity costs of ADHD are significant in terms of reduced workforce participation, absenteeism and presenteeism.

A human capital approach was adopted to estimate the productivity losses due to ADHD in Australia. The human capital approach involves calculating the difference in employment or production between people with ADHD and that of the general population, multiplied by average weekly earnings (AWE).

The four potential productivity losses due to ADHD include:

- reduced workforce participation, which may occur either through disadvantages in job-seeking (e.g. difficulty in searching for work or keeping a job) or self-selection out of the labour force;
- temporary absenteeism where a worker may take time off work due to their ADHD, while remaining in the workforce;
- presenteeism, or lower productivity at work, where a worker produces less due to lower capacity to work; and
- premature mortality, where a person who dies early due to ADHD would no longer receive future income streams (in discounted net present value terms).

Key findings

- Productivity losses of ADHD associated with absenteeism, presenteeism, reduced workforce participation and premature mortality were estimated to be \$9.98 billion in 2019, or on average \$17,483 for every Australian living with ADHD.
- ADHD may also be associated with long-term reductions in productivity through reduced educational outcomes of children and adolescents with ADHD, although more evidence is needed to robustly estimate these impacts.
- Informal carer costs were estimated to be \$210.4 million, or on average \$748 for every Australian child (0-19 years old) with ADHD.

4.1 Absenteeism

Australians with ADHD may be temporarily absent from paid employment due to their condition, and it is measured as the additional number of days per year that an employee with ADHD takes off work compared to the general population (or another comparator).

A targeted literature review was conducted to estimate the impact of ADHD on workplace absenteeism. Studies were included if they controlled for sociodemographic factors and comorbidities when comparing the outcomes of the ADHD cohort with the general population, although current ADHD status was usually self-reported. Studies were further excluded if they did not use a validated productivity tool. The identified studies are summarised as follows.

 In 2012, a sample of 108 Australian adults aged 18-44 with ADHD lost an additional 16% of work time due to absenteeism associated with their ADHD compared with controls, controlling for socioeconomic and comorbidity variables⁹¹

⁹¹ Able S, Haynes V, Vietri J, Kopenhafer L, Novick D, Upadhyaya H, et al. (2013) ADHD among adults in Europe, Australia, Japan, and the United States: Socio-demographics, comorbidities, health care resource use and work productivity. ADHD Atten Def Hyp Disord. 2013; 5: 236.

- Similar estimates exist for Europe (14.5% difference with 19.4% for ADHD versus 4.9% for controls), the United States (5.5% difference with 8.0% for ADHD versus 2.5% for controls), and Japan (15.8% difference with 17.8% for ADHD versus 2.0% for controls)^{92 93}
- In 2001-2003, a sample of 2,399 American adults aged 18-44 with ADHD lost an additional 13.6 work days per year, controlling for age, sex, race, education and occupation⁹⁴
- In 1999-2001, a sample of 2,252 American adults aged 18-65 with ADHD lost an additional 14 work days per year, controlling for age, gender, region and insurance type⁹⁵
- In 2005-2006, a sample of 173 American adults from one manufacturing firm had a higher probability of missing work due to sickness, and lost an **additional 9.4% of work time** compared to controls (not statistically significant).⁹⁶

The average additional days absent from work for people with ADHD was estimated by calculating a weighted average, based on study sample size, across each of these studies. The percent of work time lost due to absence was converted to an average number of days lost based on the Australian population average number of hours worked per week for average work time.⁹⁷ It was calculated that people with ADHD have **on average an additional 16 days absent from work** each year.

To estimate the costs of absenteeism associated with ADHD the average additional days absent from work was then applied to Australian general population employment rates and AWE by age and gender. Additional costs were also included for management time associated with the absence from work and the overtime premium to maintain work output.⁹⁸ Absenteeism associated with ADHD was estimated to cost \$2.86 billion in 2019, which is \$5,010 per working age Australian living with ADHD.

4.2 Presenteeism

Presenteeism refers to reduced productivity while an employee is at work. Presenteeism is measured as the average number of hours per day that an employee loses to reduced performance or impaired function as the result of their condition. Presenteeism is not as easily measured as absenteeism, but it has the potential to incur significant costs to employers by reducing the quality and efficiency of work produced by employees.

A targeted literature review was conducted to estimate the impact of ADHD on presenteeism. Studies were included if they controlled for sociodemographic factors and comorbidities when comparing the outcomes of the ADHD cohort with the general population, although current ADHD status was usually self-reported. Studies were further excluded if they did not use a validated productivity tool. The identified studies are summarised as follows.

 In 2012, a sample of 108 Australian adults aged 18-44 with ADHD reported 51% of their work time was impaired due to their ADHD compared to 25% in controls, after adjusting for socioeconomic and comorbidity variables⁹⁹

 ⁹² Kirino, E., Imagawa, H., Goto, T. and Montgomery, W., 2015. Sociodemographics, comorbidities, healthcare utilization and work productivity in Japanese patients with adult ADHD. *PloS One*, *10*(7), p.e0132233.
 ⁹³ Able, S.L., Haynes, V. and Hong, J., 2014. Diagnosis, treatment, and burden of illness among adults with attention-deficit/hyperactivity disorder in Europe. *Pragmatic and observational research*, *5*, p.21.
 ⁹⁴ Kessler, R.C., Adler, L., Ames, M., Barkley, R.A., Birnbaum, H., Greenberg, P., Johnston, J.A., Spencer, T. and Üstün, T.B., 2005. The prevalence and effects of adult attention deficit/hyperactivity disorder on work performance in a nationally representative sample of workers. *Journal of Occupational and Environmental*

Medicine, *47*(6), pp.565-572. ⁹⁵ Secnik, K., Swensen, A. and Lage, M.J., 2005. Comorbidities and costs of adult patients diagnosed with attention-deficit hyperactivity disorder. *Pharmacoeconomics*, *23*(1), pp.93-102.

⁹⁶ Kessler, R.C., Lane, M., Stang, P.E. and Van Brunt, D.L., 2009. The prevalence and workplace costs of adult attention deficit hyperactivity disorder in a large manufacturing firm. *Psychological medicine*, *39*(1), pp.137-147.

⁹⁷ Australian Bureau of Statistics, http://www.abs.gov.au/ausstats/abs@.nsf/mf/6202.0. This includes part time and full time employment.

⁹⁸ On average, the costs of manager time and the overtime premium increase the cost of absenteeism by 58% compared to AWE alone.

⁹⁹ Able, S.L., Haynes, V. and Hong, J., 2014. Diagnosis, treatment, and burden of illness among adults with attention-deficit/hyperactivity disorder in Europe. *Pragmatic and observational research*, *5*, p.21.

- In 2001-2003, a sample of 2,399 American adults aged 18-44 with ADHD lost an additional 21.6 work days per year, due to presenteeism, controlling for age, sex, race, education and occupation¹⁰⁰
- A study of Japanese adults with ADHD reported a 40% impairment of worktime for adults with ADHD compared to non-ADHD adults¹⁰¹
- In 2014, a sample of 100 American adults and 326 European adults reported a 15% and 29% reduction in work productivity for individuals with ADHD, compared to those without.¹⁰²

The average reduction in work output for people with ADHD was estimated by calculating a weighted average, based on study sample size, across each of these studies. It was calculated that people with ADHD have **on average 14% reduction in work output each year**, compared with the general population.

To estimate the costs of presenteeism due to ADHD the average additional reduction in productivity while at work was then applied to Australian general population employment rates and AWE by age and gender. Presenteeism associated with ADHD was estimated to cost \$3.90 billion in 2019, which is \$6,825 per working age Australian living with ADHD.

4.3 Reduced workforce participation

ADHD may result in reduced employment either through disadvantages in job-seeking (for example difficulty in searching for work or keeping a job) or self-selection out of the labour force. This can lead to significant productivity losses in the form of lost wages and other costs to the individual, such as reduced social engagement.

A targeted review of relevant literature was conducted to estimate the impact of ADHD on workforce participation. One study in an Australian setting was identified that reported on lifetime probability of employment for people with ADHD.¹⁰³ However for the purposes of estimating the cost of ADHD, the study by Fletcher et al (2014) is most suitable due to the robustness of the methodology (e.g. clinically diagnosed ADHD, results controlled for age, gender, high school test scores, health, education and school/family/occupation fixed effects) and disaggregation of the results.¹⁰⁴ Using a sample of 600 American adults, the study found those who were diagnosed with ADHD in childhood or adolescence were **10% less likely to be employed** than a population comparison group by the time they were 30 years old.

The findings of Fletcher et al (2014) are conservative compared with the results of other studies.

- In a 1999-2013 longitudinal study of 309 American adults with childhood ADHD, 49% were employed at age 25 compared with 68% for a control group¹⁰⁵
- In 2003, a sample of 500 American adults aged 18-64 with self-reported ADHD had an
 employment rate of 34% compared to 59% employment for a matched comparison group¹⁰⁶

¹⁰⁰ Kessler, R.C., Adler, L., Ames, M., Barkley, R.A., Birnbaum, H., Greenberg, P., Johnston, J.A., Spencer, T. and Üstün, T.B., (2005). The prevalence and effects of adult attention deficit/hyperactivity disorder on work performance in a nationally representative sample of workers. *Journal of Occupational and Environmental Medicine*, *47*(6), pp.565-572.

¹⁰¹ Kirino, E., Imagawa, H., Goto, T., & Montgomery, W. (2015). Sociodemographics, comorbidities, healthcare utilization and work productivity in Japanese patients with adult ADHD. *PLoS One*, 10(7), e0132233.

 ¹⁰² Able, S.L., Haynes, V. and Hong, J., 2014. Diagnosis, treatment, and burden of illness among adults with attention-deficit/hyperactivity disorder in Europe. *Pragmatic and observational research*, *5*, p.21.
 ¹⁰³ Ebejer, J. L., Medland, S. E., Van Der Werf, J., Gondro, C., Henders, A. K., Lynskey, M., ... & Duffy, D. L.

^{(2012).} Attention deficit hyperactivity disorder in Australian adults: prevalence, persistence, conduct problems and disadvantage. PLoS One, 7(10), e47404.

¹⁰⁴ Fletcher, J.M., 2014. The effects of childhood ADHD on adult labor market outcomes. *Health economics*, 23(2), pp.159-181.

¹⁰⁵ Altszuler, A.R., Page, T.F., Gnagy, E.M., Coxe, S., Arrieta, A., Molina, B.S. and Pelham, W.E., (2016). Financial dependence of young adults with childhood ADHD. *Journal of abnormal child psychology*, *44*(6), pp.1217-1229.

pp.1217-1229. ¹⁰⁶ Biederman, J. and Faraone, S.V., (2006). The effects of attention-deficit/hyperactivity disorder on employment and household income. *Medscape General Medicine*, 8(3), p.12.

 A 2013 study of 23-32 year old American males diagnosed with clinically diagnosed ADHD in childhood had **an employment rate of 75.2%**, **compared with 88.6%** for the control group. The study controlled for parental education.¹⁰⁷

To estimate the costs of reduced employment due to ADHD the relative reduction in employment was applied to Australian general population employment rates¹⁰⁸ and AWE¹⁰⁹ by age and gender. Reduced employment associated with ADHD was estimated to cost \$3.09 billion in 2019, or \$5,417 per working age Australian with ADHD.

4.4 Long-term reductions in productivity due to educational outcomes

ADHD is associated with lower educational outcomes in childhood and adolescence, compared with educational outcomes in typically developing children. A 2006 study of American and Canadian children aged 4-12 years with symptoms of ADHD found large negative effects on early education outcomes, such as test scores, grade repetition and special education placement. This study used a broad sample of children and estimated sibling fixed effects models to control for unobserved family effects.¹¹⁰

A follow up study extended these findings to a sample of older American children and found that children with ADHD face longer term educational disadvantages, including lower grade point averages, increases in suspension and expulsions, and fewer completed years of schooling. However, nearly all of these results were not robust to the inclusion of family fixed effects, suggesting that short-term consequences of educational outcomes do not lead to longer term educational consequences in a straightforward manner.¹¹¹

There is also evidence from the Australian setting of negative education effects for children with ADHD. The Young Minds Matter study of Australian 4-17 year olds with ADHD found impacts on school functioning. For example, the average number of days off school due to ADHD was 4 days for 4-11 year old and rose to 9 days for 12-17 year olds.¹¹² While these negative education outcomes for people with ADHD may reduce productivity outcomes later in life, there is insufficient evidence to conclusively estimate this impact.

4.5 **Premature mortality**

In addition to the productivity losses associated with reduced employment, absenteeism or presenteeism, productivity losses may occur when a person dies prematurely due to their condition or illness. These productivity losses represent a loss of future income for the individuals, which can be a tax revenue source for government. The productivity loss due to premature mortality is estimated (in net present value terms) by multiplying the number of deaths due to ADHD for each age and gender group (section 2.3) by their expected future earnings.¹¹³

¹⁰⁷ Kuriyan, A. B., Pelham, W. E., Molina, B. S., Waschbusch, D. A., Gnagy, E. M., Sibley, M. H., ... & Kent, K. M. (2013). Young adult educational and vocational outcomes of children diagnosed with ADHD. Journal of abnormal child psychology, 41(1), 27-41.

¹⁰⁸ Australian Bureau of Statistics (ABS). (2018). Labour Force, Australia, Detailed, Quarterly, Aug 2018, 6291.0.55.003.

 ¹⁰⁹ Australian Bureau of Statistics (ABS). (2018). Average Weekly Earnings, Australia, May 2018, 6302.0.
 ¹¹⁰ Currie, J., and Stabile, M. (2006). Child mental health and human capital accumulation: The case of ADHD.
 Journal of Health Economics, 25 1094–1118.

¹¹¹ Fletcher, J., and Wolfe, B. (2007). Child mental health and human capital accumulation: The case of ADHD revisited. *Journal of Health Economics*, 27 (2008) 794–800.

¹¹² Lawrence, D., Johnson, S., Hafekost, J., Boterhoven de Haan, K., Sawyer, M., Ainley, J., & Zubrick, S. R. (2015). The mental health of children and adolescents: report on the second Australian child and adolescent survey of mental health and wellbeing. *Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing*. Department of Health, Canberra.

¹¹³ Expected future earnings for each age and gender group were estimated by assuming that employment rates are stable over time, so that a person who is aged 15 to 19 today will be employed at the same rate as a person who is aged 20 to 24 today in 5 years' time. Similarly, average weekly earnings were estimated in a similar way, assuming no real growth in wages (a conservative approach).

All lifetime earnings were estimated in discounted NPV terms using a discount rate of 2.0% - a wage growth rate which adjusts expected long term nominal bond returns (a proxy for positive time preference) by target inflation and expected productivity growth. In the latest Intergenerational report prepared by the Treasury, long term yields over the next 40 years are expected to return to 6%, while productivity growth and inflation are expected to be 1.5% and 2.5%, respectively.

The forgone income from premature mortality due to ADHD was estimated to be \$132.1 million in 2019. Given that most deaths occur in males, and their higher AWE, most of the forgone income is in males (\$119.7 million).

4.6 Informal carer costs

Carers are people who provide care to others in need of assistance or support. An informal carer provides this service free of charge and does so outside of the formal care sector. An informal carer will typically be a family member or friend of the person receiving care, and usually lives in the same household as the recipient of care. People can receive informal care from more than one person.

While informal carers are not paid for providing this care, informal care is not free in an economic sense. Time spent caring involves forfeiting time that could have been spent on paid work, or undertaking leisure time activities. As such, informal care can be valued as the opportunity cost associated with the loss of economic resources (labour) and the loss in leisure time valued by the carer. To estimate the dollar value of informal care, the opportunity cost method measures the formal sector productivity losses associated with caring, as time devoted to caring responsibilities is time which cannot be spent in the paid workforce.

Working carers of children and adolescents diagnosed with ADHD can incur productivity losses for a variety of reasons, such as the need to attend in-school conferences, pursue or revise special education services, and manage accidents.¹¹⁴ Missing work may impact a parent's job performance and/or lead to altered employment, such as switching from full-time to part-time, or quitting jobs, both of which can negatively impact long-term career trajectories. In this study, almost a third of caregivers reported altering their employment status, which included reduced working hours or resignations, because of their child/adolescent's ADHD.¹¹⁵ The estimates presented here focus largely on missed work time (including lower participation in the workforce), rather than job performance or other carer productivity costs.

To estimate the costs of informal care for Australians with ADHD, it was necessary to estimate the proportion of people with ADHD receiving support from an informal carer, and also the additional hours of care that are provided to Australians with ADHD.

To estimate the proportion of people with ADHD receiving support from an informal carer, we have assumed only children and adolescents who use health services (63% of children aged 6-8 years, which was applied to all children and adolescents due to a lack of evidence) would have received informal care from a caregiver.¹¹⁶ Balancing this, it was assumed that no adults receive support from an informal carer.

The additional hours of care provided by parental carers of children with ADHD was estimated using the average missed hours of work. The review did not identify any studies in an Australian setting that reported the additional hours of care provided by parental carers of children with ADHD in comparison to those without. In a multi-country European study by Flood et al (2016), carers of children and adolescents aged 6-17 with medicated ADHD reported missing an average of 3.8 hours of work every four weeks, attributed to their child's ADHD.¹¹⁷ This estimate may overstate the average number of hours of carers for all children with ADHD, as children with un-

¹¹⁴ Zhao, X., Page, T. F., Altszuler, A. R., Pelham, W. E., Kipp, H., Gnagy, E. M., ... & Macphee, F. L. (2019). Family Burden of Raising a Child with ADHD. *Journal of abnormal child psychology*, 1-12.

¹¹⁵ Flood, E., Gajria, K., Sikirica, V., Dietrich, C.N., Romero, B., Harpin, V., Banaschewski, T., Quintero, J., Erder, M.H., Fridman, M. and Chen, K., 2016. The Caregiver Perspective on Paediatric ADHD (CAPPA) survey: understanding sociodemographic and clinical characteristics, treatment use and impact of ADHD in Europe. *Journal of affective disorders*, *200*, pp.222-234.

¹¹⁶ Efron, D., Moisuc, O., McKenzie, V., & Sciberras, E. (2016). Service use in children aged 6–8 years with attention deficit hyperactivity disorder. *Archives of disease in childhood, 101*(2), 161-165.

¹¹⁷ Flood, E., Gajria, K., Sikirica, V., Dietrich, C.N., Romero, B., Harpin, V., Banaschewski, T., Quintero, J., Erder, M.H., Fridman, M. and Chen, K., 2016. The Caregiver Perspective on Paediatric ADHD (CAPPA) survey: understanding sociodemographic and clinical characteristics, treatment use and impact of ADHD in Europe. *Journal of affective disorders*, *200*, pp.222-234.

medicated ADHD, which may be less severe and require less informal care, are excluded. However, the majority of children with ADHD are medicated (78% in this study).

Overall, informal carer costs were estimated to be \$210.4 million in Australia in 2019.

The findings of the Flood et al (2016) study are consistent with the findings of Zhao et al (2018) that parents of children with ADHD have a greater occupational and socio-emotional burden. While the focus in this report was on the carer time, due to a lack of robust evidence to quantify the change in roles in Australia, a recent longitudinal study has found the burden on families can be substantial.¹¹⁸ The study was conducted in American adolescents aged 14 to 17 years with clinically diagnosed ADHD, and it examined the family burden associated with a range of challenges including costs such as purchasing medications or missing time at work, and less tangible costs such as marital tension or wellbeing impacts. For parents of children with ADHD 20% changed job responsibilities (compared with 3% in the control group), 11% quit a job or got fired (compared with 0% in the control group) and 27% needed additional childcare (compared with 10% in the control group).¹¹⁹ Income loss due to missing work was also greater for the ADHD carers group compared to the control group. Other indirect costs to families may include costs of childcare, academic support, and legal services.

4.7 Summary of productivity losses

Overall, the total productivity cost of ADHD was estimated to be \$10.19 billion in 2019, or \$12,509 per Australian with ADHD, or \$17,851 per working age Australian with ADHD.

Cost component	Total cost (\$bn)	Cost per person (\$)
Absenteeism	2.86	3,511
Presenteeism	3.90	4,782
Reduced workforce participation	3.09	3,796
Premature mortality (including search, hiring and training costs)	0.13	162
Informal care	0.21	258
Total	10.19	12,509

Table 4.1 Productivity costs due to ADHD in Australia in 2019

Source: Deloitte Access Economics analysis.

Presenteeism accounts for 38% of productivity costs associated with ADHD in 2019. Presenteeism was followed by reduced workforce participation (31%), absenteeism (28%) and premature mortality (1%) as shown in Chart 4.1. In addition, informal carer costs were estimated to be \$210.4 million, or on average \$748 for every Australian child or adolescent (0-19 years old) with ADHD.

Individual and company taxation rates were used to estimate the share of productivity costs that are borne by individuals and their families (caregivers), governments and employers. The respective tax rates used in the calculation of deadweight losses were:

- 23.4% average personal income tax rate, and 12.6% average indirect tax rate; and
- 22.9% average company tax rate.

The forgone taxation revenue is estimated in section 5.3.1: employers bore 49% of total productivity costs, which was followed by government (27%), through lost taxation revenue, and

¹¹⁸ Zhao, X., Page, T. F., Altszuler, A. R., Pelham, W. E., Kipp, H., Gnagy, E. M., ... & Macphee, F. L. (2019). Family Burden of Raising a Child with ADHD. *Journal of abnormal child psychology*, 1-12. ¹¹⁹ Ibid.

individuals or their families (24%) as shown in Chart 4.1. Families bore 66% of the costs of informal care, followed by government (34%) in the form of lost taxes.

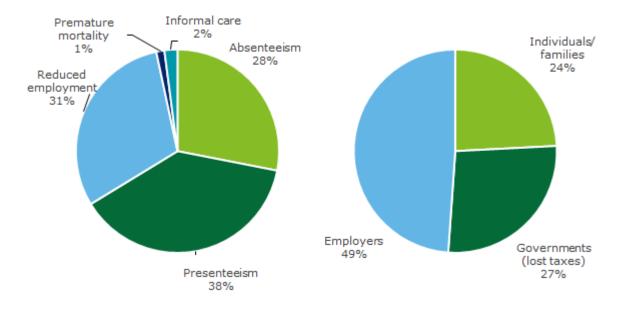


Chart 4.1 Productivity costs by component (LHS) and payer (RHS)

Source: Deloitte Access Economics analysis.

5 Other financial costs

Many services, and subsequently costs, occur through services provided for a broad range of conditions, and are not specifically provided to those with ADHD. In certain instances these services are being accessed more frequently by people with ADHD (such as children accessing educational support and adjustment services), or people with ADHD being overrepresented in the use of other government services (such as interactions with the justice system). Other financial costs include the deadweight losses resulting from higher taxes and government spending to support the provision of government services.

There are several international studies that have attempted to quantify the non-medical costs of ADHD, using various methodologies and focusing on different economic aspects (such as the burden on families, or the resultant economic impact of ADHD on the individual). For this study, a conservative approach has been taken to estimating other financial costs due to the limited availability of Australian evidence. Where the literature is of sufficient quality and relevance, data were presented from both Australian and international studies.

Key findings

- Total other costs; comprising of educational, crime and justice, reduced taxation revenue and deadweight losses of taxation payments are estimated to be \$1.82 billion.
- Educational costs comprise of over 37,000 supplementary adjustments costing an estimated \$106 million.
- Costs of crime and to the justice system of jurisdictions are estimated to be \$307 million.
- The deadweight loss from all government expenditure of services and programs for people with ADHD is estimated to be \$1.41 billion.

5.1 Education costs

Schools, as they currently operate, can be distracting environments – not necessarily catering to the unique functional needs of each student with ADHD. Within these environments, students can become bored, hyperactive, and angry and may become disruptive. Schools should – and do, in light of recent policy changes – seek to modify teaching and learning environments to better cater for individual student needs, which can increase education related costs.

Nevertheless, children diagnosed with ADHD do not always succeed in existing school environments and may experience learning difficulties.¹²⁰ There is international evidence suggesting that children with ADHD are more likely to display disruptive behaviour in the

¹²⁰ Frazier, T. W., Youngstrom, E. A., Glutting, J. J., & Watkins, M. W. (2007). ADHD and achievement: Metaanalysis of the child, adolescent, and adult literatures and a concomitant study with college students. *Journal of learning disabilities*, 40(1), 49-65.

classroom,¹²¹ leading to suspension, expulsion, disciplinary action or reduced or delayed educational completion rates.^{122,123,124,125,126}

These impacts can have short-term costs on the educational system such as the cost borne from disruption to class, and longer-term costs including impacts on the individuals' occupational status, further educational attainment, and income.^{127,128} However due to a lack of robust Australian literature and official statistics, some of these impacts on education could not be costed.

Where the impacts of ADHD are identified, classroom supports and adjustments may be provided to children with ADHD through general programs and funding for schools, or as supplementary funding for children with various learning difficulties or disability.

Due to the varying levels or service provision within schools, data on the use and cost of these services within Australia is limited. It has, however, been found that students with ADHD are accessing educational, behavioural and other services within schools more frequently than students without ADHD,¹²⁹ which can lead to higher costs.¹³⁰

Internationally, there is also evidence of the increased use of school-based educational support services for people with ADHD. While the education systems are often very different, the evidence supports the need for supplementary supports for children with ADHD. In one US based study, more than half of students accessed educational support services, including individualised learning plans, case management, and vocational support.¹³¹ Another US based study found the annual incremental cost to the US educational system per student with ADHD was \$5,007, compared with \$318 for a student from the comparison group (no ADHD) in 2011 US dollars. The cost estimate was based on (1) ADHD children who are eligible for special education services under specific US based programs, (2) students with ADHD who repeated a grade, and (3) the cost of disciplinary acts committed by ADHD students.¹³²

Only one Australian study was identified that assessed service use for children with ADHD in Australian schools. This longitudinal study of school-aged children with ADHD was based in Victorian schools (59% government, 20% catholic, 15% independent), and therefore does not account for differences in educational and funding models across jurisdictions. Overall, the study reported that 60% of participants with ADHD access school-based support services. These services for students included social support (36%), Individualised Educational Plans (IEPs; 22%), Student

¹²¹ These are not wholly educational costs per se but disruption can affect other students.

¹²² Breslau, J., Miller, E., Chung, W. J. J., & Schweitzer, J. B. (2011). Childhood and adolescent onset psychiatric disorders, substance use, and failure to graduate high school on time. *Journal of psychiatric research*, 45(3), 295-301.

¹²³ Fletcher, J., & Wolfe, B. (2008). Child mental health and human capital accumulation: the case of ADHD revisited. *Journal of health economics*, 27(3), 794-800.

¹²⁴ LeFever, G. B., Villers, M. S., Morrow, A. L., & Vaughn III, E. S. (2002). Parental perceptions of adverse educational outcomes among children diagnosed and treated for ADHD: A call for improved school/provider collaboration. Psychology in the Schools, 39(1), 63-71.

¹²⁵ Biederman, J., Monuteaux, M. C., Doyle, A. E., Seidman, L. J., Wilens, T. E., Ferrero, F., ... & Faraone, S. V. (2004). Impact of executive function deficits and attention-deficit/hyperactivity disorder (ADHD) on academic outcomes in children. *Journal of consulting and clinical psychology*, 72(5), 757.

¹²⁶ Fried, R., Petty, C., Faraone, S. V., Hyder, L. L., Day, H., & Biederman, J. (2016). Is ADHD a risk factor for high school dropout? A controlled study. *Journal of attention disorders*, 20(5), 383-389.

¹²⁷ Barkley, R. A., Murphy, K. R., & Fischer, M. (2010). *ADHD in adults: What the science says*. Guilford Press. ¹²⁸ Barkley, R. A., Fischer, M., Smallish, L., & Fletcher, K. (2006). Young adult outcome of hyperactive children: adaptive functioning in major life activities. *Journal of the American Academy of Child & Adolescent Psychiatry*, 45(2), 192-202.

¹²⁹ Capriotti, M. R., & Pfiffner, L. J. (2017). Patterns and predictors of service utilization among youth with ADHD-predominantly inattentive presentation. *Journal of attention disorders*, 1087054716677817.

¹³⁰ Marks, D. J., Mlodnicka, A., Bernstein, M., Chacko, A., Rose, S., & Halperin, J. M. (2008). Profiles of service utilization and the resultant economic impact in preschoolers with attention deficit/hyperactivity

disorder. Journal of pediatric psychology, 34(6), 681-689.

¹³¹ Murray, D. W., Molina, B. S., Glew, K., Houck, P., Greiner, A., Fong, D., ... & Abikoff, H. B. (2014). Prevalence and characteristics of school services for high school students with attention-deficit/hyperactivity disorder. *School mental health*, 6(4), 264-278.

¹³² Robb, J. A., Sibley, M. H., Pelham, W. E., Foster, E. M., Molina, B. S., Gnagy, E. M., & Kuriyan, A. B. (2011). The estimated annual cost of ADHD to the US education system. *School mental health*, 3(3), 169-177.

Support Groups (SSGs; 18%), counselling (17%), mentoring (15%), and homework support (9%).¹³³

As discussed above, services and adjustments provided within Australian schools to students with ADHD vary. The Nationally Consistent Collection of Data on School Students with Disability (NCCD) provides an outline of various adjustments that may be provided to enable a student with disability to access and participate in education on the same basis as other students. The NCCD notes that not all adjustments are included in the NCCD and that educational adjustments made solely for reasons other than disability, for example disadvantage (due to disrupted schooling and/or poverty), and are not included in the NCCD.

The four levels of adjustments and loading for various disability as defined by the Department of Education and NCCD are: 134,135

- Support provided within quality differentiated teaching practice: These adjustments are provided through usual school processes, without drawing on additional resources, and by meeting proficient-level Teaching Standards (AITSL) – no additional funding.
- **Supplementary adjustments**: These adjustments are supplementary to the strategies and resources already available for all students within the school \$4,764 per student per annum.
- **Substantial adjustments**: These adjustments are for more substantial support needs and are provided with considerable adult assistance \$16,561 per student per annum.
- **Extensive adjustments**: These adjustments are for high support needs, provided with extensive targeted measures and sustained levels of intensive support. The adjustments are highly individualised, comprehensive and ongoing \$35,390 per student per annum.

Most students with ADHD who are in need of adjustments are likely to be captured under support provided within *quality differentiated teaching practice* – that is, through ordinary schooling processes and resources. There is, however, a small proportion who have additional behavioural and learning development needs, and would likely qualify for additional resourcing.

Typical examples of adjustments that are likely to occur through *supplementary adjustment* funding, which includes modifying or tailoring learning programs; modifying instruction using a structured task-analysis approach; separate supervision or extra time to complete assessment tasks; providing course materials in accessible forms; programs or interventions to address the student's social/emotional needs; and specialised technology.

The number of students with ADHD who qualify for additional resourcing was based on the number of students who access IEPs and SSGs (22% and 18% respectively).¹³⁶ The midpoint (20%) was used for the purposes of modelling, which was applied to prevalence in school aged children to estimate the number of students who would qualify for, and access additional supports in school due to ADHD. This equated to 37,500 students across Australia in 2019.¹³⁷

¹³³ Zendarski, N., Sciberras, E., Mensah, F., & Hiscock, H. (2018). Factors Associated With Educational Support in Young Adolescents With ADHD. *Journal of attention disorders*, 1087054718804351.

¹³⁴ Department of Education and Training. (n.d.). What is the Government doing to support students with disability?, *Department of Education and Training, Australian Government*. Retrieved from https://www.education.gov.au/what-government-doing-support-students-disability

¹³⁵ Disability loading by NCCD level of adjustment is based on 2019 primary school student loading.

¹³⁶ Zendarski, N., Sciberras, E., Mensah, F., & Hiscock, H. (2018). Factors Associated With Educational Support in Young Adolescents With ADHD. *Journal of attention disorders*, 1087054718804351.

¹³⁷ This estimate is supported by the 2015 Young Minds Matter Survey which found that ADHD had a severe impact on schooling in 13% of students and a moderate impact in a further 31% of students. Given the survey is a self-reported measure, it is possible that not all students with a moderate impact would be eligible for, or require, additional supports.

Lawrence D., Johnson S., Hafekost J., Boterhoven De Haan K., Sawyer M., Ainley J., Zubrick S. R. (2015). The Mental Health of Children and Adolescents. *Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing*. Department of Health, Canberra.

It was assumed that most students with ADHD who require extra support would only need a low level adjustment, such as the supplementary adjustment. Schools receive an additional \$4,764 per annum for each student who is eligible for supplementary adjustments.¹³⁸

As children with ADHD often have comorbid conditions, it is reasonable to assume that not all of their support needs are due to ADHD alone. To account for comorbid conditions, the average funding was divided by the average number of comorbid conditions, in the absence of better data (i.e. assuming that each condition contributes equally to the need for additional supports). Around 33% of children with ADHD have one comorbid disorder, 15% have two, 18% have three and the remaining 33% are estimated to have only ADHD.¹³⁹ Using these data, it was assumed that the cost of providing supplementary adjustments to students with ADHD was approximately \$2,827 per annum due to their ADHD alone.

The total cost of educational support was therefore estimated to be 106 million in 2019 (=37,500 * \$2,827).

5.2 Cost of crime and justice system

People with ADHD are more vulnerable to engage in antisocial and criminal behaviour, likely due to their impulsive actions and behaviours, disengagement from education and comorbidities that develop in adolescence such as conduct disorder and substance use disorders.¹⁴⁰ This section estimates the cost of ADHD to the Australian criminal justice system.

Australian and international research suggests that a disproportionately high number of individuals with ADHD are involved in criminal activity and within the criminal justice system: internationally the prevalence of ADHD in incarcerated populations has been estimated at 25.5%, although there are significant differences across countries.¹⁴¹ An Australian study conducted in NSW found that 17% of inmates screened positive for a full ADHD diagnosis (DSM-IV), which is considerably higher than the prevalence in the general population.¹⁴²

Not only are people with ADHD overrepresented in prisons both domestically and internationally, there is evidence to suggest that the cost of incarceration for people with ADHD is significantly higher than those without ADHD. One UK based study estimated that the annual incremental cost of inmates with ADHD was £590 more than inmates without ADHD.¹⁴³ This cost comprises both medical treatment costs within the correctional facility, and behavioural related prison costs.¹⁴⁴

¹³⁸ Department of Education and Training. (n.d.). What is the Government doing to support students with disability?, *Department of Education and Training, Australian Government*. Retrieved from https://www.education.gov.au/what-government-doing-support-students-disability

¹³⁹ Larson, K., Russ, S. A., Kahn, R. S., & Halfon, N. (2011). Patterns of comorbidity, functioning, and service use for US children with ADHD, 2007. Pediatrics, 127;462.

¹⁴⁰ Erskine, H. E., Norman, R. E., Ferrari, A. J., Chan, G. C., Copeland, W. E., Whiteford, H. A., & Scott, J. G. (2016). Long-term outcomes of attention-deficit/hyperactivity disorder and conduct disorder: a systematic review and meta-analysis. Journal of the American Academy of Child & Adolescent Psychiatry, 55(10), 841-850.

 ¹⁴¹ Young, S., Moss, D., Sedgwick, O., Fridman, M., & Hodgkins, P. (2015). A meta-analysis of the prevalence of attention deficit hyperactivity disorder in incarcerated populations. *Psychological medicine*, *45*(2), 247-258.
 ¹⁴² Moore, E., Sunjic, S., Kaye, S., Archer, V., & Indig, D. (2016). Adult ADHD among NSW prisoners: prevalence and psychiatric comorbidity. *Journal of attention disorders*, 20(11), 958-967.

prevalence and psychiatric comorbidity. *Journal of attention disorders*, 20(11), 958-967. ¹⁴³ Young, S., González, R. A., Fridman, M., Hodgkins, P., Kim, K., & Gudjonsson, G. H. (2018). The economic consequences of attention-deficit hyperactivity disorder in the Scottish prison system. *BMC psychiatry*, 18(1), 210.

¹⁴⁴ Responsibility for inmate medical costs within Australian prisons lie with the state or territory in which the inmate is incarcerated. The health services may be delivered by government (through the respective departments of health and/or corrective services), purchased through contractual arrangements or provided by a combination of the two. The cost of providing these services is not met through Medicare because of the operation of section 19(2) of the Health Insurance Act 1973 (Commonwealth). It is likely that extra costs (both medical and operational) for Australian inmates with ADHD occur, as established in the UK study by Young (2018). However medical and behavioural related costs were not included due to a lack of Australian based data to verify the findings within the UK study.

A population attributable fraction (PAF) approach was used to estimate the additional crime and justice system related costs due to ADHD in Australia.¹⁴⁵ PAFs refer to the proportion of one outcome (e.g. the number of crimes) that can be attributed to a particular condition (ADHD). ABS data on the prevalence rate of offences and convictions in Australia in 2018 was used as an input to estimate the PAFs.¹⁴⁶

Erskine et al (2016) estimated the increased odds of people with ADHD engaging in a variety of criminal activities. Odds ratios were estimated for violence-related arrests (3.36, 95% CI 2.31-5.70), convictions (2.01, 95% CI 1.25-3.24), criminal acts (1.81, 95% CI 0.94-3.50), drug related arrests (1.69, 95% CI 0.75-3.77), arrests (2.43, 95% CI 1.62-3.65) and incarceration (2.53, 95% CI 1.38-4.63).¹⁴⁷ Each of these odds ratios show that people with ADHD are more likely to commit a particular crime, be involved in a criminal act, be arrested and/or convicted or incarcerated than people without ADHD.¹⁴⁸

The individual inputs and resulting PAF for criminal acts, and sentencing (either sentencing to a correctional facility or community service order) are shown in Table 5.1. It was estimated that 1.49% of total criminal acts could be attributed to ADHD. Similarly, 0.18% and 0.07% of sentences to a correctional facility or community service order could be attributed to ADHD in Australia. This represents an extra 8,500 criminal acts and an extra 1,400 imprisonments or community service orders due to ADHD in 2019.¹⁴⁹

(1) q1.s1+q2.s2 = p1

(2)
$$q1/(1-q1)/(q2/(1-q2)) = OR$$

where:

- q1 is the probability of having the outcome (e.g. sentencing) given that an individual has ADHD, while q2 is the probability of the same outcome given that an individual does not have ADHD and p1 is the probability of the outcome in the general population.
- s1 is the proportion of the population with ADHD, while s2 is the proportion of the population without ADHD.

¹⁴⁶ Australian Bureau of Statistics, 2019, Recorded Crime – Offenders, 2017-18, cat. no. 4519.0, viewed 20 March 2019, https://www.abs.gov.au/ausstats/abs@.nsf/mf/4519.02017-18

¹⁴⁵ PAFs were calculated using the following method based on Eide and Heuch (2001). Equations 1 and 2 were solved simultaneously to obtain estimates for q1 and q2. The PAF is then estimated using equation 3.

Eide G., Heuch I. (2001). Attributable fractions: fundamental concepts and their visualization. *Statistical methods in Medical Research*, *10*:159-193.

¹⁴⁷ Erskine, H. E., Norman, R. E., Ferrari, A. J., Chan, G. C., Copeland, W. E., Whiteford, H. A., & Scott, J. G. (2016). Long-term outcomes of attention-deficit/hyperactivity disorder and conduct disorder: a systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 55(10), 841-850.

¹⁴⁸ The odds ratio provided by Erskine et al (2016) does not specify the type of crime that has been committed, and the estimates presented here may be confounded by differing methodologies in the underlying studies (e.g. a different definition of criminal activity may have been used across studies). Therefore, applying this odds ratio to the Australian rate of offences may be subject to some bias. Given that Australian evidence supports a higher prevalence of ADHD in prison populations, these odds ratios have been accepted and used in this study.

¹⁴⁹ Calculations exclude those under the age of 14 years or over the age of 65 years.

Table 5.1 Criminal and justice system outcomes and ADHD, 2019

Outcome	Population wide prevalence (%)	Odds ratio (95% CI)	PAF (%)	Total cases	Cases attributed to ADHD
Criminal act (all)	1.95	1.81 (0.94-3.50)	1.49	487,101	8,492
Sentencing to correctional facility	0.18	2.01 (1.25-3.24)	0.18	45,181	1,006
Sentencing to community service order	0.08	2.01 (1.25-3.24)	0.07	18,836	420

Source: ABS (2019), Erskine (2016) and Deloitte Access Economics calculations.

To determine the average cost of a criminal act, and the average cost of convictions; estimates have been sourced from the Australian Institute of Criminology (AIC). Inflated to 2019 Australian dollars, the estimated cost per criminal act (excluding the cost of community service orders and correctional facilities) was estimated to be \$24,000.¹⁵⁰ This cost includes the average costs of policing, prosecution, courts, legal aid and other jurisdictional costs, although it does not include intangible costs such as lost output and productivity due to the crime. The AIC was also used to estimate the net cost of community service orders, and a year of imprisonment, at \$6,500 and \$61,000 respectively. These costs include productivity losses and reduced taxation income, as well as the cost of the correctional system.¹⁵¹

The total cost of crime due to ADHD, including the cost to the justice system, was estimated to be \$307 million in 2019.

5.3 Deadweight losses

Transfer payments represent a shift of resources from one economic entity to another, such as raising taxes from the entire population to provide welfare payments to Australians with ADHD. Transfer costs are important when adopting a whole-of-government approach to policy formulation and budgeting. Publically funding costs means the government must effectively increase tax revenue to achieve a budget neutral position. Alternatively, if all ADHD could be avoided, the government would not need to raise as much tax revenue.

The act of taxation creates distortions and inefficiencies in the economy, so transfers also involve real net costs to the economy, known as deadweight losses. Imposing taxes on a market reduces the efficiency of resource allocation within that market because it changes the price of those goods or services being taxed. For example, an increase in income tax rates will increase the relative price of work compared to leisure and therefore create a disincentive to work. Similarly businesses may be discouraged from operating in Australia if company tax rates were too high.

Accordingly, although taxation transfers are not real costs of themselves they have been estimated, along with public funding of health care to calculate the cost associated with a loss in allocative efficiency. The following sections outline the reduced taxation revenue available to government and deadweight losses associated with taxation required to fund public systems (e.g. health, justice and education).

5.3.1 Taxation revenue

Reduced earnings from lower employment participation and lower output result in reduced taxation revenue collected by the Australian Government. As well as forgone income taxation, there would also be a fall in indirect (consumption) taxes, as those with lower incomes spend less on the consumption of goods and services. Lost taxation revenue was estimated by applying an average personal income tax rate and average indirect taxation rate to lost earnings.

¹⁵⁰ Smith, R., Jorna, P., Sweeney, J. and Fuller, G. (2015). Counting the costs of crime in Australia. Canberra: *Australian Institute of Criminology*.

¹⁵¹ Morgan, A. (2018). How much does prison really cost? Comparing the costs of imprisonment with community corrections. Research Report, (5), COV-COV.

The average rates of taxation were derived by dividing net income tax and net indirect tax by the taxable income. This method was also used to derive the average company tax rate, which was then applied to lost company earnings (through reduced output). Again, net tax for companies was divided by the total taxable income for companies. The respective tax rates used in the calculation of deadweight losses were:

- 23.4% average personal income tax rate, and 12.6% average indirect tax rate; and
- 22.9% average company tax rate.

Applying these tax rates to the total productivity impacts (including informal care costs), the total lost individual income was estimated to be \$1.27 billion (including lost carer taxes), while the total lost company revenue was estimated to be \$1.48 billion in 2019.

5.3.2 Deadweight loss of taxation payments and administration

Societal inefficiencies, known as deadweight losses, increase when taxes are raised above the level that they would otherwise have been in the absence of ADHD. Thus, the inclusion of deadweight losses in this analysis implicitly assumes that governments maintain a budget neutral position despite the decreased tax revenue and increased government spending due to ADHD. This requires that governments increase taxes above what they would have been in the absence of ADHD to:

- maintain the same amount of tax revenue despite a smaller pool of taxable income from individuals and taxable profits from businesses (see section 5.3.1); and
- pay for additional government spending in areas such as health care, education, and the justice system as a result of ADHD.

To estimate the deadweight loss due to lost taxation revenue, taxes were assumed to be maintained by taxing individuals and companies more as necessary (to replace the lost tax, and to raise funds to cover the additional spending). Each tax in the economy imposes various burdens on the efficiency of society. Previous analyses have reported the marginal burden of various government taxes.¹⁵² ¹⁵³ These are:

- income tax: \$0.26 for every \$1 raised;
- company tax: \$0.51 for every \$1 raised;
- goods and services tax: \$0.19 for every \$1 raised; and
- state taxes impose a range of marginal burdens from taxes on gambling, insurance, motor vehicles, and payroll, and stamp duties.

The analysis assumes that additional tax revenue to maintain a budget neutral position is raised in the same proportions from the sources of tax from which it is currently being raised. Thus, weighted by the source of tax revenue:

- reduced income for individuals results in a 25% efficiency loss
- reduced income for employers results in a 51% efficiency loss
- welfare payments, health and other Commonwealth Government expenditure results in a 30% efficiency loss
- state and territory government expenditure results in a 48% efficiency loss.

Table 5.1 shows the estimated reduced income and health expenditure payments, the applied efficiency loss of raising taxation, and the resulting deadweight losses due to ADHD in 2019. All rates of efficiency loss include a 0.8% administrative loss which covers expenses of administering taxation.¹⁵⁴ The total deadweight losses due to ADHD were estimated to be \$1.41 billion in 2019.

¹⁵² Cao L., Hosking A., Kouparitsas M., Mullaly D., Rimmer X., Shi Q., Stark W., Wende S. (2015). Understanding the economy-wide efficiency and incidence of major Australian taxes', The Australian Government the Treasury, Canberra.

¹⁵³ KPMG Econtech. (2010). CGE analysis of the current Australian tax system. Report for the Australian Government the Treasury, March, Canberra.

¹⁵⁴ Australian Taxation Office (ATO). 2016. Annual report 2015-16, Canberra, October.

Table 5.1 Deadweight losses due to ADHD in 2019

Cost component	Total cost (\$m)	Rate of efficiency loss (%)	Resulting deadweight loss (\$m)
Lost consumer taxes	1,197.9	25	294.7
Lost company taxes	1,475.3	51	748.0
Lost carer taxes	71.5	25	17.6
Commonwealth health expenditure	517.0	30	154.6
State and territory health expenditure	147.8	48	71.0
Other government expenditure	413.4	30	123.6
Total	3,822.9	-	1,409.5

Source: Deloitte Access Economics analysis.

5.4 Summary of other financial costs

Overall, the total cost of ADHD outside the health system and productivity-related costs was estimated to be \$1.82 billion in 2019, or \$2,238 per Australian with ADHD. These costs are considered conservative, as not all aspects of education and crime, nor other costs that may fall onto society, have been considered due to the lack of robust Australian data.

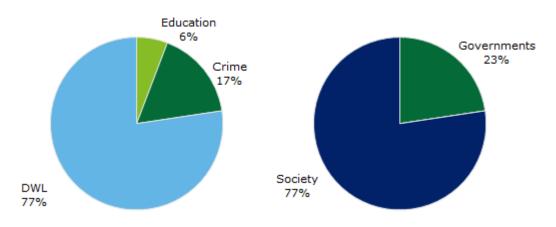
Table 5.2 Other financial costs due to ADHD in 2019

Total	1,822.9	2,238
Deadweight losses	1,409.5	1,730
Crime and justice	307.5	377
Education	106.0	130
Cost component	Total cost (\$m)	Cost per person (\$)

Source: Deloitte Access Economics. Note: components may not sum due to rounding.

Other financial costs due to ADHD make up 14.2% of all financial costs. This is comprised of deadweight losses (77%), education (6%) and justice and crime costs (17%), as shown in Chart 5.1.

Chart 5.1 Other financial costs by component (LHS) and payer (RHS)



Source: Deloitte Access Economics.

6 Burden of disease

There are substantial wellbeing losses due to ADHD. For example, ADHD is among the 15 leading causes of disability in children and adolescents aged 5-19 years. 155

This chapter adopts the burden of disease methodology to quantify the impact of ADHD on wellbeing. The approach is non-financial, where life and health can be measured in terms of DALYs.

Key findings

- ADHD was estimated to cost Australians 40,890 DALYs in 2019.
- The total cost associated with the loss of wellbeing was estimated to be \$7.6 billion by converting DALYs to a dollar value using the VSLY. This is a non-financial cost.

6.1 Valuing life and health

The burden of disease methodology was developed by the World Health Organization and is a comprehensive measure of mortality and disability from conditions for populations around the world. The burden of disease methodology is a non-financial approach, where life and health can be measured in terms of DALYs. DALYs include both years of life lost due to premature death (YLLs) and years of healthy life lost due to disability (YLDs). One DALY equals one year of healthy life lost.

Disability weights are assigned to various health states, where zero represents a year of perfect health and one represents death. Other health states are given a weight between zero and one to reflect the loss of wellbeing due to a particular condition. For example, a disability weight of 0.2 is interpreted as a 20% loss in wellbeing relative to perfect health for the duration of the condition.

The burden of disease as measured in DALYs can be converted into a dollar figure using an estimate of the value of a statistical life (VSL). The VSL is an estimate of the value society places on an anonymous life. The Department of the Prime Minister and Cabinet (2014) provided an estimate of the 'net' VSLY (that is, subtracting financial costs borne by individuals). This estimate was \$182,000 in 2014 dollars, which inflates to around \$197,315 in 2019 dollars for the VSLY using the Consumer Price Index.¹⁵⁶

The methodology the global burden of disease study uses to calculate disability weights may underestimate the burden of ADHD as it estimates burden in terms of health loss and does not take into account impacts beyond the disorder's direct health outcomes. For example, it does not take into account the burden placed on an individual's family or on societal systems such as welfare or criminal justice,¹⁵⁷ which were outlined in previous chapters of this report.

6.2 Estimating burden of disease due to ADHD

As noted, DALYs comprise both YLDs and YLLs. The YLDs associated with ADHD were estimated by applying a representative disability weight to the prevalence of ADHD.

¹⁵⁵ Erskine, H. E., Ferrari, A. J., Polanczyk, G. V., Moffitt, T. E., Murray, C. J., Vos, T., ... & Scott, J. G. (2014). The global burden of conduct disorder and attention-deficit/hyperactivity disorder in 2010. *Journal of Child Psychology and Psychiatry*, 55(4), 328-336.

¹⁵⁶ Department of Prime Minister and Cabinet. (2014). Best Practice Regulation Guidance Note: Value of Statistical Life, Australian Government, Canberra. Retrieved from

https://www.pmc.gov.au/sites/default/files/publications/Value_of_Statistical_Life_guidance_note.pdf. ¹⁵⁷ Erskine, H. E., Ferrari, A. J., Polanczyk, G. V., Moffitt, T. E., Murray, C. J., Vos, T., ... & Scott, J. G. (2014). The global burden of conduct disorder and attention-deficit/hyperactivity disorder in 2010. *Journal of Child Psychology and Psychiatry*, 55(4), 328-336.

To estimate the disability weight, data were collected from the Global Burden of Disease (GBD) study; the disability weights from the GBD are also used by the AIHW in the Australian Burden of Disease study (ABODS). The GBD provides disability weights for ADHD. The disability weight is 0.045 which would be applied across all those in the population with ADHD.

The YLLs are calculated through analysis of the mortality rate of people with ADHD and comparing it to their expected lifespan in the absence of ADHD.¹⁵⁸ YLLs due to ADHD were estimated by multiplying the number of deaths in each age and gender group (section 2.3) by the expected years of life remaining at the age of death. Average life expectancy was obtained from the ABODS.

Overall, it was estimated that there are 36,653 YLDs, and 4,236 YLLs (without discounting) were due to ADHD. Thus, there an estimated 40,890 DALYs due to ADHD in 2019.

Converting the DALYs to a dollar estimate using the VSLY (and discounting future dollars at 3% per annum), the total cost associated with the loss of wellbeing was estimated to be \$7.59 billion in 2019. DALYs were estimated to be higher in males than in females, peaking at 10 to 14 years, largely reflecting the greater prevalence in males, and in children and adolescents.

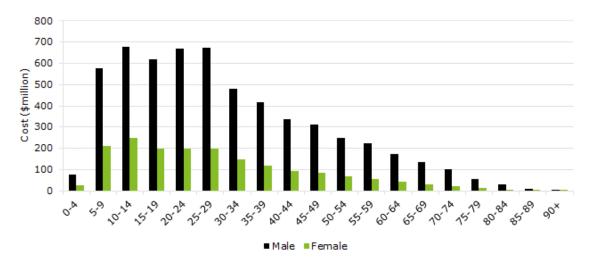


Chart 6.1 Loss of wellbeing associated with ADHD in Australia

Source: Deloitte Access Economics.

¹⁵⁸ Institute for Health Metrics and Evaluation. (2018). Global Burden of Disease. Retrieved from http://www.healthdata.org/gbd.

7 Cost summary

Key findings

- In 2019 an estimated 814,500 Australians were living with ADHD.
- Treating ADHD is costing our health system more than \$814.5 million each year, or \$1,000 per Australian living with ADHD.
- The total financial costs associated with ADHD were estimated to be \$12.83 billion and the total loss of wellbeing \$7.59 billion, which equates to a total cost of \$20.42 billion in 2019.
- This report has identified several gaps in the literature on the economic burden of ADHD in Australia.

7.1 Summary of costs

The burden of ADHD in Australia is considerable and growing. This report found an estimated 814,500 Australians were living with ADHD. Treating ADHD is costing our health system \$814.5 million each year, or \$1,000 per Australian living with ADHD.

Additionally, ADHD costs our society in other ways. Productivity costs make up 79% of total financial costs, which is followed by deadweight losses (11%), health system costs (6%), and other costs including educational and crime and justice costs (3%). Employers were estimated to bear the largest share of financial costs (39%) followed by governments (30%), individuals and their families (20%) and society and other payers (11%).

In addition to the substantial financial costs associated with ADHD, 40,890 DALYs were lost due to ADHD in 2019, which, using the VSLY, is a cost of \$7.6 billion. The total financial costs associated with ADHD were estimated to be \$12.8 billion in 2019, which equates to \$15,747 per person with ADHD. The costs associated with ADHD in Australia in 2019 are summarised by cost component in Table 7.1. The costs by age and gender are summarised in Chart 7.1.

Category	Total cost (\$bn)	Per person (\$)	Proportion of total (%)
Health system	0.81	1,000	4.0
Absenteeism	2.86	3,511	14.0
Presenteeism	3.90	4,782	19.1
Reduced employment	3.09	3,796	15.1
Premature mortality (including search, hiring and training costs)	0.13	162	0.6
Informal care	0.21	258	1.0
Education	0.11	130	0.5
Crime and justice system	0.31	377	1.5
Deadweight loss	1.41	1,730	6.9
Total financial costs	12.83	15,747	62.8
Loss of wellbeing (non-financial)	7.59	9,324	37.2
Total costs	20.42	25,071	100.0

Table 7.1 Total costs associated with ADHD, Australia 2019

Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

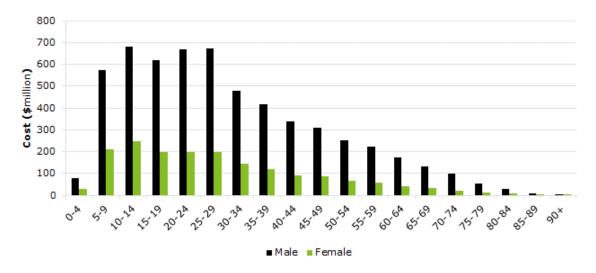


Chart 7.1 Total costs associated with ADHD by age and gender, Australia 2019

Source: Deloitte Access Economics analysis.

7.2 Discussion

This report is the first to quantify the economic burden of ADHD in children and adults in Australia. One important finding of this project is the limited literature in the Australian setting. In particular, this report identified gaps relating to the costs of hospital and out-of-hospital services, and allied health and behavioural therapies for people with ADHD in Australia. A substantial proportion of people with ADHD reportedly use complementary and alternative therapies for the treatment of ADHD and this is also an area with a need for further research into the effectiveness of these treatments.

While no other Australian studies have used cost of illness methods to estimate the cost of ADHD, there are a number of studies in other country settings that have estimated the economic burden of ADHD. While the different health systems are not directly comparable to the Australian setting due to differences in treatment practices and therefore health system utilisation, they do indicate a comparable level of economic burden. For example, Matza et al (2005) estimated the economic burden of ADHD in children and adults in the USA using data from 22 studies. Results of the medical cost studies consistently indicated that children with ADHD had higher annual medical costs than either matched controls (difference ranged from \$503 to \$1,343) or non-matched controls (difference ranged from \$207 to \$1,560) without ADHD (results in 2004 US dollars). Similarly, studies of adults found significantly higher annual medical costs among adults with ADHD (ranging from \$4,929 to \$5,651) than among matched controls (ranging from \$1,473 to \$2,771) (results in 2004 US dollars).¹⁵⁹

A 2017 US study by Gupte-Singh et al estimated the economic burden of ADHD among children and adolescents. The ADHD cohort had an estimated 58.4% higher expenditure than the non-ADHD cohort, with an estimated annual incremental cost of ADHD of \$949.25 (2011 US dollars).¹⁶⁰ Similarly, a 2007 study of US children and adolescents by Pelham et al estimated the economic impact of ADHD including the costs of ADHD treatment-related and other health care costs, education, parental work loss and juvenile justice. The study estimated an annual cost of illness of ADHD in children and adolescents of \$14,576 per person (2005 US dollars).¹⁶¹

¹⁵⁹ Matza, L. S., Paramore, C., & Prasad, M. (2005). A review of the economic burden of ADHD. Cost effectiveness and resource allocation, 3(1), 5.

¹⁶⁰ Gupte-Singh, K., Singh, R. R., & Lawson, K. A. (2017). Economic burden of attention-deficit/hyperactivity disorder among pediatric patients in the United States. *Value in Health*, 20(4), 602-609.

¹⁶¹ Pelham, W. E., Foster, E. M., & Robb, J. A. (2007). The Economic Impact of Attention-Deficit/Hyperactivity Disorder in Children and Adolescents. *Ambulatory Pediatrics*, 7, pp.121–131.

A 2014 economic impact study of ADHD in children and adolescents in Europe by Le et al found the average total ADHD related costs ranged from €9,860 to €14,483 per patient (2012 euros). These costs included healthcare, education, social services, and productivity losses of family members.¹⁶² A 2018 study by Quintero et al estimated the health care and societal costs of ADHD in Spain. The estimated average annual cost of ADHD per child or adolescent was €5,733 (2012 euros). Direct costs accounted for 60.2% of total costs of which 27.2% of total costs was attributed to a psychologist/educational psychologist and 15.5% to pharmacotherapy. Among the included non-medical costs, 65.2% of those costs were due to caregiver expenses.¹⁶³

One recent study by Zhao et al (2019) estimated the cost of raising a child with ADHD, using a longitudinal sample from the US. This study reported that the total economic burden over the course of a child's life to families was five times greater than children without ADHD, at US\$15,036 compared to US\$2,848 for children without ADHD.¹⁶⁴ This extra burden on the family was largely due to parents being more likely to change jobs, and having lower productivity.

In conclusion, ADHD imposes significant economic and wellbeing costs on the Australian population, and it can have lifelong impacts on individuals, including on educational achievement, occupational under attainment, and the increased likelihood of crime and interaction with the criminal justice system. These impacts place significant pressure on Australian society and its institutions.

As such, there is a continued need to raise awareness of the socioeconomic burden of ADHD in Australia and educate and inform key stakeholders including individuals, education systems, workplaces, and society in an attempt to reduce the burden and lifelong impact that ADHD may have. There are likely to be substantial opportunities for targeted policy interventions to help mitigate this costly condition.

¹⁶² Le, H. H., Hodgkins, P., Postma, M. J., Kahle, J., Sikirica, V., Setyawan, J., ... & Doshi, J. A. (2014). Economic impact of childhood/adolescent ADHD in a European setting: the Netherlands as a reference case. *European Child and Adolescent Psychiatry* 23:587–598.

 ¹⁶³ Quintero, J., Ramos-Quiroga, J. A., San Sebastián, J., Montañés, F., Fernández-Jaén, A., Martínez-Raga, J., ... & Eiris, J. (2018). (2018). Health care and societal costs of the management of children and adolescents with attention-deficit/hyperactivity disorder in Spain: a descriptive analysis. *BMC Psychiatry*, 18:40.
 ¹⁶⁴ Zhao, X., Page, T. F., Altszuler, A. R., Pelham, W. E., Kipp, H., Gnagy, E. M., ... & Macphee, F. L. (2019). Family Burden of Raising a Child with ADHD. *Journal of Abnormal Child Psychology*

https://doi.org/10.1007/s10802-019-00518-5.

Appendix A Persistence rates

Table A.1 Various persistence rates of ADHD from childhood into adulthood

Study design, author, year	Total sample (N)	Childhood ADHD (N)	Persistence rate (%)
Retrospective, population ba	sed		
Yang et al, 2013	1,382	196	74.7
Ebejer et al, 2012	3,795	49	55.3
Lara et al, 2009	11,422	629	50.0
Kessler et al, 2006	3,197	346	36.3
Barbaresi et al, 2013	5,718	232	29.3
Total/weighted average	25,514	1,452	46.9
Prospective, clinical based			
Cheung et al, 2015	-	110	79.0
Li et al, 2013	-	258	65.8
Clarke et al, 2011	-	36	63.2
Francx et al, 2015	-	101	58.4
Breyer et al, 2014	-	150	52.6
Chang et al, 2011	-	192	51.0
Russel et al,2007	-	158	40.7
Biederman et al, 2011	-	110	35.0
Biederman et al, 2012	-	96	33.3
Roizen et al, 2012	-	103	11.0
Total/weighted average		1,314	50.3

Source: Adapted from Caye et al, (2016).¹⁶⁵

¹⁶⁵ Caye, A., Spadini, A. V., Karam, R. G., Grevet, E. H., Rovaris, D. L., Bau, C. H. D., . . . Kieling, C. (2016). Predictors of persistence of ADHD into adulthood: A systematic review of the literature and meta-analysis. European Child & Adolescent Psychiatry, 25(11), 1151-1159. Retrieved from https://doi.org/10.1007/s00787-016-0831-8

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