

## **Mental Health Carers NSW Inc.**

### **Position Statement on Better Supports for People with ADHD and their Families, Carers, and Kin**

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## Summary

This position paper informs Mental Health Carers NSW (MHCN) stakeholders about the challenges faced by people with ADHD, and the support needs of carers.

Currently, Australia's policy landscape around neurodivergence is at a crossroads. While there is growing public awareness of neurodiversity and increasing demand for diagnosis and treatment, government responses remain fragmented and inconsistent across jurisdictions.

Family members, carers, and kin play essential roles in supporting people with ADHD, yet their contributions are often overlooked in policy and service design. This lack of recognition contributes to long-term financial, emotional, and health impacts.

MHCN calls on both state and federal governments to take decisive action by investing in sustainable, coordinated, and equitable long-term support systems in addition to improving access to diagnostic services. These should focus on:

- i. improving service accessibility and affordability.
- ii. ensuring fair and consistent diagnostic processes and,
- iii. embedding lived experience and carer-inclusive practices in neurodivergent-related policy development.

Without reform, the barriers to affordable and fair support for people with ADHD and the impacts on families and carers will continue to grow, deepening existing inequalities and comorbidities, and undermining health and wellbeing.

## Population Data

ADHD is a “common childhood onset neurodevelopmental disorder, characterised by age-inappropriate levels of attention and/or hyperactivity and impulsivity”.<sup>1</sup> Approximately 1 million Australians are believed to live with ADHD in 2025, with only 2.6% of the population diagnosed.<sup>2</sup> ABS data shows 12% of the workforce in Australia identifies as neurodivergent.<sup>3</sup>

Awareness around ADHD is growing, particularly with increased usage of social media to source information and self-diagnose. These routes pose risks around misinformation,

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<sup>1</sup> Peasgood, T., et al., (2016). ‘The impact of ADHD on the health and wellbeing of ADHD children and their Siblings’, *European Child & Adolescent Psychiatry* 25(11): 1217-1231.

<sup>2</sup> Australian Institute of Health and Welfare ‘Mental Health Services in Australia: ADHD’.

<sup>3</sup> Australian Bureau of Statistics, (2021). ‘Inclusion and Diversity | Australian Bureau of Statistics.’ <https://www.abs.gov.au/about/abs-careers/inclusion-and-diversity>.



improper and incorrect self-diagnosis, and algorithm bias.<sup>4</sup> What the uptake in sourcing health and diagnostic information tell us is that this is a system under strain.<sup>5</sup>

Central to this deficit in correct diagnosis and reliance on online information align with key issues raised in the Senate Community Affairs Committee's landmark inquiry into *Assessment and Support Services for People with ADHD*, including:

- long waitlists for public assessments between 6 months to over 2 years.
- private assessments costing between \$800-\$2,500.
- limited bulk-billing and poor regional and rural access.
- inadequate GP training to initiate ADHD assessments.
- shortages of psychologists, psychiatrists, and occupational therapists, including after a diagnosis has been attained.
- narrow pathways to accessing quality prescriptions to medication based on individual treatment needs

Self-diagnosis does not mean a person does not want to access the health system. It means that the system for a formal diagnosis is inaccessible, unaffordable, or unresponsive.<sup>6</sup> They emphasise that, even community awareness and self-recognition increase, the services and systems in place are not adequately equipped to respond.

Whether or not someone is diagnosed, untreated and unsupported ADHD negatively impacts mental health, and a lack of appropriate intervention increases the likelihood of poorer long term health outcomes.<sup>7</sup> People with diagnosed and undiagnosed ADHD experience higher rates of comorbidities including chronic physical health conditions

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<sup>4</sup> Hall, R., & Keenan, R., (2025). 'More than Half of Top 100 Mental Health TikTok's Contain Misinformation, Study Finds', *The Guardian*. May 31, 2025.

<https://www.theguardian.com/society/2025/may/31/more-than-half-of-top-100-mental-health-tiktoks-contain-misinformation-study-finds>.

<sup>5</sup> Farnood, A., Johnston, B., & Mair, F. S., (2020). 'A Mixed Methods Systematic Review of the Effects of Patient Online Self-diagnosing in the 'Smart-phone Society' on the Healthcare Professional-patient Relationship and Medical Authority', *BMC Medical Informatics and Decision Making*, 20(1).

<https://doi.org/10.1186/s12911-020-01243-6>

<sup>6</sup> NSW Branch of the Royal Australian New Zealand College of Psychiatrists, (2023). *Review of The NSW Mental Health Care System on the Brink: Evidence from the Frontline*. <https://www.ranzcp.org/clinical-guidelines-publications/clinical-guidelines-publications-library/nsw-mental-health-system-on-the-brink>

<sup>7</sup> Parliament of Australia, (2023). 'Chapter 2 – The lived experience of ADHD', *Assessment and Support Services for People with ADHD*: 2.45-54.



and metabolic disorders,<sup>8</sup> serious and persistent mental health issues,<sup>9</sup> suicide, ideation, and self-harm,<sup>10</sup> and addiction.<sup>11</sup>

### Current Policy Context

The Senate's *Assessment and Support Services for People with ADHD* inquiry received over 700 submissions and issued 15 unanimous recommendations. These included calls for a nationally coordinated framework, better access to diagnosis, equitable care, and inclusion of lived experience in policy design. The Australian Government's response to the inquiry was disappointingly modest; with just one recommendation fully supported (a commitment to developing a National ADHD Framework), nine supported in principle, and five noted without commitment to action.

The response was met with widespread criticism for not matching the urgent, comprehensive action called for by the committee.<sup>12</sup> Importantly, recommendations that were 'noted' are some of the most crucial structural needs for improving health outcomes for people with ADHD such as improving NDIS information on ADHD eligibility and providing ongoing funding for disability advocacy. These recommendations would help avoid misinformation and confusion about eligibility, improve access to occupational therapy and ADHD-relevant supports, and reduce NDIS administrative processes by ensuring staff have access to consistent criteria. It would also allow advocates to support the reform process and to identify the adequacy of changes and help raise unresolved issues on behalf of those effected.

The NDIS was designed to be diagnosis-neutral and focused on functional impact.<sup>13</sup> This remains the legislated basis of the scheme. However, the lack of transparent information means people with ADHD are discouraged from applying whereas others with similar levels of functional impact, but more 'obvious' diagnoses will find the process more favourable.

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<sup>8</sup> French, B., Nalbant, G., Wright, H., Sayal, K., Daley, D., Groom, M. J., & Hall, C. L., (2024). 'The Impacts Associated with Having ADHD: An Umbrella Review', *Frontiers in Psychiatry* 15: 1343314.

<sup>9</sup> Oscarsson, M., et. al., (2022). 'Stress and Work-Related Mental Illness Among Working Adults with ADHD: A Qualitative Study', *BMC Psychiatry*, 22(1): 751.

<sup>10</sup> Di Salvo, G., et. al., (2024). 'Assessing Suicidality in Adult ADHD Patients: Prevalence and Related Factors: Suicidality in Adult ADHD Patients'. *Annals of General Psychiatry*, 23(1): 42; Trivedi, C., et. al., (2023). 'Suicide Risk among adolescents with ADHD: An Overview from the National Inpatient Sample Data Set', *The Journal of Nervous and Mental Disease*, 211(3): 216-220.

<sup>11</sup> El Archi, S., et. al., (2023). 'Adult ADHD Diagnosis, Symptoms of Impulsivity, and Emotional Dysregulation in a Clinical Sample of Outpatients Consulting for a Behavioural Addiction', *Journal of Attention Disorders*, 27(7): 731-742.

<sup>12</sup> Australasian ADHD Professionals Association, *Media Release*. <https://aadpa.com.au/aadpa-slams-government-response-to-senate-inquiry-2/>

<sup>13</sup> NDIS Act 2013 – Section 24.



A positive step forward is the May 2025 announcement from the NSW Government allowing GPs to undertake accredited training to diagnose and prescribe for ADHD from 2026.<sup>14</sup> It is essential that this is done properly with clear guidelines and ongoing professional development to safeguard pathways to diagnoses and treatments. There should also be incentives for specialists to train and work in underserved and regional areas. The process must also be carefully monitored to maintain affordable and regulated prices as Medicare unfortunately does not cover ADHD assessments.<sup>15</sup> In recent years, there have been significant upgrades to the Pharmaceutical Benefits Scheme (PBS), such as the inclusion of Vyvanse® in 2021.<sup>16</sup> However, as recommended by the Senate Inquiry Committee, a review of the PBS including expansions to the range of subsidised medication is necessary to further improve medication accessibility.

### Families, Carers, and Kin Bridge Service Gaps

When people with ADHD cannot access formal services or diagnoses, whether because they are ineligible for the NDIS, experience long waitlists for diagnoses and specialists, or lack affordable providers, families, carers, and kin often fill the gap. This support tends to be unpaid, time-intensive, and emotionally and financially taxing, and has increased since Covid-19.<sup>17</sup> This happens across multiple domains such as:<sup>18</sup>

- Practical daily supports (cooking, cleaning, budgeting, routine planning, transport)
- Education and employment (assisting with study, time management, advocating for flexible deadlines and environments, managing burnout and hyperfocus)

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<sup>14</sup> Ritchie, R., 2025. 'NSW GPs to Be Trained in Resupplying ADHD Medication from September', *ABC News*, July 6, 2025. <https://www.abc.net.au/news/2025-07-07/nsw-government-gp-training-resupply-adhd-medication/105488960>

<sup>15</sup> "Greens Will Add ADHD and Autism Assessments to Medicare, Saving People Thousands in Out-of-Pocket Costs | the Australian Greens." 2025. *The Australian Greens*. February 26, 2025. <https://greens.org.au/news/media-release/greens-will-add-adhd-and-autism-assessments-medicare-saving-people-thousands-out>

<sup>16</sup> Australian Government Department of Health. 2021. "Greater Access to Life-Changing Medicine for Australians with ADHD." Australian Government Department of Health. January 30, 2021. <https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/greater-access-to-life-changing-medicine-for-australians-with-adhd>

<sup>17</sup> Pellicano, E., Brett, S., den Houting, J., & Heyworth, M., (2022). 'Covid-19, Social Isolation and the Mental Health of Autistic People and their Families: A Qualitative Study', *Autism* 26(4): <https://doi.org/10.1177/13623613211035936>

<sup>18</sup> Lins-Silva, D.H., et al. 2024. 'Prevalence of Mental Disorders among Family Members of Individuals on the Autism Spectrum: Systematic Review and Meta-Analysis', *European Child & Adolescent Psychiatry*: 1-13; Sanchez Amate, J.J., & A. Luque de la Rosa, (2024). 'The Effect of Autism Spectrum Disorder on Family Mental Health: Challenges, Emotional Impact, and Coping Strategies', *Brain Sciences* 14(11): 1116; See also Vohra, R., et al., (2014). 'Access to Services, Quality of Care, and Family Impact for Children with Autism, Other Developmental Disabilities, and other Mental Health Conditions', *Autism* 18(7): <https://doi.org/10.1177/1362361313512902>



## Mental Health Carers NSW

- Emotional and social support (building self-esteem, navigating conflict, encouraging participation, sourcing peer groups)
- Navigating systems and advocacy (chasing up referrals, liaising with providers, writing support letters)
- Filling gaps in formal care (locating private therapies and GPs when public services are not available)
- Bearing financial costs (paying for private providers, psychologists, tutors, occupational therapy, and assistive technology when public coverage is lacking, covering lost incomes or reducing work hours)

Submissions to the Senate Inquiry captured the intensity of caregiving. As the *ADHD Alliance* states, parenting and caring for people with ADHD “requires exceptional skills, which are difficult when [they] have to manage their own mental health issues, negotiate barriers within the home, school, and health system”.<sup>19</sup> ADHD impacts health, wellbeing, finances, and social skills and continues into adulthood.<sup>20</sup> Moreover, the stress of caring for a person with ADHD has consequences for carers, families, and kin such as lower mental health and greater stress,<sup>21</sup> higher risk of divorce and relationship breakdown,<sup>22</sup> depression and anxiety,<sup>23</sup> reduced employment, increased social isolation,<sup>24</sup> and alcohol and tobacco consumption.<sup>25</sup> ADHD Australia reported their stakeholders had negative experiences pursuing a diagnosis for themselves or a loved one that placed strain on family relations, induced high levels of anxiety, and was “traumatic”.<sup>26</sup>

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<sup>19</sup> <https://adhdalliance.net.au/empower/what-is-ADHD/parents-caregivers>

<sup>20</sup> Shaw M., et. al., (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): Article 99. See also Bangma, D. F., et. al., (2019). ‘Financial decision-making in adults with ADHD’, *Neuropsychology* 33(8): 1065–1077.

<sup>21</sup> Balachandran, K. P., & Bhuvaneswari, M., (2024). ‘I May Have to Give Up on My Career.’ Breadwinners or Caregivers? Exploring the Complexities of Work-Family Conflict Among Parents of Children with Neurodevelopmental Disabilities’, *International Journal of Developmental Disabilities*: 1–18.

<sup>22</sup> Wymbs B. T., Pelham W. E. Jr., Molina B. S., Gnagy E. M., Wilson T. K., & Greenhouse J. B., (2008). ‘Rate and Predictors of Divorce Among Parents of Youths with ADHD’, *Journal of Consulting and Clinical Psychology* 76(5): 735–744.

<sup>23</sup> Fleitas Alfonzo, L., Disney, G., Singh, A., Simons, K., & King, T., (2024) ‘The Effect of Informal Caring on Mental Health Among Adolescents and Young Adults in Australia: A Population-Based Longitudinal Study’, *The Lancet Public Health* 9(1): E26-E34.

<sup>24</sup> Parliament of Australia, (2023). ‘Chapter 2 – The lived experience of ADHD’, *Assessment and Support Services for People with ADHD*.

[https://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/ADHD/Report/Chapter\\_2\\_-\\_The\\_lived\\_experience\\_of\\_ADHD](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ADHD/Report/Chapter_2_-_The_lived_experience_of_ADHD)

<sup>25</sup> Pelham W. E. Jr., & Lang A. R., (1999). ‘Can Your Children Drive You to Drink?’ *Alcohol Research and Health* 23(4): 292–298.

<sup>26</sup> ADHD Australia, (2023). ‘Submission No. 11.1 to the Senate Community Affairs References Committee, Inquiry into the Barriers to Consistent, Timely and Best Practice Assessment of Attention Deficit Hyperactivity Disorder (ADHD) and Support Services for People with ADHD’.



These findings highlight that carers, family, and kin are more than willing to fill support and service gaps because they love and care for their children, partner, parent/s, and loved ones. But wanting the best for their person takes a toll on their emotional, mental, physical, and financial wellbeing.

### Measures to Support Family, Carer, and Kin Wellbeing

For people with ADHD, gaining and maintaining employment can be difficult as workplaces often do not understand the condition or have reasonable adjustments to support ADHD staff.<sup>27</sup> For families, carers, and kin this means their loved one may be reluctant to disclose and then struggle in or disengage from the workplace, and require additional support and care in the home.<sup>28</sup> There is a critical need for the following supports for people with ADHD, which in turn reduce stress and improve support and wellbeing of families, carers, and kin:

- i. **Accessible and affordable services** for timely diagnosis for all children and adults.
- ii. **Early intervention programs** to reduce crises and prevent escalation of support needs and functional impact.
- iii. **Affordable treatment** including subsidised medication and occupational therapy.
- iv. **Access in underserved and regional areas** to improve access to care and avoid a postcode lottery.
- v. **Funded mental health awareness and peer supports** to improve the mental health and wellbeing impacts of ADHD.
- vi. **Clear information** about NDIS eligibility for ADHD, Medicare Better Access, and state-based supports.
- vii. **Easy access** to case management or peer support services to help coordinate supports.
- viii. **ADHD resources** for schools, workplaces, medical centres, and community services to reduce stigma and improve adjustments.
- ix. **Public campaigns** to reduce stigma around ADHD by raising awareness and building community empathy.

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<sup>27</sup> Parliament of Australia, (2023). 'Chapter 2 – The lived experience of ADHD', *Assessment and Support Services for People with ADHD*: 2.22-230.

<sup>28</sup> Ibid.





Further, carer-specific resources and supports are essential to recognise their labour and contribution to society, and improve their wellbeing and self-esteem so they can continue to provide love, care, and support to their person:

- i. **Legislative recognition of family, carer, and kinship** responsibilities as protected attributes under anti-discrimination law.
- ii. **Short-term and regular respite** to attend to their own needs provided by trusted and reliable support workers.
- iii. **ADHD-inclusive after-school and holiday programs** that are affordable and accessible for regional and rural families.
- iv. **Access to carer payment** and carer allowances to reflect the out-of-pocket cost of ADHD care.
- v. **Flexible employment options** such as remote and hybrid work, job sharing, flexible hours.
- vi. **Government subsidies** for therapies and assistive technology (smart watches, alarms, noise cancelling devices) not covered by Medicare or the NDIS.
- vii. **Properly funded peer-supports** to provide community for carers to address burnout, isolation, and anxiety, and share information and advocacy.
- viii. **Trauma-informed services** recognising that many carers, family, and kin also have ADHD, other neurodivergence, mental health concerns, and/or disability.

### Conclusion

State and federal governments must invest in sustainable and co-designed projects that improve existing services and deliver new supports for people with ADHD their family, carers and kin. The current system is at capacity and inaccessible for many individuals and families, carers, and kin who experience high levels of emotional and financial strain as they try every possible avenue to access treatment and care. The following programs will drastically improve the health and social outcomes of the ever-growing cohort of people with ADHD, their families, carers and kin:

- Investing in expanding the roles of GPs, increasing the specialist workforce, and subsidising diagnoses will reduce wait times and improve financial barriers.
- Improving public awareness and education by funding ADHD organisations and peer support programs to do community outreach can reduce stigma and encourage social participation.
- Providing integrated support and psychoeducation for families, carers, and kin to navigate diagnosis, treatment, and care planning, and extending respite and in-home supports to carers of people with ADHD can reduce stress and burnout by recognising the carer's role and supporting their wellbeing.