Home Parliamentary Business Committees Senate Committees Senate Standing
Committees on Community Affairs Assessment and support services for people with
ADHD Assessment and support services for people with ADHD Chapter 9 –
Committee views and recommendations

Chapter 9 - Committee views and recommendations

Chapter 9Committee views and recommendations

- 9.1The committee has been deeply moved by the personal experiences and openness of the hundreds of submitters and witnesses who have shared their attention deficit hyperactivity disorder (ADHD) journey, with all its highs and lows. The committee appreciates the time invested by the ADHD community in sharing their experience and notes it is troubling to hear of the ways the health, education, employment and justice systems have let people down.
- 9.2Having considered the considerable and varied evidence provided, the committee is of the view that more could be done to remove barriers for people with ADHD so that they can receive the assessments, healthcare and support they need. Sufficient government funding will be vital in implementing the committee's recommendations.
- 9.3In this chapter, the committee outlines its response to the evidence received during the inquiry on the barriers to consistent, timely and best practice assessment of ADHD and support services for people with ADHD.
- 9.4Firstly, however, the committee acknowledges that the current process and systems available to members of the community wishing to provide evidence to a Senate committee may not meet the access needs of people with ADHD. Duringthis inquiry the committee took steps to improve processes in order to meet those needs. However, we are aware that despite our best efforts, barriers remained. The committee apologises for the frustration caused and commits to working with the Department of Parliamentary Services (DPS) to improve the accessibility of committee systems and processes as part of the DPS access review.

Developing a national approach

9.5This inquiry shows that ADHD is a public health concern. The committee heard from Dr Dianne Grocott at its Melbourne public hearing that 'ADHD is not just mental health issue, it's a public health issue'.[1]

Privacy - Terms

- 9.6In reviewing the evidence, it is clear that a more consistent and coordinated approach is needed across government systems to ensure these systems are accessible to people with ADHD. This includes reforms to health and education systems, to ensure people have consistent access to care at all stages of their life. This is consistent with the findings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission).[2]
- 9.7The committee is persuaded that a national framework for ADHD—supported by an action plan, targets, and regular evaluation—could help improve care and support for people with ADHD, as was canvassed in Chapter 5.
- 9.8This national framework should be funded by the Australian Government with consultation with people with lived experience of ADHD, their families and ADHD advocacy and community organisations. The framework should differentiate both medical and non-medical care pathways for adults and children with ADHD, with suggested pathways identified by submitters (as discussed in Chapter 5 and Appendix 3). The framework should also support the implementation of a range of measures, including (but not limited to):

□shared models of care;
public awareness and health promotion campaigns;
\Box the creation of additional information resources for people with ADHD, discussed further below; and
□changes to Medicare and the Pharmaceutical Benefits Scheme.

9.9A national approach also requires consultation with the experts—including professional healthcare colleges and organisations. Such consultation would identify the additional supports needed to improve access to ADHD healthcare and supports, including bulk billing, shared care models, telehealth, and access in rural, regional and remote areas.

Minister for Disability

9.10People with ADHD are at the intersection of many government systems and can experience multiple forms of discrimination. The evidence received through this inquiry points to the need for the implementation of reform across government systems, including healthcare and education.

9.11To this end, the committee notes the general approach of the Disability Royal Commission, which recommended establishing a disability portfolio and Minister for Disability Inclusion. The committee further notes that the Australian Government has established the Commonwealth Disability Royal Commission Taskforce 'to coordinate the Australian Government's response to the recommendations, engaging closely with the disability community'. While acknowledging this work is ongoing, the committee encourages this taskforce to take note of recommendations of this report where they are relevant to its work.

Recommendation 1

9.12The committee recommends the Australian Government considers funding and co-designing a *National* Framework *for ADHD*, together with people with ADHD as well as ADHD advocacy and community organisations.

Recommendation 2

9.13The committee recommends the Australian Government consult with people with lived experience of ADHD, healthcare colleges and organisations to identify additional supports to improve access to ADHD healthcare and support. This should encompass reviewing bulk billing incentives to reduce out-of-pocket expenses for diagnosis and ongoing support, shared care models, telehealth, and improving access in rural, regional and remote areas.

Making services affordable and accessible

Affordability of healthcare

- 9.14As the Public Health Association of Australia rightly pointed out, given the high prevalence of ADHD across the country, 'Australians should expect that our health system has developed a comprehensive response [to ADHD], including capabilities for diagnosing and ongoing treatment. Unfortunately, this is not yet in place'.[3]
- 9.15The evidence to the committee made clear that the cost of clinician, general practitioner (GP) and allied healthcare visits is too expensive, in many cases preventing people from getting an ADHD diagnosis and ongoing support. Forsome people, the prohibitive costs of medication resulted in them rationing medication, sharing medication, or people having to make a choice between buying food or medication for themselves or their family members. These costs are exponentially higher for families where multiple family members have ADHD.

- 9.16The clear priority for people with ADHD and healthcare professionals is safe, high-quality healthcare that is accessible in a timely way and integrates diagnosis, treatment and support.
- 9.17However, the health ecosystem is a complex one, and the committee received a wide range of evidence and recommendations on how to improve the affordability and accessibility of diagnosis and support for people with ADHD. Proposed measures included increasing the health workforce capacity and capability so it could better respond to the need for ADHD services, and addressing the costs associated with receiving care and support.

Access to care

- 9.18For those seeking a formal diagnosis there are currently many barriers. The community has described the cost of receiving a diagnosis as too expensive and has described the process as difficult, with significant wait times. These barriers are stopping people obtaining the diagnosis and the support that they need. Increasing the number of healthcare professionals who can support people with ADHD, and therefore expanding models of care for people with ADHD, was recommended by many submitters.
- 9.19The committee heard from several submitters that a range of models are needed to meet the varying needs of people with ADHD, as well as to address specific challenges like, for example, those associated with rural, regional and remote care and for people with co-occurring conditions. It is evident to the committee that expanded models of care have worked well overseas and are being successfully trialled in Australia.
- 9.20There was clear support for the implementation of multidisciplinary teams and healthcare hubs, including primary health networks, to promote holistic care.
- 9.21The Disability Royal Commission likewise recommended the development of specialised health and mental health services for disabled people, including mental health needs. It recommended that these services be delivered through specialist roles and multidisciplinary teams, supported by training and support for health providers to ensure the best care possible, with changes to be introduced by September 2026.[4]

The role of GPs

- 9.22GPs appear well positioned to expand their role as it relates to ADHD management, particularly in the co-management and co-prescribing of medications to support people with ADHD. Shared care will help to address the long wait times, and allow people to have an appointment with a clinician who best meets their needs.[5]
- 9.23Healthcare professionals expressed a range of opinions on whether GPs should be able to diagnose ADHD, particularly in the case of children. Children are still developing, and therefore may have complex developmental needs, including those arising from a co-occurring condition or conditions.
- 9.24The committee is persuaded by the evidence calling for GPs and other healthcare professionals, who are interested in playing a greater role in the identification and support of ADHD, being able to do so. This should occur where GPs, and other healthcare professionals are supported with appropriate, accredited education and training (discussed further below).

Current funding models

- 9.25Current funding models and regulations are barriers to successfully implementing shared models of care for ADHD.
- 9.26For example, many people with ADHD wanted to see easier and more affordable access to ADHD coaching. However, concerns were raised about the efficacy and regulation of ADHD coaching and the need to protect consumers from opportunistic providers. Regulation of coaching services may address some concerns. The committee also heard calls for changes to the MedicareBenefits Schedule (MBS) so that when GPs refer patients to qualified healthcare professionals who provide ADHD coaching services, these services are subsidised.
- 9.27Access to healthcare services should be improved by reducing out-of-pocket expenses. This will help ensure that access to healthcare is more equitable.
- 9.28The evidence to this inquiry shows there is a range of measures that can be implemented which would have direct and immediate impacts on reducing and removing some of the costs and barriers being experienced by people with ADHD when they engage with the healthcare system. The committee therefore calls on the Australian Government to:

review the Medicare benefits schedule to consider:	
review the Medicare benefits schedule to consider:	

promoting bulk billing for diagnosis and ongoing healthcare;
□ensuring people on low incomes or those in which multiple family members have ADHD are supported;
□expanding the range of services and providers subsidised by the MBS, including psychologists, psychiatrists, nurse practitioners, allied health professionals (including registered ADHD coaches)[6]; and
□enabling longer consultations and shared care arrangements (including liaison and upskilling between professional healthcare workers).
review the Pharmaceutical Benefits Scheme (PBS) to consider:
proactively increase the range of subsidised medications;
removing age restrictions and the requirement for a childhood diagnosis for some medications, ensuring adults can access medications they need;
□reviewing maximum dosage restrictions;
$\hfill\Box$ better enabling the combining of medications, and delivery method of medications, for optimal treatment; and
□increasing the range of healthcare professionals who have authority to prescribe subsidised medications under the PBS.
□ facilitate uniform state and territory prescribing regulations:
recognising that prescribing rules are regulated at the state and territory level, and the Australian Government is reviewing options to improve uniformity, the Australian Government should show leadership and expedite the development of uniform prescribing regulations to improve access to ADHD medications.
9.29It is the committee's view that provision of public health services for adults with ADHD alongside the expansion of paediatric services would greatly assist people to access the care that they need, but notes that this is primarily a state and territory responsibility.
9.30The committee was presented with compelling evidence for further investment in ADHD healthcare and support services would provide a positive economic benefit. Lifespan Community ADHD Clinic captures the sentiment of many:

One of the main goals of optimizing ADHD management is so that children continue to achieve at school and are fully productive in the workforce and as adults. Therefore, investment in adequate services for people with ADHD of all ages gives substantial economic benefit to society.[7]

9.31The committee would also like to see greater state and territory support for pilot schemes which test a range of models of care, to take account of the diverse needs of people with ADHD, and the diverse capabilities of clinicians treating and supporting people with ADHD.

Recommendation 3

9.32The committee recommends the Australian Government review the Medicare Benefits Schedule with a view to improving the accessibility of assessment, diagnosis and support services for people with ADHD.

Recommendation 4

9.33The committee recommends the Australian Government review the Pharmaceutical Benefits Scheme (PBS) to improve the safe and quality use of medications by people with ADHD. This review should give consideration to the requirements for a diagnosis to access some medications, age restrictions, dosage restrictions and the scope of practice for clinicians prescribing medications.

Recommendation 5

9.34The committee recommends that the Commonwealth expedite the development of uniform prescribing rules to ensure consistency between state and territory jurisdictions, through the Ministerial Council on Health.

Improving ADHD information and resources

Improving access to information and resources for people with ADHD

9.35The committee heard there are barriers to people obtaining reliable, accurate and comprehensive information about ADHD, and where to find support.

- 9.36Numerous reports were provided to the committee of people seeking information about ADHD from social media and their peers. While the identification of a like-minded support network and support strategies has been immeasurably useful for some people, people with ADHD and healthcare professionals expressed concern that this information is not always reliable.
- 9.37There were widespread calls for more accurate, reliable, and accessible information about ADHD. ADHD Australia advised 'the Australian Government has an important role to play in ensuring people can access clear, up-to-date and evidence-based information and resources about ADHD'.[8]
- 9.38Given the reliance on social media for information about ADHD, the committee suggests that reliable and accurate information from government and lived experience organisations should also be made available on social media, to make it more accessible.
- 9.39It is clear to the committee that government information about services and assistance—including through the National Disability Insurance Scheme (NDIS), Department of Social Services, Department of Health and Aged Care and Department of Education—could be easier to find and presented in more accessible and understandable ways. It is also vital that this information stays as up-to-date as possible.
- 9.40To improve access to accurate information the committee is of the view that the Australian Government should establish a dedicated ADHD information portal.

Recommendation 6

9.41The committee recommends the Australian Government, in collaboration with people with ADHD and ADHD advocacy and community organisations, develop a dedicated government ADHD information portal.

Improving public attitudes and awareness of ADHD

9.42The committee has been concerned by the levels of discrimination people with ADHD experience throughout their lives. Lived experience witnesses shared their experiences of being judged, excluded, and bullied for not meeting societal expectations in their schools, workplaces, while interacting with government services, and by their family and friends. Additionally, the committee was further concerned to hear about people's experiences with some healthcare professionals, including encounters in which they may have been dismissed, refused care, 'gas lit' and accused of drug-seeking behaviour.

- 9.43People with ADHD explained the lack of awareness of ADHD and the lack of support services has resulted in them feeling stigmatised and humiliated. Additionally, submitters described the stigma associated with the use of stimulant medication, and the impact of the current prescribing regulations leading to healthcare professionals assuming they are 'drug-seekers'.
- 9.44These encounters with inadequately trained healthcare professionals are harmful and have life-long impacts on people's health and wellbeing. In many cases, these experiences have caused people to delay seeking diagnosis and support for ADHD or discouraged them from ongoing engagement with the healthcare system.
- 9.45The committee acknowledges the intergenerational impacts of ADHD. Submitters shared their own challenges with accessing government support systems, and these challenges are compounded when advocating for a child, or multiple children. It was described by some submitters as an exhausting battle for support.
- 9.46The committee acknowledges there is inadequate support for family and extended support networks for people with ADHD, and there is an absence of formalised support for family members who realise they may have ADHD through their child being diagnosed.
- 9.47Submissions highlighted that a public awareness and education campaign could be implemented, taking a neurodiversity-affirming approach and explaining how ADHD manifests differently in different people. An education campaign could explain that there are different diagnosis requirements, various benefits and risks of a range of treatments, and the education and workplace rights of people with ADHD, and detail how people could best support someone with ADHD.[9]
- 9.48Submitters thought that such a campaign would help improve community understanding, reduce stigma and promote a more inclusive Australian society. It is important this education campaign includes information around the range of presentation of ADHD, addresses the gender bias experienced by girls, women, and gender diverse people, and the use of stimulant medication.
- 9.49The need to address ADHD preconceptions and stigma were also specifically raised in the context of First Nations and culturally and linguistically diverse communities. The committee notes the specific contexts and requirements of these communities and supports a public health awareness and education campaign addressing the needs of specific cohorts, to help ensure that the diversity of people with ADHD are supported.

9.50The committee recommends the Australian Government implement, through the Department of Health and Aged Care, a neurodiversity-affirming public health campaign to shift social attitudes and stigma associated with ADHD and to improve public awareness and promote education.

Improving access to information about the National Disability Insurance Scheme

- 9.51 Based on the evidence to this inquiry and on publicly available information, there appears to be confusion around whether or not ADHD as a primary diagnosis is eligible for the NDIS.
- 9.52While the National Disability Insurance Agency (NDIA) has shown that people can access NDIS supports with ADHD as their primary or sole disability, the reality appears far from the case.
- 9.53Many expert organisations, advocacy groups and health professionals who work in this space are under the impression that ADHD as a primary diagnosis is not eligible for NDIS support. Whether or not their understanding is correct is not the main issue—they have likely been led to believe this either through the poor communication of the NDIA in explaining eligibility criteria through its published materials, or through years of being told applications were ineligible for funding.
- 9.54The committee is concerned that the NDIA has not taken steps to correct this misunderstanding and is also concerned that the NDIA does not provide any training on ADHD to NDIS decision makers—especially given the prevalence of ADHD in Australia.
- 9.55Despite the committee being advised that the National Disability Insurance Scheme Act 2013 defines NDIS eligibility in terms of functional impairment rather than specific conditions, the continued publication of the access lists means that in reality, listed conditions appear more likely to ultimately gain NDIS financial support.
- 9.56The committee strongly encourages the NDIA to take steps to ensure that people with ADHD, and its assessors and decision makers, are aware that the NDIS allows for eligibility of ADHD as a primary condition, according to the level of impairment. The NDIA should also provide appropriate training to ensure that its staff are informed and can accurately assess applications from people with ADHD, including where ADHD is a primary condition. Service providers and providers of information to disabled people must also have accurate information.

- 9.57In addition, the committee acknowledges people with ADHD find the process of making an NDIS application difficult. Public information produced by the NDIA must be clearer and more accessible to people who are seeking assistance for ADHD under the NDIS, including information about eligibility and access requirements. Information should also be culturally appropriate and understandable for First Nations and culturally and linguistically diverse people.[10]
- 9.58There is a clear consensus from advocacy organisations and expert health professionals that the types of supports that the NDIS was established to provide are the supports that are needed by many people with ADHD. Overall, however, whether or not these supports are provided through the NDIS or through other funding mechanisms is also not the point—it is instead ensuring that people get the support they need to live more functional lives.

Recommendation 8

9.59The committee recommends the National Disability Insurance Agency improve the accessibility and quality of information around the eligibility of ADHD as a condition under the National Disability Insurance Scheme (NDIS).

Recommendation 9

9.60The committee recommends that the Department of Social Services provide ongoing funding for disability advocacy organisations, including ADHD advocacy organisations, to support people with ADHD.

Improving our schools

- 9.61So many parents and families shared their stories about the difficulties they and their children have experienced in the education system, across the country. Oureducation system is not adequately supporting neurodivergent children, including those with ADHD. Submitters reported that the current classroom environments are not supportive of their child's learning, and children are subject to punitive measures for their behaviour. Too often, a child's school experience is determined by the awareness, knowledge and understanding (orlack thereof) of their classroom teacher—and by the lack of consistency and support across their learning journey.
- 9.62The committee acknowledges that the responsibility for addressing support in schools is split between federal, state and territory governments, with curriculum implementation and the operation of schools being the responsibility of states and territories. However:

... the Australian government does play a leadership role in education, particularly as it relates to funding, which is also a shared responsibility with states and territories, who have the lead responsibility for the regulation, administration and operation of schools.[11]

9.63The committee therefore suggests that in its leadership role, there is more that the Australian Government could do to change the culture and set expectations for educational institutions to ensure that neurodivergent students can access education on the same basis as other students—as is their right. This could include strengthening the Family–Schools Partnerships Framework and expanding existing initiatives such as the National Student Wellbeing Program.

9.64There are other levers the Australian Government can pull to improve outcomes for students with disability, including through its schools funding, disability support programs, National Higher Education initiatives, the National School Reform Agreement, and Education Ministers' meetings.[12]

9.65The Disability Royal Commission also acknowledged the need for changes to ensure 'safe, quality and inclusive school education' that is consistent with human rights obligations for disabled students. To this end it recommended the Australian Government, along with states and territories develop a national roadmap to inclusive education as a priority, to drive change in the longer term.[13]

9.66The committee heard calls from educators who want to know more about ADHD so they can better support and help their students to learn. Educator training should therefore be expanded to include:

□content about neurodivergence, education delivery and learning needs for neurodivergent students (including those with ADHD);
□how to reduce stigma (including in relation to stimulant medication);
□better understanding about the presentations of ADHD and gender bias; and
□implementation of effective accommodations for these students.

9.67As highlighted by the Disability Royal Commission and throughout this inquiry, there is also scope, through initiatives like the National Teacher Workforce Action Plan, for the Australian Government to help improve the awareness and capability of teachers and school leaders to respond to the needs of disabled and neurodivergent students, including those with ADHD, through professional development courses.[14] Teacher awareness of in–school supports and referral pathways would also help

children and families, given the front line role of teachers in a school environment. As the committee was told, a teacher noticing a child might have ADHD and then taking appropriate action to help can have life-long, positive impacts on that person.

9.68While new information resources have been developed, the Australian Government could do more to ensure that online resources are available to schools and families, especially in relation to accessing support in schools and the eligibility requirements for those supports. For example, schools could be provided with clearer guidance on when and how to seek additional support via the Students-with-disability Student Resource Standard (SRS) loading.

Improving our workplaces

- 9.69Numerous people told the committee of the difficulties they have had finding a job and thriving in a work environment. People with ADHD do not always have access to the reasonable adjustments they need to be successful in their jobs and in some cases are not aware that they can ask for such adjustments. In other instances, people with ADHD might not be sure what those adjustments might look like.
- 9.70Creating a more inclusive and neurodiverse-friendly work environment is better for everybody and enables people with a range of approaches and ways of processing information to flourish.
- 9.71The committee also heard that employers are not always aware that they have a legal responsibility to not discriminate, and to consider all reasonable steps to prevent disability discrimination. This includes making reasonable workplace adjustments, such as offering flexible working options, and using different strategies to aid memory, concentration, planning and emotional regulation.

Recommendation 10

9.72The committee recommends the Australian Government works to improve training on recognising and meeting the needs of ADHD people in a variety of settings, such as in education, institutional settings and the workplace, including considering setting minimum standards for neurodiversity training.

Improving support in institutions and correctional facilities

- 9.73Over the course of the inquiry the committee was told that of those who interact with the justice system throughout their lifetime, there is a high incidence of people with ADHD. The evidence to the committee indicated that healthcare, including ADHD support services, is not always available in these environments. Lack of care in these facilities compounds the disadvantage already experienced by these adults and children with ADHD, and makes it exponentially difficult for them to access education and employment opportunities, with life-long impacts.
- 9.74The committee also heard that children in institutions, such as out-of-home care, are more likely to also have ADHD.
- 9.75People in institutions across Australia are recognised as being at high-risk and of requiring greater access to healthcare and support. The committee heard of people's experiences in institutions, including the devastating difficulties they experience accessing appropriate medication due to current regulation restrictions and authorisation requirements, jeopardising their care.
- 9.76The committee acknowledges the findings of the Disability Royal Commission, that it is vital to address the lack of suitable treatment and support pathways in institutions and the justice system, as well as the need to ensure staff are aware of the need for trauma-informed care and culturally safe approaches. This particularly applies to First Nations peoples and children.[15]

Recommendation 11

9.77The committee recommends that the Australian Government work towards improving specialised health services in institutionalised settings, including for people with ADHD.

Improve the capacity and capability of healthcare system

9.78It is clear from submissions and witness evidence to the inquiry that the healthcare system is stressed and overwhelmed and struggles to meet the needs of many people, including those with ADHD. It appears that there are not enough healthcare professionals to provide ADHD-related services, resulting in high costs and long wait times for assessment, treatment and ongoing care. Evidence further suggested that more training is needed to increase the capability of the system.

- 9.79The committee supports longstanding calls for increased Australian Government support to increase the mental health workforce. This includes psychiatrists and psychologists, as well as the broader healthcare workforce who can also provide mental health care, such as GPs, nurse practitioners, occupational therapists and counsellors.
- 9.80The committee notes the newly formed Department of Health and Aged Care 'Scope of practice review', which will examine the 'barriers and incentives health practitioners face working to their full scope of practice in primary care'.[16]

Health workforce education and training

- 9.81The committee heard extensive evidence on the need for improved training relating to neurodiversity, the social model of disability and ADHD diagnosis and support. A well-trained and available workforce of health professionals will be crucial to ensuring that assessment and support services for people with ADHD are both timely and fit-for-purpose.
- 9.82Many professional and lived experience submitters noted that poor training of healthcare professionals can result in the unhelpful treatment of patients, and also informed the committee that the training provided for healthcare professions, particularly those outside of core mental health specialities, does not provide enough upskilling on meeting the needs of people with ADHD.
- 9.83Additionally, it is the committee's view that training the broader healthcare workforce on certain ADHD related assessment or treatment functions, would help ease wait times currently being experienced by people who cannot access services in a timely fashion, and reduce backlogs across the healthcare system more broadly by creating efficiencies.

Recommendation 12

9.84The committee recommends the Australian Government, through the current 'Scope of practice review' and in collaboration with healthcare colleges, develop pathways which could include an expansion of the range of healthcare professionals who are able to provide ADHD assessment and support services, particularly General Practitioners and Nurse Practitioners, and improve the skills of all healthcare professionals who interact with people with ADHD.

Implement the Clinical practice guideline

- 9.85Another area specifically examined by this inquiry was the viability of recommendations from the Australian ADHD Professionals Association's *Australian evidence-based clinical practice guideline for ADHD* (Clinical practice guideline). While the committee received a variety of views on the Clinical practice guideline, it acknowledges there was widespread support for the guideline, including support with some amendments.
- 9.86However, it appears that more work needs to be done to implement the Clinical practice guideline and embed it into Australian ADHD policy approaches and healthcare practices. The Australian ADHD Professionals Association recognised that full implementation of the Clinical practice guideline was not funded in the development grant, and that implementation is a work in progress that needs to be supported by the Australian Government.[17]
- 9.87The committee is of the view that all levels of government should consider the allocation of funding to help implement this important framework into practice, including through raising awareness of the guideline among policy makers and healthcare professionals.
- 9.88Given the recommendations in the guideline, the committee is of the view that its implementation and greater awareness amongst healthcare professionals will promote more holistic care for people with ADHD and help them to have broader access to a range of supports, including psychoeducation.

Recommendation 13

9.89The committee recommends all levels of government consider investing in the implementation of the Australian ADHD Professionals Association's *Australian evidence-based clinical practice guideline for ADHD*, along with funding to promote the guideline to healthcare professionals and healthcare policy-makers.

Better funding for ADHD disability and advocacy organisations

9.90Lived experience non-profit support, disability and advocacy organisations clearly play an important role for people with ADHD and their families. These organisations provide information about ADHD, about where to go for further

assistance, and they can help people connect with peer support networks. They are also fierce advocates for people with ADHD, and provide other services such as telephone helplines.

- 9.91 These organisations are well positioned to understand the support needs of their communities, including what sorts of information they need and would be most useful to them, how it might best be delivered, and what the support priorities are within their community.
- 9.92It was made clear to the committee the great value of people with ADHD connecting to peers with ADHD, and the importance of finding a like-minded community. Much of this value lies in shared experience, with support and services often provided by volunteers with lived experience of ADHD and/or neurodivergence.
- 9.93However, resources are limited. The committee heard that increasing demand for support has impacted these grass-roots organisations and placed them under pressure. Additional funding would better enable lived experience non-profit support, disability and advocacy organisations to deliver public awareness campaigns to help shift social attitudes and reduce ADHD stigma, while providing practical information, resources and services to support people with ADHD.
- 9.94The Disability Royal Commission also found that this sector needs additional funding in order to better meet the demand for disability advocacy and peer support. [18]
- 9.95The committee therefore suggests the Australian Government consider investing in more public funding for lived experience non-profit support, disability and advocacy organisations to enable them to provide advice services—including an ADHD helpline, such as that operated by the ADHD Foundation—as well as legal aid and financial counselling services, research and advocacy for people with ADHD and their families.
- 9.96Improving the capacity of people to understand and respond to ADHD and the impacts on their life may, for some people, also reduce their need for formal engagement with the healthcare system.

Recommendation 14

9.97The committee recommends that the Australian Government consider investing in ADHD lived experience non-profit support, disability and advocacy organisations. Such funding would enable these organisations to provide community-based and

targeted services to people with ADHD, such as an advice and support helplines, legal aid, financial counselling and assistance in finding assessment, treatment and support pathways.

More research into ADHD and its impacts

- 9.98It is apparent to the committee that there are misunderstandings of ADHD—in the healthcare and education systems, and across the broader community. This is negatively impacting the ability of people with ADHD to obtain a diagnosis and support for their ADHD, has created stigma, and added to the trauma experienced by people with ADHD.
- 9.99Submitters told the committee that areas in which a lack of research is impacting people with ADHD include: evidence-informed clinical care (including models of care); conditions which occur alongside ADHD, including substance use conditions; gender bias, and ADHD in First Nations peoples and the aged.
- 9.100Increased research funding is needed to explore the impacts and optimal strategies to address these deficiencies. As outlined in Chapter 8, participatory research that involves people with ADHD in research conceptualisation, development and implementation would help ensure that research findings have high validity, utility and relevance.[19]
- 9.101There are opportunities for more consistent and wider national data collection in relation to people with ADHD, including for specific cohorts such as children in school, LGBTQI+ people, and First Nations peoples. Improved data collection will aid research and increase understanding of how ADHD can impact on specific cohorts.
- 9.102There are also opportunities for Australia to draw on overseas evidence, where there has been proven success with various and innovative ways to diagnose and support people with ADHD; these successful approaches should be explored for their applicability to our own local conditions.

Recommendation 15

9.103The committee recommends the Australian Government support further research, through the Australian Government's Medical Research Endowment Account (administered by the National Health and Medical Research Council) and the

Care), to better understand ADHD, and ways to address stigma. The committee suggests that further research is needed into:

| support available to people with ADHD, including evidence-informed clinical care and peer support;

| addressing the stigma that people with ADHD experience including in healthcare, education and the community;

| non-hyperactive presentations of ADHD and gender bias;

| ADHD in First Nations, culturally and linguistically diverse and LGBTQIA+ communities; and

ADHD co-occurrence with other forms of neurodivergence. Senator Janet Rice

Chair

Medical Research Future Fund (administered by the Department of Health and Aged

Greens Senator for Victoria

Footnotes

[1]Dr Dianne Grocott, Co-founder, Australian Adult ADHD Interest Group, *Committee Hansard*, 26September 2023, p. 25.

[2]Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Finalreport: executive summary, our vision for an inclusive Australia and recommendations*

(Final report: executive summary), September 2023, p. 180.

- [3] Public Health Association of Australia, Submission 122, p. 5.
- [4] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Finalreport: executive summary*, p. 232.
- [5]Dr Roger Paterson, Vice President, Australian ADHD Professionals Association, *Committee Hansard*, 24 July 2023, pp. 43-44; Associate Professor Daryl Efron, Representative, Royal Australasian College of Physicians, *Committee Hansard*, 29 June 2023, p. 37.
- [6]For example, through a scheme such as that used by the Australian Register of Counsellors & Psychotherapists, accredited training, recognition of lived experience workforce values, principles and ethics through a national peak body.

- [7]Lifespan Community ADHD Clinic, Submission 155, p. [6].
- [8]ADHD Australia, Submission 11, p. 8.
- [9]Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Finalreport: executive summary,* p. 231.
- [10]Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Final report: executive summary, our vision for an inclusive Australia and recommendations*, September 2023, pp. 145 and 213–214.
- [11]Ms Rachel O'Connor, Acting First Assistant Secretary, Improving Student Outcomes Division, Department of Education, *Committee Hansard*, 29 June 2023, p. 42.
- [12] The Hon Jason Clare MP, Minister for Education, *Transcript: interview ABC News Radio*, 7 July 2023.
- [13] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Finalreport: executive summary,* pp. 102-103.
- [14]Department of Education *National Teacher Workforce Action Plan: Priority Area 3, Action 18: Free professional development courses from 2024*, 21 September 2023 (accessed 22 September 2023); RoyalCommission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Finalreport: executive summary,* September 2023, p. 244.
- [15] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Finalreport: executive summary,* pp. 126–128, 270–271 and 280.
- [16] Department of Health and Aged Care, *Unleashing the Potential of our Health Workforce Scope of practice review,* www.health.gov.au/our-work/scope-of-practice-review (accessed 2 November 2023).
- [17] Australian ADHD Professionals Association, Submission 14, p. 20.
- [18] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Finalreport: executive summary*, pp. 76-77 and 225.
- [19]Ms Louise Brown, answers to questions on notice (no. 1) 24 July 2023 (received 8 August 2023), pp.3-4.

Contents	<u>.</u>
<u>Previous</u>	Next
Top	