## Assessment and support services for people with ADHD Submission 154

Committee Secretary Senate Standing Committee on Community Affairs PO Box 6100 Parliament House Canberra ACT 2600

9 June 2023

Dear Officer,

## Re: Assessment and support services for people with ADHD

The Australian National University Law Reform and Social Justice Research Hub ('ANU LRSJ Research Hub') welcomes the opportunity to provide this submission to the Senate Standing Committee on Community Affairs responding to terms of reference (d), (f), (g), (i) and (I) of the inquiry.

The ANU LRSJ Research Hub falls within the ANU College of Law's Law Reform and Social Justice program, which supports the integration of law reform and principles of social justice into teaching, research and study across the College. Members of the group are students of the ANU College of Law, who are engaged with a range of projects with the aim of exploring the law's complex role in society, and the part that lawyers play in using and improving law to promote both social justice and social stability.

This submission has been compiled by students with an interest in how socio-legal reforms may support social justice for those who are experiencing intersectional disadvantage. ANU LRSJ Research Hub has selected five terms of reference to respond to, based on the students' personal interest, experiences and understanding of the issues in question. The ANU LRSJ Research Hub has compiled responses to the terms of reference following analysis of the relevant legislation, peer reviewed literature and grey literature.

## Summary of Recommendations:

- 1. Clinical guidelines which outline assessment of ADHD in young people with gender variance must be established. These guidelines should incorporate gender norms of ADHD symptom manifestation into diagnostic criteria and assessment scoring.
- 2. Support services with a focus on non-disruptive, inattentive behaviours must be made more visible, and these services should particularly develop social and interpersonal relationship skills. Participation in these services must be normalised, and uptake for girls with ADHD must be encouraged.
- 3. Future research should obtain samples more reflective of the wider population to account for people with gender variance and should investigate support services providing adaptive lifespan models of care.
  The NDIS recognise ADHD as a primary disability.
- 5. The Commonwealth government should sponsor closer study and research into the ADHD symptoms differing in older Australian Adults (65+) and publish these findings to ultimately incorporate them into the assessment requirements of the NDIS
- 6. State governments should adopt an interdisciplinary approach of service by incorporating ESPs such as GPs in the ADHD assessment and prescription delivery model and administer training programs for this to occur.
- 7. Increase support for neurodiversity in education and employment, reducing comorbidities and interactions with the justice system.

## Assessment and support services for people with ADHD Submission 154

- 8. Ensure any further research on social impact of ADHD considers the positive contributions that come from ADHD in supported environments.
  9. Federal, state and territory governments embrace law and policy setting processes that consider and address intersectional disadvantage.

On behalf of the ANU LRSJ Research Hub,

Authors: Kristian Jongeling, Venni Baliyan and Linnea Burdon-Smith Editor: Nabeela Maricar

## Note on Terminology

#### Gender

The ANU LRSJ Research Hub recognises the language used to describe different gender is constantly changing. In a study completed by LaTrobe University, 19 different gender identities were presented for selection in their survey. We recognise that research, advocacy, and legal reform should consider gendered implications. For the purpose of this submission, the terms women, men (inclusive of trans and cis experiences) and non-binary have been used to be as inclusive as possible of the gender variations that fall within these categories. This submission uses language reflective of that used in the referenced studies. It is not an endorsement of this language; we have adopted it to ensure the most accurate representation of the findings of relevant studies.

## Term of Reference (d): impact of gender bias in ADHD assessment, support services and research

#### Assessment

Current research indicates that differences in gender identity correlate to variance in ADHD diagnosis rates, particularly amongst children and adolescents. Male-to-female ADHD diagnosis ratios in clinical samples have ranged from 5:1 to 9:1, despite general population estimates suggesting a 3:1 ratio is more accurate.<sup>2</sup> Research on this inconsistency suggests that ADHD in girls may go undiagnosed due to differences between the manifestation of symptoms in boys and girls.<sup>3</sup> Despite conflicting findings on inattentive symptoms, recent studies have identified lower levels of hyperactivity-impulsivity in girls with ADHD.<sup>4</sup> Comorbidities, and additional behavioural and emotional issues which are prevalent in girls with ADHD may also play a role in the rate of underdiagnosis.<sup>5</sup>

There is currently no standardised tool for ADHD diagnosis employed by clinicians consistently across Australia. Diagnosis typically involves a clinical interview conducted by a paediatrician, psychiatrist, or psychologist in combination with one of several age-tailored standardised tools available to clinicians. Some of these tools consider gender identity in the scoring of individual sub-domains, such as inattention/executive dysfunction; Conners 4, for example, incorporates small gender differences into select scales. Ultimately, these tools also evaluate criteria according to the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition ('DSM-5')

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WordPress/Learn.MHS/Manuals/conners 4 html manual full/part3/ch4 demographic.html#ch4 gender>.

<sup>&</sup>lt;sup>1</sup> Adam O.Hill et al, 'Writing Themselves In 4: The health and wellbeing of LGBTQA+ young people in Australia. National report', (2021) monograph series number 124, Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University, 24.

<sup>&</sup>lt;sup>2</sup> Alan Cheng et al, 'Factors Impacting Gender Diagnostic Differences in ADHD: A Review' (2022) 1 The Child Health Interdisciplinary Literature and Discovery Journal 25, 25; Erik W. Skogli et al, 'ADHD in girls and boys--gender differences in co-existing symptoms and executive function measures' (2013) 13 (20131109) BMC Psychiatry 298, 298.

<sup>&</sup>lt;sup>3</sup> Erik W. Skogli et al, 'ADHD in girls and boys-gender differences in co-existing symptoms and executive function measures' (2013) 13 (20131109) BMC Psychiatry 298, 298-9.

<sup>&</sup>lt;sup>4</sup> Sofia Santos et al, 'Male sex bias in early and late onset neurodevelopmental disorders: Shared aspects and differences in Autism Spectrum Disorder, Attention Deficit/hyperactivity Disorder, and Schizophrenia' (2022) 135 Neuroscience & Biobehavioral Reviews.

<sup>5</sup> Ibid.

<sup>&</sup>lt;sup>6</sup> Australian ADHD Guideline Development Group, Australian evidence-based clinical practice guideline for Attention Deficit Hyperactivity (Australian ADHD Professionals Association, 1 ed, 2022) 82 ('ADHD Guidelines').

<sup>&</sup>lt;sup>7</sup> Ibid 83.

<sup>&</sup>lt;sup>8</sup> Keith Connors, 'Demographic Considerations', Connors 4 4th Edition (Manual, July 2022)

<a href="https://mhscdn.blob.core.windows.net/mhs-web/MHS-">https://mhscdn.blob.core.windows.net/mhs-web/MHS-</a>

or International Classification of Diseases (†ICD†). All major international diagnostic guidelines are based on the DSM-5 or ICD classifications, which do not implement sex-specific criteria. It is therefore conceivable that clinicians may be more conservative with diagnosis where gender-tailored tools indicate slightly above-borderline scores but insufficient DSM-5 criteria are met

The AADPA ADHD Guidelines, released in 2022, recommend a clinical awareness of the under-recognition of ADHD in girls and women and highlight issues of non-referral, non-diagnosis, and incorrect diagnosis. No mention of non-binary or trans diagnosis differences is made by the guidelines, possibly a reflection of minimal research on gender variance in neurodivergent people. This omission is worrying given that gender variance is elevated in young people with neurodevelopmental and psychiatric conditions, including ADHD. Clinical guidelines ought to be developed for ADHD assessment of young people with gender variance – such guidelines are already available in relation to coexisting gender dysphoria and ASD.

## Support Services

Significant variation in ADHD management practices is evident in different regions around the world and internally within Australia. <sup>13</sup> Where under-recognition and under-diagnosis of ADHD is typical, for reasons including gender bias, leading clinicians have suggested that support services should be coordinated and should primarily provide care through specialist secondary care settings; specifically, psychiatrists and paediatricians trained in both diagnosing and treating ADHD, and managing common comorbid conditions. <sup>14</sup> Student and support services can include psychologists, speech pathologists, and pastoral care services – all typically provided by allied health professionals. <sup>15</sup>

The nature and structure of support services is not only important in treating those already diagnosed with ADHD, but also individuals who may be referred for or seek out diagnoses based on the support available to them. International studies have suggested that gender stereotypes and expectations regarding gendered behaviour play a role in non-referral (or self-referral) for diagnosis. <sup>16</sup> Girls displaying struggles with inattentiveness and executive functioning from an early age in some cases have not been referred due to a lack of recognition that such behaviours extended beyond 'typical' gendered behaviour. <sup>17</sup> Where behaviour is not disruptive and is attributable to 'typical' behaviour (an attribution informed by gender stereotypes)an indictment on the effectiveness of support services in addressing non-disruptive ADHD symptoms. Support services must be made more visible for girls seeking ADHD diagnoses and be more tailored to addressing non-disruptive, inattentive/executive

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<sup>&</sup>lt;sup>9</sup> Hira A. Razzak et al, 'Clinical Practice Guidelines for the Evaluation and Diagnosis of Attention-Deficit/Hyperactivity Disorder in Children and Adolescents: A systematic review of the literature' (2021) 21(1) Sultan Qaboos University Medical Journal; Corina U. Greven, Jennifer S. Richards and Jan K. Buitelaar, 'Sex Differences in ADHD' in Tobias Banaschewski, David Coghill and Alessandro Zuddas (eds), Oxford Textbook of Attention Deficit Hyperactivity Disorder (Oxford University Press, 2018) 154, 156.
<sup>10</sup> ADHD Guidelines (n 6) 76.

<sup>&</sup>lt;sup>11</sup> Lucy McPhate et al, 'Gender Variance in Children and Adolescents with Neurodevelopmental and Psychiatric Conditions from Australia' (2021) 50(3) Archives of Sexual Behavior 863, 869.
<sup>12</sup> Thid 870

Australian Commission on Safety and Quality in Health Care, '4.10 Attention deficit hyperactivity disorder medicines dispensing 17 years and under', First Australian Atlas of Healthcare Variation (1 ed, 2015) 249, 250.
 David R. Coghill, 'Organisation of services for managing ADHD' (2017) 26(5) Epidemiology and Psychiatric Sciences 453, 454-5.

<sup>&</sup>lt;sup>15</sup> Nardia Zendarski et al, Factors Associated With Educational Support in Young Adolescents With ADHD' (2020) 24(5) Journal of Attention Disorders 750, 751.

<sup>&</sup>lt;sup>16</sup> Andrea Lynch and Kevin Davison, 'Gendered expectations on the recognition of ADHD in young women and educational implications' (2022) *Irish Educational Studies* 1, 11-12.
<sup>17</sup> Ibid.

function difficulties. This increased vis bility should account for and address existing stigma around the ADHD label by normalising such support services for these behaviours to negate any disproportionate effect on girls referred for ADHD diagnosis and treatment.<sup>18</sup>

Beyond addressing stereotyped assumptions, support services must also focus on supporting social skill development through cognitive behavioural treatments and the provision of positive and contained social environments. Adolescent girls with ADHD often seek social conformity and robust social networks but may face difficulties such as rejection and social isolation. <sup>19</sup> These can lead to victimisation in social spheres, amplifying the challenge of emerging from such social isolation. Social skills and interpersonal relationships should therefore be a focus of support services for adolescent girls with ADHD and ought to be made more visible for affected individuals. <sup>20</sup>

#### Research

Research regarding non-binary and trans individuals is lacking in the field, with existing studies focusing more closely on the correlation between gender variance and neurodivergence rather than improving assessment and support services to better reflect ADHD symptoms in people with gender variance. Assessment questionnaire tools, such as Conners 4, have been unable to meaningfully incorporate non-binary gender identity into their design given insufficient sample sizes. However, given the gender variance/neurodivergence correlation noted in previous studies, more data should be expected if academics begin to seek samples more reflective of the population.

Existing studies have examined misdiagnosis and treatment concerns surrounding the prevalence of comorbidities in girls with ADHD, but further work is needed on adapting support services more formally to account for this. <sup>23</sup> This work includes investigating approaches which evaluate and monitor treatment response for women with ADHD more generally, particularly the merits of a lifespan model of care specifically adapted to unique gendered issues faced by women with ADHD. <sup>24</sup>

#### Recommendations:

- Clinical guidelines which outline assessment of ADHD in young people with gender variance must be established. These guidelines should incorporate gender norms of ADHD symptom manifestation into diagnostic criteria and assessment scoring.
- Support services with a focus on non-disruptive, inattentive behaviours must be made more visible, and these services should particularly develop social and interpersonal relationship skills. Participation in these services must be normalised, and uptake for girls with ADHD must be encouraged.
- Future research should strive to obtain samples more reflective of the wider population to account for people with gender variance and should investigate support services providing adaptive lifespan models of care.

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<sup>18</sup> Third 5

<sup>&</sup>lt;sup>19</sup> Susan Young et al, Temales with ADHD: An expert consensus statement taking a lifespan approach providing guidance for the identification and treatment of attention-deficit/ hyperactivity disorder in girls and women' (2020) 20(1) BMC Psychiatry 404, 418.

<sup>20</sup> Ibid.

<sup>&</sup>lt;sup>21</sup> McPhate (n 11).; John F. Strang et al, 'Increased Gender Variance in Autism Spectrum Disorders and Attention Deficit Hyperactivity Disorder' (2014) 43(8) Archives of Sexual Behavior 1525; Cheng (n 2) 29.

<sup>22</sup> Connors (n 8).

<sup>&</sup>lt;sup>23</sup> Young (n 19) 419-20.

<sup>24</sup> Ibid 423-4.

## Term of Reference (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

For those with Attention Deficit Hyperactive Disorder (ADHD) in Australia, there are formal and informal supports that can be accessed. The supports that someone might be eligible for is dependent on whether they have a formally recognised diagnosis, their age, residency status and whether they have received any other coexisting diagnosis.2

Informal support comes from individuals and organisations that understand neurodiversity and adjust to ensure all environments are accessible for those with neurodivergence. Often spaces that are welcoming and supportive of those with ADHD are also spaces that understand, support, and celebrate those on the autism spectrum.<sup>26</sup>

There are not-for-profit and community organisations that have grown out of a need to provide those with ADHD greater guidance, advocacy and supports. For example, ADHD Support Australia, Parents for ADHD Advocacy Australia and state/territory groups such as Canberra & Queanbeyan ADD Support Group (ADDACT). While these organisations and support groups are a great supplement to government initiatives, they do not provide adequate support on their own as they do not have the resources or authority to do so.

The National Disability Insurance Scheme has a role in supporting people with ADHD when the participant requirements are met under Chapter 3, Part 1 of the National Disability Insurance Scheme Act 2013 ('NDIS Act'). In practice, accessing NDIS for people with ADHD is not straightforward, often only being poss ble if ADHD is a secondary diagnosis. The NDIS 'doesn't consider ADHD a permanent disability or impairment' as 'you can treat and manage ADHD with medication and psychotherapy'.2

The NDIS was designed to provide support based on an assessment of the individual support needs required. The implementation of the scheme, however, has relied heavily on guiding documentation which lists diagnosis that are more I kely to meet criteria. This is an unsurprising consequence of the schemes large permit and bureaucratic streamlining. NDIS has dehumanised its users, 'participants' in the name of efficiency.

In guiding applications for NDIS support, two lists of diagnosis have been created, the first being, 'List A: Conditions that are likely to meet the disability requirements' 28 The second being, 'List B: Conditions that are likely to result in a permanent impairment'. 29 ADHD does not currently appear on either of these lists.

ANU LRSJ argues that ADHD meets the legislative requirements under section 24 Disability Requirements of the NDIS Act. The section states:

## (1) A person *meets the disability requirements* if:

(a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or the person has

<sup>&</sup>lt;sup>25</sup> ADHD Guidelines (n 6).

<sup>&</sup>lt;sup>26</sup> 'Home | Autism Adhd' < https://www.autism-adhd.org.au/>.

<sup>&</sup>lt;sup>27</sup> 'Does the NDIS Cover People With ADHD? NDSP Plan Managers' (17 October 2022)

<sup>&</sup>lt;https://ndsp.com.au/blog/ndis-news/does-the-ndis-cover-people-with-adhd/>

<sup>&</sup>lt;sup>28</sup> 'List A: Conditions That Are Likely to Meet the Disability Requirements | NDIS' (30 June 2022)

<sup>&</sup>lt;a href="https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/list-conditions-are-likely-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-participant/apply-meet-type-particip disability-requirements>.

29 'List B: Conditions That Are Likely to Result in a Permanent Impairment | NDIS' (30 June 2022)

<sup>&</sup>lt;a href="https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/list-b-conditions-are-likely-result-">https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/list-b-conditions-are-likely-result-</a> permanent-impairment>.

one or more impairments to which a psychosocial disability is attributable; and

- (b) the impairment or impairments are, or are likely to be, permanent; and
- (c) the impairment or impairments result in substantially reduced functional capacity to undertake one or more of the following activities:
  - (i) communication;
  - (ii) social interaction;
  - (iii) learning;
  - (iv) mobility;
  - (v) self-care;
  - (vi) self-management; and
- (d) the impairment or impairments affect the person's capacity for social or economic participation; and
- (e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.'

The requirement of s 24 ss 1 (a) of the *NDIS Act* is met, as ADHD is diagnosed as a neurodevelopmental disorder captured in the DSM-5.<sup>30</sup> This neurodevelopmental disorder creates a neurological impairment.

The requirement of s 24 ss 1 (b) of the *NDIS Act* is met, as ADHD creates an impairment that is permanent. While symptoms might change in severity over time, as social and physiological factors fluctuate, the impairment is always present.<sup>31</sup>

The requirement of s 24 ss 1 (c) of the *NDIS Act* is met, as the activities mentioned within this section are comparable to the impaired areas listed in the DSM-5. Requirement D of the DSM-5 diagnostic criteria for ADHD is "there is clear evidence that the symptoms interfere with, or reduce the quality of, social, academic or occupational functioning".<sup>32</sup>

The requirement of s 24 ss 1 (d) of the NDIS Act is met, as per the above.

The requirement of s 24 ss 1 (e) of the *NDIS Act* is met, as the sub section states "likely", which allows for instances when support for ADHD is not a lifelong requirement.

The impact of a particular disability and the corresponding service requirements/needs will differ greatly depending on the participants' age, culture, gender, sexuality, and even their personal goals. This is the case when a social definition of disability is applied, rather than a medical definition. A social definition of disability recognises that accessibility is determined by society, rather than the impairment itself.<sup>33</sup> The NDIS currently acknowledges this to be so, with the disabilities listed as a primary disability. The NDIS is failing to do this with ADHD.

## Recommendation:

4. The NDIS recognise ADHD as a primary disability.

<sup>30</sup> American Psychiatric Association, 'Diagnostic and statistical manual of mental disorders' (2013) (5th ed.),

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<sup>54.

31</sup> Margaret Sibley, '31.1 Variable Patterns of Remission from ADHD in the Multimosal Treatment Study of ADHD (MTA)' 60(10) Journal of the American Academy of Child & Adolescent Psychiatry 46.

32 DSM (n30), 60.

<sup>33 &#</sup>x27;Social Model Of Disability' <a href="https://www.afdo.org.au/social-model-of-disability/">https://www.afdo.org.au/social-model-of-disability/</a>.

## Term of Reference (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

This section centres its analysis around issues concerning the inadequacy of government services at the Commonwealth, state, and local level in addressing ADHD at all life stages. Specifically, we explore the limited national diagnostic guidelines and support available for older Australians in the 65+ age bracket and the inadequacies of congestion and wait times for ADHD diagnosis and prescriptions at the state level.

ADHD in older adults and available Commonwealth support

There is currently a lack of acknowledgement of ADHD experienced by older Australians in the requirements to access cover under the National Disability Insurance Scheme, notwithstanding the requirement of comorbidity to be eligible as ADHD is not recognised under the NDIS. The scheme requires that applicants be under 65 years of age at the time of application<sup>34</sup> which presents a clear barrier to the ability of older Australians to access ADHD support services later in life.

Such a barrier likely arises from the limited understanding present both in Australian and international research about a clear diagnostic tool to assess ADHD symptoms in older adults and hence older Australians are left out of significant discussions about ADHD onset symptoms. The available qualitative analysis of ADHD in older adults has found that 'the burden of ADHD across the life course' persists in reducing the income opportunities, financial stability, and quality of relationships with family and friends to overall result in a diminished quality of life.

According to available literature, this burden exists in older Adults with both diagnosed and undiagnosed ADHD and remains unaddressed by traditional ADHD diagnostic guidelines. In the Australian context, this is reflected in the most recent clinical guidelines released by the Australian ADHD Professionals Association (AADPA). While the guidelines acknowledge that 'symptom criteria should be considered based on age and developmental level'<sup>37</sup>, there is no clear direction provided to indicate how ADHD onset symptoms may differ in adults who are 65+, and this confusion correlates with the lack of NDIS guidelines or clear Commonwealth guidelines around older adult ADHD.

The current literature supports the likelihood that older adults experience ADHD differently to younger adults or children due to factors such as the maturation of the central nervous system and the likely comorbidity of other diseases 38. These findings have only been able to pinpoint 4 international studies in which participants over 50 years met all internationally accepted criteria of an ADHD diagnosis, demonstrating that in most cases, older adults experience ADHD symptoms differently to younger adults and children. [39]

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39 Ibid.

<sup>34</sup> National Disability Insurance Scheme Act 2013 (Cth) s22.

<sup>35</sup> Michielsen, M et al, 'The Burden of ADHD in Older Adults: A Qualitative Study. '(2018) 22(6) Journal of Attention Disorders 591–600.

<sup>36</sup> Ibid.

<sup>&</sup>lt;sup>37</sup> Australian ADHD Professionals Association, Australian Evidence-Based Clinical Guideline for ADHD Summary of Recommendations (Report, 2022) 6.

<sup>&</sup>lt;sup>38</sup> Goodman, D.W et al, 'Clinical Presentation, Diagnosis and Treatment of Attention-Deficit Hyperactivity Disorder (ADHD) in Older Adults: A Review of the Evidence and its Implications for Clinical Care. (2016) Drugs Aging 33, 27–36 (2016)

Such limited research about the differing ADHD symptoms present in older adults and their effects on the best pharmacological treatment requires for there to be more extensive research conducted in the Australian context. It is required that ADHD symptom definitions be refined for older adults and that treatment methods must take specifically into consideration older adults' coexisting conditions to ultimately incorporate these into future Commonwealth guidelines and to update NDIS recognition of older adult ADHD.

An interdisciplinary State-administered model of care to address system congestion

There is overwhelming evidence of rising wait times of up to two years around Australia for an ADHD diagnosis<sup>40</sup> largely due to a shortage in specialists. This issue has been exacerbated by the lack of an interdisciplinary model of care sponsored by State governments. The lack of a model of care which expands the ability of General Practitioners (GPs) to be involved in both the ADHD assessment process and repeated prescription writing is contributing to the congestion.

Currently, in New South Wales alone, it is estimated that 50-70% of paediatricians' workloads consist of ADHD patients<sup>41</sup> correlating with ADHD being the most common developmental disorder in young Australian children with approximately 5% having an ADHD diagnosis 42. This demonstrates that the issue of congestion not only affects those young people and families requiring ADHD assessment, but also has consequences for other young people with different paediatric care requirements.

While it may not be feasible to immediately increase the number of specialists available nationwide, it is possible to reduce the stress placed on psychologists and paediatricians through involving other 'extended-scope practitioners' (ESPs) such as GPs and nurse practitioners. 43 These ESPs would be capable of both assessing initial ADHD-presenting symptoms, and later, after an official diagnosis from a specialist, administering repeated prescriptions for pharmacological treatment44. The ability of GPs to write repeated prescription for ADHD patients through state-wide 'patient class' approvals'45 would significantly reduce stress on the specialist system.

Currently, similar systems adopting this interdisciplinary approach to ADHD assessment and treatment exist in Queensland and Western Australia (WA). The Queensland government administers Project ECHO - Enhancing Child Health Outcomes - which provides a virtual network for all professionals such as GPs, paediatricians and social workers involved in the ADHD diagnosis process to participate in regular case discussions and understand best

40 Andrew Whitehouse, 'Autism and ADHD assessment waits are up to two years. What can families do in the meantime?', 'University of Western Australia (Web Page, 2023) <

https://www.uwa.edu.au/news/Article/2023/April/Autism-and-ADHD-assessment-waits-are-up-to-2-years-long-What-can-families-do-in-the-

meantime#:~:text=Reports%20have%20emerged%20from%20around,deficit%20hyperactivity%20disorder%20

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<sup>(</sup>ADHD. >

All Richard Henry AM, Review of health services for children, young people and families within the NSW Health

system (Final Report, 2020) 77. ('Henry Review')
 Kids Health Information: Attention deficit hyperactivity disorder (ADHD)'. 'Royal Children's Hospital (Web Page, 2021) <

https://www.rch.org.au/kidsinfo/fact\_sheets/Attention\_deficit\_hyperactivity\_disorder\_ADHD/>

<sup>&</sup>lt;sup>43</sup> Community Development and Justice Standing Committee, Legislative Assembly, Parliament of Western Australia, Inquiry into the Adequacy of Services to Meet the Developmental Needs of Western Australia's Children (Final Report No.1, 2009) 97.

<sup>44</sup> Henry Review (n41) 78.

<sup>45</sup> Ibid.

practices. 46 This extends to include their General Practice Liaison program 47 which provides relevant training for GPs to update them with the latest ADHD assessment and reporting guidelines, ultimately creating a multidisciplinary approach to tackling ADHD. The Disability Services Commission in WA advocates for a multidisciplinary approach to tackling disabilities, in this case extended to the diagnosis and assessment of ADHD. 48

This model of care would require state governments to sponsor the training of GPs and nurse practitioners through ongoing communication and educational programs, particularly in rural and regional areas where the issue of wait times is most prevalent. <sup>49</sup> To best incorporate rural and regional professionals into the interdisciplinary approach, their local governments should set up communication hubs for complex case discussion.

### Recommendations:

- The Commonwealth government should sponsor closer study and research into the ADHD symptoms differing in older Australian Adults (65+) and publish these findings to ultimately incorporate them into the assessment requirements of the NDIS.
- State governments should adopt an interdisciplinary approach of service by incorporating ESPs such as GPs in the ADHD assessment and prescription delivery model and administer training programs for this to occur.

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

While it is argued that including NDIS as a primary disability will greatly increase the cost of delivering NDIS services, the current social economic costs of not creating NDIS supports far outweighs that. The evaluation completed by Deloitte Access Economics on behalf of Australian ADHD Professionals Association (AADPA), reviewed the health system costs, productivity costs and other financial costs. The non-financial costs, such as wellbeing were also considered. The study, found that ADHD is associated with substantial societal costs across the lifespan equating to 15,664 per person and approximately US\$12.76 billion in 2019 alone. There is evidence to suggest that the cost of raising a child with ADHD cost five times the usual amount for parents.

This section focuses on:

- Impact through comorbidities
- 2. The impact on the legal system
- 3. The difficulty quantifying the loss to innovation.

Impact through comorbidities

46 'Project ECHO'. 'Queensland Health (Web Page, 2021) <

https://www.childrens.health.qld.gov.au/chq/health-professionals/integrated-care/project-echo/ > 47 Ibid.

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<sup>&</sup>lt;sup>48</sup> Disability Services Commission WA '. 'National Disability Advocacy Framework (Web Page, 2021) <a href="https://engage.dss.gov.au/ndaf-submissions/1437637358/">https://engage.dss.gov.au/ndaf-submissions/1437637358/</a>>

<sup>&</sup>lt;sup>49</sup> Natasha May, 'Rural Australians are facing life-threatening wait times for medical specialists', *The Guardian* (online, 2 November 2021) < https://www.theguardian.com/australia-news/2021/nov/02/rural-australians-are-facing-life-threatening-wait-times-for-medical-specialists>

<sup>&</sup>lt;sup>50</sup> Emma Sciberras et al, 'Social and Economic Costs of Attention-Deficit/Hyperactivity Disorder Across the Lifespan' (2022) 26(1) *Journal of Attention Disorders* 72.

<sup>&</sup>lt;sup>51</sup> Ibid, 81.

<sup>52</sup> Ibid, 82.

ADHD remains under diagnosed. Untreated ADHD can result in comorbid diagnosis such as anxiety and depression. <sup>53</sup> While efforts have been made to capture the social and economic impact of ADHD, this assessment is limited in so much as diagnosis remains low. Some of the costs associated with other disorders may be lessened if ADHD were to be suitably treated in the first place. This is to say, if the ADHD symptoms were appropriately addressed, it might be possible to prevent further disorders from occurring.

## Impact on legal system

There appears to be a correlation between ADHD and criminal behaviour. The Deloitte report notes, 'an extra 8,500 criminal acts and an extra 1,400 imprisonments or community service orders due to ADHD in 2019'. This has been attributed to the impulsivity demonstrated by people with ADHD as well as self-medicating using drugs and alcohol.<sup>54</sup>

In addition to the evidence that those with ADHD demonstrate a higher likelihood of engaging in criminal behaviour, there is also evidence to suggest people with ADHD are vulnerable to falling victim to criminal behaviour. 55 People with ADHD may not pick up on the same emotional cues, regulate their emotions in order to physically protect themselves, or judge risk in the same manner. This can result in them being taken advantage of.

While further research may be done to better understand the number of people with ADHD interacting with different aspects of the Australian legal system, it should be accompanied by research on how this can be rectified. As with other overrepresented groups, for example Aboriginal and Torres Strait Islander people or LGBTIQA+ people, overrepresentation in systems is a symptom of discrimination in community.

### Quantifying the loss of atypical contributions

It is challenging to quantify the social and economic loss to society when ADHD goes untreated as the metrics commonly applied to these equations do not capture atypical contributions to society. Those with ADHD have numerous strengths that are underutilised and under appreciated by society, such as "right-hemisphere bias, creativity, solving problems with insight, self-transcendence and novelty seeking". Some of these strengths can translate into tremendous contributions into workforce productivity if the environmental factors take the persons' differences into account. There are other people with ADHD however, whose contributions are not so easily quantifiable as they are not attached to a productivity or monetary value.

## Recommendation:

- Increase support for neurodiversity in education and employment, reducing comorbidities and interactions with the justice system.
- Ensure any further research on social impact of ADHD considers the positive contributions that come from ADHD in supported environments.

## Term of Reference (I): any other related matters

Commented [NM15]: "Some of these strengths may contribute tremendously to workforce productivity"

<sup>&</sup>lt;sup>53</sup> Joseph Sadek, Clinician's Guide to Adult ADHD Comorbidities Case Studies (Springer International Publishing, 1st ed. 2017., 2017).

<sup>54</sup> The Social and Economic Costs of ADHD in Australia (Deloitte Access Economics)

<sup>&</sup>lt;https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-economics-social-costs-adhd-australia-270819.pdf>.

<sup>&</sup>lt;sup>55</sup> Brian T Wymbs and Christine A Gidycz, 'Examining Link Between Childhood ADHD and Sexual Assault Victimization' (2021) 25(11) *Journal of Attention Disorders* 1612.

<sup>&</sup>lt;sup>56</sup> Bruce Arnold et al, 'it Just Doesn't Add up: ADHD/ADD, the Workplace and Discrimination' (2010) 34(2)
Melbourne University Law Review 359 ('it Just Doesn't Add Up'). P371

## Assessment and support services for people with ADHD Submission 154

The focus of this inquiry has been on how we respond to high levels of ADHD in our community from a medical and social services lens. The medical approach has been critiqued by sociologists and advocates as being reductive. <sup>57</sup> This is a deficit focus. It is a focus on what supports need to be provided to the individual, so disadvantage isn't experienced by the individual.

The ANU LSRJ encourages a greater discussion about how we are structuring society so that neurodivergence is not such an anomaly. With person-centred education, health and justice systems, the need to pathologize and treat could be significantly reduced. By creating social, economic, and legal structures that better embrace diversity and appreciate all contributions to society, disadvantage would be reduced. While strides have been made at the Federal Level in recent months to introduce gender-responsive budgeting, and including a First Nations voice to parliament, governments continue to invest in band-aid solutions to intersectional disadvantage, rather than overhauling systems that continue to deepen disadvantage. Every legal reform and policy decision has ramifications for those with intersectional disadvantage.

An example is Australia's current approach to education. The education system is structured to and funded to deliver a curriculum with consideration of a neurotypical developmental arc and learning style. If someone with ADHD does not learn in that manner, they are left behind, placed in a special needs stream or if they are lucky, provided with an in-classroom teaching aid. There is little consideration of how the teaching environment might be altered to reengage the student with ADHD – when the change might benefit neurotypical students too. ADHD students learn to minimise their learning needs, adjust their goals and expectations, as the learning opportunities are not available to them.

While the ANU LSRJ recognises that access to NDIS would be invaluable for people of all ages with ADHD, providing reactive services should not be the end of the story. It is an interim measure, and an equaliser given the NDIS is the primary response to disability in community, but it should not be the final solution.

### Recommendation:

9. Federal, state and territory governments must embrace law and policy setting processes that consider and address intersectional disadvantage.

<sup>&</sup>lt;sup>57</sup> Brenton Prosser, 'Attention Deficit Hyperactivity Disorder in Australia: Perspectives from the Sociology of Deviance' (2015) 51(3) *Journal of Sociology* ('Attention Deficit Hyperactivity Disorder in Australia').

<sup>&</sup>lt;sup>58</sup> Nardia Zendarski et al, 'Examining the Educational Gap for Children with ADHD and Subthreshold ADHD' (2022) 26(2) *Journal of attention disorders* 282.

<sup>&</sup>lt;sup>59</sup> Denise Nash-Luckenbach, 'Exploring Learning Style Preferences of College Age Students with Attention Deficit Hyperactive Disorder (ADHD)' (ProQuest Dissertations Publishing, 2019)

<sup>&</sup>lt;https://search.proquest.com/docview/2323127749?pq-origsite=primo>.