SUPPORT

CANBERRA + QUEANBEYAN

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SENATE INQUIRY INTO BARRIERS TO CONSISTENT, TIMELY AND BEST PRACTICE ASSESSMENT OF ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD) AND SUPPORT SERVICES FOR PEOPLE WITH ADHD

SUBMISSION

Summary

1. Attention deficit hyperactivity disorder (ADHD) is one of the most common neurobiological conditions affecting children, adolescents, and adults. Behavioural symptoms of ADHD include inattention, hyperactivity and impulsivity while core condition symptoms include impaired executive functioning, reduced distractor inhibition and inability to self-regulate. It is a complex condition, does not consist of only one thing and each person is impacted differently. ADHD is misunderstood and has been used pejoratively and usually supported by ill-informed explanations including poor parenting and poor behaviour which has promoted stigma and ignorance.

2. The prevalence rate in Australia is no less than 7%. From a *lived experience* perspective, although ADHD is an "incurable" neurobiological condition it can be successfully managed through life if accurately diagnosed in the first instance, with early interventions using a multi-modal approach i.e. use all the tools in the toolbox. There is no singular 'silver bullet' or a curative medication as there is for a curable disease.

3. Failure to responsibly address ADHD as a significant national health issue increases the already high risk of inter-generational harm with consequential impacts not only on community health, social well-being and productivity but ultimately the national economy. The recommendations flowing from 2020 Productivity Commission Inquiry Into Mental Health are strongly supported as they are directly related to ADHD. Enabling their implementation should be the highest priority.

4. A 2019 Deloitte Access Economics report estimates the cost of ADHD to the community in the order of $20 Billion. It recommends a continued and sustained need to raise awareness of the socioeconomic burden of ADHD in Australia and educate and inform key stakeholders including individuals, education departments, youth and justice systems, workplaces, governments and society at large in an attempt to reduce the burden and lifelong impact of ADHD.

5. Barriers to access posed by the critical shortage of psychiatrists and psychologists which exacerbates the situation for adults with ADHD who are targeted by exclusion. The reasons for this exclusion need to be explored and challenged. Access to assessment services and *accurate* diagnosis of ADHD is exceedingly poor to almost non-existent in regional, rural, remote and indigenous communities in Australia. Current public and private mental health services and supports have not kept pace with demand for services related to ADHD and comorbid conditions.

6. Cost in accessing limited services is a major barrier for the most vulnerable, the poor, those on low incomes, single parents and for those in rural, remote and indigenous Australia. Undiagnosed, misdiagnosed, untreated and mistreated ADHD is a significant cause for school dropout, a direct pathway to the justice system and a significant contributor to suicide. All this must be and can be corrected.

7. Many psychiatrists and clinicians have closed their books because of demand. ADHD patients have no alternative but to rely on the private sector as the public system rarely treats ADHD and in any case is overwhelmed. As a result, those who might choose to wait longer for affordable care are being forced to choose between high fees and excessive out-of-pocket expenses, or no care at all.

8. Many primary and high schools are experiencing increase in anti-social student behaviour, some of which can be attributed to diagnosed and undiagnosed ADHD causing inability to self-regulate emotion, which with empathy, effort and persistence can be successfully addressed. It should be of concern that some schools have an active policy of not registering or accepting children who may have an assessment or diagnosis of ADHD. Some schools even request removal of the child from the school altogether if assessed or diagnosed with ADHD. This is not only traumatic for all concerned but is discriminatory, adds to stigma and contributes to even more harm.

9. Each State and Territory has differing legislation, regulation and policy dealing with ADHD stimulant medication prescription which adds additional burden and cost for those moving across borders. Harmonisation of relevant legislation and regulation dealing with ADHD should be a priority.

10. Unless another disability or another mental health condition exists, children, adolescents and adults with ADHD that results in impairment cannot access NDIS services. NDIS provisions should be immediately extended to cover ADHD which negatively impacts daily living and compromises and impairs life quality.

11. In relation to Clinical Guidelines for the assessment, diagnosis and treatment of ADHD, accuracy of diagnosis remains a key issue, as diagnosis still relies on behavioural observations of a *neurodevelopmental* rather than a *neurobiological* condition and some neuroscience evidence has not been entertained or has been excluded. Bias and some disputation exist within and between professionals which in turn eschews innovation, some related neuroscience and the application of technology. The Guidelines do not adequately address ADHD-impacted adults, adolescents, families, parents, educators, schools or employers.

12. ADHD remains debilitating into adulthood. Coping mechanisms come with significant personal and social costs. It is unacceptable to effectively write off the possibility of improved life chances for those who missed diagnosis in childhood due to narrow behaviour-based criteria and conceptions dealing with ADHD, a *neurobiological* condition. There are many 'high performers' in all human endeavours, including in science, technology, research, the arts, professional disciplines, business and sport who have been negatively impacted by ADHD but identified in early life how to successfully manage the condition when compromised.

13. In coordination with Primary Health Networks there should be more investment in general practice with education and training to accredit GPs for ADHD assessment and what to do about it, and reinstatement of mental health nurses in general practice so that ADHD is brought back into primary health care. Significant benefit would also accrue through innovation by adopting proven technology to significantly enhance early diagnostic accuracy.

SENATE INQUIRY INTO BARRIERS TO CONSISTENT, TIMELY AND BEST PRACTICE ASSESSMENT OF ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD) AND SUPPORT SERVICES FOR PEOPLE WITH ADHD

SUBMISSION

Introduction

1. Attention-deficit/hyperactivity disorder (ADHD) is one of the most common neurobiological conditions affecting children, adolescents, and adults. Behavioural symptoms of ADHD include inattention, hyperactivity and impulsivity while core condition symptoms include impaired executive functioning and reduced distractor inhibition. It is a complex condition, does not consist of only one thing and each person is impacted differently.

2. An accurate assessment and diagnosis of ADHD requires a negative impact on adaptive functioning in everyday life to be observed in terms of reduced quality of life in the family, social, academic or work domains. Authoritative, evidence-based research reveals an ADHD prevalence rate of 7%. Despite popular opinion to the contrary, ADHD symptoms[1] persist into adulthood for at least two thirds of children[2] who have been diagnosed early. Evidence-based research in Australia also reveals that no less than 6.2% of middle-aged Australians may “have (test) scores previously associated with ADHD diagnosis” and that the male to female ratio is 1:1[3]. This is a large slice of the Australian population with significant risks and negative consequences particularly where there is inadequate or no access to accurate assessment, diagnosis and effective interventions, treatment and management. Even with accurate assessment and diagnosis, suitable interventions and management regimes can be difficult to determine. Assuming an accurate diagnosis, in many cases appropriate interventions treatment regimens are denied for public health patients, particularly the most vulnerable in our communities including those in regional rural, remote, indigenous Australia and other culturally and linguistically diverse communities.

14. Although ADHD is not "curable" it can be effectively treated and managed if accurately assessed and diagnosed at the outset, with early intervention using "all the tools in the tool box" approach i.e. evidence-based multi-modal pharmacological and non-pharmacological interventions, treatment and management. There are many 'high performers' in all human endeavours, including in science, technology, research, the arts, professional disciplines, business and sport who have been negatively impacted by ADHD but identified in early life how to successfully manage the condition when compromised.

3. Based on *lived experience* and information provided by our local ADDACT support group members and our Australia-wide ADHD consumer community contacts, we are acutely aware that un-diagnosed, misdiagnosed and mis-treatment of ADHD has produced an unfair and deleterious impact on the health, well-being, education and work opportunities for children, adolescents and adults negatively impacted by ADHD, as well as their families, schools, institutions, employers and ultimately the national economy and national productivity.

4. Locally and across Australia, community-based volunteer support groups and some well-informed clinicians and practitioners continue to express acute concern for those negatively

[1] Graetz et al, 2001
[2] Wender et al, 2001
[3] Das et al., 2012

impacted by ADHD. The 2020 Productivity Commission's Mental Health Inquiry resulted in a series of recommendations for mental health system reform. The 2020 report addressed the key factors for improving access to the Australian mental health system for all people including those in regional and remote Australia. They are:

4.1. Improved access to the right services at the right time.

4.2. Better local level planning to identify the services required.

4.3. Better use of technology.

4.4. Development of strategies to grow the mental health workforce.

5. In respect of ADHD and comorbid conditions, ADDACT supports the Commission's recommendations and strongly urges their implementation. Failure to responsibly address ADHD as a significant national health issue increases the already high risk of inter-generational harm with consequential impacts on community health, social well-being, productivity and ultimately the national economy.

6. In noting the Government's commitment to research and mental health reform it is respectfully pointed out that ADHD is one of the most researched paediatric conditions in the world. It seems irrational to not utilize this great body of evidence-based research in formulating and implementing sound, un-biased ADHD health policy and identifying areas and gaps for further research and updating.

Term (a) - Adequacy Of Access To Assessment And Diagnosis Of ADHD

7. Access to assessment services and *accurate* diagnosis of ADHD is limited and is exceedingly poor to almost non-existent in regional, rural, remote and indigenous communities in all States and Territories in Australia. Current public and private mental health services and supports have not kept pace with demand for services related to ADHD and comorbid conditions.

8. Despite public information to the contrary, the prevalence rate of ADHD has most likely remained relatively stable but until recently has not been observable for many reasons. As the need for services has grown, so have waitlists. The growth of the need for services is resultant from better community awareness locally, nationally and globally that ADHD is a real condition and not as a result of myths portraying ADHD as that it does not exist, that it is as a result of "poor parenting" or ill-disciplined behaviour, or other disinformation which for many years has been liberally and sensationally broadcast in mass and social media.

9. Many psychiatrists and clinicians have closed their books because of demand. ADHD patients - particularly adults - have no alternative but to rely on the private sector as the public system rarely treats ADHD for adults. And in any case the public health system is as overwhelmed as the private sector. As a result, those who might choose to wait longer for affordable care are being forced to choose between high fees and excessive out-of-pocket expenses, or no care at all.

10. Most if not all primary and high schools are experiencing a large uptick in student behavioural issues, some of which can be attributed to ADHD. It should be of concern to all that a number of parents and teachers have advised us that some schools have an active policy of not registering or accepting children who may have an assessment or diagnosis of ADHD. Furthermore some schools even request removal of the child from the

school altogether if assessed or diagnosed with ADHD. This is not only traumatic for all concerned but discriminatory and adds to stigma. Regrettably, ADHD is not categorised as a condition in the Disability Discrimination Act although many of the comorbid conditions are.

11. We have reports that a number of clinics only offer telehealth appointments, with exceedingly high fees delivering a quick turnaround for patients seeking an ADHD diagnosis. There is no follow-up or support. This is clearly price gouging with an unacceptably high risk of misdiagnosis, most likely inappropriate consequent treatment and further harm causation.

12. Local and regional ADDACT members and other Australia-wide contacts also report the following:

    12.1. Inability to obtain timely assessment and diagnosis for ADHD which can be compounded by co-morbid conditions. This is of particular concern for the most disadvantage and vulnerable in our society.

    12.2. Access to timely assessment, diagnosis, interventions and management of a significant condition such as ADHD should be a fundamental right for all Australians in a first world wealthy country like Australia.

    12.3. Unless one can afford to pay for a psychologist as well as a paediatrician and/or psychiatrist there is little to no access.

    12.4. There are few trained and experienced clinicians and practitioners who are ADHD specialists.

    12.5. Medication is the first line of treatment and should not be.

    12.6. Different rules apply in different States and Territories for medication prescription and renewals.

    12.7. Most GPs are not well informed or trained to identify ADHD and related conditions or how to obtain reliable assessment or accurate diagnosis.

    12.8. Symptoms of many related conditions - e.g. autism, learning disorders, dyslexia, executive function disorder, oppositional defiance disorder etc - overlap and often mask ADHD in turn resulting in inaccurate assessment and diagnosis.

    12.9. It takes months to produce an *accurate* diagnosis of ADHD as it is a complex condition.

    12.10. Inaccurate assessment and misdiagnosis results in interventions and pharmacological and non-pharmacological treatments which are sub-optimal or worse, contribute to harm.

    12.11. It takes more than 12 months to obtain appointments for ADHD assessment and diagnosis.

    12.12. ADHD specialist clinicians are overloaded by demand with few being able to take on new clients/patients.

    12.13. Many people in regional, rural and remote Australia are referred to major urban centres where more services and trained ADHD specialists are more likely to be found.

12.14. Medicare rebates limit access, and costs of services are prohibitive particularly for the disadvantaged and most vulnerable.

12.15. Assessment and diagnosis are based on the DSM-V which relies on *behavioural* symptoms, whereas ADHD is a *neurobiological* condition and the new Australian Guidelines on the assessment, diagnosis and treatment of ADHD appear to ignore this.

12.16. With poor or no access to assessment and accurate diagnosis of ADHD and the negative impacts of misdiagnosed or undiagnosed ADHD, quality of life can be severely compromised, school truancy and school drop-out will continue, anti-social behaviour, suicide ideation and acts of actual suicide will all increase. As a result and without corrective action, public hospitals, education, youth and justice systems will remain ill-equipped to deal with the consequences.

12.17. The public health system caters for children with ADHD, but not adults.

Recommendations

13. The following recommendations are based on ***lived experience***. Incorporation of a co-development approach with a wide cross section of ***lived experience*** is fundamental in each of the following recommendations:

13.1. In coordination with Primary Health Networks invest more in general practice and reinstate mental health nurses so that ADHD is brought back into primary health care.

13.2. Design, develop and deliver professional development training and education to upskill GPs and mental health nurses in all Australian States and Territories on ADHD and related conditions. Such training and education should incorporate *lived experience*.

13.3. Train and accredit GPs with a specific interest in ADHD and mental health to they are capable of providing assessment, diagnosis and ongoing management of ADHD and related conditions, to bypass long waiting lists for specialist appointments, which will only get longer as time progresses.

13.4. Allow GPs in Australian States and Territories to work cooperatively alongside Paediatricians until the GPs are accredited as trained, capable and allowed to work independently.

13.5. Noting the prevalence rate of ADHD, revise professional medical and mental health education curricula and syllabi to adequately address ADHD (and comorbid conditions) by devoting more time to the ADHD condition and in more detail. Any and all education content revisions should incorporate *lived experience*.

13.6. As ADHD is a neurobiological condition, improve the accuracy of assessment and diagnosis by applying and integrating proven technology with traditional assessment and diagnostic tools.

13.7. Design develop and incorporate case management, monitoring and evaluation of any and all ADHD treatment interventions with results fed into a national database for analysis and research.

13.8. Review and accept relevant Recommendations made to the Department of Education, NSW and this Senate Inquiry if any, by Parents for ADHD Advocacy

Australia (https://parentsforadhdadvocacy.com.au) and other like-minded ADHD support groups.

13.9. Consult with, review and consider relevant policy recommendations made by the Australian Education dealing with ADHD.

13.10. Design and develop a Strategic Research Plan to:

13.10.1. Undertake wide consultations with professionals and particularly ADHD consumers with *lived experience* as part of a national ADHD Gap Analysis to identify ADHD knowledge gaps and future needs.

13.10.2. Produce a Program of Research Action Plans to address practical and applied ADHD research priorities matched to the Gap Analysis and needs, including necessary resources, and implement the Program. Review and evaluate the Action Plans and their implementation annually.

13.11. Review and update the national Guidelines on the Assessment, Diagnosis and Treatment of ADHD every 2 years at a minimum, ensuring that the Guidelines not only cover the needs of Clinicians but also the needs of all those who are negatively impacted by ADHD. This could be achieved by the development and incorporation of Fact Sheets and plain language Annexes pitched for all those negatively impacted by ADHD including children, adolescents, parents, families, spouses, schools, teachers, educators, universities, employers, managers and governments.

13.12. Regulate the growing trend of telehealth diagnosis aimed at promoting integrity and eliminating questionable practices and price gouging.

13.13. Make access affordable through the medical benefits scheme and equity requires that those diagnosed with ADHD in their adulthood be catered for by the public health system.

Term (b) - Adequacy Of Access To Supports After ADHD Assessment

14. Local ADDACT members and Australia-wide contacts are unanimous in reporting that current ADHD supports are poor, not easily accessible, expensive and have not kept pace with demand. Hence the need for community based volunteer support groups both physical and virtual. Despite best efforts of these volunteer support groups, awareness of what is available is poor with little to no active services and supports for ADHD outside major population centres in regional, rural, remote and indigenous Australia.

15. Regrettably, last year the Department of Health unilaterally suspended and currently seeks to terminate a Commonwealth Grant Agreement for the operation of a truly national ADHD consumer support organisation, without citing any reason for doing so. The Grantee organisation made all necessary arrangements ready to commence operations including incorporation and registration with the Australian Charities and Not-for-profit Commission (ACNC). The Commonwealth withdrew funding the day before the first payment under the Grant Agreement was due thus denying a pathway to governments to voice matters directly related to this Inquiry.

16. Cost is a major issue for all but in particular for the most vulnerable, the poor, those on low incomes single parents and those in rural, remote and indigenous Australia.

17. There are few ADHD specialists within the mental health, medical and allied health professional communities. It is regularly reported that diagnostic and clinical services actively avoid treating or assisting in managing complex ADHD. This is compounded by the fact that Medicare subsidies (for ADHD) are either insufficient or inefficient. A Mental Health Plan consisting of 10 visits to a professional practitioner per year is insufficient to cover complex ADHD where moderate to severe impairment exists. And public hospitals are generally geared for children with suspected or diagnosed ADHD, but not adults.

18. A marked increase in ADHD Coaching support services - based on life coaching - has been noted, but these support services require more research and evaluation to assess value and efficacy. There is great variance to how ADHD coaches are trained, how coaching programs are delivered (i.e. by group or individual), duration of services and programs, professional fees and evaluation of efficacy or outcomes.

19. Growth of telehealth services purportedly for ADHD offer telehealth appointments for high fees, deliver a quick turnaround for patients seeking diagnosis and are therefore questionable.

20. Each State and Territory has differing legislation, regulation and policy dealing with Schedule 8 prescription stimulant medication for ADHD. This adds an additional burden, including cost, on those with ADHD requiring medication repeats when moving across borders and in many cases limits access even more.

Recommendations

21. In addition to the recommendations under TOR (a) above we also recommend:

    21.1. Review Commonwealth State and Territory Legislation and Regulations in respect of Schedule 8 stimulant medication with the objective to harmonise Commonwealth, State and Territory Legislation and Regulation dealing with controlled prescribing of Section 8 stimulant medication for ADHD.

    21.2. Make access affordable through the medical benefits scheme and equity requires that those diagnosed with ADHD in their adulthood be catered for by the public health system.

    21.3. Re-instate adequate funding to commence the operation of the *independent* national ADHD consumer organisation in line with the Parliamentary Mental Health Reform Program to provide a single independent ADHD voice for all ADHD consumers.

    21.4. Promote and materially support all community-based volunteer ADHD consumer support groups which undertake all the heavy lifting.

    21.5. Develop appropriate Australian standards and regulate the growing trend of telehealth diagnosis aimed at promoting integrity and eliminating questionable practices and price gouging.

    21.6. Develop appropriate Australian standards for ADHD coaches and their services to cover Australian professional standards for coach education, training, accreditation and services delivery.

Term (c) - Availability, Training And Attitudes Of Treating Practitioners Including Workforce Development Options For Increasing Access To ADHD Assessment And Support Services

22. As demand drives the need for more services waitlists have also grown. We have been advised that many psychiatrists have closed their books because they have been overwhelmed. In addition, Specialists can set their own fee and there is no cap. Unlike in most fields of medicine, adult ADHD patients have no other option but to remain in the private health sector as the public health system rarely treats ADHD except in children. Thus the most vulnerable in our society are burdened with the risks of no assessment, no diagnosis and diagnostic substitution (to defray high costs and out of pocket expenses) with consequent mistreatment and potentially more harm. This also holds equally true for regional, rural, remote and indigenous Australia.

23. Our members and contacts have advised of long waitlists. In some cases financial "incentive" has been suggested so that individuals can be afforded higher priority on these waitlists. As a consequence, those who may choose to wait longer for affordable care are forced to choose between higher fees or no care. This is clear exploitation of some of the most vulnerable in our society.

Recommendations

24. We recommended:

    24.1. In coordination with Primary Health Networks, bring ADHD into primary care i.e. into the hands of ADHD-accredited GPs.

    24.2. Reinstatement of mental health nurses in GP practices including ADHD-accredited GP practices.

25. See other relevant recommendations in TOR (a) (b) and (c) above.

Term (d) - Impact Of Gender Bias In ADHD Assessment, Support Services And Research

26. Supported by much evidence openly available, our local and regional members and contacts have regularly reported that a bias exists in assessment, diagnosis and support for boys as they appear to be more prone to being assessed and diagnosed with ADHD than girls. The reason for this is that boys seem to get the most attention when unable to inhibit, regulate or control emotion and consequent negative behaviours. Evidence-based research in Australia reveals however, that 6.2% of adult Australians “have (test) scores previously associated with ADHD diagnosis” and that the male to female ratio is 1:1[4]. This means that female children and adolescents are not "seen" to exhibit some of the observable traits and behaviours of ADHD and are therefore overlooked. This is a most common and unanimous sentiment expressed by adult female members of ADDACT who have been assessed and diagnosed as an adult. All have expressed the strong view that early intervention would produce positive results earlier.

27. In addition we are aware of incidences where people who identify as being LGBTIQ have either been ignored or misdiagnosed, with many not seeking assessment and diagnosis because this may be seen as adding to the stigma that already exists.

Recommendations

28. In addition to relevant recommendations in the other sections above, we recommend the following:

[4] Das et al., 2012

28.1. Provide modest Commonwealth funding to design, develop and deliver an informed, consistent, evidence-based, national ADHD awareness program in all States and Territories commencing with public and private schools through to sector/industry workplaces. This could be co-designed with the aforementioned national ADHD consumer organisation and other ADHD consumer support groups.

28.2. Encourage, support and provide modest funding to develop a well-considered 5-Year Program of Research Action Plans to address practical and applied ADHD research priorities including the necessary resources, and implement the Program. Review and evaluate the Action Plans and their implementation annually. This could be a collaborative project of the aforementioned national ADHD consumer organisation and/or ADHD consumer support groups with the Australian ADHD Professional Association (AADPA). Any such plan, its research activities and its continuity should be independently reviewed and evaluated annually.

Term (e) - Access To And Cost Of ADHD Medication, Including Medicare And Pharmaceutical Benefits Scheme Coverage And Options To Improve Access To ADHD Medicines

29. See relevant comments above.

Recommendation

30. Make access affordable through the medical benefits scheme and equity requires that those diagnosed with ADHD in their adulthood be catered for by the public health system.

Term (f) - The Role Of The NDIS In Supporting People With ADHD With Particular Emphasis On The Scheme's Responsibility To Recognise ADHD As A Primary Disability

31. NDIS does not cover ADHD but it does cover the comorbidities. NDIS cover should be extended to all those with ADHD which negatively and severely impacts daily living and compromises life quality. Unless a person has another disability or another mental health condition, children, adolescents and adults with ADHD that results in impairment cannot access NDIS services at all.

Recommendation

32. Review and revise relevant legislation, regulation and policies to enable the inclusion of ADHD negative impacts in the NDIS.

Term (g) - Adequacy Of And Interaction Between Commonwealth, State And Local Government Services To Meet Needs Of People With ADHD At All Life Stages

33. Our members and contacts report that such interaction does not happen.

34. We acknowledge and agree the issues and disconnects as presented in the 2020 Final Report of the Productivity Commission's Inquiry into Mental Health as being most relevant to this Senate Inquiry into ADHD. See our references and comments in relation to the Productivity Commission's Report at para 37. below.

Term (h) - Adequacy Of Commonwealth Funding Allocated To ADHD Research

35. There seems to be no clarity around this matter. See paras 13.10, 13.11 and 27. above.

Term (i) - Social And Economic Impact Of Costs Of Failing To Provide Adequate And Appropriate ADHD Services

Productivity Commission Inquiry Into Mental Health, 2020

36. The Productivity Commission commenced an inquiry into mental health in 2018. Its final report was released publicly on 16 November 2020. The report discusses key influences on people's mental health, examines the effect of mental health on people's ability to participate and prosper in the community and workplace, and implications more generally for our economy and productivity. The inquiry noted that mental ill-health affects all Australians, either directly or indirectly through families, colleagues or friends. But Australia's mental health services and supports have not kept pace with demand for services. Although ADHD was not specifically mentioned in the report, its influences and effects on mental health and issues are as relevant as any other mental ill-health condition.

37. The Commission's final report recommends that Commonwealth, State and Territory Governments improve the mental health of people of all ages and cultural backgrounds, by working with people who have experience of mental illness, and with their families and carers to extend reform to the mental health system across workplaces, schools and universities, the justice system, community groups and services for healthcare, psychosocial support, and housing. It also provided the Australian Government with a series of recommendations to create a mental health system that:

    37.1. Places people at the centre of the design and delivery of all community and clinical mental health support services.

    37.2. Adopts a whole-of-life approach based on early intervention and prevention that empowers consumers and their families and carers, and supports them to maintain their health and recover within their community.

    37.3. Improves access to the right services at the right time — local-level planning for what services are required, better use of technology, and strategies to grow the workforce are key factors in improving access for people, especially in regional and remote Australia.

    37.4. Recognises that the value of a service is the value of the outcome to the person using the service and ensures that services are monitored and evaluated on the basis of these consumer-centred outcomes.

Deloitte Access Economics Estimate of the Socioeconomic Cost of ADHD, 2019

38. In 2019, Deloitte Access Economics was commissioned by AADPA to estimate the socioeconomic cost of attention deficit hyperactivity disorder (ADHD) in Australia. Evidence was presented in the Deloitte final report which addressed the cost burden of ADHD in Australian community which included costs to the health system, productivity and carer costs, other financial costs and quality of life. The key findings included:

    38.1. ADHD affects approximately 281,200 children and adolescents (aged 0-19) and 533,300 adults (aged 20+) *diagnosed* in Australia. Prevalence is highest during childhood and appeared to decline with age. (ADDACT Comment: the decline is

probably due to some people learning to self-manage their ADHD over time and therefore uncounted.)

38.2. The total cost of ADHD in Australia was estimated to be $20.4 billion, which comprised $12.8 billion in financial costs and $7.6 billion in wellbeing costs.

38.3. Productivity costs resulting from reduced workforce participation, absences from work and reduced productivity while at work make up 81% of total financial costs. The remaining financial costs include deadweight losses (11%), health system costs (6%) and other costs (e.g. justice system costs or education costs).

39. The evidence in the Deloitte report suggests there is a continued need to raise awareness of the socioeconomic burden of ADHD in Australia and educate and inform key stakeholders including individuals, education departments, youth and justice systems, workplaces, governments and society at large in an attempt to reduce the burden and lifelong impact of ADHD.

Recommendations

40. We recommend:

40.1. The *2019 Deloitte Access Economics Report of the Socioeconomic Cost of ADHD* in Australia be accepted as a benchmark, that to prevent further intergenerational harm resources be made available to review and update this Report before national budget formulation in 2024, and a plan of action be developed to implement recommendations with priority.

40.2. The *2020 Productivity Commission Report Into Mental Health* be accpeted as a benchmark for co-design, planning and implementation of recommendations as a matter of priority.

Term (j) - The Viability Of Recommendations From The Australian ADHD Professionals Association Australian Evidence-Based Clinical Practice Guideline For ADHD

41. The 2022 Australian Guidelines are heavily dependent on the UK NICE Guidelines and supporting research. As acknowledged in the current Guidelines, similar Clinical Guidelines developed for the UK, European and Northern American regions rely on a categorical diagnosis approach, based on the DSM or ICD classifications (Razzak et al., 2021). The authors of the Australian Guidelines also acknowledge that similar international Guidelines, including the UK's NICE Guidelines "All recommended using interview and questionnaires, as well as multiple informants, as key components of the diagnostic process".

42. We disagree with the assertion that direct "observations such as observing children in their educational setting, neuropsychological and psychoeducational assessments, computerised cognitive assessments, neuroimaging and electroencephalography (EEG) did not increase the accuracy of diagnosis." We note there has been other professional disputation with this assertion which has not been acknowledged by the authors. In short, assessment and diagnosis of ADHD and its accuracy still relies on behavioural observations of ADHD as a *neurodevelopmental* issue and some neuroscience evidence has not been entertained or excluded.

43. As ADHD is an acknowledged *neurobiological* condition, we note bias and disputation exists within and between professionals which in turn eschews innovation and related neuroscience. We also note continued assessment and diagnostic focus remains on

behavioural symptoms based on narrow criteria. ADHD remains debilitating in adulthood. Coping mechanisms come with significant personal and social costs. It is unacceptable to effectively write off the possibility of improved life chances for those who may have missed a diagnosis in childhood due to narrow behaviour-based criteria. Given the high heritability of ADHD and potential negative impacts on outcomes for children of undiagnosed and untreated adult parents the ADHD Guidelines do not appear to take into account the significant risks of intergenerational impact and harm.

44. The Guidelines also appear to avoid indicating the risk of suicide or at least suicide ideation when recommending ADHD medication as a line of treatment, particularly for children. A warning as to this risk is not evident. It has also been brought to our attention that Guidelines refer to evidence which may actually be opinion which can be challenged.

45. We are also aware of a high dependency by AADPA on pharmaceutical companies for financial support. This extends to research by AADPA members and professional and open forum events to discuss ADHD. At the very least, this gives rise to a perception of "conflict of interest".

46. In summary, we believe there has been a missed opportunity with the development of these Guidelines. See related recommendations above, in particular those at para 14.10 and 14.11.

Term (k) - International Best Practice For ADHD Diagnosis, Support Services, Practitioner Education And Cost

47. We advise the Senate Inquiry of a recent development (May 2023):

    47.1. A Canberra-based GP and Member of the RANZGP's Specialist Interest Group for ADHD and Autism has been recently awarded a Churchill Fellowship to "conduct international research on models of care for ADHD diagnosis and management". He has already departed Australia to undertake this research task in Sweden, the Netherlands, UK, Ireland and the United States to research "models of care to increase accessibility for diagnosis and management of ADHD".

    47.2. From a *lived experience* perspective, we provided Information Briefs on ADHD issues to the Churchill Fellowship Awardee and in preparation for his departure to Europe convened two meetings to discuss the key issues faced in Australia. He also accepted ADDACT's invitation to present his Findings on his return to Australia later this year at an Open Forum in Canberra, to be coordinated by ADDACT.

48. We reserve our position and comment on this Term (k) until the Awardee's research findings have been presented on his return later this year.

Term (l) - Any Other Related Matters

Adult ADHD and Access

49. The barriers to access posed by the critical shortage of psychiatrists and psychologists are exacerbated for people with adult ADHD by targeted exclusion. There are reports

that most psychiatrists will not see people who have adult ADHD[5]. The reasons for this exclusion need to be explored and challenged.

50. The validity of the persistence of ADHD into adulthood has now been well established[6], but attitudes formed in the past still need to be overcome, particularly as the wave of people now able to recognise the nature of their problems is negatively perceived as a social media phenomenon. Dismissive attitudes of GPs, in their gatekeeper role, may preclude the pursuit of diagnosis and treatment [7] [8].

51. ADHD remains debilitating in adulthood and coping mechanisms come with significant personal and social costs[9][10]. There is a cumulative psychosocial burden that cripples lives[11] [12]. It is unacceptable to effectively write off the possibility of improved life chances for those who missed diagnosis in childhood due to narrow behaviour-based criteria and conceptions which deal with a *neurobiological* condition. Triaging of resources should take account of the intergenerational impact and harm, given the high heritability of ADHD and potential negative impacts on outcomes for children of undiagnosed and untreated parents.

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