SENATE INQUIRY INTO ASSESSMENT AND SUPPORT SERVICES FOR PEOPLE WITH ADHD

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Terms of Reference:

Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD, with particular reference to:

a) adequacy of access to ADHD diagnosis

Response

There are currently increasing avenues to diagnosis from private psychology practices, private psychiatric practices, and some GP centres.

The barriers to these avenues are:

1) Higher cost, as there is little to no government funding to support private assessments and all or most of the cost is met by the client. This means that such assessments are out of reach for lower income groups, where there is likely to be a higher prevalence of ADHD given the impact of ADHD on occupational and educational challenges. There are few if any options for lower cost services in the public or community sector, especially for adults or older adults.

2) Variable quality of assessments. ACPA members are aware of numerous examples of clients being assessed for ADHD where practitioners do not follow recommended assessment protocols (e.g., as documented in the AADPA Clinical Practice Guideline) nor provide or inform of appropriate supports post-diagnosis as recommended by the AADPA Guideline. This increases the likelihood of misdiagnosis and places those individuals with ADHD at risk.

3) Not all practitioners assess for comorbid Specific Learning Difficulties (SLDs) which are often comorbid with ADHD and requires a cognitive-educational assessment. SLDs need early intervention and often ongoing support. Undiagnosed SLDs increase the chance of disengagement from school and poorer occupational outcomes. There is a significant lack of funding for cognitive-educational assessments.

4) Despite increased supply of practitioners, clients regularly report long wait times for assessments (e.g., over 6 months) especially for adult assessments.

5) Inadequate access in rural and remote areas to professionals and services that can diagnose ADHD, and especially for a cost that this population can accommodate.

6) A general lack of awareness in the community as well as in medical, education, health and allied health professionals of which professionals can conduct ADHD assessments. There is also a lack of awareness that a single practitioner model of assessment is possible, and what to look for when seeking an ADHD assessment to ensure a good quality assessment and avoid misdiagnosis.

7) A lack of general training on how to conduct ADHD assessments appropriately in medical and allied health professions. There is a perception that assessment is complex when it is does not need to be, but assessments must be appropriately conducted to assess for comorbid conditions and consider a range of differential diagnoses.

8) Barriers for culturally and linguistically diverse peoples in negotiating the health system and accessing health systems to obtain an ADHD assessment.

Recommendations

Increased training in how to assess neurodiversity including ADHD and autism spectrum disorders for psychiatrists, psychologists, paediatricians, and General Practitioners (GPs) especially those working in adult services and with adult populations. ADHD has numerous co-morbid conditions, so practitioners need to be able to assess for all these conditions. Furthermore, there are many conditions that can appear like ADHD and need to be ruled out to ensure diagnoses aren't inflated. ACPA recommends increased training about what constitutes an appropriate ADHD assessment as per the AADPA Clinical Practice Guideline and a focus on differential diagnosis and co-morbid diagnosis/assessment.

Disseminate information about how to access good quality ADHD assessments or what constitutes an appropriate assessment to members of the public, GP practices, and community centres.

Dissemination of information in a range of languages. Information about how to access an ADHD assessment should be disseminated through groups in contact with different cultural communities such as community groups, cultural hubs, etc.

Increase access to paid interpreters for private practice where most assessments are undertaken.

Increase access to appropriately trained assessors. This will require an increased skills workforce through increasing training places for clinical psychology, educational and developmental psychology, and clinical neuropsychology postgraduate masters places to help ensure access to practitioners with the competencies to appropriately conduct ADHD assessments.

Introduce a Medicare rebate for neuropsychological / educational assessment for people with ADHD and autism spectrum disorder.

b) adequacy of access to supports after an ADHD assessment

Response

We assume 'supports' means intervention services such as psychology, occupational therapy, ADHD coaches, peer support workers, financial counsellors, relationship counsellors, psychiatrists, paediatricians, GPs, and school teaching and psychology staff. Supports could also include access to assistive technology.

Observations from ACPA members in clinical practice are that there is increased provision of private practice workshops or group programs providing psychoeducation about ADHD by private allied health and psychology practices. This is useful under a staged care model but not likely to meet the needs of all clients. Again, a barrier to this provision of psychoeducation is cost as these are entirely privately paid (unless a client has access to NDIS funding, which is a minority of clients). Group programs are also notoriously time consuming to manage in a private setting so they are not readily offered.

Further barriers to accessing supports following assessment are listed below:

1) Significant lack of understanding about ADHD in the community, as well as by allied health, educational, and medical professionals of appropriate, recommended, and evidenced-based interventions following assessment.

2) Lack of training for allied health and medical staff in how to work with clients with ADHD across the lifespan and how to implement appropriate interventions.

3) Lack of coordinated care between all services across the lifespan, even within the public sector, leading to poor transitions for clients, and lack of client access to appropriate care.

4) Lack of funding for recommended supports, including but not limited to, a lack of Medicare funding for parenting training, carer training, and carer self-care. Presently only two sessions out of 10 for child or adolescent Medicare Better Access MHTP sessions can be used for parent/carer or partner-only sessions, which is insufficient for many carers especially (i) following a new diagnosis, (ii) for moderate to severe presentations, or (iii) where comorbid conditions exist. Furthermore, these two sessions are deducted from the client's 10 session allocation, limiting the identified client's access to care.

5) Cultural barriers to negotiating and accessing health systems, as well as barriers to accepting support in culturally and linguistically diverse communities.
6) Lack of ability of school and tertiary education staff to implement appropriate educational accommodations. There appear to be differences across states and territories in the degree to which accommodations are appropriately implemented.

Recommendations

Increase education on recommended intervention services to public and private health practitioners, medical professionals, educational staff, community services staff and the public about what constitutes appropriate interventions for ADHD across the lifespan.

Increase Medicare rebated sessions for carer/parent training and parent/carer self-care.

Provide a set number of Medicare sessions across the lifespan for people with ADHD under the 'Complex Neurodevelopmental Disorders and eligible disabilities' plan. People with a range of genetic and neurodevelopmental conditions such as Autistic Spectrum Disorder, have access to this Medicare rebate. ADHD is a neurodevelopmental condition often presenting with complex co-morbid diagnoses but is not included under these Medicare item numbers. Including people with ADHD under these Medicare item numbers would allow clients to access funding for ADHD assessment and intervention prior to the age of 25 years, thereby assisting with some psychoeducation and early intervention for clients and their carers.

Provide government funding for ADHD supports including appropriately trained psychologists, ADHD coaches, and occupational therapists, for clients whose ADHD symptoms lead to functional impairment on social, education, occupational, relationships, independence domains. This would go a good way to incentivising appropriate care.

Increase funding for group support for parent, partner, or carer support across the lifespan in public sector community and not for profit services as such groups can be difficult to establish in private practice.

Increase training places for clinical, educational and developmental psychology, and neuropsychology postgraduate programs.

Increase training to psychiatric, paediatric, and allied health professionals on appropriate interventions for ADHD and how to provide these across different sectors and across the lifespan.

Increase incentives to provide ADHD intervention services, in the same way that the NDIS has incentivised practitioners working with other disabilities through appropriate funding of care.

Increase government funding to provide learning support staff to all educational sectors in all states and territories. Increase education to learning support and educational staff about what are appropriate supports in the educational setting and how to work with pupils with ADHD and their carers/parents.

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

Response

Reports from clients of ACPA members indicate a lack of places for private practice psychology assessments and ongoing intervention support for ADHD across the lifespan. Additionally, across all client age groups, there is a lack of access to paediatricians or psychiatrists for medication support and ongoing regular review, or more urgent review if there are difficulties with the medication, due to long wait lists. This lack of access is exacerbated by poor uptake of psychiatric training places nationally.

Clinical observations of ACPA members are that there are still negative views or stigma associated with the ADHD diagnosis amongst treating professionals. Negative perceptions include that ADHD is hard to treat, is associated with conduct disorders or aggression, and is associated with lower socio-economic status. There is also a lack of awareness about appropriate interventions and how to work with clients and their carers to implement interventions.

Further observations are that some GPs and psychiatrists are reluctant to prescribe ADHD medication due to concerns of side-effects, potential misuse of medication and subsequent concerns of official complaints. Furthermore, it takes considerable time to learn how to prescribe these medications as this topic is not sufficiently covered despite lengthy training programs. The difficulty of the prescribing regimen and time constraints for GPs can also be a factor in the reluctance of GPs to take over prescribing from a psychiatrist.

There are significant barriers to people with ADHD to access employment in certain sectors including the armed services, paramedic services, and airline staff.

It is our perception that there continues to be stigma and myths about ADHD within the broader psychiatric and medical services that is probably not as widespread in allied health services. For example, the South Australian ADHD education sessions for psychiatry registrars was titled “ADHD is Bulls**t” as recently as last year, until it was altered due to external pressure, but the sentiment of questioning the validity of ADHD diagnosis and treatment has continued within that training program. ADHD is now presented as a topic for debate. Firsthand experience of authors of this submission has demonstrated that some psychiatrists are openly belligerent during ADHD training seminars.

Recommendations

Increase recruitment into existing psychiatry training programs.

Increase training to psychiatric, paediatric, and allied health professionals on the nature of ADHD, dispelling myths and stigma, including appropriate interventions for ADHD and how to provide these across different sectors and across the lifespan.

Increase and improve training and support to GPs and psychiatrists about the prescribing regimen for ADHD including dispelling myths and stigma.

Standardise the prescribing regulations across the nation so that psychiatrists and GPs do not have to learn different prescribing rules for different states. This is particularly important for border towns, but with telehealth it is now a more widespread issue.

Ensure there is cross border prescribing for stimulant medications, which is currently not allowed in some states or territories (e.g., in Tasmania stimulant medication can only be dispensed using a script written in Tasmania).

d) impact of gender bias in ADHD assessment, support services and research

Response

We have observed that there is an increased awareness that female persons with ADHD can present differently to males. However, there continues to be a poorer recognition of symptoms in females across the lifespan, including in transgender populations where neurodiversity appears to be more common.

There is some increased understanding that female persons may mask or compensate to a greater degree than males. More could be done in this area however as there continues to be a poorer recognition of masking, compensation of executive functioning, and cognitive processing in school, GP, psychiatry, allied health, and psychology settings.

There continues to be difficulties with medical and allied health professionals' ability to understand that women, including female adolescents or transgender people, presenting with dissociative disorders, personality disorder, post-traumatic stress disorders, anxiety and depression may have undiagnosed ADHD. Practitioners can have difficulty understanding the need for differential diagnosis as well as the need for altered intervention for such clients.

There is also a failure to understand the impact of hormones and menopause on ADHD symptomatology and medication. For example, ADHD symptoms can worsen during the premenstrual phase, and during menopause. There is a significant lack of research on this topic.

Overall, most research has been focussed on cis-gender males and there is a general lack of research on ADHD in young girls, adolescent females, adult females, and transgender/non-binary people.

Recommendations

Increase the funding of research into all aspects of how ADHD presents and can be supported for all women, including a focus on how female hormones impact ADHD symptoms and medical treatment.

Embed understanding of ADHD presentations in female, transgender and non-binary populations into routine training for medical and allied health staff as discussed above, including clear understanding of masking and compensation.

To reiterate, **training needs to emphasize the need for differential diagnosis and consideration of comorbid diagnosis**, as well as how to conduct such assessments in line with AADPA guidelines which represent best practice.

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

Response

The use of Escripts is improving access to medication when clients have lost scripts and allows clients to fill their script at any pharmacy. However, clients who receive paper scripts are still required to lodge these at one pharmacy in some states and do not have the convenience of attending another pharmacy if needed.

The cost of medication is improving for people who have been diagnosed in adulthood with most ADHD medications for people diagnosed after the age of 18 years now being on the Pharmaceutical Benefits Scheme (PBS). However, the longest-acting methylphenidate medication (Concerta) is still not on the PBS for people diagnosed as adults, nor are guanfacine and atomoxetine.

Psychiatry registrars are unable to prescribe stimulant medication, so they fail to learn prescribing skills during their training programs thus reducing the available workforce of prescribers.

Prescribing rules vary across state and territory borders such that a medication dose that is allowed in one state may not be allowed in another state.

Some people need a dose that is higher than their state prescribing authority allows, thus requiring them to locate and pay for an expensive second opinion from another psychiatrist, when many psychiatrists have their books closed due to excessive demand.

There are also restrictions as to whether scripts are accepted across borders leaving people who receive a script in one state being unable to fill it in another state if they move or are travelling. This is also problematic if there are limited prescribers in a client's state and they access care via telehealth in another state; the script they receive may be invalid when they get to the pharmacy.

Inconsistencies across states and territories are especially difficult for rural and remote communities who may need to more frequently travel across state lines for assessment.

Some states have dose limitations based on age such as a script that is allowed at one age is not allowed at another age, despite this limitation not being clinically indicated. It is a PBS restriction, not a clinical restriction.

As discussed above, there is a reluctance of GPs to prescribe medication.

Clients have reported negative attitudes amongst dispensing pharmacists, which can hinder their access to medication. Some report pharmacists discussing their medication in front of other members of the public, which they have found anxiety provoking.

Recommendations

State and federal governments must work together to ensure that prescribing rules are consistent across all states and territories, across the public and private sector and across all ages. Furthermore, state and federal governments need to work together to ensure that scripts can be filled across different states and territories and across pharmacies.

Remove the requirement for a second opinion for higher doses. Psychiatrists are the best judge of a suitable dose and clients cannot access nor afford second opinions in the current system.

Allow psychiatric registrars to prescribe ADHD medications under supervision.

Include all ADHD medications on the PBS for people of any age. ADHD must be present in childhood for it to be present in adulthood so the age-based pricing structure needs to be abolished.

Provide ongoing education to pharmacists about the nature of ADHD focussed on dispelling myths and stigma about ADHD and those with ADHD. Support pharmacists to interact with adults with ADHD with the presumption that these adults have a valid diagnosis and their medications are appropriate. Reduce any sense of making clients feel like they are 'drug seeking' or 'addicts'. Mandate that pharmacists adhere to confidentiality principles when discussing people's medications in a public setting.

Remove the requirement for GPs in some states to re-apply for stimulant prescribing rights every year. This requirement is a barrier to encouraging GPs to take over routine prescribing from a psychiatrist.

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

Response

ACPA is aware that there is currently some pushback against including further diagnoses within the NDIS. We acknowledge that the increase numbers of individuals with autism spectrum disorder accepted into the NDIS may have skewed the composition of the NDIS away from physical and intellectual disability, which was the modelling expected at the time the NDIS was set up.

It is ACPA's view that assessment and supports for ADHD need to be available, whether that be through the MBS or through the NDIS. If only one scheme can support the required assessment and supports for ADHD, ACPA's preference would be support through the MBS.

However, conceptualising ADHD as belonging within the range of neurodivergent disorders, with high levels of comorbidity amongst those disorders, supports the case for its inclusion in the NDIS. ADHD varies considerably in severity from one person to another, and across the lifespan, as the demands on people's executive functioning systems increase or decrease based on life stage, life complexity, or the availability of scaffolding supports. An example of the increase in life stage demands is when academic demands increase during high school, tertiary education, and apprenticeships. After having children there are significantly more demands on organisational and executive functioning skills with a decrease in support. An example of decrease in scaffolding is during later adolescent and early adulthood when there is a decrease in parental scaffolding and supports. Many people also have comorbid secondary mental disorders or Specific Learning Difficulties that worsen the impact of ADHD on their functional capacity. Thus, at various times in the lifespan, functional capacity may be severely compromised enough to warrant additional supports and capacity building under the NDIS.

Clients with ADHD have functional/daily living deficits that range in severity. Daily living skills, independence skills, educational and occupational skills, social skills, and ability to access supports or access the community can all be highly compromised due to executive functioning deficits and hyperactivity and/or other comorbidities. Simple examples include an inability to do grocery shopping and meal preparation, failing to pay bills and keep to a budget, not putting out the garbage, washing clothes and sheets, etc. These deficits are equivalent to those experienced by people with other NDIS recognised disabilities including autism spectrum disorder.

The Federal Health Minister and the NDIA state that individuals can apply to the NDIS based on functional impairment. However, experience amongst clinical psychologists is that most clients with significant functional impairment to the level generally seen in other NDIS clients but with a diagnosis of ADHD alone do not get NDIS funding. The stated reason for this is usually on the basis that ADHD is not a Category A or Category B NDIS disability. Even clients with significant comorbidities will not get NDIS funding unless they additionally have a Category A or Category B NDIS disability. An informal poll of Private and NDIS Psychologists indicated that they would advise

clients with ADHD alone not to seek NDIS funding due to perceived significant difficulties obtaining NDIS funding without a Category A or Category B NDIS disability.

Recommendations

In the absence of sufficient assessment and intervention items through the MBS, add ADHD to the Category A or Category B NDIS disabilities list. Alternatively, a more radical proposal would be to abolish primary disability categories within the NDIS and assess instead solely based on functional impairment.

g) the adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people

Response

Coordination of support between federal, state, and local government services continues to be poor across the board and the coordination of care between services for clients with ADHD is no exception. Clients being seen in private practice and under Medicare will have some liaison between treating professionals and GPs due to Medicare requirements.

There is generally a lack of support across the nation for students with ADHD in the school setting. The Victoria Education Department is currently trialling the provision of more in-school support to students with a broad range of educational needs. It is not clear yet whether this will improve ADHD support in schools or if it will improve coordination of care between schools and other treating professionals. Clients with NDIS funding (generally who have met NDIS criteria due to autism or another NDIS Category A or Category B disability) are better able to access improved coordination of care as treating practitioners are paid for their time liaising with other treating practitioners and educational/occupational staff.

There are significant difficulties in coordination of care in the justice system as treatment is not coordinated or integrated with the health system. Medication of ADHD is restricted in the justice system. This is particularly concerning as people with ADHD are more likely to become involved in the justice system. The issues lead to ADHD being under-recognised and under-treated in the justice system.

Some employees such as in the armed services, paramedic services, and airline staff face barriers to using ADHD medication at work or face barriers to employment.

Recommendations

Reconsider the purpose of excluding adults who use ADHD medication for certain roles such as the Defence Force. It is very limiting and difficult for these individuals to receive reasonable treatment for a valid disorder when such exclusions exist.

Improve access to diagnosis and treatment of ADHD within the justice system where ADHD is over-represented and is a barrier to successfully staying out of prison.

h) the adequacy of Commonwealth funding allocated to ADHD research

Response

ADHD research is generally underfunded and there is a severe lack of information about ADHD in different populations and about effective interventions and supports. Interventions for ADHD remain a new field and more research is needed to ensure supports are as effective as possible.

Recommendation

More research funding is required, especially for ADHD in Aboriginal peoples, gender-based differences in identification and treatment of ADHD, use of medication in pregnancy and breast-feeding, the impact of parenthood on function, and the impact of untreated ADHD on incarceration rates and recidivism.

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

Response

Deloitte Access Economics[1] has estimated that the total social and economic cost of ADHD in Australia is $20.42 billion, including financial costs of $12.83 billion and wellbeing losses of $7.59 billion.

The clinical observation of ACPA members is that failure to assist appropriate ADHD diagnosis and supports leads to poor educational and occupational functioning, parental/carer burnout, separation and divorce, increased debt and incarceration, increased domestic violence; and increased mental health issues.

[1] Deloitte Access Economics. The social and economic costs of ADHD in Australia. Report prepared for the Australian ADHD Professionals Association. July 2019.

It is clear from research that people with ADHD (treated and untreated) are more susceptible to mental health issues, suicide attempts and death by suicide, poorer occupational and educational outcomes, reduced earning capacity, increased involvement in traffic accidents, increased involvement with the justice system etc. It follows logically that increasing access to ADHD diagnosis and supports can ameliorate such issues to the benefit of individuals, the community, and the economy.

Recommendation

The substantive costs associated with ADHD in Australia fully justify **further investment in ADHD from a health and social perspective** as outlined in our recommendation in this submission. Investment in ADHD health care will likely have a significant positive impact on our economy.

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

Response

The guideline is well-considered and focuses on current best practice, which should be the aim for Australian health, educational and mental health services. Most recommendations are viable including:

1) Increasing identification of at-risk groups
2) Additional screening of at-risk groups
3) Appropriate assessments that consider evidence across areas of a person's life, multi-informant assessment, differential and comorbid diagnosis, assessment of family functioning and carer mental health, masking, and medical review.
4) Increased awareness of ADHD in professionals
5) Provision of ADHD information to people with ADHD about support options and psychoeducation about their condition
6) Liaison with other professionals
7) Ensuring good transition between services.

The guidelines do not include neuropsychological assessment. As mentioned above, this can mean that common co-morbid issues such as Specific Learning Disorders are missed, worsening outcomes for those who have these disorders. Neuro-cognitive assessments can also assess for masked inattentiveness and organisational or planning deficits. Although such assessments may not be practical to conduct in all cases – we lack the specialists and time – there needs to be acknowledgement that ADHD can sometimes present as complex disorder, with common comorbidities and requires trained practitioners to assess appropriately. This includes knowing when to conduct a neurocognitive-educational assessment and ensuring that such assessments are

accessible and affordable for all. As such, greater recognition of when to do a neurocognitive-educational assessment when a client is presenting with ADHD symptoms is needed.

Recommendations

Increase promotion of the AADPA guideline and the importance of adhering to its recommendations. This would include incorporating the guideline into training for medical, allied health and educational professionals about ADHD, ADHD diagnosis and supports.

The AADPA practice guidelines state that appropriate assessments involve that we *consider* multi-informant assessment and assessing for comorbid conditions, plus the use of neurocognitive and educational assessments where necessary. ACPA believes that the **guideline language on this should be stronger. In other words, assessment *should include* multi-informant assessment and assessment of comorbid conditions**.

Include optional Neurocognitive-Educational Assessment in the AADPA guideline when there are queries of Specific Learning Difficulties, possible masking, or other neuro-cognitive concerns. As discussed above, there need to be funding options for neurocognitive-educational assessments through Medicare or the NDIS.

The main barrier to implementing the guidelines is the cost of such services and the lack of funding for clients to access services, as well as the lack of publicly funded services. Publicly funded services need practitioners who are well-trained in assessment and differential diagnosis to prevent misdiagnosis or missing comorbid conditions and ensure optimal outcomes for clients.

k) international best practice for ADHD diagnosis, support services, practitioner education and cost; and (l) any other related matters.

There continues to be some stigma around the diagnosis. This includes stigma of diagnosis and negative views of an ADHD diagnosis by parents and schools that can prevent referral to assessment or supports.

ADHD is under-recognised among individuals who do well at school and enter professional careers. There is a perception that you cannot do well in school or become a doctor, lawyer, scientist if you have ADHD. Many a client has been dismissed by their GP, psychiatrist, or psychologist because they are deemed too intelligent and outwardly too successful in their career to have ADHD. This attitude needs to change. ADHD can affect anyone, from any walk of life.

Media outlets need to be held to account if they maintain a stigmatising attitude towards ADHD. This is mostly done by journalists who trot out the handful of well-known anti-ADHD commentators when preparing an article about ADHD in the misguided belief that a balanced story about ADHD

needs to include the debate about its validity as a diagnosis. They do not do this when they write about depression or psychosis.

It might be helpful to establish a workplace neurodiversity support website where employers can obtain information about supporting their neurodiverse staff. There could be education about recognising ADHD difficulties, and the types of accommodations and supports that can be helpful.