To: The Australian Government Productivity Commission.

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Requesting long-acting ADHD medications be available on the PBS to adults diagnosed with ADHD over the age of 18

Requesting mandatory ADHD education and training for all teachers

Requesting acknowledgement of the damaging consequences of school suspensions and expulsions on students with ADHD and policy change in this area

Background

Attention Deficit Hyperactivity Disorder (ADHD) is a complex neurobiological disorder which affects an individual's ability to regulate their thoughts, words, actions and emotions. Symptoms of the disorder in adults can include hyperactivity or restlessness, impulsive behaviour, poor ability to focus and stay on task, challenges with planning and prioritising, and difficulty tolerating boredom and frustration.

ADHD is the most common childhood mental health disorder, impacting around 1 in 20 Australian children, yet only 1-2% of children and less than 1% of adults in Australia are receiving ADHD medication treatment (Raman et al., 2018).

Research suggests the potential consequences of untreated or poorly treated ADHD in adults are significant. These consequences include the risk of:

- comorbid mental health challenges including anxiety and depression, alcohol and substance abuse issues, and eating disorders
- physical health challenges including coronary heart disease, sleeping problems, migraines and dental caries
- relationship and marriage breakdown
- negative occupational outcomes and loss of employment
- car accidents, dental trauma, traumatic brain injury and premature death from accidents
- self-harm and suicidal ideation, attempts and completion
- violence, criminality and incarceration
- reduced quality of life
- reduced life expectancy.

(Barkley & Fischer, 2018; Franke et al., 2018).

The link between ADHD and these associated risks, plus the significant financial impact of these risks on society, is evident when examining the association between ADHD and criminality.

In their meta-analysis of forty-two studies examining the prevalence of ADHD in incarcerated populations, Young, et al. (2014) found the prevalence of ADHD in prison populations to be around 30% in youth prison populations and 26% in adult prison populations. Moore, et al. (2013) when screening prisoners in four NSW correctional facilities found 35% of the sample screened positive for adult ADHD, and 17% met criteria for a full diagnosis with substance abuse and psychiatric comorbidity common. Prisoners identifying as Aboriginal were also found to be significantly more likely to receive an ADHD diagnosis (Moore, et al., 2013).

Moore, et al. (2013) also established the cost of funding police, legal aid and prosecutors, courts, prisons and community corrections, community health and hospitals, public and community housing and Centrelink at around $1 million a year per individual with complex needs and in high institutional contact.

Early diagnosis and treatment have been shown to reduce the potential risks associated with the disorder. One of the main treatments for ADHD is medication, which reduces the symptoms experienced by children, adolescents and adults with ADHD as well as the accompanying functional impairment that results due to their ADHD symptoms. Symptom reduction improves the quality of life and life expectancy of adults with the disorder and reduces the financial burden that untreated ADHD places on health care systems, employers, police and prisons (Matza, Paramore & Prasad, 2005).

Prevalence

The 2015 *Australian child and adolescent survey of mental health and wellbeing* (Lawrence et al., 2015) provides further evidence of the prevalence of ADHD in Australian children and adolescents. The study found that 4% of children and adolescents in Australia have an ADHD diagnosis – equivalent to an estimated 298,000 children and adolescents [a meta-analysis of 175 research studies worldwide on ADHD prevalence in children aged 18 and under found an overall pooled estimate of 7.2% (Thomas et al., 2015)]. ADHD diagnosis is more common in males than females with ADHD affecting 1 in 10 males and fewer than 1 in 20 females (Lawrence et al., 2015).

Low female diagnostic rates are concerning. The *2015 Australian child and adolescent survey of mental health and wellbeing* found anxiety disorders (social phobia, separation anxiety disorder, generalised anxiety disorder and obsessive-compulsive disorder) to be the most common mental disorders found in adolescent girls. However, Quinn and Madhoo (2014) concluded in their review that girls with ADHD are frequently misdiagnosed when anxiety or depression presents in association with ADHD. This is thought to be because:

- a low index of clinical suspicion exists for girls
- their presentation is often considered ‘subthreshold’ because inattentiveness is more prominent than hyperactivity/impulsivity
- they may develop better coping strategies than males to mask their symptoms

- girls with ADHD are more likely to internalise symptoms, become anxious and depressed and suffer emotional dysregulation than boys with the disorder.

Additionally, the presence of anxiety and depression can lead to missed diagnoses or misdiagnoses because the symptoms of ADHD may mistakenly be attributed to the anxiety or depression (Quinn and Madhoo, 2014).

Whilst at present there is no conclusive evidence to support any single aetiological factor causing ADHD, quantitative genetic studies (including family, twin and adoption studies) suggest ADHD is strongly genetic in origin. According to Barkley (2016):

- if a parent has an ADHD diagnosis, then their children are 6-8 times more likely to have the disorder (35-54%)
- if a child has ADHD, their biological siblings are 3-5 times more likely to have ADHD (25-35%), their mother is 3-4 times more likely to have ADHD, and their father is 5-6 times more likely to have ADHD
- if one identical twin has ADHD, the other twin is 75-90% more likely to also have ADHD.

Access to health and medical services

<u>Access to long-acting medication for adults diagnosed with ADHD after the age of 18 is an area of concern</u>

Research suggests ADHD medication can have a significant positive impact on the lives of adults with ADHD (Faraone & Glatt, 2010; Frederiksen et al., 2014; Franke et al., 2018; Fredriksen & Peleikis, 2016; Torgersen, Gjervan & Rasmussen, 2008).

For example, Frederiksen et al. (2014) examined the effectiveness of long-term stimulant and non-stimulant medication in adult ADHD in terms of dose, side-effects and comorbidity in a clinical setting. The results of their study suggest that:

- adults with ADHD who continue taking ADHD medication in the long-term experience sustain significant improvement in both inattentive and/or hyperactively/impulsivity symptoms in comparison to adults with ADHD who do not take or who discontinue medication
- long-term medication compliance significantly reduces ADHD symptoms, and improves everyday function and levels of mental distress.

One can extrapolate from the available studies that ADHD medication also reduces the risks associated with the disorder and thus their economic impact. This assertion is supported by the findings of a number of international studies:

- A large register-based Swedish study of adults with ADHD found that treatment with ADHD medication significantly reduces the risk of criminality (Lichtenstein et al., 2012).

- A Swedish register-based study found that adult males with ADHD were 58% less likely to be involved in serious traffic accidents during periods when they were medicated, compared to periods when they were not medicated (Chang

et al., 2014). A US study of individuals with ADHD found similar results among both males and females (Chang et al., 2017).

The guidelines from the National Institute for Health and Clinical Excellence (NICE) recommend pharmacotherapy be used as the first-line treatment for adult ADHD in the absence of contraindicated co-existing conditions (NICE, 2018). Stimulant medications are considered to be the first-choice pharmacological treatment option as they tend to result in the most significant reduction of symptoms (NICE, 2018). The second-line choice of medication for ADHD in adults is usually atomoxetine (NICE, 2018).

Randomised placebo-controlled clinical trials and meta-analyses convincingly suggest both stimulant and non-stimulant medications are effective and safe when used to treat ADHD in adults (Fredriksen, Halmøy, Faraone, & Haavik, 2013; Franke et al., 2018). Stimulant medications come in both immediate-release formulations and long-acting formulations.

In Australia the immediate-release medication options available to treat ADHD include:

- methylphenidate (Ritalin™)
- dexamphetamine sulphate (Aspen Dexamfetamine™, Dexamfetamine Sulfate [Sigma]™).

The long-acting medication options available to treat ADHD include:

- lisdexamfetamine dimesilate (Vyvanse™)
- methylphenidate hydrochloride (Ritalin LA™ and Concerta™).

Whilst many adults prefer immediate-release medication formulations, just as many prefer long-acting formulations (Frederiksen et al., 2014). When long-acting medication formulations are favoured it tends to be because they provide longer and more consistent symptom relief, while at the same time reducing the occurrence and severity of rebound symptoms, which makes them more tolerable.

Non-stimulant medication is used in the treatment of adult ADHD when intolerance to stimulant medication is present or when an individual has a co-existing condition in which stimulant medication is contraindicated.

In Australia the non-stimulant medication options available to treat ADHD include:

- atomoxetine (Strattera™).

Currently, the 2018 Australian Pharmaceutical Benefits Scheme (PBS) drug utilisation sub-committee report states that subsidy of long-acting stimulant medication and atomoxetine “is limited to patients diagnosed between the ages of 6 and 18 years of age inclusive.” Therefore, the guidelines exclude anyone diagnosed with ADHD as an adult from accessing these medications at a subsidised price.

As a result, adults diagnosed with ADHD after the age of 18 who gain greater symptom relief and improved functioning from long-acting stimulant medication formulas or atomoxetine are forced to pay full price for their medication. Those adults who do not have the financial means to purchase a long-acting medication or atomoxetine have no option but to take a medication formulation that does not reduce their symptoms or improve their daily functioning to the same degree as their

preferred long-acting medication option would. And if these adults do not tolerate the immediate-release formulation available to them, they are more likely to terminate their medication usage.

We know that adults with untreated ADHD have poorer outcomes in life. A systematic review of both childhood and adult studies found that individuals with ADHD that was left untreated had poorer long-term outcomes compared to treated individuals in several major categories. These included academic, antisocial behaviour, driving, non-medicinal drug use/addictive behaviour, obesity, occupation, services use, self-esteem, and social function outcomes (Shaw et al., 2012). Therefore, it is vital for both the individuals in question and for society as a whole that all adults with ADHD, regardless of their age at diagnosis, have access to the medications that work best for them.

Access to costly multimodal services

Evidence-based guidelines from around the world endorse the use of multi-modal treatment interventions for ADHD (such as NICE, 2018). Some of the reasons for this include:

- Stimulant medication does not cure ADHD or provide 24-hour-a-day coverage.
- Medication alone does not teach children and adolescents with ADHD the skills they need to function more competently, and behaviour treatment alone is ineffective when children and adolescents are unable to focus in order to absorb information and learn from interventions or instructions.
- Children and adolescents with ADHD experience problems across multiple domains and these problems may respond differently to treatments. For example, stimulant medication has been shown to reduce ADHD symptoms, whilst psychosocial interventions appear to have more impact on family relationships and academic functioning.

(Chronis et al., 2006; Pelham, 1999; Pelham et al., 1998, cited in Barkley, 2015)

Multimodal treatment interventions may include medication, psychotherapy, cognitive behavioural therapy, emotional regulation and social skills training, parent education, ADHD coaching and support groups.

Whether parents and adults can access many of the multimodal treatment options currently depends upon their financial ability to meet the costs involved in accessing these treatments, yet the consequences that result from not treating ADHD effectively can be devastating and can also place a huge financial burden on the community. Funding is required to reduce this inequity and to ensure that all individuals with ADHD, including those on a low income, can access the multimodal treatment options they require to increase their functionality and improve their quality of life.

Transitioning from paediatric services to adult services is challenging

According to David Coghill (2017), young adults with ADHD should be transferred to adult mental health services if they have continued symptoms of ADHD and other mental health conditions. However, there is a critical shortage of adult psychiatrists who treat adult ADHD. Compounding this problem, many paediatricians do not take

on new patients who are over the age of 16, whilst the majority of psychiatrists do not accept referrals for new patients until they turn 18. There are some adult psychiatrists who will agree to take on younger patients but there are often obstacles in their way. For example, the Western Australian Health Department insists that a special application be submitted by adult psychiatrists each time they accept 15 to 18-year-old patients, which can lead to a delay in assessment and treatment. This makes it very challenging for individuals aged between 15 and 18 to access the care they require and urgently needs to be addressed to ensure all individuals with ADHD receive the care they need.

Youth mental health – supporting students with ADHD at school

The *Australian child and adolescent survey of mental health and wellbeing* (2015) found ADHD to be the most common mental disorder found in Australian school students. The study also found that students with ADHD tend to underperform academically (regardless of their actual ability), with 50% of students with ADHD achieving less than the national minimum standard during NAPLAN testing. Yet teachers currently do not receive ADHD education and training.

Under the Disability Discrimination Act (DDA) and Disability Standards for Education (DSE), students with ADHD have a right to an inclusive education which allows them to access education 'on the same basis as their peers'. Yet due to the inability to access funding for students with ADHD, there are critical gaps and inconsistencies in the capacity of schools to support the learning, social and emotional needs of many students with ADHD. This assertion is backed up by the recent Parents for ADHD Advocacy (2019) survey.

Currently teachers in Australia receive little or no education on ADHD. This no doubt adds to the academic, emotional and social challenges students with ADHD experience at school. When teachers do not have a good understanding of the symptoms associated with ADHD and the challenging behaviours that can manifest from the disorder, they can add to the challenges students with ADHD experience. This is because the explanation a teacher attributes to a student's challenging behaviour greatly influences how that teacher perceives the student.

For example, a teacher's perception of a student with ADHD would influence the choice they make between implementing classroom accommodations to support the student with ADHD, or engaging behaviour management interventions to discipline that student.

Unfortunately, when teachers do not understand ADHD they are at risk of misinterpreting ADHD symptoms. This tends to increase the chances that a teacher will resort to disciplinary interventions as a way of controlling children with ADHD. Sadly, it is not uncommon for students with ADHD, despite their best efforts, to find themselves on the receiving end of constant correction, redirection, criticism and possibly social rejection and isolation.

This can have devastating outcomes as discipline will not rectify any of these challenges. Punishing students for behaviour that is a symptom of their developmental delay and lagging self-regulation skills will only crush their self-esteem, self-worth and love for learning, foster shame and exacerbate their challenges. They may come to believe they are fundamentally different, flawed or

broken and may start to anticipate future failure and thus simply give up. It can also contribute to them becoming oppositional and defiant, and developing anxiety, depression, and drug and alcohol use and the other risk factors previously discussed.

The research also suggests there is a direct pipeline between school suspension and teenage or adult incarceration (please see below).

Parents for ADHD Advocacy Australia recently surveyed 1184 parents who have children with ADHD. Ninety five percent reported that they felt teachers and key staff were in need of ADHD professional development and training. Parents lacked confidence in teachers', school counsellors' and principals' knowledge of ADHD and effective support strategies. Less than half (42%) thought classroom teachers had good or excellent knowledge in this area. The figures were even lower for principals (27%) and school counsellors (25%).

Compulsory teacher education is urgently required to ensure all students with ADHD receive the support they require at school so that they can achieve to the best of their ability, participate as an equal member of the classroom, develop meaningful relationships with their peers and feel good about themselves.

ADHD and the justice system

School-to-prison pipeline research has established a 'significant and positive association between experiences of exclusionary discipline and justice system contact' (Novak, 2018, p. 79). Disadvantaged children, Indigenous children and those with a disability are significantly overrepresented in school suspension statistics (Graham, 2018).

Removing a child from school is thought to negatively impact on school connectedness, increase alienation, intensify conflict between children and adults, and increase propensity of youths to engage in delinquent behaviour (Skiba et al., 2006).

More than one third of the parents who took part in the Parents for ADHD Advocacy survey reported that their child with ADHD had received a partial exclusion from school and 24% had received a suspension. Additionally, 30% of parents and carers had moved their child in order to find a more supportive school.

There is a very real and significant opportunity to substantially reduce the financial burden untreated ADHD places on society by addressing the experiences of children with ADHD in educational settings. There are critical gaps in how students with ADHD are accessing and receiving support in Australian schools, particularly in disadvantaged areas and in at-risk communities. Governments, departments of education, principals, teachers, medical professionals, mental health organisations and media all have a role to play in better recognising ADHD as a valid mental health disorder so both adults and children with ADHD can avoid contact with our justice system and instead reach their full potential.

In addition to this, strategies to ensure the effective identification and treatment of offenders with ADHD in the prison population need to be implemented, as

appropriate intervention is likely to have a positive impact both on the offender and on society.

For example, treatment with ADHD medication is reported to be associated with a significant reduction in violent reoffending (around 42%) on release from prison and similarly in criminal convictions (Young et al, 2014). By reducing their ADHD symptoms, the offender is likely to be better equipped to engage in and benefit from psychological, educational and occupational interventions (Young et al, 2014, pp. 6). However, although ADHD medication reduces ADHD symptoms it does not cure the disorder, therefore it is important to remember concomitant non-pharmacological treatments are nearly always necessary to help the offender develop strategies to manage their ADHD related problems and improve their behaviour (Young et al, 2014, pp. 6).

Conclusion

ADHD is a complex neurobiological condition which affects approximately 5% of the Australian population. The Australian government is both obligated to, and will benefit greatly from, implementing strategies to ensure equitable access to ADHD diagnosis, treatment and support. By making long-acting stimulant medications, as well as atomoxetine, available on the PBS to those diagnosed with ADHD in adulthood, more Australians will be able to access the ADHD medication treatment that provides them with the greatest symptom relief as well as best improves their everyday function and mental health. By implementing mandatory teacher training in best-practice approaches and strategies for teaching children with ADHD, the government will ensure students with ADHD can achieve to the best of their ability, participate as an equal member of the classroom, develop meaningful relationships with their peers and feel good about themselves. By acknowledging the latest research around the harm caused by school suspensions and exclusions and by enacting policy change in this area, the Australian government and Australian society will reap the rewards of breaking the link between these actions and criminality. And by ensuring offenders with ADHD in the prison population are effectively screened and treated for ADHD, the Australian government is likely to significantly reduce the violent reoffending rates of prisoners on release from prison and other criminal convictions.

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