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

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Living on the Spectrum was established in 2019 with the aim of providing a comprehensive online platform to support Neurodivergent individuals and their caregivers by offering a centralised location for accessing assistance, information, services, and products. A national initiative that was the first of its kind in Australia.

Since its inception, Living on the Spectrum has emerged as a crucial resource for individuals with ADHD and Autism, enabling individuals to discover relevant resources and gain a deeper understanding of ADHD, Autism, and neurodiversity. Presently, Living on the Spectrum aids over 10,000 individuals on a monthly basis, facilitating their search for valuable resources and fostering knowledge about ADHD, Autism, and neurodiversity.

Anita Aherne, the founder, developer, and funder of Living on the Spectrum, personally experienced the impact of ADHD after enduring a mental health crisis during the pandemic. With two of her three children also diagnosed with ADHD, Mrs Aherne possesses first-hand knowledge of the challenges faced by women diagnosed later in life and navigating the educational system with her ADHD-diagnosed children.

Living on the Spectrum was born out of necessity. Learning that individuals with ADHD have a reduced life expectancy of up to 25 years than that of the general population, she knew she had to do something to change this.

“The evidence to date is more than sufficient to justify alarm at the substantial adverse impact ADHD poses for long-term quality of life and reduced life expectancy.” Russell A. Barkley, Ph.D.ⁱ

Mrs Aherne also understands the implications of co-diagnosis, specifically that ADHD is often diagnosed alongside Autism. With this understanding, the directory provides numerous resources that can be effectively utilised by individuals with an ADHD diagnosis, an Autism diagnosis, or both ADHD and Autism diagnoses.

By leveraging her own lived experience, Mrs Aherne has connected with numerous individuals through the Living on the Spectrum Platformⁱⁱ who share similar frustrations and shortcomings within existing systems designed for those diagnosed with ADHD. With a strong desire to contribute to the ADHD inquiry, Mrs Aherne is eager to share her experiences and offer valuable insights and recommendations in areas where she feels she has valuable insight and lived experience with ADHD.

Barriers to consistent, timely, and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD. A personal perspective by Anita Aherne.

(a) adequacy of access to ADHD diagnosis;

The diagnostic process poses significant challenges for many individuals due to financial constraints and long waiting times. This situation negatively affects children, who often face labels of being problematic or lazy without an official diagnosis. Meanwhile, adults find themselves caught in a cycle of being referred and forth between the mental health system and the public hospital system. This is due to a lack of ADHD understanding and the lack of recognition as a disability.

Personally, I experienced the arduous and costly struggle of finding a clinician to diagnose myself and my children. The wait time exceeded twelve months, during which my children lacked the necessary support, detrimentally impacting their mental health and educational outcomes. For myself, I almost lost my life due to mental health challenges while waiting for a clinician to assess me.

It is worth noting that our ability to expedite the diagnostic process was only possible because of our financial resources, which is not the case for many members of our community. Each diagnosis costs us over \$1,500 per person.

The scarcity and demand on clinicians, which the pandemic has since exacerbated, significantly hampered our access to diagnosis and subsequent treatment, impeding our chances of achieving improved education, employment, and mental health outcomes.

Therefore, we recommend prioritising and enhancing the training of clinicians capable of diagnosing and managing ADHD. Alternatively, establishing free public diagnostic facilities would help bridge the gap created by the pandemic and ensure broader access to diagnoses and appropriate support. This would also substantially ease the public health system and greater reduce the demand for an already stretched mental health system.

Having public diagnostic clinics would enable timely diagnosis. One benefit to this is that it would significantly aid an individual's positive employment and educational outcomes and be a significant asset to the wider community due to improved health, well-being, and community contribution.

We recommend investing in platforms such as Living on the Spectrum to promote advocacy and raise awareness about ADHD. This will help combat the stigma associated with the condition and ensure consistent information and best practices.

Living on the Spectrum has effectively fulfilled this role to date without any financial burden on the government. Thousands of individuals are benefiting from its services. However, additional investment is necessary to reach and support more individuals and families. This will enable us to expand our reach and provide reliable, accessible, and timely information and resources.

Investing in our established platform, which is already reaching thousands of diagnosed individuals, makes far more economic sense than investing in new online-based information strategies.

(b) adequacy of access to support after an ADHD assessment;

The criteria for diagnosing ADHD have changed over timeⁱⁱⁱ, which means more people today meet the criteria for diagnosis. However, this, along with the backlog caused by the pandemic, is putting a lot of pressure on allied health professionals and clinicians. As a result, there are now long waitlists, sometimes up to 2 years, for individuals seeking diagnosis and support.

One of the reasons for these long wait times is that our health, disability, and education systems often require a formal diagnosis before a child can receive the necessary support. This further increases the demand for diagnostic assessments and contributes to the lengthy waiting periods.

Unfortunately, many individuals are still unable to access the support and resources they need due to these extended wait times and financial constraints.

Additionally, there is confusion, stigma, and misinformation regarding ADHD medication, which adds to the stress experienced by families.

In my personal experience, obtaining and managing medication for ADHD has been challenging. Delays and limitations in reaching the prescribing doctor for follow-up and review have caused problems. There have been instances when we experienced adverse reactions to prescribed medication, but we couldn't promptly initiate a medication review due to long wait times and delays. As a result, there were delays in obtaining the appropriate medication to address and treat the symptoms of ADHD effectively.

There is also a gap in the transition stage for children to adulthood. The difficulty and delay in transferring care between paediatrician and psychiatrist is timely and costly, and in our case, has led to delays in ADHD symptom management.

Regarding accessing support for my mental health, I was diagnosed in 2020 but have been unable to access the necessary support. This has led to ongoing challenges in my daily tasks, executive functions, and reading ability. The long wait times and shortage of mental health practitioners have made it difficult for me to engage in daily activities, ultimately affecting my work and personal relationships. The limited options have also left me without any say in my care, forcing me to continue searching for a professional to address my post-diagnosis needs adequately.

As for my children, we are currently on waitlists for occupational therapy. Unfortunately, during the waiting period, one of my children had to discontinue their formal education in the middle of year 12. The direct result of the lack of available support after their diagnosis. Their mental health remains a significant concern. Consequently, we have to rely on the public health system again to fill the gap in post-diagnosis support.

Hence, we strongly recommend the inclusion of ADHD in the National Disability Insurance Scheme (NDIS) to alleviate pressure on the public system and ensure the fulfillment of necessary requirements, thereby enhancing post-diagnosis outcomes for individuals with ADHD. Moreover, addressing long wait times for diagnosis will considerably improve overall life outcomes and alleviate burdens on the public healthcare system while fostering benefits in employment, education, and mental well-being for many individuals.

By incorporating ADHD into the NDIS, we can effectively alleviate the financial burden on the public health system and provide children who would otherwise be deprived of the opportunity with access to formal education, which will have the knock-on effect of successful employment opportunities.

In relation to medication, there needs to be more awareness and education about medications with mandatory follow-ups for medication reviews scheduled in initial appointment in advance to ensure the availability of prescribing Medical practitioners. The reviews should be available in a timely manner. Having a primary GP be able to write prescription refills would also reduce the delay and stress associated with accessing prescribed medication.

Furthermore, we propose a transition strategy to effectively address the current deficiencies in support and clarity when transitioning from a paediatrician to a psychiatrist for young adults. This strategy aims to tackle the shortage of available resources and the delays in seeking psychiatric assistance, particularly concerning medication, during the critical transition period from adolescence to adulthood.

We also suggest providing training for pharmacists on ADHD and the significant improvement medication can bring to an individual's life. I have personally experienced and heard stories where pharmacists have treated individuals as potential drug dealers or accused them of obtaining medication for inappropriate purposes. Additional training would address this all-too-common occurrence and help pharmacists better understand and support individuals with ADHD. It would also provide a safe place for individuals to seek medication assistance and advice when needed rather than relying on their prescribing practitioner.

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

Some healthcare practitioners do not understand how ADHD affects daily life and overall outcomes. Many individuals with ADHD rely on public systems to receive the necessary support, Mainly due to the long wait times for diagnosis and support following diagnosis. Living on the Spectrum has directly observed that clinics responsible for treatment and diagnosis are overwhelmed and bear the brunt of individuals' frustrations.

Based on my personal experience with the diagnosis process for three individuals, including myself, no consistent advice and support is offered across medical fields. ADHD is often overlooked, particularly in older individuals. The responsibility for diagnosis was passed around multiple times, leading to a delay in my own diagnosis. This delay in diagnosis subsequently led to mental health crises. While my immediate needs were addressed, the underlying ADHD diagnosis was overlooked for 48 years. The system was reactive, addressing my immediate needs, providing temporary solutions, and sending me on my way.

The underlying cause was never examined or addressed. This is understandable, considering the shortage of clinicians and the strain on public healthcare.

I also had an experience where a general practitioner questioned my child's medical concerns because of their ADHD diagnosis. The GP suggested that the issues might be exaggerated, despite my child clearly experiencing a medical condition. This delay in addressing the problem resulted in my child having to stay in the hospital for treatment. However, could have been avoided with GP clinical care. This situation added more pressure on an already overwhelmed public health sector and caused my child and me stress, anxiety, and, in my child's case, pain. It's crucial to understand better how ADHD affects daily life so that appropriate support systems can be put in place. With the right support, we can ensure that mental health, physical health, education, and employment are properly maintained.

Similarly, our education system lacks clarity when it comes to determining who should provide what kind of support. Often, practitioners rely on schools, but schools often depend on practitioners who may not have the resources to offer the necessary support. There is a lack of collaboration and cross-training that could ensure better educational outcomes for students.

We strongly recommend training General Practitioners (GPs) to address support gaps for individuals with ADHD, enabling them to understand the daily challenges affecting physical and mental well-being. We recommend the inclusion of the 3 different subtypes of ADHD, to ensure an understanding of how ADHD can differ between individuals and even genders.

Individuals with ADHD already face stigma associated with laziness, disorganisation, learning difficulties, and a perceived lack of ability. Therefore, it is crucial to create an environment where individuals with ADHD feel comfortable and supported by their frontline healthcare team.

Additionally, we propose cross-training between schools and treating practitioners to ensure optimal educational outcomes for our children and improve access to education. It is important to clarify the roles and responsibilities of those providing support and establish effective delivery methods. Ideally, a national educational strategy should be developed to meet the learning needs of students with ADHD and reduce the stigma associated with an ADHD diagnosis.

By prioritising education and addressing school refusal (also known as "School Can't") often experienced by ADHD students, we can achieve significant economic gains and promote accessible post-secondary education.

(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;

Currently, ADHD is not officially recognised or considered as a disability. This lack of recognition significantly impacts how society perceives ADHD and creates barriers to inclusion, awareness, and accessibility in education, employment, and overall health and well-being.

It also has a major effect on employment opportunities, as there is ambiguity with its inclusion in the Disability Discrimination Act, leaving many confused about the infringements and rights regarding inclusion and accessibility.

This is especially concerning considering that approximately 1 in every 20 Australians^{iv} is estimated to have ADHD. While ADHD is more commonly diagnosed in boys, it is often underdiagnosed in girls and adults. This in itself is problematic and further expands the gender divide, gender discrimination, and equality of every individual with ADHD.

Additionally, over 75% of children diagnosed with ADHD continue to experience symptoms into adulthood, which is a significant number. Therefore, for individuals with ADHD to be protected without ambiguity under the Disability Discrimination Act, ADHD must be officially recognised as a disability.

By recognising ADHD in the National Disability Insurance Scheme (NDIS), we can provide support and improve life outcomes for potentially one-fifth of the Australian population. This recognition would lead to better life outcomes, improved health and well-being, reduced strain on public health systems, and enhanced support for educators in assisting students with ADHD.

“The ADHD community is without doubt economically disadvantaged^v as it remains unfunded and unrecognised in The Federal Government’s List of Recognised Disability. Diagnosis and treatments are largely self-funded and expensive. Additionally, untreated ADHD can have long-term impacts on economic security and the capacity to contribute to the community. Adding ADHD to the NDIS will improve this.” In focus ADHD forum

Our recommendation is to recognise ADHD as a disability officially. Doing so would lead to better life outcomes for individuals diagnosed with ADHD. Recognising ADHD as a disability would benefit our overloaded public health system and provide opportunities for individuals to enhance their employment capacity, contributing to our local economy.

It would also enable those diagnosed with ADHD the ability to receive support from services covered by the National Disability Insurance Scheme (NDIS). This recognition would particularly benefit those who have previously been unable to afford essential support, granting them the opportunity to access vital assistance. It would also provide protection for our most at-risk by providing clarity under the disability discrimination act.

It is crucial to acknowledge that ADHD frequently accompanies Autism^{vi}, neurodevelopmental delays, mental health issues, and other medical conditions. Many of these conditions are already included in the coverage provided by the NDIS. Excluding ADHD is contradictory if we aim to adopt a comprehensive approach to care, therapy, and early interventions.

Closing statement.

ADHD has its positives for me, allowing me to embrace my unique qualities, foster creativity, and solve problems in unconventional ways. I take pride in my thinking, actions, and work. However, ADHD has been a significant barrier to achieving optimal life outcomes. I've encountered struggles in employment and accessing timely healthcare, among others. I see a similar outcome for my own children, which is worrisome.

Throughout my 13 years of formal education, my teachers and educators failed to recognise my reading, executive function, working memory, and focus difficulties. Instead, I was unfairly labeled as lazy, weak, unorganised, and at times "a waste of time." These misjudgments have had a detrimental effect on my life.

My ADHD struggles have also negatively impacted my personal relationships as people struggle to understand how my brain works and what ADHD is. I have felt worthless, inadequate, and even stupid due to the stigma surrounding ADHD. Additionally, workplace barriers have taken a toll on my well-being. Lack of awareness about available support has hindered my job performance in the past. Moreover, the limited recognition of ADHD as a disability has made me hesitant to seek support. The stigma and misinformation surrounding ADHD create obstacles in accessing timely assistance and interventions.

Regrettably, these circumstances have led to a mental breakdown and a desperate desire to end my life. The system has failed to support me adequately and should have done better.

As a result, I have been unable to pursue my educational goals and have heavily relied on public health systems. I yearn for a better future for my children and future generations of Australians. I hope they will receive the necessary support and understanding, avoiding the challenges and hardships I have faced.

I will continue my advocacy and support through my online platform, Living on the Spectrum, to ensure that support and information are available in a timely manner.



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References

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^{iv} <https://www.healthdirect.gov.au/attention-deficit-disorder-add-or-adhd>

^v <https://www.adhdforum.org.au/living-with-adhd>

^{vi} <https://adhdguideline.aadpa.com.au/diagnosis/cooccurring-conditions/>

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