

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [anghydraddoldebau iechyd meddwl](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [mental health inequalities](#)

MHI 26

Ymateb gan: | Response from: Penny Kennedy

Introduction

I am grateful for the opportunity to contribute to this important enquiry.

I am a certified ADHD Coach and trainer who works with children, young people and adults with ADHD, and with parents and teachers. Prior to specialising in ADHD, I worked as a state registered Music Therapist, Music teacher and specialist ALN teacher.

I am also the wife of a husband with ADHD and mother to two young people, aged 19 and 18 years' old, who were all diagnosed with ADHD within the last 3 years. They have all suffered a great deal from growing up undiagnosed, untreated and misunderstood. Both my children and husband had, and continue to have, mental health challenges as a result.

Which groups of people are disproportionately affected by poor mental health in Wales?

Children, young people and adults with ADHD are disproportionately affected by poor mental health. There is a great deal of evidence and research to support this worldwide.

According to the mental health charity Mind, "we know that if you have ADHD, you're more likely to experience a mental health problem. There's evidence that anxiety, depression, conduct disorder (persistent patterns of antisocial, aggressive or defiant behaviour), substance abuse, and sleep problems are all more common with people who have ADHD."¹

¹ <https://www.mind.org.uk/information-support/tips-for-everyday-living/adhd-and-mental-health/#>

Professor Russell Barkley, an internationally renowned expert on ADHD, found an increased risk of suicidal ideation and completion, depression, anxiety and other comorbid conditions in those diagnosed with ADHD; with further research showing that for those growing up with undiagnosed and untreated ADHD, the situation is worse.²

In my own experience as an ADHD coach, working with adults with ADHD and the parents of children with ADHD, it is clear that mental health issues are a major concern.

What factors contribute to worse mental health within these groups?

The symptoms associated with ADHD are listed in documents such as the Diagnostic and Statistical Manual of Mental Disorders and refer to behaviours such as impulsiveness, lack of attention and failure to complete tasks.³ However, living with the personal and social consequences of these challenges of executive function is the primary cause of the mental health issues that all too often co-occur with ADHD. These include:

- Feelings of incompetence and inadequacy
- Difficulty with emotional regulation and rejection sensitivity
- Feelings of shame when symptoms such as impaired working memory or difficulties judging the passage of time are mistaken by others for lack of care or laziness
- Dealing with a lack of empathy and understanding from those in positions of authority when the sequelae of a hidden and widely misunderstood disability contribute to missed appointments or failure to meet deadlines

Factors such as these often cause those with ADHD to feel alienated and rejected by society, leave them vulnerable to depression and anxiety and, particularly where the condition is undiagnosed or dismissed, often lead them to self-medication through the use of illicit substances.

For those who are not recognised or diagnosed as having ADHD in childhood, the outcomes are particularly poor. According to an extensive study conducted in Sweden.

² Russell Barkley: The Adverse Health Outcomes, Economic Burden, and Public Health Implications of Unmanaged Attention Deficit Hyperactivity Disorder (ADHD): A Call to Action to Improve the Quality of Life and Life Expectancy of People with ADHD. Proceedings of the ADHD Public Health Summit Washington, DC October 7, 2019, <http://www.russellbarkley.org/factsheets/Final%20ADHD%20Summit%20White%20Paper%20revised%2012-10-19.pdf>

³ <https://www.psychiatry.org/psychiatrists/practice/dsm>

“Individuals who received their ADHD diagnosis later in life also presented with a higher mortality risk compared to those who received their diagnosis earlier. Unintentional injuries and suicide were the leading causes of death among individuals with ADHD, accounting for 35.8 percent and 31.4 percent of the 414 deaths in the ADHD group, respectively.”⁴

It is unfortunate that in the education system, which has arguably the most potential to improve outcomes, there is a disappointing lack of awareness or understanding of ADHD, which makes a significant contribution to worse mental health for those with this neurological condition.

With regard to the education system, there is a general culture of behaviouralism which tends to assume that any deviation from expectations around punctuality, organisation, timeliness or conduct in the classroom are due to lack of effort or defiance. This is compounded by a received opinion that ADHD has only one presentation which is stereotypically associated with ‘naughty boys’: rather than appreciating it as a complex and multifaceted neurological condition with a number of subtypes. This means that children who are inattentive rather than hyperactive/impulsive can be lost in the classroom, not meeting their potential, but neither causing enough disruption to receive a teacher’s attention.

Furthermore, even for children who are diagnosed with ADHD in childhood, there is an assumption that the only outcome will be the prescription of medication and that little else will be needed to support the child. While medication is highly effective, alone it is not sufficient. Without understanding and compassion from teachers, support staff and practitioners, as well as specific skills to support these children to understand their own executive function and develop ways to work with their neurology and meet their academic potential, subsequent mental health challenges are highly likely.

From my work with parents and children with ADHD, and from an online community I created for students with ADHD,⁵ a major issue for those who were not diagnosed as children, is about not being understood in school and that their neurological challenges and behaviours were treated as moral failings (turning up late, forgetting important equipment and homework, emotional outbursts, daydreaming and so on). Disappointment, disapproval and frustration are common attitudes towards those with undiagnosed ADHD. Phrases such as “could do better”, “lacks motivation”, and “needs to be more organised” were on every school report I received about my children since they were 6 years old. Every parent I have trained has commented that their children’s

⁴ <https://medicalxpress.com/news/2019-08-psychiatric-comorbidity-contributes-mortality-adhd.html>

⁵ <https://discord.gg/FvhcyWRhKN>

challenges have been reported in a similar way. These are criticisms of character, which, rather than motivating a child with ADHD, undermine their self-image.

This is extremely important because having these challenges while being unaware that they are caused by a neurological condition, leaves the child or young person open to a continuous assault on their self-worth. If one has ADHD and it is not recognised, then only one other explanation springs to mind: you must be lazy, disorganised, weak-willed and unmotivated. This is how people will see you, and all too often, this is how you are likely to see yourself. And this is not what society considers to be a good person.

And so, just like my children, many of those who were not diagnosed early, believe themselves to be lazy, unmotivated and incapable and live life wondering why they are not achieving the same kinds of things as their friends and peers.

A recent example of this is one of my adult clients with ADHD who said to me, "I'm not coachable, I'll let you down, I'm an idiot." This low self-worth leads to shame and is a common experience for those with ADHD. Just before my youngest child's ADHD assessment at age 17, they said to me "God, I've hope I've got ADHD, otherwise I'm just lazy"

Even for those with a diagnosis, being misunderstood is a major concern caused by teachers not having sufficient knowledge about the condition. Sandra Rief states that:

"Awareness and understanding with regard to how to structure and modify the environment and employ positive and proactive strategies to manage and respond to the ADHD related behaviours is extremely important and comes with education and training".⁶

My own experience of training teachers and care staff shows that they do not have this awareness and understanding, not because they are not keen to help, but because the vast majority have had no training in recognising or teaching children with ADHD. It is therefore not surprising that ADHD is massively underdiagnosed in Wales and that, according to the Pupil Level Annual School Census (PLASC) 2021, most primary schools in Wales have no children diagnosed with ADHD,⁷ despite the Welsh Government advisory document stating that between 5-8% of the population has ADHD.⁸

⁶ (Rief, S, How to Reach and Teach Children with ADD/ADHD 2nd edition 2005).

⁷ <https://statswales.gov.wales/Catalogue/Education-and-Skills/Schools-and-Teachers/Schools-Census/Pupil-Level-Annual-School-Census/Special-Educational-Needs/senreports-by-la-provision-welshenglishmedium-sentype>

⁸ <https://gov.wales/sites/default/files/publications/2019-01/ways-of-supporting-learners-with-attention-deficit-hyperactivity-disorder-adhd.pdf>

This means that of the 470,000 school aged children in Wales, between 23,500 and 37,600 potentially have ADHD. However, the PLASC shows that schools reported just 3156 children as having, or are being suspected of having ADHD. This means that around 85% of Children with ADHD are likely unrecognised, undiagnosed and untreated. As a consequence, many of these children will present with secondary conditions such as depression, anxiety, or behavioural disorders that could be avoided if appropriate support were available to them.

My two children are in this category. For 11 years I fought with my eldest child's schools to get him referred for an ADHD assessment, with no success. When he reached 17 and faced going to university (a particularly challenging educational environment for those with ADHD), I finally chose to pay for a private ADHD assessment. It was clear that he was struggling significantly; psychologically, academically and socially. If I could go back, knowing what I know now about the outcomes for children and young people with undiagnosed ADHD, I would beg, steal or borrow the money to get an assessment while my child was still in primary school. My eldest has currently suspended his studies at university due to depression. This is despite being exceptionally bright with a strong desire to do well; however, I believe that the continuous assault on self-worth during his education, has left him vulnerable and with the belief that he is broken, weak willed and a disappointment to others. For my younger child, the situation is similar, again I was left with no choice but to pay for a private assessment in order to limit the deterioration in mental health.

Groups with particularly high levels of poor mental health can have the most difficulty accessing services. What are the barriers?

Aside from the excessively long waiting times for assessment and treatment (up to four years in the experience of some of my clients in Wales), the main barrier to accessing services for children, young people and adults with ADHD is the attitude of practitioners, due to lack of training and understanding. For children with suspected ADHD, if no one from their place of education or their GP are willing to refer them, then it is impossible to get support from CAMHS. Most teachers and practitioners have had no training and so are usually basing their decisions on myths and outdated knowledge (such as only young boys that are hyperactive have ADHD or that the behaviour is just laziness or naughtiness).

A personal example is that I asked every teacher of my eldest child from year 1 until sixth form to refer him for an ADHD assessment. Some said they could see the

challenges but felt that there was no point in referring him as he wouldn't get anything, others were very dismissive of my requests for referral, saying things like: "You won't get a one to one so what would you achieve by getting a label, it would only stigmatise him" or "there really isn't a huge problem, he just needs to focus and get organised" or "even if I start the process, the Educational Psychologist won't support this".

To illustrate how training for school staff can provide immediate benefits for children with ADHD, it is interesting to note that after I provided an INSET day in a primary school recently, the school later reported that they quickly recognised four children whose academic performance they had been concerned about as potentially having ADHD. They went on to request assessments from the Educational Psychology Service as part of the referral process for a CAMHS assessment but they now believe the Educational Psychologist may be a barrier as they have little understanding of ADHD. This scenario has been repeated to me often in different school and children's services settings.

Parents often report to me that they have similar dismissive or negative reactions from school staff and GPs. One parent I worked with told me that their GP was very dismissive and said that ADHD is being over diagnosed, more discipline was needed and that he would not make the referral. When this parent suggested to the GP that they would have to go private, the GP said that "private clinics are making a lot of money and will diagnose so that they can sell you medication." There is no evidence of this at all and I believe it to be another myth.

In a similar example from my own experience, following the assessment and diagnosis of my children, my husband recognised himself as having the same challenges and contacted his GP. The GP said to him, "what's the point at your age? What do you hope to get out of it?" My husband replied, "I just want an explanation for why I find life so hard". The GP replied, "well that's not enough". My husband did manage to get a referral but only after he mentioned suicidal ideation. It seems that years of depression and struggling is not sufficient.

For those who do self-refer as adults, the processes and systems themselves present a significant barrier. ADHD entails an impairment in executive function that makes every step of the process a challenge in itself. Remembering appointments when working memory is low, the challenges of disclosing information that is felt to be shameful when prone to emotional dysregulation, low self-worth leading to low self-advocacy skills, fear of rejection, emotional dysregulation; all these discourage and deter adults with ADHD from pursuing help and then persisting once the process starts.

A good example is a letter my 19-year-old son received on the 24th January 2022 detailing an appointment for his medication review. The appointment is for 24th January **2023**. While for most people, knowing a year in advance when one's next appointment is might seem to be very helpful, for a person with ADHD the very fact that this will happen so far in the future and that no other communication will be made prior to this shows that the process has little understanding or sensitivity to the impact of the condition. If he misses this appointment, he will be removed from the NHS list as a 'Did Not Attend' and will have to re-refer in order to access services. Without a more proximate reminder for the appointment, there is a significant risk that he will miss it. This exact situation just happened to a young woman I am working with. Fortunately, her mother is an articulate, determined education professional and was able to intervene to explain that her daughter's neurological condition and depression had meant that she had not been in a fit state to attend the appointment and that she had not remembered to cancel it. The very fact that one needs to explain to medical professionals how the symptoms experienced by those they care for impact on their patients seems unbelievable. Imagine if one needed to explain to a fracture clinic that a lack of an alternative to a long flight of stairs was contributing to patients missing appointments. It is clear that if the individual had a physical disability, every effort would be made to ensure accessibility, yet simple, cost-effective measures such as text reminders and flexible appointment systems are not generally considered despite the impact this could have on improved outcomes:

“Missed appointments represent a significant risk marker for all-cause mortality, particularly in patients with mental health conditions. For these patients, existing primary healthcare appointment systems are ineffective. Future interventions should be developed with a particular focus on increasing attendance by these patients.”⁹

When people do get support, their experiences and outcomes are often poorer.

When children, young people and adults do get support it is often inadequate, not specific to their needs or comes too late, therefore the outcomes are poorer.

⁹ Mcqueenie, R., Ellis, D. A., Mcconnachie, A., Wilson, P. and Williamson, A. E. (2019) 'Morbidity, mortality and missed appointments in healthcare: a national retrospective data linkage study', BMC Medicine, 17(1).

An example of this can be seen from a review of London universities. The review found that, “on the instances where any support is in place for students with ADHD, it’s usually limited to what would normally be provided for students with dyslexia.”¹⁰

There has been no review of universities in Wales but from discussions with companies that provide specialist mentors and study support assistants in Wales, the situation is very similar to universities throughout the UK. It is worth noting that in order to work as a specialist mentor for disabled university students in Wales, there is a requirement to have gained two qualifications in supporting students with Autism, this is regardless of the range of neurodiversities within people you will be working with. You do not need any other condition-specific training. Without ADHD specific support, outcomes will be poorer meaning that many will often end up being treated for depression and anxiety rather than the root cause which is ADHD.

This was the position for my eldest child. His diagnosis allowed him to access a study support tutor while at university. This tutor had received no ADHD specific training but had completed several Autism courses (a prerequisite of the job) and although he was very keen to help, he did not have the skills to support my son. The danger here is that inappropriate solutions applied to neurological conditions can be very damaging, as it often sets the individual up to fail. So many of those with ADHD live with so much failure and this further contributes to their mental health challenges.

Time management is a good example of where the solutions need to be tailored to the specific challenges in different situations. Time management for someone with ASD is often about structure and fitting things into the available time, whereas for those with ADHD, managing time is frequently an additional challenge of self-regulation. For my son, not being able to manage time and studies, even with the help of someone they considered to be a specialist helper, was an additional assault on his self-worth.

My younger child’s experience of additional support at comprehensive school and sixth form was that the adjustments were the same as those for dyslexia: extra time for assignments and exams. It is worth noting that those with ADHD, without specific treatment and support often fall back upon a sense of urgency to be able to motivate themselves for action. This means that extra time for assignments simply gives more time for anxiety to build and is generally the opposite of what is needed.

The wrong kind of help can be more harmful than no help at all but with raised awareness and training for key professionals the right help is not hard to provide.

¹⁰ <https://attentionuk.org/about/the-state-of-current-provision/university-support-for-students-with-adhd/>

How effectively can existing services meet their needs, and how could their experience of using mental health services be improved?

Existing services do not meet the needs of children, young people or adults with ADHD.

Research has shown that outcomes for those with ADHD are vastly improved the earlier the child was recognised and diagnosed and so early identification is key. The process of getting a CAMHS assessment has always been long but with recent additional pressure, long waiting lists are even more of a barrier to early assessment. It is due to existing services not meeting their needs that many parents, out of desperation, are now choosing the private assessment route; however, in my professional capacity, I am now hearing reports that some schools will not contribute written reports to private assessments and I also personally experienced this from my son's school. As educational reports are an essential component of the assessment and diagnostic process, not providing these reports stalls the process. It also discriminates against families who are forced through necessity to choose the private route; often at a significant cost they can ill afford. Schools should be required to have policies in place to ensure that private as well as NHS referral pathways are supported equally. Furthermore, many GPs will not prescribe medication if the diagnosis came from a private clinic, despite the fact that often the same private providers are regularly contracted by the NHS to complete assessments. Barriers such as these not only impact negatively on children and their families, they also contribute to longer waiting times.

As set out above, for adults, the system is complicated and does not match the needs of those who need to use it. I would like to emphasise that this is in no way intended to criticise individual practitioners who often work under challenging circumstances; however, without training and a consequent increase in understanding and awareness as well as systemic reform, they will not be able to provide a service that meets the needs of people with ADHD.

As well as the need for increased resources to address long waiting times and the provision of training for anyone who works with or supports children, young people and adults, a review and reform of the systems that those with ADHD and their families are required to negotiate should be carried out. In order for this to meet the needs of those with ADHD, this should be carried out co-productively with those who have the condition and ADHD specialists so that the key challenges experienced by the users of these services can be identified and addressed.

To what extent does Welsh Government policy recognise and address the mental health needs of these groups? Where are the policy gaps?

There is currently very little in Welsh Government policy to support the needs of this group.

The new ALN code is welcome in that it is seeking to ensure that there is universal provision in education and that school staff have training in neurological conditions such as ADHD; however, having attended and discussed this training with those who have received it, it is clear that it does not go into enough depth. There is still no widely available training on recognising or understanding ADHD as a complicated neurological condition or understanding the huge impact it can have on the self-worth, motivation and future success of children and young people with ADHD.

ADHD is not recognised as the significant public health problem that it is and there does not appear to be an overarching strategic approach on the part of the Welsh Government to develop policies in support of this. Despite the Welsh Government having produced an excellent ADHD advisory document with clear research into what works, this is mostly being ignored.

What further action is needed, by whom/where, to improve mental health and outcomes for the groups of people identified and reduce mental health inequalities in Wales?

As set out in the answers I have provided to the questions above, the primary need is for wider knowledge and awareness of ADHD in the educational and health sectors. This should be part of a comprehensive strategic approach to improving outcomes for those with ADHD, supported by policy and implemented in a way that is co-produced with those having lived experience. Without this, those with ADHD will continue to suffer mental health inequality, diminished quality of life and shortened life expectancies.