**The Maturation of ADHD:**

**A System Analysis of the United Kingdom’s Approach to ADHD Diagnosis & Treatment in Adults**

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# I N T R O D U C T I O N

## What is ADHD?

* Attention Deficit Hyperactivity Disorder (ADHD)- most common neurodevelopmental disorder in childhood1.
* Recently, recognized to persist into adulthood1.
* Divided into classifications: inattentive, hyperactive-impulsive and combined presentations2.
* 2.5% of adults have ADHD, but many go undiagnosed- number is likely higher2.
* Associated with1:
  + negative occupational outcomes,
  + significantly higher mortality rates.
* Exhibit increases in1:
  + criminality,
  + serious vehicle accidents,
  + early parenthood
  + suicidality.
* When untreated, can put a strain on public services for ongoing, long-term support.

## ADHD & Comorbidities

* Usually accompanied by comorbidities, which often masks ADHD3.
* 50% of individuals also have 1≤ psychiatric disorder(s)3.
* Depression/anxiety- prevalent comorbidities in adults4.
* High comorbidity rates make detection in adults more complicated.
* Goes unrecognised and masked by predominant mood disorders, funding may also follow suit.

## ADHD & Individual Differences

* Presentation differs6:
  + Between age and genders,
  + symptoms- believed to exist on a continuum scale, thus recognition and diagnosis is complex.
* Diagnosis often occurs in childhood, specifically in boys who present more hyperactive and external symptoms7.
* Girls go unnoticed, because usually they7:
  + internalize symptoms,
  + have inattentive presentation.
* Going unnoticed can result in7:
  + develop comorbidities,
  + masking symptoms,
  + resulting in acquiring a diagnosis in adulthood complicated.
* Children, mostly boys have been the main subjects within research, neglecting not only adults, but girls and women7.

## ADHD & Treatment/Diagnoses

* Shortcomings have been identified for adults specifically1 8:
  + significant problems in accessing support,
  + limited understanding of lived experiences,
  + stigma associated with ADHD in adults,
  + limited knowledge from healthcare practitioners, etc.
* NICE guidelines highlight pharmacotherapy as first-line treatment for adults1.
* Some studies demonstrated effectiveness of different psychological therapies9.
* The lack of research into treatment options and medications for adults' highlights concerns of1:
  + reliability/validity of the options,
  + their effectiveness,
  + acknowledgment of possible side effects.
* Limited research=limited treatment and support.

## Key Issues

* Little research, which:
  + facilitates the hindrance of diagnosis and treatment.
  + is exacerbated by underfunding (varies across the UK leading to a ‘post-code lottery’) -causing inequalities in access.
* Reliance on charities providing support where NHS can’t.
* Charities/NHS are key parts of the system, impacting service users who should be considered as main stakeholders even if they do not have lots of power.
* Through activism, service users could have more power, so more pressure is put on those in authority regarding regulations around treatment and diagnosis for ADHD.

# M E T H O D

Research was gathered by:

* Reviewing literature and identifying overarching gaps.
* Reviewing current policies and procedures.
* Conducting 5 semi-structured interviews: service users, researcher, charity and coach.

# T H E M E A N A L Y S I S

### 1.Diagnosis

#### I.I Non-stereotypical symptom presentation

One main theme outlined ADHD symptom presentation which was non-stereotypical and the lack of attention it was given. Paul stated that the Diagnostic Statistical Manual of Mental Disorders (DSM) fails to capture certain presentations.

*“There are some really important ones like this ability to hyper focus on things that you're interested in. That's just not in the DSM, on the other hand, it's characteristic of ADHD. There are things you can focus on and that can be misleading, because they're often expecting not be able to focus.”*

*– Paul*

This exemplifies one of many symptoms of ADHD which unrecognised within the DSM, highlighting the confusion those being diagnosed may face as he surmises that you shouldn’t be able to focus, when it’s common in some to be able to hyper focus. It can be argued central symptoms are overlooked and almost dismissed, which can then make the understanding of ADHD difficult.

This theme was also prominent within service users.

*“What I think is lacking is the awareness of how it can affect your emotions. Because actually, I am very strong, and I can cope with a huge amount. But I think from the emotional side it doesn't get looked at, at all., you can get really down if you work really hard for an exam and then you fail again and again, knowing you put all the work in, and it's looked over and it's really sad.”*

*-Lucy*

Lucy addresses another presentation of ADHD which has not been highly recognised, which is emotional presentations. Emotional awareness is described as misaddressed, as Lucy describes her own struggles emotionally within the education, “looked over’” reiterates the point that people may not understand the emotional effects ADHD brings and that more effort addressing these difficulties is needed.

#### I.II Knowing ‘Different’.

Another prominent theme within service users was that being diagnosed made them understand their differences, Lucy mentions below:

*“people jump on that’ I want a diagnosis; I want a diagnosis. It makes you aware you are different, you have to think, learn and try to manage things differently. It was a ‘ta da’ moment where you go, yeah, I get that now, why I'm doing certain things and why I've been doing that for so long. It kind of put the jigsaw in place, it was a relief to think there is something wrong here and I didn't realise. Friends know now when I say or do certain things, they put it down to the ADHD... whereas before, no one knew and they might make unhelpful comments, that knocked my confidence. The people that know me now and the people that I've told know to act differently. It makes people aware, if you're not aware you judge or make assumptions on somebody.”*

– Lucy

Lucy emphasises how diagnosis was a positive experience in which justification was crucial for understanding her behaviour, and how to differentiate her thinking. She felt relieved. As if she could now assign reason to her difficulties and adapt accordingly. Later, Lucy then states that in relation to peers, it gave them understanding too and can enable others to categorise behaviour to an ADHD diagnosis. This was helpful as before she faced judgement, but as soon as there was knowledge of her ADHD her peers were then able to account for the behaviour more sensitively. Importantly Lucy reiterates the importance of awareness through diagnosis to prevent judgement and assumption.

### 2.Research

#### II.I Individual Differences

*“I work … got kids ... maybe going through menopause... they look of the menopause, but not at ADHD within that or within having kids and doing a degree ... that brings different issues.”*

- Lucy

*“Stereotypical symptoms known are based around boys and how they present them. Often that hyperactive, not being able to sit still and getting in trouble, whereas girls are more likely to be daydreaming ... under the radar cause they're not as visible”.*

- Catherine

*“women being diagnosed have been diagnosed with anxiety and depression or personality disorder ... there still is a problem with people in the profession, not knowing enough about it.”*

- Paul

Individual differences impact how support is accessed. A statement by Lucy touches on the impact of family and its commitments. A busy life getting in the way of your own needs is a common one. It is shared among carers with similar difficulties making time for support for themselves10. When many people are busy in their lives and a diagnosis requiring time, energy and self-efficacy to make the first step, the onus is on the service user to make steps towards diagnosis and any subsequent support. People go undiagnosed, not getting support. Solutions could include outreach programs, educating public and GPs on the symptoms, support for ADHD and advocating for those could have ADHD. Changes that could make the process easier for service users would be to streamline the process of diagnosis and therefore making it speedier, accessible. Lucy (and others) alludes to how gender plays into the process and that women/girls are often overlooked/misdiagnosed (Paul). Symptoms are masked (discussed by Catherine) or visible but not recognised by the diagnostic teams- medical professionals need education. It’s important that education is supported by research. Gender inequality is present in research on ADHD resulting in this lack of understanding/confusion11. Research should address how symptoms differ in women/girls and hormonal (mentioned by Lucy) impact to needs.

### 3.Treatment & Funding

#### III.I Holistic vs pharmacological treatment

Society often looks to the medical industry for explanations and methods to alleviate symptomatic conditions. Recently psychology has outlined flaws in the bio-psycho-social approach western society uses. The notion implies that to heal the mind, you should heal the body first. Accordingly, participants challenged the biomedical perspective currently adopted.

*“I think the problem is there's still a lot of professionals who don't understand ADHD. It might be missed, misdiagnosed or ignored. Also handling on how severe it is. As well, having worked with a lot of students, not everyone seeks a medical treatment or diagnosis. that's valuable. if you want medical treatments you need to go to a doctor, therefore GP’s must be skilled in recognizing it and referral to appropriate services. those things are improving, but they're still patchy and have long waiting lists... I think that what is well-developed is the private arena. The coaches and psychologists who know lots about ADHD and can guide you. But generally, these aren’t well supported by the NHS. Within universities, disability teams probably do know much about ADHD, but they may or may or may not think of it as ADHD”.*

-Paul

Paul proposed a desire for a holistic method. Not rejecting medical approaches but recognising the need for sufficient and effective treatments that can be sourced through coaches, psychologists, disability screening teams and education institutes. Paul hinted at the NHS’s lack of presence in facilitating and championing such options, implying room for improvement.

Participants recalled that the first treatment option was often prescribed medication, with limited to no additional support.

*“... that pharmaceuticals are not the only option. [I believe that every person that takes medication think its life changing”]. three months later they still have to understand that their [memory and executive functioning is not as great]. Medication is not the solution, it's a part of a bigger solution.”*

-Angela

Angela’s perspective suggests the physical effectiveness of medication is as short-lived as it is psychologically. This can be interpreted as a temporary mask to the concerns. Medication has not been designed for long-term use, however the prevalence of medication distribution poses questions of how effectiveness could improve. Additionally, the expectations of medications success should be managed and articulated accurately. Angela mentioned how cognitive functioning is not address, whereby suggestions of psychologists and coaches may meet this need. As Angela stated, “it’s part of a bigger solution”, suggesting a multidimensional approach can improve mental health.

#### III.II Primary Care

*“ADHD isn’t seen as a priority by commissioners or trust leads … there’s an institutional prejudice towards ADHD as it’s seen as somehow not a real medical problem”.*

-Tom

*“physical, visible disorders are just easier … there's a lot of focus on that ... Invisible disorders are harder ... mental health isn’t seen as like a basic need”.*

- Angela

These show rejection. Service users and providers feel ADHD has been forgotten by policies. There is difficulty finding support as it lacks visible/physical characteristics. Problems concerning “invisible disorders” aren’t exclusive to ADHD and are commonly reported with mental health conditions12. Tom says ADHD receives institutional prejudice because it’s not physical or seen as “real”, causing feelings of rejection because they aren’t supported by policy makers. Their actions at the top ignore those lower down. This perpetuates the sentiment that mental health support isn’t a basic need throughout society. Society’s opinion impacts all levels of the system as it controls what’s ‘relevant’, therefore what gets funding. Increasing public awareness would help this.

#### III.III What is the need for ADHD specialism?

Issues surrounding ADHD as a niche topic arose. Participants expressed the need to widen the scope of people who can identify, diagnose and treat ADHD without specialism.

*“... we still think it's a specialist only disorder. Do you have to see a specialist? Whereas things like anxiety and depression, your GP will deal with that on the whole and there's a lot more psychological support. I think because ADHD is very common, over time, the number of people able to provide for ADHD will improve.”*

- Paul

Paul questioned why GPs don’t exercise the appropriate support for those with ADHD, comparing the scenario against other mental distresses. From this, further questions can be raised. Do they believe their able to handle cases of ADHD appropriately? If not, what fuels this?

*“The system in the UK isn’t something I'm used to, I feel like everything, notably specialism takes a long time.”*

- Angela

*“I think it must move from being a specialist only condition to a more general mental health problem. obviously, it can be viewed as a learning disability even in the absence of mental health problems. I think broadening it out so that people working with other mental health problems or learning disabilities will also be able to work with ADHD. There's no reason why those people can't be doing so.”*

- Paul

Specialism benefits the people it seeks to help; however, Angela proposes that the time scale for specialism does not serve those with ADHD well. Whilst Paul adds that ADHD shouldn’t be a specialist area. Concerns with specialism may lend to other factors, for example, affecting which regions have treatment options available, as well as facilities able to have a rotation of staff to hasten the pace of diagnoses.

#### III.IV Issues with support after diagnosis

Another theme that echoed throughout our interviews was the lack of further support after diagnosis, potentially resulting in individuals turning to private healthcare. Thus, neglecting individuals who cannot afford it. Subsequently, they will have only acquired a diagnosis- usually in hopes of further remedying it. Instead, they’ve received a reason without solutions.

*“To start at the core. If the doctor doesn't understand, how are they supposed to know how important it is for the person? Where do they send them to? Private companies are making SO MUCH money off people desperate to get an answer they deserve... the families that are privileged and have the money can go to these private places and get themselves or their kids diagnosed, a family that’s struggling and deserves support, has to wait two years”.*

- Angela

Angela highlights that when doctors themselves lack knowledge about ADHD in adults, they can’t know what further treatment would be appropriate. Emphasising this as a core issue in support after diagnosis. Moreover, she highlights that private healthcare profits enormously off this, as those individuals have few alternatives. Most importantly, she stresses that this system prioritises privilege, neglecting others who may have to wait two years to receive support, although the latter individual’s wellbeing is as important.

*“I know that there are options for treatment that would be helpful, I know there's options to do them privately as well. But I haven't ever been in a position to afford it, cause it's expensive and something that you would want relatively long-term. I couldn’t save up and pay for just one session.”*

*–* Catherine

Additionally, Catherine recognises that there are treatment options available, however considering the aforementioned issues of funding stated, waiting lists and regional availability. She recognises that private treatment is only accessible to a smaller more privileged group.

### 4. Education, Comprehension and Application

#### IV.I Limited training of GPs & professional stigmatisation

Lack of knowledge and general stigmatisation among professionals was highlighted.

*“The third time it was a female doctor and I brought it up, and she turned round and said “Well you don't have ADHD because you've been to University, you've got a degree. I see children with ADHD, and they can't sit still in my office. You don't have it.” I'm not a person who cries but I started crying and said: “sorry but if it’s not that then can you help me work out what’s wrong with me”. she then replied, “Oh well I'll look into it”.*

*–* Catherine

The doctor’s initial response isn’t uncommon in literature. They assumed that based on her education and gender, she couldn’t have ADHD as she didn’t fit the stereotypical idea of what individuals with ADHD are capable of and what symptoms they present. Catherine’s frustration and sadness regarding this is understandable, contextually this was her third attempt to get help, and she was clearly upset and in need of an answer. The doctor, assumedly surprised, agrees to explore further, later diagnosing her with ADHD. Regardless, this experience highlights the difficulty for adults seeking diagnosis. They must persist for people to believe them. The fact that she had to beg for help from a professional, who has given an oath to help people, is devastating. This would likely never happen to anyone who has a physical or more known mental health issue. The system here displays the lack of care for ADHD.

# C O N C L U S I O N S

* Data aligns with some of the initial predictions:
  + The further the differences in views of the efficacy of diagnosis and treatment in the UK, the experience of being a service-user is worsened.
* Statements from interviewees resembled issues identified by the research team via coding:
  + majority of research is from America- not always generalisable to the UK.
  + heavy demand for UK specific research.
* Education and training highlighted as key areas for improvement.
* Funding significantly interferes with:
  + problem identification,
  + establishing future solutions.
* Most solutions are dependent on/originate from lack of funding.