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Panorama
BBC
BBC Broadcasting House
Portland Place
London
W1A 1AA

11th May 2023

Dear Panorama,

Re: “Panorama: False Diagnosis: The ADHD Scandal” now retitled to “Private ADHD Clinics Exposed”

We, and many members of our ADHD communities, are concerned about the upcoming Panorama show about ADHD¹. The show is scheduled to be broadcast on Monday 15th May.

We are a large group of disabled adults and children who suffer significant stigma and discrimination in our lives. Our concerns are that this show will add to that stigma and discrimination rather than diminish it, that it will do more damage than good, and represents a potential threat to lives. The show description appears to call into question whether people have the condition at all.

We hope very much that our anxiety is unfounded; however, we do want to write to highlight to you the potential areas of damage to ensure you were aware of them and in the hope of helping you avoid causing negative outcomes.

We want ADHD Assessments to be thorough, authoritative, available and timely.

We understand that a major thrust of the show is to argue that private assessments are not thorough and authoritative - that a positive assessment of ADHD is essentially available for purchase. **It is important that ADHD Assessments are authoritative and trusted and we welcome any and all work that helps ensure that.**

However, our concern is any potential extrapolation that tarnishes anyone and everyone with a private diagnosis.

There is a significant issue with ADHD diagnosis in this country.

There has been some spurious correlation in elements of the media that the increase in ADHD assessments and ADHD medication must be an indication of false diagnosis rather than an indicator of a population and health sector acknowledging a serious and unmet need.

ADHD is a very difficult condition to live with and has been underdiagnosed and under-discussed for decades. Studies indicate around 2.6 million people with ADHD in the UK of which around 2 million do not have a diagnosis. Recognition of ADHD symptoms started in the UK in 1902 but it wasn't until the year 2000 that it was formally recognised for children and 2008 for adults². That means that the majority of people with ADHD in the UK had a near-zero chance of being identified and diagnosed as children and even now we believe we're only picking up a fraction of children and adults with ADHD³.

¹ <https://www.bbc.co.uk/programmes/m001m0f9>

² <https://adhduk.co.uk/the-history-of-adhd/>

³ <https://adhduk.co.uk/adhd-diagnosis-rate-uk/>

Much of the increase in diagnosis now relates to the overhang of people resulting from the history of underdiagnosis. The increased discussion of ADHD that we're now having means individuals learn about the condition and have the opportunity to recognise the traits of ADHD in themselves. That's the first step towards going forward to a diagnosis.

Our data shows a particular issue for women and girls. Our Freedom of Information research shows girls are much less likely to be picked up in school than we'd statistically expect (For example just 6% of referrals in Wales are for girls when they should be between 20% and 33%) and we regularly hear of women being rebuffed by GPs when requesting an ADHD Assessment. We've heard examples of individuals being told that ADHD in women doesn't exist or having their traits diminished and misinterpreted. An unwillingness to recognise ADHD means they are treated as having something else (e.g. anxiety or depression) instead of the underlying issue of ADHD.

Waiting times in the NHS for ADHD Assessments are a significant issue. They're often long and unreliably given. From the charity perspective, it is clear the majority of people looking for an ADHD assessment aren't the 'worried well', as sometimes presented in parts of the media, but are in trouble, often at a crisis point, and needing help. Our recent Freedom of Information survey found that 71% of Integrated Care Boards were unable to provide us with child ADHD assessment waiting times and 60% were unable to provide adult ADHD assessment wait times. The vast majority of wait lists we are aware of are in multiple years. We're also aware of waitlist manipulation – GPs putting people off or denying reasonable requests, trusts implementing aggressive screening and removing people from lists (this is particularly onerous as there is no right to a second opinion in the NHS), and dividing up stages so a first stage of the process comes more quickly but you are then put in a longer less-public queue for the next stage.

Faced with serious struggles in their own life and, with no end in sight, many are faced with a Private Assessment as their only practical option.

Having ADHD is tough.

There is a significant stigma for individuals with ADHD⁴. This results in individuals feeling that they can't speak about their condition for fear of discrimination and exclusion. It means parents avoid assessments for fear that the label will bring. Damage from the "label" is a euphemism for the discrimination, bullying and exclusion that occurs. It describes the discrimination of acceptance to jobs or further education that is currently happening on a daily basis.

How tough ADHD is tragically shown through the figures on suicide:

- Adults with ADHD are five times more likely to try to take their own life than those without ADHD (14.0% vs 2.7% [5.2 times the baseline])⁵. These results have been reinforced by being found elsewhere as similarly 5 times the baseline⁶.
- One-quarter of women with ADHD have tried to take their own life. (23.5% vs 3.3% without ADHD [7.8 times the baseline])⁷

We also know that a lack of identification, assessments and support for individuals with ADHD in education is resulting in individuals falling out of education and into crime. The consequences of that failure have resulted in:

⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3430836/>

⁵ Archives on Suicide Research.

<https://www.tandfonline.com/doi/abs/10.1080/13811118.2020.1856258?journalCode=usui20>

⁶ British Medical Council Psychiatry: <https://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-021-03247-6>

⁷ Archives on Suicide Research.

<https://www.tandfonline.com/doi/abs/10.1080/13811118.2020.1856258?journalCode=usui20>

- 24% of prisoners having ADHD (Circa 7 times the general adult population) and;
- 45% of individuals in youth institutions having ADHD. (Circa 9 times the child ADHD population)⁸.

We have a tragedy of lost lives and wasted lives.

To further highlight the reality of the above statement, I can inform you that, until recently, the majority of funds donated to the ADHD UK charity were from the parents of children who had lost their battle with ADHD and taken their own life.

NHS resourcing failures means for many private assessments are the only option.

Below are some of the countless cases we know of:

- A woman in South Wales was told by her GP that there was no local ADHD Assessment service. We helped her challenge it by requesting an Individual Funding Request, resulting in her GP saying “We do have an ADHD Assessment service, but it is so overwhelmed that we tell people that we don’t”.
- A woman in North Wales told she had a 7 year wait for an Assessment. She took the best job she could hold onto and saved for 11 months to afford a private Assessment to get the help and support she needed.
- A mother and son in England who both identified they likely had ADHD. They were told of a 3 year wait. The family could not wait as the son’s mental health was deteriorating and developing the first signs of suicidal tendencies. They could afford one private diagnosis so put the son forward for that. The mother remains on the waiting list and is seriously struggling.
- In Leicester a student identified he likely had ADHD. The waitlist for assessment was three years. He was finally diagnosed 4 weeks before his final exams. He has now been told he has a further 2-3 years to wait for medication. His entire University experience, his grade, and his life trajectory have all been altered by the NHS wait list and its failure to fulfil the NICE guidelines in a timely manner.
- In Coventry, the trust has set up “screening” between the referral (usually a school) of children and a formal Assessment. In the most recent figures that we have, screening was removing 92% of all referrals. 152 were referred. 140 were removed from having an Assessment. We find it impossible to believe that those school referrals are 92% wrong. The lack of perceived importance of an ADHD assessment is depriving children of being able to understand themselves and get help.
- In York rather than expand their ADHD service to meet the needs of their population, they are formally restricting ADHD assessments to those who have become suicidal, are a threat to others, need a life-saving operation for which an Assessment is needed, or under the threat of family court action⁹. Our view is that it is an outrage that access to healthcare is filtered to only after you are suicidal and not before, after family court is involved not before, after damage is done not before.
- In Scotland they haven’t adopted the NICE guidelines, and withdrawn their own guidelines for being out of date¹⁰, which means that there is no patient right to an ADHD Assessment and we are informed of areas with no adult ADHD services at all.

⁸ The World Journal of Biological Psychiatry:

<https://www.tandfonline.com/doi/abs/10.3109/15622975.2011.600319>

⁹ <https://www.yorkpress.co.uk/news/23425598.york-adult-autism-adhd-assessment-pilot-criticised/>

¹⁰ <https://www.sign.ac.uk/our-guidelines/management-of-attention-deficit-and-hyperkinetic-disorders-in-children-and-young-people/>

There is no question in our mind that lives are being ruined and lives are being lost to suicide as a result of these failures. Calls to the charity from grieving parents further reinforce this view for us.

The failure of the NHS to provide a timely ADHD Assessment service means that many are turning to private assessment services. They shouldn't need to do so, but they've been failed.

We have a significant concern that your programme will tarnish all private diagnoses and in doing so not only misrepresent the truth – as we believe the vast majority of diagnoses both private and NHS to be accurate – but also cause harm.

- Resulting in schools and companies rejecting a private diagnosis meaning individuals are not able to access the help they need.
- Resulting in increased stigma. Accusations that individuals who have ADHD are lying and have a fake private diagnosis.
- Resulting in individuals thinking they have no option but to wait for the NHS – often years - and suffer sometimes irreparable harm to themselves and their life while they do so.

We fear your programme will give volume to those trolling against ADHD and ADHD medication.

For example:

- When Adrian Chiles bravely shared that he takes ADHD medication in the Guardian¹¹, the Daily Mail's take was "Adrian Chiles reveals he's taking amphetamines"¹² immediately stigmatizing and diminishing people for taking a recognised medication. This makes it harder for people to feel they can talk about ADHD and medication and be treated fairly.
- In February 2023 Dominic Lawson in The Times wrote in his article "I'm sorry, but all this ADHD doesn't add up" that "the best treatment might be to disconnect their phone for a few hours a day"¹³. Thus reducing this serious condition to a cheap reductionist jibe and diminishing the ability of individuals to feel they'll get help when they ask for it.
- February 2023 also had Julie Burchill in the Spectator talk to "Why I'm sceptical of the ADHD epidemic"¹⁴ She writes that she doesn't think those with a diagnosis actually have ADHD "do I believe that most of the people who claim to have them really do have them? Not in a million years.", "You've heard of luxury beliefs – meet luxury maladies. I wonder how many Ukrainians suffer from ADHD?", "The only good thing about this imaginary epidemic are the laughs to be had reading about it.", "ADHD becomes a Get Out Of Jail Free card for entitled types seemingly looking for an excuse for alleged bad behaviour.", "I can't help but believe that a lot of 'neuro-diversity' is an internet-borne virus. Never mind, what today's youngsters are lacking in the three Rs they'll be able to make up for with the three As; ADHD, allergies and attention-seeking".
- In late February Giles Coren wrote in The Times an article titled "I'm calm and focused for this ADHD test . . ."¹⁵ where he says "This ADHD nonsense simply has to stop". "And then they sell us the drugs — in the case of ADHD an amphetamine derivative — and everyone's happy, or thinks they are". He works through an ADHD screener giving insincere answers that result in a positive screen. He finishes up with "I want a big bag of amphetamines to help me concentrate.". The portrayal is that of ADHD not being a real condition with those chasing it as characterised by drug-seeking behaviour. His article, and the attitudes it perpetuates, are extremely undermining for those struggling with ADHD and taking medication.

¹¹ <https://www.theguardian.com/society/2020/sep/30/my-treatment-for-add-changed-my-life-so-why-cant-i-stop-worrying-about-it>

¹² <https://www.dailymail.co.uk/tvshowbiz/article-8793831/Adrian-Chiles-53-reveals-hes-taking-amphetamines-treat-ADD.html>

¹³ <https://www.thetimes.co.uk/article/all-this-adhd-doesnt-add-up-comment-vqvl9kqvn>

¹⁴ <https://www.spectator.co.uk/article/why-im-sceptical-of-the-adhd-epidemic/>

¹⁵ <https://www.thetimes.co.uk/article/im-calm-and-focused-for-this-adhd-test-58v63w8hq>

- The above is in the public media. As you might imagine there is a lot of social media that is distinctly worse.

Private ADHD Assessment Rate of Positive Diagnosis.

We understand you have data showing that the majority of private ADHD assessments result in a positive referral. As you know correlation doesn't mean causation – a high positive assessment rate doesn't automatically mean significant false positives. I don't think it is a surprise that most who put themselves forward for an ADHD Assessment have researched enough to know they have a very strong chance of having ADHD. Being assessed is emotionally difficult and expensive. That isn't to say that there can't be bad actors, or misguided people, in the area – looking for an ADHD Assessment when they know they don't have it.

If ADHD assessments are being given out improperly, we would want to know that and want it stopped.

Our concern right now is that extrapolation is going to be used to undermine all private Assessments and cause harm to individuals with the recognised disability of ADHD. Commentary such as “We don't know how many are wrong” is to lead the viewer to conclude it is a significant percentage. It does not provide proper balance to allow fair and equal consideration. Our strong view is that such a question is too important, and the risk of harm too significant, to do so without proper data on the level of false positives and false negatives. Medical tests are rarely absolute. We would need to know if that is within the expected parameters or not. Furthermore, if your comment is to the private sector, then to show balance and impartiality we would argue that you would need comparable NHS data to indicate the difference. Any investigative tests should also be repeated with equal rigour to the NHS.

2007 Panorama ADHD Failure

Panorama failed the ADHD community significantly in 2007 when it broadcast a factually inaccurate show: ADHD drugs have "no beneficial effects"¹⁶. The BBC Trust found that an edition of Panorama breached guidelines on accuracy and impartiality by “distorting some known facts” during a programme¹⁷. This resulted in an apology and on-screen correction: “... the BBC Trust's editorial standards committee (ESC) ordered the corporation's management to broadcast the correction and apology at the beginning or end of Panorama in its Monday night BBC1 slot, "due to the serious nature of the breaches" of editorial standards”¹⁸.

Concerns.

- We have concerns that we have a group of people with a recognised disability who are about to be undermined if they've got a private diagnosis, which will likely have far-reaching consequences.
- Some individuals with ADHD are an extremely vulnerable group, as expressed by the statistics on suicide. We hope that programme makers have taken that into serious consideration to avoid creating irreparable harm.
- We want to raise the issue of the duty of care of this programme and the BBC to those with ADHD, and especially those with a private diagnosis of ADHD.
- With the above in mind, and acknowledging that the programme is yet to broadcast so we don't know the detail, we would hope that the programme and BBC have ensured that they are fulfilling all obligations under the Equality Act 2010.

¹⁶ https://www.bbc.co.uk/pressoffice/pressreleases/stories/2007/11_november/12/adhd.shtml

¹⁷ <https://pressgazette.co.uk/publishers/broadcast/bbc-trust-panorama-distorted-facts-in-adhd-programme/>

¹⁸ <https://www.theguardian.com/media/2010/feb/24/panorama-bbc-trust-ruling>

- Furthermore, the programme and BBC need to ensure they have fulfilled their equality and duty of care obligations to the BBC workforce. That it is following the BBC's own Diversity and Inclusion initiatives and following the BBC policies on disability support. There are employees of the BBC with a private ADHD diagnosis. This programme has the potential to damage the working environment of employees of the BBC with ADHD and the wider BBC needs to be comfortable that it, and Panorama, has taken all appropriate actions for their employees with ADHD.

We hold enormous respect and awe for the Panorama programme. Its strength of voice and ability to hold entities to account. We do hope that in reading this letter you can see some of the enormous challenges people with ADHD face and the abject failure of many parts of the NHS. We hope you might even consider using your position to highlight those failures and bring positive change. As a charity we're here trying to help people with ADHD thrive. Your strength and voice could really help us do that.

Thank you for taking the time to consider the contents of this letter. If you would like to contact us our press contacts are: press@adhduk.co.uk or phone on 07401 122 343

Yours sincerely,



Henry Shelford

CEO, ADHD UK

I'm a person with ADHD. Diagnosed privately initially, then (at GP request) re-diagnosed by the NHS.