

Dear Health & Social Care Committee,

I write in response to your call for the consultation on health inequalities for Welsh Citizens.

I have attached the UK Expert Consensus Statement on Failings in NHS for the 1 in 20 who have ADHD. Representatives of all Royal Colleges & Leaders from patient led groups participated in its findings which were published in the Journal 'Frontiers in Psychiatry' in March 2021.

Also attached is the results of a survey undertaken in late 2020 capturing the voices of over 700 families from across Wales, listing their concerns.

The lack of knowledge, understanding & resources - by many health practitioners and especially Commissioners for children and adults with ADHD, is of very serious concern. Undiagnosed unsupported ADHD results in:

- Reduced life expectancy of 11-13 years.
- Increased risk of inflammatory diseases.
- Increased risk of hypertension and stroke in adults
- Migraine
- Skin rashes
- Asthma
- anxiety, depression
- Obesity (& concomitant risk of Type 2 diabetes)
- Eating disorders
- Self- harm and increased risk of suicidality, increased risk of PTSD and OCD.
- Increased risk of post partem and post-natal depression in women.
- Increased risk of cognitive decline and emotional lability in peri menopausal women and during menopause.
- Increased risk of addictions

Key FACTS

- ADHD affects 1 in 20 people
- Over 50% of Autistic children also have ADHD (something that is rarely discussed- why?)
- ADHD medications cost only £700 per year per patient.
- Psycho-education on self care, healthy lifestyle choices normally offered for any 'chronic' lifespan condition (eg. such as diabetes) are invariably not offered for ADHD patients, so families are over reliant on medication - which should not be used in isolation to manage ADHD.
- Over 40% of children with ADHD also have dyslexia.
- Comorbidities that impact on learning have a prevalence in excess of 70%. In summary, ADHD rarely occurs in isolation.

- ADHD is relatively easy to assess and diagnose - utility of objective computer based cognitive functioning tests that are 86% accurate are being rolled out across England and EHSN's have researched and established that use of this technology (approx £40 per test) saved approximately £42,000 for every 10 children referred. QB test is used in only one area in Wales. www.qbtest.com

Missed diagnosis and misdiagnosis

The prevalence of missed diagnosis and 'misdiagnosis' resulting in many (especially girls and women) being overlooked or misdiagnosed and treated / medicated with ineffective treatments is an unseen cost to finite health care budgets - as well as a tragedy to many who experience physical and psychological ill health across the life span because of ADHD.

Access to CAMHS for children in psychological distress

Children who reach the threshold to access psychological therapies with CAMHS - which are self-harm, eating disorders and attempted suicide, are invariably declined access to counselling by CAMHS - "Because it's their ADHD". This is widespread practice across the UK - including Wales. This discrimination is in breach of the Equality Act of 2010. There is no clinical, legal or moral justification for this policy. It is the opinion of many parents that this 'triage' is simply a tool for waiting list management that is justified due to capacity and demand issues.

That over 40% of CAMHS referrals are declined **without** reason provided in CAMHS Benchmarking Reports, hides this discrimination that leaves many families believing that there is an institutional & cultural prejudice toward those with ADHD - be they child or indeed adult.

There will be research published later this year reporting parent's experiences of Health Services for ADHD which are damning.

The Moral and Economic Imperative - and the implications for Silo commissioning.

Inequality of access to health care has significant implications for children with ADHD who will underachieve in school, and as a result be at increased risk of unemployment and dependency on the state across the lifespan.

Health commissioners - many of whom are not clinicians, have little or no training / comprehension of the hidden costs of unmanaged ADHD - across other areas of health care, but also the unseen costs to education, social services and indeed justice system.

NHS data is presented and interpreted in a way that understandably reflects well on the service provider. Yet the experience of those who pay for such services with their taxes is often in stark contrast to the performance reports for health services for neurodevelopmental conditions such as ADHD - and the frequently co-occurring comorbidities such as autism, dyslexia, dyspraxia /DCD, Tourette's syndrome / Tics, dysgraphia, dyscalculia.

The result is not only greater health inequalities - which existed long before the pandemic, but a complete breakdown in trust and faith in the services that Welsh Citizens pay taxes for.

Those who are privileged enough to afford private assessments and diagnosis - having been told there is no service for them in their area or that there are waiting times of up to 2 years for children and up to 5 years for adults, can then be told by their GP or local NHS ADHD service that the 'Private diagnosis won't be accepted' is a gross injustice; in essence we are saying to people "We can't treat you - and we won't let anyone else give you the care you need either".

ACTIONS

1. Wales needs a national survey undertaken to discern what is the real lived experience of the ADHD population. Undertaken by an independent agency.
1. A public health campaign and mandatory training for GP's. School Nurses, health Visitors, primary care practitioners.
1. ADHD Should be a mandatory topic in the general Psychiatry training curriculum.
1. Training for all education and social care professionals.
1. A Protocol for early identification of children at risk of ADHD and frequently co-occurring neurodevelopmental conditions such as autism, dyslexia, developmental co-ordination disorder (dyspraxia), Tourette's syndrome and Tics.
2. Independent direct grant funding from Government for patient led groups and charities so they are not financially beholden to Health Care commissioners or Senior executives and able to speak openly, honestly and funded to develop the skills they need to work collaboratively with the professionals who design and deliver health services.
3. NHS must accept the clinical assessments from private providers (the majority of whom are also employed by the NHS) and agreed set of best practice protocols for diagnosis in the private sector.

Wales Early Intervention Policy - Protcols could implement the following:

Identifying children who were born pre-term with a 17% increased risk of having a neurodevelopmental condition.

early screening for children where there is a family history of neurodevelopmental conditions.

Automatic screening for children who display developmental delay in pre-school and school or who are excluded from school.

Children or adults who have epilepsy or brain injury.

Welsh Government do not appear to know the extent to which ADHD can impact on physical and mental health, educational attainment and economic independence.

Integrated service design and delivery is imperative so that greater accountability for outcomes can no longer be abdicated or accepted as the result of a *culture of silo working*. *Authentic* 'co-production' is implemented by ensuring external independent agencies are able to monitor and ensure that those who pay for and use public services, such as mental health services, can believe that their views are taken seriously and no longer dismissed in an attempt to defend systems and processes that are no longer fit for purpose.

Without doubt, health care practitioners are dedicated professionals. The culture however, defends inefficient systems and prioritises a mindset more concerned with 'who can deliver what services, - rather than what do Welsh tax paying citizens actually need' (irrespective of who delivers it). tax payers should not have to rely on private care to have their needs met - yet for those who can, out of desperation, find the money to access a private diagnosis, should have this accepted by NHS.

Other research to be published later this year by GP and Kings College Post Doctoral Researcher, Dr Vibhor Prasad, highlights that undiagnosed children with ADHD have twice as many GP visits in childhood for stress / anxiety related conditions - particularly ectopic skin rashes, asthma, respiratory infections, inflammatory digestive problems, physical injuries as a result of accidents, sleep disorders and also fibromyalgia.

The costs of undiagnosed unmanaged ADHD is unseen, as data capture is not good enough within NHS. We do applaud the work of the Wolfson Centre at Cardiff University and it's pioneering work which is an exemplar that should be replicated across the UK.

A FINAL CONCERN

Third Sector agencies concerned with mental health,- established for public benefit, often find themselves dependent on funding from NHS commissioners - to such an extent that they are no longer **independent** charitable organisations that advocate for and support those who experience disadvantage and exclusion.

In essence, their integrity of purpose is compromised when charities are dependent for funding from the very agencies / commissioners they should be challenging. Too often, Charities and patient led support groups are beholden to NHS & LA Commissioners and risk becoming low-cost sub-contractors whose advocacy is silenced and sometimes dismissed as 'incapable of working in partnership' because they speak truth to power - however diplomatic and constructive that criticism is communicated.

Finally, honesty is needed with Welsh citizens about finite resources and an over dependence on a medical model of wellbeing.

Neurodevelopmental conditions such as ADHD are not defined as 'mental illness' - yet despite the attached information stating robust research evidence of vulnerability to mental health comorbidities and an emerging field of research that highlights physical health comorbidities associated with ADHD, sadly ADHD is trivialised and deemed unworthy of the priority it should be given. Again, women and girls who experience even greater inequality of access to mental health services.

Everyone's needs are impacted by their physical and mental health. Health is impacted by housing, employment, a child centred education public services must be integrated so responsibility for effective services cannot be abdicated onto another area of public services who then carry the cost of failings in health services.

A 'Neurodiverse paradigm'

Dr Tony Lloyd
Chief Executive

ADHD Foundation – Neurodiversity Charity