

## 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 08**

**Ymateb gan: | Response from: Parents Voices in Wales CIC**

---

Dear Senedd Committee

Thank you for inviting Parents and Carers from our group to talk to you tomorrow about mental health inequalities.

Before the session we wish to submit our response to the consultation but understand that you may not have time to read this before our meeting.

We very much look forward to speaking with you and appreciate your time.

## Welsh Govt Mental Health Inequalities Consultation

Dear Sir/Madam

Thank you for notifying us of this Welsh Government (WG) consultation on mental health inequalities.

Please find below a response on behalf of Parents Voices in Wales, a parent and carer support group of children with neurodivergent conditions and mental health issues. We have aimed to consolidate all views in our response below with supporting research and evidence.

**WG Question : Which groups of people are disproportionately affected by poor mental health in Wales?**

Our Response : there has been extensive research evidencing the increased risk and link between neurodiversity ie Attention Deficit Hyperactivity Disorder (ADHD), Developmental Language Disorder, Dyspraxia, Dyslexia, Dyscalculia, Autism, Autism Spectrum Conditions, Tics, Tourette's, Fetal Alcohol Syndrome, Learning Disability and Traumatic Brain Injury with poor mental health, self harm, mental illness and suicide. This correlation has been recently outlined in this article in Psychology Today via website psychologytoday.com (Marano, H August 26, 2021).

This correlation has also been highlighted by a Wales Child & Adolescent Mental Health Services (CAMHS) survey conducted by Parents Voices and the ADHD Foundation in 2020 which showed that around 65% of those entering CAMHS were neurodivergent. Please click on in below which outlines the data from this survey and highlighted the need for early identification of neurodiverse conditions.

Stakeholders contributing to the Senedd Committees Mind Over Matter Report (2018) section 3.1 item 182 of the report also stated 'that urgent work was needed to address the lack (and in some cases absence) of services for children and young people who need support but do not meet the threshold for specialist CAMHS or neurodiversity support. Many witnesses referred to these children as the so-called "missing middle", referring to the almost complete absence of services for them.'

We also know from an important piece of research in Wales that children with neurodiverse conditions and poor mental health have increased school absence which leads to 'multiple social, educational and lifelong socioeconomic disadvantages.' Article can be found at The Lancet Psychiatry published on November 23, 2021 by Prof Ann John et al.

In addition, recent research has identified that women who are undiagnosed with ADHD will be at increased risk of recurrent depression in adult life, further highlighting the need for early identification of ADHD as the cause of their mental health issues will not be identified or treated properly at any stage of their life. Please access this article from Cardiff University website, News section, New Study on ADHD in adults with recurrent depression dated 6 January 2022.

### **WG Question : What factors contribute to worse mental health within these groups?**

Our Response : The factors that contribute to the poor mental health of children, young people and adults with neurodivergence is firstly that :

a) according to Professor Helen Minnis of the University of Glasgow, neurodivergent children have a ten fold increased risk of experiencing trauma. The research showed that neurodivergent children were less likely to recover from trauma than neurotypical children because they were 'already carrying a heavier load.' See Prof Minnis sharing this research via recorded presentation that can be found on You Tube under CPFT Research dated 15 July 2021 entitled 'Whats Behind the Trauma'.

b) neurodiversity and conditions within this term are not linked to IQ and, therefore, if challenges are not identified and supported early in a child's life, the child becomes 'aware' of their perceived social and educational deficits. These are further exacerbated with disturbances in emotional regulation due to poor executive functioning as increasing (unsupported) demands are placed upon them and this impacts negatively on their esteem, interaction, attainment and success. A poll from our group shared in 2020 on Twitter showed that school related anxiety started in primary school and yet sub diagnostic threshold neurodiversity isn't being identified in education to prevent learners journeying down the mental health spectrum. Twitter post can be found via Twitter @PCamhs dated 8 October 2021 at 11.33 pm.

c) Prof Anita Thapar in this podcast with ACAMH highlights the association between social stressors of those with ADHD and Autism and how these are the precursors to depression in later life. Podcast can be viewed via ACAMH.org website, under podcasts. Podcast published on 11 February 2021 by Prof Anita Thapar titled 'ADHD, Autism and the elevated risk of later depression'.

d) neurodivergent learners are more likely to experience school bullying and this correlation between autism and bullying has been widely publicised through the work of Wales researcher Dr Emily Lovegrove. In addition bullying is documented by UK mental health services to be a common cause of poor mental health in children and young people. See report in the PubMed website under National Library of Medicine, Autism. Article by Cook, Ogden and Winstone dated November 24, 2020.

e) it is known that 70% of school exclusions are related to learning differences as reported in the UK Government publishing service website, report from Department of Education in May 2019 by Graham, B et al. The report titled 'School Exclusion : a literature review on the continued disproportionate exclusion of certain children'.

which in itself increases a young person's risk of suicide as reported in the Samaritans report published on the Samaritans Cymru website in 2018 entitled 'The Hidden Cost of School Exclusion'.

f) the disparity between genders being diagnosed with ADHD ie girls with the inattentive subtype not being identified and leading to higher incidence of mental health inequalities. (Young et al 2020)

In addition it is estimate that only 10-20% of individuals with ADHD will be treated as cited by Dr Nancy Doyle in this recent article on the Forbes.com website b y Nancy Doyle dated January 14 2022 entitled 'ADHD Crisis in the Uk.....'. This leaves the remainder to journey down the mental health spectrum adding unnecessary pressure to public services and impacting employment economy.

School low attendance is an early indicator of unsupported neurodivergence. It has been highlighted in a research paper published in Lancet how poor identification of ADHD in early life leads to poor outcomes, as previously signposted above Prof Ann John et al, November 23, 2021, The Lancet Psychiatry.

**WG Question : For the groups identified, what are the barriers to accessing mental health services?**

Our response : mental health is on a spectrum starting with anxiety and progressing to mental illness. The barriers to accessing mental health services for neurodiverse individuals is due to a lack of knowledge and skills in communities to identify early and then support neurodiverse conditions. The historic medical model for neurodiversity and mental health has meant that services have often mistakingly correlated anxiety, depression, eating disorders, self harm and suicide ideation as a natural co-morbidity to these conditions and often decline referrals of neurodiverse patients. This is a misinformed approach and an inequality due to the lack of early support for those with additional learning needs as outlined above in the Lancet article above.

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

Our Response : We believe that neurodiverse inclusive therapies should be available from community/school based intervention to CAMHS and then adult mental health services. Training all agencies is important but in particular education and health service staff should be trained effectively to not only meet the requirements of the whole school approach and ALN Code but to support many neurodiverse 'missing middle' learners so they could access appropriate emotional and well-being support at community level. Of course this means that those with learning differences should be identified early so mental health and well-being support is provided on a needs led basis. This would make the ALN Code 2021 in Wales effective at meeting the needs of all learners. NB : identifying and treating ADHD with medication and therapy requires an integrated approach to account for co-occurring conditions. This could be achieved by a whole system approach as per the NEST Framework 2021, as per the NHS Wales Collaborative Website.

Mental Health Support for young people should allow a flexible option to stay within children's mental health services or transition to adult service especially as many neurodiverse young people will be late developing (25% in ADHD) behind their chronological age and may need the extra

support that children's mental health services can provide. Children, young people and adults should have the option of having individual, group or digital therapies and via different modes of communication. There should be visuals to support the interventions and any supporting literature should be in easy read version option and in dyslexic friendly text. There should be opportunities to make reasonable adjustments for neurodiverse patients across the age spectrum whether they prefer face to face sessions at home or clinic or digital online therapies ie a person Centred approach.

Health Boards should be working with their communities and coproducing/developing service provision and resources to meet the needs of children, young people and families as per the NEST NYTH Framework. Please see the framework via NHS Wales Collaborative website.

This means that if we truly collaborate with communities through coproduction that the views of the public should naturally direct the development of policies in Wales, to diminish inequalities, so that services do not discriminate against groups of people eg neurodiversity who are more at risk of needing their services.

Indeed an article below by a UK expert panel discusses the barriers commonly found across UK services in supporting those with ADHD who more at risk of poor mental health.

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

Our Response : in terms of children and young people the development of an early help model for neurodiversity to align to the Whole System Approach (integrated practice) through the Whole School Approach and Additional Learning Needs Code would mean that learners would have early social, educational and emotional support that would reduce the risks of poor mental health developing due to their being supported with their 'heavier load and social stressors.'

Indeed the Senedd Committee's Mind Over Matter Report (2018) in section 2.1 states 'it is crucial to develop a whole-school approach, embedding well-being into the entire school ethos, the curriculum, and staff training and professional development. A substantial step change is needed to realise this ambition. Furthermore, a whole-school approach does not mean schools meeting pupils' needs on their own – the involvement of a range of professionals from other agencies is needed.'

Parents Voices firmly believes as the evidence shows, that early identification of neurodiverse conditions through a biopsychosocial model would reduce the deficit impact on children and young people and allow them to reach their social emotional and educational potential through a strength based approach. It would also mean that we support people holistically and not see them through a single lens as either Additional Learning Needs, Trauma or Mental Health. We have to acknowledge that we are all too frequently dealing with the same learners/adults with co-occurring conditions and sharing similar experiences. We also have to acknowledge the wide evidence that neurodiverse conditions do not come alone that in fact 'co-occurrence is the rule not the exception' as stated frequently by Prof Amanda Kirby and that in fact individuals will have a multitude of differences.

Welsh Government have made great strides in the new early help frameworks in Wales but to not align neurodiversity Services's to an integrated approach is the largest barrier to improving the mental health in the Wales population.

**WG Question : 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?**

Our Response :  
Public Stakeholders

We request that there is equitable opportunity for a variety of neurodivergent stakeholders with co-occurring conditions to be included in the Autism/Neurodiversity policy development. We request that Welsh Government include stakeholders representing all neurodiverse conditions eg ADHD, Developmental Language Disorder, Dyslexia, Dyspraxia, Dyscalculia, Dysgraphia, Fetal Alcohol Syndrome, Tics, Tourette's, Brain Injury, Learning Disability, Neuro-disability as well as Autism. In order to meet the needs of all people in preventing mental health, we must approach prevention holistically using the research evidence that is now available to us on co-occurring conditions and address these cradle to grave. This is very relevant to the already established Autistic stakeholder groups.

Post Diagnosis

It is known that young people and adults when diagnosed with autism will receive an hour session at least on therapy support post diagnosis. There is no post diagnosis therapy for people who are diagnosed ADHD and who require both pharmaceutical and therapeutic support. Parents Voices in considers this discriminatory and not meeting the needs of Young people and adults equally. This is especially concerning as poorer outcomes are evidenced for those living with unsupported or undiagnosed ADHD.

Early Help for Mental Health

We request that the no wrong door approach is inclusive of all neurodivergent conditions so that an integrated approach is embedded across Wales to meet the needs of the whole child and not compartmentalise aspects of an individual who will thus receive only partial support.

We must stop depersonalising children young people and their families to suit the political narrative because if we truly want to address mental health inequalities in Wales and fulfill the recommendations in the no wrong door approach through a whole system reform, we must accept the whole individual.

Mental Health Providers

We request that mental health providers from early help in the community to tertiary care are trained in neurodiverse conditions in order to meet the needs of individuals within education and services. We also request that learners with additional needs have open access to mental health support for esteem, relationships and anxiety to prevent issues escalating. Our views on this have been submitted to Lynne Neagle and Jeremy Miled in January 2022.

We must accept that those currently on the mental health pathways or in receipt of therapy have a higher risk of being neurodivergent and that due to our current systems and current societal ignorance of neuro-differences will have undoubtedly experienced trauma and may be socioeconomically disadvantaged as a result.

We cannot change the past for those with comorbidities but we can change the future for children, young people and whole families, where genetics plays a large role in neurodivergent conditions

with it being a precursor for poor mental health outcomes without holistic early identification and support. The research evidence is robust in areas relating to all of the above and we now ask Welsh Government to join the dots in the prevention of mental health inequalities.

Kind regards