

Enable Welsh residents to access an NHS "Right to Choose" diagnosis pathway for ADHD

Y Pwyllgor Deisebau | 10 Hydref 2022
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Petition title: Enable Welsh residents to access an NHS "Right to Choose" diagnosis pathway for ADHD

Text of petition:

Unlike England, there is currently no "Right to Choose" in Wales to enable individuals to select the hospital or service they would like to have their NHS treatment. The Right to Choose within mental health services in England has been in place since 2018 allowing adults seeking an assessment for ADHD the opportunity to choose an alternative provider should they decide the waiting time for their NHS assessment is too long. Welsh residents are being discriminated against for being in Wales.



1. Background

Patient choice

In England, patients have the right to choose which hospital they're referred to by their GP. This also applies to Welsh residents in border areas who are registered with an English GP. This legal right lets patients choose from any English hospital offering a suitable treatment that meets NHS standards and costs. The ADHD.UK website provides further information about right to choose in England in relation to ADHD assessments.

The Welsh NHS does not operate a system of patient choice but looks to provide services close to a patient's home where possible. Patients registered with a GP in Wales do not have a statutory right to choose which hospital they're referred to. This extends to English residents with a Welsh GP. In Wales, patients are usually only referred outside their area if the treatment they require is not available where they live.

About ADHD

ADHD is a neurodevelopmental condition (i.e. present from birth). It affects around 1 in 20 people, although prevalence may be higher due to under-diagnosis or misdiagnosis. It commonly co-occurs with other neurodevelopmental conditions such as autism.

Undiagnosed/unsupported ADHD can result in worse physical and mental health outcomes for those affected. Children with neurodevelopmental conditions such as ADHD experience high rates of school exclusion, educational failure, family breakdown, and substance misuse.

Many children and young people face long waits (often years) for assessment and diagnosis. Some families resort to paying privately for assessment. The long waiting times may also be a particular issue for young people approaching the age of transition to adult services, where thresholds for support may be higher.

2. Welsh Government action

An all-Wales neurodevelopmental service workstream was launched in 2015/16 under the Together for Children and Young People (T4CYP) programme.

Multidisciplinary neurodevelopmental teams were established, and a neurodevelopment diagnostic assessment pathway was published. This set out six standards and aimed to develop a consistent approach to assessment across Wales.

In November 2019, the T4CYP programme was extended until 2022 with a refocused remit. Neurodevelopmental services was one of three key areas, with an objective to “further support health boards to implement the pathway and standards, and to support the development of a whole system response for children and young people with ND conditions”. TC4CYP ended in March 2022, although some legacy work is continuing until September 2022. This includes consideration of the findings of a demand and capacity review of all-age neurodevelopmental services. A summary report of the demand and capacity review was published in July 2022.

Responsibility for neurodevelopmental services recently moved to Julie Morgan as Deputy Minister for Social Services (it previously sat with Lynne Neagle as Deputy Minister for Mental Health and Wellbeing). In a statement on 6 July 2022, the Deputy Minister for Social Services acknowledged that neurodevelopmental services are under pressure, exacerbated by the pandemic. She said:

Increased awareness of autism and other neurodevelopmental conditions has led to rising demand for assessment and support, which has unfortunately led to longer waiting times and gaps in provision, which need to be addressed urgently.

The Deputy Minister’s letter to the Petitions Committee about this petition refers to her 6 July statement and delivery of a new neurodevelopment improvement programme, backed by £12million to improve waiting times, services and support for families.

As health boards are responsible for delivering services such as ADHD assessments, the Improvement Plan will examine how health boards are currently delivering their services, including the response to private diagnosis. (...)

I will be monitoring delivery of the programme closely and a new Ministerial Advisory Group on neurodevelopmental conditions has been established. This group will provide me with advice on progress, emerging areas of best practice, funding options and any other matters that may be of value to neurodivergent individuals in Wales.

3. Welsh Parliament action

The Health and Social Care Committee's April 2022 report - [Waiting well? The impact of the waiting times backlog on people in Wales](#) - made two recommendations in relation to neurodevelopmental services. These are set out below, along with the [Welsh Government's response](#) to these recommendations:

Committee recommendation 5. When she shares the findings of the neurodevelopmental services capacity and demand review with us, the Minister for Health and Social Services should also set out how and when any recommendations made by the review will be implemented and how their impact will be monitored.

Welsh Government response: (...) We are considering the action needed and will shortly be making a further statement confirming the urgent support we will be providing to reduce the immediate pressures on assessment services. Over the remainder of this term, we will work in partnership with practitioners and those seeking support to develop sustainable services which provide timely access and can provide much needed pre and post assessment care, through a person-centred holistic approach.

Committee recommendation 6. The Minister for Health and Social Services should provide an update in autumn 2022 on what action has been taken to identify and address any differences in the length of time taken in Wales to diagnose females and males with neurodevelopmental conditions such as autism.

Welsh Government response: Collecting accurate and informative data is key, the current waiting time target is not fit for purpose and does not provide us with the intelligence we need to plan and deliver neurodevelopmental condition services, and this includes the need to be able to disaggregate assessment data by gender. As part of the improvements, we will be making we will re-design the data collection so that it provides valuable information which can help us to identify how well services are delivering and whether there are any inequalities in assessment.

Neurodivergence (this includes neurodevelopment conditions such as ADHD and autism) is also a key theme in the Health and Social Care Committee's current [mental health inequalities inquiry](#).

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.