

## ADHD UK'S REPORT INTO NHS ADHD ASSESSMENT WAITING LISTS

### October 2023

For the last 6 months ADHD UK has been pursuing Freedom of Information requests into ADHD from every Integrated Health Board (or equivalent) in the Country.

*Please note the links provided link directly to the FOI response to enable you to directly fact-check.*

**There is significant variations across the country and calamitously long waiting lists across the country.**

#### For children:

- For children the variation is stark – it varies from 5 weeks to a devastating 5 years. 5 weeks if you are in Barnsley by [South London & Maudsley NHS Foundation Trust](#) and 264 weeks (5 years) expected time from [Belfast Health and Social Care Trust](#). **A child in Belfast waits 52 times the length of time in Barnsley, South London.**
- Belfast has 1,000 children waiting for an ADHD Assessment. It is also where the child has been waiting the longest. They have been waiting 347 weeks (over 6 and a half years). ([Belfast FOI response here](#))

#### For adults:

- For adults the variation is equally stark – it varies from 12 weeks at [Dorset Healthcare University NHS Foundation Trust](#) to 550 weeks (**over 10 years**) at the [Herefordshire and Worcestershire Health and Care Trust](#)
- The adult waiting the longest has been waiting 443 weeks (**8.5 years**). There are in Wales at the [Hywel Dda University Health Board](#).

#### ADHD referral screening is a significant issue.

A number of NHS organisations have instigated screening of individual ADHD referrals. This is where they use various tools to eliminate individuals formally referred to them from their NHS list. Patients do not have a right to a second opinion in the NHS so this effectively removes people from being able to get an NHS assessment. As a charity we are aware of numerous cases where individuals where removed via screening out and later found to have ADHD.

The screening is happening despite ALL NHS referrals having already been screened due to coming with a professional referral from either a GP or school. A GP is supposed to have agency for their patients. If a GP asks for a test to be done it should be actioned. Individuals cannot self-refer for an ADHD assessment. There is no NICE recommendation or agreed system for ADHD screening in the UK.

- Women and Girls are more likely to be screened out than Men or Boys. This is despite NICE guidelines specifically noting that Women and Girls are under-diagnosed.
- Where screening is used for adults 32% will be screened out. 33% for women. 29% for men. Women are 16% more likely to be screened out than men.
- Where screening is used for children on average 29% will be screened out. 21% for girls. 19% for boys. Girls are 11% more likely to be screened out than boys.

**There is significant variation in ADHD referral screening results across the country.** Getting such wide-ranging results is highly suggestive of a flawed system.

- The highest adult screening out percentage is [Sheffield Health and Social Care NHS Foundation Trust](#). In the last full year (2022-2023) they did just 33 adult ADHD Assessments (vs 80 in the prior year). They removed 1060 people from their lists. They removed 97% on average. The prior year they removed 91%. They removed more women than men. 640 women (98%) removed. 420 men (96%) removed.
- The highest child screening out percentage is [South Eastern Health and Social Care Trust](#). Screening out 85% of children on average. Screening out 91% of girls and 80% of boys.
- The lowest is 0% - those who don't screen. That is the majority of NHS organisations. Only 15% of NHS organisations of those we asked reported screening. (18 of 121 reported screening adult ADHD referrals, 17 of 121 reported screening child ADHD referrals).

The majority of NHS commissioning services don't know how long ADHD patients are waiting.

% of Health Care Boards (the commissioners of services) who know their Adult ADHD waiting list times	
England	15%
Northern Ireland	67%
Scotland	0%
Wales	33%
<b>Average</b>	<b>16%</b>

% of Health Care Boards (the commissioners of services) who know their Child ADHD waiting list times	
England	15%
Northern Ireland	67%
Scotland	31%
Wales	67%
<b>Grand Total</b>	<b>26%</b>

We are very concerned that the scale of the ADHD waiting lists is not known.

Our data shows 19,000 adults waiting and 7,200 children waiting. But only 21% of ICBs could tell us their waiting numbers. If we extrapolate for the no-answers then we have 131,000 people waiting for an Assessment. 90,000 adults and 42,000 children. Please note 131,000 waiting is roughly 5% of the estimated 2.6million people with ADHD. This is therefore a permanent problem of inadequate resourcing and not a short term spike.

	TOTAL: How many adults do you have waiting for an adult ADHD assessment? ICB ONLY	ICB answers of total ICBs	Extrapolated Total Waiting	Estimated hidden waiters	% hidden
England	11232	7 of 42	67,392	56,160	83%
Northern Ireland	2469	2 of 5	6,173	3,704	60%
Scotland	1555	4 areas of 14	5,443	3,888	71%
Wales	3582	2 of 6	10,746	7,164	67%
TOTAL	18838	15 of 67 (22%)	89,753	70,915	79%
	TOTAL: How many adults do you have waiting for an child ADHD assessment? ICB ONLY	ICB answers of total ICBs	True total	Hidden	% hidden
England	1959	3 of 42	27,426	25,467	93%
Northern Ireland	1461	3 of 5	2,435	974	40%
Scotland	3180	4 of 14	11,130	7,950	71%
Wales	653	4 of 6	980	327	33%
Grand Total	7253	14 of 67 (21%)	41,971	34,718	83%
		TOTAL	131,724		

## Background

- ADHD is a Neurodiversity that impacts a significant number of people (2.6m) in the UK with a male-to-female ratio of 3:1
- For reference, this compares to around 0.7m people with Autism. 50% of people with Autism also have ADHD.
- ADHD is a very difficult condition to live with. This is significantly shown via suicide data.
  - 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 baseline])
  - Nearly one-quarter of women with ADHD have tried to take their own life. (23.5% vs 3.3% without ADHD [7.8 times baseline])
  - Nearly one in ten men with ADHD have tried to take their own life (8.5% vs 2.1% [4 times baseline])
- ADHD is under-diagnosed because:
  - It wasn't recognised by the NHS until 2000 (for children) and 2008 (for adults).
  - GPs and Teachers have the responsibility to be gatekeepers to Assessments, but there are significant issues around training and awareness. Notably, this includes the understanding of the three types of ADHD and differing presentations of ADHD by type, gender and age. Hyperactive ADHD is just 15% of patients, and hyperactivity less likely displayed in females, yet excessive movement remains the dominant perception of ADHD for most.
  - Public awareness and understanding have been building since then but remains low. This means that recognising ADHD and asking professionals about it also remains low.
- Our estimate, using prescription data, is that at least 80% of people with ADHD in the UK are currently undiagnosed.
- Covid and Celebrities have increased awareness. That has led to most NHS services being overwhelmed. Many talk of a "spike" in assessment demand. However, it is not a spike. It is a fundamental change that requires a permanent shift in resourcing.