

Views & Experiences of People

Accessing or Requiring ADHD

Support Services

Healthwatch Stockton-on-Tees
January 2024

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About Healthwatch Stockton-on-Tees

Healthwatch Stockton-on-Tees is the health and care champion for people who live and work in Stockton-on-Tees. As an independent statutory body, we have the power to make sure NHS leaders and other decision makers listen to people's feedback to improve standards of care.

We use feedback to better understand the challenges facing the NHS and other care providers locally, to make sure people's experiences improve health and care services for everyone.

We are here to listen to the issues that really matter to our local communities and to hear about people's experiences of using health and social care services.

We are entirely independent and impartial, and any information shared with us is confidential.

Healthwatch Stockton-on-Tees is steered by a Board of volunteers, commissioned by the Local Authority and accountable to the public. Healthwatch Stockton-on-Tees are the only non-statutory body whose sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak-out on their behalf. The service is managed by [Pioneering Care Partnership](#), a leading third-sector charitable organisation aiming to improve health, wellbeing and learning for all.

As the health and care landscape begins its journey through transformation and recovery plans, we have actively ensured our work is embedded within the local Integrated Care Partnership Board, forming robust mechanisms with partners to ensure that local intelligence is escalated both at a local, regional and national level.

Healthwatch has the statutory right to be listened to:

- Providers and Commissioners must respond to Healthwatch within twenty days of submission of requests for information or reports.
- The statutory power to Enter & View publicly funded health and social care services.
- A statutory seat on the Health and Wellbeing Board.

What is Attention Deficit Hyperactivity Disorder (ADHD)

Attention Deficit Hyperactivity Disorder (ADHD) is a mental health condition that includes a combination of persistent problems, such as difficulty paying attention, hyperactivity, and impulsive behaviour. This can lead to unstable relationships, poor work or school performance, low self-esteem, anxiety, depression, and other problems.

Symptoms of ADHD tend to be noticed at an early age and may become more noticeable when a child's circumstances change, such as when they start school and continue into adulthood.

Most cases are diagnosed when children are under 12 years old, but sometimes it's diagnosed later in childhood. Adult ADHD symptoms may not be as clear as ADHD symptoms in children. Hyperactivity may decrease, but challenges with impulsiveness, restlessness and difficulty paying attention may continue.

The symptoms of ADHD may improve with age, but many adults who were diagnosed with the condition at a young age continue to experience problems.

Treatment for ADHD in both adults and children are similar, this includes medications, psychological counselling, mindfulness techniques and other treatments for mental health conditions.

Many adults with ADHD aren't aware they have it – they just aware that everyday tasks can be a challenge. Adults with ADHD may find it difficult to focus and prioritise, leading to missed deadlines and forgotten meetings or social plans. The inability to control impulses can range from impatience waiting in line or driving in traffic to mood swings and outbursts of anger.

ADHD is diagnosed only when symptoms are severe enough to cause ongoing problems in more than one area of life. These persistent and disruptive symptoms can be traced back to early childhood.

Diagnosis of ADHD in adults can be difficult because certain ADHD symptoms are similar to those caused by other conditions, such as anxiety or mood disorders. Also, many adults with ADHD have at least one other mental health condition, such as depression or anxiety.

Executive summary

Healthwatch Stockton-on-Tees began working with a Care Navigator from the Stockton Community Mental Health Team based at Wessex House. They introduced us to Larissa. Larissa has a diagnosis of ADHD and shared with us her experiences of living with the condition, the challenges she faced and what positive changes she thinks could be made to help others experiencing similar difficulties within the community of Stockton-on-Tees.

Larissa became a Healthwatch Stockton-on-Tees Champion and supported us to publish a 'Case Study' that helped us to gather additional feedback and intelligence from the local community about their experiences of ADHD, awareness of information, referral pathways and any challenges that are being experienced.

Larissa's Story.

While waiting for a diagnosis Larissa looked online for support and found that information was confusing and written in a format that was difficult for a person with ADHD to understand and gain information easily. At the time of writing this report there were no leaflets available for advice either before or after diagnosis and Larissa feels this would have been enormously helpful for both her, friends, family, and carers.

"The symptoms of ADHD can often lead to isolation as its quite often a struggle to maintain relationships. Therefore, mental health issues can develop through lack of support during a crucial time."

Larissa strongly feels that if the right support had been available earlier in her journey, her mental health difficulties may not have developed. Larissa described how medication is often prescribed following confirmation of diagnosis but is not always suitable for everyone. Although medication may help with symptoms, isolation remains a major factor, with delays having a significant negative impact.

Larissa believes that ADHD testing completed in schools would have made a big difference to her life and thinks that this could be a positive change for the future.

"No diagnosis can leave you feeling that there is something wrong with you and not able to 'fit in'."

Larissa felt that early diagnosis would allow for the right support to be put in to place at the appropriate stages. This in turn may prevent mental health problems and possibly reduce crime with a lot of people remaining undiagnosed.

During the planning process of this workplan item, it was brought to our attention by Healthwatch England that the waiting times for an ADHD assessment are now reaching 10 years in places, and that in many cases regardless of a diagnosis there was significant delay in receiving the required medication or treatment.

After discussions with professionals and the Healthwatch Stockton-on-Tees Executive Board it was decided that we would carry out additional engagement throughout October - December 2023 to identify opportunities to improve service delivery, while supporting Larissa to develop a Peer Support group for those awaiting diagnosis, families, friends, and carers.

To ensure this research was accessible we used various methods of engagement to gather feedback including surveys, focus groups, drop-in sessions and one-to-one meetings with professionals and service users.

We spoke with Carers, Service Users, and Professionals to determine what their main concerns are and to inform how services can be improved, ensuring a person-centred multi-agency approach in the decision-making and planning process.

All the feedback gathered has supported the recommendations for the local area, common themes included.

- Extensive waiting times – no clear timescales available.
- Lack of understanding or awareness of ADHD and the impact on individuals and families.
- Unclear referral pathways.
- Lack of adequate signposting to helpful information, including coping strategies.
- Questions were raised regarding private assessments – some GPs would not accept a private diagnosis for prescription purposes.
- Some professionals in other health and care services were found not to be supportive of individual needs, such as displayed behaviours and allocation of appointment times.
- The people we spoke to overwhelmingly described how peer support would prove highly beneficial in improving wellbeing, providing the ability to share

coping mechanisms, have a better understanding of the condition and potential strategies to mitigate poor mental health outcomes.

Methodology

Healthwatch Stockton-on-Tees worked closely with the Stockton Community Mental Health Team to design a survey that would support discussions and information gathering for this work plan item. We worked closely with partners to help to inform the mapping of local services in the area and began our engagement with Professionals, Families, Carers and those either diagnosed, or awaiting a diagnosis of ADHD.

At the time of this work being carried out, ADHD UK have undertaken an in-depth review into NHS Assessment waiting lists, a significant amount of time has been spent pursuing Freedom of Information requests from every Integrated Health Board in the country. There are significant variations across the country with some areas having waiting lists of five years for children and over ten years for adults.

Most NHS commissioning services did not know how long ADHD patients are waiting. To date the closest Trust who have provided data in response to the requested Freedom of Information are Cumbria, Northumberland and Tyne & Wear Foundation Trust, who report 7,682 adults are currently on their waiting list for assessment with waits of up to 347 weeks (over 6 Years) and 774 children, waiting up to 127 weeks (2.5 years).

Conversations with local professionals working within Mental Health and ADHD support services echo the concerns and are seeing similar timescales for people within the Stockton-on-Tees area.

Working together with partners we developed a standard set of survey questions. Our questions sought to discover:

- If a formal diagnosis had been received or they were awaiting assessment.
- If they had knowledge of who or where to go to for support and advice.
- What information had been provided regarding waiting times.
- What current support was in place, if so, was this useful.
- What coping strategies were used.
- Was there an additional impact accessing other health and care services.
- Had medication been prescribed, if so, was this helpful.
- What people would find helpful while awaiting assessment or post assessment.

Our engagement took place from October 2023 until December 2023. To ensure this research was accessible we used various methods of engagement to gather feedback. Our mechanisms for gathering feedback comprised of:

- SmartSurvey – A survey was developed to gain views and experiences of those awaiting diagnosis, with a diagnosis of ADHD, or their parents/carers. This was promoted throughout our networks, via our website, featured in our newsletters and e-bulletins and shared widely with colleagues and partners with direct links to this service user group. This was to ensure that we could generate as much participation as possible for those who may not be able to attend in person or reached by usual engagement methods.
- We conducted interviews to support information gathering with professionals.
- We attended day services and family hubs within Stockton-on-Tees to provide face to face interviews with parents and carers.
- We attended groups and service provision to carry out focus groups and gather additional case study information.

The number of people we were able to reach with the use of social media was:

- Newsletter – 894
- Facebook – 581
- Twitter- 411
- Direct engagement through our website – 48

The partners who we spoke to, to support the promotion of this workplan item are:

- Stockton-on-Tees Community Wellbeing Champions
- Catalyst
- Stockton-on-Tees Borough Council (SBC) Adult Carers Support Service
- Daisy Chain
- North Tees & Hartlepool NHS Foundation Trust
- Autism Parents Together
- Stockton-on-Tees Borough Council
- North East & Cumbria Learning Disability Network
- North East Autism Society
- Stockton Parent Carer Forum
- Autism Matters
- Mental Health North East
- Stockton-on-Tees Family Hubs

- Pioneering Care Partnership
- Tees, Esk & Wear Valley NHS Foundation Trust (TEWV)

Through targeted focus groups and meetings with individuals and organisations we were able to engage with 38 people who were able to provide valuable information and help to promote this work plan item. These included:

- Stockton Community Mental Health Team
- STEPS
- Community Based Family Hubs – Billingham, Thornaby, Stockton & Redhill
- Starfish Health and Wellbeing
- MAIN

In total we gathered 30 **completed** surveys.

Survey findings: Summary

What matters most to people in Stockton-on-Tees

This engagement gave us the opportunity to have targeted one-to-one conversations with a wide variety of people with a specific focus. We were able to speak with Families & Friends, Carers, Service Users and Professionals to gather information that will be used to help inform decision makers, with a view to supporting the future development and planning of services for those with, awaiting assessment or supporting and caring for people with ADHD.

This focused engagement identified challenges within the NHS and commissioned providers, the assessment process, waiting times and the overall impact on the wellbeing of service users and their carers while awaiting assessment.

Of the people we spoke to, 64% told us they were not told how long the wait would be for an assessment.

“I was advised not to contact the assessment team regarding the waiting times as this would not be disclosed, even my GP doesn’t know, this is unbearable for someone with ADHD traits.”

“I was told it would be 2 years, it has now been 3 and still no date.”

“It’s been 8 years and I’m still in the process.”

66% of people who provided feedback told us that they went to their GP for a referral, 20% sought advice from their local school. 55% of people told us they did not receive any additional information at the point of referral to provide advice and guidance regarding ADHD.

During our conversations some people told us that they had decided to go for a private assessment, however this was proving problematic as some GP’s were not accepting a private diagnosis: this was leading to challenges in receiving support and medication.

Once a referral had been made 67% told us they still did not receive any additional information that they feel would have been helpful, however 33% did, this comprised of website details, leaflets, and signposting. This demonstrates an inconsistency with referral processes.

Some people told us it did impact their ability to access other health and care services, appointments were problematic with professionals being unsupportive of specific needs.

“Unable to disclose there is an appointment until the last minute, Dentist is not supportive of needs.”

“As a carer for a child with complex needs, I feel that the services need more awareness raising around neurodevelopmental areas. This is not the first time that I have considered raising this, but it’s the first time I have had the opportunity. I was advised there was no feedback route for under 16s.”

Of people who spoke to us who had received a diagnosis 80% had received medication, 50% of those reported a delay in receiving the medication. However, 89% of people receiving medication did say it had helped.

“Waited approximately 6 years before being prescribed Melatonin for sleep problems.”

We wanted to use this opportunity to find out what support people used to help them now, counselling did feature in the responses along with STEPS (an SBC support team for people with disabilities). However, there was a clear picture that people did not know where to go for support and the negative impact that this has on their mental health.

“None, just a supportive family doing the best they can with the limits of what they're able to understand and offer.”

“I’ve heard ADHD described as a superpower. ADHD as a ‘superpower’ really negates the experiences we have and the lens we navigate the world under, it minimises the support and assessment - we should be able to access. The current system has unacceptable waiting times, services are actively withholding information about timeframes, no other support is offered, and the direct outcomes of this, including poor mental health from anxiety and depression to suicidal ideation are at a high. Myself and others on the waiting list have come to realise that ADHD’ers do have one superpower: the power of invisibility.”

“Nothing from healthcare. When I got my diagnosis privately TEWV discharged me and I no longer have any support from the private clinic, which was minimal at best and very expensive.”

“I get some reasonable adjustments at work, but they are mostly just what helps me survive with the hopes it will make me work exactly like everyone else rather than helping me thrive and utilising my unique skills.”

Family and friends were viewed as the biggest form of support, but with little advice and guidance from professionals it was felt that people just did the ‘best they could’ with the little information they had.

One person told us that the school was being helpful and looking for unique ways to support her child, including the introduction of an egg timer to assist with concentration.

We asked people what coping strategies they found helpful in dealing with day-to-day situations, exercise featured heavily with most people reporting this was a good benefit. Other strategies were mindfulness, breathing techniques, online support groups, listening to podcasts, apps that included planners and timers. Fidget spinners were mentioned as a good tool, particularly in schools.

The people we spoke described how the ability to meet people in similar situations to talk would be a great source of support, not only for them but for friends and family, having a better understanding of ADHD, the impact and how it can be effectively managed would make a positive impact on lives.

It was felt that there is not enough knowledge and understanding of the condition on a broader scale, including professionals, employers, and parents and carers. People described feeling as though they had to find ways to ‘fit in’ as opposed to their differences being understood and reasonable adjustments made to support them to live in an inclusive way.

“Embracing my neurodivergence and moving away from trying to do things the way others do them just because I feel like I’m supposed to.”

“I try to make sense of who I am and be able to function rather than feeling I’m a terrible person. This has been useful to some extent in understanding myself and not feeling alone, many online group members are USA-based, so their experiences are vastly different.”

The Right to Choose

Throughout our consultation, the Right to Choose (operating since 2018) was discussed as an alternative option to assist in the reduction of waiting times, although the awareness of this service was limited.

The Right to Choose gives people the legal right to choose where they have their NHS treatment. The NHS is offering more and more options to enable people to make choices that best suit individual circumstances, giving greater control of care.

If a GP needs to refer you for a physical or mental health condition, in most cases you have the legal right to choose the hospital or service you'd like to go to.

This can include many private hospitals if they provide services to the NHS, and it does not cost the NHS any more than a referral to a standard NHS hospital.

You can book your appointment via the NHS referral service. It can also be done while you're at the GP surgery, or online, using the shortlist of hospitals or services provided in your appointment request letter. The shortlist is selected by your GP, so make sure you tell them about your preferences during the appointment.

To agree on the shortlist, you and your GP can compare information about hospitals or consultants on this website, including quality outcomes, waiting times, parking and travel. You also have the legal right to ask for your appointment to be moved to a different provider if you're likely to wait longer than the maximum waiting time specified for your treatment. (www.nhs.uk)

This option in theory is a positive way to help to distribute waiting times equitably across the area, however, there are extensive waiting times nationally, making this approach not always a viable option.

Local Authority Position Statement

“Thank you for sharing this report with us and thank you to all the people who have contributed. The contents of the report will help greatly when reviewing service provision.”

Emma Champley, Assistant Director Adult Strategy and Transformation, Stockton-on-Tees Borough Council

NENC ICB Position Statement

“Thank you for sending us your latest report, which provides lived experience and insight from service users, carers and professionals on their concerns regarding Attention Deficit Hyperactivity Disorder (ADHD) services.

“We recognise from the feedback featured within the report that there are challenges regarding awareness and understanding of ADHD, referral pathways for support, and extensive waiting times, as well as the potential impact that peer support can have in improving outcomes for patients.”

Alex Sinclair – Director of Place (Stockton), North East and North Cumbria Integrated Care Board

To download the full response from North East and North Cumbria Integrated Care Board, please click here: [HWS Views and Experiences of People Accessing or Requiring ADHD Support Services: NENC ICB response](#)

VCSE Position Statement

“This report is important, highlighting the issues faced by people with ADHD and the need for service-providers to understand the impact of those issues and how they can be addressed.

“Catalyst will work with service providers across the VCSE sector in Stockton-on-Tees to raise awareness of the report, the concerns it raises, and the recommendations it makes to tackle those concerns.”

Jon Carling, Chief Executive, Catalyst

Conclusion

This work has highlighted the challenges facing Family, Friends, Carers, Individuals and Professionals in the understanding of the symptoms of ADHD, information and guidance regarding referral pathways, and lack of support available to help improve wellbeing and develop coping strategies to mitigate poor mental health.

The increased waiting times within the NHS due to capacity and the rising demand on services are demonstrating that to effectively support our communities, there needs to be more awareness and understanding of the condition and the potential impact, with a consistent approach to sharing clear information and advice, providing guidance and support that will increase knowledge and promotes effective coping strategies.

Throughout our work there were areas of good practice that would be beneficial to learn from for the future planning and commissioning of service delivery. This includes awareness raising among professionals of reasonable adjustments that can be made to support positive outcomes, such as quiet times within schools, fidget spinners and egg timers being used to help to improve concentration. Parenting classes and peer support sessions were also seen as important to help alleviate isolation and reduce anxiety.

Guidance for employers and services about reasonable adjustments, that would help both individuals, employers and professionals to understand what reasonable adjustments can be made to support people with the challenges of day-to-day living.

As services and the health and care landscape is changing, it is vital that clear communication and messaging becomes embedded within information and guidance, referral pathways and processes. Contingency funding needs to be made available to allow for communities to develop support pathways within local areas. Clarity around waiting times needs to be sought, with training for professionals around the effects of ADHD and reasonable adjustments that can be made to help improve the outcomes of those living with ADHD and their families and carers.

Recommendations

This focused engagement work has highlighted areas that could help to improve the lives of those living with the effects of ADHD – both prior to and post assessment.

Valuable feedback received has informed the following recommendations:

- **Communication** – Clear, timely and appropriate information to be made available at the point of first contact, providing easy read information about the potential impact of ADHD, reasonable adjustments that can be made and highlights coping strategies and signposting to appropriate sources of support. Information made available to families and friends would also help to provide a positive approach to awareness raising, social understanding and support, to help alleviate feelings of isolation.
- **Training** – Feedback received highlighted a broad lack of awareness of the impact of ADHD from professionals within health and care services, schools and employers. GPs were reported as being inconsistent in their approach and information and advice shared was sporadic. Clear training and messaging demonstrating an inclusive, consistent approach to information and support needs to be embedded within recovery plans to continue to raise awareness of the growing issue. As local wellbeing services continue to develop, including the planned Stockton-on-Tees Wellbeing Hub – robust training plans for frontline staff should include the awareness of ADHD, impact, referral pathways and coping strategies to support the development of a community approach to wellbeing.
- **Parent Classes and Peer Support Groups** – It was clear throughout our engagement that people felt that they would benefit greatly from having the support of like-minded people who could support them on a personal level, to help alleviate isolation and build positive relationships. This could provide a positive learning platform that communities could develop at a local level.
- **Exercise and Mindfulness** – Many people told us that their main sources of coping were exercise, mindfulness techniques and activities within the community to alleviate isolation and empower them to manage their condition. As the cost-of-living crisis continues it is important that consideration is given into how community activities can be developed and maintained with appropriate support and funding. Supporting people to develop positive

relationships and alleviate isolation, while feeling happy and safe within the environments that best caters for their individual needs, is the way forward.

- **Joint Working** – As current health and care systems are changing there is a strong focus on better collaboration and joined up care to improve outcomes for people. The Integrated Care Systems (ICSs) have been set up to make this happen – with a focus on prevention, better outcomes and reducing health inequalities. These systems include NHS organisations, local councils, the voluntary sector, social care providers and other partners with a role in improving local health and wellbeing. In order to facilitate community development adequate funding and support needs to be available to promote positive system change while improving outcomes in population health, tackling inequalities in outcomes, experience and access.

Next steps

The views and intelligence gathered from the public will form part of a wider piece of exploratory research work that is currently underway on a national level by Healthwatch England. This work will be shared with partners and decision makers with the Stockton-on-Tees Borough Council, Public Health, and the North East and North Cumbria Integrated Care Board (NENC ICB).

This report will help to inform the future planning and delivery of services, to help to improve the awareness and understanding of ADHD, that aims to provide support for Family, Carers, Professionals and Services Users.



Acknowledgements

We would like to express our thanks to all Service Users, Carers and Professionals who have helped us to gather this valuable information. We would like to thank our partners for their support in disseminating and promoting this workplan item, helping us to ensure the voice of service users influence the improved delivery of health and care services.



- Stockton-on-Tees Community Wellbeing Champions
- Catalyst
- Stockton-on-Tees Borough Council Adult Carers Support Service
- North Tees & Hartlepool NHS Foundation Trust
- Autism Parents Together
- Stockton-on-Tees Borough Council
- North East & Cumbria Learning Disability Network
- North East Autism Society
- Autism Matters
- Mental Health North East
- Stockton-on-Tees Family Hubs
- Pioneering Care Partnership
- Stockton Community Mental Health Team
- STEPS
- Starfish Health and Wellbeing
- MAIN
- Tees, Esk & Wear Valley NHS Foundation Trust (TEWV)

Appendix one: Survey questions and responses



1. Have you or someone you care for had a formal diagnosis for ADHD?

Answer Choices			Response Percent
1	Yes		50.00%
2	No		50.00%



2. Are you currently waiting for an assessment?

Answer Choices			Response Percent
1	Yes		73.33%
2	No		26.67%

3. If you are currently waiting for an assessment, please select which type.

Answer Choices			Response Percent
1	Initial		40.00%
2	Formal		60.00%

4. If you are waiting for an assessment, were you given an estimated time of how long it may take?

Answer Choices			Response Percent
1	Yes		0.00%
2	No		63.64%
3	Other (please specify):		36.36%






"Advise sir would take 2 years - it has now been 3 years."

“No, but the official referral/waiting letter also said not to contact the assessment team for updates on waiting times as they will not disclose this. Which leaves you in uncertainty about whether you've been forgotten, how long you may wait, and limbo about how to access support for years. Even my GP doesn't know and can't find out. This is unbearable for someone experiencing ADHD traits.”

“3 years.”

“Approximately 1 year - Right to choose.”




5. Have you been offered any other support while waiting for either assessment?

Answer Choices			Response Percent
1	Printed information such as leaflets?		18.18%
2	Website		0.00%
3	Peer support or groups		9.09%
4	Mental health support		0.00%
5	Signposting		27.27%
6	No, I was not provided with information and advice		54.55%
7	Other (please specify):		18.18%

“To Daisy Chain family support who weren't very knowledgeable in ADHD.”

“Information and advice.”

6. Who did you go to for help and advice to support the referral process?

Answer Choices			Response Percent
1	GP		66.67%
2	Health visitor		0.00%
3	School		20.00%
4	Other (please specify):		53.33%

“Went private.”

“Camhs.”

"I was very young (about 8) so don't really remember but I think it was an NHS funded organisation. It was in Northallerton called Brompton House."

"Private."

"I went to GP and got referred to TEWV but after initial assessment and finding out wait times I decided to go private."

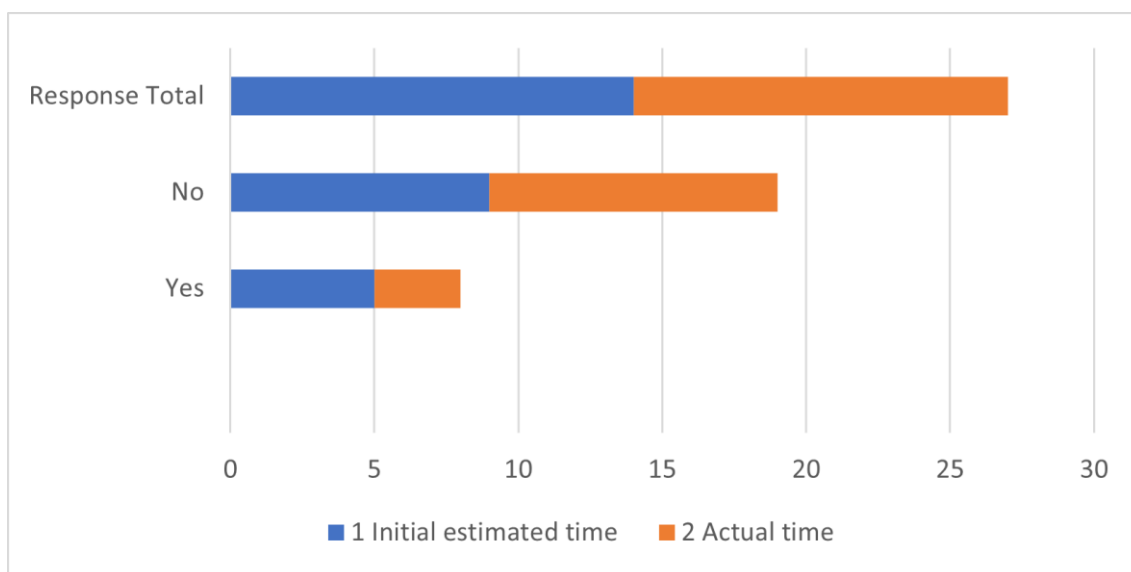
"Had to wait until aged 8 for a referral."

"Via telephone call."

"Affective disorders Foxrush House/Wessex House."

7. Were you informed how long it will take for the initial and full assessments?

Answer Choices	Yes	No
Initial estimated time	35.71% 5	64.29% 9
Actual time	23.08% 3	76.92% 10



If yes, what times were given?

"Was 11 years old."

"Again, being very young I wasn't but my parents most likely were."

"This was all complete within a month."

"Difficult to remember exactly but it wasn't clear that the initial assessment after GP referral wasn't the full assessment following that I think they did tell me that the waiting list for assessment was around two years."



"5 months approx (child)."

"Not sure."







"8 years and still in process."

"Up to 1 year by RIGHT TO choose."

8. Were you offered any additional support while waiting for assessment?

Answer Choices			Response Percent
1	Yes, I was provided with information and advice		33.33%
2	No, I was not provided with any information and advice		66.67%

9. What additional support were you offered while waiting for assessment?



Answer Choices			Response Percent
1	Printed information such as leaflets?		40.00%
2	Website		20.00%
3	Peer support or groups		40.00%
4	Mental health support		20.00%
5	Signposting		20.00%
6	Other (please specify):		60.00%

"Was offered information and advice by the school he was attending."

"Emails for mental health support during wait."

10. Does this diagnosis impact your access to health and care services?

Answer Choices			Response Percent
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2	Dentist		33.33%
3	Ophthalmology		0.00%
4	Other (please specify):		66.67%



11. How have these health and care services been impacted for you?

"Because not listened to, fobbed off."

"Will book appointments but then struggles to attend."

"She has a meltdown when she has to go to dentist, her mother has to leave telling her about the appointment until the last minute to reduce her anxiety, her dentist is not supportive of her needs, however the GP and Consultant are very supportive."

12. Have you been prescribed medication?

Answer Choices			Response Percent
1	Yes		80.00%
2	No		20.00%

13. If you have been prescribed medication, please provide more details of the medication below.

"Setrlile."

"Medicanet."

"On concerta xl 54 mg cm."

"Ritalin."

"Methylphenidate Hydrochloride - Concerta XL - 90mg."

"Titrated and trialled others."

"Elvanse, 60mg."

"Sleep medication, decided against Ritalin."

"Ritalin but aged 18 just decided to stop taking this."

"Not sure but wouldn't take it."



"Melatonin to help her sleep since aged 7, she gets very anxious about the next day."

“Not been prescribed ADHD medication as she has only been diagnosed over the telephone, she is awaiting a face-to-face appointment which is expected summertime 2024.”

“Methylphenidate 5mg x 3 daily.”

“Melatonin to help him sleep.”

14. Was there a delay in getting the medication?

Answer Choices			Response Percent
1	Yes		50.00%
2	No		50.00%

15. Have you found the medication has helped?

Answer Choices			Response Percent
1	Yes		88.89%
2	No		11.11%

“Helps my son focus.”



“It has now even though first it didn’t as the dose was too low.”

“I did but some of the side effects for me growing up were strange and hard to get used to.”

“It is helping with focus and procrastination by about 20 percent.”

“Yes, at first but think it may need to be increased as not as effective as it was.”

16. If you have NOT been prescribed medication, are you currently on a waiting list to receive it and have you been informed how long this may take?

Answer Choices			Response Percent
1	Yes, I am on a waiting list		25.00%
2	No, I am not on a waiting list		75.00%
3	Yes, I have been informed how long it will take to receive the medication		0.00%

4	No, I have not been informed how long it will take to receive the medication		25.00%
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17. What support do you currently receive e.g. family, mental health/counselling?

"Counselling and initial phase of ASD assessment."

"Nothing."

"None."

"Early help."

"Education psychology assessment."

"School support."

"ADHD assessment."

"Generic CAMHS just stopped contact over a year ago and didn't inform me the clinician has since left."

"STEPS."

"I currently receive counselling as I suffer with anxiety and OCD. I get counselling through work at the moment, and I have appointment at West Park for further support and looking in to the assessment for ADHD."

"None."

"None, just a supportive family doing the best they can with the limits of what they're able to understand and offer."

"The ableds often describe ADHD as a superpower. ADHD as a 'superpower' is really ableist, negates the experiences we have and the lens we navigate the world under, and minimises the support - and assessment - we should be able to access. With the current system where assessments have unacceptable waiting times, services are actively withholding information about timeframes, no other support is offered, and the direct outcomes of this, including poor mental health from anxiety and depression to suicidal ideation are at a high... myself and others on the waiting list have come to realise that ADHD'ers do have one superpower: the power of invisibility."

"University extra time no GP support."

"None."

"None, just medication reviews and health checks or and safety plan in place."

"Not much support at all i am having to reach out to support for everyone."

"None at all."

"Currently none medically."

"I am a member of LinkedIn, so I have great support there, amazing support from friends and family and although they don't know it, from my kids."

"Counselling, 1-1 for poor mental health/low mood/depression. STEPs for specialist support."

"Nothing provided through local GP."

"Nothing from healthcare. When I got my diagnosis privately TEWV discharged me and I no longer have any support from the private clinic, which was minimal at best and very expensive."

"I get some reasonable adjustments at work, but they are mostly just what helps me survive with the hopes it will make me work exactly like everyone else rather than helping me thrive and utilising my unique skills. "

"Footsteps."

"I get support from friends and am currently having counselling."

"Only support from the school."

"Only family support."

"Gets support from family, sometimes struggles with mental health."

"Family support."

"Has recently found Daisy Chain herself. They have sent her some links and websites."

"Currently trying to access support via affective disorders. CBT and personal development adviser."

"None."


"School has been supportive with my child, offering ways to support such as an egg timer to focus his concentration."

"None."

"No current support."

"None - medication for anxiety helps."

18. Do you find this support useful?

Answer Choices		Response Percent
1	Yes	 62.96%

2	No		37.04%
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"Too much paperwork and not able to complete fully without school buy-in."

"Not CAMHs but all the other support yes."

"I have had previous support through West Park, and it help a lot with my OCD and anxiety at the time."

"Yes, if you need it."

"I find the support from my family extremely helpful... however they aren't trained in ADHD so they're navigating their way as best they can, based on their lived experience of who I am and what may help."

"Without other meaningful and active support in place, I'm drowning in life. Without an official assessment due to waiting lists and the horrific BBC Panorama programme undermining potential options and opportunities through Right to Choose pathways, I and others can't access formal support either, from disabled bus passes, potential PIP and workplace accommodations in certain organisations to medication, therapy or access to work support."

"They don't tell u services that you can use, basically theirs your medication see you at review."

"No, just getting past from one person to another."

"We were made aware of Daisy Chain but cannot access their services due to mobility needs."

"But all CBT work similar nothing in area for ADHD specific or for girls."

19. What coping strategies have you developed e.g. exercise, meeting like-minded people etc?

"Exercising and family activities."

"Exercise, speaking with other parents in a similar situation, research, national forums, online courses."

"None."

"I try to take a calm approach to situations and help support my son to do the same."

"Dad struggle with this and has very limited coping strategies."

"EXERCISE."

"I found regular exercise at the gym or walking really help. Further to this I find writing notes to help me through my day supports me."

"Fidget Spinners, plan at school, better understanding at home."

"Mainly:

Crying and having meltdowns, because everything is so overwhelming and unbearable

Avoiding people, because that way, there's less chance my growing poor mental health and the effect it has on my already non-existent executive functioning skills will impact negatively on them or get me into trouble/sacked

Working unpaid on evenings and all weekend to try and keep on top of work in an effort to not be sacked because that's the only way to strategise around ADHD traits and executive dysfunction in a workplace

Making terrible decisions in the heat of the moment because they somehow seem to create outcomes that make me function or happy at the time (until reality sets in minutes later)

Joining as many Facebook groups led by ADHD'ers as possible to try and make sense of who I am and be able to function rather than feeling I'm a terrible person. This has been useful to some extent in understanding myself and not feeling alone, but many group members are USA based, so their experiences are vastly different. It's also a kick in the teeth when members in other areas of the UK/world say that they were kept abreast of their assessment process/timeframes or have received a speedy official diagnosis.

I have to be out of the house/doing work from 7am - 9pm minimum every day and the same on weekends, just to try to stay afloat and be where everyone else is at in life. Not counting the hours, added expense and exhaustion from looking after a household on top of this. I don't have time to exercise, and it definitely wouldn't make me feel better. I'd be too busy panicking that I should be applying myself elsewhere before I get sacked or lose my home/family. My mind gets enough exercise running at a million miles an hour as it is.

The top and bottom of it is that we don't cope. We just somehow manage to exist. Whilst often wondering why we even bother when we're so inconvenient and insignificant to those who could help but aren't."

"Rugby, boxing and the gym."

"None."

"Attending a course on Facebook groups."

Breaking tasks down into smaller, more intense bursts.

"Mindfulness, I read, and digest books based on self-development and life coaching, Buddhism and progression. For example, Tony Robbins, Shazad Charmine etc."

"Exercise/Running."

"Talking openly and honestly about my struggles even though I've felt embarrassed and ashamed about them."

"Humour."

"Trying to be kinder towards myself."

"Listening to ADHD podcasts and joining online communities (The ADHD Adults Podcast in particular)."

"Joining the disability staff network in my workplace."

"Building a toolkit of different strategies that I can rotate through when the novelty wears off."

"Psychoeducation about ADHD."

"Embracing my neurodivergence and moving away from trying to do things the way others do them just because I feel like I'm supposed to."

"Technology and apps to outsource the things I struggle with (calendars, alarms, dishwasher)."

"Going for a walk. Meeting people and helping others."

"Speaking to friends about challenges."

"None."

"Just support from family."

"Relaxation."

"Art."

"Mother found support through Starfish and Daisy Chain too."

"I'm still finding my coping strategies."

"Exercise, reading."

"Using techniques from Neuro Programme & Relax Kids."

"Use breathing techniques to calm him down."

"Make sure he understands instructions and is given plenty of time to process what is needed."

"Son aged 10 - I use distraction techniques and also a happy box, it's filled with his favourite things and helps calm him down."

"I use my skills as a parenting coach to manage challenging situations."

"An EHC plan may be helpful."

"A support group would be good, talking to others sharing similar experiences and challenges would be helpful."

"Exercise, reading, anxiety medication."

20. Is there any further support you feel would be useful e.g. Easy Read?

"No."

"Clear timescales - the unknown length of time makes the whole situation harder."

"Everything. We get nothing."

"Parenting courses to help educate around ADHD and support with challenging behaviour that are not during working hours."

"Not sure yet until I speak to West Park."

"Support. Full stop. Throughout the whole process. It's becoming more apparent to everyone I've spoken to who's in the same position of waiting for official assessment (predominately all for 4y +), that professionals either obviously don't believe ADHD is real, don't care about supporting us (making waiting list times actively secret is probably the most purposefully detrimental thing you can do to our access requirements... is this so we give up and go away one way or another?), or don't have any understanding/insight into our lived experiences and daily difficulties. All of the ADHD training I've ever seen is delivered by people without lived experience too, so it's been so far off the mark and aimed at how we inconvenience others, it's awful."

"Easy read documents, direct/personal and as frequent as possible updates in writing and funding for ADHD'er-led support groups would be a massive step in the right direction, but still won't replace an assessment."

"None."

"More access to services that support ADHD, more help with dealing when medication wears off on the night not told to do sleep hygiene course."

"Diagnosis why is it taking so long it's so stressful."

"Activity sessions, in the community so access isn't an issue."

"More ability to make appointments or contact organisations digitally. GP's e-consultation service to be available outside their working hours. Not getting discharged from a service as soon as you're diagnosed. Guidance for employers and services about reasonable adjustments. Health checks similar to the ones for people with LD or being trialled for ASD."

"More information for girls ADHD."

"Groups for parents would be very helpful."

"ADHD coaching aftercare."

"More support in schools from TA's."

"Clear direction of the ADHD referral process."

"More support and understanding at the school

Someone to listen and take responsibility instead of being passed backwards and forwards between the school and GP."

21. Would you be interested in attending a peer support group?

Answer Choices		Response Percent
1	Yes	63.33%
2	No	36.67%

"Both parents work 9-5 min to Friday."

"As a parent but not my son he lives away at uni."

"Don't like being part of group it scares me."

"I would, although my schedule is jam packed, I'd be interested in attending not only for myself but to help support others and to pass on my motivational messages and some life advice from my lessons learnt."

"If there's ever anything I can do in the future to support please feel free to get in touch. I'm open about my ADHD diagnosis and more than happy to share my experiences if it helps."

"A support group would be very useful; it would help to talk to others experiencing the same challenges."

"Think a support group would be really helpful."

22. Any other comments?

"I think a lot of people completing this form would love to be kept informed of your research and have a copy of the report - however a lot of people won't feel comfortable leaving their contact details or identifying information. I don't as I'm worried my responses may somehow be seen by people I know or be passed on in a way that affects my assessment waiting time even more. We've been told to trust the systems relating to anything regarding ADHD before... and we've learned the hard way not to put trust in much since then. Please could you make sure you publicly publicise when these are available and where from, so people in the same position as me don't miss out?"

"No."

"It took 7 years to get diagnosis the first-time referral was put in was no it not ADHD, till things became worse and risk-taking behaviours was severe and 7 year later get diagnosed bearing mind already 2 in the household with ADHD."

"Shouldn't have to go through all this should be an easy process."

"In regards to the demographics question below, it could be helpful to follow the gender question with something along the lines of 'Is this the same as the sex you were assigned at birth?', similar to how they've done it in the recent census form example.

This would help you find out if you are capturing the experiences of trans people. I'm a trans man myself but I just describe my gender as male so the trans part would get missed.

Thanks for looking into the ADHD services issues. Improvements would make such a massive impact on our quality of life!"

"Mother took him to GP when a child, the GP looked at his notes and said he doesn't have ADHD. The mother then faced the challenges of his behaviour on her own. He is now in his early thirties, and he requested an assessment via GP again of which he was referred. Her son finds it difficult to be around people, gets most support from mother."

"Mother completed on behalf of her son - a long time awaiting diagnosis but can't be specific how long."

"Support for parents would be helpful."

"More family support needed."

"There is a lot of emphasis on medication which is not always the best option."

Mood and behaviour management should be taught, as well as relaxation and problem solving

"Mother feels let down by the system. Coping with the outbursts are extremely stressful, she attends an art group at Starfish to help with the stress. Daisy Chain have also been a huge help to the family."

"My sons GP prescribed him Melatonin to help him sleep but said it is for the school to refer him for an ADHD assessment. The school have said it should be the GP. A clear process would be helpful."




"I was offered parenting classes however I am qualified to teach parenting classes."


Appendix two: Demographics

The next questions are about you.




We will use these answers to make sure we have asked a range of different people about their views and experiences.

24. Which of the following best describes your ethnic group?








Answer Choices			Response Percent
1	Arab		0.00%
2	Asian/Asian British - Bangladeshi		0.00%
3	Asian/Asian British - Chinese		0.00%
4	Asian/Asian British - Indian		0.00%
5	Asian/Asian British - Pakistani		3.45%
6	Asian/Asian British - Any other Asian background/Asian British background		0.00%
7	Black/African/Caribbean/Black British - African		0.00%
8	Black/African/Caribbean/Black British - Caribbean		0.00%
9	Black/African/Caribbean/Black British - Any other Black/Black British background		0.00%
10	Mixed/Multiple ethnic group - White and Black Caribbean		0.00%
11	Mixed/Multiple ethnic group - any other mixed/multiple ethnic background		0.00%
12	Mixed/Multiple ethnic group - White and Asian		0.00%
13	Mixed/Multiple ethnic group - White and Black African		0.00%
14	White - English/Welsh/Scottish/Northern Irish/British		79.31%
15	White - any other white background		10.34%

16	White - Gypsy or Irish Traveller		0.00%
17	White - Irish		0.00%
18	Other - any other ethnic background		0.00%
19	Prefer not to say		6.90%

25. How would you describe your gender?




Answer Choices			Response Percent
1	Female		55.17%
2	Male		37.93%
3	Non-binary		0.00%
4	Prefer not to say		6.90%
5	Other (please specify):		0.00%

26. Age category







Answer Choices			Response Percent
1	12 and under		16.67%
2	13 - 17 years		6.67%
3	18 - 24 years		0.00%
4	25 - 34 years		23.33%
5	35 - 44 years		26.67%
6	45 - 54 years		16.67%
7	55 - 64 years		0.00%
8	65 - 74 years		0.00%
9	75+ years		3.33%
10	Prefer not to say		6.67%

27. Sexual orientation

Answer Choices		
1	Asexual	
2	Bisexual	







3	Gay	
4	Heterosexual/Straight	
5	Lesbian	
6	Pansexual	
7	Prefer not to say	
8	Other (please specify):	



28. Religion or beliefs

Answer Choices			Response Percent
1	Buddhist		3.57%
2	Christian		32.14%
3	Hindu		0.00%
4	Jewish		0.00%
5	Muslim		3.57%
6	Sikh		0.00%
7	No religion		35.71%
8	Prefer not to say		21.43%
9	Other (please specify):		3.57%

"None practicing."







29. Marital or civil partnership status

Answer Choices			Response Percent
1	Single		12.50%
2	Married		29.17%
3	In a civil partnership		4.17%
4	Cohabiting		8.33%
5	Separated		4.17%
6	Divorced/dissolved civil partnership		16.67%
7	Widowed		0.00%

8	Prefer not to say		20.83%
9	Other (please specify):		4.17%

"I am married this is my daughter."

30. Carer, disability or long-term health condition?

Answer Choices			Response Percent
1	Yes, I consider myself to be a carer		18.52%
2	Yes I consider myself to have a disability		22.22%
3	Yes, I consider myself to have a long-term health condition		25.93%
4	None of the above		33.33%
5	Prefer not to say		14.81%
6	Other (please specify):		7.41%

"My partner has mental health difficulties which are worse due to our son's challenging behaviour."

"Anxiety, Depression, ADHD, possible Autism."

Appendix three: ADHD UK Report



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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.



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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%
Average	16%

	% 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%
Grand Total	26%



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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	67,362	56,160	83%
Northern Ireland	2469	2 of 5	6,173	3,704	60%
Scotland	1655	4 areas of 14	5,443	3,888	71%
Wales	3662	2 of 6	10,746	7,164	67%
TOTAL	18638	15 of 67 (22%)	89,733	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		



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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.



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