



Living with ADHD In Herefordshire

healthwatch

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What is Neurodiversity & ADHD?

Neurodiversity is a term that is used to describe different thinking styles that affect how people communicate with the world around them.

It includes dyslexia, autism, attention deficit hyperactivity disorder (ADHD), Tourette's syndrome and more.

ADHD is a disorder that is defined through analysis of behaviour. People with ADHD show a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with day-to-day functioning and/or development.

It affects a substantial amount of the population; it is estimated that around 15% of the UK's population are neurodivergent.

Using 2022 Office of National Statistics (ONS), Lancet and NICE data, ADHD UK extrapolates that it is likely that 2.5 million people are living with ADHD in the UK.

Research has shown that those living with ADHD are more likely to experience a mental health problem. There is evidence that anxiety, depression, conduct disorder, substance abuse and sleep problems are all common in people living with ADHD.

Often lots of the main symptoms of ADHD are things that impact your behaviour, mood and thinking, so often many individuals are mis-diagnosed with a mental health problem like depression, anxiety, obsessive compulsion disorder or a personality disorder.



Executive Summary

Background & Objectives

An increase in feedback to Healthwatch Herefordshire about long waits for diagnosis and people seeking support both locally and nationally, we wanted to talk to those in our communities living with ADHD to understand the impact of living with this condition, and the current experience of services and support available.

In this first phase of research, we have spoken to 18 individuals about their journey and 5 parents about their children's ADHD journey and the wider impacts it has had to the individuals and their families.

This phase of the project has been qualitative, with semi structured interviews lasting between 45 mins and 2 hours, allowing everyone to share their journey, experiences and thoughts.

The findings in this report are illustrative of the themes present in the population represented by our sample.

In doing this we aimed to ascertain information to lead to the following outcomes.

- Increase understanding locally of the impact of living with ADHD.
- Identify ideas and suggestions to improve education, training and awareness of the condition, by sharing lived experience and accurate information, to help dispel misconceptions and reduce stigma associated with ADHD in our communities.
- Provide recommendations to support advocacy for ADHD, promoting the needs and rights of individuals with ADHD to share with educators, employers and policy makers to encourage the implementation of supportive measures and reasonable adjustments.
- Explore the potential for building community support networks through the sharing of experiences and insights of those living with ADHD and their families. The report can help to foster understanding, empathy, and a shared sense of purpose for those who want to come together to support each other in the challenges they face.
- Provide insight to the NHS and Healthwatch England about what needs to be addressed in considering future models of support for ADHD diagnosis and treatment.

Key Findings

Every journey that we documented was unique; none of them could be described as easy or straightforward in getting referrals for diagnosis but some had been less traumatic than others.

There seems to be two key variables that affected the outcomes in terms of speed of diagnosis, support and the quality of each person's journey these were.

- Their school's knowledge, experience and resources relating to neurodiversity. Some schools and some individuals within schools were more able to identify potential signs of neurodiversity and offer support than others. Alongside this was the parents existing knowledge and ability to identify the possibility of their child's neurodiversity.
- For the adults we talked to it was clear that the misdiagnosis of other mental health conditions was one of the biggest challenges in the quality and the length of time it has taken to get the support they have needed or received and the recognition by professionals that they have ADHD.

**Appendix 1 gives you an example of one of the story's we captured.*

All the individuals we spoke with felt that a formal diagnosis would make a significant difference either to them or their child, and for those formally diagnosed, they had found the diagnosis of immense value.

Our conversations were emotional and often when parents spoke about their children's ADHD journey it was clear to hear the frustration. This was mainly in relation to the delays in accessing services, the lack of formal support and recognition along the way, and in some cases discrimination towards parents.

"I was told by my GP that as I was a single parent and working fulltime that maybe some of the behavioural issues my child displays are because I don't set enough boundaries or spend quality time together and that a parenting course would be more beneficial than pursuing an ADHD diagnosis".

Many individuals told us a formal diagnosis has helped them to access the right statutory support such as SEND registration for their children or an award of PIP (personal independent payments) to support those who were struggling to maintain a routine and expectations of their job. But few expected a diagnosis to automatically open doors to new levels of support such as support programmes for daily routines or support from employers and flexibility in work roles.

The key themes outlining what would make a positive difference from the adults were.

- Better understanding and reasonable adjustments from employers and professionals when going through diagnosis as an adult can be really helpful.
- A platform for local networking where adults can meet others with ADHD and share, their experiences and gain networks of like-minded people for peer support.
- A local support service that provides advocacy & support for adults and older children with ADHD that can support them with occupational issues, routes into work and improving life skills to help them keep in routine with 'life admin' and studying.

Main Report

Context

We have listened to individuals and families talking about their neurodiversity – their expectations and hopes, and the reality of their experiences both whilst waiting for diagnosis or after diagnosis. This report shines a light on their lived experience in their own words.

Even before the pandemic, waiting times for assessment of neurodiversity in Herefordshire were long. Since the pandemic, demand has continued to increase to the extent that children and young people may wait years for a diagnosis. We wanted to ensure the voice of the people most deeply affected by these waits was clearly heard by those who plan and deliver services.

Considering intractable waiting times for formal diagnosis, particularly long for adults, our aim has been to:

- highlight the benefits of a formal diagnosis,
- Identify the support that is needed and where gaps exist in services,
- to inform the development of strategies that can deliver benefits to those waiting for a diagnosis and living with ADHD after a diagnosis in Herefordshire.

Approach

This was a qualitative, listening project. What we heard represents themes that are present in the population, rather than the extent to which they are present. Our aim was to deliver insight that can provoke reflection and enrich strategy.

We used a thematic analysis approach to develop our findings and report.

We listened to 18 individuals and 5 parents in individual interviews lasting between 45 minutes to 2 hours.

The interviews were semi structured, encouraging participants to tell their or their family's story with only minimal questions for clarity. More focussed probing was introduced around their expectations, experience, impact, and feelings about living with ADHD in Herefordshire. Interviews were all face to face either in person or via video call – notes were transcribed and then typed into our Story Bank format after. See appendix 1 for an example.

We have used a thematic analysis approach to develop our findings for the report.

Who we listened to

Recruitment at this stage was undertaken through advertising seeking individuals throughout social media platforms, using the advert below, sharing with other charities and community organisations.



healthwatch
Herefordshire

Your ADHD Story

We would like to hear from anyone living with or supporting someone with ADHD in Herefordshire.

You can share your experiences with us digitally, over the phone or in person.

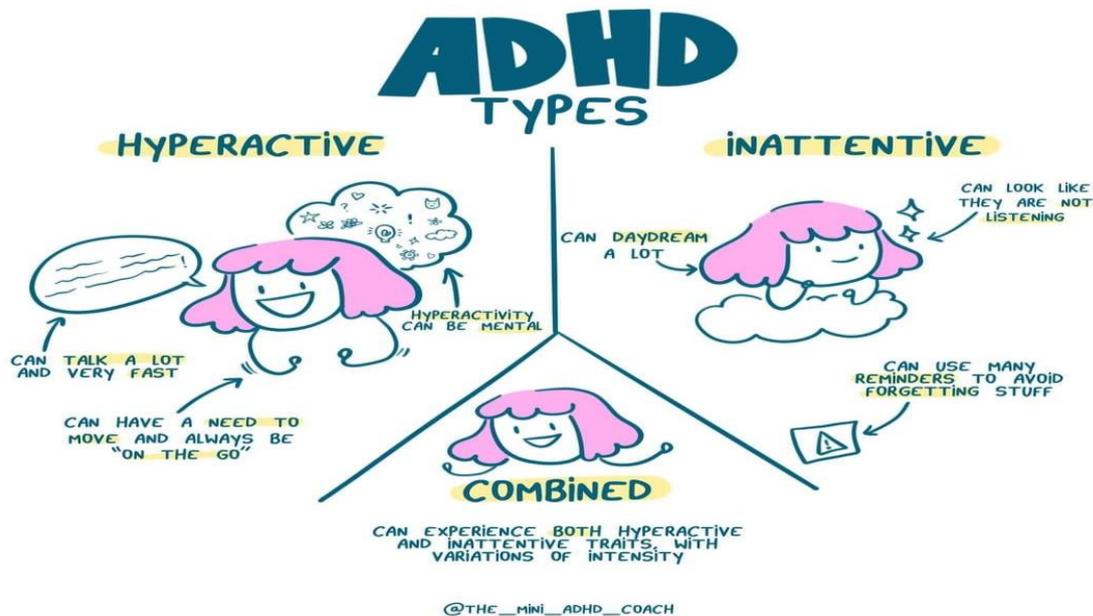
sam@healthwatchherefordshire.co.uk
or 07772 889 888

While we are confident our respondents represent a broad spectrum of experiences, we are aware there is a bias towards more engaged, articulate and connected families during this phase. We plan to engage further with a wider demographic through our local networks, organisations and schools that represent individuals experiencing more health inequalities in phase two of this work.

- 5 parents (all mothers) representing children ranging from 5 to 17 years old.
- 18 Individuals with an age range between 20 & 41 years old (all female)
- 4 individuals waiting for formal diagnosis.
- 3 children waiting for a diagnosis.
- All state funded diagnoses.
- Remainder had all been diagnosed within the last 4 years.
- 1 waiting for testing/diagnosis for ASD.
- 3 waiting for or diagnosed with another neurodiverse condition.

A range of additional conditions were experienced, and this was different for each individual with some not experiencing any that they felt were notable as part of their ADHD.

- Anxiety
- Eating disorders
- Self-harm
- Suicidal ideation and attempts
- School refusal
- Tourette's
- Hypermobility Disorder
- Development delay
- Speech and Language delays



Main Findings

Every story is unique, but the most apparent themes were as follows.

- The contribution of school. Parents depend on schools to be knowledgeable, identify problems, provide support, and facilitate access to services. While GPs and CAMHS do play a part, we heard far more about the contribution of schools, both good and not so good.
- Many expressed that they understood that the school position is a complex one and in Herefordshire it is apparent that the smaller more rural schools have offered more support and identification than the larger schools where more 'dedicated' SENCO staff are available to the parents we spoke to.
- Where schools had been less knowledgeable/supportive we heard about
 - inexperienced/junior teachers or 'older generation' teachers not believing in ADHD'.
 - specialist/support staff vacancies or long-term sickness
 - lack of focussed oversight of/familiarity with a child (larger schools in particular)
 - inexperience/lack of understanding of neurodiversity/behavioural challenges – with many telling us that 'parent blaming' was prevalent.
 - High level masking/camouflaging – we heard several experiences of parents approaching schools for help to be told "we're not seeing any of this at school".
- 3 of the parents we spoke to had been home educating their children after

removing them from mainstream school in late primary school/early high school years and too much success of the home educating – it has given these children better outcomes and opportunities to continue into education at college level or move into work-based learning.

- Labelling – this was an area that many we spoke to found hard to balance, not wanting to access support or diagnosis as others judge them and believe it's a 'modern day made up' condition still.

"It's difficult because you don't want him to be labelled, but my understanding is that without the label you don't get the support...a label helps him access the support he needs".

- Pre-existing knowledge of ADHD/neurodiversity and symptoms. Some felt they had good knowledge and had either experienced someone else they know living with ADHD and were able to spot similar signs or generationally they had better knowledge of ADHD than older generations.
- Misdiagnosis of the condition was common amongst all the females we have spoken too. Many were diagnosed with anxiety, low mood, personality disorders, or self-harm for many years. Many felt this was driven by their generation type – those who were now in their mid to late 30s and early 40s said that at school ADHD wasn't talked about or wasn't looked for especially amongst females and this has led to many of their childhood years living with the misdiagnosis and it is only down to the recent increase in prevalence of ADHD that their condition has been identified.
- Occupational consequences & having barriers to employment. Being an adult without a formal diagnosis means some employers don't recognise ADHD and has often led to loss of employment or re-deployment into other roles that the individuals didn't want, due to the manifestations of ADHD e.g. poor executive functioning skills & time keeping.
- Participants told us that there is still a lack of awareness and education (away from school age children) within Herefordshire. Stigma that this is a 'naughty childhood condition' and mainly affecting males, is still resulting in many women still 'camouflaging' or masking their ADHD when applying for jobs – longer term this is having an impact of their ability to maintain work and homelife routines.
- No local level offer of support. E.g. no peer groups that bring likeminded

individuals together locally to meet, to support each other as parents and as individuals. Using this as a platform to share skills and ideas about managing daily life and routine and creating networks of support. Using peers to demonstrate relatability in the condition and raise the profile of individuals with it.

- Self-research is heavily relied upon by the people we spoke to. All participants felt that the only option to be able to learn more was via self-research online. Some felt like this was hard to be confident about what information was from a reliable source and that the NHS information is too basic and general and doesn't outline other avenues for support or what to do on a practical level. It was highlighted that even GPs don't give suggestions for research and support individuals can turn to beyond NHS services, which are hard to access.

Main Findings

The Impacts of living with ADHD – what we have heard.

Living with ADHD can significantly impact various daily living activities. The specific challenges and their severity can vary from person to person, but here are some common ways participants said ADHD had impacted their life.

 **Time management** – Difficulty estimating the time required for tasks, leading to procrastination, missed deadlines, or a sense of being overwhelmed by time constraints. This seemed to be one of the biggest impacts of daily life for almost all of the individuals we spoke with.

 **Organisation** – Maintaining an organised environment and keeping track of belongings can be challenging. Many said this results in a disorganised living space, difficulty finding items, and increased stress. This has a big impact on family members many reported to us, making relationships harder to sustain and difficulty in looking after children alone.

 **Task initiation & completion** – Starting tasks and following through to completion can be a significant challenge for many. Participants said they found it difficult to sustain focus and may frequently switch between tasks without finishing them, often with a similar approach to jobs – some said they quickly got bored and wanted to do something new and as a result would lose interest in a current job and then were dismissed or ended up leaving employment.

 **Memory issues & Concentration** – Short-term memory challenges are common in individuals with ADHD. Forgetfulness about daily activities, appointments, and obligations. This for many led to missed appointments, which in some cases has impacted on their wider health. Likewise, this was one of the most frustrating symptoms for the children and young people throughout school times.

 **Impulsivity & social interactions** – several individuals said this can manifest as impulsive decision-making, interrupting others during conversations, and engaging in risky behaviors without fully considering the consequences. Social interactions may be affected by challenges such as difficulty listening actively, waiting for one's turn to speak, and interpreting social cues accurately. This impacts their personal relationships and can lead to misunderstandings in social contexts and friendships.

 **Emotional regulation** – many described mood swings, frustration, and impatience can be more pronounced, impacting relationships and overall well-being – this is often impacting the wider family and friends also. Some expressed swings of high and low mood, often feeling frustration and shame about their apparent short comings related to time keeping, prioritization and hampered progress in study or work.

 **Sleep difficulties** – most of the individuals we spoke to said that their ADHD had given them sleep difficulties, including insomnia. Many experiencing racing thoughts and difficulty winding down, this can make it challenging for individuals to establish and maintain a consistent sleep routine which then also has a wider impact on other daily activities as exhaustion is so overwhelming, they describe.

What else?

Below are more categorised themes of what individuals told us having ADHD has meant to them and their wider friends, family, and other interaction such as employment, some of these include some anonymous quotes that were given to us during our interviews.

Unaddressed Challenges:

Without a formal diagnosis, individuals may struggle to understand and address the specific challenges they face. They may not receive appropriate interventions or accommodations, hindering their ability to manage ADHD-related difficulties effectively.

'I didn't know why I didn't fit in. I think if the school and CAMHS (Child and Adolescent Mental Health Services) had known about the ADHD then there would have been more support and I would not have crucified myself as a person, my mental health was at rock-bottom because I just didn't know why I was like this and so I blamed myself.'

Strained Relationships:

ADHD can affect interpersonal relationships due to challenges such as difficulty with time management, impulsivity, and inattentiveness. Without a diagnosis, individuals may struggle to communicate these challenges to others, leading to misunderstandings and strained relationships.

'The people around me had put up with a lot. My family and friends have suffered through decades of missed appointments or late appearances.'

'My mum blamed me for being this way, for misbehaving, being lazy, being stupid. I just didn't understand why she didn't like me because I was trying so hard to behave. Now she says she understands [since diagnosis] why I was the way I was. I think she feels guilty now because she thought I was doing these things because I was bad rather than I couldn't help it.'

Educational and Occupational Impacts:

- In educational and professional settings, ADHD can affect performance and productivity. Without a diagnosis, individuals face challenges in academic or work-related tasks, potentially leading to underachievement, job dissatisfaction, or even job loss.

'I am currently going through an HR process with my employer as I am not performing in my role, I was put in touch with a group that have come together in the workplace to support each other with Autism but no one else in this group has ADHD like me. I have now been signed off sick for 7 weeks and I am struggling to work with my employer as I can't get the proof of diagnosis quick enough for them to take me seriously, I feel very low about this as I want to do well in my job.'

Self-esteem and Mental Health:

- The inability to understand and address ADHD contributes to lower self-esteem and increased stress. The ongoing struggle with unexplained challenges can take a toll on mental health, potentially leading to anxiety or depression.

'This has impacted my whole life and when I look back on my younger self, I feel so sorry for myself and so sad.'

'Getting the diagnosis was a big thing for me. I understand my life now, I feel that I have got the power back; I have an opportunity to rebuild, unlearn a lot of things that I've thought about myself, try to get back some confidence.'

Missed Opportunities for Treatment:

- A lack of diagnosis means missed opportunities for appropriate treatment. Medication, therapy, and other interventions that can be effective in managing ADHD symptoms. But without a diagnosis, individuals miss out on these beneficial options.

'What is the point of going to the GP as they don't know, they didn't even know about Right to Choose and I had to take the NICE guidelines to the GP to be referred, so they will not know the answers to my questions.'

Financial Consequences:

- Difficulty maintaining focus and organisation leads to financial challenges. This might include issues such as late payments, missed deadlines, or poor financial planning, all of which have lasting consequences.
- Many participants described to us the challenges and impacts that come with trying to do what are perceived as mundane tasks by most – such as shopping. This can overwhelm them and increase anxiety due to their impulsiveness.

'Getting out without spending twice as much as you intended, which means making meticulous lists and resisting the constant urge to impulse-buy.'

'It's definitely not something that's talked about – I don't see or hear a lot about ADHD and money management.'

Risk of Coping Mechanisms:

- Without a diagnosis, individuals develop less effective coping mechanisms or self-medicate with substances like alcohol or drugs to manage symptoms. This can lead to additional health issues and complicate the overall picture.

'It had a massive impact on my depression, I stopped taking my anti-depressants which had not worked for me, and my ADHD medication just made me feel better, when I don't take them for a while, I start to feel sad again.'

Impact on Parenting:

- Adults with undiagnosed ADHD face challenges in parenting, such as difficulty maintaining routines and providing consistent structure for their children. This can impact both the individual and their family dynamics.

'Living with ADHD myself, whilst it has helped me understand my son's needs more, it has at times become overwhelming and I have nowhere to go for support with everyday problems such as organisation, sustaining routines and maintaining relationships. I want to get better at these things myself so my son can learn from me'

Inclusion, understanding and forgiveness.

In almost all our interactions with those living with ADHD we were told that they generally felt lost, confused, and different and separate from others before any diagnosis was made.

There was often anger and distress; they felt alienated and misunderstood; parents were at a loss to understand why their child was behaving or developing in ways so different to their expectations and to their children's peers.

For those who have had a diagnosis, the diagnosis led to a better level of acceptance and inclusion for both children, young people and their parents. People told us that the benefits under this theme, directly or indirectly, often made a substantial contribution to improvements in mental health for both children and parents.

Several of the children and young people we talked about in this research with their families, expressed that they had suffered significant mental health issues including self-harm and attempted suicide.

For many parents, the diagnosis allowed them to forgive both their children and themselves: pre-diagnosis many children's most noticeable symptoms appeared to be behavioural; meltdowns, anger, school refusal, difficulties socialising, food refusal, self-harm, emotional dysregulation or mental health problems such as anxiety.

Many parents had felt they had been blamed and questioned about what they were doing wrong. Some had experienced parent-blaming – this was apparent in the participants, through schools and in some case primary care services, often defaulted to parent blaming.

'I was told that it was because I was a single parent and the behaviours were down to my parenting skills, they think your child is bad, that he has bad behaviour and that you are a bad parent ... even your own family. Many times, I felt judged'

For both parents and children & young people pre-diagnosis, they can feel like an 'outsider', defined by the 'difference' between themselves and their peers. A diagnosis does change this position, moving the person from being mostly different, to being "one

of the people like this/with a condition'. However, there could be support made available for those who are in the pre-diagnosis phase, as suggested by almost all of those we spoke to. Support through peer networks, better education and awareness for employers and educators, and consistency in schools' approach to identification, execution of support and support networks for parents and carers managed through schools or community initiatives.

Parents described the formal diagnosis as a trigger for investigating a wider range of charities and groups on offer and connecting with other parents or individuals, locally the landscape for this is poor and there is little on offer. Their children told us of using social media to connect with the worldwide community of neurodiverse people. Both online platforms seem to be more of a national offer.

In a similar scenario, those who had not received a diagnosis yet told us that if there were more support groups locally for those specifically with ADHD, this would bring them closer to a feeling of acceptance and understanding as it's not easy to identify and interact with others with ADHD especially as an adult when you are trying to just manage life.

Some of the individuals told us that their work had provided this platform of connection and understanding around ADHD, and this had supported them in their roles and to link with others in their workplace. However, this is still rare, and many employers still don't understand and make adjustments for those with ADHD in Herefordshire and there is an inconsistent approach to those who do offer support.

Labelling

Many of the individuals we spoke with talked about 'labelling' around ADHD. In some cases, this was in relation to schools and in others it was in relation to adults and in the workplace.

The issue around labelling is a lot more than just the negative impacts it has, and it is very contentious. The label can bring both benefits (when used in the right way) or negative impacts on mental health of the person.

'It's difficult because you don't want him to be labelled, but my understanding is that without the label you don't get the support...a label helps him access the support he needs.'

It would appear from our representative group that on balance the view was that while a diagnosis is a label, it can have positive value, particularly as NHS ADHD therapeutic support and medication is only available to those with a diagnosis.

Before diagnosis many people were carrying negative labels – even parents admitted thinking of their children as disorganised, difficult, disruptive; the children and young people had labelled themselves or been labelled by their peers. Parents knew their children were identified at school as not achieving their potential or having delayed skills.

Many felt that schools, colleges, and employers could be more active here in the stereotypes that are formed as they do with other disabilities and other neurodiverse conditions such as Autism, using the label as a positive spin to find the thing that an individual can do and really work on that.

Self-management.

Many of the conversations we had demonstrate the negative impacts that living with ADHD has had on individuals. However, we also learned that there are elements of hope and positivity for some that if shared to more could really support our ADHD communities in Herefordshire.

Here are some of the positive outcomes that came through in our interactions that have potential to be built on for others with ADHD.

Developing Strategies & control

Understanding that develops as a result of diagnosis for parents or individuals can enable methods and strategies that can be put in place to manage their child or their own behaviors and reduce the risk of heightened mental health distress.

These can be simple things such as adapting parenting styles, planning and organising techniques, being able to get more support and knowledge around specific areas such as anger management or anxiety. Many individuals felt that this gave them the opportunity to learn more about themselves and what motivates them and how to harness and use this in jobs or environments for learning.

As mentioned earlier in the report, some of the parents represented in this group have begun home schooling their children with positive outcomes, allowing them to move onto higher education and have improved social interactions.

Some parents in this group mentioned that the introduction of a pet into their lives had been of great benefit, to help establish routine and responsibility into their child's life but also to support the calm that they can't always regulate for themselves.

Self-Research & Education

Our representative group have evidenced to us that within Herefordshire at a local level there is very little ADHD specific support available.

Likewise, many felt that professional information from GPs is very limited, and also inconsistent depending on what GP you see.

Through national forums many have found access to free resources that have enabled them to expand their own knowledge on the condition and find ways to support themselves. Many tell us that self-research can be hard, and it is difficult to recognize sometimes what is 'correct' advice and what maybe an opinion.

Many have found the following useful and think that more local level versions of these could really make a difference and support an ADHD community in Hereford and market towns.

<http://www.addiss.co.uk/>

<https://chadd.org/>

<https://www.adhdcentre.co.uk/>

Some of the services above do also offer advocacy, but most come at a cost. Many of the individuals we spoke to said that having condition specific advocacy free of charge in Herefordshire would be a huge step forward and help many parents when trying to evidence their concerns to professionals.

Summary & Recommendations

Collecting the lived experience stories of those living with ADHD in Herefordshire so far has enabled us to gauge where gaps exist. Some of these gaps such as the delay in diagnosis we already knew, but other factors such as support, advocacy, education, occupational support and local level networks we knew less about.

We believe there is more research into the Herefordshire landscape of living with ADHD needed to understand the scale and shape of the demand, but these findings and recommendations can now be shared within our integrated care system to seek ways to improve what is on offer in our county.

Recommendations

- Use existing networks setup within the county – such as parent carer forums, Talk Community Hubs etc to provide specific ADHD networking opportunities. Bringing those with ADHD in a local area together and support them to build a support service for each other.
- Support Primary care services to provide more knowledge and support to those waiting for a diagnosis of ADHD – this could take many forms such as group support sessions, digital education for example and utilise some of the national support organisations that exist to start with, so individuals feel like they have a next step and a place to go while waiting for a diagnosis.
- Primary care services educated on the offer the 'Right to Choose' – its apparent many still aren't aware of this being an available option to them and in many cases has sped up referrals.
- Creating support networks for parents through schools on a very local level – the range of parents that this has the potential to bring together is huge and together they can support each other and their families.
- Providing opportunities to facilitate basic training sessions for local employers to understand ADHD and what they can do to best support employees with the condition, both reasonable adjustments and to keep them engaged in their employment and allow them the same opportunities for career progression.

Phase two of this research will research further into the inconsistency of support that is offered to children through our county's schools and employers, to see what can best support them with the increase rate of people seeking an ADHD diagnosis both nationally and locally.

Healthwatch Herefordshire will also spend some time with a range of organisations in our county that are interacting with our ADHD communities and look at what they need to both continue and enhance the support they can offer.

Next steps

- Engagement & research with local primary & secondary schools – Early 2024
- Research into local employers understanding & support for ADHD – Early 2024
- Engagement with the voluntary Sector Organisations to support the work they already do around ADHD in our communities – Early 2024.
- Support national work on ADHD with Healthwatch England to lobby NHS England to consider future models of services for ADHD. 2024

Thanks

Healthwatch Herefordshire would like to thank all the individuals who contacted us and were willing to share their ADHD journey with us. We want to recognise their courage in sharing, and we are grateful for the on-going contacts we have made through this research.



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